

THE SOCIOECONOMIC IMPACT OF MIGRAINE IN PORTUGAL



About The Work Foundation

The Work Foundation is the leading think tank for improving work in the UK. We have been an authoritative, independent source of ideas and analysis on the labour market and the wider economy for over a hundred years.

As the pace of economic change continues to disrupt the ways we work and do business, our mission is to support everyone in the UK to access rewarding and high-quality work and enable businesses to realise the potential of their teams.

To do this, we engage directly with practitioners, businesses and workers, producing rigorous applied research that allows us to develop practical solutions and policy recommendations to tackle the challenges facing the world of work.

We are part of Lancaster University's Management School, and work with a range of partners and organisations across our research programmes.

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

Acknowledgements

This project was sponsored by Novartis Portugal. It was conducted by a team at Lancaster University and the Work Foundation including: Professor Céu Mateus, Astrid Allen and Melanie Wilkes with the support of Sofia Ribeiro (MD).

The Work Foundation has retained full editorial control over the methodology, analysis and reporting.

Picture credits

Cover: Pexels

Contents

1. Introduction	5
1.2 Background: migraine in Portugal	5
1.3 Research aims, questions and structure of the report	7
2. The prevalence of migraine in Portugal	7
2.1 Introduction	7
2.2 What is migraine?	8
2.3 Migraine prevalence	9
2.3.1 Global prevalence of migraine and disability burden	9
2.3.2 Prevalence of migraine in Portugal	9
2.4 Migraine-related disability	10
3. The socioeconomic impact of migraine in Portugal	13
3.1 Introduction	13
3.2 Socioeconomic impact	13
3.3 Productivity losses	14
3.4 Direct costs	15
3.5 Out-of-pocket expenses	16
3.6 Co-morbidities	16
4. Migraine in Portugal – The experiences of people living with migraine, physicians, and stakeholders ...	16
4.1 Background	16
4.2 Results	16
4.2.1 Patients	17
4.2.1.1 Onset, frequency and severity of migraine	17
4.2.1.2 Management and treatment of migraine	17
4.2.1.3 Clinical care	18
4.2.1.4 Alternative therapies	19
4.2.1.5 Expenditures related to migraine management	19
4.2.1.6 The impact of migraine on working life	19
4.2.2 Occupational Health and Human Resources Directors	19
4.2.3 Physicians	20
4.2.3.1 General practitioners	20
4.2.3.2 Specialists and academics	21
4.2.3.3 GP training	22
5. Conclusions	23
6. Recommendations	24
Methodology	25
References	27

List of tables and figures

Table 1 – Migraine prevalence in Portugal by age and sex, 2019	9
Table 2 - Prevalence of migraine in Portugal, 1990-2017	10
Table 3 - Impact of migraine on daily activities by monthly migraine days (MMD)	13
Table 4 - Summary of the studies ^{on} productivity losses of migraine	14
Table 5 – Summary of the studies on direct costs of migraine	15
Table 6: Characteristics of the subject expert sample	26
Figure 1 – Prevalence of migraine in Portugal, by age for both sexes, 2019	9
Figure 2 – Prevalence of migraine in Portugal, all ages, 1990-2017	10
Figure 3 - What health problems cause the most disability in Portugal?	11
Figure 4 - What health problems cause the most death and disability combined in Portugal?	11
Figure 5 - What health problems cause the most disability in Portugal? 1990-2016	12



27%

of individuals aged 20-54 in Portugal experience migraine.

Source: Global Burden of Disease database (<http://ghdx.healthdata.org/gbd-results-tool>)



In Portugal, productivity losses of migraine amount to €590 per worker per month.

Source: Martelletti P, Schwedt TJ, Lanteri-Minet M, et al. My Migraine Voice survey: a global study of disease burden among individuals with migraine for whom preventive treatments have failed. *J Headache Pain* 2018;19(1):115. doi: 10.1186/s10194-018-0946-z [published Online First: 2018/11/30]

30%

17%

Prevalence of migraine in Portugal is almost twice as high among women than men. 30% of women and 17% of men in Portugal experience migraine.

Source: Global Burden of Disease database (<http://ghdx.healthdata.org/gbd-results-tool>)



Each year, an average of 8 equivalent workdays are lost per person with difficult to treat migraine

Source: Portuguese respondents to the my migraine voice study
Note: the study included mainly difficult-to-treat migraine patients (pre-defined stratification of the sample) and therefore is not representative of the full Portuguese population with migraine

1. Introduction

Migraine is the third most common disease in the world in both males and females, behind tension-type headache (TTH) and tooth decay.¹ Recent data shows it is the second highest cause of years lived with disability (YLDs) worldwide and, amongst those aged 15-49, the highest.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

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.⁴ This situation has persisted in spite of repeated calls from the World Health Organization, following its 2011 global survey of headache disorders and resources, highlighting the “neglect of a major public-health problem” and the “inadequacies of responses to it in countries throughout the world”.²

Over recent years, there has been work to increase awareness of migraine – a common and disabling primary headache disorder – and the challenges associated with the condition, particularly its impact on people’s ability to work.^{5,6}

This report assesses the prevalence and costs of migraine in Portugal, the barriers to optimal health and work-related outcomes for people with migraine and develops evidence-based recommendations address migraine’s burden.

1.2 Background: migraine in Portugal

In 1988, the International Headache Society defined common migraine as idiopathic (arising spontaneously, without a known cause), recurring hemicranial pain (pain in one side of the head) with duration between 4 and 72 hours, and with moderate to severe pulsatile quality. Classical migraine, or migraine with aura, was defined as common migraine, but accompanied by nausea, photophobia and phonophobia (abnormal sensitivity to light and sound).⁷

The Global Burden of Disease study (GBD), when looking into the number of years lived with disability for the period 1990-2017, ranked headache disorders as the third cause of years lived with disability (YLDs) in Portugal both in 2007 and 2017.⁹

The indirect costs associated with migraine due to lost productivity, mainly through absenteeism and reduced effectiveness at work (presenteeism), are substantial.⁸

Despite the number of studies that have attempted to estimate the prevalence and costs of migraine in many countries throughout the world, very few focus on Portugal, and national data is limited.

A recent study estimated the impacts of migraine on productivity in Portugal to cost €590 per worker per month.¹⁰ In a country where the average monthly wage was €970 in 2018¹¹, this represents a considerable amount which could be minimised with better diagnosis and management. In addition, there has been no research with Portuguese employers on their approach to supporting staff living with migraine.

There are two organisations in Portugal whose primary focus is headache. The *Sociedade Portuguesa de Cefaleias* (Portuguese Society of Headache) was founded in 1997 and offers post-graduate training to doctors and researchers who either specialise in or are interested in this area. The first patient group for people living with migraine in Portugal was established as recently as September 2019. MiGRA Portugal aims to represent and promote the rights of people living with migraine and/or headache. They also provide patient support services, including disease management and therapy.

1.3 Research aims, questions and structure of the report

The overall aims of the research were to:

- **Assess the prevalence and socioeconomic impact of migraine in Portugal** estimating both the indirect and direct costs attributable to it;
- **Explore the barriers to optimal health and work-related outcomes** for people with migraine; and
- **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 Portugal that experience it.

To do this, we employed a mixed-methods approach, first carrying out a rapid evidence review of the relevant academic and grey literature to understand the existing evidence on the prevalence and cost of migraine in Portugal and its impact on people's health, wellbeing and their ability to work alongside analysis of secondary data. To build on this evidence base, new qualitative research was conducted, comprising 19 semi-structured interviews with working age Portuguese adults with migraine ($n = 10$) as well as key stakeholders including GPs, neurologists and employers ($n = 9$).

The research set out to answer the following questions:

1. What is the prevalence of migraine amongst people of working age in Portugal?
2. What are the indirect costs (i.e. caused by absenteeism and presenteeism) attributed to migraine?
3. What are the direct (i.e. healthcare) costs attributed to migraine?
4. What are the barriers to optimal care for people with migraine and how can they be addressed?
5. What strategies do people with migraine use to manage their condition and how effective are they?
6. 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.

Chapter 3 answers the second and third questions, drawing on existing research and secondary data to provide an updated estimate of the indirect and direct costs associated with migraine.

Questions four, five and six are addressed in Chapter 4. Drawing on the qualitative research and supplemented with findings from the evidence review we explore the barriers to optimal care for people with migraine and how they can be addressed, we present coping and self-management strategies people with migraine use and, finally, we explore the barriers to optimal work-related outcomes for people with migraine and how they can be overcome.

In Chapter 5 we present our overall conclusions and, in Chapter 6, 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 Portugal

2.1 Introduction

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 Portuguese context. We then consider its typical attack frequency, duration, and the significant pain it causes.

2.2 What is migraine?

Migraine is a common and disabling primary headache disorder¹². 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; nausea and vomiting.

According to the International Classification of Headache Disorders¹, there are several types of migraine. The most common are migraine with aura, migraine without aura and migraine aura without headache. Aura can be defined as visual disturbances, such as flashing lights, blind spots, coloured spots and sparkles or stars in the field of vision, which may not occur at the same time.¹³

Roughly 70- 90% of patients experience migraine without aura¹³. The usual clinical presentation of migraine is a one-sided pulsating headache with a moderate to severe intensity that may last for 4 to 72 hours without appropriate treatment. Migraine is often classified as either episodic or chronic; where headaches occur between 1 and 14 days in a month an individual has episodic migraine, and this becomes chronic if headache occurs for 15 days or more (in which 8 or more days have characteristics of migraine, for at least 3 months).⁸

Medication overuse headache (MOH) can occur in migraine patients when medication is used excessively to treat a headache. It is a severe form of chronic headache often occurring in patients that have a long history of headache and unsuccessful treatments.¹⁴ MOH is a risk for increased disability and migraine chronicity. Medication overuse can also become a reason for migraine in people previously diagnosed with migraine.¹⁰

Globally, migraine is considered the most common disabling headache disorder^{15,16}, and is responsible for 6% of the total years lived with disability.¹⁷

Research regarding the genetic risk factors for migraine in the Portuguese population has produced contradictory results. A study of 77 cases with early and late onset of aura (51 of early onset and 26 with late onset) found no differences across gender, family or personal history,

symptoms or imaging findings.¹⁸ However, a study conducted with 188 people living with migraine (out of which 11 had aura and 77 did not, and 287 controls without migraine) showed a genetic link. Different genotypes were associated with an increased risk of different types of migraine.¹⁹

Contributing to the role played by genetics, another study which aimed to assess risk factors for migraine among a group of 131 Portuguese families found that hereditary risks are related to gender: females first-degree relatives faced a higher risk of experiencing migraine than males.²⁰

Migraine is also associated with depression and anxiety. This relationship seems particularly evident in migraineurs with allodynia (increased sensitivity to pain). A Portuguese study conducted on 98 patients with episodic migraine that showed that 75 patients (77%) had allodynia, and that this was associated with higher median results of anxiety and depression measured by the Hospital Anxiety and Depression Scale (HADS).²¹

Migraine impacts patients' cognitive function and impairs their ability to carry out normal day to day activities. Although one small Portuguese study showed no significant differences in neuropsychological tests between patients with migraine (n=24) and controls (n=24) without migraine²², another study from the same authors and including a sample of 100 patients showed that attack-related cognitive symptoms are intense and disabling. Cognitive symptoms (difficulty in thinking and worsening with mental effort) had the highest intensity and disability scores after pain.²³ Cognitive function has also been reported as being affected during untreated migraine attacks.²⁴

Impaired cognitive function during attacks is particularly relevant as migraine is highly prevalent among the working age population and known to contribute both to absenteeism and to presenteeism for those in the labour force.

¹ The International Classification of Headache Disorders is provided by International Headache Society (most recently updated in 2018) and recognised by the World Health Organization (WHO)

2.3 Migraine prevalence

2.3.1 Global prevalence of migraine and disability burden

The GBD study in 2017¹⁷ estimates that 18.1% of the population globally experience migraine across both sexes and all age groups. There is a clear female preponderance, with 22.6% of women experiencing migraine compared to 13.5% of men. The data show that headache disorders (largely consisting of migraine) is now the second highest cause of total YLDs worldwide (causing 5.5%) for both men and women and all age groups, second only to low back pain (7.2%) which comprises a mixture of disorders.¹⁷ This illustrates the challenge posed by migraine prevalence for healthcare systems worldwide.

2.3.2 Prevalence of migraine in Portugal

Very few studies have been conducted in Portugal to assess the prevalence of migraine among the Portuguese population.

In 1994, the first study conducted in Portugal that assessed the prevalence of migraine in medical university students (n=491), found a prevalence of 6.9% according to the Ad Hoc Committee Criteria (1962) and of 6.1% according to the International Headache Society (1988) criteria.²⁵ One year later, a population study (n=2008), reported a prevalence of 8.8% experiencing migraine of in its pure form i.e. not being associated to other headache form over the lifecourse.²⁶

The latest study, conducted in 1999, surveyed three different populations of the Central region of Portugal: active workers (N=892); university students (N=687) and high school students (N=813). The prevalence of migraine observed in the total of the three groups was 7.1% (6.1%–8.2%) and between genders there was a significant difference in prevalence: 10.6% (8.9%–12.6%) in women and 4.5% (3.5% – 5.7%) in men.²⁷

However, it should be highlighted that these studies were conducted approximately 30 years ago, with different diagnostic criteria compared to criteria currently used, and the populations are not representative of the overall Portuguese population.

The GBD 2017 estimate of migraine prevalence in Portugal – across both sexes and all age groups – is 19.3%. This rises to 26.7% among individuals aged between 20–54.¹⁷

Regarding the role played by sociodemographic factors, gender has a significant influence. As is the case with migraine globally, the prevalence of migraine in Portugal is almost twice as high in women than in men (Table 1 and Figure 1). A retrospective study of data collected from July 2011 to 2013, covering a total of 689 liaison psychiatric consultations, estimated the prevalence of headaches within psychiatric patients. 250 patients were considered in the study, of whom 84% were females with a mean age of 47. The most frequent types of headaches were tension type headache (60.8%), migraine (24.8%) and headache attributed to psychiatric disorders (7.2%).²⁸

Table 1 – Migraine prevalence in Portugal by age and sex, 2019¹⁷

Age	Male	Female	Both sexes
5-14	8.25	12.92	10.65
15-49	18.04	35.41	27.07
50-69	11.29	22.23	17.11
70+	5.24	9.04	7.48
All ages	12.95	24.22	18.98

Source: GBDx. GBD Results Tool Global Health Data Exchange; 2019

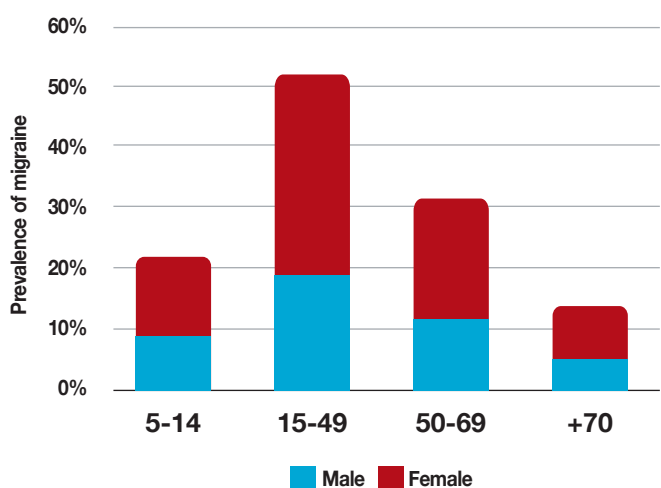


Figure 1 – Prevalence of migraine in Portugal, by age and gender, 2019¹⁷

Source: GBDx. GBD Results Tool Global Health Data Exchange; 2019

As Table 2 indicates, prevalence of migraine in Portugal has been largely constant since 1990 for both genders.

Table 2 - Prevalence of migraine in Portugal, 1990-2017

Year	Prevalence %		
	Males	Females	Total
1990	16.92	30.19	23.88
1991	17.01	30.31	23.99
1992	17.09	30.44	24.00
1993	17.18	30.56	24.20
1994	17.24	30.65	24.27
1995	17.31	30.73	24.35
1996	17.36	30.80	24.41
1997	17.41	30.87	24.46
1998	17.45	30.92	24.50
1999	17.47	30.93	24.52
2000	17.48	30.93	24.52
2001	17.47	30.91	24.50
2002	17.46	30.88	24.49
2003	17.44	30.85	24.46
2004	17.41	30.79	24.42
2005	17.37	30.73	24.38
2006	17.33	30.65	24.32
2007	17.29	30.59	24.28
2008	17.25	30.52	24.23
2009	17.21	30.45	24.18
2010	17.16	30.38	24.13
2011	17.11	30.30	24.07
2012	17.07	30.24	24.02
2013	17.03	30.18	23.98
2014	16.99	30.11	23.93
2015	16.95	30.04	23.88
2016	16.90	29.97	23.82
2017	16.86	29.90	23.77

Source: Global Burden of Disease database
(<http://ghdx.healthdata.org/gbd-results-tool>)

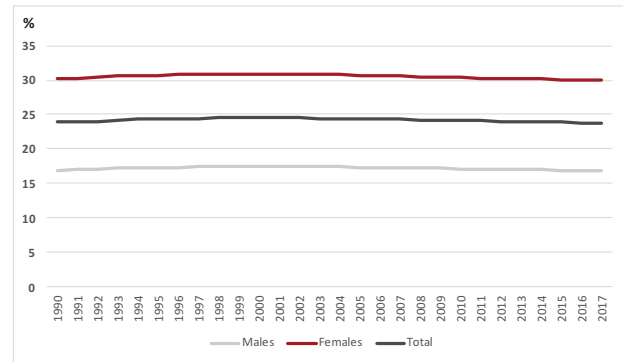


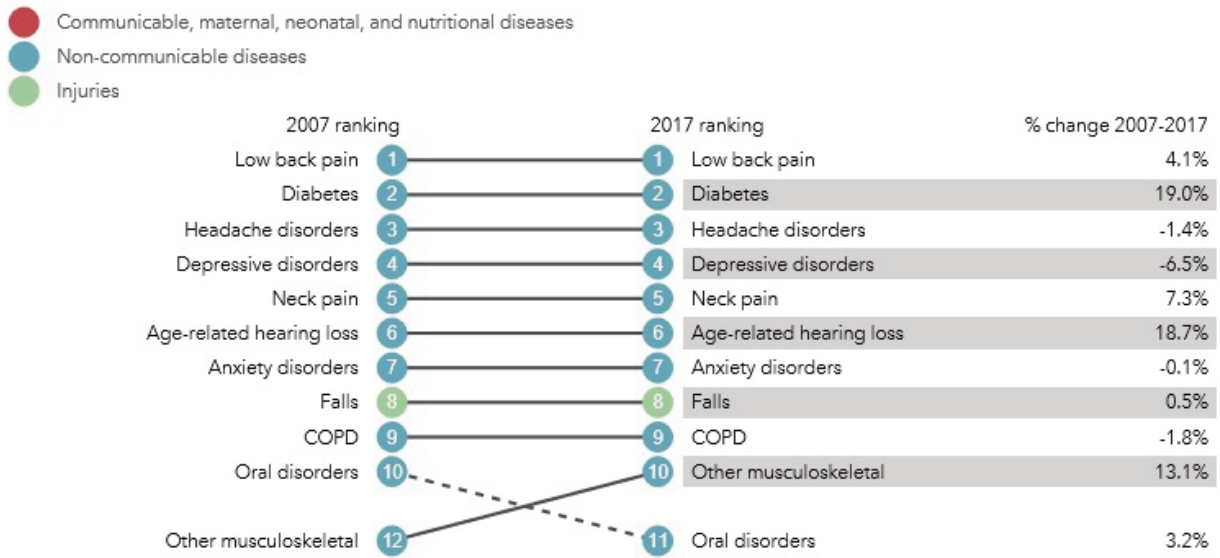
Figure 2 – Prevalence of migraine in Portugal, all ages, 1990-2017

Source: Global Burden of Disease database
(<http://ghdx.healthdata.org/gbd-results-tool>)

2.4 Migraine-related disability

Although the prevalence of migraine is lower than some other primary headache disorders, it is of particular importance in the public health context because of the significant impact it carries. This point is underlined by the fact that, of seven possible disability classes, the WHO ranks 'severe migraine' in the highest – disability class VII – alongside conditions like severe depression and terminal cancer²⁹.

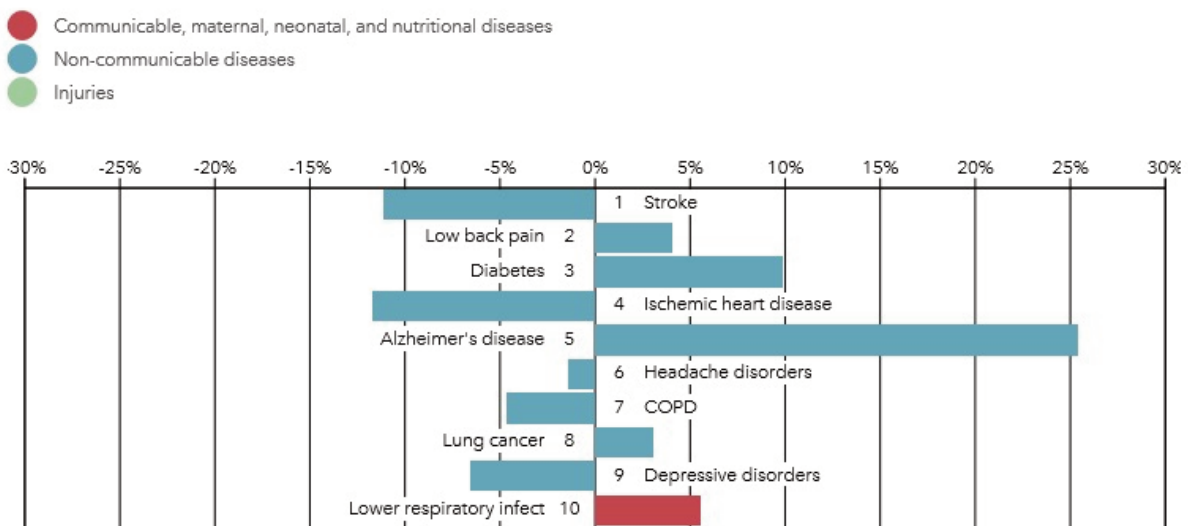
GBD ranked headache disorders as the third cause of years lived with disability (YLDs) in Portugal in 2017 (variation of -1.4% since 2007) (Figure 3). When combining ill-health, disability or early death (disability-adjusted life years, DALYs), headache disorders come as the sixth highest cause of DALYs (910.2 DALYs), after stroke, low back pain, diabetes, ischemic heart disease and Alzheimer's disease. In comparison with other countries included in the GBD study, in terms of DALYs due to headache, Portugal has the highest prevalence (**Figure 3**).⁹



Top 10 causes of years lived with disability (YLDs) in 2017 and percent change, 2007-2017, all ages, number

Figure 3 - What health problems cause the most disability in Portugal?

Source: Institute for Health Metrics and Evaluation (<http://www.healthdata.org/portugal>)



Top 10 causes of disability-adjusted life years (DALYs) in 2017 and percent change, 2007-2017, all ages, number

Figure 4 - What health problems cause the most death and disability combined in Portugal?

Source: Institute for Health Metrics and Evaluation (<http://www.healthdata.org/portugal>)

According to the report *The Nation's Health 1990-2016*³⁰, migraine was the 4th cause of disability (YLDs) increasing by 7.2% since 1990 (Figure 5). While migraine is highly prevalent and responsible for a significant amount of disability worldwide, there is evidence to suggest it is particularly problematic in Portugal. This report also highlighted that Portugal has the 2nd highest level of disability attributed to migraine, measured by disability-adjusted life years (DALYs), among a group of 11 countries with similar sociodemographic characteristics (medium-high level).

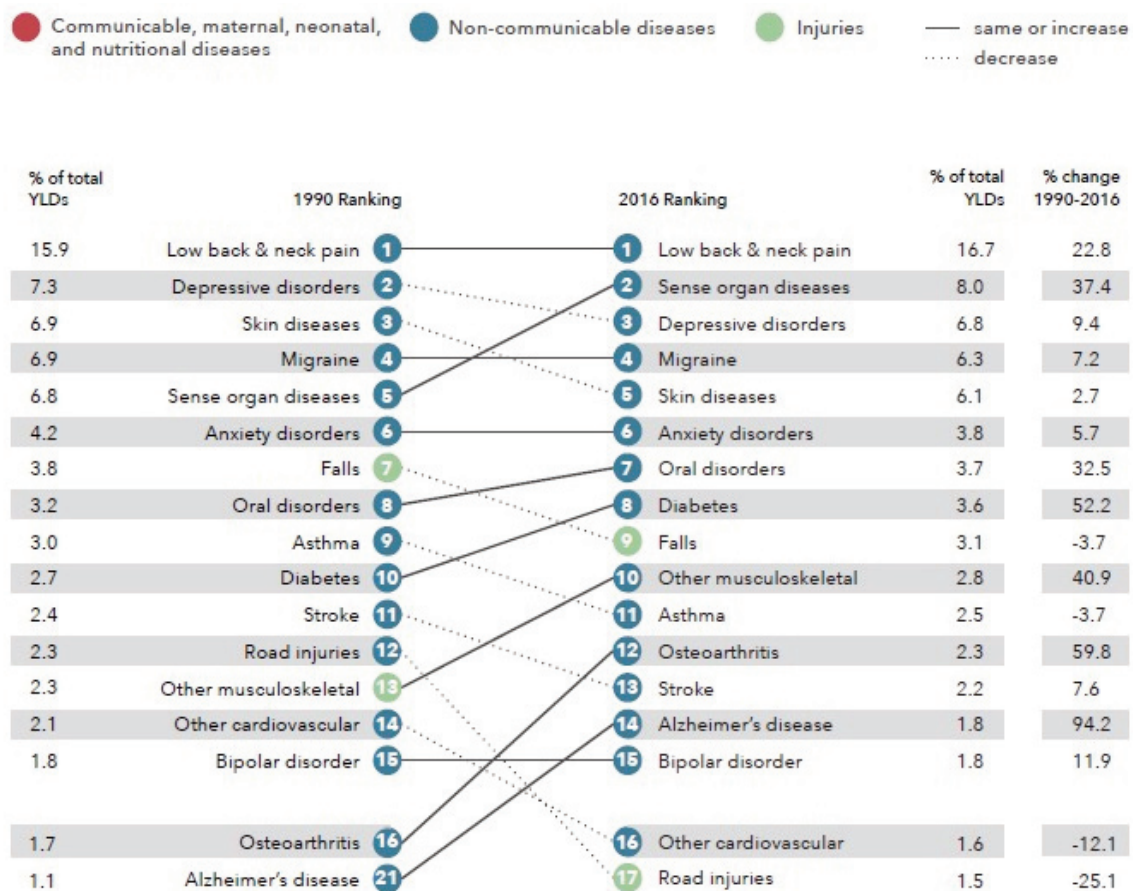


Figure 5 - What health problems cause the most disability in Portugal? 1990-2016

Source: Portugal: The Nation's Health 1990–2016: An overview of the Global Burden of Disease Study 2016 Results

In the report *Retrato da Saúde 2018*³¹ released by the Portuguese Ministry of Health, in 2016, migraine was considered the 2nd cause of disability (YLDs) in women and the 3rd in men at the age of 15-49 years, age period where migraine is more prevalent and has a higher impact on personal

development, social activities and career. Previous Work Foundation research¹ highlighted the need to consider the fluctuating nature of migraine, with attacks tending to last a day or longer and occurring between 20 and 30 times per year. Alongside this, some experience symptoms between migraine attacks³², with research involving 6,455 adults from 10 EU countries indicating that this could affect shows that 26% of people with migraine. These interictal symptoms are not monitored through the Global Burden of Disease Study, which suggests it could underestimate the true impact of migraine on those who experience it.

In *My Migraine Voice Survey*, which included a sample 143 Portuguese migraine patients, survey participants (n=11,266) had on average 9.8 days per month affected by migraine (considering all phases of the migraine attack). For 44% of respondents, migraine episodes lasted 1 to 2 days or more, and 19% reported episodes lasting longer than 3 days. On a scale from 0 to 10 (highest level), the severity of pain experienced during the last month by respondents was 7.4 on average, including 57% of respondents with a higher than

average pain severity (8-10 on a 10-point scale). So it is clear that migraine represents a significant public health problem: it is highly prevalent, amongst the top causes of disability worldwide and in Portugal, 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.

3. The socioeconomic impact of migraine in Portugal

3.1 Introduction

Having explored prevalence of migraine, this chapter of the report will look to understand the socioeconomic cost of migraine in Portugal. Migraine imposes significant costs to society that are felt deeply by people living with the condition as well as carers, employers, health services, and government. Measuring this the socioeconomic impact of migraine will be essential to understanding the case for investment in proactive and preventative health and workplace policy.

3.2 Socioeconomic impact

In the *My Migraine Voice Survey*, a total of 81% of Portuguese respondents (n=143) considered that migraine had affected their social life and activities,

and 80% reported that it had led to the cancellation of plans in the previous month. This is related to the immediate effects of migraine attacks, with 93.2% reporting a need spend extended periods in isolation and/or darkness as well as other conditions that may result from living with migraine, with 97.7% reporting migraine-related sleeping difficulties and 42%/38% reported anxiety/depression. However, another key factor related to cancelling social plans is concern about when another attack may occur, with 40% reporting they feel extremely/very fearful). Table 3 summarises the impact of migraine on daily activities by monthly migraine days (MMD) for Portuguese respondents to the study.³³

Table 3 - Impact of migraine on daily activities by monthly migraine days (MMD)

	Frequency	Overall (n=143)	4-7 MMD (n=73)	8-14 MMD (n=46)	15+ MMD (n=24)
Interference with daily activities	Very/extremely	79%	71%	89%	83%
Interference with the ability to think clearly or to focus on daily activities/tasks	Often/always	54%	48%	54%	71%
Having no energy to complete daily living or feeling fatigued	Often/always	39%	37%	46%	33%
Stopping daily activity and resting due to migraine attack	Lot of time/always	35%	33%	37%	42%

Note: N=143 Portuguese respondents to the My Migraine Voice study surveyed between September 2017 and February 2018.

Taken in combination with evidence indicating that individuals tend to experience attacks for extended 25-30 hour periods 20 – 30 times each year^{34,35}, it is clear that people living with migraine will find the condition significantly impacts their working lives.

These effects will include needing to take time off work, or 'absenteeism', well as the less tangible but also important effects of reduced concentration and capacity at work, often termed 'presenteeism'. The following sections unpack the socioeconomic impacts of migraine, considering productivity losses, direct costs and out of pocket expenses.

3.3 Productivity losses

As shown in the previous section and by Table 1 – Migraine prevalence in Portugal by age and sex, 2019¹⁷, migraine disproportionately affects people

of working age, peaking at 30-40 years. 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 Portuguese economy in general. The productivity losses of migraine may be measured considering absenteeism (number of working days missed attributable to migraine) as well presenteeism (productivity lost due to reduced capacity at work). The latter is a particularly significant issue given that studies have found that people experiencing a migraine attack are more likely to attend work than take sickness absence³⁶, meaning that costs associated with presenteeism should be a priority for employers and policy makers. Nevertheless, respondents systematically underreport due to the "common inclination to perceive oneself favourably".³⁷

Table 4 - Summary of the studies on productivity losses of migraine

Study and publication year	Sample size	Main results
Eurolight (2009)	N=8412 (50-70% of females, depending on country)	Per person per year Migraine: €1,136 (€765 reduced productivity and €371 absenteeism; productivity losses 93% of the total) Medication-overuse headache: €3,292 (€1,669 reduced productivity and €1,623 absenteeism; productivity losses 9 2% of the overall cost)
BECOME study (2019)	N=103 (99% female)	Per patient per year Absenteeism and presenteeism due to migraine: €5,432 By number of previous prophylactic treatment failures (TF): €5,225 in TF1, €5,568 in TF2+ and €5,535 in TF3+
My Migraine Voice (2018)	N=88 (76.1% female)	Per patient per month Overall productivity losses (n=92): €590 per month of which €471 due to presenteeism and €119 due to absenteeism (7.080 € per year) TF2+ (n=55): €633, of which €489 were due to presenteeism and €145 due to absenteeism.

TF- previous prophylactic treatment failures

While quantifying the impacts of presenteeism is not straightforward, a number of measures have been developed for this purpose, many of which were designed with a specific focus on migraine. Several presenteeism studies have drawn on a measure which estimates 'lost workday equivalents'. This involves individuals estimating their own effectiveness at work when they experience an attack as a percentage relative to their usual capacity. 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.

The costs of migraine in Portugal can be understood as a combination of direct and indirect costs. Migraine has a significant impact of the day to day lives of those who experience it, preventing them from making plans and limiting their working lives. A series of studies have attempted to quantify these costs, with variation in results likely resulting from methodological differences.

Table 5 – Summary of studies on direct costs of migraine

Study and publication year	Sample size	Main results
Eurolight (2009)	N=8412 (50-70% of females, depending on country)	Per person per year Migraine: €86 (direct costs 7%) Medication-overuse headache: €269 per person (direct costs 8%)
BECOME study (2019)	N=103 (99% female)	Per patient per year Migraine per patient per year for the overall sample: €352 Treatment failure: €280/€400/€576 per TF1/TF2+/TF3+

TF- previous prophylactic treatment failures

These estimates are summarised in Table 4. These data reveal opportunities for further action in Portugal. Firstly, there is a considerable gap between the onset of early symptoms and migraine diagnosis. Reasons for this could be the lack of awareness of migraine by both patients and healthcare professionals, or unmet needs due to financial or access barriers such as waiting lists and/or distance or transportation problems. Furthermore, the data indicate people living with migraine experience a considerable number of migraine days each year, and overuse of medication is high, despite the use of prophylactic and acute treatment. The number of treatment failures, and high rates of change in treatment, also indicate challenges in tailoring treatment to individual needs. This indicates possible routes for improving the treatment pathway for people living with migraine, for instance by developing a referral protocol checklist comprehending diagnostic tests to be prescribed by GPs to reduce waiting time to see a specialist

3.4 Direct costs

The direct healthcare costs of migraine to individuals in Portugal are also substantial, including investigations, hospital and outpatient treatment and medication. The *BECOME study* reported for a total annual direct cost per migraine patient in Portugal of €352 for patients being seen at headache centres. The *Eurolight project estimate for direct costs* was €185.54 on average across eight European countries involved in the study. Treatment failure and the costs associated with it are also key to capturing the socioeconomic impacts of migraine. The *Become Study part 2* found that one treatment failure was observed in 40% of participants, two treatment failures in 29%, and 31% of participants experienced three or more treatment failures³⁸. The study also found that 13.5% of patients overused medication, and about 14% of patients had suspected overuse headache. Similarly, the *My Migraine Voice* study found that

the majority of patients had two or more changes in preventive treatment (65%)¹⁰, what potentially indicates treatment failure.

Treatment failures might be a sign of existing barriers to access healthcare experienced by patients with migraine. A study conducted by QuintilesIMS in 2017³⁹, comprising online surveys issued to medical doctors (GPs, neurologists and psychiatrists) and patients identified by pharmacies, showed that an average of 63% patients try self-medication before looking for professional help. Also, 90% of the neurologists surveyed considered that migraine is underdiagnosed. Around 35% of the patients see a Neurologist after being referred by their GP due to disease severity or therapy failure. Approximately 42% of the patients referred to a Neurologist have a treatment prescribed but the majority see their treatment changed due to treatment failure.

3.5 Out-of-pocket expenses

About 82% of the Portuguese participants included in the *My Migraine Voice Survey* reported out-of-pocket expenses: 66% related with drug prescription fees, 52% with over-the-counter medication, 40% with medical appointment fees, 31% with transportation to medical appointments, 23% with emergency room visits, 20% with health

insurance, 16% with complementary treatment, and 9% with other. Overall, out-of-pocket expense averaged €102/participant/month or €1.224/participant/year. Cost drivers were drug prescription fees (30% of the overall average expense) followed by medical appointment fees (15%). Participants who failed two or more prophylactic treatments reported out-of-pocket expenses of €141 per month on average.

3.6 Co-morbidities

This research has found no studies performed in Portugal reporting costs associated with migraine-related comorbidities. However, an international evidence base indicates that migraine often co-occurs with mental health problems such as depression and anxiety⁴⁰⁻⁴³.

For example, a European study drawing on a sample of 6,624 people who experience migraine found a 19.1% probability of experiencing anxiety and a 6.9% probability of experiencing depression. Other research has indicated that migraine and common mental health problems have a bi-directional relationship – that is to say, experiencing migraine increases the probability of a mental health problem, and experience of mental health problems can also cause migraine⁴⁴.

4. Migraine in Portugal – The experiences of people living with migraine, physicians, and stakeholders

4.1 Background

This section of the report provides rich and qualitative insight into (a) the work experience of people with migraine in Portugal and challenges they face, and (b) the barriers to optimal health outcomes for people with migraine in Portugal.

The report will culminate in a series of evidence-based recommendations – aimed at national level policymakers – which have the potential to reduce the burden of migraine for the benefit of the

government, employers and the individuals that suffer from this disease in Portugal.

4.2 Results

In this section we present a summary of the main themes that have arisen during the interviews with the different groups. We start by presenting the results for the patients, followed by those for the Occupational Health Professionals/HR Directors and the GP and Specialists/Academics.

4.2.1 Patients

4.2.1.1 Onset, frequency and severity of migraine

Some participants experienced their first migraine as young as 8 years old (DS350076) and others during their teenage years. Those who had experienced their first migraine attacks at very young ages only started having migraines on a regular basis years later.

All of them reported how incapacitated they felt during the attacks, in line with findings from the literature review. Nine out of the ten participants considered their migraine to be chronic, and only one as episodic. The frequency of migraines ranged from three times a week reported by one participant to another having one every three months. Three participants reported 10-15 migraines per month, one reported 6-8 migraines per month and two reported experiencing migraines on a weekly basis.

One participant also mentioned that since they reached menopause the frequency and the severity of their migraines had been much reduced. Two participants mentioned that they had started new treatments with injections around six months ago and since then the frequency of migraines has been much reduced, from more than one migraine per week to two per month.

Some participants reported having migraine with aura. One described the impact this has on them:

“Around 4 or 5 a month are with aura. These are very characteristic and have similar severity. It is distressing, as my visual capacity is compromised for 30 minutes to an hour. However, the aura allows you to anticipate the pain that follows and take medication to prevent this from evolving. Around one or two per month have no aura and these are, sometimes, more severe. These often occur as I wake up, so I don't know if I have had aura while asleep.” (DS350061)

One female participant reported a decrease in the frequency of migraines after having had a baby. Five out of ten participants have reported that at the onset of a migraine they must lie down in a quiet, darkened room and rest in order to reduce the severity of the pain. Three participants said they resort to SOS medication when they are having an attack.

All participants reported that migraine affects their day to day life as well as their working lives. This has detrimental impacts for their mental health, with participants reporting feeling depressed and anxious most of the time, at times reaching a feeling of burnout. As found in the literature, participants reported that having the option to work flexible hours would enable them to manage the effect of migraine attacks.

4.2.1.2 Management and treatment of migraine

Eight of the participants reported that the intensity of the pain they have experienced during attacks was so severe that they had to attend a hospital accident and emergency department (A&E). Two participants reported going to A&E in private hospitals as they were concerned by long waiting times in NHS hospitals. A participant reported that there were times:

“..when migraines were very strong and I would sometimes end up going to A&E, sometimes once a month.” (DS350062).

Another participant said:

“When I was having very frequent attacks, I had to go to A&E to receive intravenous painkillers because I could not retain the tablets in my stomach. Between the ages of 45 and 55, I went to A&E half a dozen times.” (DS350063).

Another participant (DS350077) said that they went to A&E once, with their first major migraine when they were 18, a particularly frightening experience. The doctors kept asking them “if they had consumed anything”, implying that the patient had taken drugs. As a result, they never went to A&E again. Another participant said the following regarding a visit to A&E:

‘(..) even when I went to the A&E and they gave me medication, I was explaining my history, I felt that the person on the other side was not really appreciative.’ (DS350076)

Two participants said that they had stopped taking pain medication for their migraines. Less than half of interview participants referred to using Triptans by when necessary. Two participants reported having had botox injections with mixed results, with attacks gradually returning after an initial period.

4.2.1.3 Clinical care

The people living with migraine interviewed for this project were mainly being treated for their migraine by neurologists at either public hospitals (n=3) or through private care (n=5). One interview participant had not sought clinical treatment for migraine.

One participant, who was under the care of their GP, reported they felt able to manage their condition with the level of treatment they were receiving. By contrast, another who had remained under the care of his GP and reported that the experience has not been very positive:

“Just the GP, although every time that I have an appointment with the GP I complain about... I'd like one day to have the help of a professional... in the area of migraine that could help more” (DS350084)

Five participants reported they have never seen their GPs about their condition, mainly because they started treatment with a neurologist in the private sector when they experienced the first symptoms. Two participants had been referred to neurologists in NHS hospitals by their GP and were pleased with the care they received.

One participant was referred to a neurologist at a public hospital, by A&E when they got the first migraine and have been treated there since. They are very pleased with the overall care they receive to manage their attacks:

“In fact having the email for the hospital doctor is, I mean a security in case of an emergency, even if I don't get my doctor there will be another neurologist that can take care of the case. So I don't see anything that can be improved.” (DS350061)

Another participant reported their frustrations with primary care in the past mentioning the GP did not engage with their condition in a meaningful way:

“The GP didn't appreciate the migraine and ... was reluctant to refer to Neurology for a second time as they wanted to continue the existing treatment, even though it wasn't working. (DS350076).”

While another similarly felt that treatment under their GPs wasn't meeting their needs:

“The pathway needs to be improved as the first step is to see a GP where they see it as a headache and not serious. They are not sensitive enough to the seriousness and incapacitating nature of migraines.” (DS350064)

Participants being treated at public hospitals

reported high levels of satisfaction with the care they received:

“My current GP referred me to a neurologist in the hospital. This neurologist let me explain my issues completely for the first time and I'm satisfied with this connection and experience... I really liked this Doctor because she was the first Doctor that I had that allowed time for me to explain. Sometimes Doctors, it's not their fault, but I don't think they have time to listen to us... I left without thinking- oh! I forgot to say this! And that's important.” (DS350077)

Another participant described a very supportive and close doctor-patient relationship with their neurologist in a public hospital, which has enabled to faster access to treatment when attacks take place:

“So it is a closer relationship and that helps a lot, because it makes you feel more supported, sometimes there are some adjustments on the medication, and on occasions of migraine attack, if he is on call he asks me to come over and we do the neuro occipital blocker, which helps immensely. (DS350061)”

Two of the participants being treated in the private sector reported that they do not have regular appointments with their neurologist and self-manage the disease. Another two participants under the care of a private sector neurologist reported that when they started very expensive treatments (around €500 per injection), the neurologist transferred them from their private practice to their patients' list in the NHS hospital where they were working to avoid costs. Patients accessing private sector care reported shorter waiting times and easier access to their specialist when necessary. Where patients changed neurologists, this related to dissatisfaction with the treatment prescribed in some cases as well as personal circumstances, such as moving home, in others.

A few remarks were made about poor experiences within emergency services:

“I don't know if it was lack of awareness of the person who saw me that didn't know what an aura is? I can't explain. They didn't take me seriously. (...) to talk about A&E to start with, I think that the person who sees us should have more training not just being there... (DS350077).”

Another participant said that A&E waiting rooms are not suitably designed for individuals experiencing a migraine attack, with factors including bright light and high noise levels potentially exacerbating symptoms. Access to an alternative space offering relative isolation and dimmed lighting could help to mitigate this, and improve the A&E treatment experience for people living with migraine.

4.2.1.4 Alternative therapies

Four participants have tried to manage their migraine with osteopathy or acupuncture. At the time of the interview only two patients were still having osteopathy sessions. Exercise was also key to managing migraine for some, with one patient reported that yoga has helped and another finding that running had helped to manage their symptoms.

4.3.1.5 Expenditures related to migraine management

Participants interviewed reported monthly health expenditures of up to 50€ related to migraine. Some participants have private health insurance and reported paying at around €15 per appointment with their neurologist in the private sector every three or four months. For both groups, acute pain relief presented the greatest costs.

4.2.1.6 The impact of migraine on working life

Considering that participants suffer from severe forms of migraines, they reported that colleagues and managers in their organisations were aware that they had migraines. Two of them reported that their line managers were sympathetic towards them as a member of their family also suffered from migraines. Nevertheless, participants said that sometimes, due to the high frequency of attacks, they did not feel comfortable about sharing they were experiencing an episode. When waking up with a migraine, some participants would take medication and go to work later to reduce the severity of the attack. One of the participants mentioned they would usually compensate for the lost time. Participants mentioned that if they could work flexible hours and accommodate their working lives around their migraine attacks they could miss less working days.

All of them reported an impact on their work productivity ranging from 30% up to 50% when working through an attack. One participant described the impact of migraine at work as:

***'It affects my productivity; I feel slower and find it difficult to focus on my work. Moderate migraine reduces productivity by 30%, and severe migraines affect [productivity] by 50%. Not counting minor headaches which still require medication.'* (DS350064)**

Regarding workplace support, only one participant said that they felt they could work from home every time they felt that was necessary, four participants said that sometimes they would work from when suffering from an attack, while others mentioned that their work could not be done remotely. Another said that migraines were causing such incapacitating pain that they needed to take time off:

***"I can't concentrate, no matter how much I try to focus. And on top of this my headache makes me teary, and my eyes close, and I serve the public. And I can't do anything there as well, so I don't, I haven't been going (to work). It's totally depressing having to serve someone while experiencing migraine and having teary eyes... And I don't feel that I am able to have a [...] dialogue even.'* (DS350074)**

Another participant said:

"I persevere to try and stay firm and to continue to work to the limit (DS350061).'

One participant said that they felt lucky in comparison with other sufferers because they have their own business with three other partners. When having an episode, they can take a short break, but they rarely miss a full day of work.

Participants felt migraine is self-limiting, preventing them from seeking new challenges through their career. One participant reported that she had a chance to apply for a different job but would have had to undergo medical tests as part of the recruitment process:

"I didn't go because I had to go through some tests. I thought to myself, they'll find out that I have an illness, that I have migraine or whatever, so I didn't go because I didn't want to do the medical checks.(DS350066)'

4.2.2 Occupational Health and Human Resources Directors

Interviewees recognised that migraine is a chronic condition, mainly affecting women, impacting both on absenteeism and on presentism. When employees report to their line managers experiencing migraine, they are usually referred to Occupational Health Services initially. Occupational Health Services, depending on what they are told by the patients, request a visit by Occupational Health and Safety services to the individual's workplace or workstation to check working conditions and equipment.

“We try to understand [the working environment], so the first thing we do is to check the lighting, damp, in the workplace, so that the conditions are the minimum conditions that people should have. If they are in front of a screen for a long time, if the screen is appropriately adjusted with the light that comes through from the window” (DS350069)

When a trigger is identified within an individual's working conditions, employers interviewed reported they attempt to address it through improving the ergonomics of a workstation, for example changing the position of the desk, height of the chair or place of the screen. However, all stakeholders interviewed recognised this is easier to do in desk jobs than in factory lines or in customer service roles. One of the interviewees reported that there were situations where they have had to redeploy the employee to another part of the organisation in order to minimise the impact of migraine.

‘ (...) for example, people who can't tolerate night time work may need to be removed from the nightshift, this is one of the things that Occupational Health does based on sufficient evidence. (...) Every illness with visual changes could be a risk in certain positions. For example, drivers (...)’ (DS350071)

However, a series of barriers often prevent Occupational Health and HR professionals from offering this support to workers living with migraine. From the interviews it became clear that workplace data on migraine are hard to find in Portugal. This is due to both confidentiality issues, as occupational health professionals cannot disclose information on workers that is not related to their job, and because workers might prefer not to disclose to their employer that they suffer from migraines. Moreover, legally migraine is not considered as an illness that is caused by working conditions so it does not have to be reported to the authority overseeing working conditions. The only exception to this is if an employee suffering from migraine experiences workplace discrimination.

As evidenced through the interviews with people living with migraine, many times they are unable to identify their own migraine triggers and these differ from patient to patient. One of the stakeholders interviewed explained that this means *‘It is hard to put preventative strategies in place’* for workers experiencing migraine.

This means that even where employers have an established referral pathway to occupational health services, limited understanding about migraine

among line managers and concerns about sharing a diagnosis among workers must be addressed in order to realise the potential of support on offer. A resource designed to address some of these issues through facilitating more open conversations about migraine between managers and workers is a report recently produced by the Work Foundation⁶.

4.2.3 Physicians

4.2.3.1 General practitioners

We interviewed two GPs, both working in urban practices in the suburbs of big cities, one in the North of Portugal and another one in Lisbon. Their experiences are different regarding patients' complaints. Both recognise that men tend to be more dismissive about suffering from headaches than women. However, even if women are usually more likely to report migraine, many are used to live with the pain migraine brings into their lives and some would find it irrelevant to share it with their GPs.

Through the interviews, it became clear that consultations about migraine often arise following a patient requesting repeat prescriptions for painkillers, which provokes questions from the GP about the need for analgesia on a regular basis:

‘I would say that probably most of my patients with a confirmed migraine diagnosis, were officially diagnosed by chance. I realised that there was a repeated request for prescriptions that made me curious and ask “Why are you taking this? Why do you need it?” or patients that come to the appointment and say “By the way, doctor, I've got this headache, is it normal? Oh, I have migraine for many years.”’ (DS350067)

One of the GPs interviewed considered that patients living with migraine might not seek support or treatment because they may have become accustomed to the symptoms, or potentially because they even do not recognise their experiences as indicative of an illness. As long as patients can handle the pain with analgesia treatment they tend not to mention migraine in appointments with their GP. When it is mentioned it is because patients are aiming to experience fewer or less severe and incapacitating attacks.

Both GPs interviewed would refer migraine patients to a specialist when necessary, for example if a patient was not responding to

pain relief or preventive treatment or in order to manage side effects.

'I have made some referrals. Some who didn't respond to the medication, that are struggling, or those who experienced side effects with certain type of medication and it hasn't worked at all. Then I usually send to the specialist. (DS350100)'

Similarly, both GPs reported that appointments for hospital care could take more than six months after a referral from a GP. The cost of some pain treatments, like triptans, was also mentioned by the GPs as a burden on patients and their families.

Both GPs also highlighted limited awareness of migraine amongst their profession. Both have pointed out that more training for GPs with neurologists and migraine consultants could help GPs to better assess patients' complaints, to better manage their patients, and to improve GPs confidence on diagnosis. In their view, if a set of recommendations for diagnostic tests to be prescribed by the GPs was developed by the specialists, this would improve the quality of referrals and reduce pressure on the workload of hospital colleagues, as fewer patients would need to be referred to hospital specialists.

"if these recommendations were developed they could be useful in each case, even for the neurologist, if this could be set up to establish the rules of the game in a much better way, speed up the process and not having a case sent to Hospital and back to the Health Centre and so on." (DS350067)

'I think that for example if there was a training between, for example, the GPs and neurologists and even migraine consultants, maybe then, we could learn more with them and perhaps we wouldn't refer them so quickly and we would learn how to manage migraine. (...) I don't have total confidence, sometimes I am unsure. So in terms of a scale of 0 to 10, maybe, like 0 being no confidence at all, and 10 totally confident. Perhaps I'd give a 7. So obviously, if I had more training I would feel much more at ease. (DS350100)'

The views of both GPs were aligned regarding the limited awareness of migraine amongst their profession and the advantage of creating opportunities for more training for GPs with neurologists and migraine consultants.

4.2.3.2 Specialists and academics

All the specialist consultants interviewed had experience in working in large public hospitals as well as in private practice. Furthermore, a specialist working in the NHS must attend patients with a range of neurological problems leaving limited time for migraine sufferers. Migraine patients seen in specialist NHS services would have been referred to them by other specialist consultants or by GPs. In their private practices they would see more migraine patients as some of them were migraine consultants and had developed a good reputation in the field. There is a significant demand for private appointments for two reasons: 1) there are not enough specialists working in NHS hospitals and therefore waiting times can be very long; 2) patients do not need a referral in order to access private care.

'Generally, the GP correctly diagnoses migraine when they are referred to the neurologist, but only a small percentage are referred by the GPs. (DS350070)'

Specialists reported that most of their patients would be working age, with a larger proportion women than men. When asked about the impact of migraine on the working lives of their patients, specialists said that migraine sufferers might need to miss work if pain management isn't effective in reducing the severity of an attack. According to the specialists interviewed, absence from work in these circumstances might represent between two and four working days per month, and even more in extreme cases. There was an agreement among stakeholders interviewed that productivity is not only affected when patients are off work, but also through the onset of an attack while they are working, often described as presenteeism. The pain and cognitive impairments triggered by an attack can substantially limit productivity.

'But generally migraine patients complain that during the attacks, they can't think properly, they can't pay attention, they can't perform their work duties at 100% of productivity, they feel it is difficult to study, to memorize, and, so they say that it is quite disabling. They need go to bed, rest, lights off, no noise. So during these periods they are completely unable to do whatever it is. (DS350073)'

'Migraine interferes, interferes a lot, the attacks interfere with their professional activity, with school activity, with leisure activity. So it causes a significant disturbance, with an extremely high level of work and school absence which interferes with their social and family life and on medication. So there is a big economic and social impact. (DS350072)'

One of the physicians mentioned that migraine can lead to unemployment or early retirement:

'Yes, I remember a few cases that they left work, mostly women that started to stay at home and leaving work. I've had a few cases like that, that they left, they abandoned their professional activity because they were incapacitated very frequently, the employers didn't like it and they decided to stay home for a while.' (DS350072)

Migraine sufferers working in precarious or less qualified jobs as well as migrant workers might be at higher risk of becoming unemployed:

'People in precarious employment... can easily lose their job if they have attacks very often then they can't work. I think it is more frequent in the less qualified work because it is more precarious... I see a lot of this among migrant patients, they are here, they work in roles like cleaners and often ... don't have work contracts, so easily lose their job.' (DS350073)

In private practice, specialists see patients with higher, more stable incomes. These patients tend to access treatment sooner, avoiding the referral delays often reported in public health services. According to the specialists interviewed, higher income patients in more senior roles face different risks, in that many work longer and variable hours that may aggravate migraine, and may find attacks impact productivity at work:

'The more intellectual work becomes compromised straight away, because the person can't think and can't concentrate, and this ends up having repercussions.' (DS350073)

As a result, specialists interviewed perceived that this group of patients feel more impacted by the incapacitating features of migraine.

4.2.3.3 GP training

One of the specialists mentioned that he had been involved in the development and teaching of training sessions to GPs on migraine which had led to very positive outcomes:

"[After training] They would understand more... patients were referred more appropriately, and well a little sooner, (...) It [the training] had a big impact, because they (the patients) were not treated effectively [before the training] and so had more attacks..., which were much more prolonged, very severe, and a lot more incapacitating." (DS350072)

This was reinforced by another GP:

'I think it's more like a barrier to recognise the impact that [migraine] has in people's lives. (...) The response that we see most of the time is, the colleague diagnosed, but completely underappreciates the need either for treatment, or for eventually referral to a specialist. Because it is still not seen as a disease in the sense that it causes suffering and it causes incapacity. (...) At this time in Portugal... there is not a lot of communication between GP practices and hospitals ..., and it's something I think could be positive and would help.'

Specialists described migraine as causing debilitating and incapacitating effects on patients' lives, chiefly in their capacity to work leading to both absenteeism and presenteeism. Like the GPs interviewed, Specialists felt that raising awareness about migraine among GPs could lead to improved management of the disease with clear benefits for the patients.

5. Conclusions

Migraine is the third largest cause of years lived with disability in Portugal, and affects patients' working lives, as well as their social life and ability to make plans. When comparing the top ten causes of disability across countries, Portugal has the second highest level of disability attributed to migraine, measured by disability-adjusted life years (DALYs). Despite this, both patients and clinical specialists interviewed for this research emphasised that understanding of the condition among GPs in Portugal is low. While direct costs fall on health services, the indirect costs of migraine represent the greater burden to society, in large part due to productivity losses where individuals are not receiving treatment or support. Therefore, more timely treatment of migraine could deliver tangible improvements to the quality of life of those living with the condition in Portugal as well as important gains to society more widely.

The latest estimates show that overall productivity losses associated with migraine can reach €590 per working person per month, of which the largest majority is due to presenteeism.¹⁰ These losses can be higher in more complex situations, for example where treatment failures occur. These are important results given that the average wage in Portugal, in 2018², was approximately €970 per month.¹¹

The substantial productivity losses associated with migraine could be reduced significantly through improvements in treatment and management of the condition. This research indicates that to improve clinical and employment outcomes, further work is needed to improve understanding of migraine among patients, general doctors and employers in Portugal.

Despite evidence indicating prevalence is particularly high in Portugal, to date few studies examine the prevalence and costs of migraine in this country. The evidence base should be developed further to better reflect the views and experiences of patients and relevant stakeholders, like employers and patients' associations.

The qualitative research aligned closely with findings of the literature review on the impacts of migraine on the day to day lives of those who live with it. Participants report depression, anxiety and very frequent incapacitating and debilitating pain.⁴⁰⁻⁴³

Although many also reported waking up with migraine and needing time in bed to let acute medication take effect, not all had of them were allowed the flexibility in their working hours needed to use this coping strategy in practice.

Stigma around this chronic 'invisible' condition was reported by all the groups interviewed. There was recognition among patients and stakeholders alike that the wider public do not understand the debilitating impact of migraine and see it as a 'simple headache', an excuse to arrive later or leave early from work.

Migraine has an impact at a personal level including, and extending beyond, individuals' ability to perform their work.^{10,33} Light, noise, and working in shifts are some of the triggers most frequently identified through this research. Raising awareness of this among employers in Portugal and emphasising the simple adjustments that can be made to working practices and working environments, will be crucial. For example, the Work Foundation recently produced a guide for line managers on migraine, which outlines potential triggers, proposes workplace adjustments and facilitates conversations about migraine and wider workplace wellbeing⁶. In addition, policies that have showed results in other countries to address these problems, like flexible working hours or targeted support for shift workers, should be promoted to ensure that work environments can accommodate people suffering from migraine, allowing them to be productive and to enjoy life.

Finally, investing in training for GPs and improving referral mechanisms between GP practices and NHS hospitals could contribute to reduce waiting times and improve the overall management of migraine in Portugal.

² This is the latest available data on wages in Portugal at the time of writing.

6. Recommendations

Resulting from the review of the literature and the qualitative research conducted in Portugal, it is clear that the costs associated with migraine-related lost productivity at work could, in part, be addressed through better quality work environments. This is about offering 'good work', including improved psychosocial work conditions, a supportive workplace culture and better management practices, which empower employees. The following recommendations have been developed to catalyse this longer term shift in practice:

- Portuguese Health and Safety Services should improve their approach to data collection about migraine within the labour market, making sure that all sectors and occupational groups are included.
- Migraine patients' associations and Trade Unions could work in partnership to raise awareness about the changes to a role or working conditions that can enable individuals with migraine to thrive at work.
- Migraine patients' associations and workers' unions could work in partnership with employers' associations to improve routes for workers requesting flexible working hours.
- The Portuguese Medical Association could develop training programmes for GPs and occupational health physicians delivered by migraine specialists to improve support for patients in the health care system and in the workplace.
- The Portuguese Medical Association could develop a referral protocol check list including diagnostic tests to be prescribed by GPs to reduce waiting time to see a specialist.
- The Portuguese Association of Hospital Managers could develop management models to improve local referral pathways through enhanced communication and collaboration between specialist services and GPs within their local areas
- The Portuguese Association of Hospital Managers could pilot the implementation of migraine walk-in clinics in public hospitals to improve patients' care and outcomes
- The Portuguese Association of Hospital Managers could work in the development of a review model to assess the A&E experience for people living with migraine with triage process to
 - ensure the triage process fully captures the severity of migraine symptoms
 - consider establishing dedicated waiting areas for people experiencing migraine, in quieter rooms with reduced light

Methodology

The overall aims of the research were to:

- **Assess the prevalence and socioeconomic impact of migraine in Portugal** estimating both the indirect and direct costs attributable to it;
- **Explore the barriers to optimal health and work-related outcomes** for people with migraine; and
- **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 Portugal that experience it.

To do this, we employed a mixed-methods approach, first carrying out a rapid evidence review of the relevant academic and grey literature to understand the existing evidence on the prevalence and cost of migraine in Portugal and its impact on people's health, wellbeing and their ability to work. The review was supplemented by a review of secondary data sources. In addition to this, a qualitative component was carried out, comprising 19 semi-structured interviews with working age adults with migraine ($n = 10$) and relevant stakeholders such as GPs, neurologists and employers ($n = 9$).

The evidence review involved searching academic, scientific, databases including:

- Scopus, the largest abstract and citation database of peer-reviewed literature
- PubMed, which indexes citations from MEDLINE, PreMEDLINE, and other journals in the field of medicine and life sciences;
- Web of Science, which indexes most science journals; and
- Google Scholar, which provides broader coverage for most disciplines.

The above databases were searched using a combination of terms related to migraine (migraine with aura/without aura, chronic migraine, episodic migraine, migrainosus, cluster headache, vascular headache, tension-type headache, medication overuse headache etc.) in conjunction with terms associated with:

- (i) its socio-economic impact (prevalence, commonness, incidence; impact, effect,

influence; cost, burden, direct, indirect, healthcare, productivity, absenteeism, presenteeism; opportunity cost; appointment, admission, consultation, episode, referral, etc.);

- (ii) barriers to timely, accurate diagnoses, appropriate treatment and management, and optimal patient (work-related) outcomes (diagnosis, misdiagnosis, undiagnosed; treatment, care, therapy, mistreatment, undertreatment, untreated; management, mismanagement; outcomes, etc.).

In addition to the literature review, published resources from the following studies were also considered:

- The *Global Burden of Disease Study 2017* (described as "the most comprehensive worldwide observational epidemiological study to date"⁴⁵). It assesses mortality and disability from major diseases, injuries, and risk factors and is a collaboration of over 1,800 researchers from 127 countries.
- The *My Migraine Voice Survey*¹⁰, conducted between 2017-18 (comprising more than 11,000 people who had at least 4 migraine days per month from 31 countries). It is the largest ever global study of people living with migraine and included a sample of 143 Portuguese participants.
- The *BECOME study*, non-interventional study conducted between 2017-2018 across 17 European countries and Israel and comprising 2,419 patients with 4 or more monthly migraine days and at least one preventive treatment failure recruited in headache centres over a 3-month period. This study included a sample of 103 Portuguese patients from 6 headache centres⁴⁶ (three public and three private).
- The *Eurolight Study*⁴⁷, a cross-sectional survey in eight countries (Austria, France, Germany, Italy, Lithuania, Luxembourg, Netherlands, Spain and UK) which includes data, collected between 2008 and 2009, for 9,269 respondents from eight European countries, representing 55% of the adult EU population. It aimed to estimate the direct and indirect costs attributed to a range of headache disorders, including migraine. Also, as part of the Eurolight project, a systematic review of more than 30 migraine studies conducted between 1991-2009 was carried out in 2010 (producing an estimate of adult migraine prevalence of 14.7%)⁴⁸.

Publications in English and Portuguese language were considered for the purpose of this study.

This research was submitted and approved by the Faculty of Arts and Social Sciences and Management School Research Ethics Committee (FASS-LUMS REC).

The evidence review was performed between June and December 2019.

Between March and June 2020, there were 19 interviews conducted to shed light on the perceptions of migraine patients and wider stakeholders in Portugal. We conducted 19 semi-structured, qualitative interviews with working age adults with migraine (10) and experts (9) comprising clinicians, academics, and HR Directors offering rich qualitative insight into (i) the work experience of people with migraine and the challenges they face, and (ii) the barriers to optimal health outcomes for people with migraine in Portugal. All participants provided signed informed consent before being interviewed.

Interviews with working age adults with migraine

The semi-structured interview guides were designed to explore migraine's impact on their health and wellbeing (i.e. pain, functioning, anxiety, depression, etc.) as well their ability to work (i.e. effectiveness at work, capacity, productivity, performance, etc.) and how it has impacted on their earnings and progression, etc. Interviewees were recruited through MiGRA Portugal, a Portuguese migraine patient group.

Interviews with migraine experts

In the 9 interviews carried out with migraine experts (comprising healthcare practitioners/academics and Occupational Health/HR Directors), the semi-structured interview guides were designed to explore barriers to timely, accurate diagnosis of migraine, and how to achieve optimal health and work-related outcomes for people with migraine. Interviewees were recruited through Novartis Portugal's networks.

Data capture

All interviews were audio recorded. This allowed for transcriptions of the recordings to be written up. In accordance with best practice, the recordings were transcribed in Portuguese and then translated into English using an external transcription service.

Sample

Table 6 outlines the characteristics of the interviewed sample. Due to the very low number of participants in some of the areas, for the purpose of confidentiality, it was decided to combine the views expressed by Occupational Health experts and HR Directors and those of physicians and academics, all of whom were medical doctors.

Table 6: Characteristics of the subject expert sample

We interviewed an even number of male and female participants living in different regions of Portugal. They were all aged over 18, with eight participants in work and two who had already retired.

	All	Male	Female
Occupational Health/HR Directors	4	4	
Health care practitioners/Academics	5	3	2
Patients	10	5	5

References

1. Steiner TJ, Stovner LJ, Birbeck GL. Migraine: the seventh disabler. *J Headache Pain* 2013;14:1. doi: 10.1186/1129-2377-14-1 [published Online First: 2013/04/10]
2. Steiner TJ, Stovner LJ, Vos T, et al. Migraine is first cause of disability in under 50s: will health politicians now take notice? *J Headache Pain* 2018;19(1):17. doi: 10.1186/s10194-018-0846-2 [published Online First: 2018/02/23]
3. Disorders A-PPGoPH. Headache Disorders - not respected, not resources. A Report of the All-Party Parliamentary Group on Primary Headache Disorders: House of Commons, 2014:26.
4. Shapiro R, Goadsby P. The long drought: the dearth of public funding for headache research. *Cephalalgia* 2007;27(9):991-4. doi: 10.1111/j.1468-2982.2007.01396.x [published Online First: 2007/08/31]
5. Foundation TW. Society's headache. The socioeconomic impact of migraine, 2018:84.
6. Foundation W. Migraine's impact on employment in Europe. What can be done to improve work outcomes for people with migraine?, 2019:54.
7. Classification and diagnostic criteria for headache disorders, cranial neuralgias and facial pain. Headache Classification Committee of the International Headache Society. *Cephalalgia* 1988;8 Suppl 7:1-96. [published Online First: 1988/01/01]
8. Katsarava Z, Mania M, Lampl C, et al. Poor medical care for people with migraine in Europe - evidence from the Eurolight study. *J Headache Pain* 2018;19(1):10. doi: 10.1186/s10194-018-0839-1 [published Online First: 2018/02/03]
9. IHME. Portugal | Institute for Health Metrics and Evaluation [Available from: <http://www.healthdata.org/portugal> accessed Sept 15 2019.
10. Martelletti P, Schwedt TJ, Lanteri-Minet M, et al. My Migraine Voice survey: a global study of disease burden among individuals with migraine for whom preventive treatments have failed. *J Headache Pain* 2018;19(1):115. doi: 10.1186/s10194-018-0946-z [published Online First: 2018/11/30]
11. Pordata. Pordata 2020 [Available from: www.pordata.pt].
12. Headache Classification Committee of the International Headache Society (IHS) The International Classification of Headache Disorders, 3rd edition. *Cephalalgia* 2018;38(1):1-211. doi: 10.1177/0333102417738202
13. Trust TM. Migraine with aura 2019 [Available from: <https://www.migrainetrust.org/about-migraine/types-of-migraine/migraine-with-aura/> accessed Dec 18 2019.
14. Kristoffersen ES, Lundqvist C. Medication-overuse headache: a review. *J Pain Res* 2014;7:367-78. doi: 10.2147/JPR.S46071
15. Bahra A. Primary Headache Disorders: Focus on Migraine. *Rev Pain* 2011;5(4):2-11. doi: 10.1177/204946371100500402 [published Online First: 2011/12/01]
16. Weatherall MW. The diagnosis and treatment of chronic migraine. *Ther Adv Chronic Dis* 2015;6(3):115-23. doi: 10.1177/2040622315579627 [published Online First: 2015/05/09]
17. GBDx. GBD Results Tool Global Health Data Exchange; 2019 [Available from: <http://ghdx.healthdata.org/> accessed Dec 18 2019.
18. Martins IP, Goucha T, Mares I, et al. Late onset and early onset aura: the same disorder. *J Headache Pain* 2012;13(3):243-5. doi: 10.1007/s10194-012-0419-8 [published Online First: 2012/02/22]

19. Lemos C, Pereira-Monteiro J, Mendonca D, et al. Evidence of syntaxin 1A involvement in migraine susceptibility: a Portuguese study. *Arch Neurol* 2010;67(4):422-7. doi: 10.1001/archneurol.2010.37 [published Online First: 2010/04/14]
20. Lemos C, Alonso I, Barros J, et al. Assessing risk factors for migraine: differences in gender transmission. *PLoS One* 2012;7(11):e50626. doi: 10.1371/journal.pone.0050626 [published Online First: 2012/11/28]
21. Mendonca MD, Caetano A, Viana-Baptista M, et al. Association of depressive symptoms with allodynia in patients with migraine: A cross-sectional study. *Cephalalgia* 2016;36(11):1077-81. doi: 10.1177/0333102415620285 [published Online First: 2015/12/05]
22. Gil-Gouveia R, Oliveira AG, Martins IP. Sequential brief neuropsychological evaluation of migraineurs is identical to controls. *Acta Neurol Scand* 2016;134(3):197-204. doi: 10.1111/ane.12530 [published Online First: 2015/11/11]
23. Gil-Gouveia R, Oliveira AG, Martins IP. The impact of cognitive symptoms on migraine attack-related disability. *Cephalalgia* 2016;36(5):422-30. doi: 10.1177/0333102415604471 [published Online First: 2015/09/10]
24. Gil-Gouveia R, Oliveira AG, Martins IP. Cognitive dysfunction during migraine attacks: a study on migraine without aura. *Cephalalgia* 2015;35(8):662-74. doi: 10.1177/0333102414553823 [published Online First: 2014/10/18]
25. Monteiro JM, Matos E, Calheiros JM. Headaches in medical school students. *Neuroepidemiology* 1994;13(3):103-7. doi: 10.1159/000110366 [published Online First: 1994/01/01]
26. Monteiro JMP. Cefaleias: estudo epidemiológico e clínico de uma população urbana. Universidade do Porto, 1995.
27. Cardoso SM. [The weight of epidemiologic studies]. *Revista Portuguesa de Cardiologia*;23(5):18.
28. Martins V, Temotio J, Murta I. [Psychiatric comorbidities associated with headaches: the experience of the liaison consultation]. *Acta Med Port* 2015;28(1):44-50. [published Online First: 2015/03/31]
29. Organization WH. The Global Burden of Disease: 2004 update. Geneve, Switzerland: World Health Organization, 2008.
30. Saúde D-Gd, Evaluation IfHMa. Portugal: The Nation's Health 1990–2016: An overview of the Global Burden of Disease Study 2016 Results. Seattle, WA: IHME, 2018:32.
31. Saúde Md. Retrato da Saúde, Portugal. In: Saúde Md, ed. Lisbon, Portugal: Ministério da Saúde, 2018:88.
32. Steiner TJ, Stovner LJ, Vos T. GBD 2015: migraine is the third cause of disability in under 50s. *The Journal of Headache and Pain* 2016;17(1):104. doi: 10.1186/s10194-016-0699-5
33. Silva C. Impact of Migraine on Daily Activities: a Stratified Analysis by Monthly Migraine Days. Poster presented at the 13th EHF Congress ed. Athens, Greece, 2019.
34. Steiner T, Scher A, Stewart W, et al. The Prevalence and Disability Burden of Adult Migraine in England and their Relationships to Age, Gender and Ethnicity. *Cephalalgia* 2003;23(7):519-27. doi: 10.1046/j.1468-2982.2003.00568.x
35. Clarke CE, MacMillan L, Sondhi S, et al. Economic and social impact of migraine. *Qjm* 1996;89(1):77-84. doi: 10.1093/oxfordjournals.qjmed.a030141 [published Online First: 1996/01/01]
36. Lofland JH, Pizzi L, Frick KD. A Review of Health-Related Workplace Productivity Loss Instruments. *Pharmacoeconomics* 2004;22(3):165-84. doi: 10.2165/00019053-200422030-00003

37. Linde M, Gustavsson A, Stovner LJ, et al. The cost of headache disorders in Europe: the Eurolight project. *Eur J Neurol* 2012;19(5):703-11. doi: 10.1111/j.1468-1331.2011.03612.x [published Online First: 2011/12/06]
38. Silva C, Laires P, Ritter S, et al. PND61 DIRECT AND INDIRECT COSTS OF MIGRAINE IN HEADACHE SPECIALIST CENTERS IN PORTUGAL. *Value in Health* 2019;22:S748. doi: <https://doi.org/10.1016/j.jval.2019.09.1831>
39. QuintilesIMS. Migraine Project. Quantitative Results. Quantitative Market Research, 2017:136.
40. Lantéri-Minet M, Valade D, Géraud G, et al. Migraine and Probable Migraine — Results of FRAMIG 3, a French Nationwide Survey Carried out According to the 2004 IHS Classification. *Cephalalgia* 2005;25(12):1146-58. doi: 10.1111/j.1468-2982.2005.00977.x
41. Becker C, Brobert GP, Almqvist PM, et al. Migraine Incidence, Comorbidity and Health Resource Utilization in the UK. *Cephalalgia* 2007;28(1):57-64. doi: 10.1111/j.1468-2982.2007.01469.x
42. Lampl C, Thomas H, Stovner LJ, et al. Interictal burden attributable to episodic headache: findings from the Eurolight project. *The Journal of Headache and Pain* 2016;17(1):9. doi: 10.1186/s10194-016-0599-8
43. Payne KA, Varon SF, Kawata AK, et al. The International Burden of Migraine Study (IBMS): Study design, methodology, and baseline cohort characteristics. *Cephalalgia* 2011;31(10):1116-30. doi: 10.1177/0333102411410610
44. Antonaci F, Nappi G, Galli F, et al. Migraine and psychiatric comorbidity: a review of clinical findings. *The Journal of Headache and Pain* 2011;12(2):115-25. doi: 10.1007/s10194-010-0282-4
45. Lancet T. Global Burden of Disease 2021 [Available from: <https://www.thelancet.com/gbd/> accessed 09/02/2021].
46. Martelletti P, Lucas C, Pozo-Rosich P, et al. Burden and patient-reported outcomes of migraine patients with prior prophylactic treatment failure: Study design of the multinational BECOME study. *The Journal of Headache and Pain* 2018;19
47. Andrée C, Stovner LJ, Steiner TJ, et al. The Eurolight project: the impact of primary headache disorders in Europe. Description of methods. *The Journal of Headache and Pain* 2011;12(5):541-49. doi: 10.1007/s10194-011-0356-y
48. Stovner LJ, Andrée C, Eurolight Steering C. Impact of headache in Europe: a review for the Eurolight project. *The journal of headache and pain* 2008;9(3):139-46. doi: 10.1007/s10194-008-0038-6 [published Online First: 2008/04/17]