

Priority Setting
PARTNERSHIP

MYELOMA



PARTNER COMMUNICATION GUIDE

PLEASE DO NOT SHARE THE SURVEY BELOW UNTIL OCTOBER 29, 9:00 AM (EST)

Why is Myeloma Canada investing in this Priority Setting Partnership (PSP)?

As a grassroots charitable organization, it is vital to Myeloma Canada that the research they fund and support reflects the needs of Canadians impacted by myeloma. The Myeloma Priority Setting Partnership (PSP) involves and empowers those affected by myeloma to play an active role in the decisions that surround their healthcare journey. This crucial project is guided and overseen by a steering group that includes people living with myeloma, caregivers, and healthcare providers.

You are a valued partner on this exciting and important initiative, and so we need your help in sharing the Myeloma PSP survey with your network. By hearing the research priorities of the myeloma community, we can push the funders, scientists and service providers to recognize the views and needs of those affected and get their questions answered.

Survey link: <http://bit.ly/MyelomaPSP>

Why is this project important?

The Myeloma Priority Setting Partnership is a program focused exclusively on identifying the research priorities of people living with myeloma, their caregivers and healthcare professionals. Our objective is to give the Canadian myeloma community a louder voice, because no one understands myeloma better than those whose lives have been impacted by it. The Myeloma PSP will help set the right direction for myeloma research and call to funders to recognize these prioritized, unanswered questions.

How does it work?

The Myeloma PSP survey will be open as of **October 29, 2019**. Respondents will be asked to complete an anonymous survey to identify the questions they most want to see answered through research.

Once the survey closes, the Myeloma PSP team will go through all the questions received to ensure that they haven't already been answered by previous research. Questions that have not yet been addressed will be grouped together to create the questions for a 2nd survey. The 2nd survey will be sent to anyone from the 1st survey who provided their contact information and indicated that they would like to continue participating in the project. In the 2nd survey, participants will be asked to rank the questions based on what they would like to most see answered. This will help reduce the long list of questions to a short list. This short list will then be brought forward to the final stage: a face-to-face workshop involving people impacted by myeloma (patients, caregivers) and healthcare professionals. Together, they will determine the Top 10 Research Priority Questions.

These Top 10 Research Priority Questions will be shared and promoted to encourage funders to commission researchers to answer the prioritized questions. The entire process is overseen by a UK-based, non-profit organization called the James Lind Alliance (<http://www.jla.nihr.ac.uk/>).



What will happen on October 29, 2019?

Myeloma Canada will launch the Myeloma Priority Setting Partnership program via:

1. **email broadcast** — to all patients and caregivers in the Myeloma Canada database;
2. **social media** — Facebook and Twitter;
3. **landing page** — a Myeloma Priority Setting Partnership landing page (www.myeloma.ca/PSP) will be set up on Myeloma Canada's website where links to all pdfs, including the survey, will be available;
4. **web banner on Myeloma Canada's homepage** (www.myeloma.ca) — to create awareness for the survey as well as direct visitors to the Myeloma PSP landing page.

How can you help spread the word?

- **Forward this link:** <http://bit.ly/MyelomaPSP> to your database — you may have names that are not in the Myeloma Canada database;
- **Share the social media banner on your outlets** — tweet about it, post it on Facebook. Spread the word! Share the web banner and add it to your website;
- **Distribute as many posters as you can** so that those not in the Myeloma Canada database, or your database, will have a chance to learn about the program. Let's get the word out to as many people impacted by myeloma as possible;
- **Advise the Myeloma PSP coordinator of other appropriate partners who could be involved.**

After launch, until survey closing:

- Continue to share the survey link on your social media outlets and via email lists;
- Retweet @MyelomaPSP's tweets about the survey.

Survey link: <http://bit.ly/MyelomaPSP>

The Myeloma Priority Setting Partnership is led by Dr Tony Reiman, Canadian Cancer Society Research Chair and medical oncologist. The program is proudly supported and funded by Myeloma Canada and guided by the James Lind Alliance. This study has been approved by the Horizon Health Network Research Ethics Board (RS 2019-2788).

Key Myeloma PSP Information

LAUNCH DATE OF 1st SURVEY:
October 29, 2019

SURVEY LINK:
<http://bit.ly/MyelomaPSP>

WEBSITE:
www.myeloma.ca/PSP

LAUNCH DATE OF 2nd SURVEY:
TBD

It usually takes a few months to consolidate and verify all questions from the 1st survey and prepare for the 2nd survey. We will be in touch once we have a better idea of what timeframe we're looking at.

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Hashtag: #MyelomaPSP

