



Canadian Myeloma Priority Setting Partnership (PSP) – Phase II Frequently Asked Questions

Note: This document addresses questions resulting from participation in the 1st Myeloma Priority Setting Partnership (PSP) survey which closed in January 2020, as well as the 2nd survey which is currently underway.

To find out more about the Myeloma PSP, please [click here](#).

1ST SURVEY (closed)

Why is my question not included in this survey?

The 1st survey yielded 3,032 questions! We want to sincerely thank everyone who completed the 1st survey for your thoughtful comments and questions. Similar questions were combined into summary questions which were then checked to see if they had been already been answered by research. We appreciate all the responses that we got from the 1st survey, however, only those that were unanswered by previous research and were within the scope of our project were included in this 2nd survey.

What happened to the original questions I submitted?

The Myeloma PSP steering group and support team carefully examined each question that was received from the 1st survey, combined similar questions into summary questions, and checked to see if any had been answered by previous research. Only those that were unanswered by previous research and fell within the scope of our project were included in this 2nd survey.

What will happen to the questions that did not get included in the 2nd survey?

Questions not included in this 2nd survey are definitely not lost; they will be used to create FAQs and other useful material. These questions will be available on the [Myeloma Canada](#) and/or the [James Lind Alliance](#) (JLA) websites once the larger Myeloma PSP project is finished.

2ND SURVEY (underway)

How can I participate in completing the survey?

This 2nd survey is online and participating is very easy. Simply go to <http://bit.ly/Myeloma10> or visit myeloma.ca/PSP and follow the instructions. The survey will open on November 18th, 2020 and will run for approximately 6 weeks.

Can I be involved in the 2nd survey if I took part in the 1st one?

Yes, whether you participated in the 1st survey or not doesn't make any difference! **The survey is open to all people living in Canada with myeloma, their caregivers, as well as clinicians and healthcare professionals working with those impacted by myeloma.**

MYELOMA



Why is the Myeloma PSP asking for my location and role?

We want to make sure that the Myeloma PSP reaches as many people as possible, and that the research priorities we receive through the survey are representative of the opinions of all people affected by myeloma. Being able to track this information (which will be kept anonymous and separate to any contact information you may provide) will help us do just that.

How will the Myeloma PSP use and store my information?

As was the situation with the 1st survey, this survey is also anonymous and confidential. The information you provide will be kept on secure servers and will only be used to help develop the short-list of questions for the final Myeloma PSP workshop.

We're collecting optional contact information so that we can get in touch with you to see if you'd like to take part in the follow-up workshop as well as to let you know about the results of the project. Rest assured that we will not be using your information for fundraising or any other purpose, and that you are under no obligation whatsoever to give your contact information or participate in the workshop even if you do provide us with your contact information. You are always free to change your mind!

AFTER THE 2nd SURVEY

What will happen to the questions I choose?

The 2nd Myeloma PSP survey will help reduce the long list of questions obtained from the 1st survey to create a short-list of the most popular questions. This short list will then be brought forward to the final stage, an online workshop involving people impacted by myeloma and healthcare professionals. Together, they will determine the Top 10 Myeloma Research Priority Questions.

What will happen to the questions that will not be part of the final Top Ten Priority list?

None of these questions will be lost either. Those that don't make the final 'Top 10 List' will be reviewed by researchers and kept to create educational materials and content.

Can I be involved in the final workshop?

Possibly! A limited number of people can take part in the final workshop. It's important for us to ensure that we have as wide representation as possible, so it may not be possible for everyone who is interested to be involved. Anyone who expresses interest in participating and has provided their contact information will be considered.