RESEARCH SUMMARY

A European picture of patient involvement in myeloma treatment and care decision-making

Shared decision-making is a process where patients and healthcare professionals work together to make important decisions about patients' treatment and care choices. The process brings together the clinician's medical expertise with the patient's personal values, concerns, and needs.

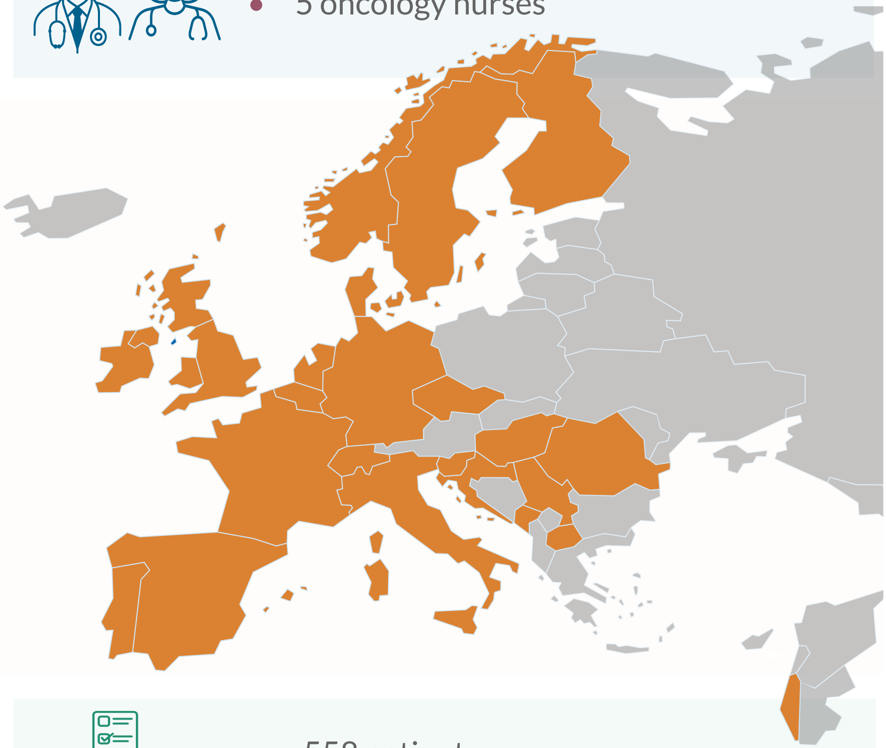
Patients with myeloma face **complex decisions** about their treatment. These decisions often involve balancing risks, benefits, and personal goals. Our research aimed to understand **how decision-making currently happens in myeloma treatment and care across Europe,** and how it can be improved to better meet patient needs.

INTERVIEWS

Explored patients' and healthcare professionals' experiences of shared decision-making and the barriers to effective shared decision-making.

- 36 patients
- Average age = 53 years (range 35-80)

- 15 haematologists
- 5 oncology nurses



🟧 Countries of recruitment

21 European countries involved in both activities

ONLINE SURVEY

To gather more views from patients and healthcare professionals across Europe.

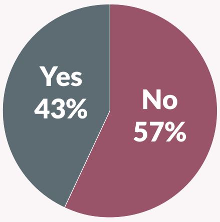
- 558 patients
- Average age = 65 years (range 32-90)

- 89 healthcare professionals
- Mostly haematologists, oncologists, nurses, and nurse specialists

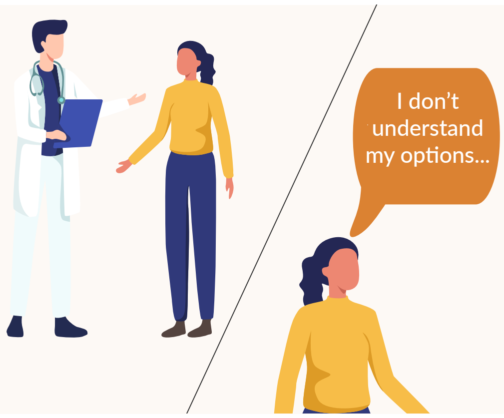
MAIN RESULTS

KNOWLEDGE

Many patients **had never heard** of shared decision-making but wanted to be involved in decisions about their treatment and care.



Had patients heard of shared decision-making before?



INCONSISTENCY

Healthcare professionals said they supported shared decision-making, but patients reported that the steps of shared decision-making **weren't consistently done.** For example, patients reported not always being asked by their doctor if they understood their options and/or not always being given the chance to share their fears or concerns.

PREFERENCES

Patients **were not routinely asked** how they would prefer to receive information (e.g. written or through discussions) nor were potential treatment options discussed

BARRIERS

Barriers to shared decision-making include **lack of time,** feeling emotionally **overwhelmed** at diagnosis, and lack of **communication skills** by some or all parties involved in conversations.

SUPPORT

Oncology nurses, family members, and patient organisations play important roles in **helping patients** understand options and feel supported.

WHY THIS MATTERS:

When patients are actively involved in decision-making, they **feel more empowered,** better **understand their treatment,** and are **more likely to stick with it.** This research shows that many myeloma patients **want to be more involved** in treatment and care decision-making. It highlights what changes are needed to improve shared decision-making and what resources are needed to support patients to be involved in decisions about their own care.

WHAT SHOULD HEALTHCARE PROFESSIONALS DO?

- **Ask patients** how they want to receive information (e.g. through leaflets, websites, or discussions in consultations).
- Get to know your **local patient organisation.** You can find a list of our members across Europe here.

WHAT SHOULD MYELOMA PATIENTS DO?

- Your voice matters. **Share your experiences and opinions** with your healthcare team and ask questions.
- **Contact your local myeloma patient organisation** for support and advice here.

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ACKNOWLEDGEMENT:

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