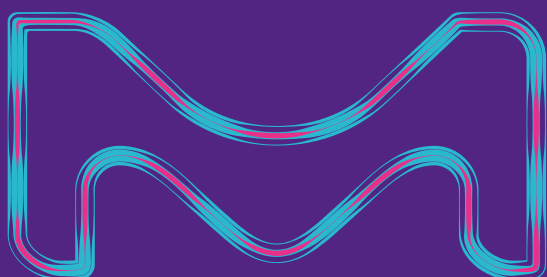




# THE SOCIOECONOMIC IMPACT OF MULTIPLE SCLEROSIS ON WOMEN IN EUROPE

October 2017

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## Executive Summary

Merck KGaA, Darmstadt, Germany (Merck) asked Charles River Associates (CRA) to investigate the socio-economic impact of multiple sclerosis (MS) on women in Europe. In particular, the objective was to develop:

- evidence of the full range of impacts that MS has on the lives of women, their families and their roles in society; and
- any policy implications that would improve the environment for this patient group.

To do this, CRA followed a three-step approach that involved: a literature review, an interview programme with patient organisations and a bespoke survey of women with MS. We focused on eight different European countries with diverse healthcare systems where previous research has highlighted differences in the support for MS patients: Czech Republic, France, Germany, Italy, Poland, Spain, Sweden and the UK. In six of these markets we undertook detailed interviews with the local patient associations and patients involved in advocacy on MS. The online survey collected data from 807 women with MS and includes data across the eight markets. In the survey, we investigated the respondents' experience with MS, the impact on the different areas of their lives and their recommendations where greater support could be provided in the future.

### *Our findings*

It has long been known that MS impacts women more frequently than men—women are two times more likely than men to be diagnosed with the condition. As there are more than 700,000 people with MS in Europe, this means there are more than 450,000 women in Europe affected by the disease. Despite the number of women affected, the burden of MS on women and the wider society and economy has not been comprehensively investigated in research or addressed in policy. Understanding the impact MS has on women, their families and the wider socioeconomic environment is the objective of this study. We have four main findings:

- 1. Being diagnosed with MS is challenging for women, often requires a number of visits to healthcare providers and is subject to misdiagnosis and months of delay.**

MS occurs earlier in women than men and at a pivotal time in their lives in terms for family and career decisions. On average, confirmation of diagnosis requires about six months from the initial consultation and requires five visits to healthcare providers. Although delays are affected by the efficiency of the overall healthcare system, particularly the availability of specialists, physician awareness of MS or availability of diagnostic tools, we note some disparities between genders. For many women, the first visit to the doctor is delayed by the other calls on their time, but it is also complicated by the earlier onset and slower progression of the disease in women than in men. Over one-fifth (21%) of women we surveyed were misdiagnosed with a different illness prior to being diagnosed with MS. Common misdiagnoses included chronic fatigue syndrome, trapped nerve, depression, brain tumour, epilepsy and chronic pain, while some women were also told they were imagining their symptoms. The delay between experiencing symptoms and receiving a diagnosis creates a period of uncertainty, not only affecting the emotional state of women but also feeding into their decision-making about careers, family and social relationships.

## **2. Being diagnosed and living with MS affects the life choices that women make regarding relationships and their families.**

In our survey, the average age of MS diagnosis for women was 32, younger than is typical for men. The impact of MS diagnosis on family life for women is profound. The survey revealed that after being diagnosed with MS, almost over two-fifths (41%) of women with MS had separated or divorced from their partners. Of these women, the vast majority (88%) reported that MS had played a factor in their relationship change. The more common occurrence of depression places an additional strain on women's relationships.

MS has a significant impact on family life planning. The survey results reveal that, on average, over one-third (37%) of women with MS either decided to not to have children or altered the timing at which they had children. This was supported by interviews with patient organisations, which revealed that family planning issues were common among women with MS. Women reported symptoms such as fatigue (17%) and pain (14%) as aspects of their MS, which influenced their choices about having children or the timing of their pregnancy. Respondents stated that often this decision is exacerbated by a lack of comprehensive and consistent information on how MS affects pregnancy, leading to a risk-averse attitude in physicians and patients.

The results also show that women are less likely to participate in social activities after being diagnosed with MS. The perceived "randomness" of MS symptoms is reported as most debilitating to women's daily lives. Also, common symptoms that women experience such as fatigue, mobility issues and pain and sleep issues impact their ability to carry out household activities or stay fit through sports and exercise. This, in part, could contribute to women's reported sense of social exclusion and adverse discrimination, although findings from interviews suggest that a lack of general public awareness of MS is also a contributing factor. The cumulative impact of these effects limits the options for women with MS, leading to a sense of a loss of independence and isolation from society.

## **3. MS has an impact on the role of women as primary caregivers.**

Women provide a disproportionate amount of care in society to children and elderly family members. The debilitating nature of MS negatively impacts the ability of women suffering from the disease to undertake the caregiving role, causing a threefold impact:

- A direct effect on women patients, who feel less able to fulfil their caregiving duties, which are very valuable to them (e.g., value of motherhood);
- An impact on those they care for, as they may be subject to less support (e.g., children that need to be self-sufficient); and
- An impact on patients' partners, who may need to undertake additional caregiving activities which they otherwise would not have had to do.

Of the women in our survey with caregiving responsibilities, 69% reported that MS to some extent diminished their ability to maintain this role. This effect was greater in more progressive stages of the disease (and those types of MS with fewer treatment and management options, such as primary progressive MS). Lost or reduced ability to care for others is an impactful issue for women, which causes emotional distress, particularly if related to childcare. The survey results show that although those women that have children have more support (largely from their families) than the overall group, in 68% of cases where additional support is provided are paid for by the patient or their family.



**4. MS imposes a significant economic cost on women and society, because women with MS are less likely to be in full-time employment or suffer from forms of presenteeism and absenteeism.**

Of all women surveyed, almost two-thirds (66%) reported that their MS had affected their employment status at some point. Of these women, almost two-fifths (38%) had left employment altogether as a result of their MS. This results in significant income consequences, as those with MS are much more likely to have a 'below average' household income. Furthermore, around 15 years after the onset of MS, 60% to 80% of patients are likely to have lost their job or exited the workforce, leading to a loss of 10 working years on average. The reasons for women with MS having to change their employment status varied, but included the workload being too high or unpredictable (33%), a lack of flexible working practices (13%) and an insufficient number of breaks to rest when tired (10%). Perhaps unsurprisingly, there is a relationship between employment status and family circumstance. The greatest number of women that were employed were also married or cohabiting (55%) and were more likely to have no caregiving responsibilities (52%), suggesting that the impact on labour force participation was greatest for those living alone or with dependents to look after.

Furthermore, over one-quarter (26%) and one-fifth (20%) of working women noted that their MS symptoms cause them to work fewer hours per day, and fewer days per week, respectively in an average month. Indeed, working women with MS estimate that they would work a median average of 40 hours per week if they did not have their condition. This would be equivalent to such women working roughly 25 hours more per week than they currently reportedly do, or a boost of an average of 2.9 days of work per week, per woman with MS across Europe.

***Policy implications***

To date, there is little recognition of the impact of MS on women in the policy debate or specific policies to mitigate this burden. Based on evidence gathered in this study, including survey responses and interviews with patients and patient organisations, further support for women with MS in a number of areas would be important and necessary to address the impact and burden of the condition. A summary of the recommendations is provided in Table 1.

**Support in diagnosis, treatment and care**

There are ongoing efforts to ensure fast and effective diagnosis, treatment and care of all MS patients, but there are limited considerations for issues affecting women with MS, such as those related to treatment choice implications for women during pregnancy, menstrual periods and menopause. Women with MS voice concern primarily regarding the expertise of healthcare professionals in detecting early and more invisible symptoms (more prevalent amongst women), access and referral to specialists, especially when patients are located in rural areas and access to multidisciplinary and coordinated care is lacking. There are therefore three key areas that could improve the diagnosis and treatment of women with MS. First, awareness needs to increase regarding the challenges women face (sometimes referred to as 'invisible symptoms') in achieving a fast and clear diagnosis. Second, a flexible patient-centric approach to treatment choice can be particularly important to women as they are treated pre- and post-pregnancy. Finally, coordinated care and multidisciplinary support are needed to ensure that patients make informed life choices that manage the impact of MS on their future.

**Support in maintaining a healthy family, social and daily life**

Women with MS receive some direct government financial support, mainly through disability payments and allowances. However, women with MS view this support as hard to access and limited in addressing the challenges MS patients face. In particular, 'invisible symptoms', such as cognitive disability, are difficult to identify and often don't result in adequate support. Even taking into account the current economic environment in most European countries, there is a case for extending the support for caregiving and household activities for women with MS through a distinct budget.

Further, although there is support by family and by healthcare professionals (e.g., a neurologist who ensures access to appropriate information, treatment and care when planning for pregnancy, or a nurse who provides continuous information on managing relationships with family members), this could be improved. Support with family planning, parenthood and sexuality is also commonly provided by patient organisations, patient support groups and peer online groups. These platforms have a critical role in improving the lives of women with MS, thus close collaboration between healthcare professionals, patient groups, women organisations and other MS peer support structures should be regarded as a best practice and shared across countries.

Finally, women with MS regard improved public understanding and awareness of MS as critical. There are efforts to improve awareness of MS in the general public, but many patients report adverse reactions to the disease from their friends and co-workers, which can lead to feelings of exclusion and discrimination. This issue has gained broader recognition at the EU level through European Commission initiatives and at the member state level through national plans and strategies on neurological diseases, which increasingly include MS. Awareness-building is commonly one of the main pillars in these plans, however, the scope should be further tailored to the unique impact that the disease has on women to ensure society not only understands the challenges women patients face, but also avoids stigmatising them.

**Support in the workplace**

MS often has a direct impact on labour force participation and further exacerbates the trade-off between family and work life. In response, flexible working practices have emerged to enable women to perform activities such as receiving treatment or resting when necessary without interfering with their work responsibilities. Although employers largely implement this on an ad-hoc basis, some countries are aiming for a more structured approach through legal provisions.

There has been positive progress, but scope is required for additional support in the workplace to address the perception of MS in the workplace, explain the problems of fatigue and cognitive issues and prevent discrimination. Patients' fear of sharing the condition with their employers and requesting additional support in the workplace needs to be overcome. Limitations in the workplace not only impact the patient, but have direct financial implications for the employer and the economy at large. Over half of the women surveyed report that, with additional support, they would be encouraged to take up employment, and those employed would be able to work more, with benefits from this boost estimated at

€7,500 per year, per patient (or a of total €1.4 billion if applied to all women).<sup>1</sup> Encouraging women with MS to work to their full potential could involve enhanced flexible working schedules, financial support from the government (e.g., subsidised childcare) or improved facility access and transportation. In addition, women noted that professional associations would also be useful to increase awareness across the workplace and ensure diminished discrimination and isolation.

**Table 1: Summary of policy recommendations**

Area	Recommendations to target MS impact on women
Diagnosis, treatment and care	Improve awareness of the challenges of 'invisible symptoms' facing women in achieving a fast and clear diagnosis.
	Establish a flexible patient-centric approach to treatment choice.
	Provide coordinated care and multidisciplinary support to ensure that patients make informed life choices that manage the impact of MS on their futures.
Family, social and daily life	Extend support for caregiving and household activities for women with MS through a distinct budget from the general disability one.
	Implement collaborative initiatives between healthcare professionals or their representatives, patient groups, women organisations and other MS peer support structures within and across countries.
	Building on existing awareness strategies, further tailor the scope to the unique impact on women to ensure society understands challenges, but also avoids stigmatisation of women patients.
Workplace	Encourage support from employers, particularly in providing more flexibility at work and building awareness in the workplace to avoid isolation.
	Provide financial support from the government in the form of subsidised childcare.
	Support improved infrastructure in the workplace and beyond for facility access and transportation to enable mobility.

<sup>1</sup> The survey revealed that with additional support, women with MS would work an estimated seven hours per week more than they currently do. We multiply this by the average weekly wage reported by women in the sample to identify the potential income gained from working additional hours. The potential income is applied across the total number of employed women with MS in Europe (in the eight countries examined) and annualised to estimate the total potential income accrued to women with MS from working more hours due to additional support in the workplace in Europe.

## 1. Introduction

Merck KGaA (Merck) asked Charles River Associates (CRA) to investigate the wider socio-economic impact of multiple sclerosis (MS) on women in Europe. In particular the objective was to:

- develop evidence of the full range of impacts that MS has on the lives of women, their families and their roles in society; and
- consider any policy implications that would improve the environment for this patient group.

### 1.1. Background

MS is a chronic and debilitating disease of the central nervous system (CNS) impacting the brain, spinal cord and optic nerves. The MS prevalence ratio of women to men stands at around 2:1 and has not significantly changed in the past 10 years.<sup>2</sup> As there are more than 700,000 people with MS in Europe, this means there are approximately 460,500 women in Europe affected by the disease.<sup>3,4</sup> There are different schools of thought about the reasons women develop MS at a higher rate, with no definitive consensus.<sup>5</sup> Although the exact cause of MS is not known, evidence suggests an interaction between genetic (e.g., differences in the human leukocyte antigen (HLA) system), hormonal (e.g., link to oestrogen-luteinising hormone balance) and environmental factors is important in the development of the disease.

While the impact of the disease has been examined in considerable detail<sup>6,7</sup> and there is a recognition that patients with MS experience changes to their physical, mental and emotional health and subsequently to their lives due to symptoms and disabilities related the disease, there has been little targeted research on whether the disease has a differential impact on women.

Looking across patients of both sexes, we know the degree of impact on a patient's life will depend on the type of MS and the symptoms experienced, which are determined by the degree and areas of inflammation in the central nervous system. The most common types of MS are relapsing-remitting MS (RRMS), secondary progressive MS (SPMS), primary

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<sup>2</sup> MS International Federation (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017].

<sup>3</sup> European Multiple Sclerosis Platform (2017). *About Us*. Available from: <http://www.emsp.org/about-emsp/>. [Accessed 15 July 2017].

<sup>4</sup> CRA analysis of data from MS International Federation (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017].

<sup>5</sup> Cruz-Orengo, L. et al. (2014). Enhanced sphingosine-1-phosphate receptor 2 expression underlies female CNS autoimmunity susceptibility. *Journal of Clinical Investigation*. 124(6): 2571-258.

<sup>6</sup> Trisolini, M., Honeycutt, A., Wiener, J. and Lesesne, S. (2010). Global Economic Impact of Multiple Sclerosis. Multiple Sclerosis International Federation. Available from: [https://www.msif.org/wp-content/uploads/2014/09/Global\\_economic\\_impact\\_of\\_MS.pdf](https://www.msif.org/wp-content/uploads/2014/09/Global_economic_impact_of_MS.pdf). [Accessed 8 August 2017].

<sup>7</sup> European Multiple Sclerosis Platform (2015). *MA Barometer 2015*. Available from: <http://www.emsp.org/wp-content/uploads/2017/02/BAROMETER-2015-28.02.2017.pdf>. [Accessed 15 July 2017].

progressive MS (PPMS) and progressive-relapsing MS (PRMS). About 85% of MS patients are initially diagnosed with RRMS,<sup>8</sup> which involves relapses that usually last for a short period of time. Over time, RRMS might advance to SPMS, which has a steady, slow progression and may or may not involve relapses. Without treatment, about half of individuals with RRMS advance to SPMS within 10 years. An additional 10% of MS patients are diagnosed with PPMS, where patients' symptoms worsen steadily from the start without periodic relapses and remissions. PRMS is the least common MS type, diagnosed in 5% of patients. PRMS patients are initially diagnosed with RRMS, which steadily deteriorates from the onset but also involves symptom flare-ups (with or without remissions).<sup>9</sup> MS symptoms may vary considerably in severity and the degree of psychological and physical impact.<sup>10</sup> Although the gender of the patient does not influence clinical symptoms as markedly as it influences prevalence, there is evidence that women usually have an earlier onset of disease and in general show less progression of disability than men.<sup>11</sup>

Previous research has investigated the impact and burden of MS on patients' lives and more broadly to the economy and society.<sup>12</sup> The literature distinguishes between a number of different types of burden, the direct costs (medical and nonmedical), indirect costs and intangible costs.

- Direct costs: The direct costs of MS on patients and society have been investigated in detail. These direct costs encompass all resources used to diagnose, treat and assist patients with MS in daily life. Several examples include medical costs to pay for diagnostics, medication, inpatient and outpatient care, nursing care, speciality care and rehabilitation services. Past research has also examined direct nonmedical costs such as formal and informal care to help with daily activities, home and car modifications, mobility devices and other resources.<sup>13</sup>
- Indirect costs: There is also literature on indirect costs of MS, or those that occur outside of the healthcare system and accumulate throughout an MS patient's

<sup>8</sup> MS International Federation (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017].

<sup>9</sup> Courtney, S. (2014). About MS: An overview of multiple sclerosis (MS) including symptoms, treatments and research. *Multiple Sclerosis Association of America*.

<sup>10</sup> MS symptoms include: anxiety, balance issues, bladder dysfunction, bowel problems, cognitive changes, depression, dizziness, fatigue, mobility and walking issues, numbness, pain, pseudobulbar affect, sexual dysfunction, sleep issues, spasticity, speech difficulties, swallowing disorders, tremor, Uhthoff's syndrome (when heat worsens visual symptoms), visual disorders, and weakness.

<sup>11</sup> Harbo, H., Gold, R. and Tintore, M. (2013). Sex and gender issues in multiple sclerosis. *Therapeutic advances in neurological disorders*. 6 (4), 237-248. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3707353/>. [Accessed 30 March 2017].

<sup>12</sup> Previous estimations of cost and burden of MS typically have been performed by disease state, disability level, country, and a number of other variables. One of the most comprehensive studies addressing these costs is the Multiple Sclerosis International Foundation study, 'Global Economic Impact of Multiple Sclerosis,' which extensively examines the tangible and intangible societal costs of MS. Quantifiable measurements are especially important to policy-makers when deciding how to allocate resources and funding to areas of greatest need.

<sup>13</sup> Trisolini, M., Honeycutt, A., Wiener, J. and Lesesne, S. (2010). Global Economic Impact of Multiple Sclerosis. Multiple Sclerosis International Federation. Available from: [https://www.msif.org/wp-content/uploads/2014/09/Global\\_economic\\_impact\\_of\\_MS.pdf](https://www.msif.org/wp-content/uploads/2014/09/Global_economic_impact_of_MS.pdf). [Accessed 8 August 2017].

care.<sup>14</sup> Indirect costs include work and earnings losses (both due to increased morbidity and early mortality) and the cost of the indirect impact of MS on family and friends. A significant amount of research documents the impact of MS on labour force participation in terms of absenteeism, presenteeism, potential job changes and early retirement. An MS patient also often has family or friends who act as informal caregivers and decrease their labour force participation as well.

- Intangible costs: The literature documents pain, psychological suffering and decreased quality of life both for the patient and for their caregivers. Although these costs are more difficult to quantify, they have a substantial impact on the patient and in aggregate on society at large.<sup>15</sup>

While a number of studies have focused on the cost of MS to the overall population, few have looked at the burden falling specifically on women. Based on evidence, women with MS are a unique patient group, both due to the high and rising prevalence of MS in women and due to their specific challenges. These challenges span from concrete physical symptoms, such as those related to pregnancy, to indirect burdens on quality of life, social exclusion/discrimination, loss of employment and more. Identifying these unique challenges and quantifying their impact is the aim of this study.

## 1.2. Approach

We conducted this research using a three-step approach that involved: a literature review, a bespoke survey with women MS patients across the targeted countries and an interview programme with patient organisations.

As a first step, we undertook a literature review to examine the existing evidence and develop our understanding of how the impact of MS on women's health varies across different countries in Europe. Our review included literature from academia (e.g., *Neurology*, *Journal of Neuroscience*), MS institutional literature such as the 'Atlas of MS' and 'Global Economic Impact of MS' developed by the Multiple Sclerosis International Foundation (MSIF) and the 'MS Barometer' developed by the European Multiple Sclerosis Platform (EMSP), and literature by women organisations (Women Enabled). We used keyword searches to identify documents addressing issues faced by women with MS. The search used the following terms: 'multiple sclerosis', 'MS', 'burden', 'challenges', 'costs', 'policy', 'program/me' and 'support'. We used additional relevant terms to identify documents with details specific to each area of women's lives. For example, to identify documents associated to women with MS and employment, we used the following terms in conjunction with the general terms described above: 'employment', 'career choice', 'workplace' and 'work'. We reviewed literature in the local languages of the countries in our sample, but English-language versions of official documents generally were available and have been referenced. The review focused on examining research published in the last 10 years covering both peer-reviewed journals and the grey literature.

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<sup>14</sup> For example, Kobelt et al. (2017). New insights into the burden and costs of multiple sclerosis in Europe. *Multiple Sclerosis Journal*. 23(8): 1123-1136.

<sup>15</sup> Trisolini, M., Honeycutt, A., Wiener, J. and Lesesne, S. (2010). Global Economic Impact of Multiple Sclerosis. Multiple Sclerosis International Federation. Available from: [https://www.msif.org/wp-content/uploads/2014/09/Global\\_economic\\_impact\\_of\\_MS.pdf](https://www.msif.org/wp-content/uploads/2014/09/Global_economic_impact_of_MS.pdf). [Accessed 8 August 2017].

- In addition to European-wide literature, we conducted further targeted research and gathered evidence and data on eight European countries. We chose these eight countries because they had diverse healthcare systems and MS policy environments and represented different parts of Europe with different labour market conditions (e.g., female labour market participation).

We also discussed the choice of countries with MS associations to verify it includes a range of different circumstances. Based on this criteria, we selected the following eight markets: Czech Republic, France, Germany, Italy, Poland, Spain, Sweden and the UK. Figure 1 illustrates the countries selected (blue).

**Figure 1: Country coverage in this study**



Source: CRA analysis

The eight European countries in our sample cover 72% of the total European population with MS,<sup>16</sup> and 77% of the estimated number of women with MS in Europe.<sup>17</sup>

As a second step, to capture the local challenges and policy debate in different markets, and to validate our findings from the literature review and help structure the survey, we undertook interviews with national patient associations and patient representatives across the eight markets. We designed the interview questions both to capture the patient organisations' high-level views on the unique challenges faced by women with MS in their respective countries and to elicit their perspectives on the strengths and weaknesses of the MS policy environment. This served to identify the remaining gaps in MS policy support in each market and to capture recommendations on how these unmet policy needs can be

<sup>16</sup> The 33 European countries with available MS prevalence data are: Albania, Austria, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, the Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, Sweden, Switzerland, Macedonia, Turkey, and the United Kingdom.

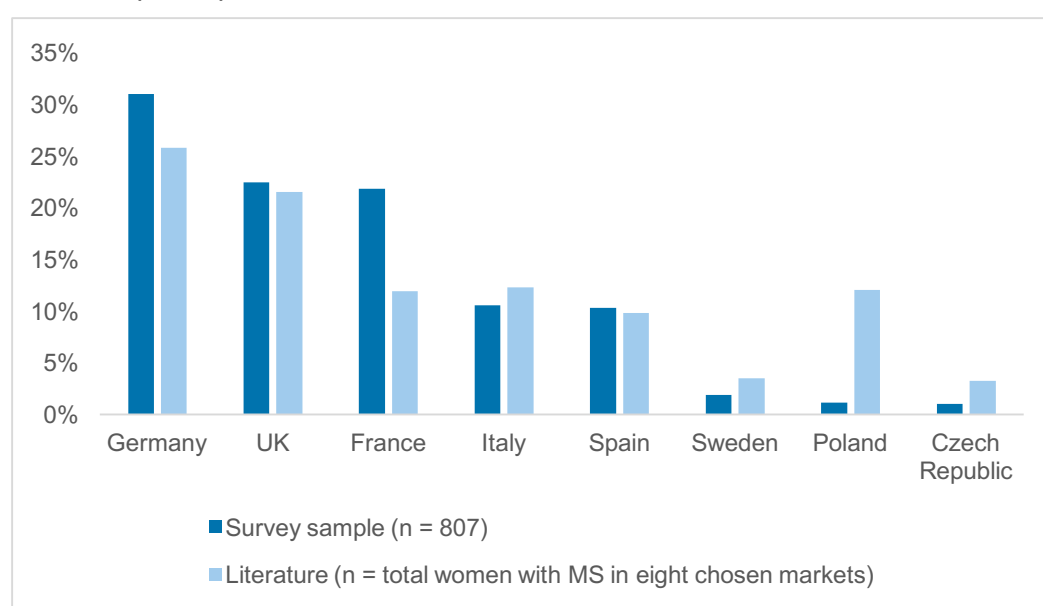
<sup>17</sup> MSIF (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 12 July 2017].

addressed. In total, we conducted 11 interviews across six of the selected countries. These are summarised in Appendix A.

In the third and final step, we commissioned an online survey of 807 women with MS across the eight European countries of interest. This was open from the 6 July 2017 to 30 August 2017. The survey was undertaken independently by a specialised market research partner, Lightspeed Health. All online surveys were conducted in local languages. Respondents were part of Lightspeed Health's own MS patient panels and their external panel partners.

Looking across the eight European countries surveyed, our sample distribution is broadly representative of the population of women with MS in each country, as Figure 2~~Error! Reference source not found.~~ illustrates.<sup>18</sup> In some countries, such as Germany, our sample is over-representative, while in markets such as Czech Republic and Poland our sample is under-representative. In countries where the sample is under-representative, we conducted further interviews with local patient associations (e.g., in Poland we conducted four interviews as compared to one in most other countries). However, for most countries the percentage-point difference between the survey sample distribution and the population statistics is negligible.

**Figure 2: Comparison of distribution of women with MS across eight European countries (n=807)**



Source: CRA analysis, MS Atlas<sup>19,20</sup>

We also endeavoured to ensure that our survey sample was representative between types of MS, as Figure 3 illustrates. The survey sample included women with benign MS and

<sup>18</sup> MS International Federation (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017].

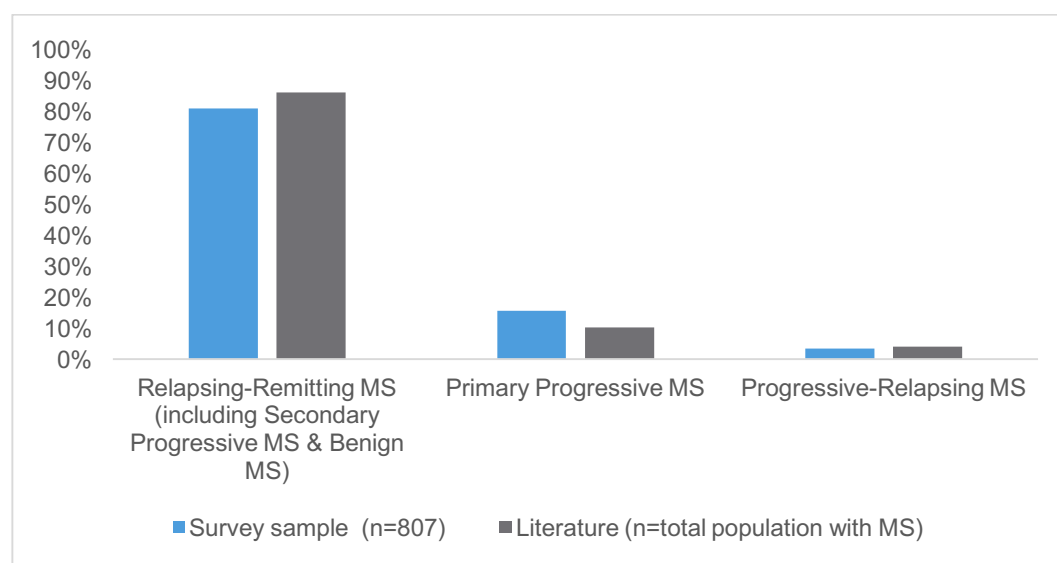
<sup>19</sup> MS International Federation (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017].

<sup>20</sup> MS International Federation (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017].



those who are unsure of their exact severity at the time they completed the survey. However, the disease type of benign MS patients is often characterised as a 'mild' form of relapsing-remitting MS (RRMS) as, with time, patients are prone to experience relapses.<sup>21,22</sup> Therefore, for the purposes of comparing the distribution in the sample to global estimates we have re-categorised respondents with benign MS as having RRMS. Figure 3 presents the results of this exercise. We find the percentage-point difference between the survey sample distribution and the population prevalence statistics is small.<sup>23</sup>

**Figure 3: Comparison of distribution of type of MS in women in survey and in population (n=807)**



Source: CRA analysis, MS Atlas<sup>24</sup>

The survey, which we designed with the input of national and European MS patient associations, sought to collect socioeconomic data to illustrate the impact of MS on women and to identify any unmet policy needs. As well as the extent to which MS prevents women from actively contributing to social and economic activities, the survey also endeavoured to capture the wider aspects of respondents' condition and sought to understand how these affected different areas of their life. It was structured around the following topics:

- Diagnosis and treatment and effect on life choices
- Employment status
- Social and family life

<sup>21</sup> MS Trust (2014). *Types of MS*. Available from: <https://www.ms-trust.org.uk/a-z/types-ms>. [Accessed 27 July 2017].

<sup>22</sup> MS Society (2016). *Benign MS*. Available from: <https://www.mssociety.org.uk/what-is-ms/types-of-ms/benign-ms>. [Accessed 27 July 2017].

<sup>23</sup> The number reported strictly as RRMS is under-representative. However, including benign MS and SPMS patients in the category with RRMS does not have a significant impact on the results or change our conclusions.

<sup>24</sup> MS International Federation (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017].

- Caregiving duties
- Support needs from the environment and policy

In order to understand whether MS has a particular impact on women we compare the results to different benchmarks. This draws on academic literature and existing surveys.<sup>25</sup> For example, we compare the average length of time to diagnosis identified in the survey to official timelines published by national health authorities. Similarly, we use national population statistics to compare to average employment figures suggested by survey data.

### **1.3. Structure of the report**

This remainder of the report is structured as follows:

- Section 2 examines the challenges women face obtaining a diagnosis of and treatment for MS.
- Section 3 reviews the subsequent impact of these delays on women's life choices, particularly family life, social life and their ability to maintain their role as a caregiver to others.
- Section 4 reviews the impact of MS on women's career choices, employment status and productivity in the workplace.
- Section 5 draws together our conclusions and the policy implications for all eight countries examined.

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An alternative methodology would have been to include both men and women in the survey instrument. We chose to focus the survey on only women so that we could gather the richest possible picture of the impact of MS on women today.

## 2. Time to diagnosis and accessing treatment

Considerable evidence shows that women with MS are diagnosed at an earlier age than men with MS, have a slower disease and disability progression and have a longer life expectancy.<sup>26-27</sup> This section examines the extent to which women are faced with specific challenges as a result of the diagnosis process and how the disease is manifested once they are diagnosed. This section goes on to illustrate how an MS diagnosis can have a profound effect on women's choices in life, such as their education and career decisions.

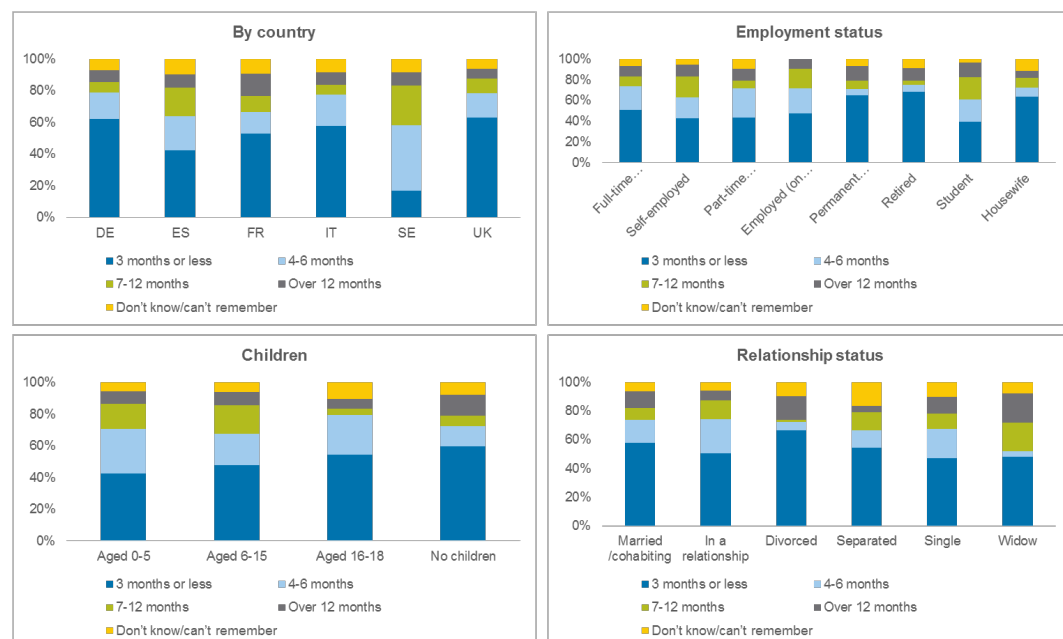
### Diagnosis

The first contact with the healthcare system is most commonly initiated by the patient, who visits a primary care physician (PCP).<sup>28</sup> The diagnosis process begins with a clinical examination of the patient by the PCP, who will take into account the patient's reported disorders and observable symptoms, and will review the patient's neurological history and family medical background. Evidence and discussions with patient associations show that women tend to generally delay their first doctor visit more than men, primarily due to multiple commitments in the household, such as looking after their children, and in the workplace.<sup>29</sup>

The survey revealed that although the majority of all the women in the sample visited a doctor in the first three months after experiencing symptoms, there are significant differences depending on the country, the employment and marital status of the patient, and whether the patient has children—we present these in Figure 4.<sup>30</sup> Patients in Germany, the UK and Italy have the earliest first doctor visits. According to interviews, this is likely due to a combination of factors, but most importantly the degree of public and PCP awareness and knowledge of MS symptoms and the ease of access to the primary health doctor/general practitioner. Whereas the general environment is likely to influence women and men with MS to a similar extent, looking after young children is a factor that will have a large impact on women with MS. In terms of their relationship status, the evidence is not conclusive on differences between women that are in a relationship and those that are not.

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- 26 Harbo, H., Gold, R. and Tintore, M. (2013). Sex and gender issues in multiple sclerosis. *Therapeutic advances in neurological disorders*. 6 (4), 237-248. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3707353/>. [Accessed 30 March 2017].
- 27 Lunde, H., Assmus, J., Kjell-Morten, M., Bo, L. and Grytten, N. (2017). Survival and cause of death in multiple sclerosis: a -50-year longitudinal population study. *J Neurol Neurosurg Psychiatry*, 1-5
- 28 Apotheken Umschau. "Multiple Sklerose (MS): Diagnose". Available from: [http://www.apotheken-umschau.de/Multiple-Sklerose/Multiple-Sklerose-MS-Diagnose-18894\\_5.html](http://www.apotheken-umschau.de/Multiple-Sklerose/Multiple-Sklerose-MS-Diagnose-18894_5.html). [Accessed 6 October 2015].
- 29 CRA interview programme with patients/patient associations in France, Spain and Poland.
- 30 This is consistent with existing evidence from Spain which shows the phase between onset of first symptoms to the first visit to a physician represents great delay in diagnosis (e.g., in Spain this stands at a median of 19 months). Fernández O., Fernández V., Arbizu T., Izquierdo G., Bosca I., Arroyo R., García Merino J.A. and de Ramón E. (2010). Characteristics of multiple sclerosis at onset and delay of diagnosis and treatment in Spain. *J Neurol*. 257 (9), 1500-7.

**Figure 4: Time from symptoms to presenting to a doctor for the first time, by country, employment and relationship status and number of children (n=807\*)**



Source: CRA analysis based on survey data

\*Note: Although the sample in Czech Republic and Poland is too small (excluded in analysis by country), the evidence would suggest that delays are significantly higher.

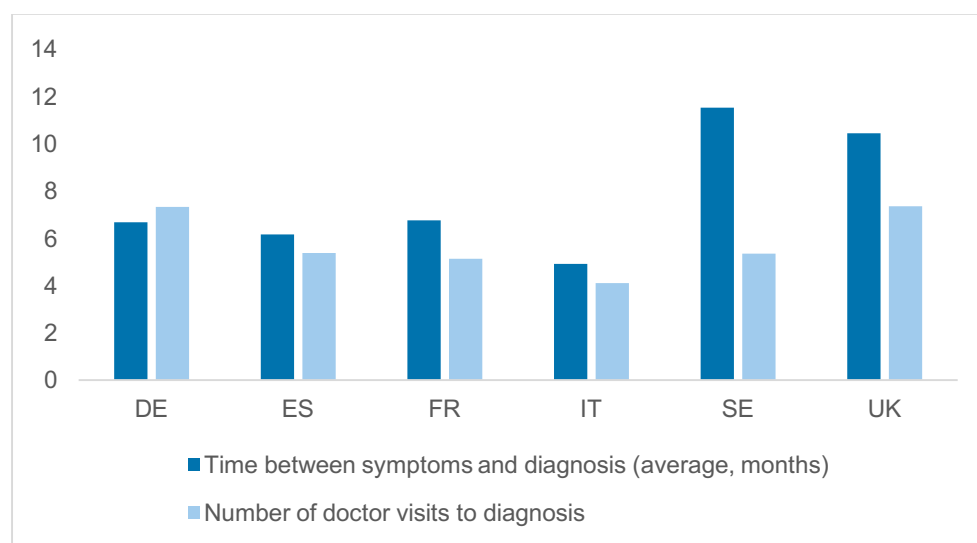
Visiting the doctor for the first time, more frequently than not, does not result in a diagnosis for MS patients. We consider the length of time between first consultation and diagnosis with MS and the number of visits to the doctor as proxies of diagnosis delays. The length of time to a diagnosis stands at around six months in the sample, but this varies significantly between EU countries from an average of four to five months in Italy and Germany to over seven in the UK and Sweden. Compared to existing evidence on delays in the total population from the MS Atlas, delays in diagnosis in the total population are significantly shorter than for women alone.<sup>31</sup>

Although not a perfect correlation, where diagnosis takes a longer time it also requires more visits to the doctor (see Figure 5). In the UK, the average number of visits to the doctor before a diagnosis was seven compared to four in Italy.

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MS International Federation (2013). *Atlas of MS 2013: Diagnosis of MS*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017].

**Figure 5: Length of time between first experiencing symptoms and diagnosis across European markets (n=807\*)**



Source: CRA analysis based on survey data

\*Note: Although the sample in Czech Republic and Poland is too small (excluded in analysis by country), the evidence would suggest that delays are significantly higher. In addition, patients that have reported not recalling the delays have also been excluded.

According to the interviews, there are a variety of potential factors that can explain the delays in diagnosis across Europe. These include the availability of qualified healthcare professionals and diagnostic tools. Drawing from wider literature, the countries with the highest delays from the six with available data<sup>32</sup> (i.e., the UK and Sweden) have a lack of awareness of MS symptoms, insufficient training in PCPs, a culture of ‘watching and waiting’ for symptoms to formalise, shortages in specialised care staff and cost and time variation in accessing MRI scanners (e.g., delays in Sweden for MRI scans are 9-12 weeks, which is one of the highest in Western Europe).<sup>33,34</sup>

We find that the type of MS affect the delay in diagnosis in women. Based on the total survey data, women were diagnosed with MS an estimated six months after first experiencing symptoms. Figure 6 illustrates that time to diagnosis varies by type of MS, as patients with RRMS and SPMS were diagnosed in the shortest time-frames—at around three to five months. In general, the graph suggests that women that suffer from relapses and therefore have more ‘obvious’ signs of MS are likely to be diagnosed earlier, relative to patients that suffer from a gradual worsening of symptoms (i.e., patients with PPMS). This is consistent with the data on PRMS, which indicated a 12 month delay (although based in a limited sample). Overall, we find that the time taken to diagnose women with MS

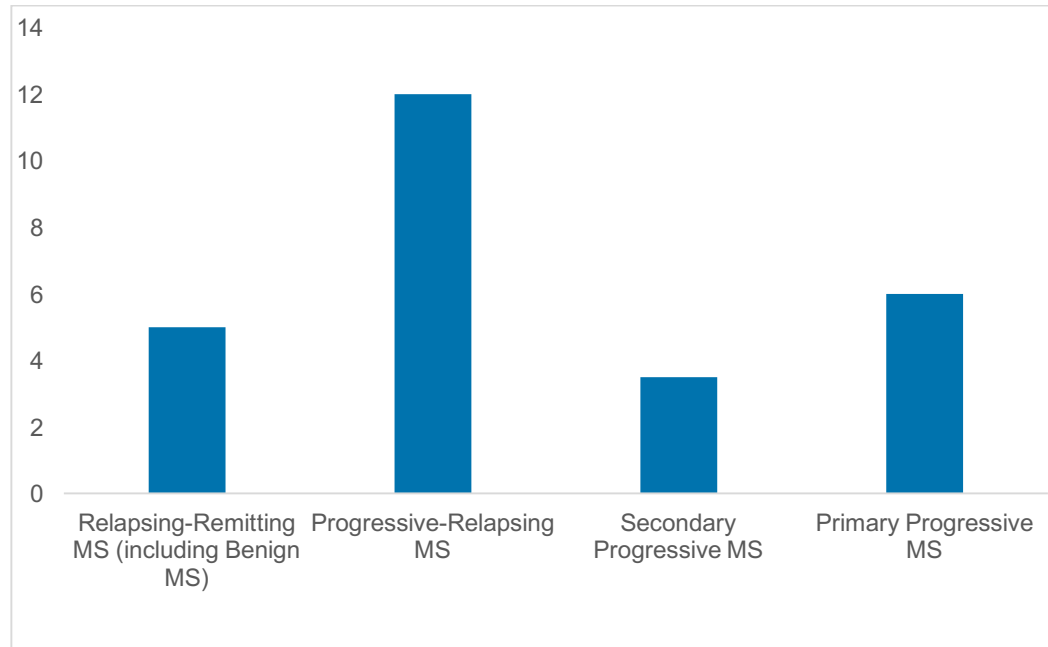
<sup>32</sup> This does not include the Czech Republic and Poland.

<sup>33</sup> Charles River Associates (2016). Policy proposals to improve access to MS treatments in Europe. Available from: <https://www.crai.com/sites/default/files/publications/CRA-Biogen-Policy-proposals-to-improve-access-to-MS-treatments-in-Europe-525.pdf>. [Accessed 20 July 2017].

<sup>34</sup> MS International Federation (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017].

is longer than for men and more challenging (women visit a healthcare professional an average of five times before being diagnosed with MS).

**Figure 6: Length of time between experiencing symptoms and diagnosis of MS (median, months) (n=807)**



Source: CRA analysis based on survey data

Finally, frequent misdiagnosis is a significant issue contributing to delays in diagnosis. Based on survey data, over one-fifth (21%) of women were misdiagnosed with a different illness prior to being diagnosed with MS. Common misdiagnoses included trapped nerve, depression, brain tumour, epilepsy and chronic pain, while some women were also told they were imagining their symptoms.

The inefficiencies in the diagnosis system are also reflected in the reported satisfaction with the process. Based on the survey results, 47% of women with MS in Europe think that the time between their first doctor visit and final diagnosis is long or very long as opposed to 46% that believe the length of time was about right. We note that the proportion of dissatisfied women patients is greater in countries where the reported delays are higher (e.g., 54% in the UK versus 42% in Germany versus 41% in Italy).

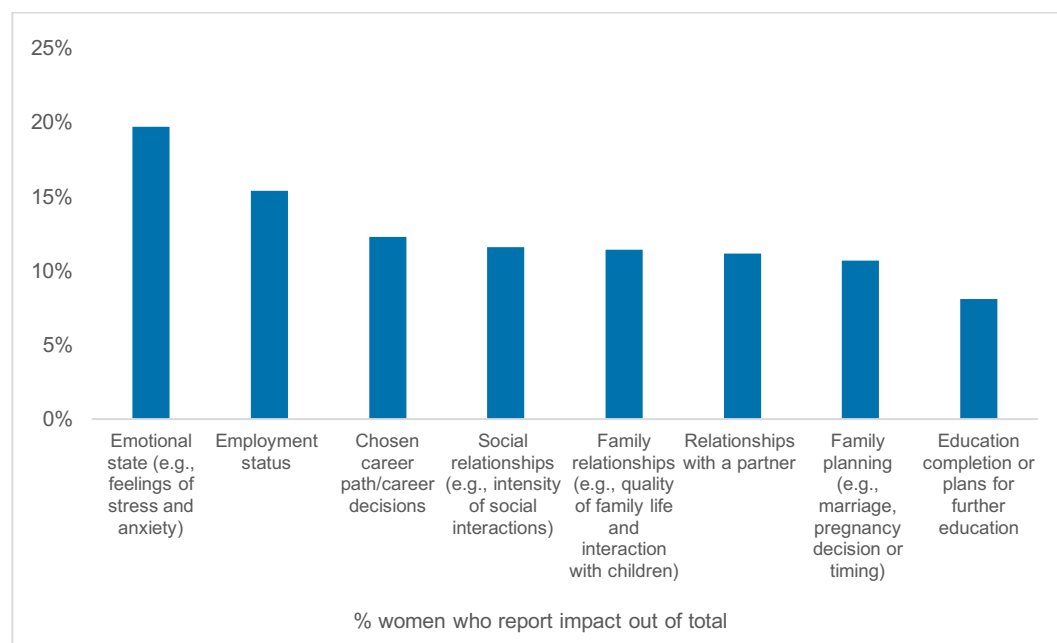
In addition to a delay in accessing treatment and care, a long diagnosis process causes uncertainty. According to interviews with patient groups, a long diagnosis process can have a significant impact on decisions women make about their lives. They emphasised that the uncertainty about their diagnosis with the disease and its likely progression has an immediate impact on the patient and their families, as it needs to be taken into account in future plans.<sup>35</sup> The survey evidence illustrates that the time taken to receive an MS diagnosis significantly impacted women's emotional state, employment status and career

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CRA interview programme with patients/patient associations.

path, and also affected a wider range of decisions on family planning and social engagement.

**Figure 7: Areas of life highly impacted by time taken to obtain receive MS diagnosis (n=807)**



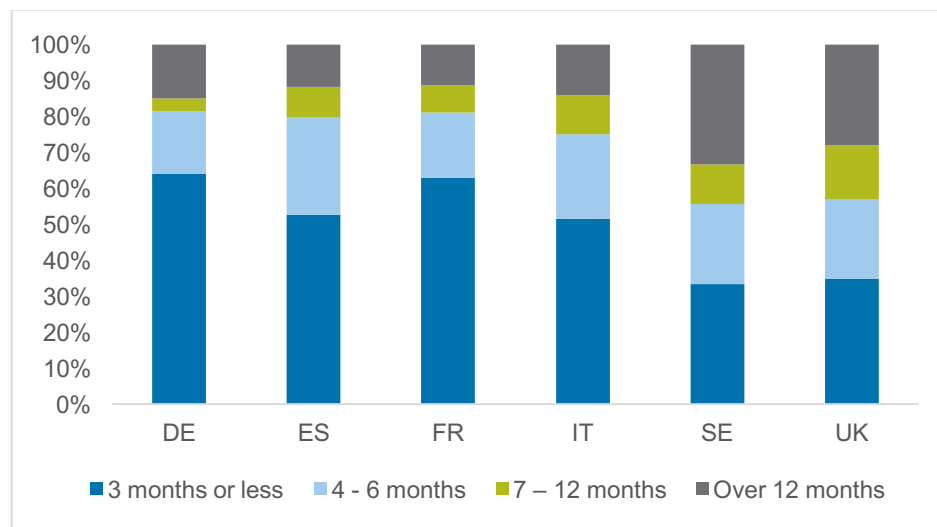
Source: CRA analysis based on survey data

### *Treatment*

Patients are typically referred to a neurologist who is responsible for initiating MS treatment. Based on survey evidence, women report different times for access to treatment across countries, as Figure 8 shows. These findings are largely in line with the prior research on access to medicines for MS patients. Studies have found that whilst European countries have guidelines on treatment initiation, these are not uniform in terms of a doctor's freedom to prescribe medication and physicians are not uniformly following them. In Germany, France and Spain guidelines are not mandatory, and neurologists are permitted to prescribe all approved disease-modifying drugs with no or few reimbursement restrictions. This allows them to initiate treatment rapidly based on their view of the best course of treatment.<sup>36</sup>

<sup>36</sup>

Charles River Associates (2016). Policy proposals to improve access to MS treatments in Europe. Available from: <https://www.crai.com/sites/default/files/publications/CRA-Biogen-Policy-proposals-to-improve-access-to-MS-treatments-in-Europe-525.pdf>. [Accessed 20 July 2017].

**Figure 8: Delay in access to treatment, by country (n=576\*)**

Source: CRA analysis based on survey data

\*Note: Although the sample in Czech Republic and Poland is too small (excluded in analysis by country), the evidence would suggest that delays are significantly higher. In addition, patients that have reported not recalling the delays have also been excluded.

### **Summary diagnosis and access to treatment**

Women with MS are diagnosed at an earlier age than men with MS are, and suffer from slower progression of the disease.<sup>37,38</sup> In this section, we show that women face a longer delay in getting a diagnosis, they need a greater number of visits to healthcare providers and there is a high proportion of women being misdiagnosed. The length of time taken before a final diagnosis has an immediate impact on women, as well as contributing to delayed access to treatment.

<sup>37</sup> Harbo, H., Gold, R. and Tintore, M. (2013). Sex and gender issues in multiple sclerosis. *Therapeutic advances in neurological disorders*. 6 (4), 237-248. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3707353/>. [Accessed 30 March 2017].

<sup>38</sup> Lunde, H., Assmus, J., Kjell-Morten, M., Bo, L. and Grytten, N. (2017). Survival and cause of death in multiple sclerosis: a 50-year longitudinal population study. *J Neurol Neurosurg Psychiatry*, 1-5.



### 3. Life choices, family, social interaction and care provision

The survey revealed that women in our sample were diagnosed with MS around the age of 32 (median of the sample), which according to our interviews is typically younger than is the case for men.<sup>39</sup> Given this is a critical age for undertaking decisions about career progression and making family plans, and because the severity of certain symptoms differs depending on whether the patient is male or female, it is possible this has a different impact on women than men. For example, existing evidence suggests that women are more prone to MS symptoms, such as depression and fatigue, compared to men,<sup>40</sup> and that the increased burden of MS symptoms on women has a greater impact on women's relationships with their partners and family, relative to those of men with MS.<sup>41</sup> This section investigates how MS can affect women's physical, mental and emotional wellbeing, and the burden on their family and social life. This section goes on to describe how MS can limit women's daily life, which can lead to them being socially excluded and even discriminated against.

#### 3.1. Impact on family relationships

MS can place a significant burden on women's relationships in a variety of ways. Figure 9 reflects the results of MS-related pressures on relationships. The survey reveals that since being diagnosed with MS, over two-fifths (41%) of women with MS had separated or divorced from their partners. Of these women, the vast majority (88%) reported that MS had played a factor in their relationship change. This is supported by the existing literature, which finds that the risk of divorce after diagnosis of MS is higher when the woman is the affected partner, implying that women with MS are more prone to separation.<sup>42</sup> Findings from interviews with patient organisations corroborate this conclusion and reveal that because women are diagnosed earlier in life, their partners are sometimes not prepared to devote time to looking after their partners, which can place pressure on relationships.<sup>43</sup> By contrast, men are diagnosed later in life and may tend to be in more stable relationships by then.

<sup>39</sup> By comparison, the average age of diagnosis for both sexes is typically reported as 34. eMedicineHealth.com (2017). "Multiple Sclerosis, Causes, Symptoms, Signs, and Treatment Guidelines." Available from: [http://www.emedicinehealth.com/multiple\\_sclerosis/article\\_em.htm](http://www.emedicinehealth.com/multiple_sclerosis/article_em.htm). [Accessed 17 October 2017]. Although it should be noted that MSIF conclude that the average age of MS onset is 30 years. MS International Federation (2013). *Atlas of MS 2013*. Available from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>. [Accessed 15 July 2017]

<sup>40</sup> Marrie, R.A. et al. (2015). Differences in the burden of psychiatric comorbidity in MS vs the general population. *Neurology*. 85:1-8.

<sup>41</sup> Harbo, H., Gold, R. and Tintore, M. (2013). Sex and gender issues in multiple sclerosis. *Therapeutic advances in neurological disorders*. 6 (4), 237-248. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3707353/>. [Accessed 30 March 2017].

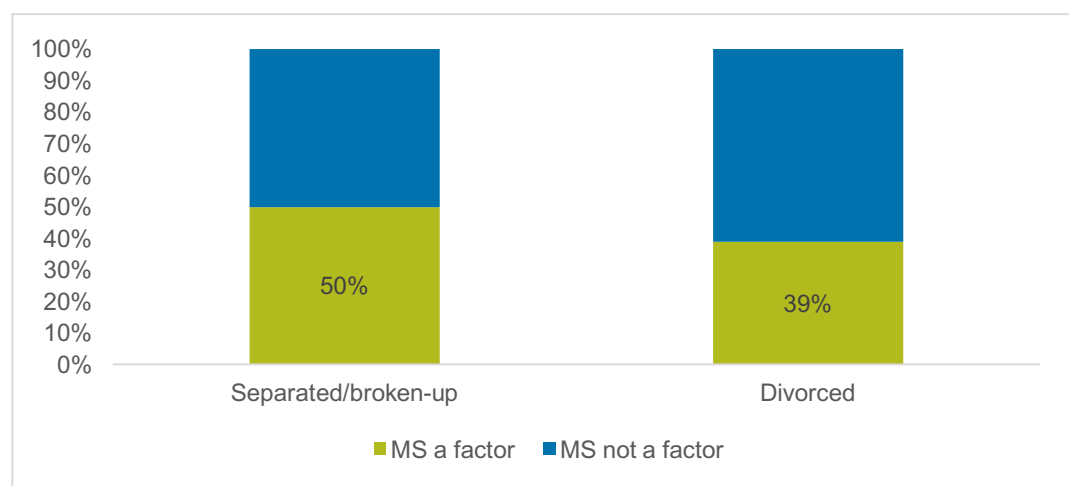
<sup>42</sup> Glantz, M.J. et al. (2009). Gender disparity in the rate of partner abandonment in patients with serious medical illness. *Cancer*. 115(22): 5237-5242.

<sup>43</sup> CRA interview programme with patients/patient associations.

Studies find that depression places an additional strain on women's relationships.<sup>44</sup> Research also finds that women with MS can suffer from sexual dysfunction, which places a further burden on relationships.<sup>45,46</sup> In addition, the survey finds that almost two-fifths (37%) of women had reported that MS-related family planning decisions had negatively impacted their relationships with their spouse or partner. However, it should be noted that all patients are different. For example, 21% of women with MS had married after being diagnosed.

However, it is clear that MS puts a strain on family relationships. Over two-fifths of these women (44%) reported that MS had played a factor in this decision. Interviews with patient organisations highlighted the need for greater support for women reducing the strain on family relationships.<sup>47</sup>

**Figure 9: The impact of MS on women's relationship status: share of women where MS played a factor in their relationship change (n=357)**



Source: CRA analysis of patient survey data

### ***Planning for a pregnancy***

There are now several disease-modifying therapies (DMTs) for relapsing forms of MS, but they are not recommended for use in patients who are pregnant, trying to become pregnant or who are breastfeeding.<sup>48</sup> In addition, the first three months postpartum are a recognised high-risk period for increased likelihood of relapse. Pregnancy issues and management

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- 44 Harbo, H.F., Gold, R. and Tintoré, M. (2013). Sex and gender issues in multiple sclerosis. *The Advanced Neurological Disorders*. 6(4):237-248.
- 45 Hakim, E.A. et al. (2000). The social impact of multiple sclerosis—a study of 305 patients and their relatives. *Journal Disability and Rehabilitation*. 22(6).
- 46 Mohammadi, K. et al. (2013). Determinants of sexual dysfunction in women with multiple sclerosis. *BMC Neurology*. 13:83.
- 47 CRA interview programme with patients/patient associations.
- 48 Coyle, P.K. (2016). Management of women with multiple sclerosis through pregnancy and after childbirth. *Ther. Adv. Neurol. Disord.* 9(3): 198-210.

concerns are likely to have a particular impact on women.<sup>49</sup> As a result, some impacts of MS are likely to be specific to women given their role in the family, particularly with regard to pregnancy.

The survey results reveal that, on average, over one-third (37%) of women with MS either decided to not have children or altered the timing at which they had children. Further, 31% of women decided to not have children altogether or had fewer pregnancies than intended prior to their diagnosis with MS. This was supported by interviews with patient organisations which revealed that family planning issues were common among women with MS.<sup>50</sup> It was also consistent with several existing studies that examine the relationship between MS diagnosis and motherhood decisions and conclude that women with MS are less likely to have children.<sup>51</sup>

Women reported symptoms such as fatigue (17%) and pain (14%) as aspects of their MS which influenced their family planning decisions. These findings are aligned with the findings from the patient organisation interviews, which reveal that many women fear the inability to look after their children and not being able to live up to their perception of being a 'good' mother.<sup>52</sup> These trends were consistent across the types of disease, although patients with RRMS were most likely to report that symptoms influence their family planning symptoms. Studies examining this issue support this, highlighting six main factors included in a woman's family planning considerations: concerns about the mother's own health and well-being; the child's well-being; coping with parenting; societal attitudes; experiencing parenting; and timing and pressure of the decision.<sup>53</sup> There is evidence that family planning decisions are linked to increased likelihood of relapse after childbirth and the need to pause MS treatment during pregnancy.<sup>54</sup>

The interviews also reveal a lack of education and awareness of pregnancy issues among women with MS. For example, according to interviews some women in Poland avoid pregnancy for fear of their MS being passed on to their children.<sup>55</sup> The interviews revealed that a breakdown in communication between physicians and patients is often to blame for this. In the UK, there is a lack of consistency in advice about implications of pregnancy whilst on treatment.<sup>56</sup> The disparity in guidance also arises because new research is being produced so rapidly. Because of this, physicians and patient groups are risk-averse,

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49 Coyle, P.K. (2016). Management of women with multiple sclerosis through pregnancy and after childbirth. *Ther. Adv. Neurol. Disord.* 9(3): 198-210.

50 CRA interview programme with patients/patient associations.

51 Carvalho, A.T. et al. (2014). Multiple sclerosis and motherhood choice: an observational study in Portuguese women patients. *Review of Neuroscience.* 59: 537-42.

52 CRA interview programme with patients/patient associations.

53 Prunty, M., Sharpe, L. and Butow, P. (2008). The motherhood choice: Themes arising in the decision-making process for women with multiple sclerosis. *Multiple Sclerosis Journal.* 14(5).

54 Harbo, H.F., Gold, R. and Tintoré, M. (2013). Sex and gender issues in multiple sclerosis. *The Advanced Neurological Disorders.* 6(4):237-248.

55 CRA interview programme with patients/patient associations.

56 CRA interview programme with patients/patient associations.

recommending that patients avoid treatment altogether when pregnant. The result is that women are presented with a difficult choice between continuing treatment and starting a family. Interviews with the Spanish MS organisation emphasised that the burden of MS on pregnancy decisions of women is reflected by the increase in demand for literature and education materials on the issue.<sup>57</sup>

### *Impact on psychological and emotional health*

The survey shows over one in ten (12%) of women were suffering from depression or anxiety which they reported as due to MS. This is greater than the average proportion of women suffering from chronic depression in the European population (8%).<sup>58</sup> Further, the survey results are consistent with the existing literature evidence that suggests that women with MS are more prone to being diagnosed with depression and anxiety than men with MS are. Interviews with a patient organisation in the Czech Republic revealed that women's psychological burdens are related to the uncertainty of the disease itself, and from the perceived inability or fear of pregnancy and lack of future career or educational prospects.<sup>59</sup>

Women with MS also suffer financially as a consequence of depression. The survey reveals that, on average across Europe, depression or anxiety costs women with MS about €720 per year. This figure covers support such as psychologist and psychotherapy sessions, the cost of antidepressants, vitamin supplements, commuting to psychologist clinics, purchasing relaxation aids such as massages and essential oils, buying extra disability equipment and cars and employing caregivers and cleaners. However, this figure likely understates the financial burden of MS-caused depression and anxiety on women. For example, several studies show the relationship between depression among MS patients and reduced productivity at the workplace.<sup>60-61</sup> This is supported by the survey findings which revealed that 7% of women perceive their depression to heavily impact their productivity and workplace participation. Furthermore, our estimate does not take into account any impact on the family and friends of those affected. For example, a population-based study in the UK found that the careers of 57% of MS patients' relatives were affected by MS patients' symptoms, including depression.<sup>62</sup>

### *Impact on daily activities*

Interviews with patient organisations revealed that the nature of the disease, particularly the perceived 'randomness' of MS symptoms that is most debilitating to women's daily

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<sup>57</sup> CRA interview programme with patients/patient associations.

<sup>58</sup> Eurostat (2014). *Persons reporting a chronic disease, by disease, sex, age and educational attainment level*. Available from: <http://appsso.eurostat.ec.europa.eu/nui/submitViewTableAction.do>. [Accessed 27 July 2017].

<sup>59</sup> CRA interview programme with patients/patient associations.

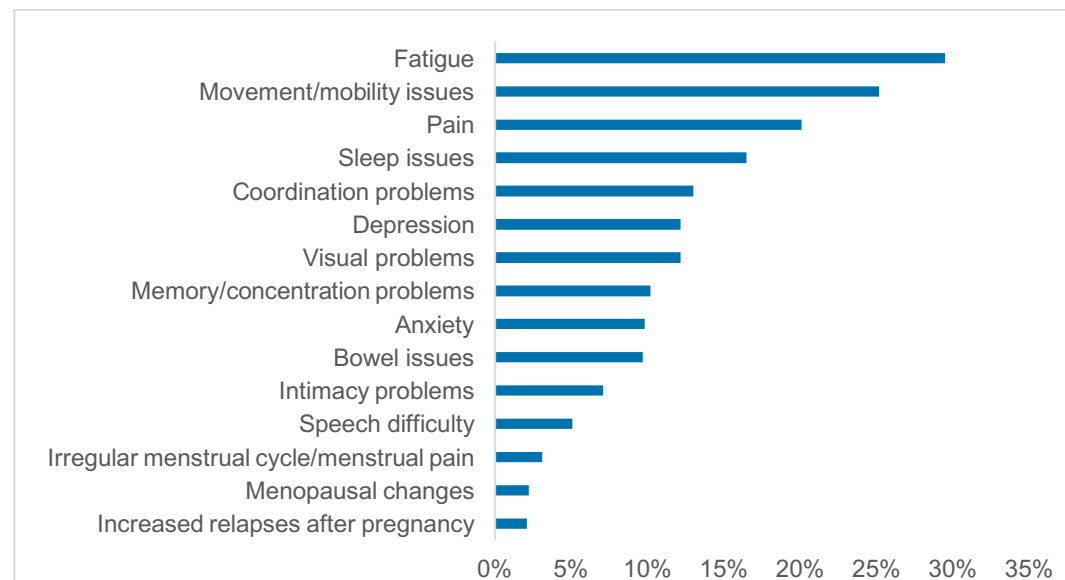
<sup>60</sup> Bevan, S. and Steadman, K. (2015). *Multiple Sclerosis & Employment in Europe: Literature Summary*. Lancaster, The Work Foundation.

<sup>61</sup> Glanz, B.I., Dégano, I.R., Rintell, D.J., Chitnis, T., Weiner, H.L. and Health, B.C. (2012). Work Productivity in Relapsing Multiple Sclerosis: Associations with Disability, Depression, Fatigue, Anxiety, Cognition, and Health-Related Quality of Life. *Value in Health*. 15(8):1029-1035.

<sup>62</sup> Hakim, E.A. et al. (2000). The social impact of multiple sclerosis - a study of 305 patients and their relatives. *Journal Disability and Rehabilitation*. 22(6).

lives.<sup>63</sup> The survey results support this by illustrating that a wide range of symptoms impact women's lives. The most commonly reported symptoms to have a heavy burden on women's lives include fatigue, mobility issues and pain and sleep issues (Figure 10).

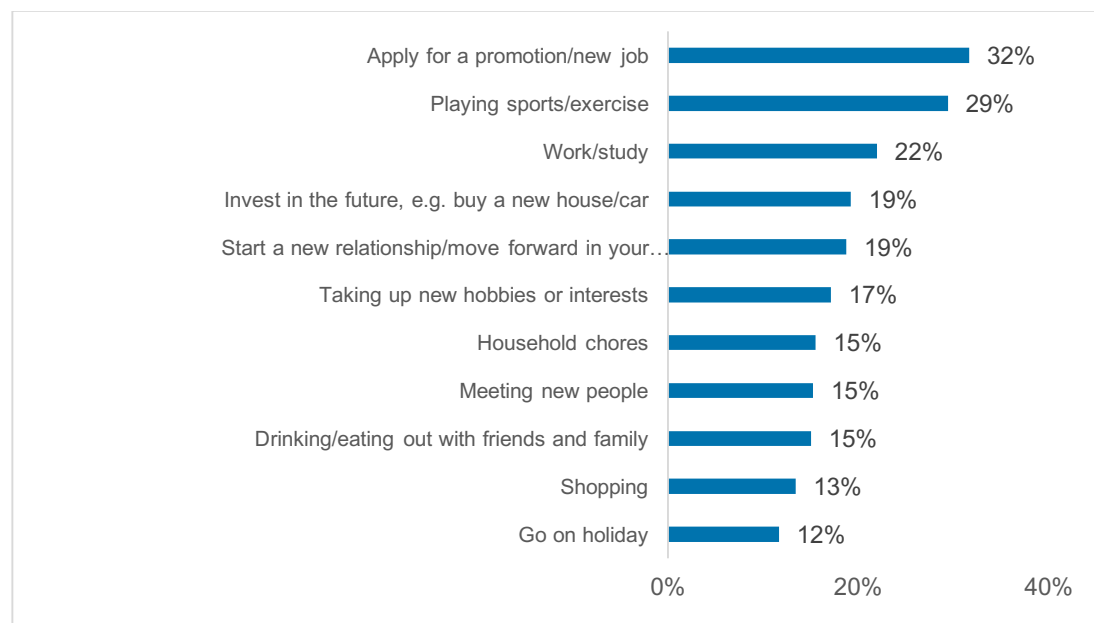
**Figure 10: MS symptoms that have a high impact on women's daily lives, percentage of all symptoms with high impact (n =807)**



Source: CRA analysis of patient survey data

Figure 11 reflects the burden of MS symptoms on women's social activities. The survey finds that women are less likely to participate in a range of activities, such as applying for a new job or promotion (32%) and staying fit through sport or exercise (29%). Notably, many women also avoid investing in the future, both in personal terms, such as starting a new relationship (19%), and financially, such as buying a new house (19%). These trends are in part explained by the evolving nature of MS, and how symptoms worsen overtime and change in composition. For example, the survey reveals that over two-fifths (46%) of women noted that their fatigue had worsened over their course of MS. In addition, approximately 35% of women noted that movement and mobility issues had become more severe over the course of their condition.

**Figure 11: Activities women are much less likely to participate in since MS diagnosis, percentage of all activities less likely to participate (n = 807)**



Source: CRA analysis of patient survey data

### ***Social exclusion***

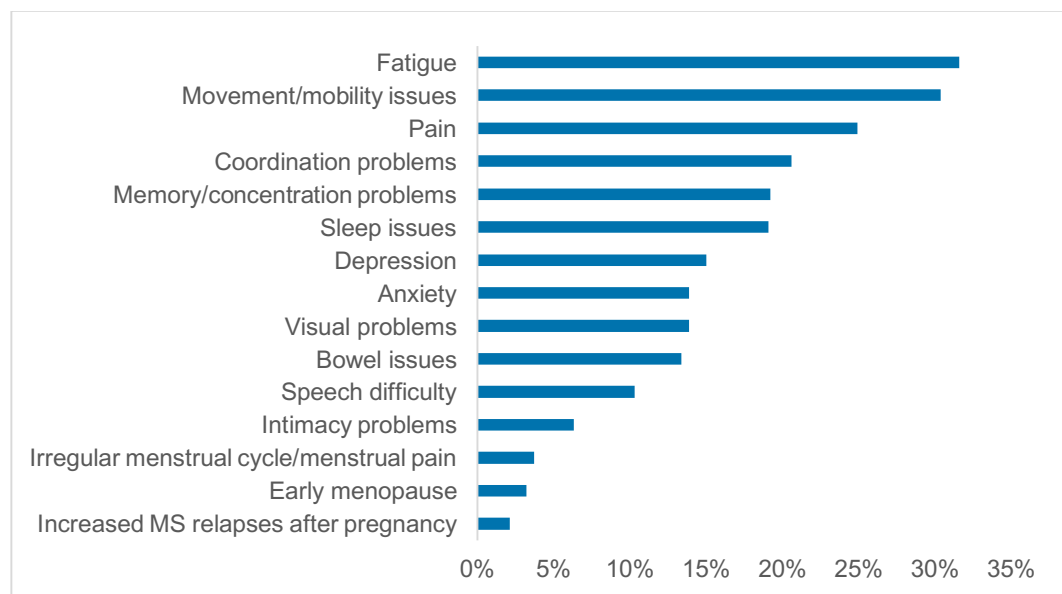
According to Women Enabled International, 'women and girls with disabilities are more likely to be discriminated against than men and boys with disabilities, and women and girls without disabilities'.<sup>64</sup> Patient organisation interviews also reveal that women with MS often feel discriminated against, especially in the workplace.<sup>65</sup> The survey results also find that the majority of women with MS (64%) feel (at least slightly) discriminated against. Women with RRMS (including secondary progressive MS) were more likely to feel socially excluded or discriminated against (50%) relative to women with primary progressive MS and progressive-relapsing MS.

Figure 12 reveals that the key contributing factors to women's sense of exclusion or discrimination were fatigue, movement and mobility issues, pain and coordination problems, all of which were rated as being an 'extreme factor' in exclusion and discrimination.

<sup>64</sup> Women Enabled International (2017). Women Enabled International Guide to CRPD General Comment No. 3: Women and Girls with Disabilities.

<sup>65</sup> CRA interview programme with patients/patient associations.

**Figure 12: MS symptoms that contribute to women's sense of social exclusion or discrimination, percentage of all symptoms (n=807)**



Source: CRA analysis of patient survey data

### ***Summary of burden and support***

The findings from the literature, survey evidence and patient organisation interviews reveal a significant burden of MS on women with respect to their social activities, mental wellbeing, family planning and relationships. We find that women with MS are more prone to depression and anxiety. They also face different challenges than men do, such as deciding between pregnancy and continuing treatment. We also find that women with MS are more likely to be divorced following diagnosis, compared to male patients. These findings highlight that the impact of MS on women is unique and differs from that of men.

MS symptoms can limit women's options, from the way they participate in social activities to their decisions about motherhood, which can lead to a cycle of depression and anxiety. This can further burden women's relationships with their families and partners. The results find that women are less likely to participate in social activities after being diagnosed with MS. This, in part, could contribute to women's reported sense of social exclusion and discrimination, although findings from interviews suggest that lack of general public awareness of MS is also to blame.<sup>66</sup> The cumulative impact of these effects limits the options women with MS have, leading to a sense of a loss of independence and isolation from society.

## **3.2. Impact on care**

Although this is changing, women continue to play a much greater role in both formal and informal caregiving and other household care responsibilities than men. Caregiving relates to personal assistance to children and older or disabled family members, such as parents or partners. This social role is regarded as cultural in European societies and persists in

most countries. Faced with ageing populations and a lack of formalised and publicly backed caregiving support in many countries, the contribution of informal caregivers is very important to society and the economy.<sup>67</sup> In this section of the analysis, we discuss two ways in which MS impacts women caregivers, as a patient or as the carer of one.

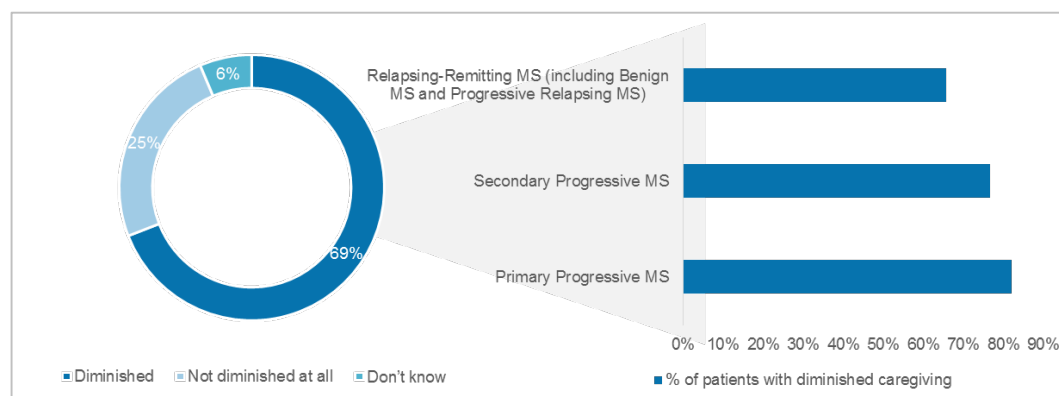
### 3.2.1. Impact on women carers with MS

Given that women are often diagnosed with MS in their 20s and 30s, they are highly likely to have a caregiving role at the time of diagnosis. This can involve care for children, elderly parents or loved ones, partners, and general household care. The sometimes debilitating nature of the disease can have three effects:

- A direct effect on women patients, who feel less able to fulfil their caregiving duties which are very valuable to them (e.g., value of motherhood);
- An impact on those they care for, as they may be subject to less support (e.g., children that need to be self-sufficient); and
- An impact on the patient's partner who may need to undertake additional caregiving activities, which they otherwise would not have had to do.

We find that a majority (69%) of women with MS who have caregiving responsibilities reported that the care they could provide was negatively affected at some point, as Figure 13 shows. A third of the affected women reported that their ability to provide care was very much diminished or was completely lost. We also note that the proportion of women with diminished caregiving roles is higher in more progressive stages of the disease (and those with fewer options to manage and treat their condition, such as women with PPMS).

**Figure 13: Diminished care capabilities across women with MS, and by type of MS (n=330)**



Source: CRA analysis

Lost or reduced ability to care for others has a large impact on women, causing emotional distress, particularly if related to childcare. We find about 40% of mothers reported some diminished ability to provide care. This has a significant impact on their own perception of

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European Commission DG Justice (2011). *Gender equality in caring responsibilities over the lifecycle*. Available from: [http://ec.europa.eu/justice/gender-equality/files/conference\\_sept\\_2011/background-paperiii-equality-in-caring\\_en.pdf](http://ec.europa.eu/justice/gender-equality/files/conference_sept_2011/background-paperiii-equality-in-caring_en.pdf). [Accessed 24 July 2017].



their ability to be a 'good mother'.<sup>68</sup> Patient representatives in France report that women struggle with the idea of losing the ability to provide care.<sup>69</sup>

In addition, a lost or reduced ability to provide care impacts the individuals who receive the care, as they need to either take care of themselves, which may not be possible or optimal, or seek other help. This emerged as an important theme in discussions with patient associations across European countries both in terms of the direct impact for children of mothers with MS and also for the mothers themselves. Past research reports that there is a considerable impact on children, and adolescents with parents suffering from MS are subject to greater responsibility and obligation than children of healthy parents.<sup>70</sup> They also exhibit a greater sense of burden and a greater degree of anger, which can result in behavioural problems.<sup>71-72</sup>

This can also have a financial impact. Indeed, based on the survey data, 68% of cases where additional support is provided are paid for by the patient or their family, as Figure 14 shows. The MS patient personally pays in two out of the three cases where professional support is provided, posing a direct financial strain. Based on the limited number of responses that suggested the magnitude of this spending, we estimate it as €40 to €100 per week (median). Interviews with a patient organisation in Poland revealed that this is a significant cost, particularly when support is needed after regular working hours.<sup>73</sup>

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<sup>68</sup> Willson et al. (2017). The impact of multiple sclerosis on the identity of mothers in Italy. *Disability and Rehabilitation*. 1-12.

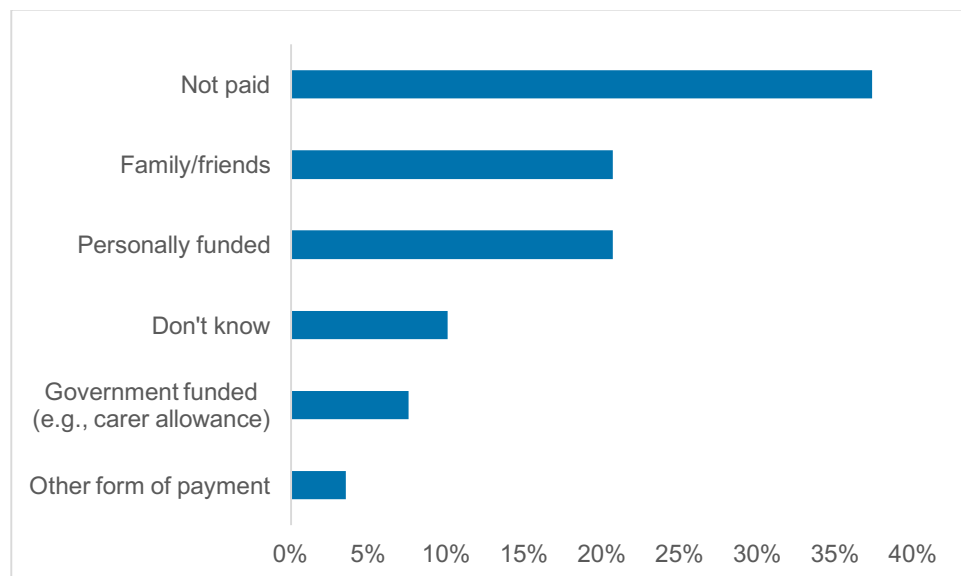
<sup>69</sup> CRA interview programme with patients/patient associations.

<sup>70</sup> CRA interview programme with patients/patient associations.

<sup>71</sup> Yahav, R., Vosburgh J. and Miller A. (2005). Emotional responses of children and adolescents to parents with multiple sclerosis. *Multiple Sclerosis Journal*. 11 (4): 464-468.

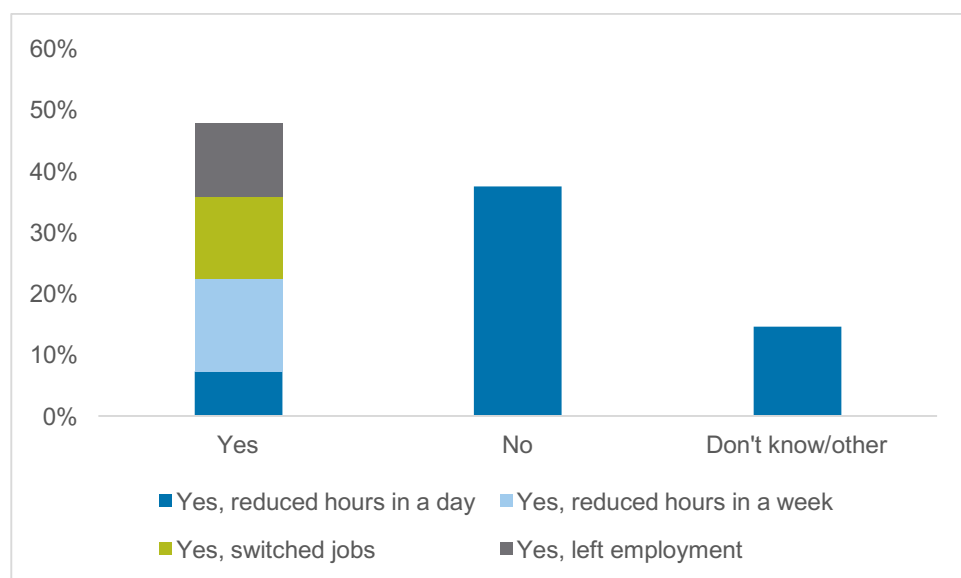
<sup>72</sup> Diareme, S., Tsiantis J., Kolaitis G., Ferentinos S., Tsalamaniotis E., Paliokosta E., Anasontzi S., Lympinaki E., Anagnostopoulos D.C., Voumvourakis C. and Romer G. (2006). Emotional and behavioural difficulties in children of parents with multiple sclerosis: a controlled study in Greece. *Eur Child Adolesc Psychiatry*, 15(6):309–318.

<sup>73</sup> CRA interview programme with patients/patient associations.

**Figure 14: Status and source of compensation for support with care (n=198)**

Source: CRA analysis based on survey data

The lack of professional support leads to care being provided by family members or friends. Indeed, as survey responses reported and Figure 15 shows, almost half of the carers have made employment changes. Of these, a significant amount (around 50%) have made drastic changes such as changing jobs or leaving employment altogether, leading to substantial burden to both carer, potentially family (e.g., if the carer is the patient's partner), and more broadly to the economy and society.

**Figure 15: Employment changes in other carers (n=192)**

Source: CRA analysis based on survey data

### 3.2.2. Impact on women as carers of MS patients

MS results in potentially progressive cognitive and physical impairments and from the moment of diagnosis patients are likely to require increasing care from family, partners and

friends. As stated above, the majority of informal caregiver duties are taken by family members and partners and in particular women. In this part of the analysis, we discuss the high level of impact on women that provide informal care to MS patients.

Overall, past research states that informal caregivers may feel uncertainty about the future, financial difficulties, social disruption and isolation, and reduced quality of life related to caregiving.<sup>74</sup> It is widely recognised that the largest share of nonmedical costs of MS is from informal care. Past studies identify two key areas of impact from informal caregivers, which are discussed briefly below:

- *Labour force participation of informal caregivers:* All past research that examined labour force participation found that the informal caregiver role had a negative impact or reported work-related strain. The cost attributed to this impact is often measured by caregivers' lost work time and foregone income as a result of the disease.<sup>75</sup> For example, over a quarter of primary caregivers of MS patients in Spain report 'work-related changes.'<sup>76</sup> In terms of work days lost, prior research provides that on average informal caregivers lose approximately 9.5 days (7.3 days to 12 days) of work a year.<sup>77</sup>
- *Indirect costs to informal caregivers:* Given the increased mortality and disability of MS, the financial burdens for diagnosis and treatment and the uncertain course of the disease, there is an additional psychological and emotional impact to informal caregivers.<sup>78</sup> This in turn leads to reduced quality of life and poorer emotional and physical health for caregivers, which in turn may increase their use of healthcare services. Although the degree of impact may change across studies, all report at least some caregiver burden or adverse impact on their quality of life. A conservative but generally accepted estimate of the economic impact of indirect cost burden to caregivers is 10% to what is estimated for MS patients.<sup>79</sup>

Because women are more involved in the informal care of MS patients they experience greater losses as a result and pose a high impact to society and the economy. The total

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74 Halper, J. (2007). The psychosocial effect of multiple sclerosis: The impact of relapses. *Journal of the Neurological Sciences*, 256, S34-S38.

75 Most studies use a replacement cost method to value informal care, meaning they apply the hourly wage rate for those who provide home care or personal assistance to the time spent by family members providing care for the person with MS.

76 Rivera-Navarro, J., J. Morales-Gonzalez and J. Benito-Leon (2003). Informal caregiving in multiple sclerosis patients: data from the Madrid demyelinating disease group study. *Disability and Rehabilitation*. 25(18), 1057–1064.

77 Multiple Sclerosis International Foundation (2014). *The Global Economic Impact of Multiple Sclerosis*. Available from: [https://www.msif.org/wp-content/uploads/2014/09/Global\\_economic\\_impact\\_of\\_MS.pdf](https://www.msif.org/wp-content/uploads/2014/09/Global_economic_impact_of_MS.pdf). [Accessed 12 July 2017].

78 Figved, N., Myhr, K., Larsen, J. and Aarslan, D. (2007). Caregiver burden in multiple sclerosis: the impact of neuropsychiatric symptoms. *Journal of Neurology, Neurosurgery & Psychiatry*. 78 (10), 1097–1102.

79 Multiple Sclerosis International Foundation (2014). *The Global Economic Impact of Multiple Sclerosis*. Available from: [https://www.msif.org/wp-content/uploads/2014/09/Global\\_economic\\_impact\\_of\\_MS.pdf](https://www.msif.org/wp-content/uploads/2014/09/Global_economic_impact_of_MS.pdf). [Accessed 12 July 2017].

impact of MS from caregiving on women, is impacted by a number of factors which lead to a potential increase or decrease of the total impact from women carers. A number of factors that lead a potential increase or decrease in the overall social impact from women carers generally also affect the total impact on women who care for MS patients. The total burden increases as men rarely drastically change their employment status or leave their job to provide care<sup>80</sup>. However, it should be recognised that although women are set to lose more hours of work, across Europe men have higher salaries,<sup>81</sup> moderating the impact from labour force participation. The impact from indirect cost to caregivers is higher in women carers as they report more caregiver strain and need for emotional support to buffer psychological and emotional distress.<sup>82</sup> However, men care partners report more physical concerns.<sup>83</sup>

Another key determinant of caregiver impact is the extent of MS patient debilitation. Indeed, previous studies have shown that the level of disability, psychiatric symptoms and cognitive impairment in MS patients are associated with caregiver's distress and affected quality of life.<sup>84</sup> For example, caring for someone with SPMS has the highest reported caregiver burden, followed by primary progressive MS and then relapsing-remitting MS.<sup>85</sup> Although we lack caregiver data by patient gender, MS type and symptoms, we can derive some implications with regards to any specific impact on women carers. Partners of men with MS sacrifice their individual and social needs for their husbands and often feel guilty if they cannot fulfil their role as caregiver<sup>86</sup>, and thus are more likely to persist with caregiving even at higher disability levels.

### *Summary of burden and support*

Women provide a disproportionate amount of care in society to children and elderly members of the family. Due to the debilitating nature of MS, it negatively affects any caregiving role, causing an impact on the caregiving women themselves, the people they care for due to the reduced support, and any other carer that needs to undertake additional caregiving. Women with MS report reduced caregiving responsibilities in 68% of cases, which is higher in more progressive stages of the disease (and those with fewer options to manage and treat their condition such as patients with primary progressive MS). Lost or reduced ability to care for others is an impactful issue for women, which causes emotional

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80 CRA interview programme with patients/patient associations.

81 Eurostat (2017). Gender pay gap statistics, Available from: [http://ec.europa.eu/eurostat/statistics-explained/index.php/Gender\\_pay\\_gap\\_statistics#By\\_age](http://ec.europa.eu/eurostat/statistics-explained/index.php/Gender_pay_gap_statistics#By_age). [Accessed 2 August 2017].

82 McKenzie et al. (2015). Care Partners and Multiple Sclerosis: Differential effect on men and women. *International Journal of MS care*. 17 (6), 253-260.

83 McKenzie et al. (2015). Care Partners and Multiple Sclerosis: Differential effect on men and women. *International Journal of MS Care*. 17 (6), 253-260.

84 Figved, N., Myhr, K., Larsen, J. and Aarslan, D. (2007). Caregiver burden in multiple sclerosis: the impact of neuropsychiatric symptoms. *Journal of Neurology, Neurosurgery & Psychiatry*. 78 (10), 1097-1102.

85 McKenzie et al. (2015). Care Partners and Multiple Sclerosis: Differential effect on men and women. *International Journal of MS Care*. 17 (6), 253-260.

86 Keykhaei et al. (2016). Marital quality in the spouses of men with multiple sclerosis: A descriptive comparative study. *International Journal of Medical Research & Health Sciences*. 5 (11), 415-423.

distress, particularly if related to childcare. The survey results show that although those women that have children have more support than the overall group, over 42% report a lack of any form of support.

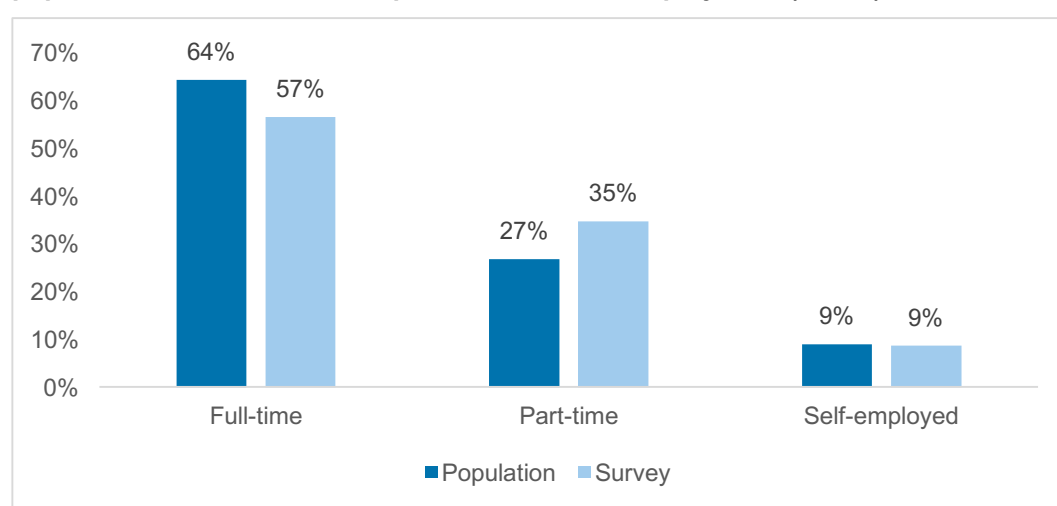
## 4. Employment status, productivity and progression

In this section we consider the impact of MS on women's employment status and productivity in the workplace. We go on to examine the extent to which women feel they are provided with sufficient support in their place of employment. Overall, the findings of the study indicate that MS has a specific impact on the employment status of women and their careers. This has a long-term impact on their lives and their contribution to the wider economy.

### *Impact on employment status*

Looking at the employment status of women with MS, a small majority (50%) reported that they were employed. Of this group, 57% were in full-time work, while 35% were part-time employed (with the remainder in self-employment). In the eight European countries we surveyed, the share of women with MS in full-time employment is lower than the European average (Figure 16).<sup>87</sup> By contrast, women with MS were more likely to be in part-time employment. This conclusion is corroborated by the MSIF, which finds that 66% of women with MS are in full-time employment and 28% work part-time.<sup>88</sup>

**Figure 16: Employment status of women with MS in survey, and average women in population, share of full-time, part-time and self-employment (n=403)**



Source: CRA analysis based on Eurostat

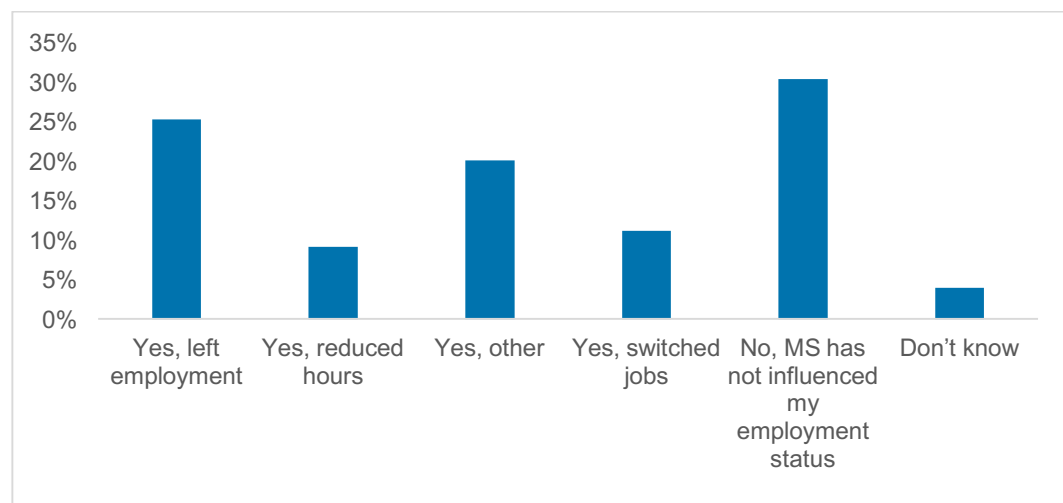
Of all women surveyed, two-thirds (66%) reported that their MS had affected their employment status at some point (Figure 17). Of these women, almost two-fifths (38%) had left employment altogether as a result of their MS. This finding is reflected in the existing literature, which finds that the majority of people with MS report that the disease affects their ability to remain in and progress in work. Studies show that this results in significant

<sup>87</sup> Eurostat (2017). *Full-time and part-time employment by sex, age and economic activity*. Available from <http://appsso.eurostat.ec.europa.eu/nui/submitViewTableAction.do>. [Accessed 15 July 2017].

<sup>88</sup> MS International Federation (2016). *Global MS Employment Report 2016*. Available from: <https://www.msif.org/wp-content/uploads/2016/05/Global-MS-Employment-Report-2016.pdf>. [Accessed 15 July 2017].

income differences, as those with MS are much more likely to have a 'below average' household income.<sup>89</sup> Further, around 15 years after the onset of MS, 60% to 80% of patients are likely to have lost their job or exited the workforce, with the result that MS can lead to a loss of 10 working years on average.<sup>90</sup>

**Figure 17: Impact on employment as a result of women's MS, share of all employment impacts (n=807)**



Source: CRA analysis based on patient survey

The survey findings indicate that the impact of MS on employment varies with age. On average, women in their late thirties were more likely to switch jobs relative to women aged over 50, who were found to leave employment altogether as a result of their MS. This early retirement of MS patients indicates a profound loss to the workforce and wider economy, as the average female population age of retirement in Europe is almost 15 years older, at 65.<sup>91</sup>

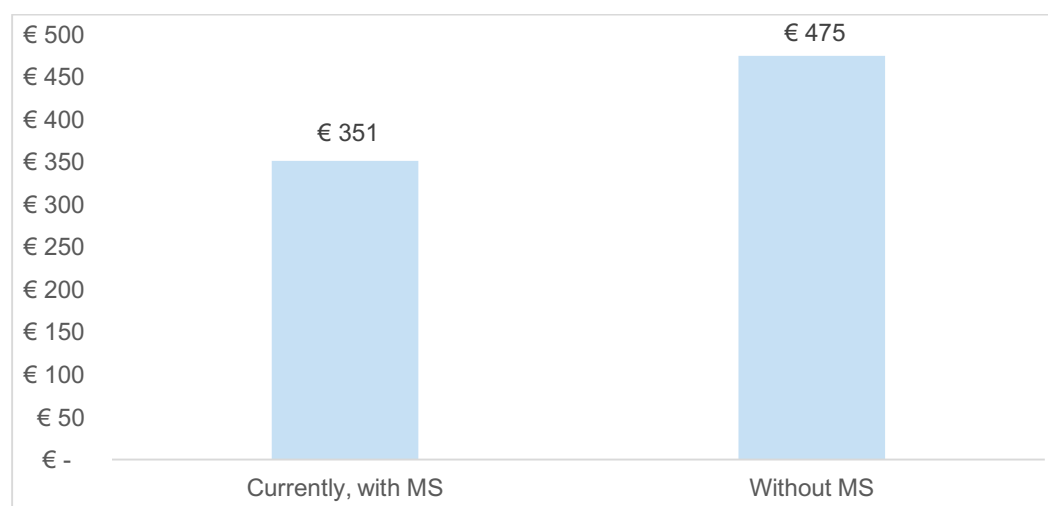
Reasons for women with MS having to change their employment status ranged from the workload being too high or unpredictable (33%) to a lack of flexible working practices (13%) and an insufficient number of breaks to rest when tired (10%).

Furthermore, over one-quarter (26%) and around one-fifth (20%) of working women in the survey noted that their MS symptoms cause them to work fewer hours per day, and fewer days per week, respectively in an average month. Indeed, working women with MS estimate that they would work a median average of 40 hours per week if they did not have their condition. This is equivalent to women working roughly 25 hours more per week than they currently reportedly do, or a boost of an average of 2.9 days of work per week, per woman across Europe.

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- 89 Green G., Todd, J. and Pevalin, D. (2007). Biographical disruption associated with multiple sclerosis: Using propensity scoring to assess the impact. *Social Science and Medicine*, 65, 524-535.
- 90 Bevan, S. and Steadman, K. (2015). *Multiple Sclerosis & Employment in Europe: Literature Summary*. Lancaster, The Work Foundation.
- 91 European Commission (2015). *The 2015 Ageing Report*. Directorate-General for Economic and Financial Affairs. Report No.3.

The women in our survey indicated that they earn an average salary of €351 per week. Assuming that women with MS would stay in the same job at the same salary, the implied boost to hours worked if women did not have MS suggests that MS symptoms cause women to lose an average of 35% of their income, or an average loss of €124 per week. This is equivalent to a total loss of €6,400 per year on average across the eight European countries. If we take this result and apply it across all working women with MS in the EU, it is still a large loss to the European economy—an estimated €1.2 billion per year.<sup>92</sup> However, in reality this is a large underestimate, as without MS it is possible that women would be able to move from part-time to full-time and be on a different career trajectory. Assuming the share of women working full-time increased to match the population average and all other factors stayed equal, women working full-time without MS could earn €360 more per week (€18,800 per year) or a gain of €0.3 billion across the previously part-time employed women in Europe, per year.<sup>93</sup>

**Figure 18: Estimated average weekly salary earned by women with MS and estimated if women did not have MS (€)**



Source: CRA analysis based on patient survey

### *Impact on productivity*

The results of the survey reveal that although just over half of women with MS are employed, they are also prone to suffering from symptoms in the workplace, which can impact their productivity.

Findings from the literature suggest that women with MS suffer from absenteeism and presenteeism as a result of their symptoms, particularly fatigue and increasing signs of

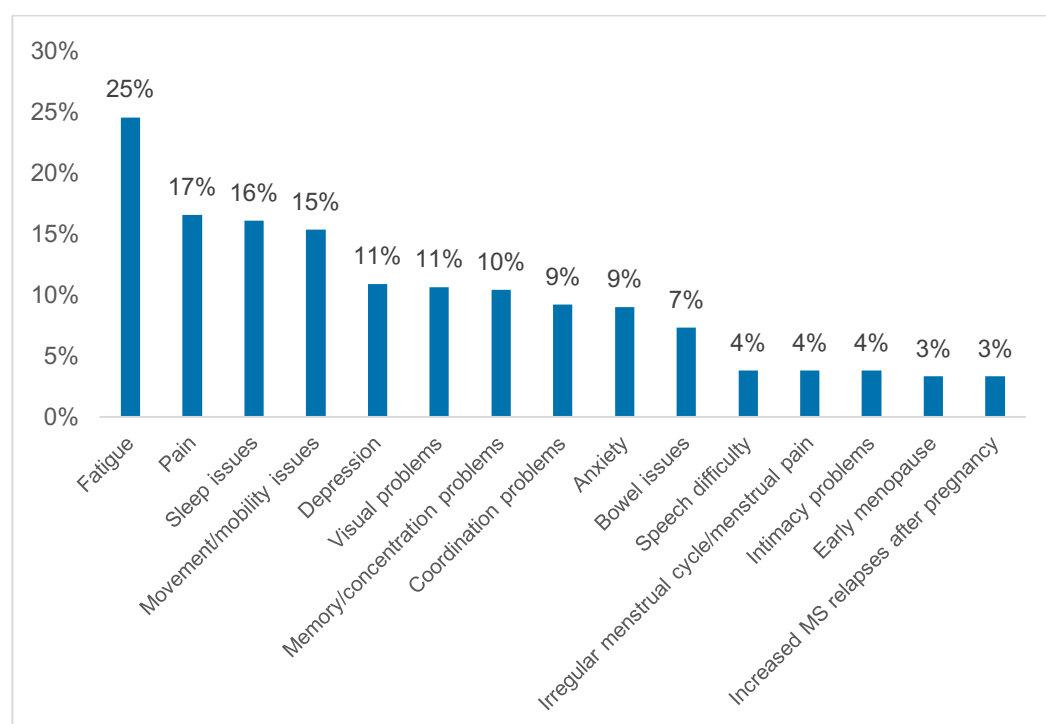
<sup>92</sup> To estimate the total loss of income across Europe (eight countries in sample), the average loss of income per year per woman with MS (€6,400) is multiplied by the average number of working women with MS in Europe.

<sup>93</sup> To match the general women population average of women in full-time employment, the number of women with MS in full-time work must increase by an estimated 14,000 across Europe. To estimate the increase to income across Europe from women with MS moving from part-time to full-time employment, the boost to full-time employment (14,000) is multiplied by the estimated increase to annual salary from moving from part-time to full-time employment (€18,800).



disability.<sup>94</sup> This is supported by the survey evidence which indicates that fatigue is the most commonly cited symptom that heavily impacts women's productivity and workplace participation (Figure 19). In addition, almost one in five women report pain, sleep issues and movement or mobility issues as symptoms that affect their productivity in the workplace. The survey reveals that women with MS are less ambitious in terms of career development and progression, which can prevent women working towards a promotion or taking a new job (see Section 3).

**Figure 19: MS symptoms that have a high impact on women's productivity in the workplace, share of all symptoms (n=424)**



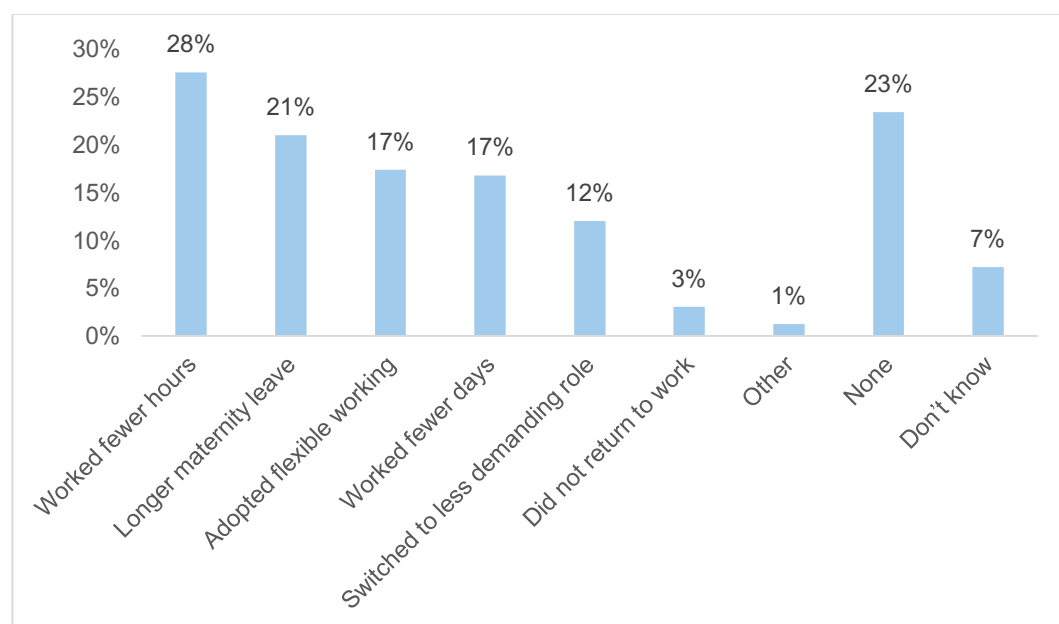
Source: CRA analysis based on patient survey

The impact on employment may be exacerbated for women with children. Findings from the survey show that for all working women who had had a child since their MS diagnosis, their MS symptoms had played a factor in their participation in the workforce (Figure 20). 21% of women reported working fewer hours after having children. This was consistent with discussions with patient organisations who highlighted the post-childbirth impact on employment. In France and the Czech Republic, interviews indicated that women with MS face an additional hurdle to employment as they are doubly discriminated against, due to their need to take time away from work to care for children and to treat their disability.<sup>95</sup>

<sup>94</sup> Glanz, B.I., Dégano, I.R., Rintell, D.J., Chitnis, T., Weiner, H.L. and Health, B.C. (2012). Work Productivity in Relapsing Multiple Sclerosis: Associations with Disability, Depression, Fatigue, Anxiety, Cognition, and Health-Related Quality of Life. *Value in Health*. 15(8):1029-1035.

<sup>95</sup> CRA interview programme with patients/patient associations.

**Figure 20: MS impact on workforce participation post-childbirth, share of all post-childbirth employment impacts (n=167)**



Source: CRA analysis based on patient survey

### ***Support from employer***

Interviews with patient organisations reveal that many countries have comprehensive laws on disability and workplace support, although nothing specifically related to MS.<sup>96</sup> Nevertheless, in practice the scope and implementation of disability legislation is limited. For example, in Poland employers can receive financial support from the government for employing people with disabilities or chronic conditions, such as MS. However, in practice they report that the time taken to receive this support is too long, which acts as a disincentive to employers hiring disabled workers.

The patient survey indicates that the vast majority of employers of women with MS (89%) were aware of their employees' condition. Women in Germany and the UK were most likely to inform their employer that they had MS. However, in 10% of cases the employer was not aware of the patient's condition. The survey also reveals that almost 60% of women do not feel comfortable asking their employer for additional support for their MS symptoms. Reasons for women not disclosing their condition to employers include fears of losing their job, appearing unprofessional, or being discriminated against, and the notion that their condition is personal and it is unnecessary for their employer to know. These perceptions are supported by evidence from interviews with patient organisations. For example, workplace discrimination was seen as a common phenomenon and significant issue in France, where there is a possibility of not being promoted due to reduced physical capacity.<sup>97</sup> Indeed, patient organisations note that while incentives for employers to hire

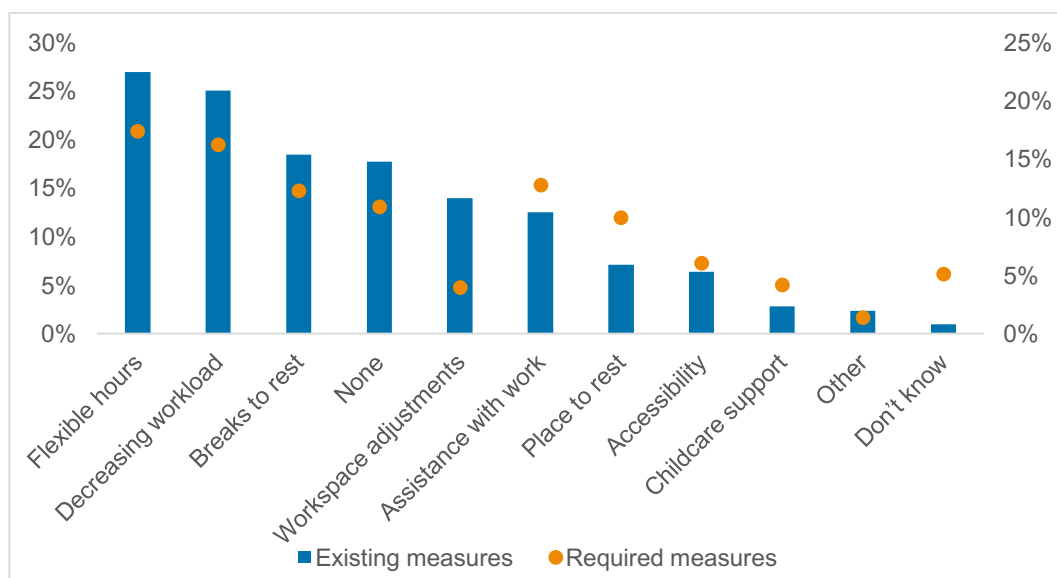
<sup>96</sup> CRA interview programme with patients/patient associations.

<sup>97</sup> CRA interview programme with patients/patient associations.

people with disabilities work, it is still often the case that some employers are not familiar with MS symptoms and are not prepared for working with an employee with MS.

Measures to support MS symptoms in the workplace are illustrated in Figure 21. By understanding women's symptoms, employers are able to provide support and take measures to ensure symptoms are accommodated in the workplace. The most commonly reported measure that employers provide is flexible working hours (27%). However, although this demand for flexible working practices is met to an extent, 17% of women note that increased provision of flexible working hours is still needed. Assistance with workload, places to rest, improved accessibility and childcare support are all measures that women report are underprovided in the workplace.

**Figure 21: Measures taken by employers to accommodate symptoms, share of all support measures provided (LHS) (n=424\*) and workplace measures that are still required, share of all required support measures (RHS) (n=424\*)**



Source: CRA analysis based on patient survey

\*Note: LHS: Left Hand Side Axis; RHS: Right Hand Side Axis

### *Summary of burden and support*

Overall, the evidence confirms that MS impacts women's employment status and career in a different way than it impacts men. Given the greater prevalence of MS among women, the MS burden of employment is likely to be greater among women. Further, women with MS face the additional, unique employment barriers. This is estimated to cost women with MS across the six examined European countries<sup>98</sup> a total average of €6,400 of lost income per year, per woman with MS. This implies a considerable knock-on cost to the wider economy. It should be emphasised that this is an under-estimate that only accounts for lost hours and does not capture losses from productivity reductions, impact of working part-time rather than full-time and the impact on career trajectory. Women with MS report that without MS they would be able to work an additional 25 hours per week—equivalent to almost three

<sup>98</sup>

No data available for Czech Republic and Poland.

additional working days per woman. This implies a significant gain to the labour force as it would boost the average number of women able to work full-time hours, and avoid women retiring earlier than intended.

## 5. Policy implications

In this section, we draw on the evidence presented in the last chapter and additional survey results about the support required to discuss the implications of the research findings for policymaking.

### 5.1. The overall burden of MS from its impact on women

Many studies estimate the overall economic burden that MS imposes on patients, the healthcare system and the economy. There are estimates of the direct (medical and non-medical), indirect costs and considerations on intangible costs.

In this report, we set out evidence that the burden of MS differs between men and women. First, women with MS are *diagnosed and start treatment* at an earlier age than men, predominantly in their 20s and 30s. This leads to a period of uncertainty affecting decisions with long-term consequences. Given the young age and multiple household and career commitments of women at the time their symptoms first appear, women are more inclined to delay their first physician presentation and require a significant number of appointments to receive diagnosis. There is also the common issue of misdiagnosis during this period. In terms of treatment, there is an additional delay and persistent inequalities across Europe.

Second, MS has a key impact on women's *family and social life*. Women experience life-changing decisions with regards to pregnancy, being able to continue to care for their children or parents and disruption of their relationships with partners due to symptoms related to the condition. Women also tend to experience greater impacts even in areas where they are prone to similar symptoms as men (e.g., depression). There is an impact on social interactions and obstacles preventing women from carrying on with daily activities or any special interests, such as sports, which contribute to their quality of life.<sup>99</sup>

Third, a final key area that has a disproportionate impact for women with MS is *employment and labour force participation*. Due to women's earlier average age of diagnosis, their role in the family and the symptoms they experience, they report employment reduction to a larger extent than men do. Women are especially affected in the status of their employment and refrain from career progression. In addition, they report lower productivity resulting from MS, where women report fewer hours/days of work but also suffer from absenteeism and presenteeism as a result of their symptoms, particularly fatigue, sleep issues and mobility. This will result in a larger proportional impact on lifetime earnings than men with MS will experience. This results in two types of cost. The first is the direct cost from lost employment (estimated at three days of work lost per week, per woman with MS) which would not have otherwise occurred at the age at which they are diagnosed, and also impacts the economy as a whole. The second is the opportunity cost caused by the lack of employment continuation, career progression and better quality of life that women could potentially have.

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One key area of impact of MS on women is that of caregiver burden, when women are carers of an MS patient. We find that in these circumstances, women carers of MS patients experience a greater impact and consequentially pose a larger burden on society and the economy.

The existing estimate of total indirect costs of MS across the eight European countries in our study is approximately €102,000 per patient, per year.<sup>100</sup> These costs capture short- and long-term absence from work, reduced hours of work, changing the type of work to a less physically challenging and stressful nature (usually at lower pay) and early retirement.<sup>101</sup> However, our analysis finds that (even after taking into account that women are often paid less than men) this figure is likely to be an under-estimate, as it fails to capture the additional burden of MS on women specifically. For example, women with MS lose an average of three working days per week, or roughly 150 working days per year, due to their symptoms. As a result, women with MS lose €6,400 per year on average due to the inability to work as much as they would without MS. This is also reflected in the loss of income that women with MS suffer as a result of not being able to work full time. If the proportion of MS in part-time employment matched the population average, women could gain a salary boost of €360 per week or €18,800 per year.

Similarly, studies estimate the average total intangible cost of MS to be roughly €7,600 per patient, per year. This cost captures the pressures imposed by MS on patients' quality of life, by impacting the mental, emotional and mental well-being of patients themselves and the people around them. Our analysis estimates that the financial cost of depression alone could account for up to 9% of this burden.<sup>102</sup>

In summary, MS imposes a high and disproportionate burden on women and thereby on society and the economy. This is above and beyond the losses that result from a higher number of women with MS (based on prevalence levels), relating to how the disease manifests in women (e.g., age, progression), symptoms that specifically affect women and losses due to their roles in society (e.g., as mothers, carers).

## 5.2. Policy tools and implications

Across European countries, despite the development of policies for MS patients, there is limited recognition of specific impacts of the disease on women and subsequent action to mitigate them. Based on evidence gathered in this study, including survey responses and interviews with patients and patient organisations, further support in a number of areas would be an important and necessary step towards improving the lives of women impacted by MS and reducing the burdens MS more widely imposes on the economy and society.

### *Support in diagnosis, treatment and care*

There is wide recognition and continuing focus on addressing challenges to the diagnosis, treatment and care of all MS patients. At the European level, the European Multiple Sclerosis Platform (EMSP) Code of Good Practice states that patients should be provided

100 Trisolini, M., Honeycutt, A., Wiener, J. and Lesesne, S. (2010). Global Economic Impact of Multiple Sclerosis. Multiple Sclerosis International Federation. Available from: [https://www.msif.org/wp-content/uploads/2014/09/Global\\_economic\\_impact\\_of\\_MS.pdf](https://www.msif.org/wp-content/uploads/2014/09/Global_economic_impact_of_MS.pdf). [Accessed 8 August 2017].

101 Trisolini, M., Honeycutt, A., Wiener, J. and Lesesne, S. (2010). Global Economic Impact of Multiple Sclerosis. Multiple Sclerosis International Federation. Available from: [https://www.msif.org/wp-content/uploads/2014/09/Global\\_economic\\_impact\\_of\\_MS.pdf](https://www.msif.org/wp-content/uploads/2014/09/Global_economic_impact_of_MS.pdf). [Accessed 8 August 2017].

102 The survey revealed that women with MS spend approximately €720 per year on support for their depression or anxiety (e.g., on medication or therapy). This is roughly 9% of the average total intangible cost of MS (€7,600) estimated by existing studies.

with a clear, certain diagnosis as early as possible, and timely and appropriate access to treatment and care should be provided by an interdisciplinary and coordinated team.<sup>103</sup> International and national organisations are frequently involved in discussions regarding the development of guidelines for diagnosis, treatment and care, but in general there are no specific considerations on women with MS. There are exceptions to this. For example, the MS Society in the UK discusses treatment and care implications for women during pregnancy, menstrual periods and menopause.<sup>104</sup>

The lack of recognition of women-specific issues emerges in discussions with women MS patients. A primary concern remains the expertise of healthcare professionals in detecting early and less visible symptoms, which are more prevalent amongst women.<sup>105</sup> There are also issues relating to access to healthcare professionals and lack of effective patient referrals. Indeed, in some of the less-developed European healthcare markets there are reported problems with access and referral to specialists, especially when patients are located in rural areas.<sup>106</sup> The establishment of specialist MS units helps to improve the coordination between a patient's general practitioner and neurologist. For example, in Spain this was implemented through pilots in collaboration between the government, the Neurology Society and the MS Society. Despite progress, the development of multidisciplinary teams remains limited and there is not a holistic approach to care including components such as depression treatment.<sup>107</sup>

Based on discussions with women with MS and patient representatives regarding support areas that would most benefit patients' diagnosis, treatment and care process (Figure 22), the following areas are critical in improving conditions for women:

- **Awareness of the challenges of 'invisible symptoms' facing women in achieving a fast and clear diagnosis needs to increase.** This is an issue particularly prominent in women due to their slower progression and milder, less visible symptoms. There is a need to ensure improved awareness both in public, in order to encourage early doctor visits, and more importantly in healthcare professionals, including general practitioners, specialists and nurses.
- **A flexible, patient-centric approach to treatment choice can be particularly important to women.** All patients face challenges in accessing treatment, but the initiation of treatment for women has additional challenges, for example around pregnancy. This suggests more flexibility is required. We find that in some countries

<sup>103</sup> European Multiple Sclerosis Platform (2015). *Defeating MS Together: The European Code of Good Practice in MS*. Available from: <http://www.emsp.org/wp-content/uploads/2015/06/140824-Revised-Code-of-Good-Practice.pdf>. [Accessed 4 August 2017].

<sup>104</sup> MS Society UK (n.d.). *Women and MS*. Available from: <https://www.mssociety.org.uk/what-is-ms/womens-health/women-and-ms#periods>. [Accessed 5 August 2017].

<sup>105</sup> CRA interview programme with patients/patient associations.

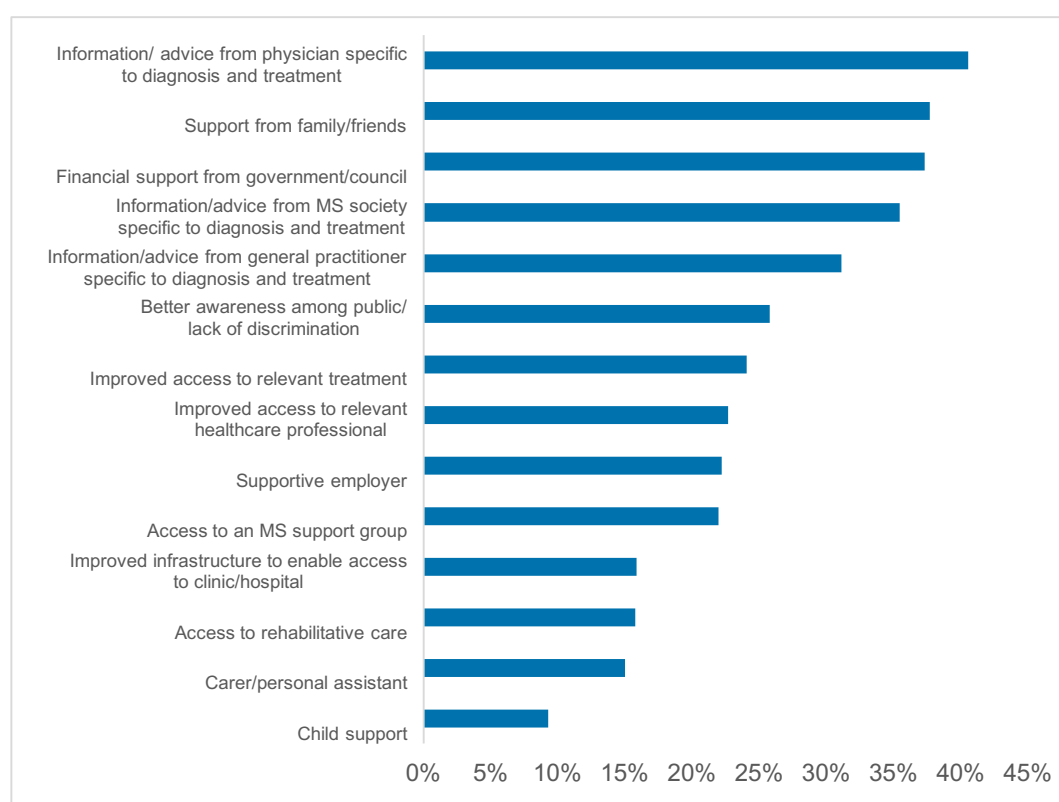
<sup>106</sup> CRA interview programme with patients/patient associations in Poland.

<sup>107</sup> CRA interview programme with patients/patient associations in Spain.

(e.g., Germany) neurologists have more flexibility in providing treatment, which is important to women particularly as they are treated pre- and post-pregnancy.<sup>108</sup>

- ***Coordinated care and multidisciplinary support ensure that patients make informed life choices that manage the impact of MS on their future.*** The earlier onset of the disease in women means the challenges from diagnosis to treatment initiation occur at a vital time in patients' lives. Broader financial and emotional support would reduce the burden this imposes. Our study finds that receiving support from a multidisciplinary team of healthcare professionals enables the inclusion of different care elements, such as psychological care, and the best support for the patient.

**Figure 22: Types of support that women with MS would want more of in support of their diagnosis, treatment and care process (n= 807)**



Source: CRA analysis based on survey results

### ***Support in maintaining a healthy family, social and daily life***

Across European countries, women with MS receive some direct government financial support in the form of disability payments and allowances. In particular, two-thirds of European countries provide financial support for carers that aims to compensate patients for their lack of income due to limitations in working time or leaving the labour market as a



result of caregiving activities.<sup>109</sup> Discussions with MS patients and organisations emphasised that although there is some degree of direct support in place, this typically addresses challenges of patients with disabilities in general and is limited in recognising issues particular to MS patients. This is notably an issue for MS patients with ‘invisible symptoms’ such as cognitive disability, which is difficult to determine.<sup>110</sup> Given that these forms of direct financial government support are a critical form of support (Figure 23), which could be used to pay for childcare support, facilitate access to holidays or respite care services or subsidise payment for household tasks,<sup>111</sup> ensuring their accessibility to women with MS is important. Given the current environment in most European countries, there is scope for **extended support for caregiving and household activities for women with MS through a distinct budget from the general disability one.**

Until recent years, women with MS had significant limitations in managing their disease and planning for a family. With better and safer treatments available, the management of MS care and having children has become easier. The key role in providing the required information and support in this space falls with healthcare professionals, particularly the neurologist, who ensures appropriate information and access to treatment and care when planning for pregnancy, and the nurse, who is regarded as key in assisting with overall and continuous information.<sup>112</sup> Similarly, healthcare professionals and particularly nurses provide important support for how to manage relationships with family members, such as children and partners, and how to enable them to better deal with MS and support the patient.

However, patient organisations and patient support groups still receive many requests about family planning, parenthood and sexuality, which suggests a gap in the support available to women. In response to this, dedicated initiatives have been developed. For example in Germany, the ‘Planbaby bei MS’ initiative by the German Multiple Sclerosis Society (Deutsche Multiple Sklerose Gesellschaft, or DMSG) provides telephone advice for young people with MS who have parenting concerns.<sup>113</sup> Competent, specially trained counsellors in all 16 regional associations of the DMSG can answer questions about children’s needs, pregnancy, childbirth and parenthood. As a result, patients view MS organisations as key in addressing information gaps on these issues. Support received from MS patient groups and increasingly from online forums and blogs is also seen as critical to patients’ understanding and sharing of information and mechanisms for coping with issues in family life.<sup>114</sup> Given the critical importance that these platforms have for improving the lives of women with MS, and patient requests for such support (see Figure 23), **close collaborative initiatives between healthcare professionals or their**

109 European Multiple Sclerosis Platform (2015). *MA Barometer 2015*. Available from: <http://www.emsp.org/wp-content/uploads/2017/02/BAROMETER-2015-28.02.2017.pdf>. [Accessed 15 July 2017].

110 CRA interview programme with patients/patient associations in the UK, France, and Spain.

111 CRA interview programme with patients/patient associations.

112 CRA interview programme with patients/patient associations.

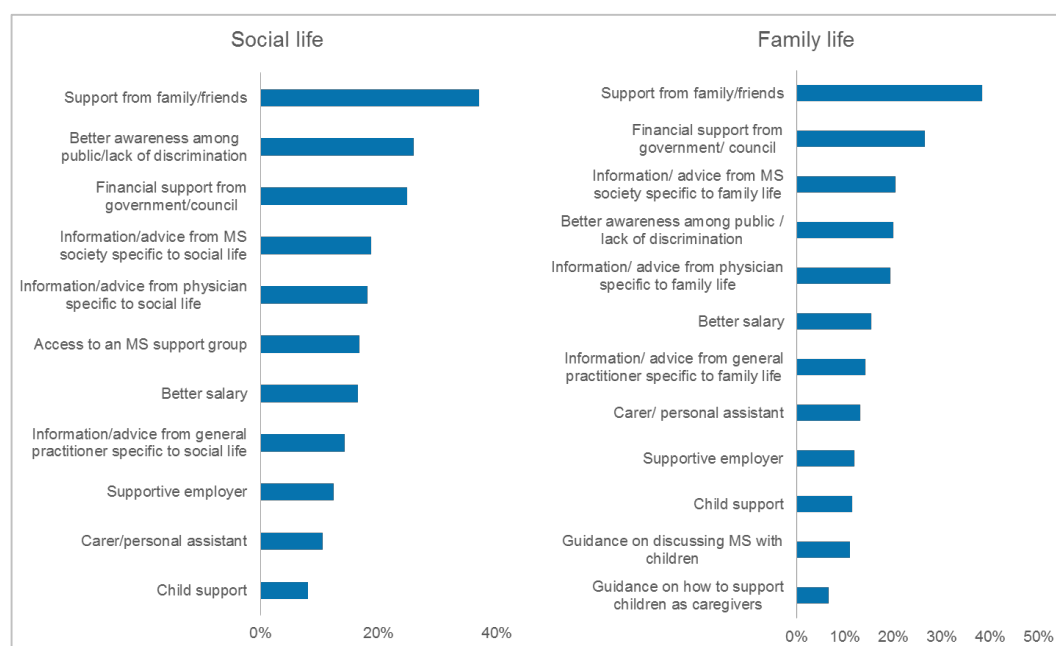
113 DMSG (n.d.). *Planbaby at MS "Planbaby bei MS" - DMSG offers telephone advice for young MS sufferers with children's needs*. Available from <https://www.dmsg.de/plan-baby-bei-ms/>. [Accessed 25 July 2017].

114 CRA interview programme with patients/patient associations.

**representatives, patient groups, women organisations and other MS peer support structures should be regarded as a best practice and shared across countries.**

In addition, MS patients regard improving MS understanding and awareness in the public as critical, because symptoms and degree of disability vary by type of MS and across patients. There are efforts to improve awareness of MS in the general public but limitations persist, and as a result of the lack of public awareness many patients get adverse reactions from their friends and co-workers, which can lead to patients feeling socially excluded and discriminated against. This is recognised as an issue at the European level through ongoing campaigns driven by the European Commission during the last 10 to 15 years.<sup>115</sup> Important steps have also been taken at the member state level as well, through national plans and strategies which have been instrumental in raising awareness and focus on multiple sclerosis. In recent years, national plans and strategies on neurological diseases, which increasingly include MS, have been key tools to tackling the overall environment and largely focusing on building better awareness in the public and among healthcare professionals. **Building on existing strategies, the scope should be further tailored to the unique impact that the disease has on women to ensure society understands challenges, but also avoids stigmatisation of women patients.**

**Figure 23: Types of support that women with MS want more of in support of their social life (n=807) and family life (n=807), as a share of types of support**



Source: CRA analysis based on survey results

### **Support in the workplace**

Women MS patients and patient representatives voice concern on the direct impact of MS on labour force participation, in addition to the direct impact on the patients' ability to

115 European Commission (2004). *Some elements of the situation of multiple sclerosis in the European Union*. Available from [http://ec.europa.eu/health/archive/ph\\_information/dissemination/diseases/neuro\\_1.pdf](http://ec.europa.eu/health/archive/ph_information/dissemination/diseases/neuro_1.pdf). [Accessed 7 August 2017].

perform at work, it affects other areas of their lives, further exacerbating the trade-off between family and work life. Thus, flexible working practices, such as receiving treatment or rest when necessary, without it interfering with their contracted employment, have emerged as critical responses from some employers.<sup>116</sup> Although employers largely implement such practices on an ad-hoc basis, some countries are aiming for a more structured approach. In Spain, the MS patient organisation is working with government to legislate protection in the workplace. This is expected to be approved by parliament by early 2018 and aims to provide financial incentives to businesses specifically to employ people with MS.

Despite some progress, the scope for additional support in the workplace is evident. First, the majority of European countries provide support for early retirement, but only 64% of countries also acknowledge that additional financial support to supplement MS patients' income is required.<sup>117</sup> Further, interviews revealed that the 'mentality' in the workplace remains a problem, and is a result of a lack of awareness of MS and its symptoms. For example, symptoms of MS such as pain, fatigue and cognitive symptoms are difficult for co-workers and employers to comprehend, and are misconstrued as the MS patient being a 'bad employee.'<sup>118</sup> Consequently, discrimination against women with MS in the workplace is common, as reflected by our findings that 10% of women have not informed their employer of their condition, and 60% of women feel uncomfortable asking their employer for additional support in the workplace. This exacerbates MS patients' inability to live normally.<sup>119</sup> Indeed, interviews revealed that discrimination is widespread, despite the existence in almost 80% of European countries of laws that protect employees with MS against dismissal from employment due to their condition.<sup>120</sup>

These limitations in the workplace not only impact the patient, but also have direct financial implications for the employer and the economy at large. Based on responses of patients in the survey, we investigated the benefits of additional support in the workplace. Indeed, over half (53%) of non-working women reported that, with additional support, they would be encouraged to take up employment. In addition, women already in employment would be able to work more, provided sufficient support. The benefits from this boost are estimated at €7,500 per year, per patient (or a total €1.4 billion if applied to all women).<sup>121</sup>

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116 CRA interview programme with patients/patient associations.

117 European Multiple Sclerosis Platform (2015). *MA Barometer 2015*. Available from: <http://www.emsp.org/wp-content/uploads/2017/02/BAROMETER-2015-28.02.2017.pdf>. [Accessed 15 July 2017].

118 CRA interview programme with patients/patient associations.

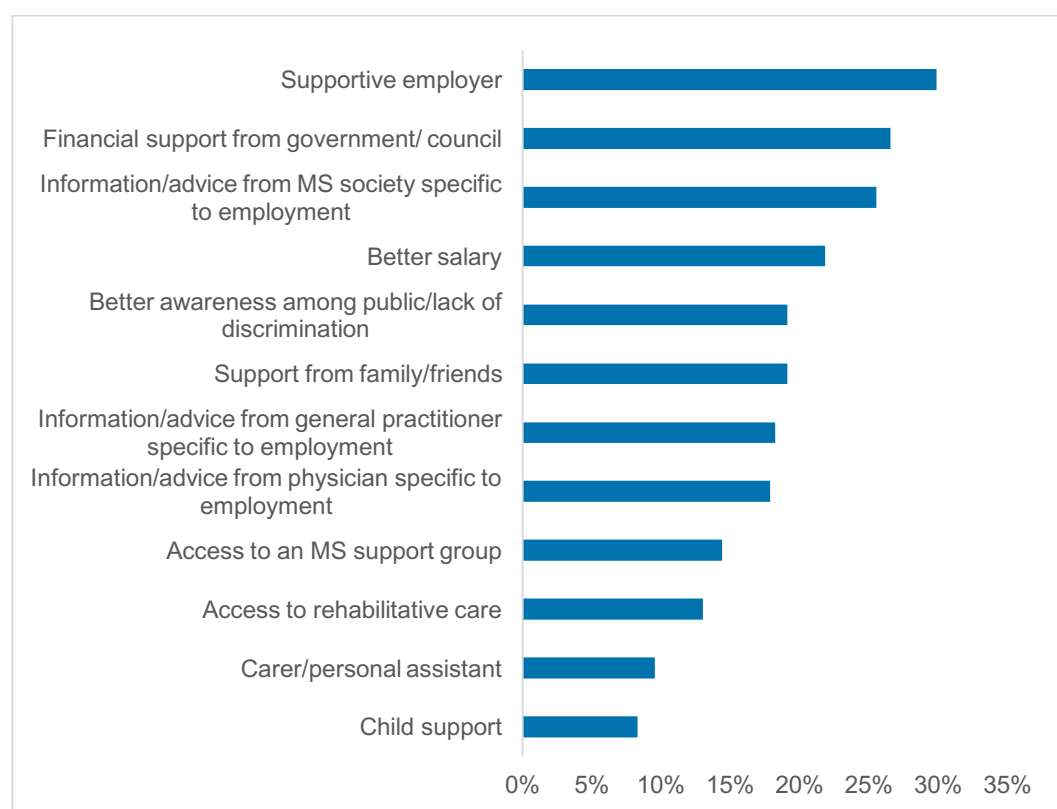
119 CRA interview programme with patients/patient associations.

120 European Multiple Sclerosis Platform (2015). *MA Barometer 2015*. Available from: <http://www.emsp.org/wp-content/uploads/2017/02/BAROMETER-2015-28.02.2017.pdf>. [Accessed 15 July 2017].

121 The survey revealed that with additional support, women with MS would work an estimated seven hours per week more than they currently do. We multiply this by the average weekly wage reported by women in the sample to identify the potential income gained from working additional hours. The potential income is applied across the total number of employed women with MS in Europe (in the eight countries examined) and annualised to estimate the total potential income accrued to women with MS from working more hours due to additional support in the workplace in Europe.

Forms of support could range from **direct support from employers (e.g., providing new flexibility in the workplace)** and **financial support from the government (e.g., subsidised childcare)**, to **improved facility access and transportation (e.g., access to transport networks, disabled access to buildings and more disabled access toilets)**, **encouraging women with MS to work to their full potential**. Women in our survey identified a range of support types that would improve their participation in the labour force (Figure 24). In addition, women noted that professional associations would also be useful to increase awareness across the workplace, and ensure that women with MS do not feel isolated.

**Figure 24: Types of support that women with MS would want more of in support of their labour force participation (n=807)**



Source: CRA analysis based on survey results

### **Summary of recommendations**

In summary, based on the evidence of impact of MS on women, the current support in the healthcare and socioeconomic system, we draw a set of recommendations on how the policy environment could improve to address this burden.

**Table 2: Summary of policy recommendations**

Area	Recommendations to target MS impact on women
<b>Diagnosis, treatment and care</b>	Improve awareness of the challenges of 'invisible symptoms' facing women in achieving a fast and clear diagnosis.
	Establish a flexible patient-centric approach to treatment choice.
	Provide coordinated care and multidisciplinary support to ensure that patients make informed life choices that manage the impact of MS on their futures.
<b>Family, social and daily life</b>	Extend support for caregiving and household activities for women with MS through a distinct budget from the general disability one.
	Implement collaborative initiatives between healthcare professionals or their representatives, patient groups, women organisations and other MS peer support structures within and across countries.
	Building on existing awareness strategies, further tailor the scope to the unique impact on women to ensure society understands challenges, but also avoids stigmatisation of women patients.
<b>Workplace</b>	Encourage support from employers, particularly in providing more flexibility at work and building awareness in the workplace to avoid isolation.
	Provide financial support from the government in the form of subsidised childcare.
	Support improved infrastructure in the workplace and beyond for facility access and transportation to enable mobility.

## Appendix A: Interviews with patient associations

We conducted a total of 11 interviews with patient associations in five of the eight case study countries, as shown in Table 3.

**Table 3: Interviews conducted with MS patient organisations**

Country	Patient Association
<b>Czech Republic</b>	Roska ( <i>Czech Multiple Sclerosis Organisation</i> )
	Občanské sdružení SMS - sdružení mladých sklerotiků ( <i>Civic Association – Multiple Sclerosis Youth Organisation</i> )
<b>France</b>	Ligue Française contre la Sclérose en Plaques ( <i>French League against Multiple Sclerosis</i> )
	AFSEP/ La sclérose en plaques ( <i>French Association of Multiple Sclerosis</i> )
<b>Germany</b>	Manufaktur für Antworten UG ( <i>Personal blog space</i> )
<b>Poland</b>	Polskie Towarzystwo Stwardnienia Rozsianego ( <i>Polish Multiple Sclerosis Society</i> )
	Fundacja Urszuli Jaworskiej ( <i>‘Urszula Jaworska’ Foundation</i> )
	SM- Walcz o siebie ( <i>‘SM - Walcz o Siebie’ Foundation</i> )
	Fundacja NeuroPozytywni ( <i>‘Neuropozytywni’ Foundation</i> )
<b>Spain</b>	Esclerosis Múltiple España ( <i>Multiple Sclerosis Spain</i> )
<b>The UK</b>	Shift MS

Source: CRA analysis

## Appendix B: Data on prevalence of MS in women in European countries

Various studies of MS patients have found different gender prevalence ratios by country as presented in Table 4.

**Table 4: MS prevalence levels across the eight European countries, by gender ratio**

Country	Gender Prevalence (Women: Men)
Italy	2.29–2.6:1 in different regions <sup>122,123</sup>
Spain	1.7–3.1:1 in different regions <sup>124,125</sup>
Poland	2.2:1 in one region <sup>126</sup>
France	2.4:1 <sup>127</sup>
Czech Republic	2.6:1 <sup>128</sup>
United Kingdom	2.5:1 <sup>129</sup>

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- <sup>122</sup> Puthenparampil, M. et al. (2013). Increased incidence of multiple sclerosis in the Veneto region, Italy. *Multiple Sclerosis*. 19(5): 601-4. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/23599184>. [Accessed 7 August 2017].
- <sup>123</sup> Millefiorini, C. et al. (2010). The prevalence of multiple sclerosis in central Italy. *Multiple Sclerosis*. 16(12): 1432-1436. Available from: <https://doi.org/10.1177%2F1352458510373263>. [Accessed 7 August 2017].
- <sup>124</sup> Modrego Pardo, P.J., et al. (1997). Prevalence of multiple sclerosis in the province of Teruel, Spain. *Journal of Neurology*. 244(3):182-5.
- <sup>125</sup> Kingwell, E. et al. (2013). Incidence and prevalence of multiple sclerosis in Europe: a systematic review. *BMC Neurology*. 13(128). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3856596/>. [Accessed 7 August 2017].
- <sup>126</sup> Pierzchala, K. et al. (2015). Demographic characteristics of MS patients in Poland's upper Silesia region. *International Journal of Neurology*. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/24946203>. [Accessed 5 August 2017].
- <sup>127</sup> Fromont, A. et al. (2010). Geographic variations of multiple sclerosis in France. *Brain*. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/20551111>. [Accessed 7 August 2017].
- <sup>128</sup> Horakova, D. et al. (2015). *ReMuS - Czech national registry of multiple sclerosis patients - 2 years' experience*. *ECTRIMS Online Library*.
- <sup>129</sup> Mackenzie, I.S. et al. (2013). Incidence and prevalence of multiple sclerosis in the UK 1990–2010: a descriptive study in the General Practice Research Database. *Journal of Neurology, Neurosurgery and Psychiatry*. Available from: <http://jnnp.bmj.com/content/early/2013/09/19/jnnp-2013-305450>. [Accessed 27 August 2017].

Country	Gender Prevalence (Women: Men)
<b>Sweden</b>	2.26:1 <sup>130</sup>
<b>Germany</b>	1.8:1 <sup>131</sup>

Sources: CRA analysis

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- <sup>130</sup> Ahlgren, C. Odén, A. and Lyke, J. (2014). High Nationwide Incidence of Multiple Sclerosis in Sweden. *PLoS ONE*. Available from <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0108599>. [Accessed 7 August 2017].
- <sup>131</sup> Puglaiatti, M. et al. (2006). The epidemiology of multiple sclerosis in Europe. *European Journal of Neurology*. 13: 700-722. Available from: <https://pdfs.semanticscholar.org/0ca9/28aa828cba9dafacdca07dc90a55585a4114.pdf>. [Accessed 7 August 2017].