

Nuffield Department of Primary Care Health Sciences **Cancer Theme PPIE Charter**

The role of the group

The role of the group is to support the wide range of projects the Cancer Theme conducts and contribute to our overall research goals by advising on what areas of research are most important to patients and the public. Specific activities that group members can get involved in include:

Providing views on the plans for design, implementation & evaluation of projects.

Providing advice and guidance to progress the work of the Nuffield Department of Primary Care Health Sciences (NDPCHS) Cancer Theme.

Providing information and advice based on lived experience.

Guiding and advising on the dissemination of the project(s).

Contributing to the development of public facing materials including lay summaries and those used in the recruitment to and dissemination of research.

Guiding the development of recommendations for further work.

For those members who want greater involvement there may be opportunities for joining the study team to co-design research plans, materials and activities.

Ways of working

The group will be chaired by Claire Friedemann Smith with the support of a co-chair.

The group will meet online/face to face a minimum of twice per year and will receive regular updates via an email newsletter.

Members will receive papers at least 1 week before each meeting where appropriate.

Members may be contacted between meetings for advice.

Smaller groups will be formed to work on specific projects. Information on what participating in a project-specific group would involve will be circulated by email for members' consideration. Membership of these groups will aim to be representative of those affected by that topic area and a place on any project-specific group cannot be guaranteed. These smaller project-specific groups will meet outside the whole group meetings. Any members not part of a project group will still be able to contribute to the whole Group meetings and will be prioritised when new project-specific groups are set up.

Our promise

We will develop a range of opportunities for patients and public members who want to be involved in the Cancer Theme's research so that their views, concerns and experiences are considered at different stages of research design.

We will support a community of members to feel confident and able to engage in a range of research topics and activities.

Through this partnership, we will raise awareness of the benefits of patient and public involvement in research.

Membership

There is no limit on the length of time that anyone can be a member. However, we will aim to review group membership every 2 years to ensure that new people get the opportunity to be involved in our activities and projects.

Non-members may be invited to join group meetings on a one-off basis to aid discussion of a particular topic, for example, as speakers, observers or invited guests.

All members should declare any conflicts that may arise from any other studies or organisations they are working with.

Group membership is open to everyone. We are committed to promoting equality and diversity because we recognise that involvement from lots of different people, with different life and cancer experiences, will make our research more relevant and useful.

The membership of the group includes a range of people some of whom have been impacted by cancer and also those who have not. Members do not need to have any experience of cancer or knowledge of research.

New members will be asked to fill out a questionnaire to provide information about their background and areas of interest in NDPCHS Cancer Theme research. There will be no obligation to complete this questionnaire but doing so will help us to ensure we are being inclusive and capturing diverse perspectives.

We understand completely that members may want or need to take a break from PPIE activities. We will ask members to let us know so that we can reduce or pause the email requests sent to them.

Members can withdraw from any activity at any time, without providing a reason. We ask members to inform us at their earliest opportunity by emailing cancer@phc.ox.ac.uk or phoning 01865 289291 if they are not able to carry on in a role or if they would like to leave the group.

If a member chooses to leave the group we will delete all personal details we hold on them unless given explicit consent to retain.

Communication

Group members will be sent information about different involvement opportunities via email. If needed, communications can also be sent by post and any member needing this should contact the research team.

No individual member is under any obligation to sign up for any particular activity, involvement is very much dependent on each individual member's experience, time, and personal interest.

Confidentiality

As a contributor to the Cancer Theme, members may be asked to review information that is not yet available to share with people outside of the group. Confidential information could be an idea for new research, project, or research findings that are not yet published. All members will be asked not to share confidential information.

As well as this, members may want to draw on and describe their personal experiences during discussions and each member is responsible for saying if a topic is confidential and not for discussion outside the group.

Expenses and Payment policy

Members are not employed by the University. However, we will offer to reimburse members for their time at a rate of £25 per hour. Members will be offered the choice of a gift voucher if they would prefer that to direct payment and should be aware that the University processes expenses as quickly as possible.

We will offer to cover reasonable travel expenses that members may incur as a result of involvement in face to face meetings.