What is the Rory Morrison Registry (RMR)?

The Rory Morrison Registry (RMR) is the name of a new database that is being set up to collect and maintain information across the UK on patients who have Waldenström’s macroglobulinaemia (WM) and its related conditions including (but not limited to) Bing Neel Syndrome, Cold Agglutinin Disease and Cryoglobulinaemia. It will contain information from a number of centres across the UK.

Who is running the RMR project?

A consortium of WMUK, doctors and patients, and Dendrite Clinical Systems is running the RMR Project.

- The Project’s Lead is Dr Shirley D'Sa, Consultant Haematologist and Lead of the WM Service at University College London Hospitals (UCLH) NHS Foundation Trust, London in conjunction with a dedicated clinical fellow, Dr Joshua Bomsztyk, who is based at UCLH, but will be in close liaison with participating centres. The data controllers are UCLH and the data custodian is Dr Shirley D'Sa.
- WMUK is a Registered Charity dedicated to improving outcomes for patients with WM and related conditions by bringing WM patients and medical professionals closer together.
- Dendrite is a British company specialising in disease Registry database systems and will be Data Processors for the RMR.

What information is being collected?

The RMR is designed to collect data at diagnosis, treatments and outcomes. The addition of direct entry of patient-related outcome measures (PROMs) will be launched within a few months, via web-based and mobile platforms.

Diagnostic data includes your Forename, Surname, Date of Birth, NHS Number and basic demographics such as gender and ethnicity. It will also include details about your clinical symptoms at presentation and results from bone marrow tests, scans and blood tests.

Treatment information includes details of the dates of treatment, what treatment you received and why it was indicated. We will also collect information from your follow up clinic appointments including blood results and examination findings.

How is this information collected?

The Registry has been set up so that doctors, clinical nurses specialists or members of the research team can upload information about their patients directly on to the Registry using the NHS number, which is unique to every person.

In each case, the doctor will be able to upload information for patients under his or her care and be able to see only their own patients’ data. There will be Registry administrators who are part of the Registry Review Committee, with additional responsibilities of training all new users and ensuring that the Registry is managed in accordance with the Data Protection Act 1998 and the General Data Protection Regulation (GDPR) 2018.
Do I need to give written consent?

Your written consent is not needed for inclusion of your data. Approval has been received from the Confidentiality Advisory Group (CAG) of the Health Research Authority (HRA) for the upload of patient data without specific consent.

All data collected is subject to strict rules of confidentiality under Acts of Parliament, including the Data Protection Act 1998, the Health and Social Care Act 2001 and GDPR 2018. No patient identifiable data will be shared or released to third parties.

You are free to ‘opt – out’ of the registry without giving a reason and any data on the RMR will be deleted. If you want to ‘opt – out’, please contact your local clinician or email registry@wmuk.org.uk or joshuabomsztyk@nhs.net. Choosing to opt out of the Registry will not affect the quality of your care in any way.

How will my information be used?

In the past few years there has been major progress in the treatment of WM. New therapeutic strategies are being developed and, for some of these treatments, trials are already underway.

When a clinical trial is being planned, it is very important that patients suitable for that trial can be identified easily and approached promptly.

The best way of ensuring this can happen is to make sure that patients' details are all collected together in a single database or "Registry" that contains all the information that researchers will need, including each patient's particular disease features and other key information about their disease.

The Registry will also provide critical information about the state of the service in the UK particularly the regional differences in treatments and the approaches of varying centres. This will act as a backdrop for the subsequent development of a WM support network for clinicians across the UK so that they can provide the most update and accurate information to the patients.

Will my information be shared with anyone?

No, your information will not be shared with anyone outside of your hospital, UCLH (the data controllers) and Dendrite Clinical Systems (the Data processors). Any information published in journals or at conferences will be anonymised. No patient identifiable data will be published in any way

Will the RMR impact upon me or my care?

The collection of information serves to assist you and your clinician in developing the best management plan. The information collected will help to assess your potential eligibility for future clinical trials or newer treatments.

If you wish for your data not to be collected and to ‘opt out’ of the Registry then contact registry@wmuk.org.uk or joshuabomsztyk@nhs.net. This will not affect your care in any way.