

MOVING FROM RESEARCH PRIORITIES TO CLINICAL RESEARCH:

IMPLEMENTING THE RESULTS OF A PRIORITY SETTING PARTNERSHIP ON MULTIPLE MYELOMA

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INTRODUCTION

Research has improved survival so that people diagnosed with multiple myeloma are living on average 2-7 years longer after diagnosis.

As a result, there are new questions being asked about the diagnosis, treatment, and management of this disease. However, when it comes to answering these questions, research is often lacking.

At the same time, given the slow uptake of study results, researchers continue to struggle to close the "knowledge-to-practice" gap.

It takes approximately 17 years to get research evidence integrated into practice.

To address these challenges, researchers need to focus on the needs of the myeloma community. To this end, our study identified the Top 10 research priorities shared by three key groups:

- ✓ People living with myeloma,
- ✓ Their caregivers, and
- ✓ The clinicians who treat them.

METHODS

To elicit and prioritize unanswered questions about MM, our project followed the robust and transparent approach developed by the James Lind Alliance.



A national steering group oversaw the project to ensure relevance of results, and people living with MM, caregivers, and clinicians all had equal representation on this committee.



REFERENCES

Morris, Z., Wooding, S., Grant, J. The answer is 17 years, what is the question: understanding time lags in translational research. *J R Soc Med* 2011; 104: 510-520.

Ludwig H, Novis Dürre S, Meckl A, Hinke B, Dürre B. Multiple Myeloma Incidence and Mortality Around the Globe: Interruptions between Health Access and Quality, Economic Resources, and Patient Empowerment. *Oncologist*. 2020;25(9):e1406-e1413. doi:10.1634/theoncologist.2020-0141

RESULTS

People across Canada living with myeloma, their caregivers, and clinicians were invited to take part in a survey to tell us their questions about myeloma.

594

People living with myeloma, caregivers, and clinicians

Asked Us

66

Questions about myeloma

These questions were then compared against previous research, including systematic reviews, clinical practice guidelines, and grey literature to ensure the question was unanswered:



Only 7 of those 66 questions asked were answered by previous research!

Forty-five of the remaining questions were selected by the steering group for inclusion in a prioritization survey, where 651 people living with myeloma, caregivers, and clinicians chose and ranked their top 10.

Finally, the prioritization workshop was held in April 2021 with 23 participants of an equal mix of people living with myeloma, their caregivers, and their healthcare providers to determine the final list of research priorities for myeloma:

Table 1: Top 10 Research Priorities for Myeloma

- 1 How can we cure myeloma?
- 2 Are novel immunotherapies effective for the treatment of myeloma?
- 3 How can we improve the diagnosing of myeloma, and what is the impact of earlier diagnosis on patient outcomes?
- 4 What are new treatments for myeloma patients that will improve life expectancy with fewer adverse side effects?
- 5 How can we personalize a patient's treatment based on their type of myeloma and genetic profile, and what is the impact of personalized medicine on treatment efficacy and disease outcomes?
- 6 How can we prevent bone deterioration and/or repair bones that have been damaged without negative side effects or surgery?
- 7 How can we safely reduce, cycle, or stop the use of medications to reduce the side effects of treatment and maintain control over myeloma?
- 8 How can we reduce or manage the short-term effects and long-term effects of myeloma treatment?
- 9 What is the most effective way to treat refractory, relapsed, and drug resistant myeloma?
- 10 Can we develop treatments specifically for high risk or aggressive myeloma that will improve outcomes for these patients?

KNOWLEDGE TRANSLATION

We have made it our mission to ensure the Top 10 priorities get into the hands of the people that can help to answer them, with the ultimate goal of closing the knowledge to practice gap for multiple myeloma and improve the lives of the 160,000 individuals worldwide living with this disease.

Traditional Approach

It is important that the research priorities we identified are made known to researchers and clinicians, because of this, we felt it was important to utilize traditional knowledge translation activities to do so:



Publication in Peer-Reviewed Journals



Conference Presentations

Primary Goal: To encourage researchers to answer our priorities.

Highlighting Experiences

Having a national steering group for this project before and during the COVID-19 pandemic gave us unique insights into best practices to engaging patients and caregivers as partners and decision makers.

With our patient partners, we hosted educational webinars to share recommendations and lessons learned for future projects.

Primary Goal: To improve patient engagement.

Promoting Uptake

To promote uptake of our priorities, we partnered with Myeloma Canada who is using our findings to accomplish its primary mission of improving the daily lives of those within the MM community. Initiatives they have taken on include:



Creating educational materials to address frequently asked questions that were already answered by research.



Funding priority-related research projects through grants that will award at least \$100,000 to research teams focusing on our identified priorities in 2022.



Primary Goal: To promote our research priorities and educate patients.

CONCLUSION

Clinical and scientific experts on MM, as well as research funders, all have a pivotal role to play when it comes to acknowledging the experiences and needs of those impacted by MM and investigating their priority concerns.

A focus on stakeholder-identified priorities is crucial as it will facilitate the uptake of meaningful research into practice and improve the quality of life of people living with MM and their caregivers.