

## **Reference group member role information - December 2022**

### **What is the overall aim of the project that the reference group contributes to?**

Macmillan recognises that there is a need for more and better cancer information and support in East Sussex. For this reason, Macmillan has invested in a new project to develop service solutions. Our goal is to build a better future for people affected by cancer. We will do this by working together with a reference group of people in the local area to:

- identify priorities for improving cancer information and support
- generate ideas for how improvements could be made
- design services that fill gaps in cancer information and support provision
- launch new services and/or deliver improvements to existing ones

### **Where and when will meetings be?**

We will have two separate reference groups, with one meeting in Hastings and another meeting in Eastbourne. You would only be part of one group – whichever is nearest to where you live.

Our meetings will take place monthly, in person for 60-90 minutes. Initially meetings will be scheduled for daytime hours so no one has to travel in the dark. We're open to reviewing this and alternating between daytime and evenings in future if we find interested people who can only attend evening meetings.

### **What activities will I be involved in?**

In this role, you will not be directly providing support to other people going through a cancer experience. Instead, you will be helping Macmillan staff to shape our plans for developing local cancer information and support services. We hope that you will find this a rewarding way to make a positive impact for people affected by cancer.

In a typical meeting, we will begin with an update from Macmillan staff on how the project has progressed since the last meeting, followed by some small group or whole group discussions about some key topics where staff would appreciate a lived experience perspective to help inform decision-making. Meetings will be focussed on the topics outlined in the agenda for that meeting, rather than being an open forum for all feedback about cancer experiences.

As an example, members could be asked to prioritise which problems to tackle, share opinions on where a service should be, describe what a potential service could look like, or vote on some options where it's not possible for all service ideas to be taken forward. These are examples and there will be other similar activities that happen at the meetings on different topics related to the project. Final decisions about services will be taken by Macmillan staff and partner organisations, taking lived experience views into account.

### **What skills or experience do I need to join the reference group?**

If you have had a cancer experience, either being diagnosed yourself or a carer, we would love you to consider joining the new reference group. We would ask that you commit to attending the monthly meetings throughout 2023 but we will always understand if your health means you're unable to make it.

You don't need any particular skills. We're looking for people who would be happy to take part in the activities described in this document. You don't necessarily need to see yourself as an 'ideas person' and you won't be expected to solve the problems for us. We just want your opinions and your willingness to tell us what you think, given that you have valuable lived experience for us to combine with our professional insights.

### **Why do you want to involve people with lived experience?**

We're looking for people who have lived experience of cancer to help us develop cancer information and support services. Helping in this sort of way is sometimes called being an 'expert by experience'. Although not everyone feels like an 'expert' in cancer because they've experienced cancer, we recognise that there is huge value in the insights that you have gained through your lived experience. You know what it was like for you, what worked well, what wasn't so great, and what would have made a difference to you. These are the things we want to hear and this is the perspective we want to keep involved with our service development work at every stage of its progress.

We're committed to giving a platform and meaningful involvement opportunities to people who have had cancer themselves. We do this because we passionately believe that people who have experienced cancer themselves need to have a voice and a role in decision-making in our service development work. By doing this, we can ensure that we're working together to build services that best serve the real needs of the community.

### **What training, support and guidance will there be?**

- You will have a named staff contact that you can talk to any time about your involvement experience - Macmillan's Information and Support Services Development Manager for East Sussex
- If you would like any training to support you to be involved as a steering group member, we may be able to arrange this
- If your involvement stirs up difficult feelings, you will be welcome to take a break at any time and we can signpost you to sources of support

### What are the benefits to me?

- Using your lived experience to help shape the immediate and medium-term future of cancer information and support for people in your local area, and improve the lives of people affected by cancer
- Feel more connected to your community by helping to make positive change
- Experience of co-production and co-design of services

### What else should I know?

- We will reimburse your out-of-pocket expenses within agreed guidelines.
- We want everyone to have an inclusive experience as a Macmillan volunteer. If you have any support, access or cultural needs relevant to your volunteering that you'd like to discuss with us, we welcome this.

### How do I let you know I'd like to join the reference group?

Please contact Megan Preston on [mpreston@macmillan.org.uk](mailto:mpreston@macmillan.org.uk) or call or text 07736 276652.

If you would like to be involved but your personal circumstances would make it difficult to do so, please speak to us. We may be able to offer additional support to enable you to participate in the group.