



Mesothelioma UK Research Centre -Sheffield

Patient and Public Involvement panel

TERMS OF REFERENCE

Background

The Mesothelioma UK Research Centre (MURC) at The University of Sheffield is funded by the charity Mesothelioma UK, and was established in 2020. We conduct a portfolio of robust and rigorous research with a reputation for excellence, to benefit the care of people diagnosed with mesothelioma and their families.

Purpose / role of the Patient and Public Involvement Panel:

The role of the MURC Patient and Public Involvement (PPI) panel is to give advice and guidance to researchers from the MURC, and other UK mesothelioma researchers. The aim in setting up the PPI panel is to harness the skills and perspectives of interested patients, carers and members of the public in order to improve the design, implementation and dissemination of our research.

The aims of the MURC PPI panel are to:

- Ensure our programme of research responds to the priorities of patients with mesothelioma and their families.
- Provide open and transparent advice on specific projects, in line with individual panel members areas of interest e.g. research methods, recruiting patients, collecting data and ethical issues.
- Help suggest ideas for new research areas, and prioritise research areas
- Assist in raising awareness of research.
- Advise on ways of sharing results and publicising our research.
- Help us develop links with relevant patient and carer organisations, advocacy groups, charities etc.
- As requested, advise other UK mesothelioma researchers on projects and studies related to mesothelioma.

Membership:

Anyone with personal experience of mesothelioma can join the MURC PPI panel. This includes patients, family members and friends, and interested members of the public. Group members may leave the PPI panel at any time.

Working Methods and Meetings:

- The PPI panel will operate as a 'bank' of advisors who will be contacted when their expertise is required.
- We will contact you by e-mail with requests for advice, or to contribute to a project. You will be under no obligation to be involved in every project or request for advice. It will be entirely up to you, depending on your availability and expertise.
- You will be invited to quarterly meetings to review progress and discuss future activity.
- Additional meetings will be held when required with appropriate members depending on the topic/project.
- Meetings will be conducted by e-mail, teleconference or face to face depending on convenience and COVID restrictions.
- You may also be invited to advise other UK mesothelioma researchers on studies outside of the MURC.
- In the main, meetings will be conducted jointly with patients, family carers and bereaved family carers. However we acknowledge the potential for upset or distress (i.e. if a bereaved family member reflects on their experiences of death/dying, this could be upsetting for people currently living with mesothelioma.) Therefore we ask panel members to be mindful of others' situations when sharing experiences. In addition, where an item for discussion within a meeting is deemed sensitive or potentially distressing (e.g. palliative care, bereavement, end of life) this will be flagged in advance so members may choose not to attend. In addition, any sensitive topics will be discussed at the end of a meeting so members can leave early if they wish. If group members have any experiences they would like to share, but would feel uncomfortable sharing with the group, please feel free to contact the researchers directly.

Expenses and reimbursement

Members of the PPI panel do not receive any payment for their involvement, however any travel expenses can be reimbursed including train, taxi, bus, mileage and car parking. Lunch and refreshments are provided at every face to face meeting. Members will be informed of any relevant training PPI opportunities as and when they arise.

Accountability and review

Prof Angela Tod (a.tod@sheffield.ac.uk) and Dr Clare Gardiner (c.gardiner@sheffield.ac.uk) are co-directors of the MURC and should be the first point of contact for any issues or complaints. These terms of reference will be reviewed every three years.



The
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Of
Sheffield.



MESOTHELIOMA UK