



The future of cancer therapy

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A Guide to the EORTC Group of Patient Partners

this guide is intended for the members of the EORTC Group of Patient Partners
and those who are interested to know more about it

Objectives of the EORTC Group of Patient Partners:

- strengthen the relevance and quality of EORTC research and make it truly patient-centred
- eliminate research proposals that might not be relevant for patients
- foster partnership between patient partners and researchers
- ensure that patient information sheet is written in plain language and that information is comprehensive for patients, their families, and caregivers

Composition

Members of this group are:

- people with lived experience of cancer
- caregivers
- close friends and family members of cancer patients
- patient advocates
- patient representatives

To avoid confusion that can arise from the terms used in the field of patient involvement and for the sake of consistency, we will use the term “patient partner”.

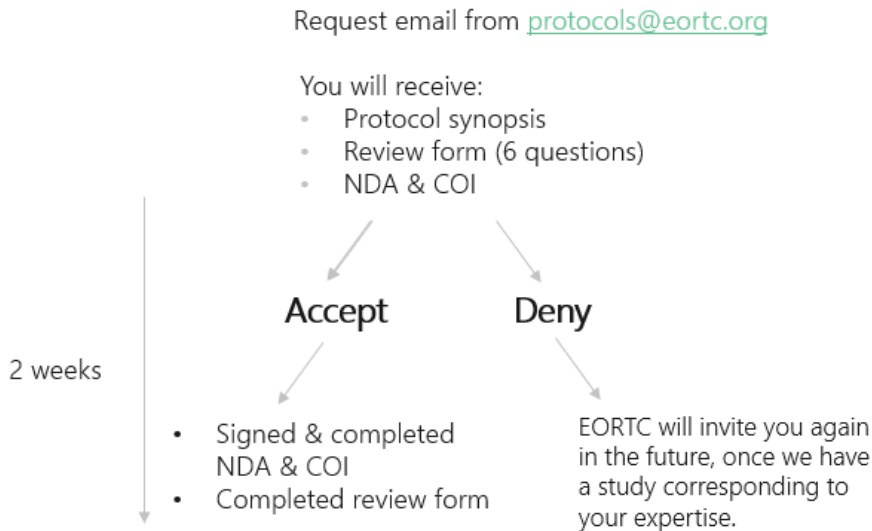
Your role as a patient partner

1. Review of protocol synopsis

A protocol synopsis is a relatively brief description of the research idea and proposed methodology. To ensure the relevance and the quality of a study or a clinical trial, every protocol synopsis is peer reviewed by the EORTC Protocol Review Committee (PRC), composed of international experts in all disciplines of oncology.

Since 2016, EORTC has been inviting patient partners to give their feedback on each protocol synopsis and thus bring into consideration the aspects that are most important from the patients' perspective.

How is the process organised?



* NDA& COI: Non-disclosure agreement & conflict of interest disclosure form

If you suspect a potential conflict of interest, please disclose it before you start the review.

2. Review of patient information sheet & informed consent (PIS IC)

PIS IC is one of the most important patient-facing documents. It explains to potential study participants what this research is about. Language and literacy have a crucial role to play here. The patient information sheet, as with all communication to patients about clinical trials, should be written in plain language which is easily understood. It must contain reliable, accurate, comprehensive information for the patient, their family, and caregivers.

Therefore, your experience can help us improve the language of this document and strike the correct balance between its readability and completeness.

Together with the PIS IC, you will receive the study protocol. We do not require you to review the full protocol, but it may provide you with background information on the study.

FAQ

1. How long does it take to review the above-mentioned documents?

Protocol synopsis typically contains 5-10 pages, PIS IC – approximately 15 pages. It might take you respectively about 1 hour and 2 hours to review.

2. How does EORTC handle my review?

Your comments on the protocol synopsis, together with those from other peer reviewers, will be used to guide the Protocol Review Committee in their assessment of the scientific value of the study.

In terms of PIS IC review, your comments will be shared with the study team who will decide on the relevance of the comments and whether and how they can be practically implemented.

When feasible, you will receive feedback on your contribution and updates on the progress of the study.

3. Will I be compensated for my contribution?

The EORTC is a not-for-profit organization and we are not able to pay you for this work.

However, we can offer you training opportunities and participation to our webinars and events.

4. What support or trainings does EORTC offer patient partners?

EORTC organizes Patient Days on a biennial basis. It is a two-days training course that helps patients, caregivers, and patient advocates better understand the whole clinical trials process, build insights into cancer translational and clinical research from the concept development stage to the reporting of results.

The 5th edition of Patient Days took place on 25-26 November 2022. More information is available on the [website](#).

5. How can I apply to become a member of the EORTC Group of Patient Partners?

If you would like to join this group and contribute your ideas to the cancer research conducted by EORTC, please complete [this form](#).

6. Whom can I contact in case of questions?

In case of questions concerning patient involvement please contact EORTC Patient relationship manager at iryana.shakhnenko@eortc.org.

Processing of your personal data

EORTC processes your personal data in strict confidentiality, under the provisions of the General Data Protection Regulation 2016/679, the Belgian Law of July 30, 2018, and its subsequent amendments (if any). EORTC will act as data controller for your personal data. We will process it for the purposes explained to you in this document and only if you consent to this by completing the application form.

Retention of your data

We will retain your personal data for the term of your membership in this group. If you prefer to cancel your membership and to be no longer involved in the EORTC activities related to patient involvement, your data will be deleted.

Please, be aware that your name (but not the contact details) may be stored for a longer period in the study related documents you have once reviewed and commented on. Archiving period for this documentation is regulated by the legislation on research with human participants. Access to your personal data will be restricted only to authorized staff members of EORTC.

Your rights

In this scope, you have the right to:

- withdraw your consent at any time,
- request access to your personal data and/or to have a copy of it free of charge
- rectify your personal data
- request the erasure of it
- object or restrict processing of your data by EORTC.

Besides, you have the right to lodge a complaint with the competent supervisory authority in the European member state of your habitual residence.

Contact details

Please, do not hesitate to contact the EORTC Data Protection Officer at privacy@eortc.org should you have any questions in relation to the processing of your personal data. You can also send a letter by regular mail to avenue Mounier 83/11, 1200 Brussels, Belgium.

For more information, please check our privacy policy available on the website <https://www.eortc.org/policies-guidelines/> (POL021).