

# RETHINKING MS IN ROMANIA

A policy brief



# ACKNOWLEDGEMENTS

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## **About RETHINKING MS**

RETHINKING MS is a research-driven project which offers tangible policy changes to improve the lives of people living with MS across Europe, building on the 2017 Value of Treatment report from the European Brain Council. The RETHINKING MS series includes *RETHINKING MS in Europe* – a policy report providing an analysis of unmet MS care and support needs across Europe, and practical and sustainable policy recommendations – and a series of reports providing an in-depth analysis of policy, care and support available for people with MS in Denmark, Italy, Romania and Spain.

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## **About the European Brain Council**

The European Brain Council (EBC) is a non-profit organisation that aims to improve the lives of those living with brain disorders by advancing the understanding of the healthy and diseased brain through bringing together science and society.

## **About The Health Policy Partnership**

The Health Policy Partnership (HPP) is an independent research consultancy, working with partners across the health spectrum to drive the policy and system changes that will improve people's health.

For more information on RETHINKING MS, please visit:

**[www.braincouncil.eu/RethinkingMS](http://www.braincouncil.eu/RethinkingMS)**



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**Multiple sclerosis (MS) is a complex and progressive disease of the central nervous system,** where the immune system destroys brain, optic nerve and spinal cord tissue.<sup>1-3</sup>

## What is happening in Romania?

There are an estimated 9,000 people with MS in Romania <sup>4</sup>
Prevalence of MS is 34.8 per 100,000 <sup>4</sup>
Average age at diagnosis ranges from 33–35 <sup>5 6</sup>
Approximately 70% of the MS population are women <sup>7</sup>

## What are the costs of MS in Romania?<sup>8\*</sup>

	Total cost (RON)	Cost per person (RON)
Total direct costs	272 million	56,500
Total indirect costs	140.5 million	29,000
Lack of productivity due to disability	100 million	-
Disability pensions	14 million	-
Transport	13.5 million	-
<b>Total costs</b>	<b>412.5 million</b>	<b>85,500</b>

\*Average costs per year. Data were collected in 2016; costs were calculated in Romanian leu (RON). Costs per person vary considerably based on disease severity; only national-level estimations are made.

# WHAT IS MISSING FROM MS CARE IN ROMANIA?

To better understand unmet needs in Romania, interviews were conducted with experts in MS and an interdisciplinary round table was organised. In order to improve MS care, experts recommended that Romanian policymakers and decision-makers should look to:

- establish a national MS registry with mandatory data submission
- increase the number of MS treatment and neurorehabilitation centres
- improve access to disease-modifying and symptomatic therapies, and educational activities for people with MS.





# COUNTRY CONTEXT

**Political and economic instability are major challenges for the Romanian healthcare system.**<sup>8,9</sup> Despite improvements to many health indicators in recent years, life expectancy at birth remains among the lowest in Europe.<sup>9</sup> High turnover of policymakers and decision-makers in the Ministry of Health results in inconsistent policy implementation, limited funding, and challenges to long-term planning and priority-setting.<sup>9-11</sup> There is a greater emphasis placed on acute care rather than chronic or long-term care.<sup>11</sup> Noted areas for future development are patient safety, accessibility and quality of care.<sup>11,12</sup>

**The Social Health Insurance system provides healthcare to the majority of Romanians, but out-of-pocket payments are frequent.** Healthcare spending accounts for 4.9% of GDP,<sup>13</sup> which is lower than the Organisation for Economic Co-operation and Development (OECD) average<sup>14</sup> and lowest in the European Union.<sup>13</sup> Approximately 85% of Romanians receive a comprehensive package of healthcare as part of the Social Health Insurance system.<sup>8,15</sup> However, as public sources account for approximately 80% of health financing, many people face significant out-of-pocket costs and informal payments to receive the care they need.<sup>9,10</sup> Evidence of people's ability to pay such costs is limited.<sup>12</sup>

**There are geographic and socioeconomic inequalities in access to healthcare across Romania.** Many services are concentrated in metropolitan areas, resulting in unequal access to adequate healthcare based on location and socioeconomic status.<sup>7-9</sup> There are regional shortages of healthcare workers and facilities;<sup>10</sup> for example, an estimated 90% of hospitals are in urban areas, and private hospitals are predominantly found in large cities.<sup>9</sup> The number of physicians and nurses is also lower than in other countries in the European Union, and they are unevenly distributed across Romania.<sup>7,8,11</sup> As a result, many people must travel significant distances to see healthcare professionals. Inequalities in access to healthcare are reinforced by poor transport infrastructure, and the significant time and costs associated with travel.<sup>9</sup> This leaves vulnerable and rural populations most at risk of poor access to care.<sup>10</sup>

**Decentralisation efforts are underway but may be hindered by limited infrastructure and resourcing.** There is currently limited use of outpatient, community and primary care.<sup>8,16</sup> Accordingly, primary, community and preventive care is often under-resourced and under-prioritised.<sup>8,11,16</sup> Recent government strategies have aimed to strengthen the role of primary and community care and address this imbalance,<sup>8,11,16</sup> but these policies are slow to take effect<sup>10</sup> and the infrastructure and resources may not be fully prepared for a shift towards primary and community care.<sup>8,15</sup> For example, between 2009 and 2017, the average number of medical consultations with family doctors increased by more than 50%, but the number of family doctors has not increased in parallel and it is estimated that 1 in 4 Romanians will not have access to a family doctor by 2022.<sup>17</sup>



**Pricing and access to medicines are highly politicised issues.** Romania uses an external reference pricing model for medicines.<sup>15</sup> Once prices have been approved, the National Health Insurance House and Ministry of Health develop their reimbursement strategies for use within the social insurance healthcare system.<sup>15</sup> This method has led to some of the cheapest medicines in the EU.<sup>15</sup> However, it has also led to parallel trade.

**The Romanian healthcare system faces significant challenges to its sustainability.** Demographic change driven by high levels of emigration and a low birth rate means that the population is ageing quicker than in other European countries.<sup>10</sup> Such changes will increase pressures on the healthcare system and require significant investment in preventive services, improved management of chronic diseases and greater integration of health and social care systems.<sup>10</sup> To date, health reforms have focused on cost-saving measures and improving access and efficiency of healthcare systems;<sup>9 10</sup> however, implementation will continue to be a challenge.





# MS POLICY LANDSCAPE

**The national plan for neurological disorders clarifies ambitions for care across Romania, but implementation is challenging.** Such nationwide strategies are considered helpful, particularly in light of significant political instability within the Ministry of Health.<sup>18</sup> However, economic constraints are a major barrier to full implementation of such plans and strategies.<sup>19</sup> Furthermore, there seems to be limited integration of different health strategies and an overarching lack of strategic vision for neurological conditions and chronic or non-communicable diseases more generally.

**Publicly available health data are extremely limited.** Many health data sets are collected by the Ministry of Health, National Health Insurance House, National Institute for Statistics and other organisations.<sup>10</sup> However, these various data collection efforts are very fragmented, may be duplicative and are not all publicly available, limiting the use of such data in decision-making.<sup>10</sup> Inadequate IT infrastructure is a noted barrier to integration of data collection systems.<sup>11</sup>

These issues are amplified in MS, and recent epidemiological data on MS in Romania are scarce.<sup>7 20-22</sup> A national MS registry was established in 2013 by the Romanian Society of Neurology,<sup>18</sup> but it is voluntary and there are many gaps in data. The Romanian Society of Neurology is looking to enhance the registry and ensure comprehensive and consistent data collection from all MS centres via legislation.<sup>23</sup>

**People with MS must navigate multiple providers and systems across health and social care.** Such organisations include the Health System, National Health Insurance Fund, National Pension House Fund, National Authority of Disabled Persons, and National Authority for Medicines and Medical Devices.<sup>8</sup> However, there is very little integration and data sharing between these different actors,<sup>10</sup> and typically people with MS must manage their own care and navigate many public and private providers alone. As a result, people with MS do not have their care and support needs met.

**National and local MS patient organisations are trying to meet the many unmet needs of people with MS.** An estimated 70% of people with MS live in rural areas,<sup>19</sup> adding additional barriers to accessing adequately specialised health and social care. To support people with MS wherever they are, volunteer organisations have been developed to help people navigate the complex care systems and provide essential social, emotional and psychological support.<sup>24 25</sup> They also provide information and education including special programmes for children, young people and women with MS, alongside limited rehabilitation support and awareness campaigns.



## What policies exist for MS in Romania?

Inclusion of MS in the national non-communicable disease or chronic disease plan	No
Neurological disorders plan	Yes
Inclusion of MS in neurological disorders plan	Yes
National strategy on MS	No
National clinical guidelines	A number of guidelines exist for the treatment of MS that have been updated in recent years by the Romanian Society of Neurology <sup>18 26</sup>
National MS registry	A voluntary national registry organised by the Romanian Society of Neurology <sup>21 23</sup>



# ORGANISATION OF CARE

***‘Care for people with MS in Romania can be extremely complicated to navigate, as the basic needs such as information, access to treatments, services and support are not properly covered. We do not have interdisciplinary MS centres, and neurorehabilitation is almost non-existent. People with MS have to advocate for themselves and organise much of their own care.’***

*Cristina Vlădău, Association of Patients with Neurodegenerative Conditions (APAN)*

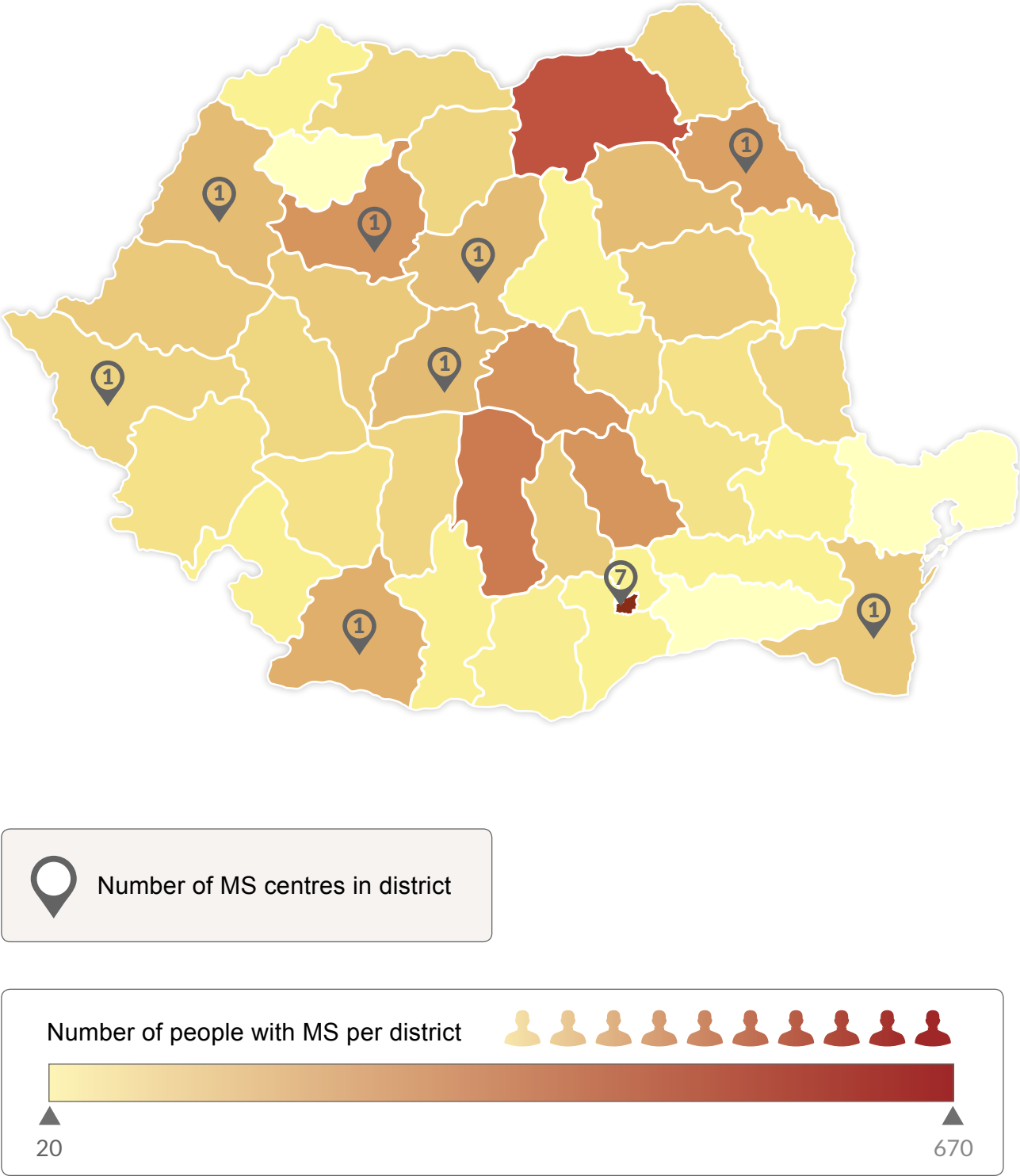
**MS management occurs in accredited MS centres located in hospital clinics, typically in large cities.** The Romanian National Programme for Treatment of Neurological Diseases delivers MS treatment across 15 MS centres.<sup>23 27 28</sup> A recent update of the accreditation criteria has been crucial in increasing access to MS care.<sup>23</sup> However, seven of these centres are located in Bucharest, and many people travel significant distances for adequate care.<sup>7</sup> One study estimated that, in 2016, people with MS in Romania travelled approximately 8.5 million kilometres as a result of medical visits.<sup>7</sup> The absence of financial and practical support to help with this travel means many people go without specialised care.<sup>29</sup> A significant priority in Romania is to extend the network of MS centres across the entire country and improve access.<sup>23</sup>

MS care is led by a neurologist, but access can be variable. Care is typically led by a neurologist in an MS centre; people with MS are able to choose any MS centre to receive treatment and can change at any time.<sup>23</sup> There is no official specialisation in MS neurology. Neurologists in Romania are often overstretched, with responsibility for managing a large number patients with different neurological conditions.<sup>23</sup>

**There is limited access to rehabilitation in Romania, and care is poorly integrated.** Rehabilitation for MS is not available in most of the 15 MS centres; accordingly, access is highly variable and waiting lists can be significant.<sup>23 29</sup> Rehabilitation services are often not well integrated into social and healthcare,<sup>8</sup> so needs are not effectively met and people may fall through the gaps.

**People face significant out-of-pocket costs to effectively manage their MS.** Romanian healthcare services prioritise inpatient and acute care, leading to significant gaps in financing of health and social care services in the community.<sup>8</sup> Many services, such as palliative care, are only accessible for inpatients,<sup>30</sup> and out-of-pocket payments are common.<sup>19</sup> Accessing financial support to help with these costs is challenging, and what funding is available is often not sufficient for people with MS.<sup>8 29</sup> For example, the recent introduction of free urban public transport for people with disabilities does not meet the needs of the many people with MS who travel between different cities to reach MS clinics.<sup>31</sup>

**Figure 1.** Distribution of people with MS and MS centres



Adapted from Association of Patients with Neurodegenerative Conditions, 2018<sup>4</sup>

## Timely diagnosis and personalised treatment

***‘A timely diagnosis is essential to starting treatment and delaying development of disability. The earlier treatment is started, the higher the chances of success. We need to better understand the drivers of delays and address them adequately.’***

*Professor Cristina Tiu, Carol Davila University of Medicine and Pharmacy*

**The diagnostic pathway seems clear, but there are limited data on why diagnosis may be delayed.** A general practitioner (GP) will refer a person with suspected MS to an ambulatory neurologist, who will subsequently refer them to an MS centre for diagnosis.<sup>23</sup> Upon presentations, neurologists follow diagnostic protocols described in the national guidelines.<sup>26</sup> However, access to primary care and neurologists varies significantly between urban and rural areas,<sup>29</sup> and there is limited information regarding the delays to diagnosis or referral.<sup>23</sup>

**Low budgets are a potential driver of diagnostic delays.** Monthly budget allocations for healthcare facilities mean there are a limited number of people who receive fully reimbursed medical tests each month.<sup>19</sup> Magnetic resonance imaging (MRI) is an essential diagnostic tool, but restricted budgets cap the number of MRI scans that can be performed in the public sector,<sup>19 23</sup> and there are a significantly lower number of MRI scans performed in Romania than most other European countries.<sup>32</sup> If a person with suspected MS is not referred for a free medical test by a specialist, they must either pay out-of-pocket for a private-sector appointment or wait for a later free appointment in the public system.<sup>7 19</sup>

**A lack of MS-specific resources and processes may hinder diagnosis.** The limited number of trained neuro-radiologists and the lack of dedicated MRI protocols are potential barriers to diagnosis.<sup>19 23</sup> There is also a lack of specialised tests for MS directly available in MS centres – for example, oligoclonal bands and antibodies.<sup>19</sup> An external laboratory is often used for such tests, increasing both cost and time to diagnosis.<sup>19</sup>

## Pharmacological management of MS

***‘Not all the therapies available for free in other European countries are available in Romania. We must change our policies to ensure equal access to life-changing MS treatment.’***

*Professor Cristina Tiu, Carol Davila University of Medicine and Pharmacy*

**Access to disease-modifying therapies (DMTs) is impeded by delays in approval and limited national budgets.** As part of the national treatment programme, the National Health Insurance House fully reimburses DMTs.<sup>8 29</sup> However, there are fewer DMTs available in Romania than in many other European countries, and there are long delays to reimbursement of new therapies.<sup>33</sup> To rectify this, patient groups are advocating for quicker approval processes, while there are currently five therapies under health technology assessment and negotiation processes.<sup>19</sup>

**Use of DMTs is limited and, despite efforts, many structural barriers remain.** Only 49% of eligible people are on DMTs.<sup>7 27</sup> Waiting lists for DMTs have recently been removed, and the average interval from diagnosis to treatment is now approximately one month.<sup>19</sup> However, if a person with MS is prescribed a DMT, they must visit the MS centre at least every three months for treatment, creating a financial and logistical burden.<sup>29</sup> People with high levels of disability may withdraw from treatment due to these barriers.<sup>19</sup>

**Access to symptomatic therapies is often based on the ability to pay.** Adequate symptom management can be hugely beneficial for people with MS<sup>34</sup> and there are many symptomatic therapies approved for people with MS in Romania.<sup>26</sup> However, symptomatic therapies often incur significant co-payments, and many people may go without treatment or face significant costs.<sup>7 8 19 29</sup>

### What pharmacological treatments are available in Romania?

Availability of symptomatic therapies	The guidelines outline the list of available symptomatic therapies. <sup>26</sup> In practice, however, few are fully reimbursed and access is limited
Availability of DMTs	Far fewer DMTs are approved than are available in other EU countries, but barriers to access are being reduced and the approval process is underway for five DMTs <sup>19</sup>
DMT reimbursement	100% <sup>35-37</sup>



## Interdisciplinary and coordinated care

***‘We need much better access to all of the specialists in MS care – too much is falling to neurologists and nurses right now. We urgently need to expand the MS care team.’***

*Associate Professor Carmen Adella Sirbu, Dr Carol Davila  
Central Military Emergency Hospital*

**Involvement of interdisciplinary roles is highly variable and depends on the scale and resources of the MS centre.** Most interdisciplinary teams are accessed only through inpatient care at MS centres. Typically, these teams comprise a neurologist and a nurse, with input from other specialists as required, but the involvement of certain specialists is highly variable:

- Access to bladder or pain specialists is very limited; they are typically available only in Bucharest.<sup>19 23 38</sup>
- The role of the pharmacist is relatively limited in Romania, and they are not frequently involved in patient care.<sup>23</sup>
- Access to social workers and other supportive roles is mostly via the General Directorate of Social Assistance and Child Protection; this may vary widely, however, based on geographical location.<sup>19</sup>
- Occupational therapy is extremely limited and palliative care is rare outside hospital settings.<sup>19</sup>

**Access to psychological support is a major unmet need.** One study found that 50% of people with MS in Romania have depression,<sup>39</sup> and one estimate of costs for depression and anxiety in all people with MS put the figure at 11.2 million RON.<sup>7</sup> Despite this, psychologists or neuropsychologists are not usually part of the interdisciplinary team, and accessing support is very difficult.<sup>7 19</sup> There is no reimbursement for such roles outside of the hospital setting, therefore people with MS must be able to pay for these services out-of-pocket.<sup>19 23</sup>

**MS nurses play a pivotal role in the MS care team.** Despite there being no formalised or mandatory specialisation in MS, highly experienced MS nurses work in each of the country’s 15 MS centres.<sup>19</sup> However, they have limited time for counselling, and predominantly provide hospital support including aspects of monitoring, follow-up and administrative and secretarial tasks.<sup>19 29</sup>

**Education around lifestyle changes is limited, and patient groups frequently provide this essential support.** There is very little education on brain-healthy lifestyles and secondary prevention for people with MS.<sup>29</sup> Medical appointments may be infrequent and too short to provide the adequate personalised education that is required.<sup>19</sup> Despite evidence of their importance, lifestyle factors associated with disease progression are often not addressed. For example, there are no specialist dietitians or support for lifestyle changes such as smoking specific to MS.<sup>19</sup> As a result, studies have seen a significant proportion of people with MS who smoke.<sup>38 40</sup> Patient associations and support groups often attempt to take on this important supportive role.<sup>19</sup>

**Most rehabilitation is not tailored to the needs of people with MS.** If the GP or neurologist refers a person with MS for rehabilitation, this is reimbursed by the healthcare system.<sup>23</sup> However, such services are limited to 21 general rehabilitation sessions per year,<sup>19</sup> which is insufficient and often based in centres that focus on post-acute rehabilitation such as cardiovascular disease, stroke or orthopaedic rehabilitation.<sup>19 29</sup> As such, the rehabilitation may not be personalised to the specific neurological needs of people with MS. Such physiotherapy is not fully reimbursed in the public healthcare system, and waiting times can be significant.<sup>19</sup> As a result, many people pay out-of-pocket for private physiotherapy and rehabilitation.

**Access to specialist rehabilitation will likely improve with new training initiatives.** There are currently no specialist neurorehabilitation centres in Romania<sup>19</sup> and no sub-specialty neuro-rehabilitation training.<sup>41</sup> However, the Romanian Society of Neurology and the Romanian Society of Neurorehabilitation have developed a training curriculum and certification for neurorehabilitation which aims to increase access to specialist rehabilitation for people with MS.<sup>18</sup> Experts estimate that more than 50 people will be trained in neurorehabilitation through this programme across the next five years.<sup>18</sup>

#### How many specialist interdisciplinary services for MS are available in Romania?

Number of interdisciplinary MS clinics	15 MS centres
Number of rehabilitation services	Rehabilitation is only available in some MS centres; there are no specialist neurorehabilitation centres in Romania
Number of neurologists and MS specialist neurologists	There is no official neurology specialisation in MS, <sup>23</sup> but each MS centre has a minimum of three neurologists experienced in MS <sup>42 43</sup>
Number of specialist nurses	There is no nationally recognised or accredited specialist training, but there are a minimum of two specialist nurses in each MS centre <sup>42</sup>

## Monitoring and long-term follow-up

***‘The Romanian healthcare system needs significant improvements for the ongoing care of patients with chronic conditions, taking into account the personalised and adaptable care required by people with MS.’***

*Professor Ovidiu-Alexandru Băjenaru, Carol Davila University of Medicine and Pharmacy; Romanian Society of Neurology*

**Neither chronic nor long-term care is prioritised in Romania,<sup>11</sup> meaning ongoing support for MS is limited.** Most MS centres are located in emergency care hospitals, so they are not adequately organised to provide quality long-term care and support for people with MS.<sup>23</sup> Furthermore, an underdeveloped and underfunded network of primary care practitioners and ambulatory care impedes follow-up in the community.<sup>11</sup> Of the estimated 7,500 people with MS in 2016, only around 5,000 accessed the public healthcare system in 2016.<sup>7</sup>

**Frequency of follow-up is highly variable.** Guidelines recommend that each person with MS should be seen at least twice a year,<sup>2 26 44</sup> but follow-up may occur every 1–3 months.<sup>19</sup> In reality, few people are monitored at this level in an MS centre,<sup>23</sup> and frequency is often dependent on the doctor or hospital organisation.<sup>19</sup> Many people are monitored by neurologists in the ambulatory care system, so it is difficult to fully assess the number of people with MS who are being followed-up according to guideline recommendations.<sup>23</sup> Experts believe the majority of people with MS have an annual evaluation in order to meet requirements for disability certification.<sup>19</sup>

**If a person with MS is not on DMTs, monitoring may be limited.** There is very little publicly available information regarding disease monitoring and healthcare use for people with MS who are not on DMTs. People with primary progressive MS frequently transition to the primary healthcare system and receive very limited support and input from a neurologist,<sup>19</sup> despite needing higher levels of specialised care.<sup>29</sup> Given the underdevelopment of the primary care system, the quality of the care received may be highly variable. As there is no specialised training on MS for GPs,<sup>23</sup> knowledge and awareness of how to manage the condition may be very limited.





## Adaptable support for daily life

***‘We need more support for people with MS and their families. Currently provision of support really is not suitable to our needs, and all the burden is placed on our family and carers. A one-size-fits-all approach to social care simply does not work.’***  
***Cristina Vlădău, APAN***

**Social support is essential but can be difficult to access and subject to regional variations.** One study found that people with MS in Romania felt that they had lost significant quality of life and wellbeing due to their MS, and 48% of participants described lack of functional independence.<sup>45</sup> In Romania, MS is considered a disabling disease<sup>46</sup> and eligible people with MS may be entitled to:<sup>8 47</sup>

- financial support in the form of cash allowances, including monthly allowances, and monthly supplementary personal budget
- social benefits including tax exemption for practical household adaptations.

Eligibility for support is determined via an annual assessment of aspects including health status, income and housing conditions.

**Financial support does not keep pace with the large out-of-pocket costs associated with MS.** Once registered with a given level of disability, a person can access financial support to help with daily activities and compensate for reduced ability to work.<sup>8</sup> However, although the costs for symptomatic therapies and rehabilitation are not covered by the health or social care systems, the financial support provided is not adequate to cover these out-of-pocket payments.<sup>19 29</sup> As a result, informal care and family support play a significant role for people with MS. While there is financial support for carers,<sup>48</sup> in practice this support is extremely limited and difficult to access.

**Practical support at home is limited in scope and not always suitable to the specific needs of people with MS.** Practical support may include physiotherapy and a personal assistant to help with daily tasks. However, such support is only available for people with the highest levels of disability, and is often not easily accessed or suitable to the needs of people with MS.<sup>19</sup> For example, typical home support for people with high levels of disability is a maximum of 90 days of home care across a one-year period, with one hour of support each day.<sup>19</sup> Such support from a personal assistant is largely dependent on local social care budgets, therefore many people must pay out-of-pocket to access all the practical support they need.<sup>19</sup>



**There are limited data on employment among people with MS.** Maintaining employment can be very challenging for people with MS, underpinned by the limited social support and rehabilitation in Romania. The largest proportion of indirect costs of MS is driven by lack of productivity due to disability.<sup>7</sup> One pan-European survey noted that for people with MS, participation in work is 80% in the very early stages of the disease, falling to less than 10% in more advanced MS.<sup>48</sup> More detailed data on part-time working or reasons for leaving work are needed to develop effective policies to support workplace retention for people with MS and other neurological conditions.

**Who are the patient groups in Romania?**

National patient groups	Asociatia Pacientilor cu Afectiuni Neurodegenerative (APAN) <a href="http://www.afectiuni-neurodegenerative.ro">www.afectiuni-neurodegenerative.ro</a> Asociatia de Scleroza Multipla din Romania (ASMR) <a href="http://www.sclerozamultipla.ro">www.sclerozamultipla.ro</a>
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## Case study 1

### APAN Romania Navigators<sup>24</sup>

Adequate information and education are not always provided in a timely manner after a diagnosis of MS. The APAN Romania Navigators programme, started in 2017, connects young and newly diagnosed people with MS with 'Navigators' – people with experience of living with MS. By sharing their real-life stories and experiences living with the disease, the Navigators support those who are coming to terms with their diagnosis to communicate about their condition and to live more positively. Around 1,000 people benefit each year from meetings, events and supportive materials produced with MS specialists. Attendees noted that the meetings have helped them come to terms with their diagnosis and help support necessary lifestyle changes.

## Case study 2

### #WomenWithMS (#FemeiCuSM)<sup>49 50</sup>

Over the course of 2018, APAN organised four workshops aiming to support women with MS and raise awareness about their condition. These fell under the umbrella of the #WomenWithMS campaign. Organised in partnership with the Romanian Society of Neurology, the campaign brought together participants from across Romania with specialists from the MS centres in Bucharest to discuss key subjects facing women with MS. The themes of the workshops were: menstruation, contraception and sex; pregnancy, birth and breastfeeding; menopause and family life; and family and carers.

Each meeting featured a diverse speaker list and ample time for networking and formal discussion. While each of the first three workshops had approximately 50 attendees, the workshop for family and carers had more than 150. After attending, people with MS reported feeling better about their life perspective and more comfortable communicating about their experiences.

### Case study 3

#### #SpiSM<sup>25</sup>

APAN identified a significant unmet need in providing psychological services for people with MS in Romania. It launched the #SpiSM project (Integrated Psychological Services in MS) in 2017, aiming to: identify and share knowledge in diagnosing and treating neuropsychological issues for people with MS; better support and enable people with MS to cope with the emotional changes they experience as MS is diagnosed and progresses; improve the research base on psychological conditions in MS and develop a psychological profile of the Romanian MS patient; and create an intervention plan for the Government to use in providing psychological services.

The project began with monthly meetings reaching 200 beneficiaries, where discussions were held on the various challenges facing people with MS. One person reported that the #SpiSM project was of great value, and that knowing their difficulties with MS were experiences shared by others helped them to adapt more quickly to their new situation, as well as becoming more communicative and expanding their perspective on life.





# APPENDIX: ABOUT MS

**MS is a complex and progressive disease of the central nervous system**, where the immune system destroys brain, optic nerve and spinal cord tissue.<sup>1-3</sup> As a result, people with MS develop irreversible motor-disability and cognitive impairment over time.<sup>1 51 52</sup> MS affects almost every aspect of day-to-day life,<sup>53 54</sup> and its personal and economic impacts grow significantly as the condition progresses and disability worsens.<sup>3 55 56</sup>

## **There are four main types of MS:**

- **Clinically isolated syndrome (CIS)** is the first clinical presentation of inflammation or lesions.<sup>57</sup> However, many people with CIS will not go on to develop MS.<sup>58</sup> If CIS becomes clinically active and fulfils the current diagnostic criteria, it can be reclassified as relapsing and remitting MS.<sup>57</sup>
- **Relapsing and remitting MS (RRMS)** is characterised by intermittent ‘relapses’ (sudden onset of MS symptoms and disability), followed by remission periods where symptoms abate.<sup>5 59</sup> Approximately 85–90% of people with MS have RRMS at diagnosis.<sup>2 5</sup>
- **Secondary progressive MS (SPMS)** is characterised by progressive accumulation of disability after an initial relapsing course. There are no clear criteria to mark the transition between RRMS and SPMS, and often SPMS is only diagnosed retrospectively.<sup>57</sup>
- **Primary progressive MS (PPMS)** is where disability accumulates without relapses from the outset.<sup>57</sup>

**MS can be a challenging condition to manage, due to its unpredictability and people’s changing healthcare needs.**<sup>60</sup> Management strategies aim to reduce disease activity and development of disability but must be tailored to each person. They typically fall into three categories:

- DMTs
- Symptomatic therapies and rehabilitation
- Lifestyle interventions.







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