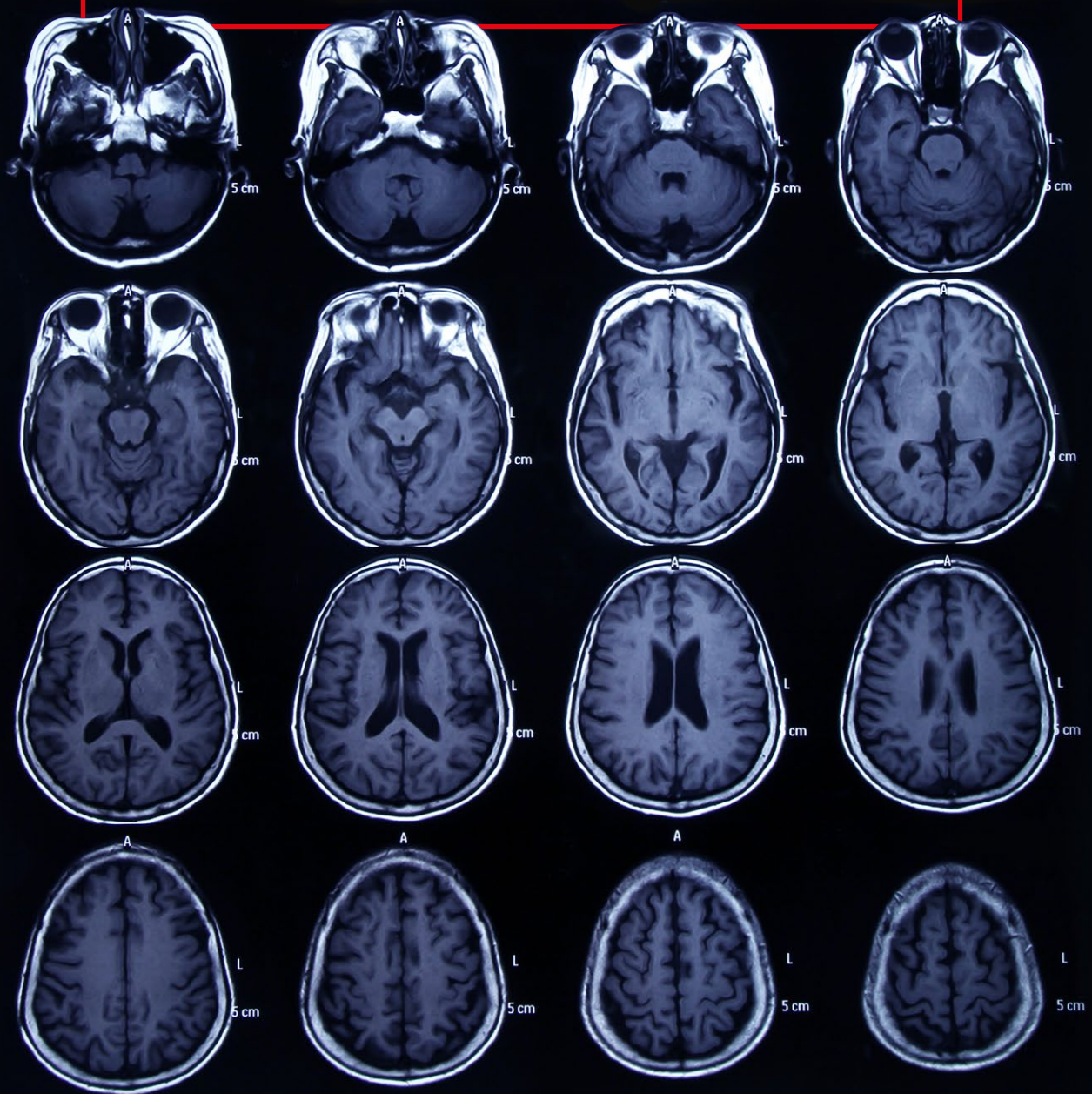




# The value of action

**The value of action: mitigating the  
impact of neurological disorders in  
the United Kingdom**

**Findings report**



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# About this report

This Economist Impact study draws heavily on the disease burden and economic analyses undertaken in 2022 *The value of action: mitigating the global impact of neurological disorders*.<sup>1</sup>

Our research compared the situation in eleven countries: Brazil, China, Colombia, Germany, Italy, Japan, Kenya, Lebanon, Romania, the United Kingdom and the United States.

Our economic analyses include both the direct and indirect costs arising from the conditions being studied. Direct costs refer to spending within health systems, such as on treatments (including drugs and procedures), facility use and specialist personnel. Indirect costs, in this case, refer to the impact on economic productivity of early mortality, disability, absenteeism and presenteeism both for those living with the conditions in question and their carers.

Benefits and costs were captured for prevention, treatment and rehabilitation. Where no intervention exists in a specific category for a given condition, none were assessed. For further details, please see the methodology section in the original publication.<sup>1</sup>

This report is focused on the UK's results from the original report, as well as substantial additional research to provide context for the situation in the country. Although this report aims to provide a picture of the UK as a whole, the differences in policy between the National Health Service in England, Scotland, Wales and Northern Ireland sometimes necessitate the use of England as the country of focus.

The research team consisted of Ashish Niraula and Anelia Boshnakova; the project was overseen by Rob Cook and the report was written by Paul Kielstra. Economist Impact would like to extend our gratitude to Roche and The Neurological Alliance for their invaluable feedback and guidance throughout the project.

# Executive summary

Neurological care in the United Kingdom has long been labelled a “Cinderella Service” – a health policy term which describes the attention and resources available to a field before the arrival of anything like a fairy godmother. More attention to this area, though, could not only reduce the health and social burden of these diseases, but benefit the country economically. This Economist Impact study – which builds on a multi-country report published in 2022<sup>2</sup> – shines a spotlight on the current state of the neurological disease burden, both human and economic, in the UK. It also highlights specific ways in which this burden might be reduced, and describes the challenges for the country in trying to do so. The key findings are:

**Around one in six people in the UK is living with at least one neurological condition, and that figure looks set to rise.** No firm definitional boundaries exist for neurological disease, making precise prevalence numbers difficult to calculate. Nevertheless, available data support the estimate of the Neurological Alliance – a patient group coalition – that one in six people is currently affected by such a condition. Economist Impact gathered prevalence figures for 10 neurological illnesses for which the best data are available: Alzheimer’s disease (along with other dementias), brain cancer, idiopathic epilepsy, migraine, multiple sclerosis (MS), Parkinson’s disease, spinal cord injury, spinal muscular atrophy (Type I), stroke and traumatic brain injury. In the UK, 14.5m people have at least one of these, meaning that they represent the bulk of the 16.5m total neurological cases

estimated by the Neurological Alliance. Age is a leading risk factor for several of these conditions, notably dementia, stroke, and Parkinson’s disease, which have already seen an increase in prevalence in recent years. As the UK’s population continues to age, so will this growth in prevalence.

**Neurological conditions cost the UK the equivalent of more than 4.3% of its GDP in 2019, or at least £96bn.** Economist Impact estimated the direct costs of these 10 conditions to health systems in the UK, as well as the indirect economic burden of lost productivity for patients and their carers. In 2019, the aggregate burden came to 4.3% of GDP or £96bn. Although, as noted above, these conditions cover most of the neurological burden in the UK, but not all, the real economic cost is likely larger. Of the costs in the calculation, roughly half (53%) comes from the indirect cost of lost productivity.

**Existing interventions for the studied diseases can substantially reduce this toll.** Economist Impact also looked at a range of specific interventions for each of the 10 conditions and determined the “amenable burden” – the extent to which it was possible to reduce the toll of these diseases. The sum of the benefits from the interventions – whether preventative, therapeutic, or rehabilitative – with the highest return on investment (ROI) for each illness came to a maximum of 1.4% of 2019 GDP or £30.8bn. Application of other interventions with a lower ROI could add to this amount.

### Three challenges impede the UK from effectively applying these interventions.

- **A lack of overarching strategy:** In England, such policy as exists for neurological illness is not holistic but falls within the purview of comprehensive plans for other kinds of ailments, such as rare diseases or cancer. The new Major Conditions Strategy will likely cover, among other conditions, stroke and dementia, but no high-level policy seems likely to address important neurological conditions with prevalence levels that fall between the rare and the very common, such as epilepsy or Parkinson's disease.
- **A lack of human resources:** According to the most recent data, the UK has 1.1 consultant neurologists per 100,000 people. The average in Western Europe is one per 12,000. This is indicative of the extent of the human resource challenge across the neurology workforce as a whole. The challenge also extends to the wider workforce, including specialist nurses, allied health professionals and professionals in rehabilitation services.
- **A lack of access:** Between April 2021 and April 2023, the waiting list for neurology treatment in NHS England grew by 76% to over 220,000 people; for neurosurgery, the equivalent figures were 37% and 60,000 people. These numbers describe people who actually obtained a referral. One recent survey found that 39% of respondents reported seeing their General Practitioner (GP) five or more times before getting referred to a specialist. One in five respondents to a Neurological Alliance national survey of people affected by neurological conditions waited more than 12 months between first seeing a GP and seeing a neurologist.

### Insights from five specific neurological conditions:

Our study takes a closer look at four neurological conditions with high amenable burdens relative to their overall economic cost – Alzheimer's disease, epilepsy (using idiopathic epilepsy as a proxy), multiple sclerosis and Parkinson's disease – as well as one rare disease – SMA (Type I).

- **Alzheimer's disease:** The prevalence of Alzheimer's disease and other dementias has grown steadily in the UK for 30 years and is currently 1,241 per 100,000 people. Its direct and indirect costs in the country came to 0.84% of GDP in 2019 or £19bn (\$24.2bn). The use of acetylcholinesterase inhibitors by all eligible patients has the potential to bring down this economic toll by 19%. A current policy void for dementia, however, could slow such improvement, as well as the potential application of newer therapies that target amyloid plaque accumulation.
- **Epilepsy:** Epilepsy currently affects 937 per 100,000 people in the UK and idiopathic epilepsy alone – with a prevalence of 358 per 100,000 – cost the economy 0.07% of GDP in 2019 or £1.7bn (\$2.1bn). The WHO estimates that a quarter of epilepsy cases are potentially preventable.<sup>3</sup> Meanwhile, existing treatments can help the majority of those living with the disease do so seizure-free. Our model shows that providing a level of primary care that enhances prevention could cut the economic burden of epilepsy by 25%. Treating everyone who could benefit with appropriate medication could do so by 52%. The quality of epilepsy diagnosis in the NHS, however, needs work, as does the frequency of medication reviews within primary care.



- **Multiple sclerosis:** MS has a prevalence of 149 per 100,000 in the UK. With per-patient average direct and indirect costs over £35,000 (\$45,000) per year, it exacted an annual burden of 0.12% of GDP in 2019 or £2.78bn (\$3.55bn). A growing number of medications can now reduce the impact of the disease, and Economist Impact estimates that their use for every appropriate patient could cut the economic toll of the disease by 17%. Rehabilitative physiotherapy, meanwhile, could bring it down by 3%. A national strategy for MS could help in securing such projected health and economic benefits.
- **Parkinson's disease:** The prevalence of Parkinson's disease in the UK is 251 per 100,000 people, and the combined direct and indirect costs arising from it came to 0.14% of GDP or £3.0bn (\$3.9bn), which is about £17,000 (\$22,000) per patient. Most of this burden arises not from treatment but the lost productivity of informal carers. Existing interventions are able to temporarily manage the motor symptoms and impairment typical of the disease, and the resultant increased patient capacity could permit carers to stay in work. The net benefit for rehabilitative physiotherapy is 33% of the total current cost; for drug therapy, it is 18%. However, only a quarter of patients are currently referred for physiotherapy at diagnosis (the optimal time).
- **Spinal muscular atrophy (Type I):** SMA (Type I) is a rare disease, affecting around 6 per 100,000 people in the UK. Most patients with this genetic condition die by the age of four. The low prevalence means that the cost is lower than for the other diseases in this study, but still reaches 0.001% of GDP or £16.9m (\$21m). At the individual level, however, it is prohibitively high, around £98,000 (\$125,000) in direct costs and a total economic burden of just under £125,000 (\$160,000) per patient. Recent progress has at long last seen a number of treatments developed for this condition. Despite high upfront costs, data available at the time of our analysis shows treatments may bring down the overall burden by 11%. These new treatments may be beneficial if used before symptoms appear. In 2018, the UK National Screening Committee (NSC) rejected screening newborns for the condition, a policy that is now being reconsidered.

# Section I: An overview of the neurological burden all around us

## The socio-economic toll

The prevalence of neurological conditions in the United Kingdom, as in much of the world, is substantial. Any estimate of its actual extent, however, would depend on what the category includes – a definitional issue on which authoritative sources sometimes disagree.

According to the oft-cited Global Burden of Disease (GBD) study, the total prevalence of “neurological disorders” in the UK was 43,761 per 100,000 people in 2019. This figure is inflated by the inclusion of tension headaches, which are typically mild and often temporary. Of the remaining neurological illnesses included in the GBD data, the collective prevalence is 8,421 per 100,000, ie, more than 8% of the population.<sup>4,5</sup>

Some individuals with more than one condition, however, are counted twice. Nevertheless, the GBD figures on neurological disorders almost certainly underestimate the reality. GBD figures draw on ground-breaking studies from the 2010s on 15 neurological conditions. Although this research went far in addressing a knowledge gap, several relevant diseases were not included in the category. Their prevalence, therefore, remains poorly understood.<sup>6</sup> Moreover, the 2019 GBD report placed certain neurological disorders in other categories, such as strokes in the cardiovascular diseases (CVD) burden and brain cancers among neoplasms. Injuries, meanwhile, including to the head and spine, are listed by cause rather than location on the body.<sup>4,5</sup>

**The collective prevalence of neurological disorders in the UK is more than 8% of the population.**

A wider ranging review of data by the Neurological Alliance – a UK patient group coalition – estimates that around one in six people in the country has a neurological condition, based on the best data from its member organisations.<sup>7</sup> In light of the limitations of the GBD figures described above, this larger estimate seems reasonable.

The current burden – which is likely an undercount of the real burden – is expected to grow. For several neurological conditions that already have high prevalence rates, such as stroke, dementia, and Parkinson’s disease, age is a substantial risk factor. More generally, population-ageing in the UK is expected to drive a steep increase in neurological disease numbers.<sup>6,8</sup>

Too many neurological illnesses exist to discuss all in detail. Therefore, a recent multi-country study by Economist Impact – on which this publication draws heavily – considered 10. The conditions were selected from among the illnesses for which the GBD studies provided data. The prevalence figures derived for the UK show the wide divergence in the number affected by each condition, while still giving an indication of the collective burden that they exert.

Although only 10 disorders are included in the present report, this selection covers much of the neurological burden: the case numbers for these 10 conditions total 14.5m, a significant portion of the 16.5m that the Neurological Alliance estimated for all neurological cases in 2016.<sup>7</sup> Accordingly, these figures and other such inputs allow for a rough approximation of the impact of neurological conditions in the UK. The



**Table 1:**  
**Estimated total cases, prevalence, and the cost of selected neurological conditions in the UK, 2019<sup>4-6, 9</sup>**

	Total cases	Prevalence per 100,000	Aggregate direct and indirect cost in UK£ (million)
Alzheimer’s disease and other dementias	900,000*	1,241	18,976
Brain cancer	16,128	24	492
Idiopathic epilepsy	272,847	358	1,661
Migraine	11,812,551	17,627	20,367
Multiple sclerosis (MS)	78,214	149	2,785
Parkinson’s disease	153,000#	251	3,046
Spinal cord injury	212,603	313	6,530
Spinal muscular atrophy (Type I)	134	6	17
Stroke	770,029	1,140.3	17,953
Traumatic brain injury	598,947	828	25,393

\* recent data from Alzheimer’s Society <https://www.alzheimers.org.uk/blog/how-many-people-have-dementia-uk>

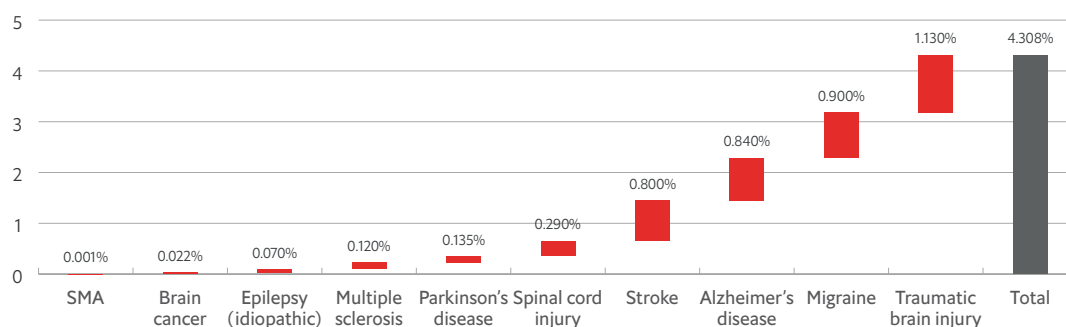
# recent data from Parkinson’s UK <https://www.parkinsons.org.uk/about-us/reporting-parkinsons-information-journalists>

demographic data needed for a full analysis are simply unavailable – the list under study has only one rare disease spinal muscular atrophy (Type I), but nearly half of the world’s more than 7,000 rare diseases are neurological;<sup>10</sup> for epilepsy, the study uses the GBD numbers for idiopathic epilepsy, which accounts for only around 40% of those with the condition in the UK. Economist Impact’s calculations are based on GBD-derived figures and broader prevalence figures in a 2023 study by Wigglesworth et al;<sup>11</sup> although this study looks at the return on investment (ROI)

of interventions for Alzheimer’s disease, the only available data is the aggregate one for all dementias.

Economist Impact examined the direct cost of these diseases to UK health systems – such as medications, hospital stays, medical services etc. – and the indirect costs to the broader economy, arising from economic productivity lost due to absenteeism, presenteeism or early retirement by those living with the disease and their informal carers. The results were striking.

**Figure 1**  
**Total economic burden (% of GDP) for selected neurological conditions in the UK, 2019**

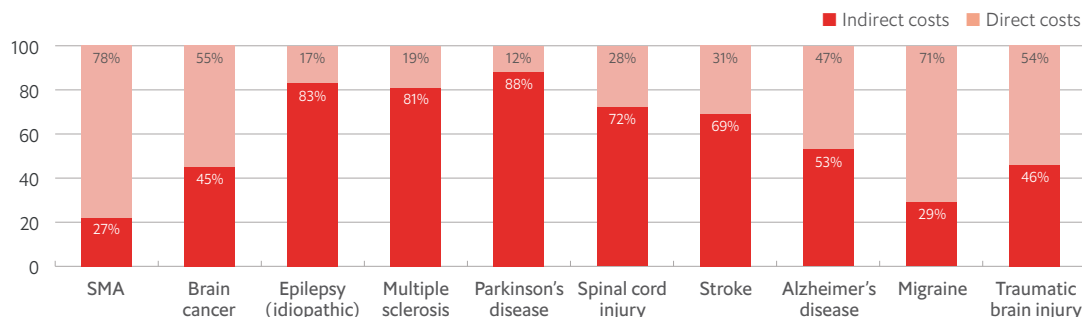


Source: Economist Impact analysis, 2023.

Figure 1 reflects the economic burden of 10 neurological conditions in the UK, expressed as a percentage of GDP in 2019. While Traumatic brain injury incurs the largest burden (1.130%), the economic burden of SMA is relatively small (0.001%). Stroke, Alzheimer’s disease, and Migraine are other conditions with a large economic burden.

Figure 2 sheds light on the share of the direct and indirect costs associated with 10 neurological conditions in the UK in 2019. While the share of the direct costs is more for SMA and Migraine (above 70%), it is less for Parkinson's disease, Multiple sclerosis, Epilepsy, and Spinal cord injury.

Figure 2  
**Percentage share of direct and indirect costs (as proportion of the whole) for selected neurological diseases in the UK, 2019**



Source: Economist Impact analysis, 2023.

In aggregate in 2019, these conditions exacted a burden on the UK economy equivalent to just over 4.3% of GDP or £96bn (\$124bn). Much of this – 53% of the total or 2.2% of GDP – comes from the indirect costs of lost productivity, although the proportion varies by disease.

### The amenable burden: scope and nature of the opportunity

While, for the large majority of cases of these diseases, complete cures do not exist, a range of interventions, varying by condition, are available to reduce the human – and economic – burden. The Economist Impact multi-country study labelled these gains from action as the “amenable burden” of neurological disease.

To estimate this amenable burden, the previous study considered the potential benefits and costs of various medical interventions – including prevention, treatment and rehabilitation – for each of these conditions. In each case, we considered the best available practice for which sufficient data were available to make a credible estimate.

Before discussing the results, an explanation of the methodology is needed. The benefits calculated for any given intervention are the maximum achievable. The model assumes that the relevant providers – public health officials or

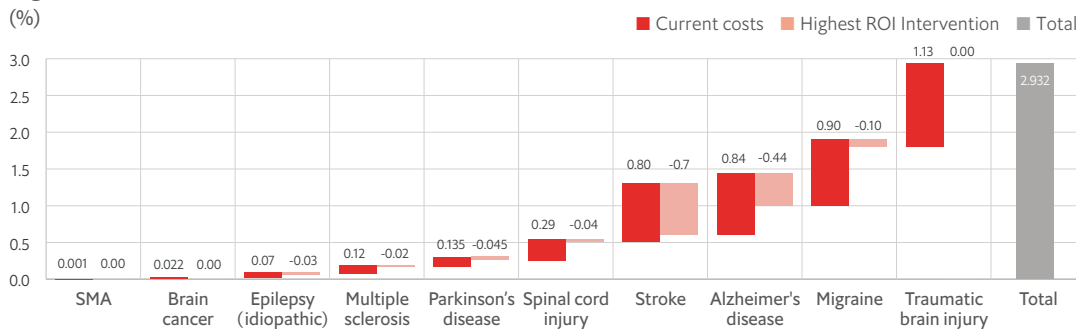
the healthcare system – go from not deploying the intervention at all to using it to the greatest extent possible, such as giving a particular therapy to all eligible patients. In some cases, this is a hypothetical situation, as some of the interventions are already being used to an extent in the NHS or through UK public health programs.

The data needed to adjust the ROI figures for the UK are not available, but a positive ROI still indicates that it would be valuable to extend the intervention to those who are not receiving it. Where therapy was relatively new at the time of the analysis in 2019, the ROI figures are much closer to what the economy as a whole could receive. Overall, then, the results are a call to implement best practices rather than a precise set of economic projections.

The research showed that substantial cost reductions are possible, even for many treatments with high upfront costs. It is difficult to summarise the total potential impact of all of these interventions since each was assessed independently of the others. Thus, the gains from their joint use would not be the same as a simple sum of their separately determined benefits. Figure 3 instead shows the baseline cost of each condition in GDP terms (from Figure 2), along with the impact of the one intervention for each condition for which the research found

Figure 3 highlights the economic burden (as a share of GDP) of 10 neurological diseases in the UK, and the returns (as a percentage of GDP) generated when investments are made towards relevant interventions (prevention/treatment/rehabilitation) to address these conditions. The values are based on baseline calculations for the year 2019.

**Figure 3**  
**Total UK economic burden (percentage of GDP) for selected neurological conditions and impact of highest ROI intervention, 2019**  
 (%)



Source: Economist Impact analysis, 2023.

the greatest economic benefit. As the data indicate, the possible improvement is substantial –with a maximum potential reduction in the economic burden by one-third or £30.8bn based on 2019 figures.

The opportunities for reduction vary by disease. The largest in absolute economic terms is for stroke. That said, the intervention in question for that condition was to implement a completely

effective programme to reduce lifestyle-related risks, such as from tobacco use and poor diet. Progress here is certainly important.

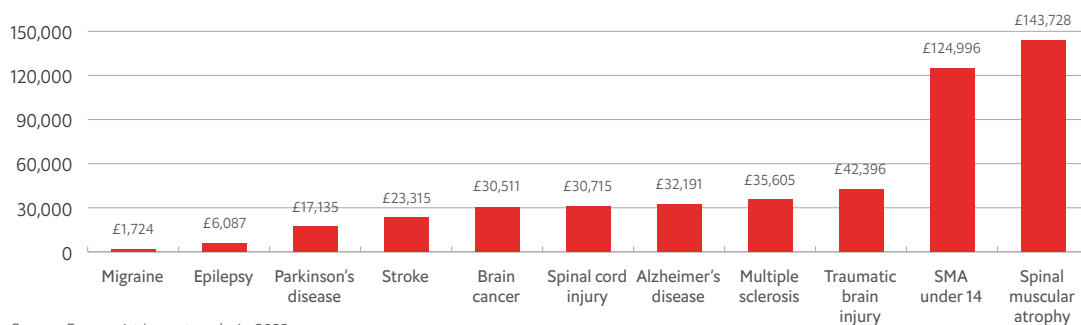
Instead, our research found that the biggest relative opportunities for intervention was for some of the conditions which, due to lower prevalence or treatment cost, exact a lower total economic burden.

**Table 2:**  
**Percentage reduction in the aggregate cost from full implementation of the highest ROI intervention for selected neurological diseases in the UK, 2019**

Disease	% reduction
Stroke	88%
Alzheimer's disease and other dementias	52%
Epilepsy (idiopathic)	43%
Parkinson's disease	33%
Multiple sclerosis	17%
Spinal cord injury	14%
SMA I	11%
Migraine	11%
Brain cancer	0%
Traumatic brain injury	0%

Figure 4 highlights the total cost incurred by an individual with any of the 10 neurological conditions in the UK in 2019. The costs are associated with either treatment or rehabilitation. While Spinal Muscular Atrophy has the highest cost per patient (above £143,000), the lowest costs are for Migraine and Epilepsy (below £10,000).

**Figure 4**  
**Total cost per patient (UK£) for selected neurological diseases in the UK, 2019**



Source: Economist Impact analysis, 2023.

Therefore, as this study cannot consider all of these diseases in the UK context in detail, it will look more closely at the four conditions for which, after stroke, the biggest proportional chance of savings exists: Alzheimer's disease, epilepsy (using idiopathic epilepsy as a proxy

for the whole), Parkinson's disease and multiple sclerosis (MS). In addition, it will report on possible interventions for SMA (Type I) because, despite its low prevalence in the population, it has by far the highest cost per patient of any of these conditions (see Figure 4).

## Section II: A brief look at neurological care in England

Before turning to these five diseases, we will first take a bird's eye view of the policies and resources related to services for people with neurological conditions in England, as well as the waiting times faced by patients for such care.

### Overlapping but uncoordinated policies

NHS England provides care for individual neurological conditions. In doing so, the health system's clinicians can draw on a wide range of expert guidelines, quality standards and advice generated by the National Institute for Health and Care Excellence (NICE) related to different aspects of the various conditions, including: brain cancer, Parkinson's disease, dementia (including Alzheimer's disease), epilepsy, migraine headaches, motor neurone disease (including Type I SMA), MS, spinal cord injury and stroke.<sup>12</sup>

At the national level, however, England lacks a general neurology policy that is similar to those targeted at cancer or diabetes. Instead, several neurological conditions fall under other broad policies. This is not necessarily a drawback. It made conceptual sense for brain cancer, for example, to be included with other malignant neoplasms under the last English cancer strategy, which lasted from 2015 to 2020.<sup>13</sup> Similarly, the English Rare Diseases Action plan<sup>14</sup> is a sensible way to improve care for those with one of the many rare neurological conditions.

One specific neurological disease has received specialised attention in England – dementia. Since 2009, the government has implemented three successive dementia strategies, the last of which – The Prime Minister's Challenge on Dementia 2020 – expired that year.<sup>15</sup> It contained

more than 50 commitments across four core themes of risk reduction, health and care, awareness and social action, and research.<sup>16</sup> The problem with such condition-specific policies and plans is that other diseases – particularly those with lower prevalence – could be left out. For example, there are no Parkinson's disease, epilepsy, or MS plans.

Currently, the most relevant policy for these, and for other neurological conditions, is the NHS Long Term Plan, published in 2019. The plan is far reaching, outlining the strategic direction for the National Health Service in England as a whole over the following decade. On the surface, neurology has a low profile. The word never even appears in the document. Of the conditions covered in the study, the plan only contains specific goals and milestones on stroke care, while dementia receives attention as part of healthy ageing, and epilepsy is covered within children's health.<sup>17</sup>

Despite these shortcomings, the plan has been acknowledged as a launch pad for two important neurology planning tools which were published in 2019.

The first is the handbook *Transforming elective care services: Neurology*. While lacking in specific goals, let alone formal commitments, it provides practical guidance on how local commissioners and providers can transform neurology services. It begins by noting weaknesses in current provision, including unwarranted variation in service, fragmented commissioning, and a shortage of neurological consultants in small and medium-sized facilities. It encourages standardised referral networks, multi-disciplinary community-based clinics and, where possible, support for self-management.<sup>18</sup>

## The Neurological Alliance calls for:

### People affected by neurological conditions to

1. Know that you are not alone: There are hundreds of organisations and millions of individuals who are here for you. If you need information or support but don't know where to turn you can find out about our members and the services they offer through our website
2. Get involved and campaign for change: Together we can help to improve services, boost investment in research and improve outcomes for people with neurological conditions now and in the future. Together, we're stronger.

### The DHSC must

3. Ensure the NHS People Plan delivers a neuroscience and brain workforce fit for the future. Work with the neurological community, including the Neurological Alliance and neuroscience professional bodies to develop the plan.
4. Ensure the Office for Health Improvement and Disparities (OHID) works with health bodies and the neurological community to develop improved data and insight on the prevalence and incidence of neurological conditions, as well as experience of and access to services.
5. Work with the Treasury to fix the current crisis in social care and bring forward a plan to create a fair, effective and sustainable social care system in line with the Care and Support Alliance (CSA) Seven Tests.

### The DWP must

6. Ensure the welfare system enables people to manage the extra costs associated with their condition, supports employment as appropriate and protects people with neurological conditions from falling into poverty by immediately uprating benefits in line with current levels of inflation.

Source: The Neurological Alliance report "Together for the 1 in 6"<sup>25</sup>

The same year, NHS England also produced, in conjunction with seven patient groups, the *Progressive Neurological Conditions Toolkit*. This has a particular focus on care pathways for those living with MS, motor neurone disease (MND), and Parkinson's disease. It also begins by noting weaknesses that need to be addressed, including delayed diagnosis and treatment, fragmented care, and a human resource shortage. The bulk of the toolkit is a high-level list of aims to which care commissioners for each condition should aspire, with links to helpful documents in pursuit of those goals.<sup>19</sup>

While both of these documents are useful, they do not provide a system-wide approach to addressing neurological disease. A stand-alone national plan is unlikely in the near future. Prior to 2023, the Department of Health and Social Care had engaged in evidence gathering to renew both England's cancer plan<sup>20</sup> and its dementia strategy.<sup>21</sup> Early this year, though, these efforts came to a halt. Instead, the department called for evidence to develop a Major Conditions Strategy, which would combine efforts to prevent, diagnose, treat and manage several major groups of health conditions in England: cancers, CVD, including stroke and diabetes, chronic respiratory diseases, dementia, mental ill health, and musculoskeletal disorders. The initial public consultation for this strategy ended in June 2023.<sup>22</sup>

What the Major Conditions Strategy has in store for neurological diseases remains to be seen. Among the diseases covered in this study, it should at least provide direction for stroke, dementia and brain cancer, as have previous individual plans. Moreover, given the common set of lifestyle-related risks for many of these major conditions, it makes sense on some level to address them collectively. On the other hand, inclusion of such a large number of conditions within a single strategy could dilute attention for them all – a concern stated strongly by some oncologists.<sup>23</sup>

The larger challenge will be for neurological illnesses that fall between rare diseases and major conditions, which seem likely to continue to be neglected as policy priorities. Accordingly, the Neurological Alliance has been campaigning for a national neurological taskforce and is now pushing for inclusion of neurological conditions more generally in the Major Conditions Strategy.<sup>24</sup>

Improved strategic direction could go far in addressing many of the weaknesses within services for people with neurological conditions in the UK, as discussed in the following sections.



### Fewer human resources than in comparable countries

The most detailed data on the neurology workforce in the UK comes from a survey of consultants conducted by the Association of British Neurologists (ABN) in 2018 and 2019.<sup>26</sup>

Consultants are obviously not the only human resources needed to provide effective healthcare. In England in March 2023, for example, there were 804 full-time-equivalent NHS neurology consultants in hospital and community health services. There were also a further 688 doctors or trainees working in the field. Moreover, there were 2,238 nurses, including over 700 specialist and advanced nurse practitioners, working in neurology.<sup>27</sup> Limiting the focus to consultants, however, allows for a better comparison of the UK workforce with that of other countries where such data is readily available.

**The ABN survey found that the UK had 1.1 consultants per 100,000 population. This is significantly low when compared with countries of similar wealth.**

The ABN survey found that, at the time it was conducted, the UK had 1.1 consultants per 100,000 population.<sup>26</sup> This is significantly low when compared with countries of similar wealth; the average in the European Union (EU), for example, is around one consultant neurologist per 12,000 people.<sup>28</sup> Within the UK, London and the South East have the largest proportion of consultant neurologists.<sup>29</sup>

Since the last year of the ABN survey, there has been some progress. Between March 2019 and January 2022, the number of neurology consultants in England rose by 11%.<sup>30</sup> Nevertheless, even at that rate, it will take some time before UK approaches the European norm.

Broader workforce challenges in the community and social care persist. For instance, despite an increase in the number of MS specialist nurses in 2021, the caseloads across the UK have significant increase, with a mean caseload of 472 people with MS per whole time equivalent (WTE). Findings further point towards a need for 50% increment in current MS nurse workforce to ensure a sustainable caseload.<sup>31</sup>

### More people facing delays in treatment

The impacts of the policy and provision deficits in neurology are made starkly clear in the time it takes to access specialist care.

In theory, under NHS England's Constitution,<sup>32</sup> as interpreted by its Handbook,<sup>33</sup> patients have a right to start non-urgent, consultant-led treatment within 18 weeks of an appropriate referral by a clinician. For neurology and neurosurgery, this is a commitment which may soon, if the neurological burden follows its current trajectory, become difficult to uphold. Of course, the NHS as a whole is currently struggling with growing waiting lists and waiting times, but the deterioration for neurology and neurosurgery will be particularly marked.

Table 3:  
**Waiting lists and waiting times for neurology**

	Patients on waiting list	Proportion waiting over 18 weeks	Proportion waiting over 1 year
April 2021	126,488	26%	2%
April 2022	185,913	39%	3%
April 2023	223,732	44%	5%

Source: Data from monthly spreadsheets of Incomplete Commissioner data on NHS Referral to Treatment (RTT) Waiting Times;<sup>34</sup> Economist Impact calculations

Table 4:  
**Waiting lists and waiting times for neurosurgery**

	Patients on waiting list	Proportion waiting over 18 weeks	Proportion waiting over 1 year
April 2021	44,169	42%	9%
April 2022	54,856	47%	7%
April 2023	60,503	49%	7%

Source: Data from monthly spreadsheets of Incomplete Commissioner data on NHS Referral to Treatment (RTT) Waiting Times;<sup>34</sup> Economist Impact calculations

The number of people in England awaiting initiation of NHS neurological treatment after referral rose by 76% in the two-year period prior to April 2023. The wait time for each individual is also growing markedly, with the median jumping from 8.9 weeks to 14.7 weeks over the same period. As of June this year, 228,480 people with neurological diseases are on the waiting list for NHS neurological treatment, with 26% of people waiting for over 18 weeks and 2% of people waiting for over 1 year. In case of neurosurgery, 61,972 are on the NHS waiting list, with 37% of people waiting for over 18 weeks and 8% of people waiting for over 1 year.<sup>34</sup>

**...services for people affected by neurological disease require more resources in order to meet the current needs of the population – needs which are only likely to grow as the population ages.**

Neurosurgery is also experiencing growing delays, with 37% more people on the NHS waiting list in April 2023 than the prior two-year period. This fact, and the slight progress made on the percentage seen within a year, may seem like less dramatic of a deterioration than for neurology. However, neurosurgery's median wait time of 16.8 weeks is now the worst of any of the 23 services for which the NHS tracks such data. Two years ago, its 13.9-week median was only the fifth worst.

Even getting an appropriate referral for neurological care is not straightforward. One survey found that 39% of more than 10,000 respondents reported seeing their GP five or more times before being referred to a neurologist.<sup>35</sup> A recent study from the Neurological Alliance reports that 40% adults and 33% of children and young people were not offered or directed to any information about their condition when they were first told about it.<sup>25</sup>

To summarise, services for people affected by neurological disease require more resources in order to meet the current needs of the population – needs which are only likely to grow as the population ages. Coping with the increased demand for care will likely require radical review of the current infrastructure and workforce. Not only do gene-specific therapies need to be delivered carefully in specialist environments, but health systems also need to prepare for the increased demand for genetic counselling and testing. In addition, we need to optimise use of existing specialist expertise across multi-disciplinary teams. On the other hand, as discussed above – and in more detail below – such spending should be seen not as pure cost but as investment with potentially positive returns.

# Section III: A closer look at the amendable burden of five neurological conditions

## Alzheimer’s disease

### Burden

Alzheimer’s disease, the most common form of dementia, induces cognitive decline, primarily among older individuals.<sup>36,37</sup> In 2019, the prevalence of Alzheimer’s disease and other dementias in the UK was 1,241 per 100,000 population.<sup>4,5</sup>

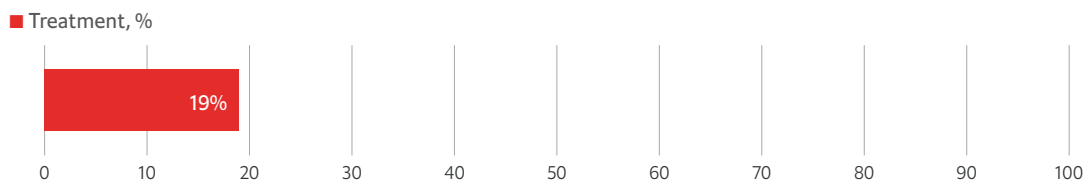
This rate grows rapidly with age: nearly one in six of those living in Britain, aged 80 years or older, has Alzheimer’s disease or another dementia. Population ageing is therefore making this condition far more common. Between 1990 and 2019, prevalence grew by 30% (Economist Impact’s calculation).<sup>4</sup> A 2017 study estimated that, largely because of longer life expectancy, the number of cases in England and Wales would grow by 57% between 2016 and 2040.<sup>38</sup> Health and social care systems will thus need to be ready for the steadily rising demand.

The economic burden of Alzheimer’s disease in the UK is already substantial, and likely to rise with this growing prevalence. In 2019, the aggregate financial burden was equivalent to 0.84% of GDP or £19bn (\$24.2bn). Nearly half of this amount (47%) is made up of direct costs. Of the remaining indirect costs, the lion’s share comes from the curtailed economic activity of informal carers because around 95% of initial Alzheimer’s disease diagnoses occur after the typical retirement age of 65.<sup>39</sup>

### Opportunities to reduce the burden

Recent advances in treatment are highly promising. New therapies that target amyloid plaque accumulation associated with Alzheimer’s disease are in the pipeline and may, in some cases, slow cognitive decline itself. The long-term impacts of these therapies, though, are still uncertain and data on the extent to which they may reduce the economic burden are lacking.

Figure 5  
**Estimated potential savings as percentage of the baseline cost for Alzheimer’s disease between 2019 and 2030**



Source: Economist Impact analysis, 2023.

Figure 5 highlights the estimated economic benefits of investing in the treatment of Alzheimer’s disease between 2019 and 2030. The economy-wide gain of better treatment for all eligible patients would be equivalent to 19% of the current aggregate financial burden of Alzheimer’s disease, i.e., the baseline cost.

Our study therefore considers the benefits for acetylcholinesterase inhibitors, the only treatment for which sufficient data were available at the time of the analysis.<sup>40-42</sup> These interventions essentially provide temporary relief from certain cognitive symptoms. Our study thus assumes that they should enable patients to stay independent for longer. This should, in turn, decrease the burden for formal and informal caregivers.<sup>43,44</sup>

The figures indicate that acetylcholinesterase inhibitors do have the potential to bring benefits. Although our analysis estimates that they raise the cost of treatment by 19%, this would be more than compensated for by the resulting increase in economic productivity, especially among carers. Overall, the economy-wide gain of treating all eligible patients with these drugs would, between 2019 and 2030, be the equivalent of 19% of the current aggregate financial burden of Alzheimer's disease, i.e., the baseline cost.

**...the system for such care remains unfair, confusing, and with little protection against catastrophic costs to patients and their families.**

House of Commons Committee Report, 2021

### Current policies

Dementia policy in England requires updating. As noted, the last strategy expired in 2020, with no available final assessment of how well it met its commitments. While it had a range of aims, given the limits of medical treatment when it was first launched in 2015, a major focus was on the provision of appropriate social care. A House of Commons Committee Report in 2021, however, found that the system for such care remains unfair, confusing, and with little protection against catastrophic costs to patients and their families. In addition, post-diagnostic support for patients and carers is highly problematic.<sup>45</sup>

The government has since indicated that dementia will be covered in the promised Major Conditions Strategy. To judge from comments made in 2022 and 2023,<sup>21,22</sup> policy on Alzheimer's disease and other dementias appears headed towards greater funding for social care, improved prevention (which can overlap with prevention of other non-communicable diseases (NCDs)) and investment in research for new treatments.

## Epilepsy (idiopathic)

### Burden

Epilepsy, one of the world’s most common neurological conditions, is a brain disorder in which abnormal electrical activity causes seizures or unusual behaviour. It can lead to disability, psychiatric side effects, social isolation and even premature death.<sup>3, 46, 47</sup>

In the UK, the most recent estimates put the total prevalence of all forms of epilepsy at 937 per 100,000 people.<sup>11</sup> This is about average for developed countries. Although the methods for making these estimates may not be comparable, data for other developed countries are available for Germany (1,998 per 100,000),<sup>48</sup> the United States (1,200),<sup>49</sup> Italy (850)<sup>50</sup> and Japan (600).<sup>51</sup>

The economic toll of idiopathic epilepsy alone – only one form of the condition – came to 0.07% of GDP in 2019 or £1.7bn (\$2.1bn). Indirect costs make up 83% of this burden. The reason is straightforward – good, effective epilepsy treatments exist that, in most cases, are not necessarily expensive. The World Health Organization (WHO) reports that generic forms of some epilepsy drugs can cost as little as \$5 (roughly £4 at the time of publication) per person per year.<sup>52</sup> Moreover, although some cases certainly require specialists, the WHO observes that most can be diagnosed and managed properly within primary care.<sup>3</sup>

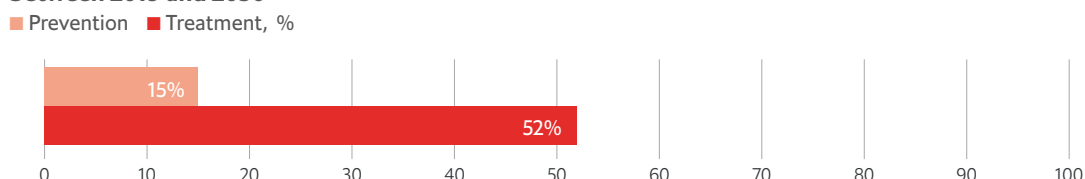
### Opportunities to reduce the burden

The WHO estimates that around 25% of epilepsy cases are potentially preventable through reductions in, among other things, central nervous system infections, head injuries during birth, and other traumatic brain injuries.<sup>3</sup> For our study of idiopathic epilepsy, we defined “prevention” as better access to healthcare services to manage conditions that cause seizures.

Treatment has an even bigger impact. The WHO estimates that 70% of patients with epilepsy can live seizure-free if they receive appropriate and timely treatment. This level of control would, in turn, likely improve their quality of life, mental health, economic productivity and employment status.<sup>53</sup> Our model therefore assumed that appropriate treatment could cut the employment-related losses of those living with epilepsy and their carers.

For the UK, then, the maximum potential savings from better prevention between 2019 and 2030, after accounting for the costs of these interventions, would be 15% of the combined direct and indirect economic burden that would occur in their absence. For treatment, the equivalent number is more than half (52%) of the baseline cost.

Figure 6  
**Estimated potential savings as percentage of the baseline cost for epilepsy by scenario between 2019 and 2030**



Source: Economist Impact analysis, 2023.

Figure 6 highlights the estimated economic benefits of investing in the prevention and treatment of Epilepsy between 2019 and 2030. The economy-wide gain of better treatment for all eligible patients would be equivalent to 52% of the current aggregate financial burden of epilepsy, i.e., the baseline cost. Similarly, the estimated gains would be equivalent to 15% from better prevention.

### Current policies

The actual savings available are probably lower, simply because epilepsy care in the UK already has some strengths. Epilepsy Action, a patient group, notes that over half of those with the condition already live seizure-free. It estimates, therefore, that the treatment gap which needs to be filled is only around 18%.<sup>54</sup> Ramping up better treatment for individuals in this group would involve lower additional costs than projected by the model, but would also have a smaller impact on the economic burden.

The treatment benefits would rise with improved diagnosis, which is a current weakness. On the one hand, around 20-30% of those diagnosed with epilepsy in the UK do not actually have the condition;<sup>55</sup> on the other, it is unclear how many cases are missed. Diagnosis is not straightforward and, depending on the symptoms, could take years.<sup>56, 57</sup> No national epilepsy registry exists, however, so it is impossible to estimate how many cases are likely missed.

The health system certainly has tools to help clinicians diagnose and manage epilepsy, including NICE's clinical treatment and management guidelines.<sup>58</sup> An NHS toolkit also exists to help local health systems understand epilepsy care priorities and reduce regional disparities.<sup>52</sup> The Neurological Alliance also has developed the 'Epilepsy Resource Navigator tool' that identifies and directs the stakeholders towards best available evidence to support services pertaining to epilepsy.<sup>59</sup> Nevertheless, general care is falling short. A study published in 2021 found, for example, that annual reviews of medication and control occurred for only 14% of people living with epilepsy.<sup>60</sup>

## Multiple sclerosis

### Burden

MS is one of the most common neurological disorders found in young adults. At diagnosis – the average age is 30 – most patients present with intermittent neurological relapses. Ten to twenty years after onset, however, many enter an advanced phase of the disease that does not have temporary remissions. Patients with moderate or severe MS make up 31.6% of the patient population, but account for 60% of MS-specific morbidity.<sup>61, 62</sup>

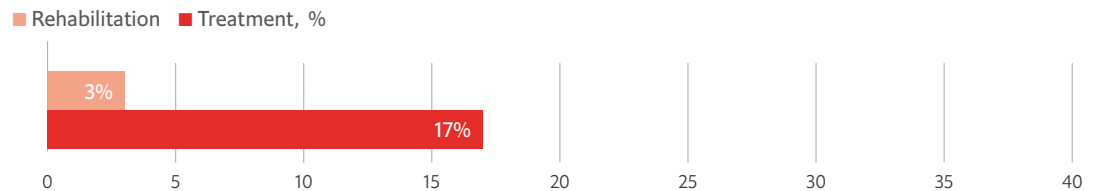
The underlying causes of MS are still not fully understood. However, research suggests several environmental and genetic factors might increase the risk of developing this disease, as can infection by the Epstein-Barr virus.<sup>61, 62</sup>

A geographic link to MS prevalence also appears to exist, with populations living farther from the equator having a higher proportional burden. This may help explain why the UK has a particularly high prevalence of MS as compared with many countries in our previous world-wide study – 149 per 100,000;<sup>4</sup> even within the UK, it is especially elevated in Scotland (217 per 100,000).<sup>4, 63</sup>

With so few cases, it may seem surprising that the MS's overall economic impact in 2019 came to 0.12% of GDP or £2.78bn (\$3.55bn). This is due to the high cost per individual, which came to more than £35,000 (\$45,000) per patient per year in 2019. 81% of costs are indirect because the high prevalence of MS among working-age individuals has significant economic consequences. One systematic review across eight countries, for example, found that affected individuals have 15-30% lower employment levels, as well as greater absenteeism and presenteeism as compared to the general population.<sup>64</sup> Meanwhile, around 36% of people with MS who need support rely on unpaid care, and a 2018 survey found that 30% of these carers were unable to keep a job due to the attendant responsibilities.<sup>65</sup>



Figure 7  
**Estimated potential savings as percentage of the baseline cost for MS by scenario between 2019 and 2030**



Source: Economist Impact analysis, 2023.

Figure 7 highlights the estimated economic benefits of investing in the rehabilitation and treatment of MS between 2019 and 2030. The economy-wide gain of better treatment for all eligible patients would be equivalent to 17% of the current aggregate financial burden of MS, i.e., the baseline cost. Similarly, the estimated gains would be equivalent to 3% from better rehabilitation.

### Opportunities to reduce the burden

The lack of understanding about the causes of MS implies that no viable prevention strategies currently exist.

A number of treatment options, though, are becoming increasingly available. NICE, for example, approved several new medications for MS between 2019 and 2022.<sup>66</sup> Many new drugs are disease-modifying therapies (DMTs). While each medication has its own impact, in mild cases of MS, some treatments can reduce days absent from work by 42%.<sup>67</sup> Furthermore, in a study that included mild and moderate cases of MS, 68% of patients who started a high-efficacy DMT achieved a result of “No Evidence of Disease Activity” after one year of treatment.<sup>68</sup>

These drugs can be expensive.<sup>69</sup> Our analysis considered their costs alongside the 68% reduction in forced unemployment, absenteeism and presenteeism for those affected by mild or moderate forms of the disease and their carers. In the UK, the net result was a potential saving to the economy as a whole – as a result of reduced productivity losses – of 17% of the aggregate baseline costs of MS (the baseline analysis used 2019 data and included an estimate for the proportion of people that were receiving DMTs at the time).

Certain rehabilitation interventions can also help. Studies indicate that physiotherapy and occupational therapy is able to improve muscle tone to an extent that corresponds with an 8% increase in function.<sup>70-72</sup> Comparing the economic activities gains from this improvement to the cost of the interventions indicated that they could cut the UK’s direct and indirect economic cost from MS by 3% from the baseline if used for all potential patients.

### Current policies

The UK has one of the largest repositories of patient-reported outcome measures (PROMs) for MS in the world – the UK MS register.<sup>73</sup> It has collected more than 30,000 individual responses over a period of nine years, linked to individual NHS medical records. Furthermore, as noted earlier, the *NHS Progressive Neurological Conditions Toolkit* encourages regional health centres to assess and benchmark their MS pathway to identify opportunities for improvement and NICE has produced evidence-based guidelines for MS treatment, as well as a care quality standard for the condition that aims to improve outcomes.<sup>74</sup>

Despite these laudable advances in MS care, no national MS plan exists in the UK and patients face the challenges, with timely diagnosis, individualised treatment and care coordination, that are common to all those affected by neurological conditions.

## Parkinson’s disease

### Burden

Parkinson’s disease, a chronic, incurable condition, is the second most common neurodegenerative disorder after Alzheimer’s disease in the UK.<sup>75</sup> The main risk for Parkinson’s disease is age, but it has also been linked to exposure to industrial chemicals and pollutants. These factors explain why the condition is more common in countries with greater levels of economic development, such as the UK where the prevalence is 251 per 100,000 people.

The current direct and indirect costs of Parkinson’s disease – our baseline – comes to 0.14% of GDP or £3bn (\$3.4bn). This is another case of the seemingly small prevalence, in absolute terms, having a large economic toll, driven by the annual cost per patient. In 2019, this came to around £17,000 (\$22,000). The limited treatment options and the long period of progressive neuromuscular decline – typically requiring informal care for 10-20 years – mean that the majority of the economic burden arising from Parkinson’s disease are due to indirect costs, especially lost economic productivity among carers. In the UK, the latter makes up 88% of the total economic toll.

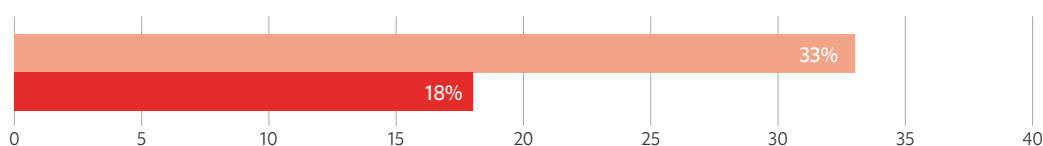
### Opportunities to reduce the burden

Current understanding of the causes of Parkinson’s disease has not given rise to any widespread preventive interventions.

Existing treatments for the condition do not change the course of the disease, but manage the motor symptoms and impairments that arise as a result. As the disorder progresses, however, these drugs become less effective and levels of disability rise.<sup>76</sup> For our cost analysis, we considered the impact of scaling up treatment using levodopa (a dopaminergic therapy), for which good evidence exists of a temporary reduction in symptoms.<sup>77</sup> Such a change, it was assumed, would also allow care givers to remain economically active for longer – until the efficacy of the drug is eventually diminished. In the UK, this led to a drop in the disease burden by a maximum of 18%. As the NHS already prescribes this drug for Parkinson’s disease, the total gains would likely be lower, but the analysis does indicate that all eligible patients should receive the treatment.

Rehabilitation does not halt the progression of Parkinson’s disease but does help with managing symptoms. We analysed the impact of physiotherapy and light exercise programmes that have the strongest evidence base for improving levels of independence and reducing caregiver burden.<sup>78-80</sup> Their provision in the UK to all eligible patients would lead to a maximum decrease in the overall economic burden of a third. However, as before, the actual benefit could be lower depending on the proportion already receiving such therapy.

Figure 8  
**Estimated potential savings as percentage of the baseline cost for Parkinson’s disease by scenario between 2019 and 2030**  
 ■ Rehabilitation ■ Treatment, %



Source: Economist Impact analysis, 2023.

Figure 8 highlights the estimated economic benefits of investing in the rehabilitation and treatment of Parkinson’s disease between 2019 and 2030. While the economy-wide gain of better treatment for all eligible patients would be equivalent to 18% of the current aggregate financial burden of Parkinson’s, the estimated gains are relatively high (33%) from rehabilitation.

### Current policies

NICE has produced national guidelines (for England) for Parkinson's disease. Also, NICE's aforementioned *Progressive Neurological Conditions Toolkit* encourages regional health centres to assess and benchmark Parkinson's disease pathways to identify opportunities for improvement.

A patient association, Parkinson's UK, provides personalised information, services and opportunities to people living with the disease. The organisation also has a strategy to improve outcomes by 2024 by accelerating research, improving support for people living with the disease, and creating better awareness about the condition.<sup>81</sup>

The Parkinson's UK Excellence Network conducts a national clinical audit every few years. The 2022 edition found that, despite several strengths in the health services, improvements still need to be made in the access to multi-disciplinary care, better medication management and standardising practice. Particularly relevant to the findings above on physiotherapy, only a quarter of patients are first referred for this service in the diagnosis stage, when NICE recommends that it be done. Perhaps more concerning, fewer than half of patients in hospital received their doses of levodopa on time – an important contributor to its effectiveness.<sup>82</sup>

**Fewer than half of patients in hospital received their doses of levodopa on time – an important contributor to its effectiveness.**

## Spinal muscular atrophy (Type I)

### Burden

Spinal muscular atrophy (SMA), a type of MND, generally presents in childhood. The disease is characterised by the loss of spinal cord motor neurons, muscular atrophy and eventual paralysis. Of the five types of SMA (0-IV), this study focuses on Type I, for which the best data exist. It is also one of the most severe expressions of the disease and the most prevalent form of childhood-onset SMA, accounting for around 60% of all patients.<sup>83, 84</sup>

SMA falls into the rare disease category, with about 10 in 100,000 live births affected by any form of the illness.<sup>83, 84</sup> Public Health England estimates that, for Type I SMA, this figure is 6.2 per 100,000.<sup>85</sup>

That said, precise incidence, prevalence and mortality data are particularly difficult to determine for rare diseases. This imprecision, along with the small number of absolute cases, mean that the decisions on Type I SMA are typically made in line with national rare disease strategies.

Our study used an approximation for prevalence data based on a proportion of the prevalence of all MNDs among those aged under 14 years. This age restriction is statistically useful in creating an estimate of the Type I SMA burden because other forms of MND dominate at older ages; according to the most recent estimates, 82% of those with Type I SMA die by age four.<sup>86</sup> The resultant estimate, 137 cases, was consistent with the 109 people living with Type I SMA that Public Health England found in 2016.<sup>85</sup>

Starting with this prevalence estimate, the study calculated that the direct and indirect economic costs of Type I SMA came to 0.001% of GDP or £16.9m (\$21.0m). In terms of the national economy, this is a low figure; but this is due to the small number of patients rather than the low cost of treatment. Our study in fact estimated that the total costs to the health system came to about £98,000 (\$125,000) per person per year in 2019. These direct costs, driven by hospital admissions and the need for specialist equipment, made up 78% of the total economic burden. Indirect costs – arising from parents having to give up work to provide round-the-clock care for their children, especially once they are put on ventilators – accounted for the other 22%.

**Opportunities to reduce the burden**

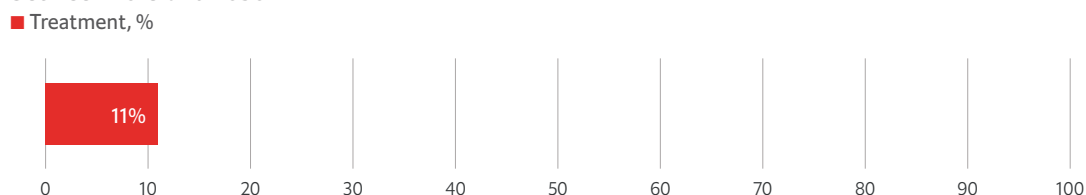
Although patients can benefit from physiotherapy and specialist equipment, these are intrinsic to certain treatment pathways rather than a part of rehabilitation services. This study therefore looks only at the costs and potential benefits of treatment.

Until recently, no such medical intervention for SMA existed. However, in the past few years, more DMTs have become available. These, when combined with ongoing physiotherapy and respiratory support, have shown evidence of improved motor function and respiratory status among those affected by Type I SMA. The long-term effects of these treatments, though, are only starting to become available given how recently they have entered the market.<sup>87, 88</sup>

Among the new therapies are those that give the body a copy of the gene that produces the SMN protein (the absence of which leads to SMA). While recently published findings were very positive for those treated as infants before symptoms arose – including a large proportion walking normally at age six<sup>89</sup> – public information on costs and benefits remain incomplete.

We evaluated one of the DMTs available and then looked at the potential return on investment. Treatments caused a small reduction in overall health service demands for treated patients, as well as a significant drop in caregiver burden.<sup>90, 91</sup> As a result, the benefits to the economy as a whole outweigh even the high costs of these drugs yielding a 11% reduction in the baseline costs.

Figure 9  
**Estimated potential savings from treatment as percentage of the baseline cost for Type I SMA between 2019 and 2030**



Source: Economist Impact analysis, 2023.

Figure 9 highlights the estimated economic benefits of investing in the treatment of Type I SMA between 2019 and 2030. The economy-wide gain from better treatment for all eligible patients would be equivalent to 11% of the current aggregate financial burden of Type I SMA.

### Current policies

England, where SMA falls within the scope of the NHS Rare Disease Action Plan,<sup>92</sup> has several strengths in dealing with Type I SMA. The most prominent is a willingness to provide the most up-to-date treatments through risk-sharing or Managed Access Agreements.

England also has 15 treatment centres offering specialised care.<sup>93</sup> Access to neurologists, physiotherapists and occupational therapists among non-sitting or non-standing paediatric SMA patients – which would cover all affected by Type I SMA – is also near universal.<sup>94</sup> Data are not available, however, on regional variation in care, which is a major issue. Two registries also exist: one for patient-submitted data, based at Newcastle University,<sup>95</sup> and the other comprising anonymised medical information submitted by clinicians and run out of Great Ormond Street Hospital.<sup>96</sup>

About 70 babies are born in the UK each year with SMA; in 2018, the National Screening Committee decided not to screen newborns for the condition. Evidence has grown, though, in support of the value in initiating treatment with new therapies before symptoms appear.<sup>97</sup> Accordingly, in November 2022, the National Screening Committee decided to review the evidence for including screening for SMA as part of the newborn blood spot screening programme. That review is ongoing.<sup>98</sup> Fearing another rejection, clinicians, academics and patients groups have formed the UK SMA Newborn Screening Alliance to campaign for the rapid adoption of screening for SMA in newborns.<sup>99</sup>

**About 70 babies are born in the UK each year with SMA; in 2018, the National Screening Committee decide not to screen newborns for the condition.**

## Section IV: Conclusion

Neurological conditions have a substantial prevalence and impact in the UK. The best estimate is that around one in six people in the country has at least one such disease. This study considers just 10 of the many conditions in this category: Alzheimer's disease, brain cancer, epilepsy, migraines, MS, Parkinson's disease, spinal cord injury, type I SMA, stroke and traumatic brain injury. The collective number of cases for these conditions in the country comes to 14.5m, and the direct and indirect economic burden hit over 4.3% of GDP in 2019.

This human and economic cost is far higher than necessary. The amenable burden – that which could be eliminated by adopting best practices in preventive treatment and rehabilitative interventions – for the disease studied was estimated as 1.4% of GDP or £30.8bn.

Achievement of these economic gains – and the better outcomes for patients and carers from which they arise – will not happen without substantial change in the status quo. Waiting lists are growing longer rapidly and, by certain metrics, neurology and neurosurgery services are performing particularly poorly, even amid a struggling NHS.

As this study shows, change is necessary at both the coalface of care provision for individual conditions and at the broader, strategic level.

A few examples of the former include: type I SMA (and SMA more broadly) should be considered for the newborn screening programme; for Parkinson's disease, more widespread use of medication and initiation of physiotherapy could give quick wins; epilepsy and MS diagnosis and treatment pathways require attention.

Such changes, though, would benefit from a more comprehensive strategic approach to neurology care and services for people affected – one that has been lacking thus far. Such a strategy should consider a full range of approaches to improve the lives of patients and carers. These begin with new and innovative treatments, but need to go beyond a purely medical approach. In particular, to bring down the high indirect costs to the economy, much of which are borne by carers, better social care for those with neurological conditions will be essential; this is particularly relevant as the prevalence of Alzheimer's disease and Parkinson's disease grow with population ageing. Use of multi-faceted and integrated interventions, however, will not occur without first having a holistic strategy targeted at reducing the burden of neurological conditions in the UK.

Perhaps the most immediate need on the strategic side is the one that so far has never been met. Those conditions for which the prevalence falls in the gap between small enough to be covered by rare disease policies and large enough to merit inclusion in the Major Conditions Strategy – such as MS and Parkinson's disease – require greater attention than they currently receive. Otherwise, the decades-old description of neurological care as a "Cinderella Service" will remain true in the years to come.



# References

1. Economist Impact. The value of action: mitigating the global impact of neurological disorders. London: Economist Newspaper Limited; [5 October 2022; cited 8 August 2023]. Available from: <https://impact.economist.com/perspectives/health/mitigating-global-impact-neurological-disorders>.
2. Economist Impact. The value of action: mitigating the global impact of neurological disorders: findings report. London: Economist Newspaper Limited, 2022. Available from: [https://impact.economist.com/perspectives/sites/default/files/download/the\\_value\\_of\\_action-\\_mitigating\\_the\\_global\\_impact\\_of\\_neurological\\_disorders\\_findings\\_report\\_sep\\_2022.pdf](https://impact.economist.com/perspectives/sites/default/files/download/the_value_of_action-_mitigating_the_global_impact_of_neurological_disorders_findings_report_sep_2022.pdf).
3. WHO. Epilepsy: key facts. Geneva: World Health Organization; [9 February 2023; cited 8 August 2023]. Available from: <https://www.who.int/news-room/fact-sheets/detail/epilepsy>.
4. Institute for Health Metrics and Evaluation. Global Burden of Disease (GBD). Seattle, WA University of Washington; [cited 9 August 2023]. Available from: <https://www.healthdata.org/research-analysis/gbd>.
5. Global burden of 369 diseases and injuries in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet*. 2020;396(10258):1204-22.
6. Global, regional, and national burden of neurological disorders, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol*. 2019;18(5):459-80.
7. Neurological Alliance. Neuro numbers 2019. Watford: Neurological Alliance, 2019. Available from: <https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-numbers-2019.pdf>.
8. Fineberg NA, Haddad PM, Carpenter L, et al. The size, burden and cost of disorders of the brain in the UK. *J Psychopharmacol*. 2013;27(9):761-70.
9. Global, regional, and national burden of traumatic brain injury and spinal cord injury, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol*. 2019;18(1):56-87.
10. The Lancet N. Rare diseases: maintaining momentum. *Lancet Neurol*. 2022;21(3):203.
11. Wigglesworth S, Neligan A, Dickson JM, et al. The incidence and prevalence of epilepsy in the United Kingdom 2013-2018: A retrospective cohort study of UK primary care data. *Seizure*. 2023;105:37-42.
12. NICE. Browse guidance by topic: neurological conditions. London: National Institute for Health and Care Excellence; [cited 9 August 2023]. Available from: <https://www.nice.org.uk/guidance/conditions-and-diseases/neurological-conditions>.
13. Independent Cancer Taskforce. Achieving world-class cancer outcomes: a strategy for England 2015 – 2020. London: NHS England, 2015. Available from: <https://www.iccp-portal.org/system/files/plans/Strategy%20-Final.pdf>.
14. Department of Health and Social Care. England Rare Diseases Action Plan 2022. London: Department of Health and Social Care, 2022. Available from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1057534/England-Rare-Diseases-Action-Plan-2022.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1057534/England-Rare-Diseases-Action-Plan-2022.pdf).
15. Brown T. All Party Parliamentary Group on Dementia report. London: House of Lords; [12 November 2021; cited 8 August 2023]. Available from: <https://lordslibrary.parliament.uk/all-party-parliamentary-group-on-dementia-report/>.
16. Department of Health. Prime Minister's challenge on dementia 2020. London: Department of Health, 2015. Available from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/414344/pm-dementia2020.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf).
17. NHS England. The NHS Long Term Plan. London: NHS England, 2019. Available from: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>.
18. NHS England. Transforming elective care services: neurology. London: NHS England, 2019. Available from: <https://www.england.nhs.uk/wp-content/uploads/2019/07/neurology-elective-care-handbook.pdf>.
19. NHS RightCare. Progressive neurological conditions toolkit. London: NHS England, 2019. Available from: <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf>.
20. Department of Health and Social Care. Results of the 10-Year Cancer Plan call for evidence. London: Department of Health and Social Care; [17 May 2023; cited 8 August 2023]. Available from: <https://www.gov.uk/government/consultations/10-year-cancer-plan-call-for-evidence/outcome/results-of-the-10-year-cancer-plan-call-for-evidence>.

21. Department of Health and Social Care. Health Secretary announces 10-year plan for dementia. London: Department of Health and Social Care; [17 May 2022; cited 15 June 2023]. Available from: <https://www.gov.uk/government/news/health-secretary-announces-10-year-plan-for-dementia>.
22. Department of Health and Social Care. Major conditions strategy: call for evidence. London: Department of Health and Social Care; [31 May 2022; cited 8 August 2023]. Available from: <https://www.gov.uk/government/consultations/major-conditions-strategy-call-for-evidence/major-conditions-strategy-call-for-evidence>.
23. Sullivan R, Aggarwal A. Proposal to scrap England's long term plan for cancer. *Bmj*. 2023;380:326.
24. Neurological Alliance. Major Conditions Strategy is a golden opportunity to improve support for people affected by neurological conditions, charities urge. Watford: Neurological Alliance; [22 March 2023; cited 8 August 2023]. Available from: <https://www.neural.org.uk/news/major-conditions-strategy-is-a-golden-opportunity-to-improve-support-for-people-affected-by-neurological-conditions-charities-urge/>.
25. Neurological Alliance. Together for the 1 in 6: England findings from My Neuro Survey. Watford: Neurological Alliance, 2022. Available from: <https://www.neural.org.uk/wp-content/uploads/2022/06/Together-for-the-1-in-6-England-findings-from-My-Neuro-Survey.pdf>.
26. Nitkunan A, Lawrence J, Reilly M. Neurology Workforce Survey conducted by the Association of British Neurologists 2018-2019: V10 28th January 2020. London: Association of British Neurologists, 2020. Available from: [https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020\\_ABN\\_Neurology\\_Workforce\\_Survey\\_2018-19\\_28\\_Jan\\_2020.pdf](https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf).
27. NHS England. NHS Hospital and Community Health Services (HCHS) staff, NHS Trusts and other core organisations in England. London: NHS England; [March 2023; cited 8 August 2023]. Available from: <https://files.digital.nhs.uk/F7/6D16AC/HCHS%20staff%20in%20NHS%20Trusts%20and%20core%20orgs%20March%202023%20-%20Area%20of%20Work%2C%20Job%20Role%20tables.xlsx>
28. Deuschl G, Beghi E, Varga T. Fact sheet: the burden of neurological diseases in Europe. Vienna: European Academy of Neurology; [24 June 2019]. Available from: <https://www.ean.org/research/resources/the-burden-of-neurological-diseases>.
29. Nitkunan A, Lawrence J, Reilly M. Association of British Neurologists UK neurology workforce survey. *ACNR*; [17 Sep 2020]. Available from: <https://acnr.co.uk/articles/neurology-workforce/>.
30. NHS Digital. NHS Hospital & Community Health Service (HCHS) monthly workforce statistics: HCHS doctors by grade and specialty in trusts and CCGs - full time equivalent. London: NHS England; [March 2023; cited 8 August 2023]. Available from: <https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Ffiles.digital.nhs.uk%2F06%2F6D1896%2FNHS%2520Workforce%2520Statistics%2520C%2520January%25202022%2520Doctors%2520by%2520Grade%2520and%2520Specialty.xlsx&wdOrigin=BROWSELINK>
31. Roberts M, Chico D, Naik P. Multiple sclerosis specialist nursing in the UK 2021: results from the MS Trust nurse mapping survey. Letchworth Garden City: Multiple Sclerosis Trust, 2022. Available from: <https://mstrust.org.uk/sites/default/files/ms-trust-specialist-nursing-UK-2021.pdf>.
32. Department of Health and Social Care. The NHS Constitution for England. London: Department of Health and Social Care; [1 January 2021; cited 8 August 2023]. Available from: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>.
33. Department of Health and Social Care. Handbook to the NHS Constitution for England. London: Department of Health and Social Care; [27 January 2022; cited 8 August 2023]. Available from: <https://www.gov.uk/government/publications/supplements-to-the-nhs-constitution-for-england/the-handbook-to-the-nhs-constitution-for-england>.
34. NHS England. Referral to Treatment (RTT) waiting times. Leeds: NHS England; [cited 8 August 2023]. Available from: <https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/>.
35. Neurological Alliance. Neuro patience: still waiting for improvements in treatment and care: the national neurology patient experience survey 2018/19 policy report. Watford: Neurological Alliance, 2019. Available from: <https://www.neural.org.uk/wp-content/uploads/2021/04/neuro-patience-2019-1.pdf>.
36. WHO. Dementia: key facts. Geneva: World Health Organization; [15 March 2023; cited 8 August 2023]. Available from: <https://www.who.int/news-room/fact-sheets/detail/dementia>.
37. Global, regional, and national burden of Alzheimer's disease and other dementias, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol*. 2019;18(1):88-106.
38. Ahmadi-Abhari S, Guzman-Castillo M, Bandosz P, et al. Temporal trend in dementia incidence since 2002 and projections for prevalence in England and Wales to 2040: modelling study. *Bmj*. 2017;358:j2856.
39. NHS England. Overview: Alzheimer's disease. London: NHS England; [ 5 July 2021; cited 8 August 2023]. Available from: <https://www.nhs.uk/conditions/alzheimers-disease/>.
40. Moss DE. Improving Anti-Neurodegenerative Benefits of Acetylcholinesterase Inhibitors in Alzheimer's Disease: Are Irreversible Inhibitors the Future? *Int J Mol Sci*. 2020;21(10).

41. Moss DE, Perez RG. Anti-Neurodegenerative Benefits of Acetylcholinesterase Inhibitors in Alzheimer's Disease: Nexus of Cholinergic and Nerve Growth Factor Dysfunction. *Curr Alzheimer Res.* 2021;18(13):1010-22.
42. Olivieri N. Nothing is right about the approval of aducanumab—and nothing's new. London: BMJ Publishing Group Limited; [4 November 2021; cited 8 August 2023]. Available from: <https://blogs.bmj.com/bmj/2021/11/04/nothing-is-right-about-the-approval-of-aducanumab-and-nothings-new/>.
43. Mioshi E, Foxe D, Leslie F, et al. The impact of dementia severity on caregiver burden in frontotemporal dementia and Alzheimer disease. *Alzheimer Dis Assoc Disord.* 2013;27(1):68-73.
44. Geldmacher DS. Long-Term Cholinesterase Inhibitor Therapy for Alzheimer's Disease: Practical Considerations for the Primary Care Physician. *Prim Care Companion J Clin Psychiatry.* 2003;5(6):251-9.
45. House of Commons Health and Social Care Committee. Supporting people with dementia and their carers. London: House of Commons [29 October 2021; cited 8 August 2023]. Available from: <https://committees.parliament.uk/publications/7662/documents/79983/default/>.
46. American Association of Neurological Surgeons. Epilepsy. Rolling Meadows, IL: American Association of Neurological Surgeons; [cited 8 August 2023]. Available from: <https://www.aans.org/en/Patients/Neurosurgical-Conditions-and-Treatments/Epilepsy#>.
47. Global, regional, and national burden of epilepsy, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.* 2019;18(4):357-75.
48. Groth A, Borghs S, Gille P, et al. PND14: Incidence and prevalence of epilepsy in Germany. *Value in Health.* 2017 Oct 1;20(9):A720. Available from: [https://www.valueinhealthjournal.com/article/S1098-3015\(17\)32261-1/pdf](https://www.valueinhealthjournal.com/article/S1098-3015(17)32261-1/pdf).
49. CDC. Epilepsy data and statistics. Atlanta, GA: Centers for Disease Control and Prevention; [29 March 2023; cited 9 August 2023]. Available from: <https://www.cdc.gov/epilepsy/data/index.html>.
50. Zaccara G, Citerio G, Del Gaudio A, et al. Clinical pathways of epileptic seizures and status epilepticus: results from a survey in Italy. *Neurol Sci.* 2020;41(6):1571-5.
51. Kurisu A, Sugiyama A, Akita T, et al. Incidence and prevalence of epilepsy in Japan: a retrospective analysis of insurance claims data of 9,864,278 insured persons. *J Epidemiol.* 2023.
52. WHO. Epilepsy: report by the Director-General. Geneva: World Health Organization, 2019. Available from: [https://apps.who.int/gb/ebwha/pdf\\_files/EB146/B146\\_12-en.pdf](https://apps.who.int/gb/ebwha/pdf_files/EB146/B146_12-en.pdf).
53. Examining the economic impact and implications of epilepsy. Cranbury, NJ: MJH Life Sciences; [13 February 2020; cited 8 August 2023]. Available from: <https://www.ajmc.com/view/examining-the-economic-impact-and-implications-of-epilepsy>.
54. Health Committee. Written evidence from Epilepsy Action (LTC 57). London: UK Parliament; [9 May 2013; cited 9 August 2023]. Available from: <https://committees.parliament.uk/publications/7662/documents/79983/default/>.
55. NHS RightCare. RightCare: Epilepsy Toolkit: optimising a system for people living with epilepsy. London: NHS England, 2020. Available from: <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2020/03/rightcare-epilepsy-toolkit-v2.pdf>.
56. Parviainen L, Kälviäinen R, Jutila L. Impact of diagnostic delay on seizure outcome in newly diagnosed focal epilepsy. *Epilepsia Open.* 2020;5(4):605-10.
57. Wightwick A. Why undiagnosed epilepsy could explain why a child struggles at school. Cardiff: Media Wales Ltd; [13 November 2018; cited 9 August 2023]. Available from: <https://www.walesonline.co.uk/news/education/undiagnosed-epilepsy-could-explain-child-15409479>.
58. NICE. Epilepsies in children, young people and adults: NICE guideline [NG217]. London: National Institute for Health and Care Excellence; [27 April 2022; cited 20 June 2023]. Available from: <https://www.nice.org.uk/guidance/ng217>.
59. Neurological Alliance. Epilepsy resource navigation tool for commissioners and providers. Watford: Neurological Alliance, 2023. Available from: <https://www.neural.org.uk/wp-content/uploads/2023/06/Epilepsy-Navigator-Tool-v10.pdf>.
60. Minshall I, Buckels L, Cox P, et al. UK general practice: Continuing to fail in the care of people with epilepsy? *Epilepsy Behav.* 2021;124:108354.
61. Office of Neuroscience Communications and Engagement National Institute of Neurological Disorders and Stroke. Multiple sclerosis: hope through research. Bethesda, MD: National Institutes of Health (NIH), 2020. Available from: [https://catalog.ninds.nih.gov/sites/default/files/publications/multiple-sclerosis-hope-through-research\\_o.pdf](https://catalog.ninds.nih.gov/sites/default/files/publications/multiple-sclerosis-hope-through-research_o.pdf).
62. Kaufmann M, Puhon MA, Salmen A, et al. 60/30: 60% of the Morbidity-Associated Multiple Sclerosis Disease Burden Comes From the 30% of Persons With Higher Impairments. *Front Neurol.* 2020;11:156.
63. Botterill S. Why does the prevalence of MS vary depending on where you live? London: AbilityNet [16 September 2019; cited 9 August 2023]. Available from: <https://abilitynet.org.uk/news-blogs/why-does-prevalence-ms-vary-depending-where-you-live>.

64. Kavaliunas A, Danylaite Karrenbauer V, Hillert J. Socioeconomic consequences of multiple sclerosis-A systematic literature review. *Acta Neurol Scand.* 2021;143(6):587-601.
65. European Association Working for Carers, International Alliance of Carer Organizations (IACO), Embracing Carers. Living with multiple sclerosis: the carer's perspective. Darmstadt: Merck. Available from: <https://www.merckgroup.com/es-es/informes/Living-with-MS-Carers-Perspective.pdf>.
66. Drugs.com. What are the new drugs used for multiple sclerosis (MS)? New York, NY: Drugs.com; [16 January 2023; cited 9 August 2023].
67. Rabadi MH, Just K, Xu C. Impact of adherence to disease-modifying therapies on employment among veterans with multiple sclerosis. *Disabil Rehabil.* 2022;44(16):4415-20.
68. Simonsen CS, Flemmen H, Broch L, et al. Early High Efficacy Treatment in Multiple Sclerosis Is the Best Predictor of Future Disease Activity Over 1 and 2 Years in a Norwegian Population-Based Registry. *Front Neurol.* 2021;12:693017.
69. Thompson D. Costs for multiple sclerosis meds tripled in past decade. United Press International; [16 January 2020; cited 9 August 2023]. Available from: [https://www.upi.com/Health\\_News/2020/01/16/Costs-for-multiple-sclerosis-meds-tripled-in-past-decade/6071579148859/](https://www.upi.com/Health_News/2020/01/16/Costs-for-multiple-sclerosis-meds-tripled-in-past-decade/6071579148859/).
70. Ziemssen T, Prosser C, Haas JS, et al. Healthcare resource use and costs of multiple sclerosis patients in Germany before and during fampridine treatment. *BMC Neurol.* 2017;17(1):62.
71. O'Brien JA, Ward AJ, Patrick AR, et al. Cost of managing an episode of relapse in multiple sclerosis in the United States. *BMC Health Serv Res.* 2003;3(1):17.
72. Taracki E, Yeldan I, Huseyinsinoglu BE, et al. Group exercise training for balance, functional status, spasticity, fatigue and quality of life in multiple sclerosis: a randomized controlled trial. *Clin Rehabil.* 2013;27(9):813-22.
73. Nicholas RS, Heaven ML, Middleton RM, et al. Personal and societal costs of multiple sclerosis in the UK: A population-based MS Registry study. *Mult Scler J Exp Transl Clin.* 2020;6(1):2055217320901727.
74. Kraft AK, Berger K. Quality of Care for Patients With Multiple Sclerosis-A Review of Existing Quality Indicators. *Front Neurol.* 2021;12:708723.
75. Global, regional, and national burden of neurological disorders during 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet Neurol.* 2017;16(11):877-97.
76. National Institute of Neurological Disorders and Stroke. Parkinson's disease. Bethesda, MD: National Institutes of Health (NIH). Available from: <https://www.ninds.nih.gov/health-information/disorders/parkinsons-disease>.
77. Cilia R, Cereda E, Akpalu A, et al. Natural history of motor symptoms in Parkinson's disease and the long-duration response to levodopa. *Brain.* 2020;143(8):2490-501.
78. NICE. Parkinson's disease in adults: NICE guideline [NG71]. London: National Institute for Health and Care Excellence; [19 July 2017; cited 20 June 2023]. Available from: <https://www.nice.org.uk/guidance/ng71>.
79. Tomlinson CL, Patel S, Meeke C, et al. Physiotherapy versus placebo or no intervention in Parkinson's disease. *Cochrane Database Syst Rev.* 2013;2013(9):Cd002817.
80. Schrag A, Hovris A, Morley D, et al. Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism Relat Disord.* 2006;12(1):35-41.
81. Parkinson's UK. Our strategy. London: Parkinson's UK; [cited 9 August 2023]. Available from: <https://www.parkinsons.org.uk/about-us/our-strategy>.
82. Parkinson's UK. UK Parkinson's audit: transforming care. London: Parkinson's UK; [cited 9 August 2023]. Available from: <https://www.parkinsons.org.uk/professionals/uk-parkinsons-audit-transforming-care>.
83. Sarv S, Kahre T, Vaidla E, et al. The Birth Prevalence of Spinal Muscular Atrophy: A Population Specific Approach in Estonia. *Front Genet.* 2021;12:796862.
84. Verhaart IEC, Robertson A, Wilson IJ, et al. Prevalence, incidence and carrier frequency of 5q-linked spinal muscular atrophy - a literature review. *Orphanet J Rare Dis.* 2017;12(1):124.
85. Public Health England. Spinal muscular atrophy type 1: NCARDRS data briefing. London: Public Health England; [cited 9 August 2023]. Available from: <https://www.gov.uk/government/publications/spinal-muscular-atrophy-type-1-ncardrs-data-briefing/spinal-muscular-atrophy-type-1-ncardrs-data-briefing>.
86. SMA News Today. SMA life expectancy and disease onset. Pensacola, FL: BioNews; [cited 9 August 2023]. Available from: <https://smanewstoday.com/sma-life-expectancy/>.
87. Ali I, Gilchrist FJ, Carroll WD, et al. Healthcare utilisation in children with SMA type 1 treated with nusinersen: a single centre retrospective review. *BMJ Paediatr Open.* 2019;3(1):e000572.
88. Scanlon D, Cifaloni E. New DMTs in SMA: Nusinersen. Cranbury, NJ: MJH Life Sciences; [11 May 2021; cited 9 August 2023]. Available from: <https://www.ajmc.com/view/new-dmts-in-sma-nusinersen>.

89. Darras B, Mercuri E, Strauss K, et al. P211 Intravenous and intrathecal onasemnogene abeparvovec gene therapy in symptomatic and presymptomatic spinal muscular atrophy (SMA): long-term follow-up study. *Neuromuscul Disord.* 2023;33:S87.
90. Aranda-Reneo I, Peña-Longobardo LM, Oliva-Moreno J, et al. The Burden of Spinal Muscular Atrophy on Informal Caregivers. *Int J Environ Res Public Health.* 2020;17(23).
91. Wadman RI, van der Pol WL, Bosboom WM, et al. Drug treatment for spinal muscular atrophy type I. *Cochrane Database Syst Rev.* 2019;12(12):Cd006281.
92. Department of Health and Social Care. England Rare Diseases Action Plan 2022. London: Department of Health and Social Care; [28 February 2022; cited 9 August 2023]. Available from: <https://www.gov.uk/government/publications/england-rare-diseases-action-plan-2022/england-rare-diseases-action-plan-2022#annexe>.
93. Spinal Muscular Atrophy UK. Treatment centres for children. Stratford-upon-Avon: Spinal Muscular Atrophy UK [cited 19 December 2022]. Available from: <https://smauk.org.uk/treatment-centres-for-children>
94. Muni-Lofra R, Murphy LB, Adcock K, et al. Real-World Data on Access to Standards of Care for People With Spinal Muscular Atrophy in the UK. *Front Neurol.* 2022;13:866243.
95. UK SMA patient registry. Newcastle: UK SMA Patient Registry; [cited 9 August 2023]. Available from: <https://www.sma-registry.org.uk/index.en.html>.
96. Great Ormond Street Hospital for Children. SMArtNet. London: Great Ormond Street Hospital for Children [22 January 2020; cited 9 August 2023]. Available from: <https://www.gosh.nhs.uk/wards-and-departments/departments/clinical-specialties/dubowitz-neuromuscular-centre-dnc-information-parents-and-visitors/dubowitz-neuromuscular-centre/smartnet/>.
97. Aragon-Gawinska K, Mouraux C, Dangouloff T, et al. Spinal Muscular Atrophy Treatment in Patients Identified by Newborn Screening-A Systematic Review. *Genes (Basel).* 2023;14(7).
98. Harris M. Work starts on reviewing the case for screening for SMA. London: UK National Screening Committee; [11 November 2022; cited 9 August 2023]. Available from: <https://nationalscreening.blog.gov.uk/2022/11/11/work-starts-on-reviewing-the-case-for-screening-for-sma/>.
99. UK SMA Newborn Screening Alliance. About us. UK SMA Newborn Screening Alliance; [cited 9 August 2023]. Available from: <https://smanewbornscreening.org.uk/about-us/>.

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