

The EUonQoL-kit

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Talk overview

- Brief description of the EUonQoL-kit development process
- Presentation of the EUonQoL conceptual framework
- Why is the EUonQoL-kit a «kit»
- EUonQoL-kit subdomains and items
- EUonQoL-kit cultural adaptation

EUonQOL Toolkit development

Existing QOL frameworks
Systematic reviews
Patient Interviews
Delphi survey
Consensus meeting



EUonQoL-kit V1



Usability testing V1



Stakeholder consultation



EUonQoL-kit V2

EUonQOL Toolkit development

Existing QOL frameworks
Systematic reviews
Patient Interviews (n=75 6 countries)
Delphi survey (n=155, 59 HCP)
Consensus meeting

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EUonQoL-kit V1

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Usability testing V1

(n=53 patients 5 countries)

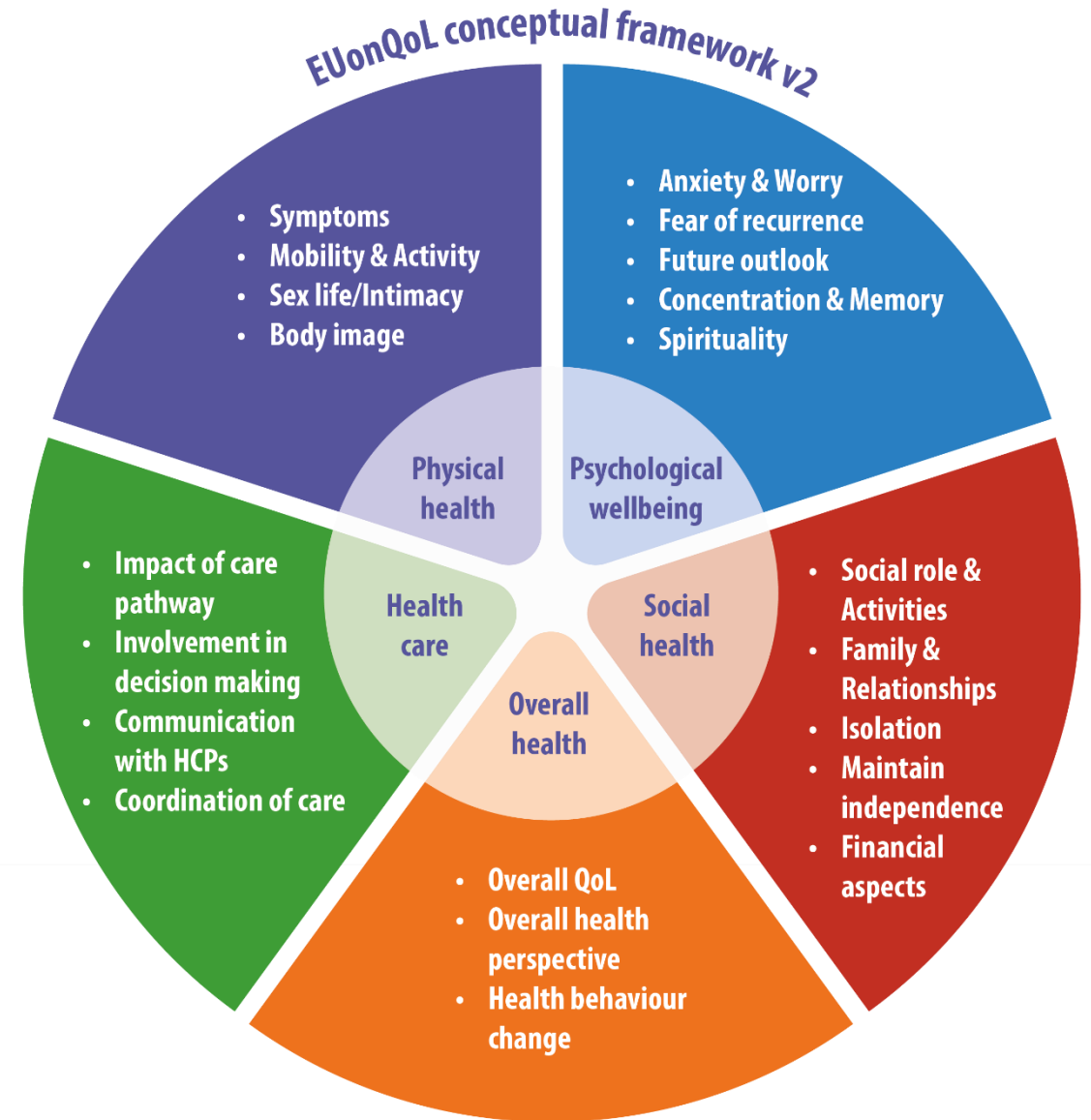
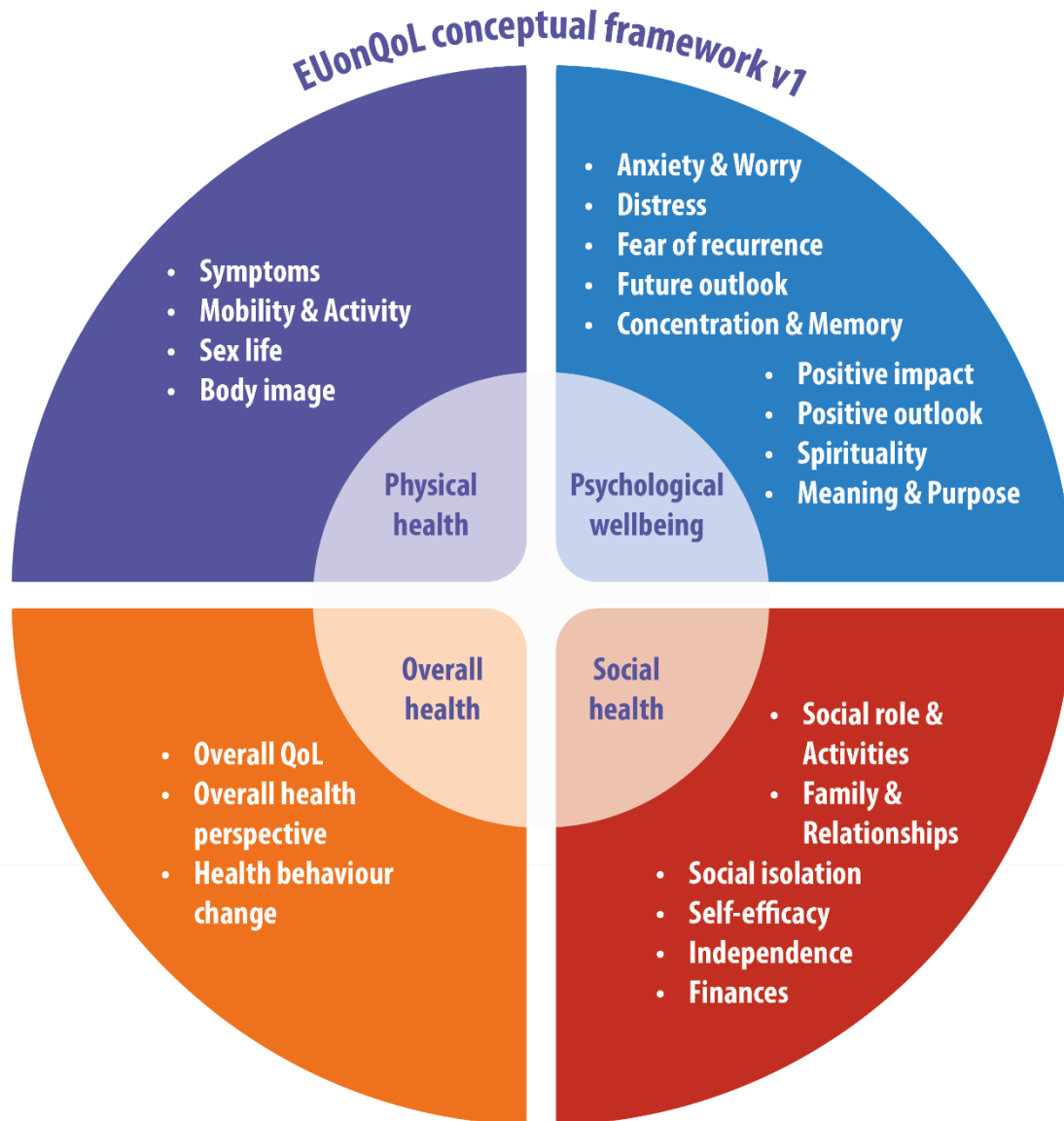
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Stakeholder consultation

(8 board members, 5 co-researchers, public forum)

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EUonQoL-kit V2

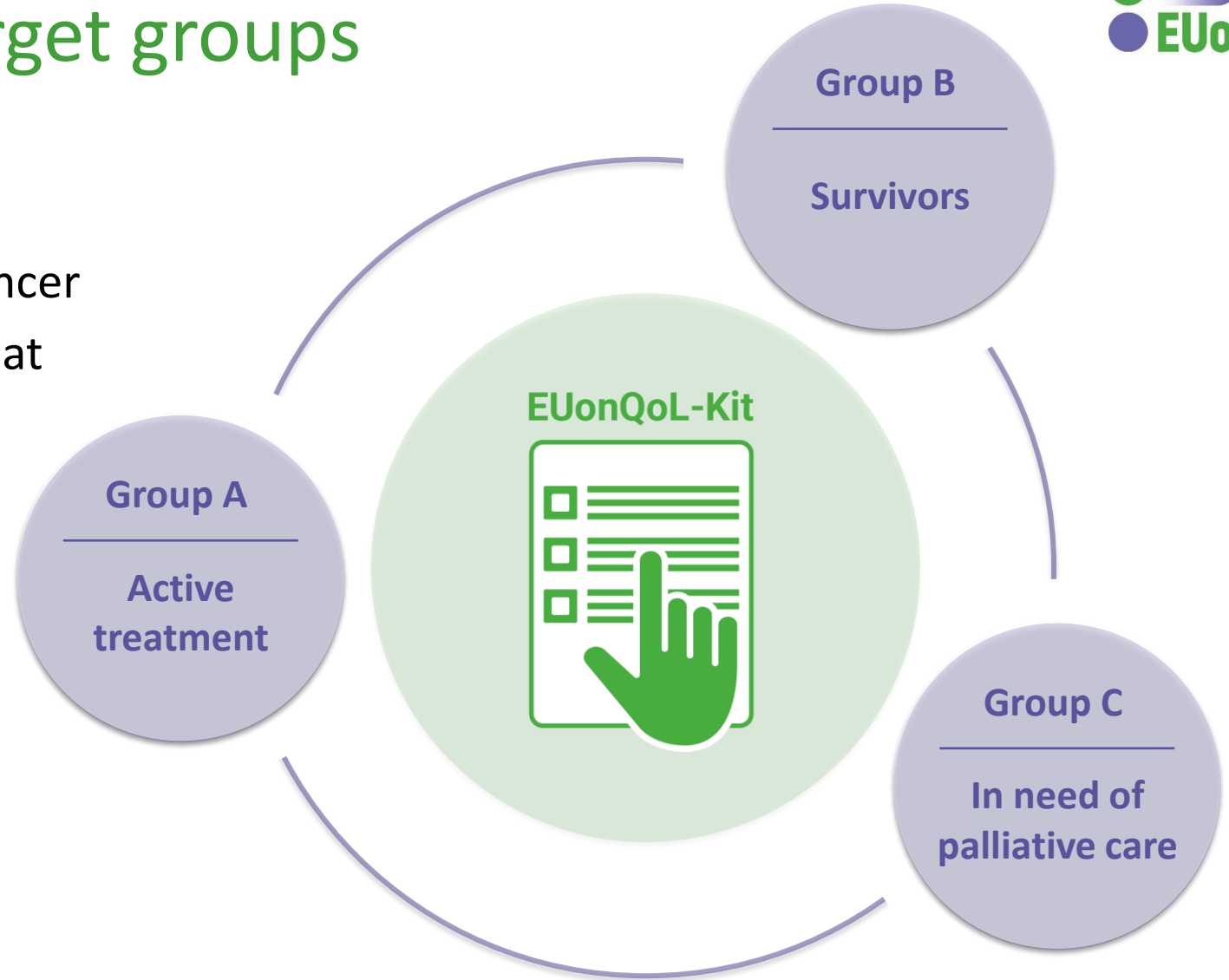
Total of
283 participants (59 HCP)
< 12 months in 2023

The EUonQoL conceptual framework



The EUonQoL-Kit: target groups

Intended to assess health related quality of life across the whole cancer care continuum, including people at different stages of their disease trajectory.



The EUonQoL-Kit: administration modes



Administered in both **static** and **dynamic** modes.



Classical testing

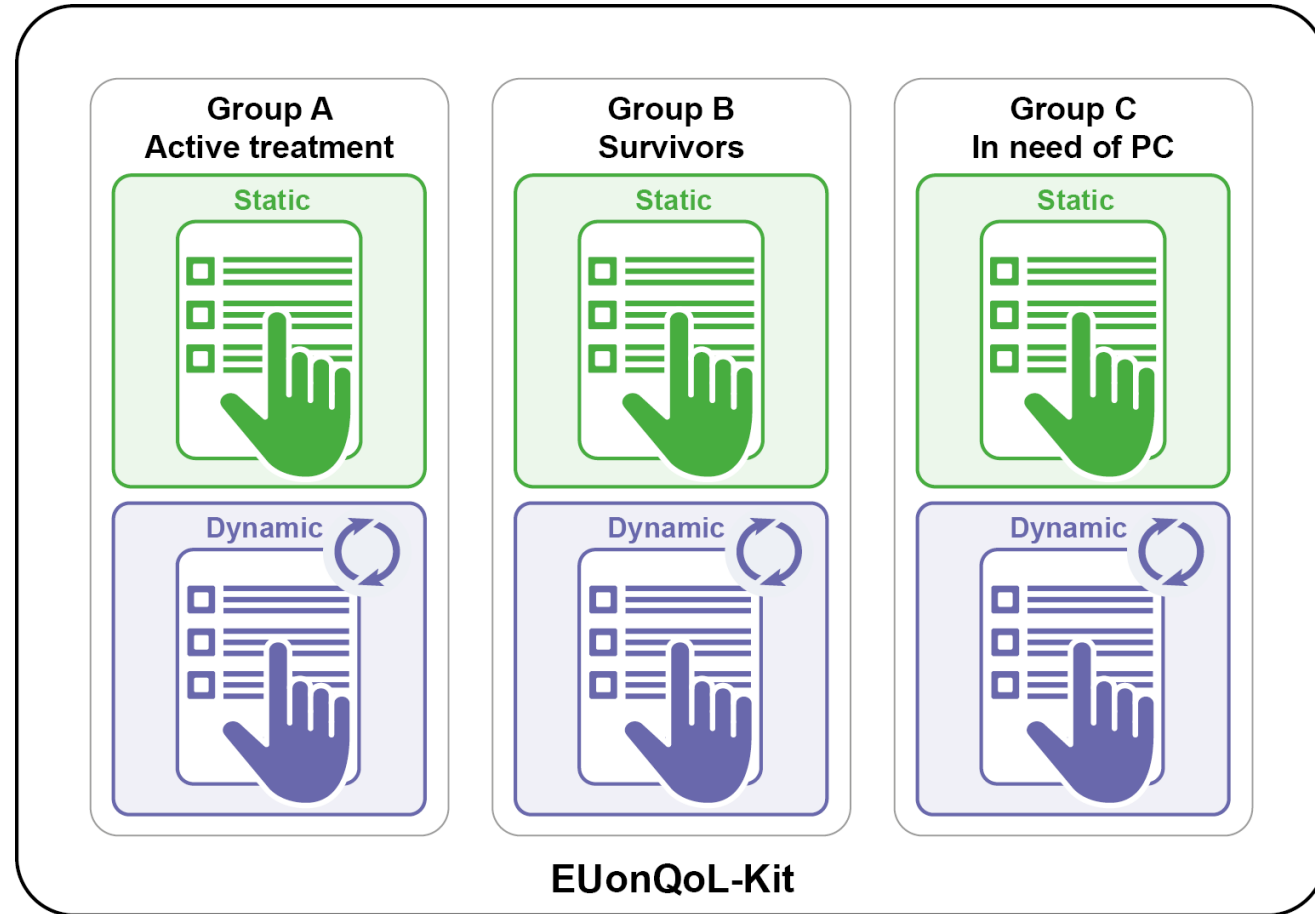
Fixed set of pre-selected questions presented to every respondent



Computer Adaptive Testing (CAT)

Questions automatically selected based on the respondent's answers during questionnaire completion

Why the EUonQoL-Kit is a «kit»



The EUonQoL-Kit: items by sub-domain



Group A Active treatment	Group B Survivors	Group C In need of PC
3	3	2
2	2	2
2	2	2
2	2	2
1	1	1
3	3	3
3	3	3
2	2	1
18	18	16

6
15
7
3
1
50

6
16
6
3
1
50

6
11
7
3
1
44

QoL sub-domain

Physical Functioning (PF)
 Role Functioning (RF)
 Pain (PA)
 Fatigue (FA)
 Sleeping Problems (SL)
 Emotional Functioning (EF)
 Social Functioning (SF)
 Financial difficulties (FI)

Other physical symptoms
 Other mixed items
 Patient experiences
 Overall health/QoL + WISP
 General QoL open-ended q.
 Total number of items

Group A Active treatment	Group B Survivors	Group C In need of PC
7	7	7
6	6	6
6	6	6
6	6	6
6	6	6
7	7	7
6	6	6
6	6	6
50	50	50

6
15
7
3
1
82

6
16
6
3
1
82

6
11
7
3
1
78



The EUonQoL-Kit: individual items



Group A Active treatment	Group B Survivors	Group C In need of PC	QoL sub-domain
3	3	2	Physical Functioning (PF)
2	2	2	Role Functioning (RF)
2	2	2	Pain (PA)
2	2	2	Fatigue (FA)
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2	2	1	Financial difficulties (FI)
18	18	16	
6	6	6	Other physical symptoms
15	16	11	Other mixed items
7	6	7	Patient experiences
3	3	3	Overall health/QoL + WISP
1	1	1	General QoL open-ended q.
50	50	44	Total number of items



During the past week, did you feel depressed?


☐ Not at all
 ☒ A little
 ☐ Quite a bit
 ☐ Very much

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The EUonQoL-Kit: individual items



Group A Active treatment	Group B Survivors	Group C In need of PC	QoL sub-domain
3	3	2	Physical Functioning (PF)
2	2	2	Role Functioning (RF)
2	2	2	Pain (PA)
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3	3	3	Overall health/QoL + WISP
1	1	1	General QoL open-ended q.
50	50	44	Total number of items



During the past week, were you limited in doing either your work or other daily activities?

☐ Not at all
 ☐ A little
 ☐ Quite a bit
 ☐ Very much

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The EUonQoL-Kit: individual items



Group A Active treatment	Group B Survivors	Group C In need of PC	QoL sub-domain
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3	3	3	Overall health/QoL + WISP
1	1	1	General QoL open-ended q.
50	50	44	Total number of items



Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?


☐ Not at all
 ☐ A little
 ☐ Quite a bit
 ☐ Very much

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The EUonQoL-Kit: individual items



Static	Group A Active treatment	Group B Survivors	Group C In need of PC	QoL sub-domain
	3	3	2	Physical Functioning (PF)
	2	2	2	Role Functioning (RF)
	2	2	2	Pain (PA)
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	50	50	44	Total number of items



Do you need help with eating, dressing, washing yourself or using the toilet?

☐ Not at all
☐ A little
☐ Quite a bit
☐ Very much

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The EUonQoL-Kit: individual items



Group A Active treatment	Group B Survivors	Group C In need of PC	QoL sub-domain
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50	50	44	Total number of items



EUonQoL

Do you have any trouble taking a long walk?

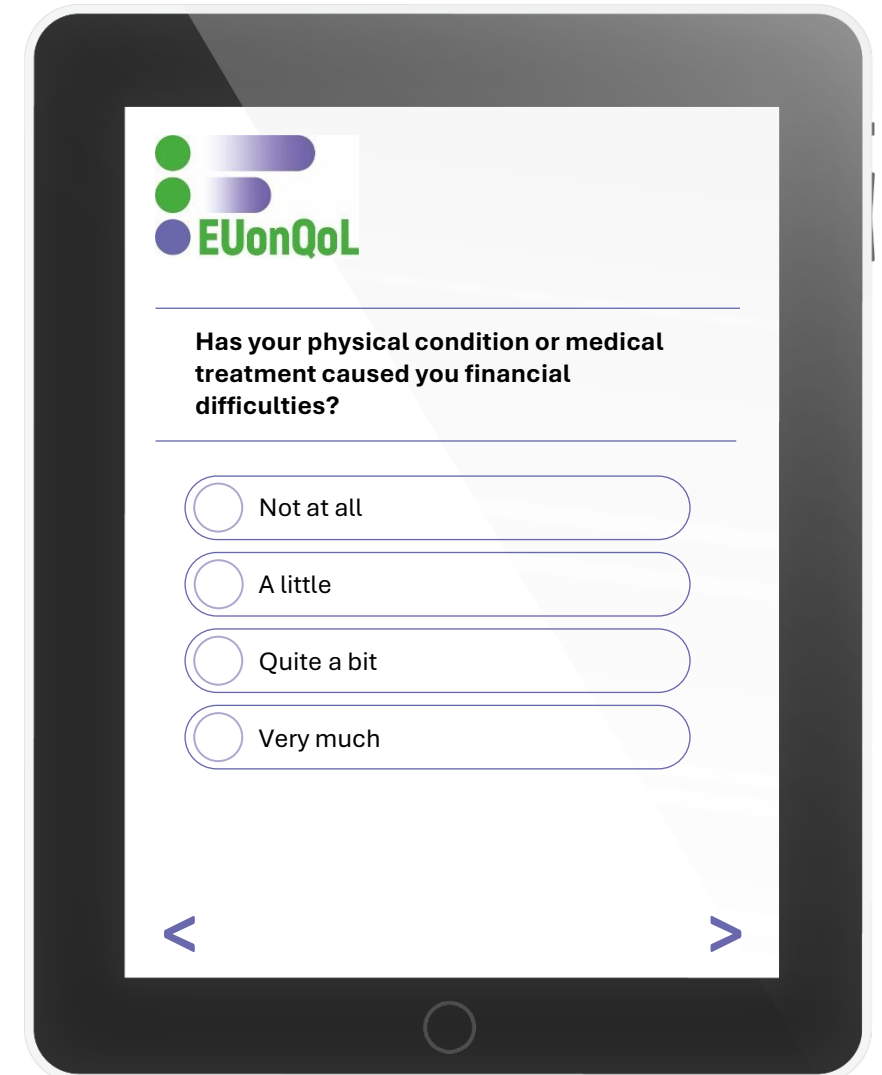
☐ Not at all
☐ A little
☐ Quite a bit
☐ Very much

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The EUonQoL-Kit: individual items



Static	Group A Active treatment	Group B Survivors	Group C In need of PC	QoL sub-domain
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	50	50	44	Total number of items



EUonQoL

Has your physical condition or medical treatment caused you financial difficulties?

☐ Not at all

☐ A little

☐ Quite a bit

☐ Very much

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The EUonQoL-Kit: individual items



Group A Active treatment	Group B Survivors	Group C In need of PC	QoL sub-domain
3	3	2	Physical Functioning (PF)
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Single items:

- Appetite
- Nausea/Vomiting
- Constipation
- Diarrhoea
- Dyspnoea
- Cognitive functioning

The EUonQoL-Kit: individual items



Group A Active treatment	Group B Survivors	Group C In need of PC	QoL sub-domain
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50	50	44	Total number of items



EUonQoL

During the past week, have you felt nauseated?

☐ Not at all

☐ A little

☐ Quite a bit

☐ Very much

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The EUonQoL-Kit: individual items



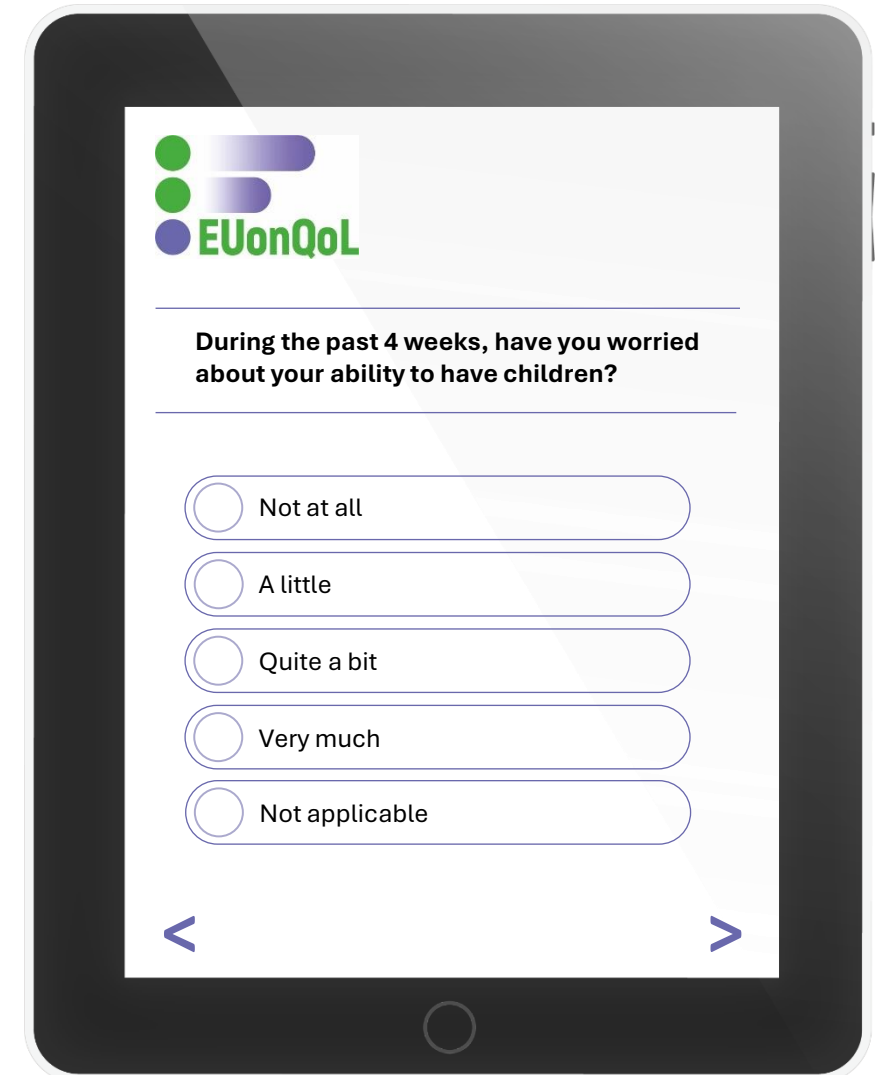
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- Fear of recurrence
- Future outlook
- Spirituality
- Concentration
- Body image
- Sex life/intimacy
- Independence
- Health behaviour change
- Isolation
- Symptom worries
- Financial aspects
- Family & relationships

The EUonQoL-Kit: individual items



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EUonQoL

During the past 4 weeks, have you worried about your ability to have children?

☐ Not at all

☐ A little

☐ Quite a bit

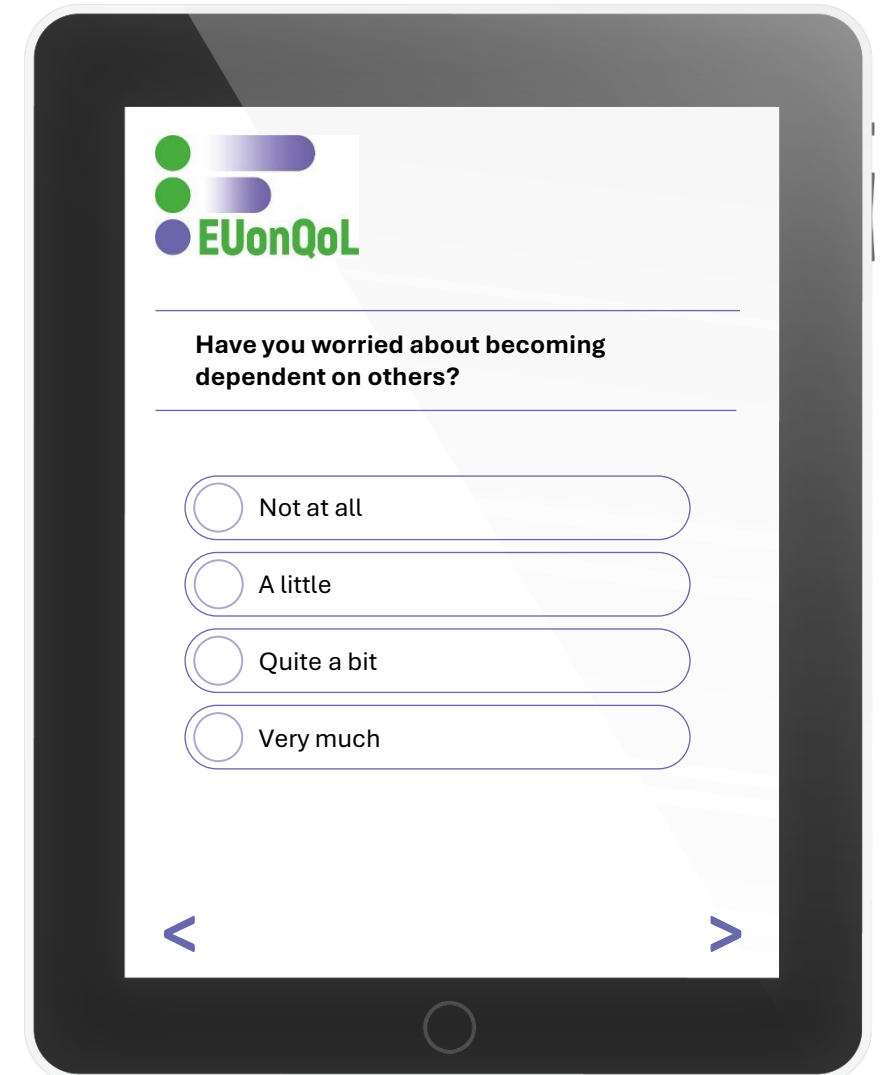
☐ Very much

☐ Not applicable

The EUonQoL-Kit: individual items



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	2	2	2	Fatigue (FA)
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EUonQoL

Have you worried about becoming dependent on others?

☐ Not at all

☐ A little

☐ Quite a bit

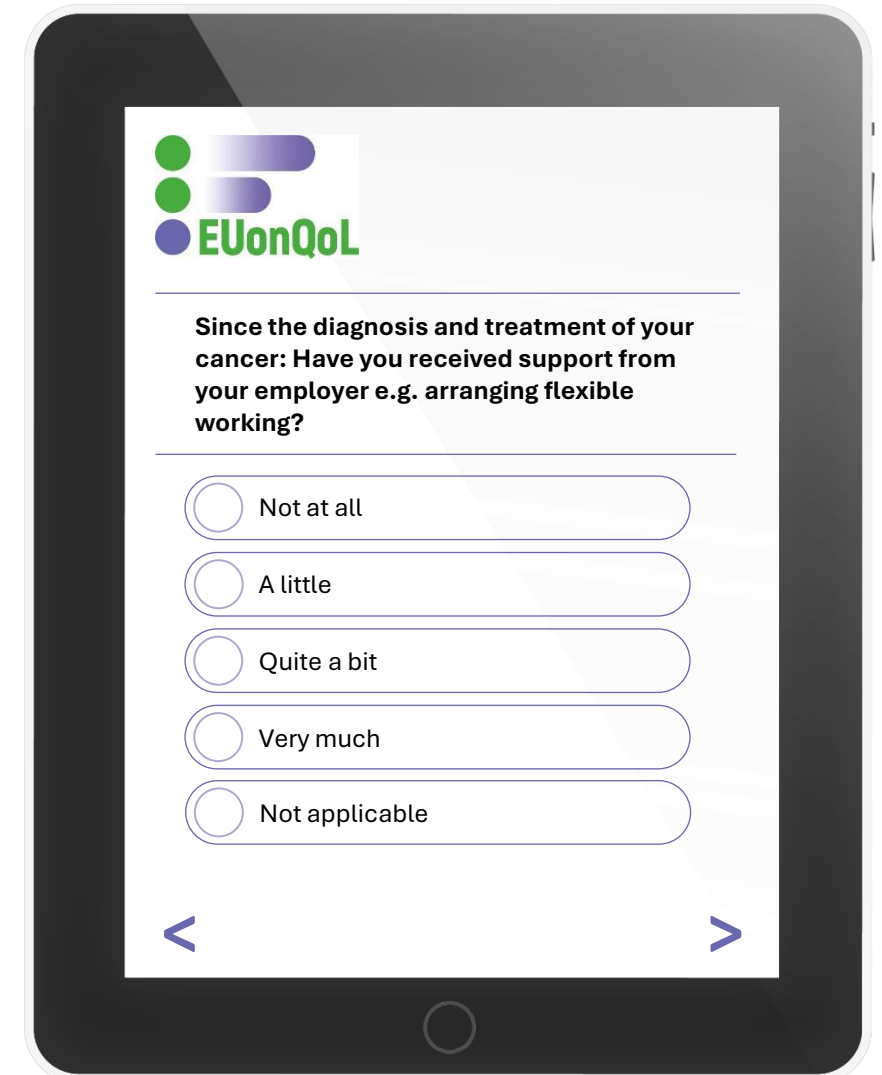
☐ Very much


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The EUonQoL-Kit: individual items



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	50	50	44	Total number of items





Since the diagnosis and treatment of your cancer: Have you received support from your employer e.g. arranging flexible working?

☐ Not at all

☐ A little

☐ Quite a bit

☐ Very much

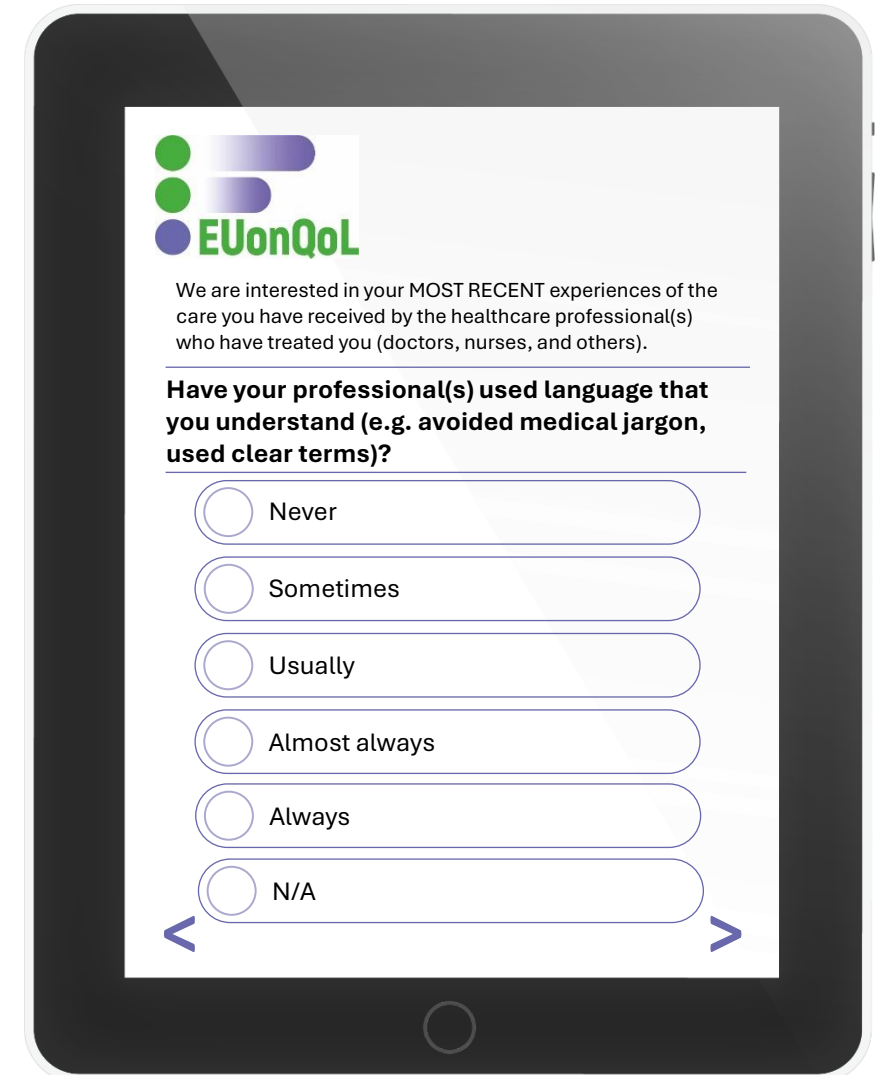
☐ Not applicable

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The EUonQoL-Kit: individual items



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	50	50	44	Total number of items



EUonQoL

We are interested in your MOST RECENT experiences of the care you have received by the healthcare professional(s) who have treated you (doctors, nurses, and others).

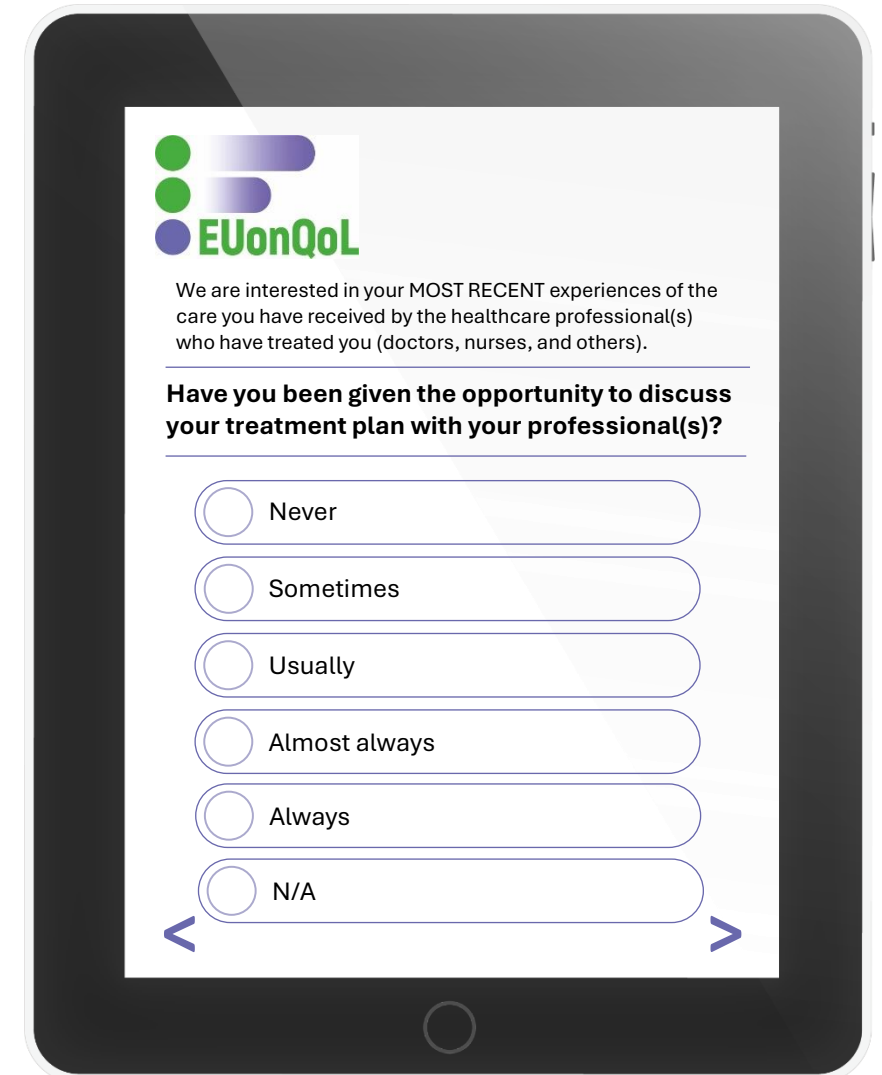
Have your professional(s) used language that you understand (e.g. avoided medical jargon, used clear terms)?

☐ Never
 ☐ Sometimes
 ☐ Usually
 ☐ Almost always
 ☐ Always
 ☐ N/A

The EUonQoL-Kit: individual items



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	50	50	44	Total number of items



EUonQoL

We are interested in your MOST RECENT experiences of the care you have received by the healthcare professional(s) who have treated you (doctors, nurses, and others).

Have you been given the opportunity to discuss your treatment plan with your professional(s)?


☐ Never
☐ Sometimes
☐ Usually
☐ Almost always
☐ Always
☐ N/A

The EUonQoL-Kit: individual items



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WISP



During the past week, have you had any other significant symptoms or problems that have not been mentioned in the questions above?

☐ No

☒ Yes

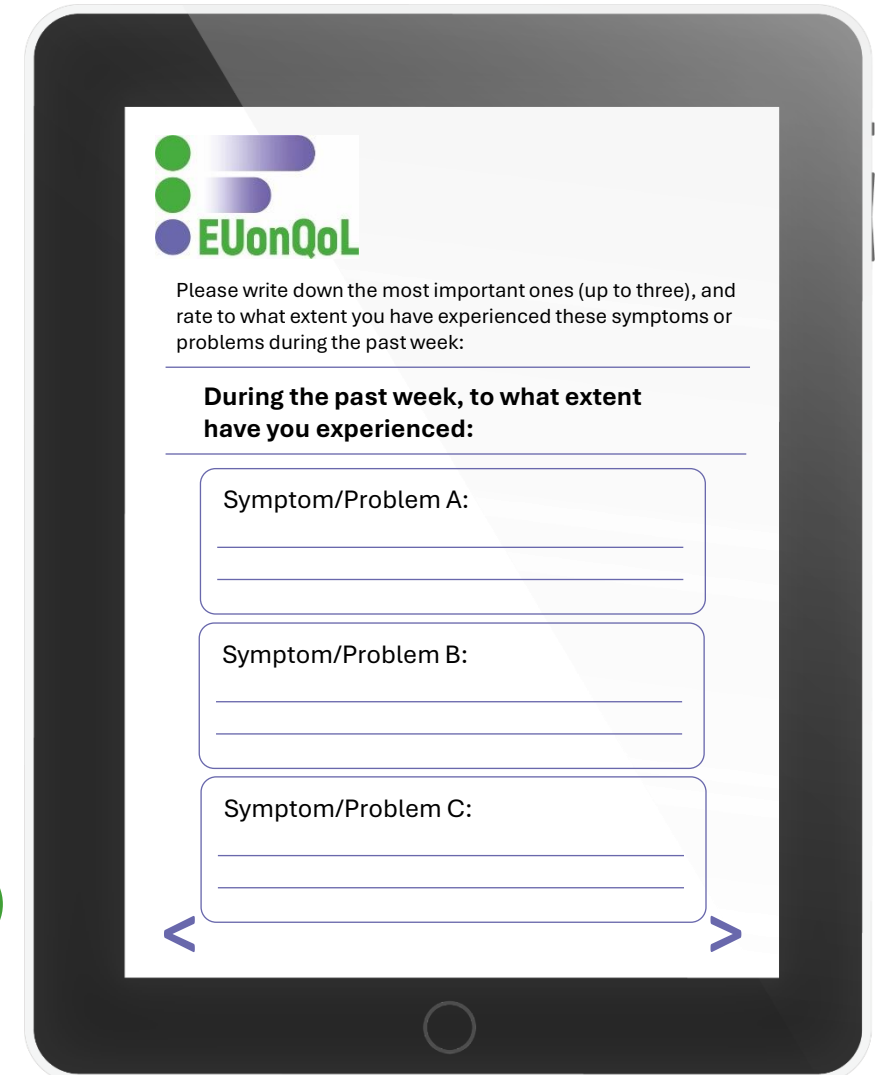
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The EUonQoL-Kit: individual items



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WISP



EUonQoL

Please write down the most important ones (up to three), and rate to what extent you have experienced these symptoms or problems during the past week:

During the past week, to what extent have you experienced:

Symptom/Problem A:

Symptom/Problem B:

Symptom/Problem C:

The EUonQoL-Kit: individual items



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EUonQoL

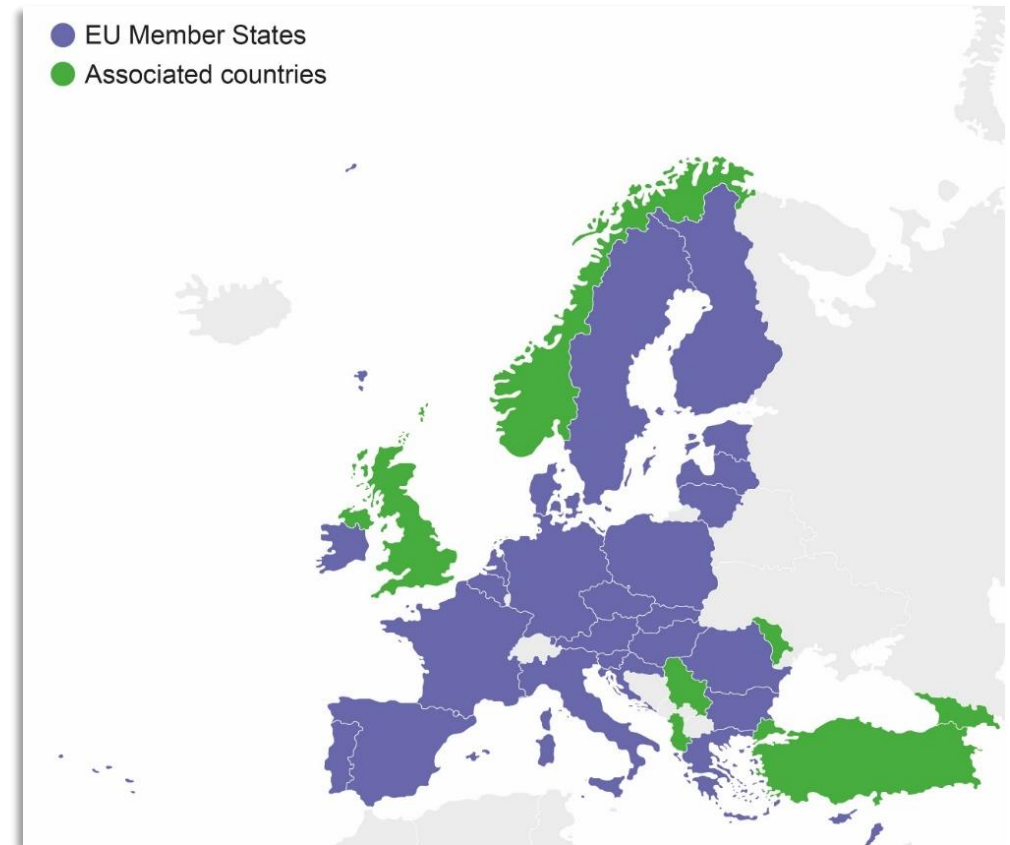
Having completed the questionnaire, what do you feel most impacts your Quality of Life?

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Translation and Cultural adaptation process (TCA)

- The EUonQoL-kit was developed in English as source language and then translated and culturally adapted (TCA process) into 30 European languages*
- It is then available in 31 languages spoken in 25 MS and 6 AC.
- TCA process was aimed at ensuring linguistic validity, cultural relevance, and overall quality of translated questionnaires, promoting cross-cultural comparability in cancer outcomes research

* Albanian, Bulgarian, Croatian, Czech, Danish, Dutch, Estonian, Finnish, French, Georgian, German, Greek, Hungarian, Italian, Irish, Latvian, Lithuanian, Maltese, Moldovan, Norwegian, Polish, Portuguese, Romanian, Serbian, Slovak, Slovenian, Spanish, Swedish, Turkish, Ukrainian



Translation and Cultural adaptation process (TCA)

- The TCA was accomplished adhering to ISPOR guidelines through an eight-step interactive procedure:
 - forward translation
 - reconciliation
 - backward translation
 - harmonization
 - cognitive debriefing
 - review
 - proofreading
 - overall final reporting
- One centre in each country among those taking part to the EUonQoL-Kit Pilot survey contributed to the TCA process by looking over the kits during the final refining and definition steps.

Summary

- EUonQoL-Kit_V2 consists of six questionnaires (static and dynamic, across the three key phases of the cancer continuum)
- It covers four conceptual QoL domains (physical, psychological, social and overall health) and one additional patient-reported experience domain.
- The static and dynamic versions have been developed based on the same conceptual framework, domains and subdomains to allow comparative scores
- EUonQoL-kit_V2 was developed in English and underwent formal translation cultural adaptation into more than 30 European languages
- It was then tested through a pan European survey which preliminar results will now be presented in the next talks.

Thank you for your attention

<https://www.euonqol.eu>



This project received funding from the European Union
Horizon Europe Research and Innovation Programme
Grant Agreement N. 101096362