



Myeloma Priority Setting Partnership (PSP) - Prioritization Survey

We want to hear what research questions about myeloma are most important to you!

Who is the survey for?

This survey is intended for all Canadians living with myeloma, their caregivers, and healthcare providers within the myeloma field. It is the second survey within the Myeloma Priority Setting Partnership initiative launched in the Fall of 2019. For more information on the Myeloma PSP program, please visit <https://www.myeloma.ca/PSP/>

Why is this survey important?

This survey gives you, **persons with myeloma, caregivers, and healthcare providers**, the opportunity to tell us what is most important to you and/or your patients about myeloma so that we can share your priorities and needs with research funders. This is the time for you to be heard and influence important research that will have an impact on lives for years to come.

What is involved if I take part in the survey?

We have made a list of questions about myeloma that people have suggested need more research to answer. We want you to read the list and, based on your own experiences, **choose up to 10 questions that YOU think are most important for researchers to answer.** It does not matter if you are a person with myeloma, caregiver, or healthcare professional. We want to know what YOU think is important to research. We expect that this activity will take 15-20 minutes to complete. For the best experience please complete this activity on a tablet or desktop computer. Your participation is voluntary, we do not expect any risks or any impact on your legal rights related to your completion of this project, and you can withdraw at any time. Unfortunately, you cannot save your progress and return later. However, the survey will not time out if you do need to take a break!

Where did these questions come from?

We did the first survey in October 2019 and it had 594 patients, caregivers, and healthcare providers submit their questions about the diagnosis, treatment, management, and living well with myeloma. We received 3032 questions! We want to sincerely thank everyone who completed the first survey for your thoughtful comments and questions. Similar questions were combined into summary questions which were checked to see if they had been answered by research. We appreciate all the responses that we got to the first survey, however, only those that were unanswered by previous research and were within the scope of our project are included in this second survey.

Questions from the first survey that do not appear here have not been lost! These questions will be used in different ways such as creating FAQs and information sessions to ensure the answers are more accessible in the future. They will be available with Myeloma Canada and/or the James Lind Alliance when the project is finished. You can find out more about the project here: <https://www.myeloma.ca/PSP>.



Will my answers be kept confidential?

Your information will be collected by Optimal Workshop which complies with European Union privacy standards. When the survey is complete the information will be securely stored at the Saint John Regional Hospital and then destroyed after seven years. All personal information will be kept confidential and when we release the results of this survey, we will never name any individual who took part in this survey. If you choose to provide us with your contact information, it will be held separately to your responses.

What will happen to the results?

After this survey has closed, we will analyze the responses to determine the most popular questions. We will then hold a workshop for persons with myeloma, caregivers, and healthcare professionals to arrive at a Top 10 list. We will publish this list of priorities widely and it will be used to encourage researchers to focus their efforts on them. At the end of this survey, you will be given the opportunity to register to be considered for a place at this workshop.

Who is supporting this survey?

The Myeloma PSP initiative is led by a research team from Horizon Health Network in New Brunswick. This team is supported by the Canadian Institute for Health Research (CIHR) and the New Brunswick Health Research Foundation (NBHRF). The project is supported and funded by Myeloma Canada (<https://www.myelomacanada.ca/>) and follows the methods of the James Lind Alliance (<http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/>), a non-profit initiative based in the United Kingdom.

Who can I contact for more information?

If you would like more information about the project, please contact:

Samantha Fowler, Myeloma Priority Setting Partnership Information Specialist
Maritime SPOR SUPPORT Unit, Saint John Regional Hospital
400 University Avenue
Saint John, New Brunswick E2L 4L2

Email:

Tel: 1 (506) 648-6189

If you wish to speak to someone not involved with the study, please contact:

The Horizon Health Network Research Ethics Office

Tel: (506) 648-6094

For more information on the Myeloma Priority Setting Partnership, please visit www.myeloma.ca/PSP. Information about the PSP process can also be found on the James Lind Alliance website: <https://www.jla.nihr.ac.uk/>

By completing this survey, you agree and provide your implied consent to take part in this research study. Your decision to participate in this study will not affect your healthcare

Thank you for your participation and helping to influence important research that will have a meaningful impact on those living with myeloma

MYELOMA



Before you begin

Please answer the following questions about your role and place of residence.

1. In relation to myeloma, what role best describes you?

- Person with Myeloma
- Caregiver of a Person with Myeloma
- Healthcare Provider for People with Myeloma

2. What is your healthcare profession?

- Nurse
- Pharmacist
- Physician
- Other (please specify): _____

3. What part of Canada do you live in?

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon



Instructions

STEP 1: In the left column is a list of unanswered questions identified from the first Myeloma PSP survey. Please read the entire list and then, based on your own experience, identify the questions that are the most important to you.

STEP 2: Drag any questions that you think are important into the 'Holding' column to help you narrow down your priority list.

STEP 3: From the 'Holding' column, pick the top 10 questions that you think are the **most** important and drag them into the 'My Top 10' column. This list is not finalized until you hit 'Finished,' so you can drag them back to the previous columns if you change your mind.

STEP 4: Drag your top 10 questions up and down to arrange them in order of importance of being answered by research.

STEP 5: Once you are satisfied with your Top 10 list, hit "Finished" in the upper right-hand corner.

Please click here if you would like to practice card sorting.

PLEASE NOTE: None of the questions in this survey will be lost. Even those that do not make the final 'Top 10 Myeloma Research Priority Questions' List will be reviewed by researchers and kept for other purposes such as creating FAQs, educational material, etc.

Categories:

- Holding
- My Top 10

Questions:

1. Can we use alternative medicines and therapies (e.g., mistletoe, curcumin, acupuncture, massage, meditation, and reiki) to manage the symptoms and side effects of myeloma among myeloma patients?
2. How effective are novel transplant procedures (e.g., allogenic or cord blood, donor stem cell transplant (SCT)?
3. How can we improve chemotherapy regimens for patients who are unable to have autologous stem cell transplant (ASCT) or want something less invasive?
4. How can we improve the diagnosing (e.g., faster, less invasive) of myeloma, and what is the impact of earlier diagnosis on patient outcomes (e.g., organ damage, bone deterioration)?
5. How can we prevent bone deterioration and/or repair bones that have been damaged without negative side effects (like those associated with bisphosphonates) or surgery?
6. Can cannabis be used to manage the symptoms and side effects of myeloma, reduce pain, improve sleep, and treat myeloma?
7. What are the environmental (e.g., radon, fertilizers, chemical exposure, etc.), physiological (e.g., lifestyle, smoking and alcohol) and genetic causes of myeloma?



8. How can we prevent decline in memory and mental functioning associated with myeloma and its treatment among myeloma patients?
9. What is the relation between myeloma and comorbid health conditions (e.g., diabetes, HIV, and osteoporosis), and how can these conditions be effectively managed while undergoing myeloma treatment?
10. What is the impact of myeloma and myeloma treatment on patients' daily living (e.g., independence, leisure, work), and how can we help patients return to their daily routines?
11. Does healthy eating, various diets (e.g., keto, sugar free, organic), vitamins, and supplements lessen the side effects and symptoms and improve disease outcomes?
12. How can we safely reduce, cycle, or stop the use of medications (e.g., Dexamethasone and Revlimid) to reduce the side effects of treatment and maintain control over myeloma?
13. How can we reduce or manage the short-term effects (e.g., diarrhea, nausea, fatigue, emotional challenges, skin reactions) and long-term effects (e.g., vision loss, loss of muscle strength) of myeloma treatment?
14. What is the risk to blood relatives of people with myeloma, and should they be monitored or tested routinely?
15. What genes are associated with the development of myeloma, and how can genetic testing be incorporated into the diagnosis and treatment of myeloma?
16. Can we develop treatments specifically for high risk or aggressive myeloma that will improve outcomes for these patients?
17. What is the impact of a holistic approach to myeloma management (i.e., psychological, faith and family, professional, and community life) on outcomes among patients?
18. How can we restore myeloma patients' immune functioning (e.g., IgG treatment) so that they might resume their daily activities (e.g., travel, work) without fear of infections?
19. Are novel immunotherapies (e.g., CAR T) effective for the treatment of myeloma?
20. What is the impact of a supportive caregiver on the outcomes of myeloma patients, and how can we help patients without caregivers manage without this support?
21. How compliant are myeloma patients with their medications, and what is the impact of medication adherence on disease outcomes?
22. How can we integrate mental health services into the treatment of myeloma to help patients and their families cope with the psychological effects of myeloma and its treatment, and what might this have disease outcomes and life expectancy?
23. What are new ways to monitor and/or treat the initial stages of myeloma (e.g. MGUS and smouldering myeloma) to delay or prevent the development of active myeloma?
24. How can minimal residual disease testing be applied in myeloma treatment to improve treatment efficacy and prognosis among people with myeloma?
25. What is the best way to administer drug therapy (e.g., infusion, subcutaneous, orally) that balances treatment efficacy and patient quality of life?
26. How can we best monitor myeloma (both active and in remission) that balances sensitivity to changes in the disease and burden on patients?



27. How can we prevent and/or manage the neuropathy associated with myeloma and its treatment?
28. What are new treatments for myeloma patients that will improve life expectancy with fewer adverse side effects (e.g., pain, nausea, neuropathy, immune suppression)?
29. How can we further refine the optimal drug regimen for newly diagnosed myeloma (e.g., drug combinations, sequence, frequency, and intensity)?
30. Does the earlier introduction to the palliative care team and regular follow-up improve outcomes (e.g., mental health and family communication) compared to end-of-life care only?
31. What are some non-opioid pain management strategies or medications to reduce pain among people with myeloma?
32. What are the underlying differences that contribute to patient variation in terms of symptoms and treatment responses, and how can we account for these differences in the diagnosis and treatment of myeloma?
33. 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?
34. What is the impact of physical activity on myeloma symptoms (e.g., bone health), mental health, and outcomes (e.g., treatment response, life expectancy)?
35. What steps can the health care system (e.g., vaccinations) and individuals (e.g., lifestyle) take to prevent the development of myeloma?
36. How does myeloma affect a person's relationships with family and friends, and what can be done to help them maintain and nurture these relationships?
37. What is the most effective way (i.e., drug combinations, sequence, frequency, and intensity) to treat refractory, relapsed, and drug resistant myeloma?
38. What is the impact of screening for myeloma in routine care (like mammogram or colonoscopy) on early detection?
39. What is the impact of myeloma and its treatment on sexual health (e.g., sex drive, contraception, etc.), and how can we help people with myeloma and their partners have healthy sex lives?
40. What is the impact of social support (e.g., family, friends, healthcare providers, support groups) on the mental and physical health of persons with myeloma and their caregivers?
41. How can the symptoms of myeloma (e.g., decreased physical and cognitive functioning, constipation) be managed?
42. What is the impact of timely access to myeloma care, including health services, supportive care, treatments, and clinical trials, for all patients, including those in rural areas?
43. How can we improve care coordination and supports to navigate the healthcare system, and what is the impact of improved care experience on patients well-being?
44. What is the impact (physical, mental, social, financial) of myeloma on caregivers, and how can we effectively support them (e.g., respite care, educational programs) to reduce their burden?
45. How can we cure myeloma?



Follow-Up Questions:

The next phase of this project involves a final workshop where the Top 10 Myeloma Research Priorities will be selected and ranked.

Are you interested in taking part in the workshop? Please note that we are not able to include all interested individuals.

Yes
No

Would you like to be informed of the progress of this project and the results?

Yes
No

If you answered "yes" to either of these questions, then please give your name and email address. Please note that this information will be kept confidential and will not be associated with your responses.

What is your name?

What is your email address?

Thank you for your participation.

Your answers will help to influence future research decisions in myeloma.

You may now close this window or navigate to another page.

Card Sorting Practice

Please complete the following fun exercise to learn about card sorting.

Instructions

Please select and rank your Top 5 favourite ice-cream flavours

STEP 1: In the left column is a list of ice-cream flavours. Please read the entire list and identify the ones that you like.

STEP 2: Drag any flavours that you like into the 'Holding' column to narrow down your list.

STEP 3: From the 'Holding' column pick the five flavours that you like **most** and drag them into the 'My Top 5' column. This list is not finalized until you hit 'Finished,' you can put them back into the previous columns if you change your mind.

STEP 4: Drag your 5 favourite flavours up and down to rank them in order of importance.

STEP 5: Once you are satisfied with your Top 5, hit "Finished" in the top right-hand corner.



Categories:

- Holding Column
- My Top 5

Cards:

- Chocolate
- Vanilla
- Strawberry
- Mint Chocolate Chip
- Chocolate Chip Cookie Dough
- Rocky Road
- Peanut Butter Fudge Crunch
- Salted Caramel
- Bubble Gum
- Cotton Candy
- Black Cherry
- Cookie and Cream
- Butter Pecan
- Maple Walnut
- Butterscotch
- Rum Raisin
- Almond Fudge
- Coffee
- Pralines N' Cream
- Strawberry Cheesecake

Thank you!

We hope this exercise made you more comfortable with card sorting. Please return to the previous window to complete the Myeloma PSP Prioritization Exercise.