Role profile

Steering group for drug consent form project

Type of opportunity
Patient representative to sit on Steering Group

Time commitment
Teleconference every 4 months, one face-to-face meeting per year and ongoing email consultations

Payment and expenses
Agreed travel expenses and £50 optional honoraria per meeting

Summary of the opportunity

Cancer Research UK (CRUK) is supporting Guy’s and St Thomas’ NHS Foundation Trust in the development of the national library of drug consent forms for cancer patients. These forms are concise and informative, and support doctors to provide consistent information for their patients.

The forms have a key role to play in starting useful discussions between patients and their doctors - and we want to ensure they are being used to maximum benefit. To support this, we have a Steering Group to oversee the future development and revision of the library of drug consent forms.

CRUK is committed to putting people affected by cancer at the heart of our work. We are looking for a new Patient Representative to be involved in this initiative to ensure that the important perspective of people affected by cancer informs the project.

We want to hear from you to make sure that your needs and opinions are at the centre of our work and activities. We’re looking for people who have a personal experience of cancer, either as a patient or as the carer for a patient who has had systemic anti-cancer therapy (e.g. chemotherapy, immunotherapy). As a member of the panel you will help to shape the information we provide.

In this role, you will be required to...

- Respect the views and experiences shared within the steering group meetings and email exchanges
- Read materials ahead of meetings to be able to contribute to the discussions. This should not take longer than an hour.
- Reply and contribute in email exchanges or teleconferences.
- Meet approximately every 4 months for two hours via teleconference. We also have one
face-to-face meeting every year in London (Stratford).

- Share your views and experiences of information and consent forms for cancer.
- Provide feedback on consent forms.

We’re looking for people who have...

- Have been affected by cancer either as a patient, or as a carer for a patient, who has had systemic anti-cancer therapy (i.e. drugs that circulate throughout the body - You might have these as an injection into a vein (intravenous), or just underneath the outer lay of the skin, or as a tablet or capsule. For example, chemotherapy and/or immunotherapy).
- Have good communication skills and the ability to confidently and constructively participate in meetings and group discussions.
- The ability to listen and respect different opinions.
- Can objectively represent the needs of a broad range of people affected by cancer.
- The ability to maintain confidentiality where required.

You do not need to have:

- Any prior knowledge of Cancer Research UK or the work we do.
- An understanding of research.
- In depth knowledge of cancer drugs.

In this role, we promise to support you by...

- Giving you with a key contact who will answer any questions or concerns you have.
- Offering you a telephone introduction or meeting to give you a better understanding of the project and the remit of the steering group.
- Providing timely, clear and easy to understand information throughout the project to make it easy for you to understand and share your opinions.
- Asking for your feedback to understand and improve your experience of the role.

Additional Information
Length of role: At least 2 years

Confidentiality: Some of the information that CRUK shares with you may be confidential or commercially sensitive. Therefore:

- You will be expected to sign a confidentiality agreement.
- You will treat the information you receive from CRUK as confidential and will not share it with any other individual or organisation.

Reviewing the role and requesting feedback: CRUK will continually review your work to shape longer term plans for involving people affected by cancer in its work. To support the review, you’ll be invited to:

- Share any feedback about your experience on an ongoing basis.
• Provide formal feedback.

Payment: You will be offered an optional honorarium of £50 for each meeting to reflect the time you will need to give to prepare for and attend the meetings.

Travel expenses: We’ll cover all reasonable travel expenses, in line with our Patient Involvement Payment Policy.

Equal Opportunities: At CRUK we value diversity and we’re committed to creating an inclusive environment which facilitates the involvement of all people affected by cancer. We actively encourage applications from people of all backgrounds and cultures and believe that a diverse involvement network (or range of views and insight) will help us to better represent people affected by cancer and make a difference for cancer patients.

How to join the panel?
• Request an application form from involvement@cancer.org.uk or 0203 469 8777
• Complete an application by Tuesday 1st September
• We will contact you during the week commencing 7th September with the shortlisting outcome.
• Telephone interviews take place during the week commencing 14th September.

The first steering group meeting will be Thursday 15th October 2020. If you would like to join this panel or have any questions, please contact helen.wilkinson@cancer.org.uk

Background information about the role:
The first consent forms were generated for national use in August 2016 and the library includes many forms for specific drugs and combination of drugs for the different types of cancer. There are still several cancer type consent forms to be completed. We are also extending the project to include childhood tumours and teenage and young adults.

The existing forms will be updated in a rolling 3 year programme as appropriate. Issues which have emerged as important during this process have been included in the forms making this an iterative process.

You can view the library on CRUK’s website: http://www.cancerresearchuk.org/health-professional/treatment-and-other-post-diagnosis-issues/consent-forms-for-sact-systemic-anti-cancer-therapy

The Steering Group for this project will have representatives from the consent form team, as well as lead doctors for each cancer type.

Interested in finding out more about how people affected by cancer are shaping our work?

See the latest opportunities to shape our work
http://www.cancerresearchuk.org/support-us/volunteer/patient-involvement-at-cancer-research-uk/involvement-opportunities

Join Your Involvement Network to be kept up-to-date about all the latest opportunities to shape our work:
http://www.cancerresearchuk.org/support-us/volunteer/patient-involvement-at-cancer-research-uk/your-involvement-network

Find out how people affected by cancer have shaped our work: