

Guidance for **Patient Involvement in EORTC Quality of Life Group**



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on behalf of the EORTC Quality of Life Group

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Introduction

This guidance is produced within the scope of the project EORTC-RP-2126-QLG “*Expanding partnerships with patients and carers in the EORTC to optimise clinical trials and quality of life (QoL) measurement*”. Co-developed with patient partners, this project aims (1) to develop a coherent framework for patient involvement and (2) to establish specific guidelines for involving patients in the design and coordination of health-related quality of life (HRQoL) questionnaire development studies, including supporting studies and projects to facilitate its use.

The development of this guidance followed a multi-method, collaborative approach involving patients, researchers, and healthcare professionals throughout the process. Built on previous work conducted within the EORTC Quality of Life Group (QLG), the project team conducted two comprehensive literature reviews: a published scoping review on incorporating patients’ input in the development and validation of patient-reported outcome measures in oncology¹, and a review of existing patient involvement frameworks conducted in the scope of the second work package of the project.

These reviews were further complemented by extensive consultations with patient partners and a collaborative survey, co-developed with the EORTC Patient Panel and QLG members. The survey gathered 88 responses – 59 from clinical investigators/researchers, and 29 from patient partners representing 17 countries. The responses helped identify priorities, challenges, and suggested improvements for patient involvement in the EORTC QLG.



Aim of this guidance document

This guidance is designed to support the EORTC QLG and potentially other EORTC research Groups in their patient involvement activities. It outlines good practices for engaging patient partners specifically in the development and validation of HRQoL questionnaires.

The guidance provides practical, phase-specific recommendations and checklists that can be readily applied within EORTC QoL research and adapted for use beyond EORTC contexts. Its main aim is to promote consistent, transparent, and meaningful patient involvement across all stages of QLG research.

¹ doi.org/10.1186/s12955-026-02500-4

Current patient involvement practice

EORTC has a long-standing culture of involving patients in the development and conduct of clinical trials. Patient contributions are integrated throughout the research process, including assessing the relevance of research proposals, improving patient information materials, and participating in oversight committees such as the Independent Data Monitoring Committee (IDMC). In many EORTC QLG projects, patients' voices are included at multiple stages of research, which reflects a strong commitment to patient-centred research.

However, patient participation where patients contribute data as research participants (e.g. through interviews or questionnaire testing), differs from patient involvement, which refers to an active partnership role in shaping research priorities, design, conduct, interpretation of findings, and dissemination. This distinction is not always consistently recognised, and the terms are sometimes used interchangeably, potentially leading to miscommunication.

This guidance addresses this gap by defining patient involvement as a collaborative process and outlines concrete examples of patient involvement across different types and phases of QLG research.

Target audience

The guidance is intended for members and collaborators of the EORTC QLG who are involved in the development, validation, implementation, or dissemination of QoL research instruments and related activities.

This document may also be relevant for other EORTC Groups, as well as non-EORTC academic or non-profit researchers seeking structured guidance on patient involvement in oncology research processes.

While this guidance aims to promote consistency and good practice, it does not intend to prescribe a one-size-fits-all approach. Patient involvement can vary depending on the specific context, research objectives, and resources of each project.

Definitions

In the scope of this document, we will be using the following terms and abbreviations:

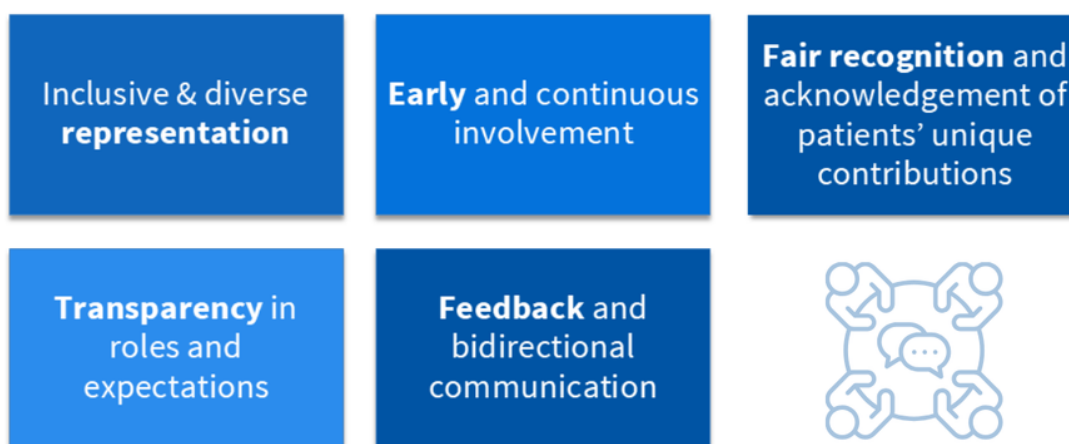
- **EORTC:** European Organisation for Research and Treatment of Cancer
- **Issue:** experience identified as having an impact on the QoL of cancer patients, e.g. “difficulties walking”
- **Item:** question with a timeframe and a response scale created to assess an issue, e.g. [During the past week] “Have you had difficulties walking?” [Not at all / A little / Quite a bit / Very much]
- **Module study:** development of a new QoL measure (module) in accordance with the EORTC QLG Module Development Guidelines, involving generation of new data
- **Non-module study:** research aiming at applying or further refining existing EORTC QoL measures, involving generation of new data

- **QLG:** Quality of Life Group of EORTC
- **QoL:** Quality of Life
- **Research project:** retrospective analysis of existing datasets (incl. patient data) or collection of new but non-patient data
- **Patient involvement:** active partnership with patients and caregivers in the design and conduct throughout the research lifecycle, from defining research priorities, designing research, to evaluating, interpreting and disseminating study results
- **Patient participation:** voluntarily taking part in a study or trial as a study participant by providing samples, testing a new treatment, or answering surveys
- **Patient partner:** an individual with lived experience of cancer, a family member or a supporter of a cancer patient, caregiver, or a patient representative who helps to shape the research activities
- **PRO:** patient-reported outcome – direct patient-derived information about their health condition, symptoms, wellbeing, and quality of life, typically collected through self-reported questionnaires or surveys
- **PROM:** patient-reported outcome measure; instruments to measure PROs.

Principles

Effective and meaningful patient involvement is grounded in a shared and equal understanding of the values that guide collaboration between patient partners and investigators. Drawing on findings from the EORTC-RP-2126-QLG survey, which captured perspectives from 88 patient partners and investigators, a set of core principles has been established to inform patient involvement within the QLG.

These principles reflect the collective expectations of both stakeholder groups and are intended to foster and promote partnerships that are respectful, transparent, and impactful, while providing a foundation for consistent engagement of patient partners across all QLG activities.



- **Early and continuous involvement**

Involve patient partners from the conceptualisation of a project proposal and maintain their involvement throughout the entire research process so their perspectives shape decisions at every stage.

- **Inclusive & diverse representation**

Engage patient partners from a wide range of backgrounds, ages, gender identities, disease stages, treatment experiences, and cultural contexts – depending on the scope and objectives of your project, to ensure their perspectives reflect the full target population. Where full diversity cannot be achieved, this should be transparently acknowledged, along with potential implications.

- **Transparency in roles and expectations**

Briefly explain the project, agree with patient partners on their roles and responsibilities within the project, as well as expected workload, travel or participation requirements, meeting frequency, and the tasks they are expected to contribute to.

- **Fair recognition and acknowledgement**

Ensure that patient partners' unique contributions and lived experience are recognised and acknowledged, e.g. through authorship, acknowledgment, or other mutually agreed forms of financial or non-financial recognition.

- **Feedback and bidirectional communication**

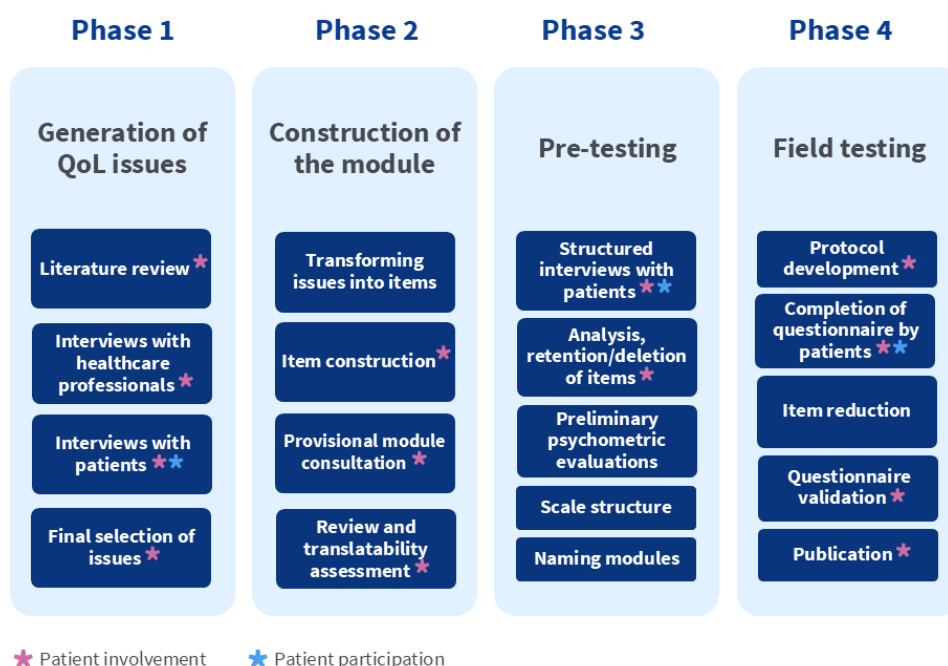
Maintain open and respectful two-way communication between patient partners and researchers throughout the research process. Patient partners should be regularly informed about project progress, decisions, and outcomes, while providing opportunities for them to respond and ask questions. Equally important, researchers should provide timely feedback to patient partners on how their contributions have been considered and used and remain receptive to feedback from patient partners.

Involvement per study type

This section presents an overview of patient involvement activities taking place within three main types of EORTC QLG research: module studies, non-module studies, and research projects.

Module studies

Patients' input is already included in PROM development, primarily as participation in qualitative interviews to ensure content validity in Phase 1 and in structured interviews in Phase 3 to assess clarity and acceptability of the items. However, there are opportunities in other phases of module development to further integrate patient partners' input as active involvement:



This figure is developed for the present guidance and informed by content from the EORTC Module Development Guidelines: <https://qol.eortc.org/manual/the-module-development-guidelines-2021/>

Phase 1: Generation of QoL Issues

Phase 1 focuses on the generation and refinement of relevant QoL issues through literature review and interviews with healthcare professionals and patients. Patient partners can contribute at several stages to enhance relevance, comprehensiveness, patient comprehension, and content validity.

Literature review

Although patient partners are not expected to conduct systematic database searches, they may contribute by

- reviewing relevant materials, reading (summaries of) the literature and using their experiences and those of other patients to help identify important themes and gaps from patient perspectives,
- reviewing and commenting on the preliminary list of QoL issues derived from the literature,
- identifying potentially missing issues based on lived experience,
- highlighting terminology that may be unclear or overly technical, or
- advising on whether identified domains reflect real-world patient priorities,
- contributing to the interpretation of findings from the literature, e.g. by commenting on whether reported conclusions resonate with patient experience.

Their involvement at this early stage can help ensure that the issue list generated from the literature reflects both theoretical/clinical knowledge and experiential knowledge.

Interviews with healthcare professionals and patients

Before interviews with healthcare professionals and patients begin, patient partners can contribute to the design and preparation of interviews:

- review draft issue lists for clarity and comprehensibility,
- advise on recruitment of patients for interviews to ensure inclusivity and all voices are heard,
- review the interview guides and patient information sheet to ensure the content is understandable, e.g. advising on wording,
- act as co-facilitators during patient interviews by helping clarify or translate jargon or complex terminology into patient-friendly language, when appropriate,
- comment on overlapping, ambiguously worded, or missing issues,
- advise on the potential sensitivity of certain topics and how these should be approached,
- suggest additional topics or questions that may need an in-depth discussion with patients.

This involvement can strengthen the quality of open-ended concept elicitation and improve the richness of data collected.

Final selection of issues

After interviews are completed, patient partners may be invited to join an expert consensus panel to:

- review the compiled list of issues from all sources,
- provide input on interpretation of patient feedback,
- contribute to discussions regarding overlapping issues,
- help interpret disagreement between healthcare professional and patient feedback,
- participate in discussions on inclusion and exclusion decisions to ensure that patient-relevant issues are not overlooked due to clinical or statistical considerations.

Phase 2: Construction of the module (provisional module)

Patient partners in Phase 2 help ensure that the provisional module reflects patient perspectives, is comprehensible, and minimises potential confusion or misinterpretation.

Item construction

Patient partners can help ensure clarity, relevance, and comprehensibility of newly constructed items by:

- reviewing proposed items for plain language and patient-friendly wording,
- commenting on ambiguous, confusing, or overly technical language,
- highlighting any potentially sensitive topics and advise on wording to reduce discomfort,
- checking that screening questions (e.g. “Do you have a stoma bag?”) and conditional instructions (e.g. “Answer this question only if you have lost any hair”) are clear and easy to follow,
- confirm that response options (e.g. “Not at all” to “Very much”) make sense and are interpretable.

This input can help ensure that the items reflect patient experiences and can be answered accurately.

Provisional module consultation

During the review of the provisional module, patient partners can:

- review the compiled list of items for clarity, overlap, and comprehensiveness,
- ensure that all key issues identified in Phase 1 are represented,
- comment on item grouping/ordering,
- advise on prioritisation of items when the list is long or some issues are redundant.

Phase 3: Pre-testing

Structured interviews among patients

In Phase 3a, structured interviews are conducted with patients from the target population who were not involved in earlier phases of module development. These patients complete the provisional module and participate in interviews to assess the clarity, relevance, and acceptability of the items.

Although patient partners are not participants in these interviews, they may contribute to this stage of module development by:

- advising on the recruitment strategy,
- reviewing and refining the structured interview guide prior to data collection ([Appendix 5 of the EORTC QLG Module Development Guidelines](#)),
- providing feedback on patient-facing materials (e.g. information sheets or invitations),
- act as co-facilitators during interviews by helping clarify or translate jargon or complex terminology into patient-friendly language, when appropriate,
- identifying items that may require particular attention during interviews (e.g. potentially sensitive or ambiguous items),
- suggesting whether related items should be combined into scales.

Their involvement helps ensure that the structured interview process remains patient-centred and respectful.

Analysis and retention/deletion of items

Following completion of the structured interviews, patient partners may be involved in reviewing and interpreting the results. Their role may include:

- reviewing summaries of patient comments regarding clarity, relevance, and acceptability of items,
- providing input on items perceived as confusing, irrelevant, or upsetting,
- contributing to discussions on relevance and importance ratings,
- participating in discussions on predefined decision rules for item retention, deletion, merging, or rewording,

Patient partner involvement at this stage helps ensure that final decisions about item inclusion reflect not only the threshold, but also the lived experience and priorities of patients.

Phase 4: Field testing

Protocol

Patient partners may be involved in the development and review of the field-testing protocol by:

- revisiting and confirming that the study objectives remain aligned with patient priorities and lived experiences,
- providing input on feasibility and burden (e.g. length of questionnaire, frequency and timing of completion),
- reviewing patient-facing documents (information sheets, consent forms, debriefing questionnaires templates) for length, clarity, and accessibility.

Completion of questionnaire by patients

In Phase 4 of the module development, questionnaires are completed by patients from the target population who were not involved in earlier phases. Patient partners are not study participants but can contribute by:

- advising on strategies to minimise respondent burden,
- reviewing the debriefing questionnaire ([Appendix 7 of the EORTC QLQ Module Development Guidelines](#)) to ensure meaningful feedback is captured,
- identifying potential barriers to completion (e.g. fatigue, cognitive burden, sensitive questions),
- suggesting practical measures to improve acceptability and patient-friendliness.

Validation

During analysis and validation of the module, patient partners can:

- contribute to the interpretation of findings related to acceptability and relevance to the patients,
- participate in discussions about item retention to balance statistical considerations with experiential importance,
- support the interpretation of findings from a patient perspective, in qualitative data, such as free-text comments, where patients' lived experience can highlight issues that may not be fully captured by quantitative analyses.

Their involvement can help ensure that validation decisions are not based only on statistical criteria but also reflect experiential relevance.

Publication

Patient partners can contribute to dissemination activities by:

- co-writing manuscripts,
- participating as co-authors, in line with authorship policies,
- reviewing manuscript drafts for clarity and appropriate representation of patient perspectives,
- supporting dissemination to patient communities, advocacy groups, patient organisations or advising on different dissemination channels.

This may include commenting on the relevance of the findings to patients, highlighting implications for daily life and QoL, identifying aspects of the patient experience that may not be fully captured by quantitative results, and contributing to the development of lay summaries and other patient-friendly materials.

It is strongly recommended that at least 2 patient partners are included as study collaborators, ideally from the proposal development stage. Integrating them into the collaborator group facilitates continuous engagement throughout the study and publication process, rather than limiting involvement to late-stage dissemination activities.

Early discussion of roles, expectations, and authorship is recommended to ensure transparency and fair recognition of contributions. Further information is available on page 15 and in the FAQ section.

Non-module studies

New research proposals for non-module studies submitted to the EORTC QLQ Grant Review Committee (GRC) can be reviewed by patient partners. They are provided with a structured review form (see Appendix 1), which includes both closed-ended questions with predefined response options and open-ended questions. This form guides patient partners in assessing the clarity, relevance, and patient-centredness of each proposal before it is approved by the QLQ.

Involving patient partners at this stage helps ensure that research funded by the QLQ reflects the real needs and priorities of patients. In addition, it is recommended that throughout the entire development and conduct of a non-module study, at least one patient partner is actively involved as part of the research team to ensure continuous integration of the patient perspective.

Research projects

Patient partners may also contribute to broader QLQ research projects beyond module and non-module studies. Their input helps ensure that project objectives, methods, and expected outcomes are understandable, relevant, and aligned with patient priorities. Including patient perspectives early in project development strengthens the quality, feasibility, and patient-centred value of QLQ-led research.

Identifying patient partners

To identify patient partners with relevant experience, it is important to understand the target population for your project and the potential barriers they may face engaging with research, and to adapt the approach accordingly. Utilising a mixed-methods recruitment approach is recommended to achieving a representative and inclusive pool of patient partners.

Recruitment, including of caregivers where appropriate, should involve individuals of different ages, sexes, gender identities, tumour types (if applicable), disease stages, ethnic and cultural backgrounds to incorporate a broad range of perspectives.

It is important to avoid relying on the same individuals to prevent overloading them. Having a small pool of patient partners (e.g. 2-6 per project) can help share responsibilities, maintain continuity, ensure diversity of perspectives, and provide opportunities for peer support. Collaborating with established patient organisations – umbrellas or cancer-specific, can also support recruitment by identifying potential partners from their existing networks.

For projects conducted within the scope of EORTC, the HQ can provide practical guidance on identifying appropriate patient partners and may help connect research teams with patients or patient organisations.

Training needs

When inviting patients to partner on a project, it is important to assess their training needs. The first step is to ask whether they are familiar with relevant terminology and whether they would like to learn anything in advance that could support their involvement. Training could include an introductory session on research methodology, a glossary of terms, or plain language materials.

EORTC Patient Days are an example of a structured learning opportunity. Held every two years, this training course provides cancer patients and their family members with a stimulating experience to better understand cancer, treatments, and research. The course is conducted in English. More information about upcoming events is available at <https://www.eortc.org/events/>.

Involving a non-clinical facilitator during meetings can serve as a bridge between patients and researchers, help manage power imbalances, and create a supportive, inclusive atmosphere for collaboration. Nominating a dedicated patient partner lead can further support effective communication and coordination between the research team and patient representatives.

Researchers and clinical investigators may also benefit from resources that facilitate collaboration with patient partners. Some examples include *UK NHS Patient and Public Involvement In Health And Social Care Research: A Handbook For Researchers* or *Canadian CIHR SPOR Patient Engagement Framework*. Some checklists and practical tips are also available at the end of this guidance.

Reimbursement, remuneration, acknowledgement

Remuneration

Remuneration refers to offering payment or something of monetary value in exchange for patient partners' time and contribution.

In several EU member states, individual patients and caregivers involved in research are legally classified as volunteers. As a result, direct payments to individual patient partners are limited, with compensation often provided through patient organisations instead.

In Belgium, for instance, patients, caregivers, and patient advocates involved in research on a voluntary basis may receive only limited non-taxable flat-rate reimbursements: a maximum of €44.02 per day and €1,760.83 per year for 2026². These limits apply across all organisations or projects in which a volunteer participates during one calendar year. In the UK, however, National Institute for Health Research Guidance needs to be followed, and it is customary for patient partners to be remunerated directly via bank transfer or vouchers. It is therefore highly recommended for researchers to consult country-specific regulations before offering a fee to patient partners.

Collaboration with patient organisations may in some cases be administratively simpler. It allows for a formal contractual relationship that facilitates remuneration. However, potential administrative or

² <https://finances.belgium.be/fr/asbl/benevoles#q2>

tax-related complexities associated with remunerating individual patient partners should not negatively impact or even exclude their involvement. Direct outreach to individual patients remains highly valuable and should be supported wherever feasible, taking into account national regulations and any limitations they may impose.

If no budget can be allocated to patient involvement, it is essential to communicate this to the patient partner before their participation. Transparent communication from the beginning of the project helps prevent misunderstandings, build trust between the patient and the research team, and foster a trustworthy environment throughout their involvement.

Reimbursement

Reimbursement refers to repayment of out-of-pocket expenses, such as travel, accommodation, meals, parking. When inviting patient partners to attend a QLG meeting or any other study-related meetings, their travel and accommodation expenses should always be reimbursed. For this reason, it is highly recommended to include a budget for patient involvement when planning your research.

Please note that some patient partners may not be able to afford upfront costs or may experience difficulties booking travel and accommodation, particularly when they are involved in multiple research initiatives and should repeatedly wait for reimbursement. This can have a negative impact on their personal finances. Therefore, whenever possible, researchers should offer to arrange travel and accommodation for patient partners attending QLG or other project-related meetings. In addition, the QLG offers travel grants enabling patient partners to participate in QLG meetings ensuring that their perspectives are represented in discussions.

Acknowledgement

Patient partners' contributions should be formally recognised wherever appropriate. This can include acknowledgment in publications, co-authorship on manuscripts when their input contributed to the work, or opportunities to co-present research findings at conferences. The form of acknowledgement should be discussed with patient partners in advance to ensure it aligns with their preferences and expectations.

It is also important to consider journal- or conference-specific requirements, as most journals have clear rules regarding authorship and acknowledgements.

When patient partners are included as authors on journal publications, please provide them with practical support, e.g. how to respond to journal correspondence, complete authorship confirmation forms, or manage other publication-related requests.

Feedback, impact evaluation, and continuous improvement

To ensure an ongoing improvement, patient involvement activities should be reviewed every three months. This can include feedback surveys, phone or video call consultations for patient partners and research teams on both their experience and suggestions.

It is also recommended to provide regular updates to the involved patient partners on the progress of the study, either via a newsletter or email, so they remain informed and connected to the project.

In addition, the impact of patient involvement should be assessed. Even though it is not a single project exercise, this can be done by documenting specific changes, such as modifications to study design based on patient partners' input, refinement or rewording of QoL issues, or improvements to study materials to enhance clarity and relevance. Maintaining a brief record of patient suggestions, actions taken in response, and meeting summaries, e.g. in a patient involvement impact log /tracker, can help monitor the progress of patient involvement during each project and demonstrate how patient contributions have influenced the project and what actions/support might be needed for future studies. As good practice, the log may additionally capture dissemination activities in which patient partners are involved.

FAQ

How many patient partners should I involve in my project?

There is no fixed or 'correct' number. Involving 2-6 patient partners may often be sufficient to ensure diverse perspectives. The appropriate number will depend on the scope, aims, and complexity of the project, as well as the stage at which patients are involved.

Larger studies, such as questionnaire development, may benefit from involving a higher number of patient partners, either simultaneously or at different time points (e.g. at least 2 patient partners in each project phase), and through different methods of involvement (e.g. workshops, focus groups, or written feedback).

Setting up a patient advisory group of approximately 4-8 individuals may be appropriate. Such a group can provide continuity, long-term engagement, and shared perspectives.

At which stage of the project should patient partners be involved?

Patient partners can contribute to the project across its whole trajectory. Ideally, patient partners are involved from the earliest stages, including the formulation of research questions, providing input on study design, and importantly, shaping and planning their own involvement. However, patient involvement can take place at any point: proposal development, item generation, interviews, pilot testing, interpretation of findings, or dissemination.

How to identify a patient organisation suitable for my project?

Suitable patient organisations can be identified through the EORTC's several established channels, such as the EORTC patient involvement network. In addition, national patient advocacy networks, disease-specific groups, and established patient umbrella organisations across Europe can be valuable partners. Ideally, when selecting an organisation, it should have experience in QoL research and be able to appoint patient partners who can meaningfully contribute to your project.

How to approach a patient organisation?

A clear and concise email introduction is usually the best approach. Briefly describe the project, what type of input you need, expected commitment time, and any available support (e.g. training, reimbursement/remuneration). This can be followed by an optional follow-up call to discuss the opportunity in more detail and answer any questions. If your project does not have a patient involvement budget, be transparent about that in your communication.

What if a patient organisation or a patient partner expects a fee for their time and expertise?

EORTC supports fair recognition of patient partners' contributions. However, financial compensation depends on national legislation and institutional rules. It is advisable to consult EORTC administrative staff to determine whether remuneration, reimbursement of expenses, or alternative forms of recognition are allowed for your project. If EORTC is not the study sponsor or leading institution, please check the remuneration/reimbursement rules applicable in the country of the lead institution.

How should contributions from patient partners be acknowledged?

Patient partners should be acknowledged in reports, presentations, and manuscripts according to their level of contribution. Co-authorship can be considered when their involvement significantly contributed to the study design, interpretation, and/or dissemination. Further information can be found in the EORTC Publications Policy: <https://www.eortc.org/policies-guidelines/>.

Points of contact

EORTC QLQ: chair.eortcqlg@soton.ac.uk

EORTC HQ: iryna.shakhnenko@eortc.org

Templates, appendices

Appendix 1. Patient partner review form for new non-module proposals

EORTC Quality of Life Grant Review Committee

Patient partner reviewer form

QLG study title	Example: The EORTC Norm Data Study 2.0: A 10-year update and expansion of general population normative data for the EORTC CAT Core and the EORTC QLQ-C30
Reviewers' name	
Review date	
Guide	
- The EORTC Quality of Life Group (QLG) funds research studies which aim to improve the understanding of the effects of cancer and its treatment on the quality of life of people living with and beyond cancer. Quality of life includes physical, psychological and social aspects of daily life. - As part of the review process, we are approaching you to provide us with your patient or caregiver perspective on this QLG grant proposal. You are not expected to have medical or scientific training to complete the review. We value your feedback based on your experience of what is important to people living with and beyond cancer. It will help us ensure the research funded by the QLG truly reflects patients' needs and priorities. - Confidentiality: Your feedback will be shared in an anonymous and confidential way. Please treat this research proposal in strict confidence and do not share with anyone else. <i>Please note, AI tools should not be used as part of the review process.</i>	

1. Is the lay summary of this research proposal easy to understand?

- ☐ Yes
☐ No

If **No**, please provide more details in the box below:

2. Are the study outcomes relevant to people living with and beyond cancer?

- ☐ Very relevant
☐ Relevant
☐ Somewhat relevant
☐ Not at all relevant

If you would like to provide more details regarding your response, please do so in the box below:

3. Are there any other study outcomes that would be important to include?

- ☐ Yes
☐ No

If **Yes**, please provide more details in the box below:

4. Do the inclusion criteria ensure that all relevant groups will have the opportunity to take part in the proposed research?

- ☐ Yes
☐ No

If **No**, please provide more details in the box below:

5. Is the effort of taking part in the proposed research acceptable to participants?

(e.g. is the number of questionnaires participants are asked to fill out or the proposed length of participant interviews acceptable?)

- ☐ Yes
☐ No

If **No**, please provide more details in the box below:

6. Do you think the proposed research has the potential to improve the quality of care people receive?

- ☐ Yes
☐ No

If you would like to provide more details regarding your response, please do so in the box below:

7. If you have any additional comments on this research proposal, please provide them in the box below

8. How would you rate the overall relevance of this research proposal?

(where 1 is Poor and 5 is Excellent)

Poor

☐

1

Fair

☐

2

Good

☐

3

Very good

☐

4

Excellent

☐

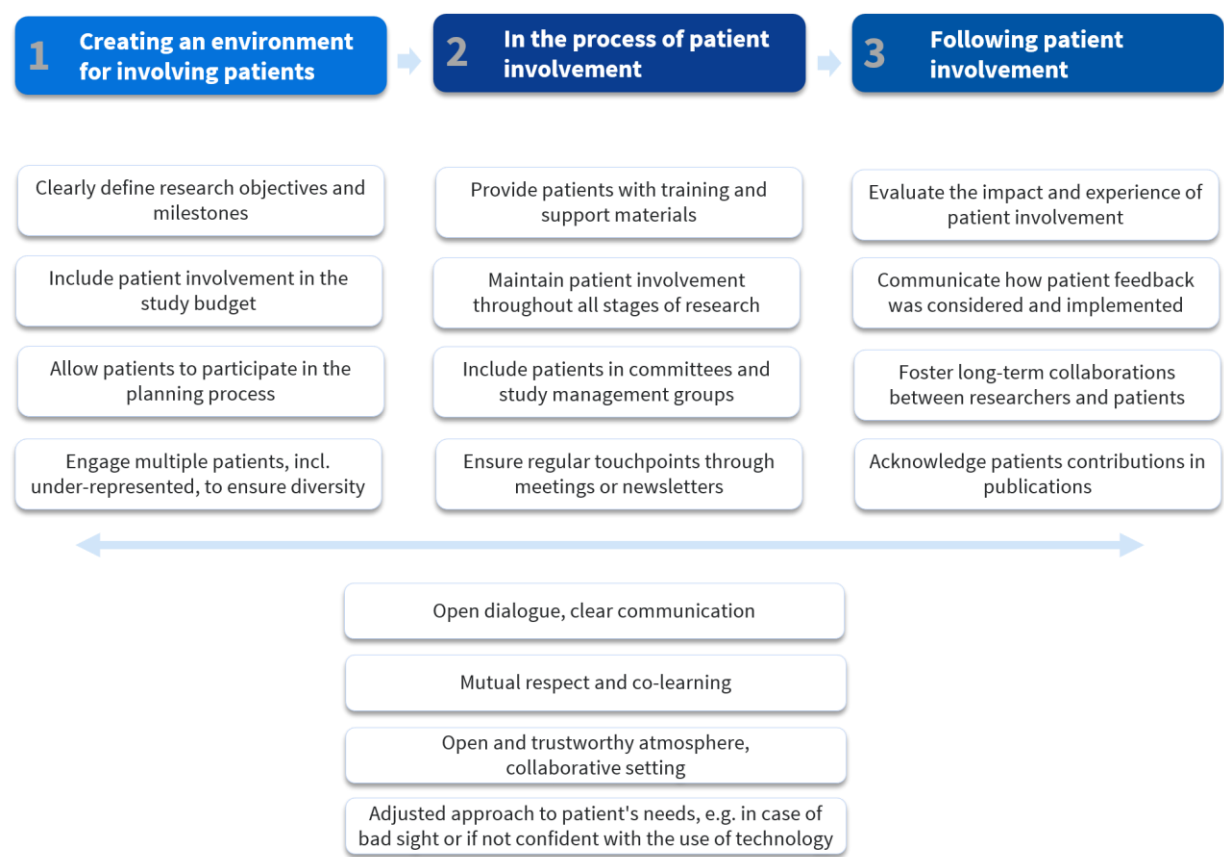
5

Thank you for your feedback.

Appendix 2. Am I ready to involve patients in my research? (a self-check)

- ☐ I can clearly explain my research question in plain language
- ☐ I know where and at what stage I want patients' input (research idea, item list, protocol, interviews, dissemination)
- ☐ I have time allocated to support patient partners before meetings
- ☐ I have considered reimbursement of patient partner(s)' expenses related to project activities (e.g. travel to project-related meetings, accommodation, meals)
- ☐ I have considered remuneration or non-financial recognition for patient partners' time and expertise (e.g. honoraria, vouchers) in line with local regulations
- ☐ I can provide feedback to patient partners on how their input influenced my study
- ☐ I am prepared to listen and adjust – not defend my protocol

Appendix 3. Stages of patient involvement & good practices



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³ Shakhnenko I, Husson O, Chuter D, van der Graaf W. Elements of successful patient involvement in clinical cancer trials: a review of the literature. ESMO Open. 2024 Apr;9(4):102947. doi: 10.1016/j.esmoop.2024.102947. Epub 2024 Mar 15. PMID: 38492274; PMCID: PMC10959641.

Appendix 4. Practical strategies for involving patients

Common barriers	Practical solutions
Time & resources constraints	Plan patient involvement activities early. Include involvement costs in study budgets. Provide flexible participation options (virtual, hybrid, face-to-face). Reimburse expenses and offer compensation where feasible.
Identifying suitable patient partners	Look beyond the "experienced" or "professional" patient. Consider patients with diverse experiences and caregivers where appropriate. Involve several patient partners whenever feasible to ensure diverse perspectives and reduce the burden of participation on a single individual.
Educational support	Offer training and orientation for patient partners. Support researchers with guidance, tools and examples of good practice. Promote opportunities such as EORTC Patient Days, EUPATI, and patient involvement workshops.
Uncertainty about impact	Document patient feedback and explain how it influenced decisions. Where suggestions cannot be implemented, communicate the reasons openly. Provide regular project updates.