The State of the Migraine Nation

What is the impact of migraine in the UK?

Rapid research review







Foreword

We're delighted to publish the second in a three-part series of evidence reviews into migraine as part of our 'State of the Migraine Nation' programme.

While the first review in this series looked at the characteristics of the UK migraine population to try to better understand our community, this review examines the wider impact that migraine has on individuals and society as a whole.

We're looking at this issue because we know it matters a great deal to people affected by migraine. In our latest consultation of over 1,800 people affected by migraine, we heard loudly and clearly that migraine significantly impacts on many different aspects of people's lives and that our charity needs to do more to raise public awareness and understanding of what living with this disabling brain disease is really like.

To make a more compelling case to decision makers for the greater focus, investment and prioritisation that our community needs, we must be able to better explain and demonstrate the impact that migraine has on communities, the NHS and our overall economy and society. There are around 10 million people living with migraine in the UK so it is highly likely that migraine is having a major impact. But we need to build an evidence-led case for change.

This review compiles published research from across the UK and around the world in order to help us make that case.

We hope the findings from this review will help us and the wider migraine community tell a better story and, along with our first evidence review looking at the migraine population, underpin the case for change that our 'State of the Migraine Nation' report is looking to make.

Please do let us know what you think about the findings by emailing policy@migrainetrust.org or tweeting us using the hashtag #MigraineNation.



Gus Baldwin
Chief Executive



Main messages

Setting the scene

About ten million people in the UK live with migraine, a serious neurological condition that can have debilitating effects. As part of our 'State of the Migraine Nation' programme, The Migraine Trust explored research about the impact that migraine has on individuals and UK society. This rapid review summarises 97 studies about the impacts of migraine in the UK and abroad.

Impact for individuals

Migraine can have a significant impact on the health and wellbeing of individuals. People living with migraine report reduced health, wellbeing and quality of life. There are also negative impacts on family members and relationships. This includes people's reduced ability to take part in housework and social activities and increased stress placed on close relationships.

Health costs

In addition to impacts for individuals, research suggests that migraine has significant societal impacts. One of the most frequently researched societal impacts is the cost of healthcare. Some estimates suggest that in the UK migraine costs the NHS £1 billion per year, mostly from GP visits and prescribed medications.

Productivity impacts

Migraine also affects the UK economy, with up to 43 million days off work due to migraine each year. The most recent UK estimates of the total healthcare and productivity costs of migraine were released in 2018. Migraine may cost the UK economy between £6 billion and £10 billion per year.

Gaps in knowledge

It is clear that migraine can have significant effects on the economy as well as individuals. However much remains unknown about the impact of migraine on wider aspects of society, including the amount of informal caregiving involved, the impact on the work or schooling of family members, and the impact on culture, educational attainment or other aspects of society. The migraine community could help to fill this gap so that the full impact of migraine is better understood.



Contents

Background	4
Scope	4
Approach	5
Individual impacts	6
What is migraine?	6
Health impacts	7
Quality of life	10
Home life	12
Economic impacts	14
Healthcare use and costs	14
Impact on work	16
Total costs	20
Summary	23
What we know	23
Knowledge gaps	24
Implications	25
References	27

Acknowledgements

This rapid review was produced for The Migraine Trust by an independent organisation, The Evidence Centre, in January 2020. To maintain the independence of the review, it has not been edited by The Migraine Trust. The review summarises the findings from published research. That research does not necessarily reflect the views of The Migraine Trust or The Evidence Centre.



Scope

Migraine is a complex condition with a wide variety of symptoms, including painful headaches, vomiting, disturbed vision and sensitivity to light, sound and smells. The symptoms vary from person to person and between migraine attacks.¹

Migraine is the third most common health condition in the world, after dental caries and tension type headache. It is more common than diabetes, asthma and epilepsy combined.²

Around 10 million people in the UK are living with migraine. It is estimated that up to one in five adults in the UK lives with migraine (23% of those aged 15 to 69 years).³ On average, there may be more than 190,000 migraine attacks every day in the UK.⁴

The Migraine Trust is the largest research and support charity for people affected by migraine in the UK. Our role is to fund and promote new research into migraine, provide day to day support for people affected by migraine and campaign for change. In a recent consultation by The Migraine Trust with more than 1,800 people affected by migraine, people spoke passionately about the impact that migraine has on themselves and their families. The Migraine Trust wanted to build on these stories by exploring what published literature can tell us about the impact of migraine in the UK.

This rapid review addresses the question:

What research is available about the impact of migraine on the UK economy and society as a whole?

This review forms a part of The Migraine Trust's 'State of the Migraine Nation' project which seeks to identify the issues that matter most to people with migraine and draw the migraine community together around shared priorities for change.



Approach

The Migraine Trust wanted to summarise themes from recent published research to get a sense of what is known and where there may be gaps in existing knowledge.

An independent team searched 18 bibliographic databases for relevant research.¹ More than 3,500 studies were read to see whether they were relevant.

Studies were eligible for inclusion in the review if they:

- were published in a journal or book
- were published between January 2000 and December 2019
- were of any research design as long as they included empirical data
- focused on the impact of migraine in the UK. As limited UK research was found, a selection of examples from other regions, particularly Europe, North America and Australasia, were also included to provide background information. Studies from these countries were not the priority.

Opinion pieces and articles that did not contain empirical data were not included.

97 studies with relevant information were included, 23 from the UK and 74 from other countries. All of the studies were read in detail and themes from the findings were summarised and grouped.

A systematic process was used to identify research, but the rapid review did not aim to be an exhaustive overview of the impacts of migraine in the UK. The Migraine Trust is carrying forward a wide programme of evidence gathering, including workshops and surveys, to add to these findings and better understand the state of the nation related to the impact of migraine in the UK. This rapid review is one step in that journey.

¹ The databases were Ageline, Academic Search, Cumulative Index of Nursing and Allied Health Literature, the Cochrane Library and Controlled Trials Register, Current Contents, EMBASE, Global Health, Google Scholar, IngentaConnect, PsycINFO, Pubmed, PubPsych, NHS Evidence, ScienceDirect, SearchTeam, Scopus, Web of Science and WorldWideScience.



Individual impacts

What is migraine?

Migraine is a disabling disorder with various symptoms. It usually involves a headache on one side of the head with throbbing or pulsating pain. One of the things that differentiates migraine from other headache disorders is the intensity of pain and disability experienced.⁵

Migraine is responsible for 2.9% of all years of life lost to disability and is the leading cause of disability among all neurological disorders.⁶ The World Health Organization classifies migraine as one of the most disabling conditions in the world, comparable in impact to psychosis, dementia and quadriplegia.⁷

More than three quarters of people living with migraine experience at least one attack each month, and more than half experience severe impairment during attacks.⁸ Migraine attacks usually last between four and 72 hours.

The International Classification of Headache Disorders identifies several types of migraine, the most common being migraine with aura, migraine without aura and migraine aura without headache. The term 'aura' usually refers to visual disturbances including coloured spots, blind spots and flashing lights in front of the eyes. Often migraine is defined as episodic if people have an attack on 14 or fewer days per month, whereas chronic migraine involves 15 or more affected days per month.

This section describes research into the impact of migraine on people's individual health, wellbeing and relationships.



Health impacts

International research

There is surprisingly little information about the health impacts of migraine for people living with migraine in the UK so this section explores some of the international literature, highlighting where relevant UK studies are also available.

Disability

Global studies have emphasised that migraine and other headaches are a major worldwide public health concern. Across the world, more than one billion people are estimated to live with migraine. People with migraine can have active and fulfilling lives and be valuable members of the community. However they may do this whilst experiencing devastating disability.

Data from a large global study, including participants from the UK, were used to calculate the years of life lived with disability amongst people with migraine. The calculation was based on the average time spent with headache multiplied by the relative severity of the consequences. Migraine was estimated to cause 45.1 million years of life lived with a disability globally in 2016. Migraine was most burdensome in women aged between 15 and 49 years, causing 20.3 million years lived with disability in this group in 2016. The researchers concluded that migraine is an important cause of disability worldwide which deserves greater attention in health policy and increased research funding.¹⁰

A study in the USA found that about one third of those with episodic migraine and three quarters of those with chronic migraine had moderate to severe headache related disability.¹¹

People living with migraine may experience a number of symptoms in addition to headache, including feeling tired, having difficulty concentrating and stiff neck. 12 However it is not straightforward to document the health impacts of migraine, because migraine is not experienced similarly by everyone. A systematic review of nine studies found that people living with migraine experience difficulties during and between migraine attacks, with considerable variability between each day in terms of the impact on movement, ability to perform everyday activities and social activities and emotions. 13



Other health conditions

In addition to specific symptoms of migraine, research suggests that people living with migraine are more likely than others to live with other health conditions, including:

- anxiety and depression (including UK studies)^{14,15,16,17}
- asthma¹⁸
- bipolar disorder¹⁹
- chronic pain²⁰
- epilepsy²¹
- hearing loss (including UK studies)²²
- hole in the heart (patent foramen ovale)²³
- Meniere's disease (inner ear disorder)²⁴
- musculoskeletal pain (including UK studies)^{25,26}
- neurofibromatosis in children (tumours on nerve tissue)²⁷
- poor self rated health²⁸
- psychosomatic symptoms²⁹
- pregnancy complications, particularly vascular events.³⁰
- primary open angle glaucoma³¹
- psychological distress³²
- restless legs syndrome³³
- sarcoidosis (lumps and swollen tissue)³⁴
- sleep problems (including UK studies)^{35,36}
- stroke and transient ischemic attack, particularly associated with migraine with aura (including UK studies)^{37,38}
- suicidal thoughts and suicide attempts³⁹

This is not an exhaustive list.

It is not possible to say that migraine causes or is a result of these conditions, simply that people living with migraine often also have other health burdens.

People with chronic migraine are more likely than those with episodic migraine to report depression, disability and other health impacts. ^{40,41} A study of 7,160 people in the USA found that those with chronic migraine were more likely to experience severe headache impacts than those with episodic migraine. Generally the negative health impact of migraine was not influenced by gender, ethnicity or body mass index. ⁴²



Examples of physical conditions

In the UK researchers analysed data from the General Practice Research Database from 1994 to 2001. People living with migraine had more than double the chance of having a stroke or transient ischemic attack compared to other people. However analyses from other countries have not always found the same associations. At a study in the USA found that adolescents living with migraine may be at greater risk of stroke than others, but not children living with migraine.

A systematic review found an average six fold increase in the risk of stroke among women living with migraine who took combined hormonal contraception. The risk of gestational hypertension, pre-eclampsia, low birth weight and preterm birth was increased in pregnant women living with migraine. The reviewers concluded that healthcare professionals should screen women for migraine and follow up to reduce the risk of negative pregnancy outcomes.⁴⁶

Another review of 51 studies identified difficulties associated with migraine including reduced vitality and fatigue, emotional problems, pain, difficulties at work, general physical and mental health decline, reduced social functioning and disability.⁴⁷

A compilation of data from ten studies found that migraine was not associated with an increased risk of death, although migraine with aura may be associated with increased cardiovascular risk.⁴⁸

Examples of mental health conditions

A review of 178 studies examined the relationship between migraine and psychiatric conditions. The reviewers found that the associations were complex. People living with migraine were more likely than others to have major depression and panic disorder and vice versa. The researchers suggested that optimising treatment of either migraine or psychiatric conditions might help to reduce the burden of both conditions. They said that comprehensive evaluation was needed of psychiatric disorders in people with migraine to support integrated care.⁴⁹

Another review of 16 studies found that people living with migraine were about twice as likely as others to report depression.⁵⁰

People who experience severe pain, such as is the case with migraine, have been identified as at risk for suicide. A review of 17 studies examined suicidal thinking and behaviours amongst people living with migraine. People with migraine were more likely than others to think about and to report attempting suicide, particularly people living with migraine with aura.⁵¹



Similarly, an analysis of data from almost 150,000 people in six studies found that those living with migraine were around twice as likely to say they thought about suicide compared to others.⁵²

Researchers in Taiwan found that people living with migraine were more likely to think about suicide than other people (47% of those with chronic migraine compared to 3% of those without migraine). People who experienced frequent migraine with aura were most likely to be at risk of suicide.⁵³

Quality of life

UK research

In addition to impacts of physical and mental health, migraine may also affect people's quality of life.

There is limited published research about the quality of life of people living with migraine in the UK. A small number of comparative studies have suggested that people living with migraine have lower general and health related quality of life than others.⁵⁴

A study comparing people from the UK and the USA found that people living with migraine in both countries had lower health related quality of life than people without migraine.⁵⁵

In another UK study, 106 people living with migraine were surveyed about the level of pain they experienced during an attack and their health status. The researchers found that mild, moderate and severe migraine pain were all associated with reduced health related quality of life. The more severe the pain, the worse people reported their quality of life was.⁵⁶



International research

In other countries, research has consistently found that children and adults living with migraine have lower quality of life than others⁵⁷ and that people's ability to undertake their usual day to day activities may be reduced.⁵⁸ Those with chronic migraine consistently report lower quality of life and poorer health than people with episodic migraine.^{59,60,61,62,63}

A study in the UK, France, Germany, Italy and Spain found that people who had migraine attacks on four or more days per month had significantly lower quality of life than those not living with migraine.⁶⁴

A survey in 31 countries collected feedback from more than 11,000 adults who had monthly migraines and for whom preventive treatments had been unsuccessful. Key findings were:

- Six out of ten people said that there were positive things about living with migraine such as becoming a stronger person or learning to cope with difficult situations.
- But nine out of ten people said that migraine also impacted negatively on their professional, private or social life (87%).
- Eight out of ten people reported that living with migraine made them feel helpless, depressed and misunderstood (85%) and said that they had difficulty sleeping (83%).
- Half said their daily activities were limited due to migraine (49%) and that they were afraid of when their next attack would occur (55%).

The researchers concluded that migraine is associated with significant health burden, but people living with migraine were resilient and that if effective preventive treatments were available these people would be able to further maximise their contribution to society.⁶⁵



Home life

UK research

Research has also been conducted into the impact of migraine on the family members of those living with migraine.

One study, interviewed people living with migraine and their partners. More than 1000 people from England and the USA took part. People with migraine and their partners said that migraine impacted on family life and relationships. Those living with migraine said they:

- were less able to do housework and chores than people without migraine (85%)
- missed family social and leisure activities (45%)
- avoided making plans in case they needed to cancel them due to migraine (32%)
- were more likely to argue with their partners (50%) and children (52%)

Up to 60% of partners reported that migraine had negative effects on their relationships and also meant that they were required to do more work around the home. There was no difference in the findings between countries.⁶⁶

International research

These trends are replicated in international studies. A review of 49 studies published over a 25 year period found that people with migraine encountered significant burden, including impact on their families, school, work and finances.⁶⁷ They may also worry that they are not able to be as good a parent or partner as they could be.⁶⁸

In a study of more than 13,000 people living with migraine in the USA, around 17% of those not living with a partner said that migraine had contributed to relationship problems. Three percent of those in a relationship said that that they had chosen not to have children, delayed having children or had fewer children because of migraine. 33% said that living with migraine had negatively affected their career and 32% were worried about their long term financial security due to migraine. The perceived impact of migraine was greater among those with chronic migraine than people with episodic migraine. Women and men described similar impacts.⁶⁹



Research from various countries consistently suggests that migraine reduces people's ability to take part in usual household activities, including housework, leisure and social activities. For instance, a study in the USA tracked 520 people with chronic migraine and 9,424 people with episodic migraine over time. Over a three month period, about half of those with chronic migraine and one quarter with episodic migraine missed five or more days of household work. 37% of those living with chronic migraine and 10% of those with episodic migraine missed five or more days of family activities due to migraine.⁷¹

Women aged 18 to 35 years with migraine were surveyed in Israel, Finland, Germany, Greece, Italy, Norway, Spain, Sweden and The Netherlands. More than half of reported one or more times that they were unable to spend time with family or friends (62%) or unable to enjoy recreational or leisure activities (67%) because of migraine.⁷²

Other research has specifically examined how family members are affected when people live with migraine. A review of four studies of chronic headache, including migraine, found that these conditions could place significant strain on relationships. The reviewers suggested that chronic migraine could have a profound effect on people's lives. 4

A study in the USA examined the impact on more than 1,400 children aged 13 to 21 years who lived with a parent with migraine. The main impacts reported by children were:

- loss of parental support
- the need for children to support their parents instead of parents supporting children
- anxiety
- depression
- · interference with school
- missed activities and events

Perceived negative impacts were most apparent in children with a parent living with chronic migraine. The researchers concluded that optimising migraine care would not only benefit those living with migraine, but also their families.⁷⁵



Economic impacts

Healthcare use and costs

UK research

Studies evaluating the economic impact of migraine are complicated to conduct and may become outdated quickly, as treatments, costs and healthcare systems evolve.⁷⁶ However some information is available, particularly about the healthcare services used by people living with migraine and the estimated costs of those services.

Healthcare use

One study assessed patterns of clinic visits, diagnosis and medication use in adults with migraine in England and the USA. More than 8,000 people reporting six or more migraine headaches per year were interviewed. People living with migraine in the UK were more likely to have consulted a doctor for headache at least once in their lifetime (86% versus 69%), but were also more likely to have lapsed from medical care (37% versus 21%) than those in the USA. People in the UK were more likely to receive a medical diagnosis of migraine (67% versus 56%). Patterns of medication use were similar in both countries, with most people using over the counter medications. People who never consulted a healthcare professional reported substantial disability (60% UK versus 68% USA).⁷⁷

Other studies have found that in the UK, about 4% of GP consultations are for headache⁷⁸ and about 30% of neurology consultations are for headache. Migraine is the most common diagnosis in these consultations.⁷⁹

Healthcare costs

In the UK, in 2010 an All Party Parliamentary Group estimated that migraine cost the NHS £150 million per year, mostly from the cost of GP visits and prescribed medications. However a more recent analysis conducted in 2018 estimated that if 23% of working age adults had migraine, direct healthcare costs would be would be almost £1 billion per annum. This included outpatient care, investigations, medications for migraine attacks, preventive medications and hospitalisations. If the proportion of adults with migraine is 15%, healthcare costs were estimated at about £600 million per year. The prevalence rates of 15% versus 23% come from the two main studies conducted in the past two decades about the proportion of adults living with migraine in the UK.



In another study, researchers estimated the economic impact of migraine amongst people referred to specialist clinics in the UK. People with migraine receiving care from specialist headache clinics provided self reported data about service use and lost work days over a four month period. The average cost of NHS use over a four month period was £857. The average total cost including lost employment was £6,588. More severe symptoms were associated with higher costs. The annual cost to the country for people referred to migraine specialists was estimated at £835 million, including healthcare costs and lost productivity costs (2018 prices).⁸²

International research

The healthcare systems in other parts of the world are different from the UK so it is not possible to make direct comparisons related to healthcare usage or costs. Examples of international studies are provided here to give a favour of the types of research available.

Healthcare use

Research in 31 countries with more than 11,000 adults living with monthly migraine found that 38% had visited a hospital emergency department in the past 12 months (average of three visits) and 23% had been admitted to hospital overnight due to migraine in the past 12 months.⁸³

A survey with people living with migraine found that those in the UK, France and Germany were less likely than those from the USA, Canada and Australia to visit the emergency department for migraine.⁸⁴

In Finland, medical records were used to compare over 369,000 people living with migraine and others. People with migraine visited health professionals 1.7 times more than others and had an average of 1.8 times more sick leave days per person year. People living with migraine taking preventive treatments had less clinic visits (14 versus 26) and fewer sick leave days (17 versus 30 per person year) compared to those who did not take preventive treatments.⁸⁵



Healthcare costs

Other researchers have examined healthcare usage and costs in five European countries: the UK, France, Germany, Italy, and Spain. People living with chronic migraine had a higher level of disability and more prevalent psychiatric disorders compared to those with episodic migraine. It is therefore perhaps unsurprising that those with chronic migraine also had more visits to healthcare professionals, emergency department / hospital visits and diagnostic tests. Medical costs were three times higher for chronic migraine than for episodic migraine. Annual costs per person were highest in the UK and Spain and lower in France and Germany. The researchers concluded that chronic migraine was associated with higher medical resource use and total costs compared to episodic migraine in all countries, so treatments that reduce headache frequency may decrease the overall clinical and economic burden of migraine in Europe.⁸⁶

In the USA people pay directly for healthcare services (either out of pocket or covered by insurance). Research from a decade ago suggested that in the USA the medical services most commonly used by people living with migraine included headache medication, primary care visits, emergency department visits and diagnostic testing. The average migraine related costs paid per year were US\$4,144 for people with chronic migraine and \$1,532 for people with episodic migraine (2010 prices).⁸⁷

Impact on work

In a recent survey conducted by The Migraine Trust of over 1,800 people, 41% of people with migraine strongly agreed that migraine had a significant impact on their career.

This review aimed to explore research about the impact of migraine on people's work. However, apart from the research presented previously where people said that they felt their work was affected, there was little research seeking to quantify impacts on career progression, earnings, opinions amongst other employees or similar. The research available about work impacts focused mainly on the number of days of work lost and what this might cost the economy.



UK research

People may need to take time away from work or school to cope with the symptoms of migraine. International studies have estimated days lost and associated costs, but there is little such research in the UK. One of the most recent UK studies was conducted almost two decades ago. This estimated that each year £2.25 billion is lost to migraine related work loss, with 25 million days off work each year. This is likely to be underestimate as it is based on old data and does not account for presenteeism (working during an attack), which has also been found to have a significant impact on work productivity.⁸⁸

A more recent estimate drawing on research released in the past five years is that 43 million workdays are lost in the UK each year due to migraine absences, and the same number to working at reduced productivity due to migraine symptoms. This is equal to about 11 days per year lost by each working age adult with migraine.⁸⁹

Amongst non manual workers, migraine and chronic headache are the second most commonly cited cause of short term absence from work (accounting for 47% of absences).⁹⁰

A UK study found that women had more work time spent at under 50% productivity if migraine occurred during a menstrual period compared to migraine outside a menstrual period.⁹¹

International research

A number of studies from different parts of the world have sought to quantify what proportion of people with migraine take time off work and the number of days lost due to migraine. The estimations vary, but the themes were:

- about half of people living with migraine may take time off work due to migraine
- the number of work days lost to migraine vary greatly, but may average about six per person per year
- around half of people with migraine say they have worked during a migraine attack and this reduced their productivity
- the more frequent and severe migraine attacks are, the more likely people are to miss work or school
- little research has quantified the number of days children with migraine may miss from school or the impact on their educational achievement



'Presenteeism' means that people are at work but not functioning at full productivity. A review of research found that the cost of presenteeism of migraine is much larger than the direct healthcare cost, but the researchers said that it was not possible to estimate the exact financial cost.⁹²

Proportion of people losing work time

A survey of more than 8,000 people with migraine or other headache was conducted in the UK, Austria, France, Germany, Italy, Lithuania, Luxembourg, Spain and The Netherlands. About 18% of males and 28% of females lost more than 10% of productive days due to migraine.⁹³

In a study with people from the UK, France, Germany, Italy and Spain, people with migraine attacks on four or more days per month were more likely than people without migraine to report being absent from work (14% versus 9%), working whilst unwell and potentially impaired (36% versus 21%), overall work impairment (39% versus 23%) and activity impairment (44% versus 28%).⁹⁴

In an Italian study, about one quarter of people living with migraine said that they had missed at least one day of work in the past three months due to migraine and around 10% lost two or more days. Over half said they worked for one to seven days per month whilst they had migraine symptoms and 15% said this reduced their productivity level on those days by 50% or more.⁹⁵

A study in the USA used four years of data from a large national survey to examine missed workdays among people aged 18 to 65 years living with migraine. 77% people living with migraine reported missing work time due to migraine. The average number of missed workdays was 4.4 per year. Those taking preventive medication and who had been admitted to hospital were more likely to miss workdays.⁹⁶

Women aged 18 to 35 years with migraine were surveyed in Israel, Finland, Germany, Greece, Italy, Norway, Spain, Sweden and The Netherlands. During the past six months, 46% of these women had missed at least one day of work or school and 74% said they were prevented from functioning fully at work or school because of migraine. The average number of days absent from work or school due to migraine was 1.9 days over six months. Those aged 18 to 24 years, those who were separated, widowed, or divorced and those with more frequent migraines or severe headaches had the highest number of days away from work.⁹⁷

A review of research found that children with migraine commonly have reduced school attendance. The greater the number of migraine attacks, the greater the amount of time away from school.⁹⁸



Amount of time lost

A survey of more than 1000 people with migraine and their family members in the UK, Europe, USA and Canada found that on average, in the past three months people with migraine had missed 2.4 days of work or school and 4.2 days of family or leisure activities. Productivity at work or school was reduced by at least half on an average of 6.2 days within the past three months. Participants reported an inability to perform household work on an average of 6.5 days over the past three months.⁹⁹

In another study, over 3,100 people living with migraine in 17 European countries reported an average of 2.3 workdays missed per month due to migraine. At least one in four migraines led to work absenteeism.¹⁰⁰

In Lithuania, migraine was associated with an average 4.5% loss in paid work time per affected man and 3.5% per affected women. Among the entire workforce, lost productivity due to migraine was estimated at 0.7% of the gross domestic product (GDP). Similar findings were suggested in other countries.¹⁰¹

A longitudinal study in the USA with more than 11,000 people examined the impact of migraine on 'lost productive time', including missed work hours and reductions in productivity whilst working. People with chronic migraine were more likely to lose productive time than people with episodic migraine. On average, those with chronic migraine lost 4.6 hours per week from headache. Those with three or less headache days per month lost an average of 1.1 hours per week due to migraine attacks.¹⁰²

Another study in the USA using data from a large financial services corporation with over 80,000 employees estimated that annual corporate costs from migraine related absenteeism were at least US\$21.5m. Reduced on the job productivity was worth US\$24.4m (2002 figures).¹⁰³



Total costs

UK research

A number of studies have sought to estimate the total economic cost of migraine by compiling healthcare costs (direct costs) and lost productivity costs (indirect costs). Most of this research is international, but there is a recent UK example.

Drawing data from other UK studies, analysts estimated that 23% of working age adults in the UK live with migraine and they lost an average of 5.7 days of work due to migraine each year. This equates to 43 million workdays lost every year in the UK to migraine related absences, at a cost of almost £4.4 billion. A more conservative estimate if 15% of the adult population have migraine is 28 million days lost at a cost of £2.8 billion (2018 prices).¹⁰⁴

These researchers assumed that lost productivity whilst working with migraine symptoms accounted for an equal amount of lost productivity as work absences. Thus lost productivity due to migraine related absences plus working at reduced productivity was equivalent to 86 million workdays lost per year, at a cost of just under £8.8 billion in lost productivity. If using the lower 15% prevalence estimate, 55 million days would be lost at a cost of more than £5.6 billion per year.

Direct healthcare costs for outpatient care, investigations, medications for migraine attacks, preventive medications and hospitalisations were estimated at almost £1 billion per annum.

Adding together direct and indirect costs, migraine was estimated to cost the UK economy between £6.2 billion (if using 15% prevalence) and £9.7 billion per year (if using 23% prevalence). Direct healthcare costs accounted for just 10% of this.

Other impacts related to quality of life, lost social and family time, anxiety and depression and lost earnings due to impacts on career advancement and potential earnings are difficult to quantify. However recognising these factor, the economic cost of migraine to UK society is likely even greater than estimated here.



International research

Similar international research is also available, although the cost estimates may not be directly applicable to the UK. For instance, one study estimated the annual cost of migraine at €27 billion in Europe, US\$1.4 billion in the UK and US\$16.6 billion in the US.¹⁰⁵

A survey of more than 8,000 people from eight European countries estimated the direct and indirect annual costs of migraine per person. Direct costs included medications, outpatient healthcare, hospitalisation and investigations. Indirect costs included work absenteeism and reduced productivity at work. The average annual cost for migraine was €1,222 per person, of which indirect costs accounted for 93% (2009 prices). The total annual cost of migraine amongst adults aged 18 to 65 years in the European Union was estimated at between €50 billion and €111 billion, of which 64% related to indirect costs.¹⁰⁶

In another study, researchers from the USA compared direct and indirect costs between more than 50,000 people with and without migraine. Those living with migraine had larger average annual direct costs (US\$13,032 versus \$3,234), indirect costs due to absence (US\$4,104 versus \$3,531) and short term disability costs (US\$1,131 versus \$52).¹⁰⁷

A similar study in the USA examined direct healthcare use costs and indirect costs (absenteeism and short and long term disability) over a one year period, comparing people with and without migraine. People with migraine had total annual direct plus indirect costs that were US\$8,924 higher than a matched comparison group without migraine (2014 prices). On average, people living with migraine had annual healthcare costs US\$6,575 higher than those of a matched group without migraine. Average annual indirect costs were US\$2,350 higher in people with migraine. People with migraine were more likely to have time off work and longer periods of work loss, leading to significantly higher indirect costs.¹⁰⁸

Another large study in the USA compared the economic cost of headache amongst people with episodic or chronic migraine. The average total annual cost among people with chronic migraine was more than three times of those with episodic migraine (US\$8,243 versus \$2,649). People with chronic migraine had greater direct medical costs (US\$4,943 versus \$1,705) and indirect (lost productivity) costs (US\$3,300 versus \$943). Much of the direct medical cost was due to medication costs.¹⁰⁹



Similarly, a survey of 630 adults with migraine in Sweden found that the total cost per person increased with the number of migraine days per month. This varied between about €5,000 per year for those with less than three migraine days per month and €24,000 per year for those with over 20 migraine days per month. About 80% of costs were due to productivity loss.¹¹⁰

The economic impact of migraine depends on workforce demographics and the cost of labour. Researchers in the USA modelled lost productive time in the workplace due to episodic and chronic migraine. In a simulated service sector workforce of 10,000 individuals, the estimated lost productive time due to migraine was US\$2.9 million annually compared with US\$2.1 million for a manufacturing workforce. Individuals with moderate frequency episodic migraine accounted for 42% of the cost. People with high frequency episodic migraine or chronic migraine comprised 10% the migraine population and accounted for 22% of the lost productive time. This shows that the type of work people do may influence the economic impact of migraine. In the UK no published studies have been identified about the work people with migraine do that would allow this type of sophisticated analysis.

Elsewhere in the USA researchers investigated whether conditions that people have in addition to migraine may account for the association between migraine and work performance. Data from more than 9,000 people were analysed. The researchers found that even after accounting for other conditions, people with persistent migraines had more time off work than others. The societal level annual value was US\$9.3 billion for people with 'severe or persistent' migraine.¹¹²



Summary

What we know

Many people living with migraine lead fulfilling lives, but migraine can have debilitating consequences. It can impact on people's health, wellbeing, family and social life.

Migraine affects around 10 million adults in the UK and is most common amongst those aged 15 to 49 years. This is often when people are very productive economically and socially, developing their careers and starting families. Migraine may thus have a significant impact on people's families, work and the economy in general, as well as the disabling impacts for individuals.

Research from the UK and elsewhere shows that many people with migraine experience pain and disability. They may also be more likely to have other conditions such as difficulty sleeping, anxiety, depression and musculoskeletal pain. They may be more likely to think about and attempt suicide than other people.

Migraine also impacts on people's families and relationships, with research suggesting that people may be less involved in house chores and family activities, may not think they are as good parents as they could be and may put off having children due to migraine.

The impacts in the published literature reinforce feedback from more than 1,800 people surveyed by The Migraine Trust in 2019. Those surveyed said that people with migraine may find it difficult to plan in advance and feel that they cannot relied be on. This may lead to reduced opportunities in all aspects of life. The impacts people described and the strength of feeling about them were similar to the issues highlighted in published research in the UK and elsewhere.

In addition to exploring the impacts for individuals and their families, international studies have estimated the societal and economic costs of migraine. There is little such research in the UK. The most recent UK estimates of total healthcare and work related costs associated with migraine were released in 2018. It is estimated that migraine costs the UK economy between £6.2 billion and £9.7 billion per year (depending on whether the proportion of adults with migraine is estimated at 15% or 23%).



Knowledge gaps

Migraine is common, burdensome and costly in the UK and in other parts of the world. It is the seventh most disabling health condition across the world. Despite its significant health, social and economic impacts, migraine is relatively neglected. It is the least publicly funded of all neurological diseases relative to its economic impact in Europe. 114

Minimal published research has been undertaken about the impact of migraine in the UK. Although examples from almost 100 studies are included in this review, only around one guarter were from the UK.

Particular gaps in knowledge about the impact of migraine in the UK include:

- validation of existing information about healthcare usage and cost and the overall economic impact
- the impact on work life, including whether different types of employment are more affected and impacts on career progression and earnings
- · the impact on family life
- the impact on children's school attendance and educational attainment
- the impact on other aspects of society, such as cultural activities
- whether the greater rates of suicidal thinking and suicide attempts found amongst people with migraine in other countries are replicated in the UK
- the highest priority impacts for people living with migraine and their families



Implications

Migraine is a substantial public health issue that mainly affects working age adults. Research from the UK and abroad highlights the considerable impact that migraine has on people lives, including education, work, home and family life, and physical and mental health and wellbeing. In summarising the research themes, this rapid review cannot hope to do not do justice to the range and scale of impacts of migraine and the frustration and disability that those living with migraine may experience, but it gives insight into some of the issues – and some of the considerable gaps in knowledge.

Box 1 provides The Migraine Trust's initial reflections about the implications of this review.

In the UK migraine is associated with poor health and disability, increased use of healthcare and medication and reduced productivity at home, work and school. The impacts are felt not only by individuals and their families, but also the UK economy. With around one in five working age adults in the UK potentially affected, if effective care and support was available, healthcare costs may be significantly reduced and economic productivity may increase. The greatest opportunity for cost savings comes from the potential to reduce lost productivity from migraine. Even small changes may help to reduce the £9.7 billion lost to the UK economy due to migraine each year.

Additional research and awareness raising about migraine may help to develop more structured self care and healthcare services and pathways to reduce the burden for both individuals and society. Migraine is a significant issue. By working together the migraine community, researchers, policy makers and healthcare professionals have the potential to help people with migraine live even happier and more productive lives.



Box 1: The Migraine Trust's first thoughts about what this review tells us

Since we launched our 'State of the Migraine Nation' project last year, hundreds of people living with migraine have shared their stories about the impact this condition has had on their lives and let us know how much they want the full impact of migraine to be better understood and recognised.

We undertook this review to get a better understanding of exactly that – the full impact of migraine. The reviewers looked for research about migraine's impact across a wide range of topics, including on the health and wellbeing of individuals, on families and communities, the health service, in the workplace, on our economy, on the built environment, on art and culture, and civil society.

While the review does include compelling insights into the impact of migraine on some of those areas, we're most struck by what the review is not telling us. Quite simply – there is a huge lack of UK research on the impact of migraine. After searching all studies published in the last twenty years, only 23 were found focusing on the impact of migraine in the UK. Those 23 studies focus on three categories only: the impact for individuals and families, the impact on healthcare resources and the impact on economic productivity.

But even those topic areas are very limited and sparsely researched. For example, the reviewers only found one UK study in the past five years assessing the days lost at work due to migraine. No studies were identified that looked at how else migraine impacts people at work, such as whether migraine impacts on career progression, career choice, earnings potential, workplace satisfaction or work patterns. There have been no UK studies about whether or not migraine impacts specific industries more than others or specific kinds of work.

We think there is a huge opportunity for the research community to fill these gaps over the next five years and beyond. Migraine affects around 10 million people in the UK and is the third most common condition in the world. It is in everyone's interest that we better understand how that high prevalence impacts across society.

More research is one of the ways that we'll find solutions that can help individuals and families better manage migraine, help the NHS spend its resources more efficiently and support the efforts of specific industries and employers to meet this workforce challenge more effectively. We'll be doing our part through our 'State of the Migraine Nation' project to fill some of these gaps and encourage research funders to invest in building the migraine evidence base. If you're a migraine researcher and would like to help us prioritise some of these evidence gaps, please get in touch by emailing policy@migrainetrust.org.



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