

# Patient Memorandum on the improvement of multiple myeloma care in Central Europe & the Baltics



## Executive Summary

Multiple myeloma, the second most common type of blood cancer, for many patients is quickly evolving from a rapidly fatal condition to a chronic disease. While still primarily affecting older patients, a troubling trend is starting to show multiple myeloma prevalence in younger adults. The situation is becoming especially critical in Central and Eastern Europe and the Baltics (CEB), where multiple myeloma incidence is rising, and mortality rates are worsening.

The disease carries a heavier symptom burden than other blood cancers, often leading to substantial complications, morbidity, and disability, highlighting the urgency for improved diagnosis, treatment, and patient support. A significant delay gap exists in the time between European Medicines Agency (EMA) approval and the availability of best recognised therapies between Western Europe and the CEB region, compounded by delayed diagnostic and treatment advancements. These factors make multiple myeloma a rapidly growing challenge for the CEB region.

In striving towards a future where every patient in Europe has equitable and timely access to the best recognised treatment and care we, the patient organizations in the region, are calling for better awareness of the disease as well as the following steps.



# 01

## Improving access to comprehensive multidisciplinary care

Provide comprehensive, patient-centered care to address unique patient needs, improve treatment outcomes, and provide high-quality long-term support.

# 03

## Long-term comprehensive support

Provide ongoing assistance to help patients and their families cope with emotional, psychological, and social challenges of the disease, including continuous psychological support, assistance with social reintegration, and end-of-life care.

# 02

## Optimizing the patient journey (care pathway)

Secure rapid pathway to diagnostics. Ensure availability of early diagnostics via varied diagnostic options to all patients, promote access to the best recognised treatments, and encourage clinical trials to improve patient outcomes and quality of life in multiple myeloma patients.



# 04

## Data-driven decision making

Encourage precise data collection and sharing amongst patients, medical professionals and stakeholders to improve diagnosis and access to treatment, and foster a culture of transparency and cooperation for better policy decisions.

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Multiple myeloma, the second most common type of blood cancer, is quickly changing its face for many patients from a rapidly fatal condition to a longterm chronic disease. Having previously mostly affected people between 70 and 75, currently 37% of patients are under 65.<sup>123</sup> A greater number of younger people in the age groups of 30 to 50 years are also suffering from this disease, indicating a troubling shift toward an earlier onset.<sup>45</sup>



Incidence and mortality figures for multiple myeloma are especially concerning when it comes to the Central and Eastern Europe and the Baltics (CEB). While global trends have been showing lower mortality rates in the past three decades, our region is experiencing an alarming increase in mortality for multiple myeloma.<sup>6</sup> The number of new myeloma patients over 60 is also

expected to rise in virtually all the CEB countries by 2050.<sup>7</sup>

Furthermore, the Patient W.A.I.T. Indicator 2022 Survey highlighted a significant delay gap in the time from European Medicines Agency (EMA) approval to when innovative therapies are available as reimbursed treatment options between Western Europe and the CEB region. While in Germany the average delay is 128 days, the average in CEB region is 587 days.<sup>8</sup>

Lower health care investments, lack of awareness and knowledge within society as well as primary care physicians, delayed rollout of diagnostic and treatment advances, and health system challenges, likewise contribute to the deepening disparity between the CEB region and Western Europe.<sup>9</sup> This makes multiple myeloma a growing challenge for patients in the region. The disease carries a heavier symptom burden than other blood cancers, often leading to substantial complications, morbidity, and disability, highlighting the urgency for improved diagnosis, treatment, and patient support.

<sup>1</sup> Palumbo A, Anderson K. Multiple myeloma. *N Engl J Med*. 2011 Mar 17;364(11):1046-60.

<sup>2</sup> Mousavi, S.E., Ilaghi, M., Aslani, A. et al. A population-based study on incidence trends of myeloma in the United States over 2000–2020. *Sci Rep* 13, 20705 (2023). <https://doi.org/10.1038/s41598-023-47906-y>

<sup>3</sup> Cancer Research UK. Myeloma incidence trends over time. Available from: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/myeloma/incidence#heading=Two>

<sup>4</sup> Bennink C, van der Klift M, Scheurer H, Sonneveld P, Duijts SFA. Perspectives on returning to work of multiple myeloma patients: A qualitative interview study. *Eur J Cancer Care (Engl)*. 2021;30(6):e13481. doi:10.1111/ecc.13481

<sup>5</sup> Forbat L. Multiple myeloma in people of working age in Czechia, Germany, and Poland: findings from a qualitative interview study. *J Cancer Surviv*. Published online December 20, 2023. doi:10.1007/s11764-023-01510-1

<sup>6</sup> Zhou L, Yu Q, Wei G, et al. Measuring the global, regional, and national burden of multiple myeloma from 1990 to 2019. *BMC Cancer*. 2021;21(1):606. Published 2021 May 25. doi:10.1186/s12885-021-08280-y

<sup>7</sup> IARC. WHO. Cancer tomorrow. Available at [https://gco.iarc.fr/tomorrow/en/dataviz/bubbles?sexes=0&cancers=35&populations=428\\_203\\_348\\_703\\_705\\_100\\_233\\_440\\_688\\_191&age\\_start=12&types=0](https://gco.iarc.fr/tomorrow/en/dataviz/bubbles?sexes=0&cancers=35&populations=428_203_348_703_705_100_233_440_688_191&age_start=12&types=0)

<sup>8</sup> QVIA. EFPIA Patient W.A.I.T. Indicator 2022 survey [Internet]. Available from: [https://www.efpia.eu/media/s4q1eqo/efpia\\_patient\\_wait\\_indicator\\_final\\_report.pdf](https://www.efpia.eu/media/s4q1eqo/efpia_patient_wait_indicator_final_report.pdf)

<sup>9</sup> Santucci C, Patel L, Malvezzi M, et al. Persisting cancer mortality gap between western and eastern Europe. *Eur J Cancer*. 2022;165:1-12. doi:10.1016/j.ejca.2022.01.007

# Patient Call for Putting Multiple Myeloma Under the Spotlight

We, the patient organizations active in Central Europe and the Baltics, have joined our forces and efforts to improve awareness of this disease and call on our respective national governments in the region and the European institutions, to take action, and ensure equal and quality treatment and care for people with multiple myeloma.

In striving towards a future where every patient in Europe has equitable and timely access to optimal treatment and care, we are calling for the following steps:

## 01 Improving access to comprehensive multidisciplinary care

**All CEB states should ensure comprehensive care with a patient-centered approach.**

Multiple myeloma has the highest symptom burden and shows the lowest health-related quality of life among hematological malignancies. Severe symptoms range from extensive fatigue and gastrointestinal issues to neuropathy, bone fractures and organ failure. Despite this, patients face significant barriers to accessing the essential comprehensive multidisciplinary care. We need coordinated teams of primary care physicians as well as specialists—hematologists, nephrologists, orthopedic surgeons, radiation oncologists, palliative care experts, nurses, rehabilitation teams, and social workers—but access to their expertise is often limited, delayed, or otherwise complicated.

Complex professional treatment ensures that patients receive personalized care, addressing our unique needs and improving treatment outcomes. Many health systems in the region lack systematic structure when it comes to treating multiple myeloma patients, resulting in delays, more severe symptoms and increased reliance on inpatient care. Living with a long-term condition poses numerous challenges, particularly for younger adults, including concerns about fertility, financial pressures, and re-entering the workforce. Improving access to comprehensive care with a strong emphasis on the patient-centered approach is imperative in helping multiple myeloma patients cope with an already difficult diagnosis.

# 02 Optimizing the patient journey (care pathway)

## Secure rapid pathway to diagnostics, early diagnosis, and varied methods of diagnostics

### **2a** Let's secure rapid pathway to diagnostics, ensuring early diagnosis and a range of diagnostic options to extend patients' lives and improve quality of care.

Multiple myeloma has one of the longest intervals to diagnosis among all cancers. A Myeloma Patients Europe survey estimated the median time from onset of symptoms to diagnosis as less than 3 months in some Western European countries,<sup>10</sup> while other studies indicate that in CEB countries, it ranges from 4 to as much as 12 months.<sup>11,12</sup> Myeloma symptoms are often vague and variable, mimicking many other diseases. Delayed diagnosis often leads to severe end-organ damage, with patients experiencing debilitating symptoms like bone fractures, paralysis-causing spinal cord compression, severe anaemia, kidney failure, and repeated infections. These complications reduce patient quality of life and increase the demand on healthcare resources. Therefore, rapid pathway to diagnostics is essential.

There must be a coordinated effort to improve awareness and increase speedy access to diagnostic tools, such as blood tests, bone marrow examinations, and imaging studies to detect the disease in its early stages – right after any suspicions of the disease are raised. European guidelines and standardized protocols should also be followed in all countries of the region regarding the optimal diagnostic pathway, including the use of primary care specialists and general practitioners. Further streamlining referrals to specialists, as fast as possible from the root diagnostics, will ensure myeloma patients are diagnosed and treated swiftly, improving their quality of life by reducing the need for intensive inpatient care.

<sup>10</sup> MPE Atlas. 2018 Atlas access survey. Available at <https://atlas.mpeurope.org/surveys-data/atlas-2018-survey>

<sup>11</sup> Varga G, Mikala G, Andrikovics H, Masszi T. Mennyit vár ma Magyarországon egy myelomás beteg a diagnózisig? [How long does a myeloma patient currently wait for the diagnosis in Hungary?]. *Orv Hetil.* 2014 Sep 28;155(39):1538-43. Hungarian. doi:10.1556/OH.2014.30000. PMID: 25240875

<sup>12</sup> Dapkevičiūtė A, Šapoka V, Martynova E, Pečeliūnas V. Time from Symptom Onset to Diagnosis and Treatment among Haematological Malignancies: Influencing Factors and Associated Negative Outcomes. *Medicina (Kaunas)*. 2019 Jun 3;55(6):238. doi:10.3390/medicina55060238. PMID: 31163661; PMCID: PMC6631661

## Treatment availability

### **2b** Promote access to the best recognised treatments for all patients.

The best recognised treatments, according to international and European guidelines, must be available to patients with minimal delays. Prompt treatment is particularly important in the earlier stages of the disease, where it can provide considerable benefits and significantly improve the patients' quality of life. Access to advanced therapies for multiple myeloma in the CEB region is often restricted by lengthy approval processes and patients frequently face significant delays in obtaining treatments that are already available in the rest of Europe. As a result, they are not treated in line neither with European nor international guidelines, which worsens their outlook and symptom management, and can potentially result in life-threatening complications. It is imperative that equal access to the best recognised and effective treatments is guaranteed for all myeloma patients to ensure they can achieve and maintain the best possible health outcomes and enjoy the highest possible quality of life, even in the face of such a severe condition.



## **2c** Encourage clinical trials to help both patients and research.

Patients from the CEB deserve equal opportunities to participate in clinical trials like their counterparts in Western Europe. Clinical trials offer a pathway for patients to access emerging treatments for multiple myeloma and give these patients an active role in contributing to medical research, benefiting not only themselves, but potentially improving the lives of many others. Regulatory and practical hurdles need to be reduced to make clinical trials more accessible, with the safety of patients in mind as the primary concern. Better cooperation between all stakeholders, including pharmaceutical companies, healthcare professionals and institutions as well as decisionmakers, should result in better infrastructure for clinical trials and enable smooth and timely access and patient participation in the trials.

## Long-term comprehensive support

### **2d** Provide ongoing assistance to help patients and their families cope with the impact of the disease.

Apart from physiological symptoms, multiple myeloma patients face significant emotional, psychological, and social difficulties. Adequate, timely and continuous comprehensive support and rehabilitation, including psychological, nutritional, and social support, is needed for patients and their families to help with managing anxiety, emotional distress as well as any other difficulties during their clinical journey. This applies to all stages of the treatment, including both resocialization and entering the workforce, but also comprehensive palliative and end-of-life treatment and care. We need to provide resources and create safe spaces for emotional expression for the patients and their families to help them build resilience and improve their overall well-being throughout the patient journey. It is equally important to guarantee an adequate palliative and end-of-life care to those that need it to ensure a supportive and dignified approach towards the whole patient journey.

## **03** Data-driven decision making

### Encourage data collection and sharing to improve patient care and drive research

Collecting and sharing data helps to enhance our understanding of currently incurable multiple myeloma and make informed decisions in diagnosis and treatment. This involves creating patient registries to track clinical outcomes, improving the care pathway and ensuring the best possible diagnosis and treatment for the patients. Collected data provides the groundwork for research initiatives, driving innovation and directly benefiting myeloma patients. Extensive data collection is paramount for the development of new therapies and improving the efficiency of clinical trials, and helps healthcare providers refine treatment strategies, ultimately leading to better patient care and outcomes. We need to foster a culture of knowledge sharing between the patients, medical professionals and stakeholders to advance the field of multiple myeloma diagnosis and treatment, bringing benefits to all.

# Signatories

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Myeloma Under  
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