

# Myeloma UK Patient and Carer Research Panel

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## Information and Application Form

### Myeloma UK Research Programme

The Myeloma UK Research Programme is an ongoing active partnership between people living with myeloma, carers and family members and the research community. As the only national charity dedicated to myeloma in the UK, Myeloma UK is tackling issues experienced by people living with a myeloma diagnosis today, and conduct research that will lead to a better future for everyone affected by myeloma.

We target our research into areas that show the most promise and will make the most difference to those living with myeloma. From unravelling the intricacies of myeloma genetics and discovering and testing new ways to treat myeloma, to understanding how health services can better meet the needs of patients, our research is sharply focused on improving the lives of everyone affected by myeloma.

### What is the Patient and Carer Research Panel?

People affected by myeloma are the driving force behind all our research decisions, ensuring that we use limited resources wisely and only carry out research that is high quality and strategically important. All our research is aligned to our organisational strategy, which is driven by and centred on patients.

Our research benefits hugely from having patient and carer involvement and we're constantly seeking new opportunities for people to get involved and contribute to our Research Programme.

Our Patient and Carer Research Panel brings together volunteers who are directly affected by myeloma and who have an interest in research. It will consolidate a range of opportunities for volunteers to help ensure our research is the best it can be and makes the biggest difference to patients and families. Panel volunteers will have opportunities to:

- Put forward ideas and suggestions for research
- Comment on applications for funding
- Review surveys and other research materials
- Get involved in individual research projects as members of steering groups
- Communicate with others about the results of research

By sharing their views on being involved in the pilot, volunteers will also be key to helping us expand the Patient and Carer Research Panel in the future.

## Who can volunteer for the Patient and Carer Research Panel?

If you have personal (non-professional) experience of myeloma, either as a myeloma patient, a carer/family member or a former carer you are invited to become a volunteer in our pilot Patient and Carer Research Panel.

You do not need any experience in research and whatever your experience you will be able to contribute. Your views and opinions are what counts and we will provide you with support and tips to help you participate in different activities.

We recognise that your circumstances may change and it will not always be possible to participate. You can choose to put your membership on hold at any time and you can get involved in as much or as little as you choose.

## How does it work?

The Patient and Carer Research Panel will operate flexibly to accommodate opportunities that may arise and we will communicate with volunteers regularly about opportunities for getting involved.

Operating as a virtual group means that anyone can take part. We will communicate with you by email and phone.

There may be opportunities to take part in face-to-face meetings too, for example, to participate in a focus group. If you choose to do this we will ensure that your travel and accommodation needs are met in line with our organisational guidance.

## How can I join?

1. Complete the application and conflict of interest forms in this pack.

2. Return both forms to us by post or email:

Research Team  
Myeloma UK  
22 Logie Mill  
Beaverbank Business Park  
Edinburgh EH7 4HG.

[research@myeloma.org.uk](mailto:research@myeloma.org.uk)

3. Your application will be acknowledged within two weeks and you will receive a confirmation and welcome email.

# Myeloma UK Patient and Carer Research Panel



## 1. Application Form

### I want to volunteer for the Patient and Carer Research Panel.

- I am a myeloma patient
- I am a carer or family member of a myeloma patient
- I am a former carer or family member of a myeloma patient

### Personal details

Title:	<input type="checkbox"/> Mr	<input type="checkbox"/> Mrs	<input type="checkbox"/> Miss	<input type="checkbox"/> Ms	<input type="checkbox"/> Dr	<input type="checkbox"/> Other (please specify)	<input type="text"/>
First Name:	<input type="text"/>			Surname:	<input type="text"/>		
Address:	<input type="text"/>						
	<input type="text"/>				Postcode:	<input type="text"/>	
Phone:	<input type="text"/>			Mobile:	<input type="text"/>		
Email:	<input type="text"/>						

### Background information

Please write a few paragraphs of background information about yourself below, including your personal experience of myeloma. The Myeloma UK Research Team will treat this information in confidence. This information will help us get to know the members of the Patient and Carer Research Panel and, if appropriate, invite individuals to take part in projects that may be of particular interest or relevance.

Please continue typing overleaf >

## Background information (continued)

## Confirmation and your data

Myeloma UK will not disclose or share any confidential service user or supporter data with pharmaceutical companies or their agencies. Data Protection law including the General Data Protection Regulation, Regulation (EU) 2016/679 sets out the principles we must adhere to and other conditions which must be satisfied. Full details of our privacy policy can be found at <https://myeloma.org.uk/privacy-policy>.

I would like to volunteer for the Myeloma UK Patient and Carer Research Panel. I understand that my personal details will be kept securely and entered onto the Myeloma UK database. I understand that this information will be kept in accordance with data protection law, and General Data Protection Regulation.

I am happy for Myeloma UK staff to contact me by: **(please tick as appropriate)**

post     phone     mobile     email

I am happy for my contact details (please tick as appropriate) to be circulated to other Research Panel Members for networking purposes.

address     phone number     email

Signed:

Print name:

Date:

# Myeloma UK Patient and Carer Research Panel



## 2. Potential conflict of interest form

If you are in one of the categories listed below then volunteering for the Patient and Carer Research Panel may result in a potential conflict of interest.

- Employee of Myeloma UK
- Employee at a university or other organisation receiving funds from Myeloma UK
- Employee of a pharmaceutical company
- Owner of shares in a pharmaceutical company that currently markets medication relevant to myeloma treatment, or plans to
- Government/NHS policy maker

Please consider whether for this, or for any other reason, your membership could result in a conflict of interest and then tick the appropriate statement and sign below.

**Note:** a potential conflict of interest will not exclude you from membership of the Patient and Carer Research Panel. However, it may exclude you from specific activities relating to particular projects.

I confirm that there is no potential conflict of interest as a result of my potential membership of the Patient and Carer Research Panel

OR

I have to declare a potential conflict of interest as a result of my potential membership of the Patient and Carer Research Panel

Declaration details:

### Confirmation

Signed:

Print name:

Date:

### For more information

For any queries on the Patient and Carer Research Panel process please contact the Research Team.

0131 557 3332 [research@myeloma.org.uk](mailto:research@myeloma.org.uk)

Email your completed form to [research@myeloma.org.uk](mailto:research@myeloma.org.uk) as an attachment, or print and post to: Myeloma UK, 22 Logie Mill, Beaverbank Business Park, Edinburgh EH7 4HG.

[myeloma.org.uk](http://myeloma.org.uk)

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