

MESOTHELIOMA UK

Mesothelioma UK Research Centre (MURC) – Patient & Public Involvement (PPI) Panel

Guidance for Researchers

This guidance document is aimed at mesothelioma researchers who want to consult the MURC PPI panel.

The PPI panel is made up of around 20 individuals with personal experience of mesothelioma. This includes people with mesothelioma, family members, carers, friends and bereaved family members. The role of the PPI panel is to give advice and guidance about mesothelioma research, in order to improve the design, implementation and dissemination of research.

The PPI panel have quarterly on-line meetings and regular e-mail contact between meetings. If you would like to attend a meeting to present your research, or make a request to the panel by e-mail please contact Prof Clare Gardiner (c.gardiner@sheffield.ac.uk).

Top tips

We hope the following tips will help you get the most out of working with the PPI Panel:

- When attending a meeting or sending a request by e-mail please ensure you provide a suitable lay summary of your research, this should be no more than one side of A4 and written in lay language, avoiding technical/scientific terms. Advice on how to prepare a lay summary can be found <u>here</u>.
- Rather than make a request for generic feedback on a document or proposal we suggest asking 3-4 specific questions e.g. is the research important, are the methods acceptable to mesothelioma patients, is the research ethically acceptable etc.
- Please ensure you give the PPI panel enough time to feedback on research, we suggest a minimum of one month between making a request and any deadline.
- Where possible, try and minimise the number of documents you send with any e-mail request.
- For requests which involve reviewing a larger number of documents, we suggest attending a meeting rather than asking for feedback via e-mail. Meeting slots are usually 10-20 minutes long.
- The PPI panel act as a bank of advisors and individuals choose which research they want to contribute to. Unfortunately this means we cannot guarantee a response to every request.
- All PPI panel members are unpaid volunteers and many have other working/caring responsibilities. Please be mindful of this when considering requests and deadlines.
- More advice about working with patients and the public can be found <u>here.</u>

More details about the PPI Panel can be found on our website: https://www.sheffield.ac.uk/murc/patient-and-public-involvement