CanGene-CanVar: Patient Reference Panel (PRP)

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Description of the Patient Reference Panel Member's Role

Post	Patient and Public Involvement Research Partner member of CanGene-CanVar Patient Reference Panel (PRP)
Duration	March 2020 to March 2023
Expenses	Payment and expenses for time and travel will be paid according to INVOLVE guidelines
Training/Induction	Training about the programme and being a member of the PRP group will be given at the meetings.

The CanGene-CanVar Study Programme

A group of leading researchers across the country have been funded by Cancer Research UK to run the CanGene-CanVar Programme of Research for the next 5 years. This programme will look at UK research, infrastructure development and clinical translation to improve cancer genetic risk estimation and variant (mutation) interpretation. The aim of the programme is to ensure coordinated, safe, effective delivery of clinical cancer susceptibility genetics, enabling the best outcomes for patients, optimum impact from resources used for screening/prevention in saving lives from cancer, and the avoidance of harm and litigation.

Identifying individuals with inherited genetic cancer susceptibility prevents cancer and saves lives by effectively targeting resources for enhanced screening and/or prevention. Recent advances in sequencing technology has shown a dramatic expansion in genetic cancer susceptibility testing, with imminent roll-out of population-level screening for cancer susceptibility. However, interpreting the significance of variants (mutations) and associated genetic risk has become increasingly challenging.

This programme of work has 6 inter-related work packages and will do the following:

1) Review current datasets and link these to analyse cancer risk and mutations.
2) Produce a national variants (mutation) data system within the NHS IT network.
3) Produce Clinical Management Protocols.
4) Develop and test patient facing decision aids around cancer genetic risk and risk management options.
5) Produce educational resources for broad clinical groups (primary care, oncology clinicians, geneticists) around genetic cancer susceptibility and how best to interpret and communicate complex data on genetic risk.
6) Look at any ethical issues, attitudes and hurdles to data sharing.

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Membership of the Patient Reference Panel

The Patient Reference Panel (PRP) will be made up of patients, carers and members of the public who are affected by cancer and have an interest in genetics. Also as required, other members of the CanGene-CanVar research team will attend the Patient Reference Panel's meetings.

We understand the term *user* as one that describes those people who make use of cancer care services (including carers and family members); and the term *patient and public involvement* as one that describes involving patients and members of the public in health research. When we use the term *patient and public*, we include people affected by cancer: patients living with and beyond cancer; potential patients or members of the public; carers and people who use health and social care services for people with cancer; as well as people from organisations that represent people living with and beyond cancer. When we use the term *involvement* we use the INVOLVE definition, which defines "public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (http://www.invo.org.uk - Briefing Notes for Researchers).

Rather than use the terms *person affected by cancer* or *user*, we prefer to use the term *research partner* which, we feel, better reflects the role of people affected by cancer/service users in our research activities.

The PRP will be chaired by a Research Partner (Lesley Turner) and the chair will be involved in setting the agenda with the research team, focusing the structure of the meeting and checking minutes prior to circulation.

Purpose of the PRP

The PRP has been set up to involve our research partners working together with our research team to look at how the CanGene-CanVar programme is set up and running, to make sure it is in the best interests of those who may be considering genetic testing, as well as making sure of good research outcomes. A key role of the PRP will be to ensure that the patient/public views regarding the release and use of nationally collected datasets are incorporated into the project recommendations; work closely with the team to develop and test patient decision tools; act as a place for discussion and decision-making about the public/patient perception of risk; and act as ambassadors for the CanGene-CanVar programme.

All members of the PRP will bring their own individual expertise. Research partner members will use their knowledge and experience to work with the research team in making sure that the research remains in tune with the concerns and needs of patients and the public.

This PRP is not a support group, pressure group or a representative body for research partners but PRP members should act in an advisory capacity to the research programme.

Research partner members will take a broad view of a range of study areas and research methods and have the confidence and experience to take an active part in the PRP meetings.

The main duties will involve having the time and confidence to read documents about the research and being prepared to talk about the views of people affected by cancer and genetic testing at the PRP meetings without speaking for one group above others.

Attendance at all PRP meetings is desired. Some meetings may take place by Skype or teleconference. Communication between meetings will take place by phone, e-mail or post.

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Main Responsibilities

1. **To attend PRP meetings**
   PRP meetings will take place approximately twice a year over the course of the CanGene-CanVar programme, with the first meeting being in 2020, and the timing of the subsequent meetings arranged between PRP members. It is likely that the meetings will be held in Southampton. There will be up to 10 members appointed.

2. **To deal with the paperwork of the PRP**
   PRP members may be required to read paperwork sent out in advance of a meeting. They may also be asked to give their opinion on documents sent out between meetings.

3. **At meetings**
   PRP members will be asked to take part in discussions and make sure that a wide range of issues for people affected by cancer and genetic testing (rather than individual or only researcher viewpoints) are discussed, and to make sure that the final decisions take into account issues of concern to people affected by cancer overall.

4. **Link with CanGene-CanVar Committees**

   4.1 Pan Programme Meeting/Think Tank
   The Chair of the PRP and up to 5 other members of the PRP will form a PPI Panel and attend the annual Pan-Programme meeting in London (This 2 day meeting will give advice on the overall progress of the study).

   4.2 Think Tank Meetings
   There will also be PRP representation at the Think Tank meetings which will be held in year 1 and year 3 to which a broad group of experts and external collaborators will be invited to present new research and stimulate new ideas as the programme evolves (likely to be held on day 2 of the Pan Programme meeting).

5. **Confidentiality**
   Membership of the PRP includes respecting the confidential nature of the PRP discussions and documents, and any information associated with the research study and should not be discussed with anyone outside the CanGene-CanVar Programme.

6. **Ownership**
   Members of the PRP agree that the research study is owned by The Institute of Cancer Research, but that the contributions of the PRP members to this study will be acknowledged in any resulting presentations and publications.

7. **Payment**
   Member of the PRP will be eligible for payment for meeting attendance and work done for the CanGene-CanVar programme and their expenses, for example travel, accommodation costs etc., reimbursed in line with INVOLVE guidance (http://www.invo.org.uk/posttypepublication/involve-policy-on-payments-and-expenses-for-members-of-the-public-including-involve-group-members-february-2016/)

Guidelines for working together in the PRP

All PRP members bring their own individual expertise and experiences, and will work in active partnership with each other with mutual respect for all members.

In all meetings members will agree that all those present will follow the standards below:

- **Confidentiality will be agreed and respected**.
- There will be respect for each person's opinion and point of view.
- We will be non-judgemental and sensitive to each other's experiences.
- All experience will be valued.
- One person will speak at a time and be offered the respect of being listened to.
- Everyone will be given the opportunity to take part.
- We will support and be honest with each other.
- If anything is not clear it is ok to ask, and it will be made clear.
- We can disagree with each other, but this should be done with respect and as above

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Personal Experiences and Qualities for Members of the CanGene-CanVar Patient Reference Panel

Factor	Essential	Desirable
Qualifications	Affected by cancer with an interest in genetics	Interest in research.
Experience	Direct or indirect experience of cancer services/research/genetic testing	Committee/Group working experience. Links with user networks, partnership groups. Previous/ongoing experience in research.
Special Skills	Willingness to get to know and use medical and research language.	To keep up to date with current research issues in this programme.
Specialist knowledge	Knowledge of user point of view.	To have an understanding of research.
Personal qualities	Good at talking about thoughts, feelings, or information to another person. Able to listen to others and express own views about service user concerns in discussions.	Self confidence in a mixed group of professionals and service users. Able to respond to challenging tasks. Experience of receiving agenda papers and preparing for meetings.
IT, computers and the internet	Familiar with email, the internet and word processing packages	Familiar with social media

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