

Role Profile for Consumer Members of NCRI Clinical Studies Groups (CSGs)



We involve patients and carers (consumers) at all stages of our work, which include developing clinical trials and high quality studies for specific cancer types of treatment approaches. All of our consumers join our NCRI Consumer Forum, which functions according to its guiding principle:

Working together to build a community with the common purpose of providing patient and public perspectives throughout the research process, to deliver research with better outcomes and experiences for all

Role	Consumer member of an NCRI Clinical Studies Group
Duration	The usual term of office is three years, with a possibility of a two-year extension in agreement with the CSG Chair
Expenses	Travel expenses and other reasonable out of pocket expenses are reimbursed and members may claim an attendance fee for agreed meetings. Members are currently subject to the NCRI expenses policy

Role description

Members are required to contribute to the activities of the NCRI CSGs by:

- Regularly attending and actively participating in CSG meetings. Each group meets on average two to three times per year with additional email and telephone correspondence as well as teleconferences outside of these meetings.
- Assisting the Group in understanding the perspectives of patients, carers and the public that are relevant to the work of the Group.
- Preparing for CSG meetings by reading meeting papers and raising any issues for clarification with the NCRI CSG Executive or CSG scientific mentor.
- Working in collaboration with a scientific mentor, identified by the CSG Chair, to support proactive engagement with and contribution to the group's meetings and work.
- Engaging with local patient networks and patient involvement activities. This includes, and not limited to, NIHR's [Local Clinical Research Network](#) and involvement in the [Patient Research Ambassador](#) initiative.
- Attending and providing appropriate regular feedback on consumer activity to the Consumer Forum.
- Abiding by any requests for confidentiality and to declare any actual, potential or perceived conflicts of interest if they arise, in accordance with the [Nolan Principles](#).

- Identifying personal learning and development needs with the NCRI Consumer Lead, and participating in appropriate learning and development opportunities to address these needs as required, within available resources.
- Providing feedback on the impact of their personal involvement activities via a written report or update to each CSG meeting.
- Taking relevant consumer issues from the Consumer Forum to the CSG and vice versa, including sharing good practice and advocating shared Consumer viewpoints.
- Taking an active role in the regular review of their role on the NCRI CSG as well as contributing to any broader evaluations of the CSG.

Role requirements

Members are required to have:

- Experience of cancer services as a patient, carer or relative, which are relevant to this role
- Willingness and ability to familiarise with relevant research and medical language.
- Knowledge and understanding of consumer perspectives, with an ability to research and raise a broader range of consumer perspectives beyond their own personal experience.
- The ability to recognise and encourage diversity of input from cancer research and service user communities.
- An understanding of the importance of and need for cancer clinical research.
- Good communication skills with an ability to listen to others and constructively express one's own view from a consumer perspective.
- An ability to work effectively and constructively as part of a team within a mixed group of consumers and professionals.
- Willingness to make links with some of the following as part of their role: Clinical Trials Units, Experimental Cancer Medicine Centres, local research and service user networks, consumer research panels and trial management groups (TMGs).
- Computer literacy and sufficient time to keep abreast of email communications and information in a timely fashion.

It is also desirable for members to have:

- An understanding of the relevance of consumer involvement in the work of the NCRI.
- Experience of participating in formal meetings and committees where there is a routine expectation for group members to prepare and comment upon meeting papers that may be complex.
- Knowledge and understanding of the issues important to both cancer and wider patient networks and groups.
- Interest in keeping up to date with current cancer research issues.
- Ability to respond appropriately and in timely fashion to challenging tasks, including distilling key information from meeting papers and other relevant documents and responding to requests for comment or evaluation.

Term of office

The usual term of office for membership of a CSG is three years, with a possibility of a two-year extension in agreement with the relevant CSG Chair. Consumers appointed to any NCRI initiative or committee (including CSGs) are automatically core members of the NCRI Consumer Forum.

Time commitment

The majority of CSGs meet twice a year, however a few groups meet three times a year. CSG meetings are held in London, normally from 10.30 to 14.30. In addition, the Consumer Forum will meet two to three times per year. There is also the 4 day NCRI Conference each November, and 2 consecutive days of Induction Training for successful applicants. Members should attend CSG and Consumer Forum meetings regularly as invited and are expected to read meeting papers and, when requested, to provide feedback on documents. It is advisable to allow up to 8 hours of preparation work for each CSG meeting. In addition, sometimes members may be invited to work on specific tasks that emerge from the work of the CSGs.

Attendance fees and expenses

Attendance and expenses fees will be paid in accordance with NCRI's current payment policy. Payments will be made without deduction of Income Tax although they are regarded as income for tax purposes. Individuals are responsible for declaring their income to HM Revenue and Customs.

People in receipt of state benefits and allowances are required to declare changes in their circumstances to their local Jobcentre Plus office. If you are concerned about the possible impact of accepting payment on your benefits and allowances, please contact your local Jobcentre Plus office and/or your local benefits advice agency.

More detailed information about the process of reclaiming attendance fees and expenses will be provided to successful applicants.

Training and support

Members are required to attend induction and relevant training as part of their role. Members will be offered the support of a scientific mentor from their CSG as well as a fellow consumer buddy from their CSG. In addition, wider buddy support is available from other members of the Consumer Forum, which currently has over 80 consumer members. There is a template for the consumer to update their CSG, and advice and help is freely available from the NCRI Executive staff, the Consumer Lead and other consumers.

Declaration of interests

All CSG members are required to declare if they have any interests that might be in conflict with the work of the CSG of which they are a member. A conflict of interest does not stop you from being a member of a CSG. However, it may mean that you cannot take part in some discussions or decisions made on projects/issues where you may have a conflict of interest. If in doubt you should seek advice in the first instance from your CSG Chair or from the NCRI CSGs Executive. The [Nolan Principles](#) provide useful guidance in this area.

Equal Opportunities

NCRI, in line with the Cancer Research UK at Work Policy, is committed to creating and encouraging a culture that promotes respect for each other and values individual differences. In order to

achieve this, we will provide equal opportunities to all job applicants and employees of any colour, nationality, ethnic origin, marital status, religion or belief, gender, disability, sexual orientation, age or employment status. We will not condone, tolerate or ignore any form of discrimination or unacceptable behaviour in our recruitment or employment practices. We align with the Cancer Research UK Dignity at Work policy, which states our intentions and underlying principles. A full copy of our policy is available from the Cancer Research UK Resourcing Team (recruitment@cancer.org.uk). Please advise Natalie Salhov on 0203 469 8600 or email natalie.salhov@ncri.org.uk, if you require any reasonable adjustments in order to apply.

Confidentiality

CSG members must not communicate any confidential information that they learn as a result of being a member of a CSG. However, there may well be occasions on which CSG members are specifically asked to share information within their own communities or seek the opinions and views of others. If you are unclear about whether or not information that you have access to is confidential please seek clarification in the first instance from the NCRI CSGs Executive or the Chair of the CSG.

Further Information

If you would like any more information before making an application please visit www.ncri.org.uk, or contact Ian Lewis on 0203 469 5392; email ian.lewis@ncri.org.uk or Natalie Salhov on 0203 469 8600; email natalie.salhov@ncri.org.uk.

Application Process

If you are interested in applying please complete the online form the following link: (INSERT LINK)

Recruitment and Selection Process

NCRI would like to increase the diversity of their consumer representation and applications are encouraged from individuals based throughout the UK, from all ethnic groups and age groups, and from people with experience of all kinds of cancer. The post(s) will be openly advertised and shortlisted candidates will be invited to attend for an interview. Interview dates already agreed are shown on the advert. The interview panel will usually include the Chair of the relevant CSG, the NCRI Consumer Lead and the Head of Clinical Research Groups. Interviews usually take place face to face.

Please also note that attendance at CSG meetings and at Induction Training is expected, and if you know in advance that you cannot attend on any known dates, we would ask you to declare this at interview, as it may affect a successful candidate's initial pathway onto their CSG and the timing of the ending current post holder's term of office.