

Patient, caregiver and stakeholder involvement in research: the role of co-design

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Today's agenda

1. Introduction
2. Why patient, caregiver and stakeholder involvement?
3. How do we plan to achieve co-design?
4. What have we done so far?
5. Presenting our co-researchers
6. What will follow next?
7. Questions and discussion

Introduction: EUonQoL team: patient, caregiver and stakeholder involvement



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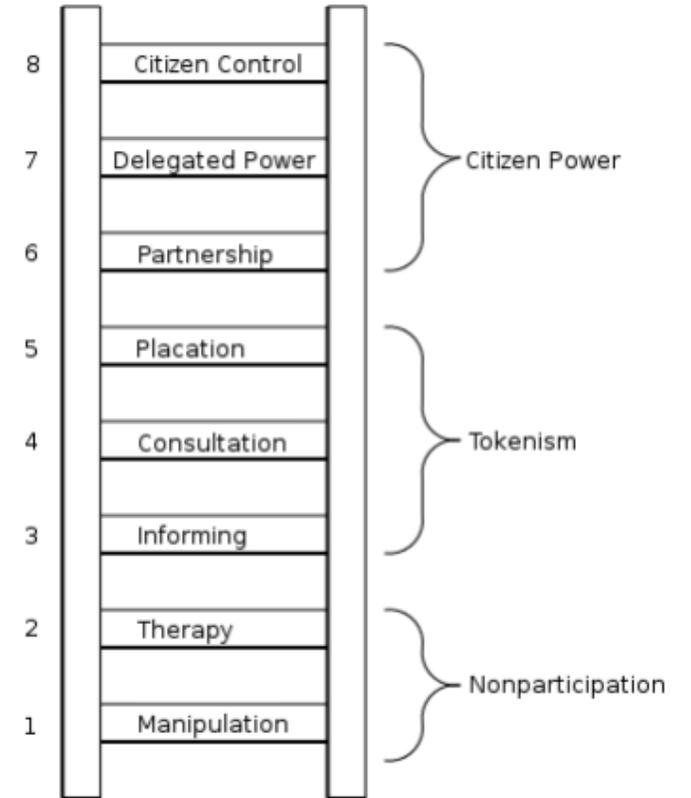
Nivel is an independent non-profit research institute with strong roots in primary care, patient experience measurements and health system performance assessment.

Nivel's mission is to carry out high quality research which has a demonstrable impact upon society.



What is patient and caregiver involvement?

- Patient and public involvement (PPI):
“Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”
- Some values and principles of PPI: *respect, support, transparency,*
- Arnstein’s Ladder of Citizen Participation (1969)



Why patient and caregiver involvement?

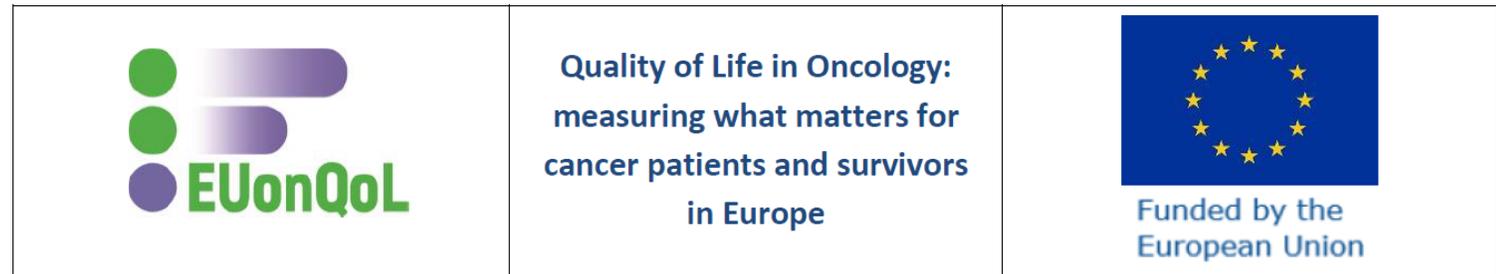


- Some benefits of PPI include:
 - Improving relevance of research
 - Reducing ‘research waste’
 - Bringing science and society closer together
- Patients have a right to have an input to research on their condition, and reducing the knowledge gap between researchers and patients is a moral duty of researchers

How do we plan to achieve co-design?

Patient and caregiver involvement:

- Handbook & checklist: Collaborations in participatory cancer research



4. 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

What have we done so far?

Patient and caregiver involvement:

- Recruitment - call for action
- Selection of 5 co-researchers
- The first 2 online meetings/training sessions took place
- Connecting co-researchers to work packages based on their preferences

Quotes from our co-researchers (1)



Tapani, Finland

I want to participate as a co-researcher, because I believe that this project is really important. And I believe, that I have something to give to the project.

I am proud to be part of the group co-researchers in EUonQoL. I love the idea that so many countries and so many organizations are working together to improve the assessment of quality of life in cancer patients and survivors and are willing to listen to the experiences of survivors like us. Together we can make it work!



Inke, The Netherlands

Quotes from our co-researchers (2)



Laura, Italy

Listening to patients and their needs is the way forward in healthcare. Being a co-researcher in this project is an enormous opportunity to strengthen the bond between patients and healthcare workers and help gain the best results for us all.

I am so happy but also feeling a huge sense of responsibility for being a co-researcher in EUonQoL! Quality of life is the main goal for a cancer survivor and it is thus a privilege to be able to contribute to such aim.



Carina, Portugal

Quotes from our co-researchers (3)



Caitriona, Ireland

I'm delighted to have been invited to participate in this project. It represents something I strongly believe in, that the cancer patient's voice on what matters to them is heard in healthcare.

What will follow next?

Patient and caregiver involvement:

- Assign 'buddies' to co-researchers for extra support and mentorship
- Connect co-researchers to the work packages of EUonQoL
- Further train co-researchers for the required tasks and responsibilities (if needed)
- Formally introduce co-researchers to the work package researchers
- Organise regular support meetings with co-researchers
- Creating a strong connection between co-researchers and consortium members

European Cancer Organisation (ECO)



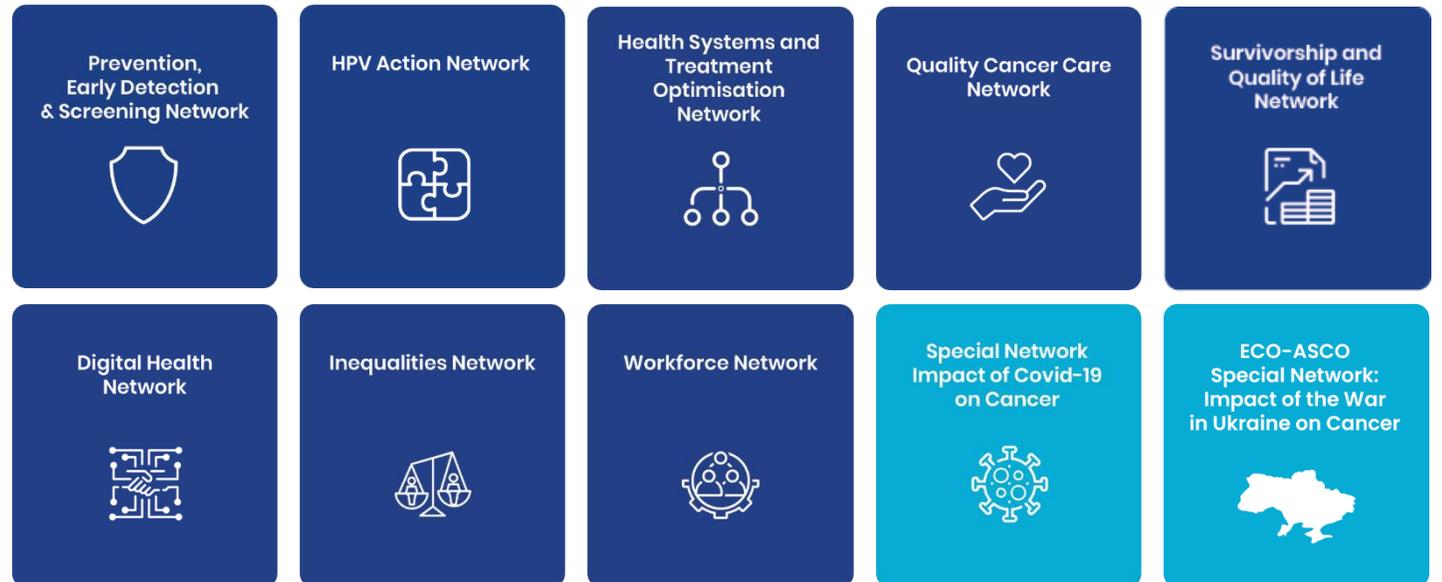
The European Cancer Organisation (ECO) convenes oncology professionals from 42 Member Societies and 21 Patient Groups to develop policies, advocate for change and speak up for the European cancer community.

Our Focus

Enhancing and expanding cancer care across Europe through a multidisciplinary, collaborative approach.



Our 10 Focused Topic Networks



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Treatment
Optimisation
Network



Quality Cancer Care
Network



Survivorship and
Quality of Life
Network



Digital Health
Network



Inequalities Network



Workforce Network



Special Network
Impact of Covid-19
on Cancer



ECO-ASCO
Special Network:
Impact of the War
in Ukraine on Cancer



EU projects ECO is coordinating



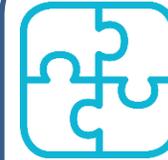
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Stakeholder involvement



Relevance of stakeholder involvement for the EUonQoL project:

- **Awareness and visibility of the project** among the patient, clinical, research, stakeholder and political communities is high from the outset;
- **Alignment of work** conducted within the EUonQoL and other relevant initiatives and sharing of best practices;
- EUonQoL-Kit is built in a way that **matches expectations** from both the cancer community and of wider relevant stakeholder groups.

How do we plan to achieve co-design?



Stakeholder involvement:

- D2.2 Report on stakeholder needs and requirements: Specifics on stakeholder involvement and engagement plan:
 - Identification and mapping of relevant stakeholders
- Planning activities to involve stakeholders in the co-design (i.e. Stakeholder Forum)

How do we plan to achieve co-design?



Name of the activity	Attendees	Timelines	Focus
Pre-consensus meeting	Stakeholder Board	July	Presentation of the overall project and of the first EUonQoL draft questionnaire
Stakeholder Consensus Meeting	Stakeholder board + co-researchers + consortium partners	September	In-depth discussion of the consolidated EUonQoL draft questionnaire
Stakeholder Forum	Stakeholder board + co-researchers + consortium partners + relevant stakeholders	December	Community wide agreement on the final EUonQoL questionnaire

What have we done so far?

Stakeholder involvement:

- Stakeholder mapping has been completed
- Stakeholder Board composition proposed
- Pre-consensus meeting planning
- Stakeholder Forum planning

What will follow next?

Stakeholder involvement:

- Final composition of Stakeholder Board
- Organising Stakeholder Board meetings
- Organising a Stakeholder Forum
- Including stakeholders in consensus meetings

Questions and discussion

