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Preface

This report 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 express their gratitude to everyone that participated in the consensus process of the EUonQoL-Kit, including researchers involved in the EUonQoL project, members of the EUonQoL Stakeholder Board, and all individuals that participated in the Stakeholder Forum as external stakeholders.

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Summary

Health research is increasingly being conducted with patients and other stakeholders, rather than only for or about them. This collaboration is also termed Patient and Public Involvement, or PPI. To date, achieving successful PPI that lives up to moral, methodological, and educational expectations is a struggle for many, because of its situational and dynamic nature. Therefore, there is a general need for sharing practical examples within the research field that can serve as inspiration on how to organize collaboration with patients and other stakeholders and how to deal with challenges that are encountered. In this report, we will share lessons learned about PPI with patients and other stakeholders from all over Europe within the project "Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe (EUonQoL)". We aim here to provide an insight into the consensus process that preceded the finalization of the EUonQoL-Kit (a new set of questionnaires, specifically designed for the digital self-assessment of quality of life of (former) cancer patients). Specifically, we evaluate the involvement of cancer patients and informal caregivers as co-researchers, and stakeholders as members of the Stakeholder Board, in the decision-making process.

The consensus process consisted of four major events: two consensus workshops, a consensus meeting, and a stakeholder forum. The first consensus workshop aimed to present and bring together the results of systematic reviews, a Delphi study, and interviews, as input for the draft EUonQoL-Kit. It was an all-day hybrid meeting in which both researchers and co-researchers participated. The second consensus workshop aimed to give an update of the results as presented in the previous workshop meeting, and to plan the next steps in the development of the EUonQoL-Kit. This was an online meeting that lasted for two and a half hours, to which researchers and co-researchers were invited to join. The aim of the consensus meeting was to reach unanimity on which subdomains would be included in the EUonQoL-Kit. It was an all-day hybrid meeting in which researchers, co-researchers and Stakeholder Board members could participate. The stakeholder forum aimed to introduce the EUonQoL project to a wider stakeholder audience and to sense-check a preliminary version of the toolkit to externals not yet acquainted with it. It was a two-hour online meeting, which gathered a large crowd of participants, including researchers, co-researchers, Stakeholder Board members, and other stakeholders. We evaluated and categorized the events and the inputs provided during the events by using the Cube Framework to conduct a document analysis of the event documents, e.g., agendas, presentation slides, minutes of the events written by researchers and event facilitators, and minutes of regular meetings with co-researchers before and after the events.

Across all four dimensions of the Cube Framework, which was used to analyse and structure results, we observed a significant development in the involvement of co-researchers and Stakeholder Board members during the consensus process. Within the dimension 'Organization's concerns – Public concerns' the focus of the discussions shifted from focusing mostly on technical aspects of the EUonQoL-Kit towards opinions and experiences of co-researchers and Stakeholder Board members. Within the dimension 'One way to be involved – Many ways to be involved' PPI methods were increasingly adapted to the needs and wishes of co-researchers and Stakeholder Board members. In later meetings more attention was paid to preparing co-researchers and Stakeholder Board members and providing them with space to share their opinions. Within the dimension 'Organization changes – Organization resists change' researchers became more open to co-researchers' and Stakeholder Board members' input, by asking follow-up questions and

providing feedback on how their input would be incorporated in the development of the toolkit. Finally, these developments contributed to a stronger voice of the co-researchers and Stakeholder Board members within the dimension 'Weak voice – Strong voice'. A shift took place from them mostly providing input when prompted by researchers towards active involvement in the meetings that were organized.

The characterization of the consensus process along the four dimensions of the Cube Framework provided valuable lessons learned for PPI in general. An important lesson is that PPI takes time and needs effort and resources to develop during a project. Another lesson learned is that there is a critical difference between equal and equitable collaboration, in other words, it is important to not treat co-researchers in the exact same way as researchers. Researchers can accomplish equitable collaboration by proactively involving co-researchers and Stakeholder Board members in discussions, asking them specific questions, and making space for providing input. Also, we learned to not underestimate the added value of informal contact. Informal moments such as social activities, but also coffee breaks and lunch breaks, are essential to feel comfortable working together and for providing critical feedback. Finally, we learned that collaborating with co-researchers and stakeholders in an international context is different to collaborating in smaller-scale, national contexts. Meetings mainly take place online, and linguistic and cultural differences need to be overcome to be able to work together.

In conclusion, PPI in the consensus process of the EUonQoL project can be visualized as a steep learning curve. Factors that helped with this development, are a good preparation for all parties, provision of support by researchers specifically responsible for the PPI activities, taking the time and providing the space in the process to develop the collaboration further, and realising the importance of informal contact. Additionally, we can conclude that collaboration between researchers and Stakeholder Board members comes more naturally than with co-researchers. Being used to formal collaboration structures, not experiencing a power imbalance and not being in a vulnerable position are factors that all contribute to this.

1. Background on 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, thereby contributing to the EU initiatives against cancer. The EUonQoL project aims to review existing scales and develop new metrics by harnessing the strengths and overcoming the limitations of previous tools. The EUonQoL-Kit will be a new set of questionnaires, specifically designed for the digital self-assessment of quality of life (QoL), 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 other stakeholders in all project phases.

The EUonQoL project consists of ten work packages (WPs) in total that all focus on a different step in the toolkit development process: from reviewing literature to implementation. Table 1 provides a brief description of the different work packages.

Table 1: Description of the work packages in the EUonQoL project

Work package (WP)	Description
WP1	Ethic requirements
WP2	Involvement of stakeholders and patients
WP3	Review of existing quality of life databases, measures, and item libraries
WP4	Development of the EUonQoL-Kit
WP5	Cross-cultural determinants of quality of life, and linguistic and cultural adaptation of EUonQoL-Kit
WP6	Digital tools for data collection
WP7	EUonQoL-Kit pilot survey
WP8	Implementation and exploitation
WP9	Dissemination and communication
WP10	Project management and coordination

This current report is written in the context of WP2, which focuses on involving patients, informal caregivers, and stakeholders in the EUonQoL project. This involvement is essential to the project to ensure that the EUonQoL-Kit captures the aspects of QoL that matter most to patients, as well as to ensure that it produces output that stakeholders can use to address (unmet) needs, expectations and preferences of patients and caregivers. The work package leader of WP2 is Nivel (Netherlands Institute for Health Services Research), in good collaboration with the partner organisation 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/.

1.1. Aim of the report on consensus on instruments

The aim of this report is to provide an insight into the consensus process that preceded the finalization of the EUonQoL-Kit. Specifically, it focuses on the involvement of cancer patients and informal caregivers as co-researchers, and stakeholders as members of the Stakeholder Board, in the decision-making process, and the dynamics of interaction within the key meetings of the consensus process. It outlines the methods and findings of a series of meetings: two consensus workshops, an in-person consensus meeting and an

online Stakeholder Forum. Additionally, we describe what lessons we learned from this process regarding the future involvement of co-researchers and Stakeholder Board members in the EUonQoL project. These lessons might also prove to be relevant for all researchers collaborating with patients, informal caregivers, and other stakeholders in their research.

2. Introduction

Health research is increasingly being conducted with patients and other stakeholders, rather than only for or about them. This collaboration is also termed Patient and Public Involvement, or PPI (1). The literature provides many arguments for collaborating with patients and stakeholders in health research. These arguments can be divided into three overall categories: moral, methodological, and educational. According to moral arguments, having a say in decision making that will (eventually) affect people's lives is a fundamental right (2, 3). Methodological arguments focus on improvements in the quality and relevance of research. PPI contributes to improved research questions and methodologies that match the needs and wishes of patients and stakeholders (4, 5). Educational arguments suggest that PPI is an enriching experience to patients, stakeholders, and researchers, as they obtain new skills and knowledge through their collaboration (4, 6).

To date, achieving successful PPI that lives up to these expectations is a struggle for many. This is the result of its situational and dynamic nature (7, 8). PPI processes strongly depend on those involved, e.g. the researchers, patients and other stakeholders, and the context it takes place in, e.g. the type of research, deadlines and organizational systems (3). This means that there is no blueprint for doing PPI right: it is created in continuous interaction between all stakeholders (8). Additionally, it is often not clear in advance how PPI processes will develop, which can cause feelings of discomfort among researchers who are generally used to setting protocols and plannings (9). Other practical challenges to PPI include the high demands in terms of time and resources, power imbalances, uncertainties about roles and responsibilities, and unfamiliarity of patients and other stakeholders with research (10).

There is a general need for sharing practical examples within the research field that can serve as inspiration on how to organize collaboration with patients and other stakeholders and how to deal with challenges that are encountered (11, 12). Consequently, an increasing number of examples are available in the literature, addressing a wide variety of patient groups and themes in health research (13). These examples have been a valuable addition to the knowledge base about PPI. However, to our knowledge, none of them addresses collaboration with patients and other stakeholders that cross national borders, as in the EUonQoL project. Although similar challenges may be expected when conducting PPI in an international, European context, it is likely that specific challenges also emerge, for example, language barriers, cultural differences, and a greater dependency on online collaboration.

In this report, we will share lessons learned about PPI with patients and other stakeholders from all over Europe within the EUonQoL project. We have selected the Cube Framework by Gibson and colleagues (14, 15) as a framework to analyse and describe specific PPI activities. This framework assumes that PPI involves the dynamic interaction of different forms of knowledge, i.e., that of researchers, patients, and other stakeholders (15, 16). The situations where experiential, professional and scientific evidence, interpretations, and opinions come together in dialogue to inform decision making, are termed 'knowledge spaces' (14, 15).

The Cube Framework describes four dimensions that underpin successful interactions within knowledge spaces (14, 15). These four dimensions are depicted as a cube (Figure 1), and include: (1) *one way to be involved-many ways to be involved*, referring to the number of ways patients and other stakeholders were involved; (2) *organization's concerns-public concerns*, referring to the balance between research and

public priorities; (3) *weak voice-strong voice*, referring to how much influence patients and other stakeholders had on decision making; and (4) the overall dimension *organization resists change-organization changes*, referring to the extent researchers were able and willing to make changes to the research based on the input of patients and other stakeholders (15, 16). The dimensions are meant to characterize and map the dynamics within PPI processes, not to distinguish between 'right' and 'wrong'.

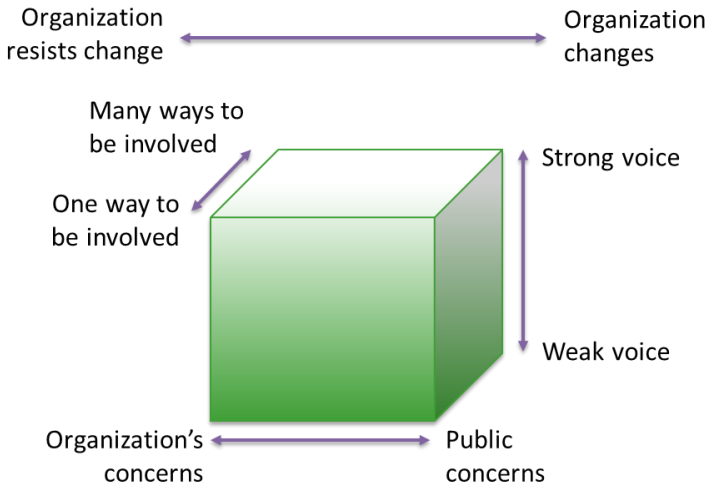


Figure 1: The Cube Framework, adapted from Gibson et al. (2017)

In the EUonQoL project, co-researchers are assigned to all WPs, and they collaborate closely with researchers in the WP teams. However, in the present report we focus specifically on the consensus process that took place in the EUonQoL project. During the consensus process, we built knowledge spaces with researchers, (former) cancer patients and relatives, and other stakeholders by organizing four major consensus events. Before and during the consensus process, researchers within WP3 and WP4 collected data about cancer and relevant domains of quality of life. The consensus process was a means to involve co-researchers and stakeholders in the discussion of the obtained data, and to collect their reflections and advice on the development of the final EUonQoL toolkit. We have evaluated the consensus process by addressing the following research questions:

1. How were co-researchers and stakeholders involved in the consensus process, and how can their involvement be characterized according to the four dimensions of the Cube Framework?
2. What factors facilitated or impeded the involvement of co-researchers and stakeholders in the consensus process?
3. What lessons can be learned from the involvement of co-researchers and stakeholders in the consensus process for their future involvement in the EUonQoL project?

3. Methods and findings

The consensus process took place between July 2023 and December 2023 (Figure 2). It consisted of four major events: two consensus workshops (July), a consensus meeting (October) and a stakeholder forum (December). In this section, we will describe the methodology for each event in the consensus process and the findings regarding the involvement of co-researchers and Stakeholder Board members. The findings are based on a qualitative analysis of the event documents, e.g., agendas, presentation slides, minutes of the events written by researchers and event facilitators, and minutes of regular meetings with co-researchers before and after the events. We categorized the events and inputs during the events based on the Cube Framework. This document analysis was conducted using MAXQDA software for qualitative analyses.

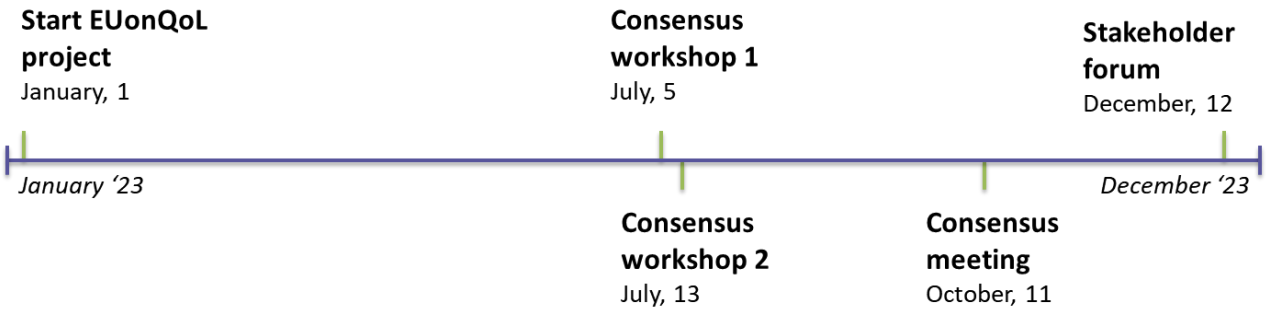


Figure 2: Timeline of the four major events during the consensus process

Below, we will describe the methods and findings regarding PPI for each part of the consensus process, i.e., the consensus workshops (3.1), the consensus meeting (3.2) and the stakeholder forum (3.3). Table 2 presents the overall aims and contents of each event in the consensus process. A description of the recruitment of the diverse types of participants is provided in Text box 1.

Table 2: Aims and contents of each event in the consensus process

Date	Meeting	Aim of meeting	Input for discussion	Participants	Modality
July 5th, 2023	Consensus workshop 1	Present and bring together the results of the systematic reviews, the Delphi study, and interviews, as input for the draft EUonQoL-Kit	Findings from systematic reviews, initial findings from Delphi study and interviews	Researchers, co-researchers	Hybrid (in-person and online)
July 13th, 2023	Consensus workshop 2	Give an update on the results, and plan the next steps in the consensus process and the development of the EUonQoL-Kit	Results from first consensus workshop, findings from systematic reviews, initial findings from Delphi study and interviews	Researchers, co-researchers	Online

October 11th, 2023	Consensus meeting	Reach consensus on which subdomains will be included in the EUonQoL-Kit	Results from both consensus workshops, findings from systematic reviews, findings from Delphi study and interviews	Researchers, co-researchers, Stakeholder Board members	Hybrid (in-person and online)
December 12th, 2023	Stakeholder Forum	Introduce the EUonQoL project to a wider stakeholder audience, sense-check a preliminary version of the toolkit, and discuss the sustainability of the project in the long-term with a policy angle	Results from the usability testing study, results from the consensus meeting and both consensus workshops, findings from systematic reviews, findings from Delphi study and interviews, policy outreach plan	Researchers, co-researchers, Stakeholder Board members, wider stakeholder audience	Online

Text box 1: Description of the recruitment of co-researchers and Stakeholder Board members

Co-researchers were recruited for the project via a call for action that circulated on the social media pages (LinkedIn, X) of Nivel, ECO, and EUonQoL, and through the OECI Newsletter. Potential co-researchers who expressed their interest first received additional information via e-mail and were then invited for a video call to meet, to provide information about the project, and to discuss their potential involvement. In total we held eleven interviews with potential co-researchers. Following these interviews, six co-researchers were selected in which we strived for diversity in age, gender, country of origin, cancer type they have experience with, whether they are a patient or informal caregiver, and experience with patient advocacy and health research. One co-researcher dropped out of the project shortly after being recruited, therefore the collaboration continued with five co-researchers. Four participants have (had) cancer themselves, and one is an informal caregiver for a relative with cancer. They originate from different countries in Europe: Finland, Ireland, Italy, Portugal, and The Netherlands.

The Stakeholder Board was constituted based on a stakeholder mapping exercise developed by ECO. As an initial step, relevant stakeholders working in topics related to quality of life and mental health of cancer patients, as well as data infrastructure systems, were identified. The identified stakeholders included policymakers, representatives of European and international research bodies, representatives of medical societies, health economists, patient advocates, social workers, hospital managers and representatives of EU projects. Also, ECO used its EU-funded projects contact database to identify relevant stakeholders. After the mapping was completed, ECO proceeded to contact the stakeholders identified and extended an invitation to join the EUonQoL Stakeholder Board. Currently, the EUonQoL Stakeholder Board is constituted of eleven experts from different geographic backgrounds and with a wide range of expertise. The Board includes two experts from international renowned centres, two professional society representatives, one representative for social work, one representative for health managers and federations and three coordinators from three different EU-funded projects (i.e., smartCARE, ONCORELIEF, TEHDAS).

3.1. Consensus workshops

Methods

The first consensus workshop took place on July 5th, 2023, in the headquarters of the EORTC in Brussels, Belgium. The aim of this consensus workshop was to present and bring together the results of the systematic reviews conducted by WP3, and the Delphi study and interviews conducted by WP4, as input for the draft EUonQoL-Kit. Researchers of WP2, WP3 and WP4, and all five co-researchers were invited to join. It was an all-day hybrid meeting enabling both in-person and online participation.

The morning program focused on in-person discussions, during which several researchers and one co-researcher were present. All participants were seated equally, in a U-shaped setting of chairs and tables. Some researchers were present online during the morning session, but mainly to listen. The morning program started with a brief introduction on the plans for the workshop. Then, WP3 and WP4 researchers spent two hours presenting the preliminary results of the literature reviews, the interviews, and the Delphi study, and another fifteen minutes to discuss with participants how to bring the results together in the toolkit.

The afternoon program focused on discussions with online participants. The three co-researchers who wished to join online could log in from this moment. In the afternoon program, WP3 and WP4 researchers shortly presented the preliminary findings again in fifteen minutes. After that, they summarized some critical issues encountered in bringing together all the data to form the toolkit, followed by ten minutes of discussion about how to manage each issue.

The second consensus workshop took place on July 13th, 2023. The aim of this consensus workshop was for WP3 and WP4 to give an update of their initial results, and to plan the next steps in the consensus process and the development of the EUonQoL-Kit. It lasted for two and a half hours, and researchers of WP2, WP3 and WP4, and all co-researchers were invited to join. During this meeting, only online participation was possible. As the Stakeholder Board was not yet formed, stakeholders were not present during both consensus workshops.

Several researchers and three co-researchers attended this second consensus workshop. The meeting started with an introduction to the aims and structure of the meeting. Then, approximately one hour and a half spent presenting the preliminary findings of the literature reviews, interviews, and Delphi study, and in the final hour issues that had arisen from the analysis and tool development were summarized and discussed with participants.

Findings

<u>Organization's concerns – Public concerns</u>

As the topic of the consensus workshops was about the results of the systematic reviews and the work leading up to the draft toolkit, the discussions took place in the context of the dimensions that will be addressed in the questionnaires, i.e., physical health, psychological health, social health, and healthcare.

Co-researchers provided input on two distinct levels: the practical/technical side of the toolkit and the actual content of the toolkit. Firstly, they asked explanations from the researchers about the research methodologies being used for toolkit development and the definitions of the domains. They also gave input on which question(s) they think should be chosen within a domain, and the wording of the questions and domains. Secondly, co-researchers shared opinions on why certain topics are important/relevant from their point of view and should therefore be addressed in the questionnaire. Some examples of topics the co-researchers provided input on, include communication with healthcare professionals, physical fitness and sports, body image, anxiety in relation to the care pathway, positive aspects of having cancer, having hobbies, stigmas on (former) cancer patients and impact of treatment side effects.

<u>One way to be involved – Many ways to be involved</u>

The involvement during the consensus workshops was characterized by the fact that the researchers considered the co-researchers as equal collaborators in the EUonQoL project, and therefore treated them in a comparable way to researchers. However, the co-researchers were relatively new to the project, and some did not have experience in conducting health research. This made it difficult for them to keep up with the amount of information that was being provided by the researchers (e.g., presentation slides) and the topics of the discussions that were going on. During the first consensus workshop, the researchers had scheduled some time in the afternoon to present the results specifically to the co-researchers and to have a discussion, but this time was too limited for the co-researchers to grasp the amount of information that was being provided. During the second consensus workshop there was also time scheduled for presentations and discussions, but this was not specifically aimed at co-researchers. Additionally, due to tight schedules, the consensus workshops were planned at a relatively short notice, providing the co-researchers with limited time to familiarize with the agenda and to prepare for the workshop meetings.

In line with this, it was noticeable that researchers are used to proactively providing input during meetings, and therefore had the expectation that co-researchers would do the same. However, for co-researchers this felt (a bit) threatening, and hampered their involvement during this early stage of the project. During the consensus workshops, researchers asked the co-researchers whether they in general understood the information that was being provided and discussed, however, no specific questions were asked to actively involve them in the discussions. As a result, discussions mainly took place among the researchers instead of together with the co-researchers. During both consensus workshops WP2 researchers suggested asking specific questions to the co-researchers and on both occasions the other researchers were responsive to this, trying to involve the co-researchers more actively.

<u>Organization changes – Organization resists change</u>

Researchers responded to the co-researchers' input in several ways. They explained definitions of terminology, the methods of developing the toolkit and reasons for in- or excluding certain items in the questionnaire. Additionally, they complimented the co-researchers on giving good and useful input and wrote down input to give it some more thought later. Follow-up questions were not frequently asked based on the input of co-researchers.

During the second consensus workshop an updated version of the domains and items to be included in the questionnaires was presented. The input of the co-researchers from the first consensus workshop was

considered by the researchers in this version. To learn more about the ways in which participants' feedback was incorporated in the EUonQoL-Kit, we would like to refer to the WP4 report describing how patient priorities and preferences informed the development of the toolkit (17).

Weak voice – Strong voice

Co-researchers provided most input during the afternoon session of the first consensus workshop (both in-person and online). They gave input when being prompted by the researchers, but also asked questions and gave their opinions proactively. Co-researchers acted in a comparable way during the second consensus workshop. During the morning session of the first consensus workshop there were fewer opportunities for co-researchers to provide input since that part was more focused on the researchers. This caused some uncertainty among co-researchers; they declared that they did not know enough about the project and therefore would be asking the wrong questions.

During the second consensus workshop, less input was provided by the co-researchers compared to the first consensus workshop. This may be explained by the repetitive nature of the second consensus workshop compared to the first one.

Emotions and actions resulting from the process

Two additional, emerging themes that were identified during the document analysis but that are not addressed in the Cube Framework include the emotions resulting from the consensus process and new actions resulting from the consensus process.

One co-researcher expressed disappointment prior to the first consensus workshop, because information about the meeting had not been shared in a timely manner in their opinion. After the consensus workshops, the co-researchers responded more positively and shared that they found it interesting to participate.

In response to the consensus workshops, WP2 signalled the need for educating the researchers more about collaborating with co-researchers. For most researchers this was the first time they collaborated with co-researchers and so the idea was introduced to provide a training workshop to all the researchers on collaborating with co-researchers (more information on the training workshop is provided in Text box 2).

Text box 2: Aim and content of the training workshop on co-researcher involvement

WP2 developed a training workshop on co-researcher involvement with the aim to provide practical training to researchers on how to collaborate with co-researchers, and to kick-start their collaboration. Both researchers and co-researchers were invited to this online workshop. The workshop lasted two hours and was organized twice, so that researchers and co-researchers could join one of the workshops based on availability. During the workshop we introduced researchers to the four Rs of co-researcher involvement in research: Relationship, Roles, Right conditions, and Reflection. The workshop combined presentations with interactive sessions and creative methods, to help facilitate this new way of interaction between researchers and co-researchers. The uses of the creative methods provided a route to easier communication during the workshop as the discussion was on a level playing field.

3.2. Consensus meeting

Methods

On October 11th, 2023, the consensus meeting was organized at the Netherlands Institute for Health Services Research (Nivel) in Utrecht, the Netherlands. The aim of this consensus meeting was to reach unanimity on which subdomains would be included in the EUonQoL-Kit. It was an all-day hybrid meeting which participants could join both in-person and online. Central to the meeting were four co-researchers and five Stakeholder Board (SB) members. For the SB members, this was their first participation in the consensus process. A pre-consensus meeting took place before the consensus meeting, in which the SB members were informed about the EUonQoL project and prepared for the meeting (more information on the pre-consensus meeting is provided in Text box 3).

The co-researchers and SB members discussed the domains and subdomains to be potentially included in the toolkit. In this role, they were positioned centrally in the meeting room facing each other. Several researchers from all WPs were present to listen to these discussions, take notes, and clarify specific issues when they were asked to. They were sitting in the back of the room, behind the co-researchers and SB members. An independent moderator (not related to the EUonQoL project) chaired the meeting.

The morning program started with a word of welcome, presentation of the agenda and rules of the meeting, as well as a round of introduction between all participants. Then, WP3 and WP4 researchers presented evidence for the inclusion or exclusion of subdomains for each of the four domains of the EUonQoL toolkit, i.e., social health, psychological wellbeing, physical health, and overall health & healthcare. After each presentation, co-researchers and SB members had 35 minutes of discussion about the domain and its subdomains and voted about inclusion or exclusion. During the informal lunch of one hour, the chair of the consensus meeting counted the votes. The afternoon program consisted of a short presentation of the results from the voting, and 35 minutes of discussion between the co-researchers and SB members during which they reflected on them. Participants were then invited to make suggestions for new topics and items that should be added to the questionnaires.

Text box 3: Aim and content of the pre-consensus meeting with SB members

A pre-consensus meeting was organised by the ECO team with the aim to provide an overview of the EUonQoL project to the Stakeholder Board members and to help them familiarise further with it, as well as to share early input and feedback on the draft EUonQoL-Kit. Besides Stakeholder Board members, principal researchers of the EUonQoL project were also invited to this online meeting that lasted one hour and a half.

Findings

<u>Organization's concerns – Public concerns</u>

Like the consensus workshops, the content of the consensus meeting evolved around the potential domains and subdomains of the EUonQoL-Kit. However, in this meeting, the focus was primarily on the opinions and experiences of the co-researchers and SB members to shape the toolkit to stakeholders'

needs and preferences. There were some comments on the technical aspects of the toolkit, such as the wording of several subdomains, the possibility to add an open question and to make patients rate the degree of importance for them.

Most of the input provided by co-researchers and SB members was based on their own experiences, and how these influenced their opinion on which subdomains are important. A selection of the topics that were addressed by the participants included: stigma and competition in the workplace, flexibility in return to work needs, the central role of informal caregivers, the importance of support systems and patient communities, financial burden of cancer, impact on family relationships, post-traumatic growth, and the importance of having one 'key' health care professional available.

<u>One way to be involved – Many ways to be involved</u>

Even though the discussion topics of the consensus meeting were comparable to the consensus workshops, the manner of involvement was quite different. There was a longer preparation time for the consensus meeting, and this resulted in a better preparation for all parties. Co-researchers were better prepared because they spend more time in the project and they received supporting materials for the meeting well in advance, the SB members were prepared by participating in the pre-consensus meeting, and researchers were better prepared for the involvement aspect of the meeting by following the training workshop on co-researcher involvement.

The consensus meeting featured different presentations on the subdomains of the toolkit, but the time scheduled for discussions was far more considerable. The seating arrangements put co-researchers and SB members at the centre of the discussions. The discussions were moderated by an independent researcher, who made sure that there was a lot of space for providing input and all participants could have their say. Discussions on the relevance of the different subdomains was concluded with a round of voting for each subdomain, in which only co-researchers and SB members could participate. The results of the voting rounds were reported back to the participants in the afternoon session, resulting in a short feedback loop where the participants got immediate feedback on the input they provided. Furthermore, in the afternoon session there was an opportunity for participants to freely provide topics and insights that might be included in the toolkit, giving the floor completely to co-researcher and SB members to provide insights, not being influenced or restricted by the information provided by researchers.

<u>Organization changes – Organization resists change</u>

Since the discussion evolved around the co-researchers and SB members, there was less emphasis on the interaction with the researchers during this meeting. However, in the cases where researchers did get involved in the discussion, it could be seen that their responses to input provided by the participants was slightly different compared to the workshop meetings. In addition to giving explanations about terminologies and methods, researchers responded much more openly. For example, there was a lot more agreement between researchers and the other participants. Researchers indicated to take follow-up actions and to include co-researchers in this. On occasions there was a more open, equal discussion going on and researchers asked the participants follow-up questions. The input provided by co-researchers and SB members was considered in the further development of the toolkit. To learn more about the ways in

which participants' feedback was incorporated in the EUonQoL-Kit, we would like to refer to the WP4 report describing how patient priorities and preferences informed the development of the toolkit (17).

Weak voice – Strong voice

During the consensus meeting there was a lot of input provided by both co-researchers and SB members. The discussion took place among the participants, resulting in an open, equal discussion that was guided well by the moderator. The moderator opened the discussion, prompted participants with questions and made sure all participants had their turn in contributing to the discussion. This made it noticeably easier for co-researchers to provide input here and make their voice heard than during the consensus workshops.

Emotions, and actions resulting from the process

Before the consensus meeting the co-researchers looked forward to it. They were mostly eager to meet the other co-researchers and the researchers in real life, as they felt like this was a big step that could potentially change things in the project in a positive way.

Afterwards, the co-researchers reported they had indeed enjoyed meeting each other, the SB members, and the researchers. The social program (a group dinner and a boat trip through the canals of Utrecht) was also valued greatly. Co-researchers felt privileged to be seated in the front of the meeting and that the discussion mostly took place among co-researchers and SB members.

SB members highlighted the productivity of the meeting, largely supported by the face-to-face interactions. They stressed the high-level discussion, as well as the valuable input and personal experiences shared by co-researchers. Overall, they acknowledged the relevance of the four sub-domains chosen, rightfully encapsulating the complexity of quality-of-life related research.

3.3. Stakeholder forum

Methods

The stakeholder forum took place on December 12th, 2023. The aim of the forum was to introduce the EUonQoL project to a wider stakeholder audience and to sense-check a preliminary version of the toolkit to externals not yet acquainted with it. It was a two-hour online meeting, which gathered a large crowd of participants. Next to the co-researchers and SB members, other (former) cancer patients, (informal) caregivers and stakeholders were invited as well. A total of 111 participants joined the forum.

The program started with a word of welcome, followed by presentations about the overall EUonQoL project and the methodological development of the toolkit. Then, participants were invited to choose between four break-out rooms, each focusing on a specific domain of the toolkit. The latter were chosen in the consensus meeting, as summarised in section 3.2 of this deliverable, i.e., social health, psychological wellbeing, physical health, and overall health & healthcare. In each break-out room, a researcher from either WP3 or WP4 presented the findings of the research efforts relevant to that domain. Participants were encouraged to reflect on these findings during 30 minutes of discussion that were moderated by a WP2 researcher, through targeted questions. A Miro board – an interactive mind-mapping digital tool - was used by assigned note-keepers from WP2, WP3, and WP4 to record all contributions. After the

discussions, all participants returned to the main room, where the moderators summarized the major points that had arisen from the discussion in each break-out room to the wider audience. The final half-hour was used for presentations of other EU-funded projects (i.e., The Cancer Inequalities Registry, SmartCARE, My Path) to discover common ground and build synergies. Finally, the implementation and sustainability of the project in the long-term were briefly touched upon. The project having started fairly recently, such topics will be reflected in future stakeholder fora.

Findings

Organization's concerns – Public concerns

The stakeholder forum was the last major event in the consensus process, and therefore, the domains and subdomains of the toolkit were discussed again, but now with a wider audience. As with the previous consensus events, a distinction could be made between a discussion of technical aspects and of opinions related to the content of the toolkit. The audience for this meeting was much more varied than other meetings, and this is also reflected in the variation of topics that were discussed.

Regarding the technical aspects of the toolkit, it was mentioned that there should be a clear distinction between the different patient groups (active treatment, survivor, palliative care), yet also that the toolkit should be user-friendly and easy to navigate. There should also be an option to add free text, and to rate the different subdomains according to personal relevance. It was debated that the questions should be tailored to different age-groups, as each encounter different obstacles that may alter their quality of life significantly. Finally, topics that were deemed important in relation to the content of the toolkit were financial toxicity, sex life and intimacy, communication between healthcare professionals and patients, oral health, and post-cancer follow-up care.

One way to be involved – Many ways to be involved

The involvement method of the stakeholder forum was comparable to the consensus meeting, but online and with a much wider audience. Comparable to the consensus meeting was the fact that presentation time was limited, and the focus was on the discussions between patients, relatives, and stakeholders (here taking place simultaneously in break-out rooms). Discussions were moderated and, therefore, many participants had the opportunity to provide input. Co-researchers, SB members and wider stakeholders all participated in the same manner and therefore could engage in open, equal dialogue with each other. The co-researchers were asked beforehand if they wanted to introduce themselves to the wider audience during the consensus meeting, either on the spot or by delivering a quote, and several co-researchers made use of this. This opportunity presented the co-researchers to a wider audience as project collaborators, thereby safeguarding and validating their contribution to the meeting and the project.

Organization changes – Organization resists change

After finalisation of the break-out room discussions, all discussion points were collected and presented to the wider audience, including project researchers. Researchers received the feedback and took this with them in the finalisation of the toolkit. To learn more about the ways in which participants' feedback was

incorporated in the EUonQoL-Kit, we would like to refer to the WP4 report describing how patient priorities and preferences informed the development of the toolkit (17).

Weak voice – Strong voice

A lot of input was provided by participants, mostly by the wider stakeholders who were new to the project and the toolkit. Co-researchers and SB members provided input to a lesser extent; however, this may be explained by their extensive involvement in the consensus process to this point and the repetitive element of the different meetings.

Emotions and actions resulting from the process

All participants were enthusiastic about the stakeholder forum. Several stakeholders have sent emails to the organization expressing their positive feelings about the meeting.

One SB member presented the Cancer Inequalities Registry during the final panel discussion, and other SB members were also present during the meeting, actively engaging during the breakout room. Overall, they applauded the initiative, which allowed to confirm the results of the consensus meeting.

Partners emphasised the need to reiterate the exercise, which will prove of beneficial use for next steps of the project and future dissemination of the toolkit.

4. Discussion

The aim of this report was to provide an insight into the consensus process that preceded the finalization of the EUonQoL-Kit, and specifically the PPI of co-researchers and SB members in this process. We aimed to evaluate the consensus process by addressing how co-researchers and SB members were involved in the consensus process, how their involvement can be characterized according to the four dimensions of the Cube Framework, what factors facilitated or impeded their involvement in the consensus process, and what lessons can be learned from their involvement in the consensus process for future efforts in the EUonQoL project.

Cube Framework evaluation

Across all four dimensions of the Cube Framework, we observed a significant development in the involvement of co-researchers and SB members during the consensus process. Firstly, within the dimension 'Organization's concerns – Public concerns' the focus of the discussions shifted from focusing mostly on technical aspects of the EUonQoL-Kit and the methods used for its development towards opinions and experiences of co-researchers and SB members to determine the most important and relevant topics for the questionnaires. Secondly, within the dimension 'One way to be involved – Many ways to be involved' PPI methods were increasingly adapted to the needs and wishes of co-researchers and SB members. Initially researchers treated co-researchers in a comparable way to the researchers, but this created difficulties among co-researchers in keeping up with the fast pace of the meetings. In later meetings more attention was paid to preparing co-researchers and SB members and providing them with space to share their opinions. Thirdly, within the dimension 'Organization changes – Organization resists change' researchers became more open to co-researchers' and SB members' input. Researchers increasingly asked follow-up questions and provided feedback on how all their input would be incorporated in the development of the toolkit, in addition to explaining and complimenting the input that was provided. Finally, all these developments also contributed to a stronger voice of the co-researchers and SB members within the dimension 'Weak voice – Strong voice'. A shift took place from them mostly providing input when prompted by researchers towards active involvement in the meetings that were organized.

Facilitators and barriers

The developments within the four dimensions were experienced as positive by everyone involved, since it facilitated interactions within the knowledge spaces that were created. They contributed to a better collaboration and a more open, equal dialogue between researchers, co-researchers, SB members and wider stakeholders. There were several factors that facilitated this. Preparation of all involved parties is important for a good collaboration. Co-researchers preferred to have written information send to them beforehand timely, and to learn about new topics that may be discussed. SB members also responded positively to receiving information beforehand. Increased familiarity with the project resulted in more confident co-researchers and SB members. Preparation for the researchers turned out to be important as well, as the training workshop on co-researcher involvement that was organised in preparation of the consensus meeting was described as 'a turning point' in their collaboration with co-researchers. Additionally, the support provided to the co-researchers by the researchers responsible for PPI, both during the consensus process events and during regular support meetings, was perceived to be important. Furthermore, the informal, social aspect in the form of a social activity the evening before the consensus meeting in Utrecht and several breaks during the meeting itself turned out to be facilitators. Getting to

know each other better had important added value for the collaboration. Another facilitator was the seating arrangement during the consensus meeting, in which the co-researchers and SB members were seated at the centre of the discussion, helping them to strengthen their position in the meeting. Other facilitators included proactively involving co-researchers and SB members and asking them follow-up questions when input was provided.

In addition to facilitating factors, several barriers to involvement were identified. Co-researchers were not involved from the beginning of the project, and the consensus process workshops were the first actual research activities in which they were involved. This meant that the researchers had already started working on the project, making it difficult for co-researchers to deal with the amount of information while still learning about the purpose of the project in general. Additionally, PPI in the consensus process was new to all those involved. For the co-researchers, this included a lot of new people that participated in the process, unfamiliar methods that were being applied, and lots of new terminology. In the beginning of the process, this resulted in the co-researchers not feeling comfortable enough to provide input, and not knowing which questions to ask. For most researchers, PPI was also new, which resulted in discomfort and not knowing how to involve the co-researchers in the process. During the first meetings this showed because, for example, co-researchers' involvement was not specifically facilitated and researchers rarely asked follow-up questions to the co-researchers. Furthermore, the modality of the first meetings was mostly online, which is a barrier in getting to know each other and for informal contact. Additionally, there was a repetitive element to the consensus process events: the (sub)domains of the toolkit were discussed on all occasions. Although the aims of the events differed, for co-researchers it felt like they were listening to and saying the same things on multiple occasions.

In addition to our reflection from the researchers' side, we have asked the co-researchers that are involved in the EUonQoL project to write their own reflections on the consensus process. In Text box 4 this reflection from the co-researchers' side is provided.

Text box 4: Co-researchers' reflections on the consensus process

When reflecting upon the results described in this report, the co-researchers all concurred that the description fitted perfectly with the experience had. Their comments have shed light on three major aspects regarding this experience. The first is the development of their involvement in the project, the second concerns the Nivel team's fundamental role as mediators between the researchers and themselves, and the third focuses on the co-researchers' reflections as contributors to the project.

As far as their involvement in the project is concerned, the co-researchers recognized it slowly and steadily evolved over the weeks. In the first consensus meeting, partly owing to their own uncertainties and lack of information knowledge, partly owing to the fact that the researchers had already been working on the project for some time (for example, the co-researchers had no idea how the CAT-system worked), the co-researchers felt somewhat excluded from the discussions. They lament having felt 'invisible' and not recognized in their role. However, this soon changed. In the second consensus meeting, the co-researchers perceived they were being treated in a very different way, finally able to take on a more prominent role in the discussions. Indeed, after a few months enormous progress had been made between the way researchers and co-researchers were collaborating. The mediation of the Nivel team was fundamental in this process.

The Nivel team's mediating work undoubtedly facilitated that, on the one hand, the co-researchers acquire more confidence in collaborating with the researchers and that, on the other hand, the researchers realize they needed to actively involve the co-researchers more. Thanks to regular support meetings set up by the Nivel team, the co-researchers grew as a group and as active collaborators in the project. The conversations between the Nivel team and the co-researchers in fact allowed the latter to get to know the project better and to understand how to participate in the work and in the activities required. By providing the time and place in which to update one other on their involvement in the different work packages as well as be a support mechanism where any issues or queries could be raised and resolved within the group, or communicated to WP leads/groups if needed, these meetings allowed the co-researchers to get to know each other better, to become aware that uncertainties were common to them all, and that the initial obstacles could be overcome as a team. The support from the researchers at Nivel, which entailed meetings of an hour every two weeks, enabled the co-researchers to reflect constantly on the activities and how the project was progressing, strengthening the relationships between one another along with the perception of their own roles.

While not having been involved straight away surely put them in a weaker position at the outset, the co-researchers now feel they are active contributors to this project. They are fully aware that this is greatly owing to the importance given to the communication between the researchers and themselves. The exchange of information and active involvement between the two groups (thanks also to the sharing of electronic files and databases) has not only given the co-researchers more voice in the project, but has also helped the researchers see the non-expert's point of view better too. This project, that has been a learning curve for both researchers and co-researchers, demonstrates the need to plan and share non-expert/patient involvement from the start. It also underlines how it is necessary to be able to continually evaluate, facilitate, and adapt this involvement as both groups work through the process. This collaboration is emblematic of how future healthcare systems should be planned and how research and society can and should be bridged.

Lessons learned

The characterization of the consensus process along the four dimensions of the Cube Framework, the identification of facilitators and barriers, and the reflections of the co-researchers provided valuable lessons learned for PPI in general. An important lesson is that PPI takes time and needs effort and resources to develop during a project. Knowledge spaces are built in close collaboration between researchers, co-researchers and other stakeholders (8). This is inevitably a messy and complex process that requires a lot of work from everyone, since different people are brought together who use different languages, have different experiences, and hold different degrees of decision-making power (8, 18). This may be especially the case in international projects that bring together people from diverse cultures, such as the EUonQoL project. At the beginning of the consensus process, all different people involved had different understandings of PPI, but they learned together and developed along the way, in an iterative process of listening, observing, and experiencing what works, for whom and why. In line with Dedding (8), we learned that the friction we experienced in this process was an important aspect of the learning process. The differences between co-researchers, SB members and researchers, led to interesting interactions but also in difficult moments and confusion (18). We are used to only celebrate the joyful moments, but we learned to recognize and celebrate disturbances and frictions as well (8). These led to new knowledge and more inclusive practices. For instance, the discomfort of researchers with PPI led to the organization of a

training workshop and the uncertainty of co-researchers led to better preparation and a different planning of the consensus events.

Another lesson learned is that there is a critical difference between equal and equitable collaboration, in other words, it is important to not treat co-researchers in the exact same way as researchers. We noticed that striving for equal collaboration can lead to the exact opposite. It has previously been described that striving for absolute openness and equality can lead to co-researchers feeling overwhelmed by the amount of information, confused as to what they are expected to do with all the information, and overburdened by including them in discussions of topics that are of little interest or relevance to them (19). Co-researchers are generally not familiar with the formal working structures, procedures, and terminology in research. In addition, they contribute from a vulnerable position, as they are often a minority compared to the researchers and share very personal experiences. As such, they have other needs in collaborating than researchers. This applies to a lesser extent to SB members, as they are more used to formal collaboration structures and contribute based on professional experiences.

Researchers can accomplish equitable collaboration by proactively involving co-researchers and SB members in discussions, asking them specific questions, and making space for providing input. This can be reflected in, for example, seating arrangements during meetings and the ways in which meetings are organized. Good preparation and support of everyone involved are also key. Clear details of a meeting's objectives and agenda should be circulated in advance (19), as well as information on the practicalities of the meeting, and written materials to read in preparation of the meeting. Also, it takes time to get used to a project, so in general a longer participation in the project also leads to a better preparation. Researchers need to be prepared as well, especially when they are not familiar with PPI. While we wrote in the EUonQoL handbook & checklist on PPI only about training co-researchers (10), it turned out that researchers needed to be trained as well. Additionally, support is important for co-researchers in the shape of a designated and trusted point of contact that they can approach if they, for example, have any concerns about their involvement that they do not feel comfortable raising with the wider team (19). These researchers, such as WP2 in the EUonQoL project, monitor how things are going, intervene if they see friction, can be approached in case of problems, and can bridge the power differences between researchers and co-researchers.

PPI is a profoundly relational and interactional process (20), and therefore we learned to not underestimate the added value of informal contact. It is important to get to know each other early in the process, to be able to create good conditions for collaboration. Without strong connections and a firm grounding, it is difficult to build actual participation practices (8). Informal moments such as social activities, but also coffee breaks and lunch breaks, help to break down social barriers and increase approachability (19), which is essential to feel comfortable working together and providing critical feedback. Specifically, regarding the vulnerable position that co-researchers find themselves in and the personal experiences they share. But also, to promote collaborative discussion between researchers, co-researchers, and other stakeholders.

Finally, we learned that collaborating with co-researchers and stakeholders in an international context is different to collaborating in smaller-scale, national contexts. Meetings mainly take place online, and linguistic and cultural differences need to be overcome to be able to work together. Facilitating online PPI may mean that people previously excluded on the basis of travelling difficulties or problems of access to buildings can now participate in meetings (21). Additionally, it enables people that live far away from each

other to work together, and it accommodates those that are at risk due to clinical vulnerability (22). Also, online collaboration takes less time than meeting in person which can be of added value for people with little time to spare. However, online PPI can also cause difficulties with regard to digital exclusion if access to technology is limited, and with regard to the formal nature of the meetings (21). One could state that 'distance creates distance', meaning that the actual measurable distance between participants makes it harder to feel connected to each other and to the project. One reason for this is the lack of informal contact and small talk during online meetings. This informal connection is necessary to create a good relation and the right conditions for collaboration.

Conclusion

In conclusion, PPI in the consensus process of the EUonQoL project can be visualized as a steep learning curve. Where initially researchers and co-researchers felt some discomfort in working together and were exploring the best way to do so, later there was a mutual connection and understanding established that benefitted the collaboration. Factors that helped with this, are a good preparation for all parties, provision of support by researchers specifically responsible for the PPI activities, taking the time and providing the space in the process to develop the collaboration further, and realising the importance of informal contact. Additionally, we can conclude that collaboration between researchers and SB members comes more naturally than when co-researchers are involved. Being used to formal collaboration structures, not experiencing a power imbalance and not being in a vulnerable position are factors that all contribute to this. In the continuation of the EUonQoL project the described factors will all be taken more into account as we proceed in our collaboration with co-researchers and SB members.

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