



# Canadian Myeloma Priority Setting Partnership (PSP)

Do you have questions about myeloma? If so, we want to hear from you.

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## 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 about myeloma so that we can share your priorities with research funders. This is the time for you to be heard and influence important research that will have an impact on your life.

## Who should take part in this survey?

- People with myeloma
- Caregivers, family, and friends of people with myeloma
- Healthcare providers (including nurses, physicians, pharmacists, and others) who care for people with myeloma

## What is involved if I take part in the survey?

You will be asked to complete a brief survey about your own experience with myeloma and questions you have because of your experience. The survey will take about 10 minutes to complete and you do not need to answer any questions that you do not want to answer. You do not need to complete the survey all at once, you can save your progress and return later.

At the end of the survey you will be asked if you would like to take part in a second phase of this project by helping to decide which of the identified research topics are the most important. If you agree, you will be asked to provide your name and contact information.

## Will my answers be kept confidential?

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. Data will be securely stored at the Saint John Regional Hospital and destroyed after seven years.

## Who is supporting this survey?

This project 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 England.

### What will happen to the results?

Your question(s) will be gathered together and examined with questions we receive from everyone else who takes part in this survey. We will combine similar questions into summary questions and check to see if these have been answered by research. Questions that have not been answered by research will be sent out in a second survey so that they may be prioritized. Based on responses to the second survey, a steering group of persons with myeloma, caregivers, and healthcare providers will make a top 10 list.

The list will be published and will be used to influence future research decisions.

### Who can I contact for more information?

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

**Lauren Cook – Myeloma Priority Setting Partnership Coordinator**  
Maritime SPOR SUPPORT Unit, Saint John Regional Hospital  
400 University Avenue  
Saint John, New Brunswick E2L 4L2  
Email: [Lauren.Cook@HorizonNB.ca](mailto:Lauren.Cook@HorizonNB.ca)  
Tel: (506) 638-2410

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

**By answering the questions that follow, you are consenting to participate in this project.**

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

## STEP 2: Your Information

In this step, we ask for your problems and challenges related to myeloma. When answering think about your understanding of myeloma, this is what makes you an expert. Your question(s) can be about whatever you think is important and went unanswered for you.

When answering, remember that research can be very broad. Researchers study many aspects of myeloma from tiny changes in cells to the effects of social support for patients and caregivers.

Do not worry about which box to write your question(s) in. Some questions may seem similar or overlapping. If so, when you write your question(s), you can use any box and we will analyse the responses.

Do not feel like you need to check if there is already research on your question(s). We will check if there is research that has answered the questions.

1. What question(s) about the **diagnosis** of myeloma would you like to see answered by research?

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2. What question(s) about the **treatment** of myeloma would you like to see answered by research?

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## STEP 2: Your Information

3. What question(s) about the **management** of myeloma (e.g., symptoms, side effects, navigating health services etc.) would you like to see answered by research?

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4. What question(s) about **living well** with myeloma (e.g., mental health, relationships, leisure etc.) would you like to see answered by research?

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5. What **other** question(s) about myeloma would you like to see answered by research?

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## STEP 2: Your Information

**Please complete the following section to the best of your abilities.** This will help us keep track of who is completing the questionnaire and make sure we hear from all groups.

6. In relation to myeloma, which role best describes you?

- Person with myeloma
- Caregiver of a person with myeloma
- Healthcare provider for people with myeloma
- Other, please specify:

7. What is your gender?

- Male
- Female
- Other

8. What is your age in years? \_\_\_\_\_

9. What is your race (check all that apply)?

- Indigenous (First Nations, Inuit, and Métis)
- Arab or West Asian
- Black
- Chinese
- Filipino
- Japanese
- Korean
- Latin American
- South Asian
- South East Asian
- White (Caucasian)
- Other, please specify:

10. 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

## STEP 2: Your Information

11. Which category best describes the community in which you live or practice?

- Very large population center (more than 500,000)
- Large population center (100,000 – 500,000)
- Medium population center (30,000 – 99,999)
- Small population center (1,000 – 29,999 people)
- Rural area (less than 1,000)
- Do not know

**Complete questions 12 and 13 if you are a person with myeloma:**

12. How many years ago were you diagnosed with myeloma? \_\_\_\_\_

13. Are you currently receiving treatment for myeloma (including maintenance therapy)?

- Yes
- No

**Complete question 14 if you are a partner, relative, or friend of a person with myeloma:**

14. How many years ago was your family member or friend diagnosed with myeloma?

\_\_\_\_\_

**Complete questions 15 and 16 if you are a healthcare provider to people with myeloma:**

15. What is your healthcare profession?

- Physician
- Nurse
- Pharmacist
- Other, please specify:

16. How many years have you been caring for people with myeloma?

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\_\_\_\_\_

**Thank you.**

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

**Please answer a few questions regarding the follow-up to this survey  
on the following page.**



The next phase of this project involves putting the research topics identified from this questionnaire into order of importance. Are you interested in taking part in the next phase?

- Yes
- No

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

- Yes
- No

If you answered “yes” to either of these questions, then please provide your name and contact information below. Your name and contact information will be kept confidential and will not be associated with your responses.

Your Name: \_\_\_\_\_  
Email: \_\_\_\_\_  
Tel: \_\_\_\_\_

How would you prefer to be contacted?

- Email
- Mail

If you would like to be contacted via mail, please complete the section below:

Street Address: \_\_\_\_\_  
City/Town: \_\_\_\_\_ Prov: \_\_\_\_\_  
Postal Code: \_\_\_\_\_

You may also provide your contact information by contacting the project office:

**Lauren Cook – Myeloma Priority Setting Partnership Coordinator**  
Maritime SPOR SUPPORT Unit, Saint John Regional Hospital  
400 University Avenue, Saint John, New Brunswick E2L 4L2  
Email: [Lauren.Cook@HorizonNB.ca](mailto:Lauren.Cook@HorizonNB.ca)  
Tel: (506) 638-2410

**Thank you for your time and collaboration.**

If you are interested in learning more about Myeloma Canada or joining their community please visit [www.myelomacanada.ca](http://www.myelomacanada.ca).