

Society's headache

The socioeconomic impact of migraine

The Work Foundation



About the Work Foundation

Through its rigorous research programmes targeting organisations, cities, regions and economies, now and for future trends; The Work Foundation is a leading provider of analysis, evaluation, policy advice and know-how in the UK and beyond.

The Work Foundation addresses the fundamental question of what Good Work means: this is a complex and evolving concept. Good Work for all by necessity encapsulates the importance of productivity and skills needs, the consequences of technological innovation, and of good working practices. The impact of local economic development, of potential disrupters to work from wider-economic governmental and societal pressures, as well as the business-needs of different types of organisations can all influence our understanding of what makes work good. Central to the concept of Good Work is how these and other factors impact on the well-being of the individual whether in employment or seeking to enter the workforce.

For further details, please visit www.theworkfoundation.com.

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Executive summary

Migraine is a common and disabling primary headache disorder. It is the third most common disease in the world (behind dental caries) in both males and females. Globally, it is the highest cause of years lived with disability (YLDs) amongst those aged 15-49. This is generally when people are at their most productive, furthering their careers and starting families – it therefore has a huge impact on people's career paths and the economy in general.

The indirect costs associated with migraine due to lost productivity, mainly through absenteeism and reduced effectiveness at work (presenteeism), are substantial. Yet, despite its significant socioeconomic impact, migraine is neglected: according to one study, based on data from Europe, migraine is the least publicly funded of all neurological diseases relative to its economic impact.

Although a number of studies have attempted to estimate migraine's prevalence and associated cost burden in many countries throughout the world, relatively few have focused exclusively on the UK. The most recent study was conducted in 2003. It estimated that each year £2.25 billion is lost to migraine-related absenteeism. Being based on older data, this figure is likely to be outdated. Furthermore, it does not account for presenteeism, which is reported to have an equal or greater impact on work productivity.

The substantial indirect costs associated with migraine could be reduced significantly if it were treated and managed better: it is underdiagnosed and undertreated and public and professional understanding of the condition is poor. These problems are compounded by vague patient pathways. As such, patients that could be treated in primary care end up in secondary care. Headache is the most common neurological reason for accident and emergency attendance. This is inefficient, resulting in unnecessary waste and variation in care, contributing to the relatively small (when compared to the indirect costs), yet still significant, direct healthcare costs caused by migraine.

Better care, as well as better quality work environments comprising improved psychosocial work conditions – i.e. 'good work' – can reduce these costs and improve the welfare of millions of people with migraine in the UK.

The study

The overall aims of the research were to:

- (i) **assess the prevalence and socioeconomic impact of migraine on the UK**, estimating both the indirect and direct costs attributable to it;
- (ii) **explore the barriers to optimal health and work-related outcomes** for people with migraine; and
- (iii) **develop a series of evidence-based recommendations** – aimed at policymakers – which have the potential to reduce migraine's burden for the benefit of government, employers and the millions of individuals (and their families) in the UK that experience it.

To do this, we employed a mixed-methods approach, first carrying out an evidence review of relevant academic and grey literature. This was supplemented by analysis of secondary data sources, including the Global Burden of Disease Study, the Labour Force Survey and Public Health England Hospital Episode Statistics. In addition to this, a qualitative component was carried out, comprising semi-structured interviews with people with migraine ($n = 5$) and

migraine ‘experts’ ($n = 9$) including healthcare professionals, academics and third sector organisations.

The research set out to answer the following questions:

1. What is the prevalence of migraine in the UK?
2. What is the socioeconomic cost of migraine to the UK?
3. What are the barriers to optimal care for people with migraine and how can they be addressed?
4. What strategies do people with migraine use to manage their condition and how effective are they?
5. What are the barriers to optimal work-related outcomes for people with migraine and how might they be overcome?

Principal findings

Prevalence and costs

Migraine is highly prevalent in the UK. Recent estimates from the Global Burden of Disease study (GBD) 2016 put adult¹ migraine prevalence at 23.3% while older estimates for the UK and Europe put it around 15%². For many, attacks occur frequently and often cause significant pain. Even when not experiencing an attack, people with migraine contend with an ‘interictal’ (i.e. between attacks) disability burden characterised by worry about the next one and avoidance of perceived ‘triggers’. All of this carries a substantial socioeconomic cost.

Based on a 23.3% adult prevalence taken from GBD 2016 and an average of 5.7 days lost per person with migraine, we estimate that 43 million workdays are lost every year in the UK to migraine-related absenteeism alone, at a cost of almost £4.4 billion. A more conservative estimate using 15% prevalence indicates that 28 million days are lost costing £2.8 billion. Assuming migraine-related presenteeism is responsible for an equal amount of lost productivity (published studies suggest it is usually responsible for more), we calculate (using GBD 2016 prevalence) that the equivalent of 43 million workdays are lost to presenteeism in the UK, at a cost of £4.4 billion. Using a lower prevalence, equivalent days lost amount to 28 million a year costing £2.8 billion.

Migraine-related absenteeism and presenteeism combined is, therefore, responsible for 86 million equivalent workdays lost per annum (11.4 for each person with migraine) at a cost of just under £8.8 billion in lost productivity (using GBD 2016 adult migraine prevalence data). Our second, more conservative, calculation based on a lower prevalence of 15% estimates that a total of 55 million equivalent days are lost at a cost of more than £5.6 billion per annum.

Broader indirect costs, although difficult to quantify, can be attributed to migraine’s interictal disability burden. Although considerably less disabling than the ictal state, people with migraine, on average, spend 317 days a year in the interictal state. Common symptoms include ‘interictal anxiety’ and avoidance behaviour, which impacts on people’s relationships, personal time and leisure – i.e. their quality of life.

Additional costs, which are again difficult to quantify, relate to the often significant negative impact migraine has on career advancement and potential earnings – this represents a

¹ Aged 15-69 years

² For adults aged 16-65 years

personal cost and a financial loss to the Exchequer. Furthermore, common co-morbidities include psychological conditions like anxiety and depression, both of which are responsible for a significant – and increasing – amount of lost workdays according to the Labour Force Survey.

Although greatly outweighed by the indirect costs, direct costs attributed to migraine are still worthy of consideration. Using data from the Eurolight project³ (comprising outpatient care, investigations, acute medications, hospitalisations, and prophylactics) applied to GBD 2016's UK adult migraine prevalence, we calculate direct healthcare costs of almost £1 billion per annum. A more conservative estimate, again using 15% prevalence, calculates direct costs at just under £600 million a year. Thus, direct costs are responsible for around 10% of the total, with the vast majority attributed to indirect costs, which is in line with existing studies.

When combined, the indirect and direct costs attributed to migraine are of the order of £9.7 billion a year, with a more conservative estimate of £6.2 billion. Although the estimates are inexact and affected by the assumptions used, both indicate that the cost is substantial.

Navigating the barriers to optimal care for people with migraine

Most cases of migraine – and headache generally – can and should be treated effectively in primary care, but this would require structured headache services operating in a hierarchical or partnership model. While there are difficulties in implementing such a service, similar models operating at local level may have the potential to be scaled up. Such a system, combined with clearer migraine patient pathways, will help address the highly variable care people with migraine currently receive and reduce the likelihood of delayed diagnosis, misdiagnosis and inappropriate referrals. It would however depend on improving general practitioners' capability around and understanding of migraine – currently they do not know enough about it and appear to have little interest in it given the wide range of competing medical conditions. Educational programmes, particularly as part of multifaceted interventions, have the potential to help address this.

This should be supported by action aimed at improving patient education and understanding of migraine with a potential role for community pharmacists facilitating effective self-management. The need for this is underlined by evidence suggesting that people with migraine often employ complex coping strategies – which themselves have a significant impact on their quality of life – to avoid migraine attacks despite the lack of reliable evidence on their effectiveness. People with migraine would also benefit from education and training in the recognition of premonitory symptoms, which could help reduce attack severity.

Addressing these barriers to optimal care has the potential to reduce both the indirect and direct costs attributed to migraine:

- better care and self-management would help people with migraine control and manage their condition effectively, enabling them to stay in, return to or find work, which, in turn, would reduce costs associated with lost productivity; and
- treating the majority of migraine in primary care, underpinned by clear pathways, would help reduce unnecessary and variation in care characterised by delayed diagnosis, misdiagnosis and inappropriate referrals

³ See: http://www.l-t-b.org/index.cfm/spKey/horizontal_activities.learning.the_eurolight_project.html

Navigating the barriers to optimal work-related outcomes for people with migraine

Another means of reducing the indirect costs associated with migraine is by addressing barriers to optimal work-related outcomes for people with migraine. Several barriers can in part be addressed by 'good' work comprising improved psychosocial work conditions, a supportive workplace culture and better management practices which empower employees to more effectively manage their health conditions and therefore optimise their performance at work. The general lack of public understanding of migraine, which extends to employers, is a significant barrier. This is compounded by a lack of available information as well as short-term sickness absence policies that do not accommodate the fluctuating nature of migraine. Though they would help, it is difficult to get reasonable adjustments (migraine is not always a disability under the Equality Act 2010) and there is a lack of evidence on their effectiveness for people with migraine. In addition, not all jobs and workplaces are amenable to adjustments. While disclosing one's condition can help with getting support this can present risks, e.g. an adverse employer response.

Improvements in the public's understanding of migraine, which extends to employers and indeed the benefits system, are needed. Many of the barriers we found stem from this. It would address the 'lottery' people with migraine face at work, which is also a feature of their care; too often a good work experience depends on the 'luck' of having an understanding employer or line manager. As such, the importance of 'good' work and the positive contribution it can make to work outcomes for people with migraine should not be understated. The value of a healthy psychosocial work environment for all employees – and particularly those with long-term conditions – has been explicitly recognised in several recent Government publications. People with migraine would benefit in several ways, e.g. through enhanced control empowering them to manage their condition and social support from management when they need it.

The substantial, mainly indirect, costs associated with migraine in the UK demand the Government's attention. Even allowing for some imprecision, it is clear migraine creates a huge socioeconomic burden yet public – and professional – understanding of it is generally poor and it is poorly managed by the health system. This seems unjustified particularly when

- (i) migraine is treatable with good effect;
- (ii) implementation of relatively low cost measures aimed at improving patient and public understanding could improve the welfare of millions leading to significant socioeconomic savings; and
- (iii) the often negative impact migraine has on work-related outcomes can, to some extent, be avoided in 'good' working conditions.

Key recommendations

These recommendations aim to provide a way forward, given the substantial costs associated with migraine, to improve health and work-related outcomes for people with migraine and, as a result, reduce its socioeconomic burden on the UK. This requires action in three 'settings':

- (i) the health system;
- (ii) the individual; and
- (iii) the workplace

All three are mutually reinforcing: better organisation of care is supported by improved patient and public understanding, both of which support better work-related outcomes for people with migraine.

Improving care

There are several barriers to optimal care preventing efficient and effective treatment and management of people with migraine resulting in waste, inefficiency and significant variation in what is delivered and its effectiveness.

Vision

Migraine should be treated within a national framework of structured services comprising three levels: primary care (level one), intermediary care (level two) and secondary/specialist care (level three). This should be underpinned by a clear and unambiguous patient pathway. This would better address avoidable waste and variation in care for patients in different parts of the UK. The vast majority of people with migraine would be managed in the community (at level one and two). This would require informed patients and general practitioners (GPs), operating at level one, with sufficient knowledge/skills to correctly diagnose and treat migraine, support effective self-management or refer appropriately – acting as ‘gatekeepers’. Intermediary clinics (level two) could be staffed by GPs with a special interest (GPwSI) in headache and/or Clinical Nurse Specialists (CNS), possibly with some (arm’s length) cover from a neurologist.

There are currently several initiatives and national bodies active in improving headache care, presenting an unprecedented opportunity to bring about a transformation in care provision and significantly reduce migraine’s socioeconomic impact.

Recommendations for the way forward

- National bodies currently active in improving public health and clinical care (e.g. the National Neurology Advisory Group (NNAG); NHS RightCare; Neurology Intelligence Network (NIN); National Advisory Committee for Neurological Conditions (NACNC)) should work with the network of headache and migraine stakeholder groups in the UK to include the British Association for the Study of Headache (BASH), the Migraine Trust, Headache UK, relevant academics, expert bodies, health professional groups and people with migraine and their families, to develop a strategy/plan for headache and migraine care in the UK.
- This would need to identify and convene an expert multi-stakeholder group with relevant expertise to agree on a proposal to integrate current initiatives and address gaps to produce a coherent national framework for structured headache services and support for self-management and consistent public health messaging.
- The proposal would require comprehensive cost-benefit analyses to demonstrate how much such a system would cost and how much it would save (currently available cost-effectiveness data, though limited, suggests the findings would be positive).
- Action from local and national health decision-makers and commissioners would be needed to implement the strategy.

Improving patient and public understanding

Many people with migraine may not recognise they have migraine and self-manage their headaches inappropriately or, despite knowing they have migraine, do so ineffectively due to a lack of reliable information and prevalence of ‘migraine myths’. A particular danger is

overuse of analgesics (painkillers) bought over the counter (OTC), promoting medication overuse headache.

Vision

People with migraine should be empowered to effectively self-manage their condition. Their decision about whether to self-manage or not should not, as is often the case, be predicated on the assumption that the marginal benefit of professional involvement in their care would be small and therefore not worth it. Rather, it should be informed by information and education provided by clear, unambiguous, messaging provided by a reliable source such as the NHS. Relatively low cost measures implemented effectively have the potential to improve the welfare of millions leading to substantive socioeconomic savings.

A national public health campaign to educate people – ideally from a young age – on migraine and how to manage it is therefore needed. This should include information on lifestyle changes that can be made to manage symptoms effectively (during the ‘ictal’ and ‘interictal’ state and the role of ‘triggers’); when – and where (supported by a structured headache service) – to seek medical help; and effective signposting to reliable and useful sources of information provided by BASH and third sector organisations e.g. Migraine Trust and Migraine Action. A clear message should be that a ‘migraine prevention lifestyle’ is a healthy lifestyle for everyone comprising healthy eating, regular exercise, etc.

This should be underpinned by community pharmacies and pharmacists supported to play an expanded, more active role in empowering patients to manage their own health with the right diagnosis, advice, OTC treatment and, if needed, support with lifestyle changes. Community pharmacists are also in a good position to identify people at risk of analgesic overuse and thereby help prevent medication overuse headaches.

Recommendations for the way forward

- Convene a group of relevant stakeholders, government and expert health bodies comprising the Department of Health and Social Care and devolved health representatives from the UK’s different nations to work with the network of headache and migraine stakeholder groups in the UK (including BASH, the Migraine Trust, Headache UK, relevant academics, expert bodies, health professional groups and people with migraine and their families). This group should decide on the shape of a national public health campaign to educate people – ideally from a young age – on migraine and provide consistent, clear messaging to aid self-management. People with migraine should be involved in developing the campaign.
 - The campaign should help with effective dissemination of existing resources, such as those provided by BASH, the Neuro Network Vanguard, the Migraine Trust and Migraine Action.
- A strategic partnership between government and pharmacy bodies – with input from relevant third sector organisations and stakeholders – should explore the potential for community pharmacies and pharmacists playing a greater role in facilitating the self-management of people with migraine and prevention of analgesic overuse.
- Government – DHSC, Public Health England and the NHS – should explore the potential for using technology, e.g. a phone ‘app’, as a means of empowering patients with self-records of their symptoms, treatment trials and lifestyle goals as well as disseminating advice and information to help people with migraine effectively

self-manage and ‘bust’ migraine myths. NHS England’s ‘digital programme’ – approving apps to manage health conditions – is already underway

Improving work-related outcomes

Employers’ understanding of migraine is poor, it is difficult for people with migraine to get reasonable adjustments and work demands can often be difficult to reconcile with symptoms. This risks inhibiting individuals’ effectiveness at work and business’ productivity.

Vision

Everyone – including people with migraine – has the right to a ‘good’ job. Employers should – and increasingly do – provide healthy work environments which support a happy, healthy and engaged workforce. This is most likely to be achieved by businesses that adopt an integrated and proactive approach to managing people at work through ‘high performance working’ practices. These put people at the heart of businesses and seek to ensure business success by empowering the workforce, enabling them to actively contribute to performance improvements. People with migraine, therefore, should not be ‘singled out’ for special treatment unnecessarily but rather be able to benefit from (as any other employee would) a ‘good’ psychosocial work environment. More control and autonomy would allow them to manage their workload and perceived ‘triggers’; manageable demands reduce the risk of stress – a ‘trigger’; social support from colleagues and managers helps them manage their condition; and workplace flexibility enables them to manage their hours and fit work around symptoms. A healthy migraine workplace is a healthy workplace for all.

That said, employers should also be empowered to understand their employees’ needs. For those with health conditions, such as people with migraine, this means knowing how to make workplaces amenable to employees with long-term, fluctuating, chronic conditions and seeking specialist advice as and when appropriate to tailor support accordingly, i.e. depending on the nature of their employees’ conditions. This requires a review of health policies, including inflexible short-term sickness absence policies, better access to occupational health services, recognition of the crucial role that line managers play and a stronger evidence base around ‘what works’ regarding reasonable adjustments. This would enable employers – and occupational health professionals – to better support employees in general and specifically those with migraine. Furthermore, when and if they need it, Jobcentre Plus should be able to provide effective support for people with migraine.

Recommendations for the way forward

- In its response to the *Work, Health and Disability* green paper and the *Taylor Review of Modern Working Practices*, the Government identified ‘good work for all’ as a national priority, recognising its positive relationship with health specifically as well as driving improvements in business performance more generally. Making progress on promoting health and wellbeing at work, ensuring individuals’ needs are supported, requires effective joined up working between various agencies (especially those operating locally) – employers, Jobcentre Plus, Local Enterprise Partnerships (LEPs), professional bodies, Chambers of Commerce, the NHS and local authorities. In concordance with the *Taylor Review*, relevant government departments – Business Energy and Industrial Strategy, Department for Communities and Local Government, Department for Work and Pensions and DHSC – should explore ways of supporting and incentivising local authorities and partners (e.g. city regions and combined authorities) to develop more specialist and integrated approaches to improving health

and wellbeing at work, with emphasis on supporting – and empowering – those with fluctuating, chronic conditions and supplementing general management practices with specialist support as required.

- Addressing these challenges requires robust knowledge of current employer practices and how decision-making differs across businesses. Thus, local partners should work with employers through recognised business communities, at local level, supported through trade and professional bodies as well as national bodies, including Be the Business, and government departments to support wider adoption and take-up. The intention here is to support collaborative action, developing case study materials, and sharing knowledge, learning and good practice to support the health and productivity of people with migraine at work. Bodies such as Be the Business are currently working with LEPs, and other local partners, to increase the quality of management practices generally and this work can be supplemented to enhance the benefits for the better management of health at work too.
 - There should be an emphasis on co-produced solutions (i.e. developed by the employer and employee) meeting local industry needs.
 - The crucial role that line managers play in supporting employees' health and productivity at work should be recognised.
- To enable employers to support the health and productivity of people with migraine, develop an online repository – 'hub' – of information curated by employers, expert bodies and relevant third sector organisations signposting them to reliable sources of information, such as those provided by the Migraine Trust and Migraine Action.
- Government working with local partners should explore the need to commission new research into the business case for supporting the productivity of people with migraine at work, serving as a platform for further advice and tools to support effective reasonable adjustments for people with migraine, i.e. 'what works'.
- Government should explore how sickness absence policies can be adapted to better accommodate people with fluctuating conditions and, building on commitments set out in *Improving Lives*, improve access to occupational health and support schemes such as Access to Work.

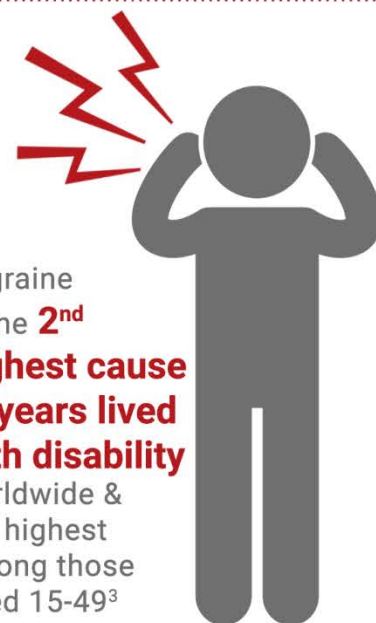
The Cost of Migraine to the UK



An estimated
23.3%
of adults aged
15-69 have migraine¹



10m adults aged 15-69
are estimated to
have migraine²



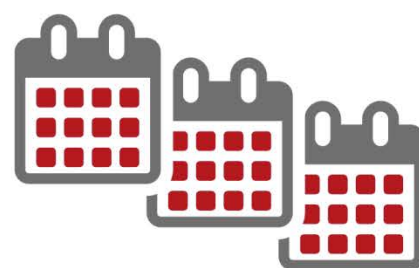
Migraine
is the **2nd**
highest cause
of years lived
with disability
worldwide &
the highest
among those
aged 15-49³



Each year, an average
of **11.4 equivalent**
workdays are lost
per person with
migraine⁴



The **indirect costs of**
migraine due to lost
productivity are
estimated at just under
£8.8bn per annum⁵



Each year, an estimated
86m equivalent
workdays are lost
due to migraine-
related absenteeism
and presenteeism⁶



The **direct healthcare**
costs of migraine are
estimated to be in the
region of **£1bn** a year
(outpatient care, investigations,
acute medications, hospitali-
sations, and prophylactics)⁷



Across the **44 Sustainability**
Transformation Partnership
(STP) regions in England,
estimated **emergency**
hospital admissions with
a primary diagnosis on
admission episode of
headache or migraine, have
increased by an average of
15% since 2012/13⁸

¹This is a weighted average of Global Burden of Disease (GBD) study 2016 data taking migraine prevalence amongst those aged 15-49 and 50-69, which is 25.4% and 17.7% respectively; ²based on 23.3% prevalence taken from GBD 2016; ³GBD 2016; ⁴this assumes that 5.7 days are lost to migraine-related absenteeism each year (based on population-level data from Steiner et al. 2003) and, in line with existing studies, assumes that are further 5.7 workday 'equivalents' are lost to reduced effectiveness at work – presenteeism – which generally has an equal if not greater impact on the productivity of people with migraine; ⁵calculated on the basis that 86m equivalent workdays are lost each year to migraine, accounting for current workforce size and average wage; ⁶incorporating actual days lost and equivalent days lost due to reduced effectiveness at work; ⁷using Eurolight data, we estimate a mean per-person with migraine annual direct cost of £94.03, which is then multiplied by the number of adults aged 15-69 with migraine based on a 23.3% prevalence; ⁸hospital admissions with an ICD-10 code indicating a primary diagnosis on admission episode of headache or migraine (England, age 20+)

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1 Introduction

1.1 Background

Migraine is a common and disabling primary headache disorder. It is the third most common disease in the world (behind dental caries) in both males and females⁴. Recent data show it is the second highest cause of years lived with disability (YLDs) worldwide and, amongst those aged 15-49, the highest⁵. This is generally when people are at their most productive, furthering their careers and starting families – it therefore has a huge impact on people's career paths and the economy in general⁶.

The indirect costs associated with migraine due to lost productivity, mainly through absenteeism and reduced effectiveness at work (presenteeism), are substantial⁷. Yet, despite its significant socioeconomic impact, migraine is neglected: according to one study, based on data from Europe, migraine is the least publicly funded of all neurological diseases relative to its economic impact⁸. This situation has persisted in spite of repeated calls from the World Health Organization, following its 2011 global survey of headache disorders and resources⁹, highlighting the “neglect of a major public-health problem” and the “inadequacies of responses to it in countries throughout the world”¹⁰.

A number of studies have attempted to estimate migraine's prevalence and associated cost burden in many countries throughout the world. However, relatively few have focused exclusively on the UK¹¹. The most recent study was conducted in 2003¹²; it estimated that each year £2.25 billion is lost to migraine-related absenteeism. Being based on older data, this figure is likely to be outdated. Furthermore, it does not account for presenteeism, which is reported to have an equal or greater impact on work productivity¹³.

The substantial indirect costs associated with migraine could be reduced significantly if it were treated and managed better: it is underdiagnosed and undertreated¹⁴ and public and professional understanding of the condition is poor. These problems are compounded by vague patient pathways¹⁵. As such, patients that could be treated in primary care end up in secondary care, which is expensive. Also, headache is the most common neurological reason for accident and emergency attendance¹⁶. This is inefficient, resulting in unnecessary waste and variation in care, contributing to the relatively small (when compared to the indirect costs), yet still significant, direct healthcare costs attributable to migraine.

In addition to better care, the costs associated with migraine-related lost productivity at work could, in part, be addressed through better quality work environments comprising improved

⁴ Steiner, T. J., Stovner, L. J., & Birbeck, G. L. (2013). Migraine: the seventh disabler. *The Journal of Headache and Pain*, 14(1), 1.

⁵ Steiner, T. J., Stovner, L. J., Vos, T., Jensen, R., & Katsarava, Z. (2018). Migraine is first cause of disability in under 50s: will health politicians now take notice? *Journal of Headache and Pain*, 19(1), 17.

⁶ APPG on Primary Headache Disorders. (2010). *Headache Disorders - not respected, not resourced*.

⁷ Katsarava, Z., Mania, M., Lampl, C., Herberhold, J., & Steiner, T. J. (2018). Poor medical care for people with migraine in Europe – evidence from the Eurolight study. *Journal of Headache and Pain*, 19(1).

⁸ Shapiro, R. E., & Goadsby, P. J. (2007). The long drought: The dearth of public funding for headache research. *Cephalalgia*, 27(9), 991–994.

⁹ A Global Campaign against Headache project

¹⁰ Steiner, T. J., Stovner, L. J., Vos, T., Jensen, R., & Katsarava, Z. (2018).

¹¹ Stovner, L. J., & Andree, C. (2010). Prevalence of headache in Europe: A review for the Eurolight project. *Journal of Headache and Pain*, 11(4), 289–299.

¹² Steiner, T. J., Scher, A. I., Stewart, W. F., Kolodner, K., Liberman, J., & Lipton, R. B. (2003). The prevalence and disability burden of adult migraine in England and their relationships to age, gender and ethnicity. *Cephalalgia*, 23(7), 519–527.

¹³ Steiner et al. (2003).

¹⁴ Katsarava, Z., Mania, M., Lampl, C., Herberhold, J., & Steiner, T. J. (2018).

¹⁵ APPG on Primary Headache Disorders. (2014). *Headache Services in England*. London: Houses of Parliament.

¹⁶ APPG on Primary Headache Disorders. (2014).

psychosocial work conditions, a supportive workplace culture and better management practices which empower employees, i.e. 'good' work, which the workforce in general would benefit from.

1.2 Research aims, questions and the structure of the report

The overall aims of the research were to:

- (i) **assess the prevalence and socioeconomic impact of migraine on the UK**, estimating both the indirect and direct costs attributable to it;
- (ii) **explore the barriers to optimal health and work-related outcomes** for people with migraine; and
- (iii) **develop a series of evidence-based recommendations** – aimed at policymakers – which have the potential to reduce migraine's burden for the benefit of government, employers and the millions of individuals (and their families) in the UK that experience it.

To do this, we employed a mixed-methods approach, first carrying out an evidence review of relevant academic and grey literature. This was supplemented by analysis of secondary data sources, including the Global Burden of Disease Study, the Labour Force Survey and Public Health England Hospital Episode Statistics. In addition to this, a qualitative component was carried out, comprising semi-structured interviews with people with migraine ($n = 5$) and migraine 'experts' ($n = 9$) including healthcare professionals, academics and third sector organisations.

The research set out to answer the following questions:

1. What is the prevalence of migraine in the UK?
2. What is the socioeconomic cost of migraine to the UK?
3. What are the barriers to optimal care for people with migraine and how can they be addressed?
4. What strategies do people with migraine use to manage their condition and how effective are they?
5. What are the barriers to optimal work-related outcomes for people with migraine and how might they be overcome?

The first question is answered in Chapter 2 by drawing on the current evidence, existing data and insights gained from the expert interviews. Migraine is a complex condition with a variety of symptoms; therefore we begin the chapter by providing a definition of migraine – and other primary headache disorders. This is followed by an assessment of migraine's global prevalence and disability burden, before we look at it in a UK context. We then consider its typical attack frequency, duration, and the significant pain it causes.

Chapter 3 answers the second question, drawing on existing research and secondary data to provide an updated estimate of the indirect and direct costs associated with migraine. We also consider the broader costs attributed to migraine, i.e. those related to its 'interictal' burden (i.e. between attacks) and commonly occurring co-morbidities such as anxiety and depression.

Questions three and four are addressed in Chapter 4. Drawing on the qualitative research and findings from the evidence review we explore the barriers to optimal care for people with migraine and how they can be addressed – first from their perspective and then the experts'.

This is followed by a section on the coping and self-management strategies people with migraine use and their effectiveness.

The final research question is answered by Chapter 5. We draw on the insights from the people with migraine and the experts we spoke to, supplemented with evidence from the published literature, to explore the barriers to optimal work-related outcomes for people with migraine and how they can be overcome.

In Chapter 6 we present our overall conclusions and, in Chapter 7, we set out our recommendations, informed by the experts and our research findings, aimed at addressing the barriers to optimal health and work-related outcomes for people with migraine and reducing the substantial socioeconomic costs associated with migraine.

2 The prevalence of migraine in the UK

2.1 Introduction

This chapter of the report will answer the following research question:

1. What is the prevalence of migraine in the UK?

Before we can answer this question, however, we must be clear about what – exactly – we are measuring the prevalence of.

2.2 What is migraine?

Migraine is a common and disabling primary headache disorder¹⁷. It is a complex condition comprising a wide variety of symptoms. For many people, the main feature is a painful headache. However, other symptoms include disturbed vision, sensitivity to light, sound and smells, feeling sick and vomiting. The International Classification of Headache Disorders, which is provided by International Headache Society (most recently updated in 2013¹⁸) and recognised by the World Health Organization (WHO), identifies several types of migraine. The most common are migraine with aura, migraine without aura and migraine aura without headache¹⁹. ‘Aura’ generally refers to visual disturbances including blind spots in the field of eyesight, coloured spots, sparkles or stars, flashing lights before the eyes, etc.²⁰ Migraine without aura is, however, more common, affecting roughly 70-90% of people with migraine²¹. Typically, it is characterised by headache on one side of the head with throbbing or pulsating pain with attacks lasting between 4 and 72 hours when untreated or not treated properly. Migraine is often characterised as being either episodic, with headache occurring between 1 and 14 days a month, or chronic, with 15 or more headache days a month²² (though in some cases broader criteria for chronic migraine are used²³).

Other primary headache disorders include tension-type headache (TTH), which is the most common primary headache disorder with a global prevalence of almost 30% according to the Global Burden of Disease study (GBD) 2016²⁴. Symptoms include pressure or tightness around the head, possibly including pain in the neck and shoulder muscles. Unlike migraine, which causes pain that can be disabling, TTH is characterised by mild to moderate pain. TTH is, generally speaking, episodic in nature, with attacks lasting a few hours (although potentially lasting for several days). While it can graduate to chronic TTH, which can be unremitting and significantly more disabling, only around 1-3% of the adult population is affected²⁵.

¹⁷ International Classification of Headache Disorders. (2016). IHS Classification ICHD-3 Beta. Retrieved November 18, 2017, from <https://www.ichd-3.org/1-migraine/>

¹⁸ Olesen, J. (2013). The International Classification of Headache Disorders, 3rd edition. *Cephalalgia*, 33(9), 629–808.

¹⁹ NHS Choices. (2016). Migraine. Retrieved November 20, 2017, from <https://www.nhs.uk/conditions/migraine/>

²⁰ Migraine Trust. (2018). Migraine with aura. Retrieved November 20, 2017, from <https://www.migrainetrust.org/about-migraine/types-of-migraine/migraine-with-aura/>

²¹ Migraine Trust. (2018). Migraine without aura. Retrieved November 21, 2017, from <https://www.migrainetrust.org/about-migraine/types-of-migraine/migraine-without-aura/>

²² Katsarava, Z., Buse, D. C., Manack, A. N., & Lipton, R. B. (2012). Defining the Differences Between Episodic Migraine and Chronic Migraine. *Current Pain and Headache Reports*, 16(1), 86–92.

²³ Olesen, J., Boussier, M. G., Diener, H. C., Dodick, D., First, M., Goadsby, P. J., ... Steiner, T. J. (2006). New appendix criteria open for a broader concept of chronic migraine. *Cephalalgia*, 26(6), 742–746.

²⁴ Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 12, 2017, from: <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/f1d9bda777b0ce99a6d9df413a056217>

²⁵ APPG on Primary Headache Disorders. (2014). *Headache Services in England*. London: Houses of Parliament.

Cluster headache is another primary headache disorder. Although it can cause extremely severe headache pain, it is significantly less common than migraine and TTH, affecting fewer than 1 in 1,000 adults worldwide according to the WHO²⁶.

Finally – although not a primary headache disorder – medication overuse headache (MOH) can occur when medication is used excessively to treat a headache. It arises from migraine and TTH but primarily the former. It is a severe form of chronic headache often occurring in patients that have a long history of headache and unsuccessful treatments²⁷. Due to its origin it is difficult to estimate but recent data suggest prevalence is 1-2% globally²⁸.

2.3 Migraine prevalence

As we have established, migraine is but one of several primary headache disorders. Although TTH is the most prevalent of these, migraine is considered to be the most common *disabling* headache disorder^{29,30}. This is illustrated by the fact that, despite having a higher global prevalence, TTH is responsible for less than 1% of total years lived with disability (YLDs), while almost 6% is attributable to migraine³¹. It is for this reason that, primarily, we are interested in estimating the prevalence of migraine. An additional reason is that epidemiological data available for TTH and other primary headache disorders are relatively poor. Having said that, because it was outside the scope of this report to conduct our own survey to estimate prevalence, we are reliant on secondary data that, in some cases, does not distinguish between different types of headache or migraine. Thus, some estimates will include both headache *and* migraine.

2.3.1 Global prevalence of migraine and disability burden

The latest iteration of the GBD (described as “the most comprehensive worldwide observational epidemiological study to date”³²) was published in 2016. It estimates that migraine’s global prevalence – across both sexes and all age groups – is 14.7%. There is a clear female preponderance, with 19% being affected compared to 10% of men³³. The data show that migraine is now the second highest cause of total YLDs worldwide (causing 5.7%) for both men and women and all age groups, second only to low back pain (7.2%) which comprises a mixture of disorders³⁴. This illustrates the challenge posed by migraine prevalence for healthcare systems worldwide.

2.3.2 Prevalence of migraine in the UK and sociodemographic variation

The best known and most widely cited report estimating the prevalence of migraine in the UK (based on a representative sample from England) is a 2003 study from Steiner et al.³⁵. No such study has been conducted since. A random sample ($n = 4,007$) of the population aged 16-65 of mainland England was surveyed via telephone. Interviewers used a

²⁶ World Health Organization. (2016). Headache disorders. Retrieved December 12, 2017, from <http://www.who.int/mediacentre/factsheets/fs277/en/>

²⁷ Kristoffersen, E. S., & Lundqvist, C. (2014). Medication-overuse headache: A review. *Journal of Pain Research*

²⁸ Westergaard, M. L., Munksgaard, S. B., Bendtsen, L., & Jensen, R. H. (2016). Medication-overuse headache: a perspective review. *Therapeutic Advances in Drug Safety*.

²⁹ Bahra, A. (2011). Primary Headache Disorders: Focus on Migraine. *Reviews in Pain*, 5(4), 2–11.

³⁰ Weatherall, M. W. (2015). The diagnosis and treatment of chronic migraine. *Ther Adv Chronic Dis*, 6(3), 115–123.

³¹ Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 6, 2017, from:

<http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/9f7e5346443beb6afbdd6b77b31f2995>

³² The Lancet. (2018). Global Burden of Disease. Retrieved November 23, 2017, from <http://www.thelancet.com/gbd>

³³ Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 6, 2017, from:

<http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/2053a118a9c0a2d0678a5aad11e2fe2a>

³⁴ Institute for Health Metrics and Evaluation. (2017). GBD Compare. Retrieved December 6, 2017, from:

<http://ihmeuw.org/4d2v>

³⁵ Steiner, T. J., Scher, A. I., Stewart, W. F., Kolodner, K., Liberman, J., & Lipton, R. B. (2003). The prevalence and disability burden of adult migraine in England and their relationships to age, gender and ethnicity. *Cephalalgia*, 23(7), 519–527.

previously validated diagnostic tool and the response rate was relatively high (76.5%). Participants were only classified as having migraine if they met slightly modified International Headache Society diagnostic criteria for migraine with or without aura. Therefore, despite some methodological shortcomings (one of which is elaborated on later) the study can be described as being of high quality. It estimated the one year prevalence of migraine in adults in England as 14.3% (which, when weighted according to the demographic statistics of the UK population was 15%) affecting a higher proportion of females (18.3%) than males (7.6%).

Its findings are very similar to those from studies across Europe. Stovner and Andree³⁶ – as part of the Eurolight project³⁷ – reviewed 32 studies from 15 European countries³⁸, all of which sought to estimate migraine prevalence. The findings, from over 170,000 adults, showed a prevalence rate of 14.7%, with 8% in men and 17.6% in women. This may be an underestimate, however, due to a methodological issue highlighted by both Stovner and Andree and one of the academic experts we interviewed.

Historically, most studies on the prevalence of migraine (including Steiner et al.) only report 'strict' or 'definite' migraine, i.e. those that meet (in some cases slightly modified) diagnostic criteria provided by the International Headache Society. What's called 'probable' migraine – where patients fulfil all migraine criteria except one³⁹ – is normally excluded from these studies. However, more recent studies conducted through the Global Campaign against Headache⁴⁰, which have generally yielded higher prevalence estimates, have grouped definite and probable migraine together⁴¹. The rationale for this is twofold. Firstly, as put by one of the academic experts we spoke to:

“the thing about ‘probable’ migraine is that it’s probably migraine... it’s more likely to be migraine than everything else it could be” (Expert interview)

Secondly, although migraine severity and disability is relatively lower in people with probable rather than definite migraine, the effect is still significant and places a similar burden on the person with migraine⁴².

As a result, historical estimates of UK prevalence most likely *underestimate* the prevalence of migraine in the UK and, as Stovner and Andree argue⁴³, if definite and probable migraine were grouped, the proportion of people with migraine would be almost twice as high. One of the academic experts we interviewed suggested that, on the basis of the prevalence rates reported by more recent studies using this updated methodology^{44,45,46}, the 'true' prevalence of migraine in the UK is “somewhere between 20 and 25% in adults”. This would suggest

³⁶ Stovner, L. J., & Andree, C. (2010). Prevalence of headache in Europe: A review for the Eurolight project. *Journal of Headache and Pain*, 11(4), 289–299.

³⁷ http://www.l-t-b.org/index.cfm/spKey/horizontal_activities.learning.the_eurolight_project.html

³⁸ Including Austria, Croatia, Denmark, France, Germany, Greece, Hungary, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, Turkey and the UK.

³⁹ Lantéri-Minet, M., Valade, D., Géraud, G., Chautard, M. H., & Lucas, C. (2005). Migraine and probable migraine - Results of FRAMIG 3, a French nationwide survey carried out according to the 2004 IHS classification. *Cephalalgia*, 25(12), 1146–1158.

⁴⁰ Steiner, T. J. (2005). Lifting the burden: The global campaign to reduce the burden of headache worldwide. *Journal of Headache and Pain*, 6(5), 373–377.

⁴¹ Steiner, T. J., Rao, G. N., Kulkarni, G. B., Gururaj, G., & Stovner, L. J. (2016). Headache yesterday in Karnataka state, India: prevalence, impact and cost. *Journal of Headache and Pain*, 17(1), 74.

⁴² Lantéri-Minet, M., Valade, D., Géraud, G., Chautard, M. H., & Lucas, C. (2005)

⁴³ Stovner, L. J., & Andree, C. (2010).

⁴⁴ Kulkarni, G. B., Rao, G. N., Gururaj, G., Stovner, L. J., & Steiner, T. J. (2015). Headache disorders and public ill-health in India: Prevalence estimates in Karnataka State. *Journal of Headache and Pain*, 16(1).

⁴⁵ Manandhar, K., Risal, A., Steiner, T. J., Holen, A., & Linde, M. (2015). The prevalence of primary headache disorders in Nepal: a nationwide population-based study. *Journal of Headache and Pain*, 16(1), 95.

⁴⁶ Mbewe, E., Zairembiama, P., Yeh, H. H., Paul, R., Birbeck, G. L., & Steiner, T. J. (2015). The epidemiology of primary headache disorders in Zambia: a population-based door-to-door survey. *Journal of Headache and Pain*, 16(1).

that the estimates from Steiner et al. and Stovner and Andree – of around 15% – might be underestimates. The GBD 2016 estimate of migraine prevalence for UK adults⁴⁷, which is 23.3%⁴⁸, may, therefore, be more accurate.

Regarding the role played by sociodemographic factors, gender has a big influence. As is the case with migraine globally, women (24.4%) are more likely to have migraine than men (12.1%) in the UK⁴⁹. Also, as Steiner et al. found, prevalence varies with age rising through early adult life and peaking in middle age (see Table 1 below).

GBD 2016 does not provide data on race, education or income but what data are available suggest that prevalence of migraine in non-Caucasians (black, Asian, Bangladeshi, Chinese and other races) is half of what it is in Caucasians for both men and women⁵⁰. Similar findings were reported in a US study⁵¹. It is unclear what explains these differences. Regarding socioeconomic status, although some US studies have shown a negative correlation between migraine and income⁵² and education⁵³, UK data suggest they are not related to migraine prevalence⁵⁴. Other studies conducted outside the US report similar results^{55,56}.

Table 1 – Migraine prevalence in the UK by age and sex⁵⁷

Age	Male		Female		Both sexes	
	Number	Prevalence	Number	Prevalence	Number	Prevalence
5-14	270,160	8.9%	267,272	8.8%	537,431	8.9%
15-49	2,223,772	15.6%	5,205,783	34.8%	7,429,555	25.4%
50-69	892,643	11.6%	1,878,460	23.5%	2,771,103	17.7%
70+	215,658	6.2%	387,205	8.7%	602,864	7.6%
Totals	3,602,233	-	7,738,720	-	11,340,953	-

2.3.3 Migraine-related disability

Although migraine's prevalence is lower than some other primary headache disorders, it is of great public health importance principally because of the significant disability burden it carries. Other headache disorders, e.g. TTH, do not carry the same burden⁵⁸. This point is underlined by the fact that, of seven possible classes, the WHO ranks 'severe migraine' in

⁴⁷ Aged 15-69 years

⁴⁸ Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 19, 2017, from: <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/13f50842e7cb4fca6de7e497f826c9f6> (this is a weighted average taking migraine prevalence amongst those aged 15-49 and 50-69, which is 25.4% and 17.7% respectively)

⁴⁹ Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 16, 2017, from: <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/ee152e410ae995c6bfb243bea89f5cd>

⁵⁰ Steiner et al. (2003).

⁵¹ Stewart, W. F., Lipton, R. B., & Liberman, J. (1996). Variation in migraine prevalence by race. *Neurology*, 47(1), 52–59.

⁵² Stewart, W. F., Lipton, R. B., Celentano, D. D., & Reed, M. L. (1992). Prevalence of Migraine Headache in the United States: Relation to Age, Income, Race, and Other Sociodemographic Factors. *JAMA: The Journal of the American Medical Association*, 267(1), 64–69.

⁵³ Stang, P., Sternfeld, B., & Sidney, S. (1996). Migraine headache in a prepaid health plan: Ascertainment, demographics, physiological, and behavioral factors. *Headache*, 36(2), 69–76.

⁵⁴ Steiner, T. J., Scher, A. I., Stewart, W. F., Kolodner, K., Liberman, J., & Lipton, R. B. (2003)

⁵⁵ Rasmussen, B. K., Jensen, R., Schroll, M., & Olesen, J. (1992). Interrelations between migraine and tension-type headache in the general population. *Archives of Neurology*, 49(9), 914–8.

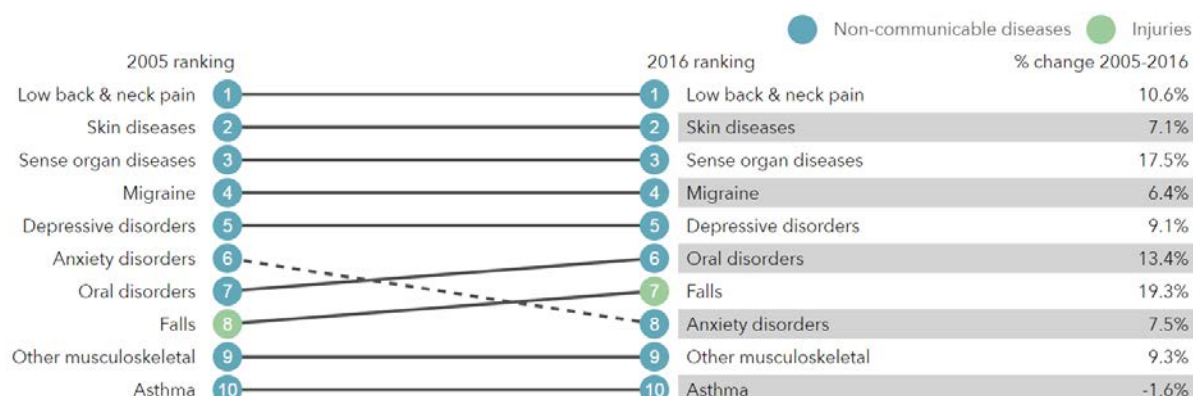
⁵⁶ Launer, L. J., Terwindt, G. M., & Ferrari, M. D. (1999). The prevalence and characteristics of migraine in a population-based cohort: The GEM Study. *Neurology*, 53(3), 537–537.

⁵⁷ Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 6, 2017, from: <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/233a2067ce971d8121e5b3c4a39f0c4d>

⁵⁸ While it is true that MOH is more disabling than TTH at an individual level, there is not sufficient data available to reliably estimate its prevalence in the population

the highest – disability class VII – alongside conditions like severe depression and terminal stage cancer⁵⁹.

Figure 1 – What health problems cause the most disability in the UK?⁶⁰



Top 10 causes of years lived with disability (YLDs) in 2016 and per cent change, 2005-2016, all ages

The latest data from GBD 2016 show that migraine is responsible for 5.9% of total YLDs in the UK, across all age groups⁶¹. As expected, due to the gender variation in prevalence, it accounts for a higher proportion of YLDs in women (7.1%) than men (4.3%)⁶². As Figure 1 (above) shows, migraine is a top 10 cause of disability, increasing by 6.4% since 2005 (though some of this increase may be due to changes in how it was recorded during that period). This arguably understates migraine's importance, however. 'Skin diseases' and 'sense organ diseases' (ranked 2nd and 3rd respectively), comprise a range of different conditions. Thus, when we analyse GBD 2016 data at a lower, more detailed, level, migraine is in fact the 2nd highest cause of YLDs in the UK⁶³, second only to 'low back & neck pain', which itself comprises more than one disorder.

While migraine is highly prevalent and responsible for a significant amount of disability worldwide, there is evidence to suggest it is particularly problematic in the UK. Table 2 (below) shows that the level of disability attributed to migraine in the UK, measured by disability-adjusted life years⁶⁴ (DALYs), is significantly above the group mean⁶⁵, i.e. it is higher in the UK than it is in countries with similar sociodemographic characteristics.

⁵⁹ World Health Organization. (2004). *Disease incidence, prevalence and disability*. Geneva: World Health Organization.

⁶⁰ Institute for Health Metrics and Evaluation. (2018). United Kingdom. Retrieved January 12, 2017, from <http://www.healthdata.org/united-kingdom>

⁶¹ Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 5, 2017, from: <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/4bcd1e43f14d0cdf888fa2aa800e93a5>

⁶² Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 2, 2017, from: <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/ff60ac5c00ce86f90111646af4a0f0f6>

⁶³ Institute for Health Metrics and Evaluation. (2017). GBD Compare. Retrieved December 6, 2017, from: <http://ihmeuw.org/4d3a>

⁶⁴ DALYs for a disease or health condition are calculated as the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for people living with the health condition or its consequences

⁶⁵ Comparison groups are chosen based on the GBD regional classifications, known trade partnerships, and sociodemographic indicators (SDI)

Table 2 – DALYs attributed to migraine⁶⁶

	UK	Comparison group mean (High SDI ⁶⁷)	Austria	Belgium	Canada	Croatia	Cyprus	Czech Republic	Poland	Switzerland	Taiwan	United States
Migraine	732	667	833	781	685	709	796	704	709	779	423	599

Significantly lower than mean
 Statistically indistinguishable from mean
 Significantly higher than mean

Age-standardized rate per 100,000, 2016

Given the fluctuating nature of migraine⁶⁸ it is instructive to consider its attack frequency and duration, i.e. how often people with migraine experience the ‘ictal’ state and how much time they spend in it. Studies tend to report attack frequency ranging between 20-30 times a year, usually lasting one day but often more. For example, a staff survey of an English hospital trust found 158 people with migraine reporting an average of 20 attacks per year, each lasting 20 hours on average⁶⁹. Similar results were reported by a Canadian population survey of 445 people with migraine: 20 attacks per year with a mean duration of 31 hours⁷⁰. These findings contrast with those from a Swedish postal survey of 423 people with migraine, which reported a slightly lower attack frequency of 16 a year with a mean duration of 19 hours⁷¹. Data collected from a random sample of the adult population in England, however, reveal a higher mean attack frequency (per year) of 26.3 for men and 23.6 for women, as well as a mean duration of 28 and 37 hours for men and women respectively. It also found that a quarter (25%) reported high levels of pain (9-10 on a 10-point scale); mean pain intensity for both sexes was still relatively high: 7.5⁷². Similar findings come from a US postal survey of 3,577 people with migraine: almost 50% of those with a diagnosis reported 12-48 attacks per year with 80% experiencing either ‘severe’ or ‘extremely severe’ pain⁷³. Similarly high levels of pain (7-10 on a 10-point scale) were reported by more than two-thirds of a sample of 1,663 people with migraine in a US population survey⁷⁴.

Finally, there is also evidence to suggest that ‘interictal’ disability in migraine (i.e. between attacks) is real and measurable⁷⁵. Recent research involving 6,455 adults from 10 EU

⁶⁶ Institute for Health Metrics and Evaluation. (2016). United Kingdom: <http://www.healthdata.org/united-kingdom>

⁶⁷ ‘SDI’ = Socio-Demographic Index

⁶⁸ World Health Organization. (2004).

⁶⁹ Clarke, C. E., MacMillan, L., Sondhi, S., & Wells, N. E. (1996). Economic and social impact of migraine. *QJM: Monthly Journal of the Association of Physicians*, 89(March 1994), 77–84.

⁷⁰ Pryse-Phillips, W., Findlay, H., Tugwell, P., Edmeads, J., Murray, T. J., & Nelson, R. F. (1992). A Canadian population survey on the clinical, epidemiologic and societal impact of migraine and tension-type headache. *Can J Neurol Sci*, 19(3), 333–339.

⁷¹ Linde, M., & Dahlöf, C. (2004). Attitudes and burden of disease among self-considered migraineurs - A nation-wide population-based survey in Sweden. *Cephalalgia*, 24(6), 455–465.

⁷² Steiner et al. (2003)

⁷³ Lipton, R. B., Diamond, S., Reed, M., Diamond, M. L., & Stewart, W. F. (2001). Migraine diagnosis and treatment: Results from the American migraine study II. *Headache*, 41(7), 638–645.

⁷⁴ Stewart, W. F., Lipton, R. B., & Simon, D. (1996). Work-related disability: Results from the American migraine study. *Cephalalgia*, 16(4), 231–238.

⁷⁵ Steiner, T. J., Stovner, L. J., & Vos, T. (2016). GBD 2015: migraine is the third cause of disability in under 50s. *Journal of Headache and Pain*, 17(1).

countries shows that 26% of people with migraine experience symptoms during the interictal state. Although the ictal state is considerably more disabling, people with migraine spend considerably more time in the interictal state – on average 317 days a year⁷⁶ (the interictal burden is explored in greater depth in Section 3.3.1). As GBD 2016 only considers the disability burden associated with the ictal state of migraine⁷⁷ it probably underestimates migraine’s ‘true’ disability burden.

2.3.4 Summary

It is clear that migraine represents a significant public health problem: it is highly prevalent, amongst the top causes of disability worldwide and in the UK, often occurs frequently in sufferers and causes them significant pain. Furthermore, due to the limitations of existing data, migraine prevalence – and the disability burden associated with it – may be even higher than what the data reported here show. This carries a substantial socioeconomic cost which will be explored in the following section.

⁷⁶ Lampl, C., Thomas, H., Stovner, L. J., Tassorelli, C., Katsarava, Z., Laínez, J. M., ... Steiner, T. J. (2016). Interictal burden attributable to episodic headache: findings from the Eurolight project. *Journal of Headache and Pain*, 17(1), 1–10.

⁷⁷ Steiner et al. (2016).

3 The socioeconomic cost of migraine

3.1 Introduction

Having explored the global prevalence of migraine, with particular attention paid to the UK, this chapter of the report will answer our second research question:

2. What is the socioeconomic cost of migraine to the UK?

The socioeconomic costs attributable to migraine are significant and felt by all sections of society including the health system, government, employers, people with migraine and those related to them. This section will explore these costs.

3.2 Indirect costs

As shown in the previous section and by Figure 2 (below), migraine disproportionately affects people of working age, peaking at 30-40 years⁷⁸. This is generally when people are at their most productive, furthering their careers and starting families and, therefore, it has important implications for the career paths of people with migraine, but also employers and the UK economy in general⁷⁹.

Despite the variation in severity and symptoms (e.g. with or without aura, etc.) experienced by people with migraine, many report interference with their daily activities⁸⁰. For example, Clark et al.⁸¹, who surveyed 4,200 employees of a hospital trust in England, found that, of the 158 people with migraine sampled, 76% “always had to lie down” when experiencing migraine, 73% agreed that their migraine limited their ability to work, and 72% had difficulty performing work activities during an attack. Similar findings are reported by Steiner et al.: 73% of people with migraine claimed that headaches interfered with their daily activities “more than rarely”⁸². Given this, and the fact that people with migraine experience attacks on roughly 20-30 days a year with a mean duration of 25-30 hours (based on studies mentioned above), often accompanied by severe or extremely severe pain, it is not surprising that migraine has a profound impact on the functioning of people with migraine and, therefore, their working lives. This is well-established in the current literature and was reflected in the interviews we conducted with five people with migraine, who spoke at length about their experiences in employment.

Thus, in the following sections we explore the impact migraine has on work, focusing on lost productivity in the form of missed workdays (absenteeism) and reduced capacity at work (presenteeism). These indirect costs greatly outweigh the healthcare costs associated with migraine⁸³ (though these are still significant and are explored in Section 3.4) and fall upon people with migraine, employers and the wider economy.

⁷⁸ Steiner, T. J., Scher, A. I., Stewart, W. F., Kolodner, K., Liberman, J., & Lipton, R. B. (2003). The prevalence and disability burden of adult migraine in England and their relationships to age, gender and ethnicity. *Cephalalgia*, 23(7), 519–527.

⁷⁹ APPG on Primary Headache Disorders. (2010). *Headache Disorders - not respected, not resourced*. London: Houses of Parliament.

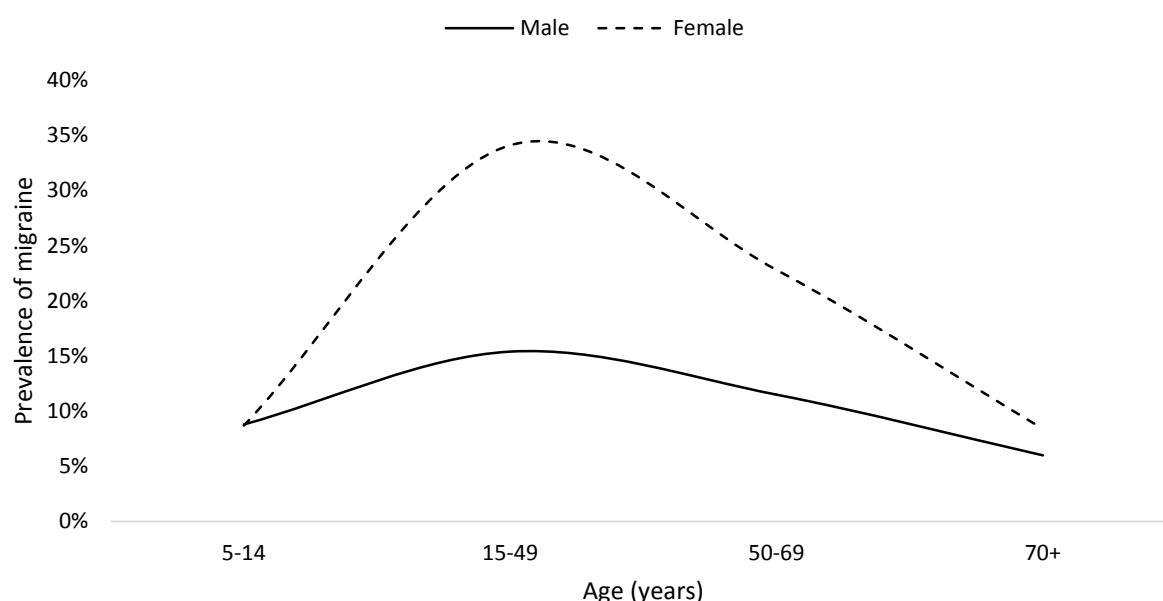
⁸⁰ D'Amico, D., & Tepper, S. J. (2008). Prophylaxis of migraine: General principles and patient acceptance. *Neuropsychiatric Disease and Treatment*, 4(6), 1155–1167.

⁸¹ Clarke, C. E., MacMillan, L., Sondhi, S., & Wells, N. E. (1996). Economic and social impact of migraine. *QJM: Monthly Journal of the Association of Physicians*, 89(March 1994), 77–84.

⁸² Steiner et al. (2003).

⁸³ Steiner, T. J., Gururaj, G., Andrée, C., Katsarava, Z., Ayzenberg, I., Yu, S. Y., ... Stovner, L. J. (2014). Diagnosis, prevalence estimation and burden measurement in population surveys of headache: presenting the HARSHIP questionnaire. *Journal of Headache and Pain*, 15(1).

Figure 2 – Prevalence of migraine by age for both sexes⁸⁴



3.2.1 Absenteeism from work

Several studies have sought to measure the number of working days lost attributable to migraine. As we are interested in estimating costs for the UK we will focus on studies conducted in European countries and the US which have a similar sociodemographic profile to the UK.

Two US population-based surveys, one of which involved 800 adults with migraine, reported an average loss of 2.8 days per year⁸⁵, while another, using a sample of 1,663 adults with migraine from the American Migraine Study, reported a mean yearly loss of 7.4 workdays⁸⁶. These compare to findings from a Norwegian population-based study of 38,192 adults reported an average of 4.4 lost workdays per year for both sexes due to migraine headaches⁸⁷. Similar results are reported in a systematic review⁸⁸ of five studies conducted in five European countries (France, Netherlands, Spain, Sweden and the UK) which found, based on data from over 1,500 people with migraine, that the average number of workdays lost to migraine was 2.5⁸⁹ per year. Thus, the average number of workdays lost per person with migraine tends to be in the range of 3-7 per year.

The best – and most recent – data for the UK regarding absenteeism come from Steiner et al., who estimated that an average of 5.7 workdays were lost for every person with migraine each year in England. From this they calculated that around 25 million workdays are lost every year in the UK⁹⁰, presenting a bill estimated at £2.25 billion in lost productivity⁹¹.

⁸⁴ Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 9, 2017, from: <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/84a81141204850e99d8a638c017955c0>

⁸⁵ Von Korff, M., Stewart, W. F., Simon, D. J., & Lipton, R. B. (1998). Migraine and reduced work performance: A population-based diary study. *Neurology*, 50(6), 1741–1745.

⁸⁶ Stewart, W. F., Lipton, R. B., & Simon, D. (1996). Work-related disability: Results from the American migraine study. *Cephalalgia*, 16(4), 231–238.

⁸⁷ Fiene, I., Haugland, M. E., Stovner, L. J., Zwart, J. A., Bovim, G., & Hagen, K. (2006). Sick leave is related to frequencies of migraine and non-migrainous headache - The HUNT Study. *Cephalalgia*, 26(8), 960–967.

⁸⁸ Berg, J. (2004). Economic evidence in migraine and other headaches: A review. *European Journal of Health Economics*, 5(SUPPL. 1).

⁸⁹ France: 2.2 days; Netherlands: 3.2 days; Spain: 8.5 days; Sweden: 2.7 days; UK: 2.0 days

⁹⁰ Steiner et al. (2003).

These figures are based, however, on population and wage data from 2003 and a migraine prevalence of 15% amongst adults⁹². As stated in the previous chapter, migraine prevalence amongst UK adults⁹³ is – according to the latest Global Burden of Disease (GBD) 2016 data – 23.3%⁹⁴. Using this updated figure, and taking into account the size of the current UK workforce⁹⁵ and average wage⁹⁶, we estimate that just under 43 million workdays are lost every year resulting in a cost of almost £4.4 billion in lost productivity⁹⁷.

In the interests of being conservative, as other reports in this field have been⁹⁸, we will offer a second estimate based on the prevalence found by Steiner et al. – 15% – which is very similar to the 14.7% reported by the Eurolight study in the previous chapter⁹⁹. Again, taking the average 5.7 workdays lost per person with migraine and accounting for the current size of the UK workforce and average wage, a 15% prevalence produces an estimate of 28 million workdays lost each year at a cost of £2.8 billion in lost productivity.

In addition to the data for lost workdays provided by Steiner et al., the Labour Force Survey (LFS) – a long-running national survey of the employment circumstances of the UK population with a sample size of 100,000 individuals¹⁰⁰ – collects data describing the sickness absence rates of workers in the labour market and the reasons given for their absence. Respondents choose from several options, one of which is ‘headaches and migraines’. The latest available data indicate that, of a total 137.3 million days lost through sickness absence, 2.8 million were attributable to ‘headaches and migraines’. This represents a 100% increase since 2012 (see Figure 3 below), indicating significantly more people reporting absence from work due to headache – for context, the increase in total days lost for this period was around 2% (137.4 million to 137.3 million).

Clearly this estimate is significantly lower than the above estimate of 40 million workdays lost. There are several possible reasons for this. Firstly, the interviewer conducting the LFS survey will not be an expert in migraine and is therefore reliant on the interviewee accurately self-reporting that headache or migraine symptoms prevented them from working. This is problematic because many people with migraine mistake their symptoms for ‘regular’ headache¹⁰¹ and less than 50% seek medical help¹⁰² and therefore do not get a formal diagnosis (even those that do often remain undiagnosed – an issue we explore in Chapter 4). This, combined with the widespread perception that headache symptoms are typically not considered ‘serious’ medical conditions – ‘everyone’ gets a headache from time to time¹⁰³ – may result in underreporting. Indeed, the people with migraine and experts we spoke to

⁹¹ APPG on Primary Headache Disorders. (2010).

⁹² Aged 16-65 years

⁹³ Aged 15-69 years

⁹⁴ Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 6, 2017, from: <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/13f50842e7cb4fca6de7e497f826c9f6>

⁹⁵ 32.2 million people as of January 2018: Office for National Statistics. (2018). UK labour market: January 2018. London: Office for National Statistics.

⁹⁶ £511 per week as of January 2018: Office for National Statistics. (2018). UK labour market: January 2018. London: Office for National Statistics.

⁹⁷ This assumes average number of days lost per person with migraine is 5.7, based on Steiner et al. (2003).

⁹⁸ APPG on Primary Headache Disorders. (2010).

⁹⁹ Stovner, L. J., & Andree, C. (2010). Prevalence of headache in Europe: A review for the Eurolight project. *Journal of Headache and Pain*, 11(4), 289–299.

¹⁰⁰ Office for National Statistics. (2015). Labour Force Survey (LFS) QMI. London: Office for National Statistics.

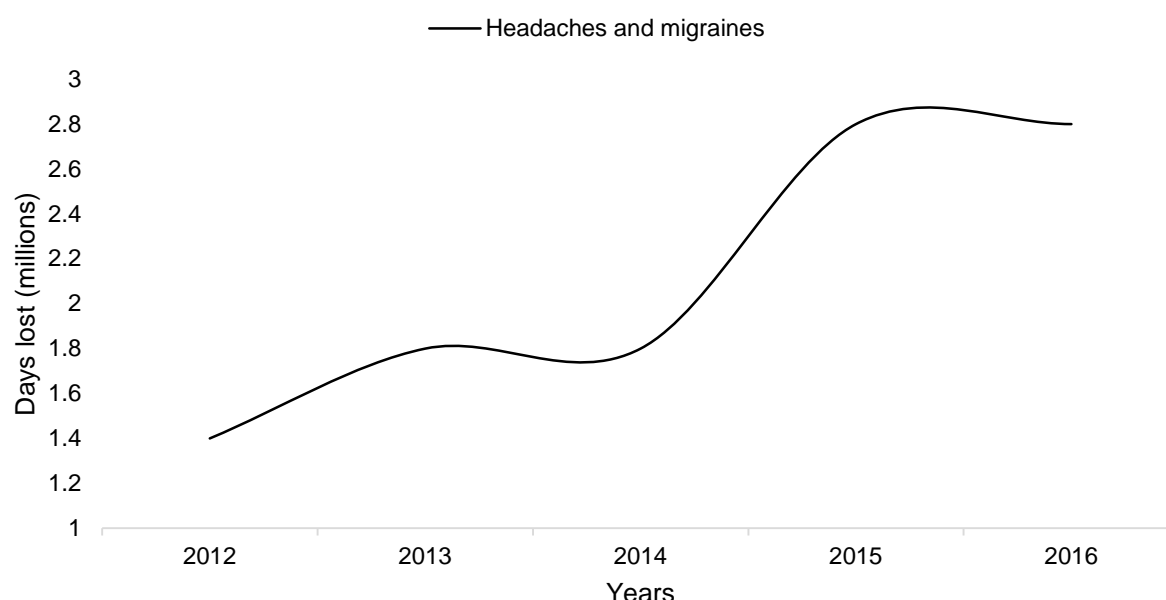
¹⁰¹ Linde, M., & Dahlöf, C. (2004). Attitudes and burden of disease among self-considered migraineurs – A nation-wide population-based survey in Sweden. *Cephalalgia*, 24(6), 455–465.

¹⁰² APPG on Primary Headache Disorders. (2014). *Headache Services in England*. London: Houses of Parliament.

¹⁰³ Stovner, L. J., Zwart, J. A., Hagen, K., Terwindt, G. M., & Pascual, J. (2006). Epidemiology of headache in Europe. *European Journal of Neurology*, 13(4), 333–345.

agreed that migraine and its symptoms are not, generally speaking, respected or seen as ‘genuine’ and, as a result, people with migraine can be reluctant to cite them as serious medical problems.

Figure 3 – Number of working days lost attributable to headaches and migraine, 2012-2016 (LFS data¹⁰⁴)



Another issue related to this, and to how the LFS collects data, is that interviewees are forced to choose a single reason for the absence. Given that migraine often involves symptoms like nausea and blurred vision, etc., it may end up being incorrectly categorised as ‘minor illnesses’ (responsible for the greatest number of days lost – 34 million¹⁰⁵) or ‘eye ... problems’. Again, the stigma surrounding headache may partly drive this. There is support for this in the literature: with sickness absence of people with migraine sometimes being attributed to co-morbidities¹⁰⁶. Indeed, mental health conditions like anxiety and depression are well known correlates of – and are thought to be caused by – migraine^{107,108} and, as a result, a significant proportion of people with migraine may be attributing lost workdays to these conditions (which are responsible for 15 million lost days) when in fact migraine is the underlying cause. Due to all of this, it is likely that the LFS significantly underestimates migraine’s contribution to the number of working days lost per year in the UK.

3.2.2 Presenteeism

Having explored the costs associated with absenteeism we now turn to so-called ‘presenteeism’, i.e. reduced effectiveness at work. Research suggests that people with migraine are more likely to report to work with symptoms – and work at reduced capacity –

¹⁰⁴ Office for National Statistics. (2017). Number of days lost through sickness absence by reason, 2009 to 2016, UK. November 28, 2017, from

<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/adhocs/007211numberofdayslostthroughsicknessabsencebyreason2009to2016uk>

¹⁰⁵ Office for National Statistics. (2014). Sickness absence in the labour market: 2016. Retrieved December 12, 2017, from <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/articles/sicknessabsenceinthelabourmarket/2016>

¹⁰⁶ Michel, P., Dartigues, J. F., Duru, G., Moreau, J., Salamon, R., & Henry, P. (1999). Incremental absenteeism due to headaches in migraine: Results from the Mig-Access French national cohort. *Cephalalgia*, 19(5), 503–510.

¹⁰⁷ Lampl, C., Thomas, H., Tassorelli, C., Katsarava, Z., Láinez, J. M., Lantéri-Minet, M., ... Steiner, T. J. (2016). Headache, depression and anxiety: associations in the Eurolight project. *Journal of Headache and Pain*, 17(1).

¹⁰⁸ Linde & Dahlof. (2004).

than take a day off¹⁰⁹ and there is indeed evidence to suggest that migraine-related presenteeism has an equal, if not greater, impact on work productivity than actual missed days^{110,111}. This point is underlined by the fact that migraine is one of the several ailments that are ‘commonly associated’ with presenteeism¹¹². The problem is that, relative to absenteeism, it is difficult to measure and therefore difficult to quantify¹¹³; estimating a worker’s ‘effectiveness’ or ‘efficiency’ at work is not an exact science.

Several instruments have been developed to measure workplace productivity loss. A recent review of them¹¹⁴ found that half of the instruments designed for this purpose have been developed explicitly for individuals with migraine – which is probably indicative of the significant impact it has on workplace productivity. Existing studies that have sought to measure the impact of presenteeism due to migraine have used a range of methods¹¹⁵. One method, which involves estimating ‘lost workday equivalents’¹¹⁶, has been adopted by several studies^{117,118,119}. With this method, people with migraine are asked to rate, from 0 to 100%, their level of ‘effectiveness’ at work on days they were experiencing migraine symptoms. If, for example, they worked two days in the previous month at 50% effectiveness, this would count as one ‘lost workday equivalent’, i.e. one day lost to sickness absence for that month.

Using this method, Clarke et al. surveyed 4,200 UK hospital trust staff, asking them to recall, over the previous three months, their level of effectiveness at work when affected by a migraine episode. On average, when affected by an episode, people with migraine were only 56% effective. This amounted to an equivalent of 5.5 days a year being lost¹²⁰. This same study reported only 2 days being lost to migraine-related sickness absence, thus, out of 7.5 workdays lost to migraine over 73% were attributable to presenteeism rather than absenteeism. A similar study conducted in the US, which estimated ‘reduced effectiveness workday equivalents’, interviewed 7,970 people with migraine via telephone, asking them to recall how effective they were at work over the last week/month/year when experiencing migraine. Although mean estimates for reduced effectiveness were not provided, it was reported that, on average, 2.9 days were lost to presenteeism and 1.3 to actual missed days each year, i.e. reduced effectiveness accounted for 70% of the total 4.2 amount of lost days.¹²¹ The findings of two additional studies employing similar methods are provided in Table 3 (below).

¹⁰⁹ Lofland, J. H., Pizzi, L., & Frick, K. D. (2004). A review of health-related workplace productivity loss instruments. *PharmacoEconomics*, 22(3), 165–184.

¹¹⁰ Steiner et al. (2003).

¹¹¹ Berg, J. (2004).

¹¹² Caverley, N., Cunningham, J. B. & MacGregor, J. N. (2007). Sickness presenteeism, sickness absenteeism and health following restructuring in a public service organisation. *Journal of Management Studies*, 44, 304-319

¹¹³ Blau, J. N. & Drummond, M. F. (1991). *Migraine*. London.

¹¹⁴ Lofland & Pizzi. (2004).

¹¹⁵ Berg. (2004).

¹¹⁶ Von Korff et al. (1998).

¹¹⁷ Clarke et al. (1996).

¹¹⁸ Stewart et al. (1996).

¹¹⁹ Von Korff et al. (1998).

¹²⁰ Clarke et al. (1996).

¹²¹ Schwartz, B. S., Stewart, W. F., & Lipton, R. B. (1997). Lost workdays and decreased work effectiveness associated with headache in the workplace. *Journal of Occupational and Environmental Medicine / American College of Occupational and Environmental Medicine*, 39(4), 320–327.

Table 3 – Studies estimating days lost to migraine-related absenteeism and presenteeism

Country	Time period	Method	Sample size	Definition	Effectiveness (%)	Actual days lost*	Equivalent days lost*	Total days lost*	Days caused by presenteeism (%)
United Kingdom ¹²²	3 months	Self-completed questionnaire	158	IHS	56	2.0	5.5	7.5	73.3
United States ¹²³	3 months	Daily diary	122	IHS	59	2.8	5.6	8.4	66.7
United States ¹²⁴	1 week / 1 month / 12 month	Telephone interview	7,970	IHS	-	1.3	2.9	4.2	69.0
United Kingdom ¹²⁵	3 month	Self-completed questionnaire	374	IHS	57	1.5	4.1	5.6	73.2
Netherlands ¹²⁶	2 weeks	Self-completed questionnaire	436	IHS	72	3.2	2.7	5.9	45.8
Totals	-	-	9,060	-	64.5	2.2	4.2	6.3	65.6

IHS = International Headache Society diagnostic criteria for migraine¹²⁷

**Per person with migraine per year*

¹²² Clarke et al. (1996).

¹²³ Von Korff et al. (1998).

¹²⁴ Schwartz et al. (1997).

¹²⁵ Cull R, Wells N, Moiechevich M (1992) The economic cost of migraine. *Br J of Med Econ* 2:103-115 cited in Berg. (2004).

¹²⁶ van Roijen, L., Essink-Bot, M. L., Koopmanschap, M. A., Michel, B. C., & Rutten, F. F. H. (1995). Societal Perspective on the Burden of Migraine in The Netherlands. *Pharmacoeconomics*, 7(2), 170–179 cited in Berg. (2004).

¹²⁷ International Classification of Headache Disorders. (2016). IHS Classification ICHD-3 Beta. Retrieved November 18, 2017, from <https://www.ichd-3.org/1-migraine/>

All of the studies mentioned so far estimated presenteeism by asking respondents to try and remember how effective they were when experiencing migraine over the last week, month, three months, etc. Such an approach can be prone to recall bias, where respondents systematically underreport due to the “common inclination to perceive oneself favourably”¹²⁸. A US study by Von Korff et al.¹²⁹ does not suffer from this limitation: 122 people with migraine, drawn from a population survey comprising 5,071 respondents, with regular paid employment, completed a daily diary over a 3-month period. The findings, in some respects, are comparable to those reported above. On the days people with migraine worked when experiencing headache their mean effectiveness was estimated at 59%. The number of workdays lost to this, however, is notably higher: 5.6 days were lost each year due to a reduction in work effectiveness. As with other studies, absenteeism accounted for fewer lost workdays (2.8), meaning that a total of 8.4 workdays were lost to migraine, thus, over 65% were attributable to presenteeism.

It is interesting to note that this study, which was not prone to respondents underreporting their reduced effectiveness, estimated the highest number of workday equivalents lost. This suggests that, potentially, the other studies discussed here underestimate the detrimental effect migraine has on employees’ effectiveness at work. This is significant because the average amount of days lost to presenteeism according to these studies (discounting the diary study) is still substantial: 3.2.

Although the diary-based study is arguably more reliable, because the recall period it used only covers three months (as is the case with the majority of the other studies mentioned above) it is prone to bias caused by seasonal variation¹³⁰. This can be counteracted by administering a survey over a 12 month period, as a recent study involving 7,200 employees of an automotive company in Turkey did. The study found that the average productivity loss per employee was 1.2 days a month, i.e. 14.4 days a year¹³¹. The vast majority of this was attributed to presenteeism rather than absenteeism for reasons largely specific to the workplace culture and country setting. As such, how much we can infer from this in relation to the UK is unclear, but it does at least provide some indication that, regardless of season, migraine-related presenteeism has a significant impact on workdays lost.

Although the sample of people with migraine we collected data from for the purposes of this report is very small ($n = 5$) – as is customary with qualitative inquiry – what they told us regarding the impact of their migraines on their ability to work is consistent with the evidence outlined above. Three of the five people with migraine we interviewed estimated their capacity when working with migraine at 50%, with the remainder estimating it at 70% and 0% (if they were not symptom-free they could not perform their job at all due to how demanding it was).

One of the people with episodic migraine we spoke to experienced migraines on “almost a weekly basis” and would always try to go into work despite their symptoms. On those days they estimated that they worked at “about 50% less capacity”, explaining how they were there “in body but not in spirit”. Assuming they worked two days each month at this capacity,

¹²⁸ Linde, M., Gustavsson, A., Stovner, L. J., Steiner, T. J., Barré, J., Katsarava, Z., ... Andree, C. (2012). The cost of headache disorders in Europe: The Eurolight project. *European Journal of Neurology*, 19(5), 703–711.

¹²⁹ Von Korff et al. (1998).

¹³⁰ Skagen, K., & Collins, A. M. (2016). The consequences of sickness presenteeism on health and wellbeing over time: A systematic review. *Social Science and Medicine*, 161, 169–177.

¹³¹ Selekler, H. M., Gökmen, G., Alvur, T. M., & Steiner, T. J. (2015). Productivity losses attributable to headache, and their attempted recovery, in a heavy-manufacturing workforce in Turkey: implications for employers and politicians. *Journal of Headache and Pain*, 16(1), 1–8.

they would lose one workday per month (i.e. 12 days a year). Another interviewee, who had chronic migraine and worked on 10 out of 16 days a month that they had symptoms, explained that working under the influence of a migraine one day would create more work for them the next, owing to the mistakes they would have likely made while operating at a lower capacity. Thus, studies estimating the impact on productivity on 'migraine days' alone may be missing residual effects carried over into subsequent days.

The studies reviewed in this section (see Table 3 above) provide a useful basis from which we can estimate the costs of migraine-related presenteeism in the UK. All of these studies were carried out in high income countries with similar sociodemographic profiles to the UK (two in fact were conducted in the UK) and all used established International Headache Society diagnostic criteria for migraine with a combined sample size of just over 9,000 people with migraine. The studies were in broad agreement with regards to the number of 'equivalent' days lost, i.e. those attributable to presenteeism rather than absenteeism (ranging from 4.2 to 8.4 with an average of 6.3). The same can be said of the proportion of total days lost: in all studies but one, over 65% of lost days were caused by reduced capacity at work (with an average of 65.6%). Given that our primary interest is in the UK it is worth noting that the two studies from this country produced the highest estimates (both being 73%).

These findings, combined with the data on absenteeism provided by Steiner et al.¹³², can be extrapolated to the present-day UK. We will provide a conservative estimate. Steiner et al. estimated that, every year, each person with migraine loses 5.7 days to absenteeism. Let us assume that this comprises a 50% share of total days lost (rather than the average of 34.4% reported by the studies above), meaning that 5.7 days would effectively be lost for each person with migraine to presenteeism every year. Using the 23.3% migraine prevalence estimate for adults¹³³ from GBD 2016, this would mean that almost 43 million workday equivalents are lost every year to reduced effectiveness at work at a cost of almost £4.4 billion in lost productivity.

A more conservative estimate, based on the 15% prevalence for adults¹³⁴ reported by Steiner et al. (and close to that of Eurolight¹³⁵), would produce an estimate of 28 million workday equivalents lost each year to reduced effectiveness at work at a cost of £2.8 billion in lost productivity.

It should be noted that the Steiner et al. estimate of 5.7 workdays lost is relatively high compared to some of the studies listed in Table 3 (above), relatively high. For example, the two other studies conducted in the UK estimated that only 2¹³⁶ and 1.5¹³⁷ days were lost each year to absenteeism. Although Steiner et al. had a bigger sample of people with migraine ($n = 574$ compared to 158 and 374, respectively) and used more recent data, it is not clear why their estimate of absenteeism is around three times larger than the other UK estimates. Steiner et al. do point out that the majority of lost days, 85% (4.8), were attributed to the "worst affected 10%"¹³⁸, meaning 90% of the sample were absent from work on 0.9 days a year. This is somewhat closer to the other estimates. The fact that the estimate from

¹³² Steiner et al. (2003).

¹³³ Aged 15-69 years

¹³⁴ Aged 16-65 years

¹³⁵ Stovner & Andree. (2010).

¹³⁶ Clarke et al. (1996).

¹³⁷ Cull et al. (1992). Cited in Berg. (2004).

¹³⁸ Steiner et al. (2003).

Clarke et al. is lower could be partly explained by the fact that their sample, which only consisted of employees, had, overall, a lower level of disability than the population-based study by Steiner et al. Another factor could be the age of the studies in question, with Clarke et al. and Cull et al. being conducted several years before Steiner et al. There are, however, few reasons to suggest why migraine-related absenteeism would have increased in the UK by that amount during the intervening period.

One possibility is that, when asked to estimate their absenteeism *and* presenteeism in a single survey, people with migraine may underestimate the impact of the former and, conversely, when asked only about absenteeism, overstate its impact. Though this is speculation, it is worth noting that the studies, discussed earlier in Section 3.2.1, estimating only absenteeism reported a higher range of 3-7 workdays being lost each year to migraine.

In addition, more recent data¹³⁹ comprising 8,271 participants from several Western European countries¹⁴⁰, collected for the Eurolight project, report a relatively high figure of 12.8 workdays lost to absenteeism and presenteeism combined¹⁴¹. The exact contribution of absenteeism to this overall figure is not given, but if we take the average of the studies in Table 3 (34.4%), that would mean 4.4 workdays are lost to absenteeism – which is closer to the estimate from Steiner et al.

3.2.3 Summary

The indirect costs in lost productivity attributed to migraine are substantial. By taking account of: (i) migraine prevalence in the UK estimated by GBD 2016, (ii) the size of the UK workforce and the average daily wage, and (iii) the latest UK estimate, from Steiner et al., of 5.7 days lost per person with migraine each year, we estimate that migraine-related absenteeism causes almost 43 million lost workdays every year at a cost of nearly £4.4 billion in lost productivity. Our second, more conservative, calculation based on a prevalence of 15% produces an estimate of 28 million workdays lost each year at a cost of £2.8 billion in lost productivity.

While the LFS gives a significantly different estimate we have given reasons for this. In any case, it still shows that the number of workdays caused by migraine (and headaches) has increased 100% since 2012.

Regarding migraine-related presenteeism, which by all accounts is more costly than absenteeism, we again produced two estimates. The first, which is higher, assumes the number of days lost each year to migraine-related absenteeism in the UK per person with migraine (5.7 according to Steiner et al.) accounts for 50% of total days lost, with reduced effectiveness at work accounting for the other 50%. This would mean that nearly 43 million workday equivalents are lost each year to migraine-related presenteeism at a cost of almost £4.4 billion lost productivity. A more conservative estimate, based on a calculation using 15% prevalence, would be 28 million workday equivalents lost each year to presenteeism totalling £2.8 billion in lost productivity.

Thus, when combined, absenteeism and presenteeism due to migraine cause the loss of 86 million equivalent workdays per annum at a cost of around £8.8 billion. This is based on an adult migraine prevalence of 23.3% and assumes that the equivalent of 11.4 days is lost per

¹³⁹ Not included in Table 3 as it only reports total days lost, i.e. not broken down by absenteeism and presenteeism

¹⁴⁰ Austria, France, Germany, Italy, Lithuania, Luxembourg, Netherlands, Spain and United Kingdom

¹⁴¹ Steiner, T. J., Stovner, L. J., Katsarava, Z., Lainez, J. M., Lampl, C., Lantéri-Minet, M., ... André, C. (2014). The impact of headache in Europe: principal results of the Eurolight project. *Journal of Headache and Pain*, 15(1), 1–11.

person with migraine each year. A more conservative calculation, using 15% adult prevalence, produces a still substantial estimate of 55 million equivalent workdays lost each year at a cost of more than £5.6 billion per annum.

Clearly, regardless of the estimate used, the cost is substantial. As Steiner himself puts it, accurately estimating indirect costs attributed to migraine is difficult because some of the data supporting them are imprecise, however: “the numbers are such that the message they give rise to is unambiguous”¹⁴²; the costs are simply too great for governments and employers alike to ignore (particularly when there are solutions – as we explore later in the report). Despite the scale of these costs, however, there are still reasons to suggest that they may underestimate the indirect economic impact. Firstly, people tend to underreport absence and reduced effectiveness at work for cultural reasons; secondly, common measures typically miss ‘hangover’ effects, i.e. where the following day’s productivity is reduced due to the need to check work performed while experiencing migraine symptoms; and thirdly, a person with migraine missing days or working at reduced capacity can create more work for colleagues and impact on their efficiency¹⁴³. Furthermore, so far we have only explored the indirect costs associated with migraine episodes, yet there is evidence that the burden of migraine extends beyond this.

3.3 Broader, indirect, costs associated with migraine

To fully appreciate the socioeconomic impact of migraine we must look beyond lost productivity attributed to migraine episodes. As such, in this section we consider the broader indirect costs attributed to migraine, which – although difficult to monetise – are significant.

3.3.1 The ‘interictal’ burden

As stated in the previous chapter, a significant proportion of people with migraine experience symptoms between migraine episodes, i.e. during an interictal state. The reasons for this are fairly straightforward. An individual who frequently experiences unpleasant migraines will inevitably seek to avoid them and in some cases worry about when they might next occur¹⁴⁴. This can cause avoidance behaviour and anxiety¹⁴⁵.

A recent study of 6,455 adults from 10 EU countries suggests this is the case: it found that around a quarter of people with migraine (26%) experience symptoms during the ‘interictal’ state (i.e. between attacks); on average people with migraine spend 317 days a year in this state¹⁴⁶. Furthermore, ‘interictal anxiety’ was reported by 10% of people with migraine and avoidance behaviour by about 15%. Although interictal anxiety differs to ‘general’ anxiety in that it is specifically related to anxiety about the next migraine episode it was found to be – perhaps unsurprisingly – correlated with it, though the direction of causation was unclear¹⁴⁷. This is significant given that anxiety is a known correlate of migraine¹⁴⁸ and itself contributes to lost productivity and public ill health¹⁴⁹ (something we explore Section 3.2.2).

¹⁴² APPG on Primary Headache Disorders. (2010)

¹⁴³ Schwartz et al. (1997).

¹⁴⁴ APPG on Primary Headache Disorders. (2010)

¹⁴⁵ Linde & Dahlof. (2004).

¹⁴⁶ Lampl, C., Thomas, H., Stovner, L. J., Tassorelli, C., Katsarava, Z., Láinez, J. M., ... Steiner, T. J. (2016).

¹⁴⁷ Lampl, C., Thomas, H., Stovner, L. J., Tassorelli, C., Katsarava, Z., Láinez, J. M., ... Steiner, T. J. (2016).

¹⁴⁸ Lampl, C., Thomas, H., Stovner, L. J., Tassorelli, C., Katsarava, Z., Láinez, J. M., ... Steiner, T. J. (2016).

¹⁴⁹ Henderson, M., & Madan, I. (2013). Mental health and work. In N. Mehta, O. Murphy, & C. Lillford-Wildman (Eds.), *Annual Report of the Chief Medical Officer 2013. Public Mental Health Priorities: Investing in the Evidence* (pp. 157–169). London: Department of Health.

Interictal anxiety and avoidance behaviour have implications for quality of life. People with migraine may, for example, be reluctant to perform certain activities they have identified as ‘triggers’ for their migraines¹⁵⁰. Also, leisure activities and social events may be avoided and, in the future, no longer planned¹⁵¹. A Swedish population survey comprising 423 people with migraine found that the majority (59%) reported a negative effect on leisure time¹⁵². The impact this has is difficult to measure but is likely to be negative for their health and wellbeing. Experiences reported by the five people with migraine we interviewed attest to this. For example, one of the people with chronic migraine we spoke to described how their long-term symptoms had “increased problems with stress and anxiety”, while another, with episodic migraine explained how their condition “needs constant attention and management”. Furthermore, all people with migraine talked about the lifestyle changes they felt forced to make due to their migraines in an attempt to manage them. This often impacted on their personal and, to a greater extent, their professional lives.

It has been suggested – and it is indeed plausible – that having migraine can have negative implications for career advancement and earnings¹⁵³. Findings from population-based surveys support this. Of 6,455 people with migraine in 10 EU countries, 7.4% believed their careers had suffered while 5.9% felt having migraine had reduced their lifetime earnings¹⁵⁴. Similar findings were reported in a Swedish population study of 423 people with migraine with 30% reporting a negative effect on their financial position. Again, our qualitative findings are very much supportive of this; all of the people with migraine we spoke to said their careers had been adversely affected in some way. Two of the five felt they had been ‘managed out’ of the workplace. Following two years of bad performance ratings one female interviewee ended up taking redundancy:

“when redundancy came up I was steered towards taking it and by that time I wanted to take it anyway” (Person with migraine)

They felt they had been singled-out because of their symptoms despite having worked for the organisation for many years. Another interviewee, who suffered chronic migraines, explained how her condition affected colleagues’ and managers’ perception of her:

“I’ve been viewed by a few people as being ‘unreliable’ [but I am] very reliable around the migraine” (Person with migraine)

Thus, despite being a competent worker when not having an attack, this interviewee still suffered from its effects in other ways.

Four of the five people with migraine we spoke to had specifically sought and found jobs that could be reconciled with their symptoms: two had taken a pay cut and accepted more junior roles, while another was restricted to informal work. One of the female interviewees with episodic migraine, put it bluntly:

“I don’t have a career. I have a job that pays my bills – I don’t feel able to pursue a career” (Person with migraine)

¹⁵⁰ Steiner et al. (2014).

¹⁵¹ Lampl, C., Thomas, H., Stovner, L. J., Tassorelli, C., Katsarava, Z., Laínez, J. M., ... Steiner, T. J. (2016).

¹⁵² Linde & Dahlof. (2004).

¹⁵³ Steiner et al. (2014).

¹⁵⁴ Lampl, C., Thomas, H., Stovner, L. J., Tassorelli, C., Katsarava, Z., Laínez, J. M., ... Steiner, T. J. (2016).

Case study 1 – Forgoing a career to manage living with migraine

This woman has had headaches since childhood but was diagnosed with migraine in her 20's – about thirty years ago. She experiences both menstrual and stress related migraine – generally without aura: “They are severe but they don't last as long as they used to – because I know how to treat them. They are never the same and I can't predict how each one will be. Some mild ones I can manage. But some are so painful I can't turn over in the bed. I can never predict where it will go at the start.” Establishing a routine is a key aspect of her strategy for managing life with migraine, but an attack leads to pressure points at work which in turn may trigger a secondary migraine.

She described the negative impact of migraine on her working life: “I don't have a career. I have a job that pays my bills – I don't feel able to pursue a career. I need a job where I am safe and kept in employment.” Though her current line manager is ‘understanding’ and ‘supportive’ and cannot ‘physically do anything better’, she still often goes into work when she is unwell – to reduce the number of sick days taken – with implications for her productivity: “I'm there in body but not in spirit. It takes me longer to do anything and I make mistakes... I work at about 50% less capacity. I literally just keep things ticking over – I don't get involved in anything that involves complicated thought.” Accommodation made by her employer included being able to make up time lost to migraine, and being able to take a day sick leave if needed without having to explain the reason. The employer also allowed adjustments to lighting.

In contrast to her current manager, some previous employers were not supportive: “when I've taken time off for migraine I have had to meet with my line manager and get a grilling about taking time off – with them asking why I've not cured my migraine – and being told that they have to monitor it. They think migraine is a euphemism for something else – she is not coming in today. The stress this causes is not helpful with managing migraine. My current employer doesn't do that. But it is very difficult when you not being there has an impact on other people and their workload.”

Limited income – a result of the negative impact of migraine – meant she was unable to afford to pay for alternative therapies she knew worked. For example, Indian head massage helps but it costs hundreds of pounds a month.

She lacks confidence in the ability of her GP to manage her migraine, saying they lacked the specialist knowledge that was needed; and suggests, “Diagnosis was slow because the GP wouldn't refer me but tried to treat me – I don't know why. It took another couple of years before I was put on the correct medication and that was because work were concerned and paid privately for a referral to a neurologist, who asked the GP to make a referral to the Migraine Clinic in London. The specialist identified that I was addicted to painkillers – medication overuse – and recommended a course of action for coming off that. I had to do that on my own because my GP wasn't happy that I'd seen a neurologist.

Another interviewee, who had episodic migraine, had been unable to find work since becoming unemployed as a result of his migraines 1-2 years ago. These findings are reflected in the population-based survey mentioned above: 2.1% of people with migraine sampled had specifically taken easier jobs and a smaller minority, 1.4%, had been unable to find work¹⁵⁵. These costs, though difficult to monetise, undoubtedly add to the substantial

¹⁵⁵ Lampl, C., Thomas, H., Tassorelli, C., Katsarava, Z., Laínez, J. M., Lantéri-Minet, M., ... Steiner, T. J. (2016). Headache, depression and anxiety: associations in the Eurolight project. *Journal of Headache and Pain*, 17(1).

socioeconomic burden attributable to migraine. Not only do they represent personal costs but also, due to reduced tax take, a financial loss to the exchequer.

3.3.2 Co-morbidities

There is evidence, from several studies, that suggest a higher probability of anxiety and depression occurring in people with migraine^{156,157,158,159}. Recently collected population-based data from 10 EU countries showed, using a sample of 6,624 people with migraine, that migraine was significantly associated with depression and anxiety and that people with migraine carried a 19.1% probability of co-morbid anxiety, 6.9% of depression and 5.1% of both, which was higher than the representative general population sample¹⁶⁰. Similar results are reported in a French nationwide survey comprising 2,245 people with migraine: compared with non-migraine subjects they were significantly more likely to report depression and anxiety¹⁶¹.

Our qualitative findings echoed these. All five mentioned that, at some point in their lives, they had experienced depressive symptoms and periods of anxiety. Two female interviewees with migraine, one chronic and one episodic, felt that their migraines, and the pervasive impact it had on their lives, had prompted these symptoms. Whereas two interviewees with episodic migraine, one man and one woman, perceived depression and anxiety (and stress) as triggers for their migraines. These findings are consistent with those reported in a recent review of clinical findings that the relationship between migraine and depression and anxiety is bi-directional (i.e. having one of these conditions increases your risk for developing the other and vice versa)¹⁶².

The co-morbid relationship between migraine and depression and anxiety is significant given the substantial indirect costs attributed to them. Data from the 2016 LFS show that, since 2009, the number of workdays lost to 'stress, depression and anxiety' has increased 17.2% from 12.8 million per year to 15 million¹⁶³. This represents a yearly cost to the economy in lost productivity of just over £1.5 billion. Of course, not all or even most of these cases are attributable to migraine but they are nevertheless indicative of the wider socioeconomic burden created by it.

3.3.3 Summary

Though difficult to quantify, it is clear that the broader indirect costs attributable to migraine – comprising those attributable to the interictal burden and co-morbidities – are significant in their own right and only add to the already substantial socioeconomic burden associated with lost productivity caused by migraine. They also entail personal costs that impact on the

¹⁵⁶ Lantéri-Minet, M., Valade, D., Géraud, G., Chautard, M. H., & Lucas, C. (2005). Migraine and probable migraine - Results of FRAMIG 3, a French nationwide survey carried out according to the 2004 IHS classification. *Cephalalgia*, 25(12), 1146–1158.

¹⁵⁷ Becker, C., Brobert, G. P., Almqvist, P. M., Johansson, S., Jick, S. S., & Meier, C. R. (2008). Migraine incidence, comorbidity and health resource utilization in the UK. *Cephalalgia*, 28(1), 57–64.

¹⁵⁸ Lampl, C., Thomas, H., Tassorelli, C., Katsarava, Z., Láinez, J. M., Lantéri-Minet, M., ... Steiner, T. J. (2016).

¹⁵⁹ Payne, K. A., Varon, S. F., Kawata, A. K., Yeomans, K., Wilcox, T. K., Manack, A., ... Blumenfeld, A. M. (2011). The International Burden of Migraine Study (IBMS): Study design, methodology, and baseline cohort characteristics. *Cephalalgia*, 31(10), 1116–1130.

¹⁶⁰ Lampl, C., Thomas, H., Tassorelli, C., Katsarava, Z., Láinez, J. M., Lantéri-Minet, M., ... Steiner, T. J. (2016).

¹⁶¹ Lantéri-Minet et al. (2005).

¹⁶² Antonaci, F., Nappi, G., Galli, F., Camillo, G., @bullet, M., Calabresi, P., & Costa, A. (2011). Migraine and psychiatric comorbidity: a review of clinical findings. *J Headache Pain*, 12, 115–125.

¹⁶³ Office for National Statistics. (2017). Number of days lost through sickness absence by reason, 2009 to 2016, UK.

November 28, 2017, from

<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/adhocs/007211numberofdayslostthroughsicknessabsencebyreason2009to2016uk>

quality of life people with migraine and their professional ambitions – something we explore in more detail in Chapters 5 and 6 respectively.

3.4 Direct costs attributed to migraine

Having explored the indirect costs associated with migraine we now turn our attention to the direct costs. Although outweighed by the indirect costs¹⁶⁴, they are still significant and therefore warrant attention.

3.4.1 Healthcare costs

Several studies have estimated the healthcare costs attributed to migraine. Evidence submitted to the 2014 All-Party Parliamentary Group (APPG) on Primary Headache Disorders suggests the direct cost to the NHS of headache treatment is estimated at £1 billion a year¹⁶⁵. This is based on a study of 18 general practices in south-east England with 488 eligible patients consulting general practitioners (GPs) for primary headache and 81 patients referred to neurologists¹⁶⁶. As such, it may not be representative of the UK as a whole. Furthermore, its focus is headache in general – rather than migraine specifically – so although it is a useful indicator it does not provide an accurate representation of the healthcare costs attributed to migraine.

The International Burden of Migraine Study (IBMS) has more recent cost data for migraine patients. Healthcare costs are estimated from visits to various healthcare professionals, diagnostic tests, headache-related procedures, nights spent in a hospital or clinic, total number of visits to the emergency department for headache-related treatment, and medications used¹⁶⁷. For the UK, it reported a total annual direct cost per migraine patient of €3,718 for people with chronic migraine ($n = 57$) and €857 for people with episodic migraine ($n = 1,013$)¹⁶⁸. This study offers useful insight into the cost differences between chronic and episodic migraine – which was the study's main aim – but it is difficult to extrapolate these patient data to the general migraine population given that many people experiencing headaches do not seek medical help¹⁶⁹. Furthermore, the study suffers from some limitations. Firstly, resource use data were collected as part of a voluntary online survey, necessitating internet access; and secondly, due to the survey's voluntary nature, it may be biased to more severe migraine participants¹⁷⁰. As the authors themselves acknowledge, the findings may not be generalisable and may overestimate costs. Due to this – and the fact it uses patient rather than population data – we cannot infer total UK healthcare costs attributed to migraine from these data.

Compared to the above two studies, the Eurolight project¹⁷¹ provides more comprehensive data collected from eight countries¹⁷² representing 55% of the adult EU population¹⁷³. Using data from 8,412 questionnaires, it estimates direct healthcare costs comprising outpatient

¹⁶⁴ Steiner et al. (2014).

¹⁶⁵ APPG on Primary Headache Disorders. (2014).

¹⁶⁶ Ridsdale, L., Clark, L. V., Dowson, A. J., Goldstein, L. H., Jenkins, L., McCrone, P., ... Seed, P. T. (2007). How do patients referred to neurologists for headache differ from those managed in primary care? *The British Journal of General Practice: The Journal of the Royal College of General Practitioners*, 57(538), 388–95.

¹⁶⁷ Bloudek, L. M., Stokes, M., Buse, D. C., Wilcox, T. K., Lipton, R. B., Goadsby, P. J., ... Martelletti, P. (2012). Cost of healthcare for patients with migraine in five European countries: Results from the International Burden of Migraine Study (IBMS). *Journal of Headache and Pain*, 13(5), 361–378.

¹⁶⁸ Bloudek et al. (2012).

¹⁶⁹ McCrone, P., Seed, P. T., Dowson, A. J., Clark, L. V., Goldstein, L. H., Morgan, M., & Ridsdale, L. (2011). Service use and costs for people with headache: a UK primary care study. *The Journal of Headache and Pain*, 12(6), 617–623.

¹⁷⁰ Bloudek et al. (2012).

¹⁷¹ See: http://www.i-t-b.org/index.cfm/spKey/horizontal_activities.learning.the_eurolight_project.html

¹⁷² Austria, France, Germany, Italy, Lithuania, Luxembourg, Netherlands, Spain

¹⁷³ Linde et al. (2012).

care, investigations, acute medications, hospitalisations, and prophylactics for a range of primary headache disorders including migraine. Mean per-person annual costs due to migraine amongst adults¹⁷⁴ in all countries was €1,222; the vast majority (93%) of this, however, was attributable to indirect costs (absenteeism, presenteeism), with the remainder – €85.54 – being attributable to direct, healthcare costs¹⁷⁵.

Methodologically, the Eurolight study is stronger than the two previously mentioned. Its major strength is that the populations of the countries it studied (180 million adults) make up 55% of the EU27 (385 million adults), and, as the authors point out, the country mix in the sample is representative of the EU27, in terms of population size, healthcare system set-up and income level¹⁷⁶ – its findings are therefore generalisable. Furthermore – and unlike the two studies described above – it captures data from people who had not sought medical help, were unemployed, not insured or diagnosed earlier and even counted medications that were not registered for diagnosis, or when bought over the counter¹⁷⁷. The evidence this study provides is, therefore, particularly useful for our purposes. Although it does have its limitations¹⁷⁸ – no study is perfect – we can, reasonably, apply its direct, healthcare cost estimates to migraine prevalence estimates for the UK.

The Eurolight estimates for mean per-person annual direct costs for migraine are €85.54, based on data collected between November 2008 and August 2009. Taking account of historical exchange rates¹⁷⁹ and inflation¹⁸⁰, we converted this value into 2017 GBP, resulting in a mean per-person annual direct cost for migraine of £94.03 in the UK. Applying this to the latest prevalence estimates from GBD 2016 for migraine in the UK amongst adults¹⁸¹ (23.3%¹⁸²), we calculate that healthcare costs attributable to migraine are in the region of £1 billion per annum in the UK¹⁸³. The main caveat to this is that the Eurolight data, although taken from several European countries, do not include the UK. While this is a limitation, the Eurolight study – as described above – is population-based and representative of the EU27 with regards to socio-demographics; therefore extrapolation to the UK is reasonable. Its validity is further underlined by the fact that the Eurolight study's cost estimates are concordant with those from previous studies¹⁸⁴.

As we did with the estimates on indirect costs we will provide a more conservative figure. Using the UK prevalence of 15% for adults¹⁸⁵ reported by Steiner et al.¹⁸⁶, which – as stated

¹⁷⁴ Aged 18-65 years

¹⁷⁵ Linde et al. (2012).

¹⁷⁶ Linde et al. (2012).

¹⁷⁷ Linde et al. (2012).

¹⁷⁸ Linde et al. (2012).

¹⁷⁹ Monthly average EUR to GBP exchange rate for August 2009 was 0.861822 (<http://www.x-rates.com/average/?from=EUR&to=GBP&amount=1&year=2009>); thus 85.56 2009 EUR was converted into 73.74 2009 GBP

¹⁸⁰ Using the Bank of England's 'inflation calculator', 73.74 2009 GBP was converted into 94.03 2017 GBP – inflation averaged 3.1% a year (<https://www.bankofengland.co.uk/monetary-policy/inflation>)

¹⁸¹ Aged 15-69 years

¹⁸² Institute for Health Metrics and Evaluation. (2017). GBD Results Tool. Retrieved December 16, 2017, from:

<http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2016-permalink/13f50842e7cb4fca6de7e497f826c9f6>

¹⁸³ This was calculated by multiplying the mean per-person healthcare costs for migraine in the UK (£94.03) by the number of adults aged 15-69 with migraine in the UK according to GBD 2016 (10,200,658 based on a prevalence of 23.3%). See Table 1, Chapter 2 for prevalence by age and sex

¹⁸⁴ Linde et al. (2012).

¹⁸⁵ Aged 16-65 years

¹⁸⁶ Steiner et al. (2003).

before – is very close to the Eurolight prevalence (14.7%¹⁸⁷), we estimate that healthcare costs due to migraine are just under £600 million¹⁸⁸.

Both estimates can, in some respects, be considered conservative. They do not take into account the cost of treating co-morbidities commonly associated with migraine, e.g. anxiety and depression (which we explored earlier in Section 3.3). People with migraine that also have co-morbidities will likely be more reliant on NHS resources and therefore incur greater healthcare costs¹⁸⁹.

3.4.2 Hospital admissions

Having estimated the direct, healthcare costs attributed to migraine we now look at migraine-related hospital admissions. Our analysis of Hospital Episode Statistics (HES) data reveals a marked increase in the use of hospital resources due to headache and migraine. Unless otherwise stated, the analysis in this section has been prepared using the data provided in the Public Health England (August 2017) Neurology Intelligence Network Hospital Activity Compendium¹⁹⁰.

In 2015/16, there was a total of 85,801 hospital admissions with an ICD-10 code¹⁹¹ indicating a primary diagnosis on admission episode of headache or migraine (in England amongst patients age 20 years or older). This is an increase of 17% on the total number of equivalent admissions in 2012/13. The biggest increase (53%) was in the number of day case admissions – however the total number of this type of admission (12,612) was lower than the number of ordinary inpatient admissions (73,189). The latter increased by 12% over the same period. By way of context, population growth over the same period was about 3%¹⁹². Figure 4 (below) illustrates these findings.

Figure 4 – Inpatient and day case admissions, 2012 to 2016¹⁹³

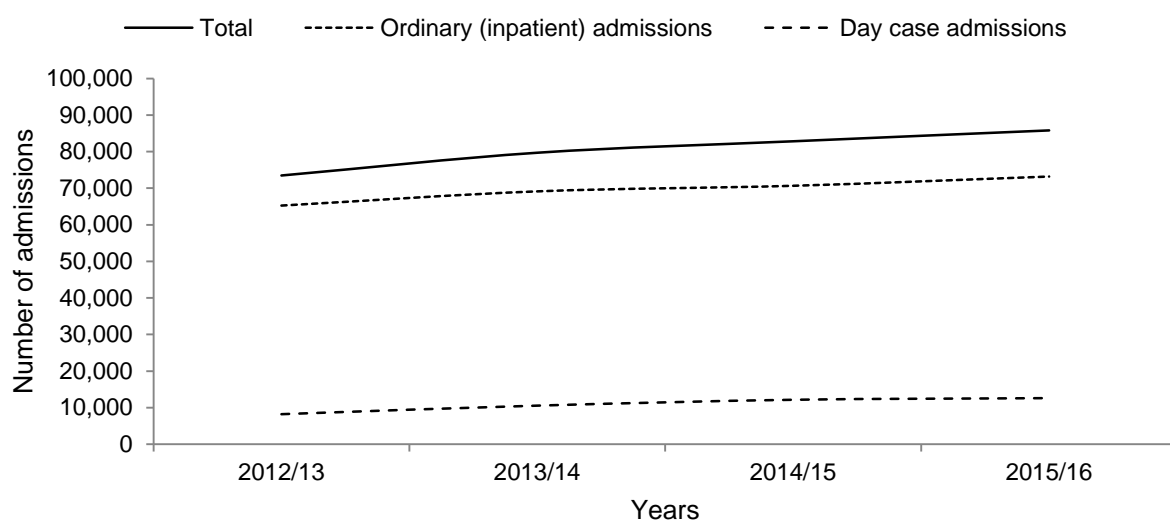


Chart shows hospital admissions with an ICD-10 code indicating a primary diagnosis on admission episode of headache or migraine (England, age 20+)

¹⁸⁷ Stovner & Andree. (2010).

¹⁸⁸ This was calculated by multiplying the mean per-person healthcare costs for migraine in the UK (£94.03) by the number of adults aged 16-65 with migraine in the UK according to a migraine prevalence of 15% taken from Steiner et al. (6,304,206).

¹⁸⁹ APPG on Primary Headache Disorders. (2014).

¹⁹⁰ See: <https://www.gov.uk/government/publications/neurology-services-hospital-activity-data>

¹⁹¹ International Statistical Classification of Diseases and Related Health Problems 10th Revision

¹⁹² Office for National Statistics. (2016). Overview of the UK population: February 2016.

¹⁹³ Analysis of data provided at: <https://www.gov.uk/government/publications/neurology-services-hospital-activity-data>

As illustrated in Figure 5 (below), analysis of the latest available HES data shows that emergency admissions now account for 97% of all hospital inpatient admissions with an ICD-10 code indicating a primary diagnosis on admission episode of headache or migraine. In addition, although there is evidence to suggest that emergency admissions are increasing in general¹⁹⁴, data for 2015/16 show that emergency admissions for headaches and migraine have increased 13% since 2012/13. This is a third higher than the increase seen across all neurological conditions (10%)¹⁹⁵. Although we cannot be certain of the cause, these data could indicate that people with migraine are increasingly relying on emergency services for medical care, rather than going through primary care. Indeed, on the basis of these data, it has been argued that the way in which these conditions are managed needs to be reviewed¹⁹⁶. This issue is explored in greater detail in the following chapter.

Change over time in the number of emergency admissions is of particular interest as this is where – according to the 2014 APPG on Primary Headache Disorders – there are likely to be significant, avoidable costs to the NHS¹⁹⁷. Headache is already the most common neurological reason for accident and emergency attendance and the data presented here and elsewhere¹⁹⁸ suggests admissions are rising.

Figure 5 – Emergency admissions as a percentage of all hospital inpatient admissions¹⁹⁹

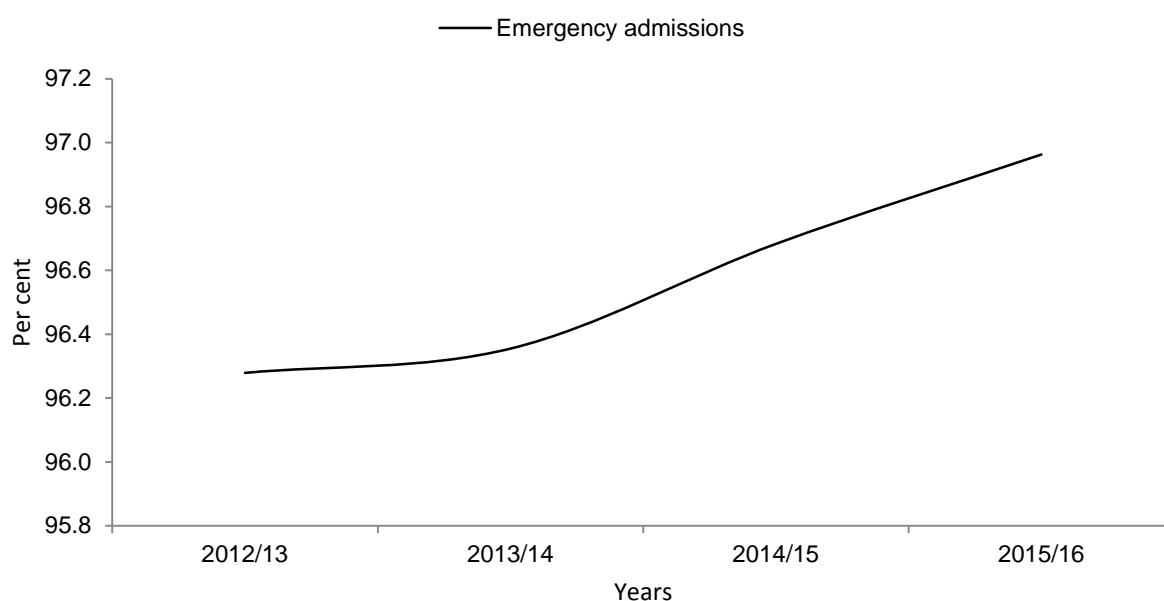


Chart shows hospital admissions with an ICD-10 code indicating a primary diagnosis on admission episode of headache or migraine (England, age 20+)

As illustrated in Figures 6 and 7 (below), analysis of the same HES data shows marked variations across the 44 Sustainability and Transformation Plans (STPs) in emergency admissions and the numbers in treatment²⁰⁰ between 2013/13 and 2015/16. The data show both admissions and numbers in treatment have increased for the vast majority of STPs, with only a few exceptions.

¹⁹⁴ National Audit Office. (2016). *Reducing emergency admissions*. London: National Audit Office.

¹⁹⁵ Analysis of data provided at: <https://www.gov.uk/government/publications/neurology-services-hospital-activity-data>

¹⁹⁶ Thams Valley Strategic Clinical Networks. (2017). *Headache pathway case for change*.

¹⁹⁷ APPG on Primary Headache Disorders. (2014).

¹⁹⁸ APPG on Primary Headache Disorders. (2014).

¹⁹⁹ Analysis of data provided at: <https://www.gov.uk/government/publications/neurology-services-hospital-activity-data>

²⁰⁰ 'In treatment' = the number of individuals using hospital services in a given year

Figure 6 – Percentage change, 2012/13 to 2015/16, in estimated emergency hospital admissions with an ICD-10 code indicating a primary diagnosis on admission episode of headache or migraine by STP region²⁰¹

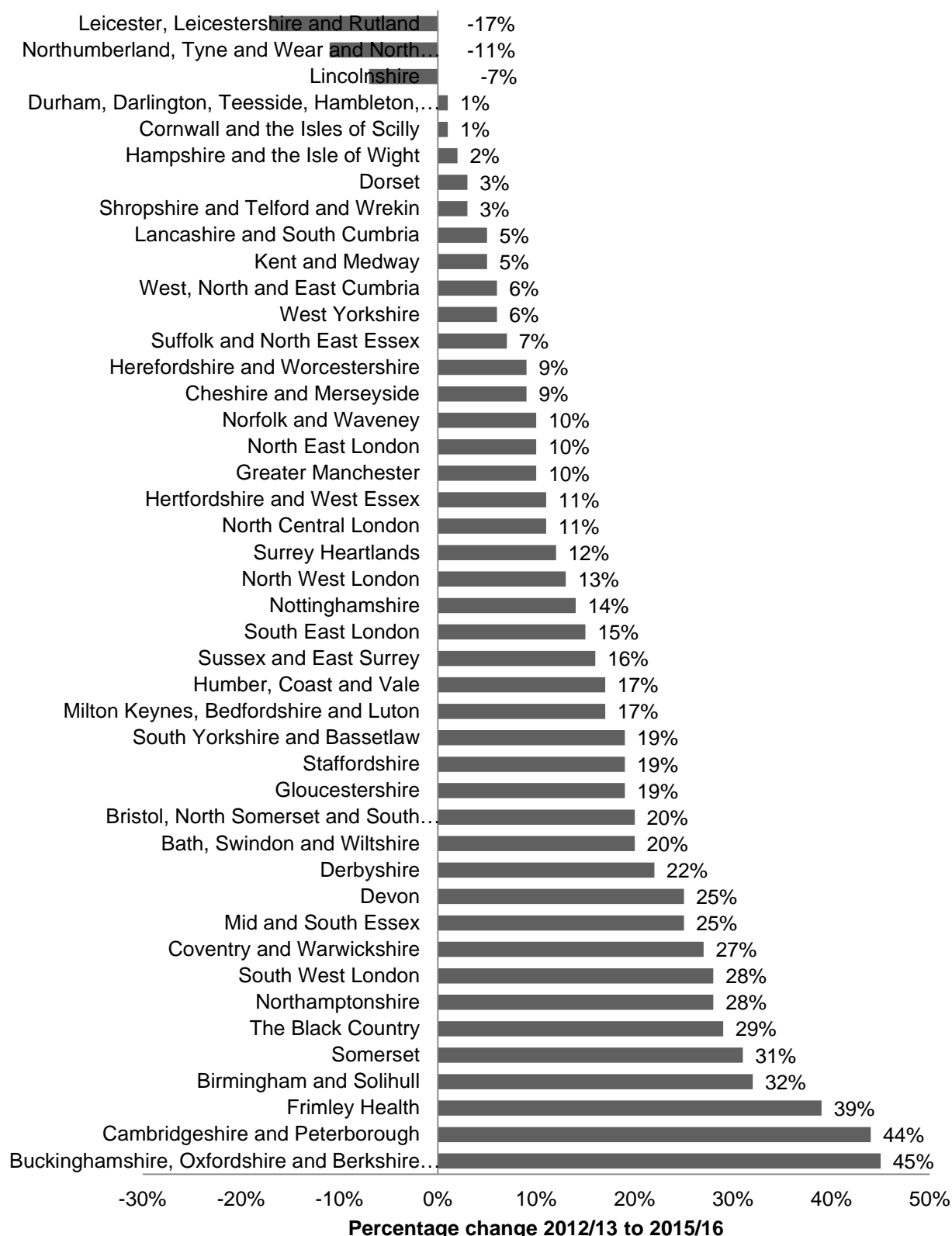


Chart shows hospital admissions with an ICD-10 code indicating a primary diagnosis on admission episode of headache or migraine (England, age 20+)

²⁰¹ Analysis of data provided at: <https://www.gov.uk/government/publications/neurology-services-hospital-activity-data>

Figure 7 – Percentage change, 2012/13 to 2015/16, in estimated numbers in treatment with an ICD-10 code indicating a recorded diagnosis of headache or migraine by STP region²⁰²

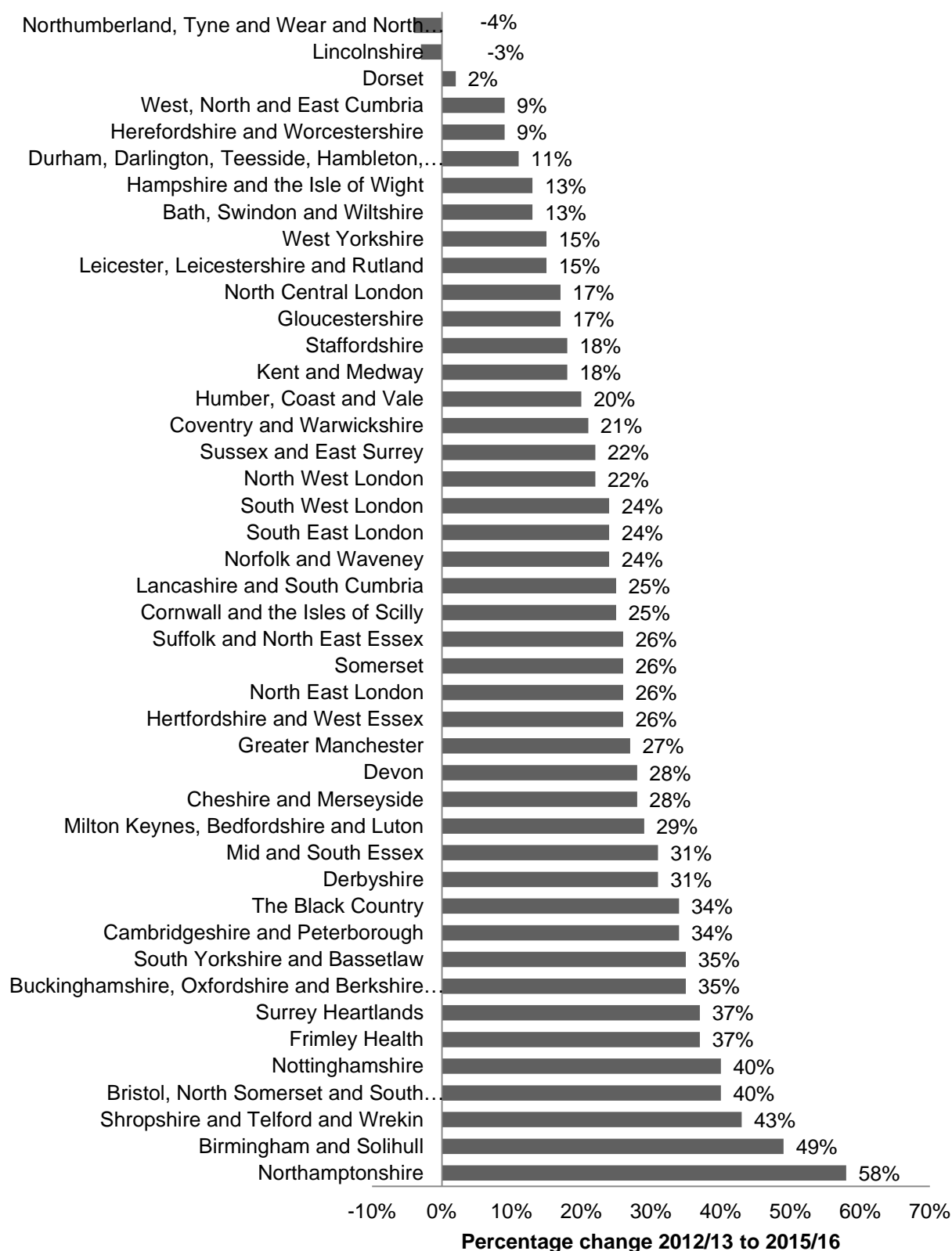


Chart shows numbers in treatment with an ICD-10 code indicating a recorded diagnosis of headache or migraine (England, age 20+)

²⁰² Analysis of data provided at: <https://www.gov.uk/government/publications/neurology-services-hospital-activity-data>

3.4.3 Summary

The evidence presented here shows that direct costs, although outweighed by indirect costs, are significant. These estimates may underestimate the true direct costs as co-morbidities are excluded. HES data analysis suggests hospital admissions for headache and migraine are rising and that emergency admissions, as a proportion of all inpatient admissions, are rising as well. This could be indicative of increasing reliance on emergency care for headache and migraine, which is expensive. Increases in emergency admissions and numbers in treatment across all STP regions – with a few exceptions – are evident.

3.5 Concluding comments

Based on the latest adult migraine prevalence data from GBD 2016 (23.3%), migraine-related absenteeism causes the loss of almost 43 million workdays every year in the UK at a cost of nearly £4.4 billion. A more conservative estimate, using 15% prevalence, indicates 28 million days are lost per annum, costing £2.8 billion. Assuming that migraine-related presenteeism has an equal impact on lost work productivity (published studies suggest the impact is greater), it would be responsible for the equivalent of 43 million workdays lost, costing £4.4 billion (using GBD prevalence data). Using a lower prevalence, 28 million workday equivalents would be lost each year costing around £2.8 billion.

Thus, when combined, absenteeism and presenteeism account for the loss of around 86 million equivalent workdays a year (11.4 for each person with migraine) at a cost in the region of £8.8 billion in lost productivity. A more conservative calculation, using 15% prevalence, produces an estimate of 55 million equivalent workdays lost at a cost of more than £5.6 billion per annum.

Although small in comparison, direct costs (comprising outpatient care, investigations, acute medications, hospitalisations, and prophylactics) are still significant: almost £1 billion per annum assuming an adult prevalence of 23.3% – or £600 million assuming 15% prevalence.

When both indirect and direct costs are combined, the economic burden of migraine is of the order of £9.7 billion a year, with a more conservative estimate of £6.2 billion (using a lower prevalence). This indicates that direct costs are responsible for 10% of the total cost burden, with indirect costs making up the vast majority. This is line with the published literature²⁰³.

Even allowing for some imprecision – which to an extent is inevitable in calculating such costs – the economic burden migraine creates is substantial. On its own, it make a compelling case for the need for government action. The cost is simply too high to ignore – particularly when there are solutions (as explored later in the report). Furthermore, these estimates do not fully capture migraine's cost burden: they do not account for the impact of interictal symptoms and co-morbidities – both of which affect indirect and direct costs. How these costs can be reduced is explored in the following chapters.

²⁰³ Linde et al. (2012).

4 Barriers to optimal care for people with migraine

4.1 Introduction

Having assessed the prevalence of migraine in the UK and the costs associated with it, we now turn our attention to the barriers people with migraine face to getting optimal care and the self-management strategies they use. Thus, this chapter of the report will answer the following research questions:

3. What are the barriers to optimal care for people with migraine and how can they be addressed?
4. What strategies do people with migraine use to manage their condition and how effective are they?

This chapter is divided into three parts. The first considers the barriers to efficient and effective care and management of migraine from the perspective of people with the condition. The second part looks at this issue from the experts' point of view and discusses potential solutions. The third and final part explores the coping and self-management strategies people with migraine use and their effectiveness.

4.2 Migraineurs' experience of care

In this section we explore migraineurs' experience of care, drawing on our interview findings and the relevant literature. We consider their level of satisfaction with the care they receive; their experience with delayed diagnosis and misdiagnosis; the importance of finding a GP that understands; their use of prophylactic medication; non-pharmacological therapies; and, finally, getting a referral to a specialist.

4.2.1 Satisfaction with care

In general, the people with migraine we spoke to were not satisfied with their care and often described it in negative terms. This finding is consistent with evidence from the literature that indicates low levels of satisfaction with the care people with migraine receive^{204,205}. For example, one of the interviewees, a woman with chronic migraine, described her frustrations with primary care:

"Because you can only see your GP for 5-10 minutes it feels like you're getting a 'oh here you go just try this and get out'" (Person with migraine)

They felt their GP did not engage with their condition in a meaningful way – although they seem to attribute this to a systemic problem with the health system (i.e. the lack of time GPs can spend with individual patients, rather than a lack of concern or interest). However, another female interviewee, who had episodic migraine, reported a similar experience and did attribute it to a lack of interest from GPs:

"Doctors just aren't interested in us. They don't appreciate – and this is a generalisation – how serious it is or could become" (Person with migraine)

This perception – that GPs, regardless of the reason, do not show enough interest in or concern for people with migraine – may be related to the following finding. Interviewees had low expectations of, and a lack of confidence in, physicians' ability to provide effective care

²⁰⁴ Rutberg, S., & Öhrling, K. (2012). Migraine - More than a headache: Women's experiences of living with migraine. *Disability and Rehabilitation*, 34(4), 329–336.

²⁰⁵ Migraine Trust. (2018). Facts and figures. Retrieved February 7, 2018, from <https://www.migrainetrust.org/about-migraine/migraine-what-is-it/facts-figures/>

and solutions to their symptoms. For example, one interviewee – a man with episodic migraine – did not see much point in seeing his GP:

“I’ve resigned myself to the fact it won’t go away and there isn’t much I can do to stop it” (Person with migraine)

This sense of resignation – that nothing can be done to relieve symptoms – is also reported in the literature^{206,207}. Indeed, many people with migraine feel that a physician can do nothing to help them: findings from a UK population-level survey found that almost one in four (22%) migraine patients cited this as the reason for never consulting a physician for headache and over a quarter (26%) gave it as the reason for lapsing from care²⁰⁸. Similar findings were reported in a Swedish nation-wide survey²⁰⁹. This is also reflected in qualitative research; a recent study of people with chronic migraine reported their frustration with the lack of improvement in their condition despite seeing a specialist and taking medication²¹⁰.

4.2.2 Delayed diagnosis and misdiagnosis

The people with migraine we spoke to also reported not being believed by their GP, which contributed to their dissatisfaction with their care. For example, one interviewee, a woman with chronic migraine, described her frustration at trying to get a diagnosis, having initially been told that she “must have tension type headache or something else”. There is support for this in the literature²¹¹.

Not being believed played a key role in difficulties people with migraine faced getting a diagnosis and their experience of misdiagnosis, which was a common theme in the interviews. Again, there is support for this in the literature^{212,213}. A recent study concluded that, despite migraine being a frequent reason for presentations to primary care, “misdiagnosis is a significant problem”²¹⁴.

In our interviews with experts it was often suggested that just 50% of people with migraine have been diagnosed – a claim that is supported by published evidence²¹⁵. Other studies, however, have found the extent of undiagnosed migraine to be lower. For example, in a UK-population level survey, a third of respondents who were categorised as having migraine, i.e. fulfilling the relevant diagnostic criteria, had not received a medical diagnosis²¹⁶. Comparable data from a US survey reported it being closer to half of all people with migraine (44%)²¹⁷.

²⁰⁶ Silberstein, S. D. (2016). Considerations for management of migraine symptoms in the primary care setting. *Postgraduate Medicine*, 128(5), 523–537.

²⁰⁷ British Association for the Study of Headache. (2012). *BASH Guidelines 2010*. Retrieved December 10, 2017, from <https://www.bash.org.uk/guidelines/>

²⁰⁸ Lipton, R. B., Scher, A. I., Steiner, T. J., Bigal, M. E., Kolodner, K., Liberman, J. N., & Stewart, W. F. (2003). Patterns of health care utilization for migraine in England and in the United States. *Neurology*, 60(3) cited in Silberstein. (2016).

²⁰⁹ Rutberg & Öhrling. (2012).

²¹⁰ Palacios-Ceña, D., Neira-Martín, B., Silva-Hernández, L., Mayo-Canalejo, D., Florencio, L. L., Fernández-de-las-Peñas, C., ... Cuadrado, M. L. (2017). Living with chronic migraine: a qualitative study on female patients' perspectives from a specialised headache clinic in Spain. *BMJ Open*, 7(8), e017851.

²¹¹ Rutberg & Öhrling. (2012).

²¹² Cevoli, S., D'amico, D., Martelletti, P., Valguarnera, F., Del Bene, E., De Simone, R., ... Cortelli, P. (2009). Underdiagnosis and undertreatment of migraine in Italy: A survey of patients attending for the first time 10 headache centres. *Cephalalgia*, 29(12), 1285–1293.

²¹³ Kernick, D., Stapley, S., & Hamilton, W. (2008). GP's classification of headache: Is primary headache underdiagnosed? *British Journal of General Practice*, 58(547), 102–104.

²¹⁴ Silberstein. (2012).

²¹⁵ Rutberg & Öhrling. (2012).

²¹⁶ Lipton et al. (2003). cited in Silberstein. (2016).

²¹⁷ Lipton et al. (2003). cited in Silberstein. (2016).

It is not just those with less severe symptoms that remain undiagnosed. UK data suggest that almost two-thirds (64%) of people with migraine without a formal diagnosis experience “substantial disability”²¹⁸. This was reflected in our small sample of people with migraine: regardless of whether their migraine was episodic or chronic all but one had struggled to get a diagnosis.

Published qualitative research on living with migraine has described achieving a diagnosis as “a long and tortuous process, reminiscent of an obstacle course” often involving the person with migraine visiting several healthcare professionals before being diagnosed²¹⁹. One of the female interviewees with episodic migraine struggled to get a diagnosis from her GP and therefore sought one from a specialist – her GP did not support her with this. This process – getting a diagnosis – was often characterised as a ‘fight’. It required persistence, as this female interviewee with episodic migraine explains:

“Though I’d consulted many health professionals, doctors, alternative healthcare professionals, dentists, etc., over those years I don’t think anyone ever said to me it might be migraine” (Person with migraine)

This excerpt offers insight into the difficulties people with migraine face pursuing a diagnosis. As they indicate, the process can take years and requires the person with migraine to take the initiative.

4.2.3 Finding a GP that understands

People with migraine felt that the ‘invisibility’ of their condition was, in part, responsible for GPs doubting them and, in turn, their difficulties getting diagnosed. Indeed, much has been written about the nature of migraine being “always present, and yet invisible to others”²²⁰ and the often negative implications this has for their care – and life in general²²¹. It is therefore not surprising that the people with migraine we spoke to impressed upon us the importance of finding a GP that ‘got it’, i.e. understood what they were going through and the effect it had on them.

This is reflected in existing research: to provide effective care and approaches to managing the condition, it is important that the GP understands – or attempts to understand – the profound impact migraine has on their patient’s life^{222,223}. This is not easily achieved given how little time clinicians typically spend with their patients, though there are efficient ways of doing it, for example: providing reassurance by offering “information in the form of explanations”²²⁴ and showing “sincerity, support and involvement” during the consultation²²⁵. These principles are reflected in the British Association for the Study of Headache (BASH) guidelines, which stress the importance of listening to the patient²²⁶.

²¹⁸ Silberstein. (2016).

²¹⁹ Palacios-Ceña D. et al. (2017).

²²⁰ Rutberg & Öhring. (2012).

²²¹ Palacios-Ceña D. et al. (2017).

²²² Rutberg & Öhring. (2012).

²²³ Palacios-Ceña D. et al. (2017).

²²⁴ Probyn, K., Bowers, H., Mistry, D., Caldwell, F., Underwood, M., Patel, S., ... Pincus, T. (2017). Non-pharmacological self-management for people living with migraine or tension-type headache: A systematic review including analysis of intervention components. *BMJ Open*, 7(8).

²²⁵ Palacios-Ceña D. et al. (2017).

²²⁶ British Association for the Study of Headache. (2012).

Case study 2 – Delayed diagnosis presents additional barriers to working with migraine

This case study is of a 58 year old woman who started getting headache in her 20s but was not diagnosed with migraine until about four years ago, despite consultations with many health professionals, including doctors, alternative healthcare professionals and dentists. By this point she had already self-diagnosed after finding that a triptan bought over-the-counter was an effective remedy. However, it was not until some years later that she was finally diagnosed with migraine by a neurologist, after “a long process of seeing different health professionals”.

It was only when she was in her 50s that the migraine started to have an impact on her work: “I started getting headache more and more frequently so that four out of five days I had a headache and they were bad enough to affect my concentration at work and made it very difficult for me to function at work. I didn’t get aura or vomiting or visual disturbance. Only had pain itself.”

She believes that her problems at work were exacerbated because she did not talk to her line manager about the migraine: “But the situation at my work was very fraught and it was really stressful, there were numerous re-organisations going on and numerous changes of manager and director and it was all a bit crazy and I thought my position was vulnerable so I kept quiet”. She says that “foolishly in retrospect” she kept going into work: “I would’ve been better taking sick leave. And I had a stressful job and the stress got worse and the headaches got worse and it was all compounding each other”. When things became more stressful and the headaches got much worse, feeling unable to continue, she disclosed her condition. She was then placed in a less demanding role, but consequently lost her substantive post within the organisation, and the problems became worse: “I definitely had a problem with my subsequent manager not believing in the severity of my condition because... when they did the performance ratings at the end of the year he said my migraines hadn’t been ‘severe’ enough to justify the drop in performance”.

Limited access to an NHS neurologist care led her to pay privately for specialist care, and to see an acupuncturist and a physiotherapist: “because I was in despair at that point would’ve done anything”. At the private consultant appointment she had a thorough evaluation of her lifestyle and the changes she needed to make: “I put that down as a turning point in my treatment because before then I was always looking for a cure and I realised at that point there wasn’t really a cure out there and it’d be a long process and a lot of it was down to me.” As a result, she cut down on the medication and made lifestyle changes – helped by taking time off work – two months full-time and three months part-time doing a phased return to work, and then when she fully returned she reduced her working days from five to four. About a year later she took voluntary redundancy, though clearly feels this was something she was pushed into.

She got a new job in March 2017 and now works two days a week: “the new job is more junior, less well paid, less stressful so I can now manage migraine within those parameters”. She says that working two days a week she does not need to have time off for migraine: “because I can always make it up some time later in the week”. A key benefit of her current job is that it is flexible, and that was one of the main reasons why she took up the job: “that suits me really well”. However, she did not disclose her condition until she had been in the job about six months.

This was a common theme in our interviews. For example, a male interviewee with chronic migraine explained that:

“I’ve had a considerable amount of problems with GPs but now I’ve got one I think I can work with... he is listening rather than coming to conclusions, we actually sit and discuss together” (Person with migraine)

This interviewee had been undiagnosed for years and struggled to manage his condition effectively, but having found a GP that listens he is more optimistic – again underlining the importance of showing understanding.

Listening to the patient is an effective means of enabling co-production, i.e. ‘working with’ rather than ‘doing to’²²⁷. Most of the people with migraine we spoke to had found a GP that listened to them and, as one interviewee put it, could ‘work’ with. However, the process had often been one of trial and error, and they frequently reported negative experiences of GP attitudes to their condition in the past. One example was that GPs would recommend treatments the patient had already tried and found to be ineffective:

“Every time I have to re-register and see a new doctor ... they always think they will be able to cure my migraines— ‘you need to go on this and this and this’ – and I’m like ‘no, I’ve tried that’” (Person with migraine)

This excerpt, from a female interviewee, provides insight into the frustration caused by not being listened to. This specific situation, according to a recent qualitative study involving people with chronic migraine, can hinder the physician-patient relationship:

“When a doctor prescribes a treatment that has already been tried unsuccessfully in the past, when inefficient treatments are maintained for a long time, when migraine is viewed as a minor symptom or affliction”²²⁸

Thus, to provide effective care and ways of managing migraine, it is important that physicians listen to and, in turn, co-produce solutions with their patients.

4.2.4 Prophylactic (preventative) medication

Of the five people with migraine we spoke to, three had tried prophylactic medication with varying degrees of success. One of the female interviewees, who had chronic migraine, initially avoided using them due to the associated tiredness but now uses them effectively, reducing her ‘migraine days’ from 16 to six per month. This contrasts with the experience of another interviewee, a woman with episodic migraine, who takes preventative medication everyday but is unsure whether it helps or not, adding that she has: “taken loads but this was the only one without nasty side-effects”.

Her experience compares with another of our interviewees; a man with chronic migraine who had tried prophylactic medication but discontinued it due to troublesome side effects with stress and anxiety. He described trying many different medications to manage his migraine attacks – none of which were effective without causing unwanted side effects. This issue is recognised in the literature. Due, in part, to “limited efficacy and significant tolerability and safety issues with available preventive therapies”²²⁹, many people with migraine – as many

²²⁷ NHS England. (2016). Joining up “co-production” and “patient leadership” for a new relationship with people who use services. Retrieved January 5, 2018, from <https://www.england.nhs.uk/blog/david-mcnally/>

²²⁸ Palacios-Ceña D. et al. (2017).

²²⁹ Mannix, S., Skalkicky, A., Buse, D. C., Desai, P., Sapra, S., Ormeier, B., ... Hareendran, A. (2016). Measuring the impact of migraine for evaluating outcomes of preventive treatments for migraine headaches. *Health and Quality of Life Outcomes*, 14(1).

as 40% – who might benefit from preventative treatment do not use it²³⁰. This raises the possibility that (i) there is significant unmet medical need for migraine prophylaxis²³¹ and (ii) preventative therapy would benefit many more of those with migraine than currently receive it²³².

Insights gained from existing qualitative research into people's lived experience of migraine – supported by our own qualitative findings – suggests people with migraine have “low expectations” and “fear of side effects” which made “using acute medications more acceptable than using prophylactic drugs on a daily basis”²³³. For example, one of the male interviewees with episodic migraine was reluctant to try preventative medication, partly because he thought they would not be effective, but also because he was more comfortable using painkillers.

It should be pointed out that preventative medication, although it has been shown to be effective in the treatment of migraine by numerous studies²³⁴, and underutilised²³⁵, should not be offered to all patients. It is usually considered when “headache frequency or severity increases to a point when it is significantly interfering with work, school or social life”²³⁶. Exactly what ‘significant interference’ amounts to is open to interpretation and the criteria for preventative treatment have been described as “somewhat arbitrary”²³⁷. Although people with chronic migraine – as one might expect – normally meet these criteria²³⁸ there is uncertainty, due to a lack of high quality evidence (from randomised controlled trials), over when an individual should be offered preventative drugs for migraine²³⁹.

Despite this, the National Institute for Health and Care Excellence (NICE) does provide some specific criteria for preventative treatment, suggesting that it should be considered if “attacks are causing frequent disability (for example, if there are two or more attacks per month that produce disability lasting for 3 days or more)” and if the person is at risk of medication overuse headache (MOH)²⁴⁰. This corresponds with our qualitative findings: of the three people with migraine we spoke to that used preventative therapies, two had chronic migraine.

In addition to these specific criteria NICE recommend that an individual's broader circumstances should inform whether they are offered preventative medication, suggesting that the following should be taken into account: “the person's lifestyle (such as their job and extent of absenteeism) and their attitude to chronic medication”²⁴¹. The fact that only three of the people with migraine we interviewed had used preventative therapies despite all of them reporting significant problems at work (as we explore in more detail in Chapter 5) – i.e. meeting the above criteria – may be indicative of the variable and inconsistent care people

²³⁰ Weatherall, M. W. (2015). The diagnosis and treatment of chronic migraine. *Ther Adv Chronic Dis*, 6(3), 115–123.

²³¹ Mannix et al. (2016).

²³² Dekker, F., Knuistingh Neven, A., Andriessse, B., Kernick, D., Reis, R., Ferrari, M. D., & Assendelft, W. J. J. (2012). Prophylactic treatment of migraine; The patient's view, a qualitative study. *BMC Family Practice*, 13.

²³³ Palacios-Ceña D. et al. (2017).

²³⁴ Weatherall. (2015).

²³⁵ Lipton, R. B., Bigal, M. E., Diamond, M., Freitag, F., Reed, M. L., & Stewart, W. F. (2007). Migraine prevalence, disease burden, and the need for preventive therapy. *Neurology*.

²³⁶ Weatherall. (2015).

²³⁷ Lipton et al. (2007).

²³⁸ Weatherall. (2015).

²³⁹ National Institute for Health and Care Excellence. (2018). Clinical Knowledge Summaries: Migraine. Retrieved February 2, 2018, from <https://cks.nice.org.uk/migraine>

²⁴⁰ National Institute for Health and Care Excellence. (2018).

²⁴¹ National Institute for Health and Care Excellence. (2018).

with migraine receive, which was a notable theme both in our interviews and in the literature²⁴².

4.2.5 Non-pharmacological therapies

There is some evidence to suggest that non-pharmacological treatments, such as acupuncture and psychological interventions, may be beneficial for people with migraine²⁴³. One of the experts we spoke to told us that a significant amount of people with migraine have sought such therapies. Two interviewees we spoke to had done so. Another, who had episodic migraine, claimed that while going through a period of seeing various healthcare professionals she saw an acupuncturist several times which “helped initially” but was too expensive to sustain. A recent Cochrane Review²⁴⁴ concluded that while there is evidence of the effectiveness of acupuncture for migraine, methodological problems make it difficult to draw strong conclusions²⁴⁵.

Regarding psychological interventions, evidence suggests that when used in chronic pain management they may be associated with positive outcomes²⁴⁶, particularly when delivered to people in groups²⁴⁷. Though, again, it is difficult to draw strong conclusions given the heterogeneity in the trials that the evidence is drawn from²⁴⁸. One of the interviewees, a man with chronic migraine, was offered to attend a course provided by the local mental health unit and, although he wanted to attend, it was cancelled. NICE guidelines do not include recommendations for non-pharmacological treatment in people with migraine – although they do recommend a course of acupuncture for another primary headache disorder – tension-type headache²⁴⁹. BASH guidelines, however, do indicate that these approaches may be beneficial²⁵⁰ and our limited evidence suggests people with migraine would be willing to try them. However, this may simply be a reflection of their willingness to ‘try anything’ owing to their dissatisfaction with ‘conventional’ therapies and the emotive nature of the condition. As such, there is potentially a need for better patient education highlighting the limitations of the evidence underpinning these therapies, or, conversely, inclusion of them in guidelines but with necessary caveats.

4.2.6 Referral to a specialist

All the people with migraine we spoke to had seen a specialist – specifically a neurologist – at some point during their migraine ‘journey’. Most of them reported GP reluctance to refer them for this specialist care and they characterised this experience as having to ‘fight’ or ‘push’ to get a referral – they suspected this was due to cost-saving. Their dissatisfaction with the care their GP provided and the problems they had getting a diagnosis (explored earlier in Sections 4.2.1 and 4.2.2) played a big part in this. One of our interviewees in particular was justified in this approach: upon seeing a neurologist (privately) she was diagnosed with MOH and given a recommended course of action – despite this her GP was reportedly unhappy she had seen a neurologist.

²⁴² APPG on Primary Headache Disorders. (2014). *Headache Services in England*. London: Houses of Parliament.

²⁴³ Sándor, P. S., & Afra, J. (2005). Nonpharmacologic treatment of migraine. *Current Pain and Headache Reports*, 9(3), 202–205.

²⁴⁴ Cochrane Reviews are systematic reviews of primary research in human health care and health policy, and are recognised as the highest standard in evidence-based health care resources

²⁴⁵ Sándor & Afra. (2005).

²⁴⁶ Nichols, V. P., Ellard, D. R., Griffiths, F. E., Kamal, A., Underwood, M., & Taylor, S. J. C. (2017). The lived experience of chronic headache: a systematic review and synthesis of the qualitative literature. *BMJ Open*, 7(12).

²⁴⁷ Probyn et al. (2017).

²⁴⁸ Probyn et al. (2017).

²⁴⁹ Probyn et al. (2017).

²⁵⁰ British Association for the Study of Headache. (2012).

Whether this was the optimum treatment pathway or not, there was a strongly held belief amongst the people with migraine we spoke to that, in order to get ‘proper’ treatment, one had to see a specialist. For example, one of the interviewees, a woman with chronic migraine, felt that:

“You have to fight to get the right diagnosis and treatment. You can’t leave it up to a GP” (Person with migraine)

Existing qualitative research reports similar themes: a study involving people with chronic migraine describes their frustration at what they perceived as the clinician’s failure to refer them to a specialist²⁵¹. This desire to see a specialist is probably due in part to the fact that GPs find it difficult to diagnose and manage the condition properly²⁵². However, as we explore in more detail in Section 4.3, most migraine patients do not need to see a specialist and could be treated in primary care providing GPs have the necessary knowledge and expertise. As one of our interviewees, who had chronic migraine, explains, she did not necessarily want to see a specialist but felt the GP could not provide her with enough information about her condition and what to do about it.

4.2.7 Summary

The satisfaction that people with migraine get from the care they receive is generally low, which is, in part (from the evidence) attributable to their experiences of delayed diagnosis and misdiagnosis. They rarely believe their GP can help, partly because consultations are so short but also because they believe GPs are uninterested in migraine. Similarly, they have low expectations of the effectiveness of treatment, particularly prophylactics, and can be reluctant to use them. Thus, many people with migraine that might benefit from such treatment do not use it. This underlines the need for treatments to be aligned with what people with migraine want – i.e. for solutions to be ‘co-produced’ with them – rather than medication being foisted on them. As such, finding a GP that listened to them was considered important.

In addition, non-pharmacological therapies were generally welcomed by interviewees, though the evidence underpinning them has problems and the guidelines recommending them are lacking. This may indicate the need for more patient education on this matter, or further inclusion of them in guidelines with appropriate caveats – or further investigation into their potential benefits. Finally, there was evidence of a strongly held belief that GPs cannot help people with migraine and therefore they must be seen by a specialist – usually a neurologist. This is partly attributable to low expectations of GPs’ ability to treat them effectively, which, as we explore in the next section, may, to some extent, be justified.

4.3 Experts’ views on the barriers to efficient and effective care

In this section we explore the barriers to efficient, effective and more systematic care from the perspective of the experts we spoke to, comprising healthcare professionals, academics and third sector organisations, with reference to the relevant literature. In considering this more effective system for care we look at different dimensions including: the pathways for migraine patients; GPs’ capability with migraine and their referral behaviour; whether structured headache services might provide effective migraine care; and patients’ understanding of migraine and community pharmacists’ potential to help them manage it.

²⁵¹ Palacios-Ceña et al. (2017).

²⁵² Kernick et al. (2008).

4.3.1 The patient pathways for migraine are vague

A strong theme running throughout the expert interviews was the lack of clarity surrounding the patient pathways for treating migraine. This was also reported in the interviews with people with migraine, with one lamenting the lack of a 'gold standard' for treatment. The inconsistency of the care interviewees received reflects this. This aligns with a principal finding from the recent 2014 All-Party Parliamentary Group (APPG) report on primary headache disorders, which found "a lack of clearly defined pathways for headache patients across Clinical Commissioning Groups and Strategic Clinical Networks in England"²⁵³. All expert interviewees stressed that this problem was compounded by a lack of GP knowledge, which has been noted in the literature²⁵⁴ and was reported by the people with migraine we spoke to.

Although our review found that some elements of the care pathways – mainly those around the use of medication therapies in the acute stage or as prophylaxis – are supported by reasonably clear guidelines²⁵⁵, the evidence suggests that GPs do not make full use of them. A UK study of general practices in the UK found that established guidelines do not play a role in the diagnosis of patients presenting with headache²⁵⁶. As a result, underuse of the specific recommendations for diagnosing migraine may be a factor in the delayed diagnosis and misdiagnosis of migraine²⁵⁷. As made clear in Section 4.2.2 above, being unable to get a formal diagnosis caused patients a significant amount of frustration – indeed, an accurate diagnosis is not only the 'first step' to appropriate treatment but also allays patients' anxiety and fears of more serious underlying conditions²⁵⁸.

4.3.2 Lack of GP capability around migraine care

The expert interviews supported the findings from the people with migraine and published literature²⁵⁹ that those who do see a GP rarely get appropriate treatment and management. The experts attributed this, in part, to GPs' lack of education and training on the subject of headache and migraine. As a result they are unsure which treatments are appropriate for someone presenting with migraine and when to refer to a specialist. It was suggested that each GP has their own ideas about when to refer and may not do so when they should – as indicated by our interviews with people with migraine – or, they may do the opposite, and make unnecessary referrals. This is consistent with the literature which finds that GPs lack "competence and confidence" managing patients with headache and migraine²⁶⁰.

The experts we interviewed consistently identified the need for improved education and training as a means of improving GPs' capability to treat and manage people with migraine effectively. Interviewees were less clear, however, about how this could be achieved. Amongst them, a number had offered training and/or education to GPs in various formats but with limited success. Take up was low and all agreed that medical professionals were generally uninterested in migraine and headache. A link was frequently drawn here with the limited time spent on these issues in the medical curriculum – about one hour was frequently

²⁵³ APPG on Primary Headache Disorders. (2014).

²⁵⁴ Ridsdale, L., Doherty, J., McCrone, P., Seed, P., Clarke, L., Das, R., ... Steiner, T. (2008). A new GP with special interest headache service: Observational study. *British Journal of General Practice*, 58(552), 478–483.

²⁵⁵ National Institute for Health and Care Excellence. (2018).

²⁵⁶ Bösner, S., Hartel, S., Diederich, J., & Baum, E. (2014). Diagnosing headache in primary care: A qualitative study of GPs' approaches. *British Journal of General Practice*, 64(626), e532–e537.

²⁵⁷ Silberstein. (2016).

²⁵⁸ Silberstein. (2016).

²⁵⁹ Kernick et al. (2008).

²⁶⁰ Ridsdale et al. (2008).

mentioned – though it has been reported that “headache teaching is not on the curriculum for approximately 75% of the undergraduate medical schools in England”²⁶¹. It was pointed out that this lack of emphasis in medical training appears unjustified given that headache (with migraine being the most common diagnosis²⁶²) “is one of the most frequent causes of consultation in both general practice and neurological clinics”, and the most common neurological reason for visiting accident and emergency (A&E)²⁶³.

The logistical problem of achieving improvements in GP education around migraine were recognised, described by one expert as follows:

“Even if they [GPs] only need a few hours training how do you give it to them? ... most GPs will actually resist this training because they don’t think they need it, they don’t think headache is important and they don’t want to treat it, they’d rather push it up to specialist clinics” (Expert interview)

This same expert acknowledged that, at present, there are no obvious solutions to this problem. However, a recent pioneering study carried out in Estonia, which aimed to develop, implement and test an educational model to improve GPs’ ability to treat migraine effectively in a primary care setting, produced some positive results²⁶⁴. The intervention comprised two educational one-day (six hour) courses combined with educational materials and managerial aids for all participating GPs. The study reported less dependence on referral and greater willingness to initiate treatment²⁶⁵, providing some, albeit limited, evidence that structured educational programmes can positively affect GP behaviour.

Another expert was more sceptical about the efficacy of educational programmes. They suggested that improving GP knowledge, whilst necessary, was insufficient to effect change. Therefore, they recommended exploring the viability of placing alerts on the GP’s clinical system to ‘nudge’ them to make the right choices:

“Is there any way of having an alert on their system saying if someone’s got a headache and they’re looking for an opiate then actually that’s the wrong thing to prescribe... it might be something on their computer system that reminds them” (Expert interview)

This is consistent with the findings of a review into interventions that change clinician behaviour, which concluded that education is a necessary but not sufficient condition for behaviour change and is more effective if part of a multifaceted intervention combined with other reinforcing strategies²⁶⁶. Thus, the potential effectiveness of educational programmes combined with ‘nudges’ should be explored in future research. Empowering patients to take a more active role in the consultation could also play a part – something we explore in Section 4.3.5 below.

In addition to the problems associated with GPs’ capability, it was suggested that they lack awareness and understanding of the reality of life with migraine. As reported above in Section 4.2, this was a strong theme throughout our interviews with people with migraine

²⁶¹ Migraine Trust. (2018).

²⁶² Migraine Trust. (2018).

²⁶³ British Association for the Study of Headache. (2012).

²⁶⁴ Braschinsky, M., Haldre, S., Kals, M., Iofik, A., Kivisild, A., Korjas, J., ... Steiner, T. J. (2016). Structured education can improve primary-care management of headache: the first empirical evidence, from a controlled interventional study. *Journal of Headache and Pain*, 17(1).

²⁶⁵ Braschinsky et al. (2016).

²⁶⁶ The King’s Fund. (2006). *Interventions that change clinician behaviour: mapping the literature*. London: The King’s Fund.

and there is support for it in the literature; recent studies highlight the need for more qualitative research about the experience of migraine to “help healthcare providers develop a deeper understanding of the experience their patients are undergoing”²⁶⁷. However, the experts we spoke to suggested it is difficult to do this given the relatively short length of time – 10 minutes on average²⁶⁸ – that GPs spend with patients. This creates an additional problem: consultations are too short to be effective in terms of taking a full headache history and providing patients with advice about how to take their medicines:

“It’s really important you get the right dose and are taking it for several months before you know it’s effective – it’s often very difficult to get that across in a typical GP consultation” (Expert interview)

The average consultation length of 10 minutes in the UK is thought to be the shortest in the developed world²⁶⁹ and the British Medical Association have called for longer, 15 minute consultations, claiming that 10 minutes is insufficient to treat all patients properly²⁷⁰. Clearly people with migraine – and the GPs treating them – would benefit from longer consultations and there is some appetite for reform in this area. Thus, the barriers to providing people with migraine with effective primary care are not solely due to GPs’ lack of education, training and knowledge but also attributable to the relatively short time they can spend with patients.

4.3.3 Avoidable A&E presentations

As discussed in the previous section, GPs’ lack of capability around migraine can lead to unnecessary referrals to specialists, which “denies specialist access to some who really need it”²⁷¹. Experts pointed out that it can also cause avoidable A&E presentations. As one expert put it, current practice is a “very expensive” way of treating and managing migraine. Indeed, non-specialist healthcare providers in primary care should be able to meet the needs of most people consulting for headache and migraine²⁷². This would, however, require better organisation of headache services in the UK – a subject we turn to in the next section.

4.3.4 The organisation and delivery of migraine care

A potential solution to low GP capability with migraine, put forward by several experts, was to provide an intermediate – or community-based – clinic service staffed by GPs with a specialist interest (GPwSI) in headache and/or Clinical Nurse Specialists (CNS). They described what they saw as an ‘ideal’ model of care where GPs provided care for the majority of migraine patients, but in more complex cases – where GPs lacked certainty about diagnosis, treatment or management – they could refer to an ‘intermediary’ clinic:

“Having a community-based sort of care, whether run by a GPwSI or specialist nurse or some other allied health professional, but the majority of patients being seen in the community before they’re referred in [to a hospital], that seems to make sense... getting the diagnosis correct first time and getting them onto the right treatment early on... that will hopefully improve that” (Expert interview)

²⁶⁷ Rutberg & Öhring. (2012).

²⁶⁸ BBC. (2017). NHS Health Check: Short GP consultations crazy, say GPs. Retrieved January 10, 2018, from <http://www.bbc.co.uk/news/health-38881464>

²⁶⁹ BBC. (2017).

²⁷⁰ British Medical Association. (2016). Doctors set out safe working plan for general practice. Retrieved January 12, 2018, from <https://www.bma.org.uk/news/2016/august/doctors-set-out-safe-working-levels-plan-for-general-practice>

²⁷¹ Steiner, T. J., Antonaci, F., Jensen, R., Lainez, M. J. A., Lanteri-Minet, M., & Valade, D. (2011). Recommendations for headache service organisation and delivery in Europe. *Journal of Headache and Pain*, 12(4), 419–426.

²⁷² Steiner et al. (2011).

This ‘ideal’ model is similar to what has been proposed in the current literature²⁷³. The model comprises three ‘levels’:

- (i) primary care, staffed by GPs;
- (ii) specialist interest headache care, staffed by GPwSI in headache or nurse specialists; and
- (iii) headache specialist centres, which are likely to be academic, supported by specialist neurological expertise²⁷⁴.

The first level would handle the vast majority of cases referring a small proportion to level two, and an even smaller proportion to level three – effectively acting as a gatekeeper²⁷⁵. Patients seen at level two could also be referred to the next level. There was therefore general agreement between the experts and the literature regarding how headache and migraine services should be organised:

“I think there is quite a lot of consensus that that is the right model given how prevalent headache is... there is no way it could all be managed in the hospital so having that kind of hierarchical structure in that sense makes sense” (Expert interview)

As they allude to, the high prevalence of headache and migraine in the population makes it very difficult to be managed by specialist centres.

However, the experts were very much aware of the barriers to providing this type of service across the country, in part due to the small number specialist clinicians – as reported by the 2014 APPG report on headache²⁷⁶. Experts consistently talked of there being only around 30 GPwSI in headache in the UK, and, in addition to that, explained that GP interest in specialising in this area is low. Furthermore, there are very few nurse specialist clinics – recent information indicates there are just 12 in England²⁷⁷, though an expert interviewee suggested the number had increased in recent years, due to the availability of Botox treatment for migraine, and that the figure was in fact 32. CNS are well placed to provide accessible information on optimal headache management, signpost to other services and provide specialist treatment (e.g. Botox). It was pointed out that the introduction of new treatments for migraine that were currently in the pipeline would potentially result in increased demand, and therefore the creation of more roles, for CNSs in headache to handle the administration of the new products.

An additional barrier to the provision of this type of service again concerns GPs’ capability. If they are to fulfil their role as gatekeepers effectively, it is crucial that they “have the skills and competencies to diagnose and manage most patients with migraine”²⁷⁸ and know when a patient should be referred on. One expert argued that this would only require GPs to know “just a little bit more than they currently do about headache”. This is consistent with the literature, which suggests that headache diagnosis and management requires no more than basic knowledge of a few common disorders, and “only standard clinical skills, which every

²⁷³ Antonaci, F., Valade, D., Lanteri-Minet, M., Láinez, J. M., Jensen, R., & Steiner, T. J. (2008). Proposals for the organisation of headache services in Europe. *Internal and Emergency Medicine*.

²⁷⁴ Steiner et al. (2011).

²⁷⁵ Antonaci et al. (2008).

²⁷⁶ APPG on Primary Headache Disorders. (2014)

²⁷⁷ Migraine Trust. (2018).

²⁷⁸ Steiner et al. (2011).

physician should have”²⁷⁹. However, as highlighted above in Section 4.3.2, GPs often resist training and do not, generally speaking, think headache is important. Thus, while there was consensus – amongst interviewees and the literature – that this model did represent the way forward, it was acknowledged that improving GPs’ capability represents a logistical problem without obvious solutions.

Recent interventions, such as the initiative in Estonia (described above in Section 4.3.2) that successfully changed GPs’ behaviour through an educational programme, are worthy of consideration to draw potential lessons from for the UK – particularly if part of a multifaceted intervention. In addition, some of the experts we spoke to drew our attention to the existence of community-based GPwSI clinics operating in two UK regions where community headache pathways have been developed²⁸⁰. They work in ‘partnership’ with primary and specialist care, with most patients being seen by GPs. Both have been successfully managing the majority of headache and migraine patients’ needs. Such models clearly warrant further investigation to explore their potential viability in order to shape solutions that could operate at a larger scale across the UK.

In sum, it is clear that migraine – given how prevalent it is – cannot be treated and managed effectively in specialist settings. The consensus is that headache and migraine services must be reorganised so that care is delivered at three levels, primary, intermediary and specialist, in a hierarchical or ‘partnership’ model. Primary care would perform a vital function: treating the majority of patients and acting as a gatekeeper. Though delivering this model presents problems without obvious solutions, there are potential ways of doing it that warrant further investigation.

4.3.5 Enhancing patient understanding and community pharmacist support

One final point to consider, which we touched on in Section 4.3.2, concerns patient empowerment and education and the role it can play in helping people with migraine achieve optimal outcomes – and in shaping a more effective care system. One expert suggested that patient-held records, i.e. an up-to-date summary of illnesses and drug treatment held by the patient, could be called upon during a GP consultation to ‘steer’ them towards taking appropriate action. For example, if a patient is repeatedly prescribed analgesics (painkillers), the record may empower the patient to raise this directly with their GP and, in future, take a more vested interest in understanding their own headache.

Experts agreed that improved patient understanding of migraine was needed and – as discussed earlier in Section 4.2 – could help with the co-production (between patient and practitioner) of an appropriate course of action that satisfies both parties. In particular, there is a need for better understanding of analgesic use, which can help guard against MOH²⁸¹.

Alongside this, our review also pointed to the potential for community pharmacists to play a more enhanced role in helping patients manage their condition better, as one expert explained:

“I think educating pharmacists is important—when someone comes in and is repeatedly asking for codeine for their headache then the pharmacist should know that that’s not an appropriate medication or any analgesic if they’re being used

²⁷⁹ Antonaci et al. (2008).

²⁸⁰ Oxfordshire CCG and new Devon CCG

²⁸¹ Rossi, P., Di Lorenzo, C., Faroni, J., Cesarino, F., & Nappi, G. (2006). Advice alone vs. structured detoxification programmes for medication overuse headache: A prospective, randomized, open-label trial in transformed migraine patients with low medical needs. *Cephalgia*, 26(9), 1097–1105.

repeatedly ... the pharmacist is often a very good point in the community to say 'well, actually have you thought about a migraine preventative instead rather than taking all the analgesics'" (Expert interview)

Despite the lack of consensus among experts regarding pharmacists' ability to perform this function, community pharmacies are well-placed to support people with a long-term condition to manage their migraine better, given that they are "the nation's most accessible healthcare providers"²⁸²; around 90% of the English population live within 20 minutes walking distance of a pharmacy and their services can be accessed without the need for an appointment²⁸³. Furthermore, they have a professional responsibility to prevent medication overuse and are trained to intervene if they suspect a patient is at risk of developing MOH²⁸⁴. Indeed, a recent study concluded that, with proper knowledge, community pharmacists are well placed to help prevent MOH²⁸⁵. This is supported by the experience of one of the interviewees with episodic migraine, who explained how their pharmacist picked up on their overconsumption of triptans (abortive medications to stop a migraine once it starts).

Thus, while improving GP capability with migraine must be a priority – as outlined in previous sections – there is an argument for educating community pharmacists, enabling them to play an enhanced role – particularly around prevention of MOH – alongside efforts to improve patient understanding of migraine.

4.3.6 Summary

To a large extent, the evidence reviewed in this section justifies the lack of confidence our interviewees had in GPs' ability to treat them effectively. Migraine pathways are vague and GPs do not make full use of them, which is in part responsible for delayed diagnosis and misdiagnosis. GPs' lack of capability with migraine compounds the problems associated with vague pathways – they are unsure how to treat or when to refer patients. This causes unnecessary referrals and avoidable A&E visits, which are expensive.

There was agreement that GPs needed education and training – given how little time is spent on headache and migraine in the medical curriculum – but it was unclear how to do this. Evidence from a recent intervention in Estonia could indicate a way forward. It was felt that any educational programme, to be successful, should be part of a multifaceted intervention comprising 'nudges' to influence GP behaviour. However, it was acknowledged that GPs face a difficult task given how short a typical consultation is.

There was a consensus that structured headache services, comprising three levels in a hierarchical or partnership model, is a viable means of treating headache and migraine properly. However, there are barriers to implementing such a service. There is a lack of GPswSI and CNSs with expertise in headache. The model also depends on GPs' capabilities. Thus, existing research showing the effectiveness of an educational programme to change GP behaviour and the existence of intermediary clinics successfully operating in two UK regions could provide useful insight and therefore warrant further investigation.

²⁸² Pharmacy Voice. (2016). *Community pharmacy forward view*.

²⁸³ Todd, A., Copeland, A., Husband, A., Kasim, A., & Bamba, C. (2014). The positive pharmacy care law: An area-level analysis of the relationship between community pharmacy distribution, urbanity and social deprivation in England. *BMJ Open*, 4(8).

²⁸⁴ Migraine Trust. (2018). Community pharmacy. Retrieved December 20, 2018, from <https://www.migrainetrust.org/living-with-migraine/seeking-medical-advice/community-pharmacy/>

²⁸⁵ Hedenrud, T., Babic, N., & Jonsson, P. (2014). Medication overuse headache: Self-perceived and actual knowledge among pharmacy staff. *Headache*, 54(6), 1019–1025.

Finally, in addition to improving GPs' capability it was felt that there is potential for community pharmacists to play an enhanced role, facilitating effective self-management of migraine particularly around prevention of MOH.

4.4 Coping and self-management strategies people with migraine use

Having assessed the barriers to efficient and effective care and management of migraine, we now explore the coping and self-management strategies people with migraine use and their effectiveness.

4.4.1 Migraine's pervasive impact

For all five of the people with migraine we spoke to, their migraine was a driving force behind the way they lived their life – a finding that is consistent with previous qualitative studies²⁸⁶. Each of them had, over time, developed their own personal strategy for managing life with migraine, again reflecting the findings of the existing literature²⁸⁷. The strategies they described included preventative strategies, as well as strategies to cope with an attack. Most of them had managed to get a relative degree of control over their symptoms during an acute attack, having found a medication that worked. Managing an acute attack, however, only accounted for a relatively small part of the way migraine affected their lives; a huge amount of effort went into avoiding, and living with the threat of, an attack – as we explore below.

4.4.2 Avoiding 'triggers'

Much of the energy expended by interviewees on managing their condition went into avoiding activities that they perceived might 'trigger' an attack. Avoidance behaviour – as discussed in Chapter 3 – affects 15% of people with migraine according to a recent study of 6,455 adults from 10 EU countries²⁸⁸. Interviewees reported that, at its extreme, this meant almost total withdrawal from normal day-to-day activities, including work and social gatherings, and in the most severe of cases, it affected their family responsibilities; though we also heard that partners and other family members played a key role in helping them manage during an attack.

These findings are consistent with those from existing qualitative research, which report the dominance of trigger avoidance in the individual management strategies of people living with migraine²⁸⁹. Clinical guidelines also put emphasis on this²⁹⁰. However, the evidence from observational studies to support the role of triggers in migraine is limited²⁹¹. Somewhat contrary to the widespread belief about the relevance of triggers evidenced in our interviews and the published literature, existing evidence indicates that only "about 20% of people can reduce the frequency of their attacks by identifying and avoiding triggers"²⁹². NICE guidelines acknowledge this, advising that people should be aware of the limitations of avoidance of triggers, and that the costs of enforced lifestyle changes may not be offset by improvements in migraine symptoms²⁹³.

²⁸⁶ Nichols et al. (2017).

²⁸⁷ Rutberg & Öhring. (2012).

²⁸⁸ Lampl, C., Thomas, H., Stovner, L. J., Tassorelli, C., Katsarava, Z., Láinez, J. M., ... Steiner, T. J. (2016). Interictal burden attributable to episodic headache: findings from the Eurolight project. *Journal of Headache and Pain*, 17(1), 1–10.

²⁸⁹ Palacios-Ceña et al. (2017).

²⁹⁰ Weatherall. (2015).

²⁹¹ National Institute for Health and Care Excellence. (2018).

²⁹² National Institute for Health and Care Excellence. (2018).

²⁹³ National Institute for Health and Care Excellence. (2018).

Further findings from qualitative research with people with chronic migraine identify 'self-control' as a means of managing migraine²⁹⁴. On the face of it, this appears to be an extension of the concept of avoiding triggers, and one which places the responsibility for managing migraine on the individual. Given the relatively weak evidence supporting the role of triggers this suggests there is a need for improved patient education on this issue.

4.4.3 Living with the threat of an attack

Avoiding activities believed to trigger migraine comprises just one element of the 'interictal' (between attacks) burden associated with migraine. The impact of living with the threat of an attack was a dominant theme in our interviews with people with migraine, and this is supported by the literature²⁹⁵. They structured their lives around their migraine – even when migraine-free their lives were affected by the threat of attack. One interviewee, a woman with chronic migraine, when asked if her condition affected all of her decisions, she said she tried not to let it, and compared her situation to that of a hay fever sufferer choosing not to go out on a high pollen day:

“If I know there's something that would affect it then I will take it into account ... you've got to be aware of yourself” (Person with migraine)

Clearly, in this person's case, migraine was never far from their mind. To an extent, one might expect this from someone with chronic migraine, given how frequently they experience migraine (e.g. headache on at least 15 days per month). However, one of the female interviewees with episodic migraine explained how her condition needed “constant attention and management”. This is consistent with findings from a recent international survey of people with migraine that suggests mean time spent in the interictal state is 317 days a year²⁹⁶.

As such, it has been argued that “migraine can be viewed as an ongoing cycle of suffering, because it involves treating the current attack and worrying about the next one”²⁹⁷, and there is indeed clear evidence that the interictal burden brings anxiety, anticipation and worry about the next attack²⁹⁸. The findings from our interviews reflect this, with a strong theme emerging around anxiety over when the next attack might occur.

4.4.4 Managing an attack

Research shows that people living with migraine frequently have symptoms in advance of an attack that enable them to predict it with some certainty – described as the 'premonitory' phase²⁹⁹. The people with migraine we spoke to described how action taken in the early stages of an attack could prevent onset of a 'full-blown' migraine, providing that they 'caught it' early. As with other aspects of managing life with migraine, the strategies used involved lifestyle adjustments and taking medication. The literature tells us little about the non-pharmacological management of a migraine attack in its early stages, but clearly indicates the benefits of early administration of acute or abortive medication³⁰⁰ while the pain is still mild³⁰¹.

²⁹⁴ Palacios-Ceña et al. (2017).

²⁹⁵ Mannix et al. (2016).

²⁹⁶ Lampl et al. (2016).

²⁹⁷ Rutberg & Öhrling. (2012).

²⁹⁸ Mannix et al. (2016).

²⁹⁹ Becker, W. J. (2013). The premonitory phase of migraine and migraine management. *Cephalalgia*, 33(13), 1117–1121..

³⁰⁰ Becker. (2013).

³⁰¹ Weatherall. (2015).

Although most people with migraine have premonitory symptoms – up to 87% according to a recent review³⁰² – many do not recognise them until they are prompted³⁰³. It has therefore been suggested that people with migraine may benefit from ‘training’ in the recognition of these symptoms and how to prevent an attack – or at least minimise its severity³⁰⁴. Findings from a recent study involving 120 people with migraine suggest this may be worthwhile: it concluded that “migraineurs who report premonitory symptoms can accurately predict the full-blown headache”³⁰⁵. However, for such training to be effective, improved understanding of the efficacy of different drugs taken during the premonitory phase is needed; this requires further clinical trials to test different approaches³⁰⁶. Clinical guidelines, overall, provide relatively little information about management during this phase³⁰⁷, though using triptans too late in the attack is given as a potential reason for poor response to treatment in the acute phase³⁰⁸. Further advice for clinicians on this subject may therefore be beneficial.

All of the people with migraine we spoke to experienced the premonitory phase. While it was different for each of them, bed rest, or lying down, was often required; this is consistent with the literature³⁰⁹. One interviewee, a man with episodic migraine, complained of an ‘optical’ – aura – effect that would only sometimes develop into a “full-blown headache”. He explained that one morning he experienced this on the way into work and had to park in a backstreet until it passed. Another male interviewee but with chronic migraine suggested that he can “usually tell if I’m going to get one because I become overtired”. He described how he sometimes uses triptans if the pain is particularly bad, but they are not always effective.

One of our interviewees, a woman with episodic migraine, had a carefully planned routine, which to some extent was representative of all the people with migraine we spoke to:

“If I feel an attack coming on, it is that balance knowing if it will go from being a headache into a proper migraine attack ... if it is a headache that is getting worse I’ll take ibuprofen, paracetamol and aspirin – phased over a couple of hours – and make sure I’ve eaten something. If that doesn’t work I will take a relpax [triptan] – but I have to go home to do that as it knocks me out. I rub peppermint oil on the back of my neck and put a hot water bottle on my feet. When I wake up – when the attack is over – I have food cravings” (Person with migraine)

This excerpt offers insight into the great lengths people with migraine go to in order to minimise the impact of an attack. It also illustrates the complexity of the strategies they employ and the broad impact it has on their life; clearly, it extends beyond the pain felt during the ‘ictal’ state.

The debilitating pain experienced in an attack, however, should not be understated. Qualitative studies describe the ictal state as “being besieged by pain and other symptoms, thereby making it impossible to function as normal”³¹⁰. Findings from our interviews support this: for example, one interviewee explained how “sometimes they’ll [migraines] be really terrible and I can’t function at all”, while another described feeling “extremely tired and poorly

³⁰² Becker. (2013).

³⁰³ Becker. (2013).

³⁰⁴ Becker. (2013).

³⁰⁵ Giffin, N. J., Ruggiero, L., Lipton, R. B., Silberstein, S. D., Tvedskov, J. F., Olesen, J., ... Macrae, A. (2003). Premonitory symptoms in migraine. *Neurology*, 60(6), 935 LP-940.

³⁰⁶ Becker. (2013).

³⁰⁷ British Association for the Study of Headache. (2012).

³⁰⁸ National Institute for Health and Care Excellence. (2018).

³⁰⁹ Mannix et al. (2016).

³¹⁰ Rutberg & Öhring. (2012).

with balance problems and could not function". Overall, the experience seems to be characterised by withdrawal from life and other people, thus compounding the isolation brought by the avoidance of the triggers believed to cause migraine. This of course has implications for migraineurs' capacity to work, which we explore in Chapter 5.

4.4.5 Summary

People with migraine employ complex coping and life-management strategies to avoid the pain of a migraine attack. However, this in itself has a profound impact on their lives and the evidence supporting the role of triggers is in fact quite weak. Therefore, improved patient education on the role of triggers may be helpful. They may also benefit from education on premonitory symptoms. With proper training people with migraine can accurately predict a 'full-blown' headache in the premonitory phase, which could help minimise its impact. However, little is known about the efficacy of different drugs. Further trials to test this can inform clinical guidelines enabling clinicians to provide better information about management during this phase. Advice should, however, extend beyond the pain of the attack itself and, where possible, consider the broader impact on the lives of people with migraine.

4.5 Concluding comments

Several barriers stand in the way of people with migraine getting optimal care. They are primarily related to GPs' lack of capability around migraine, which is attributed to inadequate education, training and interest in the condition, as well as short consultation times. All of this is compounded by vague patient pathways. As such, the quality of migraine care is highly variable – people with migraine face a 'care lottery'. They often experience delayed diagnosis and misdiagnosis and inappropriate referrals. Consequently they have little faith in GPs' ability to treat them and the efficacy of treatments, particularly prophylaxis.

Most cases of migraine can and should be treated effectively in primary care but this would require structured headache services operating in a hierarchical or partnership model. Although there are practical difficulties involved in implementing such a service, similar models are operating at local level and could have the potential to be scaled up.

Barriers to optimal care can also be addressed through patient education and improved understanding of migraine supported by community pharmacists.

Finally, people with migraine go to great lengths to manage their condition. They make personal sacrifices to avoid perceived triggers and, when migraine-free, often worry about when the next attack will come. Most have symptoms preceding an attack but many do not recognise them. They typically have carefully planned routines, which often involve bed rest, designed to minimise the burden caused by an attack. Attacks can be extremely debilitating, making it impossible to function.

Although commonly used, there is little evidence to support the effectiveness of avoiding triggers; clinical guidelines are therefore wary of putting too much emphasis on them. This illustrates the potential benefit of improved patient understanding. People with migraine may also benefit from training in the recognition of premonitory symptoms – clinicians could also benefit from advice about management during this stage.

5 Barriers to optimal work-related outcomes for people with migraine

5.1 Introduction

Having looked at the barriers to optimal care we now explore migraineurs' experience of work and the barriers they face to optimal work-related outcomes. Thus, this chapter answers the following research question:

5. What are the barriers to optimal work-related outcomes for people with migraine and how might they be overcome?

5.2 The barriers to optimal work-related outcomes

As described in Chapter 2, migraine disproportionately affects people of working age, peaking at 30-40 years³¹¹, which is generally when people are at their most productive. It therefore is no surprise that – as our experts told us – working life is where migraine seems to have the biggest impact. Evidence of this impact is set out in Chapter 3 where we showed that migraine causes absenteeism, presenteeism and negatively affects career advancement and earnings – all of which comes at a significant socioeconomic cost.

In this section, however, we look beyond these costs and explore the principal barriers to optimal work-related outcomes for people with migraine, why they are so difficult to navigate and – in Section 5.3 – how they might be overcome. As we explore, many barriers can in part be addressed by 'good' work comprising improved psychosocial work conditions, a supportive workplace culture and better management practices which empower employees.

5.2.1 Poor understanding of migraine

There was a consensus amongst the people with migraine and the experts we spoke to that a lack of understanding of the nature of migraine, and the impact it has on one's ability to function, was a significant barrier to optimal work-related outcomes for people with migraine. This lack of understanding was evident in employers' attitudes and, in some cases, colleagues', and was considered to be a reflection of the low level of understanding of migraine in society at large.

One of the female interviewees with episodic migraine described how her manager had claimed her migraines were not 'severe' enough to justify what he saw as a drop in her performance – even going as far to say that although he did not consider himself an "expert on migraine", that was his opinion. Another female interviewee with episodic migraine reported a similar experience where, in a previous job, her line manager asked why she had not 'cured' her migraine yet. This corresponds with what our experts had to say. They felt employers did not see migraine as 'genuine' – not helped by the stigma surrounding the condition and market research surveys that suggest migraine is one of the most common reasons for 'pulling a sickie'³¹² – and therefore do not respect it. As one expert explained:

"Even if people know what it is it's not necessarily understood just how debilitating the condition can be..." (Expert interview)

Therefore, it was suggested that it is not simply an issue of awareness – most people are aware of migraine and what it is – but rather one of understanding.

³¹¹ Steiner, T. J., Scher, A. I., Stewart, W. F., Kolodner, K., Liberman, J., & Lipton, R. B. (2003). The prevalence and disability burden of adult migraine in England and their relationships to age, gender and ethnicity. *Cephalalgia*, 23(7), 519–527.

³¹² Business Advice. (2017). Revealed: The UK's ten worst sickie excuses used to get out of work. Retrieved January 12, 2018, from <http://businessadvice.co.uk/hr/employment-law/revealed-the-uks-ten-worst-sickie-excuses-used-to-get-out-of-work/>

Case study 3 – Migraine as a barrier to work

This case study is of a man with chronic migraine who has experienced migraine symptoms since about 2002, but was diagnosed with migraine only in September 2009. He described having some symptoms almost perpetually, but that the nature of the symptoms changed.

Over time he has developed a strategy for managing life with migraine – concentrating on avoiding the triggers: “If I can remain... in a darkened room... in the house without going out... If I can get by without having my sleep disturbed or without any stress – I can manage it.” But the reality of daily life makes this preventative strategy hard to maintain. Most of the time he does not take any medication for symptoms because they are relatively vague; and because he has struggled with the side effects of prophylactics, he only takes them if “the symptoms are so bad that they can’t be controlled with [painkillers]”. Long term prophylactics (preventative medications) had caused “long term symptoms that left me with increased problems with stress and anxiety.” His local unit had offered him Botox, but he was unwilling to try this treatment. He was however, interested in ongoing work with preventative drugs at King’s College London. He described how tests to try different types of lenses had been inconclusive - just one seemed to work and the cost was prohibitive – £120: “It’s a lot of money to spend on something that may not work.”

Migraine clearly has a significant impact on his working life. He describes how living with migraine makes it difficult to do certain types of work, but that work is possible with certain small adjustments: “If I am working at a work station I have to have something in place where I can take longer breaks; if I am poorly, I need to have time to recover; if there is glaring light I need to be able to shield myself from it somehow... such as wearing a cap or glasses”. However, in his experience, the difficulties of working with migraine have been compounded by employers’ failure to make reasonable adjustments: “Employers’ response has been quite poor I’m afraid. I’m really struggling to get employers to understand I need to have adjustments in place. They start to hassle me. Eventually it turns into something adversarial and confrontational and I have to take it through the Tribunal process. I’ve had to do that a few times unfortunately.”

He said that employers’ attitude to migraine and failure to make reasonable adjustments meant that migraine has had a devastating impact on his career. He was limited to working on an ad hoc basis, taking on short term contracts, and working at a reduced capacity when he did find work: “I do the occasional bits of work – which might pay but might not ...The work I can find is very erratic – not something I can rely on to live off.” He had never gone through any proper occupational health process, and his experience of Access to Work was that it “scared the employer because they thought it was a government department coming to examine them and they have never been able to comprehend that it was something that was actually to their benefit”. The employer didn’t listen to the outcome of the assessment and bought “completely inappropriate” equipment.

Contact with care services: “I’ve had a considerable amount of problems with GPs... But I’ve now got a GP who I think I can work with... He is listening, rather than coming to conclusions... I’m struggling to get (the neurologists) to understand what I think would be good for me... I went to a GP led clinic... and I’ll go back there at some point because my local unit is offering me something that is not compatible with my lifestyle. I’m not being heard so I need to go somewhere else where I am being heard.”

Indeed, the people with migraine and the experts we spoke to agreed that popular misconceptions about migraine being ‘just a headache’ – also reflected in the literature³¹³ – were largely to blame. It was felt that this was partly due to the ‘invisibility’ of the condition:

“People don’t understand it – it’s not like a broken limb – you can’t see it” (Expert interview)

Employers’ lack of understanding, then, can be thought of as an extension of the low level of understanding of migraine in society at large, and not necessarily simply a case of employers being ignorant.

5.2.2 Lack of knowledge and information

One of the experts argued that employers’ lack of understanding of migraine was at least partly attributable to the lack of available information on how to support people with migraine in work: it “isn’t necessarily because the employers are ‘bad’ or don’t care – it’s that there is very little information out there and support for the employer about how to do this”. As a result, whether a person with migraine feels supported at work or not often depends on whether their employer, or line manager, understands their condition. Thus, not only do people with migraine face a ‘lottery’ of care – as we outlined in Chapter 4 – they are faced with a similar situation at work.

A potential solution to this problem involves disseminating useful information to employers, ‘signposting’ them to relevant resources and tools. One of the experts suggested people with migraine themselves can do this by taking a proactive role at work, pointing their employer to useful guidance like the *Employment Advocacy Toolkit* by the Migraine Trust³¹⁴. Indeed, two of the people with migraine we interviewed indicated that, had they been aware of such information at the time, they would have taken a more proactive approach with their employer to ameliorate the impact their migraine had on their work. Improving migraineurs’ awareness of relevant resources and tools is, therefore, worthwhile.

5.2.3 The fluctuating nature of migraine

In addition to the problems associated with a lack of knowledge and information, migraine’s fluctuating nature can make it difficult for employers and managers to understand the reality of the condition. One of the experts we spoke to suggested this was the most common challenge people with migraine face:

“People appear well when they’re working, they’re productive, and then they’re suddenly out for two days, the condition is hidden, then they come back to work” (Expert interview)

As a result, people with migraine have relatively high rates of short-term sickness absence – as we explored in Chapter 3. This is problematic because it means that people with migraine often fall foul of employers’ sickness absence policies.

One interviewee with episodic migraine explained that although she had a “very understanding line manager”, if she did not go into work it would still register as sick leave. Our experts agreed that short-term sickness absence policies are often unnecessarily inflexible and punitive, with frequent occurrences of short-term absence rarely being tolerated. People with migraine suffer as a result.

³¹³ Luna, P. (2016). More than just a headache. *The Lancet Neurology*, 15(3), 242–243.

³¹⁴ See: <https://www.migrainetrust.org/wp-content/uploads/2015/09/employment-advocacy-toolkit-the-migraine-trust.pdf>

5.2.4 Difficulty getting reasonable adjustments

Poor understanding of migraine, a lack of information, and its fluctuating nature combined make it difficult for people with migraine to get reasonable adjustments, which, for most interviewees, compounded the difficulties they faced at work. One interviewee with chronic migraine explained:

“Many employers don’t like making adequate adjustments... I’m really struggling to get employers to understand I need to have adjustments in place” (Person with migraine)

He went on to say the adjustments he required were “not huge”; for example, something in place to enable him to take longer breaks and, if there is glaring light, a cap or glasses to shield himself from it. These attempts were typically unsuccessful however and relations between him and his employer had broken down more than once, ending in an employment tribunal.

His experience was not unique. Another interviewee, with episodic migraine, had tried and failed to get his employer to listen to him about the ways in which his work content could be adapted to suit his needs (shorter shifts). This was despite the fact he had been diagnosed with migraine by a private neurologist through his employer. Eventually they offered to make changes but by that point the relationship had broken down, with the interviewee raising a grievance.

There was agreement between the people with migraine and the experts that difficulty getting reasonable adjustments is, in part, due to the fact that migraine is not always considered a ‘disability’ under the Equality Act 2010 (employers are obligated to make adjustments for workers who have a disability³¹⁵). One of our experts suggested this has to change, thereby allowing people with migraine to take time off work when needed and not be penalised for it. This echoed what the people with migraine said in our interviews – one felt it was difficult to push for adjustments because migraine “technically isn’t covered as a disability”. Another had tried to use the Equality Act but “to no avail”, calling it a “waste of time”.

Difficulty getting adjustments was also attributed to poor access to occupational health services. Although it was acknowledged that there is a lack of evidence regarding the effectiveness of reasonable adjustments for people with migraine, there was agreement that, if possible, having access to a dark, quiet room was beneficial. In addition, the chance to take frequent breaks and access to drinking water – dehydration being a trigger for migraine³¹⁶ – is welcome.

5.2.5 A lack of ‘good’ work

It was evident, from the people with migraine and experts we spoke to, that the barriers people with migraine face at work are, in part, attributable to a lack of ‘good’ work – i.e. a low quality psychosocial work environment, unsupportive workplace culture and poor management practices. Clearly, people with migraine – and the workforce in general – would benefit from increased access to ‘good’ work³¹⁷; previous Work Foundation research has

³¹⁵ Migraine Trust. (2010). *Employment Advocacy Toolkit*. Retrieved February 1, 2018, from <https://www.migrainetrust.org/wp-content/uploads/2015/09/employment-advocacy-toolkit-the-migraine-trust.pdf>

³¹⁶ Migraine Trust. (2010).

³¹⁷ Work Foundation. (2016). *Commission on good work*. Retrieved February 2, 2018, from <http://www.theworkfoundation.com/wp-content/uploads/2016/10/The-Commission-on-Good-Work.pdf>.

highlighted a number of ways in which people with chronic, fluctuating conditions can benefit³¹⁸. The following would be particularly beneficial:

- **increased autonomy and control** – allowing them to manage their workload and perceived ‘triggers’;
- **manageable demands** – reducing the risk of stress, which is trigger;
- **social support from colleagues and managers** – to help them manage their condition; and
- **workplace flexibility** – enabling them to manage their hours, work from home if necessary and fit their work around their migraine.

There is a vast body of evidence showing the positive effect that these components of the psychosocial work environment have on employee health and wellbeing³¹⁹. This is especially true when part of an integrated and proactive approach to managing people at work through ‘high performance working’ practices that support good work. This puts people at the heart of businesses and seeks to ensure business success by empowering people, giving them the space to be happy and healthy and actively contribute to performance improvements. In its response to the *Taylor Review of Modern Working Practices* the Government identified ‘good work for all’ as a national priority, placing obligations on local authorities to support better management practices which, in turn, support better health at work³²⁰. It is clear that people with migraine would benefit from increased access to good work several ways.

5.2.6 The physical work environment

In addition to the psychosocial work environment, aspects of the physical work environment can act as barriers to optimal work-related outcomes for people with migraine. As our experts told us, people are often forced to work in “hot, stuffy environments”, often with low quality lighting, computer screens, poor ventilation, loud noises and the presence of strong odours.

All of the people with migraine we spoke to complained of sensitivity to light and in some cases loud noises and strong smells. These aspects of the work environment were therefore perceived as triggers for migraine and as such our interviewees were at pains to avoid them. However, given employers’ reported attitude to reasonable adjustments, this was not always possible. However, the failure to make adjustments cannot always be attributed to the employer – as we explore in the next section.

5.2.7 Limitations due to job type and organisation size

While people with migraine would clearly benefit from small adjustments to aspects of the psychosocial and physical work environment, this is not always feasible. For example, one of the interviewees with chronic migraine explained that her job – as an online project manager – did not have “that kind of flexibility in it” due to the need to meet clients’ deadlines. While another, who had episodic migraine, used to work 12 hour shifts in a very demanding job with a one hour break. Though both would have benefitted from adjustments to the psychosocial work environment, e.g. flexible hours and the ability to work from home, they felt the nature of the work made it unfeasible.

³¹⁸ Steadman, K., Bajorek, Z., & Bevan, S. (2015). *Fluctuating conditions, fluctuating support*. London: Work Foundation.

³¹⁹ Marmot, M., Allen, J., Goldblatt, P., Boyce, T., McNeish, D., Grady, M., & Geddes, I. (2010). *Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England Post-2010. The Marmot Review*.

³²⁰ Department for Business Energy & Industrial Strategy. (2018). *Government response to the Taylor review of modern working practices*. London: Department for Business Energy & Industrial Strategy.

Similarly, it was recognised that certain accommodations were only possible in organisations of a sufficient size; for example, only larger organisations would be able to provide a rest room. Also, it was felt that larger organisations, relative to smaller ones, are better placed to ‘absorb’ the impact of someone being off sick, which is reflected in the literature³²¹. Conversely, smaller organisations can show more flexibility and less rigidity than larger ones³²². The point here is that there is no ‘one-size-fits-all’ solution – what can be implemented depends, in part, on the job type, sector and organisation size.

Case study 4 – The impact of late onset migraine on an established career

Our third migraineur first experienced migraine around 2010, at the age of 55. He would have sudden fierce headaches, visual problems, or both – initially intermittently but now almost continuously on a weekly basis.

He works in an industry with a very stressful working environment, including twelve hour shifts with few breaks, and little opportunity for part time or flexible working. With an optical migraine he found it possible to work, but with the full headache work was impossible. He was taking about 3-4 days a month off work – about one day a week.

When the migraines started in 2010 he saw a neurologist through his employer’s company health scheme who gave a diagnosis. A CAT and MRI scan found no physical reason for the migraines, and the doctor attributed them to stress in the workplace. The doctor wrote a letter for his employer, and: “About six months after it started I put in an extensive email in about the pressures I felt and my situation from my point of view.” The employer made some ‘very small changes’ including reducing the length of his shifts from twelve to six hours, but these were not effective. Over the years he had 10 occupational health visits and they made recommendations but the recommendations were basically ignored - his employer was ‘not in the least’ supportive. Things came to a head at the end of 2015 and he withdrew his labour until they prepared a workplace health assessment, which they did not do. He raised a grievance as well. He gave up his job in 2016 and is in the process of taking his case to an employment tribunal.

“My employer’s reaction to all this has been abysmal really... I’ve never really been unemployed – it’s more or less the first time I’ve ever tried claiming benefits. I’ve always managed to be in work. I’m not looking for a handout, but recognition that it’s a disability I think would be a big help. I would still like to work but would prefer part-time just to get my foot back in the door and then just take it from there...”

He believes migraine has had a negative impact on his career – losing his job and not being able to find a job since then. When applying for jobs he has not disclosed his migraine in the application form but has done so in interviews. On one occasion he was called back for a second interview, which was mainly about his condition: “I think they decided my condition was too unpredictable to entertain”.

Since becoming unemployed he has applied for disability allowance, but did not qualify because he is ‘fine’ on six days of the week. He describes receiving little help from health care professionals other than the private neurologist through his company health scheme: “I have resigned myself to the fact it won’t go away and there isn’t much I can do to stop it. There are no drugs out there”.

³²¹ Chartered Institute of Personnel and Development. (2014). *Absence Management*.

³²² García-Serrano, C. (2011). Does Size Matter? The Influence of Firm Size on Working Conditions, Job Satisfaction and Quit Intentions. *Scottish Journal of Political Economy*, 58(2), 221–247.

5.2.8 Disclosure

Published guidance for people with migraine suggests that an employer is less able to provide support and understand the condition if the person does not disclose it to their employer³²³. This is of course logical but disclosing one's condition can be daunting and does present some risks. The employee may be unsure whether their employer is committed to supporting them or not³²⁴ and as such disclosing may result in unfavourable treatment. However, related research on another neurological condition – multiple sclerosis – provides empirical support for the positive role of disclosure in maintaining employment³²⁵.

The issue of if, when, and how to disclose was raised frequently in our interviews. One interviewee with episodic migraine regretted not disclosing her condition to her employer early enough, suggesting it may have helped her keep her job (which she later felt forced out of). However, she recognised that, at the time, her organisation was being re-structured and therefore thought it best to “keep quiet”. Other interviewees said the same, with one describing the pressure not to disclose as the need to stay ‘professional’. Our experts also acknowledged that people with migraine, particularly if working in an insecure job, may be reluctant to raise it with their employer for fear of a negative response.

The issue of disclosure was also mentioned in the context of applying for a new job; the people with migraine we spoke to were unsure whether it was wise to bring it up or not. Generally, they thought it best not to. One interviewee with chronic migraine however felt it was incumbent on her to raise it as soon as possible, given how frequently her condition affected her. This would also allow the employer to provide support early on. This suggests that the decision to disclose – and when to do it – may be informed by whether the person has chronic or episodic migraine. It also suggests that people with migraine may benefit from a better understanding of their rights. For example, employers cannot ask questions about health status until after a job offer has been made³²⁶.

5.1.1 The benefits system

For interviewees that had come into contact with it, the benefits system was considered a barrier to returning to work. Two of the five people with migraine we spoke to had tried – unsuccessfully – to claim Employment Support Allowance and the Personal Independence Payment. These benefits provide financial support for those with health conditions or disabilities³²⁷. Interviewees felt that more recognition of migraine as a disability would help them access these benefits. Some of our experts agreed, with one suggesting that the eligibility tests, which test physical functioning, do not give people with migraine a fair chance of qualifying. It was also suggested that the system is not accommodating of people with fluctuating conditions, which has been reported elsewhere³²⁸.

In addition to the difficulties associated with accessing benefits, another person with migraine complained that the support she received from Jobcentre Plus – and specifically the work coach assigned to her in finding a new job – was inadequate. Although it was

³²³ Migraine Trust. (2010). *Employment Advocacy Toolkit*.

³²⁴ Steadman et al. (2015).

³²⁵ Kirk-Brown, A. K., Van Dijk, P. A., Simmons, R. D., Bourne, M. P., & Cooper, B. K. (2014). Disclosure of diagnosis of multiple sclerosis in the workplace positively affects employment status and job tenure. *Multiple Sclerosis Journal*, 20(7), 871–876

³²⁶ Migraine Trust. (2010). *Employment Advocacy Toolkit*.

³²⁷ GOV.UK. (2018). Financial help if you're disabled. Retrieved February 2, 2018, from <https://www.gov.uk/financial-help-disabled>

³²⁸ Steadman et al. (2015).

recognised that, due to her migraine, she would not be able to commute as far as someone without the condition, no other concessions were made, which she felt was unfair. The effectiveness of Jobcentre Plus and work coaches received a lot of attention in the recently published command paper, *Improving Lives: the future of work, health and disability*³²⁹. It highlighted the need for work coaches to be able to provide tailored support, have specialised knowledge and an understanding of common health conditions and medication. Our findings suggest that knowledge of migraine is needed.

5.2.9 Summary

There are a number of barriers for people with migraine to optimal work-related outcomes. First and foremost, the general lack of public understanding of migraine extends to employers and as such they do not see migraine as 'genuine'. This is not helped by a lack of available information on how to support people with migraine in work. Problems caused by this are compounded by short-term sickness absence policies that punish the fluctuating nature of migraine. Though reasonable adjustments would help, the fact migraine is not always considered a disability under the Equality Act makes it difficult for people with migraine to get them. Improvements in the psychosocial quality of work, i.e. increased access to good work characterised by manageable demands, adequate control, sufficient support and workplace flexibility, would be especially beneficial for people with migraine; though aspects of the physical work environment represent barriers too. Furthermore, the extent to which the work environment can be modified or adapted is necessarily limited by the type of job the person does or the size of the organisation they work for. Disclosing one's condition can help with getting support but this can present risks, e.g. an adverse employer response. Finally, the benefits system is not well suited to supporting people with migraine, though proposals in the *Improving Lives* command paper could be beneficial.

5.3 Navigating the barriers to optimal work-related outcomes

Having discussed the key barriers, arising from our interviews, to optimal work-related outcomes for people with migraine, we now consider what our interviewees told us about how they might be overcome, again with reference to the literature.

5.3.1 The importance of 'good' work

As discussed in Section 5.2.3, people with migraine can benefit in a number of ways from increased access to 'good' work. In particular, interviewees with migraine emphasised the importance of having flexibility at work. One described how, in a previous job, her employer insisted on her being in the office, despite her being able to carry out her duties from home. One expert commented that everyone will benefit – not just people with migraine – from employers practicing flexibility.

As well as flexibility, the people with migraine we spoke to frequently talked of the importance of adequate social support at work – another component of good work – for positive work-related outcomes. This support was instrumental in maintaining the productivity of people with migraine. Indeed, it is well established that social support at work enhances and protects employees' health and wellbeing, whether they have a health condition or not, and is a vital component of good management practices that value and empower people³³⁰.

³²⁹ Joint publication from the Department for Work and Pensions and the Department of Health and Social Care

³³⁰ Stansfeld, S. A., Shipley, M. J., Head, J., Fuhrer, R., & Kivimaki, M. (2013). Work characteristics and personal social support as determinants of subjective well-being. *PLoS One*, 8(11), e81115.

Case study 5 – Being a working mother with migraine

This case study is of a woman with chronic migraine who had her first migraine around the age of twelve, though she was not diagnosed until she was seventeen. Her early experience was that “People did not understand - you feel like you’re not believed—I was told ‘just take some medicine and go to bed for a while you’ll be fine’. So you do, you ‘get on with it’”.

As well as migraine, she also describes co-morbidities including depression and anxiety issues around being able to cope at work with migraine symptoms. Generally, she does not get migraine with aura – “they start with pain in the back of my neck or a light headache and then evolve into extreme pain with noise/smell sensitivity, and often light sensitivity - sensory overload”. The severity varies: “Sometimes they’ll be really terrible and I can’t function at all but most of the time I can get the drugs into me so I can minimise the impact that it has and I would call them ‘medium’—I know they’re there, I know they’re affecting my cognitive abilities... I can’t do certain things but I can still function”. When she has a migraine she takes a prophylactic, but a lot of the management is around lifestyle factors – getting sufficient sleep and eating well. Currently, she has a migraine about six times a month – “but that’s because I’ve got some good prophylactics. Without those I’m at around the 16 a month mark”. Over the years, she has tried “all sorts of medicine” and initially avoided prophylactics because the associated tiredness had caused too many problems at work. However, she is now in a work situation – working from home with a lot of flexibility and autonomy, and an understanding employer – where that tiredness is manageable so she tried them again.

She found her current employment through a friend, and described her employer as ‘totally supportive’. However, in the past she had employers who offered no support: “It’s a lottery with employers who you get and even within employers as well (with line managers)”. She described how because of her condition some employers viewed her as ‘unreliable’, and said: “that’s affected my ability to get promotions and progress in jobs”.

She suggests working in an office is not a good environment for a migraineur who needs flexibility, such as coming into the office late if you wake up with a migraine you need to get under control. Whereas, generally working in an office you are expected to be in at a certain time and work until a certain time of day regardless of what is happening, and the rigidity causes stress which makes migraine management more difficult.

Generally she does not disclose her migraine during an interview process, but does try to address it relatively early with an employer because it is a chronic condition that needs to be managed. She presents it as: “something that I deal with and I’m minimising the impact on you... and I’ve generally had no problem with that”. She felt that smaller companies can’t necessarily cope with someone who isn’t always there, whereas a big company will be able to absorb that better.

She also gave some examples of how migraine impacts on parenting, such as choosing not to exclusively breastfeed because of the implications for getting enough sleep, and not being able to take the needed medication if a migraine hit. Or being at home with children and a migraine: “I mean you can’t walk in a straight line and you’re looking after two completely helpless people – it’s scary... I remember a day when that happened; my husband was overseas on a conference, there was nobody I could call. You’re really stuck and alone with that”.

5.3.2 Showing awareness and understanding

Both the people with migraine and the experts highlighted the importance of an employer showing awareness and understanding of the condition and its impact. In some ways this is an extension of good work. For example, an interviewee with chronic migraine explained that because her employer showed understanding by asking her what she needed to do her job effectively, “it made it easier to cope with it all”. Thus, although no adjustments were made in this case, the fact the employer’s attitude was supportive made a significant difference to the person with migraine and their ability to cope.

An employer, or line manager, showing understanding also paved the way for effective reasonable adjustments to be made. As migraine is not always recognised as a disability, employers are not obliged to provide adjustments; thus, whether they do or not partly depends on their attitude. The benefits of reasonable adjustments, e.g. providing a dark room to rest in or modifications to the psychosocial work environment such as increased flexibility, were frequently mentioned by our experts. Interviewees with migraine were generally positive about them too; one with chronic migraine highlighted the effectiveness of simple adjustments like transition lenses to block out blue light. The point is that relatively simple – and cheap – adjustments can be effective but whether they are made or not often depends on the employer’s, or line manager’s, attitude.

5.3.3 Effective care

There was agreement amongst the people with migraine and the experts we spoke to that effective care, comprising timely diagnosis and appropriate treatment, was one way of achieving positive work-related outcomes. For example, an interviewee with episodic migraine described feeling empowered by her diagnosis – which she eventually got from a neurologist – helping her convince her employer that her condition was ‘genuine’.

In addition to the benefits of having a ‘proper’ diagnosis, two people with migraine mentioned the positive impact that effective medication had on their work experience. It enabled them to manage their symptoms effectively, to attend work more often and maintain their productivity. Our experts agreed, suggesting that effective care was a necessary step to securing optimal work-related outcomes for people with migraine, singling out Botox as an appropriate treatment. As we explored in Chapter 5, there is already a strong case for the need to improve migraine care – this only serves to underline it.

5.3.4 Summary

Successfully navigating the barriers to optimal work-related outcomes for people with migraine depends, to a large extent, on the employer’s, or line manager’s, attitude and whether employee is in a ‘good’ job or not. A good psychosocial work environment not only helps the person with migraine maintain their productivity at work through flexibility and support, but also brings psychological benefits and paves the way for practical adjustments to be made. In addition, positive work-related outcomes can be supported by an efficient and effective care system.

5.4 Concluding comments

It is clear that improving public – and employer – understanding of migraine is needed. This would help counter popular myths that migraine is ‘just a headache’ and make it easier for people with migraine to get the adjustments they need to maintain their productivity at work. Adjustments are not always possible, however – due to limitations imposed by job type and organisation size – and employers often do not know how to help even if they want to.

People with migraine could help address this by playing a more active role but they would have to disclose their condition. Increasing access to good work would help in a number of ways, enabling people with migraine to manage their condition better with adjustments to the psychosocial and physical work environment as well as being more confident about disclosure.

Better recognition of migraine as a disability would also help secure reasonable adjustments and access to certain disability benefits and support to work schemes. The experts we spoke to, however, were unsure about whether this was a good idea or not because:

- (i) migraine is a broad spectrum – encompassing people that have symptoms several times a week to several times a year; and
- (ii) this may only serve to increase the stigma surrounding it, particularly in the eyes of employers

In terms of how the barriers can be navigated, it was widely acknowledged that a more efficient and effective care system would be very helpful, enabling people with migraine to manage their condition better at work. Furthermore, having flexibility, support and an understanding employer or line manager – i.e. a ‘good’ job – is vital for positive work-related outcomes. The importance of good work, particularly for those with long-term health conditions, has received a lot of attention from government recently, being the subject of recent publications including: the *Taylor Review of Modern Working Practices*³³¹, the *Improving Lives*³³² command paper and the Stevenson/Farmer review of mental health and employers, *Thriving at Work*³³³. It is clear that people with migraine can benefit from, and be empowered by, these general developments to raise the quality of management practices across businesses and support conditions to create more good work. The challenge, however, will come in how to achieve it – for this there is no ‘silver bullet’. We provide some thoughts on how this research might contribute to the wider debates and programme of action underway in Chapter 7.

³³¹ See: <https://www.gov.uk/government/publications/good-work-the-taylor-review-of-modern-working-practices>

³³² See: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/663399/improving-lives-the-future-of-work-health-and-disability.PDF

³³³ See: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/658145/thriving-at-work-stevenson-farmer-review.pdf

6 Conclusions

Migraine represents a significant public health problem. It is the most common disabling primary headache disorder and the second highest cause of years lived with disability worldwide and in the UK. It is also highly prevalent: recent estimates from the Global Burden of Disease study (GBD) 2016 put adult³³⁴ migraine prevalence at 23.3% while older estimates for the UK and Europe put it around 15%³³⁵. For many, attacks occur frequently and often cause significant pain. Even when not experiencing an attack, people with migraine contend with an 'interictal' disability burden characterised by worry about the next one and avoidance of perceived 'triggers'. All of this carries a substantial socioeconomic cost.

Based on a 23.3% adult prevalence taken from GBD 2016 and an average of 5.7 days lost per person with migraine, we estimate that 43 million workdays are lost every year in the UK to migraine-related absenteeism alone, at a cost of almost £4.4 billion. A more conservative estimate using 15% prevalence indicates that 28 million days are lost costing £2.8 billion. Assuming migraine-related presenteeism is responsible for an equal amount of lost productivity (published studies suggest it is usually responsible for more), we calculate (using GBD 2016 prevalence) that the equivalent of 43 million workdays are lost to presenteeism in the UK, at a cost of £4.4 billion. Using a lower prevalence, equivalent days lost amount to 28 million a year costing £2.8 billion.

Migraine-related absenteeism and presenteeism combined is, therefore, responsible for 86 million equivalent workdays lost per annum (11.4 for each person with migraine) at a cost of just under £8.8 billion in lost productivity (using GBD 2016 adult migraine prevalence data). Our second, more conservative, calculation based on a lower prevalence of 15% estimates that a total of 55 million equivalent days are lost at a cost of more than £5.6 billion per annum.

Broader indirect costs, although difficult to quantify, can be attributed to migraine's interictal disability burden. Although considerably less disabling than the ictal state, people with migraine, on average, spend 317 days a year in the interictal state. Common symptoms include 'interictal anxiety' and avoidance behaviour, which impacts on people's relationships, personal time and leisure – i.e. their quality of life.

Additional costs, which are again difficult to quantify, relate to the often significant negative impact migraine has on career advancement and potential earnings – this represents a personal cost and a financial loss to the exchequer. Furthermore, common co-morbidities include psychological conditions like anxiety and depression, both of which are responsible for a significant – and increasing – amount of lost workdays according to the Labour Force Survey.

Although greatly outweighed by the indirect costs, direct costs attributed to migraine are still worthy of consideration. Using data from the Eurolight project (comprising outpatient care, investigations, acute medications, hospitalisations, and prophylactics) applied to GBD 2016's UK adult migraine prevalence, we calculate direct healthcare costs of almost £1 billion per annum. A more conservative estimate, again using 15% prevalence, calculates direct costs at just under £600 million a year. Thus, direct costs are responsible for around 10% of the total, with the vast majority attributed to indirect costs.

³³⁴ Aged 15-69 years

³³⁵ For adults aged 16-65 years

When combined, the indirect and direct costs attributed to migraine are of the order of £9.7 billion a year, with a more conservative estimate of £6.2 billion. Although the estimates are inexact and affected by the assumptions used, both indicate that the cost is substantial.

With proper treatment and effective management of migraine, a large part of these costs can be avoided, or at least significantly reduced. As we explored in Chapter 4, most cases of migraine – and headache generally – can and should be treated effectively in primary care. This would require structured headache services operating in a hierarchical or partnership model. While there are difficulties in implementing such a service, similar models operating at local level may have the potential to be scaled up. Such a system, combined with clearer migraine patient pathways³³⁶, will help address the highly variable care people with migraine currently receive and reduce the likelihood of delayed diagnosis, misdiagnosis and inappropriate referrals. It would however depend on improving GPs' capability around and understanding of migraine – currently they do not know enough about it and appear to have little interest in it. Educational programmes, particularly as part of multifaceted interventions – as demonstrated in the literature – have the potential to help address this, enabling them to make better diagnoses and, when appropriate, initiate treatment.

This should be supported by action aimed at improving patient education and understanding of migraine with a potential role for community pharmacists facilitating effective self-management. The need for this is underlined by evidence suggesting that people with migraine often employ complex coping strategies – which themselves have a significant impact on their quality of life – to avoid migraine attacks despite the lack of reliable evidence on their effectiveness. People with migraine would also benefit from education and training in the recognition of premonitory symptoms, which could help reduce attack severity.

Addressing these barriers to optimal care has the potential to reduce both the indirect and direct costs attributed to migraine:

- better care and self-management would help people with migraine control and manage their condition effectively, enabling them to stay in, return to or find work, which, in turn, would reduce costs associated with lost productivity; and
- treating the majority of migraine in primary care, underpinned by clear pathways, would help reduce unnecessary and variation in care characterised by delayed diagnosis, misdiagnosis and inappropriate referrals

Another means of reducing the indirect costs associated with migraine is by addressing barriers to optimal work-related outcomes for people with migraine. As we explored in Chapter 5, several barriers can in part be addressed by 'good' work comprising improved psychosocial work conditions, a supportive workplace culture and better management practices which empower employees to more effectively manage their health conditions and therefore optimise their performance at work. The general lack of public understanding of migraine, which extends to employers, was considered a significant barrier. This is compounded by a lack of available information as well as short-term sickness absence policies that do not accommodate migraine's fluctuating nature. Though they would help, it is difficult to get reasonable adjustments as migraine is not always a disability under the Equality Act 2010. There is also a lack of evidence on their effectiveness for people with migraine. In addition, not all jobs and workplaces are amenable to adjustments. While

³³⁶ NHS RightCare is currently developing a 'framework for optimal care'/headache and migraine pathway' in England

disclosing one's condition can help with getting support this can present risks (e.g. an adverse employer response).

It is clear that improvements in the public's understanding of migraine, which extends to employers and indeed the benefits system, are needed. Many of the barriers we found stem from this. In particular it would address the 'lottery' people with migraine face at work, which is also a feature of their care; too often a good work experience depends on the 'luck' of having an understanding employer or line manager. As such, the importance of 'good' work and the positive contribution it can make to work outcomes for people with migraine should not be understated. Indeed, the value of a healthy psychosocial work environment for all employees – and particularly those with long-term conditions – has been explicitly recognised in several recent government publications. Clearly, people with migraine would benefit in several ways, e.g. through enhanced control empowering them to manage their condition and social support from management when they need it. The challenge is how to do this – a subject we explore in the following and final chapter.

In sum, the substantial costs – mainly due to lost productivity – caused by migraine in the UK demand the Government's attention. Even allowing for some imprecision, it is clear migraine creates a huge socioeconomic burden, yet public – and professional – understanding of it is generally poor and it is currently poorly managed by the health system. This seems unjustified particularly when:

- (i) migraine is treatable with good effect;
- (ii) implementation of relatively low cost measures aimed at improving patient and public understanding could improve the welfare of millions leading to significant socioeconomic savings; and
- (iii) the often negative impact migraine has on work-related outcomes can, to some extent, be avoided in 'good' working conditions

Thus, in the next chapter we outline recommendations aimed at addressing the barriers to optimal health and work-related outcomes for people with migraine.

7 Recommendations

7.1 Introduction

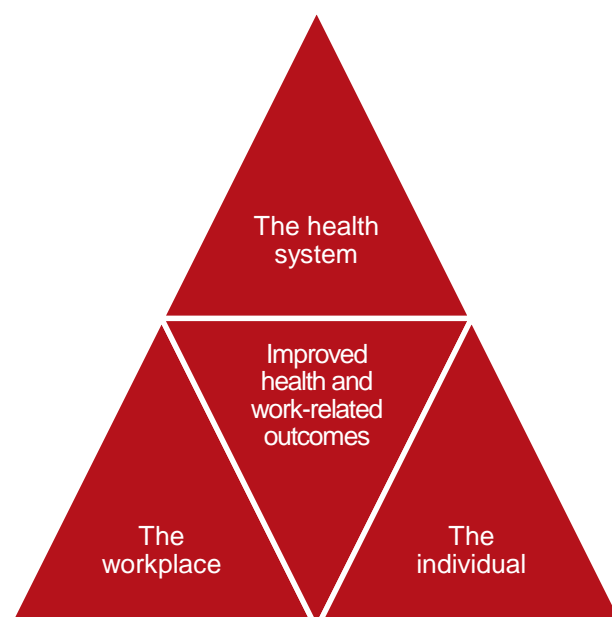
The aim of these recommendations is to provide a way forward, given the substantial indirect and direct costs associated with migraine, to improve health and work-related outcomes for people with migraine and, as a result, reduce the socioeconomic burden on the UK. This will require action in three 'settings' (see Figure 8 below).

- First and foremost, **improving care**: there are several barriers to optimal care preventing efficient and effective treatment and management of people with migraine resulting in waste, inefficiency and significant variation in what is delivered and its effectiveness.
- Second, **improving patient and public understanding**: many people with migraine may not recognise they have migraine and self-manage their headaches inappropriately or, despite knowing they have migraine, do so ineffectively due to a lack of reliable information and prevalence of 'migraine myths'. A particular danger is overuse of analgesics (painkillers) bought over the counter, promoting medication overuse headache (MOH).
- Third, **improving work-related outcomes**: employers' understanding of migraine is poor, it is difficult for people with migraine to get reasonable adjustments and work demands can often be difficult to reconcile with symptoms. This risks inhibiting individuals' effectiveness at work and business' productivity.

All three areas are mutually reinforcing: better organisation of care is supported by improved patient and public understanding, both of which support better work-related outcomes for people with migraine.

In each of these areas we first set out the **rationale** for taking action – the 'why' – before outlining our **vision** for the future – the 'what'. This is followed by **recommendations for the way forward** detailing 'how' we can, at least in part, deliver on this vision. Then, finally, we outline any relevant **existing developments and opportunities** to explore that contribute to our main recommendations.

Figure 8 – Recommendations' three 'settings' for action



7.2 Improving care

7.2.1 Rationale

Migraine is highly prevalent and the vast majority of people with migraine are ‘episodic’ rather than chronic and generally can and should be treated effectively in a primary care setting. However, current pathways for treating migraine are vague and all too often it depends on the patient’s motivation and education, as well as the clinician’s motivation and knowledge. GPs typically have little specific training in migraine causing delayed diagnosis and misdiagnosis; persistent headache combined with patient dissatisfaction can lead to inappropriate referrals and emergency department attendances. Therefore, patients that could be treated effectively in primary care end up in secondary care, which is expensive. Indeed, headache is the most common neurological reason for accident and emergency attendance. This is inefficient and results in unnecessary waste and variation in care and reduces capacity in the health system.

7.2.2 Vision

Migraine should be treated within a national framework of structured services comprising three levels: primary care (level one), intermediary care (level two) and secondary/specialist care (level three). This should be underpinned by a clear and unambiguous patient pathway. This would better address avoidable waste and variation in care for patients in different parts of the UK. The vast majority of people with migraine would be managed in the community (at level one and two). This would require informed patients and GPs, operating at level one, with sufficient knowledge/skills to correctly diagnose and treat migraine, support effective self-management or refer appropriately – acting as ‘gatekeepers’. Intermediary clinics (level two) could be staffed by GPs with a special interest (GPwSI) in headache and/or Clinical Nurse Specialists (CNS), possibly with some (arm’s length) cover from a neurologist.

There are currently several initiatives and national bodies active in improving headache care, presenting an unprecedented opportunity to bring about a transformation in care provision and significantly reduce migraine’s socioeconomic impact.

7.2.3 Recommendations for the way forward

- National bodies currently active in improving public health and clinical care (e.g. the National Neurology Advisory Group (NNAG); NHS RightCare; Neurology Intelligence Network (NIN); National Advisory Committee for Neurological Conditions (NACNC)) should work with the network of headache and migraine stakeholder groups in the UK to include the British Association for the Study of Headache (BASH), the Migraine Trust, Headache UK, relevant academics, expert bodies, health professional groups and people with migraine and their families. Collectively, they should develop a strategy/plan for headache and migraine care in the UK.
- This would need to identify and convene an expert multi-stakeholder group with relevant expertise to agree on a proposal to integrate current initiatives and address gaps to produce a coherent national framework for structured headache services and support for self-management and consistent public health messaging.
- The proposal would require comprehensive cost-benefit analyses to demonstrate how much such a system would cost and how much it would save (currently available cost-effectiveness data, though limited, suggests the findings would be positive).
- Action from local and national health decision-makers and commissioners would be needed to implement the strategy.

7.2.3.1 Existing developments and opportunities to explore

- NHS RightCare is already developing a ‘framework for optimal care’/‘headache and migraine pathway’ in England. There remains a lack of ‘national system enablers’, including robust data and consistent public health messaging to underpin it; this should be addressed by NHS England/Department of Health and Social Care (DHSC) working with the UK Headache Network.
- GPwSI clinics – or other types of community-based headache clinics – are crucial to readily accessible headache services. There are a few examples around the UK³³⁷ and case studies/evaluations could be conducted on them with a view to exploring sustainability and scalability.
- Lack of GP knowledge/training is a barrier to care and currently only one hour is dedicated to headache/migraine in the medical curriculum; there is scope for this to be reviewed, particularly in the context of Public Health England (PHE) recently commissioning a review of the national medical curriculum’s emphasis on health and work³³⁸.
- There is some evidence in the published literature³³⁹ of the effectiveness of educational programmes targeted at GPs to improve their understanding of headache disorders including migraine. Drawing on this evidence, government stakeholders comprising DHSC, PHE and the NHS should consider trialling such interventions at local level.
- Government is already testing new models of care delivery and establishing ‘clinical champions’ for mental health and musculoskeletal (MSK) conditions, partly on the basis that these conditions are big contributors to lost productivity. Migraine’s comparable contribution provides a further basis for the reorganisation of care and possible establishment of ‘headache and migraine clinical champions’.
- Clinical Nurse Specialists (CNS) in headache could play an important role in structured headache services, providing accessible information on optimal headache management, an ability to dynamically manage caseloads, signpost other services effectively and to provide specialist treatment interventions such as Botox injections. The availability of nurse specialists is very variable and the impact of such variation on headache care should be explored.
- The British Medical Association have called for longer primary care consultations; this would enable GPs to provide more patient-centred care, listen to their patients and co-produce effective solutions with people with migraine.

7.3 Improving patient and public understanding

7.3.1 Rationale

It is estimated that only 50% of people with migraine seek medical care, with the remaining 50% self-managing. It is probably not feasible and not necessary for all of them to visit their GP – many can self-manage with over-the-counter (OTC) medication. However, they generally lack the resources to do so effectively. Public understanding of migraine is poor, even amongst people with migraine. This is due, in part, to a lack of reliable information

³³⁷ Oxfordshire CCG and new Devon CCG have developed community headache pathways which could be replicated elsewhere

³³⁸ See:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/639189/Health_and_work_mapping_study.pdf

³³⁹ Braschinsky, M., Haldre, S., Kals, M., Iofik, A., Kivisild, A., Korjas, J., ... Steiner, T. J. (2016). Structured education can improve primary-care management of headache: the first empirical evidence, from a controlled interventional study. *Journal of Headache and Pain*, 17(1).

regarding self-management and inconsistent messaging from patient awareness campaigns. This has a negative impact on patient outcomes: people with migraine using treatments incorrectly (including analgesics, opioids and triptans) are at risk of analgesic overuse or opioid dependency. This can cause MOH, a highly disabling disorder that can be very difficult to treat.

7.3.2 Vision

People with migraine should be empowered to effectively self-manage their condition. Their decision about whether to self-manage or not should not, as is often the case, be predicated on the assumption that the marginal benefit of professional involvement in their care would be small and therefore not worth it. Rather, it should be informed by information and education provided by clear, unambiguous, messaging provided by a reliable source such as the NHS. Relatively low cost measures implemented effectively have the potential to improve the welfare of millions leading to substantive socioeconomic savings.

A national public health campaign to educate people – ideally from a young age – on migraine and how to manage it is therefore needed. This should include information on lifestyle changes that can be made to manage symptoms effectively (during the ‘ictal’ and ‘interictal’ state and the role of ‘triggers’); when – and where (supported by a structured headache service) – to seek medical help; and effective signposting to reliable and useful sources of information provided by BASH and third sector organisations e.g. Migraine Trust and Migraine Action. A clear message should be that a ‘migraine prevention lifestyle’ is healthy lifestyle for everyone comprising healthy eating, regular exercise, etc.

This should be underpinned by community pharmacies and pharmacists supported to play an expanded, more active role in empowering patients to manage their own health with the right diagnosis, advice, OTC treatment and, if needed, support with lifestyle changes. Community pharmacists are also in a good position to identify people at risk of analgesic overuse and thereby help prevent MOH.

7.3.3 Recommendations for the way forward

- Convene a group of relevant stakeholders, government and expert health bodies comprising DHSC and devolved health representatives from the UK’s different nations to work with the network of headache and migraine stakeholder groups in the UK (including BASH, the Migraine Trust, Headache UK, relevant academics, expert bodies, health professional groups and people with migraine and their families). This group should decide on the shape of national public health campaign to educate people – ideally from a young age – on migraine and provide consistent, clear messaging to aid self-management. People with migraine should be involved in developing the campaign.
 - The campaign should help with effective dissemination of existing resources, such as those provided by BASH, the Neuro Network Vanguard³⁴⁰, the Migraine Trust and Migraine Action.
- A strategic partnership between government and pharmacy bodies – with input from relevant third sector organisations and stakeholders – should explore the potential for community pharmacies and pharmacists playing a greater role in facilitating the self-management of people with migraine and prevention of analgesic overuse.

³⁴⁰ See: <https://www.thewaltoncentre.nhs.uk/uploadedfiles/leaflets/Migraine%20-%20A%20Comprehensive%20Guide.pdf>

- Government – DHSC, PHE and the NHS – should explore the potential for using technology, e.g. a phone ‘app’, as a means of empowering patients with self-records of their symptoms, treatment trials and lifestyle goals as well as disseminating advice and information to help people with migraine effectively self-manage and ‘bust’ migraine myths. NHS England’s ‘digital programme’ – approving apps to manage health conditions – is already underway

7.3.3.1 Existing developments and opportunities to explore

- NHS RightCare is already developing a ‘framework for optimal care’/‘headache and migraine pathway’ in England; any proposed public health campaign should seek to complement it.
- Pharmacy Voice, the Pharmaceutical Services Negotiating Committee and the Royal Pharmaceutical Society, recently published the *Community Pharmacy Forward View*³⁴¹ which makes the case for community pharmacies and pharmacists as a means for empowering people to manage their own health and facilitating effective self-management for people with long-term conditions; it should serve as a platform for proposals going forward.
- Government and the DHSC – as set out in the *Improving Lives* consultation response – are already trialling the use of phone ‘apps’ as a means of facilitating self-management with other long-term, chronic conditions such as MSKs. For example, in Scotland, the ‘NHS 24 MSK Help’ app was developed with patients, doctors and pharmacists to support patients to self-manage their condition, providing useful advice, information, and more; this should serve as a blueprint for the use of technology in the self-management of migraine.
- An *Improving Lives* initiative: NHS England’s digital programme is underway, approving apps to manage health conditions to support patients in managing their health; apps for migraine management should be part of this.

7.4 Improving work-related outcomes

7.4.1 Rationale

Migraine has a hugely significant impact on people’s working lives (and those of homemakers and with parental or caring duties) and it is often reported as their biggest concern. This is in part due to the fact it predominantly affects people during their prime working age, but also because, amongst employers, awareness and understanding of migraine is poor – as it is in the general population. Due to the stigma and common misconceptions surrounding it, employers rarely understand the impact migraine can have on one’s ability to function. This is in part due to the ‘invisibility’ and fluctuating nature of the condition, and not helped by market research surveys suggesting migraine is a common reason for ‘pulling a sickie’.

Short-term sickness absence policies do not accommodate the fluctuating nature of migraine well and, partly due to a lack of employer understanding, it can be difficult to get reasonable adjustments. Difficulty accessing occupational health services contributes to this. People with migraine – and the workforce generally – would benefit from access to ‘good’ work comprising flexible working, autonomy and control, manageable demands, and social support from colleagues and managers.

³⁴¹ See: <http://psnc.org.uk/wp-content/uploads/2016/08/CPFV-Aug-2016.pdf>

Employers who want to help, are not always sure how due to a lack of available information on how to support people with migraine. Whether a person with migraine gets support too often depends on the ‘lottery’ of working for an employer – or having a line manager – that understands the condition. Furthermore, when and if they do need it, people with migraine struggle to get appropriate return to work support from government services, e.g. Jobcentre Plus.

7.4.2 Vision

Everyone – including people with migraine – has the right to a ‘good’ job. Employers should – and increasingly do – provide healthy work environments which support a happy, healthy and engaged workforce. This is most likely to be achieved by businesses that adopt an integrated and proactive approach to managing people at work through ‘high performance working’ practices. These put people at the heart of businesses and seek to ensure business success by empowering employees, enabling them to actively contribute to performance improvements. People with migraine, therefore, should not be ‘singled out’ for special treatment unnecessarily but rather be able to benefit from (as any other employee would) a ‘good’ psychosocial work environment. More control and autonomy would allow them to manage their workload and perceived ‘triggers’; manageable demands reduce the risk of stress – a ‘trigger’; social support from colleagues and managers helps them manage their condition; and workplace flexibility enables them to manage their hours and fit work around symptoms. A healthy migraine workplace is a healthy workplace for all.

In addition, employers should be empowered to understand their employees’ needs. For those with health conditions, such as people with migraine, this means knowing how to make workplaces amenable to employees with long-term, fluctuating, chronic conditions and seeking specialist advice as and when appropriate to tailor support accordingly, i.e. depending on the nature of their employees’ conditions. This requires a review of health policies, including inflexible short-term sickness absence policies, better access to occupational health services, recognition of the crucial role that line managers play and a stronger evidence base around ‘what works’ regarding reasonable adjustments. This would enable employers – and occupational health professionals – to better support employees in general and specifically those with migraine. Furthermore, when and if they need it, Jobcentre Plus should be able to provide effective support for people with migraine.

7.4.3 Recommendations for the way forward

- In its response to the *Work, Health and Disability* green paper and the *Taylor Review of Modern Working Practices*, the Government identified ‘good work for all’ as a national priority, recognising its positive relationship with health specifically as well as driving improvements in business performance more generally. Making progress on promoting health and wellbeing at work, ensuring individuals’ needs are supported, requires effective joined up working between various agencies (especially those operating locally) – employers, Jobcentre Plus, Local Enterprise Partnerships (LEPs), professional bodies, Chambers of Commerce, the NHS and local authorities. In concordance with the *Taylor Review*, relevant government departments – Business Energy and Industrial Strategy, Department for Communities and Local Government, Department for Work and Pensions and DHSC – should explore ways of supporting and incentivising local authorities and partners (e.g. city regions and combined authorities) to develop more specialist and integrated approaches to improving health and wellbeing at work, with emphasis on supporting – and empowering – those with

fluctuating, chronic conditions and supplementing general management practices with specialist support as required.

- Addressing these challenges requires robust knowledge of current employer practices and how decision-making differs across businesses. Thus, local partners should work with employers through recognised business communities, at local level, supported through trade and professional bodies as well as national bodies, including Be the Business, and government departments to support wider adoption and take-up. The intention here is to support collaborative action, developing case study materials, and sharing knowledge, learning and good practice to support the health and productivity of people with migraine at work. Bodies such as Be the Business are currently working with LEPs, and other local partners, to increase the quality of management practices generally and this work can be supplemented to enhance the benefits for the better management of health at work too.
 - There should be an emphasis on co-produced solutions (i.e. developed by the employer and employee) meeting local industry needs.
 - The crucial role that line managers play in supporting employees' health and productivity at work should be recognised.
- To enable employers to support the health and productivity of people with migraine, develop an online repository – 'hub' – of information curated by employers, expert bodies and relevant third sector organisations signposting them to reliable sources of information, such as those provided by the Migraine Trust and Migraine Action.
- Government working with local partners should explore the need to commission new research into the business case for supporting the productivity of people with migraine at work, serving as a platform for further advice and tools to support effective reasonable adjustments for people with migraine, i.e. 'what works'.
- Government should explore how sickness absence policies can be adapted to better accommodate people with fluctuating conditions and, building on commitments set out in *Improving Lives*, improve access to occupational health and support schemes such as Access to Work.

7.4.3.1 Existing developments and opportunities to explore

- PHE are in the process of developing new 'healthy workplace standards'; this is an opportunity to ensure that these standards cater to the more general needs of people with chronic, fluctuating conditions at work.
- The Migraine Trust, Migraine Action and BASH have published materials to support people with migraine in the workplace. There is scope for government to work with these organisations to widen the specialist information and advice available.
- The *Improving Lives* green paper recently set out its ambition for the Civil Service being an 'exemplar' in terms of supporting its employees with long-term conditions; there is an opportunity for the NHS to serve a similar role in a migraine context – it has already committed, through the recent consultation document, *Facing the Facts, Shaping the Future, A health and care workforce strategy for England to 2027*, to being a 'model employer'.
- *Improving Lives* also sets out the Government's commitment to making the business case for recruiting and retaining people with long-term conditions and that this is only possible with a sophisticated understanding of current employer behaviours; it is important that the needs of people with migraine are factored into this.

- Complementing the commitments set out in *Improving Lives* work coaches should be supported, e.g. through training, to provide tailored support to people with migraine and those with chronic, fluctuating conditions generally.
- The potential for the scaling-up of existing local programmes aimed at people working with migraine, e.g. 'ID migraine'³⁴², should be explored through a case study/evaluation.

³⁴²See:
http://www.exeterheadacheclinic.org.uk/sitebuildercontent/sitebuilderfiles/Reducing_the_impact_of_migraine_in_the_workplace_feb2013.pdf

