

Practical application of PROs in stepped care for late effects

Danish Cancer Research Days, 2025



Improvements in cancer survivorship care needed



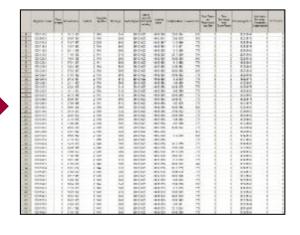
Accessibility under pressure



PROMs in clinical practice to improve survivorship care







Patient Reported Outcomes

- Quality of life
- Symptoms
- Anxiety, Depression
- (Lifestyle)

Use in clinical practice:

- Supportive care in personalized way
- Referral (Center for Quality of Life)

Use of data:

 Redesigning pathways of supportive care



PROMs at the NKI

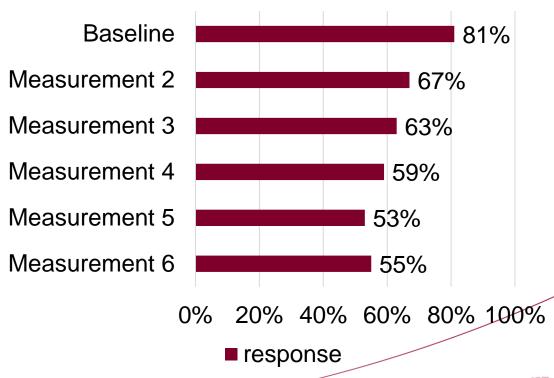


PROMs implementation at the NKI¹

Completed for:

- 9 cancer types
- 1500-2000 new patients/year
- EORTC QLQ-C30 + module
- Fixed measurement intervals
 - e.g. baseline, 3-6-9-12-18 months post-diagnosis, annually in follow-up

Response in 2024²





Which care do they currently receive?







Referral to:	Excellent QoL (N=448)	Psychosocial concerns (N=229)	Poor QoL (N=100)
Supportive care nurse at	161	94	36
Center for Quality of Life	(36%)	(41%)	(36%)



From PRO profiles to actionable interventions



Excellent QoL

Supported self-management



Psychosocial concerns

Specific interventions

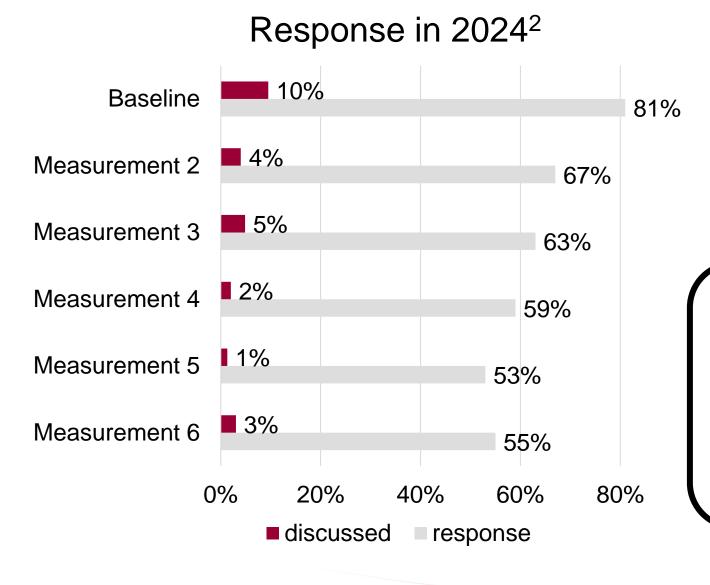
- QoL at baseline to stratify supportive care for patients
- Low transition probabilities between subgroups (1-5%)



Poor QoL

Complex case management





Implementation evaluation study¹

"What do you expect me to do? I cannot fix everything!"

"If I discuss PROs with patients, they will all want supportive care – there is no capacity for that!"

Pilots of PRO-based stepped care

Screening for cognitive issues in breast and III/IV melanoma¹

Step 1

Patients complete PROMs



- EORTC QLQ-C30 cognitive functioning
- 6 months surgery/ start neo-adj chemo



Stratified care options for cognitive impairment



No/little impairment

Additional information



Mild impairment

E-health tool for cognitive rehabilitation



Severe impairment

- Extensive neuropsychology evaluation
- Symptom clusters with fatigue and insomnia



Screening for cognitive issues¹

Melanoma Breast

Step 1: Who completed PROMs at 6 months?

n=154

n=107

Step 2: Who reported clinically relevant cognitive impairment?

38/154 (25%) 43/107 (40%)



- Disease progression (5)
- Not interested/no time (17)
- No response (14)
- Unknown (12)

Step 3: Who was invited to the ACS?

15/38 (40%) 18/43 (42%)



- Deceased (1)
- Disease progression (1)
- No computer (1)
- Unknown (3)

Step 4: Who received ACS feedback?

12/38 (32%)

15/43 (35%)



Cognitive impairment

Melanoma: 4/154

Breast: 10/107

What's next?

Improving and extending PRO-based stepped care at the NKI

- Implementing+evaluating stratified care for breast cancer patients
 - Grant application in the making ©
- Pilots included much manual labor -> automated processes
 - Automatic referral based on decision algorithm
 - Chatbot to inform patient about PROs and appropriate care options
- Improving discussion of PROs in clinical practice
 - Technology could support, but not replace human interaction!



Thank you for your attention!

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All partners in PROMs implementation:

- Lonneke van de Poll Group
- Centre for Quality of Life
- PROMs steering committee

All patients who complete PROMs and participated in our pilots

