Role Description for Patient Representative Members of the CR-UK Population Research Committee (PRC) Expert Panel

<table>
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<th>Role:</th>
<th>Patient Representative Member of the Population Research Committee (PRC) Expert Panel</th>
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<tbody>
<tr>
<td>Duration:</td>
<td>The usual term of office for members is 3 years. A 2 year extension may be offered if agreeable to the office and committee member</td>
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<td>Working Relationships:</td>
<td>Other members of the Expert Panel (particularly the Chair), CR-UK staff serving the Expert Panel, the NCRI Consumer Liaison Group, and where feasible, other CR-UK consumers and/or consumers involved in developing or influencing the applications that come to the expert panel.</td>
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<td>Expenses:</td>
<td>Travel expenses and other appropriate out of pocket expenses are reimbursed, in addition to an Honorarium payment.</td>
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Role Description and Person Specification for the Patient Representative Members of the Population Research Committee (PRC) Expert Panel

Aim of role

To ensure due process and that peer review of new research is carried out to the highest of standards; to provide a consumer perspective on applications; to be an exemplar of CR-UK’s commitment to engaging consumers in all aspects of its work.

Main role responsibilities

Patient Representative members are required to contribute to the activities of the Expert Panel by:

- Attending and participating in 2 meetings a year, which are usually held in the months of May and November over one full day in London.
- Attending and participating in an informal annual review meeting with the PRC Chair, to consider the aspects of consumer contributions that are working well, what might be improved, and how. (NB this review meeting will usually be held during the course of one of the PRC meetings.)
- Assisting the Expert Panel in understanding the perspectives of patients and the public about the research proposals that come to the Expert Panel.
- Preparing for the meetings by reading the meeting papers, including the applications, the peer review comments, and any other relevant papers; providing written comments for committee records and where appropriate for applicants, and providing verbal comments at the meeting where relevant to the discussion, including a critique and/or raising any
issues for clarification (after first discussing these with the CR-UK research nurse who acts as consumer mentor).

- Continuing or developing active membership of the NCRI Consumer Liaison Group.
- Responsible for informing PRC of any relevant issues raised by the NCRI Consumer Liaison Group and for providing regular written reports to the NCRI CLG on relevant activities of PRC.
- Respecting requests for confidentiality, and to declare any conflicts of interest if they arise.
- Identifying personal learning and development needs through discussion with a CR-UK research nurse and participating in appropriate learning and development opportunities as advised.
- Involvement in the Expert Panel processes.
- Regular review of role in discussion with a CR-UK research nurse.

Length of membership
The Patient Representative members will initially serve for a three year period, with a possibility to extend by two years where this is considered in the best interest of the Expert Panel.

Time commitment
Members of Expert Panels are expected to attend up to two meetings a year (May and November), on average each meeting is held over one full day in London. Members are expected to put aside sufficient time to read the relevant paper work before the meeting.

Attendance fee
CR-UK offers an honorarium to all Committee members of £300 (a daily rate) for attendance and participation at the meetings. These payments will be made directly into your bank account and Income Tax will be deducted at the standard rate. 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.

Further guidance on payments is available from INVOLVE at http://www.invo.org.uk/pdfs/involvepaymentdocument2011.pdf

Expenses
Travel expenses to attend the meetings will be reimbursed at standard class only.

Training and support
Patient Representative members of Expert Panels will be offered support from a CRUK research nurse as a mentor. The CRUK research nurse will be available to support and assist in the
understanding of the meeting papers and reports, both before and during the meeting. Meeting materials will be provided at least one week before the meeting.

Declaration of interests
All Expert Panel members are required to declare if they have any conflict of interests with any of the paper work/discussions of the Expert Panel. A conflict of interest does not prohibit anyone from being a member of the Expert Panel. However, it does mean that member(s) cannot take part in any discussions or decisions made on a research project/issue where they have a conflict of interests; under these circumstances members are asked to leave the room for the relevant item on the agenda. If in doubt you should seek advice in the first instance from the Expert Panel Secretariat.

Confidentiality
Members of the Committee must not communicate any confidential information and outcomes from the meetings, which they have gained knowledge of as a direct result of attending an Expert Panel. If members are unclear about whether information that they have access to is confidential or not, please seek clarification from the Expert Panel Secretariat.

Skills and Attributes
The types of skills and attributes that we are looking for are;
- Experience of cancer (either personally or through the experience of a loved one)
- A keen interest in research
- Objectivity, with the ability to consider the needs of all people with experience of cancer in relation to the work and share thoughts and concerns appropriately
- Knowledge and interest in keeping up to date with current issues important to those affected by cancer, particularly issues relevant to research such as clinical trials recruitment, research funding, and communicating about our research
- Confidence to voice your opinions clearly and participate in group discussion
- Good communication skills with an ability to listen to and respect differing opinions and constructively express own view
- Ability to maintain confidentiality where required

Want to find out more?
Visit the website to find out more about the Population Research Committee Expert Panels or contact prc@cancer.org.uk.

Application Process
If you are interested in applying please complete and sign the application form and diversity monitoring questionnaire and email to: involvement@cancer.org.uk
Closing date for applications is Friday 11th March 2016

Selection Process
Short listed candidates will be interviewed by telephone interview by the Population, Prevention and Behavioural research team and a member of the patient engagement team.

The interviews will take place by telephone on Monday 14th March 2016
Background Information

Cancer Research UK
Cancer Research UK (CR-UK) is the largest single funder of cancer research in the UK and the world’s largest independent organisation dedicated to cancer research. It supports research on all aspects of cancer, from the most basic aspects of cell biology to large studies of entire populations, funding the work of over 4,000 scientists, doctors and nurses across the UK, and running specialised institutes dedicated to cancer research. CR-UK is one of the few independent organisations in the world with the ability to transform pioneering research into treatments for cancer patients and is one of the leading public sector funders of cancer trials in the UK.

Our vision is to bring forward the day when all cancers are cured.

In the 1970s, less than a quarter of people with cancer survived. But over the last 40 years, survival has doubled – today half will survive. Our ambition is to accelerate progress and see three-quarters of people surviving the disease within the next 20 years.

What is the National Cancer Research Institute?
The National Cancer Research Institute (NCRI) is a UK-wide partnership between the government, charity and industry which promotes co-operation in cancer research among the 21 member organisations for the benefit of patients, the public and the scientific community.

Since the inception of the NCRN and NCRI and as stated in the NCRI Strategic Plan 2008-2013, patient and public (“consumer”) involvement in cancer research has been considered as crucial for improving the quality and relevance of research for the benefit of patients and the public.

As part of a national strategy to improve cancer patients’ outcomes¹, the NIHR-NCRN was established by the Department of Health in England in 2001 to benefit patients, the public and the NHS by improving the coordination, integration, quality, inclusiveness and speed of delivery of cancer research. The NIHR-NCRN consists of 32 research networks² and a Coordinating Centre in England and these are closely aligned to service delivery through the Cancer Service Networks. In addition NIHR-NCRN has built robust partnerships and working relationships with Cancer Research Networks in Scotland, Wales and Northern Ireland, providing the NHS infrastructure to support cancer clinical research.

The NCRI plays a strategic role in the development and oversight of the NIHR-NCRN and both organisations collaborate closely on a range of issues that directly impact on the quality and management of cancer research. Through its Coordinating Centre (CC), the NIHR-NCRN manages,

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PRC Patient representative role description and person specification – 2016

administers and supports a variety of initiatives on behalf of the NCRI Partners including the NCRI Clinical Studies Groups (CSGs) and the NCRI \(^3\) Consumer Liaison Group (CLG).

The strong partnership between NCRI and the NIHR CRN, Cancer supports a coordinated approach to research from concept, prioritisation and funding through to delivery through the local research networks of which patient and public involvement (PPI) is an integral part.

\(^3\) NCRI & NCRN define consumers as patients, carers and members of the public affected by cancer