



About the Myeloma UK Advocacy Partner Panel (APP)

Making the patient voice count

What is the Myeloma UK Advocacy Partner Panel?

The Myeloma UK Patient Advocacy team makes sure the patient voice counts with decision makers. We press for access to new treatments and improvements in care and services to help patients live longer and with a better quality of life.

Our Advocacy Partner Panel (APP) helps shape our advocacy work with politicians, Government and senior figures in the NHS, drug approval bodies and industry.

APP members share their insight, views and experiences on important issues in myeloma with Myeloma UK and other influential organisations and decision makers. The role has a national focus, both at a UK level and across the devolved nations.

Appointments are for an initial period of three years, with members attending one to two panel meetings each year, as well as other external events. Members also receive requests for feedback or advice on an ad hoc basis.

As part of the Myeloma UK Advocacy Partner Panel, members will have opportunities to:

- Help us shape our future advocacy work programme
- Work with Myeloma UK in engaging with external stakeholders such as parliamentary groups and drug approval bodies, attending meetings and taking part in workshops
- Share personal experiences of myeloma and services for media opportunities
- Respond to requests for comment and feedback on consultation documents and responses
- Participate in both Myeloma UK and external events and meetings

The Advocacy Partner role does not include general awareness-raising, fundraising activities or providing peer support, either locally or through Myeloma UK services. Myeloma UK offer lots of opportunities to be involved with this type of work through other volunteering activities, and it is possible to be a member of the APP and still take part in those activities.

What skills and experience are needed?

We will review applications against the criteria below. This is to ensure that applicants understand what the role of Advocacy Partner involves, the skills required and to help ensure that our appointment process is fair and transparent.

APP members should:

- Be interested in, or have experience of, policy and influencing with a desire to learn about the work of Myeloma UK and the wider policy landscape
- Listen to and engage with others respectfully
- Respect confidentiality
- Understand the demands of working within a complex and sensitive policy environment
- Have the ability to be objective and represent the needs of myeloma patients and their friends and families
- Have good communication skills
- Work constructively and collaboratively, respecting difference and understanding the need for compromise
- Commit to around one day a month, including attendance at one to two Advocacy Partner Panel meetings (virtual or in-person) each year
- Be over 18 years old

What are the benefits of becoming an APP member?

- **The opportunity to contribute to Myeloma UK's advocacy work** – Partners will be able to share their opinions and experiences with Myeloma UK and with the people who have the power to make a difference
- **Support from Myeloma UK in generating new skills and experience** – We will support our partners in their involvement and representation by providing skills development and relevant information and hope that over time partners develop expertise in particular policy areas that reflect their skills, interest and experience
- **Expenses** – Myeloma UK will cover reasonable travel, subsistence and accommodation expenses
- **Networking** – Partners will be able to meet others who are living with everything that a diagnosis of myeloma brings with a shared interest in policy issues

Who can volunteer for the Advocacy Partner Panel?

Anyone with personal (non-professional) experience of myeloma can become a member of the Advocacy Partner Panel, i.e. patients with a diagnosis of myeloma, smouldering myeloma or an associated condition such as AL amyloidosis, and carers, friends and family. No experience in advocacy or policy is needed. By being personally affected by myeloma, our partners will bring a valuable contribution through their experiences.

We aim to recruit 15–20 partners in the initial panel. Successful recruitment will reflect the diversity of the myeloma patient population and experience. It may be that we are not able to accommodate all the expressions of interest in the role that we receive. If so, we hope we will be able to work with applicants in other aspects of our advocacy work. We recognise that circumstances may change and it will not always be possible for partners to participate. Therefore partners may choose to end their involvement at any time.

Panel membership is initially for three years with the opportunity to extend. We understand that circumstances change and you may, of course, choose to leave the panel at any time.

How can I join the Advocacy Partner Panel?

Please complete the online application form at:

myeloma.org.uk/research-and-patient-advocacy/advocacy-partner-panel

The Myeloma UK Patient Advocacy Team will acknowledge your application within two weeks.



For more information on the Advocacy Partner Panel process
please contact the Patient Advocacy Team

 0131 557 3332

 policy@myeloma.org.uk

 myeloma.org.uk