Multiple Myeloma REGISTRY

Helping improve care and research for people living with Multiple Myeloma in Ireland

to be activated

What is the Multiple Myeloma Registry?

A **voluntary** national research platform for adults living with Multiple Myeloma or a related blood condition in the Republic of Ireland. It allows participants to express their interest in research while allowing secure collection of clinical information about their condition. Participants may also chose to receive information about opportunities to take part in, such as biobanking* and clinical trials.

Why was the Registry created?

- To help address a national gap in detailed longitudinal real-world data in the Republic of Ireland.
- To support the generation of real-world evidence.
- Improve understanding of disease progression and treatment resistance.
- Facilitate the integration between clinical data and biobanking infrastructures.

Who is eligible?

Adults (18 years and over) who are resident in, or receiving care in the Republic of Ireland and have been diagnosed with Multiple Myeloma or a related condition.

What information is collected if I agree to take part?

We may ask for some details such as:

- Contact details (name, address) to make sure we are recording information about the right person.
- Basic health information such as your age, sex, type of cancer, treatment and disease progression

How many people will take part?

As this is a nationwide initiative, we hope to recruit as many eligible participants as possible from the Republic of Ireland. By building a large and diverse registry, we hope to better understand this condition and improve treatment outcomes, as well as patient experience.

Why take part ?

- Help improve understanding of Multiple Myeloma and related blood conditions.
- Support the development of new treatments.
- Be informed about research opportunities and clinical studies.

How does the Registry work ?

1 Discover the registry through

- Hospital posters
- Registry website
- Your healthcare team
- Patient organisation, social media

2 Register interest (online)

- Eligibility check
- Learn about the registry
- Contact details requested

3 Choose how to proceed

I feel ready to give consent
Proceed to online questionnaire

I require more information
Speak with someone from our team

Provide consent
- Online (QuestionPro questionnaire)
or
- Paper consent form

4 Join the Registry

- Your information is stored securely
- You can withdraw at any time
- Unique Registry ID assigned
- Optional: express your interest in the Blood Cancer Biobank and future clinical trials.

5 Longitudinal follow-up

Your clinical information will be securely updated over time, allowing researchers to better understand treatment response and disease progression.

Diagnosis → Treatment → Disease evolution & treatment response → Maintenance → Relapse

Optional opportunities

If you express an interest in participating in the Blood Cancer Biobank or clinical trials, you will receive further information and be asked to provide separate informed consent before taking part.

What if I change my mind?

You are free to change your mind at any time without giving a reason. If you choose to withdraw, no new information will be collected. Information already collected may continue to be retained where required by law or ethical approval.

Privacy and confidentiality

Protecting your privacy and keeping your information confidential is one of our highest priorities.

If you join the Registry, authorised members of the research team will collect only the information needed for this project. Your data will be stored using a unique study ID rather than your name, so researchers will work only with coded information.

All information will be stored securely and handled in accordance with GDPR and University of Galway data protection policies.

Who do I contact if I have any questions or concerns?

If you have questions about your treatment or care, it is best to speak with your doctor, nurse or haematology team.

If you have broader questions about the Registry, you can contact the following:

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If you wish to speak in confidence with someone who is a neutral third party, please contact:

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For more information visit: website (once it is made) * https://www.universityofgalway.ie/bloodcancers/