



Role Profile for Consumer Members of NCR I Clinical Studies (Development) Groups [CS(D)Gs]

Role:	Consumer Member of an NCR I Clinical Studies (Development) Group and Core Member of the NCR I Consumer Liaison Group
Duration:	The usual term of office is three years, with a possibility of a two-year extension in agreement with the Group Chair(s)
Working Relationships:	Other members of the NCR I Clinical Studies (Development) Groups and NCR I Consumer Liaison Group, NCR I Secretariat and NCRN Coordinating Centre including the CSG Secretariat
Expenses:	Travel expenses and other reasonable out of pocket expenses are reimbursed and members may claim an attendance fee for agreed meetings and training events subject to the NCRN consumer reimbursement policy

Role description

Consumer members are required to contribute to the activities of the NCR I CSGs and CLG by:

- Regularly attending and actively participating in CSG and CLG meetings. Each group meets on average two to three times per year
- Assisting the groups in understanding the perspectives of patients, carers and the public that are relevant to the work of the groups
- Preparing for group meetings by reading meeting papers and raising any issues for clarification with the NCR I CSG Secretariat, CSG Scientific Mentor, NCRN Consumer Liaison Lead during or before the meeting as appropriate
- Working in collaboration with a scientific mentor, identified by the CSG Chair, to support proactive engagement with and contribution to the group's meetings
- Providing appropriate regular feedback on consumer activity to the CLG within the agreed rules of confidentiality outlined by the CSG Chair
- Abiding by any requests for confidentiality and to declare any conflicts of interest if they arise
- Identifying personal learning and development needs with the NCRN Consumer Liaison Lead, participating in appropriate learning and development opportunities to address these needs as required, subject to adequate resource being available
- Providing feedback on the impact of their involvement with support from the NCRN Consumer Liaison Lead
- Taking an active role in the regular review of their role on the NCR I CLG and CSG as well as contributing to any broader evaluations of the groups themselves.

Role requirements:

Consumer members are required to have:

- Current or recent experience (ideally within the past three years) of cancer services as a patient, carer, relative, member of the public
- Willingness to familiarise with relevant research and medical language
- Knowledge and understanding of the consumer perspective, with an ability to 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 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
- An understanding of the relevance of consumer involvement in the work of the NCRI and NCRN
- 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.

It is also desirable for consumer members to have:

- 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 consumer networks and groups
- Interest in keeping up to date with current cancer research issues
- Ability to respond appropriately to challenging tasks, including distilling key information from meeting papers and other relevant documents.

Term of office

The usual term of office for membership of a CS(D)G is three years, with a possibility of a two-year extension in agreement with the Group Chair(s). Please note that consumers are normally recruited as members of one Clinical Studies (Development) Group and will also become core members of the Consumer Liaison Group for the duration of their membership. Please see the section below: **Membership of the NCRI Consumer Liaison Group** for further information.

Time commitment

The majority of CS(D)Gs meet twice a year; however, a few groups meet three times a year. All CS(D)G meetings are held in London. In addition the CLG meets three times per year, usually in January, May and September. CLG meetings usually run from 11:00am until 4:00pm and are held in various locations including London, Leeds and Birmingham. Members should attend CSG and CLG meetings regularly as invited and are expected to read meeting papers and when requested, to provide feedback on draft documents. In addition, sometimes members may be invited to work on specific tasks that emerge from the work of the groups.

Attendance fee

The NCRN offers an attendance fee to consumer members for preparation, attendance and participation in its CS(D)G meetings. This is offered to people who are not working in the public sector and whose time would otherwise not be paid for. These 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.

Please be aware that 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. The NCRN Consumer Liaison Lead can also offer assistance with accessing advice on benefits and payments which may include signposting consumers to their local Citizens Advice Bureau for free, confidential, expert advice if needed.

Payment will be made directly into your bank account. Attendance fees are also available for agreed CS(D)G sub-group meetings in agreement with the NCRN Consumer Liaison Lead. More detailed information about the process of claiming an attendance fee will be provided by the NCRN Consumer Liaison Lead.

Expenses

All reasonable expenses that arise from involvement in agreed group meetings as part of the consumer's role will be reimbursed, subject to the University of Leeds expenses policy. This includes: travel, food and drink, accommodation, childcare, carer costs, appropriate agreed office costs, training and conference fees. More detailed information about the process of reclaiming expenses will be provided by the NCRN Consumer Liaison Lead.

Training and support

Consumer 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 CS(D)G as well as a fellow consumer *buddy* (peer) from their group. In addition wider *buddy* support is available from other consumer members of the CLG. They will also be offered support from the NCRI CSG Secretariat and NCRN Consumer Liaison Lead with all the practical issues of group membership such as help with claiming expenses and access to meeting papers and reports.

Declaration of interests

All CS(D)G and CLG group members are required to declare if they have any interests that might be in conflict with the work of the group that they are in. A conflict of interest does not stop you from being a member of a group. However it does mean that you cannot take part in any discussions or decisions made on a project/issue where you have a conflict of interests. If in doubt you should seek advice in the first instance from the appropriate Group Chair or from the NCRI CSG Secretariat.

Confidentiality

CS(D)G and CLG group members must not communicate any confidential information that they learn as a result of being a member of the group. However, there may well be occasions on which group 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 or not, please seek clarification from the NCRI CSG Secretariat or the Chair of the group.

Further Information

If you would like any more information **before** making an application please visit: www.ncrn.org.uk and www.ncri.org.uk or contact Karen Inns on 0113 343 2254 email: k.inns@ncrn.org.uk

Application Process

If you are interested in applying please complete and sign the application form and diversity monitoring questionnaire and return to:

Karen Inns
Patient & Public Involvement Lead
NCRN Coordinating Centre
University of Leeds
MacMillan Wing, Fairbairn House
71-75 Clarendon Road
Leeds
LS2 9PH
Email: ppi@ncrn.org.uk

Recruitment and Selection Process

NCRI/ NCRN would like to increase the diversity of their consumer representation and applications are welcomed from consumers based throughout the UK, from all ethnic groups, all 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 interview. The interview panel will usually include the Chair of the relevant CS(D)G/ CLG, the NCRN Patient & Public Involvement Lead and a member of the NCRI/ NCRN Patient & Public Involvement Steering Group. Interviews may take place face to face and/ or by telephone.

Membership of the NCRI Consumer Liaison Group

There are two types of membership of the CLG:

1) Core membership of the NCRI Consumer Liaison Group (approx. 60 members)

This is made up of consumers with current or recent experiences of cancer services as a patient, carer, relative, member of the public, who have been specifically recruited as members of the NCRI Clinical Studies Groups.

2) Associate membership of the NCRI Consumer Liaison Group

In addition to the **core membership** of the CLG the following groups/individuals contribute as **associate members** of the CLG:

i) Other consumers who are not members of the NCRI Clinical Studies Groups but who are involved in cancer research as part of their role in other areas at local and/ or national level; for example, consumers who are members/ formally involved with:

- The NCRI Board and Board Sub Group on Clinical and Translational Radiotherapy
- NCRI/ NCRN Projects and Initiatives
- Former consumer members of CS(D)Gs
- Consumer research panels
- Clinical trials units
- Experimental Cancer Medicine Centres
- Local cancer research and service networks

These members are regularly invited to attend/ input to CLG meetings but may not attend every CLG meeting.

ii) Professionals directly engaged in cancer research with a role in consumer involvement as part of their work e.g. NCRI/ NCRN Patient & Public Involvement Steering Group professional members, NCRI partner organisations, relevant patient and cancer support organisations, NCRN, NIHR, UKCRC, INVOLVE.

These members are regularly invited to attend/input to CLG meetings but may not attend every CLG meeting.

In addition there are wider opportunities for interactions with the CLG via the consumer mailbox (ppi@ncrn.org.uk) and through the feedback section on the NCRN website. In addition all agreed CLG meeting papers and reports are made publically available on the website at www.ncrn.org.uk by following the link to *Patient and Public Involvement*.