

Patient involvement in the EUonQoL-kit open-ended question analysis

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Patient and Public Involvement (PPI)

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

Added value of PPI

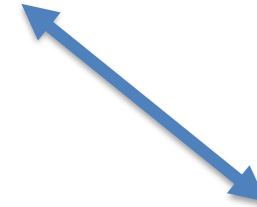
- Moral right to be included in research
- Improving quality and relevance of research
- Enriching experience for researchers and public members



PPI in EUonQoL

Roles and tasks

- Determine roles together
- Online meetings and email
- In-person meetings



Evaluation

- Continuously
- PPI impact logs 3 times a year
- Conversations with selected researchers



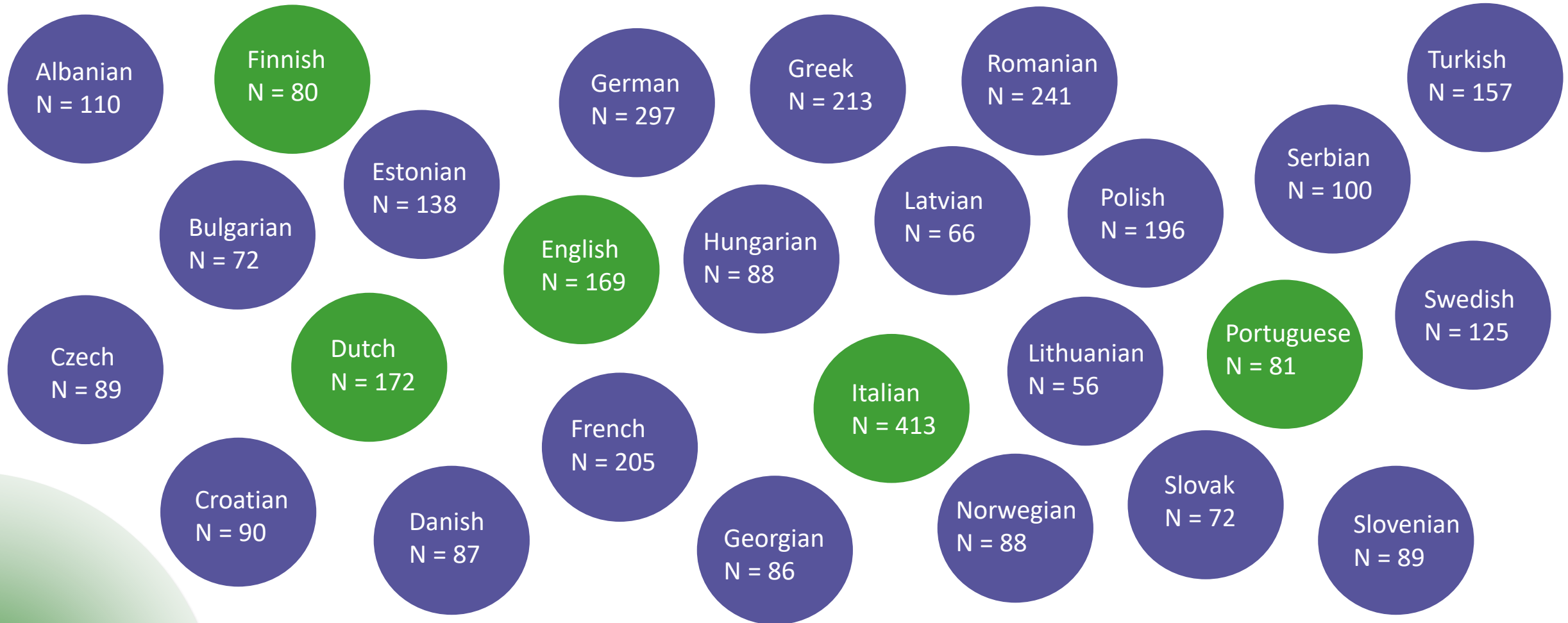
Collaboration and support

- Team dedicated to PPI
- Support meetings

Open-ended question of the EUonQoL-kit

- ‘Having completed the questionnaire, what do you feel most impacts your Quality of Life?’
- Final question of the EUonQoL-kit
- Added based on co-researcher and stakeholder input

Number of open answers per language



Aims of open-ended question analysis

- To gain insight into what impacts quality of life most for cancer patients and survivors that participated in the EUonQoL pilot survey
- To perform the analysis according to PPI research principles, by using creative methods

Open coding through a creative exercise

- Co-researchers read the open answers in their own native language (Dutch, English, Finnish, Italian, Portuguese)
- And created a visual representation of the most important topics/themes using a creative method of their own choice

Italian results



Eduard Manet's "The family"

Italian results



Edgar Degas' "Tired dancer"

Italian results

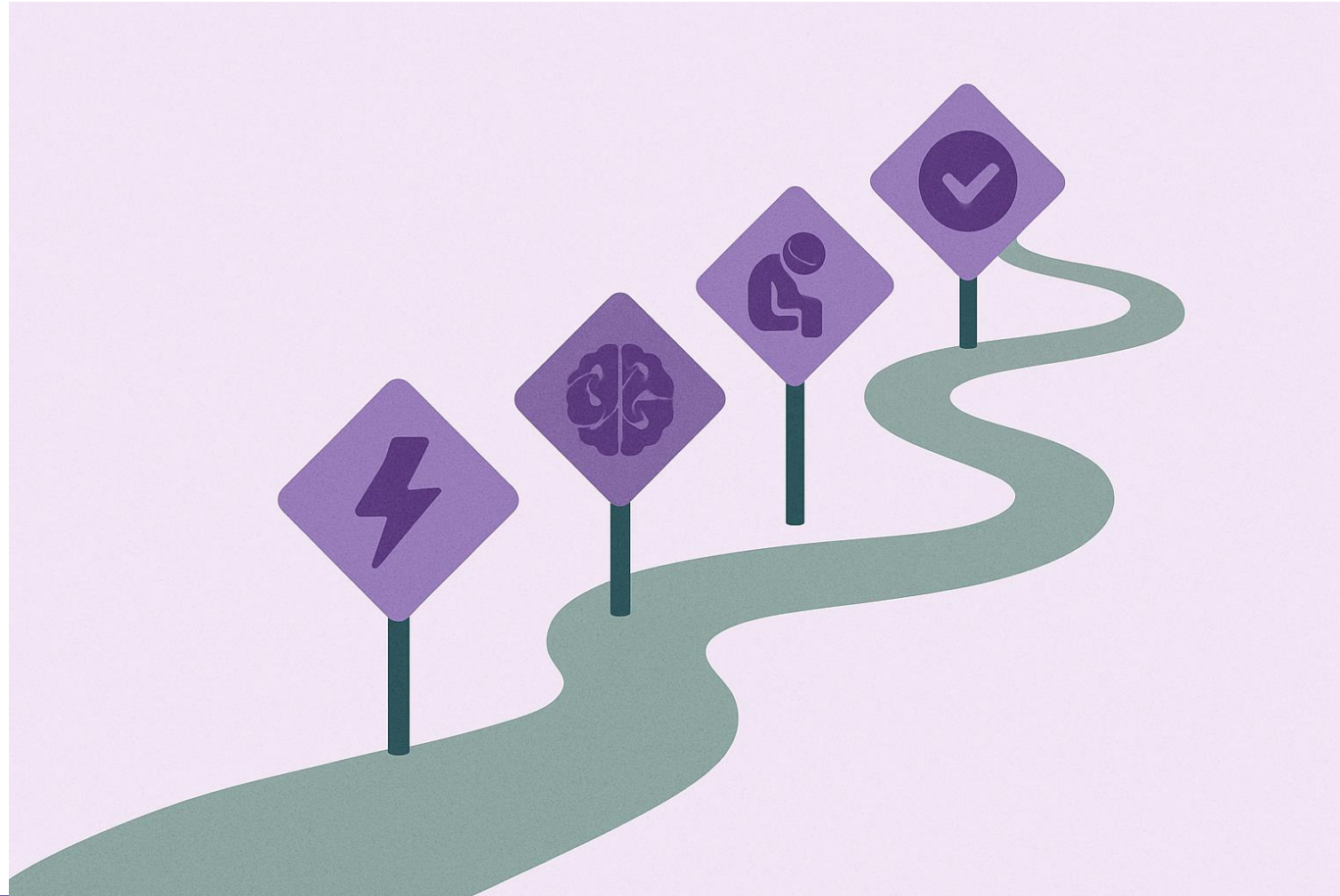


Edvard Munch's "Death in the sick room"

Finnish results



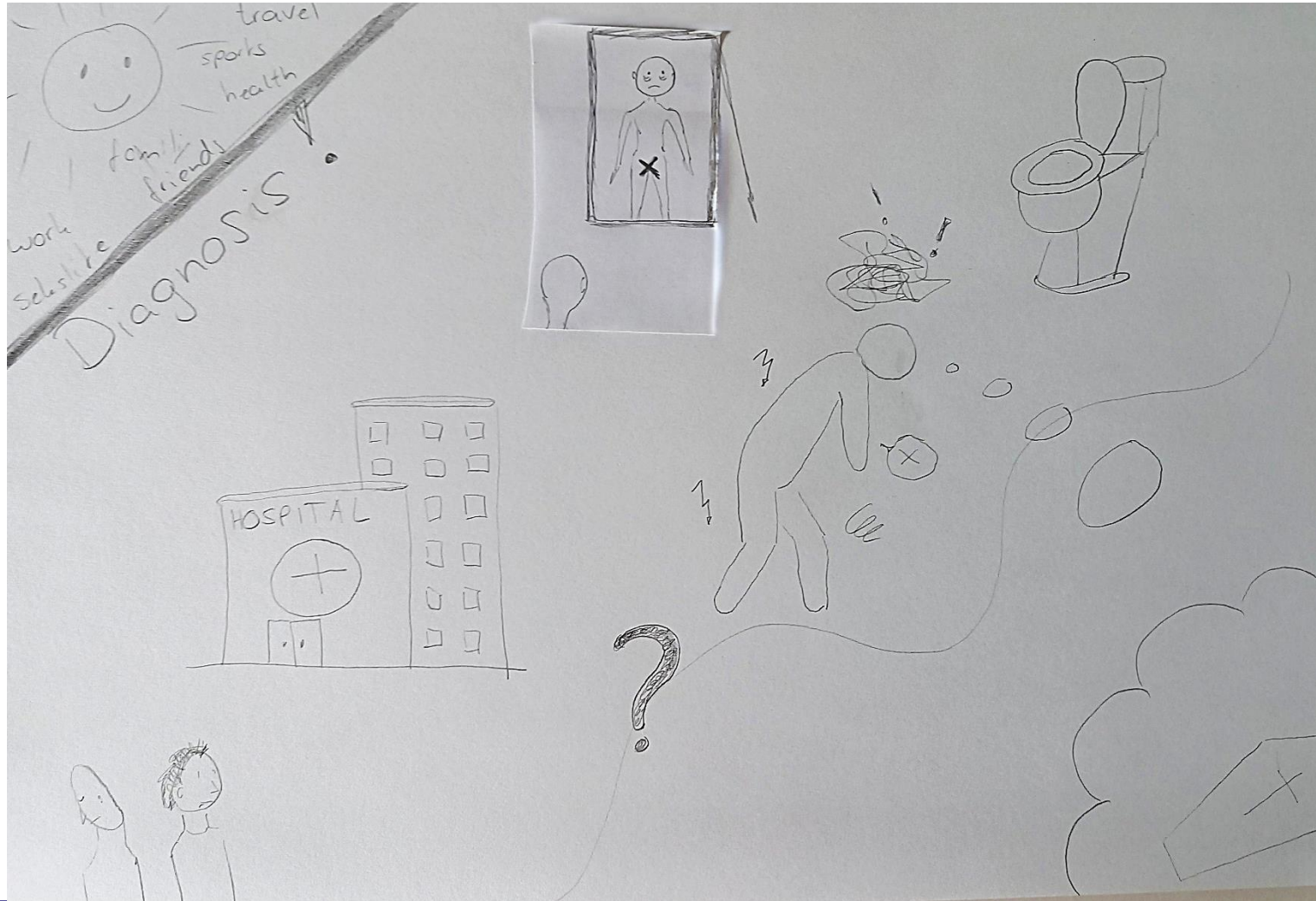
Portuguese results



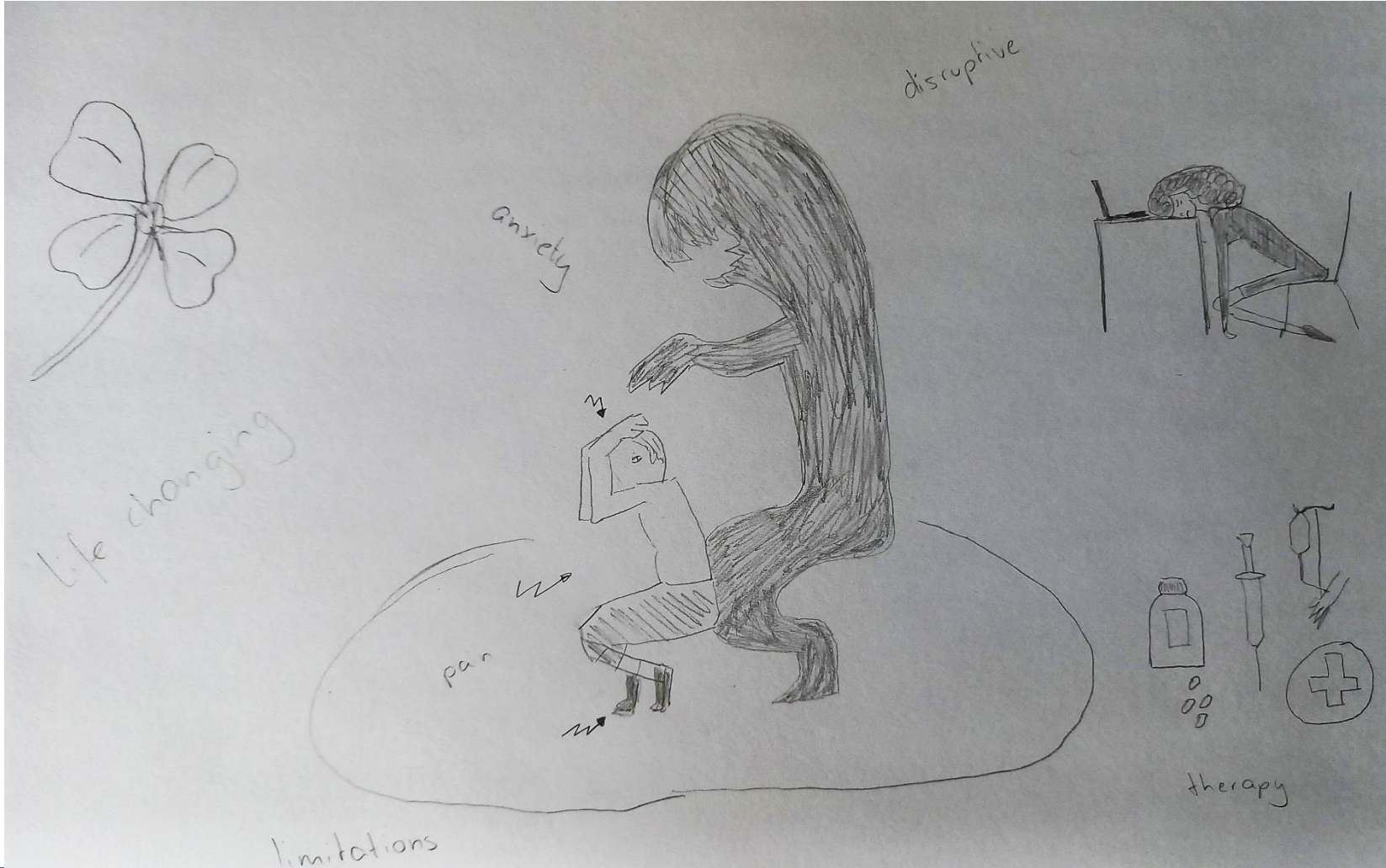
English results



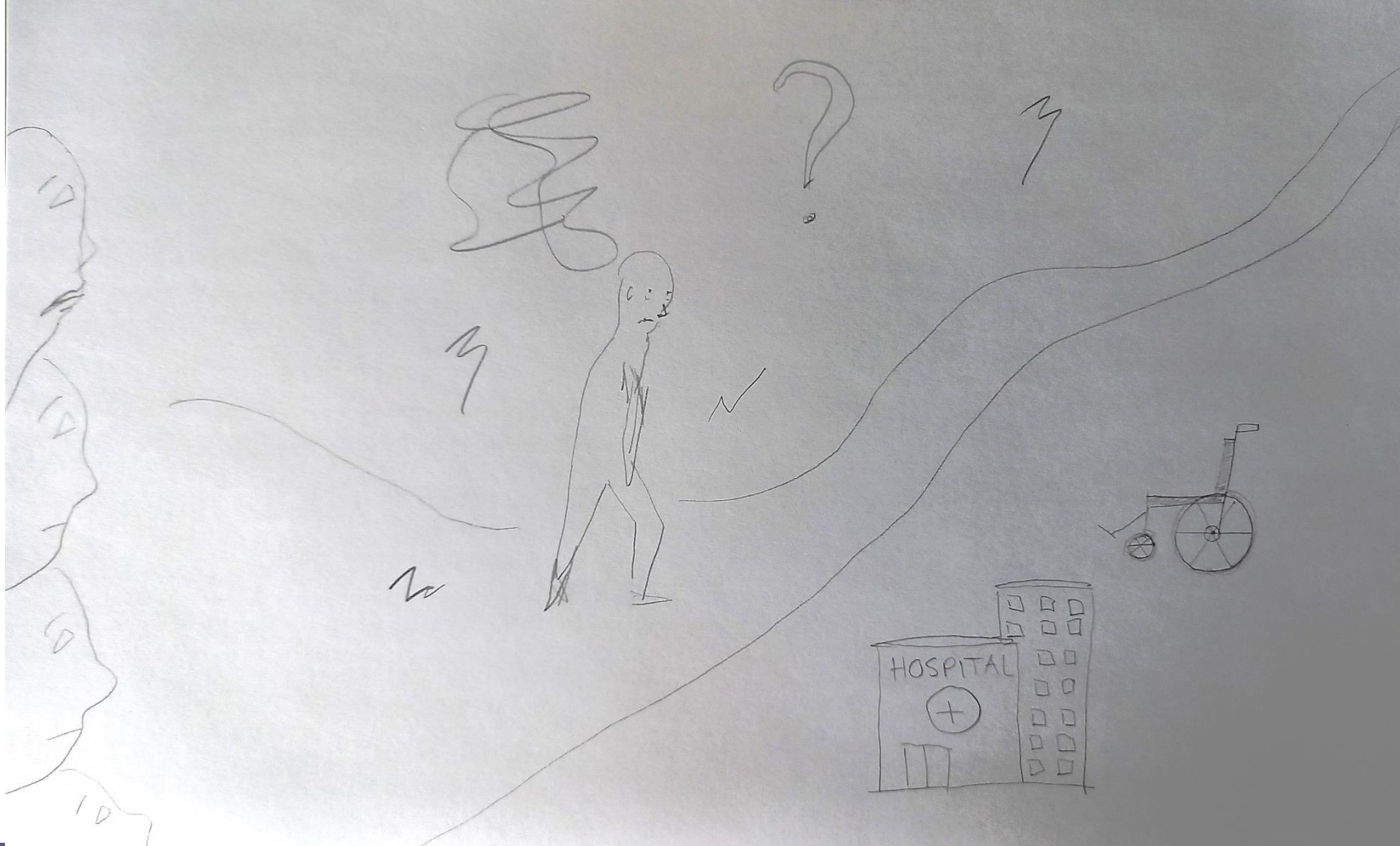
Dutch results – active treatment



Dutch results - survivors



Dutch results – palliative care



Next steps

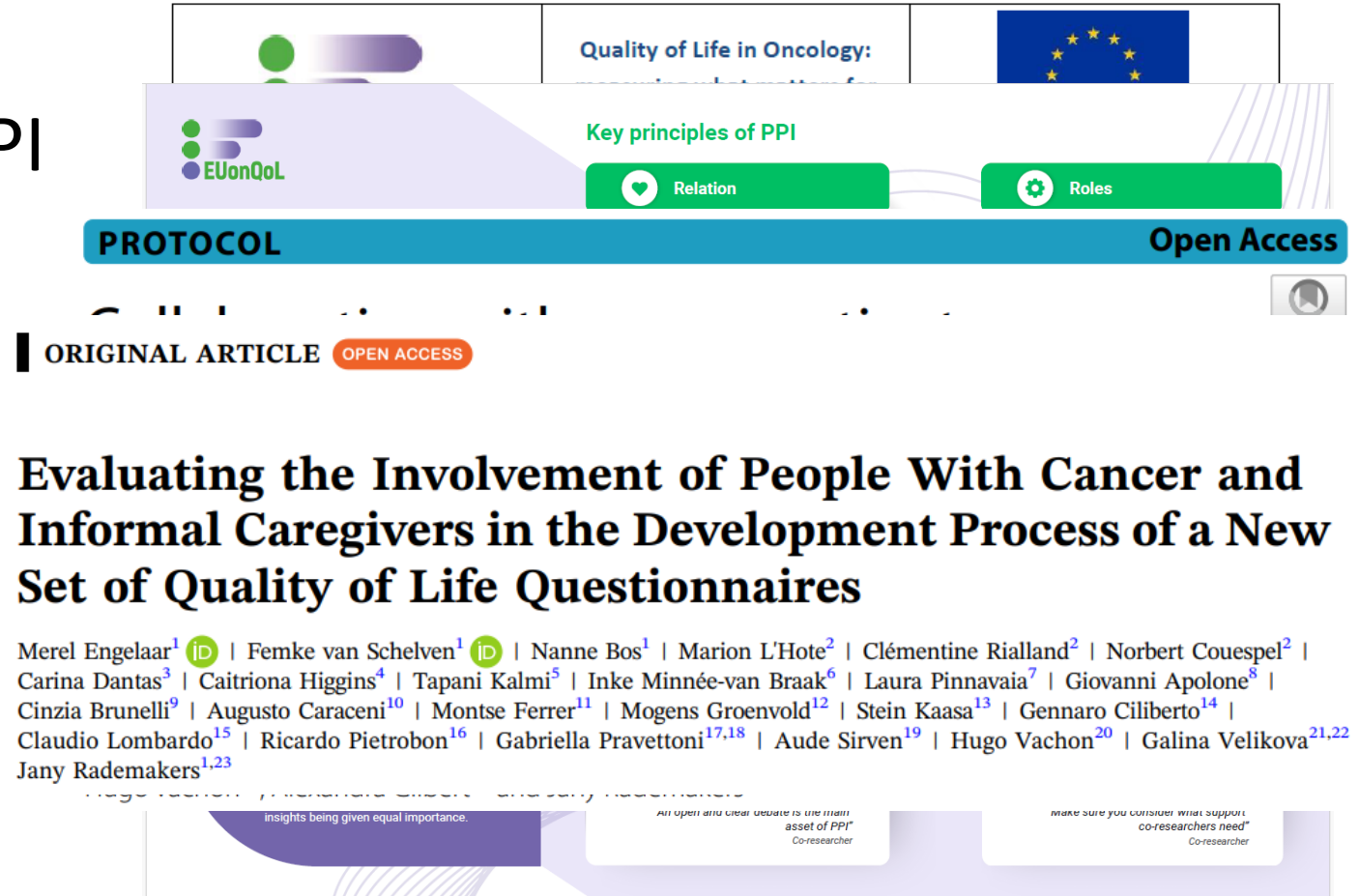
- All open answers were translated to English – these translations need to be checked
- Establishing a coding tree based on the open coding exercise and the EUonQoL quality of life framework
- ‘Conventional’ qualitative analysis, supplemented by a creative mapping of the process using Miro

Thank you for your attention!

Want to learn more about PPI
in EUonQoL?

- EUonQoL Handbook & leaflet
- Protocol paper
- Process evaluation article

euonqol.eu/results



The screenshot displays the EUonQoL website interface. At the top, there is a header with the EUonQoL logo, the text 'Quality of Life in Oncology:', and the European Union flag. Below this, a navigation bar includes 'Key principles of PPI' and two buttons: 'Relation' and 'Roles'. A blue banner across the page reads 'PROTOCOL' on the left and 'Open Access' on the right. The main content area features the text 'ORIGINAL ARTICLE' followed by an 'OPEN ACCESS' button. The title of the article is 'Evaluating the Involvement of People With Cancer and Informal Caregivers in the Development Process of a New Set of Quality of Life Questionnaires'. The authors listed are Merel Engelaar¹, Femke van Schelven¹, Nanne Bos¹, Marion L'Hote², Clémentine Rialland², Norbert Couespel², Carina Dantas³, Caitriona Higgins⁴, Tapani Kalmi⁵, Inke Minnée-van Braak⁶, Laura Pinnavaia⁷, Giovanni Apolone⁸, Cinzia Brunelli⁹, Augusto Caraceni¹⁰, Montse Ferrer¹¹, Mogens Groenvold¹², Stein Kaasa¹³, Gennaro Ciliberto¹⁴, Claudio Lombardo¹⁵, Ricardo Pietrobon¹⁶, Gabriella Pravettoni^{17,18}, Aude Sirven¹⁹, Hugo Vachon²⁰, Galina Velikova^{21,22}, and Jany Rademakers^{1,23}. At the bottom, there are three quotes: 'insights being given equal importance.', 'An open and clear debate is the main asset of PPI*', and 'make sure you consider what support co-researchers need*'. The website footer includes the EUonQoL logo and the text 'EUonQoL'.