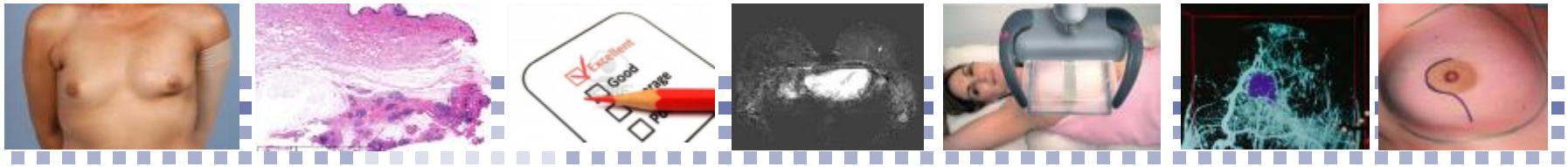
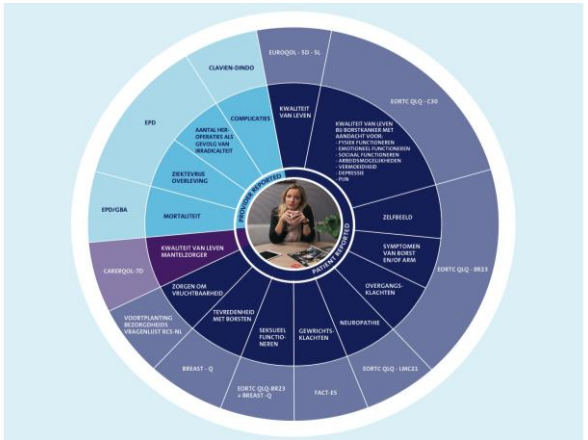
Erasmus MC
Universitair Medisch Centrum Rotterdam



Healtchcare related outcomes to improve quality of care

Mandy van Rosmalen

Nurse practitioner



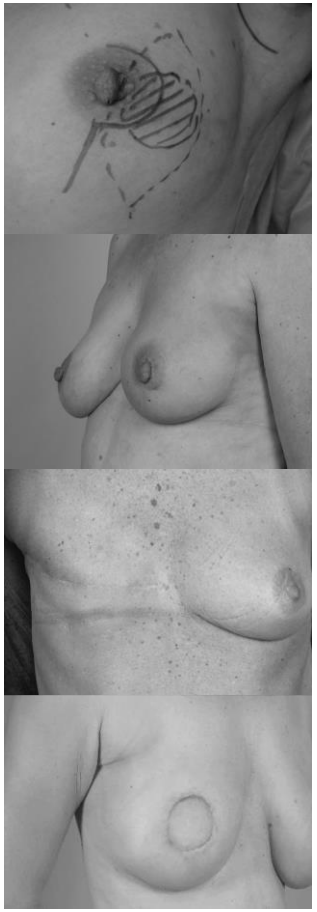
Kwaliteit

- Prognosis of breast cancer relatively good[1,2]
- Quality of Live in the outpatient clinic
- BCT versus ablation with or without reconstructive surgery
- Equivalent breast cancer specific survival

  (n=130.000 patients)[3]

Wich outcomes are the most important for the patients?

"Value based healtch care"



[1] *Vos, Koppert et al. Eur J Cancer 2015* [2] *Vos, Koppert et al Br Ca Res Treatment 2017* [3] *Lagendijk, Koppert et al. Int J Cancer sept '17*

Value-based healthcare

$$\text{Value} = \frac{\text{Patient health outcomes achieved}}{\text{Cost of delivering those outcomes}}$$

1) ‘Shared decision making’
2) Transparency & improvement
3) ‘comparative effectiveness research’

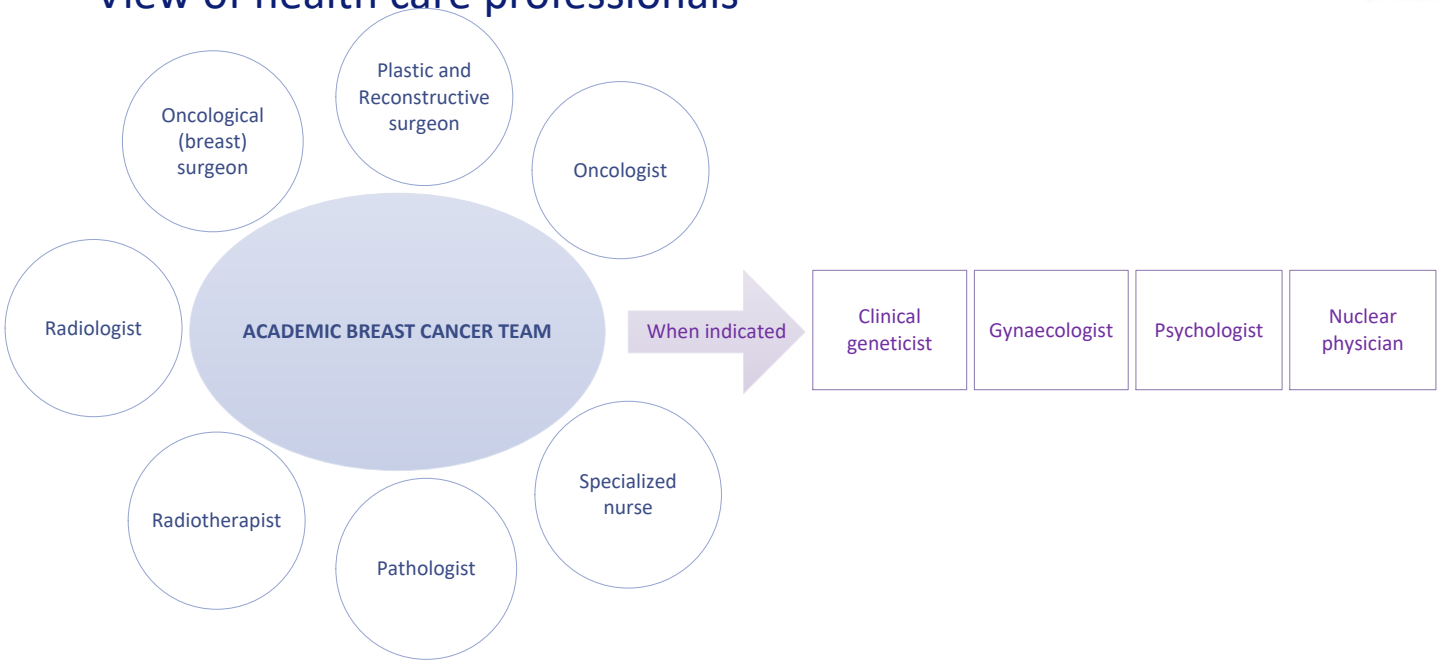
The answer for ‘good quality’?!

<u>But need for consistent outcomes!</u>

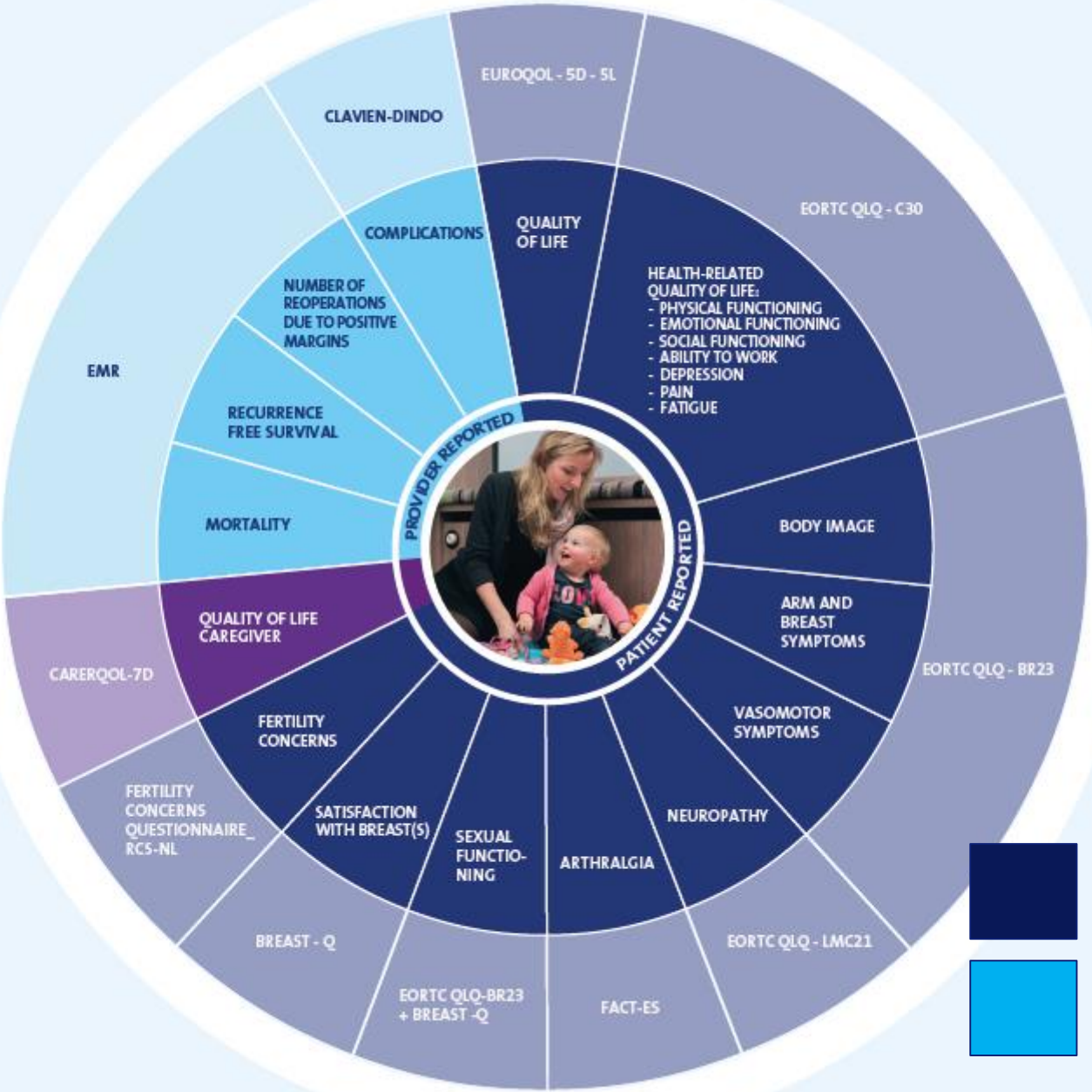
Our ‘outcome journey’ since 2014

In need of outcomes who are the most important for the patients

- View of health care professionals

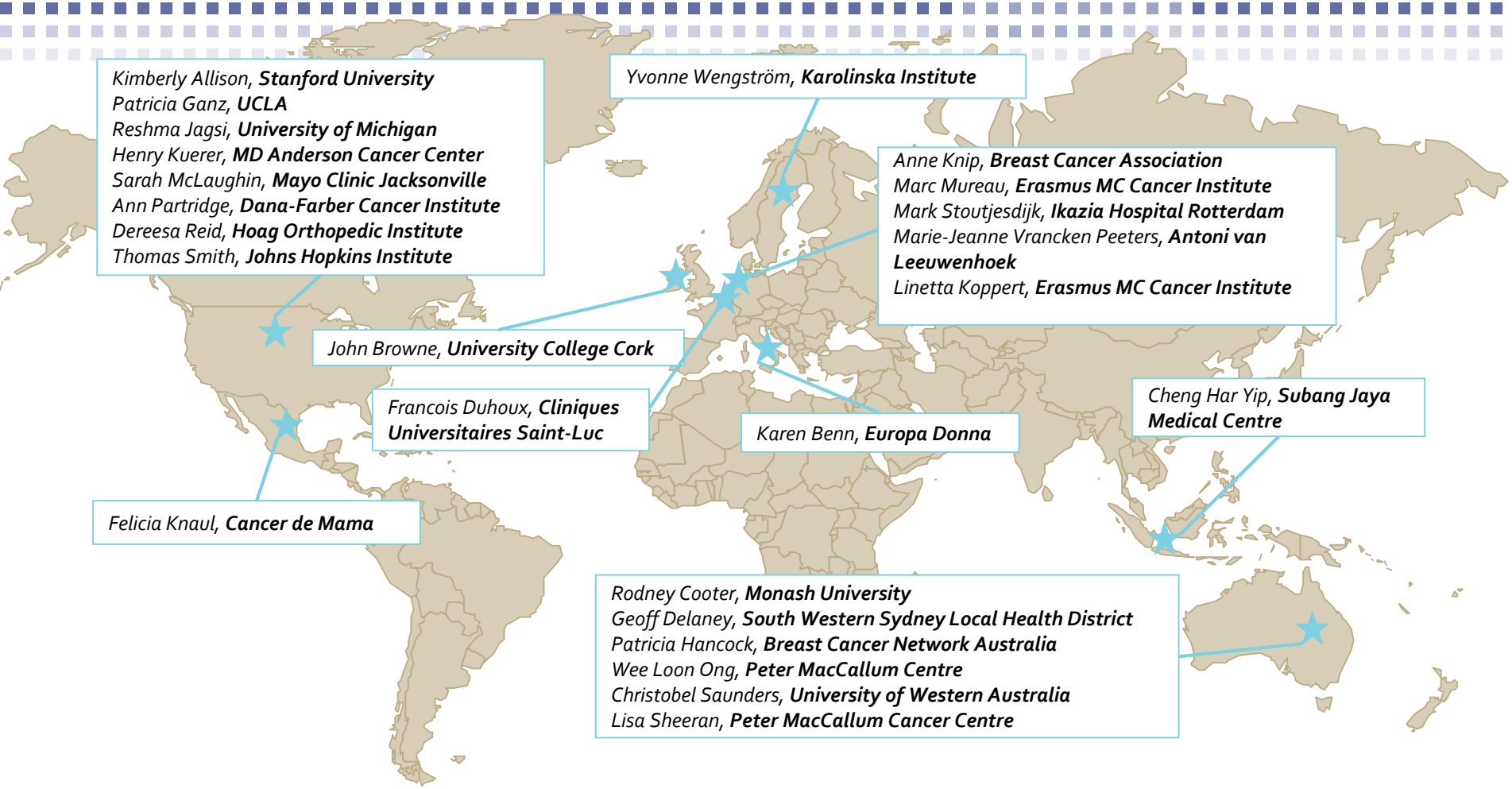


- View of patients
- Methodological panel: validated questionnaire



Overlapping the 'ICHOM breast cancer set' published by Ong, Vrancken Peters, Koppert, Mureau, Schouwenburg et al. JAMA Oncol. 2017;3(5):677-85.

'Breast Cancer Standard Set' developed by multidisciplinary team including patients from 9 countries



Published: JAMA Oncology 2017

External advisors: Barbara Levy (ACOG), Beth Daley Ullem (DePaul University), Catherine Calderwood (NHS), Paulien Brunings (Achmea)

Evidence?

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial

Ethan Basch, Allison M. Deal, Mark G. Kris, Howard I. Scher, Clifford A. Hudis, Paul Sabbatini, Lauren Rogak, Antonia V. Bennett, Amylou C. Dueck, Thomas M. Atkinson, Joanne F. Chou, Dorothy Dulko, Laura Sit, Allison Barz, Paul Novotny, Michael Fruscione, Jeff A. Sloan, and Deborah Schrag

See accompanying editorial on page 527

Ethan Basch, Mark G. Kris, Howard I. Scher, Clifford A. Hudis, Paul Sabbatini, Lauren Rogak, Thomas M. Atkinson, Joanne F. Chou, Dorothy Dulko, Laura Sit, Michael Fruscione, and Deborah Schrag, Memorial Sloan Kettering Cancer Center, New York, NY; Ethan Basch, Allison M. Deal, and Antonia V. Bennett, University of North Carolina, Chapel Hill, NC; Amylou C. Dueck, Mayo Clinic, Scottsdale, AZ; Allison Barz, Children's Hospital of Philadelphia, Philadelphia, PA; Paul Novotny and Jeff A. Sloan, Mayo Clinic, Rochester, MN; and Deborah Schrag, Dana-Farber/Harvard Cancer Center, Boston, MA.

Published online ahead of print at www.jco.org on December 7, 2015.

Supported by the National Cancer Institute and a grant from the Society of Memorial Sloan Kettering.

The National Cancer Institute and the Steps for Breath Fund of Memorial Sloan

A B S T R A C T

Purpose

There is growing interest to enhance symptom monitoring during routine cancer care using patient-reported outcomes, but evidence of impact on clinical outcomes is limited.

Methods

We randomly assigned patients receiving routine outpatient chemotherapy for advanced solid tumors at Memorial Sloan Kettering Cancer Center to report 12 common symptoms via tablet computers or to receive usual care consisting of symptom monitoring at the discretion of clinicians. Those with home computers received weekly e-mail prompts to report between visits. Treating physicians received symptom printouts at visits, and nurses received e-mail alerts when participants reported severe or worsening symptoms. The primary outcome was change in health-related quality of life (HRQL) at 6 months compared with baseline, measured by the EuroQol EQ-5D Index. Secondary endpoints included emergency room (ER) visits, hospitalizations, and survival.

Results

Among 766 patients allocated, HRQL improved among more participants in the intervention group than usual care (34% *v* 18%) and worsened among fewer (38% *v* 53%; $P < .001$). Overall, mean HRQL declined by less in the intervention group than usual care (1.4- *v* 7.1-point drop; $P < .001$). Patients receiving intervention were less frequently admitted to the ER (34% *v* 41%; $P = .02$) or

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Comparative Effectiveness Research to Inform Medical Decisions: The Need for Common Language

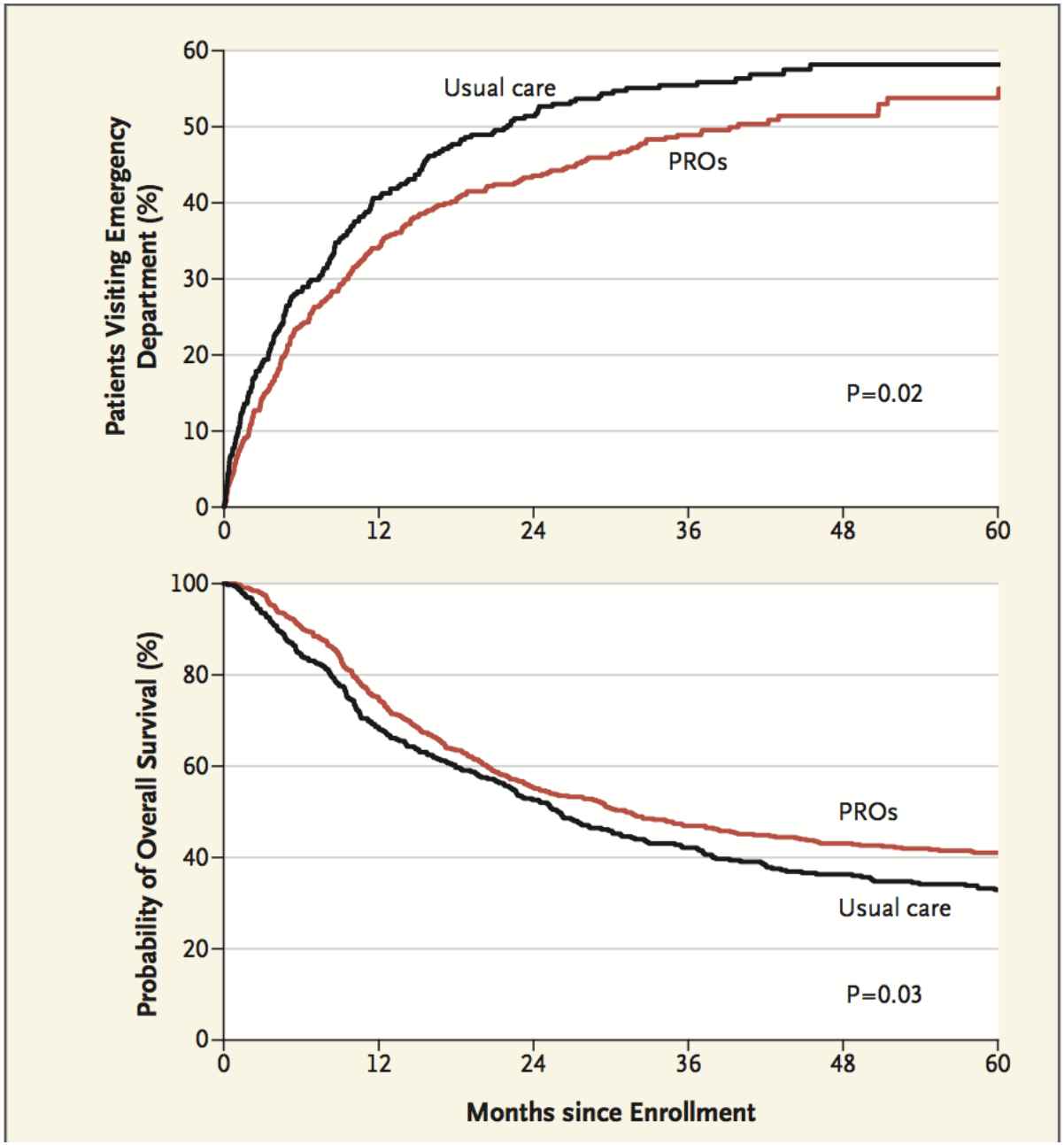
Neal J. Meropol, *University Hospitals Case Medical Center Seidman Cancer Center, Case Comprehensive Cancer Center, Case Western Reserve University, Cleveland, OH*

On a daily basis, oncologists and their patients must make choices regarding the approach to treatment. Although treatment selection is often straightforward, decision making in oncology is increasingly complex because of expanding treatment options, the toxicity of treatment, uncertain outcomes, out-of-pocket cost of therapy, and a highly charged clinical setting in which mortality is a central element. A key consideration in these decisions is the value of available therapeutic options. The ability to integrate considerations of clinical benefits, toxicities, and costs and compare alternative approaches has become essential for physicians and patients. Reliable information and the skills to clearly communicate this information to patients are tools that are needed to assist clinical decision making, but unfortunately, these tools are currently inadequate. Although the importance of integrating patient preferences into the decision-making process has been long recognized, data are not routinely available to predict the patient experience of care and hence inform the application of these preferences. Clearly, our success in growing the clinical armamentarium has brought new challenges. If we can learn to accurately define the value of specific interventions for individual patients, treatment decisions and population health will improve, care will be more efficient, and payment systems will be better aligned with societal goals.

How do we best define the value of cancer care? Certainly, the randomized phase III trial remains the gold standard for comparing interventions. However, the end points in phase III studies are often narrowly defined (eg, progression-free or overall survival, toxicity per the National Cancer Institute's Common Terminology Criteria for Adverse Events), and the patients enrolled may not be representative about the generalizability of results. Even when collected, quality-of-life data are often not reported in the medical literature in association with the high-level treatment outcomes. In short, there is a clear information gap between the needs of patients and providers and the available data regarding patient experience of cancer treatments that would enable relevant patient-centered comparisons between treatment options.

Comparative effectiveness research (CER) is defined by the Institute of Medicine as "the generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition or to improve the delivery of care."[1(p13)] Although the purity of the randomized clinical trial represents a Platonic ideal, data regarding patients, treatments, and outcomes in the real world must be obtained elsewhere. As exemplified in the articles that accompany this editorial,[2-4] a dialogue relating to the tools that are needed to generate meaningful patient-centered outcomes data and apply them in the clinical setting is well underway.

The articles by Basch et al,[2] Miriovsky et al,[3] and Tunis et al[4] each address methodologic considerations and offer solutions to bring us closer to achieving the goals of CER. A common theme expressed in this group of articles is the need for a consistent language and approach to collection of outcomes data and the disposition of these data once collected. A major challenge involves the identification of the shared goals of all stakeholders, including patients, physicians, payers, government, data platform developers, and the producers of treatments and diagnostics. When my daughter arrives at college in Cali-



Basch E et al. J Clin Oncol 2016; 34:557-65.

RESEARCH LETTER

Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment

Symptoms are common among patients receiving treatment for advanced cancers,[1] yet are undetected by clinicians up to half the time.[2] There is growing interest in integrating electronic patient-reported outcomes (PROs) into routine oncology practice for symptom monitoring, but evidence demonstrating clinical benefit has been limited.[3]

We assessed overall survival associated with electronic patient-reported symptom monitoring vs usual care based on follow-up from a randomized clinical trial.[4]

Methods | The study was approved by the Memorial Sloan Kettering institutional review board and written informed consent was obtained from participants. Consecutive patients initiating routine chemotherapy for metastatic solid tumors at Memorial Sloan Kettering Cancer Center in New York between September 2007 and January 2011 were invited to participate in a randomized clinical trial. Participants were randomly assigned either to the usual care group or to the PRO group, in which patients provided self-report of 12 common symptoms from the National Cancer Institute's Common Terminology Criteria for Adverse Events at and between visits via a web-based PRO questionnaire platform. Participation was continuous until cessation of cancer treatment, voluntary withdrawal from the trial, transition to hospice care, or death.

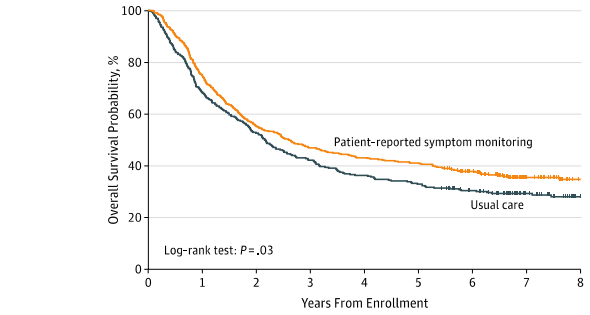
When the PRO group participants reported a severe or worsening symptom, an email alert was triggered to a clinical nurse responsible for the care of that patient. A report profiling each participant's symptom burden history was generated at clinic visits for the treating oncologist. The usual care group received the standard procedure for monitoring symptoms in oncology practice: symptoms were discussed during clinical encounters, and patients could contact the office by telephone between visits for concerning symptoms.

The protocol-specified primary outcome was change in health-related quality of life at 6 months compared with enrollment and was the basis of the sample size determination.[4] Significant benefits in quality of life as well as secondary outcomes of 1-year quality-adjusted survival (mean: 8.7 months in the PRO group vs 8.0 months in the usual care group; $P = .004$), duration of chemotherapy, and emergency department use were found and previously reported.[4] A post hoc decision to analyze overall survival was made prior to data analysis. Mortality was verified from the National Death Index. Overall survival was estimated using the Kaplan-Meier method and compared between groups using a log-rank test and Cox proportional hazards regression adjusting for age, sex, race, education level, level of prior computer use, and primary cancer type. All analyses were conducted using SAS (SAS Institute), version 9.4, and testing was 2-sided with P values less than .05 considered significant.

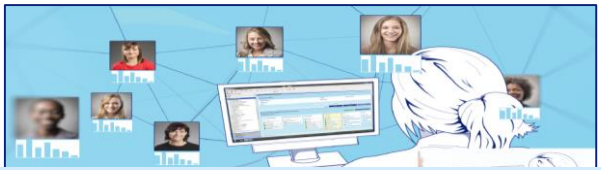
Results | Of 766 patients randomized, the median age was 61 years (range, 26-91), 86% were white, 58% women, 22% had less than a high school education, and 30% were computer inexperienced, as reported.[4] Baseline variables were well balanced between study groups.

Overall survival was assessed in June 2016 after 517 of 766 participants (67%) had died, at which time the median

Figure. Overall Survival Among Patients With Metastatic Cancer Assigned to Electronic Patient-Reported Symptom Monitoring During Routine Chemotherapy vs Usual Care



Crosses indicate censored observations. Enrollment in the patient-reported symptom monitoring group was enriched for a preplanned subgroup with low baseline computer experience as part of a feasibility substudy with a 2:1 randomization ratio in that subgroup (N = 227) and a 1:1 ratio in the computer-experienced subgroup (N = 539), yielding 441 participants in the patient-reported symptom monitoring group, and 325 in the usual care group. With a minimum follow-up of 5.4 years, median follow-up was 6.9 years (interquartile range, 6.5-7.7) for the electronic patient-reported symptom monitoring group and 7 years (interquartile range, 6.6-8.1) for the usual care group.



Erasmus MC Ezafung

PATIENT INFO

Patiënt nummer		**Patiënt**	
Geboren op		**Opmerkingen**	
Email			

Annuleren | Wijzig | Afspraken | Trajecten | Vragenlijsten | Dossier export | Email log | Logboek overig | Verwijder | Relaties

Voeg toe Trajecten | voor Patiënten | voor Medewerkers

ACADEMISCH BORSTKANKERCENTRUM

Soort borstoperatie: Lumpectomie (borstsparend) Neo-adjuvante chemotherapie: Nee Operatiedatum 17 dec. 2015
Start datum: 16-11-2015

11 | 3 | 21

MDO Behandelplan
16-11-2015
Zorgprofessionals
2

Preoperatief
23-11-2015
Patiënten
3
16-11-2015
Patiënten
1
23-11-2015
Patiënten
1

Definitieve behandelkeuze
24-11-2015
Zorgprofessionals
1

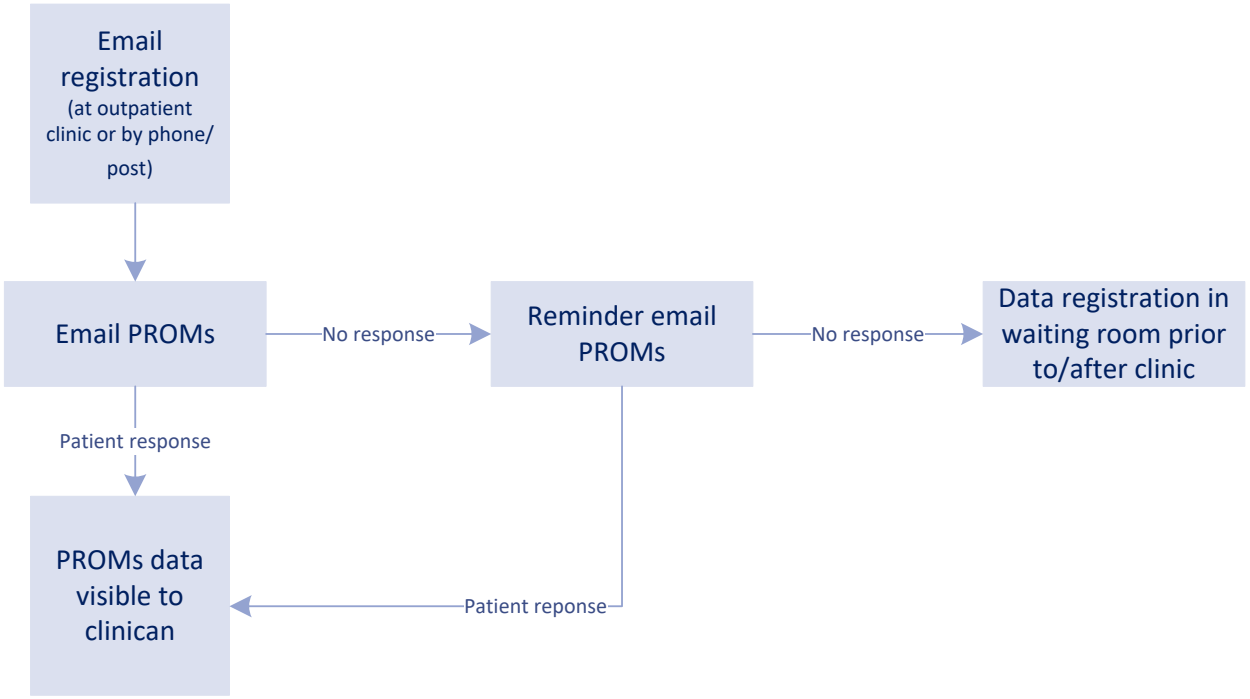
T6
17-03-2016
Patiënten
Breast-Q Module Borstsparende Therapie (Postoperatief)
EQ 5D 5L
EORTC QLQ C30
EORTC QLQ BR23
17-06-2016
Patiënten
De Lastmeter
Directe naaste
CarerQoL Instrument

T12
17-12-2016
Zorgprofessionals
1
Patiënten
5
Directe naaste
1

T24
17-12-2017
Zorgprofessionals
1
Patiënten
1

T36
17-12-201
Zorgpro
Patiënte

Implementation in the outpatient clinic



- Essential: **discuss the outcomes with the patient**
- Still looking for the ‘normal score’,

Implementation of Value Based Breast Cancer Care. Van Egdom, Koppert et al. EJSO jan ‘19

Getting to work

1. **Retrospective data**: cross-sectional, historic cohort, norm scores

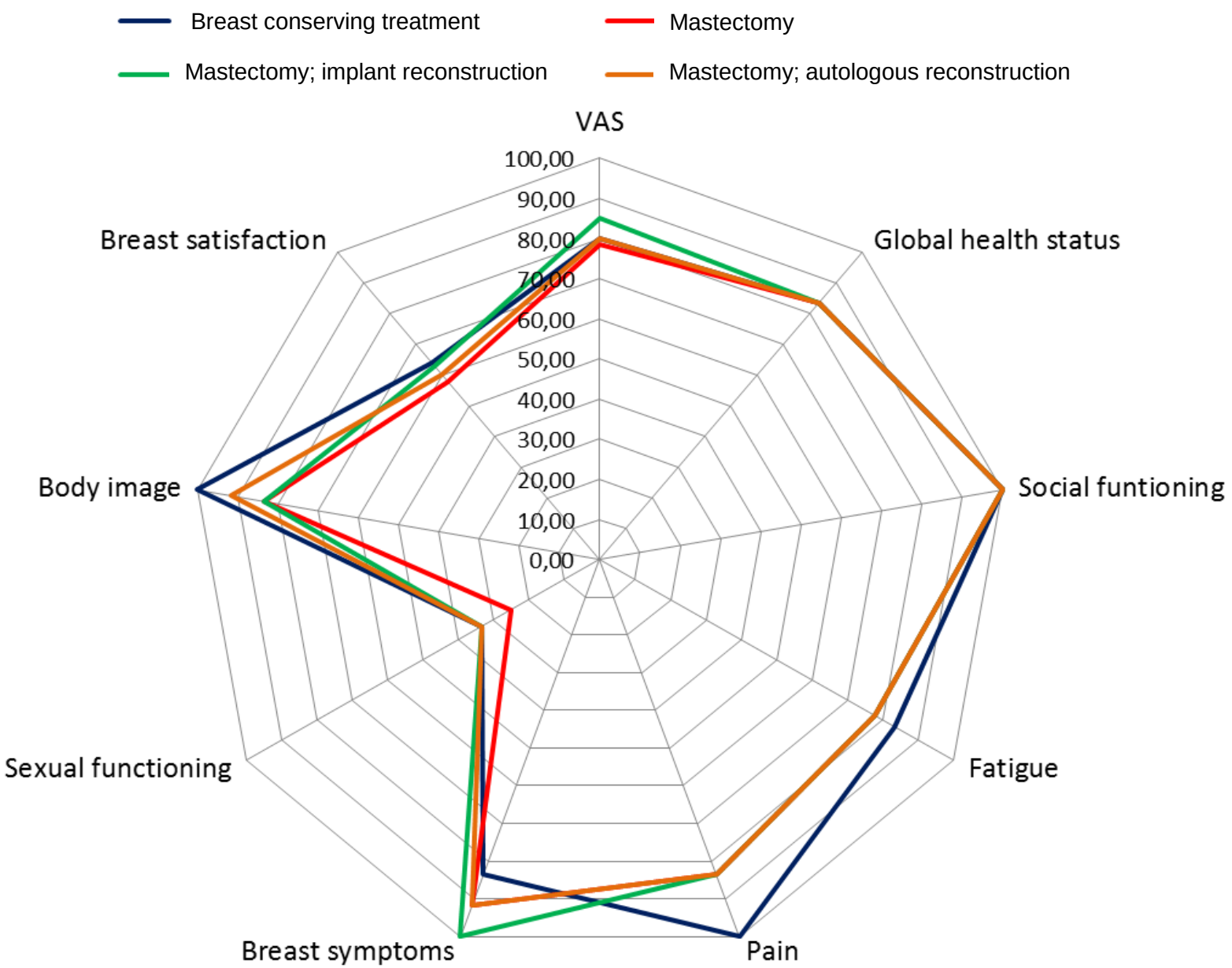
2. **BVN survey**:
   1. norm scores
   2. **patiënt perspective** (do PROMs add value?)

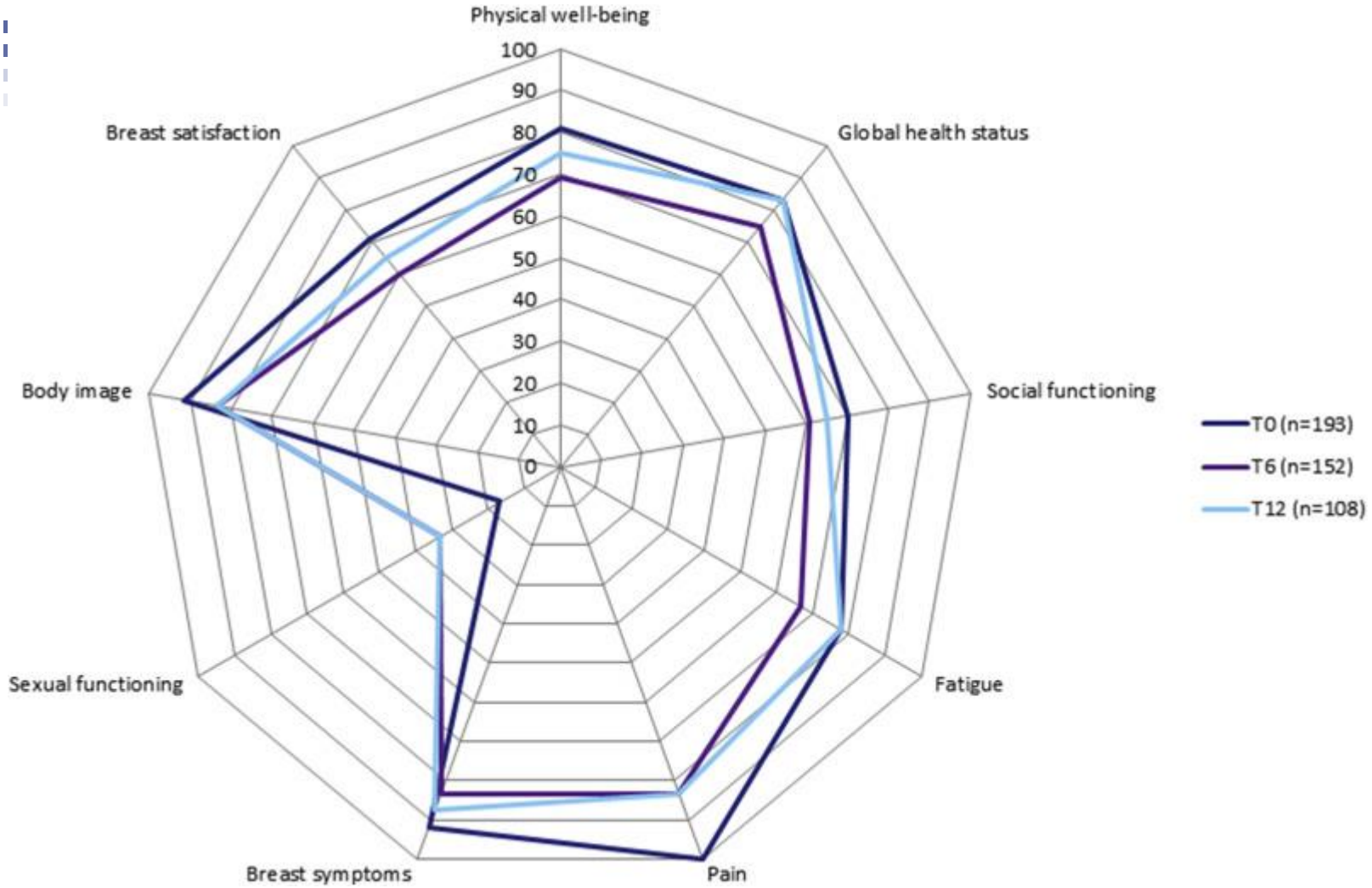
1. Retrospective

- Historic cohort
  - Median time after surgery 6.3 years (3.3-9.4)
- N=764
- pTis-3N0-3M0
- PROMs: EORTC-QLQ-C30/-B23, BREAST-Q, EQ-5D-5L
- Casemix: age, type of surgery and systemic therapy

Lagendijk, van Egdom, et al. Ann Surg Oncol 2018

PROMs type of surgery





Implementation of Value Based Breast Cancer Care. Van Egdom, Koppert et al. EJSO jan '19

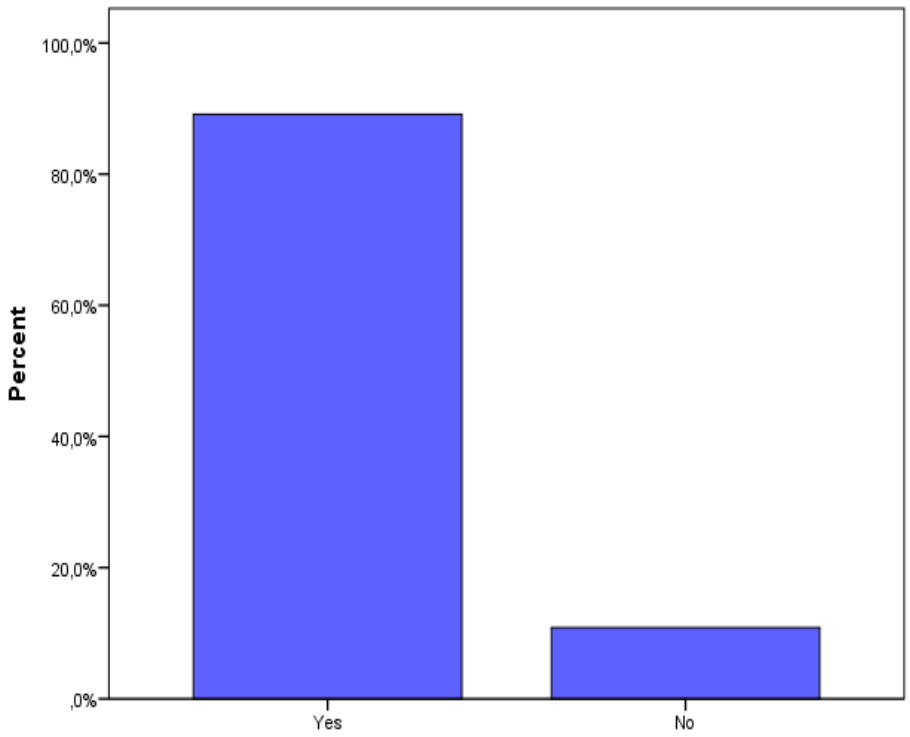
2. Survey BVN: Patient perspective

- N= 496
- PROMs: EORTC-QLQ-C30/-B23, BREAST-Q, EQ-5D-5L
- Casemix: age, type of surgery and systemic therapy
- With the main question ‘Do PROMs add value?’

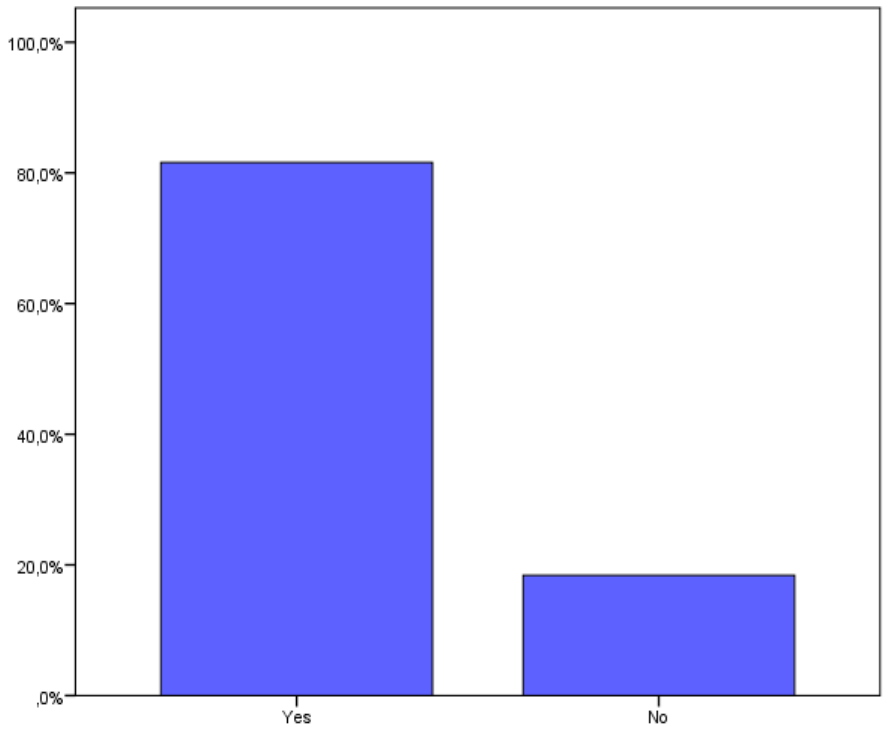
borstkankervereniging nederland
Met elkaar. Voor elkaar.

VBHC | *Nominee Prize 2018*

Lagendijk, van Egdom. Eur J Surg Oncol ‘18



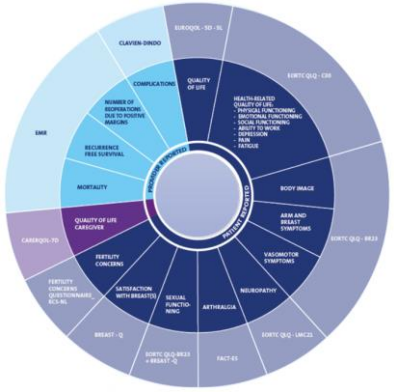
Is adding the PROMs at several time points and discussing the results with the healthcare professional meaningful



Are the PROMs potential also suitable as "self-management." instrument'?

Lagendijk, van Egdom et al. Eur J Surg Oncol '18

Now is the time..



Prospective data collection

- National taskforce
- Collaboration of 7 regional hospital
- European University Hospital Alliance (9 centra in Europa)

- Normscores in > 1300 patients; data-> opportunity to improve and learn
- Shared decision making: project Information for choosing in breast cancer care (collaboration of multiple parties)

- The set ‘does the questionnaires measure what we want to know?’, ‘is there overlap what makes it possible to reduce the amount of questions?’ (ICHOM, Pusic (Boston), Klassen (McMaster University, Hamilton)

- EORTC questionnaires: no room for reducing the amount of questions because of the license agreement; also no good comparative for the normscores pausible

Discussing outcomes with the patients

- Provide the questionnaires a few days before a planned visit
- Intregated in follow up care

- Big role for nurse practitioners and specialized nurses!
  - Responsibility of case manager

Conclusion

- Value based healthcare provides is a chance for the breast cancer patient
- It is crucial to discuss the outcomes with the patient
  - Delegate to nurse practitioners and specialized nurses
- Integrate in Electronic Patient Dossier
- Comparative effectiveness research! -> at the outpatient clinic

With many thanks to

- Patients
- PhD's Mirelle Lagendijk, Elvira Vos, Pien van Egdom, Inge Apon
- Michele van der Kemp
- VBHC team Erasmus MC

NBCA Taskforce

- **Marc Mureau**, plastisch chirurg, voorzitter (NBCA/Erasmus MC)
- **Vera Goldwijk/Carlijn Olde Reuver**, projectleider Patientfeedback (DICA/MRDM)
- **Erik Heeg**, arts-onderzoeker (NBCA/DICA)
- **Linetta Koppert**, oncologisch chirurg (Erasmus MC)
- **Danny Young-Afat**, AIOS plastische chirurgie (VUMC)
- **Carol Richel**, projectleider Monitor borstkankerzorg en B- force (BVN)
- **Marjan van Hezewijk**, radiotherapeut-oncoloog (Radiotherap[illegible])
- **Barbara van Leiden-Vriens**, beleidsadviseur (ZN)
- **Cathelijne Ziedses des Plantes**, medisch adviseur (Zilverenkruis)
- **Michel Wouters**, oncologisch chirurg (DICA/NKI-AvL)

STICHTING COOLSINGEL

Regionale Oncologienetwerken