

# Collaborating with cancer patients and informal caregivers in the EUonQoL project: why, how, and what we learned so far?

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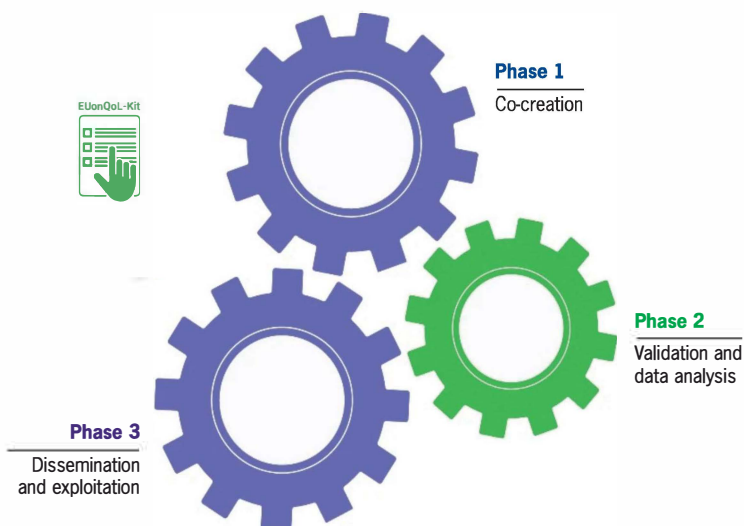
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Health research is increasingly conducted with patients and members of the public, rather than for or about them. This is also called Patient and Public Involvement (PPI). PPI has the potential to increase research relevance, quality, and impact, and can be an enriching experience for everyone involved. Important values and principles of PPI include respect, openness, inclusion, diversity, transparency, responsiveness, and accountability. We describe here how PPI is applied within the European project “Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe” (EUonQoL), and what the lessons are that we have learned so far.

The EUonQoL project (<https://www.euonqol.eu/>), already introduced in recent issues of this magazine, started in January 2023 and aims to develop the Oncology Quality of Life Toolkit (EUonQoL-Kit), a new set of quality of life questionnaires aimed at (former) cancer patients in Europe. The project is based on PPI principles; therefore, five cancer patients and informal caregivers are involved as co-researchers in all project phases. The workload of the EUonQoL project is divided over multiple ‘work packages’ focusing on the various stages of the project, such as EUonQoL-Kit development, validation, and dissemination.

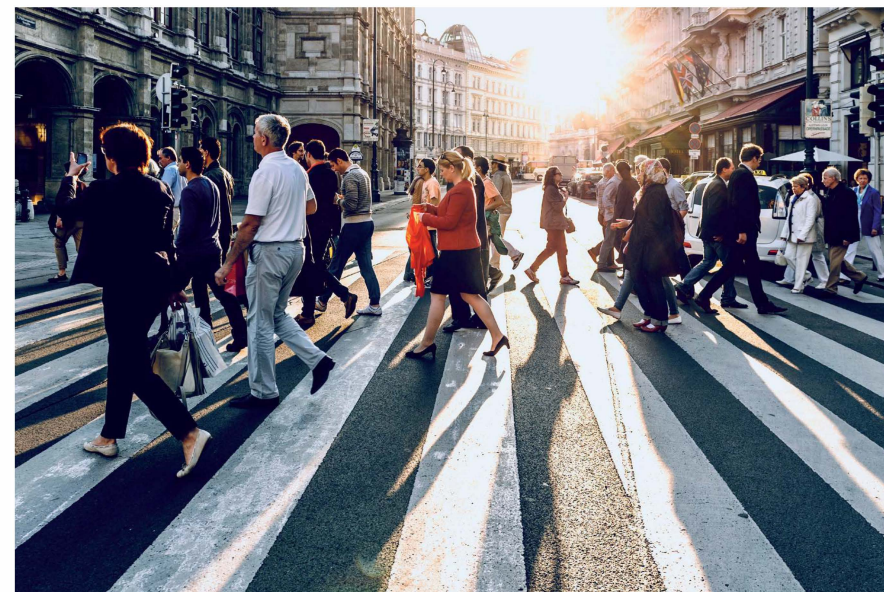


## How did we start: preparation of PPI in EUonQoL

Co-researchers were recruited via a call for action that circulated on social media (LinkedIn, X) and through the OECl Newsletter. Especially the Newsletter proved to be a fruitful way of recruitment because of its pan-European reach and wide audience. 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 the final selection, attention was paid to diversity in age, gender, country of origin, cancer type, disease stage, and treatment phase.

To ensure good implementation of PPI principles in the EUonQoL project, a group of researchers with expertise in PPI (hereafter referred to as “PPI researchers”) were identified to facilitate PPI activities and to support co-researchers. At the start of the project, they wrote a handbook for the EUonQoL consortium on how to collaborate with co-researchers. It contains a theoretical background on PPI, practical aspects that need to be considered when engaging in PPI, and good practices for collaborating with co-researchers. The handbook also includes a checklist of items to be completed at the start of research activities, such as agreement on roles, tasks and responsibilities, language, frequency of contact, reimbursement, and support possibilities.

The PPI researchers also organized training for co-researchers. They asked other EUonQoL researchers to describe in which specific tasks co-researcher would be involved in at various stages of the EUonQoL project and discussed this with the co-researchers. Based on their needs, training sessions were developed. The training program consisted of three sessions: a kick-off meeting in which the co-researchers and PPI researchers got to know each other and the EUonQoL project was introduced, a second session where the project and its work packages were discussed more in detail, and a third session reserved for specific training wishes of the co-researchers. However, it turned out that the co-researchers did not have many specific training wishes. Instead, the PPI researchers organized a training workshop for the other researchers because many of them were doing PPI for the first time and it turned out that they had a need for practical tools to do so.

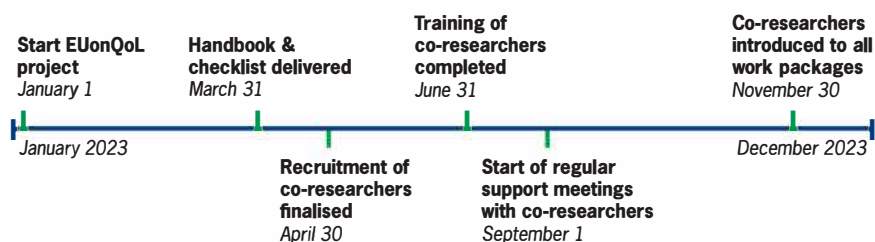


## What are we doing now: PPI in all stages of the EUonQoL project

After training, the co-researchers were each linked to three of the projects’ work packages based on their skills and preferences. The researchers leading each work package were asked to schedule a formal introductory meeting with the co-researchers and the work package teams to get to know each other, and jointly discuss roles, tasks, responsibilities, and expectations of co-researchers. A tool that can be used to guide this conversation, and was in fact used in several work packages, is the Involvement Matrix. This tool helped researchers and co-researchers to discuss roles and tasks of co-researchers in distinct phases and activities of a work package.

The introductory meetings were the starting point for further collaboration in the work packages. This is taking place now, mostly through online and in-person meetings and consultation through other means, such as e-mail. Regular meetings between co-researchers and researchers of different work packages are planned during the EUonQoL project to optimize collaboration. The frequency of these meetings varies between once a week to once every few months and depends entirely on the needs of both the researchers and the co-researchers.

To maintain an overall view of the workload and needs and wishes of co-researchers when collaborating with different researchers in various work packages, the PPI researchers organize regular support meetings. These informal meetings focus on building relations to create a safe space where co-researchers feel confident to ask for help and share experiences with each other and with researchers. Co-researchers also have the possibility to reflect on their roles and contributions in the research teams and discuss specific topics of interest in more depth, for example, the development of the EUonQoL-Kit and the consensus process that preceded its finalisation.



*Timeline of co-researcher involvement in the EUonQoL project during its first year.*

### How will we proceed: future outlook

Regarding PPI, the first year of the project was mostly dedicated to starting up and making sure everything goes well. We learned that this can be a messy process, during which it is important to invest time in getting to know each other and the project. Building a good relation is key to create a comfortable and safe space for collaboration. Everyone involved needed to explore new ways of working together and we found that flexibility is important. On multiple occasions, approaches were adapted based on the continuous reflections that were conducted with both researchers and co-researchers.

We are now well underway in the second year of the project and find that there is more room for structured evaluation and reporting of the PPI process and impact. PPI researchers have developed an evaluation form to be used within the EUonQoL project, based on the existing PPI impact log. Also, the standardized GRIPP2 reporting checklist will be used to systematically report on PPI activities. Structured evaluation and reporting will gradually lead to the development of a stronger PPI evidence base, which will facilitate more effective implementation of PPI in future (cancer) research.

### TOOLBOX – to start with PPI in your own research

- Handbook & checklist on participatory research:  
[https://www.euonqol.eu/docs/results/D2-1\\_Handbook\\_checklist\\_final.pdf](https://www.euonqol.eu/docs/results/D2-1_Handbook_checklist_final.pdf)
- Involvement Matrix:  
<https://www.kcrutrecht.nl/involvement-matrix/>
- PPI impact log:  
<https://arc-w.nihr.ac.uk/patient-and-public-involvement/resources/patient-and-public-involvement-impact-log/>
- GRIPP2 reporting checklists:  
<https://www.bmj.com/content/358/bmj.j3453>