

Patient involvement in research: Pilot survey co-design

Nanne Bos, program lead patient-centered care, Nivel

Laura Pinnavaia, co-researcher

Inke Minnée – van Braak, co-researcher

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Definition of patient and caregiver involvement

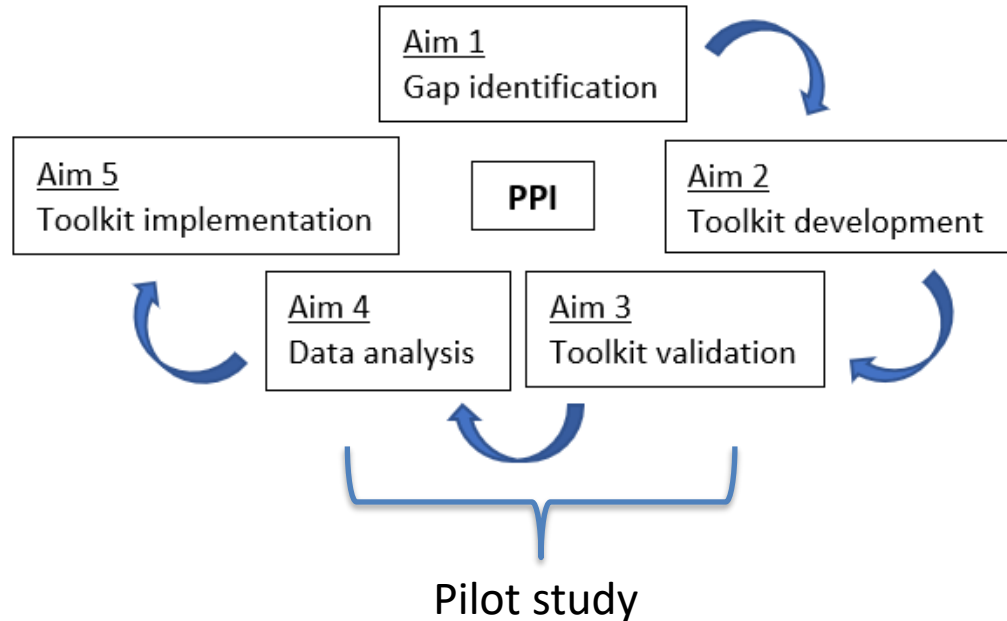
Patient and public involvement (PPI):

*Research being carried out **with** or **by** members of the public rather than **to**, **about** or **for** them*

Why patient and caregiver involvement?

- Patients have a right to provide input to research (and care)
- Benefits:
 - Improving relevance of research (questions, methods, results)
 - Reducing ‘research waste’
- Bringing science and society closer together. Reducing the knowledge gap between researchers and patients.

PPI in EUonQoL



Ambition of EUonQoL:

- to contribute to the EU initiatives against Cancer;
- by developing the European Oncology Quality of Life Toolkit ([EUonQoL-kit](#));
- a patient-centred unified tool for the assessment of quality of life among cancer patients and survivors.

Engelaar, M., Bos, N., van Schelven, F. *et al.* Collaborating with cancer patients and informal caregivers in a European study on quality of life: protocol to embed patient and public involvement within the EUonQoL project. *Res Involv Engagem* **10**, 59 (2024). <https://doi.org/10.1186/s40900-024-00597-9>

Co-researchers in EUonQoL

Caitriona Higgins, Ireland

Tapani Kalmi, Finland

Carina Dantas, Portugal

Laura Pinnavaia, Italy

Inke Minnée-van Braak

How we started

- Selection process by Nivel
- Meetings online
- Work-packages/ activities of preference
- Talents and tasks in relation to aim of the packages
- Collaboration and getting to know each other

Challenges


- We were not all familiar with research in health care
- Researchers are used to certain terminologies
- For most researchers, it is new to collaborate with co-researchers
- It is hard to find time to meet and discuss with researchers because we have jobs and/or other obligations in life

Advantages

- Flexibility to fill in the tasks as desired
- Co-researchers are involved in several (3 to 4) work packages
- We keep each other updated every two weeks (professional and personal)
- We are learning from each other and navigate through the process of being co-researchers

Q&As – do’s and don’ts in interacting with patients

During the survey

1) Recruitment phase		
✓	✗	
2) Questionnaire administration phase		
✓	✗	

Why is it important?

- Patients receive all the information they need to decide whether or not to participate in the study
- The phases of patient recruitment and questionnaire administration are handled correctly.

Co-researchers value in the pilot study

- Posters and flyers etc. to inform and convince potential participants to agree to participate
- Use of social media to show that EUonQoL is trustworthy and that the patient's voice will be heard.

Patient and Public Involvement



- For us it feels important to use our personal experiences for a good purpose
- Learning about research and meeting new people
- To researchers:
 - new insight into patient's perspective
 - using those insights to validate the process of measuring what matters to cancer patients and survivors in terms of quality of life

Questions and discussion

