

Patient and Care Partner Programs

2023 Impact Report: Survey Results Summary

The goal of the Patient and Care Partner Programs is to engage, educate, and empower patients and care partners to improve their outcomes through their whole myeloma journey. In 2023, the IMF partnered with Evaluation into Action LLC to understand the impact of the Patient and Care Partner Programs on participants, focusing on three specific programs:

"I am informed, feel part of a community, have greater hope for the future."



Regional Community Workshops

Half-day educational events customized for local myeloma communities that offer information, resources, and support.

Patient and Family Seminars

Two-day educational events that provide information on treatment advances, novel therapies, supportive care strategies, and clinical trials.

Myeloma Support Groups

Peer-led local or virtual communities that offer a space where those affected by myeloma can come together for emotional support, practical education, and empowerment.

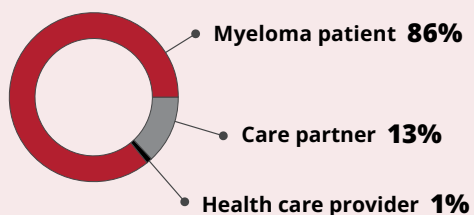
Overview

This report summarizes key findings from a 2023 survey of people who participated in one or more of these three programs in the past year¹. The survey results showed these programs improved the participants' knowledge of myeloma and treatment options, their connection to others in the myeloma community, and their sense of hope as they faced a serious health challenge. The following section explains the impact that these programs had on participants and describes the specific ways in which they experienced growth in knowledge, connection, and hope.

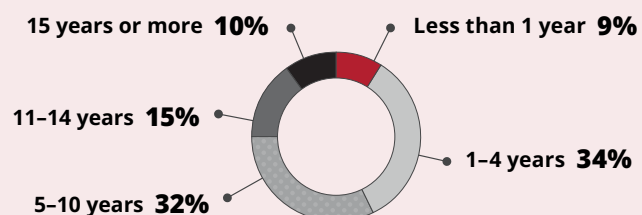
¹ Online survey link emailed to 1,458 unique email addresses of those who had participated in one or more of the programs. A total of 197 responses were received yielding a 14% response rate.

Survey Participation

Survey Participants



How long have you been navigating the myeloma journey?



Results: Impact

As a result of participation in program activities, change is expected in the three key areas described below.

Knowledge. To increase knowledge of the latest research and treatment options so patients and care partners can make informed decisions about their care.

The greatest impact of these programs resulted from the education that patients and their care partners received. They explained how their growth in understanding of the disease, the available treatments, and ongoing research helped to alleviate their stress and build their confidence in making the best decisions for themselves on their cancer journey.

- **95% of respondents reported that their understanding of myeloma had increased.**
- **95% said their knowledge about the latest research had expanded.**
- **93% stated their knowledge about treatment options was better.**
- **85% felt their ability to make informed health-care decisions had improved.**



“The up-to-date information and willingness of presenters to share the positives and challenges honestly, directly, and in a way that is understandable has helped me be able to navigate this journey, advocate for myself, ask questions, and sometimes even provide new information to my team.”

“These programs have kept me abreast of the latest treatment options and [have provided] a better understanding of myeloma.”

“Being better informed gives me more control of my treatment.”

Connection. To facilitate increased information exchange through connecting patients/care partners with experts as well as with each other.

Opportunities to connect with others who share the myeloma journey was a key area of impact for nearly a quarter of survey respondents. Participants shared that these connections resulted in not only an increase in knowledge for managing life with myeloma, but a stronger sense of community and support. Many expressed gratitude for these opportunities and described what this meant for them. As one participant shared, “I value these in-person seminars very much as I learn new things and have the chance to interact with patients and doctors.”

When connecting with others, **56% reported that they exchanged information.** The **most common type of information shared was general conversation on navigating the myeloma medical journey (73%).** Other sharing included: **online educational resources (52%), suggestions about experts who can help (48%), and information about being part of a support group (44%).**



“Being able to connect, meet with others, and talk to the experts is very critical.”

Hope. Strengthen engagement with the myeloma community to serve as a source of emotional support and increase a sense of community.

Facing a myeloma diagnosis can feel overwhelming and IMF's Patient and Care Partner Programs aim to lessen this feeling. **As a result of program participation, 67% of survey respondents felt more emotionally supported, with 82% feeling an increased sense of hope.** Participants noted that hope stemmed from becoming more knowledgeable, learning about research focused on a cure, and feeling supported by those with whom they share the cancer journey. **"I am informed, feel part of a community, [and] have greater hope for the future,"** explained a participant.

Most (73%) experienced an increased sense of community that served as a source of strength and support. "Every single person I spoke to whether a doctor, nurse, attendee, or IMF staff was gracious, informative, really listened (not looking off to find who they were going to talk with next), and really made me feel like I belonged in this group that no one really wants to join." Some who have been navigating myeloma for a longer period of time have been inspired to reach out to newly diagnosed patients to offer support and guidance, continuing to build community.



"When I first was told about this disease I was scared and felt helpless. The conversations and meetings have made me feel hopeful and I feel so much better."

"Knowing we're not alone and there is much to be hopeful for."

Conclusion

The Patient and Care Partner Programs aim to help participants cope with their myeloma journey by engaging, educating, and empowering them. While the survey results illustrated the program's impact, they also revealed suggestions for improvement. The three most frequently cited areas were: offering more customized educational content to meet the needs of diverse patient groups, providing greater opportunities to connect, and improving accessibility and inclusion. The IMF is currently exploring ways to address these suggestions and appreciate ongoing feedback to best meet the needs of the myeloma community.

The survey results showed positive impacts on program participants across all three defined outcome areas. Program participants gained more knowledge about myeloma, treatment options, and research advances. This knowledge helped them manage their cancer journey better, make informed treatment choices, and advocate for themselves more effectively. The participants also felt more hopeful and supported as a result of connecting with other people in the myeloma community and learning about the efforts to find a cure. The IMF Patient and Care Partner Programs are making a difference in the lives of those navigating the myeloma journey by increasing knowledge, building community, and inspiring hope.



This report was prepared in partnership with
Evaluation into Action, LLC

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