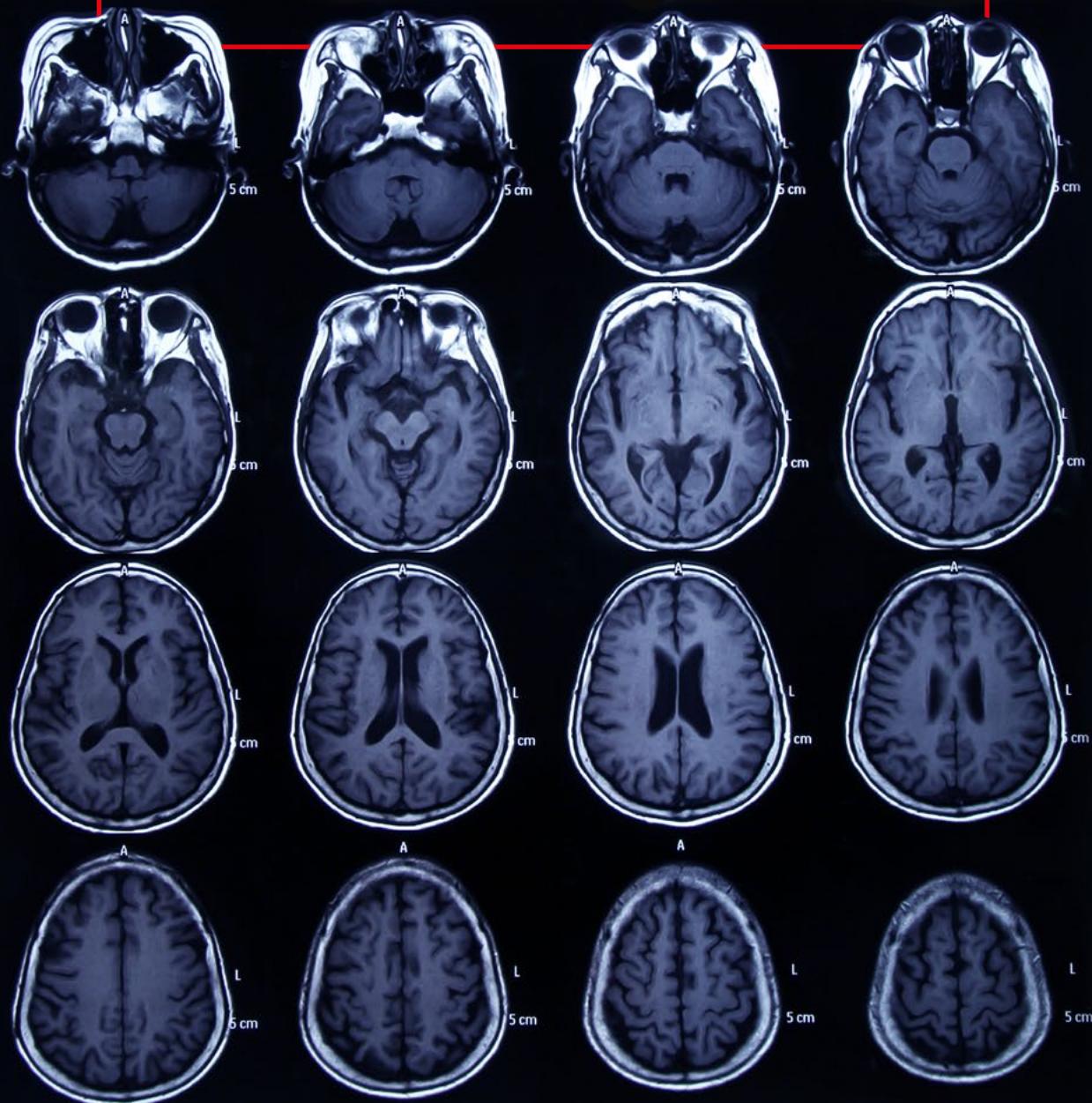


# The value of action

Mitigating the global impact  
of neurological disorders

Findings report



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# Executive summary

Neurological disorders are the leading cause of disability worldwide.<sup>1</sup> The greatest impact of neurological disorders is in low- and middle-income countries (LMICs) where 90% of the global burden is concentrated.<sup>2</sup> In Europe, the direct costs associated with neurological disorders are greater than the direct costs for cancer, cardiovascular disease and diabetes, according to a recent analysis.<sup>3</sup> Strategies and programmes that reduce the burden of neurological disorders are in great demand. However, progress in this regard, as well as in reducing inequalities in health and social care support for neurological disorders, has been insufficient in terms of meeting the UN Sustainable Development Goals targets by 2030.<sup>4</sup> Further exacerbating the global burden of neurological disorders is changing demographics, including ageing populations, which is expected to increase the burden of neurological disorders in the coming years, representing a significant threat to health systems and national economies.<sup>5</sup> It is clear that urgent action is needed to prevent neurological disorders from occurring in the first place where possible, to offer more effective care for those experiencing neurological disorders, and to leverage policy and funding to reach achievable advances in neurological outcomes.

The first step to creating effective change, however, is a clear understanding of the issue. While current literature captures a number of dimensions of neurological disorders, it is often reported and studied in silos. Developing a systemic, cross-disorder understanding that allows for effective prioritisation of limited resources is

critical, particularly in LMICs. *The Value of Action: Mitigating the Global Impact of Neurological Disorders* seeks to do just this: provide a multi-country, multi-disorder platform to understand the importance and impact of neurological disorders. More importantly, it quantifies the value of action across these disorders, showing that progress is not only achievable, but critical to meeting wider economic sustainability and resiliency goals across the globe.

Based on an in-depth literature review, extensive consultation with multi-disciplinary experts in the neurological field, and detailed analysis using 2019 disorder information, this cross-sectional analysis shows potential savings from a range of disorder-calibrated scenarios through 2030. The resulting costs, presented as a percentage of gross domestic product (GDP), allow for stakeholders to benchmark potential savings within a broad economic context both in the short and relatively longer term. The analysis also provides powerful insight into understanding where individuals and their caregivers are most affected by neurological disorders. Subsequent findings will demonstrate how appropriate care can mitigate this burden for all impacted, including the individuals themselves, caregivers, employers and the wider economy.

Ultimately, this research provides a rigorous, evidence-based platform for stakeholders to gain a deeper understanding of the amenable impact of neurological disorders, gaps in current neurological policies and, most importantly, the value of action in addressing it.

# About this report

To focus efforts on reducing the burden from neurological disorders, Economist Impact presents this research to stimulate a multi-dimensional debate which showcases the impact from three angles: the epidemiological burden, the economic burden and the current policy landscape with reference to where urgent changes are required. In order to gain a global perspective across these dimensions, Economist Impact conducted analysis across ten neurological disorders (stroke, Alzheimer's disease and other dementias, Parkinson's disease, spinal muscular atrophy, multiple sclerosis, brain and nervous system cancers, epilepsy, migraine and tension headaches, traumatic brain injury, and spinal cord injury) within eleven different countries (Brazil, China, Colombia, Germany, Italy, Japan, Kenya, Lebanon, Romania, the UK and the USA). Economic analysis is based on 2019 data.

In this report we use the success stories in developed countries as benchmarks of best practice to help develop a culture of change and prioritise resource allocation to cost-saving policy actions in LMICs. To highlight the burden, we used a return-on-investment (ROI) analysis which explores the benefits of scaling up recommended prevention, treatment and rehabilitation interventions for select neurological disorders. The results of this analysis are described in specific disease profiles, within which we also explore national and regional policies and strategies for managing each disorder, as well as opportunities for improvement.

At key milestones during the research process, we engaged with a group of expert stakeholders which we refer to throughout this report as the advisory council. The advisory council included neurology

specialists who have experience in each country featured in this study, within both the public and private healthcare sector.

Below lists in alphabetical order, the experts involved in the research:

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- **Richard Dodel**, Professor, Chair for Geriatric Medicine, University of Duisburg-Essen, Germany
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- **Muthoni Gichu**, Medical Gerontologist; Head of the Division of Geriatric Medicine, Ministry of Health, Kenya
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- **Huali Wang**, Professor and Chair for Clinical Research, Director of the Dementia Care and Research Center; Associate Director, Beijing Dementia Key Lab, Peking University Institute of Mental Health, China

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This research was led by Chrissy Bishop. Analysis was led by Triangulate Health Ltd, in collaboration with Economist Impact. Data collection and analysis were led by Towo Babayemi and Camilo Gutierrez, with input from Bernardo Dias de Aquino Nascimento. This report and accompanying deliverables were written and edited by Chrissy Bishop, Towo Babayemi and Amanda Stucke. All members of the research team were employed by or contracted by Economist Impact. A more detailed description of the methodology for this research can be found in the accompanying Methodology Appendix, available on the Economist Impact website.

# Background: the global impact of neurological disorders

Neurological disorders are the leading cause of disability and the second leading cause of death worldwide.<sup>1,2</sup> With a 40% increase in the number of deaths due to neurological disorders over the last 30 years, strategies and programmes aiming to reduce the burden of neurological disorders are in great demand.<sup>2</sup> The increase in prevalence is particularly prominent in low- and middle-income countries (LMICs) and it is expected to continue to rise due to population growth and ageing.<sup>1</sup> Despite these increases, progress so far has been insufficient in terms of meeting the UN Sustainable Development Goals Targets by 2030.<sup>2</sup>

There are approximately 400 neurological disorders. The Global Burden of Disease (GBD) study helps outline those which have the greatest epidemiological impact on populations, of which there are fifteen.<sup>6</sup> These include: stroke, Alzheimer's disease and other dementias, Parkinson's disease, motor neuron diseases (e.g., ALS, spinal muscular atrophy), multiple sclerosis, brain and central nervous system cancers, meningitis, encephalitis,

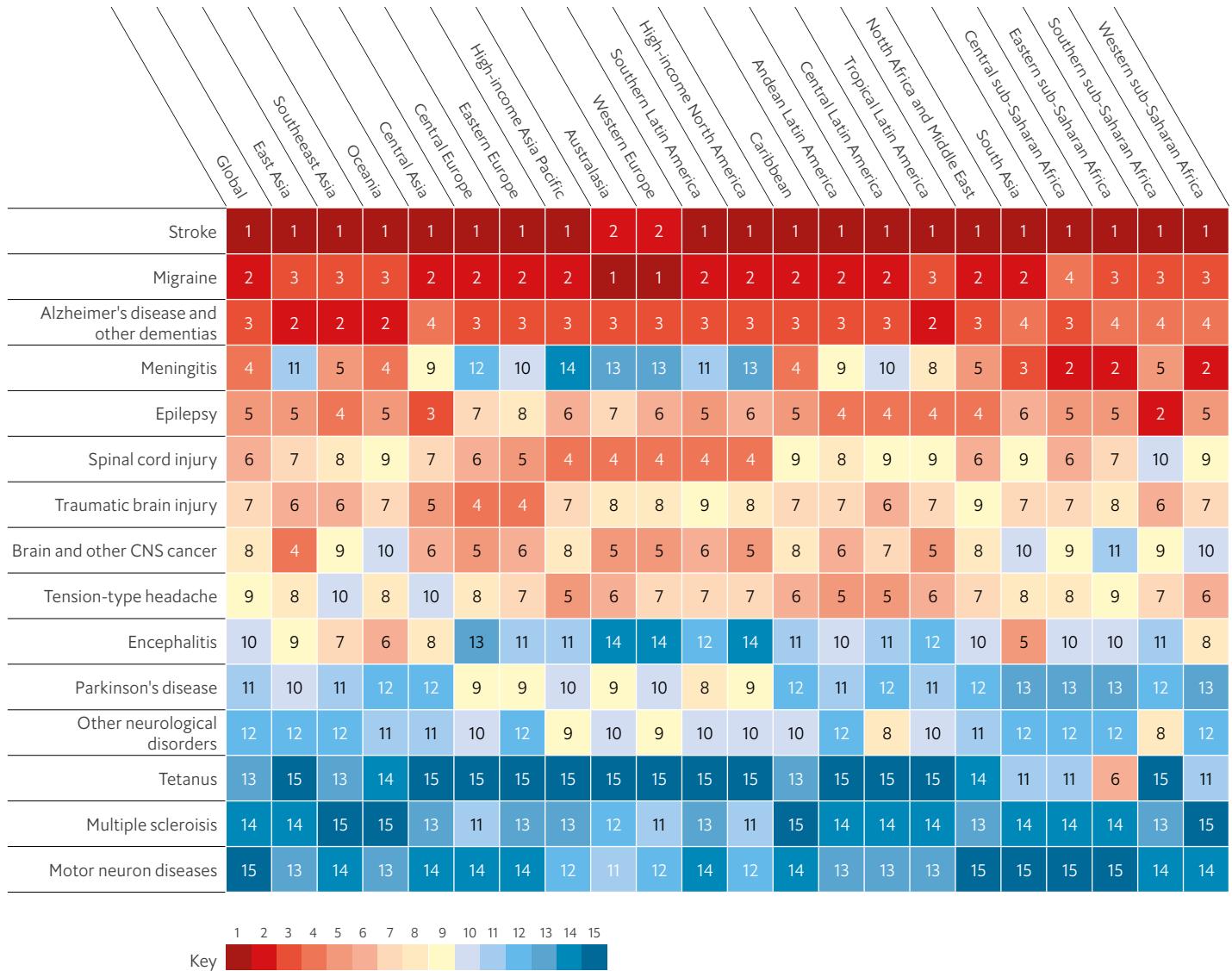
tetanus, idiopathic epilepsy, migraine, tension-type headaches, traumatic brain injury, spinal cord injury, and 'other' neurological disorders.<sup>7</sup> Infectious diseases were excluded from this research leaving the following ten disorders:

- 
- 1 Stroke
  - 2 Alzheimer's disease and other dementias
  - 3 Multiple sclerosis
  - 4 Migraine
  - 5 Parkinson's disease
  - 6 Spinal muscular atrophy
  - 7 Epilepsy
  - 8 Spinal cord injury
  - 9 Traumatic brain injury
  - 10 Brain and nervous system cancers
- 

Looking at the burden of neurological disorders by region reveals variations in prevalence, yet there is consistency in how the different disorders rank in terms of their overall impact on populations. Stroke, migraine, Alzheimer's disease and other dementias consistently rank as the top three disorders in terms of age-standardised disability-adjusted life year DALY rates (**Figure 1**). A search of the global scientific literature on neurological disorders found that the majority of research focuses on stroke, dementia and multiple sclerosis,

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Figure 1  
Ranking of age-standardised DALY rates for all neurological disorders by region (2016)



Source: Theadom et al, 2019.

with fewer studies featuring Parkinson's disease, epilepsy, motor neuron diseases and migraine. Even fewer studies investigate injuries and brain and nervous system cancers. Neurological disorders are responsible for a significant financial burden. Both individuals and families of individuals with

neurological disorders may incur more hidden costs and incremental burden over time than any other disease area. The direct medical costs of managing a disorder and the productivity losses accrued from taking time out of work are exacerbated by a number of factors according to experts interviewed

for this research. These include laborious diagnostic processes, trial and error with emerging treatments, lack of specialist understanding and, in some countries, non-existent clinical guidelines for managing complex neurological disorders. Carers or family members often take time off work or quit their jobs completely to care for a loved one who may be suffering from the effects of a neurological disorder for up to two decades.

While it is true that policymakers and funding bodies rely on accurate and updated epidemiological burden data to make cost-effective healthcare decisions, in this report we explore the value-add of understanding what proportion of this burden is amenable.<sup>7</sup> The ‘amenable burden’ refers to the costs that could be avoided if people with neurological disorders and their carers were better supported, making it more feasible to engage in regular activities. Many components feed into ‘support’ and in this Findings Report we define it as a combination of health system access, policies and strategies, prevention, treatment and rehabilitation, social care support systems, and research agendas. Previous research has demonstrated that the costs of neurological disorders are large, but what proportion of this burden can be avoided? Understanding the amenable burden and the epidemiological burden combined will bolster the financial sustainability of neurological policy decisions, help justify investments into diagnostics and interventions, and will fill a research gap in previous studies.

To capture global variations in burden, in this report we focus on the prevalence, policy approaches and economic burden of neurological disorders in the following 11 countries. The countries chosen span global regions, with varying income levels and health system maturity.

**Table 1  
Countries and regions included in study**

<b>The Americas</b>	USA Brazil Colombia
<b>Asia</b>	China Japan
<b>Europe</b>	Germany Italy Romania UK
<b>Sub-Saharan Africa and the Middle East</b>	Kenya Lebanon

### Research objectives

The overall aim of this research was to develop compelling, collaborative research around the socio-economic burden of neurological disorders, while raising awareness of the value of neuroscientific research and action across the globe. This was accomplished through an in-depth review of literature, expert insight from multidisciplinary specialists and economic analysis and projections. In the Findings Report, we address this aim in three parts:

- **Part 1:** Explore the epidemiological burden of neurological disorders globally, highlighting regional variations in prevalence and need.
- **Part 2:** Profile ten neurological disorders:
  - a. Establish and where possible, quantify, what degree of burden is amenable to preventative, therapeutic and rehabilitative action using an economic analysis.
  - b. Explore the current policy landscape framing neurological care and delivery, discussing policy gaps and opportunities for action by country.
- **Part 3:** Conclude and make global recommendations discussing the implications of the findings for the future of neurological practice.

# Part 1: Global variation in approaches to neurological disorders

## Surveillance, policy, workforce and social care

Accurate estimates of disease burden are pivotal for driving neurological policy agendas. The unfortunate truth about the burden of neurological disorders globally, is that it is largely unknown. Data are scarce even in high-income countries (HICs), which is the primary barrier to effectively planning neurological healthcare services. There are profound differences between men and women suffering from neurological disorders yet a huge data gap exists around gender-specific research. Few studies explore sex- and gender-related factors that impact neurological disorders beyond prevalence (i.e. symptom presentation, disease progression, outcomes, etc.) and may have important implications on drug development and global policies. The GBD has attempted to bridge data gaps by providing the best possible estimates of prevalence, but this should not deter the reader from the reality that registries and standardised approaches to data collection are inconsistent and highly variable by country.<sup>8</sup>

As populations continue to grow and age, governments will face increased pressure to provide treatment, rehabilitation and support services for neurological disorders. Unlike other non-communicable diseases (NCDs) such as heart disease, cancers and diabetes, the scarcity of modifiable risk factors for most neurological diseases means more research is required to catalyse effective prevention and treatment

strategies.<sup>1</sup> Although biopharmaceutical companies are deeply engaged in providing funding and resources to drive clinical research in most disease areas, more engagement among other private and public stakeholders is needed to increase capacity to address neurological disorders effectively around the globe.

Health systems have generally failed to adequately respond to the burden of neurological disorders across the life course. While approximately 70% of people with neurological disorders live in LMICs, it is poorly recognised by their governments.<sup>4</sup> Only 28% of LMICs have a dedicated neurological policy, which refers to specific plans or actions outlined by governments to manage neurological disorders.<sup>4</sup> Public health system expenditure also remains low from a global perspective with just 12% of all countries in the World Health Organization's (WHO) Neurology Atlas (2017) reporting a separate budget for neurological disorders.<sup>9</sup>

A recent study on the global burden of neurological disorders published in *The Lancet* makes a clear call to action for increased resources for neurological disorder management.<sup>1</sup> This study noted the need for better country-specific priority setting and financing of health services, including workforce development. Access to neurologists is also a huge global barrier to effective care. HICs as well as LMICs all suffer from long waiting lists, according to expert feedback. There is a historical pattern of medical students choosing other disciplines

to specialise in over neurology.<sup>10</sup> Practising neurologists refer to this as “neuro-phobia”, caused by the time-intensive and inadequately compensated work required in neurology in comparison to other specialties. A survey conducted in the USA found neurologists have the second highest rate of burnout across all medical specialties.<sup>11</sup> Where neurologists are present, they are often clustered within cities, making it difficult to reach rural communities with neurological care needs.<sup>10</sup> This shortage is exacerbated in LMICs, with the number of neurology specialists reported to be 0.1 per 100,000 population compared to 7.1 per 100,000 population in HICs.<sup>9</sup>

Strategies to support carers of those with neurological disorders also require a revolution as the burden on the caregiver is often overlooked and is not supported adequately by local policy. Caregiver burden relates to the stress resulting from physical tasks, emotional demands and restricted ability to socialise as a consequence of caring for a chronically ill person.<sup>12</sup> Despite a number of policies directly targeting family carers, combining a caring role with work is still causing increased mental health problems for carers suggesting policies could do a lot more.<sup>13</sup> Addressing the needs of carers is especially important in neurology. Most neurological disorders result in a complicated lifespan for both the patient and the carer.<sup>14</sup> Unpaid carers are often expected to fill in a care gap when local health services cannot. Caregiving is also associated with a significant reduction in employment and hours of work, irregular attendance at work and lack of concentration.<sup>13</sup> To support unpaid carers, there needs to be a facilitation of policy discussions

around the world which identify unpaid carer needs, share best practices and recognise the invaluable role carers play. Furthermore, although many people with neurological disorders are able and willing to work, employers have restrictive benefits which leave people with no choice but to leave their job. This creates greater economic losses and contributes to additional strain on caregivers. While in some countries (largely HICs), laws which prevent disability discrimination do exist, in others they are still absent.<sup>15</sup> Additionally, there is a need for better support systems for the long-term care of all neurological disorders, which address the symptoms of disease and also aim to optimise functional and emotional ability, promoting well-being in older age.

### The financial burden

Neurological disorders and injuries have a significant economic impact. Despite advances in medicine, few neurological disorders are actually curable which means the direct costs and indirect costs will continue to accrue throughout the duration of the impacted individuals' lives. People can live with a neurological disorder for decades. As independence levels decline, the indirect costs associated with caregiving and the inability to work at full capacity or at all, gradually rise. A study conducted in Canada from 2000-2001 estimated that neurological disorders cost around \$8.8bn Canadian dollars in one year.<sup>16</sup> This study found the indirect costs associated with eleven neurological disorders amounted to C\$6.5bn. Indirect costs were also reported for specific disorders, including stroke (C\$2.1bn), Alzheimer's disease (C\$1bn), multiple sclerosis (C\$811m) and brain tumours (\$805m).<sup>16</sup> The most costly of these disorders, in terms of direct costs were stroke (\$665m), Alzheimer's disease (\$431m) and headaches (\$411m).<sup>16</sup>

Studies examining the costs of neurological disorders in Europe and the USA have produced dramatic findings. One study in Europe estimated the cost of neurological disorders at €798bn in 2010, of which 63% was attributed to indirect

**Strategies to support carers of those with neurological disorders also require a revolution as the burden on the caregiver is often overlooked and is not supported adequately by local policy.**

costs and non-medical costs.<sup>3</sup> This is equivalent to the cost of heart disease, cancer and diabetes combined in Europe. In the USA, the annual cost of nine neurological disorders was \$789bn in 2014.<sup>17</sup> Both of these cost studies argued that neurological disorders deserve the investment and focus cancers and heart disease receive, before the burden becomes impossible to manage financially. The health and social care costs are compounded by limited universal health coverage in many countries, especially LMICs. Studies outlining the burden of neurological disorders are also limited in LMICs, which leaves governments with little leverage to make a case for change.

### **Understanding the amenable burden of neurological disorders**

Because of the significant financial burden reported in the literature, in this report we wanted to establish and, where possible, quantify, what degree of this burden is amenable to preventive, therapeutic, rehabilitative or political action. By taking a global approach, we wanted to identify which neurological disorders and which countries require more action than others, to broadly inform resource allocation.

To do this, we estimated the economic impact of 10 neurological disorders and the ROI of scaling up access to specific care in 11 countries. For each neurological disorder, we estimated the total costs, both direct and indirect, for the following hypothetical scenarios:

- Baseline or no treatment – The baseline costs are defined as the current status of care for each disorder, including the prevalence, treatment cost, productivity loss due to presenteeism<sup>1</sup> and absenteeism<sup>2</sup>, and cost of informal care as of 2019.

- Prevention – Captures the proportion of the disease burden amenable to effective public health prevention policies (some of the disorders highlighted are not preventable so for consistency, we did not assess impact of prevention for each disease in the scenarios).
- Treatment – The costs and impact associated with scaling up treatments for each disorder to all eligible members of the population according to guidelines or recommended best practice
- Rehabilitation – The costs and impact of scaling up rehabilitation for each disorder to all eligible members of the population

We report our cost analyses and the impact of each scenario using the following measures:

- Direct cost of medical care as a percentage of countries GDP
- The cost of patient productivity losses due to absenteeism, presenteeism, unemployment and early retirement
- The cost of informal caregiver productivity losses due to care for the patient
- The DALYs resulting from each scenario, where DALYs averted reflect a positive effect on health outcomes

The total cost of each scenario was also projected to 2030. We determined that this step was important as the benefit of many interventions for neurological disorders are gleaned long after implementation. These future costs, albeit broad estimates, provide more insight as to when the ROI in these disease areas could be realised.

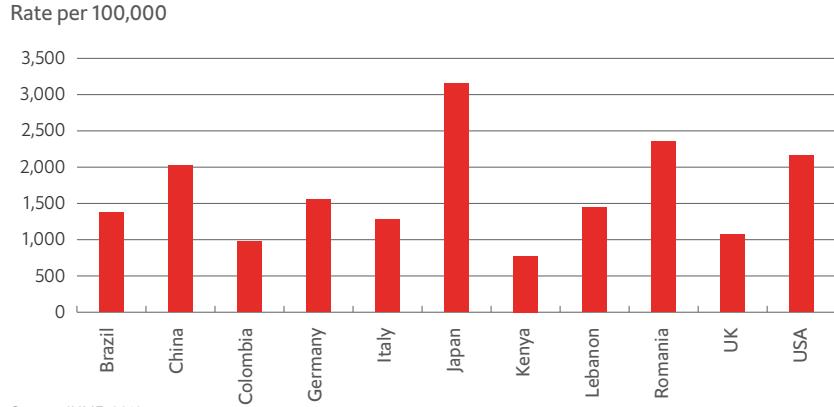
<sup>1</sup> Presenteeism refers to the lost productivity that occurs when employees are not fully functioning in the workplace because of an illness, injury, or other condition.

<sup>2</sup> Absenteeism refers to absence from work that extends beyond what would be considered reasonable and customary due to vacation, personal time, or occasional illness.

## Part 2: The costs of inaction by type of disorder

In this section we discuss the results of our cost analysis by the type of disorder and the implications for each country when considering the local healthcare context. Each disorder profile begins by exploring individual country readiness to effectively treat and support people with neurological disorders and their carers. We assessed readiness as the availability of policies and guidelines, national strategies, disease registries, patient groups, the availability of treatment and rehabilitation facilities, and support for caregivers via social care systems. We conclude each disorder profile by discussing the amenable burden in light of our cost analyses and global opportunities for improvement in each disorder area.

**Figure 2**  
**Prevalence rate of stroke by country (2019)**



Source: IHME, 2019.

### Stroke

Stroke is the second leading cause of death and a major cause of disability worldwide.<sup>6</sup> With more people ageing, there is expected to be a greater incidence of stroke among the global population. Furthermore the frequency of stroke is expected to vary for women before and after experiencing menopause. Women post-menopause are at highest risk when compared to men of the same age, some experts highlight. This is an important distinction which warrants further study as there are sex specific risk factors for stroke amongst women that are not well known (i.e. birth control medications, pregnancy, migraine, etc.). The majority of strokes are ischaemic, meaning they arise from blocked arteries, whereas haemorrhagic strokes result from bleeding in the brain and are responsible for more deaths and DALYs lost.<sup>18</sup> There have been significant improvements to the prevention, acute treatment and neuro-rehabilitation of stroke, primarily in HICs, which has led to a substantial decrease in the burden of stroke over the past 30 years.<sup>18</sup> Despite this, stroke remains a leading cause of disability and death globally, with long-term care and support for stroke survivors falling short of the required need. **Figure 2** describes the prevalence rate of stroke in each country of interest according to 2019 GBD data.<sup>6</sup> Japan has the highest burden of stroke followed by Romania and the USA, with Kenya and Colombia at the bottom end of the scale.

As previously mentioned, the high prevalence in HICs often reflects better data reporting systems and the low prevalence in LMICs is often due to poor or non-existent data reporting systems. Therefore, the prevalence in LMICs should be interpreted with caution, understanding that in the absence of local data, often global epidemiological estimates do not reflect the true burden of disease.

### The Americas

The USA ranks third in stroke prevalence after Japan and Romania in a country by country comparison (**Figure 2**). The USA has one of the most advanced systems for treating stroke. Despite this, treatment may not be easily accessible for individuals without health insurance, or those experiencing geographical or financial barriers to care. The American Heart Association/American Stroke Association developed national guidelines for stroke prevention and treatment, along with a national stroke registry to improve quality of care and outcomes for transient ischaemic attack (TIA) and stroke.<sup>19</sup> Some states have passed laws which help create stroke systems of care via networks of local health services to help stroke patients receive timely and appropriate treatment through rehabilitation.<sup>20</sup> Accrediting organisations and state agencies often certify hospitals as either a Primary Stroke Centre (PSC), Comprehensive Stroke Centre (CSC), Acute Stroke Ready Hospital (ASRH) or Thrombectomy Capable Stroke Centre (TCSC), which are specifically prepared to diagnose, treat and initiate rehabilitation for most stroke patients, including complex and severe stroke cases.<sup>21</sup> In the USA, more than 1500 hospitals are certified as stroke centres. Care coordination across hospitals and emergency services are organised regionally through collaboration and continuous performance monitoring.<sup>21</sup> The US Centers for Disease Control and Prevention (CDC) supports state and territorial health agencies, healthcare systems, and community partners to improve hypertension diagnosis and control in communities by supporting the implementation

of evidence-based practices through funding and data collection.<sup>22</sup> Despite these efforts, waiting time for treatment and clinical outcomes for patients suffering from a stroke are worse in rural areas for those that live further aware from stroke centres. Outcomes are also particularly poor in elderly populations, American Indians and the uninsured.<sup>23</sup> Furthermore, access to follow-up care for stroke survivors is still far from perfect and progress towards supporting families once they have left the hospital is lacking.<sup>24</sup>

In Latin America, Brazil has a National Stroke Policy led by the Ministry of Health, which stipulates financial incentives and reimbursement for stroke care, promotes telemedicine to help access remote patients, and outlines a stroke care pathway.<sup>25</sup> As of 2013, there were 156 stroke centres in Brazil but most of these are in the southeast and southern regions of the country, with the centre-east and northern regions receiving the least care (only two centres).<sup>25</sup> Thrombectomy is available in two public and 64 private hospitals. While, in-hospital rehabilitation is widely available in those with stroke units, access to rehabilitation after discharge is limited.<sup>25</sup> Additionally, public health strategies have also been rolled out to reduce exposure to the risk factors of stroke, including smoking cessation programmes.

In Colombia, according to one 2019 study, 34 stroke centres provide thrombectomy.<sup>26</sup> Endovascular treatment is only available in Colombia's largest cities (i.e., Bogotá, Medellín, Cali, Barranquilla, Cúcuta, Bucaramanga and Tunja).<sup>26</sup> Another study estimates a total of 48 stroke centres with thrombolysis available in all 48 centres and thrombectomy available in three private hospitals.<sup>27</sup> In-hospital rehabilitation is available, however, there is no data describing rehabilitation after discharge. Furthermore, Colombia does not appear to have a national plan for stroke.<sup>26</sup> However, there is a bill in progress which aims to guarantee effective access to health services, adequate care, diagnosis and treatment to patients with stroke, but this is yet to be approved.<sup>28</sup>

## Asia

The prevalence of stroke is particularly stark in Asia. In China, stroke is associated with the highest DALYs, above any other disease, and this country alone accounts for almost one-third of the world's stroke mortality.<sup>29, 30</sup> Ageing is a major contributor to the prevalence of stroke and in 2015, roughly 15% of China's population was over the age of 60.<sup>30</sup> By 2050, this figure is predicted to more than double, representing 36.5% of the population.<sup>30</sup> The average age of stroke patients in China is 66.3 years, which is almost a decade younger than in Europe. Additionally, 15% of strokes occur in individuals under the age of 50, hence impacting the working-age population.<sup>30</sup>

In the past decade, China has made several improvements to its stroke prevention and treatment strategy. The Chinese government created public education and prevention initiatives for stroke to control risk factors and increase awareness.<sup>30</sup> Additionally, China has national and

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regional stroke registries. In order to improve the quality of stroke care and patient outcomes, the Chinese government has sponsored regional and national quality improvement interventions and research studies.<sup>31</sup> However, there continues to be large variations in stroke care across the country. While hospital care has improved because of greater availability of reperfusion therapies and supportive care, adherence to secondary prevention strategies and long-term care are inadequate.<sup>30</sup> Chinese herbal products are still widely used in stroke rehabilitation despite insufficient supporting evidence.<sup>32</sup> The vast availability of neuroimaging in hospitals exists only

in larger Chinese cities, which has also led to an over diagnosis of "silent stroke".<sup>29</sup> This highlights the need for the proportionate provision of specialised stroke services across the country.<sup>29</sup> In response, China has established regional stroke networks and funding for healthcare information integration.<sup>30, 33</sup> The Chinese Stroke Association developed the China Stroke Centre Alliance, a quality improvement project, which resulted in hundreds of comprehensive stroke centres being distributed across 31 provinces, although primarily concentrated in the east.<sup>34, 35</sup> China created the National Telestroke Centre, which functions as a hub for rural hospitals, providing diagnosis and treatment advice to underserved communities.<sup>36</sup> Local governments and the National Health Ministry have also worked together to launch maps under a unified platform that labels the location of hospitals offering thrombolytic treatment.<sup>35</sup> Stroke prevention and treatment have been incorporated into China's "Healthy China 2030" program, pointing to a national approach to stroke action that consists of technical and personnel training, increasing patients' health literacy, and disease prevention and control.<sup>37</sup>

In Japan, a national research centre has been established to lead the nation's research on stroke and operate the national registries of stroke and cardiovascular diseases.<sup>38</sup> Japan's national stroke policy mandates that central and local governments create medical institutes which collect and provide data on stroke and cardiovascular disease.<sup>38</sup> This policy also aims to increase education on prevention, improve local emergency transport systems, medical facilities, coordination of the healthcare team, improve patients' quality of life and promote research.<sup>39</sup> Rehabilitation therapy for stroke patients is covered by Japan's national medical insurance (acute phase hospitalisations) and long-term care insurance (LCTI) systems (after discharge).<sup>40</sup> The Japanese government also aims to build community-based integrated care systems to foster coordination between medical and LCTI providers,

with the inclusion of a comprehensive database between the medical care and LTCI systems.<sup>40</sup> Although Japan has many stroke centres and rehabilitation hospitals, data on their distribution is not available.<sup>41</sup> Therefore, while Japan has the appropriate policies in place, these could be aspirational rather than operational.

### Europe

In Romania, there does not appear to be a dedicated national stroke strategy, which is likely to be one of the reasons why it has poorer outcomes for stroke patients when compared to other European countries. In the absence of a national strategy, the Romanian Society of Neurology is

is now available in most regions, but on a much lower scale as compared to other European countries.<sup>44</sup> During 2015–2016, the annual number of intravenous thrombolysis patients was 10.3 in Romania, while the average of 42 other European countries was 142.<sup>45</sup> There is also no national data collection on secondary prevention of heart attack and stroke and a negligible number of national registries.<sup>42</sup> This renders benchmarking and continual improvement of services difficult. There is also a significant shortage of rehabilitation services in Romania and a restriction on the amount of rehabilitative care patients can receive under the national health insurance. This contributes to unmet patient needs and highlights the importance of national policy on stroke management.<sup>42</sup> Nonetheless, stroke outcomes can be improved with concerted efforts to address gaps in preventative care and rehabilitation.

In Germany, care for patients who have had a stroke is generally comprehensive. The rate of intravenous thrombolysis in Germany is more than twice as high as the European average, and more than 50% of German cities report that access to specialist stroke unit care is above 75%.<sup>45</sup> However, there are some areas in Germany that are underserved and they tend to be clustered in the east and south-east, which have reduced access to stroke care.<sup>46</sup> There are also some gaps in the ability of stroke units to assess adherence to medications prescribed for secondary prevention. Over half of stroke patients in Germany do not receive rehabilitation during the post-acute period.<sup>47</sup> Older people and women were found to be less likely to receive rehabilitation and less likely to receive lipid-lowering medications than younger patients and men.<sup>47, 48</sup> The Stroke Alliance for Europe pointed out that although the survival rate of patients with stroke is increasing, there is no structured or standardised care management for stroke patients when they return home.<sup>49</sup> Stakeholders in Germany have evidenced that they are working to improve this too. In 2017, the German Stroke Foundation initiated a project called "STROKE OWL" which involves specialised

**The Stroke Alliance for Europe pointed out that although the survival rate of patients with stroke is increasing, there is no structured or standardised care management for stroke patients when they return home.**

actively involved in implementing the Stroke Action Plan for Europe 2018–2030, yet a lack of stroke patient associations makes advocacy and raising awareness very difficult.<sup>42</sup> The demand for stroke care is apparent, and reflected in the high hospital costs associated with stroke patients, representing a sizeable part of the healthcare budget. The cost of stroke in Romania is high relative to other diseases, but is also one of the lowest in Europe, partly explained by the level of economic development in the country.<sup>45</sup> Romania spends only €16 per capita on direct healthcare costs for chronic heart disease and cardiovascular disease combined, the second lowest spending in the European Union.<sup>42</sup> Until recently (2019), Romania had problems with access to intravenous thrombolysis treatment. It

stroke managers who get in touch with patients in a stroke unit and help them integrate back into their communities and daily routine.<sup>49</sup> Also, the German Stroke Society has vastly improved neurovascular networks to improve multi-disciplinary stroke care which includes rehabilitation.<sup>50</sup>

Policies and guidelines for stroke care exist in abundance in Germany, which may actually be a hindrance rather than an asset. Some experts report that the number of policies is convoluting the standardisation of care rather than informing it. For example, guidelines for secondary prevention of ischaemic strokes were published by the German Neurological Society and the German Stroke Foundation, however general practitioners (GPs)

treatment, and distribution of treatment facilities. Consequently, a lack of access to care may negatively impact stroke outcomes for patients in Italy. According to 2017 data, stroke centres are unevenly distributed. Despite housing 34% of the population, only 11% of the 130 acute stroke centres are located in southern Italy.<sup>55</sup> Less than a third of stroke patients are admitted to stroke units and around a third of hospital patients do not receive risk-reducing medications following stroke.<sup>55, 56</sup> Similar to Germany, Italy's delivery of post-acute rehabilitation services lacks standardisation and varies across regions.<sup>57</sup>

In the UK, there is a National Stroke Strategy, which was developed by the National Health Service (NHS) England and the Stroke Association, a patient organisation.<sup>58</sup> This strategy has multiple aims, which include improving post-hospital stroke rehabilitation for stroke survivors, delivering a ten-fold increase in access to thrombolysis, improving independence levels post-stroke, training more consultants in thrombolysis and ensuring better follow-up.<sup>58</sup> This strategy also emphasises the UK's ongoing commitment to the collection of stroke prevalence and outcomes data within the national stroke registry, the Sentinel Stroke National Audit Programme.<sup>58</sup> There are also national guidelines, produced by the National Institute for Clinical Care Excellence (NICE) and a National Stroke Service Model that outlines care delivery guidelines for Integrated Stroke Delivery Networks, for specialist stroke units.<sup>59</sup> There are currently up to 30 specialist stroke centres in England, and when stroke patients are admitted to non-specialist units, flexible options for providing Thrombectomy from afar (such as telemedicine to video call a stroke consultant) are also being encouraged to provide access 24/7.<sup>59</sup> Despite a comprehensive stroke pathway in the UK, there are still disparities in stroke care regionally, and 45% of stroke survivors report feeling abandoned after leaving the hospital as they are not able to access rehabilitation.<sup>60</sup>

## In the UK, there is a National Stroke Strategy, which was developed by the National Health Service (NHS) England and the Stroke Association, a patient organisation.

have their own guidelines for both primary and secondary prevention of stroke which are slightly more conservative. While Germany does not have specific targets for stroke in the national health policy, a national cardiovascular disease strategy is currently being developed.<sup>51</sup>

Italy has a national stroke guideline which was co-created with 46 scientific bodies and four patient associations.<sup>52</sup> Additionally, the Ministry of Health developed a national plan of prevention for NCDs in 2019, which includes a general primary prevention strategy for cardiovascular diseases.<sup>53</sup> However, there is no national stroke registry, hindering forward planning of services.<sup>54</sup> Compared to Germany, stroke care is not as well established in terms of referrals, access to

### Sub-Saharan Africa and the Middle East

Countries in North Africa and the Middle East, on the whole, have younger populations than Western Europe and North America, yet life expectancy has increased over the last 20 years. As a result, the prevalence of stroke is expected to increase. In Lebanon, the prevalence of stroke is higher than other Arab and other developing countries, but lower than most developed countries. Stroke is the second leading cause of death in Lebanon, yet there is limited reliable research on the disease.<sup>61</sup> Where epidemiological studies do exist, it is suggested that a higher prevalence of stroke is clustered in areas of socio-economic privilege.<sup>62</sup> Despite its high prevalence, Lebanon struggles to provide the appropriate resources to treat stroke. One of the main diagnostic concerns is the time lag between a patient arriving at a hospital and having a CT scan.<sup>61</sup> As part of a plan towards stroke innovation, in 2018 a Comprehensive Stroke Centre was set up in Beirut. However, as this is the only comprehensive stroke centre in Lebanon, many patients remain without access to appropriate care.<sup>63</sup> An additional concern from industry leaders is that the Lebanese healthcare system's financial ability to manage the large stroke caseload may be compromised as a result of economic depression and local currency depreciation.

Transportation to hospitals and/or telehealth to improve access to specialists could help expand the reach of the hospitals that do exist. Currently around 80-85% of stroke patients are transported to hospital by their families.<sup>64</sup> Following discharge from hospital, stroke management also requires improvements, particularly for ongoing medication management, support to caregivers and rehabilitation.<sup>64</sup> According to expert opinion, in Lebanon and many other parts of the Middle East, there is a lack of disease registries, which makes accurate data collection and prevalence estimates difficult. Data that is available is primarily based on those with insurance coverage, providing an inaccurate representation of the whole population.

There are further concerns around the lack of Lebanese national policies related to stroke.

The international guidelines for prevention and management of stroke need to be adapted to the Lebanese context.<sup>64</sup> This is especially important given smoking and hypertension, two of the key risk factors for stroke, are relatively common in Lebanon.

In Kenya, stroke is a leading cause of death. The estimated mortality due to cardiovascular diseases is 13.8% with stroke accounting for 6.1% of deaths.<sup>65</sup> One of the main challenges is to educate the Kenyan population on the risk factors of stroke. The Stroke Association of Kenya has prioritised producing and disseminating stroke facts and has attempted to influence decision-makers. The Association has also led public health campaigns to promote blood pressure screening and lifestyle change awareness.<sup>66</sup> Some other improvements include the launch of a new strategic plan for the prevention and control of NCDs by the Ministry of Health. This plan aims to enrol 50% of those eligible to receive drug therapy and counselling to manage stroke risk factors (a significant increase from the 6.2% reported on the NCD STEP survey in 2015).<sup>67</sup> Furthermore, another challenge lies in improving quality of life for people who have had a stroke and have been discharged from hospital. Rehabilitation services are largely absent in Kenya, as is support for the mental health needs of those who have had a stroke. This is likely to place a significant burden on caregivers in Kenya in comparison to those living in HICs.

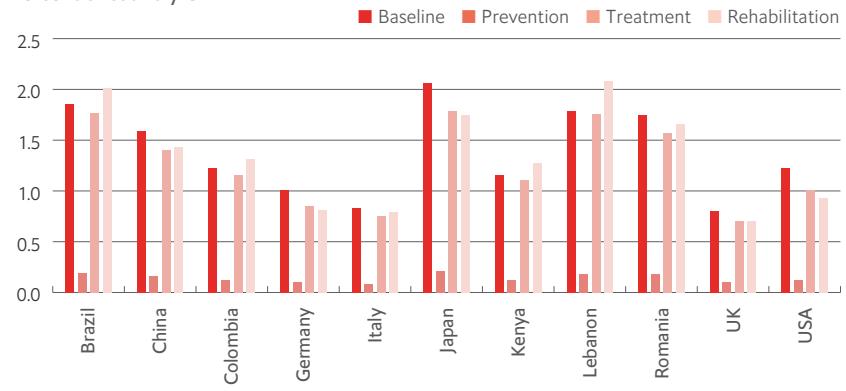
### Stroke: the amenable burden

Our analysis found that choosing to ignore the amenable burden resulted in the highest care costs in all countries. Implementing prevention, treatment and rehabilitation were all cost-saving compared to baseline, with the exception of Brazil, Colombia, Kenya and Lebanon where rehabilitation cost was higher than the baseline. The prevention scenario dominated the other intervention decisions as it was both less expensive and resulted in the highest

Figure 3

**Total cost of stroke scenarios (2019)**

Percent of country GDP

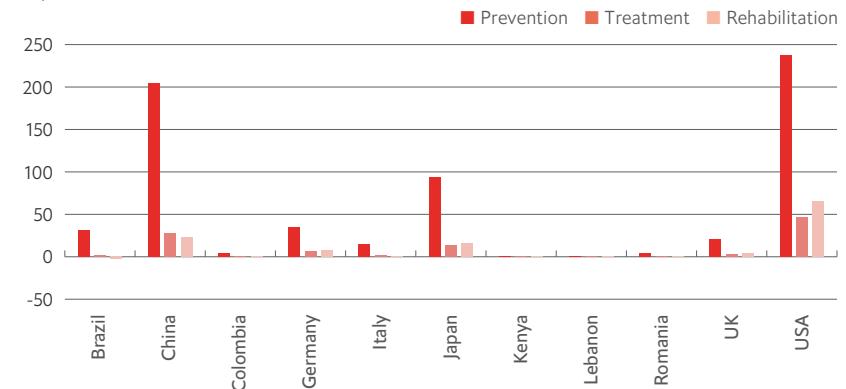


Source: Economist Impact analysis, 2022.

Figure 4

**Potential savings on total costs with implementation of stroke scenarios compared to baseline (2019)**

US\$bn

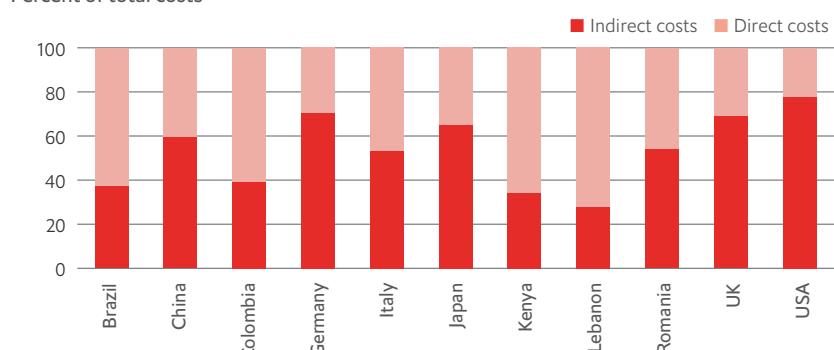


Source: Economist Impact analysis, 2022.

Figure 5

**Composition of stroke costs at baseline (2019)**

Percent of total costs



Source: Economist Impact analysis, 2022.

health-related quality of life (DALYs averted) in all countries. The picture was not so well-defined for treatment and rehabilitation, with variation in the costs observed across settings. For example, in **Figure 3**, scaling up treatment was more expensive than scaling up rehabilitation in Germany, Japan and the UK, but rehabilitation was more expensive in a majority of countries. **Figure 4** reiterates that the prevention scenario yielded the highest savings relative to baseline in the one-year time horizon.

**Figure 5** shows that the indirect costs of stroke were significantly large in all countries for both individuals and their caregivers. Indirect costs were responsible for greater than 50% of the total costs of stroke at baseline in the majority of high and upper middle-income countries included (China, Germany, Italy, Japan, Romania, the USA and the UK) and only dropped below 50% in Brazil, Colombia, Kenya and Lebanon. Scaling up rehabilitation could help to reduce indirect costs significantly as stroke survivors are likely to be more independent and more likely to be able to return to work.

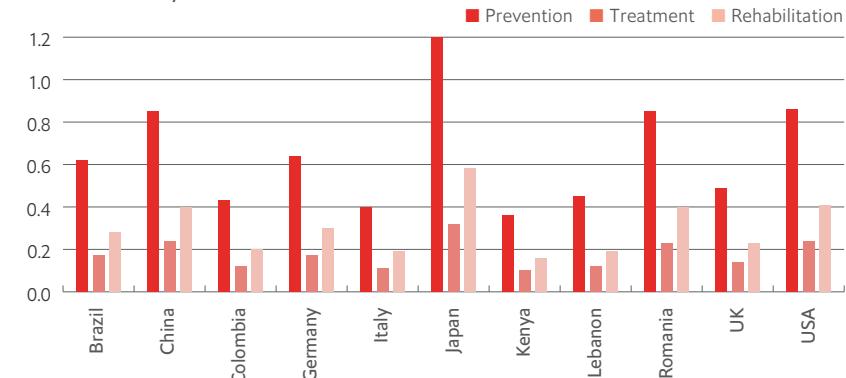
**Figure 6** further describes indirect savings and shows the productivity losses which could be avoided from scaling up the scenarios as a proportion of country GDP. Implementing appropriate stroke prevention could save between 0.36% and 1.20% of GDP (**Figure 6**). Scaling up rehabilitation resulted in less productivity losses than treatment in all countries. In Japan, prevention and rehabilitation accrued the highest savings of all countries. This is most likely driven by the high prevalence of stroke in this country. The smaller proportion of indirect costs recorded at baseline in LMICs are likely to be impacting the savings on total costs (**Figure 8**). The reason for indirect costs being smaller in LMICs may also be attributed to low detection rates or under-reporting.

The ROI of scaling up treatment and rehabilitation becomes more apparent over time. **Figure 7** shows the cost of each scenario between 2019 and 2030 in the USA. We assume that the costs of prevention and treatment were only incurred in

Figure 6

**Potential savings on productivity losses with implementation of stroke scenarios compared to baseline (2019)**

Percent of country GDP

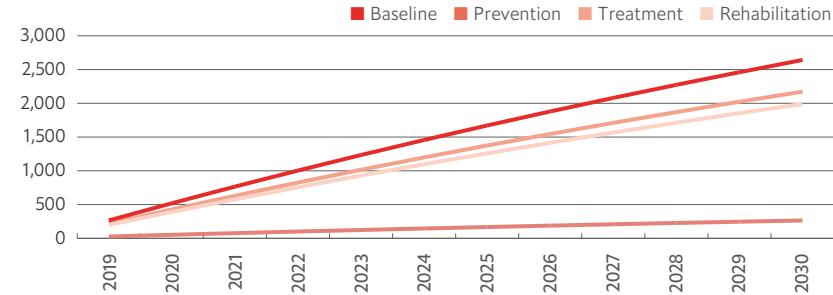


Source: Economist Impact analysis, 2022.

Figure 7

**Stroke costs per scenario from 2019 to 2030 in the USA**

US\$bn

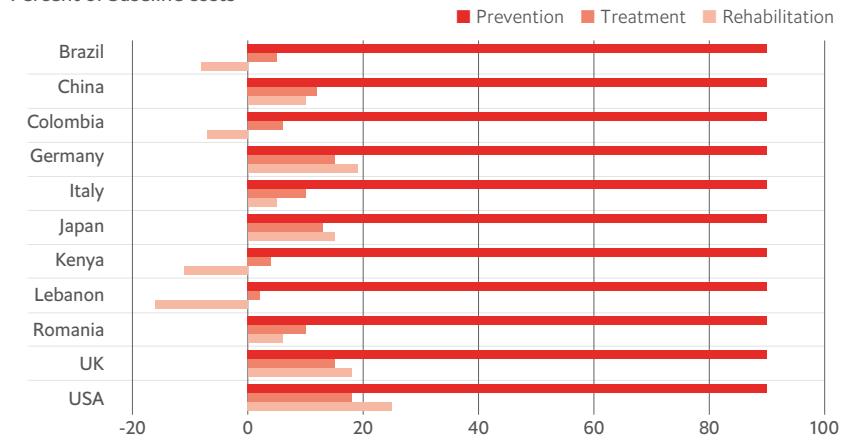


Source: Economist Impact analysis, 2022.

Figure 8

**Potential savings of costs for stroke by type of model between 2019 and 2030**

Percent of baseline costs



Source: Economist Impact analysis, 2022.

2019, whereas rehabilitation costs were incurred each year. Compared to baseline, implementing rehabilitation each year was responsible for savings of around \$650bn by 2030 and treatment was responsible for around \$469bn in savings by 2030 in the USA. The prevention scenario resulted in the greatest savings (around \$2.38tn) when compared to baseline. These savings are generated as a result of the health gains and indirect costs avoided from implementing each scenario compared to baseline. As stroke rehabilitation was noted as an area of improvement in all countries, these figures help justify rehabilitation benefits in terms of cost savings and health gains to support policy decisions. **Figure 8** shows the estimated potential savings for each scenario, by country between 2019 and 2030. Despite the costs of treatment and prevention being incurred in 2019 and rehabilitation costs being incurred each year, there are still cost-savings for treatment and prevention in every country. A small cost was incurred for rehabilitation in Brazil, Colombia, Kenya and Lebanon.

### Global opportunities for stroke care

Across all countries, but particularly in LMICs, rehabilitation is lacking. Even in countries with high treatment rates, such as Germany and the USA, there are gaps in access and follow-up care once patients are discharged from stroke units.<sup>56</sup> Prevention of stroke remains an issue in all countries but for varying reasons. In more affluent countries, risk factors including smoking, drinking and unhealthy diets are a problem, whereas in countries like Kenya, high blood pressure remains undiagnosed or misunderstood.<sup>68</sup> Timely thrombolysis is also not available to all patients due to the uneven distributions of stroke centres and untrained doctors. The psychological and emotional impacts of stroke, which often only become apparent after in-hospital care, are also largely ignored.

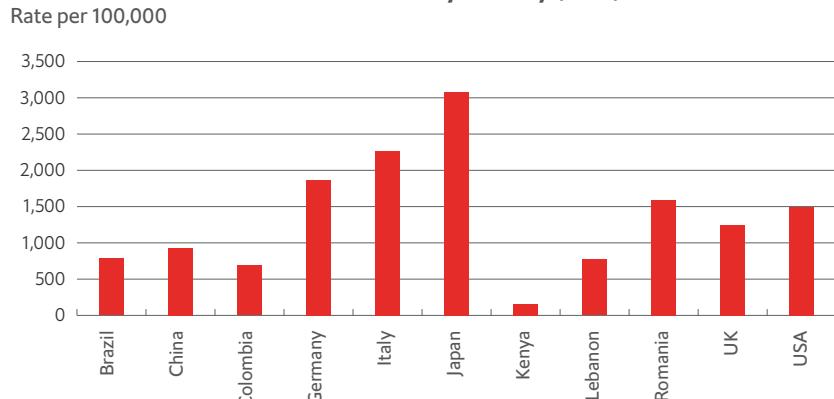
The literature suggests that primary prevention such as the reduction of modifiable risk factors (by adopting healthy lifestyle habits and taking blood pressure lowering treatments), could reduce the risk of stroke by as much as 90%.<sup>69, 70</sup> If prevention is not achieved for those who do have a stroke, there is still an amenable burden which can be reduced by facilitating timely treatment. This is essential not only for survival, but also for reducing the severity of the disability which has significant impact on the productivity of the individual and the downstream impact on the caregiver.<sup>71, 72</sup> Access to rehabilitation means stroke survivors may experience lower disability, less unemployment and lower productivity losses for informal caregivers.<sup>73, 74</sup>

## Alzheimer's disease

Alzheimer's disease and other dementias predominantly impact older individuals and their cognitive function, resulting in cognitive decline.<sup>75</sup> The number of people being diagnosed with dementia is increasing at a striking rate, due to population ageing and improved detection. More than 55 million people are living with dementia, and the number is expected to reach 139 million by 2050.<sup>76</sup> Alzheimer's disease is the most common cause of dementia, and is therefore the primary focus of cases of dementia in this study.<sup>77</sup>

Until very recently, there were no approved disease-modifying treatments (DMTs). Of those that exist today, their clinical impact remains a topic of debate.<sup>78</sup> Most Alzheimer's disease treatments treat symptoms. At the time of this Findings Report, only the US Food and Drug Administration (FDA) had approved a DMT which functions to reduce amyloid plaques, lesions in the brain associated with Alzheimer's disease.<sup>79</sup> Still, the impact of DMTs on slowing disease progression has yet to be established.<sup>80</sup> Because they are not expected to reverse disease progression, to be effective, DMTs likely rely on strong healthcare systems that allow for early detection, diagnosis and care. If additional evidence on the efficacy of DMTs should emerge, it is important to note that upfront investment would be required to ensure equitable access, which could create a lag in traditional measures of cost-effectiveness. A body of fairly recent science has established that there are in fact several risk factors for Alzheimer's disease that can be mediated through lifestyle change, which may delay the onset and reduce the number of people with Alzheimer's.<sup>81-83</sup> Despite this glimmer of hope, the overall scarcity of treatment and solutions for people with dementia, means a heavy burden is placed on the patients, their family and society.<sup>75</sup> Countries are at varying stages of developing and implementing national dementia plans, and there has never been a greater need for appropriately funded social care services and

**Figure 9  
Prevalence rate of Alzheimer's disease by country (2019)**



Source: IHME, 2019.

support for families and caregivers globally. The WHO launched an 8-year Global Action Plan on the Public Health Response to Dementia (2017–2025) to provide guidance to Member States who are developing national plans. These cover Europe, the Eastern Mediterranean, the Western Pacific (Including China and Japan) and the Americas but exclude countries in the African region.<sup>84</sup> Demographics are shifting in all global regions including LMICs, therefore no countries should be exempt from implementing a dementia strategy. **Figure 9** demonstrates the prevalence of Alzheimer's disease by country.<sup>6</sup> It should be noted that the differences in prevalence can be significantly affected by age structures in each country so this should be taken into account when comparing prevalence rates across countries.

### The Americas

According to the Alzheimer's disease Facts and Figures report, which was published in 2021 by the Alzheimer's Association, six million Americans are living with Alzheimer's disease and around 11 million Americans are estimated to be unpaid carers for people with dementia.<sup>85</sup> The USA has a national plan to address Alzheimer's disease called the National Alzheimer's Project Act (NAPA), which was developed with input from public and private organisations.<sup>86</sup> This policy is dedicated to reducing the financial burden on patients and their families, improving treatment and healthcare services, and advancing research.<sup>87</sup> The plan calls for an Inter-agency Group on Alzheimer's disease and related dementias, which consists of partnerships between several national government organisations and is updated annually.<sup>87</sup> Additionally, the US National Institute on Aging (NIA), which is a branch of the National Institutes of Health (NIH), leads national efforts in clinical, behavioural and social research in Alzheimer's disease and related dementias.<sup>87</sup> Along with clinical research, the NIH funds research into disparities and socio-economic barriers that may influence disease progression.<sup>88</sup>

The CDC created the Alzheimer's disease and Healthy Aging Program which is focused on developing evidence-based scientific information to educate and inform public health practice.<sup>87</sup> Other functions of this programme include monitoring of the public health burden of cognitive impairment and enhancing understanding about how diverse groups perceive cognitive health (biases, misinformation, etc.).<sup>87</sup> Recently, the USA created a national uniform public health infrastructure which supports the CDC's Alzheimer's disease and dementia public health interventions by partially funding local public health departments, increasing data analysis and timely reporting, early detection/diagnosis, and promoting dementia caregiving.<sup>89</sup> Additionally, the federal government provides funding for states and home and community-based service providers to develop and implement patient-centred support and services.<sup>87</sup>

Despite a comprehensive list of policy and research initiatives in the USA, federal spending on research for Alzheimer's patients continues to fall short of the need. It is projected that in the next 40 years, the USA's expenditure on Alzheimer's care will rise to \$20tn, yet for every \$28,000 of government spending on care for Alzheimer's patients, only \$100 goes directly towards Alzheimer's research.<sup>90</sup> Given the projected growth in dementia cases in the USA, the RAND Corporation highlights the limited capacity of dementia specialists to evaluate and diagnose patients, long wait times and limited accessibility to Alzheimer's disease treatment centres.<sup>91</sup> The 33 NIA-funded Alzheimer's Disease Research Centers are primarily located in the south, northeast and west.<sup>92</sup> Advancements in home treatments may be required in future Alzheimer's disease care to overcome the limitations in in-person treatment.

The USA has a national database of standardised clinical and neuro-pathological research data that is freely accessible to researchers in efforts to foster collaborative research and record cumulative

enrolment of NIA-funded Alzheimer's disease centres.<sup>93</sup> The CDC maintains a database of national and state level surveillance data on health and well-being indicators for older adults including caregiving, subjective cognitive decline, screenings and vaccinations, mental health that informs national prioritisation and evaluation of public health interventions.<sup>89</sup>

In Latin America, according to the GBD, Alzheimer's disease and other dementias rank third in terms of age-standardised DALY rates when compared to all neurological disorders, and are expected to increase. Between 2000 and 2016,

## This figure is particularly striking in Colombia, where the number of individuals with dementia is expected to increase as much as five times by 2050.

the age-standardised prevalence of Alzheimer's disease and other dementias in Brazil increased by 7.8%, from 961.7 per 100,000 to 1,036.9, equating to roughly 1.5 million people.<sup>94</sup> Additionally, dementias rose from fourth to second as the cause of death over the same period of time in individuals aged 70 and older.<sup>94, 95</sup> This figure is particularly striking in Colombia, where the number of individuals with dementia is expected to increase as much as five times by 2050.<sup>95</sup> In addition to the burden on the individual, fragile health systems in the region, unstable economies and extensive inequalities, the caregiver burden in Latin America is among one of the highest in the world.<sup>12</sup> Long-term care options are scarce and predominantly accessible to the wealthy, with a cultural expectation that family members take care of relatives who are chronically ill.<sup>12</sup>

Brazil is working towards passing a national dementia plan with the support of Alzheimer's disease International and other national Alzheimer's associations.<sup>96</sup> These associations provide training, education, resources, counselling and

caregiver support.<sup>97, 98</sup> Currently, Brazil does not have any reported government funding available for dementia-specific research programs, and research on this topic primarily receives funding from international or private organisations. Accessibility of treatment remains an issue for Alzheimer's disease patients in Brazil.<sup>99</sup> Alzheimer's disease care is fragmented in Brazil; although there are many trained staff at dementia facilities, they only treat a fraction of patients. Specialised centres for dementia are mainly located in bigger cities and often associated with public universities.<sup>100</sup> Outside of these centres, accessing specialised health professionals is rare.<sup>100</sup> There are some healthcare programs and policies geared towards Brazil's elderly population which promote physical, social and mental health; however, implementation, training and funding for these programs remain a challenge.<sup>98</sup> In Brazil, there is a registration of medicines that are dispensed for Alzheimer's disease which is managed by the SUS (Brazil's Public Health Care System), however there is no national registry of patient cases of Alzheimer's disease.<sup>101</sup>

In Colombia, the Ministry of Health and Social Protection guarantees care for Alzheimer's disease and other mental health conditions including fronto-temporal dementia and Parkinson's disease.<sup>102</sup> Alzheimer's Prevention Initiative (API) Colombia Trial is a collaborative project, involving the Neurosciences Group of Antioquia and other international organisations, that studies the efficacy of certain treatments on delaying Alzheimer's disease in cognitively impaired individuals with a specific genetic mutation.<sup>103</sup> Through the API initiative, there is an Alzheimer's registry, but this is not exclusive to Colombia. In the registry, leading research organisations (including organisations in the USA) built an online community focused on ending Alzheimer's disease. The Registry connects research scientists to study participants who are eager to advance their knowledge of Alzheimer's disease and its prevention.<sup>104</sup> According to one study, Colombia has five epidemiological studies in dementia, alongside 16 clinical trials, three local

and regional research initiatives, and one local and regional clinical-public policy.<sup>105</sup> Apart from the aforementioned study, there is no reported national plan for Alzheimer's disease in Colombia.

### Asia

Japan released a National Dementia Plan in 2012, known as the Orange Plan, which was followed by an updated 'New Orange Plan' in 2015. The New Orange Plan developed dementia-friendly communities, created a standardised dementia care pathway, improved community-based healthcare services and long-term care, and accelerated training for healthcare staff.<sup>106, 107</sup> Recently, Japan created a cross-ministerial national strategy, the Framework for Promoting Dementia Care, which focuses on prevention, risk reduction, support for caregivers and healthcare workers, and promotes research.<sup>107</sup> According to this framework, ministries are required to promote awareness about people suffering from cognitive impairment, as well as target taxi drivers, retail employees, police, bankers and those working in the criminal justice system to support barrier-free spaces and services for patients with dementia.<sup>108</sup> The Basic Law for Dementia, implemented in 2019, requires national plans to be re-examined and updated regularly.<sup>107</sup> Japan has hospital and university-based Alzheimer's disease registries, but there is no reported national registry.<sup>109</sup> Clinical practice guidelines for managing dementia have been outlined by six

major societies dedicated to treating neurological disorders, including dementia, which mainly align with the USA's consensus for managing Alzheimer's disease.<sup>110</sup> These clinical practice guidelines also include recommendations for reducing caregiver burden and stress caused by long-term care of patients with Alzheimer's disease.<sup>110</sup> Treatment and long-term care facilities appear to be well-distributed in the country, though most patients in Japan receive in-home care. The total societal cost of dementia was estimated in one study to be around 14.5tn Japanese Yen (JPY), of which JPY 1.91tn was attributed to healthcare, JPY 6.44tn for long-term care and JPY 6.16tn for informal care.<sup>111</sup>

In China, there are over 100 epidemiological studies on dementia; despite this, there are still disparities around prevalence rates as these studies all use different methods to collect data.<sup>112</sup> China has implemented some strategies to tackle the burden, including the recent launch of a National Dementia Plan, covering risk reduction, family and caregiver support, public awareness, prevention and treatment guidelines.<sup>113</sup> Additionally, this plan aims to improve community-based dementia care by creating a multi-disciplinary, collaborative network between specialists and primary care services as this proved critical to dementia care during the covid-19 pandemic.<sup>113</sup> This will hopefully improve support for patients living in rural communities in China where the diagnosis and management of dementia is inadequate. Even after the Chinese government created a new policy to increase care facilities for people aged 65 and over, most patients with dementia receive care at home.<sup>112</sup> Access to appropriate assessment and diagnosis is currently limited as only a few physicians in major Chinese hospitals screen for cognitive impairment or have the knowledge of the diagnostic criteria for dementia.<sup>114</sup> Implementation of the new National Dementia Plan may help tackle this; the plan is to be introduced across 60 demonstration areas in China where local health departments will set up working groups to provide technical support and

**Recently, Japan created a cross-ministerial national strategy, the Framework for Promoting Dementia Care, which focuses on prevention, risk reduction, support for caregivers and healthcare workers, and promotes research.**

multi-level training.<sup>115</sup> Additionally, despite the wide availability of Western medicines for managing symptoms, many patients prefer to use traditional methods of treatment. These factors all contribute to the under-reporting of dementia and needs to be explored further in future research.<sup>112</sup>

Most patients with mild or moderate dementia receive care at home.<sup>116</sup> To provide support for homecare, the Chinese government created community day-care services which provide leisure and entertainment activities for older people and are funded through social pension.<sup>117</sup> However, there are a limited number of these day-care centres that provide specific care for people with dementia. Despite the availability of many long-term care facilities (i.e., older people's apartments, care homes, hospice, etc.), there continues to be a shortage of those with dementia care units. Memory clinics are common in China though these are concentrated in the southeast and northern tips of the country.<sup>117</sup> There are a few national research registries for Alzheimer's disease in China which are ongoing, but there are inconsistencies within their data collection methods.<sup>118, 119</sup>

## **Europe**

Alzheimer's disease and other dementias are one of the three most common causes of disability (measured in DALYs) in the European Union (EU) and larger WHO-Europe region, along with stroke and headaches.<sup>118</sup> Prevalence varies across the region, with more than six million cases in Western Europe and 1.5 million cases in Eastern Europe. A study conducted in Finland reported that education level, socio-economic status, and household income was associated with higher dementia mortality.<sup>121</sup> Low household income was the strongest independent predictor for dementia mortality, followed by education level. These findings are important as they point to amenable factors that may help to improve prevention, outcomes, and cost savings in relation to dementia.

Romania currently does not have a national dementia strategy.<sup>122</sup> Access to long-term care support is also poor. Around 33% of Romanian women and 31% of Romanian men reported poor social support in 2014, which is higher than the EU average of 18% for the same year.<sup>123</sup> Around 6–7% of older people required homecare services, but only 0.23% received them and there is almost no coverage in rural areas.<sup>123</sup> Long-term care support therefore mainly relies on family caregivers, a fact which is as much cultural as it is systemic. In a survey carried out in Bucharest in 2015, 50% of employed women expected and were prepared

## **Low household income was the strongest independent predictor for dementia mortality, followed by education level.**

for care responsibilities of an older relative to impede their career at some point.<sup>123</sup> Even with the support of family caregivers – which are on the whole women – counselling and respite services are scarce, which means the mental and physical health of family caregivers is a concern.

In July 2020, the German Government adopted a National Dementia Strategy, which included a funding programme, and aimed to advance long-term care services for people with dementia and promote the health of carers.<sup>124</sup> Germany is also one of the few countries in Europe with a dedicated insurance system for long-term care, which is funded through employer/employee and pensioner contributions. This system does not cover all services required and many out-of-pocket costs remain, but there is also government support for low-income patients who are unable to afford out-of-pocket payments. This is called the German Social Assistance Safety Net which provides certain benefits without added out-of-pocket costs, meaning that everyone in Germany has access to a certain level of care.<sup>125</sup> Even with the existence of a government-funded social care support system, an

estimated 5-6% of the population provides informal care regularly.<sup>126, 127</sup>

Italy also has a National Dementia Strategy, which was implemented in October 2014, alongside a multi-stakeholder dementia observatory.<sup>124</sup> The main purpose of this strategy was to promote specialist interventions for people with dementia and to better support patients and families.<sup>124</sup>

Despite being one of the first countries with such a plan, its implementation had been largely underfunded until 21 December 2020 when the Italian government announced that funding for Italy's National Dementia Plan had been approved for 2021.<sup>128</sup> There is also means-tested long-term care support provided by the public healthcare system which largely targets people aged over 65.<sup>125</sup> Regional disparities in care and care-seeking are also apparent. In northern Italy, where there is a larger proportion of women in the labour market, efforts have been made to improve the long-term care system. However, in the south, the care burden mainly falls upon families, particularly women, with poor public support.<sup>129</sup>

In 2015, the UK published its third National Dementia Strategy in light of having the ambitious aim of becoming the best country in the world for the support of people with dementia and their carers.<sup>84</sup> Further updates to this strategy are expected in 2022, though there are concerns that these changes will be insufficient to provide ongoing support for dementia services and eliminate extreme care costs for individuals with dementia and their families.<sup>130</sup> Wales, Scotland and Northern Ireland also have their own strategies. Social care support and long-term care is means-tested in England – thus, it is only available free-of-charge to people with the highest needs and the lowest assets. People are usually expected to contribute to the cost of publicly funded care services or supplement the public funding.<sup>131</sup> In England, only 43% of people who request social care support receive it, leaving over 50% of people who go without.<sup>131</sup> There is a national dementia registry in the UK that also aims to

engage the public in Alzheimer's research. It is led by the National Institute for Health Research, in partnership with three charities: Alzheimer's Scotland, Alzheimer's Research UK and Alzheimer's Society.<sup>132</sup>

### **Sub-Saharan Africa and the Middle East**

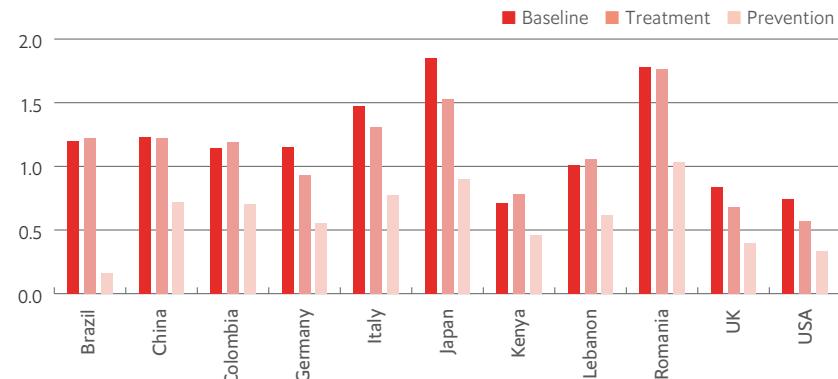
Epidemiological studies in North Africa and the Middle East have demonstrated that the prevalence of Alzheimer's disease and other dementias ranges from 1.1% to 2.3% amongst individuals over the age of 50, and from 13.5% to 18.5% among individuals aged 80 years and above.<sup>133</sup> Although the Eastern Mediterranean has developed a WHO dementia plan, Lebanon, which sits within this region, has no National Dementia Strategy or plan and does not incorporate dementia in any part of its national health plan.<sup>134, 135</sup> Similar to other countries in the Arab region, cultural and religious values mean that family support plays a central role in dementia care. There is a reported lack of public health programs to educate people on vascular risk factors.<sup>136</sup> Access to care for people with dementia is very limited in Lebanon, due to poor awareness, a lack of financial resources, the high out-of-pocket costs of healthcare, poor coverage of public health insurance, and a healthcare system which is largely dominated by private providers. Dementia is rarely addressed by social and health authorities in Lebanon.<sup>137</sup> Although anti-dementia medications are approved in Lebanon, there is limited availability of generic anti-dementia medications, implying that those that could be accessed are expensive.

Kenya also has no National Dementia Strategy, but the Ministry of Health is currently working to develop one. A common problem arising from living with dementia in an African country is the stigma, with cultural and religious belief systems categorising dementia and other mental health problems as a supernatural occurrence or even a normal part of ageing, rather than a health disorder which requires action.<sup>138</sup> According to experts,

## Epidemiological studies in North Africa and the Middle East have demonstrated that the prevalence of Alzheimer's disease and other dementias ranges from 1.1% to 2.3% ... in adults over the age of 50

there is a general lack of knowledge around what dementia is and how to manage it. All care for people with dementia is provided by families, as formal homecare is not an option in most of Africa aside from some wealthier cities such as Nairobi. Where it is an option, it is often socially stigmatised to send a loved one to a care home. There are also significant problems with dementia diagnosis, treatment and access to care, meaning the true burden of dementia is unknown.

**Figure 10**  
**Total cost of Alzheimer's disease scenarios (2019)**  
Percent of country GDP



Source: Economist Impact analysis, 2022.

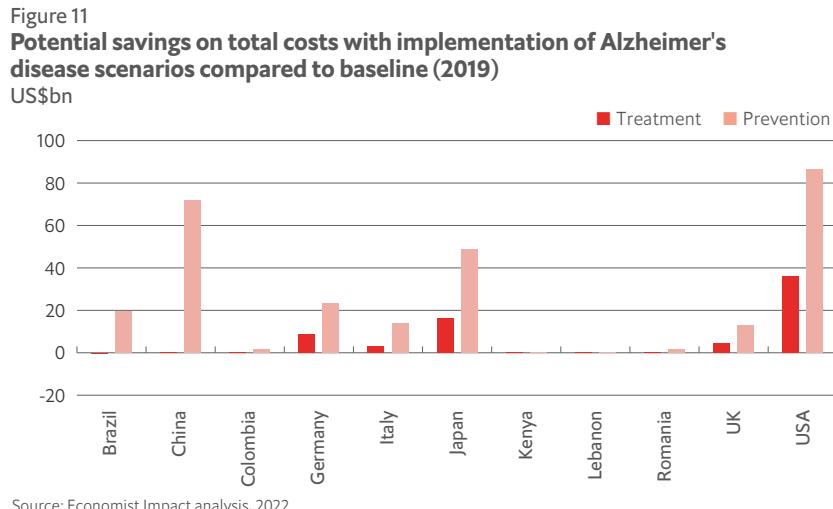
### Alzheimer's disease: the amenable burden

In our cost analyses, we only included Alzheimer's disease and excluded other dementias. This was partly because 60-70% of dementia cases are diagnosed as Alzheimer's and because the evidence suggests available treatments are only effective and approved for Alzheimer's disease.<sup>76</sup> We analysed the ROI of two scenarios, prevention and treatment. A prevention scenario was included in the analysis based on current evidence. A recent life-course model of dementia prevention published in 2020 and conducted by the Lancet Commission estimated that around 40% of Alzheimer's disease cases worldwide can be prevented or delayed based on 12 potentially modifiable risk factors (i.e., excessive alcohol consumption, traumatic brain injury, less education, hearing impairment, physical inactivity, hypertension, low social contact, depression, diabetes, obesity, air pollution and smoking).<sup>139</sup> The treatment scenario looked at the impact of acetylcholinesterase inhibitors, one of the only treatments supported by the evidence base in 2019, the data year of this study.<sup>140-143</sup> While one DMT was recently approved for Alzheimer's treatment in the USA, along with others in review, there was not enough evidence at the time of this study to warrant inclusion in our analysis. Aside from the hypothetical prevention of Alzheimer's disease, treatments considered in this report do not stop the disease or slow the progression of it, but they do reduce symptoms, which may enable patients to stay at home for longer and decrease the burden faced by formal and informal caregivers.<sup>80</sup>

<sup>144, 145</sup> Therefore, the significance of treatments is acknowledged through their impact on direct and indirect costs for both the patient and the caregiver.

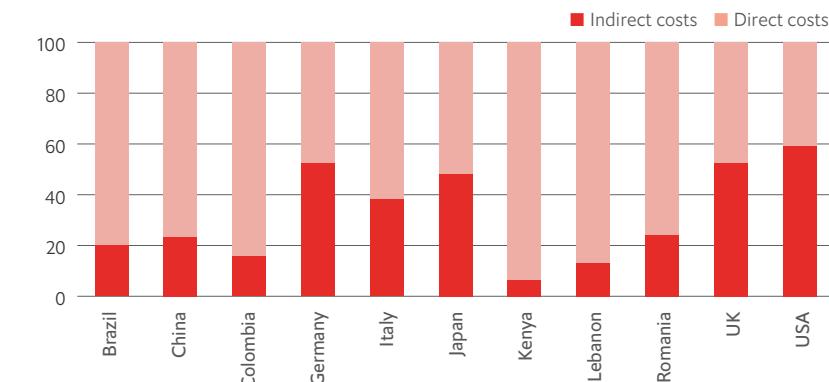
**Figure 10** shows the total cost of each scenario as a percentage of GDP. Japan, Romania and Italy have the highest baseline and treatment costs. In Japan, the workforce participation rate is high, which means there are higher indirect costs accrued at baseline, in addition to the high prevalence of Alzheimer's disease. In Romania and Italy,

workforce participation is lower, so rather than the indirect costs driving baseline, high prevalence and the costs of care are high relative to the countries' GDP. The total cost of the treatment scenario was slightly lower than baseline in Germany, Italy, Japan, Romania, the USA and the UK, and dominated the baseline in these countries as it was both less expensive and, in terms of benefits, resulted in the highest health-related quality of life (DALYs averted). Treatment cost was more than baseline in Lebanon, Kenya, Colombia and Brazil, which means the direct costs of care are higher in proportion to the reduction in indirect costs for these countries.



**Figure 12**  
**Composition of Alzheimer's disease costs at baseline (2019)**

Percent of total costs



Source: Economist Impact analysis, 2022.

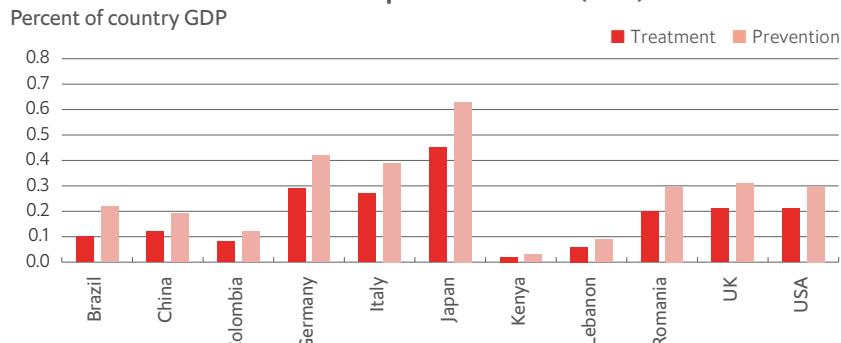
Although we broadly adjusted the costs of treatment for HICs and LMICs, in practice pricing adjustments during procurement will need to compensate for countries' GDP to ensure that they are affordable. **Figure 11** reiterates that both the prevention and treatment scenario yielded savings from baseline in the one-year time horizon except for the treatment scenario in Brazil, Colombia, Kenya and Lebanon.

The indirect costs of Alzheimer's are known to be large (**Figure 12**). In every country in this study, policies and plans for dementia have stated the need to provide social care and financial support to caregivers. Our cost analyses show that the indirect costs at baseline were >50% of the total cost of care in Germany, the USA and the UK. This finding is slightly misleading because in countries where social care support is poor (as in all the LMICs included in this study), the burden on caregivers is likely to be larger. Countries without national dementia registries (such as Lebanon and Romania) are also likely to have huge hidden indirect costs.

**Figure 13** shows the savings on productivity losses from implementing prevention and treatment. Again, prevention averts the largest costs, but treatment also averted productivity losses in all countries. To calculate the total cost from 2019-2030 in **Figure 14**, it was assumed that the treatment costs of Alzheimer's care were incurred in each year. When looking at the cost savings over time for the USA, where the prevalence data are more reliable and registries exist, treatment has the potential to accrue \$362bn worth of savings and prevention may accrue \$863bn worth of savings by 2030 compared to the baseline. **Figure 15** shows the total savings rate of the prevention and treatment scenarios between 2019 and 2030. The figure shows prevention savings greater than 35% in all countries, with the greatest savings found in Brazil (86%). Kenya, Lebanon and Colombia had the least prevention savings compared to the other countries. Over time, the savings on treatment were as much as 23% in the USA and 19% in the UK and Germany. There were no savings for treatment in Brazil,

Figure 13

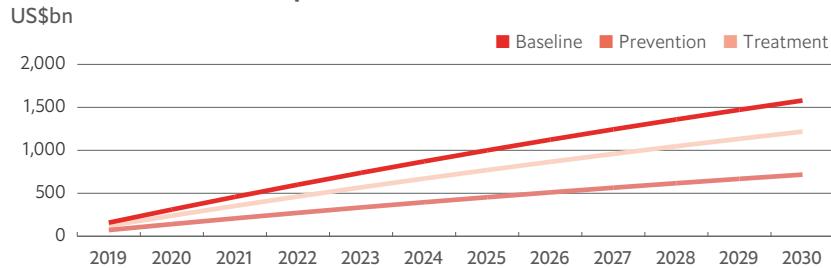
**Potential savings on productivity losses with implementation of Alzheimer's disease scenarios compared to baseline (2019)**



Source: Economist Impact analysis, 2022.

Figure 14

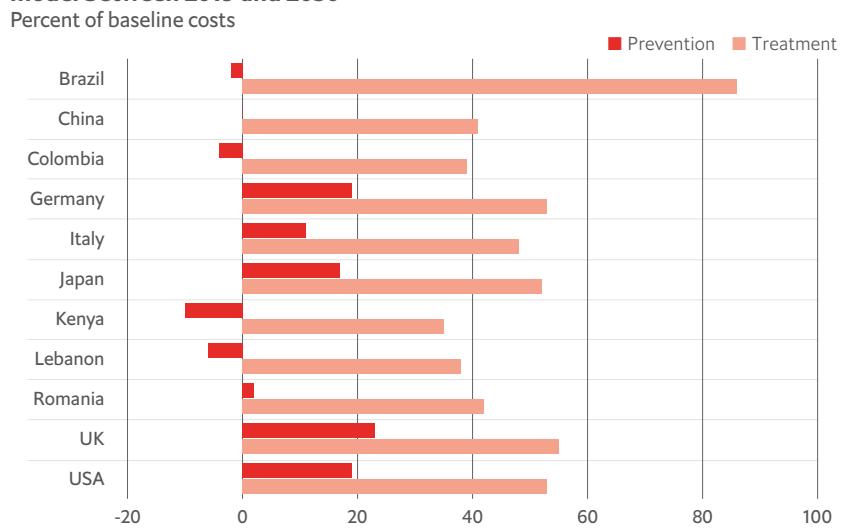
**Alzheimer's disease costs per scenario from 2019 to 2030 in the USA**



Source: Economist Impact analysis, 2022.

Figure 15

**Potential savings of costs for Alzheimer's disease by type of model between 2019 and 2030**



Source: Economist Impact analysis, 2022.

China, Colombia, Kenya and Lebanon. Again, this is most likely due to the true burden of Alzheimer's disease remaining unrecognised in these countries, which means the indirect benefits accrued from the treatments will not be realised. These figures may be impacted in the future should effective DMTs become widely available. Further analysis is warranted as efficacy data becomes available.

**Global opportunities for Alzheimer's disease care**

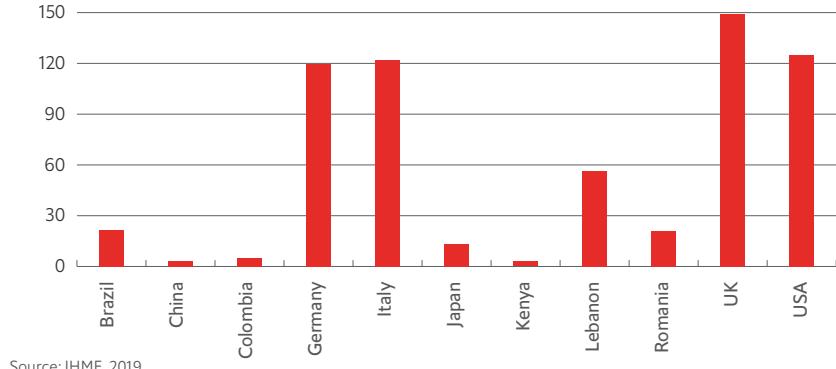
Sustainable financing solutions for the long-term care of people with dementia, and innovative treatments, must be a key part of the dementia research agenda moving forward. To succeed, both these solutions must work in synergy to manage the rising numbers of people diagnosed with Alzheimer's disease and other forms of dementia. The reasons for this synergy have been demonstrated in our cost analyses. At the time of this analysis, treatments for Alzheimer's disease are able to mediate the severity of symptoms, but do not necessarily alter the need for long-term care. Regardless of treatment or no treatment, the need for long-term care will remain, though the intensity of care may be impacted based on whether a person receives treatment. In our cost analyses, implementing treatment still results in significant cost savings as the care burden is not as severe. As most people with moderate to severe dementia will require long-term care, and the fact that social care support systems are lacking in all countries, solutions such as scaling up treatment to minimise the care burden are paramount. Even in countries with more robust social care systems such as Germany, the availability of care does not meet demand leaving informal caregivers or families to fill the care gap.

Although these insights apply to LMICs, countries with developing healthcare systems have additional priorities. The prevalence of dementia remains largely unknown in places like Kenya and Lebanon because of the lack of registries and active research communities. This is also true of

neurological disorders more widely, and is reflected in our cost analyses, where countries with lower prevalence rates (because of missed diagnosis and poor data collection) have less pronounced cost savings. Age distribution may also play a role. This does not mean that LMICs lack caregiving responsibilities, but it is a need that is hidden by poor data collection systems. Therefore, LMICs need to ensure that national dementia plans are in place so they can justify developing a research agenda for dementia in the first place. Additionally, more developed healthcare systems need to better develop their social care systems to support caregivers.

**Figure 16**  
**Prevalence rate of multiple sclerosis by country (2019)**

Rate per 100,000



Source: IHME, 2019.

## Multiple sclerosis

Multiple sclerosis (MS) is the most common inflammatory neurological disorder found in young adults.<sup>146</sup> While patients who are either asymptomatic or at a mild disease stage represent 68.4% of the MS population, they only account for 39.8% of MS-specific morbidity.<sup>147</sup> The remaining 60% stems from patients at moderate or severe stages of the disease.<sup>147</sup> The average age of diagnosis is around 30, with most patients presenting with intermittent neurological relapses. Ten to twenty years after onset, many MS patients enter a progressive phase of the disease. The underlying cause of MS is still not fully understood. However, research suggests several environmental and genetic factors might alter the risk for developing this disease. At the time of analysis, 15 medications have been approved by the US FDA for MS. Their long-term benefits remain unclear.<sup>148</sup> MS has significant economic consequences, particularly because it is prevalent among working-age individuals between the ages of 20 and 60. According to an Italian study, MS has a strong impact on patient's employment status, as the mean unemployment rate was 59%.<sup>149</sup> Roughly half of MS patients in Sweden in particular are unemployed within ten years of diagnosis.<sup>150</sup> A study conducted in the USA found individuals with MS reported about two additional visits to healthcare professionals on average over a six-month period when compared to individuals without the disease (5.48 visits v 3.27 visits).<sup>151</sup>

**Figure 16** describes the prevalence rate of MS in each of the countries of interest.<sup>6</sup> The UK has the highest burden of MS followed by the USA with Kenya and China at the end of the scale.

## The Americas

In the USA, there is a smattering of research initiatives for MS, including industry-funded research. Firstly, MS research and clinical trials are funded by the federal government, national non-profit agencies that support patients and caregivers, and private companies.<sup>152, 153</sup> There are also various MS treatment centres, many of which are associated with leading research universities.<sup>154</sup> The US Department of Veterans Affairs (VA) created the VA MS Centers of Excellence, a network of programmes, information and telemedicine to improve care for veterans, MS education and research efforts.<sup>155</sup> The CDC has a national surveillance system for neurological disorders, which includes MS.<sup>156</sup> In addition, other national registries have been created to meet the unique research needs.<sup>158</sup> It was also noted that some ethnic groups were underserved in MS research, which resulted in the creation of the National African Americans with MS Registry.<sup>159</sup> The USA also participates in the North American Research Consortium on MS.<sup>160</sup> There are also efforts to implement quality measures for people with MS to better measure outcomes and guide value-based initiatives. Despite these pockets of initiatives, there is still no national action plan for MS care.<sup>152</sup>

In Latin America, a systematic review noted that prevalence data on MS was, on the whole, limited.<sup>161</sup> The availability of essential resources for diagnosing and treating MS such as MRI scanners and DMTs are variable across countries, with some Latin American countries having access to nearly all DMTs approved in the USA and Europe and others with one or no treatments. Generally, there is a lack of government support for MS, which means that resources for research are lacking.

In Brazil in 2019, Conitec, an independent organisation linked to Brazil's Ministry of Health and responsible for providing policy recommendations, shared Brazil's national guidelines for the diagnosis and treatment of MS.<sup>162</sup> There are few reported centres in Brazil that are

able to provide multi-disciplinary care for patients with MS.<sup>163</sup> According to DATASUS, the medical record database for the public health system in Brazil, there is only one drug distribution centre located in the state of Paraíba, which specialises in MS.<sup>164</sup> While there are some MS treatment centres, there is no centralised list of these facilities available to the public.<sup>165</sup>

In Colombia, in response to the 1993 Colombian health policy reform, healthcare organisations are required to cover MS patients' diagnostic examinations and certain treatments and drugs.<sup>166</sup> Despite this, there are significant administrative barriers and drug delivery issues that limit access, benefits and quality of care for patients.<sup>166</sup> Colombia has a patient-reported national MS database, called the Individual Registry of Health Care Provision, which is monitored by Colombia's health system. However, Colombia does not have a national action plan for MS treatment.<sup>167</sup>

## Asia

Japan published national guidelines in 2017 for MS which inform appropriate treatment recommendations for MS patients.<sup>168</sup> Research studies suggest MS patients receive different levels of care from a variety of Japanese medical facilities, including large hospitals and smaller clinics.<sup>169</sup> There are no reported specialised MS treatment centres in Japan. These variations in care might be influenced by the limited epidemiological data on MS in Japan.<sup>170</sup> There is no national MS registry but experts contribute to an international MS registry, known as The Atlas of MS.<sup>171</sup> Japan's Multiple Sclerosis Society functions as a part of the Multiple Sclerosis International Federation and aims to increase public awareness and MS education, fund research, and support MS patients.<sup>172</sup> In China, most MS patients are diagnosed and managed in China's 1600+ tertiary hospitals. Private hospitals and traditional Chinese medicine hospitals rarely treat MS patients.<sup>173</sup> There is also no national MS registry and epidemiological data are lacking.<sup>174</sup> As a result, developing medical policies for MS in China

is as challenging as it is in Japan without the data to guide priorities. There is no national strategy or treatment guidelines for MS management in China either.<sup>175</sup>

### Europe

Health systems in Western Europe have developed strategies for treating MS patients, but continue to face challenges around timely diagnosis, individualised treatment, coordination of care and the availability of formalised social care. The UK has one of the largest repositories of MS patient-reported outcomes, known as The UK MS register.<sup>176</sup> This register\* has collected more than 30,000 individual responses over a period of nine years, linked to individual medical records from the NHS in the UK. The NHS also released the Progressive Neurological Conditions Toolkit, which includes MS.<sup>177</sup> This toolkit encourages regional health centres to assess and benchmark their MS pathway to identify opportunities for improvement. The toolkit was launched following a study which revealed people with progressive neurological disorders were experiencing delays in diagnosis and treatment, as well as fragmented and uncoordinated services.

The UK also has national, evidence-based guidelines for the treatment of MS, produced by NICE, as well as a quality standard for MS care which aims to improve MS outcomes.<sup>178</sup> There is no national plan for MS in the UK, however the Neurological Alliance is campaigning for a National Neurology Strategy more broadly. The motivations for this campaign were driven by a survey which found that 39% of the 10,339 that responded reported seeing their GP five or more times before being referred to a neurologist and waited up to a year for a consultation.<sup>179</sup> People with MS are no exception –around 36% of people with MS who need support rely on unpaid care. A survey conducted in 2018 shows that 30% of UK carers felt unable to keep a job due to caring responsibilities.<sup>180</sup>

In Romania, there is a national plan for neurological disorders, including MS, but it is not adequately funded. There is a national MS registry in Romania, which was established in 2013 by the Romanian Society of Neurology, but as it is voluntary and receives little funding, the data are inconsistent.<sup>181</sup> MS care is delivered by MS treatment centres in Romania, of which there are 15, but seven of these are located in Bucharest.<sup>181</sup> This means people with MS living in rural areas have to travel long distances at their own expense for care and medications. Rehabilitation is also in short supply and its availability in MS treatment centres is scarce. While rehabilitation sessions are reimbursed, there is a limit to the number of sessions each MS patient is entitled to, which generally falls short of what is required.<sup>181</sup> On the whole, any extra care beyond acute and inpatient treatment is paid out of pocket.

A recent study suggests that 19% of people with mild MS in Germany require informal or family care, which rises to 60% for moderate and 84% for severe MS-related disability.<sup>182</sup> In 2021, a new guideline on the diagnosis and treatment of MS was introduced in Germany with the aim of making it a “living guideline”, meaning it will be updated regularly through interaction with a range of stakeholders, thus creating a culture of improvement.<sup>183</sup>

The German MS Registry was founded in 2001 by the Multiple Sclerosis Society, which is a long-term data repository that informs MS research.<sup>184</sup> This registry has greatly informed MS research both within Germany and internationally. For example, it helped reveal that fatigue was one of the most common side effects of MS, and was only treated in about one-third of affected people. The registry has its limitations – there is currently no legal requirement to report MS cases in Germany, and the registry is not population-based or supported by long-term funding.

\* UK MS register is financially supported by Roche

In Italy, there is no National Strategy for MS, no neurological disorders plan, and MS is not currently included in the national NCDs or chronic disease plan. However, there is a national MS registry founded in 2014, and there are efforts to establish national guidelines for MS.<sup>185</sup> The majority of MS care is provided in MS centres in Italy, and is largely related to symptomatic therapies and DMT provision.<sup>186</sup> Access to rehabilitation is unequal across Italy and provided by a mixture of public and private providers. There are significant deficits in the social care system, which means that informal carers play a large role in the care of people with MS. Although some financial support from the Italian government is available for the families of people with MS, it is suggested that homecare is in need of the most improvements when it comes to MS support.<sup>186</sup> A survey conducted in 2018 found that 22% of Italian carers felt they were unable to keep their job due to caring for a family member with MS.<sup>180</sup> Home adaptations are critical to help enable people with a long term disability to stay at home and manage their activities of daily living as independently as possible, which helps also reduce the impact on caregivers. However, in Italy, of those who had installed home adaptations, only 47% received tax breaks or financial contributions to support them.<sup>187</sup> Psychological support is only delivered out of a quarter of the MS centres in Italy meaning many patients access support privately.

### **Sub-Saharan Africa and Middle East**

In Lebanon, there is a national MS Society that advocates for the needs of patients with MS. Social support is one of the main ways people deal with stressful events in Lebanon. A pilot study conducted amongst MS patients found that social support enabled people to cope better with their disorder.<sup>188</sup> Similarly in Kenya, due to the shortage

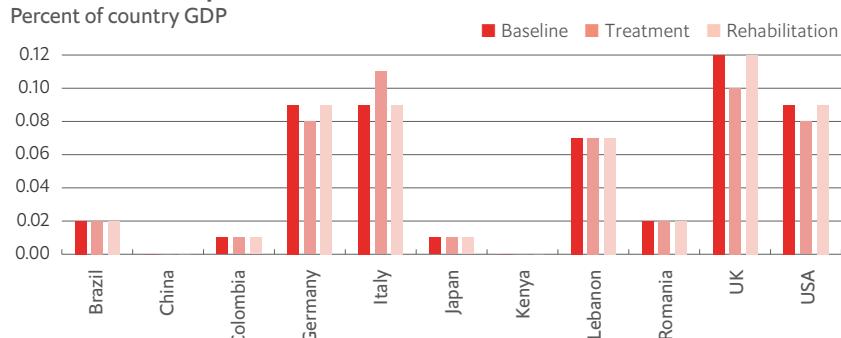
of neurologists, MS clinics and registries, MS care remains challenging in terms of access and adequate support. One study found the average delay from the onset of the first symptom to initial MRI scan was 5.04 years, clearly reflecting a lack of resources.<sup>189</sup> Efforts to improve training and access to MRI equipment are underway.

### **Multiple sclerosis: the amenable burden**

In our cost analyses, we considered the ROI of treatment (defined as DMTs) and rehabilitation which largely refers to the support of physiotherapy and occupational therapy to improve independence in daily activities. DMTs slow the progression of MS and reduce the frequency of relapses but do not prevent the disease.<sup>190</sup> Nevertheless, DMTs have a considerable effect on the productivity of the individual and on caregivers. In mild cases of MS, DMTs can enable a reduction of 42% in the days missed from work.<sup>191</sup> In a study including mild and moderate cases of MS, 68% of patients who started a high-efficacy DMT achieved "No Evidence of Disease Activity" after one year of treatment.<sup>192</sup>

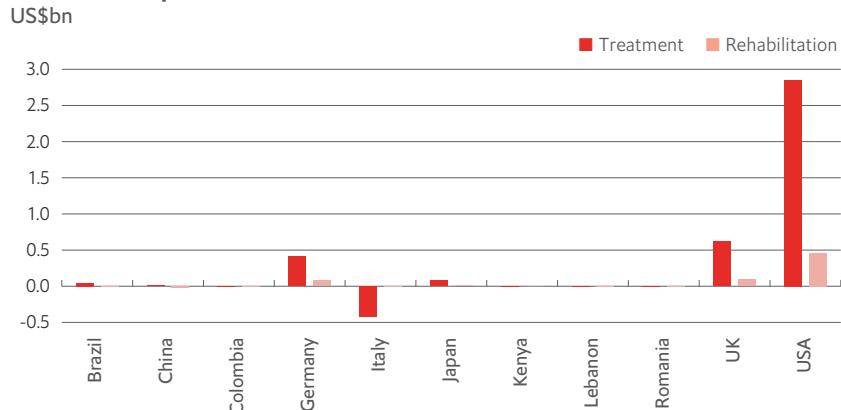
Therefore, for the analysis, we assumed treatment with DMTs results in the maintenance of independence levels — which increases the likelihood that the patient can work — and reduces the impact on caregivers by 68%. We only applied this assumption to those who are able to work, which meant excluding severe cases of MS. We included a rehabilitation scenario, as it has been shown to improve muscle tone and function in people with MS recruited to randomised controlled trials.<sup>193</sup> Therefore, the amenable burden is a measure of the independence levels and participation in normal activities achieved through timely access to DMTs and rehabilitation, which can also reduce the burden on the caregiver.

Figure 17

**Total cost of multiple sclerosis scenarios (2019)**

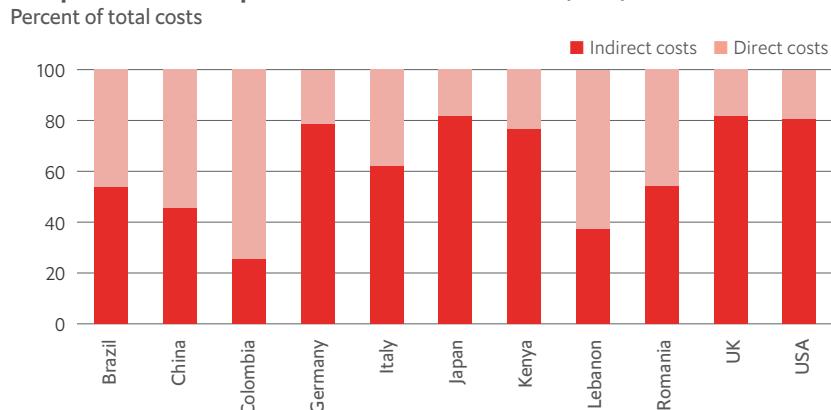
Source: Economist Impact analysis, 2022.

Figure 18

**Potential savings on total costs with implementation of multiple sclerosis scenarios compared to baseline (2019)**

Source: Economist Impact analysis, 2022.

Figure 19

**Composition of multiple sclerosis costs at baseline (2019)**

Source: Economist Impact analysis, 2022.

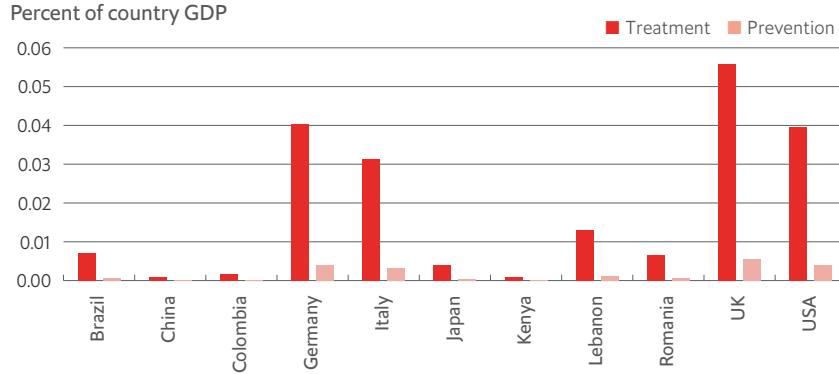
**Figure 17** illustrates how costs for MS vary across countries. The total cost of the treatment scenario was higher than the baseline in Colombia, Italy and Lebanon. The total cost of the rehabilitation scenario was higher than the baseline in all countries except Germany, the USA and the UK.

**Figure 18** reiterates that there is variation in the costs of treatment and rehabilitation across settings. **Figure 19** shows the indirect costs of MS at baseline are significant and represent over 50% of the total costs in eight out of the 11 countries. This is partly driven by MS affecting people of working age, but is also linked to high unemployment, early retirement rates and caregiver costs.

**Figure 20** shows that when considering the indirect burden averted from implementing treatment and rehabilitation, there are savings to be made in all countries. Despite variations in the cost savings, implementing treatment and rehabilitation yielded health gains in all countries. **Figure 21** highlights the costs of the treatment and rehabilitation scenarios, compared to baseline between 2019 and 2030 in the USA. The figure shows that relative to baseline, treatment can result in savings of around \$29bn and rehabilitation results in savings of around \$5bn by 2030.

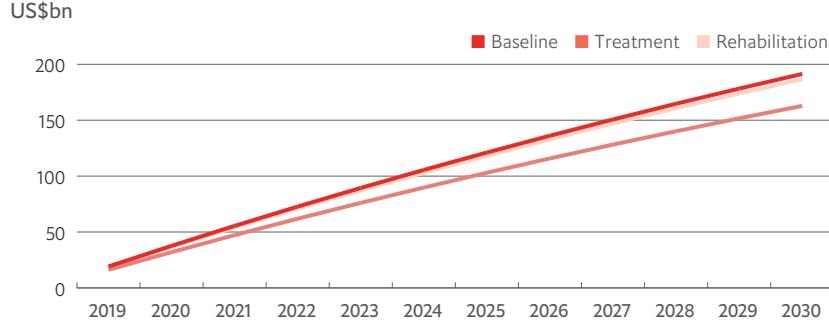
**Figure 22** shows the total savings rate of the treatment and rehabilitation scenarios between 2019 and 2030. Over time, treatment incurred cost savings compared to the baseline for all countries apart from Colombia, Italy and Lebanon. There were also modest savings for rehabilitation in Germany, Japan, Kenya, the USA and the UK. As for the rest of the countries, this intervention incurred costs when compared to the baseline. Despite this, treatment and rehabilitation were cost-effective in most countries. In Italy, treatment incurs significantly more expenses over time rather than savings; this is driven by the low MS mortality rate for the 0-24 age group compared to other countries. Additionally, the treatment cost is high, which further impacts savings.

**Figure 20  
Savings on productivity losses after implementation of multiple sclerosis scenarios compared to baseline (2019)**



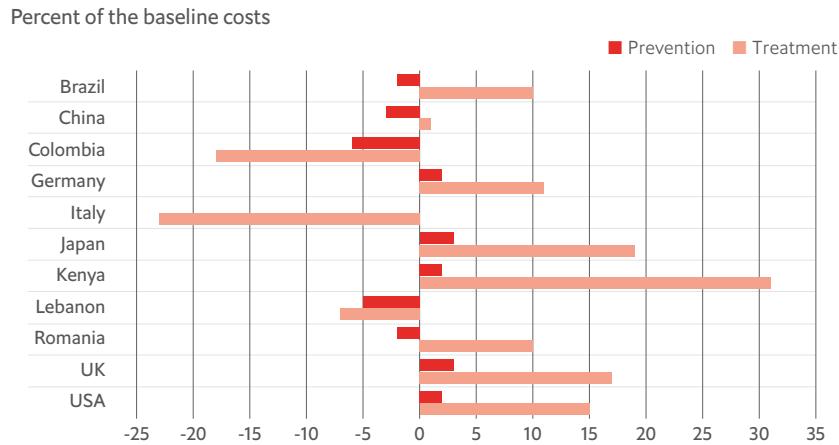
Source: Economist Impact analysis, 2022.

**Figure 21  
Multiple sclerosis costs per scenario from 2019 to 2030 in the USA**



Source: Economist Impact analysis, 2022.

**Figure 22  
Potential savings of costs for multiple sclerosis disease by type of model between 2019 and 2030**



Source: Economist Impact analysis, 2022.

## Global opportunities for multiple sclerosis care

The indirect costs or productivity losses incurred from having MS are one of the most significant across all the neurological disorders included in this study. This is largely because MS affects people when they are in the productive prime of their lives (30s and 40s). The cost of DMTs for MS are also high, which makes the proportion of the costs attributable to indirect causes lower in some countries. For example, a recent study conducted in the USA found Medicaid spending across 15 MS drugs had increased from \$453m to \$1.3bn between 2011 and 2017.<sup>194</sup> Despite the high cost of DMTs, our analyses show they are cost-saving because productivity losses are averted. The effects of DMTs are more pronounced if taken at earlier stages of the disease so that less damage occurs to the nerve cells, and the accumulation of symptoms can be deferred. This means there is a huge opportunity to improve the lives of people with MS through timely treatment. However, in most countries, this advantage is lost as patients experience delays in care.

Most of the HICs in this study continue to report delays in access to neurologists. These waits are compounded by a shortage of neurologists, and poor coordination of care. In China and Japan there are opportunities to create national strategies for MS and registries which are currently absent. In LMICs such as Kenya, the wait for a diagnosis is devastating and can last multiple years.<sup>189</sup> MS is not a research priority for governments in Kenya or Lebanon yet, meaning accessing treatments is only possible if patients travel abroad or have money to pay unreasonably high fees for DMTs. However, there is hope for transformation in LMICs, as Brazil and Colombia have made several steps in the right direction, including developing treatment guidelines for MS and having a national MS registry in Colombia's case.

## Migraine

In 2016, roughly three billion individuals were estimated to suffer from migraine or tension-type headaches.<sup>195</sup> The majority of individuals (1.89 billion) suffer from tension-type headaches compared to migraine (1.04 billion), while migraines are responsible for more years lived with disability (YLD), at 45.1 million compared to 7.2 million for tension-type headaches.<sup>195</sup> Migraine and tension-type headaches are most burdensome in women compared to men, and affect people at the prime schooling and productivity ages of between 15 and 49.<sup>195</sup> As migraines are non-fatal, they have been largely neglected from policy conversations. Migraine was also excluded from the GBD studies until the year 2000, and no data was reported for over half of countries globally when it was initially added.<sup>195</sup> This has since changed, as based on GBD 2019 data, **Figure 23** demonstrates the prevalence of migraine across the 11 countries of interest. The highest burden is found in Italy and Germany while Kenya and Japan sit at the other end of the spectrum.<sup>6</sup>

### The Americas

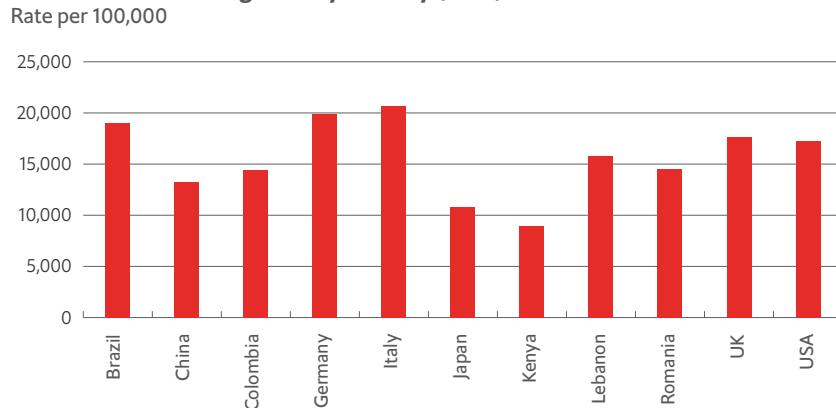
The US has made several developments in migraine research in recent years. There is a national, non-profit, non-governmental organisation that advocates for migraine treatment reform and

reflects the needs of patients, promotes awareness, education and research.<sup>196</sup> These organisations also mobilise communities and provide support for migraine patients. The American Headache Society (AHS), a professional society of healthcare providers, is focused on the study and treatment of headache and face pain and publishes evidence-based national treatment recommendations which are regularly updated.<sup>197-199</sup> The USA also has a national migraine registry, The American Registry for Migraine Research, which is a longitudinal study aimed at monitoring healthcare resource utilisation, diagnostic and management strategies, headache patterns, and responses to treatment.<sup>200</sup> Certified headache specialists also exist, but are concentrated along the east and west coasts, as well as in Texas and Florida. Fewer headache specialists are found in the Midwest and southern states.<sup>201, 202</sup> Despite being advanced in the field of headache disorders, the USA does not seem to have a national policy or strategy for migraine treatment.

In Brazil, accessing comprehensive, tertiary migraine treatment facilities or migraine specialists is difficult. Likewise, quality of care and access to resources outside of a few private specialty clinics is limited.<sup>203</sup> The Brazilian Headache Society, created in 1978, has spurred several developments in research and clinical practice.<sup>204</sup> This includes recommendations which introduced pharmacological and non-pharmacological treatments for chronic migraine and the development of headache specialists. The main aims of the recommendations were to prevent treatment overuse and to reduce complications, but access to this information and awareness in the community is currently unclear.<sup>205</sup> In Brazil's attempt to improve quality of life, treatment and diagnosis for people suffering from migraines, the Brazilian Headache Society developed and implemented a national registry to collect data to feed into further research initiatives.<sup>204</sup>

The Colombian Association of Neurology has outlined treatment recommendations for people

Figure 23  
Prevalence rate of migraine by country (2019)



Source: IHME, 2019.

suffering from migraines, which emphasises preventative measures.<sup>206</sup> There are also five migraine centres in Colombia that vary in size. However, there does not appear to be a national plan or registry for migraines in Colombia.<sup>207</sup>

### Asia

A comprehensive review of literature from 1998–2019 which included China and Japan found that a majority of research evidence conducted in East Asia focused on the prevalence of migraine, rather than solutions for its clinical management. The study also found a low level of migraine awareness among the public, and very few patients saw a physician for their migraine or took medication.<sup>208</sup> Over time, there have been some innovations in the migraine field in this region. In 2013, the Japanese Headache Society and Japanese Society of Neurology published guidelines for diagnosing and treating chronic headaches.<sup>209</sup> However, Japan does not have a national migraine registry, but some epidemiological studies have been conducted using hospital or national wellness survey data that includes information on migraines.<sup>210</sup> Additionally, there is no reported centralised data collection for migraine or headache treatment facilities in Japan, meaning most patients visit primary care physicians for diagnosis and treatment.<sup>210</sup>

Headache disorders are under-diagnosed, under-prioritised and under-treated in the Chinese healthcare delivery systems. Non-standard diagnoses (such as “nervous headache”) are also commonplace in clinical practice, which can lead to inappropriate treatment recommendations or unnecessary examinations.<sup>211</sup> Unorthodox diagnoses most likely stem from the lack of healthcare resources for headache disorders.<sup>211</sup> The scarcity of healthcare resources for migraine treatment hasn’t gone totally unnoticed by Chinese decision-makers. China has launched an educational program, ‘SMART’, which aims to standardise diagnostic and treatment techniques, improve neurologists’ knowledge of migraine, and improve patient outcomes.<sup>212</sup> Through this

programme, 615 neurologists have been trained, and 135 headache clinics have been established.<sup>212</sup> According to a 2012 study, these headache clinics were concentrated in the northeast and scarce in western and southern China.<sup>33</sup> Apart from the SMART educational program, there is no reported national plan for migraine management. In 2017, the China Headache Registry Study was sponsored by Zhejiang University, but registry data are currently unavailable.<sup>213</sup>

### Europe

Despite having developed healthcare systems in much of Europe, migraine remains under-diagnosed and under-treated. Additionally, less than half of migraine sufferers consult a doctor about their disorder in Europe and when they do, the process to diagnosis is lengthy and usually involves trial and error with various different medications.<sup>214</sup> In the UK, migraine and/or chronic headache is the second most frequently identified cause of short-term absence from work, accounting for 47% for non-manual employees.<sup>215</sup> There is a guideline for the prevention and management of migraine in the UK and an active research charity, The Migraine Trust, advocating for the needs of people with migraine. A recent report by The Migraine Trust states that despite treatments being recommended by NICE and provided by the NHS, health trusts in some areas refuse to pay for the drugs.<sup>216</sup> GPs’ knowledge of migraine is also variable, causing delays in referrals to migraine specialists.

Italy also has legislation which recognises chronic primary headaches, including migraine, as a disease with social impact. Even with legislation in place, in one survey study across 10 European countries, consulting a medical professional for migraine treatment was the lowest in Italy at 15.8% and only 1.6% of eligible participants were using preventative medications.<sup>217</sup> In 2004, Romania introduced a treatment guideline for primary headaches, which includes migraine. Yet, the availability of and access to treatments for migraine is unclear due to the limited published evidence

from this country.<sup>218</sup> In Germany, there is a guideline for migraine treatment from the German Migraine and Headache Society and the German Society of Neurology, which approves several preventative migraine treatments that are provided by the health service.<sup>219</sup> One study in Germany recruited 7431 adults and found that awareness of migraine as a diagnosable and preventable neurological disorder and recognition by health professionals was low.<sup>217</sup> Furthermore, in certain regions in Germany, a population-based study found that only 2.3% of people with migraines used preventative medications.<sup>217</sup>

### Sub-Saharan Africa and the Middle East

In general, in addition to a lack of research evidence on migraine, epidemiological data in Arab countries on the prevalence of migraine are lacking. In these two regions, patients are more likely to consult a doctor with a tension-type headache than a migraine due to the lack of recognition of migraine as a neurological disorder, according to expert opinion. The International Headache Society provides guidelines which can be used by all countries to help with diagnosis and treatment in addition to or in the absence of country-specific guidelines.<sup>220</sup> According to the WHO, the use of the

International Headache Society diagnostic criteria is lower in the Eastern Mediterranean and Africa, and professional organisations for headache disorders are also the least likely to exist in these countries.<sup>221</sup> The absence of professional guidelines and stakeholder participation in these regions does not mean that migraine does not exist. In fact, the GBD estimates the prevalence of migraine in Lebanon is above that of China, Romania, Japan and Colombia and is not far behind the USA. On the other hand, Kenya has the lowest migraine prevalence of all the countries in this study (**Figure 23**), and relatedly, advocacy and understanding of migraine as a legitimate neurological disorder requiring treatment is the lowest of all countries in this study.

### Migraine: the amenable burden

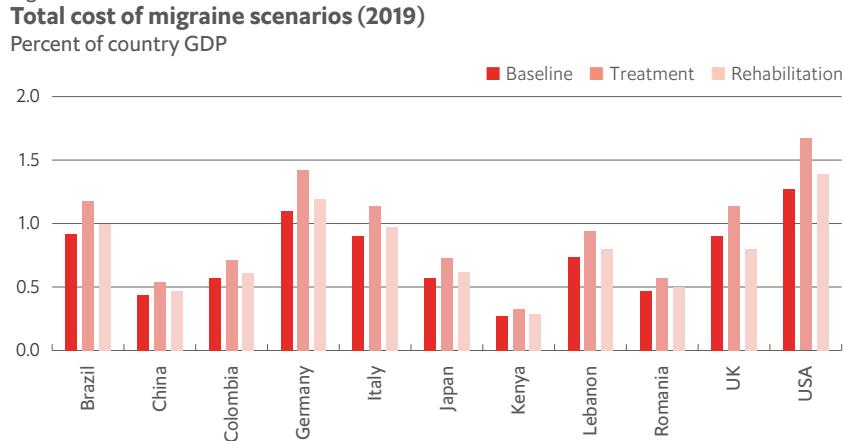
In **Figure 24**, the total cost of the preventative treatment scenario was highest in all countries. The total cost of the symptomatic treatment scenario was lower than preventative treatment in all countries and dominated the other intervention decisions as symptomatic treatment was both less expensive and resulted in the highest health-related quality of life (DALYs averted).

**Figure 25** reiterates that there were no savings for preventative treatment on total costs compared to baseline for any country. In the UK, the symptomatic treatment scenario resulted in about \$3bn in savings relative to baseline costs.

**Figure 26** demonstrates the significant impact of migraine treatment costs in proportion to indirect costs. While lost productivity due to migraines is significant, preventative and symptomatic treatments can be expensive, and may not always be covered by health insurance schemes. Costs also vary by migraine type (episodic or chronic), duration and age of onset.

**Figure 27** illustrates the scenario impacts on productivity for both patients and informal caregivers. The preventative treatment averted more productivity losses than symptomatic treatment in all countries.

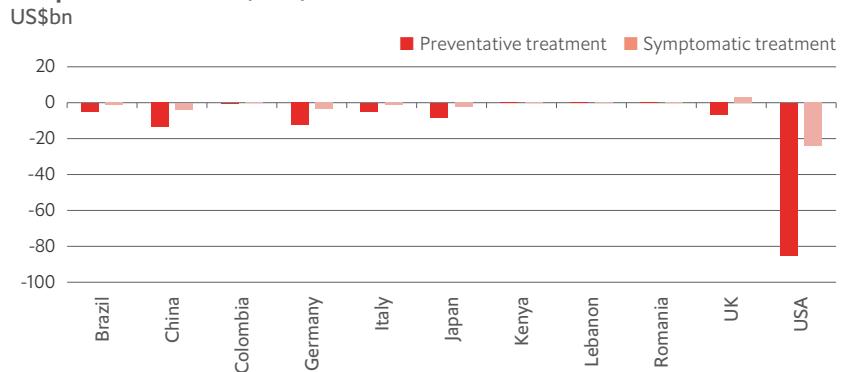
Figure 24 Total cost of migraine scenarios (2019)



Source: Economist Impact analysis, 2022.

Figure 25

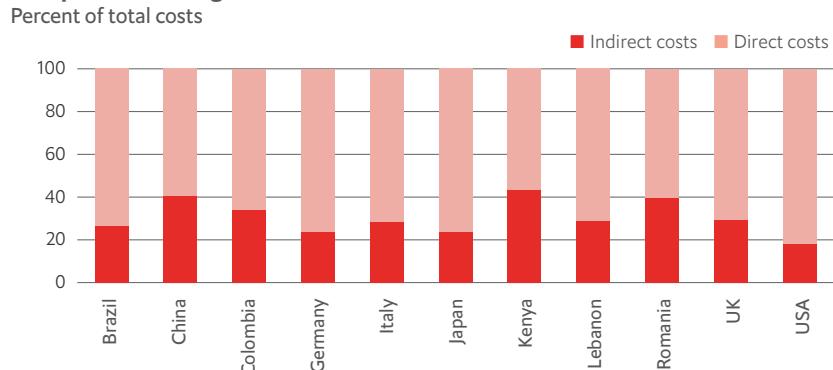
**Potential savings on total costs with implementation of migraine scenarios compared to baseline (2019)**



Source: Economist Impact analysis, 2022.

Figure 26

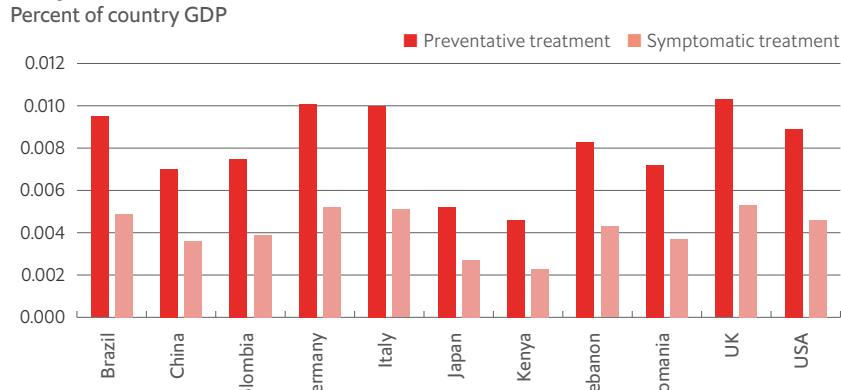
**Composition of migraine costs at baseline (2019)**



Source: Economist Impact analysis, 2022.

Figure 27

**Savings on productivity losses after implementation of migraine scenarios compared to baseline (2019)**



Source: Economist Impact analysis, 2022.

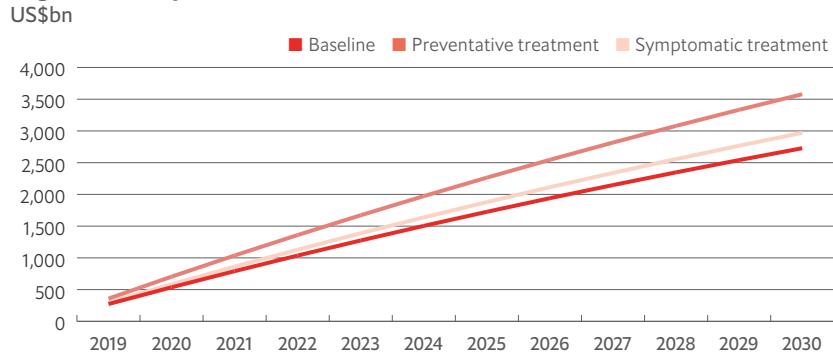
**Figure 28** shows that over time, the treatment scenarios resulted in increased costs when compared to baseline. Specifically, the preventative treatment scenario resulted in about \$48bn increased costs and the symptomatic treatment resulted in about \$14bn increased costs. The cost-effectiveness of treating patients with migraine may vary depending on the type (i.e., episodic v chronic).<sup>222</sup> Population health policies and proper training for migraine management among primary care physicians may also increase the cost-effectiveness of migraine treatment.<sup>223,</sup><sup>224</sup> Despite the cost, migraine treatment has the potential to positively impact productivity and societal gains.

**Figure 29** illustrates that the total savings rate of the preventative treatment and symptomatic treatment scenarios is constant over time across countries. There were negative savings for both treatment scenarios of the moderate version of the disease for all countries apart from the UK, which showed 11% savings in the symptomatic treatment scenario relative to baseline. The figure also shows that symptomatic treatment incurs lower costs than the preventative scenario when compared with the baseline for all countries.

### Global opportunities for migraine care

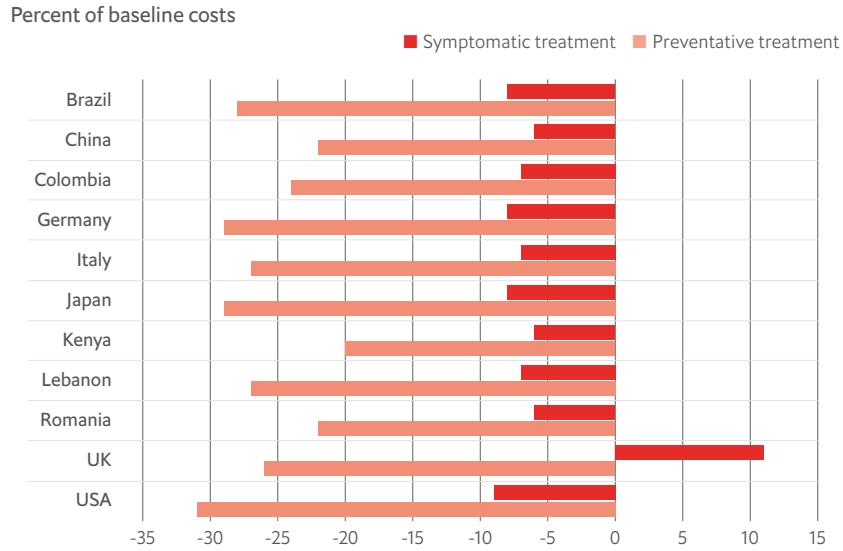
Migraines inflict significant burden on individuals, aged between 15 and 59, across all countries, particularly among women.<sup>195</sup> Despite this far-reaching impact, migraines have largely been neglected from policy conversations and research, only recently earning a spot in GBD studies. Migraines are under-diagnosed and under-treated, even in regions with advanced health systems like Europe. Access to treatment and quality of care are consistent issues across all countries. In some LMICs (e.g., Kenya), migraine is yet to be recognised as a legitimate neurological disorder resulting in under-reporting, low awareness and few treatment options.<sup>221</sup> In HICs, even where there is progress in migraine management, capacity constraints,

Figure 28

**Migraine costs per scenario from 2019 to 2030 in the USA**

Source: Economist Impact analysis, 2022.

Figure 29

**Potential savings of costs for migraine by type of model between 2019 and 2030**

Source: Economist Impact analysis, 2022.

insufficient research funding, and a lack of migraine specialists and facilities contribute to treatment delays or unnecessary care.<sup>214, 218</sup>

Making migraine a national priority may create the opportunity for more research funding, centralised data collection systems and even more specialised training. In this regard, some countries have already made progress. For example, through the involvement of Chinese decision-makers, the country has been able to train more neurologists and establish several headache clinics.<sup>212</sup> However, in China and other nations with advanced migraine strategies, preventative medications and treatment centres are still not broadly accessible or utilised by patients.<sup>33, 201-203</sup> Mitigating capacity constraint issues and providing better integrated care pathways may improve migraine treatment. Access to timely, quality treatment may allow migraine patients to experience greater quality of life, fewer years with disability and greater productivity. This may have positive downstream impacts on caregivers and potentially reduce unemployment and productivity losses.

## Parkinson's disease

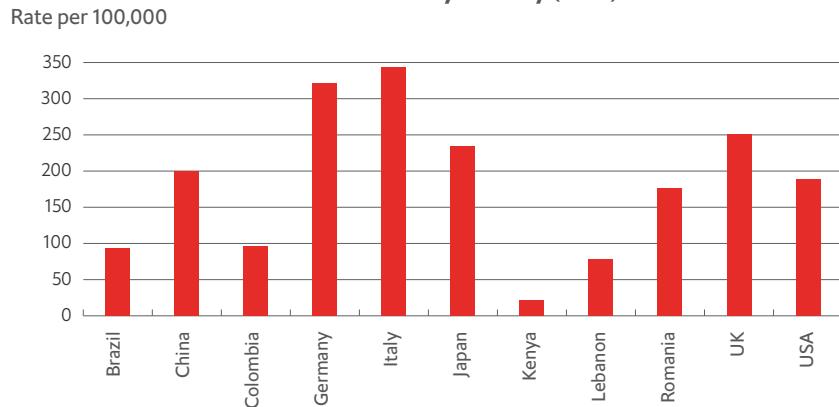
Parkinson's disease is a chronic, incurable disease and the second most common neurodegenerative disorder after Alzheimer's disease.<sup>225</sup> The main risk factor for Parkinson's disease is age, but it has also been linked to exposure to industrial chemicals and pollutants. **Figure 30** illustrates the burden of Parkinson's disease across the countries of interest within this study, with Italy and Germany carrying the greatest burden, and Kenya and Lebanon, the least. As previously mentioned, data collection and reporting in LMICs may not be robust due to limited resources. Prevalence estimates should, therefore, be considered accordingly. Over the last 20-30 years, the number of people with Parkinson's disease has more than doubled.<sup>226</sup> For example, in 2016, Parkinson's disease was considered to be the fastest growing neurological disorder of all those included in the GBD Study.<sup>227</sup> As well as the number of rising cases, people with Parkinson's are also living with the disease for around 2.5 years longer every decade according to one meta-analysis. Other research finds a correlation between rising rates of Parkinson's disease and industrialisation.<sup>226</sup> Generally, the prevalence of a disease is found to be greater in areas with lower socio-economic levels, but for Parkinson's, this trend is the opposite (**Figure 30**).<sup>6</sup> The burden of Parkinson's disease is higher in areas

with higher socio-economic levels, suggesting the association is linked to environmental factors which are the result of industrialisation. The treatments for Parkinson's focus on managing the motor symptoms, but as the disease progresses, treatments become less effective and patients experience significant levels of disability.<sup>228</sup> The progressive nature of Parkinson's disease means patients require constant monitoring and creativity from clinicians as the motor and non-motor symptoms (such as memory loss and mood disorders) increase. Managing caregiver burden in Parkinson's disease, like with all progressive neuromuscular disorders is significant, as informal caregivers incur both the physical and financial demands of caring over a period of approximately 10-20 years as the disorder worsens.

### The Americas

The USA has several national non-profit organisations that advocate for patient's rights, support caregivers, provide resources and fund research initiatives for Parkinson's disease, such as the American Parkinson Disease Association, Michael J. Fox Foundation and the Parkinson's Foundation. Although the USA's government provides funding for novel research and clinical trials for Parkinson's, access to treatment remains elusive for many patients.<sup>229</sup> To mediate this, some non-profit organisations help connect patients to networks of care. For example, the Parkinson's Foundation Global Care Network creates opportunities for patients to receive equitable, high-quality care through an expansive network of specialists. This Foundation designates treatment facilities that meet certain research, training, outreach and education requirements as "centres of excellence". There are 33 such centres in the USA.<sup>230</sup> There are also six designated federal Parkinson's disease research centres in the USA that provide diagnosis and treatment services. These research centres are primarily located in the west, south and northeast.<sup>231, 232</sup> The CDC has established a surveillance system that captures Parkinson's disease and other neurological disorders, but there

Figure 30  
Prevalence rate of Parkinson's disease by country (2019)



Source: IHME, 2019.

is no national Parkinson's registry.<sup>233</sup> While there are research-based treatment strategies, the USA does not have a national plan.<sup>234</sup>

In Brazil, it is not yet compulsory to report cases of Parkinson's disease, meaning prevalence reported for this country is based on estimates from individual studies that are few and far between.<sup>235</sup> In 2017, the Ministry of Health approved the "Clinical Protocol and Therapeutic Guidelines of Parkinson's Disease".<sup>164</sup> These guidelines describe the diagnostics criteria, treatment and regulation mechanisms, control and assessment of Parkinson's disease that should be followed. Brazil has several non-governmental associations devoted to supporting patients and caregivers through donations or private actions.<sup>236</sup> As of 2016, Brazil had 1919 tertiary ambulatory centres that specialise in neurology and geriatrics, of which 547 were located in southeastern Brazil.<sup>235</sup>

There are certain benefits that are ensured through the Brazilian public health care system such as access to medication for the disease and associated comorbidities, access to care (when it's available) in specialised neurological or geriatric services, disability benefits and tax exemption.<sup>235, 236</sup> In some Brazilian municipalities, free or reduced-cost therapy is provided for patients with Parkinson's disease by non-governmental organisations or universities.<sup>235</sup> Despite some specialist Parkinson's disease clinics existing, it is very difficult for patients who are publicly insured to access them due to lack of funding and lack of training for doctors working in the public system. Specialist clinics and rehabilitation services for people with Parkinson's disease are mainly available through public universities that have a Parkinson's disease team, which only provides access to people living in larger cities.<sup>235</sup> According to DATASUS, Brazil has five private establishments that specialise in Parkinson's disease, but all of them are in the south or southeast regions of Brazil and none of them are accessible to patients who are publicly insured.<sup>237</sup> Access to specialist care is therefore highly variable by state. Many patients, families and healthcare

professionals are unaware of the benefits available for those with Parkinson's disease due to a lack of training and awareness.<sup>235, 236</sup>

In Colombia, there is currently no government or public health programme reported for patients who suffer from Parkinson's disease. Additionally, most patients are unable to afford continuous check-ups with neurologists or attend educational programs. According to Colombia's Ministry of Health, between 2016 and 2017, there was a shortage of neurology specialists and one study reported that many patients often utilise the judicial system to access treatment.<sup>238</sup> To better support patients with Parkinson's disease, experts in the field developed an initiative based in a private, university hospital in Cali, Colombia, which empowers patients and caregivers and increases knowledge of Parkinson's disease through research and education.<sup>239</sup> Some outpatient hospitals may maintain a registry of patients, but there is no national registry and there are no rehabilitation centres for Parkinson's disease in Colombia.<sup>239</sup>

## Asia

In Japan, there are national treatment guidelines for Parkinson's disease that are regularly updated according to current research. Japan's large national medical claims database is used to inform Parkinson's disease research studies though there is no national registry for patients with Parkinson's.<sup>240</sup> Non-profit and government organisations sponsor clinical trials and innovative research initiatives to improve treatment strategies for Parkinson's disease, including collaborative research with international neurological organisations.<sup>241-243</sup> From the evidence, the number and distribution of Parkinson's disease treatment centres in Japan is unclear.

In China, there has been growing attention towards the care of patients with Parkinson's by the Chinese government. This has resulted in better reimbursement systems, lower costs of care, and standardising specialist training

processes for the diagnosis and treatment of mild and moderate cases of Parkinson's.<sup>244</sup> Additionally, the Chinese Parkinson's Disease and Movement Disorder Society have published guidelines for the therapeutic management of Parkinson's and launched a national patient registry.<sup>245, 246</sup> China has several clinical trials studying medical treatments, and multi-centre cohorts utilising traditional Chinese rehabilitation have been established in various cities. To improve access to specialists, at least 12 Parkinson's disease clinics have been created.<sup>245</sup>

### Europe

In Europe, there is a specialist European Parkinson's Disease Association which represents 45 member organisations, and advocates for the rights and needs of around 1.2 million people living with Parkinson's disease and their families.<sup>247</sup> This association has provided a consensus statement that has been endorsed by Parkinson's disease specialists, patients, carers and the 45 national organisations involved.<sup>247</sup> This statement contains guidelines for policymakers on how Parkinson's disease should be managed and what needs to change. Despite this overarching governance, individual European countries are at differing levels of readiness.

In Italy, there is no dedicated plan for Parkinson's, but there is a National Plan on Chronic Diseases that includes a section on Parkinson's disease.<sup>248</sup> The plan states that regional health authorities should aim to implement dedicated networks to manage neurological disorders, including Parkinson's disease. Efforts to set up a disease-centred, regional network are aiming to reduce inequalities in treatment and harmonise the use of regional resources. Currently, most centres for treating patients with Parkinson's disease are clustered around Milan, with the north and southeast having barely any centres.<sup>248</sup>

Germany has its own Parkinson's disease guidelines, and was one of the first European countries to publish national guidelines as treatment standards

for physicians.<sup>249</sup> Parkinson's disease networks have also been established which has helped integrate and streamline the multi-disciplinary services required to care for patients and includes rehabilitation.<sup>250</sup> These networks also enable faster diagnosis and optimisation of treatment. The German Society for Parkinson and Movement Disorder has helped establish networks and facilitate Parkinson's-specific knowledge exchanges. Despite this, specialised Parkinson's disease care remains heterogeneous and dependent on where you live. Certified and reimbursed models for Parkinson's disease also do not exist.

Romania has its own Parkinson's disease diagnosis and treatment guidelines from the Romanian Society of Neurology.<sup>251</sup> Despite this, there is limited availability of specialists, and diagnosis and management is often led by general neurologists. If a second opinion is required regarding a diagnosis of Parkinson's disease, patients are referred to a movement disorder clinic, which are usually located in cities. These referrals are sometimes delayed, which means treatment optimisation for patients in Romania is not achieved. Although long-term care support exists by law in Romania, with a national legal act regulating the provision of support services for older people with care needs, the cash benefits provided by the government are severely disproportionate to the care needs in the country and are also unequally distributed.<sup>123</sup> The provision of community care and homecare is particularly poor, and the demand on institutional care is high. This means that most of the care is provided by family members.

In the UK, there are national guidelines for Parkinson's disease produced by National Institute for Health and Care Excellence (NICE), and an active patient association called Parkinson's UK, which provides personalised information, services and opportunities to people living with the disease. Parkinson's UK also has a strategy to improve outcomes by 2024 by accelerating research, improving support for people with Parkinson's disease and creating better awareness about

the disease.<sup>252</sup> There is no national registry for Parkinson's disease in the UK but there is a national audit hosted by the Parkinson's UK Excellence Network, which in 2019 recruited 10,335 patients.<sup>253</sup> The 2019 edition of this audit found that while on paper, the UK has a supportive system of care, there still needs to be improvements in access to multidisciplinary care, better medication management and standardising practice across the UK. As mentioned in the MS section, NICE also produced the Progressive Neurological Conditions Toolkit which encourages regional health centres to assess and benchmark Parkinson's disease pathways to identify opportunities for improvement.

### **Sub-Saharan Africa and the Middle East**

There are limited studies on Parkinson's disease care and treatment based in Arab countries. There is a noted lack of specialists, accurate epidemiological data, educational programmes, availability of drugs, advanced therapy and healthcare resources. Most patients in the Arab region receive care for Parkinson's disease, at best, in general neurology clinics or general medicine clinics.<sup>254</sup> While access to basic care is possible, specialised treatments for advanced Parkinson's disease are not available. There is also a lack of rehabilitation centres for ongoing support and management of motor symptoms.

Similarly in Kenya, very little is known about the epidemiology of Parkinson's disease, a theme which runs through Africa as a whole. While the GBD reports prevalence rates for this country, they are largely based on estimates due to the lack of data collection and registries for Parkinson's disease in Kenya. There are no national guidelines for managing Parkinson's disease, and it is thought that many patients in sub-Saharan Africa remain undiagnosed and unable to access care.<sup>255</sup> However, there are active patient advocacy groups.<sup>256</sup> There is not only a shortage of specialist services for Parkinson's disease in Kenya but also a lack of affordable medications, especially in public

pharmacies, where costs are generally lower.<sup>257</sup> The high average cost of medications implies that they are out of reach for many people without insurance in Kenya.

### **Parkinson's disease: the amenable burden**

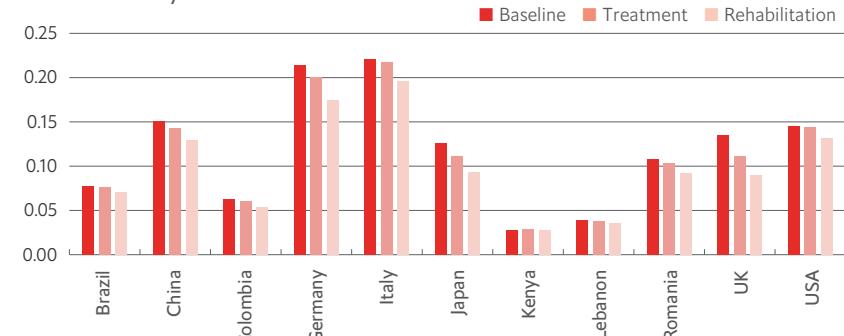
In our cost analyses, we estimated the ROI of scaling up treatment and rehabilitation services for Parkinson's disease. In the treatment scenario, the effect of levodopa was estimated, as there is a strong body of evidence that identifies this treatment as the most widely used and effective option for controlling the motor symptoms associated with Parkinson's disease.<sup>258</sup> Levodopa enables the management of symptoms such as uncontrolled, involuntary movements across all severity levels, although it can be less effective as the disease reaches its end stages. Levodopa does not slow the progression of Parkinson's disease but it does enable greater independence in daily tasks, so we assumed greater independence would also reduce informal caregiver burden.<sup>259</sup> Similar to 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 which have the strongest evidence base in favour of improving levels of independence and reducing caregiver burden.<sup>260-262</sup>

**Figure 31** shows that the total cost of the baseline scenario was the highest in all countries except for Kenya, indicating that treatment and rehabilitation resulted in savings when compared to no treatment or rehabilitation. Although the rehabilitation scenario resulted in more cost savings than treatment, the treatment scenario had the highest gains in terms of health-related quality of life. The savings are least pronounced in Lebanon, Kenya, Colombia and Brazil. Incidentally, these countries also have a lack of legislation and national plans that advocate for diagnosis and care and potentially play a part in masking the true prevalence of Parkinson's disease. **Figure 32**

Figure 31

**Total cost of Parkinson's disease scenarios (2019)**

Percent of country GDP

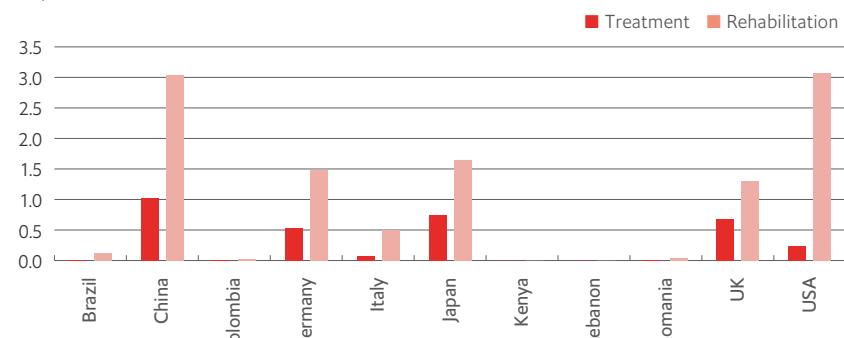


Source: Economist Impact analysis, 2022.

Figure 32

**Potential savings on total costs with implementation of Parkinson's disease scenarios compared to baseline (2019)**

US\$bn

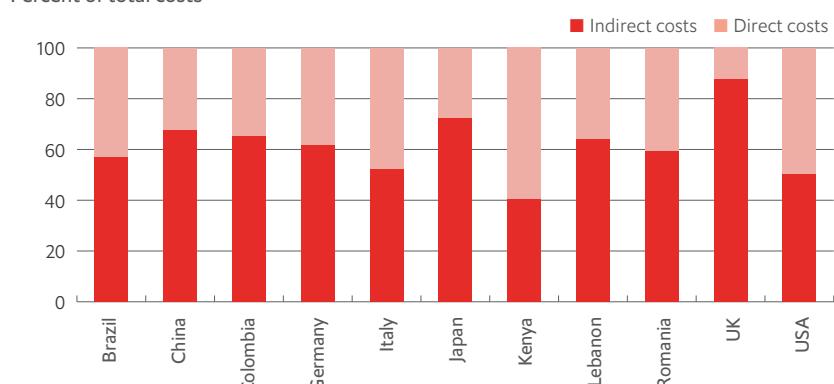


Source: Economist Impact analysis, 2022.

Figure 33

**Composition of Parkinson's disease costs at baseline (2019)**

Percent of total costs



Source: Economist Impact analysis, 2022.

reiterates that the rehabilitation scenario yielded more savings from baseline in the one-year time horizon as compared to the treatment scenario.

**Figure 33** helps demonstrate the significant impact of Parkinson's disease on productivity for both the individual and informal caregivers. Indirect costs accounted for >50% of the total cost of care at baseline in all countries except Kenya. Therefore, it is not surprising that the savings on productivity losses after scaling up treatment and rehabilitation are so pronounced (**Figure 34**). The rehabilitation scenario averted more productivity losses than the treatment scenario, a significant difference across all settings (**Figure 34**).

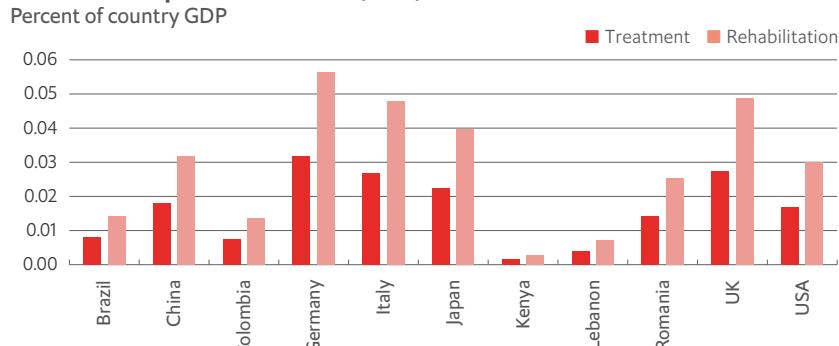
**Figure 35** demonstrates the difference in savings between each scenario over time for the USA and indicates that in comparison to baseline, treatment can result in savings of around \$2bn and rehabilitation results in savings of around \$31bn by 2030. Finally, **Figure 36** shows the total savings rate of treatment and rehabilitation between 2019 and 2030. Rehabilitation incurs the most cost savings over time at a rate of as high as 33% in the UK, and the lowest at 10% in Lebanon and the USA. Both treatment scenarios resulted in negative savings for Kenya.

### Global opportunities for Parkinson's disease care

The indirect costs or productivity losses incurred from having Parkinson's disease are probably one of the most significant across all the neurological disorders included in this study. Other studies have commented on the significant economic burden of Parkinson's, but also note that much remains unknown even in developed healthcare systems. A study published in Nature in 2020, found the total economic burden of Parkinson's disease in the USA was \$51.9bn, with greater than 50% of that burden attributed to indirect costs, which is similar to the findings in our study.<sup>263</sup> Other studies note that indirect costs may outweigh direct costs, a balance which becomes even more pronounced as the

Figure 34

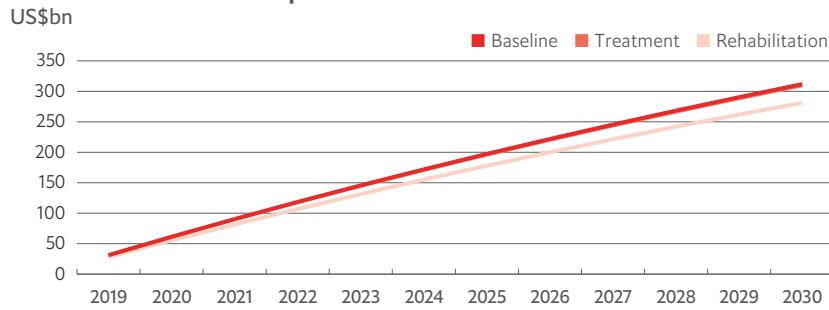
**Savings on productivity losses after implementation of Parkinson's disease scenarios compared to baseline (2019)**



Source: Economist Impact analysis, 2022.

Figure 35

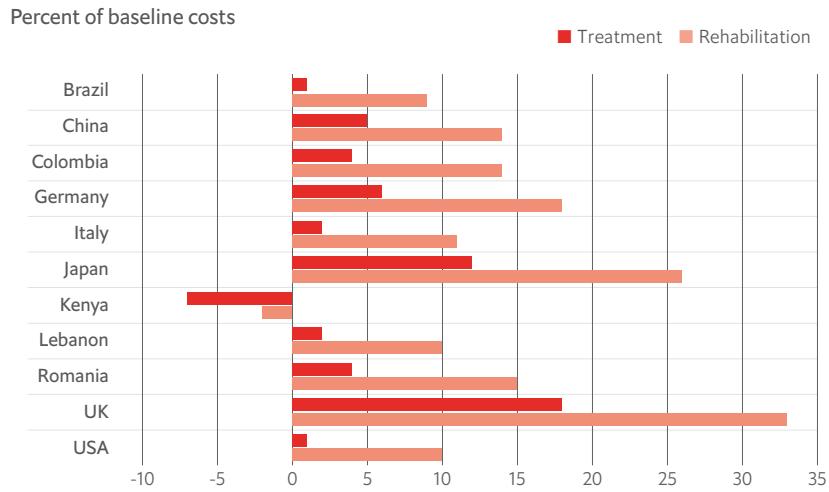
**Parkinson's disease costs per scenario from 2019 to 2030 in the USA**



Source: Economist Impact analysis, 2022.

Figure 36

**Potential savings of costs for Parkinson's disease by type of model between 2019 and 2030**



Source: Economist Impact analysis, 2022.

disease progresses to moderate disease, but levels out in the severe phase of the disease.

Unlike in diseases where many people affected are of working age (e.g., MS), the large indirect costs associated with Parkinson's are largely caregiver-related. We excluded the impact of Parkinson's disease on people of working age in our analysis, which means that the productivity losses accrued are all due to the burden on the caregiver. Shortages of neurologists is also a concern but in the absence of face-to-face consultations, better use of telemedicine could encourage remote assessments and prescription of Parkinson's treatment. The fields of telemedicine and novel digital technologies for Parkinson's are growing in their availability. Future research needs to help establish whether remote monitoring improves outcomes, and how digital technologies might be leveraged for diagnosis, prevention and treatment.

There are also opportunities in most countries to improve integrated care and access to specialist Parkinson's disease neurologists and rehabilitation. Germany provides a good example of how integrated networks could work to facilitate timely access to diagnosis and treatment through collaborative, accessible care. Timely treatment can also help reduce productivity losses and improve quality of life for individuals with Parkinson's and their caregivers. In Kenya and Lebanon especially, Parkinson's disease care is virtually non-existent. In the absence of treatment guidelines and specialists in resource-poor settings, support from international aid is desperately needed to provide diagnosis and treatment. If providing international neurologist support is not possible, local geriatric assessments that include comprehensive medical and psychological evaluations, should be the bare minimum.

## Spinal muscular atrophy

Spinal muscular atrophy (SMA) is a type of motor neuron disease (MND), which generally presents in childhood and affects around 1 in 10,000 births.<sup>264</sup>,<sup>265</sup> The disease is characterised by the loss of spinal cord motor neurons, muscular atrophy and paralysis. There are five different types of SMA (0-IV), which are based on the age of onset and highest physical milestone achieved. Type 0 and type I are the most severe expressions of the disease.<sup>265</sup> However, emerging research suggests that with treatment, long-term survival is possible for type I SMA.<sup>266</sup> Type I is also the most common form of childhood-onset SMA, accounting for around 60% of patients.<sup>265</sup> Types II and III have a later onset, and children can survive into adulthood but may have significant disability without treatment. Type IV is mainly associated with a normal lifespan.<sup>266</sup> Newborn screening and treatment intervention for SMA have shown to lead to better outcomes, especially if newborns can be treated before symptoms begin.<sup>267</sup> Since the outcomes of SMA differ significantly depending on type, we focused our analysis on where the burden of SMA is greatest (Type I) to reduce variability and utilise the strongest data available.

**Figure 37** shows the prevalence of all MNDs according to GBD 2019 data because SMA prevalence alone was unavailable.<sup>6</sup> Since the

majority of SMA cases (type I) occur amongst children and other types of MND primarily affects adults in mid-life or older, we restricted the MND prevalence to people under 25 in **Figure 37**.<sup>268</sup>

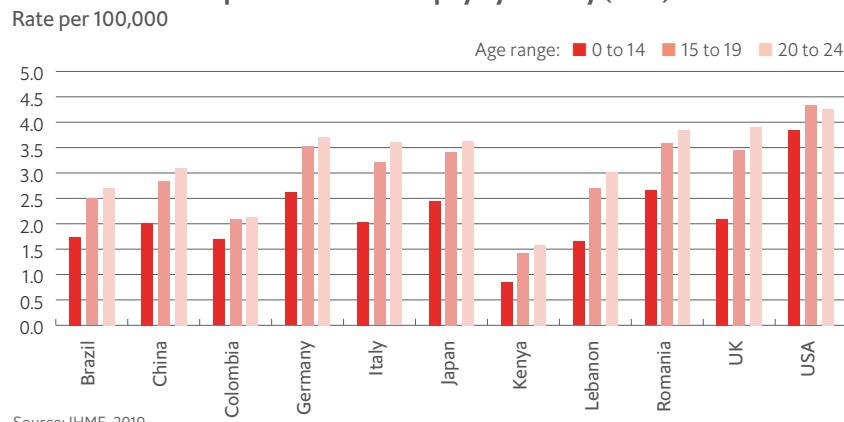
<sup>271</sup> The USA and UK have the greatest burden, with Kenya, Colombia and Lebanon at the lower end of the spectrum in terms of prevalence. Epidemiological research and case monitoring are scarce in LMICs, particularly for rare disorders such as SMA; consideration of potential data gaps must, therefore, be taken into account when interpreting these results.

According to clinical opinion, SMA types respond differently to treatment. Until recently, there were no treatments available that specifically influenced the disease course of SMA. DMTs, as well as ongoing physiotherapy and respiratory support, can improve function outcomes for these individuals (i.e. motor function and respiratory status), but due to the short follow-up periods of these trials, the long-term effects of the DMTs and their ability to increase life expectancy is less clear.<sup>272</sup> Long-term clinical trials are ongoing which may eventually present more evidence in terms of survivability and preservation of function.<sup>272</sup> However, the main barrier for health systems and patients is the high cost of SMA treatments. With or without treatment, the impact of SMA is so significant on parents and relatives that it is common for one parent to give up work to look after their child full-time; children with type I SMA require round-the-clock care either in a facility or at home. Another barrier to the effectiveness of SMA care is a lack of epidemiological studies, which can make addressing resource issues difficult. As SMA is a rare disease, countries require rare disease strategies to indicate priority allocation.

### The Americas

In the USA, the government has provided both funding for SMA research and created a clinical trials network – NeuroNext. This network fosters the rapid implementation and development of clinical trials for many neurological disorders and

Figure 37  
Prevalence rate of spinal muscular atrophy by country (2019)



Source: IHME, 2019.

aims to develop biomarkers for SMA.<sup>273</sup> National SMA patient organisations in the USA also exist, and provide education, research funding, and supportive resources to patients, families and healthcare providers.<sup>273</sup> They also conduct their own basic research and convene working groups to develop guidelines. Unfortunately, there is no reported national strategy for SMA care, nor a rare disease strategy. Many clinicians in the USA follow guidelines published in 2017 after an International Conference for SMA.<sup>274, 275</sup> SMA care centres are largely concentrated in the northeast with a few centres in the west and south.<sup>275</sup> Despite the lack of a national strategy for SMA management, however, there is a SMA clinical data registry in the USA managed by Cure SMA\*, a non-profit organisation.<sup>276</sup> Cure SMA also has educational programs for healthcare providers through their SMA Care Center Network.<sup>276</sup> There is also legislation in the USA supporting rare diseases the Rare Disease Act of 2002.

In Latin America, many patients with SMA and other neuromuscular diseases receive little to no treatment currently.<sup>280</sup> People living in remote rural areas lack access to conventional health systems and often turn to traditional healers. In contrast, in certain regions, such as large cities in Brazil, care is comparable to that found in major western nations.<sup>280</sup> An annual training program, the Euro-Latin-American Summer School of Myology (EVELAM), is conducted in several Latin American countries by local and foreign neuromuscular experts with the aim to increase specialty training.<sup>280</sup> About 100 to 150 Latin American clinicians and researchers attend the training every year, which has facilitated research into SMA and the publication of clinical studies in the Latin American context. This programme has demonstrated the importance of training young neurology specialists, as well as the significance of a referral system to connect patients to tertiary care.<sup>280</sup>

In Brazil, since 1950 the Association for the Welfare of Disabled Children has existed as a centre of

excellence for rehabilitation of patients with disabilities.<sup>277</sup> Since then, 12 more rehabilitation centres and a hospital for rehabilitation and assessments have been created.<sup>277</sup> As a part of the global organisation TREAT-NMD, a network of key opinion leaders within the neuromuscular community that aims to facilitate research for neuromuscular treatments, Brazil has a neuromuscular disease registry, but this database is not specific to SMA.<sup>278, 279</sup> There is no reported national plan or strategy for SMA treatment in Brazil, but there is a rare disease strategy.

Colombia also has a patient-centred national registry established through TREAT-NMD. Furthermore, Colombia participates in an expanded access programme (EAP) which provides investigational treatment to patients who are without other treatment options.<sup>280</sup> There is no reported national plan in place for SMA in Colombia, apart from a set of guidelines for intervention.<sup>281</sup> There is, however, a rare disease strategy.

## Asia

In Japan, there is limited data on SMA treatment and epidemiology in Japan as most of the collected data are from one island; epidemiological investigation is, however, expanding.<sup>282</sup> On the whole, SMA is under-diagnosed in the country; in order to address this, a pilot study was introduced in 2017 to support national implementation of newborn SMA screening, and Japan now has a national registry for adults with SMA.<sup>282, 283</sup> It is not clear from the published evidence if or how many treatment centres for SMA exist, but one study suggests that SMA patients are treated at local facilities and university hospitals.<sup>282</sup> There is no national strategy for SMA care reported in Japan, but there is a rare disease strategy.

In 2021, China launched a national initiative that relies on hospital networks to promote SMA patient education, provide rehabilitation and support for patient's families, and raise public awareness of

\* Roche Pharmaceuticals is an industry partner with The Cure SMA Industry Collaboration.

SMA.<sup>284</sup> The first SMA therapy was approved in China in February 2019 and since then, 39 hospitals across 23 cities have formed a national network for SMA diagnosis and treatment.<sup>284</sup> The China Primary Healthcare Foundation assists patients in accessing SMA care.<sup>284</sup> SMA treatments have been added to China's National Reimbursement Drug List, making the drugs affordable for patients and families.<sup>285</sup> China has non-profit organisations dedicated to supporting SMA families through network-building, information, and services.<sup>286</sup> As part of the global TREAT-NMD network, China has several registries including the Chinese Genetic Disease Registry (CGDR), a national registry of people diagnosed with Duchenne/Becker muscular dystrophy and SMA which is patient-reported and clinician verified, the clinician-operated Chinese Neuromuscular Disease Registry (NRDRS-NMD), and the Chinese SMA Patient Registry focused on promoting clinical trials in China.<sup>279</sup> There is no national plan for rare diseases, but there is a national strategy called the Rare Disease Clinical Cohort Study, which aims to establish a registry for rare diseases.

### Europe

SMA Europe\* is an umbrella organisation comprising 24 patient organisations across 23 European countries, which campaigns to improve the quality of life for people who live with SMA and bring effective therapies to patients in a timely way.<sup>287</sup> A recent initiative by SMA Europe advocates for newborn screening for SMA.<sup>288</sup> Alongside the developments in drug treatments for SMA, there is also research which suggests treatments should begin as early as possible.

Some countries have developed their own guidelines for SMA based on the international standards of care for SMA published in 2017.<sup>289</sup> However, as these international guidelines had been developed before effective treatments were discovered, they are in need of an update. Germany, Italy, Romania and the UK have all adopted the international SMA care guidelines,

but they have not yet adapted them to include developments in treatment. Due to such outdated guidelines and diverse reimbursement policies, the availability of treatment can vary across regions within European countries.

There are specialist SMA centres in Europe, but their distribution is uneven. Furthermore, treatment centres are often not obligated to provide patients with specific drugs for SMA treatment. Cross-border care is, therefore, required in some cases to access treatment.<sup>288, 290</sup> Italy and Germany have fairly easy access to specialist centres for SMA, with dedicated legislation for such in Italy, whereas in Romania and for adult cases of SMA in the UK, access is more limited.<sup>291</sup> In the UK, coordination of care for patients is under-resourced, with one study reporting that 71% of the parents of children with SMA were responsible for coordinating their own care, which is partly due to the rarity of the disease. The disparity of treatment across Europe means that some families have to travel to a different country for care and have to pay for treatment upfront and claim reimbursement later.<sup>292</sup> Given the high costs of SMA treatments and care, many families cannot afford to pay upfront even if they can be eventually reimbursed. There is a great need for policies and action by governments to resolve these barriers. To highlight disparities in care, a European policy and access tracker was created, which shows current gaps in policy and care affecting SMA patients.<sup>293</sup> In the absence of specific strategies for SMA, rare disease strategies are helpful in setting priorities and allocating resources.

Integral to the survival of children with SMA is physiotherapy and respiratory care.<sup>288</sup> A common theme across all the neurological disorders featured in this study is the limited access to physiotherapy. Specialist equipment is needed for SMA, which is often very difficult to acquire and sometimes requires financial investment from families. In Germany, Italy, Romania and the UK, government policies enable financial support from the state to buy specialist equipment and support families

\* SMA Europe is financially supported by Roch

and caregivers, but this varies in its availability.<sup>288</sup> Germany and Italy have more care provisions that are reimbursed for both the patient and the caregiver than Romania and the UK.

### **Sub-Saharan Africa and the Middle East**

In Lebanon, there is a lack of data on MNDs, which makes it difficult to understand and quantify the impact of diseases like SMA.<sup>294</sup> There is no SMA patient registry or research initiative in this country, which is especially pertinent as the reported carrier frequency of SMA is much higher in the Middle East and North Africa when compared with Europe, Australia and the USA.<sup>265</sup> Rare diseases, in general, are more prevalent in this part of the world partly due to consanguineous marriages. The awareness about rare diseases in both the patient and healthcare community needs to be addressed with cultural sensitivities. There is a fundamental lack of national policy for rare diseases nationally and regionally in the Middle East, which needs multi-stakeholder action before access to treatment for rare diseases can improve.

In sub-Saharan Africa, research into motor neuron diseases is also unsurprisingly scarce, yet the studies which do exist indicate many reasons for further research. For example, according to experts, many children with flaccid paralysis are much more likely to be classified under polio numbers or even cerebral palsy rather than under an MND like SMA. Some studies show there may be population-specific causes of MNDs among Africans, due to different genetic underpinnings, though genetic studies are rare. There are a few studies which suggest much fewer homozygous deletions of the SMN1 gene in black South African SMA patients when compared with other continents.<sup>265</sup> During the 11<sup>th</sup> International Conference on Rare Diseases and Orphan Drugs in 2016, the Africa-Rare initiative was mentioned which aims to raise awareness of the multiple challenges and opportunities for Africans living with rare diseases.<sup>295</sup> As the evidence suggests, rare diseases manifest differently in

African patients, and thus research conducted on this continent will have huge benefits globally for addressing the need for nuanced treatment in communities of African descent. Although conversations around rare disease are developing in Africa, the elephant in the room will always be resource scarcity and the cost of orphan drugs. Because of this, rare diseases research and the development of clinical infrastructure in Africa needs to be internationally and globally integrated. This will both encourage access to funding streams and allow those providing financial investments to benefit from the results of clinical research conducted in the African setting.

### **Spinal muscular atrophy: the amenable burden**

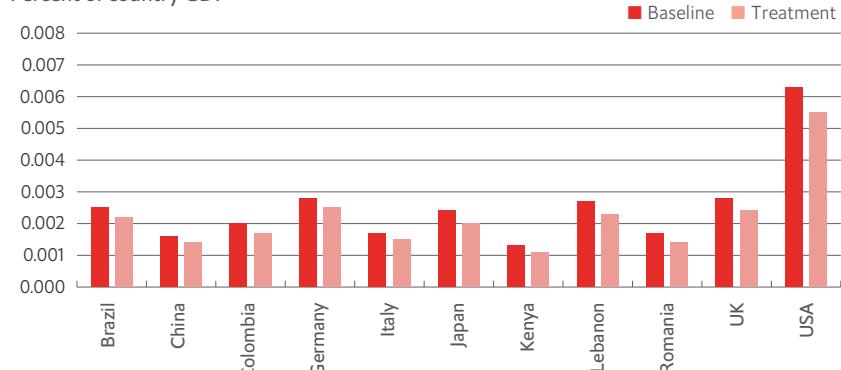
In our SMA cost analyses, we firstly made a decision on the type of SMA to include based on the research outlining treatment response. Type I SMA is the most common form of SMA in terms of incidence, and accounts for around 60% of cases.<sup>265</sup> While the treatment landscape is fast-moving in this space, type I also typically has a positive response to treatment according to expert opinion, and has been featured in pivotal treatment studies. Thus, we limited our analyses to patients with type I SMA only. Consequently, the analysis only includes children up to the age of five, because, overall, and according to the most recent available estimates, about 68% of children with type I SMA die by age two and 82% die before age four.<sup>296</sup> Though research into the impact of DMTs on life expectancy is ongoing, the risk of mortality for type I SMA may change in light of recent approval of treatments.<sup>297</sup>

We also only considered the ROI of a treatment scenario, omitting prevention as there is currently no evidence that SMA is preventable. Rehabilitation was also omitted from the analysis because most patients with type I SMA require physiotherapy and specialist equipment simply as treatment modalities to survive. It was therefore both unrealistic and challenging to disentangle these costs from the baseline costs of care. In

Figure 38

**Total cost of spinal muscular atrophy scenarios (2019)**

Percent of country GDP

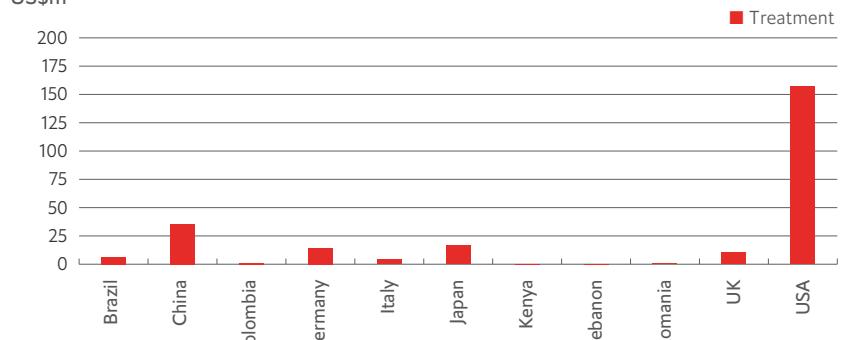


Source: Economist Impact analysis, 2022.

Figure 39

**Potential savings on total costs with implementation of spinal muscular atrophy scenarios compared to baseline (2019)**

US\$m

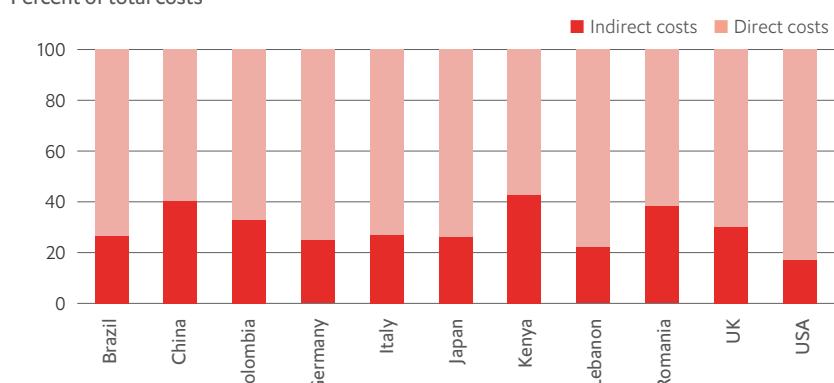


Source: Economist Impact analysis, 2022.

Figure 40

**Composition of spinal muscular atrophy costs at baseline (2019)**

Percent of total costs



Source: Economist Impact analysis, 2022.

the treatment scenario, we only analysed the effectiveness of nusinersen because it has a strong evidence base supporting its effectiveness in slowing the progression of the disease and was the only oral drug widely available to treat SMA in 2019, the data year of this study. As mentioned in previous sections, the main limitations of this treatment are its cost, which can grow to millions in just the first two years of treatment. Despite the costs, patients treated with DMTs have been associated with lower resource use as DMTs stabilise the disorder which translate to fewer hospital admissions. DMTs also increase benefits in terms of reducing caregiver burden. For example, treatment with nusinersen means fewer children require full-time ventilation over a 6–12 month time period; since caregivers report more hours of care for ventilated patients (12.39 hours per day) compared with caregivers of patients who do not need breathing support (8.17 hours per day), treatment with nusinersen would significantly reduce daily caregiving hours and lower carer burden.<sup>298, 299</sup>

**Figure 38** shows the cost of treatment for SMA is higher than the baseline costs without treatment. These increases ranged from 0.0001% of GDP in Kenya to 0.0013% of GDP in the USA. **Figure 39** reiterates that the treatment scenario yielded more cost savings in the one-year time horizon.

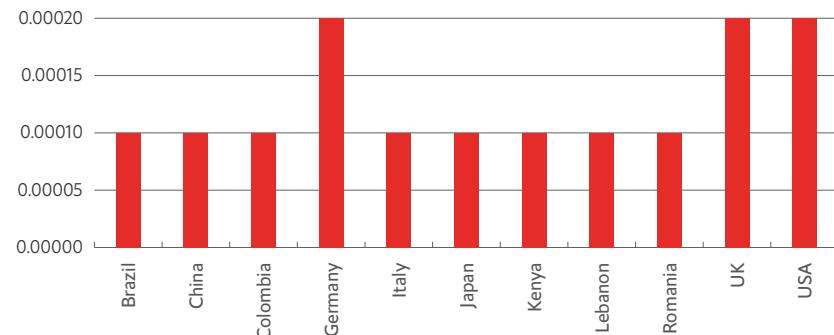
**Figure 40** shows the composition of SMA costs at baseline. Indirect costs are made up of productivity losses due to informal caregiving time and are responsible for >37% of the total cost of SMA at baseline. The direct costs, even without the addition of nusinersen, remain large due to the costs of ongoing hospital admissions and specialist equipment for children with SMA.

**Figure 41** shows that savings due to mitigated productivity losses are still possible in all countries compared to baseline. These savings are accrued because of the reduction in caregiver time associated with children who are not on ventilation as a result of treatment.<sup>298, 299</sup> These savings range from between 0.0002% and 0.0014% of GDP. **Figure**

Figure 41

**Potential savings on productivity losses with implementation of spinal muscular atrophy scenarios compared to baseline (2019)**

Percent of country GDP



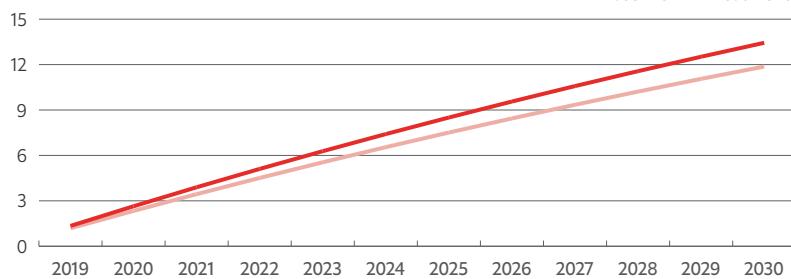
Source: Economist Impact analysis, 2022.

Figure 42

**Spinal muscular atrophy costs per scenario from 2019 to 2030 in the USA**

US\$bn

■ Baseline ■ Treatment

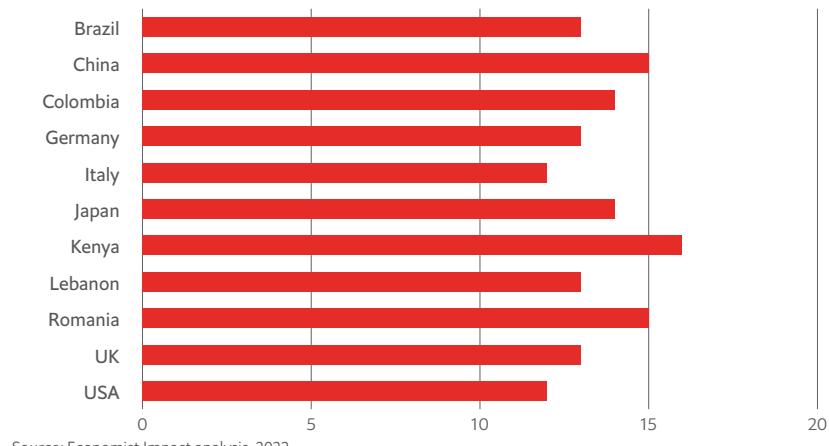


Source: Economist Impact analysis, 2022.

Figure 43

**Potential savings of costs for spinal muscular atrophy by type of model between 2019 and 2030**

Percent of baseline costs



Source: Economist Impact analysis, 2022.

Figure 42 shows that over time, the treatment scenario results in \$1.6bn in savings when compared with the baseline. Treating patients with SMA is deemed cost-effective in all countries included in our analysis. Figure 43 illustrates that the total savings rate of the treatment scenario is relatively constant over time (ranging from 12-16%). Though costs of care are incurred in each year, the indirect benefits will grow over time at the same discounted rate.

NICE reports that although the incremental cost-effectiveness ratios (ICERs) are above their usual cost-effectiveness threshold for SMA treatment, due to the difficulties in modelling SMA, the beneficial effects of treatment are not fully captured in existing clinical and cost-effectiveness studies. For example, the ENDEAR study, which was initiated to study the safety and efficacy of nusinersen, only included type I SMA children and demonstrated improved overall survival and motor function in participants. However, it did not provide evidence of long-term survival benefits because of its time-frame.<sup>300, 301</sup> Meanwhile, the CHERISH study demonstrated statistically significant benefits in motor function for children with later-onset SMA.<sup>302</sup> Additionally, the cost-effectiveness estimates of treatments for rare diseases are generally difficult to achieve by nature of the disease (i.e., its rarity). Cost-effectiveness studies in other diseases benchmark similar ICERs to rare diseases that present with a similar level of disability (such as Duchene muscular dystrophy).

### Global opportunities for SMA care

Access to treatment for SMA can cost individual patients millions over the first few years of treatment. Despite the high cost, these treatments have substantial value for the patient and their families. Many cost-effectiveness studies have deemed SMA treatments too expensive for reimbursement, but due to the lack of reliable, long-term clinical and cost-effectiveness studies, some health systems have made their own decisions about benefits and as a result, these drugs are approved and reimbursed in some

countries. There are still opportunities to reduce the cost of SMA treatments to make them available in more countries so they can benefit a greater number of people.

One of the main factors for future cost-effectiveness analyses in SMA is to better consider resources within society as a whole, rather than just relative costs and benefits alone. The costs of living with SMA are so variable they are likely underestimated both in our cost analyses and those reported elsewhere. A further consideration for cost-effectiveness analyses is that treatment may be more effective if delivered early according to the two landmark clinical trials (ENDEAR and CHERISH). This means that early detection of SMA could improve survival and function for certain patients. Epidemiological studies, which estimate the burden of SMA, are currently in short supply, but would greatly help justify the need for treatments.

Many of the countries in this report are also struggling to prioritise SMA above other competing diseases, especially LMICs. National strategies for SMA are missing in most countries and Europe, which probably has the most advanced care for SMA, still requires children with SMA and their families to travel across borders for care. One of the main issues with cross-border care in Europe is that in some countries, people have to pay for treatment up front and are only reimbursed later, which for SMA treatment can be cost prohibitive.

In Lebanon and Kenya, treatment and care options are scarce, yet these countries have the potential to be innovative research platforms for the rest of the world because of the genetic determinants affecting SMA presentation. Global funding donors could help initiate these research initiatives, which could also lead to setting standards of care for people with SMA in these countries.

## Epilepsy

Epilepsy is a disease of the brain characterised by abnormal electrical activity that can cause seizures or abnormal behaviour.<sup>303</sup> Epilepsy can lead to disability, psychiatric side-effects, social isolation and premature death.<sup>304</sup> There have been many advances in diagnosis, treatment and research of epilepsy in the last five years, which has transformed future prospects for those living with the disease. In November 2020, during the 73<sup>rd</sup> World Health Assembly, an Inter-sectorial Global Action Plan on Epilepsy and Other Neurological Disorders set out a clear set of actions aiming to change the course of neurological disorders.<sup>305, 306</sup> Specifically, the prevention of epilepsy was mentioned as being particularly important as it can be one of the most tangible symptoms of underlying neurological disorders.<sup>305</sup> Better epilepsy services can potentially serve as an entry point for broader neurological care.

Epilepsy was declared a public health priority and the most common severe chronic neurological disorder, yet there remain stark inequities in access to epilepsy care across the globe.<sup>307, 308</sup> Nearly 80% of the 50 million people with epilepsy live in LMICs; treatment gaps exceed 75% in most low-income countries and 50% in most middle-income countries.<sup>309</sup> There are many factors known to contribute to this gap. These include the costs of medications, a lack of trained healthcare professionals or prescribers, a lack of healthcare facilities, cultural issues such as stigma, a lack of awareness among local populations, and a reliance on traditional remedies in some countries rather than drugs.<sup>309</sup> Even in HICs, funding for epilepsy research represents a small proportion of overall funding, and in the USA, only accounted for 0.09% of the National Institutes of Health budget in 2019.<sup>310</sup> In a large survey assessing accessibility to anti-seizure medications in different global regions, drug price regulation was highlighted as the most effective method for improving access.<sup>311</sup> Since about 25% of epilepsy cases are preventable, there

is a great incentive to improve access to treatment modalities that prevent conditions which can cause epilepsy.<sup>309</sup> These include central nervous system infections, perinatal risk factors such as age at delivery, maternal health conditions such as HIV infection status or poor nutritional status, and traumatic brain injuries. Because many of the risk factors for epilepsy are common in Africa and other LMICs, in contrast to the other neurological disorders featured in this report, the prevalence of epilepsy in Kenya is much higher than that of many developed healthcare systems (**Figure 44**).<sup>6, 312</sup> Around 20% of the global burden of epilepsy resides in Africa alone.<sup>6</sup>

### The Americas

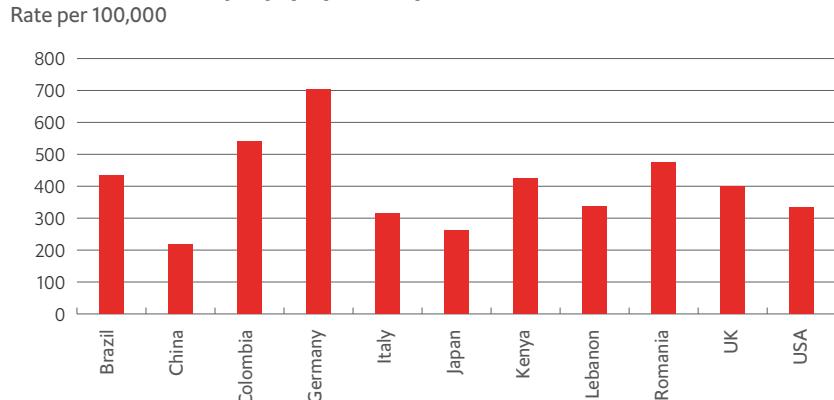
In the USA, local Epilepsy foundations function as information hubs for people with epilepsy and their families, offering referral assistance, support services, community-based education and advocacy for the rights of epilepsy patients.<sup>313</sup> The USA has a national epilepsy programme created by the CDC, which leads research, programme implementation, disease surveillance and data collection, health promotion and disease prevention.<sup>314</sup> To address gaps in epilepsy care, the NIH National Institute of Neurological Disorders and Stroke created the Epilepsy Therapy

Screening Program to support the discovery of new therapeutic agents.<sup>315</sup> In 2012, the National Academy of Medicine (formerly known as the Institute of Medicine), a non-profit organisation in the USA, produced a report on tackling epilepsy in the public health system.<sup>316</sup> Some of the recommendations included a stronger focus on prevention, better data surveillance and improving community resources. The USA also launched the Sudden Death in the Young Case Registry in 2014, which captures cases of unexpected death due to epilepsy, along with other sudden deaths in young adults or children.<sup>317</sup> There is also a registry which captures rare cases of epilepsy.<sup>318</sup> Apart from these registries, the USA does not appear to have a dedicated national registry for epilepsy, but the CDC does collect data from national surveys.<sup>317</sup>

In Latin America, epilepsy is ranked fourth in terms of the impact of DALYs, which is the highest rank when compared with other regions featured in this report.<sup>6</sup> The treatment gap for epilepsy in Latin America has been recognised by decision makers in the region. The Pan American Health Organization (PAHO) reported in 2013 that around two-thirds of Latin American countries do not have a health sector programme or action plan to treat epilepsy, and around 80% of countries do not have legislation related to epilepsy.<sup>306</sup> Furthermore, 68% of people with epilepsy in Latin America seek traditional or alternative types of care with healers, rather than medical professionals.<sup>306</sup> Only 62% of Latin American countries report that they can access one of four basic anti-epileptic drugs in the region.<sup>306</sup> Both Colombia and Brazil are on the higher end of the prevalence scale compared with the other countries in this study, ranking second and fourth, respectively (**Figure 44**).

In Brazil, there is a national action plan/programme collaboratively developed by Brazil's Ministry of Health and international epilepsy organisations.<sup>319, 320</sup> The purpose of the plan is to improve the health system's response to epilepsy by creating long-term care programmes, and promoting prevention, treatment and

**Figure 44**  
**Prevalence rate of epilepsy by country (2019)**



Source: IHME, 2019.

rehabilitation measures.<sup>319</sup> There is limited data regarding the proportion of federal health budget allotted for epilepsy care.<sup>320</sup> In Brazil there are a few professional, specialist and community-focused associations specifically related to epilepsy, but the level of participation in these groups is mostly unknown. These associations are particularly important to increase awareness and enable policy change given the high incidence of discrimination, stigmatisation and fear that many people suffering from epilepsy face in Brazil. While one study reports 25 epilepsy surgery centres in Brazil, there does not appear to be any public information regarding the number and distribution of epilepsy care centres or services or rehabilitation centres.<sup>320</sup>

Colombia has a national action plan/programme and legislation for the care of people with epilepsy.<sup>324</sup> The National Plan for Epilepsy aims to "establish special protection measures for people with epilepsy and dictate guidelines for full attention".<sup>321</sup> It acts through education, health and rehabilitation. It also condemns discrimination and establishes rights for people who are living with epilepsy. It is presumably financed through the Ministry of Health and Social Security, but there is limited data regarding the proportion of the government's health budget allocated for epilepsy care and whether there are prospects for expansion.<sup>320</sup> However, Colombia has several associations devoted to epilepsy, including neurologist-driven and community associations. These organisations are designed to promote education programs and civil participation in the general population, provide training, and research.<sup>324</sup> Colombia has 45 centres or specialised services for epilepsy care, with 26.2% of them concentrated in the capital. Of these centres, 12 have a paediatric specialisation. Additionally, Colombia has four surgery centres, one of which is in the capital, Bogotá, and offers rehabilitation and psychiatric services to epilepsy patients.<sup>324</sup>

## Asia

The Asian countries featured in this report have the lowest prevalence of epilepsy overall compared with the other countries (**Figure 44**). Nonetheless, this equates to around 10 million people who require treatment and similar to the situation in Latin America, there is a vast treatment gap driven by poor access to healthcare and social discrimination. WHO's Global Campaign Against Epilepsy in China demonstrated that it was possible to treat epilepsy in primary care settings.<sup>321</sup> There are now around 353 epilepsy centres in China, most of which are public and tertiary grade treatment centres equipped with specialised imaging equipment and at least one epilepsy specialist.<sup>322</sup> Three-quarters of these centres are in China's eastern and western regions leading to care disparities in the northern and southern regions.<sup>323</sup> Furthermore, the China Association Against Epilepsy, founded in 2005, has served as a necessary force to stimulate interest in epilepsy care and research. China has a national strategic plan for the prevention and control of epilepsy, which includes a consortium of experts and outlines plans for rural and urban epilepsy care programs, a big data platform, coordination with the Chinese government, and international collaboration.<sup>322</sup> China does not currently have a national epilepsy registry, but many large epidemiological datasets exist.<sup>322</sup> The majority of research so far has been related to epidemiology and clinical research, but there are significant inequalities in access to epilepsy care in China that warrant further study.

Japan has the second lowest prevalence of epilepsy (**Figure 44**). In a study looking at people with epilepsy over 40 years of age, older people were more likely to have epilepsy than the middle-aged, most likely caused by stroke.<sup>324</sup> The Japan Epilepsy Society advocates for the rights of patients with epilepsy and helps set standards for epilepsy centres and research initiatives.<sup>325</sup> This society, alongside the Japan Epilepsy Association, helped create the Japanese Declaration on Epilepsy in 2013 as a call to action for decision-makers to improve

care. According to the Japan Epilepsy Association, Japan has 35 centres which provide diagnosis and treatment for refractory epilepsy in collaboration with local medical facilities.<sup>326</sup> Aside from these efforts, there does not seem to be a national plan or registry for epilepsy in Japan.

### Europe

Even with access to more advanced healthcare systems, Europeans with epilepsy still report suffering from significant stigmatisation and social exclusion, highlighting the continuous need for trans-European awareness campaigns.<sup>327</sup> In a survey conducted in 2013 by the International League Against Epilepsy (ILAE), an organisation of professionals focused on promoting knowledge sharing and best practices, although Europe had the highest number of epilepsy specialists, misdiagnosis rates remained high.<sup>328</sup> Some researchers estimate that up to 40% of people with epilepsy in Europe may be untreated and there are 33,000 deaths each year, 13,000 of which could have been prevented.<sup>329, 330</sup>

Just behind Poland, Romania has the highest prevalence of Epilepsy in Central Europe. There are no professional guidelines or standard of care specific to Epilepsy in Romania. There is, however, a patient organisation founded in 1998, called the Romanian Society against Epilepsy.<sup>321</sup> Romania is also part of the ILAE. According to expert opinion, there is a deficiency in resources for diagnosing epilepsy in Romania, particularly a shortage of MRI scanners.

Italy has the lowest prevalence of epilepsy compared to the other European countries featured in this Findings Report, and the third lowest prevalence overall (**Figure 44**). In Italy, there are national guidelines for the treatment of epilepsy, which were published in 2006.<sup>331</sup> A position paper has since advised on how treatment has advanced since 2006, but aside from this, the guidelines have not been updated.<sup>332</sup> The Italian League Against Epilepsy is a fairly active member

of the ILAE, partly due to the immediate past president being Italian (Emilio Perucca), which has greatly helped to improve Italian epilepsy services.<sup>331</sup>

Since 2002, the German Neurological Society has regularly published epilepsy clinical practice guidelines.<sup>333</sup> Germany has a strikingly high prevalence of epilepsy in comparison to the other countries in this study and according to the GBD 2019 data, the highest prevalence in Europe.<sup>6</sup> Despite this, there is not a huge amount of research or clarity in terms of how Germany manages the large numbers of patients or the specific causes for this high prevalence.

In the UK, the NHS produced an epilepsy toolkit in 2020 to help health systems understand priorities in epilepsy care and reduce regional disparities.<sup>334</sup> This initiative was launched when decision-makers became aware of the 20-30% misdiagnosis rate in the UK and the discrepancies in epilepsy data collection.<sup>334</sup> The registry for epilepsy that exists excludes children under the age of 18, implying that many cases are missed. In 2021, the latest results of the Epilepsy12 survey, a multi-year clinical audit focusing on the unique needs of children with epilepsy, were released.<sup>335</sup> This audit has helped advocate for the psychosocial needs of children with epilepsy and encourages standardised approaches to epilepsy care. There are clinical treatment and management guidelines for Epilepsy in the UK produced by NICE, and similar guidelines in Scotland produced by the Scottish Intercollegiate Guidelines Network (SIGN).<sup>336, 337</sup> The main issue in the UK is the variability of access to care across different regions leading to clusters of unmet needs. In 2014, because the standard for the clinical care of epilepsy was removed from the UK NHS Quality and Outcomes Framework, there are no measurable targets for epilepsy or remuneration incentives for local healthcare providers.<sup>338</sup> This has resulted in a reduction in annual check-ups for people with epilepsy in the UK and poor control of the disease.

## Sub-Saharan Africa and the Middle East

In Africa, purchasing and distributing anti-seizure medications is more difficult than in other global regions mainly due to resource scarcity and a lack of drug procurement legislation and processes.<sup>339</sup> One study found that only 7-29% of children with epilepsy receive anti-seizure medications.<sup>340</sup> Due in part to lack of access to medications, and cultural and religious beliefs, a greater reliance on traditional healing methods is reported in some African countries.<sup>341</sup> Having epilepsy can place Kenyans, especially women, in extremely vulnerable positions.<sup>342</sup> Because the disease is stigmatised as being “the result of witchcraft”, women who have seizures could be abandoned by their communities or face the risk of sexual exploitation.<sup>343</sup> Kenya has made some encouraging developments despite scarce resources. In March 2014, the National Guidelines for the Management of Epilepsy were released, aiming to reduce the treatment gap by improving the availability of drugs and scaling up epilepsy advocacy and awareness.<sup>344</sup> Two other non-profit organisations, the Kenya Society for Epilepsy and the Kenya Association for the Welfare of People with Epilepsy (KAWE), are also helping to raise awareness of how to detect, treat and manage the disorder.<sup>345, 346</sup>

The rigour of epilepsy care in Lebanon is difficult to ascertain. In 2010, the WHO published a report on epilepsy care in the Eastern Mediterranean region.<sup>347</sup> The report highlighted the fact that there were very few studies addressing the magnitude of the problem of epilepsy in the region, and very few resources available for diagnosing the disease. Genetic factors are known to play a role in the prevalence of epilepsy, partly due to consanguineous marriage.<sup>348</sup> In addition to limited data collection and surveillance systems, many people refuse to admit they have the disease because of the associated stigma. In a study looking at self-reported attitudes to anti-epileptic

medication in Lebanon, people did not really trust or have a positive view towards therapies.<sup>349</sup> Out-of-pocket payment is unfortunately the primary source of financing for epilepsy care placing a huge financial burden on those diagnosed with the disease. Despite the stigma, there are advanced hospitals capable of treating epilepsy in Lebanon, such as the American University of Beirut. Lebanon is also a member of the ILAE.<sup>350</sup>

## Epilepsy: the amenable burden

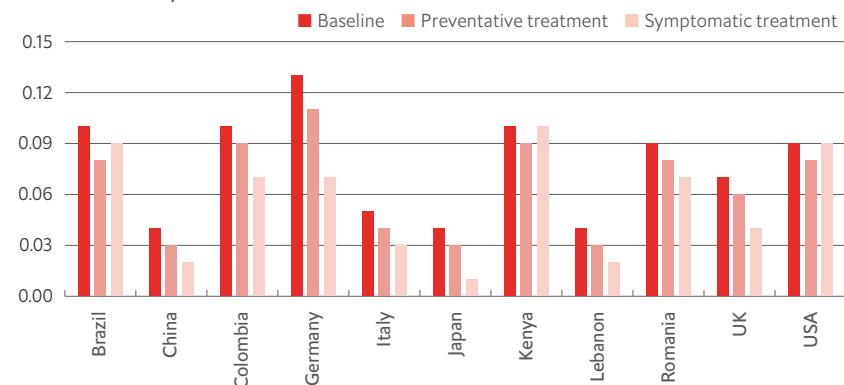
In our epilepsy cost analyses, we considered the impact of preventative and symptomatic epilepsy treatment. Prevention in this case is defined as better access to healthcare services to manage conditions which cause seizures, such as traumatic brain injuries and perinatal risk factors. Symptomatic epilepsy treatment refers to access to treatment and medications for epilepsy. These scenarios were adjusted for the income level of each country, due to the stark differences in prevalence and treatment gaps previously discussed. We followed the WHO advice which states that 25% of seizures in HICs and 15% of seizures in LMICs could be prevented.<sup>309</sup> Similarly, WHO estimates a greater reduction in the prevalence of seizures in HICs and LMICs with appropriate access to symptomatic treatment.<sup>309</sup> The evidence also suggests that up to 70% of people living with epilepsy could become seizure-free with appropriate use of anti-seizure medicines, which can improve quality of life, mental health, as well as productivity and employment status.<sup>351</sup> We therefore assumed that people with controlled epilepsy are 70% more likely to be able to work, and less likely to retire early.

**Figure 45** shows that the cost of the baseline scenario was the highest in all countries, meaning implementing both preventative and symptomatic treatment led to cost savings. Overall, symptomatic treatment resulted in cost savings across a majority of the countries, which

Figure 45

**Total cost of epilepsy scenarios (2019)**

Percent of country GDP

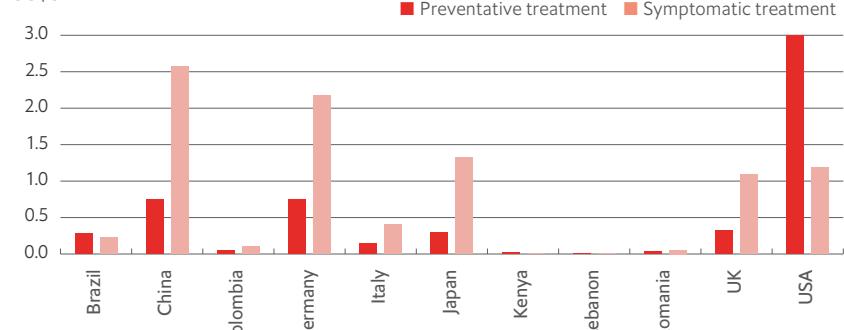


Source: Economist Impact analysis, 2022.

Figure 46

**Potential savings on total costs with implementation of epilepsy scenarios compared to baseline (2019)**

US\$bn

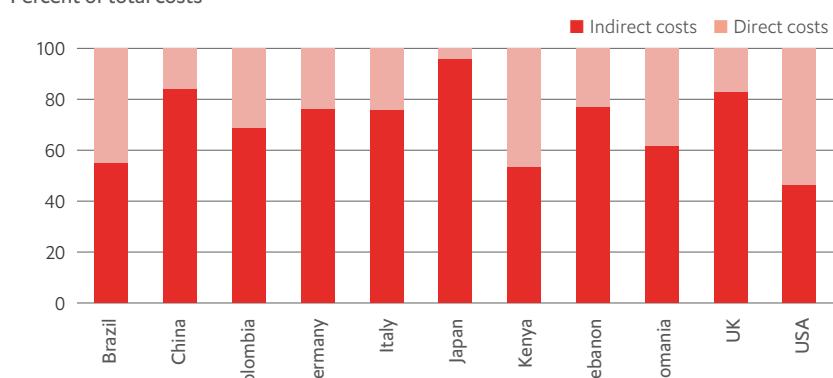


Source: Economist Impact analysis, 2022.

Figure 47

**Composition of epilepsy costs at baseline (2019)**

Percent of total costs



Source: Economist Impact analysis, 2022.

is due to our assumptions about the success rate of anti-seizure medication. **Figure 46** reiterates that the preventative treatment scenario yielded the highest savings from baseline in the one-year time horizon in Brazil, Kenya, and the USA.

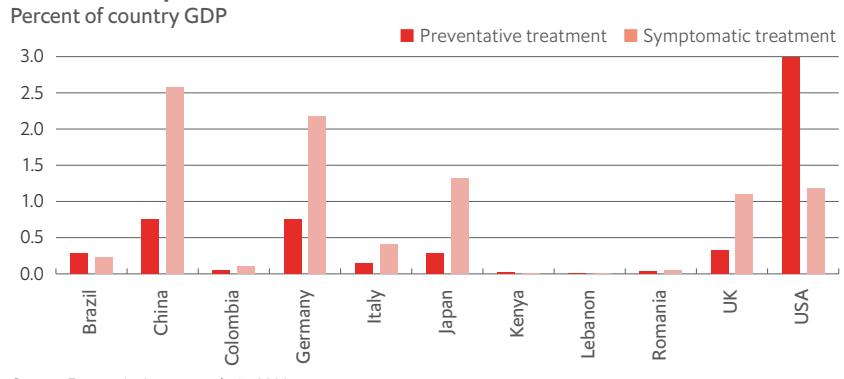
**Figure 46** also illustrates that the symptomatic treatment scenario, on the other hand, yielded the highest savings from baseline in the one-year time horizon in China, Colombia, Germany, Italy, Japan, Lebanon, Romania and the UK. **Figure 47** shows that the indirect costs of epilepsy are responsible for more than 60% of the total costs at baseline, emphasising the significant disruptions unmanaged seizures can have on productivity. This finding is comparable to other studies looking at the indirect cost burden of epilepsy. One study looking at the costs of epilepsy in children in Germany found 44.8% of total costs were attributable to indirect costs accrued from parents having to give up work to look after their child.<sup>352</sup> This study excluded the indirect costs accrued from working-age adults with epilepsy, which helps explain the lower figure when compared to our results. A further study considering epilepsy among African adults found indirect costs were associated with 73% of the total cost of epilepsy.<sup>353</sup>

**Figure 48** highlights the savings on productivity losses that are possible following the implementation of prevention and treatment. Given the high prevalence of epilepsy in Germany, the impact of productivity savings that are possible in this country stands out among the others.

Similarly, in Kenya, Brazil, and Colombia, where both prevention of epilepsy risk factors and the high prevalence of epilepsy need tackling in equal measure, there are significant savings that can be made. **Figure 49** highlights the difference in the treatment scenarios from baseline over time in the USA. Compared to the baseline, preventative treatment can result in cost savings of around \$30bn and symptomatic treatment in \$12bn by 2030.

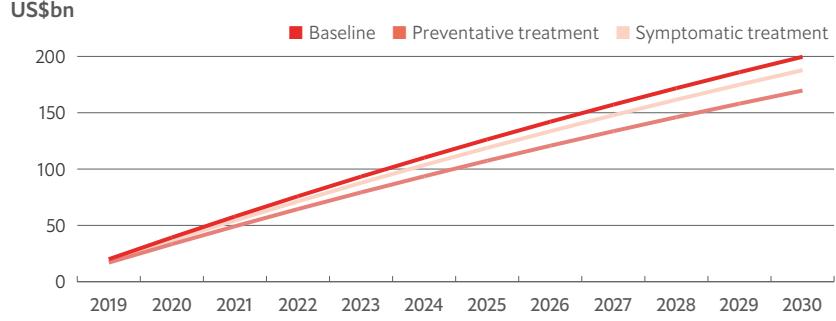
**Figure 50** shows the estimated potential savings rate possible between 2019 and 2030 due to the

**Figure 48  
Potential savings on productivity losses with implementation of epilepsy scenarios compared to baseline (2019)**



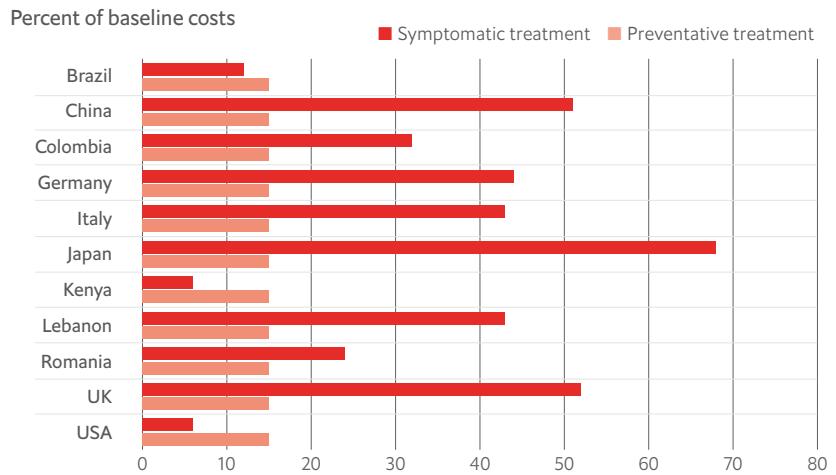
Source: Economist Impact analysis, 2022

**Figure 49  
Epilepsy costs per scenario from 2019 to 2030 in the USA**



Source: Economist Impact analysis, 2022.

**Figure 50  
Potential savings of costs for epilepsy by type of model between 2019 and 2030**



Source: Economist Impact analysis, 2022.

indirect benefits accrued. The savings rate in the preventative treatment scenario is constant across all countries. More countries accrue savings over time from implementing symptomatic treatment rather than preventative treatment, except in Brazil, Kenya and the USA. Again, Brazil and Kenya would greatly benefit from better access to healthcare to reduce risk factors for epilepsy. In the USA, preventative treatment also accrues more savings as the cost of care in this country makes symptomatic treatment expensive, resulting in less savings over time.

### Global opportunities in epilepsy care

There is a unique opportunity for epilepsy care to evolve into a multi-faceted practice area that serves a dual purpose in the neurology space. This includes both better prevention and early identification of other neurological disorders, as well as preventing the number of epilepsy cases by reducing risk factors for the disease. Considering epilepsy as a disease in isolation (as seems to be the case in many countries) is therefore hugely detrimental to the prevention and early identification of other neurological disorders. The second opportunity is improving access to anti-seizure medications, which the WHO reports can cost as little as \$5 per person per year for generic forms of the drug.<sup>357</sup> Indeed, scaling up symptomatic treatment in our cost analyses was deemed very effective, or less than one percent of the GDP per capita in all countries. Although generic forms of epilepsy medications exist, branded options are often more readily available in LMICs. One study that collected data on available epilepsy treatments across 91 pharmacies in Madagascar found that 84.6% of them had sodium valproate, 68.1% and 36.3% had carbamazepine and phenobarbital, respectively, and none had phenytoin.<sup>354</sup> The main source of epilepsy drugs in LMICs are private pharmacies, which have little to no price regulation, meaning the financial burden for most patients is huge. Another study looking at

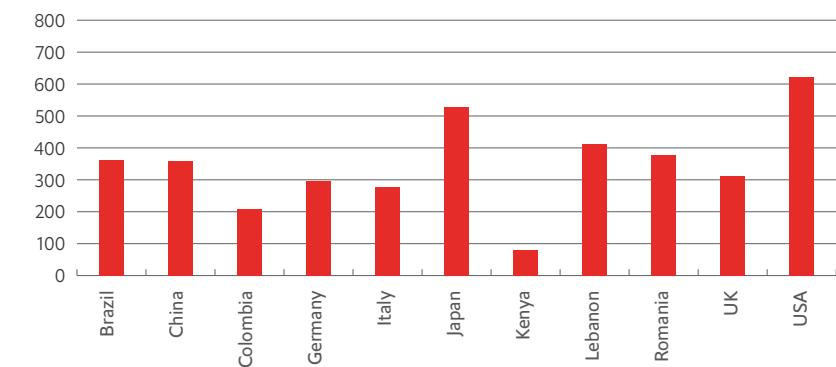
access to epilepsy treatment in 46 countries found the availability of generic treatments was less than 50%.<sup>355</sup> Better access to treatments via the public sector and price regulation needs to be developed. The opportunities for improving access to epilepsy medications is not limited to LMICs; they are available to as few as 48% of patients in some European countries too.<sup>356</sup>

A final opportunity lies in bolstering the epilepsy research agenda, given this disease is of central importance to all neurological disorders. Even in regions such as Europe, which have, high numbers of epilepsy specialists and centres, misdiagnosis and stigma remain a problem partly due to limited research capabilities and awareness. For the greatest benefit, epilepsy research must be integrated with a holistic neurology agenda to aid early detection and treatment across a range of disorders, a partnership which may help attract funding.

## Spinal cord injury

Damage to the spinal cord occurs either due to trauma or from a disease that causes degeneration of the spine.<sup>357</sup> Around 90% of spinal cord injuries (SCIs) are due to traumatic causes, which are more prevalent in LMICs due to a general lack of road safety regulations.<sup>358</sup> The severity of the SCI is largely dependent on the availability of timely medical care, including the transport method to hospital after injury and time to hospital admission. After the acute phase of care, access to rehabilitation is essential to manage the disability associated with a SCI.<sup>358</sup> Specialist equipment, which often require customising, are needed to help with mobility, communication and self-care. In countries where patients struggle to gain access to specialist equipment because of the expense and lack of expertise, people with SCIs are even more dependent on caregivers. The combination of medical costs, specialist equipment, rehabilitation costs and absence from the workforce for individuals and carers creates a significant cost to society.<sup>359</sup> Around 30% of people with SCIs also experience depression according to one study conducted in Taiwan.<sup>360</sup> The evidence suggests people with SCIs have better outcomes when treated in a specialist SCI centre, yet not all countries have established such treatment networks.<sup>361</sup> Many countries do not have registries for SCIs which means the true burden is not fully known. Across the countries in this report, the USA has the highest prevalence of SCIs and Kenya the lowest (**Figure 51**).<sup>6</sup>

**Figure 51**  
**Prevalence rate of spinal cord injury by country (2019)**  
Rate per 100,000



Source: IHME, 2019.

## The Americas

The US VA and other government departments devote significant funding to SCI research, creating SCI-specific research programs and rehabilitation services for veterans with SCI.<sup>362</sup> VA SCI services can be found in 25 regional SCI centres which offer multi-disciplinary care in partnership with primary care teams or clinics at local VA medical centres around the country.<sup>363</sup> Non-profit organisations

offer support to SCI patients and caregivers, fund research, and, in some cases, connect patients to rehabilitation centres within the USA. SCI injury data are collected and managed in a national research database.<sup>364</sup> Data are also collected and held in a national registry as part of a clinical trial to inform neurological assessments and classification of SCIs.<sup>365</sup> Some government agencies have research strategies for SCI treatments, and there are clinical practice guidelines published by national non-profit organisations, but there is no national plan for SCI management.<sup>363, 366, 367</sup>

In Brazil, there are clinical guidelines on the care and treatment of patients with SCI, but no national plan for prevention or public health interventions. There is no reported national registry for SCI. Brazil has at least nine SCI rehabilitation centres in various regions, which are run by an independent institution created under Brazilian federal law.<sup>368</sup> SCI rehabilitation may be available at private institutions, but this data are decentralised and not publicly available. In Colombia, there is currently no national registry for SCI. There are local organisations that advocate for rights and adaptations of workplaces to improve accessibility, as well as provide education and support to those with SCIs.<sup>369, 370</sup> The main treatment centre for SCI is located in Cali, Colombia, meaning most individuals need to travel for care.<sup>371</sup>

### **Asia**

Japan has several organisations that promote SCI research, data sharing, education, and provide resources to people with SCIs.<sup>372</sup> In 2021, Japan established its first national database on spinal instrumentation surgeries, which includes patients who have sustained SCIs.<sup>373</sup> Apart from this database, there is no national SCI registry. A nationwide survey was conducted in 2018 to determine the burden of SCI in Japan.<sup>374</sup> The survey found that SCI patients are primarily treated at emergency and acute care hospitals in Japan. Rehabilitation centres for persons with disabilities are available in Japan, but their geographical

distribution is unknown, and it is unclear whether these facilities cater solely to SCI patients.<sup>370</sup> There is no national strategy for SCI management.

There are a few organisations in China devoted to research, training, information exchanges and rehabilitation support for patients with SCI.<sup>375</sup> The China Rehabilitation Research Centre, a prominent rehabilitation facility in Beijing, collaborates internationally and with local universities and hospitals to conduct research and offer rehabilitation services to SCI patients.<sup>370, 376</sup> Other SCI rehabilitation centres are present in China though, again, their geographical distribution is unknown. Initial treatment typically occurs at a tertiary hospital. Due to regional differences in SCI epidemiology, researchers advocate for region-specific public health interventions.<sup>377</sup> Comprehensive management strategies have been published in China for SCI, which includes evaluation, diagnosis, rehabilitation training and complications management, but there is no reported national SCI database in the country.<sup>377</sup>

### **Europe**

In Italy, there is no national registry for SCI. Therefore, current incidence estimates are unreliable. There are specialised spinal units to treat traumatic injuries, but they are mainly located in the northern regions.<sup>378</sup> For non-traumatic SCIs, there is no dedicated pathway of care. According to expert opinion, there is also poor communication between inpatient spinal units and community rehabilitation centres once the patient has been discharged. Social care and vocational rehabilitation in Italy for people with SCIs are variable in quality and access.<sup>379</sup> Vocational rehabilitation is currently not part of Italian rehabilitation facilities unless patients have work injury insurance.<sup>379</sup> This most likely contributes to more than half of patients with SCI in Italy reporting that they are unemployed. There are, however, several patient associations that support people with SCI and help raise awareness.

In Germany, there is a data collection system on diagnostic and therapeutic interventions provided to patients with SCIs, and routine data provided by the German Health Surveillance System, but there is no national registry.<sup>380, 381</sup> The exact number of cases and the rehabilitation needs of people with SCIs in Germany is, therefore, also unknown. Access to care for SCIs is available in 60% of German hospitals, which include specialist SCI units where rehabilitation is available, spread across the country making regional care possible.<sup>381</sup> The German health insurance system also funds the cost of medical care, rehabilitation and changing life circumstances, such as job loss or early retirement.<sup>382</sup> The German social insurance code mandates that disabled people receive benefits to help them participate in everyday life. This includes, for example, redesign of the workplace, and re-training for a new job if the old job can no longer be performed. Despite these regulations, it is largely unknown to what extent they are implemented.

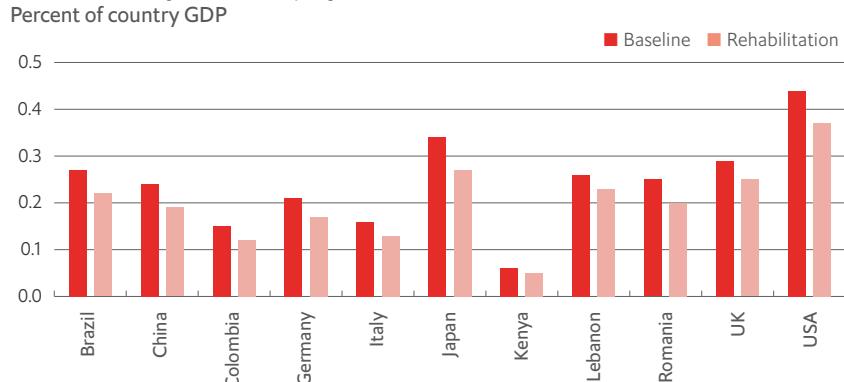
According to GBD 2019 data, in Romania, the prevalence of SCIs is on the higher end of the scale when compared with the other countries in this report; the country ranks fourth overall.<sup>4</sup> Research and strategies on the management of SCIs in Romania is difficult to find and there is no reported national strategy or plan. In a study of 12 respondents with SCIs, provided by the Motivation Romania Foundation, poor definitions of SCI, and consequential difficulties in retrieving medical record data, make it very difficult to understand people's unique needs. In this same study, participants reported significant problems with the accessibility of shops and buildings in Romania for wheelchair users, and none of the participants were in employment. There are laws in Romania which protect people with disabilities against discrimination in the workplace and a consequential lack of employment, but implementation of these in practice is rare.<sup>383</sup> As a result, disability and poverty are closely linked in the country. Over the last ten years, the Romanian government has tried to tackle disability and poverty via EU-funded assistance programmes, but there is limited data on their achievements so far.

In England, the treatment and care of people with SCIs is directed by the NICE guideline on SCI assessment and initial management.<sup>384</sup> In both England and Scotland, integrated trauma networks were set up to organise regional care and coordinate multi-disciplinary care for people with trauma-related illness.<sup>385, 386</sup> There is also a national registry for collecting data and outcomes of people with trauma called the Trauma Audit and Research Network and a registry specific to SCIs called the National Spinal Cord Injuries Database.<sup>387, 388</sup> There are eight specialist providers of SCI care across England and data are collected on the number of referrals to these providers and the outcomes of care.<sup>389</sup> The most frequent causes of delays reported in SCI specialist centres were the provision of care packages to support people with SCI at home, awaiting nursing or residential care, awaiting appropriate housing and specialist equipment and adaptations.<sup>390</sup> The National Audit Office in the UK estimates that the annual lost economic output due to trauma is between £3.3bn and £3.7bn.<sup>391</sup> The initial hospital costs of trauma are estimated to be between £0.3bn and £0.4bn annually, but the additional costs of rehabilitation and homecare support are unknown.

### **Sub-Saharan Africa and the Middle East**

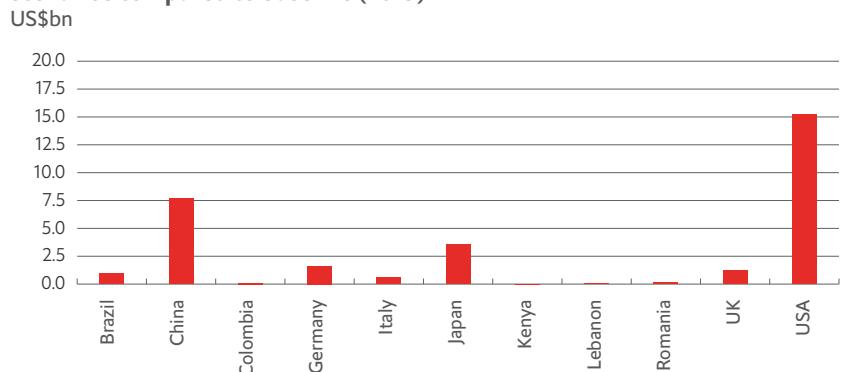
Research on SCIs in the Middle East is sparse. The management and rehabilitation of SCIs are inadequate not just in the Middle East, but in most developing countries. This starts even at the acute phase of care, which is hindered by a lack of imaging equipment and access to early surgery.<sup>392</sup> The high costs of spinal surgery makes it very difficult to access for most patients, and there is also a lack of rehabilitation services.<sup>392</sup> In the African region, transport and road traffic accidents account for nearly 70% of SCI cases. The inconsistent use of helmets and seatbelts in cars is one of the factors that contributes to this high rate, despite social media campaigns for their importance.

Figure 52

**Total costs of spinal cord injury scenarios (2019)**

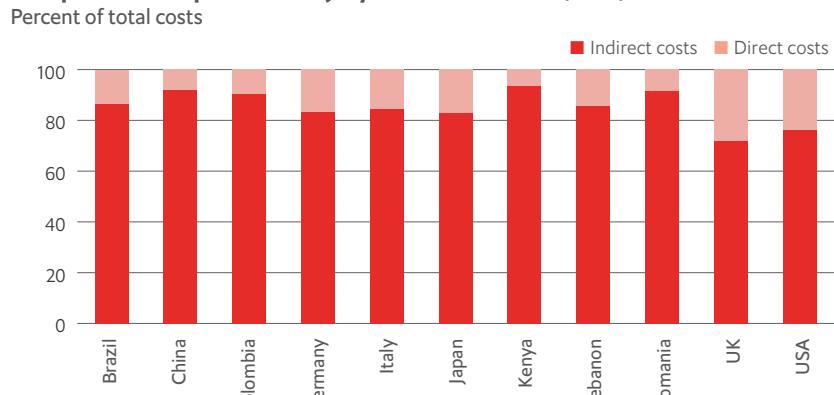
Source: Economist Impact analysis, 2022.

Figure 53

**Potential savings on total costs with implementation of spinal cord injury scenarios compared to baseline (2019)**

Source: Economist Impact analysis, 2022.

Figure 54

**Composition of spinal cord injury costs at baseline (2019)**

Source: Economist Impact analysis, 2022.

**Spinal cord Injury: the amenable burden**

Analysing the cost of acute injuries is quite a difficult undertaking as the medical care associated with each injury is highly variable person to person, dependent on the resources of the hospital, and the distance travelled to receive care. Because of these complications, we only analysed the impact of a rehabilitation scenario for SCIs. In some countries, disability is closely linked with poverty; therefore, physiotherapy, occupational therapy and vocational rehabilitation are fundamental to enable people with SCIs to re-integrate into society. One study suggests that vocational rehabilitation enables a return-to-work (RTW) rate of 17% in moderate to severe cases of injury, and another study found 69% of people with mild traumatic brain injury returned to employment following vocational rehabilitation.<sup>393, 394</sup> A randomised controlled trial found a rate of 14% RTW in moderate to severe cases.<sup>395</sup> We therefore assumed a higher RTW for mild cases and a lower RTW for severe cases. Accordingly, we assumed an increase in patient productivity and decrease in caregiver burden by 69% for mild cases and by 17% for moderate/severe cases.

**Figure 52** shows that the rehabilitation scenario resulted in cost savings in all countries. **Figure 53** reiterates that the rehabilitation scenario yielded savings from baseline in the one-year time horizon.

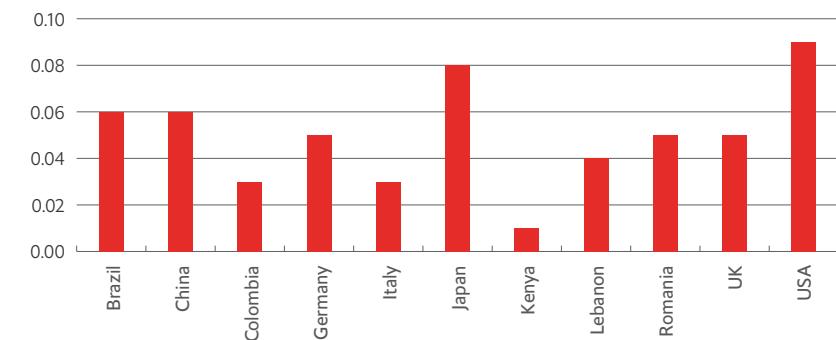
**Figure 54** shows the composition of the total costs of SCIs at baseline. Indirect costs were responsible for more than 80% of the total cost of SCIs in all countries except for the UK (71.6%).

**Figure 55** shows the possible cost savings from scaling up rehabilitation in all countries – they are most pronounced in Japan and the USA, which is most likely driven by the high prevalence of SCIs in these two countries (**Figure 51**). **Figure 56** demonstrates the difference in savings between the rehabilitation scenario and baseline over time in the USA, and indicates that rehabilitation can result in savings of around \$12bn from baseline by 2030.

Figure 55

**Potential savings on productivity losses with implementation of spinal cord injury scenarios compared to baseline (2019)**

Percent of country GDP

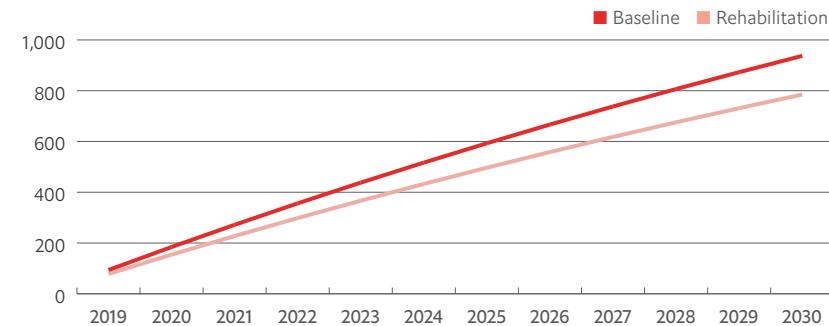


Source: Economist Impact analysis, 2022.

Figure 56

**Spinal cord injury costs per scenario from 2019 to 2030 in the USA**

US\$bn

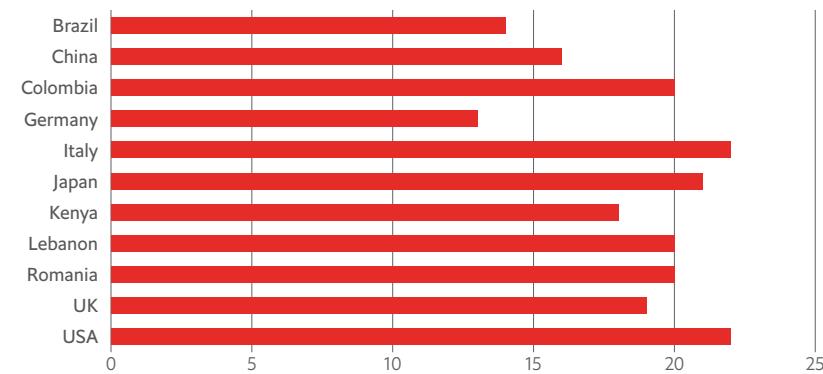


Source: Economist Impact analysis, 2022.

Figure 57

**Potential savings of costs for spinal cord injury by type of model between 2019 and 2030**

Percent of baseline costs



Source: Economist Impact analysis, 2022.

**Figure 57** shows the estimated potential savings rate of the rehabilitation scenario due to the indirect benefits accrued between 2019 and 2030. All countries accrued cost savings over time, but they were most pronounced in China, Kenya and Japan.

**Global opportunities for spinal cord injury care**

The most obvious opportunity in SCI care across the globe is the development of national strategies or plans to guide treatment and rehabilitation. In all countries studied here, except the UK, national strategies outlining a multi-disciplinary plan of care were absent. Secondly, the importance of physiotherapy, occupational therapy and vocational rehabilitation are central to the recovery from a traumatic injury, yet in many countries, even HICs, access to these services are limited. The variability in vocational rehabilitation services across countries is linked to different employment rates for people with SCIs. As the average age of people with SCIs (49 years) is during their prime productivity stage, without appropriate support to return to work, individuals face significant financial hardship and the losses to the workforce are large. In all countries, access to care support at home for SCIs was lacking. In the UK, which has a national plan for SCI, access to homecare, or housing adapted according to individual disabilities were the main causes for care delays. Many people with SCIs face discrimination and exclusion from society due to the limits of the healthcare systems.

## Traumatic brain injury

The effects of a traumatic brain injury (TBI) are life-long and consist of both cognitive, emotional and behavioural changes for the individual.<sup>396</sup> The incidence of TBI is on the rise, partly driven by a rise in road traffic accidents and trauma-related violence in LMICs, which is where 90% of TBI-related deaths occur.<sup>397, 398</sup> The most critical component of TBI care that can greatly affect outcomes is the pre-hospital, emergency care given at the scene of the injury, followed by inpatient care and post-acute care, all of which, but especially the latter, are rarely available in LMICs.<sup>397</sup> Access to CT scans during the acute phase is integral to assessing the severity of a head injury. Yet this often only identifies a small proportion of people with a severe head injury that require admission to a specialist centre.<sup>399</sup>

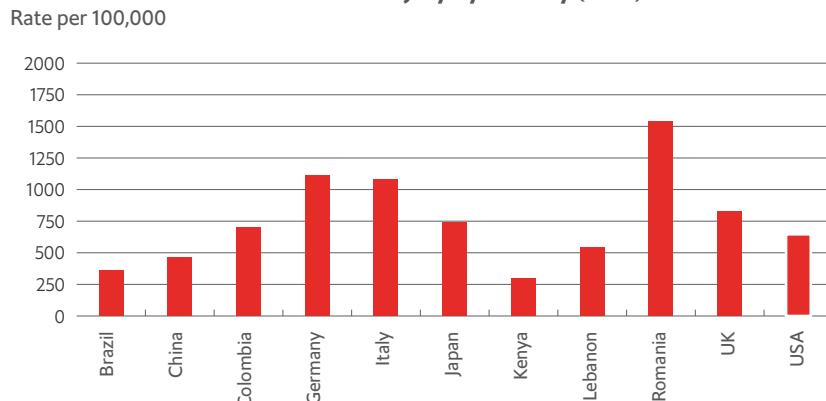
Similar to SCI, access to specialist centres for TBI and long-term care planning, which includes rehabilitation, are often in short supply and vary in quality. This means many TBIs become more severe in the absence of appropriate treatment and/or the individual is unable to return to work or normal life due to disability.<sup>400</sup> One study estimated that around 85% of HICs have emergency specialised doctors.<sup>397</sup> An estimate from 59 LMICs found the availability of emergency doctors at 28%. There

are also large variations in data collection of TBI cases and the reported prevalence globally. One of the main reasons for this is the methodological diversity of scientific studies, the variation in hospital admission policies for TBI, and the classification of different types of TBI.<sup>401</sup> There is a particular paucity of research and case data in LMICs, where the prevalence of TBI is likely to be higher than reported numbers. Injuries have largely been neglected from global health policy until recently.<sup>402</sup> They are now included in the 2030 Sustainable Development Goals – goal three focuses on NCDs with a specific target pertaining to injury, and halving the number of deaths and injuries due to road traffic accidents.<sup>403</sup> **Figure 58** outlines the prevalence of TBI by country.<sup>6</sup> Romania has the highest prevalence followed by Germany, Italy and the UK, which is quite a different pattern from the prevalence of SCI. The reported low prevalence in Kenya and Brazil as suggested by the evidence is likely due to under-reporting.

### The Americas

In 1996, the USA passed a TBI Act that authorised state surveillance of the cause, severity and prevalence of TBI.<sup>404</sup> Through state partnerships, the government provides coordinated services and support to patients, their families and caregivers.<sup>405</sup> Federal agencies have created an inter-agency TBI research database in addition to a National Research Action Plan, which aims to improve prevention, diagnosis and treatment of TBI and other mental health conditions.<sup>406</sup> Additional studies are being developed by the US VA to assess the long-term impact of TBI in veterans.<sup>400</sup> There are also plans to create a national TBI registry in the USA to increase surveillance and prevention opportunities, as well as provide families and patients with access to up-to-date treatment information.<sup>407</sup> A centralised record of TBI treatment and rehabilitation centres is not available, but TBI treatment is generally accessible in major hospitals.

Figure 58  
Prevalence rate of traumatic brain injury by country (2019)



Source: IHME, 2019.

In Brazil, there is no national public health plan for TBI prevention, but it has established clinical guidelines on best practices and rehabilitation recommendations for TBI patients.<sup>408</sup> Additionally, the Brazilian Society of Neurosurgery (BSN) developed a public education programme to prevent neurotrauma (i.e. TBI and SCI). Implementation was initially carried out by volunteer neurosurgeons, but has since gained support from the Brazilian federal government.<sup>409</sup> There does not appear to be a national registry dedicated to TBI, but as the majority of people depend on the Brazilian public health system (SUS), TBI epidemiological data are typically obtained from DATASUS.<sup>410</sup>

Colombia has a national plan for TBI focused on clinical practice guidelines and treatment management.<sup>411</sup> There are barriers to the implementation of these guidelines due to scarcity or absence of resources that are critical to treatment. TBI experts in Colombia suggest a stratified approach to interventions based on resources available at each stage of care.<sup>412</sup> The needs of caregivers and patients suffering from TBI, unfortunately, are often unmet because of a lack of interventions targeted at these needs.<sup>413</sup> Also due to incomplete clinical data, lack of IT support and limited resources, there is no national neurotrauma (TBI and SCI) registry in Colombia.<sup>414</sup>

### **Asia**

In Japan, TBI data are registered in the Japan Trauma Data Bank, which also includes data on patients with other trauma-related injuries or burns.<sup>415</sup> Similar to other neurological disorders, TBI patients seem to be treated at local or regional hospitals with no TBI-specific treatment centres available in Japan. Japan has national guidelines for the management of severe head injury, which are based on expert consensus and national and international research studies.<sup>416</sup>

In China, TBI is considered a public health issue as there are more patients with TBI than most

countries in the world, which is often masked when looking at per capita rates because of the size of the population.<sup>417</sup> Additionally, there are significant regional differences in care (i.e., high-level care is not universally available). China has made some progress, and has passed safety legislation to reduce road traffic accidents, published evidence-based TBI management guidelines, and established specialised care units.<sup>417</sup> Collaborations between China and international agencies have been beneficial to advancing the country's research quality, TBI care and patient outcomes.<sup>401, 421</sup> Researchers have also developed a Chinese TBI registry, based on a registry established in Europe.<sup>418</sup> Many challenges remain in China, which are exacerbated by regional differences in the access to care.

### **Europe**

In Europe, where the availability and quality of care for TBI is among the best in the world, there are large numbers of people who survive TBI annually and live with the consequences of the injury.<sup>419</sup> The emphasis in Europe is therefore a little different to that in LMICs – the main opportunities lie with public health policy and evidence-based clinical guidelines which aim to reduce the ongoing disability caused by TBIs.

Trauma care in Germany has greatly improved in the last decade. In 2010, a longitudinal study revealed significant discrepancies between TBI treatment guidelines and their implementation.<sup>420</sup> For example, only 56% of patients received a Glasgow Coma Scale examination and only 19.3% of patients received a CT scan in a study conducted in 2021.<sup>421</sup> However, the development of the German Trauma System has ensured expert hospitals for TBI patients to help reduce the prevalence of severe disability.<sup>422</sup> There were around 600 trauma centres in 2013 giving almost the whole of Germany access to a specialist trauma service.<sup>422</sup> There is a national trauma registry in Germany and dedicated guidelines, developed by the German Trauma Society.

In the UK, around 200,000 people are admitted to hospitals with TBIs every year. The incidence of death from TBIs is low, with as few as 0.2% of all patients attending emergency departments with a head injury dying as a result.<sup>423</sup> This is a great outcome, but it does leave many people with a disability or in need of rehabilitation. The NICE guidelines for the management of TBI guide clinical practice in the UK, and similar to SCI, major trauma centres exist in the UK that specialise in the treatment of injuries and follow a specific pathway of care.<sup>423, 424</sup> Rehabilitation is often the bottle-neck in the care pathway, which is poorly implemented post discharge, often leaving patients with no outpatient follow-up.<sup>425</sup>

The prevalence rate of TBI per 100,000 population in Italy is the third highest among the countries featured in this Findings Report (**Figure 58**).<sup>6</sup> There is a national association that provides assistance and rehabilitation to people suffering from TBI.<sup>426</sup> There is also a national registry for severe, acquired TBI, which aims to help with the evaluation and planning of rehabilitation pathways as well as assess disparities in care and rehabilitation.<sup>427</sup> Studies from Italy also report major criticisms of rehabilitation quality, such as delayed admissions and complications of TBIs (e.g., pressure sores) that are not dealt with effectively.

In Romania, the prevalence rate of TBI per 100,000 population is the highest of all the countries in this Findings Report; this finding is also supported by other studies (**Figure 58**). The death rate from TBI is largely due to road accidents, responsible for 92 deaths per one million citizens.<sup>428</sup> Romania also lacks neurologists who can help with memory recovery after injuries, and there are only a few centres which offer multi-disciplinary neuro-rehabilitation.<sup>185</sup> There is no reported national plan or registry for TBI in Romania either. There have been some achievements such as the set-up of the Society for the Study of Neuroprotection and Neuroplasticity (SSNN), created in 2005 with the aim to boost clinical research into neuro-protection and neuro-regeneration.<sup>429</sup>

## Sub-Saharan Africa and the Middle East

As previously mentioned, the rate of road traffic accidents leading to traumatic injuries and mortality is high in African countries such as Kenya.<sup>430</sup> Evidence-based guidelines for the management of TBI and a national registry do not exist, and the low prevalence of post-acute rehabilitation for injuries around the world is further exacerbated in Kenya.<sup>431</sup> The ratio of neurosurgeons to members of the population in Africa is as low as 1 per 10 million. This means there is considerable uncertainty around what actually happens to TBI patients who survive and are discharged from hospital. Often, the only option is for patients to be discharged home and rely on family members for care. This means the indirect costs associated with TBI are likely to be significant in Kenya, but difficult to quantify due to under-reporting. There is an urgent need to both prevent TBIs and establish rehabilitation services, and a clinical screening process, to identify specific cognitive impairments as early as possible.

Similar to Kenya, the status and prevalence of people with TBI is largely unclear in Lebanon. In a systematic review looking at the epidemiology and clinical characteristics of TBI in this country, services providing rehabilitation were rarely mentioned in the literature, as were mortality rates.<sup>432</sup> There is also no national data collection or surveillance of TBI in Lebanon.

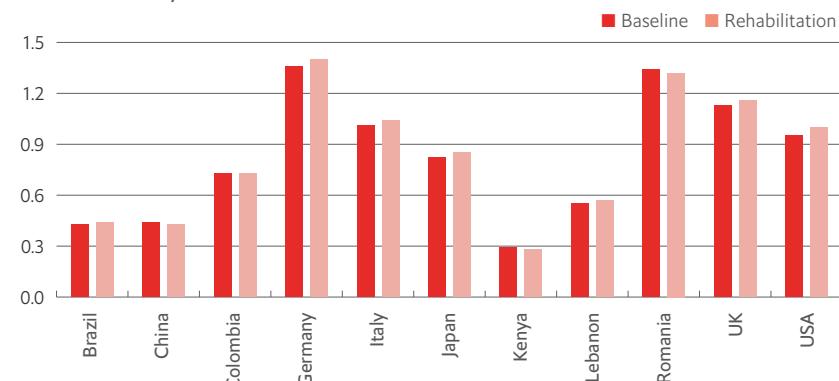
## Traumatic brain injury: the amenable burden

To analyse the cost of TBI, we looked at the impact of scaling up rehabilitation services to help people reintegrate into society and eventually RTW. Similar to the SCI cost analyses, we excluded a treatment scenario as inpatient care is too variable to accurately estimate and many of the treatment costs are already included in baseline care.

Figure 59

**Total cost of traumatic brain injury scenarios (2019)**

Percent of country GDP

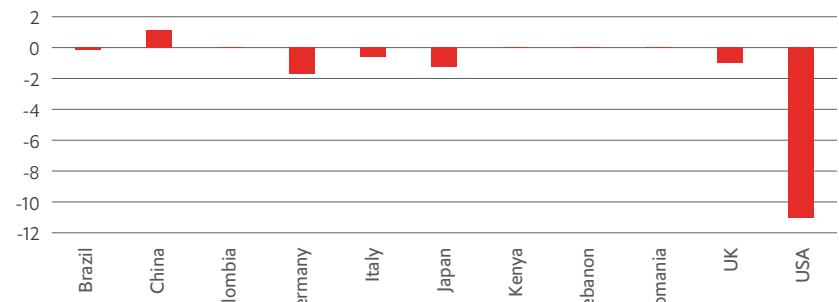


Source: Economist Impact analysis, 2022.

Figure 60

**Potential savings on total costs with implementation of traumatic brain injury scenarios (2019)**

Rehabilitation, US\$b

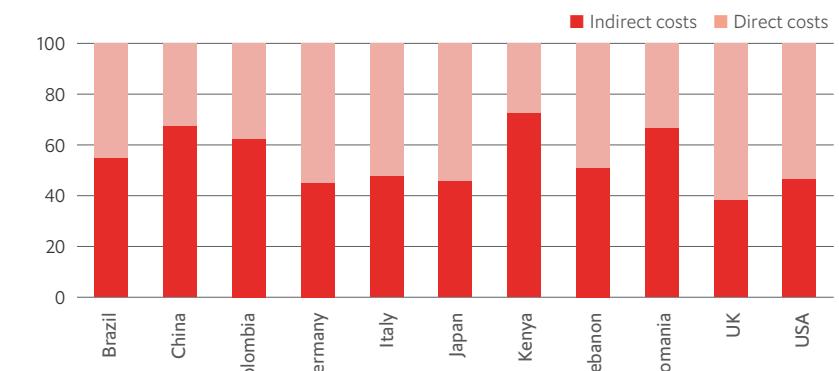


Source: Economist Impact analysis, 2022.

Figure 61

**Composition of traumatic brain injury costs at baseline (2019)**

Percent of total costs



Source: Economist Impact analysis, 2022.

**Figure 59**

shows that the total cost of the rehabilitation scenario was lower than baseline in China, Colombia, Kenya and Romania. **Figure 60** reiterates that the rehabilitation scenario yielded cost savings from baseline in the one-year time horizon in China and Romania. The magnitude of the savings possible from scaling up rehabilitation is further reflected in **Figure 61**, which shows that more than 40% of the total cost of TBI care at baseline is due to indirect costs in all countries except for the USA (38%). The indirect costs associated with TBIs are generally significant across all countries. This is because the average age at which people experience a TBI falls within the most productive period of an individual's life (between 20 and 50 years). Many of these indirect costs can be avoided if people with TBIs receive effective rehabilitation.

**Figure 62**

shows the savings possible as a percentage of country GDP if rehabilitation was scaled up. These savings are most pronounced in Romania and Germany, followed by Italy which are the three countries with the highest prevalence rate of TBI according to the GBD 2019 data (**Figure 58**).

**Figure 63** shows the difference in savings between the rehabilitation and baseline scenarios over time in the USA, and indicates the in comparison to baseline, rehabilitation can result in higher costs of around \$111bn by 2030. Despite seeing no savings on productivity losses in Brazil, China and Lebanon in **Figure 62**, **Figure 64** shows that over time savings for both direct and indirect costs combined accrue in all countries apart from the UK. These savings were most pronounced in Kenya and China.

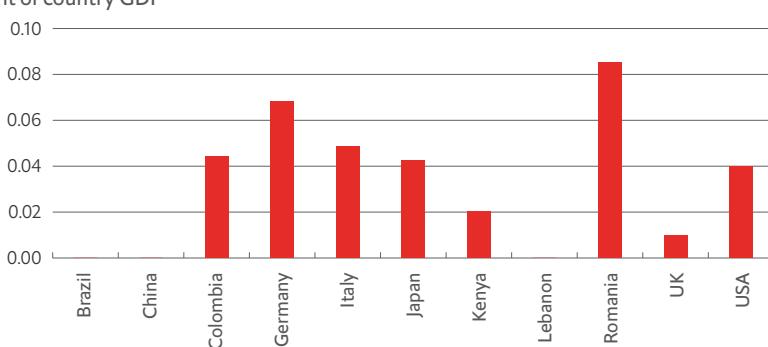
**Global opportunities for traumatic brain injury care**

For both injury categories, SCI and TBI, prevention is the biggest opportunity. All countries need to develop national strategies that address best practices in prevention. These policies could be targeted at reducing road traffic accidents and maintaining roads, falls-prevention strategies, reducing alcohol overuse, and improved access

Figure 62

**Potential savings on productivity losses with implementation of traumatic brain injury scenarios compared to baseline (2019)**

Percent of country GDP

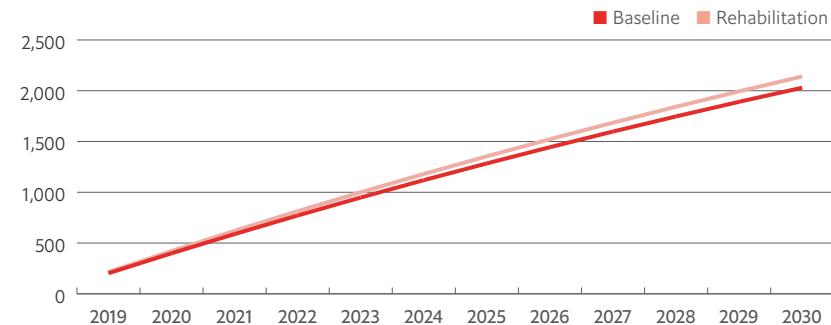


Source: Economist Impact analysis, 2022.

Figure 63

**Traumatic brain injury costs per scenario from 2019 to 2030 in the USA**

US\$bn

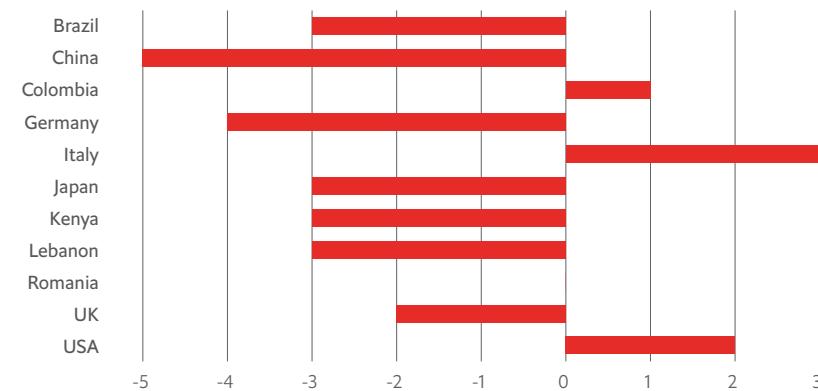


Source: Economist Impact analysis, 2022.

Figure 64

**Potential savings of costs for traumatic brain injury by type of model between 2019 and 2030**

Percent of baseline costs



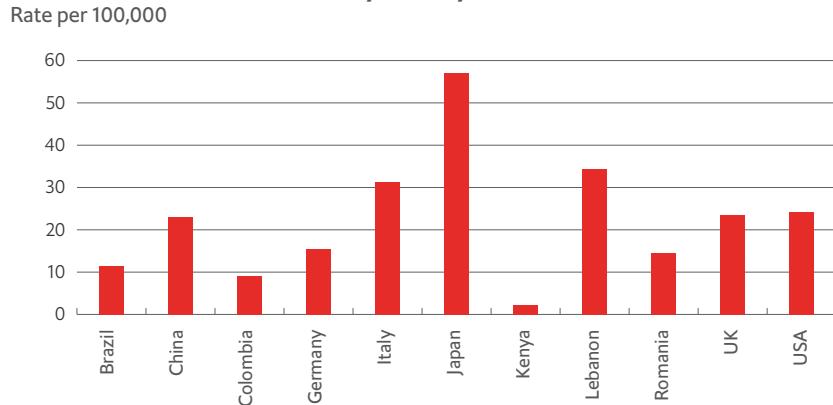
Source: Economist Impact analysis, 2022.

to medical and social care. Furthermore, comprehensive clinical guidelines need to be developed that are adaptable depending on resources available. In LMICs where access to scanning equipment is low or wholly unavailable, there are currently no alternative management guidelines for TBI. Some countries such as Germany and the UK have specialised trauma pathways and healthcare units dedicated to trauma, but such pathways need to be expanded in other countries along with specialised training in trauma. Epidemiological studies on TBI are also lacking, which is partly driven by the dearth of national registries.<sup>433</sup> Vocational rehabilitation, and rehabilitation services in general, need to be expanded as they are in short supply even in HICs.

## Brain and nervous system cancers

Brain and nervous system cancers are among the deadliest cancers.<sup>434</sup> The estimated 5-year survival rate stands at 32.6% according to the National Cancer Institute in the USA, and it is likely to be much lower in countries with limited access to healthcare. There are very few known risk factors for brain and nervous system cancers, meaning prevention strategies are difficult to determine. The survival rate has changed very little in a generation, and there is a significant need for developing better treatments. The field of neuro-oncology combines the skills of both oncologists and neurologists to treat brain and nervous system cancers.<sup>435</sup> It is a field that is fairly new, originally developing in the 1970s in the USA, followed by Europe.<sup>436</sup> The treatment and management of brain and nervous system cancers requires extensive resource allocation and sophisticated diagnostic and therapeutic technology. The treatments also vary depending on the type of cells affected, the grade of the cancer, and the size and location of the tumour.<sup>437</sup> The complexity of clinical management has led to the development of brain tumour centres (centres for neuro-oncology) in some countries, which are multi-disciplinary clinical and research entities capable of providing all aspects of care.<sup>438</sup>

Figure 65  
Prevalence rate of brain cancer by country (2019)



Source: IHME, 2019.

The most common type of brain cancer in adults is glioblastoma, which spreads quickly and is very challenging to treat.<sup>439</sup> Descriptions of global patterns and trends of brain and nervous system cancers are rare, but those that do exist report large variability in incidence rates.<sup>440</sup> In the Western world, the incidence of brain cancer has been rising largely due to improvements in diagnostic technology and increased availability of CT and MRI scanners.<sup>440</sup> Despite limited improvements in research and development, there is an association between the mortality to incidence ratio and levels of economic development, suggesting better access to early detection and treatment leads to improved outcomes.<sup>441</sup> **Figure 65** illustrates that the burden of brain and nervous system cancers is significantly higher in Japan when compared with Kenya, which has the least burden.<sup>6</sup> After Japan, Lebanon and Italy share a high burden of brain and nervous system cancers as well.

### The Americas

The USA's government has established a rare brain and spine tumour network to provide patients with access to better care.<sup>449</sup> This network is an information source for patients and caregivers, and funds clinical trials and other research initiatives. Health professionals have access to palliative care information and other support resources from the National Cancer Institute.<sup>450</sup> In 2010, the Congress of Neurological Surgeons established guidelines for treating adults with metastatic brain tumours which was updated in 2019.<sup>451</sup> National brain cancer non-profit organisations in the USA advocate for patients' rights, fund research, and increase public awareness of brain tumours.<sup>448, 452</sup> The USA does have a centralised brain tumour registry dedicated to the collection and dissemination of data on primary brain tumours.<sup>453</sup> Additionally, this database aims to broaden the scope of data collection on brain tumours in some populations. There are 71 federally funded cancer centres recognised by the National Cancer Institute, and most are comprehensive care centres.<sup>454</sup> These

treatment centres are distributed across the northeast, west and southern regions with few locations in the Midwest. Treatment for brain cancer can also be found at community-based or private medical institutions around the country as well.

Brazil does not have a national brain cancer registry, but there are some regional cancer registries.<sup>442</sup> There is no national plan specifically for brain cancer care in Brazil, but there is a national cancer control plan implemented through the Ministry of Health.<sup>443</sup> According to this plan, every cancer patient has the right to receive multi-disciplinary care at each step of treatment; however, due to the shortage of medical professionals, there might be discrepancies between the plan's recommendations and implementation on the ground. Northern Brazil, which has fewer specialist hospitals, is known for having longer inpatient stays and higher mortality rates from central nervous system tumours than the other four regions.<sup>444</sup> This is due in part to comparatively lower rates of surgical management of these tumours, lack of access to care, greater travel distances to healthcare, as well as fewer healthcare professionals and training facilities. A majority of surgical treatment for these types of cancer is concentrated in the southeast region of Brazil.<sup>444</sup> There are many private cancer treatment facilities, but there is no data on their distribution or whether they specialise in brain cancer care.

While Colombia has managed to achieve near-universal health care, problems remain with the accessibility to preventative, diagnostic and treatment services.<sup>445</sup> There is a dedicated National Cancer Control Plan in Colombia, which is funded by different sources.<sup>446</sup> There are also four regional population-based registries in Colombia, but these cover all cancers rather than being specific to brain cancers.<sup>447</sup> These registries also only include data from mainly urban areas, capturing just 10% of the population. There is a comprehensive brain cancer treatment hospital in Colombia located in Medellín and another cancer institute in the capital

city of Bogotá (but it is unclear if this institute also provides brain cancer treatment). There is limited data on the location and distribution of brain cancer treatment centres in the country. Colombia does have several non-profit organisations that provide social and financial support, education, and advocacy for cancer patients.<sup>448</sup>

## Asia

The Japan Society for Neuro-Oncology developed treatment guidelines for three types of brain tumours (glioblastoma, primary central nervous system lymphoma and brain metastasis) because of the complexity of therapies and outcomes.<sup>455</sup> These guidelines have helped highlight gaps in evidence and reduce variability in care. Japanese clinicians also adhere to the USA's National Comprehensive Cancer Network treatment guidelines.<sup>456</sup> Japan's Cancer Registry Act requires all hospitals in the country to submit basic data pertaining to new cancer patients to the national cancer registry, which includes a separate registry for brain tumours.<sup>457</sup> Hospital-based registries also function in larger cancer care hospitals; these complement national registries by collecting more detailed clinical data. Japan has many cancer treatment facilities, but data are unclear on whether there are brain cancer-specific hospitals in the country.<sup>458, 459</sup>

China has a national brain tumour registry which facilitates data sharing between different hospitals in multiple regions in China and allows for multi-centre research.<sup>460</sup> This registry includes 54 national and regional neurosurgery centres located in 27 different Chinese municipalities/provinces.<sup>460, 461</sup> More detailed information on brain cancer treatment centres is not available. China has a clinical practice guideline that highlights diagnostic and disease management recommendations.<sup>323</sup>

## Europe

The European Association of Neuro-Oncology began as a European initiative, but is now an international collaboration with several partner societies aiming to promote advances in neuro-oncology through innovative research and concerted education and training.<sup>462</sup> This organisation provides multi-disciplinary guidelines to support the development of high quality care of patients with central nervous system cancers across Europe.

Germany has a dedicated National Cancer Control Plan, launched in 2008, which includes palliative care guidelines, patient-centred care, and specific targets and indicators for care.<sup>463</sup> There is also a national cancer registry in Germany, but not a specific registry for brain tumours. The German Centre for Cancer Registry Data (ZfKD) is located within the Robert Koch Institute in Berlin.<sup>464</sup> It is responsible for pooling and assessing the quality of data it receives from the population-based cancer registries in each German federal state.

In the UK, the National Cancer Research Institute (NCRI) was established in 2001 to ensure collaboration and coordination amongst cancer research funders in order to maximise the value and benefits of cancer research for patients and the public.<sup>271</sup> Within the NCRI, clinical studies groups (CSGs) were established across the major cancer sites to provide a forum for stakeholders to develop trials and build a strategic portfolio within their areas of expertise. There is a CSG dedicated to brain tumours.<sup>465</sup> There is a national cancer registry in the UK, but there is no registry specific to brain tumours.<sup>466</sup> There were also nine centres across the UK that have been awarded “centre of excellence” status.<sup>467</sup> In the UK, NICE has specific guidelines for brain and nervous system cancers.<sup>468</sup>

In 2016, under the EU’s Cancer Control Joint Action (Cancon), Romania launched the National Cancer Control Plan at a conference held in Bucharest.<sup>468</sup> According to the Prime Minister’s declarations at the event, the plan would be an “integrated” and “multi-annual” one.<sup>470</sup> The press release from the

Ministry of Health at the time mentioned that the scope of the plan would be: promoting preventive behaviour, screening programmes for breast and colorectal cancer, measures to ensure and control the quality of diagnosis and treatment, rehabilitation and reintegration measures for cancer patients, and also research projects in oncology. The plan was announced to be adopted by June 2016. At present, there is no public document describing in detail the plan launched in 2016. The National Cancer Control Plan is mentioned in the National Health Strategy 2014-2020 as some of the strategic objectives are correlated with Romania’s National Cancer Control Plan: establishing disease registries, primary prevention of NCDs and secondary cancer prevention, treatment provided by the national oncology programme, palliative services, and radiotherapy services.<sup>471</sup> By law, there are eight regional registries, with eight local institutes or hospitals that are in charge with implementing the registries and monitoring the quality of the cancer data collected.

In Italy, there is a Centre for Neuro-Oncology located in Turin.<sup>436</sup> About 30% of patients are referred to this centre from other Italian regions.<sup>436</sup> The Centre for Neuro-Oncology is also a referral centre for rare brain tumours within the Italian Network of Rare Cancers. The Turin centre is hosted by the Division of Neuro-Oncology/Neurology, which acts as the coordinator of the Multi-disciplinary Brain Tumour Board (MTB) in Italy, to provide continuity of care (diagnosis, specific treatments, supportive and palliative care) for primary and secondary brain tumours. There are six other hospitals with neurosurgery and oncology facilities in Italy for patients requiring standard treatments, but they are all referred to the specialist centre in Turin for complex treatments. The Centre for Neuro-Oncology produces its own guidelines for all major tumour types, which are also shared at the regional level and updated every two years.<sup>436</sup> The Italian Association for Neuro-Oncology also set up a specific registry for collecting data on patients with glioblastomas.

## **Sub-Saharan Africa and the Middle East**

Cancer registration faces multiple obstacles in LMICs, including low resource allocation, inadequate health informatics infrastructure, lack of death records, inaccurate data, cultural taboos, and conflict-induced population mobility and instability.<sup>472</sup> Importantly, according to the International Agency for Research on Cancer (IARC), population-based cancer registries in LMICs have been developing at a much slower pace than those in HICs because of under-investment and a resulting lack of human resources, despite considerable awareness of their importance.<sup>472</sup> There is a national cancer registry in Lebanon, but no cancer control plan.<sup>473</sup> The Lebanese Cancer Society was established in 1954, and is one of the largest voluntary, non-governmental health organisations in Lebanon.<sup>474</sup>

In Kenya, there is a national cancer control strategy.<sup>475</sup> With 36% of the population living below the international poverty line of \$1.90 per day, access to affordable cancer testing and treatment remain out of reach for the majority of the population.<sup>476</sup> The Cancer Act of 2012 (amended in 2015) provides the legislative framework for the decentralisation of health services, including cancer testing and treatment in the country.<sup>283</sup> Together with the National Cancer Control Strategy: 2017–2022, the policies address current gaps in the concentration of cancer services in Nairobi and major towns (Mombasa, Kisumu and Eldoret) and the need for a national cancer registry. However, the establishment of county-level cancer diagnosis and treatment facilities as part of these policies should include county-level cancer registries to complement existing data.<sup>283</sup> These registries can respond to the current gaps in Kenya's cancer incidence and mortality data.

Cancer registries are needed to provide data that would enable the country to support its cancer surveillance and plan for adequate resources to improve access to timely cancer diagnosis and

treatment. The NCCS 2017–2022 plan aims to improve national cancer surveillance through the establishment of the Nairobi Cancer Registry, training healthcare personnel, quality assurance measurement and electronic data collection.<sup>283</sup> However, this requires establishing hospital-based cancer registries in each county to feed into the National Cancer Registry. To respond to these needs, the current policies can be amended to designate a portion of the budget allocated to cancer services to be applied to the establishment and management of county-level cancer registries as part of the national cancer registry.

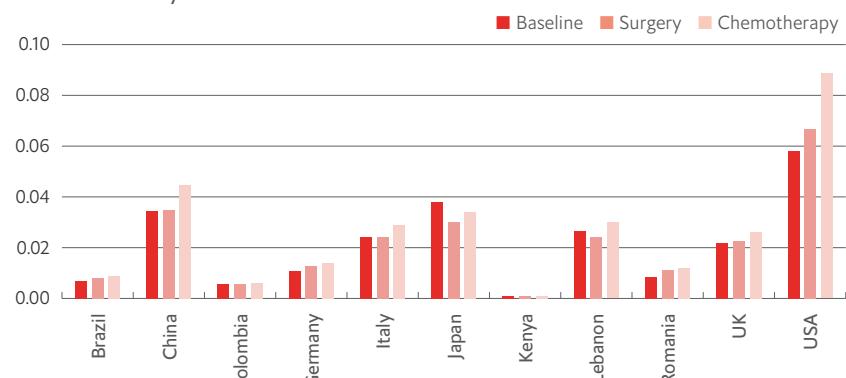
## **Brain and nervous system cancers: the amenable burden**

In our brain and nervous system cancer cost analyses, we considered the impact of surgery and chemotherapy separately. Due to the complexity of treatments for this cancer, the evidence base did not provide sufficient clarity on the effectiveness of a treatment scenario that included surgery and chemotherapy together, so we did not include this in our analyses. For low grade glioma, surgery is typically the only treatment needed. In some cases, low grade glioma and, more often than not, high grade glioma are also treated with radiation therapy and chemotherapy after surgery.<sup>477</sup> Therefore, since we know that at some point in the patient's treatment cycle they will receive both surgery and chemotherapy, the results of this analysis for both scenarios should be interpreted as a range. Rehabilitation is not supported by a significant evidence base, and was therefore omitted. In the surgery scenario, brain cancer mortality was reduced by 30% (in the one-year time horizon). This figure is based on literature which finds that tumour re-section can improve median survival by 30% for patients with grade IV gliomas.<sup>478</sup> To make this figure realistic for low grade gliomas, we further reduced mortality by 50%. In the chemotherapy scenario, the brain cancer mortality was reduced by 16.3% for all patients.<sup>479</sup>

Figure 66

**Total cost of brain cancer scenarios (2019)**

Percent of country GDP

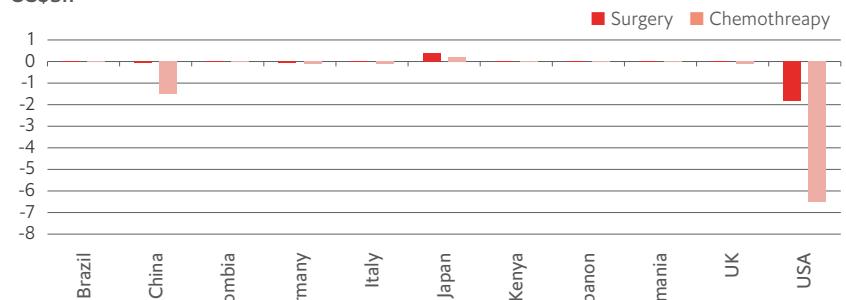


Source: Economist Impact analysis, 2022.

Figure 67

**Potential savings on total costs with implementation of brain cancer scenarios compared to baseline (2019)**

US\$bn

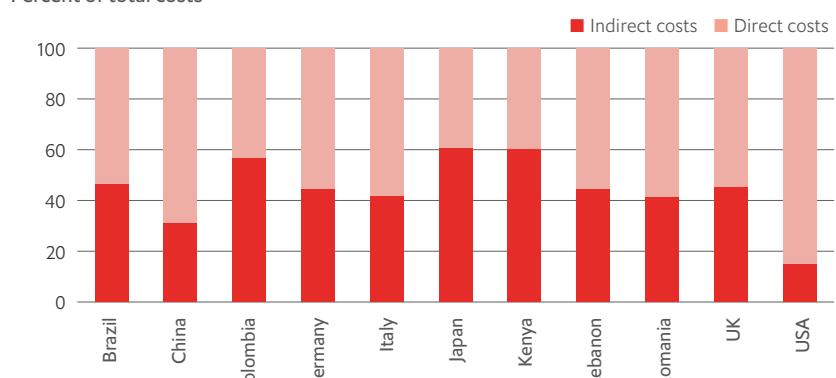


Source: Economist Impact analysis, 2022.

Figure 68

**Composition of brain cancer costs at baseline (2019)**

Percent of total costs



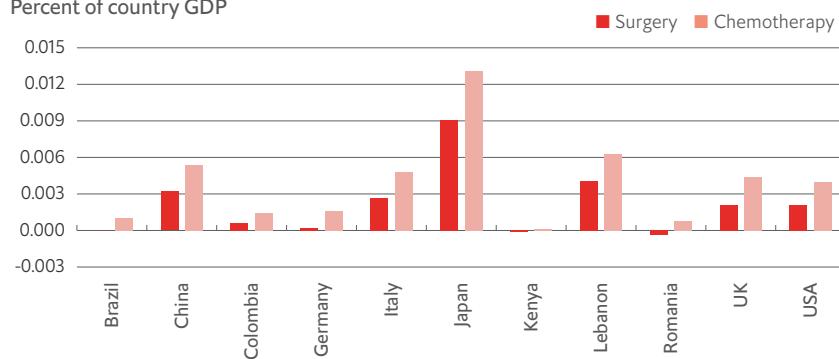
Source: Economist Impact analysis, 2022.

We increased the cost of care from baseline with the inclusion of chemotherapy and surgery by 61% and 5.7%, respectively.<sup>480</sup> Surgery eliminated seizures in at least 43% of patients with low grade glioma and glioneuronal tumours.<sup>481</sup> We assumed that the reduction in seizures might enable people to work and reduce absenteeism by 43%. Chemotherapy reduced seizure frequency by 59% in patients with low grade glioma, which also impacts caregiver burden. This study explicitly states that the patients had not received surgery.<sup>482</sup> We therefore assumed that informal caregiver burden would decrease by 59%.

Surgery may enable an RTW rate of 52% in the year following diagnosis (for stages I and II).<sup>483</sup> Surgery and adjuvant treatment (chemotherapy and radiotherapy) may enable an RTW rate of 70.7% for stage II and III gliomas.<sup>484</sup> We were not able to remove the effect of radiotherapy from this scenario. For metastatic and terminal gliomas, we assumed no RTW as no one would be employed. We assumed, however, there would be an impact on caregivers.

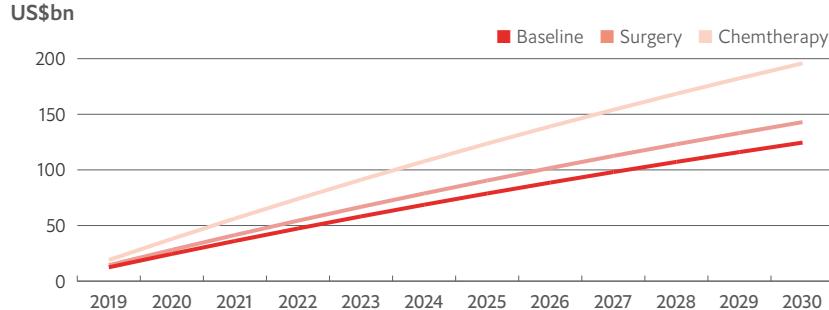
In **Figure 66**, the total cost of the baseline scenario was lowest in all countries except Japan. The total cost of the surgery scenario was lower than the cost of chemotherapy, although chemotherapy resulted in the highest health-related quality of life (DALYs averted) in all countries except Lebanon. Despite **Figure 66** showing baseline as the lowest proportion of GDP as compared with the other treatment scenarios, **Figure 67** demonstrates cost savings from baseline in Japan, with surgery yielding greater cost savings from baseline as compared with chemotherapy in the one-year time horizon. Brain and nervous system cancers have a significant impact on productivity for both patients and informal caregivers, thus savings may be particularly pronounced for Japan given its high prevalence of brain cancer. **Figure 68** shows that indirect costs were responsible for more than 40% of the total cost of brain cancer at baseline in all countries except the USA (15%) and China (31%).

**Figure 69**  
**Potential savings on productivity losses with implementation of brain cancer scenarios compared to baseline (2019)**



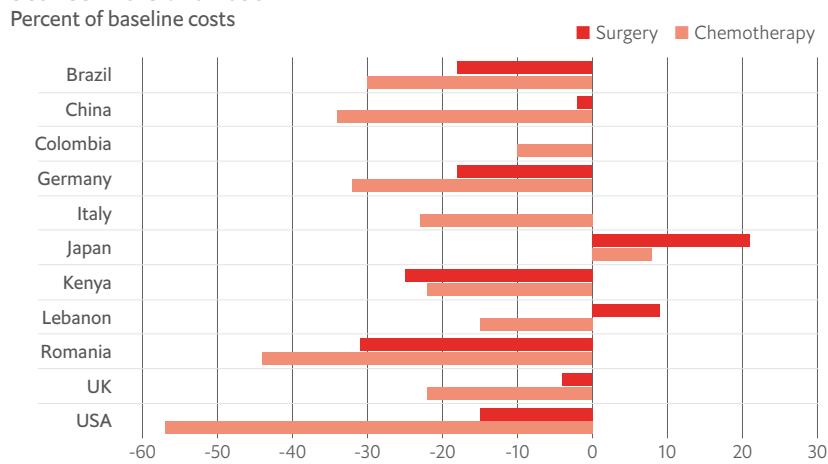
Source: Economist Impact analysis, 2022.

**Figure 70**  
**Brain cancer costs per scenario from 2019 to 2030 in the USA**



Source: Economist Impact analysis, 2022.

**Figure 71**  
**Potential savings of costs for brain cancer by type of model between 2019 and 2030**



Source: Economist Impact analysis, 2022.

**Figure 69** illustrates the scenario impacts on productivity for both patients and informal caregivers. In all countries, chemotherapy averted more productivity loss as compared to the surgery scenario. **Figure 70** shows that over time, the chemotherapy and surgery scenarios do result in an increase in costs compared to baseline. This increase is equivalent to \$71bn for chemotherapy and \$18bn for surgery by 2030. Brain cancer treatments are expensive, but they have positive effects on indirect costs for all countries included in our analysis.

**Figure 71** illustrates that negative savings accrued for chemotherapy in all countries apart from Japan, which had a cost savings rate of 8% beyond 2019. Similarly, there are negative savings for the surgery scenario from baseline in all countries apart from Lebanon and Japan, which displayed positive savings of 9% and 21%, respectively.

### Global opportunities for brain and nervous system cancer care

Brain tumours, while being less prevalent compared to the other major neurological disorders (stroke, dementia, MS, epilepsy), represent the second biggest cause of costs (estimated around €21,000 per person per year) following only MS. Major health costs are due to neuroimaging investigations, neurosurgical techniques, radiation facilities, antineoplastic drugs, repeated hospitalisation for complications, and end-of-life care. Social costs are extremely important as well; due to physical and cognitive impairment of patients, there is often a reduction of working capabilities and a need for continuous assistance involving family caregivers and social assistants.

# Part 3: The value of action: where lies the biggest opportunity?

Neurological disorders are the largest contributors to DALYs worldwide, with stroke, Alzheimer's disease and other dementias, and migraines consistently ranked as the top three. Globally, neurological disorders are also the second largest contributor to mortality.<sup>6</sup> The burden of neurological disorders is projected to increase, particularly in LMICs, due to population growth and ageing.<sup>488</sup> As this occurs, increased demand will be placed on already overstretched resources and services. Therefore, there is an urgent need to improve prevention and management of neurological disorders across the globe.<sup>6</sup>

Based on the findings of our cost analyses, it is clear that neurological disorders lead to a significant burden on society. This is visible through both direct costs to patients and health systems, as well as the indirect costs accrued from patients' presenteeism and absenteeism at work and the burden on caregivers.

Addressing the needs of people with neurological disorders, and their caregivers, begins with increasing understanding and awareness, but also addressing stigma and discrimination which act as barriers to seeking care. For instance women are the majority of patients for some neurological disorders (i.e. migraine, Alzheimer's disease) yet minimal research is available that explore potential sex and gender differences in terms of presentation, progression and outcomes.<sup>6</sup> The prevention of neurological disorders rests upon the promotion and development of optimal

brain health across the life course. Investments in neurology should therefore always include solutions that enable resource mobilisation, strategies and approaches to increase investment into early interventions and diagnostic methods, as well as training of specialists and non-specialists.

## Opportunities by type of disorder

### Stroke

- A large proportion of strokes are preventable, which means the physical and financial burden on the individuals and society can be avoided. Public knowledge about the risk factors for stroke are however variable. Health literacy can be improved in LMICs and also among some marginalised populations within HICs.
- Access to rehabilitation services for people with a stroke-related disability are under-resourced in most countries. Scaling up rehabilitation is a key cost-saving opportunity as it reduces the likelihood of early retirement post-stroke and enables greater participation in the workforce.

### Alzheimer's disease

- Government social care support systems need rapid innovation in order to cope with the always expanding number of people diagnosed with dementia.

- Among ongoing clinical developments, it is hoped that DMTs will show more pronounced effects on quality of life for individuals with dementia and the caregivers in clinical trials.
- Although treatments largely do not currently slow progression of dementia, they can help control symptoms, which has a significant impact on carer burden and can reduce productivity losses – and costs – to society.
- LMICs need more robust data collection systems and national dementia plans that may help justify improving the dementia research agenda.

### **Multiple sclerosis**

- National registries and strategies for MS require global improvement to help accurately estimate the prevalence of MS. Continuous data monitoring can bolster research initiatives, which may further help produce lower-cost treatments for MS
- Many people with MS experience significant delays between onset of symptoms, diagnosis and treatment across both HICs and LMICs. Improved access to CT and MRI scans, as well as training programmes is greatly needed. In countries with a large landmass and long distances to travel to specialist centres (China, the USA and Brazil), telemedicine should be utilised to improve access to neurologists.

Progress has been made towards lowering the costs of MS treatments and there are now generic MS treatments available. Despite this, the costs of other non-patented DMTs have almost tripled in the current decade. More avenues for equitable access, particularly for vulnerable populations, need to be considered.

### **Migraine**

- Migraine needs to be made a research priority in LMICs to improve data collection and reporting of the disorder. This may help increase awareness and understanding of the prevalence of migraine in LMICs, resulting in more accessible care.

- National strategies, policies and disease registries for migraine were lacking in many countries, indicating that it is often a low national priority. There needs to be more specialised training, monitoring, and migraine research to increase health capacity for migraine treatment, and improve quality of care.
- Better integrated migraine care systems are needed to allow for timely treatment, which may have positive downstream impacts on productivity and quality of life for migraine patients.

### **Parkinson's disease**

- It is hoped that in the future, DMTs for Parkinson's will be able to slow the progression of disease and have a more pronounced impact on quality of life.
- While rehabilitation has a greater impact on productivity losses than treatment, levodopa is a fairly cheap drug. Therefore, in the absence of rehabilitation facilities in many countries, there is a huge opportunity to improve access to levodopa in resource-poor or developing healthcare systems.
- Telemedicine may provide an encouraging alternative to the issue of neurologist shortages, by providing remote assessments and prescription of treatment. Like telemedicine, the use of novel digital technologies is ripe for growth in terms of Parkinson's disease. As such, future research needs to help establish the impact of remote monitoring and technologies on prevention, diagnosis, treatment and Parkinson's outcomes.
- Many countries need improvements in integrated care for Parkinson's and access to specialist neurologists and rehabilitation. Such improvements can help facilitate timely access to diagnosis and treatment through collaborative, accessible care. Further benefits in terms of reduced productivity losses and improved quality of life may result from timely to timely care.

- In resource-poor settings, support from international aid is desperately needed to provide diagnosis and treatment. At the very least, specialist geriatric assessment should be provided when international neurology support is infeasible.

### **Spinal muscular atrophy**

- Improving accessibility and equity in screening and treatment for SMA is the most obvious opportunity, which we show can have significant benefits to the carer as well as the individual.
- National strategies, policies and disease registries for SMA were lacking in a majority of countries, making it difficult to prioritise this disease above other neurological disorders. There needs to be better data collection of SMA and if this is not possible in a SMA specific registry, it should be better incorporated into rare disease registries.
- Despite the scarcity of treatment options, Kenya and Lebanon present a unique global opportunity to be innovative research platforms for the rest of the world because of the genetic determinants affecting SMA presentation. Funding donors could help initiate these research initiatives, which may ultimately create a foundation for standards of care in these countries.

### **Epilepsy**

- Epilepsy has been globally recognised as a leverage point for the early detection of many other neurological disorders. Because of this, it should become a much higher global priority. As it stands now, all countries experience an ‘epilepsy gap’ whereby many people go without care due to a combination of stigma surrounding the disease and a lack of specialists.
- The price of epilepsy drugs requires better regulation, especially in LMICs to improve access. This is pertinent given they are an effective solution in all countries.
- Prevention of epilepsy is possible by reducing risk factors and enabling better access to healthcare,

mainly in LMICs, but on a global scale.

- Better epilepsy research is needed to increase awareness, reduce misdiagnosis and stigma, and improve innovation in care. This research agenda should be integrated within the holistic neurology agenda to aid early detection and treatment across a range of disorders, a partnership which may help attract funding.

### **Spinal cord and traumatic brain injuries**

- Prevention of injuries, both SCI and TBI, lies with the management of clearly defined risk factors. These include road safety measures, road maintenance, falls-prevention strategies, reducing alcohol overuse, and improved access to medical and social care
- Aside from the specialised trauma networks that exist in the UK and Germany, national strategies and policies, as well as the monitoring of injuries cases are one of the least served disease areas across neurological practice. Despite their high prevalence, injuries seem to be treated as an acute, unavoidable consequence of life, rather than a preventable and amenable disorder
- Vocational rehabilitation has significant outcomes for improving workforce participation for those who have sustained injuries, and proven cost savings in all countries. Vocational rehabilitation is however in short supply in HICs, and almost non-existent in LMICs.

### **Brain and nervous system cancers**

- More avenues for equitable access, particularly for vulnerable populations, need to be considered given the significant financial burden associated with brain tumours and treatment.
- Government social care support systems must be improved to keep up with the high social costs incurred from cancer treatments and their outcomes (i.e., long-term care, unemployment, etc.).

# Conclusion: opportunities to mitigate the global impact of neurological disorders

It is clear that the impact of neurological disorders looms large over advanced and emerging economies alike. However, encouragingly, this analysis shows that action, particularly over time, has immense value. Specifically, we have demonstrated that ensuring effective and timely diagnosis, treatment, rehabilitative and supportive care often means that value can be maximised. While these investments can reduce the impact of productivity losses on carers, people with neurological disorders may still face upstream policy-related barriers to re-entering the workforce. Neurological disorders must be made a national priority, through both policies and economic prioritisation, to yield the greatest benefits for both those directly affected and wider society.

When we think about the impact of preventing and managing neurological disorders at the global

level, there is an opportunity to chart the path towards reducing early mortality, disability and improving quality of life more generally. Our model shows that this has important knock-on effects, such as the impact on the families of patients, their carers, employers, etc. This may be a challenging feat to accomplish, particularly for resource-poor countries, but there is hope. Our global analysis highlights both gaps and areas of strength from which countries can learn. Furthermore, a foundational understanding of the significant need in many countries acts as a call to action for global leaders to provide international aid where possible.

Moving forward, this analysis is designed to serve not only as a platform for understanding the problem, but as an avenue for the urgent action that is needed to achieve health and economic goals more widely.

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