Society’s headache

The socioeconomic impact of migraine

Executive Summary

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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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 15-49⁵

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 annum⁶

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, hospitalisations, 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; ³GD 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 the further 0.7 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 Euroilght data, we estimate a mean per-person migraine annual direct cost of £34.03, 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+)
Executive summary

Migraine is a common and disabling primary headache disorder. It is the third most common disease in the world in both males and females[1]. Globally, it is the highest cause of years lived with disability (YLDs) amongst those aged 15-49[2]. 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[3].

The indirect costs associated with migraine due to lost productivity, mainly through absenteeism and reduced effectiveness at work (presenteeism), are substantial[4]. 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[5].

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[6]. The most recent study was conducted in 2003[7]. 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[8].

The substantial indirect costs associated with migraine could be reduced significantly if it were treated and managed better: it is underdiagnosed and undertreated[9] and public and professional understanding of the condition is poor. These problems are compounded by vague patient pathways[10]. 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[11]. 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:

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8 Steiner et al. (2003).
11 APPG on Primary Headache Disorders. (2014).
(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 adult migraine prevalence at 23.3%\textsuperscript{12,13} while older estimates for the UK and Europe put it around 15%\textsuperscript{14,15,16}. 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’\textsuperscript{17}. 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\textsuperscript{18}, 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\textsuperscript{19}. A more conservative

\textsuperscript{12} 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/13f50842e7cb4fca6de7e497f626c9f6 (this is a weighted average taking migraine prevalence amongst those aged 15-49 and 50-69, which is 25.4% and 17.7% respectively)
\textsuperscript{13} Aged 15-69 years
\textsuperscript{14} Steiner et al. (2003)
\textsuperscript{16} For adults aged 16-65 years
\textsuperscript{17} Steiner et al. (2003)
\textsuperscript{18} Ibid.
\textsuperscript{19} This accounts for the size of the current UK workforce (32.2 million people as of January 2018; Office for National Statistics. (2018). UK labour market: January 2018. London: Office for National Statistics) and average wage (£511 per week as of January 2018: Office for National Statistics. (2018). UK labour market: January 2018. London: Office for National Statistics) and assumes average number of days lost per person with migraine is 5.7, based on Steiner et al. (2003).
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, 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.

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20 Steiner et al. (2003)
30 See: http://www.1-t-b.org/index.cfm/spKey/horizontal_activities.learning.the_eurolight_project.html
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

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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

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.

**Fig. 2 – Recommendations' three ‘settings’ for action**

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’. Intermediate 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.