Information about the Rory Morrison Registry (RMR)

**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 eleven NHS (11) centres across the UK.

**Why is there a need for the RMR?**

There are 350 new cases of WM in the UK every year.

In order to fully understand WM in the UK, there is an urgent need to collect real time data on patients affected by WM and related conditions.

Recently there have also been major developments in the treatment of WM with the advent of new treatments.

The RMR will help the WM Team, based at UCLH, to collect, maintain and analyse the information needed to understand the impacts of these new pioneering treatments.

The RMR will also help to provide the evidence for further applications to the Cancer Drug Fund (CDF) and National Institute for Health and Care Excellence (NICE) to provide these treatments for WM patients in the UK in the future.

**Your Information and the RMR**

The information handling activities of the Registry across the UK will be governed by UCLH as data controller i.e. the body who determines the purpose of the data collection. For the full Privacy and Fair Processing Notice of UCLH, please visit [http://www.uclh.nhs.uk](http://www.uclh.nhs.uk)

We have received Confidentiality Advisory Group (CAG)* support to allow us to collect personal and clinical information without the need for explicit consent.

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 joshuabomsztyk@nhs.net. Choosing to opt out of the Registry will not affect the quality of your care in any way.

We are working with Dendrite Clinical Systems ([http://www.e-dendrite.com/](http://www.e-dendrite.com/)) as our data processor to help design the RMR and assist in data analysis and processing. No personal data will be shared outside the Data Sharing Agreement between UCLH and Dendrite.

Information in the RMR will be stored and retained for 15 years.

**Further Information**

For further information about data protection, please visit [www.ico.org.uk](http://www.ico.org.uk)

The RMR team is headed by Dr Shirley D’Sa of University College London Hospital (UCLH).

For further information about the RMR please contact joshuabomsztyk@nhs.net or visit [www.uclh.nhs.uk](http://www.uclh.nhs.uk)

*The Confidentiality Advisor Group (CAG) facilitates the appropriate use of confidential patient information for purposes beyond direct patient care and advises the Secretary of State for Health. For a full understanding of CAG and Section 251 visit [http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/](http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/)