

W25: The Rory Morrison Registry (RMR) for Waldenström Macroglobulinaemia: A successful doctor-patient collaboration for comprehensive data collection on all-WMers

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In order to capture the UK picture of WM (estimated incidence 0.55/100,000ⁱ) including disease characteristics, prescribing habits, clinical outcomes, and work towards more equitable access to novel therapies, an online registry was developed using funds raised by donations to the WMUK Charity.

A consortium of clinicians and patients developed a comprehensive data set, secured ethical approval and established a review committee to ensure high quality data entry and compliance with data protection laws.

To capture 'all-comers', including less 'internet savvy'/ engaged patients, approval was obtained from the National Health Service's (NHS) Confidentiality Advisory Group and Research Ethics Committee to upload data without patient consent. The approval was future-proofed for the introduction of the EU's General Data Protection Regulation (GDPR) in May 2018 including a robust 'opt out' mechanism and Fair Processing and Privacy Notices.

So far, 16 'WMUK Network Centres' across the UK are on board with more to follow to cover the extent of the UK. Funding for data acquisition teams was secured from educational grants. Since the start of retro/prospective data entry in August 2017, over 500 patients are registered. 437 patients have a diagnosis of WM and 71 have an IgM-related disorder. 267 out of 437 (61%) are male; median age at diagnosis 63 (range 34 to 89). 289 out of 437 (66%) have had ≥ 1 treatment; a further 153 (35%) have had ≥ 2 lines (Max. 10 lines of treatment).

Over 27 different regimes were used at 1st line in this cohort. Since January 2013, 147 patients have been received 1st line therapy, 41 (27%) receiving DRC and 34 (23%) Bendamustine based therapy.

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58 patients have received a BTK inhibitor; 32 (55%) as part of a clinical trial. Only 4 patients received a BTKi as first line treatment, the majority 24 (41%) receiving it as second line therapy and 30 patients receiving it third line or beyond.

95 out of 117 patients tested were MYD88 mutated and 19 out of 69 patients were CXCR4 mutated. 34 tested positive for anti MAG antibodies and 18 were positive for cryoglobulins at diagnosis. 20 patients were treated for Bing Neel Syndrome including 4 patients treated for CNS high grade transformation. In total 21 patients were treated for high grade transformation.

Overall median survival is 17 years; for those aged >65 at diagnosis median survival is 11 years. Further analysis looking at indications for treatment, response rates, time to next treatment as well as tracking immunoglobulins levels, paraprotein, haemoglobin and other biochemical parameters are within the scope of the registry (reported separately).

A bespoke bolt-on tool has been created for patients who have consented to provide their email addresses to directly input PRO data (EORTC QLQ C30, EQ5D, HADS and the BIP Score) onto the RMR through an online link.

This collaborative approach between clinician and patient, and the wide-reaching nature of RMR, ensures a comprehensive overview of WM in the UK and has the potential to be rolled out internationally subject to local data protection rules. With ongoing recruitment of patients and centres, the RMR will become crucial in steering the management of WM in a positive direction.

ⁱ Owen et al. Guidelines on the diagnosis and management of Waldenström Macroglobulinaemia; British Journal of Haematology 2014; 165; 316 - 333