

Migraine's impact on employment in Europe

What can be done to improve work outcomes for people with migraine?



About the Work Foundation

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

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

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Executive summary

What is migraine?



Migraine is a **serious neurological condition** associated with recurrent and debilitating headaches of moderate to severe intensity that can **affect the ability to perform daily activities**¹.

The Work Foundation has conducted research to explore how to **improve the experience of work for people living with migraine**. It had three aims:

- 1** Demonstrate that **migraine is a serious condition** with a substantial – **but addressable** – cost and impact on individuals' working lives.
- 2** Establish what a **'migraine friendly' workplace** looks like.
- 3** Recommend **what steps can be taken to make workplaces more migraine friendly** and thus improve the experience of work for people with migraine.

What does a 'migraine friendly' workplace look like?

People with migraine can benefit from **'good' work** and **'high performance working'** practices²

- **increased autonomy and control** helps manage workload and perceived triggers
- **manageable demands** reduces the risk of stress (a trigger)
- **social support** from managers and colleagues helps with condition management
- **workplace flexibility** to manage hours more easily and work from home

An effective **workplace health management** system

-  **promote good health and wellbeing** educating employees on how to live a healthy lifestyle and manage health conditions
-  take **preventative action** which enables early identification of a health issue and referral to a specialist if needed and intervene
-  ongoing **health management** to sustain performance over time ensuring effective case management

Access to **reasonable adjustments**³

-  disregard disability-related **sickness absence**
-  promote **flexible working** practices
-  provide access to **drinking water**
-  access to a **quiet room**
-  **Time off** work for medical appointments

How to improve work-related outcomes for people with migraine in Europe

A **range of policy options** can be deployed (in different ways and/or adapted) by policymakers at EU and/or Member State level to improve the experience of work for people living with migraine.

 **Making laws** compelling or obliging different actors (e.g. employers) to act more responsibly. European standards set a minimum legal 'duty of care' safeguarding workers' rights.

 **Advice and guidance** through the sharing of good practice, information and training to secure better work practices by influencing employee and employer behaviour, equipping them with tools to manage migraine in the workplace effectively.

 **EU and national strategies** and targets, supporting data collection, monitoring and reporting, provide overall coordination, oversight of national policies and help track progress to ensure better employment outcomes.

Sources

¹ICD-11 for Mortality and Morbidity Statistics

²Work Foundation. (2018). Society's headache: the socioeconomic impact of migraine. London: Work Foundation

³The Migraine Trust (2010). Employment Advocacy Toolkit. London: Migraine Trust.

Icons from www.flaticon.com

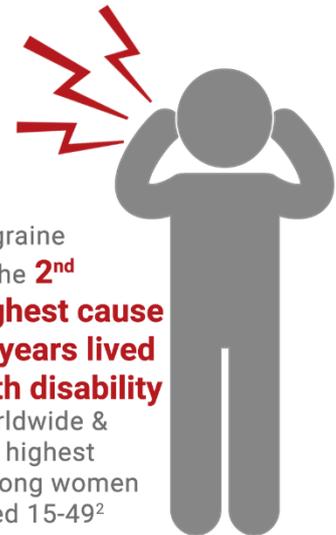
 **Specific employment programmes** delivering better working practices job retention and/or specific support to aid a quick – and sustained – return to work.

 **Awareness raising and campaigning** to promote high standards in working conditions, promoting 'migraine literacy' among employers and supporting a 'culture of care', risk prevention, and better health management at work.

The impact of migraine on Europe – infographic summary

160m

adults across Europe aged 15-69 are estimated to have migraine¹



Migraine is the **2nd highest cause of years lived with disability** worldwide & the highest among women aged 15-49²



The direct and indirect **costs of migraine** are **€95bn** per annum³ – **93%** are due to indirect **lost productivity** costs⁴



People with migraine are estimated to **lose 2–7 workdays per year** due to migraine⁵ and those with frequent migraine⁶ up to **46 workdays per year**⁷



The impact of migraine on work life⁷

72% of people with frequent migraine⁶ feel that their migraine has impacted on their professional life



Although **63% of people** with frequent migraine⁶ reported their condition to their employer only **18% were offered support**



¹This is based on a prevalence of 28% derived from a weighted average of Global Burden of Disease (GBD) study 2017 data taking migraine prevalence amongst those aged 15-49 and 50-69, which is 30% and 23.4% respectively; ²GBD 2017; ³This figure has been calculated using cost estimates provided by the Eurolight study, which, on the basis of a 15% adult migraine prevalence (derived from a systematic review of studies), estimated that migraine costs Europe €50 billion per annum. Using these cost data, this figure was re-calculated using the GBD 2017 prevalence estimate (28%), resulting in an estimated cost of €95 billion per annum; ⁴Linde, M., Gustavsson, A., Stovner, L. J., Steiner, T. J., Barré, J., Katsarava, Z., ... André, C. (2012). The cost of headache disorders in Europe: The Eurolight project. *European Journal of Neurology*, 19(5), 703–711; ⁵Stovner, L. J., Andree, C., & André, C. (2008). Impact of headache in Europe: a review for the Eurolight project. *J. Headache Pain*, 9(3), 139–146; ⁶At least four 'migraine days' a month; ⁷Results from the 'My Migraine Voice' survey (for Europe), conducted between 2017-18 (comprising more than 11,000 people who had at least four 'migraine days' per month from 31 countries).

1. Introduction

This paper is the culmination of a programme of work which aims to improve the experience of work for people living with migraine (PLWM). In doing so, it has sought to establish:

- i. the case for action on migraine in the workplace, demonstrating that migraine is a serious condition with a substantial, but addressable, cost and impact on individuals' working lives;
- ii. what a 'migraine-friendly' workplace looks like; and
- iii. what steps can be taken to make workplaces more migraine-friendly and thus improve the experience of work for PLWM.

The work has been informed by an evidence review of relevant academic and grey literature, analysis of the latest data on migraine from a range of sources, and insights gained from qualitative interviews with a number of EU and country level stakeholders with expertise in areas ranging from the management of migraine and other health conditions – in both clinical and workplace settings – to organisational change and workplace innovationⁱ. It therefore offers an account of how to improve the experience of work for PLWM from the perspective of a diverse range of stakeholders (i.e. covering not just health but also social and employment policy).

This paper is split into three parts. The first (**Chapter 2**) provides a definition of migraine, an estimate of its prevalence and costs, and its impact on employment in Europe. The second part (**Chapter 3**) draws on evidence of the challenges PLWM experience in the workplace and, in turn, maps out what a 'good', 'migraine-friendly' work environment would look like. In the third part (**Chapter 4**) we consider what policy action can be taken to create more migraine-friendly work environments which will, in turn, improve the experience of work for PLWM. Finally, we outline our conclusions and recommendations (**Chapter 5**).

This paper does not seek to provide definitive answers, but rather present a range of policy options, all of which have the potential to significantly improve the experience of work for PLWM.

1.1. Background

Today, an estimated 50 million EU citizens have two or more long-term, chronic health conditions¹ and the 'disease burden' in Europe is increasingly defined by disability rather than premature mortality. The costs associated with treating chronic conditions are considerable and rising – though they are not confined to health and social care budgets. Chronic conditions carry societal costs, affecting wages, workforce participation and productivity, as well as increasing early retirement, high job turnover and disability². In the UK, for example, the employment rate for people with a long-term health condition is 60%, while it is 80% for those without^{3,4}.

Working while managing a long-term condition can be difficult – and it can be made harder by poor working practices. This often results in lost productivity (mainly due to absenteeism or reduced effectiveness at work, i.e. 'presenteeism'ⁱⁱ). The rising prevalence of chronic conditions therefore has profound implications for economies, employers and government. However, with appropriate management and support, and often small adjustments, these costs can, in part, be avoided or substantially reduced.

Migraine is a highly prevalent, chronic health condition with episodic presentation. It is responsible for a significant – and rising – proportion of years lived with disability (YLDs). It is the third most common disease in the world in both males and females⁵. Recent data show it is the second highest cause of YLDs worldwide⁶ (behind low back pain) and even more common

ⁱ For a more detailed description of the research methods employed, see Annex 1

ⁱⁱ Coming to work when ill and working at reduced capacity

amongst those aged 15-49⁷ (amongst women in this age group it is now the first cause of disability⁸). During these years, people are, generally speaking, at their most productive, furthering their careers and starting families. Migraine therefore has a huge impact on people's career paths and the economy in general. The substantial costs in lost productivity attributed to migraine (mainly through absenteeism and presenteeism) illustrate this. But, importantly, these can be managed.

Migraines typically last around a day or more usually occurring around once a month, though a significant proportion (over 10%) have attacks once a week⁹. Attacks are often accompanied by severe or extremely severe – sometimes debilitating – pain. It is therefore unsurprising that they interfere with people's daily lives. As migraine disproportionately affects people of working age (peaking between 30 and 50 years), the economic impact of the condition is particularly pronounced. Based on Eurolight estimates of the costs attributed to migraine and an adult¹⁰ migraine prevalence in Europeⁱⁱⁱ of 28%¹¹, the direct and indirect costs attributed to migraine are estimated to be more than €95 billion per annum for all of Europe, of which the vast majority (93%) are attributed to indirect lost productivity costs¹².

Action from policymakers is sorely needed. European data indicate that migraine is the least publicly funded of all neurological diseases relative to its economic impact¹³. This situation has persisted despite the World Health Organization, following its 2011 global survey of headache disorders and resources¹⁴, highlighting the “neglect of a major public-health problem” and the “inadequacies of responses to it in countries throughout the world”¹⁵.

In the context of an ageing population and rising numbers of people with chronic conditions, migraine's economic burden is simply unaffordable. It is, however, potentially avoidable. Though a number of barriers stand between PLWM and optimal work-related outcomes, recent evidence from the UK suggests that, with the right support, and often modest accommodations, they can be overcome. For example, supportive work environments that create good work – incorporating reasonable adjustments – and appropriate management practices that empower PLWM to maintain employment and their productivity at work. These benefits extend beyond the individual, helping employers maintain healthy bottom lines and keep staff turnover costs low, while reducing the impact on governments' social security budgets.

In response to rising numbers of people with chronic conditions and disabilities, many governments have sought to make access to disability support payments criteria more stringent and to promote ‘work first’ principles. High employment is essential for the functioning of any society – and the EU have explicitly recognised this, aiming for 75% employment in all Member States (as outlined in the Europe 2020 strategy). This target is not realistic, however, unless those with reduced work capacity, such as PLWM, are supported and integrated into the workforce. There is a vast amount of untapped potential currently excluded from the labour market for health reasons. Given current demographic trends, organisations will, increasingly, be reliant on this potential pool of workers. Policymakers should, therefore, encourage and incentivise the creation of ‘good’ quality work, as this is vital for job retention – particularly for those with health conditions – and, thus, sustainable employment. This brings wider social and economic benefits and benefits individuals' health and wellbeing.

The EU and Member States will need to consider how to compel and/or incentivise more employers to take action to improve work environments and employment opportunities at work, as well as what policy interventions will be most effective in this regard. Not doing so will cost significantly more in the long run, and put into jeopardy its commitment to high employment,

ⁱⁱⁱ These prevalence data for ‘Europe’, taken from the GBD 2017, refer to the European region, which includes the European Union as well as other countries of greater Europe

social inclusion and job quality (as outlined in the Europe 2020 strategy). Taking action, therefore, offers vital economic and social benefits for employers, individuals, local economies and society at large.

There is a firm basis for action in EU law and the European Pillar of Social Rights which states that all workers have the right of “equality of opportunity”, “fair working conditions” and “social protection and inclusion”. These basic rights are complemented in individual Member States by various employment and social policy initiatives that aim to optimise employment opportunities for all. Improving the experience of work for PLWM specifically will require a range of actions from policymakers – incorporating both ‘hard’ and ‘soft’ policy measures, compelling employers to act, by, for example, changing laws at one extreme to nurturing good working practices at the other by providing information, support and guidance and creating employer incentives. The blend of policies needed to create migraine-friendly work environments in different Member States will in part depend on the local social and economic context, and the demands of the working population.

This paper does not seek to provide definitive answers, but rather present a range of policy options, that potentially can be deployed in different ways and/or adapted by policy makers in the EU and/or Member States to improve PLWM’s experiences in future.

2. Migraine's impact in Europe

The purpose of this chapter is to establish migraine as a 'serious condition' with significant, but addressable, costs/impact in Europe. It begins by providing a *definition of migraine*, followed by *estimates of prevalence and costs* in Europe, and ends with an assessment of its *impact on employment and people's ability to work*.

2.1. What is migraine?^{iv}

The International Headache Society (IHS) describes migraine as a common and disabling primary headache disorder¹⁶. In its most recent (third) edition of the International Classification of Headache Disorders (ICHD-3), migraine is described as having two major 'types'. These are migraine with, and migraine without, aura. 'Aura' generally refers to visual disturbances including blind spots in the field of eyesight, coloured spots, sparkles or stars, flashing lights before the eyes, etc.¹⁷ Migraine without aura is, however, more common, affecting the vast majority of people with migraine¹⁸.

2.1.1. Migraine symptoms; attack frequency, duration and severity

Migraine is a complex condition, comprising a wide variety of symptoms. In its recently updated International Classification of Disease (ICD-11), the World Health Organization (WHO), drawing on ICHD-3, describes migraine as primarily episodic, comprising disabling attacks typically lasting 4-72 hours (when untreated or not treated properly), and characterised by moderate or severe headache¹⁹.

International evidence from studies of migraine in North America and Europe tend to report attack frequency and duration (i.e. the 'ictal' state) ranging between 15-30 times a year, normally lasting about one day but often more. Migraine can be extremely debilitating; the majority of PLWM report 'severe' or 'extremely severe' pain. They are also prone to anxiety, depression, tiredness, difficulty concentrating and irritability^{20,21}.

Due to its symptoms, and the frequency with which they occur, migraine has a profound – often negative – effect on people's ability to work.

Migraine is normally classified as being either 'episodic' or 'chronic' depending on how often it occurs. Both cause debilitating pain. Also, in epidemiological studies, migraine is often defined as either being 'definite' or 'probable'. Again, both are debilitating. Furthermore, migraine is distinct from other, less disabling headache disorders like tension-type headache.

2.2. The prevalence of migraine in Europe^v

The latest available data on migraine suggest it is highly prevalent in Europe²². According to the Global Burden of Disease (GBD) study 2017, prevalence is 22.4% for both sexes and all ages^{23,vi}. Women are disproportionately affected (28.5% compared to 15.8% for men)²⁴, as are people of working age²⁵ (28%)²⁶. Years Lived with Disability (YLDs) caused by migraine for both sexes and all ages is 6%²⁷, with higher rates recorded for women (7.3% compared to 4.3% for men)²⁸ and working age²⁹ adults (8.1%)³⁰. Though undoubtedly a global issue, the data suggest that migraine is particularly prevalent in Europe, causing a significant amount of disability. Given that people of working age are disproportionately affected, this has significant implications for its

^{iv} See Annex 2 for a more comprehensive definition of migraine

^v See Annex 1 for more information on the sources used to estimate migraine prevalence

^{vi} Previous iterations of GBD treated 'medication overuse headache' as a separate cause to migraine, however, it is now considered a sequela of either migraine or tension-type headache. As a result, recent estimates (from GBD 2016 onwards) show higher levels of migraine prevalence (see Stovner et al., 2018, Global, regional, and national burden of migraine and tension-type headache, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*, 17(11), 954–976.)

impact on employment in Europe. Before we consider these implications, however, we explore how migraine's prevalence varies across the continent.

2.2.1. Migraine prevalence within Europe

GBD 2017 provides prevalence data for the majority of European countries. We, however, confine our analysis to countries where comparable data are available in the existing literature, so as to provide some context to GBD's figures. This is done for the simple reason that sharing and discussing these data will promote a better understanding of migraine prevalence and, therefore, support steps to take action and, in turn, better manage the condition. Recent data³¹ are available for 10 of the countries featured in the 2010 Eurolight review³², as well as three countries which have been studied since (Belgium³³, Italy³⁴ and Spain³⁵). The average migraine prevalence of the 13 countries with recent, comparable data available is 17.1% in the published literature, and 23.4% according to GBD 2017 (see Table 1 below).

Table 1 – Migraine prevalence in Europe in 13 countries with recent comparable data (all ages)

Country	GBD 2017 prevalence (%)	Published literature prevalence (%)
Austria	25.3	10.2
Belgium	28.5	25.8
Croatia	20.3	19
Denmark	17.4	19.1
France	18.4	21.3
Georgia	23.2	15.6
Germany	21.3	11.4
Italy	28.8	25.9
Norway	25.4	23
Spain	28.9	12.6
Sweden	23.9	4
Turkey	21.1	19.9
United Kingdom	21.9	14.3
Average	23.4	17.1

Migraine prevalence appears to be highest in Belgium and Italy – according to both GBD 2017 and recent, comparable data in the published literature. Some caution is advised in interpreting these findings, however, particularly those relating to Italy. This is because they are based on data from one area in Italy (Parma) – though the authors do argue their findings are representative of the national picture. Prevalence also appears to be particularly high in Spain but only according to GBD 2017. Findings from the published literature suggest it is relatively low. Caution is advised when comparing prevalence findings because of differences in study subjects' demographic profiles and survey methods³⁶. For example, medication overuse headache is subsumed as a sequela of either migraine or tension-type headache in GBD 2017, but not in all published studies. These factors, to some extent, may account for some the variation in prevalence between countries and sources. The results should therefore be interpreted with this in mind. That said, they still provide some indication of how migraine prevalence varies within Europe and serve as a basis to inform how to respond.

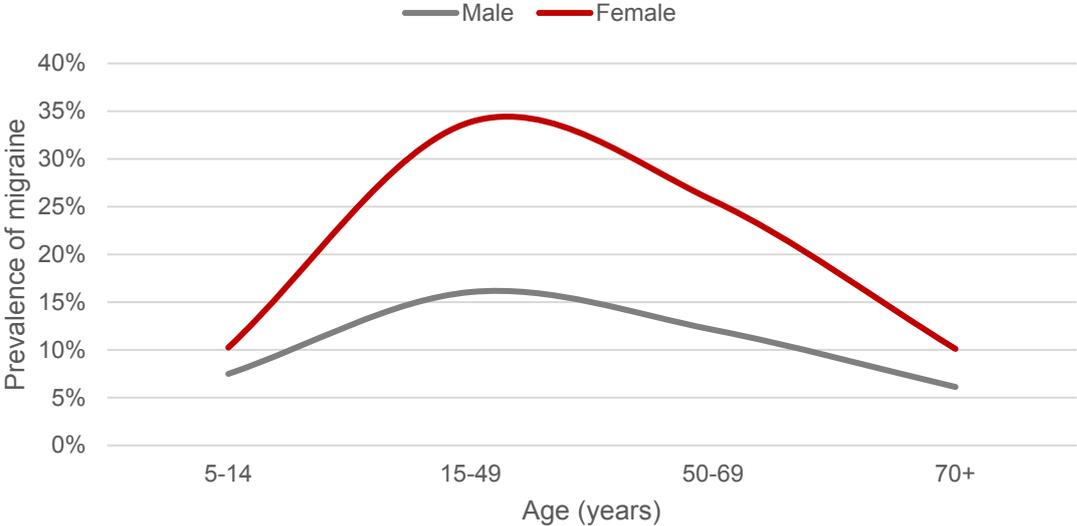
2.2.2. Variation in migraine prevalence by demographics

Migraine prevalence varies significantly according to demographic characteristics. Several studies from Europe^{37, 38, 39}, as well as data from GBD 2017⁴⁰, show that migraine is at least twice as common in women as it is in men. Although the exact reasons why are not fully understood, there is evidence^{41, 42} to suggest it is related to hormones. It is thought that, for similar reasons, it is more common amongst people of working age.

GBD 2017 data for Europe show migraine affects almost a third of adults aged 15-69 years⁴³, also reflected in the published literature. Evidence from various European countries shows

migraine peaking around the ages of 30-50⁴⁴ and 20-40⁴⁵ (see Figure 1 below). Generally speaking, these are the years when people are at their most productive and – significantly – furthering their careers. Migraine’s impact is therefore greatly magnified during these years⁴⁶, with profound implications for PLWM and their ability to stay in and remain productive at work.

Figure 1 – Prevalence of migraine by age for both sexes in Europe



Source: Global Burden of Disease study

2.2.3. Migraine in working age people

The literature suggests that *stress – specifically work-related stress – can act as a trigger for a migraine episode*^{47, 48, 49}. Indeed, an academic neurologist we consulted for this project, who runs a headache clinic in Belgium, suggested that 80% of his patients mention stress as a trigger for their migraines⁵⁰. This is important because it is well established in the wider literature that poor working conditions (i.e. adverse psychosocial work environments – a lack of ‘good’ work – characterised by e.g. employees having little control at work, high demands, low support, bad management practices, etc.) promote stress⁵¹. This, in turn, increases people’s risk of several negative health outcomes (including mental health problems, cardiovascular disease and musculoskeletal disorders)⁵².

Some studies have explored the relationship between poor quality work and migraine. For example, a case-control study conducted in France in 2003 comprising 250 participants concluded that managing work stress is potentially one way of improving the quality of life of PLWM⁵³. Furthermore, a 2014 study of 10,000 workers in Brazil found a strong correlation between poor quality work (i.e. low control, high demands, etc.) and migraine attacks, positing stress as the likely causal mechanism⁵⁴. A European study of 6,000 workers reported similar findings: higher demands at work and lower levels of control were related to more severe headache at follow up⁵⁵. These findings are consistent with the views of a workplace innovation expert we consulted: certain work practices can act as migraine triggers, thus reducing exposure to them can serve as a means of ameliorating symptoms⁵⁶.

The evidence shows that *there is a causal link between poor quality work and stress, and that stress can act as a trigger for migraine*. Therefore, improving the quality of work, thereby reducing workers’ exposure to stress, not only promotes health and wellbeing generally but can benefit PLWM in particular (potentially reducing attack frequency).

2.2.4. The workplace as a setting for health promotion

For a number of reasons (e.g. the amount of time people spend at work and its well-established impact on employees' health), policymakers increasingly see the workplace as an important 'intervention point' at which health can be improved^{57,58}. This would seem especially relevant for PLWM, who are, disproportionately, working age. This has important policy implications (at international-, country- and employer-level): *if migraine was better managed in the workplace, its impact could be reduced.*

2.3. The impact of migraine on employment in Europe

Clearly, migraine can be severely debilitating and is highly prevalent. This carries a significant social and economic – as well as individual – cost. We explore these costs in this section, with a particular emphasis on migraine's impact on employment and people's ability to work.

2.3.1. Lost productivity costs attributed to migraine^{vii}

The most recent attempt to calculate the lost productivity costs associated with migraine in Europe comes from Eurolight⁵⁹. It includes data from eight European countries⁶⁰, collected between 2008 and 2009, representing 55% of the adult EU population⁶¹. Using data from almost 10,000 respondents, it estimates the direct and indirect costs attributed to a range of headache disorders, including migraine. Direct costs include, for example, healthcare costs such as outpatient care, medications, hospitalisation, etc. Indirect costs relate to lost productivity through absenteeism and presenteeism. Of all the headache disorders Eurolight studied, migraine was found to be the most costly by far.

Using the cost data reported by Eurolight⁶² combined with the latest estimates of migraine prevalence in Europe amongst working age adults⁶³ (28% according to GBD 2017⁶⁴), *the direct and indirect costs attributed to migraine are estimated to be more than €95 billion per annum* for all of Europe^{viii}. The vast majority of these costs (93%) are attributed to indirect lost productivity costs, i.e. absenteeism and presenteeism (with the latter being responsible for around two-thirds of lost productivity)⁶⁵.

2.3.2. Variation in costs by country

According to Eurolight, the cost of migraine is highest in Germany (see Table 2 below), though we might, to some extent, expect this given that it has the largest population of the countries studied. Indeed, migraine costs are generally higher in countries with larger populations. That said, there are some notable exceptions. For example, migraine costs are higher in Spain than in Italy, despite the former having a smaller population. Furthermore, costs appear to be relatively low in France despite it having the second largest population (behind Germany); while its population is greater than both Spain and Italy, migraine costs are less than half as much. As with prevalence data, variation between countries may be accounted for (in part) by the use of different methods to record data, etc. Furthermore, different country systems and how migraine is treated in clinical settings and managed in the workplace will also likely account for some variation. Nevertheless, the Eurolight findings provide an indication of how migraine costs vary within Europe. Caution must, however, be advised when interpreting the figures.

^{vii} See Annex 1 for more information on the sources used to estimate migraine costs

^{viii} This figure has been calculated using cost estimates provided by the Eurolight study, which, on the basis of a 15% adult migraine prevalence (derived from a Eurolight systematic review of studies published between 1991-2009 – see Annex 1), estimated that migraine costs Europe €50 billion per annum. Using these cost data we re-calculated this figure using the GBD 2017 prevalence estimate (28%), resulting in an estimated cost of €95 billion per annum. This method is consistent with that used in the Eurolight report which applies a European migraine prevalence to EU cost data.

Table 2 – European country-level costs for migraine

Country	Cost (EUR bn)	Population (15-64)
Austria	1.6	5,876,348
France	7.2	41,746,605
Germany	17.1	54,141,932
Italy	15.2	38,426,674
Lithuania	0.2	1,871,228
Luxembourg	0.2	415,089
Netherlands	4.7	11,076,563
Spain	15.4	30,679,847

Source: *The Eurolight study*

Irrespective of variations between countries, it is widely acknowledged that *the vast majority (i.e. more than 90%) of the costs caused by migraine are attributed to indirect, lost productivity costs.* Furthermore, more than two-thirds of these lost productivity costs are attributed to reduced productivity at work (i.e. presenteeism), with absenteeism being responsible for the remainder. Thus, there is potential to reduce these costs by enabling PLWM to stay productive at work – but how? While there are many possible answers to this question, for this piece of work we are interested in the role of *the work environment and how it can be modified to support the productivity of PLWM at work.* This extends beyond ‘reasonable adjustments’ for people with migraine to include the psychosocial work environment (i.e. whether people have access to ‘good’ work), management practices, the organisation of work and so on. But what aspects of the workplace should be changed to support the productivity of PLWM? To answer this question we must first consider the ways in which migraine affects people at work.

2.3.3. The personal impact of migraine

Due to the frequency and length of migraine attacks – and the pain they cause – it is not surprising they cause disruption to people’s lives. Findings from a 2017 European-level survey of more than 6,000 PLWM (*My Migraine Voice*^{ix}) found that the vast majority (74%) reported being either “extremely” (36%) or “very” (38%) limited during an attack. More than half (54%) reported an attack duration of at least 12 hours.⁶⁶

Although migraine’s burden is greatest during an attack (i.e. the ‘ictal’ burden), the ‘interictal’ burden (between attacks) is also significant and should not be ignored⁶⁷. Migraines are, clearly, unpleasant and, therefore, individuals that experience them will try and avoid them and perhaps worry about when the next one will occur⁶⁸. This can cause avoidance behaviour and anxiety⁶⁹.

Quality of life for PLWM is also compromised by the emotional burden created by the condition. It is reported that PLWM have difficulty sleeping and concentrating, leading to tiredness and irritability^{70,71,72}.

2.3.4. Migraine’s impact on employment

The personal impact of migraine has obvious implications for employment. Not only does it disproportionately affect people of working age, the nature of the condition can make it difficult for PLWM to either attend work or be fully productive when there. Attacks happen frequently, often lasting at least a day and cause significant pain. During an attack, capacity for performing daily activities and tasks can be significantly diminished. Thus, experiencing an attack at work is highly problematic. What’s more, when not experiencing an attack, the threat of one remains. This, combined with the emotional burden created by migraine, has negative (primarily mental) health implications, often leading to anxiety or depression, a loss of confidence and self-esteem.

^{ix} All of whom experienced ‘frequent’ migraine i.e. more than four episodes per month

Survey findings from the *My Migraine Voice* survey of more than 6,000 PLWM across Europe offer insight into migraine's impact on employment. More than half of respondents (53%) claimed that, due to their migraines, they "cannot concentrate at work". This inevitably makes it difficult to perform job tasks effectively. Symptoms often cause absenteeism (absence from work): PLWM tend to lose 2-7 workdays per year^{73,74}. Migraine-related presenteeism (reduced effectiveness at work) accounts for an equal, if not greater, loss^{75,76,77}. International evidence indicates that the effectiveness of PLWM at work is reduced by about one third when experiencing symptoms^{78, 79, 80, 81, 82, 83}.

There is also evidence that people with migraine suffer in terms of career advancement and earnings⁸⁴. Eurolight data show that (based on 6,455 PLWM in 10 European countries) 7.4% of PLWM believe their careers have suffered while 5.9% felt having migraine reduced their lifetime earnings⁸⁵. Furthermore, based on evidence from the *My Migraine Voice* survey, significant proportions of PLWM claim to have changed their job, missed out on promotion, or lost their job, due to migraine⁸⁶.

2.3.5. Work-related barriers for PLWM

Migraine's negative impact on employment can be made worse by adverse working conditions (i.e. work-related barriers). These include, for example, how people with migraine are treated in the workplace (by management and colleagues) as well as prevailing working practices and policies (see Box A below for a list).

Box A – Work-related barriers for PLWM

- Difficulty concentrating on work-related tasks
- Lack of understanding of migraine from managers and colleagues
- Lack of support from managers and colleagues
- Feeling judged for taking days off
- Feeling stigmatised
- Lack of knowledge/information available on how to support people with migraine in work
- Problems reconciling migraine's fluctuating nature with employers' sickness absence policies
- Difficulty getting 'reasonable adjustments' at work

Source: *Society's headache: The socioeconomic impact of migraine and My Migraine Voice*

Evidence from a 2018 UK case study offers several examples of in-work barriers⁸⁷. It found that there is a **lack of understanding of migraine the workplace**, evident in employers' and colleagues' attitudes. This is arguably an extension of the poor understanding of migraine amongst the public and more general healthcare professionals – evident in the UK and across Europe⁸⁸. Also, *employers do not perceive migraine as a 'genuine' condition*, in part due to popular misconceptions of migraine being 'just a headache'. Similar findings have been reported in the pan-European *My Migraine Voice* survey of 6,000+ PLWM. More than a quarter of respondents (26%) felt that "colleagues do not understand my condition or take it seriously" and 24% felt "judged" for taking days off⁸⁹. Furthermore, 1 in 10 felt "stigmatised". Thus, interventions to improve the experience of work for PLWM should not only be targeted at them and their employer, but also account for their colleagues.

UK guidance for people working with migraine suggests that employers are better able to understand and provide support if the person discloses their condition⁹⁰. However, evidence from the recent European *My Migraine Voice* survey of PLWM found that, despite most employers being informed about their employee's migraine (63%), fewer than 1 in 5 (18%) offered any support⁹¹. Thus, disclosing one's condition does not necessarily lead to better support.

Further evidence from a UK case study found that additional barriers include: (i) **lack of existing knowledge and information** on how to support PLWM in work; (ii) **employers' sickness absence**

policy and the problems reconciling it with migraine's fluctuating nature; and (iii) the *difficulty PLWM have getting 'reasonable adjustments'* at work⁹².

Even if they wanted to, employers are often unsure how best to support PLWM given the lack of reliable publicly available information. While there are some resources provided by third sector organisations, these are primarily aimed at employees⁹³. Also, because PLWM may have several instances of short term absence in a given period, they are unfairly punished; employer policy tends to accommodate either one or two periods of short or long-term absence only. Finally, in part due to the ambiguity around whether migraine is a disability or not, PLWM are often unable to get their employer to make reasonable adjustments. This makes adverse aspects of physical work environments, which can potentially act as triggers for an attack, difficult to avoid, e.g. lighting, loud noises and strong smells.

2.4. Key messages

Migraine is a serious condition that can cause debilitating pain, with attacks occurring between 15-30 times a year, normally lasting a day but often more. It is highly prevalent, particularly amongst people of working age. As a result, it carries a significant – but addressable – cost. Modifications to the work environment – ensuring that workplaces are 'migraine-friendly' – have the potential to significantly reduce migraine's impact on people's ability to work – and, in turn, address the costs associated with it. Thus, in the following chapter we explore what a migraine-friendly workplace looks like.

3. What does a migraine-friendly workplace look like?

This chapter explores what a migraine-friendly workplace would look like. It draws on existing evidence and insights gained from interviews with a range of expert stakeholders. As PLWM are disproportionately working age and the majority of the costs associated with migraine are due to absence from and/or reduced capacity at work, policymakers increasingly see the workplace as an ‘intervention point’ at which health can be improved. Furthermore, PLWM experience many challenges in the workplace. Thus, if migraine was better managed in the workplace, its impact could be reduced significantly.

We begin by looking at *how PLWM can benefit from ‘good’ work* and *its importance to the EU*. We then explore *how to improve work quality* and the merits of a *workplace health management system*, with a focus on modest workplace adjustments that potentially offer significant benefits to PLWM.

3.1. How PLWM can benefit from ‘good’ work

There is a vast body of literature showing the *positive impact that a good work environment* has on employee health and wellbeing – as well the negative effects of an adverse environment⁹⁴. The common components of good work are presented in Box B (below). A lack of good work causes stress which, in turn, leads to several negative mental and physical health outcomes⁹⁵. People with chronic health conditions, e.g. PLWM, tend to suffer more – relative to employees without health conditions – from poor quality work. However, at the same time, they may benefit more from good conditions⁹⁶.

Box B – The components of ‘good’ work

- The workplace is seen to be fair.
- There is secure employment.
- There is an appropriate balance between efforts made and rewards received.
- Work is *not* characterised by monotony and repetition.
- Appropriate demands are placed on the working person.
- Employees have autonomy, control and task discretion.
- Employees possess the skills they need to cope with periods of intense pressure.
- Employees are given adequate support.
- Workplace relationships are strong (i.e. ‘social capital’).

Source: *Society’s headache: The socioeconomic impact of migraine*

There is evidence to suggest that *people with chronic health conditions can benefit greatly from a supportive work environment*^{97, 98}. PLWM, specifically, can benefit in a number of ways. For example, it was shown in the previous chapter that significant numbers of PLWM identify a lack of understanding and support from colleagues and managers as a particular problem for them in the workplace. Good work, comprising adequate social support from colleagues and managers could, therefore, have the potential to significantly improve their experience in the workplace. In fact, *research has identified several aspects of a ‘good’ work environment considered particularly beneficial for PLWM* (see Box C below)⁹⁹:

Box C – How PLWM can benefit from ‘good’ work

- *Increased autonomy and control* – allowing them to manage their workload and perceived ‘triggers’.
- *Manageable demands* – reducing the risk of stress, which is trigger.
- *Social support from managers and colleagues* – to show understanding and help them manage their condition.
- *Workplace flexibility* – enabling them to manage their hours, work from home if necessary and fit their work around their migraine.

The value of support from managers/colleagues and workplace flexibility for people with health conditions was highlighted by the experts we spoke to¹⁰⁰. Where employees are able to discuss their personal needs with their line manager, the organisation is more able to provide support meeting those needs¹⁰¹. Furthermore, a flexible workplace culture, where people can (where the job allows) work from home or adjust their hours according to their needs/symptoms, empowers workers to manage their condition effectively. Where possible, employers’ HR policies should promote this¹⁰².

In addition to helping PLWM navigate a number of the barriers they face in the workplace, *good work environments – overall – reduce employees’ exposure to stress*, which is a migraine trigger. Studies have found that managing work stress through better work conditions is one way of improving the experience of PLWM in the workplace¹⁰³. This is based on evidence that good work – e.g. where employees have control and support, etc. – reduces migraine frequency and severity^{104, 105}. Indeed, as outlined by a workplace innovation expert we interviewed for this project, such working practices can potentially ameliorate migraine symptoms¹⁰⁶.

3.2. The importance of good quality work to the EU and how it is measured

Over the recent years, *the EU has addressed job quality through a range of strategies*, including the European Employment Strategy¹⁰⁷, the Lisbon Strategy¹⁰⁸ and more recently the European 2020 strategy¹⁰⁹ and the European Commission’s ‘Agenda for new skills and jobs’¹¹⁰.

Job quality has attracted a wide interest and various frameworks have been developed over the last decade (e.g. ILO Decent Work Indicators, UNECE Framework for Measuring Quality of Employment, OECD job quality framework). The first EU framework to systematically measure job quality was developed in 2001 (the Laeken indicators). *Eurofound has addressed the quality of work in its research and it has been monitoring changes in working conditions through its European Working Conditions Survey (EWCS) since 1990*. It studies both ‘extrinsic’ and ‘intrinsic’ aspects of work organised into four ‘indices’ (see Box D below).

Box D – Eurofound model of job quality

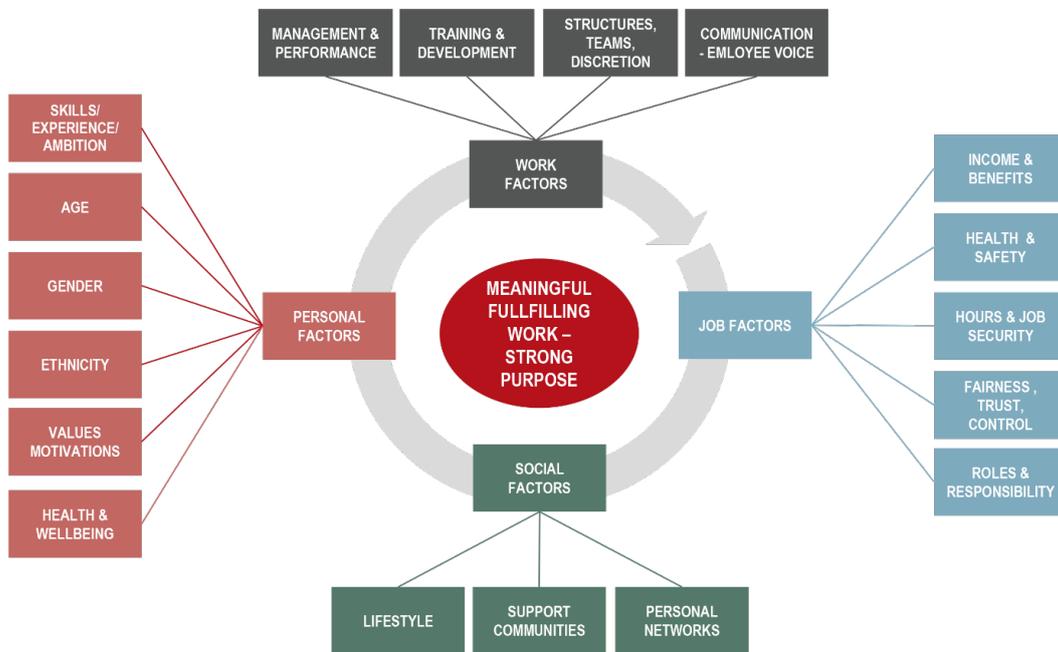
Aspect	Index	Components
Extrinsic job features	Earnings	Hourly earnings
	Prospects	Job security, career progression, contact quality
Intrinsic job features	Intrinsic job quality	Skills and discretion, autonomy, good social environment, good physical environment, work intensity
	Working time quality	Duration, scheduling discretion and short-term flexibility over working time

Wider European social partners also recognise the importance of good quality work. For example, the European Trade Union Institute (ETUI) identify the following as indicators of work quality: *wages; non-standard forms of employment; working time and work-life balance; working conditions and job security; health and safety; skills and career development; and collective interest, representation and voice*. The European Trade Union Confederation (ETUC) also consider good quality work a key priority, underpinning their campaigns for better workplace health.

Models of work quality have, at their root, a basic requirement for fairness, ensuring that workers are paid fairly, have security, equality of opportunity, etc and therefore employers meet a minimum “duty of care”. Good work – however – goes beyond ‘*job factors*’, i.e. fairness and adherence to minimum legal standards. Integral to the concept of good work is creating conditions for fulfilling, meaningful work which gives employees a sense of pride and, thus, purpose. It is concerned with wider social aspects of the work environment that are needed to secure commitment, motivation and employees’ discretionary effort. As such, emphasis is placed

on how people are managed consistently as a collective – *work factors* – whilst also allowing room to customise practices to meet individuals’ varying needs – *personal factors*. Furthermore, consideration is given to the way in which an organisation connects to and interacts with its local community, i.e. whether it has a sense of broader social responsibility. Figure 2 below gives an overview of these wider components of good work.

Figure 2 – Wider components of good quality work



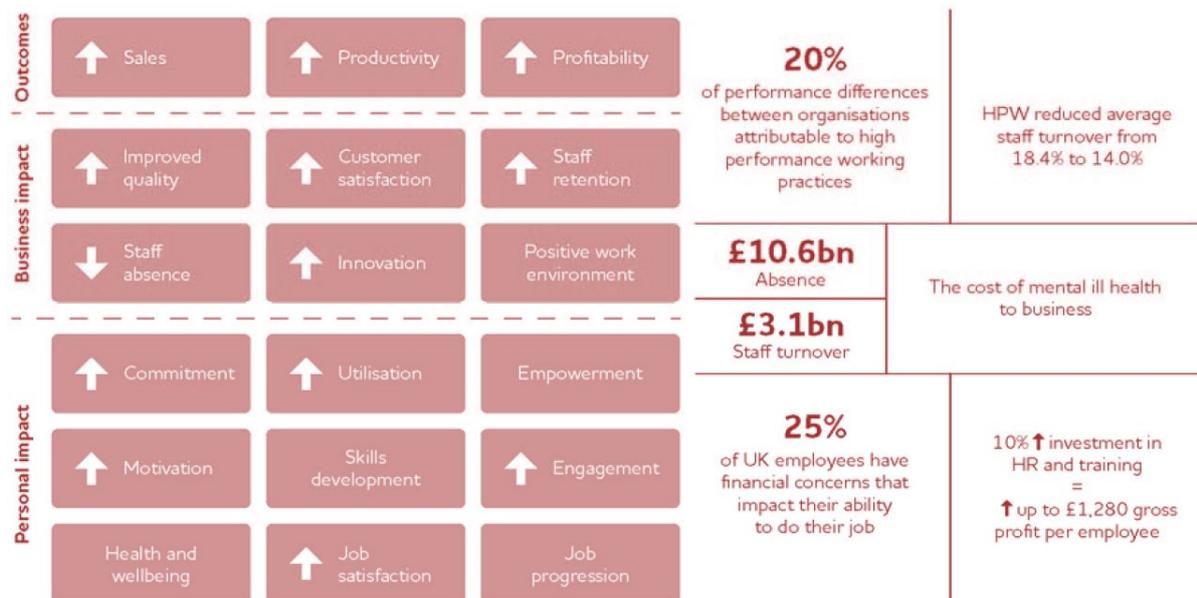
Thus, ‘good’ work is a multidimensional concept which can, in several ways, improve the experience of work for PLWM. It is also a central feature of European-level public policy, drawing interest from multiple key stakeholders. In the following section we explore how to create more good work.

3.3. High Performance Working – a route to good work?

One route to good work is through *better management practices associated with High Performance Working* (HPW). HPW is an integrated and proactive approach to managing businesses that is *people-centred* and seeks to ensure business success by *empowering people*¹¹¹. Studies show a strong positive relationship between HPW practices, business performance and employee outcomes, including *higher job satisfaction and motivation, employee involvement and commitment, and lower labour turnover*¹¹². See Figure 3 below for an overview of the benefits associated with HPW.

The goal is to drive up the quality of management to achieve improvements in performance and innovation, as well as workforce health, wellbeing, and the quality of working life. Research by social partners in the UK points to the importance of practices that support good work through *better job design, creating a ‘climate of trust’* where individual employees are confident that their contribution will be valued¹¹³. This is made possible by ensuring that employees have representation, e.g. on work councils and employee forums. This, in turn, positively shapes their quality of work¹¹⁴.

Figure 3 – The benefits of High Performance Work practices



There is support for this approach at EU-level, demonstrated by the European Commission’s backing of the European Workplace Innovation Network (EUWIN). Launched in 2013, this Europe-wide learning network aims to improve organisations’ performance and job quality in a sustainable way, enhancing quality of working life and creating healthier, more productive workplaces (see Box E below). It does this by bringing together different stakeholders (managers, employees, unions, researchers, policymakers, etc.) to share knowledge and experience.

Box E – European Workplace Innovation Network

In 2013, the European Commission announced the creation of the European Workplace Innovation Network. This Europe-wide learning network launched to improve the performance of organisations and the job quality in a sustainable way to enhance quality of working life and create healthier, more productive workplaces. Its focus is primarily to stimulate greater workplace innovation within Member States. The network has been managed jointly by TNO and UK WON with partners in several other countries.

The Network:

- distributes evidence on the benefits of modernising the workplace and working conditions;
- focuses on awareness-raising via dedicated regional workshops and social media;
- provides a valuable resource for managers and employee representatives through the [Knowledge Bank](#); and
- is open to practitioners, social partners, policymakers, representatives of intermediary organisations, and others with an interest in the workplace.

It is hoped that EUWIN will pave the way for a sustained policy commitment to closing the gap between ‘leading’ employer practice and common practice in Europe’s workplaces.

EUWIN has built a network which includes many hundreds of managers, employees, union representatives, social partner organisations, researchers, public policymakers and consultants. It has organised highly interactive conferences and workshops in several parts of Europe, enabling different stakeholders in the workplace to share knowledge and experience. It has led to the creation of local and sectoral networks.

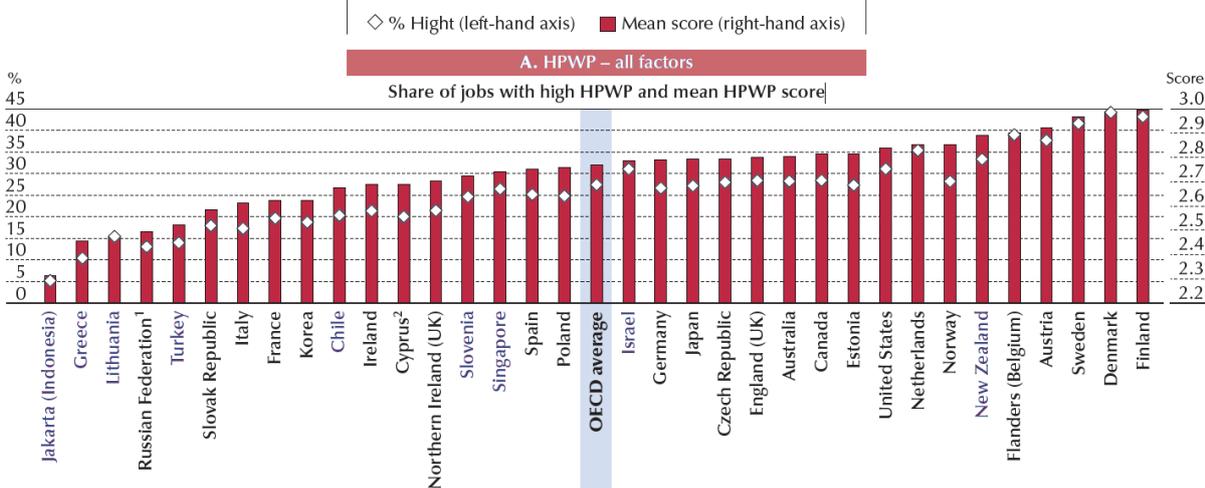
The focus on workplace innovation to inspire more HPW also puts an important emphasis on the future of work and the importance of securing ongoing improvements in working practices in future that (i) are still going to support the conditions for good work and, in turn, (ii) better working conditions for PLWM. The effects of globalisation, technological advances and innovation at work, which are supporting totally new ways of working, offer real advantages to support people

living with health conditions (such as migraine) in future – and a focus on workplace innovation can help to realise these advantages. For instance, new technologies and increasing ‘digitalisation’, which are facilitating more flexible working practices and allowing for flexible start/finish times and remote/homeworking, can ‘unlock’ opportunities for workplace adjustments which, in the past, may not have been as feasible (owing to more traditional working practices).

3.3.1. Variation in High Performance Working practices

There is significant variation in the adoption of HPW amongst different countries. For example, countries with the highest incidence of HPW include Denmark, Finland and Sweden, where around two fifths of people are working in organisations with HPW (see Figure 4 below). According to a workplace innovation expert consulted for this research, this is helped by the alignment of different stakeholders, including policymakers, trade unions, employer organisations, chambers of commerce, etc. (i.e. countries with a tradition of ‘social partnership’). This helps ensure employees have ‘voice’, which can lead to better work practices and more good work¹¹⁵.

Figure 4 – Take up of HPW across OECD member countries



Source: OECD (2016) Employment Outlook

Countries with lower uptake of HPW, e.g. Greece, Turkey and Italy, which have less of a tradition of social partnership, can benefit from exposure to good practice at the ‘enterprise level’ (i.e. the organisation-level), which helps them develop their own pathways towards high performance working and high quality work¹¹⁶.

Just as the distribution of HPW practices varies between countries, so does the provision of ‘good’ work. The OECD has organised countries into three groups based on their ‘OECD job quality framework’ score¹¹⁷ (see Box F below).

Box F – Job quality in OECD countries

- Australia, Austria, Denmark, Finland, Germany, Luxembourg, Norway, and Switzerland have the *highest job quality* among OECD countries.
- Belgium, Canada, the Czech Republic, Estonia, France, Ireland, Israel, Japan, Korea, Mexico, the Netherlands, New Zealand, Slovenia, Sweden, the United Kingdom, and the United States display an *average performance in terms of job quality*.
- Greece, Hungary, Italy, Poland, Portugal, the Slovak Republic, Spain and Turkey have the *lowest performance in terms of job quality*.

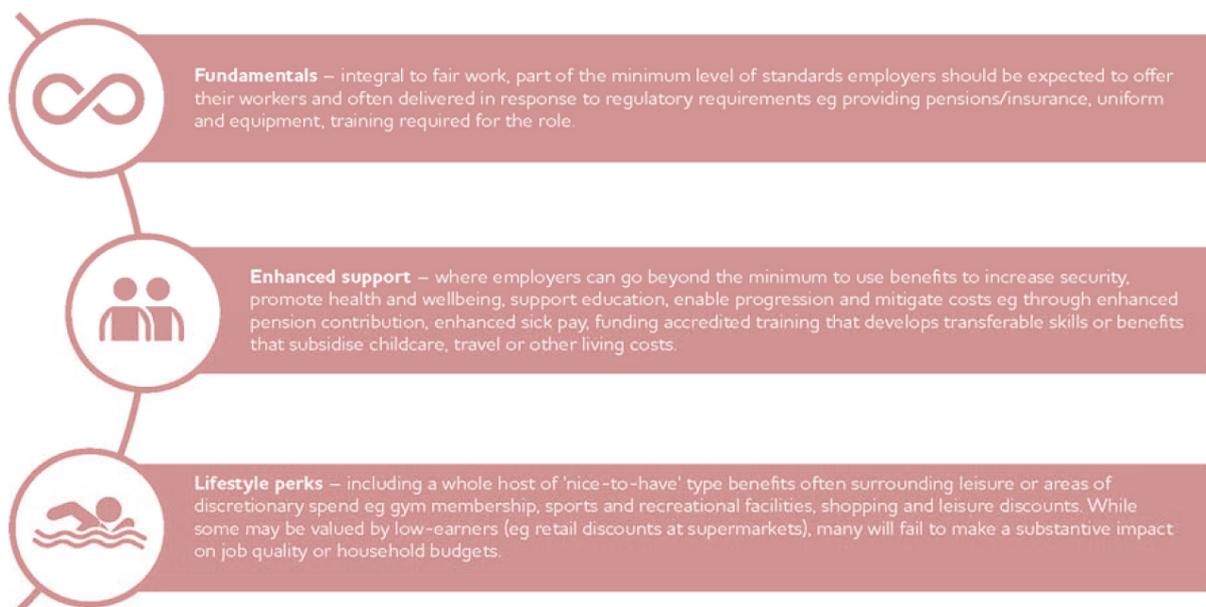
Source: OECD Job Quality database (2016)

3.4. Workplace health management

As well as benefitting in many ways from general improvements in the quality of working environments, PLWM can also benefit from specific workplace health interventions and approaches to workplace health management, which provide access to more specialist support at the point of need, as and when required.

Employers are increasingly aware of the importance and value of protecting and improving their employees' health and wellbeing. UK evidence suggests that almost half (45%) of employer 'health and wellbeing strategies' have been put in place in the last three years. Furthermore, 46% of employers currently without a strategy intend to put on in place in the next year¹¹⁸. These packages tend to cover a spectrum of benefits/health services (see Figure 4 below), ranging from fundamentals (e.g. fair work, minimum standards, etc.) to enhanced support (e.g. health and wellbeing promotion, enhanced sick pay, etc.). Such packages could benefit PLWM, particularly enhanced sick pay, and could also be tailored to their specific needs.

Figure 5 – A spectrum of employee benefits/health services



An effective workplace health management framework should, ideally, take a proactive approach and involve the following actions: (i) *promote good health and wellbeing*, educating employees on how to live a healthy lifestyle and effectively manage their health condition(s); (ii) *preventative action*, which enables early identification of a health condition (such as migraine), early referral to a health specialist (at the point of need as required), and early intervention to address it (to prevent the condition from progressing/becoming more severe); and (iii) *ongoing health management* to sustain performance over time, ensuring effective absence and case management, and occupational health and safety oversight. For an overview see Box G below.

The success of a workplace health management system does, in part, depend on access to *occupational health services*. This requires a degree of integration between employers and health services, which could be facilitated by government. Indeed, while coordination between employers and health care professionals is, in many European countries, lacking¹¹⁹, it is arguably increasing (evidenced by, for example, by the UK's cross-government Work and Health Unit, jointly sponsored by the Department for Work and Pensions and the Department of Health and Social Care¹²⁰). Occupational health covers a range of *specialist prevention and early intervention services*, including: pre-employment health screening; strategies to prevent illness and injury; and assisting staff to return to work quickly after absence. It can also help ensure that a return to

work is 'sustained', i.e. where the working person does not 're-lapse' and fall out of work again¹²¹. Additional services might include: lifestyle management advice; counselling services; and wider prevention and health improvement services.

Box G – An effective workplace health management system

Promotion	<ul style="list-style-type: none"> • Optimise physical health • Lifestyle/dietary advice and support • Discounts for gym membership, bicycles and recreational facilities to keep fit • General health improvement counselling and guidance
Prevention	<ul style="list-style-type: none"> • Open dialogue between line managers and their teams • Early identification of health problems and early referral to appropriate care • Reasonable adjustments to work • Avoid risks and hazards • Referral to occupational health therapists • Access to GP services • Customised health improvement counselling and guidance • Rehabilitation & return to work programmes • Self-management • Healthcare plans/insurance/health screening
Health management	<ul style="list-style-type: none"> • Develop a health and well-being strategy • Conduct regular employee reviews • Ongoing reasonable adjustments to work • Consult workforce e.g. staff satisfaction/employee engagement tools • Collect outcome data to track and evaluate progress e.g. sickness absence, return to work times, lost productivity, voluntary resignation, ill-health retirements, referral times to occupational health therapists

Closer integration of work and health via an occupational health service would benefit PLWM in many ways. For example, it was highlighted in the previous chapter that *a particular problem for PLWM in the workplace is the lack of employer knowledge and available information on how to provide support*. Access to an occupational health specialist would help fill this knowledge/information gap, giving PLWM access to specialist support if and when they need it.

Furthermore, access to an occupational health service would make it easier for PLWM to get reasonable adjustments at work. Several specific *reasonable adjustments* can help PLWM effectively manage their condition alongside their work responsibilities and maintain productivity at work. Often, these adjustments are not complex or expensive and are therefore cost-effective. Adjustments that would effectively support PLWM include changes to sickness absence policies, by, for example, disregarding disability-related sickness absence (see Box H below).

While beneficial for people with health conditions generally, PLWM would particularly benefit due to the *unpredictable and episodic nature of the condition*. Several instances of short term absence (which may be typical for PLWM) can be unfairly punished as policies tend to better accommodate either one or two periods of short or long-term absence only. This should therefore be considered a priority for PLWM. In addition, they would benefit from access to a rest room, time off for medical appointments, and flexible working hours. For a comprehensive list of adjustments thought to benefit PLWM, see Box H below.

Box H – Examples of reasonable adjustments for PLWM

The following is a list of reasonable adjustments that may be helpful for PLWM in the workplace.

Sickness absence policies:

Disregard disability related sickness absence: asking an employer to disregard a reasonable amount of disability related sickness absence can help to ensure an employee is not put at a substantial disadvantage by any absence-management procedure.

Working practices:

Flexible working hours: by not having rigid hours an employee can manage their time and reduce stress. For example, not always having to take sick leave or worry about being late.

Flexible location: by being able to work at home, an employee can make up hours an employee may have missed without the stress of having to rush to work with migraine.

Flexible breaks: breaks give an employee the time to stretch, relax muscles and manage trigger factors. They are particularly beneficial if an employee is working at a computer or managing machinery.

Rotation of tasks: by being able to share or rotate tasks within a team, an employee may still be able to work without doing prolonged activities that trigger their migraine.

Access to drinking water: dehydration is a major trigger for migraine.

Rest room: if space allows, having access to a quiet room can help an employee to rest at the onset of an attack which may enable them to recover quicker.

Time off for medical appointments: it can be helpful to discuss and reach an agreement with an employer in advance so that an employer can be flexible to accommodate this.

Redeployment: moving to a different site or team, a reduction of hours or a new role entirely may help an employee in the workplace to manage their migraine.

Stress management:

Stress risk assessments: by working with their manager to identify and manage stress factors an employee may be able to reduce stress levels which can be a trigger for migraine.

Stress management training: workshops on time and stress management strategies can be beneficial for all staff.

Regular supervisions: having regular one-to-one meetings with a manager can help identify work triggers or stress factors and lead to discussions about how they may be able to support an employee.

Health buddy: a colleague or representative who has an understanding of or training about migraine can provide support to an employee which can ease anxieties about attacks happening at work.

Physical work environment:

Work stations: key areas to consider are the organisation of a workspace or office, individual posture and furniture. Correct posture is important if an employee is sitting at a desk; a stiff back and neck can trigger migraine. Ensure that an employee's desk is positioned in such a way that glare from the window can be managed with a suitable light absorbing blind or curtain.

Source: Migraine Trust 2018^x

3.5. Key messages

PLWM can benefit from 'good' work and HPW practices in a number of ways. Overall, they promote employee health and wellbeing, reducing exposure to health hazards like stress – which benefits everybody but particularly PLWM insofar that it is a migraine trigger. More specifically, they empower employees, giving them control and autonomy but also the support they need from management. They therefore address many of the key work-related challenges experienced by PLWM outlined in the previous chapter. The benefits of an effective workplace health management system are, in many ways, complementary. For example, a good work environment, where individuals' needs are understood and, in turn, met, should facilitate access to reasonable adjustments for PLWM. An effective workplace health management system would reinforce this, providing access to more specialist support as and when required, ensuring that employees have access to the adjustments they need. Furthermore, through access to an

^x The Migraine Trust is a leading charity funding research, providing evidence-based information, campaigning and support for people affected by migraine in the UK.

occupational health specialist, employers would be better equipped to provide PLWM with the correct support.

Thus, a 'migraine-friendly' workplace would incorporate 'good'/'high performance' working practices alongside an effective health management system – with access to more specialist support at the point of need as and when required – that promotes employee health and wellbeing while preventing and managing employees' health conditions. In the following chapter we explore how to create more migraine friendly work environments.

4. How to improve employment-related outcomes for people with migraine

In this section we consider what policy action can be taken to create more migraine-friendly work environments and, in turn, improve the experience of work for PLWM. It draws on existing evidence and particularly upon the insights gained from interviews with a range of expert stakeholders operating, at EU and country level, in areas including the management of migraine and health conditions in clinical and workplace settings, social policy, organisational change, workplace innovation, and disability.

Given that the primary focus is on work and the workplace, a key aim is to influence employers and employees. This will require action in three areas including the labour market, welfare system, and health system. There are three policy frameworks of interest: (i) employment and social policy (including social security); (ii) occupational safety and health policy; and (iii) health policy. Policy action in these areas has the potential to improve work-related outcomes for PLWM, enabling them to stay in or find work and enhance their in-work capacity and progression.

There is no 'silver bullet' or single action that can enhance the work experience for all PLWM across Europe. A range of policy measures – combining 'hard' and 'soft' approaches – is needed to shape the effective running of any country's employment and health system in the context of seeking more migraine-friendly work environments.

While responsibility for employment and health policy lies primarily with Member States, the EU also plays an important role in, influencing what is done, establishing common objectives and targets, making laws, providing guidelines, assisting implementation, and setting minimum standards to enhance good practice. That said, the 'blend' of policies that will be most effective (or not) in creating more migraine-friendly work environments in any specific country must be conditioned by its particular social and economic context and local knowledge of 'what works'. Thus, not all policy measures will be appropriate in all contexts and different trade-offs will be needed to suit varying national circumstances. It is therefore important to consider the complementarity of policy interventions at EU and Member State level.

The range of policy options that can potentially be deployed (in different ways and/or adapted) by policymakers at EU and/or Member State level to improve the experience of work for PLWM comprise:

- **Making laws** (i.e. directives, decisions, recommendations), *compelling/obliging different actors (e.g. employers) to act* more responsibly. European standards set a minimum legal 'duty of care' safeguarding workers' rights, health and safety at work, and protection from discrimination, etc.
- **EU and national strategies and targets, supporting data collection, monitoring and reporting**, provide *overall coordination, oversight of national policies and help track progress* to ensure better employment outcomes.
- **Specific employment programmes** delivering *better working practices* (e.g. encouraging more HPW, good work and proactive early intervention and health management in workplaces), *job retention* and/or *specific support* to aid a quick – and sustained – return to work.
- **Advice and guidance**, through the *sharing of good practice*, information and training, to secure better workplace practices by influencing employee and employer behaviour and their representatives (e.g. employer and professional bodies and trade unions), as well as equipping relevant actors (e.g. employers) with the necessary tools/resources to effectively manage migraine in the workplace.
- **Awareness raising and campaigning to promote high standards** in working conditions and work environments, promoting *'migraine literacy' among employers/managers* and

supporting a ‘culture of care’, risk prevention, early intervention and better health management at work.

4.1. Making laws

4.1.1. Setting minimum standards

The EU can compel employers to act more responsibly through legislation. Every EU worker has certain minimum rights relating to, for example, *health and safety at work, equal opportunities/treatment at work, protection against discrimination based on disability, and working hours*. Individual Member States must make sure that their national laws protect these rights. This is based on Art. 153 Treaty on the Functioning of the EU (TFEU), which encourages improvements in the work environment to protect workers’ health¹²². Workers’ rights to *“equality of opportunity”, “fair working conditions” and “social protection and inclusion” are also set out in the European Pillar of Social Rights* and backed by Charter of Fundamental Rights of the EU¹²³. Thus, the EU and, in turn, Member States, have a clear legal duty to ensure that working conditions are both healthy and fair. This is a useful platform which can be built on to make workplaces more ‘migraine-friendly’ and thus improve the work experience of PLWM.

For example, equal opportunities/treatment at work for PLWM could ensure that they have access to specific equipment, i.e. *‘reasonable adjustments’*, in order to do their job effectively – an employer’s failure to provide this could (at least in some Member States) amount to *discrimination*. Furthermore, EU laws protecting against discrimination based on disability, if extended to PLWM, could prevent them being punished for migraine-related absence or reductions in productivity caused by their symptoms. This can be achieved through directives (see Section 4.1.3 below) or with ‘softer’ instruments (i.e. recommendations) that allow EU institutions to make their views known and suggest a line of action without imposing legal obligations on actors (such as employers), e.g. recommending that PLWM are entitled to reasonable adjustments at work depending on their particular needs. However, these instruments, generally speaking, only serve as a very general ‘template’ ensuring that actors (i.e. employers) have ‘something’ in place and therefore tend to be focused on compliance, i.e. the minimum standard¹²⁴.

4.1.2. Beyond basic rights

Guidelines set out in the current EU Occupational Safety and Health (OSH) Strategic Framework (2014-2020) go further than merely protecting workers’ basic rights. The Framework states that *“special attention” must be given to “chronic conditions”*¹²⁵ (e.g. migraine) and identifies stress – a common migraine trigger – as one of the “main challenges” to OSH (based on the fact that the majority of EU workers consider stress the main ‘occupational risk’¹²⁶). Furthermore, the European Parliament takes the view that *“work must be adapted to people’s needs, and not vice versa”*, while also accounting for the special needs of vulnerable workers (which could include PLWM)¹²⁷. This is also articulated in *Chapter 2 of the European Pillar of Social Rights*, which stipulates that *workers – particularly disabled workers – have the right to an adapted work environment* that helps “prolong their participation in the labour market”¹²⁸, irrespective of whether their condition is episodic (e.g. migraine) or permanent.

Thus, in addition to protecting workers’ basic rights, the EU legislative framework contains specific provisions for people with chronic conditions, while also highlighting the risks presented by workplace stress. Furthermore, there is clear recognition from the European Parliament and Commission that *workplaces must be adapted to people’s needs, not only but particularly if they are considered disabled*. PLWM would benefit from reduced exposure to workplace stress – a migraine trigger – as well as workplace adaptations (as shown earlier in Box G) enabling them to manage their symptoms and stay productive at work. Particularly useful adjustments would include *flexible working hours and changes to sickness absence policy*.

4.1.3. Anti-discrimination legislation

Provisions in EU law, e.g. the Employment Equality Directive (EED)¹²⁹, that protect people from discrimination at work could benefit PLWM. Migraine could, for example, be included and recognised in the EED on the basis that it can hinder full and effective participation in society on an equal basis with others¹³⁰. The scope of anti-discrimination legislation does, however, vary between Member States with respect to the 'level' of protection it affords individuals and whether a particular health condition like migraine 'qualifies' as a disability. Fluctuating conditions like migraine can be covered but it often depends on the individual case, i.e. the frequency and severity of attacks. For example, in the UK – under the Equality Act 2010 – migraine can (but not always) be considered a disability. As shown by Box I (below), *if PLWM were considered to have a disability they would be entitled to protections* (many of which complement existing EU law) that would improve their experience of work. This could be achieved through recognition of migraine (for example, in the EED) as a disability across the EU (thereby enabling PLWM to benefit from certain rights at work); or, EU institutions could make their view clear, for example through a recommendation, that PLWM should be entitled to certain provisions at work, e.g. reasonable adjustments (the fuller policy implications of this are considered later).

Box I – Example of the rights of people with disabilities at work (UK Equality Act 2010)

The UK Equality Act 2010, which serves to implement the EU's Equal Treatment Directive 2006¹³¹, is a good example of how EU-level legislation can direct and inform policy and practice at Member State level (and, in turn, improve the experience of work for PLWM).

The Act protects those whose medical condition satisfies the definition of disability from unlawful discrimination at all stages of the employment relationship. Where a disabled employee is put at a substantial disadvantage by his or her working conditions or a feature of the workplace, the employer may have a duty to make reasonable adjustments for the employee. It protects against:

- **Direct discrimination:** where an employer treats an employee less favourably than they would others because of their disability (or other protected characteristic).
- **Indirect discrimination:** where an employer has a rule, policy or practice that applies to all employees but puts employee(s) with a particular protected characteristic (in this case disability) at a substantial disadvantage when compared with others and which the employer cannot justify.
- **Discrimination by failing to make reasonable adjustments:** where an employer has a rule, policy or practice that puts a disabled person at a substantial disadvantage in comparison with non-disabled people and the employer fails to take reasonable steps to avoid that disadvantage (special provision is made for reasonable adjustments to physical features of the workplace and in relation to auxiliary aids).
- **Harassment:** A harasses B where A engages in unwanted conduct related to B's disability (or other protected characteristic) and the conduct has the effect of violating B's dignity or creating an intimidating, hostile, degrading, humiliating or offensive environment for B.
- **Victimisation:** occurs when an employee is treated badly because they have made or supported a complaint or grievance under the Act.

Lack of knowledge of a disability may provide an employer with a defence to a claim of discrimination.

Source: *Migraine Trust 2018*.

We explored the implications of migraine being recognised as a disability through expert interviews. The majority of experts consulted felt that recognition of migraine as a disability would, overall, help improve the experience of work for PLWM. The Belgium-based academic neurologist we spoke to suggested that this would enable PLWM to take medication in the workplace, or (if available) use a quiet space to lie down when necessary¹³². It was also suggested, by the CEO of the UK Business Disability Forum, that if migraine was recognised as a disability, employers would be compelled to provide accommodations and consider the impact of workplace policies, e.g. 'hot desking', on PLWM specifically¹³³. Without such protections, PLWM would not be exempt and reliant on employers', and, indeed, individual managers' discretion. Furthermore, a European social policy expert we consulted argued that recognition of

migraine as a disability would have a significant impact on PLWM in Member States with comparatively fewer provisions for people with health conditions/disabilities – *through recognition comes action*¹³⁴.

There were, however, alternative views. Labour market analysts at the OECD (with expertise on job quality and the health and work interface) that we spoke to worried about the implications of 'labelling' PLWM as disabled, suggesting it may harm the chances of PLWM finding work, particularly 'good' work¹³⁵. Furthermore, the neurologist we spoke to suggested that because of migraine's fluctuating nature, and the vastly different ways in which PLWM experience it, it does not necessarily fit with 'traditional' conceptions of disability¹³⁶. Thus, it was felt that classifying it as a disability may be counterproductive, potentially signalling to employers that PLWM can only work at reduced capacity.

More broadly, a workplace innovation expert we spoke to suggested that a change in legislation, even if it, in turn, changes employer-level policies, may not lead to a change in behaviour and practice¹³⁷. Indeed, several experts we consulted highlighted the limitations of legislation, pointing to its varying impact on organisations of different sizes (with smaller ones i.e. employing 1-250 people – which comprise the majority of organisations across the EU – being less likely/able to implement/comply with it) and in different Member States¹³⁸. It was argued that, to effectively change employer behaviour, and treatment of PLWM in the workplace, legislation should be complemented by additional, 'softer', measures, making use of employer incentives and the role of social partners¹³⁹ – both of which we explore in the following sections below.

Finally, changes in legislation, requiring actors (i.e. employers) to comply, should be supported by measures that give them the tools/resources to act. While defining migraine as a disability will, in many cases, give PLWM the ability to request reasonable adjustments at work, unless employers know what effective reasonable adjustments for migraine are, the change in legislation may not amount to much. Furthermore, if migraine is not perceived (by employers and colleagues) as a 'genuine' condition with debilitating effects, legislation may again achieve little – we explore these issues in Sections 4.4 and 4.5 respectively below.

4.1.4. Employer incentives and obligations

Many Member States have put in place measures to incentivise employers to act in certain ways. One such example is *'quota' systems*. These are used to incentivise employers to recruit and retain people with disabilities or chronic health conditions. Such schemes could improve work-related outcomes for PLWM (should they qualify for them), enabling them to stay in or find work. For example, in Cyprus, people with disabilities are recruited into the public sector at a quota of 10% of the number of vacancies. Labour market analysts at the OECD (with expertise on job quality and the health and work interface) that we consulted, however, were ambivalent about the value of quota systems¹⁴⁰. While potentially helpful in ensuring people with disabilities and chronic conditions find work, there is a risk that employers perceive it as a 'tick box' exercise, simply adhering to guidelines rather than actively employing somebody with a health condition/disability in a role they are suited to. Furthermore, a workplace innovation expert we consulted suggested that such measures may only produce short term results – without genuine employer 'buy-in', in which they see the value of employing somebody, playing an active role in it, any beneficial effects may not be sustained in the long run¹⁴¹.

Other countries have extended the formal obligations on employers compelling them to provide further support to employees experiencing health problems. For example, going further than the minimum standards set out by the EU (which is actively encouraged), in the Netherlands employers are liable to pay for up to two years of sick pay at 70 per cent of the employees' salary. Furthermore, by the 6th week of absence, employers must pay for an independent occupational health physician assessment; by the 8th week the employer and employee must agree to a

rehabilitation plan. Only after 91 weeks, if the employee is formally assessed as ‘unfit for work’ can they receive state benefits. This scheme effectively incentivises employers to provide support to employees to keep them in work, in a healthy and productive state. It therefore helps people with disabilities/chronic conditions, e.g. PLWM, *stay connected to the labour market*.

Systems such as those existing in the Netherlands, which essentially compel employers to be more responsible for their employees’ health and wellbeing, offer an additional way of ensuring that they provide better quality, health-enhancing working conditions. If employers must cover the cost of absent employees they will take a greater interest in helping them return to work, and ensuring that that return to work is sustained¹⁴². This should, therefore, help ensure that employees with health conditions, such as migraine, have access to adjustments and accommodations that allow them to manage their condition and remain healthy and productive at work. These systems are not, however, feasible in all Member States. They carry significant costs, especially for small businesses. As such, any attempt to shift the ‘cost burden’ of workplace ill health from the state to the employer would likely face resistance, particularly where there are not strong traditions to do so.

Additional measures, which more specifically address the episodic nature of migraine have been pioneered in the Nordic countries. ‘*Part time sick pay*’ systems are designed to accommodate people with fluctuating conditions, helping them remain in work by providing sick pay to compensate for temporarily reduced working hours at times of poor health¹⁴³. A ‘partial sickness allowance’ was introduced in Finland in 2007. The system enables employees experiencing a period of ill health (e.g. a migraine attack and its after-effects) to temporarily reduce working hours for a defined period, during which time they will receive their salary for the hours they continue to work, and sick pay for those they have dropped. This provides the opportunity to continue to do some work, to remain active and to avoid a prolonged period of absence, while reducing pressure to return to full time work prematurely¹⁴⁴. Again, this enables people with fluctuating conditions, e.g. PLWM, to stay connected to the labour market. Such approaches are not necessarily feasible in all Member States, given variation in their economic, political and social structures; that said, by considering the ‘principles’ behind the policy, (i.e. making sick pay more flexible to better accommodate people with fluctuating conditions), they can still be instructive.

4.1.5. The role of social partners

As stated in Section 4.1.3, while legislation may be effective in setting minimum standards, which in turn will shape employer-level policy, this may not always result in the desired behaviour change within workplaces due to a range of factors (e.g. there may be a lack of awareness, policies may be seen as too difficult/costly to implement and not all policies are always taken seriously¹⁴⁵). Hence, having changed a policy, there is still a question around how it is implemented/enforced. If an organisation does not understand the rationale or reasoning behind a policy change, its impact may be limited. Social partners and social dialogue can be key in this context, ensuring all stakeholders are aligned and their interests being served.

In accordance with the Treaty, *EU ‘social partners’* (i.e. bodies representing the ‘two sides’ of industry: employers and employees) play an important role in enforcing and improving on minimum standards, i.e. legislation, as well as promoting safe and healthy work environments across Europe. They have shown capacity to find solutions that meet both employers’ and employees’ interests and have directly contributed to implementing EU strategies in these areas. ‘*Framework agreements*’ implemented by social partners include agreements on inclusive labour markets, harassment and violence at work and work-related stress. Social partners can therefore play an important role in improving work-related outcomes for PLWM while ensuring that employers’ interests are upheld.

There is therefore a balance to be struck, between ‘harder’ regulations (e.g. changing laws) and ‘softer’ interventions (e.g. creating employer incentives), in seeking to improve the experience of work for PLWM. This balance will vary between EU countries, in part based on their tradition of social partnership and social dialogue¹⁴⁶. The *infrastructure supporting the involvement of social partners varies between Member States* and, in turn, their influence over work environments. For example, in Sweden, employee involvement in the management of businesses is mandated by legislation. Sweden’s co-determination laws force employers to negotiate with unions before making changes to business strategy or practices and can enhance provisions. In contrast, UK employment regulations are more limited, union membership is lower, and there are fewer provisions for employee involvement across different parts of the economy. In other parts of Europe, such as Poland and Hungary, where employees typically have less representation, and there is little, if any, tradition of social dialogue, legislation may be the most effective means (at least in the first instance) of changing employer practice and securing improvements in working conditions¹⁴⁷.

Thus, social partners’ influence may be more limited in some Member States and this, in turn, dictates what blend of action will be effective (with legislation perhaps being relied upon more in countries without a social partnership tradition). That said, the EU has a longstanding commitment to supporting social partnership and dialogue. Furthermore, it has, generally speaking, been instrumental in improving working conditions beyond minimum statutory obligations, creating healthier and safer work environments, and thus is a potentially effective means through which the experience of work for PLWM can be improved.

4.1.6. Key messages

EU legislation ensures employers’ adherence to minimum standards. Workers’ rights are also articulated in the European Pillar of Social Rights. Specific frameworks go further, giving special attention to chronic conditions and stressing the need to adapt work to people’s needs – not vice versa. Anti-discrimination legislation further protects people with disabilities and quota systems can help them stay in and find work. Finally, social partners play an important role in facilitating agreements between employers and employees. All of this provides a platform to build on to create more migraine-friendly workplaces; PLWM can benefit from:

- *basic, minimum rights* ensuring that work conditions are ‘healthy and fair’;
- *equal opportunities/treatment* ensuring they are not treated unfairly for migraine symptoms affecting their work;
- *protection against discrimination* due to their condition/symptoms;
- *occupational safety and health interventions* reducing exposure to workplace stress;
- *access to reasonable adjustments/workplace adaptations* to maintain productivity;
- *working time regulations* that offer flexibility in working hours, limit excessive hours and encourage the right to rest breaks and paid leave;
- *employer incentives/obligations to retain employees with disabilities/chronic conditions* including specific schemes designed for people with fluctuating/episodic conditions;
- *regulations around consultations with workers*, facilitated by social partners, allow social dialogue between employers and employees to improve workplace practices;

4.2. EU and national strategies and targets

4.2.1. The Europe 2020 strategy

Employment and social policies shaping labour markets across Europe are coordinated at EU level by the Europe 2020 strategy¹⁴⁸. Building on the minimum standards and frameworks outlined above, it sets targets for *high employment* (75% of 20-64 year olds in work) and its Guidelines put a strong emphasis on *increasing labour market participation, promoting social*

inclusion and *improving job quality*. Complementary EU strategies aimed at improving job quality include the Lisbon Strategy, the European Employment Strategy (EES) and the ‘Agenda for new skills and jobs’ (both part of Europe 2020).

These commitments can benefit PLWM: (i) meeting the goal of ‘high employment’ will require retention and reintegration of people with disabilities/chronic conditions (e.g. migraine) into the labour market – particularly in the context of an ageing population¹⁴⁹ and (ii) as demonstrated earlier, PLWM benefit in many ways from ‘good’/better quality work environments. Thus, to improve the experience of work for PLWM it is not necessarily the case that PLWM must be ‘singled-out’. An inclusive approach, focused on improving the quality of work and working practices generally, is not only consistent with specific EU employment-related policy but also the EU’s underlying philosophy which promotes inclusive action benefitting all citizens¹⁵⁰. Indeed, there is growing acknowledgement amongst EU policymakers that, in the face of demographic challenges, organisations will become increasingly reliant on workers that are currently excluded from the labour market for health reasons¹⁵¹. For this to happen, the quality of work offered by organisations must also increase, so that it allows them to effectively manage their health conditions.

4.2.2. Integrating work and health policy

The above policy initiatives are implemented through the annual *European Semester* – promoting policy coordination between Member States and the EU – and build on the EU minimum standards (outlined earlier) ensuring healthy and safe working conditions. This is based on a recognition that unhealthy work environments often lead to early exit from the labour market¹⁵². Thus, the aims complement the EU OSH Framework and EU health strategy: *Together for Health*¹⁵³, which explicitly recognises the importance of good quality work for health in the context of an ageing population with more chronic conditions and disabilities.

Closer integration of work and health policy can, in turn, make workplaces more amenable to people with health conditions, by *instilling a ‘culture of care’, facilitating early intervention and risk prevention*, as well as *better health management* at work supported by access to an occupational health specialist. PLWM – and their experience of work – would greatly benefit from such an environment. An example of how this can work in practice is provided by the UK, where government departments responsible for health (Department of Health and Social Care) and work (Department for Work and Pensions) jointly sponsor a unique, cross-government ‘Work and Health’ unit¹⁵⁴. This approach encourages ‘joined-up’, non-siloed working across departments that share similar goals: a healthy working-age population.

4.2.3. Funding

The European Social Fund (ESF)¹⁵⁵ supports the Europe 2020 strategy and associated health and OSH policy initiatives, supplementing national sources of funding. It aims to: *promote high levels of employment* and *job quality* and *enhance social inclusion, non-discrimination* and *equal opportunities* by co-financing national and regional programmes¹⁵⁶. It is considered to be the main instrument for improving work conditions and ensuring people with disabilities are given work opportunities¹⁵⁷.

It can therefore play a potentially important role in improving work-related outcomes for PLWM in future. Specifically, funding is available to support quality employment and social inclusion, including the recruitment and retention of people with chronic conditions and disabilities¹⁵⁸. PLWM would benefit in particular from “individualised support, counselling, guidance, access to general and vocational education and training, as well as access to services, notably health and social services”¹⁵⁹.

4.2.4. Policy treatment of PLWM

Currently, *migraine is not formally defined from an employment policy perspective or recognised at EU level*. As a result, the various strategies, policies and targets discussed here (as well as the protections in EU law outlined earlier) designed to benefit people with chronic conditions/disabilities may not be applicable to PLWM. As a result, PLWM may be treated the same as employees without health conditions, which would unfairly disadvantage them; they would not, for example, have access to reasonable adjustments or protection from discrimination based on their condition.

Migraine may be recognised, in some Member States, as a ‘chronic disease’ (i.e. a long-standing illness/health problem that has lasted for six months or more) and therefore could be treated as a disability in employment terms¹⁶⁰. Policymakers, recognising the condition limits individuals’ work capacity, would have an incentive to ensure PLWM have access to support to stay in work and maintain their productivity.

Chronic conditions, defined in this way, would align with the EU concept of ‘labour disability’ – recognised by all Member States’ social security systems¹⁶¹ – which recognises impairments that reduce capacity to work. Furthermore, it would fall under most countries’ legal definition of disability (i.e. long-term diseases and health conditions/difficulties in performing basic (work) activities)¹⁶². Ensuring that migraine is recognised in this way could significantly improve the experience of work for PLWM, enabling them to benefit from EU laws and strategies aimed at improving work outcomes for people with chronic conditions/disabilities. As stated by one of our expert interviewees: *through recognition comes action*¹⁶³.

An example of how this can work in practice comes from Belgium. The neurologist we consulted highlighted a recent change in government policy in this country which has the potential to improve the experience of work for PLWM – particularly those who have lost touch with the labour market. The government provides return-to-work support for people with a range of medical conditions, and – significantly – migraine is now recognised as one of these conditions. This is based on the fact that migraine constitutes an ‘occupational’ or ‘labour’ disability. This demonstrates how recognition of migraine as a disability can potentially improve employment outcomes for PLWM.

However, despite these potential benefits, there are – as outlined earlier in Section 4.1.3 – potential drawbacks in recognising migraine as a disability. Though better recognition may entitle PLWM to certain protections or allow them to benefit from employment quotas or initiatives for people with disabilities, there is a risk that labelling PLWM as disabled may result in a perception, amongst employers, that they are not able to perform to a certain standard, potentially deterring organisations from employing them. Thus, any potential benefits must be weighed carefully against these potential risks.

If not recognised as disabled, PLWM may still be able to access support based on the severity of their condition and how it compares to other chronic diseases. Some Member States, e.g. Ireland, provide support for people with conditions that *cause partial or reduced work capacity*.

Given this ambiguity, *more formal recognition of migraine* in employment, social and health policy/frameworks is arguably needed to ensure more equal and consistent treatment of PLWM across Europe in future, ensuring they can benefit from provisions for people with chronic conditions and disabilities. A *clear and unambiguous definition* will also support better data collection, monitoring and reporting of migraine from an employment perspective across the EU and in Member States. In turn, this will allow for comparisons and benchmarking to direct and inform appropriate action. This will inform whether the aims of various strategies and targets discussed here deliver for PLWM, e.g. increased labour market participation. It is, however, a

moot point as to whether this needs to go as far as formally recognising migraine as a disability or not.

4.2.5. Key messages

Various policy initiatives/frameworks promote high employment, social inclusion and job quality. Meeting these goals will require retention and reintegration of PLWM – who will benefit from better quality work – in the labour force. ESF funding can support this and closer integration of employment and health policy – the aims of which overlap – will benefit people with health conditions. Most importantly, migraine's recognition in employment policy as a chronic condition/disability will help PLWM access a range of employment-related supports that have the potential to significantly improve their experience of work (though there are potential risks associated with this that need to be more fully considered and managed).

4.3. Specific employment programmes and support

Despite the common overarching goal of high employment across Europe, the nature of employment programmes and degree of active employment support available to people generally and those with health conditions specifically varies in practice.

4.3.1. General labour market programmes

Member States vary in the importance they attach to being in work, demonstrated by the emphasis on *active or passive labour market programmes*. 'Active' labour market programmes (ALMPs) place a greater importance on work and finding and returning to employment compared to 'passive' programmes (PLMPs). PLMPs, in contrast, tend to put more emphasis on social support and protection and compensation for people out of or at risk of falling out of work. In systems where PLMPs predominate, where somebody has fallen out of work (e.g. due to a chronic condition like migraine) there tends to be a smaller chance of them re-entering it, leading to a higher likelihood of long-term benefit dependency. In contrast, ALMPs are more likely to improve work-related outcomes for PLWM, helping them stay in and/or quickly return to work (and, once they have returned to work, to sustain it). This is significant because there has been a general move across European countries towards ALMPs, in part due to the growing acknowledgement amongst policymakers – owing to the EU's demographic challenges – that people currently excluded from the labour market for health reasons will have to be more actively encouraged into it in future.

4.3.2. Dedicated employment programmes

There is also variation in the range of *dedicated employment programmes* open to people with a chronic condition and disability. Whether PLWM can benefit on the full the range of available programmes, however, depends on their 'status' in employment policy and law. 'Active', dedicated employment programmes are offered in the Nordic countries, Austria, and Netherlands but only to those individuals *recognised* with a relevant condition. In some cases, e.g. in Belgium, migraine *is* recognised as a 'relevant' condition – but this is not always the case. These supported employment schemes aim to integrate people with a chronic condition and disability into work by first providing a 'trial' workplace and then offering training and support once in the job. Providing further support once the individual has *found* work is important because it is more likely that work will be *sustained*, i.e. the individual is less likely to 're-lapse' and fall back out of work.

Other approaches include *vocational rehabilitation*, supporting people with disabilities by restoring and developing their skills and confidence and, in turn, return to employment after a period of absence. Early intervention is prioritised: e.g. in Austria as soon as a benefit claim is registered efforts are made to rehabilitate. See Box J (below) for an example in Belgium.

Box J – Belgium case study: reintegrating workers with health problems into the workforce¹⁶⁴

While employers, clinicians and state agencies are frequently aware of the benefits of work for people with longstanding health conditions, often, the lack of coordination between the different actors involved in the reintegration process results in missed opportunities, lost skills, long-term unemployment and social exclusion.

To address and improve this situation the '*Intro_DM*' (*Introduction in Disability Management*) partnership has been developing two new job profiles to support reintegration in the Belgian workplace: the Disability Manager (DM) for implementing and overseeing disability management policy within companies, and the Disability Case Manager (DCM) to offer individual support within the reintegration process.

Two partners are involved in the partnership. *Prevent*, a Belgian multidisciplinary institute working on the prevention of occupational risks by promoting quality in working conditions and improvements in work organisation, is a specialist in providing support, advice and information to companies, institutions and other social actors. *UCBO-University Ghent* is a vocational training and coaching centre for people with disabilities, which has an extensive record of assisting individuals with the integration process through individual coaching and training. In October 2006, the project started the first disability training programme.

Line managers are often not trained to see the reintegration situation from the HR point of view, but rather focus on the immediate requirement to deliver business results. As a result, they may hastily dismiss an employee with disability or long-standing health problem as unfit for the job without considering the particular skills this employee may bring to the company if the 'disabling' factors like inaccessible working space and the negative attitudes of other workers are removed. The practical examples provided by the instructors from companies such as Volvo provided the participants with particular approaches to managing disability and should also help them to assume the role of DMs by guiding the introduction and implementation of a reintegration policy within their businesses.

The training provided for the DCMs was similarly successful. DCMs were offered a training package with relevant tools and knowledge that will enable them to support employees returning to the workplace. The DCM coordinates the reintegration process among the different parties involved and informs individuals of the available support services and relevant legislation. To improve the programme, 50 reintegration cases were also monitored and analysed, which helped refine the methodology put into practice and discover the best possible reintegration processes, which can serve as a model for others.

4.3.3. Workplace improvement programmes and the role of networks

Specific programmes have also been developed in Member States to support improvements in management practices to secure more migraine-friendly workplaces. Various country-level programmes drive the *adoption of HPW practices* with emphasis on dedicated health interventions. Usually, they comprise targeted projects focused on a limited number of businesses, involving testing, piloting and 'proof of concept' phases, which can then support attempts to scale up.

A key outcome is building the internal management capability within organisations and wider *active communities of practices* which they are part of (i.e. within supply chains and/or sectors) so that there is more self-sufficiency to create and then manage healthy work environments. By strengthening partnership working and developing and using a range of co-designed tools (e.g. toolkits, advice, guidance, case studies) within these business communities, this helps encourage a greater use and take up of HPW.

As the workplace innovation expert we interviewed pointed out, this is crucial because peer-to-peer learning, i.e. between employers amongst enduring and active business communities, is a particularly effective means of sharing knowledge, overcoming implementation challenges and, in turn, stimulating change¹⁶⁵. Different stakeholders (e.g. trade unions, private organisations and research institutions) are usually involved, working alongside government agencies. In the context of the future of work and developments in ways of working due to technological change and the effects of ongoing globalisation, such initiatives have a vital role to play.

Typically, improvements in working practices are secured incrementally so that businesses can trial new approaches, learn what works and gradually build internal capability (i.e. ‘incremental innovation’) – rather than through ‘giant leaps’. The development of EUWIN is an example of attempts to enhance and accelerate the spread of good working practices and lessons learned through these programmes across Member States. An example of one specific workplace initiative is found in France: ‘Anact’. Created in 1973, it aims to improve working conditions with the support of social partners and an emphasis on supporting those with disabilities and health conditions in work. This is exemplified by its latest initiative: the ‘Fund for the Improvement of Working Conditions’. Such approaches can play an important role in improving the experience of work for PLWM given the emphasis on developing and sharing good practice guidelines on managing people with chronic conditions (see Box K below).

Box K – French National Agency for the Improvement of Working Conditions (ANACT)

The French National Agency for the Improvement of Working Conditions (ANACT) aims to support job retention and the reintegration into employment for workers with chronic health diseases.

In its 2014–2019 plan it sets out its goals including:

- improving work solutions for people with chronic diseases and adapting them to their personal needs;
- raising awareness among companies;
- co-ordinating better partnerships amongst those key stakeholders involved in job access or maintenance.

ANACT has developed a range of new resources and tools (information, training and intervention) for supporting employees affected by chronic diseases and published guidelines on good practices for employers in 2012.

Social partnerships are also integral to these kinds of workplace developments. Indeed, policies promoting *good industrial relations and collective bargaining* can also play a key role in helping improve good work and high performance working practices throughout Europe, across sectors and business communities tailored to local needs. The extent to which this can impact different workplaces however will in part depend on existing infrastructure, customs, and relations between social partners. Member States with comparatively strong traditions of social partnership and dialogue will, inevitably, be able to more effectively use such methods to improve of PLWM at work (for example in the Nordic countries). Other countries, without such infrastructure, will perhaps be more reliant on legislation to achieve change^{166, 167}.

An example of the social partnership/dialogue approach working in practice is the ‘Workway Initiative’ in Ireland: developed and established in 2004 by social partners, the Irish Congress of Trade Unions and the Irish Business and Employers’ Confederation, it aimed to improve the experience of work for people with disabilities. Similar approaches can be used to support PLWM in work.

These types of dedicated programmes, which seek workplace improvements and to align employment support with specialist health support, acknowledge the importance of work to health. Closer integration of work and health policy can benefit PLWM in several ways, e.g. *better coordination between employers and the health system*, involving occupational health services and practitioners, and in turn enhancing the effectiveness of employment programmes, improving job retention, return to work, and rehabilitation whilst in work. This enables effective health promotion, prevention and management at work – as discussed earlier (see Box L below for an employer example). It also helps ensure that return to work is sustained, i.e. in the case of individuals returning to work after a period of absence.

Better coordination between employers and health practitioners was also considered a potentially effective means of improving the experience of work for PLWM by the majority of experts we

consulted. The academic neurologist we spoke to, for example, lamented the lack of coordination between themselves and their patients' workplace¹⁶⁸. They had, on occasion, provided support (e.g. a written letter) for a patient's reasonable adjustments at work, but pointed out that there was no formal mechanism for this, and as a result it happened rarely (despite patients requesting it). Thus, better coordination could help PLWM secure reasonable adjustments. One potential mechanism was identified (by labour market analysts we interviewed from OECD) as occupational health, or, more specifically, occupational health physicians (OHPs). Serving as a 'bridge' between the work and health system, they have the potential to facilitate integration between these two domains and thus improve the experience of work for PLWM. One limitation, however, is the number of OHPs operating in Member States, which does vary but is generally speaking quite low¹⁶⁹.

Box L – UK employer case study: John Lewis Partnership (JLP)

Health services were first established in the Partnership in 1929, in recognition that the Partners working in the company (employees) needed to be fit to provide the quality of service the customers expected and for which JLP have become renowned. Whilst the services have changed many times over the years the original premise remains as valid today as it did in 1929. Whilst JLP hasn't historically talked in the language of "Wellbeing" many of its initiatives and opportunities have developed a culture which aligns strongly with a health and wellbeing agenda and explicitly supports the first of the Partnership's seven principles which underpin how the business is run: Principle One – *"the John Lewis Partnership's ultimate purpose is the happiness of all its members, through their worthwhile and satisfying employment in a successful business"*.

JLP is a large business with 94,000 'Partners' (i.e. employees) working across 400 sites, with the majority working in shops or the supply chain, often in physically demanding roles, but also including a diverse range of other functional roles including manufacturing, hospitality, farming and back-office IT, Marketing, Buying, Personnel and Financial roles. Its Health Services approach combines an internal team of occupational health nurses and allied health professionals, working alongside an independent network of podiatrists and a single national physiotherapy provider, Physio Med, and a psychological service provider, Rehab Works.

The health service is structured to channel all incoming referrals through a central Health Hub, accessed via a portal, enabling greater accessibility, transparency and routing through online referral. 90% of all referrals arrive electronically and allow centralised triage and organisation of work flow across the whole service. The Hub is supported by regional Clinical Case Managers who support the business management and Partners locally in returning Partners to work.

In addition to the value of providing occupational health services to maintain employee health, some employers have introduced more 'holistic' employee health and wellbeing packages. These might include *lifestyle management advice, counselling services*, (particularly for those with mental health problems), and *wider prevention and health improvement services*, including smoking cessation, health screening and anti-obesity services as well as the use of services of groups such as health trainers. See Box M (below) for an employer example. PLWM would benefit from better integration of work and health in the form of access to occupational health services and more holistic packages.

Box M – Multinational employer case study: AstraZeneca

The company launched a whole package of health and well-being initiatives ranging from a counselling and life-management programme, health promotion activities and ergonomic workspace design to fitness opportunities, healthy eating options and flexibility arrangements for a better work-life balance.

The company reported savings in the range of GBP 500,000–700,000 through improved productivity after counselling. GBP 80,000 was saved on health insurance costs for psychological illness. Global accident and occupational illness rates went down by 61%.

The programme has also served company's image among its staff well. 84% of employees are proud to work for AstraZeneca and 82% would recommend the company as a good place to work, 80% of employees said they had enough flexibility in their job to be able to balance work and personal life, and 88% said AstraZeneca demonstrated commitment to the health and well-being of its employees.

4.4. Advice and guidance

Building on a platform of EU laws, system-wide policies and targets and dedicated programmes, the *provision and dissemination of advice and guidance* plays a crucial role in ensuring that potential improvements in work-related outcomes for PLWM are fully understood and then actually delivered. As discussed in earlier sections, PLWM can benefit, in a number of ways, from 'high performance' working practices that empower them to effectively manage symptoms alongside their professional responsibilities. Such working practices are unevenly spread across Member States, however, and their widespread adoption amongst European employers is not inevitable. The European Commission and national governments can play a key role in driving this by, for example, providing mechanisms for the pooling and sharing of existing information and resources working through recognised networks and partnerships – as well as advice and good practice generally. This would complement EU strategies like Europe 2020.

Advice and guidance is crucial for effectively delivering policy change – particularly when the change sought is in employer behaviour and practice. Thus, it is important that policy changes designed to improve the experience of work for PLWM are complemented by advice and guidance that not only explains why employers should act, but also how to do so. There is, therefore, a need for guidelines on 'what works' regarding *reasonable adjustments* for PLWM as well as how to unlock the benefits of certain working practices such as more *flexible working*. Guidance given in migraine-specific resources, such as the *Employment Advocacy Toolkit*¹⁷⁰ (from the UK charity the Migraine Trust), which provides information and advice on how migraine can be managed in the workplace, is therefore vital.

More broadly, the important role that managers generally and line managers more specifically play in determining an employee's work experience should also be paid attention. It is therefore important that line managers – and senior management more broadly – are equipped with the skills and abilities needed to effectively manage PLWM. Line manager 'toolkits' provided by organisations like the UK's Business Disability Forum are useful in this regard¹⁷¹, and play a key role in disseminating advice and guidance. Though not migraine-specific, they outline how people with health conditions and disabilities can be best managed in the workplace. Additional EU-level guidance is provided by the European Disability Forum in the form of projects and publications that aim to highlight, promote and share good practice amongst employers¹⁷².

Such information and guidance helps ensure that employers who care about their employees' health, wellbeing and productivity, are able to provide effective support. Where practical tools, advice and guidance are developed and provided by business networks themselves, and/or co-designed with local partners through active local communities of practice (as discussed earlier in Section 4.3.3), it is more likely that they will be used, as they will be more relevant and suited to

their needs. As such, it is important to consider how these mechanisms could be exploited for the benefit of PLWM.

Coordinated action, from social partners, government bodies and networks, e.g. the European Commission-backed European Workplace Innovation Network (EUWIN), can play an important role in promoting, disseminating and sharing such guidance. Clearly, *different approaches will be needed in different Member States*, depending on the local infrastructure, politics, economics, and industrial relations climate, but they should always embrace a multi-stakeholder approach to enhance relevance and engagement.

4.5. Awareness raising, campaigning and sharing good practice

Finally, the success of all the approaches described above is in part dependent on awareness and understanding of migraine amongst the general public, which is currently poor. Thus, awareness-raising campaigns can play an important role in improving the experience of work for PLWM. They help to align employers' and co-workers' perception of the condition with the reality, i.e. the significant impact it has on the personal and professional lives of PLWM. Furthermore, where some employers have developed best practice on managing PLWM in the workplace, it is vital that this information is disseminated to a wider audience.

To effectively improve the experience of for PLWM across Europe, it is essential that people are aware of its impact. The effectiveness of any policy designed to improve the situation for PLWM at work will in part depend on whether the actors involved in delivering change at organisation-level (i.e. employers, line managers and even colleagues) understand the impact that migraine has – and therefore the need to do something about it¹⁷³. A shared understanding – spanning multiple stakeholders – of migraine and its effects should therefore be prioritised.

Box N – the '#Move4Migraine' campaign in Belgium

The #Move4Migraine campaign in Belgium starts from the premise that although migraine is 'familiar' to people in that they have heard of it, it is misunderstood, i.e. it is more than 'just a headache' and in fact causes a significant number of lost workdays in Belgium (estimated to be over 1.6m each year)¹⁷⁴. Migraine is not given the attention it deserves.

#Move4Migraine is an independent, multidisciplinary platform. The initiative works with patients and different actors spanning government, the health, social and employment system. Based on experience of people with migraine, it aims to increase the understanding of the condition, improve patients' quality of life, and ultimately reduce its impact on society.

It aims to do this by providing information and eight action-oriented evidence-based policy recommendations, which are:

- Correct information for the patient
- The establishment of a 'Foundation Against Migraine'
- Empowerment of the patient through better access to health information
- Information on excessive use of medicines or non-adapted treatment
- Increase knowledge about migraine through further training of primary care
- Clear figures about the health economic implications of migraine on society
- Access to a 'quiet' or rest room at the workplace
- Financial support for employers to make accommodations for employ people with migraine

Source: #Move4Migraine 2018

An example of a recent, migraine-specific campaign designed to achieve this (or at least start the process) exists in Belgium (see Box N above). Comprising stakeholders from the government, health, social and employment system, it recognises that migraine is a societal issue that affects everybody – and therefore requires coordination from multiple parties in different fields to work collaboratively and find solutions. In doing so it outlines eight 'action points', two of which explicitly focus on the workplace (the need for reasonable adjustments, e.g. access to a

'quiet room', for PLWM at work and financial support for employers to make accommodations for/employ PLWM).

Another migraine-specific campaign, which is explicitly focused on raising awareness, was recently launched in the UK: the 'Migraine Effect' (see Box O below). Though more limited in scope compared to #Move4Migraine, both campaigns could form the basis of a more ambitious, wide-ranging EU-level campaign.

Box O – The 'Migraine Effect' campaign

The Migraine Effect – or #FOMA (Fear of Migraine Attack) campaign – is an international campaign challenging perceptions of migraine as 'just a bad headache' and shedding light on the devastating impact it can have on people's personal and working lives.

It aims to raise awareness of the millions affected by migraine in the UK. Its website provides information on the condition and features case studies – stories – of those affected and encourages more PLWM to share their own experiences.

The campaign is building evidence-based insights to develop a 'call to action' aimed at Governments, health bodies, migraine expert organisations, employment groups, trade unions and patient groups to come together to devise an improvement strategy for migraine.

Source: The Migraine Effect 2018 (<http://www.themigraineffect.co.uk/FOMA/>)

More broadly, there are a number of campaigns, which are not migraine-specific, at European and national level aiming to improve workplace health management, e.g. the European Agency for Safety and Health at Work's (EU-OSHA) 'Healthy Workplaces' campaign¹⁷⁵. In addition to this campaign, EU-OSHA plays a crucial role in collecting/disseminating relevant information on OSH, facilitating the exchange of good practice (e.g. how to manage people with certain health conditions), thus contributing to more efficient implementation of OSH policy at EU level. It has also developed a 'good practices database', helping employers implement EU policy and learn from peers. These non-legislative tools are essential for making a difference 'on the ground' given variations in employer size, type, workforce, etc.¹⁷⁶. Few campaigns in Europe have focused on migraine specifically.

Box P – European Network for Workplace Health Promotion – Promoting Health at Work

The European Network for Workplace Health Promotion (ENWHP) was established in 1996, when the EU adopted the Programme of Action on 'Health Promotion, Education, Information and Training' to improve public health standards in Europe in which workplaces were accorded a special role. Health promotion for employees serves the common interest and promotes social and economic prosperity.

ENWHP aims to prevent work related diseases and improve workplace wellbeing. Strong consensus between organisational and personnel development departments in the company is necessary to run voluntary activities that lie outside the legal requirements of traditional safety and health laws

Workplace Health Promotion (WHP) is the combined efforts of employers, employees and society to improve the health and well-being of people at work. This can be achieved through a combination of:

- improving the work organisation and the working environment
- promoting active participation
- encouraging personal development.

Since it was established, the ENWHP has grown steadily with a current 31 members from national safety and health and public health organisations from the EU Member States, Switzerland and countries of the European Economic Area.

The ENWHP has also developed a 'European toolbox' of successful practices and identified strategies to help keep workers longer in employment. In addition, national networks were established by the Network in recent years on national level to disseminate information on WHP to a wider audience.

Though not focused on migraine, one of the most significant and long-running European workplace health campaigns is the European Network for Workplace Health Promotion (ENWHP)

initiative: ‘Promoting Healthy Work for Employees with Chronic Illness – Public Health and Work’¹⁷⁷. It aims to bring together best practices to keep employees with chronic diseases in work, promote their health status and, if needed, help them return to work. To do this, it has developed ‘standardised criteria for good quality workplace health promotion’, publishing reports with models of good practice from a wide range of industrial sectors where it has supported employees with health conditions to remain in work (see Box P above). Many European countries have participated in this programme and therefore it has wide reach. Given its focus on chronic conditions, it has the potential to improve the experience of work for PLWM.

4.6. Key messages

There are a range of policy measures – combining hard and soft approaches – policymakers can employ to improve the experience of work for PLWM. While responsibility for employment and health policy lies primarily with Member States, the EU plays an important role shaping European-wide action. Of course, not all policy measures will be appropriate in all contexts and different trade-offs will be required to suit differences in national conditions and to avoid simple ‘policy borrowing’. However, it has been important to consider the complementarity of policy interventions at an EU and Member State level to get a sense of what blend of policies are likely to be most effective (or not) to create more migraine-friendly work environments and what additional steps could be taken to improve employment opportunities for PLWM.

EU legislation – with explicit backing in the European Pillar of Social Rights – ensures working conditions are ‘healthy and fair’, that employees are treated equally, protected from discrimination and work reasonable hours. It therefore provides a *basic platform to build on* to improve work-related outcomes for PLWM and better working environments in Member States.

Additional steps have also been taken to ensure these EU-backed minimum standards are further enhanced by establishing common objectives and targets that promote high employment, social inclusion and job quality, as well as promoting specific guidelines and frameworks. These include, for example, the OSH frameworks, which aim to promote even further protections in specific areas, such as for people with recognised chronic conditions and disabilities, stressing the importance of adapting work to people’s needs (not vice-versa), as well as closer integration of work and health policy. A key question is whether these frameworks go far enough.

These EU-level measures are complemented by different interventions at country level. This means that a range of employment programmes, which can be instrumental in supporting individuals to retain and quickly find work, are potentially ‘in scope’. This includes, for example, ‘active labour market policies’. In turn, specific workplace-based schemes, especially those led by businesses themselves and which support workplace innovation, are important for incentivising improvements in working conditions and practice that businesses take ownership of, thus facilitating better employment opportunities, more ‘good work’, and a wider take up of ‘high performance’ working practices. In a context of a modern economy and ongoing developments connected to the future of work, the notion of workplace innovation and new ways of working open up many new opportunities for better supporting PLWM at work. Indeed, some workplace adjustments, e.g. flexible working, may be more easily supported in such a climate. Advice and guidance and awareness raising campaigns have been developed at EU and country level to encourage certain actions, enhance knowledge, support education and then promote the adoption and sharing of good practice. But is there scope to enhance these activities further?

Whilst PLWM can benefit from ‘general drives’ to increase employment, social inclusion and job quality in various ways, it is apparent that there is currently some ambiguity around how adequately the condition is diagnosed and/or recognised across European countries. This undoubtedly risks unequal treatment and thus provides ‘room for improvement’ in the specialist

support individual PLWM can access. It seems that PLWM, therefore, could potentially benefit from *better recognition of migraine as a chronic condition and disability* – as well as its impact on work capacity.

Though there are some potential risks associated with it, recognition of migraine as a chronic condition and disability *would help ensure PLWM are entitled to certain protections*. For example, they would have better *access to reasonable adjustments*, enabling them to manage their condition effectively alongside their work. It would also give PLWM easier access to *dedicated employment programmes* and *vocational rehabilitation* support. Such schemes provide additional targeted help to recruit people with health conditions into the workforce. Furthermore, closer integration of work and health, and better coordination between employers and the health system, can stop them falling out of work in the first place. Formal recognition will also *support better data collection, monitoring and reporting* of migraine from an employment perspective across the EU and in Member States. In turn, this will allow for comparisons and benchmarking to direct and inform appropriate action. It should therefore be a priority.

Funding is also available – through ESF – to undertake further activities. For instance *more research may help to better understand the impact of migraine* on people at different stages in their ‘life course’ (e.g. when they are in education, work, and retirement) and what additional action might be taken to improve work quality and inclusion and encourage the recruitment and retention of people with chronic conditions and disabilities. This might help to extend and scale up the range of health and wellbeing support they need, building on existing networks and programmes such as ‘ANACT’.

5. Conclusions and recommendations

This paper has set out the insights gained from this research assessing the impact of migraine on employment in Europe. In doing so, it has considered what a ‘migraine-friendly’ workplace might look like and explored what actions could be taken – in policy and employment practices – to support better working conditions in more workplaces that benefit PLWM. This has been informed by an evidence review of relevant academic and grey literature, analysis of the latest data on migraine from a range of sources, and insights gained from qualitative interviews with a number of EU and country level stakeholders with expertise in areas ranging from the management of migraine and other health conditions – in both clinical and workplace settings – to organisational change and workplace innovation. It therefore offers an account of how to improve the experience of work for PLWM from the perspective of a diverse range of stakeholders (i.e. covering not just health but also social and employment policy), which we argue is necessary to achieve lasting change.

There is no ‘silver bullet’ or single action alone that can improve the work experience for all PLWM across Europe. A range of policy measures is needed to shape any given country’s employment and health system and thus a wide range of policy ‘levers’ must be in scope in seeking to create more migraine-friendly work environments in future.

While responsibility for employment and health policy lies primarily with Member States, the EU also plays an important role in influencing what is done by establishing common objectives and targets, making laws, providing guidelines, assisting implementation, and setting minimum standards to enhance good practice. This will then be complemented by specific employment programmes supported by advice and guidance and awareness-raising, campaigning and good practice sharing.

Thus, improving work-related outcomes for PLWM will require a range of ‘hard’ and ‘soft’ approaches, grounded in legislation, with coordinated action from EU and national level policymakers working with social partners to influence employers and in cooperation with wider stakeholders (such as health professionals, industry and professional bodies).

This report does not seek to provide definitive answers, but rather present a range of policy options, that can be considered and potentially deployed in different ways and/or adapted by policymakers in the EU and/or Member States to improve PLWM’s experiences in future.

The blend of policies needed to create migraine-friendly work environments in different Member States will in part depend on the local social and economic context, support for and traditions of social partnership/dialogue, as well as the demands of the working population. That said, it is important to consider the ‘complementarity’ of policy interventions at an EU and Member State level.

What is clear – above all – is that *a number of different stakeholders – including policymakers, employers, and health professionals – must work together* to improve the experience of work for PLWM. The benefits extend beyond individuals to families, organisations, and society as a whole, including healthcare systems. Based on the research carried out, below, we set out a short list of *fundamental actions* that stakeholders should prioritise:

- Improved *understanding and awareness of migraine* as a serious – but manageable – condition through campaigning is needed in all Member States.
- Better *recognition of migraine as a serious health condition* to improve treatment of PLWM at work and the protections they are entitled to. This will require an assessment of the costs and benefits of recognising migraine as a *chronic condition and disability* in EU law, which would

ensure that, across all Member States, PLWM are entitled to certain benefits/protections that should improve their experience of work.

- Better recognition of migraine will in turn support better *data collection, monitoring and reporting* of the condition from an employment perspective across the EU and Member States.
- More *research is needed to better understand the impact of migraine* on people at different stages in the life course (e.g. in education, in work, in retirement) and the disruption it causes.
- Having speculated on the blend of approaches that will be needed in different Member States, *subsequent research should specifically investigate this, exploring what is needed in different country contexts* to improve the experience of work for PLWM
- Further research is needed to *explore what approaches would work in different industries and sectors*, with active local communities of practice to drive more high performance and good working practices, and to establish what reasonable adjustments and changes in working policies and practices can realistically be made to support PLWM.

Annex 1: Research methods

The research method comprises a rapid evidence review of the relevant academic and grey literature supplemented by analysis of secondary data sources, namely:

- The *Global Burden of Disease Study* 2017 (described as “the most comprehensive worldwide observational epidemiological study to date”¹⁷⁸). 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, conducted between 2017-18 (comprising more than 11,000 people who had at least four ‘migraine days’ per month from 31 countries). It is the largest ever global study of people living with migraine¹⁷⁹.
- The *Eurolight Study*, which includes data, collected between 2008 and 2009, for 9,269 respondents from eight European countries, representing 55% of the adult EU population. It estimates the direct and indirect costs attributed to a range of headache disorders, including migraine¹⁸⁰. 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%)¹⁸¹.

In addition, eight qualitative interviews were carried out with EU and country level stakeholders with expertise in a range of areas relevant to improving the experience of work for people living with migraine in Europe (i.e. covering not just health but also social and employment policy). They comprise:

- a workplace innovation expert who helped build the European Workplace Innovation Network (EUWIN);
- an academic neurologist running a headache clinic at a university hospital in Belgium;
- a labour market analyst at OECD with expertise at the health and work interface;
- a labour market analyst at OECD with expertise on job quality;
- CEO of the UK’s Business Disability Forum;
- an expert in organisational change and co-author of a recent EU-OSHA report on health and wellbeing at work;
- a social policy expert at Eurofound; and
- a labour market analyst with expertise in health conditions and work at Eurofound.

Annex 2: Migraine definition

The International Headache Society (IHS) describes migraine as a common and disabling primary headache disorder¹⁸². In its most recent (third) edition of the International Classification of Headache Disorders (ICHD-3), migraine is described as having two major ‘types’. These are migraine with, and migraine without, aura. ‘Aura’ generally refers to visual disturbances including blind spots in the field of eyesight, coloured spots, sparkles or stars, flashing lights before the eyes, etc.¹⁸³ Migraine without aura is, however, more common, affecting the vast majority of people with migraine¹⁸⁴.

Migraine symptoms; attack frequency, duration and severity

Migraine is a complex condition, comprising a wide variety of symptoms. In its recently updated International Classification of Disease (ICD-11), the World Health Organization (WHO), drawing on ICHD-3, describes migraine as primarily episodic, comprising disabling attacks typically lasting 4-72 hours (when untreated or not treated properly), and characterised by moderate or severe headache¹⁸⁵. This is usually accompanied by nausea, vomiting, and sensitivity to light, sound and smells.

International evidence from studies of migraine in North America and Europe tend to report attack frequency and duration (i.e. the ‘ictal’ state) ranging between 15-30 times a year, normally lasting about one day but often more. For example, a staff survey of an English hospital trust found 158 people with migraine reporting an average of 20 attacks per year, each lasting 20 hours on average¹⁸⁶. Similar results were reported by a Canadian population survey of 445 people with migraine: 20 attacks per year with a mean duration of 31 hours¹⁸⁷. A Swedish postal survey of 423 people with migraine reported a slightly lower attack frequency of 16 a year with a mean duration of 19 hours¹⁸⁸. Data collected from a random sample of the adult population in England, however, reveal a higher mean attack frequency (per year) of 26.3 for men and 23.6 for women, as well as a mean duration of 28 and 37 hours for men and women respectively¹⁸⁹.

In addition to attack frequency and duration, the pain caused varies too. Migraine can be extremely debilitating. So much so that the WHO ranks ‘severe migraine’ in the highest disability class (VII), alongside conditions like severe depression and terminal stage cancer¹⁹⁰. A US postal survey of 3,577 people with migraine reported almost 80% experiencing either ‘severe’ or ‘extremely severe’ pain¹⁹¹. Similarly high levels of pain (7-10 on a 10-point scale) were reported by more than two-thirds of a sample of 1,663 people with migraine in a US population survey¹⁹². Furthermore, an English population survey reported a mean pain intensity of 7.5 for both sexes, with a quarter (25%) reporting very high levels of pain (9-10 on a 10-point scale)¹⁹³.

As well as causing significant pain, people with migraine are prone to anxiety, depression, tiredness, difficulty concentrating and irritability¹⁹⁴,¹⁹⁵. Furthermore, significant numbers experience an ‘interictal’ burden (between attacks)¹⁹⁶. This includes, for example, anxiety about the next attack and avoidance of perceived ‘triggers’¹⁹⁷.

Due to its symptoms, and the frequency with which they occur, migraine has a profound – often negative – effect on people’s ability to work. We explore its impact on employment in Europe in greater detail in a later chapter.

Different types of migraine

As described above, there are two major migraine ‘types’ (migraine with and without aura). There are, however, a number of additional ways of categorising migraine, e.g. episodic or chronic and ‘probable’ or definite. We explore these below¹⁹⁸.

Though the vast majority of people with migraine experience it on an episodic basis, a small minority have ‘chronic’ migraine. The former is characterised by 0 to 14 headache days per

month¹⁹⁹ and the latter is characterised by 15 or more days per month²⁰⁰. Recently revised, more specific, criteria for chronic migraine state that headaches must occur 15 days or more for three or more months, of which eight or more days meet the criteria for migraine²⁰¹. Though both part of the migraine ‘spectrum’, episodic and chronic migraine are considered distinct, with the latter causing a higher degree of disability albeit in a much smaller number of cases worldwide²⁰².

Because there are no biological markers for migraine, with no decisive pathological or radiological finding, diagnosis is mainly based on clinical features²⁰³. It has therefore been argued that the concept of a ‘probable’ diagnosis is needed in making a migraine diagnosis²⁰⁴. ICHD-3 defines ‘probable migraine’ as “migraine-like attacks missing one of the features required to fulfil all criteria for a type or sub-type of migraine” (i.e. migraine with or without aura)²⁰⁵. Historically, most studies of migraine prevalence in Europe only report ‘strict’ or ‘definite’ migraine²⁰⁶. More recent studies, however (e.g. those conducted through the Global Campaign against Headache²⁰⁷), include both definite and probable migraine^{208, 209, 210}. This, inevitably, has implications for estimating prevalence and impact which are explored in the following chapter.

The rationale for including both definite and probable migraine in prevalence estimates is as follows. First, academics have argued that probable migraine, despite not fulfilling all relevant criteria, is more likely to be migraine than anything else it could be²¹¹. Thus, reporting the prevalence of probable migraine as distinct from definite serves little purpose in studies of population health^{212, 213}. Second, according to the findings of a population level survey conducted in France (comprising over 10,000 subjects), migraine severity and disability is similar in people with probable and definite migraine²¹⁴. In fact, quality of life impairment was identical among both groups. Similar findings were reported in a Korean population level survey comprising 1,500 people²¹⁵. Probable and definite migraine therefore warrant similar treatment and management.

Other headache disorders

Other headache disorders include (but are not limited to, tension-type headache (TTH), cluster headache, and medication overuse headache (MOH).

Unlike migraine, which causes pain that can be disabling, TTH is characterised by mild to moderate pain. Symptoms include pressure or tightness around the head, possibly including pain in the neck and shoulder muscles. It is generally episodic in nature, with attacks lasting a few hours (although potentially lasting for several days)²¹⁶. In contrast, cluster headache, can cause severe pain²¹⁷. It is, however, significantly less common than migraine and TTH, affecting fewer than 1 in 1,000 adults worldwide according to the WHO²¹⁸. In contrast to other headache disorders, MOH originates from either migraine or TTH (mainly the former). It can occur when medication is used excessively to treat headache²¹⁹. Though severe, prevalence estimates suggest it is rare (affecting 1-2% globally – but this is hard to estimate due to its origin)²²⁰.

¹OECD/EU. (2016). Health at a Glance: Europe 2016: State of Health in the EU Cycle. Paris: OECD. Available at: <http://www.oecd.org/health/health-at-a-glance-europe-23056088.htm>

² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5662668/>

³ Department for Work and Pensions (2015) Labour Force Survey analysis of disabled people by region and main health problem

⁴ For clarification, it should be stated that this figure does not imply that the *unemployment* rate is around 20%. This rate only counts individuals who are actively seeking work/are available to start work immediately and does not apply to all people out of work.

⁵ <http://ihmeuw.org/4pxv>

⁶ <http://ihmeuw.org/4pxw>

⁷ <http://ihmeuw.org/4pxy>

⁸ <http://ihmeuw.org/4pxz>

⁹ Steiner, T. J., Scher, A. I., Stewart, W. F., Kolodner, K., Liberman, J., & Lipton, R. B. (2003). The prevalence and disability burden of adult migraine in England and their relationships to age, gender and ethnicity. *Cephalalgia*, 23(7), 519–527.

- ¹⁰ 15-69 years
- ¹¹ <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2017-permalink/1a8a6de6729c51ef7086e1d8cf4b9be3> (this is a weighted average taking migraine prevalence amongst those aged 15-49 and 50-69, which is 30% and 23.4% respectively)
- ¹² Linde, M., Gustavsson, A., Stovner, L. J., Steiner, T. J., Barré, J., Katsarava, Z., ... André, C. (2012). The cost of headache disorders in Europe: The Eurolight project. *European Journal of Neurology*, 19(5), 703–711.
- ¹³ Shapiro, R. E., & Goadsby, P. J. (2007). The long drought: The dearth of public funding for headache research. *Cephalalgia*, 27(9), 991–994.
- ¹⁴ A Global Campaign against Headache project
- ¹⁵ Steiner, T. J., Stovner, L. J., Vos, T., Jensen, R., & Katsarava, Z. (2018).
- ¹⁶ International Classification of Headache Disorders. (2016). IHS Classification ICHD-3 Beta. Retrieved November 18, 2017, from <https://www.ichd-3.org/1-migraine/>
- ¹⁷ Migraine Trust. (2018). Migraine with aura. Retrieved November 20, 2018, from <https://www.migrainetrust.org/about-migraine/types-of-migraine/migraine-with-aura/>
- ¹⁸ Migraine Trust. (2018). Migraine without aura. Retrieved November 21, 2018, from <https://www.migrainetrust.org/about-migraine/types-of-migraine/migraine-without-aura/>
- ¹⁹ <https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/669367341>
- ²⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5360747/>
- ²¹ <http://ebc-brussels.org/wp-content/uploads/2015/07/Migraine-fact-sheet-Sept-2011.pdf>
- ²² 'Europe' as defined in GBD 2017 i.e. the European region, which includes the European Union as well as other countries of greater Europe
- ²³ <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2017-permalink/4acc5901b1ed4554d3e756ac2bc31fb>
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- ²⁵ 15-69 years
- ²⁶ <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2017-permalink/1a8a6de6729c51ef7086e1d8cf4b9be3> (this is a weighted average taking migraine prevalence amongst those aged 15-49 and 50-69, which is 30% and 23.4% respectively)
- ²⁷ <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2017-permalink/9268079815bd57d8b7d06eacb2379d1d>
- ²⁸ <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2017-permalink/9268079815bd57d8b7d06eacb2379d1d>
- ²⁹ 15-69 years
- ³⁰ <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2017-permalink/923865aeef2dcdee085304a374ac1773> (this is a weighted average taking YLDs caused by migraine amongst those aged 15-49 and 50-69, which is 9.5% and 5.2% respectively)
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- ³² Austria, Croatia, UK, Denmark, France, Norway, Turkey, Sweden, Georgia, Germany
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- ³⁴ <https://www.ncbi.nlm.nih.gov/pubmed/22287564>
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- ³⁶ One-year prevalence of migraine using a validated extended French version of the ID MigraineTM: A Belgian population-based study
- ³⁷ The PACE study: Past-year prevalence of migraine in Parma's adult general population
- ³⁸ One-year prevalence of migraine in Spain: A nationwide population-based survey
- ³⁹ One-year prevalence of migraine using a validated extended French version of the ID MigraineTM: A Belgian population-based study
- ⁴⁰ <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2017-permalink/4864d461909e521eba53f04d58be9683>
- ⁴¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4216045/>
- ⁴² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3311830/>
- ⁴³ <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2017-permalink/1a8a6de6729c51ef7086e1d8cf4b9be3> (this is a weighted average taking migraine prevalence amongst those aged 15-49 and 50-69, which is 30% and 23.4% respectively)
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- ⁴⁶ Migraine is first cause of disability in under 50s: will health politicians now take notice?
- ⁴⁷ The impact of a worksite migraine intervention program on work productivity, productivity costs, and non-workplace impairment among Spanish postal service employees from an employer perspective
- ⁴⁸ Stress, anxiety, depression and migraine
- ⁴⁹ The association between stress and headache: A longitudinal population-based study
- ⁵⁰ Evidence from interview with an academic neurologist running a headache clinic at a university hospital in Belgium
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- ⁵⁶ Evidence from interview with a workplace innovation expert who helped build the European Workplace Innovation Network (EUWIN)
- ⁵⁷ Bambra et al., 2007; p. 1028; see also Bambra et al., 2010
- ⁵⁸ http://www.who.int/occupational_health/topics/workplace/en/
- ⁵⁹ See: http://www.l-t-b.org/index.cfm/spKey/horizontal_activities.learning.the_eurolight_project.html

- ⁶⁰ Austria, France, Germany, Italy, Lithuania, Luxembourg, Netherlands, Spain
- ⁶¹ Linde et al. (2012).
- ⁶² Linde et al. (2012).
- ⁶³ 15-69 years
- ⁶⁴ <http://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2017-permalink/1a8a6de6729c51ef7086e1d8cf4b9be3> (this is a weighted average taking migraine prevalence amongst those aged 15-49 and 50-69, which is 30% and 23.4% respectively)
- ⁶⁵ Linde, M., Gustavsson, A., Stovner, L. J., Steiner, T. J., Barré, J., Katsarava, Z., ... André, C. (2012). The cost of headache disorders in Europe: The Eurolight project. *European Journal of Neurology*, 19(5), 703–711.
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