Abstract Submission

14. Myeloma and other monoclonal gammopathies - Clinical

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THE MYELOMA CANADA RESEARCH NETWORK CANADIAN MULTIPLE MYELOMA DATABASE (MCRN CMM-DB): MULTI-INSTITUTIONAL SHARING OF CLINICAL DATA FOR RESEARCH

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Background: We have seen dramatic improvements in survival for patients living with multiple myeloma (MM). To better understand the current national landscape for patients with MM the Myeloma Canada Research Network (MCRN) developed a centralized Canadian Multiple Myeloma Database (MCRN CMM-DB) aimed at collecting all disease specific outcomes-based endpoints.

Aims: The goals of the MCRN CMM-DB are to: 1) benchmark current outcomes of MM patients treated with available treatment strategies in Canada; 2) identify regional therapeutic differences across the country; 3) inform future care strategies with evolving funded novel treatment approaches and 4) better inform future trial initiatives and national translational programs.

Methods: Sites with recognized expertise in treating MM across Canada were invited to participate in data collection. Capitalizing on existing local disease specific databases, endpoints were identified to determine the final data dictionary and mandatory data elements used in the MCRN CMM-DB. Given broad representation across multiple regions and institutions a governance structure was developed, which included Operations and Steering Committees. This was essential to ensure the development of a representative data collection platform, data quality and integrity, protection of patients' privacy, financial sustainability, guide data access, prioritize data usage and disseminate findings to the broader MM community nationally and internationally. The aim is to enroll all newly diagnosed patients from participating sites over the next 10 years. Where available, legacy data on previously diagnosed patients going back to 2007 will also be uploaded to represent the patient experience through the novel agent era.

Results: To date, 13 sites representing the major MM treating and academic centres across Canada have committed to the initiative. After user acceptance testing was completed the final MCRN-MM-DB was built according to agreed specifications approved by the organizing and steering committees. Using the eCancerCare platform a user-friendly web-based interface was developed to facilitate the entry of anonymized data to a secure centralized data repository. In parallel to the system build, each participating site obtained research ethics approval consistent with local requirements. Institutions signed a data sharing agreement with MCRN to facilitate ease of data transfer across jurisdictions.

Access to the MCRN-MM-DB was deployed to sites with ethics approval, a signed data sharing agreement and with designated data coordinators to consent patients and enter data. Six sites that had existing data registries obtained REB approval to migrate legacy data.

The first site was activated in July 2017. Thirteen sites representing the provinces of Ontario, Quebec, Alberta, Nova Scotia, Manitoba, Saskatchewan, British Columbia and New Brunswick are now contributing data. 20 users across sites have received formal training and were provided with Case Report Form Completion Guidelines. A total of 50 records from different sites have been audited centrally. Prospective data on 102 patients have been entered. The legacy dataset is estimated at 4000 patients. An aggregate summary of pooled data available in the MCRN-MM-DB will be presented at the meeting.

Summary/Conclusion: We anticipate that the MCRN CMM-DB will be one of the largest, most comprehensive nation-wide disease specific repositories. It will provide locally and nationally relevant benchmarks for current outcomes and better inform future clinical and academic ventures.

Keywords: Clinical data, Clinical outcome, Myeloma