



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



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EUonQoL

Quality of Life in Oncology: measuring what matters for cancer
patients and survivors in Europe

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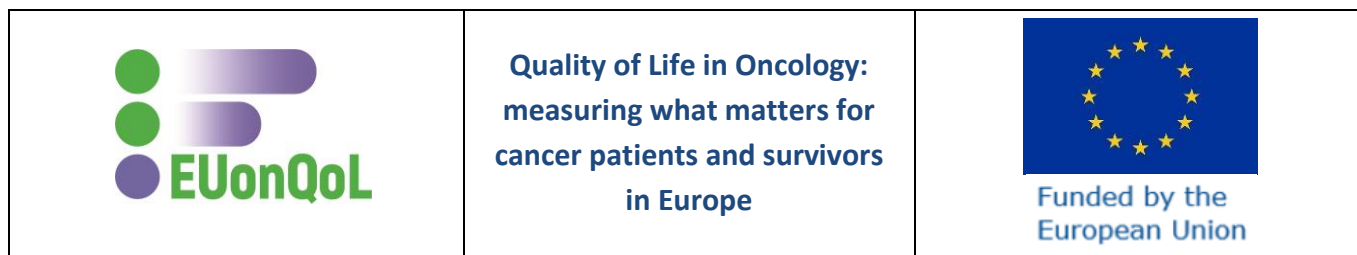
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Preface

This Handbook is written as a product of the project “Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe (EUonQoL)”. This project is funded by the European Union.

The authors would like to thank the European Cancer Organisation’s Patient Advisory Committee for their early involvement and for providing their valuable feedback on the Handbook. Their input and suggestions made it possible for us to incorporate the patient’s perspective from the very beginning on. Also, we would like to thank the EUonQoL Executive Committee for providing us with input on the tasks, roles, and responsibilities that co-researchers will be involved in. This helped us shape the trainings and support processes for the co-researchers. Furthermore, the Executive Committee has provided us with feedback on the Handbook, for which we are also very grateful.

This is a first version of the Handbook. As participatory research is an ongoing, iterative process, this Handbook will be updated annually with the latest information and experiences from all the work packages.

Hopefully, this Handbook will prove to be a useful tool in the collaboration with co-researchers in the EUonQoL project.

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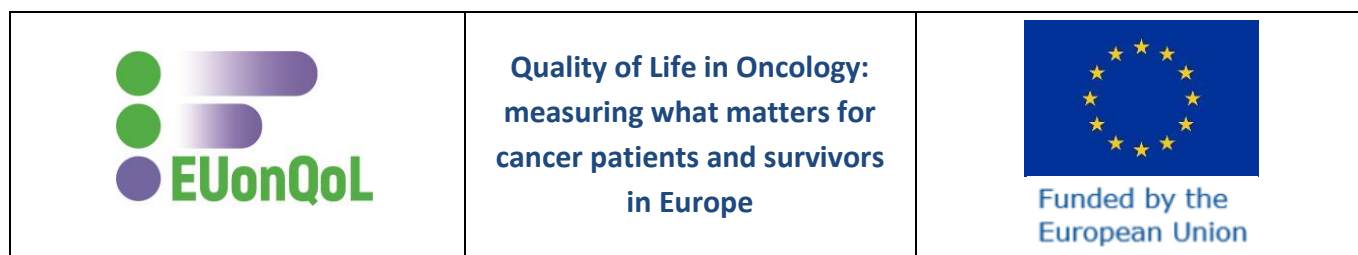
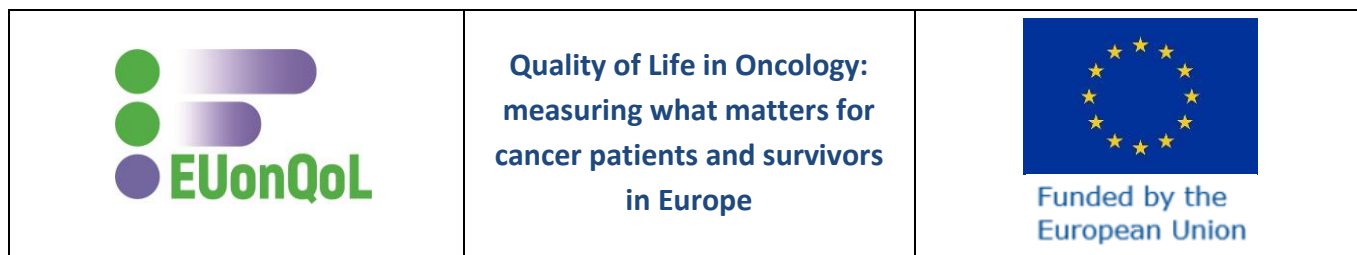


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1. Introduction

In this chapter we will introduce the aim and content of the Handbook, and introduce the EUonQoL project as well as the work package in which context this report is written.

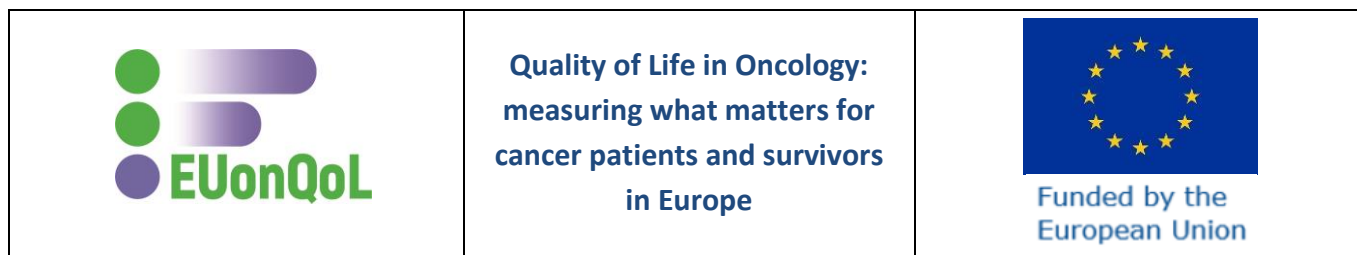
1.1. Aim of the Handbook

The aim of the Handbook is to facilitate collaborations in participatory cancer research between researchers and persons that have been diagnosed with cancer and their relatives (called 'co-researchers'). It is written for all researchers engaging in such research, and specifically for the researchers involved in the EUonQoL project. Patient and public involvement (PPI) is a complex and dynamic process. Researchers inexperienced in PPI can use the Handbook as theoretical and practical guidance in shaping and executing PPI. More experienced researchers can employ it to refresh their memories and guarantee comprehensive consideration of all relevant aspects in their collaboration with co-researchers. The Handbook contains a theoretical background on PPI and its benefits and barriers, followed by practical aspects that need to be considered when engaging in PPI. After that, the good practices of working with co-researchers are discussed. Finally, the Handbook contains a checklist with items that have to be completed when research activities start, such as agreement on roles, tasks and responsibilities, frequency of contact, reimbursement, and support possibilities.

1.2. The EUonQoL project

The EUonQoL consortium was founded to develop, validate, and disseminate the European Oncology Quality of Life toolkit (EUonQoL-Kit) among European cancer patients. The EUonQoL project aims to review existing scales and to develop new metrics by harnessing the strengths and overcoming the limitations of previous tools. The EUonQoL-Kit will be a new digital system for QoL self-assessment, available in several European languages and developed from the patient's perspective. The overall project is based on participatory research principles, through the involvement of a representative panel of patients and public members throughout all project phases.

The EUonQoL project consists of 10 work packages in total, of which this current report is written in the context of work package 2 (WP2). This work package is focused on involving patients, caregivers and stakeholders in general in the EUonQoL project. The involvement of patients, caregivers and stakeholders is essential to this project to ensure that the EUonQoL-Kit captures the aspects of QoL that matter most to patients and caregivers, as well as to ensure that the EUonQoL-Kit produces output that stakeholders can use to address (unmet) needs, expectations and preferences of cancer patients and caregivers. The work package leader of WP2 is Nivel (Netherlands Institute for Health Services Research), in good collaboration with participating partner the European Cancer Organisation (ECO). Further description of the project, its work packages and the participating organisations can be found on the EUonQoL website: <http://www.euonqol.eu/>



2. Background

In this chapter we will give background information on participatory cancer research, starting with information on the main topics of the EUonQoL project: cancer and quality of life. After this we will give a more general introduction into the topic of patient and public involvement in research.

2.1. Cancer and quality of life

Cancer is the second cause of death and the first cause of suffering for patients and caregivers in Europe, as well as having an enormous financial impact on health services and individuals. There were 2.7 million new cases of cancer and 1.3 million deaths in 2020, which is expected to increase with about 25% by 2035. Additionally, there is an unacceptable variability in terms of access to innovation, quality of care, and outcomes (including quality of life), within and between countries in Europe. Quality of life (QoL) can be interpreted as satisfaction and happiness measured as the achievement of aspirations and/or the realization of individual expectations. In this definition, the perception that an individual has of one's health is one of the many possible determinants of QoL. The burden of cancer and cancer treatment on QoL is well-recognized. Nonetheless, implementation of QoL assessment in routine oncology practice is not yet part of standard of care. In the same way, health care systems and cancer control programs do not take into consideration QoL measures when developing clinical, societal, and healthcare policymaking systems [1].

2.2. Patient and public involvement in research

Patient and public involvement (PPI) has become an essential part of health research in recent years. PPI refers to the involvement of 'laypersons' in research. A layperson is someone who is not an expert in or does not have a detailed knowledge of a particular subject, including patients, caregivers and other members of the public [2]. PPI addresses issues and uncertainties about the research through the involvement of the public. A common definition of PPI is "Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" [3-5]. In this way PPI aims to improve the design and conduct of research rather than providing data to answer research questions [5].

Arnstein's Ladder Of Citizen Participation [6] demonstrated that participatory research is an important, yet complicated and vulnerable process. The ladder consists of eight 'rungs' that correspond to three general forms of citizen participation: nonparticipation (no power), degrees of tokenism (a false sense of power), and degrees of citizen power (actual power). This illustrates that there are significant differences in degrees of citizen participation (see figure 1). According to Arnstein, citizen participation should be equivalent to citizen power. It is the redistribution of power that enables citizens to be deliberately included in the future. It is the means by which they can induce significant social reform which enables them to share in the benefits of the induced change. That being said - there is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process. Participation without redistribution of power is an empty and frustrating process.

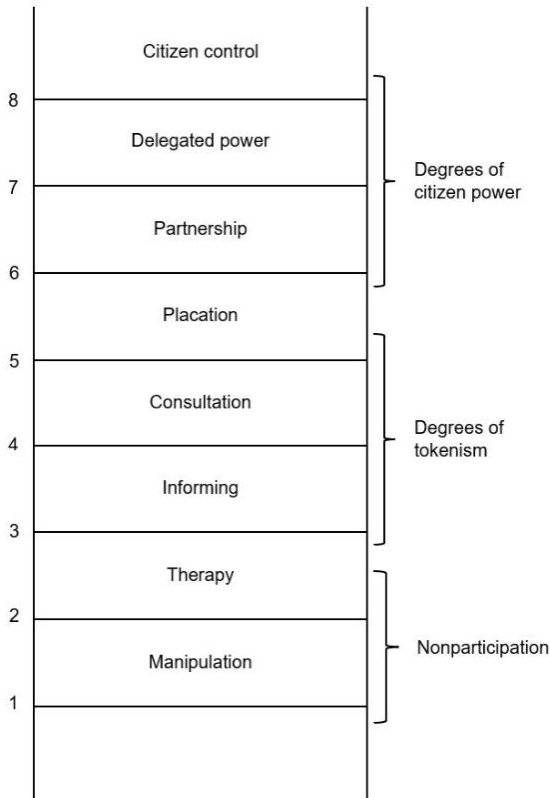
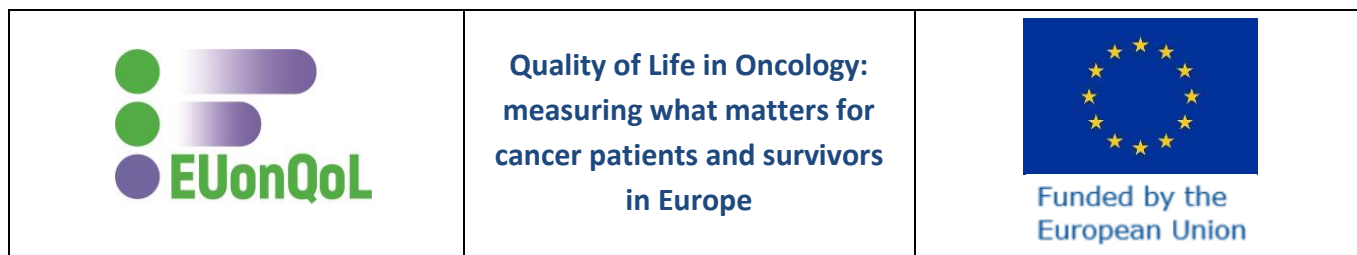


Figure 1: Adapted illustration from Arnstein's Ladder of Citizen Participation (1969).

Nowadays, involving citizens and patients in research is seen more often as one of the key tools to drive innovation processes within the research landscape. To ensure that research is highly relevant to the public, there is a need for meaningful involvement of patients and the public with the aim to improve relevance, reduce 'research waste' and bring science and society closer together [7]. PPI should be an active, creative, and open process in which all relevant stakeholders are involved and work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge [8]. It can be applied in all stages of research or a project, from clarifying a problem and formulating a question to the stage of implementation and dissemination. PPI is more than simply applying a certain method: it is a mindset in which you come to a suitable solution for a collectively defined problem with all those involved [9]. Important values and principles of PPI include respect, support, transparency, responsiveness, fairness of opportunity and accountability [10].

Additionally it is argued that patients have a right to have an input to research on their condition and that reducing the knowledge gap between researchers and patients is a moral duty of researchers, especially with vulnerable and seldom-heard groups [11]. The assumption is that those who are affected by research have skills and knowledge of equal importance to the researchers, and should contribute to research and development projects from the beginning [8].



Text box 1: Terminology used in EUonQoL

In EUonQoL the term ‘co-researchers’ is used for persons who will collaborate with the researchers. The group of co-researchers will consist of persons that have been diagnosed with any kind of cancer, and their caregivers.

2.3. Benefits and barriers to PPI

There are several benefits and barriers to implementing PPI in research. In this section benefits and potential barriers for research as well as for patients and public members (including co-researchers) will be discussed. Finally, solutions to overcome potential barriers will be addressed.

2.3.1. Benefits for research

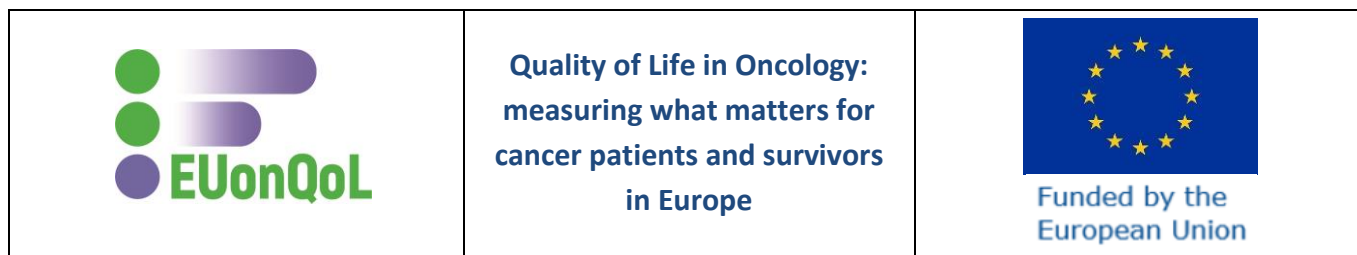
From the perspective of a researcher, perhaps the most important argument in favour of PPI is that it improves the quality, relevance and impact of research by ensuring that it focuses on the issues of importance to patients and the public [4]. PPI aids with identifying the most relevant research questions and thereby gaining a better understanding of and insights into gaps and priorities in the research area. Research outcomes become more relevant and there will be a wider impact and a larger applicability of your findings [3, 7]. Furthermore, it ensures that research outcomes are more applicable, acceptable, accessible, and appropriate for those intended to benefit from them [5, 12].

Stronger ties with patient and public communities can also be a benefit regarding increased participant enrolment and decreased participant drop-outs [3, 7]. PPI makes it easier for researchers to create patient-friendly study materials, and facilitates interpretation of results from a patient perspective which provides researchers with opportunities to increase patient insights into individual research fields [3]. Another benefit is ensuring that the role of people taking part in the research is clearly explained, the burden for the participants is reasonable, and recruitment strategies are effective [5]. Additionally, PPI may extend the range of people represented in research studies and improves the dissemination of findings beyond academic audiences [11].

Funders are also more recognizing the importance of PPI, and it is therefore increasingly a requirement for research projects. Hence it may be an effective way of attracting resources for future research projects [7, 11].

2.3.2. Benefits for patients and public members

Besides benefits for research, PPI also has many benefits for patients and public members (including co-researchers). The most described benefit of involving patients and the public in research is increased empowerment of patients and others with lived experience [3, 7]. Introducing PPI into research projects may introduce a shift of power and ownership towards patients and the public [7]. Additional benefits for co-researchers include positive emotional outcomes, such as increased confidence in their daily life and a sense of pride and accomplishment [12]. They provide a valuable contribution to society and make an impact. Additionally, PPI may provide a space to share personal experiences and stories, while also recognizing their own lived experience as expertise [7].



Co-researchers can also benefit from increased knowledge about and increased skills for contributing to the research process and managing their medical condition [12]. They can influence the questions that are explored and researched, while enriching their personal resumes and building networks. This may also lead to building trust and rapport with researchers and other stakeholders [7].

These benefits reflect in co-researchers' motivations for participation that were found in a study by Scheffelaar et al. [13]: being committed to quality improvement, being of worth to other service users, being part of a social group, creating a new social identity, and personal development/acquiring new skills.

2.3.3. Barriers for research

In addition to many benefits, there may also be some barriers to using PPI for researchers. Several barriers result from a lack of knowledge: not knowing how to involve patients or the public, a limited understanding of potential roles and levels of involvement, and the fear of doing it wrong. In line with this is a general resistance to change, and backlash from colleagues that may act as barriers [7].

PPI requires a significant investment of time, effort, and other resources, which may lead to increased research cost and duration, and an increased experienced burden on researchers. On an international level, there is some debate on the balance between the costs and benefits of PPI [3, 12]. A lack of organizational support and other processes may complicate PPI as well [7]. There may also be some tensions between researchers and co-researchers regarding study design and decision-making, which could result in the feeling that scientific rigor is sacrificed for the preferences of co-researchers [12].



2.3.4. Barriers for patients and public members

Among barriers and challenges for co-researchers that are described, the one most mentioned is the concern of tokenism [3]. Tokenism is the practice of making a symbolic effort in doing something, in order to show that you are following rules, doing what is expected, and 'ticking the box' [14]. Other concerns include that the process of discussion and deliberation should be fair and that co-researchers' perspectives should be taken seriously [15]. Inequality between co-researchers and researchers and inadequate relationship building could result in the perception of being in a disadvantaged position on the research team [3]. Negative previous experiences with research/academia or with the (healthcare) system could also play a role in this [7].

Regarding the research process, unfamiliarity with research and jargon and lack of confidence in research abilities and literacy may be barriers. Uncertainty of the potential roles, tasks and responsibilities they could have may also contribute to this [7]. Additionally, the time and effort of involvement may lead to significant burdens on co-researchers [3].

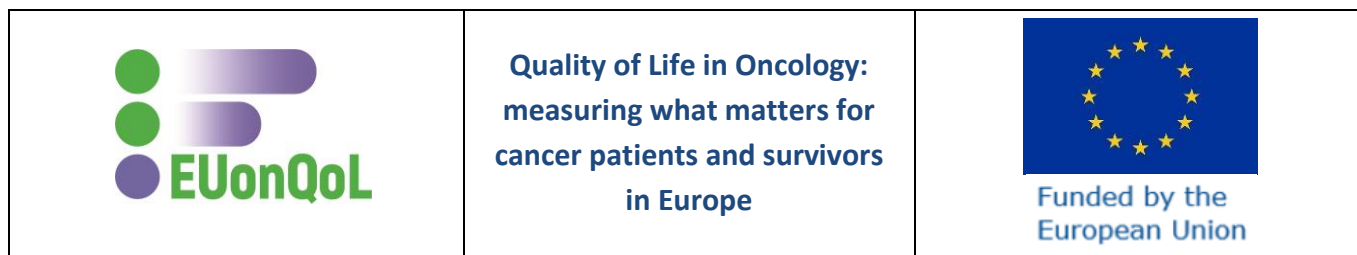
2.4. Addressing potential barriers

Even though some barriers to PPI are discussed here, all researchers are encouraged to focus on the benefits and the positive sides of PPI. However, some comments on addressing potential barriers must be given. The aim of this first version of the Handbook is to provide sufficient guidance and information so that barriers may be prevented or overcome. The Handbook will be updated annually based on gained experiences, for instance if the Handbook does not prove sufficient guidance to address a barrier. The authors of the Handbook are open for comments and feedback.

 <p>The logo for EUonQoL features three circles (two green, one purple) stacked vertically on the left, followed by a horizontal bar with a gradient from purple to green. To the right of this graphic, the text 'EUonQoL' is written in a bold, sans-serif font, with 'EU' in green and 'onQoL' in purple.</p>	<p>Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p>Funded by the European Union</p>
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Text box 2: Addressing potential barriers in EUonQoL

In the case that researchers working on EUonQoL encounter a barrier, and this Handbook is not sufficient to resolve it, they can reach out to WP2 researchers for consultation and support. They will think along in solving any problems that might occur.



3. Practicalities

In this chapter, the practical aspects of involving co-researchers into research will be discussed. Recruitment and reimbursement will be discussed first, and after that training of co-researchers for participation will be addressed.

3.1. Recruitment

In the involvement of co-researchers, about 6 patients or members of the public with lived experience on a specific topic should be recruited [7]. To ensure a range of perspectives amongst the co-researchers it is recommended to aim for a heterogeneous group [10]. Also, it is recommended to set up a contingency plan in case of drop-out of co-researchers.

Text box 3: Recruitment of co-researchers in EUonQoL

In EUonQoL, 6 co-researchers are recruited based on the following characteristics: speaks English, lives in Europe, is/was diagnosed with any kind of cancer OR is/was a caregiver for an individual with any kind of cancer, and has a minimum age of 18 years. Additionally, an interest in research related to cancer and/or quality of life is considered helpful. Extra attention will be given during recruitment to diversity in age, gender, country of origin, cancer type, disease stage, and treatment phase.



Recruitment for co-researchers takes place via a call for action that circulates on social media (LinkedIn, Twitter), through (the network of) patient organizations, and other patient platforms.

Text box 4: Contingency plan for EUonQoL in case of dropouts

Due to the research topic of EUonQoL and the possible related health issues of co-researchers and/or their caregivers we aim to anticipate to cases of drop-out. Options in case of drop-out include replacement by another trained co-researcher, recruitment and training of a new co-researcher, and temporary reduction of level of patient involvement. To span moments of reduced patient involvement, patient input can be obtained by arranging a meeting with patient representatives.

3.2. Reimbursement

When involving co-researchers, it should be considered to honour and value their expertise by asking what would be beneficial for them regarding compensation for their efforts (monetary and non-monetary). At the very least, travel costs should be reimbursed, and expenses should be covered. Childcare might be reimbursed as well, if needed [7].

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Text box 5: Reimbursement of co-researchers in EUonQoL

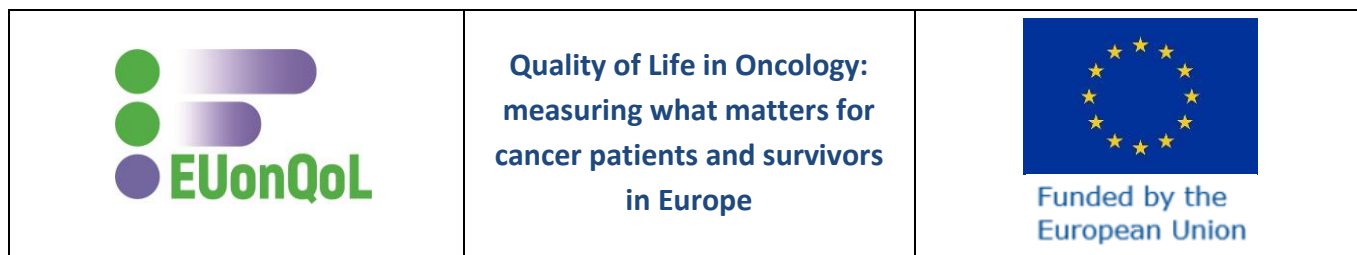
Patients and caregivers acting as co-researchers in EUonQoL will be offered financial compensation for their time and work but will be free to opt out from this compensation. Individual contracts to support this will be drafted by WP2 researchers. Payment will be defined as a certain hourly rate corresponding to usual practice in the field, and a maximum amount will be defined per co-researcher for the entire duration of the project, which they will be informed about. In case where co-researchers are asked to participate in in-person project activities that are necessary for the provision of their input into the project, their travel and accommodation costs will also be covered, following rules for eligibility of travel and accommodation costs defined in the project grant agreement as well as any relevant internal policy or other usual practice in-place in the WP2 partner in charge of the reimbursement.

3.3. Training for co-researchers

Co-researchers need specific training and skills to ensure that they can successfully complete the tasks they have been asked to do [10]. A “one-size-fits-all” training approach is not useful for PPI projects. Instead, individual training formats, content design and process need to be co-developed together with the research team and participating co-researchers. Generally speaking, training should be tailor-made, flexible, needs-oriented and co-creative [7]. To be able to develop appropriate training for co-researchers, researchers should be able to answer the why, what, and how of patient involvement during the research project.

Text box 6: Developing trainings for co-researchers in EUonQoL

To develop trainings for co-researchers in EUonQoL, all WP leaders and co-leaders were enquired to send information on the tasks that the co-researchers will need to participate in. Based on this, trainings are developed for these specific tasks (in addition to a basic training on the research project and the research process). Trainings are also customized based on input of experienced patient representatives.



4. Good practices during PPI

This chapter addresses good practices of involving co-researchers in research activities.

4.1. General considerations

Some general principles should be considered when involving co-researchers. Effort should be made to make meetings as easily accessible as possible, whether they are physical or digital [16]. Availability of co-researchers needs to be considered (will they be available during working hours? If not, what are other possibilities? E.g., late afternoon, weekends, public holidays). Co-researchers should meet with the research team on a regular basis (i.e., once a month, or as appropriate and feasible for the individuals and the research activities) [7].

Support should be provided for co-researchers on demand and on a regular basis (e.g., every 8 weeks) [7]. Furthermore, effort should be made to increase the emotional safety of engagement initiatives. A consideration that could be made is whether additional counselling support can be provided to co-researchers in the case that the sharing of their experiences results in emotional distress [16].

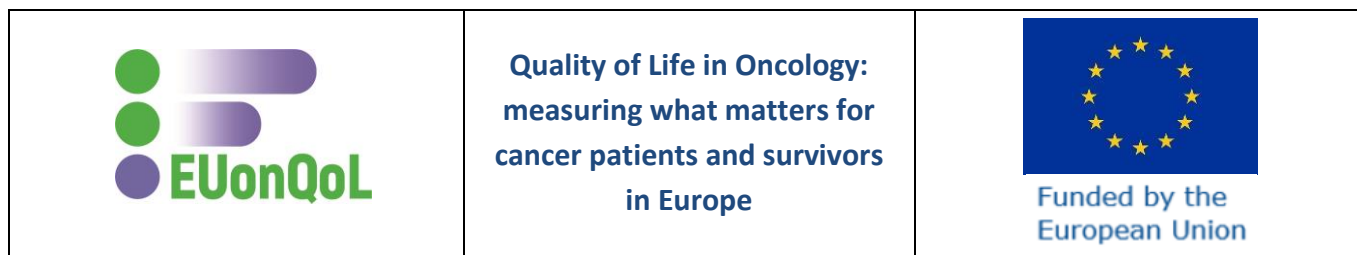
Involvement in research activities offers many opportunities for personal development for co-researchers that need to be considered. Learning activities may be provided for co-researchers, as well as career development opportunities (e.g., visit events, workshops, conferences, etc.). Additionally, co-researcher contributions to the project should be made visible, for example by co-writing (peer-reviewed) publications and folders for patients and the public (official co-authorship should be ensured) [7].

However, it is of equal importance to be aware of asking too much of co-researchers or providing them with too much information all at once. To ensure a sustainable collaboration between researchers and co-researchers, the workload should always be kept manageable for co-researchers. This should be checked with them continually and roles, tasks and responsibilities should be adapted accordingly.

Text box 7: Meetings with co-researchers and support provided in EUonQoL

Appointments between co-researchers and different researchers are planned during EUonQoL, so that co-researchers feel supported and to optimize collaboration. Researchers from all relevant WPs organize meetings with co-researchers on a regular basis. WP2 researchers organise support meetings for co-researchers in which we will reflect on their roles and contributions in the research teams.

In addition, setting up a buddy system can help to provide ongoing support, by linking co-researchers to experienced patient representatives that take on the role as ‘buddy’ on a voluntary basis. In EUonQoL, this ‘buddying’ system will include experienced voluntary members of the European Cancer Organisation’s Patient Advisory Committee, who will provide mentorship to the co-researchers, thereby ensuring further leveraging the vast amount of experience in the cancer patient and caregiver community regarding being co-researchers and participating in research studies, including on quality of life specifically.



4.2. Interactions between researchers and co-researchers

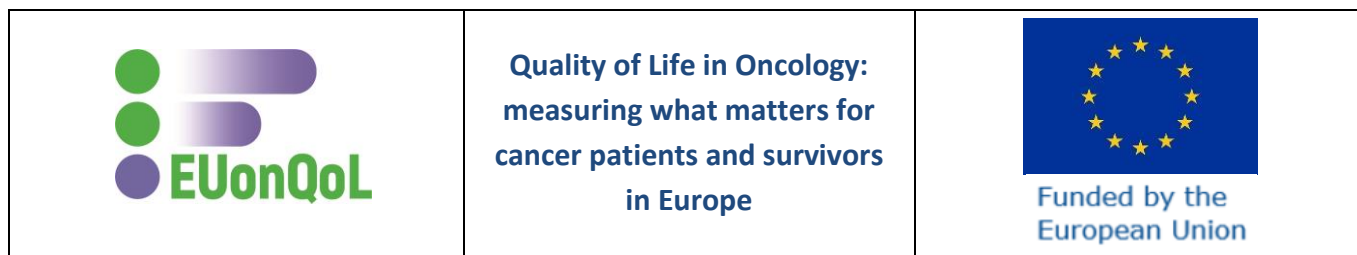
Interactions between researchers and co-researchers are key for a user-centred approach and in actively and meaningfully involving the latter in specific research activities [7]. Here, good practices on language and communication during the involvement of co-researchers in research activities are provided.

Open, honest, continuous, and transparent communication should always be considered. Provide information, provide contact details, and clarify availability, use informal language (avoid using academic titles), give regular project updates, send newsletters, use social media, etc. Avoid the use of (academic/research/medical) jargon to describe the research project and results and avoid the use of abbreviations. Always clearly inform co-researchers about how research activities will be adapted based on their contributions [7]. Give co-researchers material to read in advance and make sure materials are easily accessible [10].

Furthermore, build trust with co-researchers. Invest time on getting to know each other and stay in regular contact with them. Developing a bond makes fruitful collaboration possible as team members can then estimate what can be expected from each other and build enough trust to share ideas and give each other feedback [13]. Power imbalances should be avoided at all costs. Aim for flat hierarchies among researchers and co-researchers [10, 15, 16]. Researchers' skills that are needed for equal positioning include: a researcher needs to be willing to cooperate, to be able to listen well, to let someone finish talking and not interrupt too soon, to accept opinions from others, and to be good at deliberation [13].

Empower and nurture participants so that they are confident enough to engage with researchers and the research process [12]. Discussing the reasons for involvement and sharing their wishes concerning the collaboration creates a shared understanding of what each team member wants to accomplish in performing the research together [13]. Provide co-researchers with clear expectations and job descriptions. Agree together on their roles, tasks and responsibilities to avoid miscommunication and disappointment, also regarding time investment [7]. Time for collaboration is an essential requirement of participatory research. Substantial time and effort are needed from all team members. Additionally, attention from researchers is required to take into account the individual situations of co-researchers, for example any needs or constraints that co-researchers might have as a result of their or their loved one's cancer and treatment [13]. Researchers should adapt to these needs to optimize collaboration.

Co-researchers should be seen as equal partners in conversations or decision-making around research, bringing their unique experiences and perspectives to complement and enhance academic and clinical expertise [5]. Researchers should reflect on how their understanding may differ from those of their co-researchers [15]. Try to understand the perspectives/positions of the co-researchers and be mindful of the personal investments people can hold in how topics are interpreted [10].



Text box 8: Communication with co-researchers in EUonQoL

In addition to the good practices described above, it is important to note that in EUonQoL all communication (written and verbal) with co-researchers will be in English. A reason for this is that English is the language of the EUonQoL project. To be able to collaborate with co-researchers on a higher level of participation and avoid tokenism, a common language is essential.

To gain additional perspectives from non-English-speaking patients and public members, co-researchers can reach out to broader communities for input from more languages, and possibly more diverse and inclusive populations. This ‘community engagement’ can be established by reaching out to the voluntary buddies, other patient representatives, or the co-researchers’ own social circle (family, friends, neighbours, etc.).

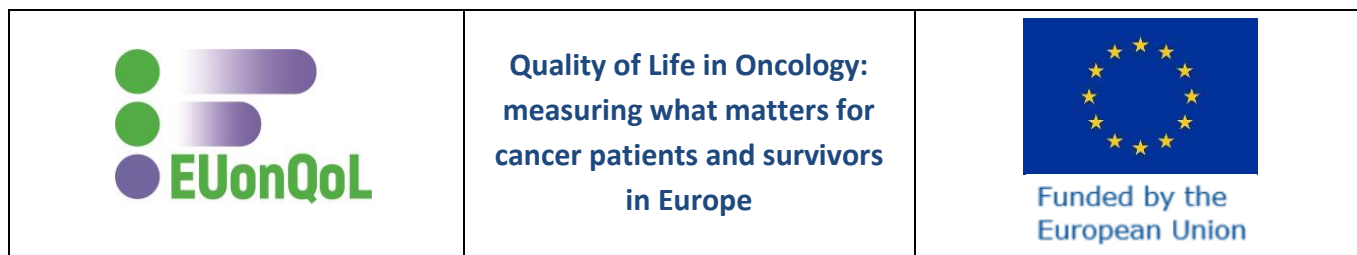
4.3. Research practices to improve PPI

For research involving PPI, member checking can be utilized to follow-up with co-researchers. A summary of what was understood and what decisions were made based on co-researchers’ recommendations could be used to initiate this discussion and followed up with questions such as, “have I understood correctly what you intended to communicate to me?” or “do you see yourself or your experience(s) reflected in these findings or suggestions for the design of the study?” [16]. Keep consulting and verify everything with co-researchers [10].

In research involving ongoing collaboration and partnership with several engaged co-researchers, it is important to keep evaluating, comparing, and refining the research process. Suggestions may result in refinement of earlier decisions made about study design or conduct, and as such, the research process becomes more iterative rather than linear. In this way, co-researchers are able to provide their input and experience to improve each step of the research process, such as determining best approaches to conducting the research and sharing it with those most affected by the outcomes [16]. Furthermore, allow adaptation of the tasks, roles, and responsibilities of co-researchers during the collaboration; be flexible about the methods of involvement [7, 15].

PPI can generate a wealth of information from very diverse perspectives. Each iteration of involvement may yield new information. Knowing when enough information has been gathered to make decisions with the research team (that includes co-researchers) about how the research may be designed or conducted can be challenging. An approach from qualitative research that can be adapted for PPI is theoretical saturation, or “the point in analysis when further data gathering and analysis add little new to the conceptualization, though variations can always be discovered.” [16]. In the case of PPI, this refers to input given by co-researchers. Continue until all input is collected and no new input is being brought up anymore. Additionally, listen to and explore differences of opinion. When non-consensus occurs, try to create novel synthesis to acknowledge the range of perspectives [10].

The concept of reflexivity can be applied to research involving PPI by continually and explicitly considering how decisions about research are made. All researchers must consider: (1) how co-researchers are invited to participate in research planning and decision-making; (2) how their input is received relative to other team members; and (3) whether co-researchers feel sufficiently safe, able, and respected to share their



experiences, preferences, and recommendations with the research team. Ideally, reflexivity becomes a practice within the research team and may be operationalized through regular check-ins with co-researchers about their comfort in sharing their views, and whether they feel that their views have been considered and taken onboard [16].

Based on research on the topic of collaboration, shared leadership between co-researchers and researchers is recommended during team meetings and research activities [15]. For example, co-researchers can aid with agenda setting for PPI meetings in collaboration with the research team and with providing a governance function to ensure that research activities are conducted appropriately [17].

Text box 9: Project governance in EUonQoL

A strong participation of patient and caregiver organisations in the governance of EUonQoL is highly recommended – this may for instance be the case via providing leading roles to their representatives in the project’s Stakeholder Advisory Board.

4.4. Evaluating and reporting the impact of PPI

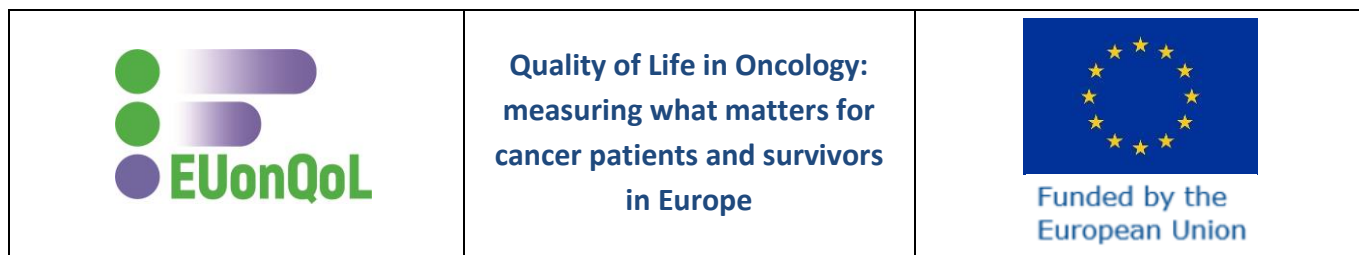
As described earlier, continuous evaluation of the co-researchers’ workload is important to ensure good collaboration. In addition, it is important to evaluate and appropriately report the process and impact of PPI activities, for example by regular and continuous evaluations on the context, process and impact of engagement [12]. After completion of the research activities, researchers and co-researchers may start with valuing and evaluating the impact of co-producing research [8]. Identifying and sharing the difference that PPI makes to research can lead to improvement for future research projects [18].

The outcomes of PPI often contribute to decision making in “real time” as the result of conversations in which researcher and co-researcher perspectives are concurrently and equally considered. Outputs from PPI meetings are usually captured via informal means for example via flip charts or comments written on sticky notes. PPI meetings may be recorded but agreement for this must be obtained from all individuals taking part, ideally before arrival at the event. The recording is not transcribed, nor the content formally analysed, but kept only briefly as a reminder of the meeting before being deleted. Quotes from PPI meetings may be used in research applications but only with the permission of the co-researcher [5].

Sharing research knowledge and educating other relevant stakeholders about research (e.g., by giving verbal updates, writing reports, presenting at or attending conferences and meetings) is also a crucial element of the research process in which co-researchers should be involved. In this way, they can contribute to guiding the direction of future research [17].

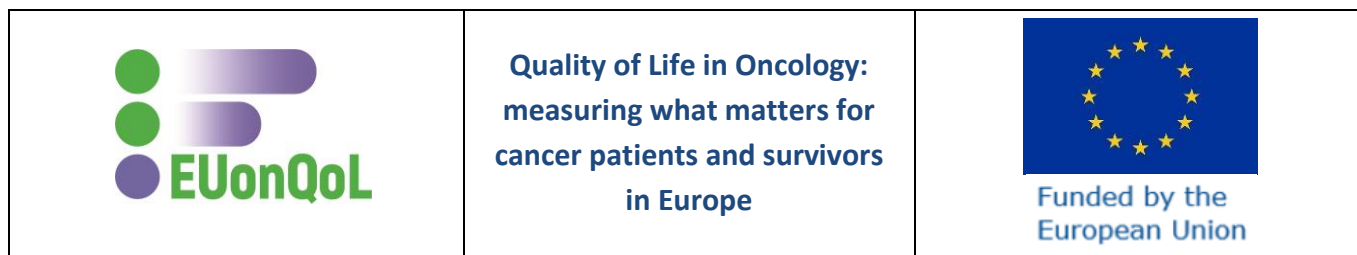
To date, most studies involving PPI provide limited details about their engagement processes and who was engaged. However, reporting of PPI using some aspects of dense description of co-researchers (as appropriate), the ways that they were engaged, and recommendations that emanated from co-researchers can contribute to greater transferability and understanding of how PPI influenced the design and process of a research study [16].

The impact of involvement in individual research projects where researchers collaborate with co-researchers might be more usefully conceived as a form of experiential knowledge, expertise that is gained



through the researchers' direct experience of collaborating with co-researchers. With this understanding, researchers' accounts of involvement provide a source of insight and learning that might usefully inform the approaches used by others, in the same way that insights and learning from the co-researcher experience can usefully shape research processes. However, researchers' accounts of involvement to date have not been sufficiently detailed, in that they do not always describe the context, mechanism and expected outcome of any chosen approach. These details are important to understanding the potential causal links [19].

To aid in reporting of PPI in research, the Guidance for Reporting Involvement of Patients and the Public (GRIPP) was developed. In 2017, a revised version of this guideline was published (GRIPP2), introducing a long version (LF) and a short version (SF). GRIPP2-LF and GRIPP2-SF are the first international, evidence based, community consensus informed reporting guidelines. The checklists provide key PPI concepts that authors should report in papers, to enhance the overall quality and transparency of the PPI evidence base. GRIPP2-LF and GRIPP2-SF aspire to guide PPI reporting in different types of studies, from reporting on PPI in trials (GRIPP2-SF) to reporting of PPI focused studies (GRIPP2-LF). Researchers can use the reporting guideline prospectively to plan PPI in studies and retrospectively as a quality assurance step in the writing up of PPI in publications and reports. Higher quality reporting will gradually lead to the development of a stronger PPI evidence base that will facilitate more effective synthesis of PPI studies [4].



5. Checklist

This chapter provides a checklist with important items that need to be considered before, during and after PPI activities in research. The checklist is based on Kaisler and Missbach [7] and adapted to be used in the EUonQoL project.

Before the research activities start (WP2):

- Recruitment of co-researchers
- Clear the legalities with co-researchers (e.g., usage of data)
- Set up financial compensation
- Training co-researchers (research project and research process)
- Development of contingency plan for dropouts
- Assign experienced voluntary buddies to the co-researchers for extra support and mentorship

Beginning of the research activities:

- Have a formal introduction meeting with co-researchers
- Clarify and describe the roles, tasks, responsibilities, and expectations of co-researchers
- Consult co-researchers on your description of their roles, tasks, responsibilities, and expectations, and adjust according to co-researchers' wishes and capacities
- Guideline for raising complaints and concerns
- Emotional and psychological support plan developed and set up
- Evaluation plan and assessment of activities (may be co-created with co-researchers)

During the research activities:

- Regular updates on project progress, results, and plans to co-researchers
- Meet regularly with co-researchers for feedback and consultation on research activities
- Be always attentive of the workload for co-researchers; adjust if necessary
- Mentorship of co-researchers by the voluntary buddies
- Co-design and co-analyse elements of the research
- Co-write (scientific) publications and media coverage
- Co-lead (scientific) presentations
- Co-convene conferences and events
- Create learning opportunities and further career development for co-researchers

After the research activities:

- Updates and dissemination of research outcomes and future opportunities to be involved in
- Co-lead in conference presentations and events
- Co-write funding applications for future projects
- Use GRIPP-LF checklist to report on PPI activities (checklist can be accessed through the accompanying article by Staniszewska et al. [4])



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