

Project Partners

- Radboud university medical center, Nijmegen, The Netherlands
- University of York, Heslington, York, United Kingdom
- Medizinische Universität Innsbruck, Innsbruck, Austria
- Groupe Francophone des Myélodysplasies, Paris, France
- Karolinska Institutet, Huddinge / Stockholm, Sweden
- European LeukemiaNet Foundation, Mannheim, Germany
- Westfälische Wilhelms-Universität Münster, Münster, Germany
- Università Degli Studi di Pavia, Pavia, Italy
- VU University Medical Center Amsterdam, Amsterdam, The Netherlands
- Leeds Teaching Hospitals NHS Trust, Leeds, United Kingdom
- University for Health Sciences, Medical Informatics and Technology, Hall in Tirol, Austria
- Fondazione GIMEMA (Gruppo Italiano Malattie EMatologiche dell'Adulto) Onlus, Rome, Italy
- La Fundación para la Investigación del Hospital Universitario La Fe, Valencia, Spain
- Fundación Instituto de Estudios de Ciencias de la Salud de Castilla y Leon, Salamanca, Spain
- Universitair Medisch Centrum Groningen, Groningen, The Netherlands

Project Website

The MDS-RIGHT project website (www.mds-right.eu) has been integrated into a comprehensive MDS Europe online platform that is gradually expanded and aims to provide the various MDS stakeholder groups with:

- information on MDS-RIGHT and its progress
- access to MDS-related resources, research groups, information on clinical trials, registries, scientific publications, links
- information on existing MDS-related practice recommendations and a dynamic therapeutic interactive algorithm tool for professionals
- information on MDS-related news and events
- a community platform for information exchange, mailing list subscription and feedback opportunity

For more information, please visit:



Contact Information

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Providing the **right care
to the **right** patient with
MyeloDysplastic Syndrome
at the **right** time**

- Project** A 'Personalising Health and Care' European research project comparing the effectiveness of existing healthcare interventions in the elderly (> 65 years of age)
- Focus** Lower-risk MDS and anaemia in the elderly
- Funding** This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 634789
- Duration** 1 May 2015 – 30 April 2020
- Coordination** Stichting Katholieke Universiteit (Radboud university medical center), Nijmegen, The Netherlands



What is MDS?

The term Myelodysplastic Syndromes (MDS) describes a group of bone marrow disorders, where the body's bone marrow (the Greek prefix 'myelo-' means 'marrow') produces unhealthy, abnormally shaped ('dysplastic') blood cells. As a result, not enough healthy blood cells are provided, leading to low blood cell counts ('cytopenias'). The affected blood cells include:

- red blood cells ('erythrocytes') which are responsible for carrying oxygen to organs and body tissues
- white blood cells ('leukocytes') which collectively fight against infection
- blood platelets ('thrombocytes') which prevent the body from bruising and bleeding

A decrease in the amount of red blood cells ('anaemia') is the most frequent symptom experienced by people diagnosed with MDS. Other symptoms include infection, spontaneous bleeding and easy bruising.

MDS is predominant in the elderly (people above 65 years of age), but it can also affect younger people. Failure of the bone marrow to produce healthy blood cells is a gradual process and there are different levels of MDS, including:

- very low-risk MDS
- low-risk MDS
- intermediate-risk MDS
- high-risk MDS
- very high-risk MDS

Roughly 30 percent of the patients diagnosed with MDS develop acute myeloid leukaemia (AML), a cancer of the white blood cells. Depending on the type of MDS, the primary goal of MDS treatment is to increase the number of healthy blood cells in the body.

MDS-RIGHT Objectives

- To compare outcomes and costs of existing healthcare interventions, using established (e.g., survival and progression to high-risk myeloid cancers) and new core outcome sets (blood transfusion dependency, bone marrow failure, and Health-Related Quality of Life (HRQoL), over and above the established set). This, alongside health technology assessment (HTA), will provide robust evidence to underpin the sustainable use of healthcare resources.
- To enhance compliance with diagnostic procedures in MDS by introducing new minimally-invasive diagnostic methods. This will increase the number of correctly and timely diagnosed MDS patients.
- To raise awareness of the relevance of obtaining the right diagnosis in elderly by comparing HRQoL between EUMDS and against a non-MDS cohort. This will improve HRQoL of individual patients through better tailoring of healthcare interventions.
- To improve outcome predictability of available healthcare interventions by refining classification of cases, using molecular characterization to incorporate response to healthcare interventions and to provide evidence for personalised medicine.
- To establish improved, evidence-based, practice recommendations supporting the regulatory process, and providing information to patients and physicians to promote personalised decisions in MDS care.
- To create a European MDS competence network of all stakeholders in the field.



Expected Impacts

Efficacy

- ✓ Better defined patient-specific factors and measurements
- ✓ More cost-effective utilisation of interventions
- ✓ Better access to safer healthcare interventions

Compliance

- ✓ Enhanced diagnostic compliance through new technologies
- ✓ Increased number of correctly diagnosed patients
- ✓ Improved awareness of the relevance of the right diagnosis of anaemia

Personalisation

- ✓ Better restriction of interventions to patients who are likely to benefit
- ✓ Improved individual patient outcome
- ✓ Safer interventions and higher HRQoL

Evidence

- ✓ Better treatment-outcome prediction models
- ✓ More rational, personalised treatment decisions and robust economic analyses

Practice

- ✓ New evidence-based diagnostic and interventional recommendations

Guidance and information

- ✓ Regulatory guidance to professionals and authorities
- ✓ Better information to patients
- ✓ Improved awareness of anaemia in the elderly and vigilance
- ✓ Better compliance
- ✓ Less undertreatment and less overtreatment
- ✓ More effective use of healthcare resources