

Master assignment Health Sciences

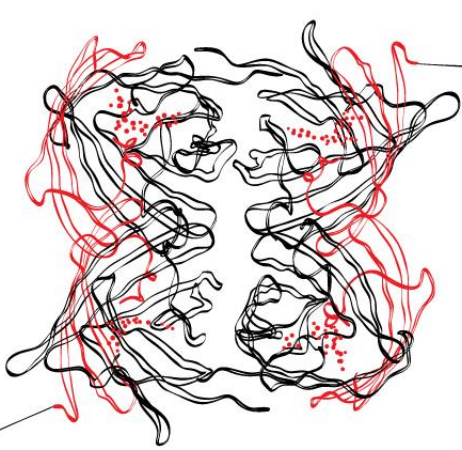


SYSTEMATIC REVIEW ON ACCURACY OF IMAGING TECHNIQUES DURING NEOADJUVANT CHEMOTHERAPY USED IN RESPONSE- GUIDED PROCEDURES TO BREAST CANCER SUBTYPES

&

VALUE ASSESSMENT FOR PATIENT, HEALTHCARE INSURANCE COMPANY AND SOCIETY BASED ON
OUTCOME INDICATORS FOR BREAST CANCER TREATMENT — A PRACTICAL APPROACH

AUGUST 2015



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Master thesis

August 2015

Systematic review on accuracy of imaging techniques during neoadjuvant chemotherapy used in response-guided procedures to breast cancer subtypes & Value assessment for patient, healthcare insurance company and society based on outcome indicators for breast cancer treatment

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Preface

This thesis report is the result of the master assignment in order to accomplish the master, Health Sciences at the University of Twente. This research was conducted at the Netherlands Cancer Institute (NKI) which is, in combination with the Antoni van Leeuwenhoek hospital, the only official cancer centre in the Netherlands.

Hereby I want to thank the NKI for the opportunity to perform my master assignment in such a dedicated specialized hospital. It was a challenging, educative and renewing experience. In addition I especially want to thank my supervisors Wim van Harten, Valesca Retèl, Anna Miquel-Cases and Joost Deetman for their knowledge, feedback, motivation, inspiration and guidance during this master project. Finally I want to thank all the external partners that helped during the project, i.e. clinicians, nurse practitioners, patients, the Dutch breast cancer association for patients, VGZ and all others that contributed to the result.

I enjoyed working on the assignments and I hope that results are useful in further research and investigations.

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Executive summary

Introduction thesis

This master assignment consists of two compartments. The systematic review first aimed at finding the most effective imaging technique or biomarker to predict response on chemotherapy and most effective second-line treatment in case of non-response in three specific breast cancer subtypes. During the project, the scope to breast cancer subtypes was broadened, the biomarker part was excluded and only second-line treatment that were identified in the accuracy studies on imaging techniques were included. The final research question was: What are the preferred imaging techniques and potential second-line treatments in response-guided NACT to defined breast cancer subtypes according to recent literature? The second, practical, assignment aimed at defining value of breast cancer treatment out of the perspective of a patient, insurer and the society. Due to limited time, focus was moved to developing outcome indicators, determination of options for operationalization and chose the most relevant indicators per perspective. The final question was: Which outcome indicators should be operationalized according to recent literature, patients and experts to describe the outcome, quality, of breast cancer treatment towards patients, insurers and societal perspective?

Assignment 1 – abstract literature review

Background Monitoring early response to neoadjuvant (chemo)therapy (NACT) by imaging allows for an adaptative treatment approach likely to improve NACT effectiveness in breast cancer. As imaging accuracy seems to vary on tumour subtype, we aimed at creating an overview of current knowledge on the accuracy of imaging techniques in monitoring NACT for the luminal B, HER2+/ER- and triple negative (TN) breast cancer subtypes. Furthermore, we presented treatment options for non-respondents at imaging based on the identified literature.

Methods By means of a systematic literature search we selected studies that tested imaging techniques for its prediction of pathologic complete response (pCR) during NACT in breast cancer subtypes defined by the expression of HER2, ER or PR. Studies' level of evidence (LOE) was assessed by the Grading of Recommendations Assessment, Development and Evaluation system (GRADE) tool. Negative predictive value (NPV), positive predictive value (PPV), (pooled) sensitivity, specificity and accuracy were calculated. Based on LOE and performance scores, preferred imaging technique(s) were chosen. From the included studies, treatment options were identified for non-respondents at imaging, that served to construct decision trees on possible response-guided therapy scenarios per subtype.

Results Out of 106 articles 17 were selected and showed low or very low LOE due to small sample sizes (12 studies) and treatment switches during the study (5 studies). In HER2-negative/ER-positive FDG-PET/CT showed pooled sensitivity and specificity of 53% and 92%, whereas its use in TNBC showed 73% and 96% respectively. In TNBC, MRI also seemed promising. In HER2-positive/ER-unknown MRI showed sensitivity and specificity of 83% and 95%. In HER2-positive/ER-positive use of FDG-PET/CT showed sensitivity and specificity of 59% and 80%, whereas in HER2-positive/ER-negative FDG-PET showed 40% and 83% respectively. In HER2-positive/ER-negative, the addition of bevacizumab in non-respondents showed a response rate of 58% vs 40% in the control group. In HER2-negative/ER-positive a switch from AC to DC could be effective in unfavourable respondents.

Conclusion Based on our findings in the literature, further research on response-guided procedures is necessary to conclude on the most effective imaging technique and potential treatment options in non-respondents to first-line treatments.

Assignment 2 – value assessment

Introduction

Recent changes in the Dutch healthcare system made costs and health outcomes increasingly important as the competition between healthcare providers shifted from a purely financial perspective towards an outcome based perspective. Since the AVL wants to attract more breast cancer patient to create a more efficient and qualitative process and create better scientific research conditions, showing value of their breast cancer treatment process is important. According to Michael Porter value is defined by health outcomes divided by costs of treatment. Outcomes could be determined based on treatment outcomes, Patient Reported Health Outcomes (PROMs) and patient compliance towards treatment, treatment preparation and rehabilitation. Outcome measure were described in a hierarchy of three tiers: health status achieved or retained, process of recovery and sustainability of health. This assignment aimed at designing outcome indicators, based on the theory of Porter, applicable in defining value of breast cancer treatment out of a patients, insurers and societal perspective.

Methods

A literature study was conducted towards current sets of outcome indicators, quality of life literature in breast cancer survivors and general literature towards quality of healthcare to describe a definition of quality of care and create the first conceptual framework of outcome indicators. This framework, was discussed with experts in quality of healthcare on appropriateness, completeness and to find options to operationalize the indicators which resulted in a final conceptual framework. Based on literature and the interview with experts, top lists were created in the three perspectives: patients, insurance company and society. In patients perspective a survey was employed to verify the top lists and towards the insurers perspective an interview by telephone was held with an employee of an insurance company to justify this top lists. In the societal perspective, due to the limited available time, it was not feasible to verify our results.

Results

The NABON, Pink ribbon and EUSOMA set of, mainly process, indicators were identified. The set of the International Consortium for Health Outcomes Measurement (ICHOM) included PROMs and is currently developing a set for breast cancer. Quality of life literature (QOL) showed three clusters that are important for QOL: time schedule, education and focus on patient. Thereby the following aspects were relevant towards QOL: breast conserving therapy or mastectomy, receiving of information about fertility and menopausal effect, dysfunctionality of the arm, pain, insomnia, fatigue and loss of appetite. These aspects were considered in the first conceptual framework that was discussed with seven experts. The final conceptual framework included 25 indicators: Survival, irradiation, recurrence, short term complications, long term complications, process time, waiting time, NACT, MARI, breast contour saving, mammaprint, duration chemo, multidisciplinary process, awareness and application of current research, innovative, patient empowerment, fertility information, treatment information, after care information, arm functionality, pain, fatigue, loss of appetite, physical appearance and recovery time. Out of the survey, respondents of breast cancer stage I and II considered, information provision, number of treatments performed, waiting time and patient empowerment as important. In breast cancer stage III the same aspects but patient empowerment, were presented. These aspects differed from the expectations based on literature and interviews with experts. The priority lists showed the following important aspects: survival, recurrence, chance on long-term complications, arm functionality, number of treatment performed, preventing overtreatment and no clear priority in category experience of treatment (waiting time, information provision and patient empowerment). The insurance company VGZ described three levels of information used to contract healthcare providers: clinical, patients and systematic level. The experience of the treatment by patients is important information since it allows comparison to the information that was provided on clinical level. The following aspects on patients level were suggested: information provision, patient empowerment, communication towards the patient,

patients experience of cooperation within the medical team, recommendation of the hospital, experience of treatments effect and the experienced complications. On clinical level the following were suggested: recovery time, complications, survival and irradiability. In societal perspective six indicators were suggested based on interviews with experts and literature: survival, irradiability, recurrence, long-term complications, arm functionality and recovery time.

Conclusion

In the patients perspective the following aspects were suggested to operationalize in breast cancer stage I and II: survival, long-term complications, arm functionality, number of treatments performed, preventing of overtreatment in chemotherapy, information provision and patient empowerment. In breast cancer stage III the same indicators were suggested, including recurrence and waiting time towards treatment. Two additional aspects should be kept in mind: a multidisciplinary work process and waiting time on diagnostic results. Out of the insurance perspective, survival, irradiability, recurrence, long-term complications, recovery time and two indicators that would assess patients experience of the treatment should be operationalized. Finally out of a societal perspective, survival, irradiability, recurrence, long-term complications, arm functionality and recovery time should be assessed.

Discussion

There were several limitations in designing the conceptual framework, survey and the interview. The literature study was not systematic, some indicator sets were identified after designing of the conceptual framework and the input from clinical experts was limited. Since only 23 respondents filled in the survey, selection bias exists and in addition analysis towards breast cancer stage should be discussed. Finally as the interview was not structured, confirmation bias could exist. It is recommended to discuss our results in a meeting in which the different perspectives are represented (clinical, patient and insurer) to choose the final indicators for operationalization and assess them. In addition we recommend to calculate the costs of breast cancer treatment within the hospital to conclude on value of the breast cancer treatment in the hospital.

Introduction

After my bachelor Health and Technology (bachelor of nursing) I wanted to broaden and deepen my view and knowledge to the organization of health care. Therefore I started the master Health Sciences and chose the specialization: Health Services and Management. After discussing several potential master assignments I started at the NKI with a combination of two assignments: A systematic literature review and a practical assignment about value based health care. Both subjects are of interest as I am interested in research towards economic evaluations as well as in the highly discussed subject of “quality of healthcare”.

Therefore this master assignment consists of two compartments: a systematic review on accuracy of imaging techniques during neoadjuvant chemotherapy used in response-guided procedures to breast cancer subtypes and a value assignment for patient, healthcare insurance company and society based on quality indicators for breast cancer treatment process. Both compartments are included in this thesis.

In the following sections the main organization of the master assignment and the development of the two research compartments is discussed. Thereby I want to highlight that, in respect of this master assignment and grading of it, the literature study was the most important part.

Organization

Antoni van Leeuwenhoek / Dutch Cancer Institute

Both projects were executed at the Antoni van Leeuwenhoek. Which is a specialized hospital in cancer and in combination with the research institution Dutch Cancer institute it is the only cancer centre of the Netherlands. It was established on October 10, 1913 and plays an important role as a national and international centre of scientific and clinical expertise. They connect research and results with every day practice and strive to deliver customized care to achieve the best health outcome in every individual and unique patient. The literature review was conducted to assess data for a cost-effectiveness analysis within the institution.

Supervisors

Four supervisors were included to guide me in this project. The first and second supervisor were both involved in the two assignments. The other two supervisors were specialized towards one of the two assignments. Table 1 shows an overview of the supervisors and its roles.

Name	E-mail	Role	Institution
Prof. W. van Harten MD PhD	w.v.harten@nki.nl	First overall supervisor	University Twente and Antoni van Leeuwenhoek
V. Retèl PhD	v.retèl@nki.nl	Second overall supervisor	University Twente and Antoni van Leeuwenhoek
A. Miquel-Cases MSc	a.miquel@nki.nl	Supervisor literature study	Antoni van Leeuwenhoek
J. Deetman MSc	j.deetman@nki.nl	Supervisor practical assignment	Antoni van Leeuwenhoek

Table 1 - Supervisors

Research process

Literature review on response-guided neoadjuvant chemotherapy in breast cancer subtypes

Background and research objective

Since a couple years, Neoadjuvant chemotherapy (NACT) in breast cancer treatment is part of current practice. Although chemotherapy before surgery showed no improvement in survival rates, two significant advantages arose: surgery may be less invasive and it allows pathologic complete response prediction (pCR) of given chemotherapy regimen. This second advantage could be beneficial in terms of survival as enables a switch to second-line treatment options in case of non-response. Since response-guided NACT is still being investigated towards its use, cost-effectiveness could help in choosing whether this procedure should be implemented in standard breast cancer treatment.

This literature review was conducted to provide the input data for the Cost-Effective analysis (CEA). In order to perform a CEA it was necessary to investigate the accuracy of response prediction and the effectiveness of second-line therapies in recent literature. Response could be predicted by several imaging techniques, i.e. MRI, PET, PET/CT, US, and recent literature showed promising results towards biomarkers, i.e. Ki67 and P53. Application of both imaging technique and biomarkers were investigated in this literature study. In addition we aimed at providing an overview of the most effective switches in treatment regimens.

The study was specified towards three breast cancer subtypes defined by Human Epidermal Receptor 2 receptor status and hormone receptor (estrogen (ER) or progesterone(PR)) status: Luminal B, HER2+/ER- and triple negative (TN). As we were only interested in subtypes in which pathologic complete response (pCR) was associated with survival.

In this literature study we aimed at finding the most effective imaging technique or biomarker in each breast cancer subtype to predict pathologic complete response and in addition the most effective second line treatment in case of non-response according to recent literature. The following research question was defined in the beginning of the project:

Which response guided techniques, imaging and biomarkers, and secondary treatments in case of non-response are most (cost)-effective for the three specific breast cancer subtypes in neoadjuvant chemotherapy according recent literature?

In order to answer this question we executed three literature searches in order to find:

1. Accuracy of imaging techniques in pCR prediction during NACT in breast cancer subtypes
2. Potential biomarkers that could be used in pCR determination in breast cancer subtypes and their effectiveness
3. Effective second-line treatment in non-respondents

Development of the project

Just as in each extensive project, the objective of the project changes according to results and other developments. In this project the scope of breast cancer subtypes was broadened, the biomarker part was excluded and the search towards second-line treatments was restricted to the ones that were identified in selected imaging techniques. The following sections will describe each of these three changes within the project. These developments were also shown in a time-table (figure 1).

Inclusion of other subtypes

It was experienced that literature on accuracy of imaging techniques to our specific subtypes was very limited. We therefore contacted authors, in total eight, that described imaging results towards one receptor status but not to the specific subtype as it requires, presentation of two receptor statuses. However only one author replied to us with useful data to one of our specific subtypes. Because of the limited results in specific subtypes, the scope was broadened to include articles that presented their results towards only one receptor status.

Exclusion biomarkers

In conducting the systematic literature review on biomarkers, potential biomarkers i.e. P53, Ki67 and BRCA1, were defined to specify the literature search. However the biomarkers were excluded from the literature review because of the feasibility of the project. This mainly was because the other two literature searches, imaging and treatment, took more time than we had foreseen. Although the extent of the biomarker search made accomplishment of it ambitious. Still it would be a very interesting addition to our research as it is expected to be of added value in response prediction.

Focus second-line treatments

We aimed at finding potential second-line treatments for non-respondents in recent literature. Since response-guided therapy is still very recent it was hard to find literature on potential switches in which efficacy in first-line treatment and second-line treatment were presented in a neoadjuvant setting. Only some articles in metastatic breast cancer were identified that specified both first-line treatment, treatment on which the patients progressed, and second-line treatment. As specification to breast cancer subtypes was rare and clinical understanding of the several treatments was missing the focus was shifted to second-line therapies that were identified in imaging studies. The two articles that described a full response-guided procedure were included in the paper and the additional literature that was identified was shortly described.

These changes resulted to our final research objective and research question in which we specifically focused on imaging's accuracy and potential second-line therapies.

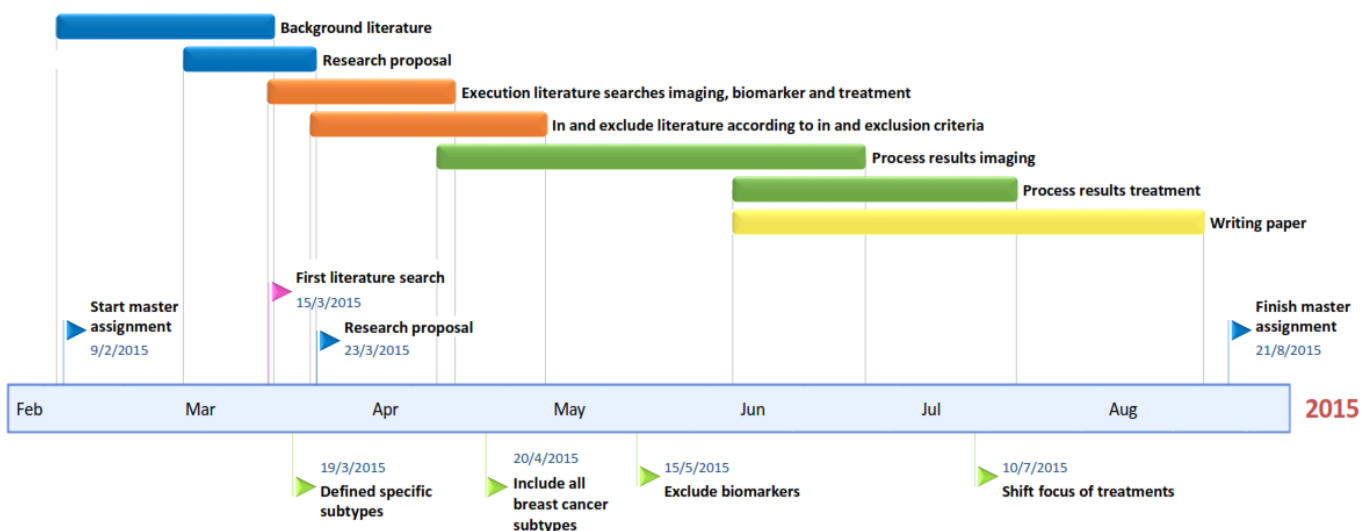


Figure 1 – Timeline of the literature study with process steps in a Gantt chart structure and milestones showing the developments within the project.

Final research question and objective

We aim at creating an overview on accuracy of NACT response monitoring by imaging techniques in breast cancer subtypes based on current knowledge. Additionally we aim to show options for second line treatments based on current experiences in practice for the subtypes luminal B, HER2+/ER- and triple negative. Our final research question was:

What are the preferred imaging techniques and potential second-line treatments in response-guided NACT to defined breast cancer subtypes according to recent literature?

Value assessment for patient, healthcare insurance company and society

Background and research objective

Recent changes in the Dutch healthcare system made costs increasingly important for healthcare providers, patients and insurance companies. In the Netherlands, healthcare providers have to compete to each other to achieve an attractive contract with the insurance company. This competition is moving from a purely financial perspective to a more value based or outcome based perspective. The breast cancer department of the NKI-AVL wants to attract more patients which should create a more efficient and qualitative process and better research environment.

Showing value of breast cancer treatment towards patients and healthcare insurers is important to accomplish this. In order to describe value of breast cancer treatment, outcomes of the provided healthcare should be measurable. In this assignment we aimed at designing a conceptual framework of outcome indicators based on literature, experts' opinion, patients perspectives and former sets of indicators in order to measure quality. In addition we want to determine ways to operationalize these and finally to define value for patient, healthcare insurance company and society. Eventually these quality indicators should be applicable for internal registration within the NKI-AVL, but also in terms of benchmarking. The conceptualization of value based healthcare by Michael Porter was used in this project to systematically design the set of outcome indicators.

Development of the project

Due to the explorative nature of this practical assignment the objective and aim changed along the way to secure feasibility of the assignment. Eventually we focused mainly on the development of a conceptual framework of outcome indicators and ways to determine these in practice. If it was possible within the given time it would be nice to include patients and an insurance company for their perspectives. The following sections are presenting some of the challenges and changes during the process. These developments were also showed in a time-table (figure 2).

Cooperation of the experts

Several experts were approached to think along the project. However some could not find the time to think along. Since some of these experts were involved in committees and former initiatives that focused on designing outcome indicators, valuable input stayed unnoticed.

Survey

In order to create the survey towards patients perspective, the final conceptual framework should be determined. The final conceptual framework took more time than foreseen due to holidays of the included experts. As a result the survey was distributed in the end of the project, which could have an effect on the response rate.

Costs

Since we aimed at defining value in three perspective we should also assess the costs of the provided healthcare. These costs should be calculated from the moment that the patient started with the treatment until the moment of recovery, thus this also includes the costs of home care, physical therapy and other health expenses. Thereby it is still unknown how to divide the outcomes by costs to calculate value. To ensure the feasibility of the assignment this analysis was excluded and therefore focus remained to determination of outcome indicators.

Focus towards patients and insurers

Each perspective, patient, insurance company and society was provided with a top list of outcome indicators. In both patients and insurers perspective these lists were verified. Because of the feasibility we were unable to verify the societal perspective.

These aspects resulted to our final objective and research question in which we specifically focused on the development of measurable outcome indicators and some input out of patients and insurers to verify these perspectives.

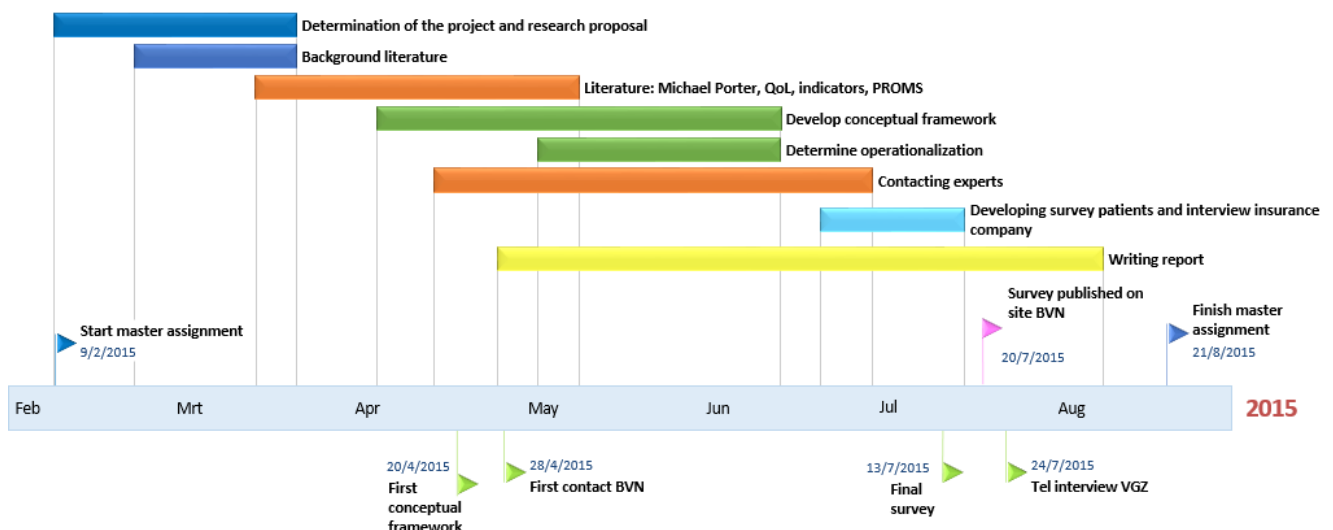


Figure 2 - Timeline of the second assignment with process steps in a Gantt chart structure and milestones showing the developments within the project.

Final research question and objective

We aim at determination of outcome indicators that could describe value of breast cancer treatment out of the perspective of a patient, insurance company and society. Therefore our final research question was: *Which outcome indicators should be operationalized according to recent literature, patients and experts to describe the outcome, quality, of breast cancer treatment towards patients, insurers and societal perspective?*

Assignment 1

Systematic review on accuracy of imaging techniques during neoadjuvant chemotherapy used in response-guided procedures to breast cancer subtypes

We aim to publish this paper, therefore this part is confidential. If you are interested please send an email to: melanielindenberg@gmail.com

Assignment 2

Value assessment for patient, healthcare insurance company and society based on outcome indicators for breast cancer treatment

Practical approach

Value assessment for patient, healthcare insurance company and society based on outcome indicators for breast cancer treatment

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1. Introduction

This chapter describes the problem statement, research question, research's objective and a theoretical framework of the value based healthcare concept which was used in conduction of this project.

1.1 Problem statement

Recent changes in the Dutch healthcare system made costs increasingly important for healthcare providers, patients and insurance companies. In the Netherlands, healthcare providers have to compete to each other to achieve an attractive contract with the insurance company. This competition is moving from a purely financial perspective to a value based or outcome based perspective, mainly because the government wants to guarantee access to qualitative healthcare. This year's theme of the healthcare department, transparency, is typical for this.

At this moment the Netherlands Cancer Institute – Antoni van Leeuwenhoek, wants to attract more breast cancer patients in the coming years to create a more efficient process, more qualitative breast cancer treatment and to provide better scientific research conditions. To achieve this, showing the value of the provided breast cancer treatment, outcomes for money, towards insurance companies and patients is important. To accomplish this kind of transparency, clear indicators, reflecting the value of breast cancer treatment, should be developed.

1.2 Aim

This project is aiming at defining outcome indicators applicable to define value of the breast cancer treatment process towards patient, insurance companies and society. These indicators should be useful for internal registration as well as for benchmarking on a national level. In order to provide inputs for improvement cycles, transparent information for patients select their hospital and information for insurance companies to select qualitative healthcare providers.

The main research question of this project is:

Which outcome indicators should be operationalized according to recent literature, patients and experts to describe the outcome, quality, of breast cancer treatment towards patients, insurers and societal perspective?

The project focuses towards three objectives:

1. Definition of a conceptual framework of quality indicators based on literature, current sets of indicators towards quality and experts opinions.
2. Determination of options to operationalize the indicators in the conceptual framework
3. Determination of outcome indicators in order to describe value towards three perspectives: patient, healthcare insurance company and society.

Unfortunately the third objective could not be fully conducted within the given time.

1.3 Value based healthcare

Value based healthcare (VBHC) was first conceptualized by Michael Porter. He described value as health outcomes achieved by provided healthcare services per dollar spent (Porter, 2010). Value based healthcare could guide in improvement cycles and thus lead to improvement of healthcare. Introduction of VBHC contributes to generate value for patients as this should be the main focus of healthcare.

According to Porter (2010) value should be defined to costumers in order to describe healthcare outcomes from the perspective of a patient. For that, the population should be clearly defined prior to value description since value is perceived differently per medical condition. The combination of the health outcomes in this population and costs of treatment allow for the calculation of value.

In this moment value based healthcare is being investigated internationally. Also in the Netherlands several health care societies and hospitals aim to create outcome indicators towards quality of care. An example is the program "healthcare for outcome" of the Santeon group, a collaboration between several

hospitals, aiming for transparency of outcomes on quality indicators (Santeon, 2015). In 2007 the American Society of Clinical Oncology (ASCO) formed the Task Force in 2007, due to the costs of cancer care, which published in 2012 a top five of common clinical practices that are not supported by high level of evidence (Schnipper et al., 2013). These insights, guided to a conceptual framework that assessed value of cancer treatment options (Schnipper et al., 2015). Finally in respect of VBHC we want to highlight the organization of healthcare in Australia that is also engaged to quality of healthcare (Australian Commission on Safety and Quality in Healthcare, 2010).

The attention towards VBHC is increasing because process and structure indicators, the current indicators in the sets to assess quality, seemed less appropriate to conclude on value. Since structure indicators present information about the organizational conditions of the healthcare processes i.e. number of staff or the availability of a MRI scanner. These indicators are fundamental to provide healthcare but do not guarantee quality of healthcare. Process indicators provide information about healthcare processes within the organisation i.e. following guidelines, waiting times. Although the results of these indicators will have an effect on quality they could not guarantee qualitative healthcare.

Figure 1 shows the relation between process, structure and outcome indicators. As you can see here, the structure provides a condition in which the healthcare process contributes to health outcomes. It would be interesting to measure health outcomes as these are the true result of the treatment and thus would give information about the quality of the provided healthcare.

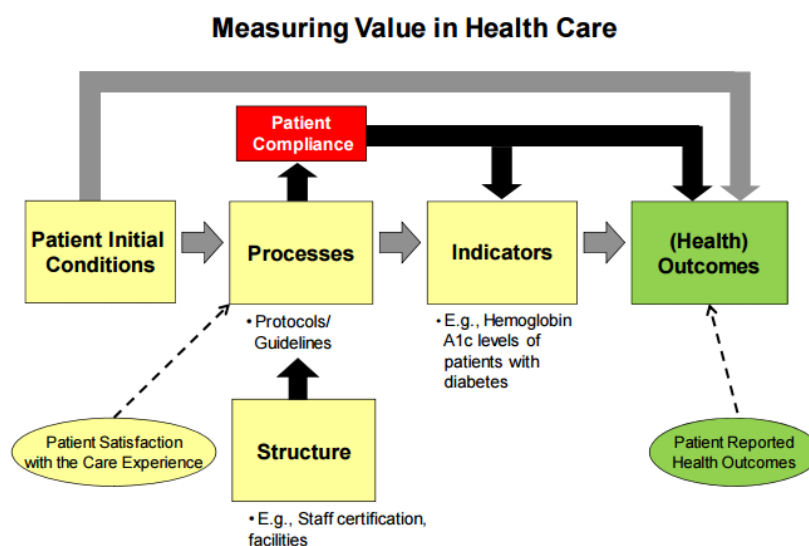


Figure 1 - Actors that influence health outcomes. The figure shows the connection between process, structure and outcome indicators. (Porter, 2010)

Measuring outcomes

Following the model in figure 1, outcomes of a treatment could be determined based on the outcomes itself, Patient Reported Health Outcomes (PROMs) and patient compliance towards treatment, treatment preparation and rehabilitation.

The set of outcome indicators should therefore involve:

- Health circumstances that are most relevant for patients
- Near-term and longer-term patient health conditions
- Cover the full range of services and providers that jointly determine the patient's results
- Sufficient measurement of risk factors to allow risk adjustment (i.e. case mix)

(Porter, 2010).

The set of quality indicators should jointly define the success of the treatments process. Porter (2010) described a hierarchy of outcome measures in a tier system which is shown in figure 2. The top tier is generally the most important, as it describes the achieved health status. The results of each tier show

performances of the provided healthcare and could therefore be used in improvement cycles. However in metastatic diseases improvement of the most important tier, tier one, is not possible, tier three would be the most important tier.

Since this model will differ across the different health conditions, the levels that should be included in the set of outcome indicators will vary. A level should be included if it shows importance to patients, as they are easy to measure or that the aspects are in need of improvement. In an ideal situation the final set includes one criteria of each level and thus two per tier (Porter, 2010). For the health condition of interest, breast cancer, all levels are assumed to be important to patients.

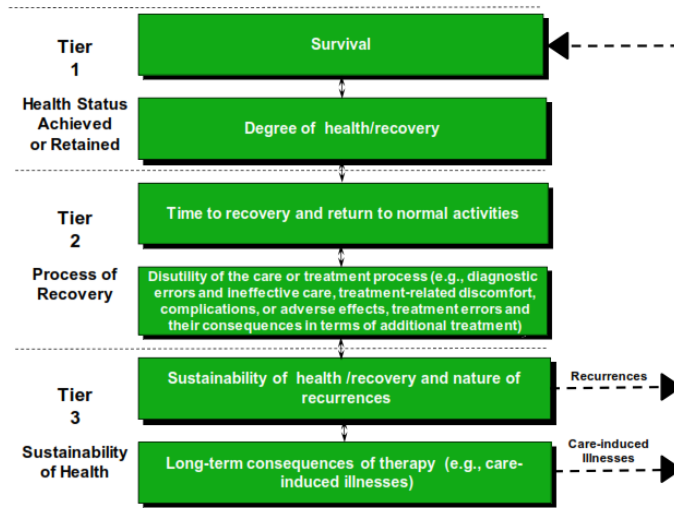


Figure 2 - Outcome Measures hierarchy (Porter, 2010)

Costs

To eventually describe value of breast cancer treatment, costs should be calculated as the second input for the equation. Although calculating the costs was out of scope, it is included in this paragraph to provide a complete overview of VBHC. Porter (2010) recommends to use Time-Driven Activity-based Costing. In this method costs are aggregated around the patient to find the real costs per time unit for provided care in a specific medical condition. This is very complex because the costs of all involved healthcare providers and services i.e. homecare, hospital and physical therapy should be included. Following the theory of Porter (2010) value is improved if the total costs are reduced but the same health outcomes are achieved. At this moment it is not known how the calculation will be executed in detail. To compare value of care across medical conditions, QALYs, DALYs or monetizing of outcomes are often used (Porter, 2010). Other methods to measure the outcomes and compare these with their costs should be developed.

2. Methods

This chapter describes the research methods. The following aspects are discussed: total research design, definition of quality, literature review, interviews with experts, survey design towards patients perspective and interview towards insurance perspective.

2.1 Total research design

In figure 3 the total research design is visualized. To design a conceptual framework of measurable outcome indicators towards breast cancer treatment a literature study was conducted towards current sets of outcome indicators, general literature on quality of healthcare and quality of life literature in breast cancer survivors. Based on this literature a quality definition was designed in order to structure the conceptual framework which allowed building a first conceptual framework based on the literature results. Afterwards the framework was discussed during interviews with internal and external experts in quality of healthcare. These interviews guided to a final conceptual framework that was used to define the most important outcome indicators per perspective (patient, insurer and society). In the patients perspective these indicators were verified with a survey to patients. In the insurers perspective an interview with an employee of the insurance company was used to check our expectations. In the societal perspective we were unable within the given time to verify the indicators that were identified as important.

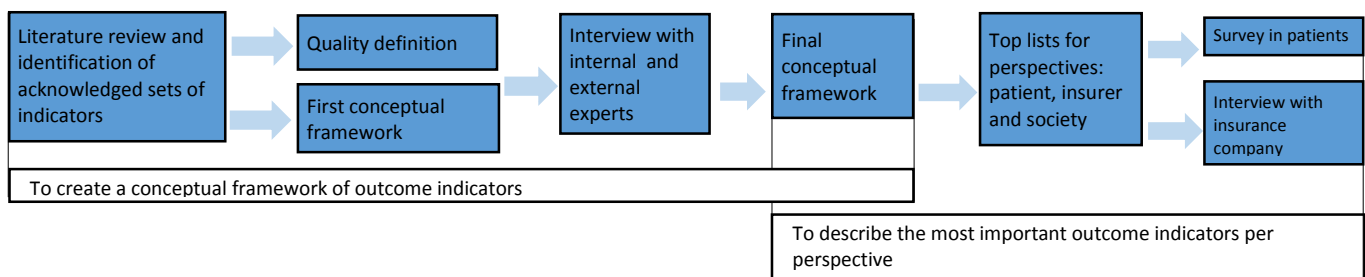


Figure 3 – Visualization of the total research design of the project.

2.2 Quality definition

To define value, healthcare outcomes should be determined. Since outcomes of healthcare are closely related to quality of healthcare, a definition of quality of healthcare was designed. The institute of Medicine (IOM) (2001) reports six aims for improvement which could lead to quality of healthcare. This definition was the starting point of our definition since it is frequently used to define quality of healthcare in scientific literature.

Qualitative healthcare should be:

- Effective
- Efficient
- Timely
- Patient-centred
- Equitable
- Safe (2001)

In this project we focused towards four of these aspects (shown below) as these are measurable and would describe healthcare outcomes. Equitable and efficient are important towards healthcare quality but were excluded as these focuses to the healthcare process itself. We included timely, a process indicator, as it is mainly included in the current sets of indicators and perceived as important out of a patients perspective.

Patient-centred: Patient-centred healthcare is described as healthcare that is respectful to the individual patient preferences, needs and values and these values guide clinical decisions.

Timely: Timeliness healthcare is described as healthcare services that are preventing waits and harmful delays for those who receive care.

Safe: Safe care is described as healthcare that aims to avoid injuries to patients from the provided services that intended to benefit them.

Effective: Effective care is described as healthcare services that are based on scientific knowledge provided, to those who could benefit and refraining these services to those who are not likely to benefit.

After identification sets of the Patient Reported Outcomes Measures (PROMS) by the International Consortium for Health Outcomes Measurements (ICHOM) we combined the four chosen aspects of quality with some of their categorizations of outcome indicators to describe quality and structure the conceptual framework. The following categories of the PROMS were combined to the four identified aspects of quality (patient-centred, timely, safe, effective)

- Survival
- Complications
- Degree of health

Outcome indicators that fall in the categories: complications, degree of health and survival give information towards two aspects, safe and effective, out of the quality definition of IOM. Therefore, the categorizations: survival, complications and degree of health were included whereas the category safe was excluded as this will be described by a combination of the included categories. Effective was still included as we could think of other outcome indicators that would present results on effectiveness. Hence, we identified six categories to describe quality of healthcare: survival, complications, timeliness, effectiveness, patient centeredness and degree of health:

1. **Survival** focused on overall survival, chance on re-excision and recurrence
2. **Complications** focused on the chance on long term and short term injuries that should been avoided in the provided health services.
3. **Timeliness** focused on waiting and process time to prevent waits and harmful delays.
4. **Effectiveness** focused on delivering best healthcare practice in those who were likely to benefit from this treatment according to scientific knowledge.
5. **Patient centeredness** focused on patient involvement and information provision about health status, treatment and after care.
6. **Degree of health** focused on symptoms that may occur after treatment.

2.3 Design conceptual framework

As shown before in figure 3 a literature review was conducted and interviews with experts were scheduled to design the final conceptual framework of outcome indicators. This paragraph provides details about the three activities: literature review, interviews with experts and designing the final conceptual framework.

2.3.1 Literature review

Literature was reviewed on general literature towards quality of breast cancer treatment, quality of life (QOL) in breast cancer survivors and finally a search towards existing or set of indicators in order to operationalize quality within breast cancer treatment. The literature searches (Google scholar, web of sciences, PubMed) comprised of the terms: "breast cancer" (MeSH breast neoplasm), "quality", "process" (i.e. treatment, diagnosis, process) and in quality of life studies: "quality of life", "physical appearance", "breast conserving therapy", "younger patients" and "arm functionality". The QOL search was specified

after determination of the main aspects that affected QOL according to the general QOL literature in breast cancer survivors. Existing initiatives for operationalization of quality and existing sets of indicators were mainly introduced by the experts and supervisors, whereupon further details were explored.

2.3.2 Interviews with experts

Breast cancer clinicians and other experts were approached to discuss the outcome indicators gathered out of literature on their appropriateness, clinical relevance and operationalization. The meetings were semi-structured as questions were prepared but allowed for ideas or other relevant points of discussion.

2.3.3 Final conceptual framework

Based on the selected literature and input of experts a first conceptual framework was designed, categorized to our quality definition described in paragraph 2.2. For each indicator the following aspects were presented: quality category, type of indicator, short motivation to determine the indicator, possible operationalization option(s), whether the indicator was already recognized in former indicator sets and finally the tier and level of the indicator according to the hierarchy that Porter (2010) described. As the indicators should be applicable for benchmarking, case-mixes were described in the operationalization column.

2.4 Outcome indicators per perspective

In each perspective, patients, insurers and society, a list of important indicators is designed based on literature and input of experts. In addition the tier and level per indicator were described. Since value should be described in a clearly defined population, definition of patients perspective towards either breast cancer stage or age of the patient was considered. Age of the patient seemed relevant as differences in level of importance were expected, i.e. physical appearance, recovery time, and specific indicators were identified in younger breast cancer patients, i.e. fertility needs. Eventually the patients perspective was described according to breast cancer stage as differences were expected to be found in the level of importance and it seemed consistent to the concepts of Porter considering that outcome sets should be designed to the specific health condition. Besides, this way of categorization was supported by the experts.

To justify the overviews in each perspective we verified the results to the target group. Therefore a survey was conducted in breast cancer patients to verify patients perspective and an interview by phone was held with an insurance company to verify the insurance perspective. We were unable to verify our results in societal perspective as time for this project was limited.

2.4.1 Survey design patients perspective

An online Dutch survey with mainly closed questions was designed to verify our top lists based on results of the literature review and experts input (appendix 2). The survey was composed with input from S. van Soelen and C. Richel, both from the Dutch breast cancer society for patients (Borstkanker Vereniging Nederland). Due to the closed nature of the questions we included an option of "I do not know" or "other" to prevent that patients were forced to pick an answer that did not reflect their opinion. The survey consisted out of four parts: "general", "aspects of quality", "priority of the aspects" and "additional aspects".

It was distributed by the website of Borstkanker Vereniging Nederland, several forums of other breast cancer patient associations and other social media. In the following section the four parts of the survey are described in more detail.

In the first part, “general” we asked for gender, age, time since treatment, tumour stage, whether the respondent sees itself as a patient or a survivor and in what kind of hospital the respondent was treated. These information was used to draw the research population.

The second part, “aspects of quality”, included the fifteen quality aspects that were chosen as most important out of a patients perspective: survival rate, irradicality, recurrence, information provision, patient empowerment, recovery time, cosmetically result, arm functionality, long term complications, volume, waiting time between results and treatment, possibility of participating in research trials, possibility of receiving neoadjuvant chemotherapy, preventing overtreatment (chemotherapy) and the possibility of a direct reconstruction after mastectomy. These indicators were chosen in consultation with one of the experts related to the breast cancer society for patients, based on a more detailed description of the indicators which is presented in appendix 1. Patients were asked to choose a maximum of five indicators that were perceived as most important and a maximum of five that were perceived as less important.

The third part, “priority of the aspects”, presented the same indicators of quality as the second part however in each question, two indicators were presented and the respondent had to choose the most important one. The fifteen indicators were divided into four categories and where opposed to eachother. This allowed us to conclude on the indicators that were perceived as most important in each category. In the last part, “additional aspects” the other aspects of the conceptual framework, also considered as important for patients, were presented. In this part respondents could choose the aspects of their interest without a maximum of options. In addition an open question was included in which respondents could describe any other important aspects.

2.4.2. Insurance perspective

To gain more insight into the insurance perspective a non-systematic interview was held with an employee of insurance company VGZ. It was a non-systematic interview because time on both sides was limited. As he was no expert on breast cancer nor was he involved in development of indicators the meeting resulted in a general interview towards quality of care.

3. Results

In this chapter results are described of the literature review, experts meetings, conceptual framework, and the results towards each perspective: patient, insurance company and society.

3.1 Literature review

As previously described in the methods section, literature was reviewed towards three aspects: general literature on quality of healthcare, quality of life literature in breast cancer survivors and existing sets of indicators were identified. The general literature towards quality of healthcare was used in the quality definition and introduction of value based healthcare. Therefore, the following section only included results of identification of current indicator sets and quality of life literature.

3.1.1 current indicator sets

The National Breast Cancer Consultation Netherlands - NABON

A project team of NABON, consisting of members of professional breast cancer associations, started in 2009 with the development of a multidisciplinary set of quality indicators (NBCA, n.d.-a). Since breast cancer treatment is continuously in development, each year the set of indicators is updated. The set currently consists of 30 indicators mainly presenting process indicators, i.e. details of pathology, waiting and process times and treatment options that may be provided. Each indicator is described extensively with an explanation to operationalize the indicator. This indicator set is acknowledged in current practice and thus implemented in every hospital in the Netherlands.

The NABON Breast Cancer Audit, NBCA, part of Dutch Institute for Clinical Auditing (DICA) registers breast cancer diagnostics, treatments and the treatment results (DICA, n.d.; NBCA, n.d.-b). Participation to this national registration is also one of the NABON indicators.

Pink ribbon

The Dutch breast cancer association for patients (Borstkankervereniging Nederland) developed criteria, the pink ribbon criteria, which should help patients in choosing the preferred hospital for their breast cancer treatment. In 2015, 78 hospitals of the 89, including the AVL, achieved the pink ribbon as a quality certification, and thus fulfilled the stated criteria (Borstkankervereniging Nederland, 2015). The indicators of this monitor refer to waiting time, a multidisciplinary process, experience of the hospital in this kind of treatment, information provision, way of reporting results and process and finally guidance during and after treatment (Borstkankervereniging Nederland, 2014).

International Consortium for Health Outcomes Measurement - ICHOM

This international organization focused on standardization of Patient Reported Outcomes (PROM's) (ICHOM, n.d.). Currently there are twelve indicator sets available of which three concerning cancer care, i.e. prostate cancer, lung cancer and localized prostate cancer. However the set for breast cancer is in development and will be available in the end of this year. As an example the PROMS of prostate cancer are presented in figure 4.

The PROMS for this health condition were divided in: complications (tier 3) survival and disease control (tier 1) and degree of health (tier 1) (ICHOM, 2015). As both prostate cancer and breast cancer survivors have high life expectancies, living with the disease and the possible disadvantages are important for the quality of the treatment. This indicator set is related to patients experience or quality of life after treatment.



Figure 4 - Patient reporting outcomes developed for advanced prostate cancer (ICHOM, 2015)

The European Society of Breast Cancer Specialists - EUSOMA

The EUSOMA selected in 2008 the main process and outcome indicators for quality assurance of breast cancer care based on international literature (Del Turco et al., 2010). These indicators are categorized per process phase:

- Diagnosis
 - Appropriate diagnostic techniques in the right moment and with a certain specificity
- Surgery and loco-regional treatment
 - Proportion DCIS patients with one surgery; axillary clearance, radiotherapy after BCT and avoidance of overtreatment
- Systematic treatment
 - Appropriate chemotherapy and hormonotherapy
- Staging, counselling, follow-up and rehabilitation
 - Appropriate staging procedure, follow-up and availability of nurse counselling

3.1.2 Quality of Life in survivors

Quality of life (QOL) studies in breast cancer survivors were used to find important factors in treatments' experience.

General aspects influencing QOL

De Kok et al., (2007) aimed at developing a questionnaire for determination of quality of care in breast cancer patients. In their study six clusters were developed ordered to perceived importance: time schedule; education; focus on the patient; continuity of care; respect for the patient; period of admission. These aspects included for instance: information provision, time between follow-up consultation and the ability of getting results at scheduled appointments. The three clusters that were perceived as most important, i.e. time schedule, education and focus on the patient, were considered in development of the conceptual framework.

Further review of QOL literature was specified towards the treatment process and differences in survivors: type of surgery, younger breast cancer patients and several symptoms, as these aspects stood out in the overall QOL studies.

Type of surgery: Breast conserving therapy or mastectomy

Janni et al. (2001) evaluated the effect on quality of life in patients that underwent mastectomy and patients treated with a breast conserving therapy. Using EORTC QLQ-C30 questionnaire the following aspects were perceived more positively after breast conserving therapy: cosmetic result, physical appearance, emotional stress by physical appearance and the opinion on the decision of treatment (Janni et al., 2001). Engel, Kerr, Schlesinger-Raab, Sauer, & Holzel (2004) and Al-Ghazal, Fallowfield, & Blamey

(2000) concluded that breast conserving therapy should be encouraged based on patient satisfaction. In addition as no significant difference in survival was identified after mastectomy or breast conserving therapy in small breast cancers, van Dongen et al., (2000) and Veronesi et al. (2002) also recommended the use of breast conserving surgery in small tumours.

Since patients experienced less fear of recurrence after a mastectomy (Janni et al., 2001), sometimes a mastectomy is the preferred treatment option. In some cases mastectomy will be the only option in which, according to Jagsi et al. (2015), a direct reconstruction should be considered because it showed similar cosmetic satisfaction compared to breast conserving surgery.

Based on these literature the use of breast conserving therapy seems to create better health outcomes then only mastectomy in terms of physical appearance and emotional stress.

Younger breast cancer patients

In younger breast cancer patients fertility is an important factor that could affect the experience of quality of treatment. Howard-Anderson, Ganz, Bower, & Stanton (2012) and Gorman, Su, Roberts, Dominick, & Malcarne (2015) showed fertility and menopause-related concerns are related with a lower QOL in breast cancer survivors aged 50 years or younger. Information and discussing of these concerns should help in reduce these concerns. Thus a qualitative breast cancer process should provide patients with information about fertility and menopausal effects and the available (treatment) options.

Symptoms

Kwan et al. (2002) studied prevalence and impact on QOL of chronic arm morbidity. Dysfunctionality of the arm had a negative impact on QOL after breast cancer treatment (Kwan et al., 2002). Mols, Vingerhoets, Coebergh, & van de Poll-Franse (2005) reviewed QOL in long-term breast cancer survivors, in which arm injury was mentioned often as a negative impact on QOL. Other symptoms such as pain, fatigue, loss of appetite also affected QOL after breast cancer treatment (Engel et al., 2004; Goedendorp et al., 2012; Ivanauskienė, Rugilė, Kregžytė, Rima, Padaiga, 2010). Since these symptoms showed their relevance towards QOL, measuring these aspects is relevant for measuring health outcomes.

3.2 Interview with experts

A first conceptual framework based on the literature review was discussed, as described in the methods section with internal and external experts. In the following section the included experts and their expertise are presented, besides a short description of the meeting is given.

Dr. G.S. Sonke – works at the medical oncology department of the AVL (internist), he has history at IKNL and is connected to A. de Raaf with whom he described a small list of outcome indicators some years ago. He was the first medical expert that described his perspective towards the quality indicators that were described and provided valuable input onto the use of case mixes in the operationalization phase and described some indicators that should be included, i.e. use of mammaprint; multidisciplinary work process; duration of chemotherapy; participation in European and international research projects and neutropenia as a short term complication. In addition he helped in determination of some indicators, i.e. availability of NACT, use of mammaprint, recurrence, waiting time. Finally he referred us to A. de Raaf for the small list of outcome indicators.

Dr. A. de Raaf – works at IKNL as a board advisor. In an interview by phone he described some ongoing researches towards quality of breast cancer care and shared his ideas on the literature of Michael Porter, i.e. measuring costs by time driven activity based costing. Finally he shared the limited list of indicators: Overall survival, dysfunctionality of arm, breast conserving vs mastectomy, recurrence, treatment according to guidelines, treatment in clinical trials and the percentage of direct reconstruction.

Dr. M.T.F.D Vrancken-Peeters – works as an oncologic surgeon at the AVL, she has history in quality of healthcare at the Dutch association for surgery and is currently involved in NBICA and the development of PROMS by ICHOM. She was involved after some first conceptual versions of the framework. EUSOMA was introduced EUSOMA as an additional commission that was worth to include and besides she gave her feedback on several indicators that were not operationalized in a clinically correct way, i.e. recurrence, irradiability, NACT, long term complications, MARI and Breast conserving therapy versus mastectomy.

Drs. S. van Soelen – is vice-president of the Breast cancer association Netherlands (BVN) and works as a strategic policy advisor innovation at Achmea, insurance company. Besides she is a former breast cancer patient. She was involved during the selection of indicators that should be included in the survey towards the patients perspective. She missed one indicator in the final conceptual framework, experience of a hospital, which was therefore included in the survey. In addition she shared her opinion towards the survey design allowing us improving it to a more understandable questionnaire. With her help the survey was published on the website of the breast cancer society for patients.

J. Rimmelzwaal – works as a clinical project manager at the AVL. She is involved in the breast cancer process within the AVL and deals with the Consumer Quality Index (CQI). She was involved in the operationalization of the patient-centred quality indicators. The meeting resulted in valuable information towards the possibilities of QOL and CQI questionnaires and the current results of the CQI lists. Based on this information options for operationalization were defined.

M. van Schaik – is a healthcare agent at the AVL and is responsible for the relations with the insurance companies and selling healthcare of the AVL to insurers. Before, he was working at an insurance company, VGZ, as a healthcare purchaser. He was involved in the end of the project and shared his perspective and ideas towards the development of the framework. He contacted employees of VGZ that were willing to participate in the project.

3.3 Final conceptual framework quality indicators breast cancer

In this section the final conceptual framework is presented. First a limited overview is given in table 1. In which the identified outcome indicators are presented according to the six defined categories of quality. In the full framework, table 2, each outcome indicator is accompanied with a motivation for determination, options of operationalization, whether the indicator is already acknowledged as an indicator and finally the tier and level according to the model of Porter (2010).

3.3.1 Limited overview of indicators

In total 25 outcome indicators were created categorized to the six categories of quality: survival, complications, timeliness, effectiveness, patient centeredness and degree of health.

1. Survival	Survival (OS)	5. Patient centeredness	Patient empowerment
	Irradicality		Fertility information
	Recurrence		Treatment information
2. Complications	Short term complications		After care information
	Long term complications	6. Degree of health	Arm functionality
3. Timeliness	Process time		Pain
	Waiting time		Fatigue
4. Effectiveness	NACT		Loss of appetite
	MARI		Physical appearance
	Breast contour saving		Recovery time
	Mammaprint		
	Duration chemo		
	Multidisciplinary process		
	Awareness and application of current research		
	Innovative		

Table 1 – Summarized view of the conceptual framework of quality indicators.

3.3.2 Conceptual overview quality indicators

Table 2 shows a more extensive overview of the 25 outcome indicators.

#	Quality Indicator	Type of indicator	Motivation to determine	Operationalization	Already acknowledged	Tier (level)
Category 1: survival						
1	Overall survival	Outcome	- Efficacy (insurer, patient, society) - Experience of treatment process (patient)	# breast cancer patients that survived 2, 5 and 10 years / # all breast cancer patients for each time interval (2,5,10) Case mix: - Stage - Age - Social economic status - Subtype - Comorbidity	Already registered via IKNL Could be possible to assess national numbers	1 (1)
2	Irradicality	Outcome	- Efficacy and efficiency (insurer, patient, society) - Experience of treatment process (patient) - Safety (insurer, patient)	# irradical patients within 4 weeks after surgery / # all patients with breast cancer surgery in one year Case mix:	Already registered on national level, but not as an outcome indicator	1 (2)

				• # Mastectomy / # BCT • Stage • Subtype		
3	Recurrence	Outcome	• Efficacy and efficiency (insurer, patient, society) • Experience of treatment process (patient)	Per time unit: # patients with recurrent breast cancer / # breast cancer patients Case mix: • Mastectomy / BCT • Stage • Subtype	Already registered internally at AVL. In future on national level.	3 (1)
Category 2: complications						
4	Long term complications	Outcome	• Efficacy and efficiency (patient, insurance) • Safety (patient)	Per time unit: • # patients with heart damage after radiation / # patients treated with radiation. • # patients with heart damage after chemotherapy / # patients treated with chemotherapy. • # patients with inflamed lung tissue after radiation / # patients treated with radiation. • # patients with brachial plexopathy / # patients treated with radiation. • # patients with osteoporosis / # patients treated with hormonal therapy • Earlier menopause / # pre-menopausal patients treated with hormonal therapy	Already registered internally if toxicity reaches a determined level. Data of EPD could be extracted.	3 (2)
5	Short term complications	Outcome	Patient satisfaction: • Efficacy • Efficiency • Safety	Per time unit: • # patients with wound infections / # patients that had surgery • # patients with wound healing problems after surgery / # patients with breast cancer surgery • # patients with neutropenia / # patients that were treated with chemotherapy	Not registered in this moment. Could be measured during control appointments	2 (2)
Category 3: Timeliness						
6	Process time	Process	Patient satisfaction: • Experience of treatment process • Efficiency	• Average time from first appointment to diagnose (cancer/ no cancer) • Average time from diagnose cancer (1-0 result) to decision cancer is curable or not.	In NBCA list: Time from diagnose (cancer/no cancer) to start treatment Others not yet.	–

				• Average time from diagnose (cancer/no cancer) to start treatment		
7	Waiting time	Process	Patient satisfaction: • Experience of treatment process • Efficiency	• Average time it takes from first discovery of breast cancer to first appointment • Average time from first appointment to diagnose (cancer/ no cancer) • Average time from diagnose (cancer/no cancer) to start treatment	Currently not registered in this way.	–
Category 4: Effectiveness						
8	Neoadjuvant chemotherapy	Process	• Efficacy (patient, insurer) • Creates time to decide on type of surgery (patient)	# NACT / # Breast cancer patients T2–T4 / N1 – N3 (grade IIB, IIIA, IIIC, IV)	Currently in NBCA	–
9	MARI procedure provided	Process	• Functionality arm (patient, insurer, society) • Pain (patient)	# MARI is used / # patients with positive lymph nodes (N1 – 3) • Combine to functionality of arm	Currently not registered	–
10	Breast contour saving	Outcome	Patient satisfaction • Physical appearance • Less emotional stress	• # BCT of patients after NACT treatment / Patients with NACT treatment • # patients direct reconstruction after mastectomy / Patients that undergo ablation • # patients BCT / # patients that were treated locally	Currently in NBCA: • BCT in invasive BC • BCT in DCIS BC	1 (2)
11	Mammaprint to avoid chemotherapy	Process	• Less symptoms (patient, insurer) • Reduced recovery time (patient, insurer, society)	% patients that were treated with chemotherapy in patients with breast cancer T2 or higher and N1–3 that received mammaprint Combine to recurrence	Internal registration; could be extracted from EPD data.	–
12	Duration of chemotherapy	Process	• Less symptoms (patient, insurance) • Reduced recovery time (patient, insurance, society)	Average # cycles of chemotherapy that are given in patients receiving any chemotherapy. Connect to % recurrence in chemotherapy patients and use of mammaprint Casemix: • Age • Stage • Subtype	Not registered in this moment	–
13	Multidisciplinary work process	Process	• Trust in treatment (patient, insurer) • Experience of treatment (patient)	Possibility of CQI or standard questionnaire in patients about their experiences in specialists collaboration, sharing information and discussing treatment procedures.	In NBCA list: • Prior to treatment MDO with digital report. • After treatment: MDO with digital report.	–

14	Awareness and application of current research	Process	• Experience of treatment (patient) • Image of organization (institution)	• # clinical trials in BC in which patients could participate in. • # patients that participate in scientific research studies within the institution/ # all patients with diagnosed invasive BC • # of collaborations within European and international committees	In Pink ribbon NABON criteria	–
15	Innovative	Process	• Latest treatment possibilities (patient and insurance) • Ahead of its time (patient)	• # of adjustments in BC process or new treatment and/or new diagnosis options, implemented in current practice last year • # articles published by the institution about diagnose and treatment in breast cancer in one year • # of hours that were spent on research to treatment and diagnose options in breast cancer on average per week / # hours of medical tasks on average per week	• Staff registration • Research registrations	–
Category 5: Patient centeredness						
16	Patient empowerment	Process	Patient satisfaction and insurance: • Engagement • Experience of treatment	Patient reporting after treatment process in survey	CQI list and pink ribbon	–
17	Fertility information	Process	Patient satisfaction • Less concerns • Risk decrease depression • Engagement	Patient reporting after treatment process in survey	Not yet. Possibility in CQI?	–
18	After-care information	Process	Patient satisfaction and interesting for insurance • Engagement • Experience of treatment process	Patient reporting after treatment process in survey	CQI list	–
19	Treatment information	Process	Patient satisfaction and interesting for insurance • Engagement • Experience of treatment process	Patient reporting after treatment process in survey	CQI list and pink ribbon	–
Category 6: Degree of health						
20	Arm functionality	Outcome	• Functionality (patient, insurance, society) • Pain (patient)	• Swollenness (cm outline of affected arm vs unaffected arm) • Pain (VAS) in the arm at control appointments	Use QLQ BR23 or BR30	3 (1)
21	Pain	Outcome	Patient satisfaction • Functionality	VAS after treatment at control appointments	Use QLQ BR23 or BR30	2 (2)

22	Fatigue	Outcome	Patient satisfaction: • Energy	FSS, KSS or VAS after treatment at control appointments	Use QLQ BR23 or BR30	2 (2)
23	Loss of appetite	Outcome	Patient satisfaction: • Normal nutrition • Energy	VAS score at control appointment or SNAQ/CNAQ	Use QLQ BR23 or BR30	2 (2)
24	Physical appearance	Outcome	• Less distress (patient) • Less emotional stress (patient) Eventually also interesting towards insurance company	Body image scale / Questions 39 – 42 from QLQ-BR23	Use QLQ BR23 or BR30	1 (2)
25	Recovery time	Outcome	• Less risk on depression (patient) • Efficiency (patient, insurance and society)	• # patients that started to work after 3 to 6 months (second/third control appointment) # patients that worked full- or part time before diagnosis (anamneses) • # patients that work full time after 3 to 6 months and 6 months to 1 year / patients that worked full time before diagnosis. (anamneses)	Not registered in this moment	2 (1)

Table 2 – Final conceptual framework of quality indicators.

3.4 Outcome indicators per perspectives

Since operationalization of these 25 indicators and comparison between hospitals is not that simple we aimed at developing top lists that showed the most relevant aspects in three perspectives. These top lists were based on the results of literature review and interviews with experts. In each overview several indicators are presented with its operationalization, indicator category and level and tier according the hierarchy of Porter (2010). The results of the patients survey and interview with the insurance company are presented in the paragraphs that are dealing with the correlating perspective.

3.4.1 Patients perspective

In patients perspective two tables are presented towards breast cancer stage, as it was assumed that relevance of the outcome indicator was influenced by breast cancer tumour stage. The indicators in table 3 and 4 are most relevant out of the patients perspective, that focussed to the following question: What quality indicators are most important out of a patient perspective when it comes to quality of treatment and therefore a positive experience of delivered care?

Breast cancer tumour stage I and II

Table 3 shows six outcome indicator that were considered as relevant in breast cancer stage I and II. Although these tumour stages have a relatively high prognosis, still all the aspects of survival are assumed to be important. In addition the long term complications and recovery time were seen as relevant because of the good prognosis and life expectancy. The final indicator, patient empowerment based on sufficient information provision, contributes to making the right decisions in treatments process and thus benefits the experience of the treatment.

#	Indicator	Category	Operationalization (all per unit of time)	Tier (level)
1	Overall survival	Survival	# breast cancer patients that survived 2, 5 and 10 years / # all breast cancer patients for each time interval (2,5,10) Case mix: Stage; Age; Social economic status; Subtype; Comorbidity	1 (1)
2	Irradicality	Survival	# irradical patients within 4 weeks after surgery / # all patients with surgery in treatment process in one year Case mix: # Mastectomy / BCT; Stage; Subtype	2 (2)
3	Recurrence	Survival	Per time unit: # patients with recurrent breast cancer/ # breast cancer patients Case mix: Mastectomy / BCT; Stage; Subtype	3 (1)
4	Long-term complications	Complications	Per time unit: # patients with heart damage after radiation / # patients treated with radiation. # patients with heart damage after chemotherapy / # patients treated with chemotherapy. # patients with inflamed lung tissue after radiation / # patients treated with radiation. # patients with brachial plexopahty / # patients treated with radiation. # patients with osteoporosis / # patients treated with hormonal therapy Earlier menopause / # pre-menopausal patients treated with hormonal therapy	3 (2)
16	Patient empowerment	Patient centeredness	Patient reporting after treatment process in survey about information provision and involved in decision making.	–
24	Recovery time	Degree of health	# patients that started to work after 3 to 6 months (second/third control appointment) # patients that worked full- or part time before diagnosis (anamneses) # patients that work full time after 3 to 6 months and 6 months to 1 year / patients that worked full time before diagnosis. (anamneses)	2 (1)

Table 3 – Outcome indicators considered as most relevant in patients perspective towards breast cancer tumours stage I and II.

Breast cancer tumour stage III and IV

Table 4 shows six outcome indicators that were considered as relevant in breast cancer stage III and IV. Survival and recurrence seemed also important, however irradicality was less important as we assumed survival, no matter what, is their main concern. Waiting time, information and patient empowerment were considered as important as these aspects reduced concerns and allow some control and preparation on unexpected turns within the treatment plan. Finally long-term complications were considered as important since the survival rate is still relatively high.

#	Indicator	Category	Operationalization (all per unit of time)	Tier (level)
1	Overall survival	Survival	# breast cancer patients that survived 2, 5 and 10 years / # all breast cancer patients for each time interval (2,5,10) Case mix: Stage; Age; Social economic status; Subtype; Comorbidity	1 (1)
3	Recurrence	Survival	Per time unit: # patients with recurrent breast cancer/ # breast cancer patients Case mix: Mastectomy/BCT; Stage; Subtype	3 (1)
4	Long-term complications	Complications	Per time unit: # patients with heart damage after radiation / # patients treated with radiation. # patients with heart damage after chemotherapy / # patients treated with chemotherapy. # patients with inflamed lung tissue after radiation / # patients treated with radiation. # patients with brachial plexopathy / # patients treated with radiation. # patients with osteoporosis / # patients treated with hormonal therapy Earlier menopause / # pre-menopausal patients treated with hormonal therapy	3 (2)
6	Waiting time	Timeliness	Average time it takes from first discovery of breast cancer to first appointment; Average time from first appointment to diagnose: Cancer/ no cancer; Average time from diagnose (cancer/no cancer) to start treatment	–
15	Patient empowerment	Patient centeredness	Patient reporting after treatment process in survey about information provision and involved in decision making.	–
18	Treatment information	Patient centeredness	Patient reporting after treatment process in survey	–

Table 4 – Outcome indicators considered as most relevant in patients perspective towards breast cancer tumours stage III..

Survey patient perspective

This section presents the main results of the survey in patients.

General information

In total twenty-three female patients filled in the questionnaire with a median age between 40 and 49. The majority, ten patients, was treated more than a year ago and saw themselves as a breast cancer survivor. Five respondents described a breast cancer of stage I, five stage II and nine of stage III. Four respondents filled in that they did not know the breast cancer stage. sixteen of the twenty-three patients were treated in a regional hospital.

Most important aspect of quality

As shown in figure 5 the most relevant aspects in the total population were: information provision, waiting time between diagnose and treatment, number of treatments performed (experience), patient empowerment, cosmetic result of local treatment, preventing of overtreatment with chemotherapy, functionality of the arm and chance on long-term complications. Recovery time was the only aspect that was not chosen as a relevant aspect. Possibility of NACT and irradiation rate were chosen two times. Recurrence rate by three respondents. Five respondents chose: the possibility of direct reconstruction, survival rate and the possibility of participating in clinical trials.

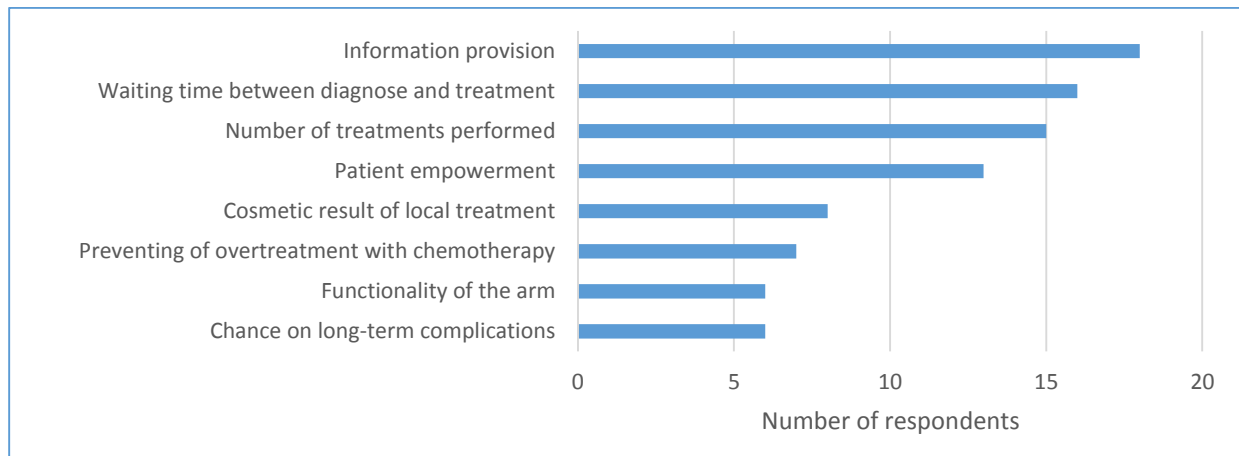


Figure 5 – Aspects reported as important out of the fifteen given indicators in the complete population (n=23)

In the ten respondents that described breast cancer stage I or II, the following aspects were considered as important: information provision (n=8), number of treatments performed (n=8), waiting time (n=7), patient empowerment (n=6). Three respondents chose: long term complication and cosmetical result. Two chose survival, the functionality of the arm, preventing of overtreatment and the possibility of direct reconstruction.

In the nine respondents that described breast cancer stage III the following aspects were considered as important: information provision (n=7), waiting time between diagnose and treatment (n=6) and number of treatments performed (n=5), four patients chose: preventing of overtreatment with chemotherapy, cosmetic result of local therapy and patient empowerment. Three respondents chose survival rate and long term complications and two chose the possibility of participation in a clinical trial and the functionality of the arm.

Less important aspects of quality

As shown in figure 6 the aspects that were less important according to the survey were: recovery time, recurrence rate, possibility of direct reconstruction, cosmetic results, possibility of NACT, irradiability rate, possibility of participation in clinical trials and I don't know. The following aspects were chosen by three respondents: survival rate, information provision, functionality of the arm, chance on long-term complications, number of treatments performed, waiting time between diagnose and treatment and preventing overtreatment with chemotherapy. Only two respondents chose patient empowerment.

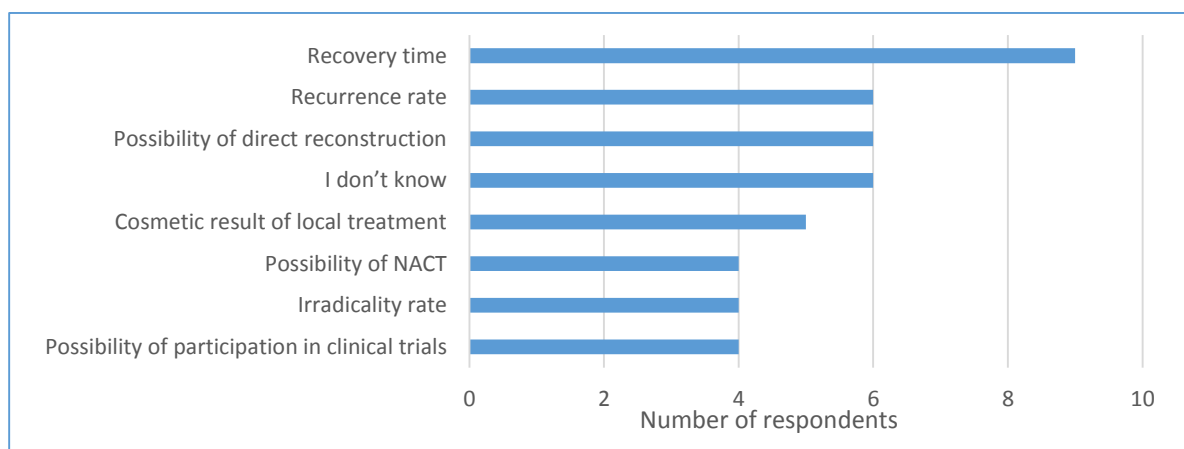


Figure 6 – Aspects reported as less important out of the fifteen given indicators in the complete population (n=23)

In the ten respondents that described breast cancer stage I or II, the following aspects were considered as less important: irradiability, recovery time and recurrence (n=4), survival, possibility of treatment with neoadjuvant chemotherapy and I don't know (n=3). Finally waiting time between diagnose and treatment and the possibility to participate in a clinical trial were chosen by two respondents.

In the nine respondents that described breast cancer stage III the following aspects were considered as less important: possibility of direct reconstruction (n=5), recovery time (n=4) and cosmetic result of local treatment (n=3). Three respondents chose the option I don't know.

Priority of aspects per category

In the first category, survival, survival rate was chosen over recurrence by twenty-one respondents and over irradiability by twenty-two respondents, recurrence was chosen over irradiability by twenty respondents. Thus priority in this category was: survival rate, recurrence rate, irradiability rate.

The analysis per subtype showed the same priority.

The second category, treatment results, showed the following priority: chance on long-term complications, arm functionality, cosmetic result and recovery time. Since long-term complications was chosen over arm functionality by eighteen respondents, twenty-two respondents chose arm functionality over cosmetic result and finally thirteen respondents chose cosmetic result over recovery time.

Analysis to breast cancer stage I and II presented the same priority. In breast cancer stage III and IV it showed a slightly different priority: chance on long-term complications, arm functionality, recovery time and cosmetic result.

The third category, treatment aspects, showed no clear priority, since some indicators showed a similar level of importance. However by comparing all aspects together we could conclude on a final priority: number of treatments performed, preventing overtreatment with chemotherapy, possibility to receive NACT, possibility to participate in clinical trials and finally the possibility of direct reconstruction after ablation.

Analysis to breast cancer stage I and II showed a slightly different priority: preventing overtreatment with chemotherapy followed by number of treatments performed, possibility to receive NACT, possibility of direct reconstruction after ablation and finally the possibility to participate in clinical trials. Analysis in breast cancer stage III and IV showed also a different priority: number of treatments performed, preventing overtreatment with chemotherapy, possibility to receive NACT, possibility of direct reconstruction and possibility of participation in clinical trials.

The final category, experience of treatment, showed no clear priority since information provision was chosen over patient empowerment (n=14), patient empowerment over waiting time (n=12) and waiting time over information provision (n=12).

Analysis to breast cancer stage I and II showed that information provision was considered more important than patient empowerment and waiting time, but no difference was presented between patient empowerment and waiting time. Analysis in breast cancer stage III and IV showed no distinctive priority.

Additional important quality aspects (closed)

As shown in figure 7 the aspects that were considered as important out of the additional presented aspects were: multidisciplinary work process, waiting time on diagnostic results, cooperation between different hospitals, information provision on after treatment, the innovative image of the hospital, short term complications and information provision about fertility. Seven respondents chose insomnia after treatment and six chose pain after treatment. Only one respondent chose a loss of appetite and one "I don't know".

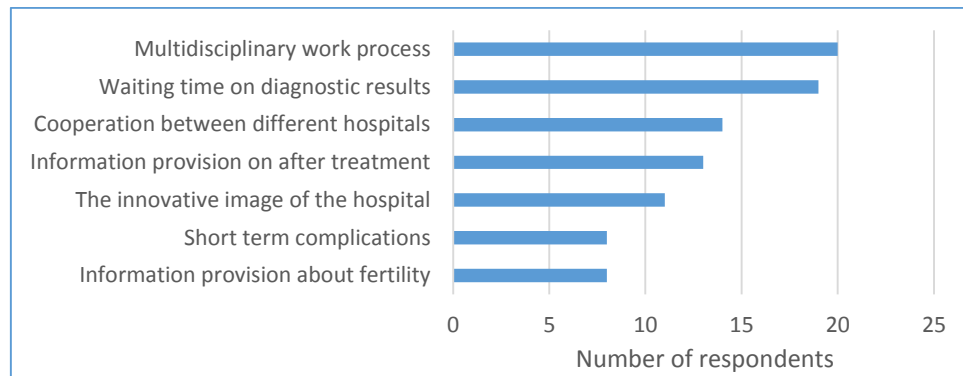


Figure 7 – Aspects reported as important out of the additional presented indicators in the final part of the survey. (n=23)

Additional important quality aspects (open)

In the final question respondents were asked to describe any additional aspect that they considered as important in describing quality of breast cancer treatment. The following aspects should be investigated further on its appropriateness and importance:

- Information on demand to receive the quantity of information that you want
- Information about radiotherapy, sexuality, chemotherapy and their side effects and information on long term effects
- Information provision by the hospital to the working place of the patient.
- That hospitals also recommend other hospitals if that would be the best option
- One healthcare professional that is responsible during the whole treatment process and thus one contact person for the patient.
- Distance to the hospital
- Image of the hospital

Comparison of the outcome indicators

The aspects that were considered as important shown in table 3 and 4 were not similar to the results in the survey.

Breast cancer tumour stage I and II

Table 3 presented the following aspects as important: overall survival, irradicality, recurrence, long-term complications, patients empowerment, recovery time. The survey supported operationalisation of patient empowerment but none of the other aspects of table 3. Contrary, provision of information, number of performed treatments and waiting time showed their importance.

Following the priority lists overall survival would be the most important aspect in the category survival. In the other categories the following aspects were perceived as most important: chance on long-term complications, arm functionality, preventing overtreatment with chemotherapy, number of performed treatments and information provision. These indicators reflected some of the aspects that were chosen as important in the first part of the survey. Therefore it is suggested to operationalize the following seven aspects in tumour stage I and II: overall survival, chance on long-term complications, arm functionality, preventing of overtreatment in chemotherapy, number of performed treatments, information provision and patient empowerment.

This set of indicators included aspects towards tier one level one (survival) and the two levels of tier three (sustainability or health over time and long-term consequences of therapy). However no aspect was included that operationalized tier two.

Breast cancer tumour stage III

Table 4 presented the following aspects as important: overall survival, recurrence, long-term complications, waiting time from diagnose to treatment, patient empowerment and information provision. The survey supported operationalization information provision, waiting time between diagnose and treatment but none of the other aspects of table 4. Contrary the number of treatments performed, prevention of overtreatment with chemotherapy, cosmetic result and patient empowerment were described as important.

Following the priority lists, the following aspects were perceived as most important: overall survival, recurrence, chance on long-term complications, arm functionality, number of performed treatments and preventing overtreatment with chemotherapy. As none of these six aspects were described as less important it was suggested to operationalize nine aspects as we included information provision, waiting time and patient empowerment that were described as important in the first part of the survey. The final aspects are: overall survival, recurrence, chance on long-term complications, arm functionality, number of treatments performed, preventing overtreatment with chemotherapy, waiting time, information provision and patient empowerment.

This set of indicators included aspects towards the two levels of tier one (survival and degree of recovery), and the two levels of tier three (sustainability or health over time and long-term consequences of therapy). However no aspects were included that operationalized tier two.

3.4.2 Insurance company perspective

In this section one table presents outcome indicators that were considered as most relevant towards the insurance perspective. It focusses to the following question: What quality indicators would be most important for an insurance company to make sure that their members get qualitative breast cancer treatment? Afterwards the results of the interview with VGZ are described whereafter the outcome indicators from table 5 are compared with the results of the interview.

Insurers perspective

Table 5 shows six outcome indicators that were considered as relevant out of the insurance perspective. As the insurer is mainly interested in good healthcare to a good price, each indicator of survival was perceived as important. Long-term complications and a long recovery time were also considered as important as these conditions could result in additional healthcare costs. Finally the ability of direct reconstruction after mastectomy was assumed to reduce infection risks and increase efficiency of the process. As this overview included an indicator on each level of the model of Porter (2010) it would be considered as an ideal set of outcome indicators.

#	Indicator	Category	Operationalization (all per unit of time)	Tier (level)
1	Overall survival	Survival	# breast cancer patients that survived 2, 5 and 10 years / # all breast cancer patients for each time interval (2,5,10) Case mix: Stage; Age; Social economic status; Subtype; Comorbidity	1 (1)
2	Irradicality	Survival	# irradical patients within 4 weeks after surgery / # all patients with surgery in treatment process in one year Case mix: # Mastectomy / BCT; Stage; Subtype	2 (2)
3	Recurrence	Survival	Per time unit: # patients with recurrent breast cancer/ # breast cancer patients Case mix: Mastectomy / BCT; Stage; Subtype	3 (1)
4	Long-term complications	Complications	Per time unit: # patients with heart damage after radiation / # patients treated with radiation. # patients with heart damage after chemotherapy / # patients treated with chemotherapy. # patients with inflamed lung tissue after radiation / # patients treated with radiation. # patients with brachial plexopahty / # patients treated with radiation. # patients with osteoporosis / # patients treated with hormonal therapy Earlier menopause / # pre-menopausal patients treated with hormonal therapy	3 (2)
9	Breast contour saving	Effectiveness	# patients direct reconstruction after mastectomy / Patients that undergo ablation	1 (2)
24	Recovery time	Degree of health	# patients that started to work after 3 to 6 months (second/third control appointment) # patients that worked full- or part time before diagnosis (anamneses) # patients that work full time after 3 to 6 months and 6 months to 1 year / patients that worked full time before diagnosis. (anamneses)	2 (1)

Table 5 – Outcome indicators considered as most relevant out of an insurance perspective.

Insurance company VGZ interview

The interview was held with S. van Es, an employee of insurance company VGZ. It was a general interview towards quality of care, however some interesting aspects were discussed. In this section the main results are described.

Guarantee quality of care – VGZ vision

VGZ presents three levels of information that are used to contract qualitative healthcare providers and in that way provide qualitative and affordable healthcare to their customers. The first level, patient level, includes patient-centeredness and health outcomes perceived by the patient. The second level, clinical level, includes health outcomes that were perceived by the clinician or healthcare provider and the final level focusses on costs and provision of effective healthcare, the systematic level. Insurers want to contract good, qualitative and even innovative care but not at all costs as premiums have to be low enough to attract patients. In respect of that the balance between quality of health care and its costs is very relevant.

Registration of VGZ in this moment

Currently VGZ presents clinical quality to its patients on a website to compare different hospitals. The following indicators are included to describe clinical quality per institution: participation to national registration, number of patients that are operated in one year (minimal 100 per year), percentage invasive breast cancer tissue that remained after surgery (max 10%), percentage of DCIS tissue that remained after surgery (max 30%), receiving the pink ribbon certificate, waiting time between diagnose and chemotherapy and waiting time between diagnose and surgery (minimal 90% gets treatment or surgery within 5 weeks).

Suggested outcome indicators on patients and clinical level

S. van Es described several outcome indicators of interest. The following aspects would preferably be operationalized on the patients level: information provision, patient empowerment, communication towards the patient, patients experience of cooperation within the medical team, recommendation of the hospital, experience of treatments effect and the experienced complications.

In addition recovery time, complications, survival and irradicality would be interesting to measure at a clinical level. In all of these indicators case mix is important to create comparable outcomes, however the possibility of registration bias should be taken into account as measurement mainly takes place at the hospital.

Comparison of the outcome indicators

Since the interview was not focused towards outcome indicators, comparison with the table of outcome indicators was difficult. Thus the following results should be handled with care.

During the interview the majority of the outcome indicators that were presented in table 5 were described: overall survival, irradicality, recurrence, long-term complications and recovery time. In addition the patients perspective was more important than expected based on literature and interviews with experts. The eventual set of outcome indicators should include at least two indicators towards patients experience of treatment. Because no specific outcome indicators were discussed it was not possible to describe the two most relevant indicators that should be included.

This indicator set included aspects on both levels in tier one, level one in tier two and both levels in tier three.

3.4.3 Societal perspective

In this section one table (table 6) presents outcome indicators that were considered as most relevant out of the societal perspective. It focussed to the following question: What quality indicators are most important for internal evaluation of the quality status of the care that is delivered to their patients? Verification was not conducted in this perspective, thus no further analysis is presented.

Societal perspective

Table 6 shows six outcome indicators that were considered as important out of a societal perspective. The total survival category was included as it affects healthcare costs and shows effectiveness. Recovery time and arm functionality were included as these have an effect on the labour market and thus on national economy. The final indicator, long-term complications was considered as relevant since these could result in extra costs and delay in recovery. In this overview only level two of tier one was not operationalized, which made it almost an ideal overview.

#	Indicator	Category	Operationalization (all per unit of time)	Tier (level)
1	Overall survival	Survival	# breast cancer patients that survived 2, 5 and 10 years / # all breast cancer patients for each time interval (2,5,10) Case mix: Stage; Age; Social economic status; Subtype; Comorbidity	1 (1)
2	Irradicality	Survival	# irradiated patients within 4 weeks after surgery / # all patients with surgery in treatment process in one year Case mix: # Mastectomy / BCT; Stage; Subtype	2 (2)
3	Recurrence	Survival	Per time unit: # patients with recurrent breast cancer/ # breast cancer patients Case mix: Mastectomy / BCT; Stage; Subtype	3 (1)
4	Long-term complications	Complications	Per time unit: # patients with heart damage after radiation / # patients treated with radiation. # patients with heart damage after chemotherapy / # patients treated with chemotherapy. # patients with inflamed lung tissue after radiation / # patients treated with radiation. # patients with brachial plexopathy / # patients treated with radiation. # patients with osteoporosis / # patients treated with hormonal therapy Earlier menopause / # pre-menopausal patients treated with hormonal therapy	3 (2)
19	Arm functionality	Degree of health	Swollenness (cm outline of affected arm vs unaffected arm) Pain (VAS) in the arm at control appointments	3 (1)
24	Recovery time	Degree of health	# patients that started to work after 3 to 6 months (second/third control appointment) # patients that worked full- or part time before diagnosis (anamneses) # patients that work full time after 3 to 6 months and 6 months to 1 year / patients that worked full time before diagnosis. (anamneses)	2 (1)

Table 6 – Outcome indicators considered as most relevant out of a societal perspective.

4. Conclusion and discussion

The aim of this project was to determine outcome indicators that could be used to describe value of the provided breast cancer treatment towards, patients, insurers and societal perspective. A final conceptual framework of outcome indicators was described based on literature review towards quality of life, already acknowledged sets of indicators and experts' opinions. This chapter is presenting a conclusion and discussion on the results.

4.1 Conclusion

Within this project we aimed to answer the following research question: Which outcome indicators should be operationalized according to recent literature, patients and experts to describe the outcome, quality, of breast cancer treatment towards patients, insurers and societal perspective?

Based on our results, discussed in the previous chapter, we suggest aspects that are relevant to operationalize out of a patients, insurers and societal perspective. Since the patients perspective was divided towards breast cancer stage two lists of possible outcome indicators were designed. In breast cancer tumour stage I and II the following aspects are suggested:

- Overall survival
- Chance on long-term complications
- Arm functionality
- Number of treatments performed
- Preventing of overtreatment in chemotherapy
- Information provision
- Patient empowerment

In tumour stage III the following aspects are suggested:

- Overall survival
- Recurrence
- Chance on long-term complications
- Arm functionality
- Number of treatments performed
- Preventing overtreatment with chemotherapy
- Waiting time towards treatment
- Information provision
- Patient empowerment

Multidisciplinary work process and waiting time on diagnostic results were also described as important, and therefore could be included in the final indicator lists out of a patient perspective.

Eventually the division in breast cancer stage showed no major differences since all the aspects that were presented in stage I and II were also described in stage III, however some additional aspects were described in stage III. These indicator sets included aspects on tier one and three but no aspects were included of tier two. The sets included both outcome and process indicators. In breast cancer stage I and II five out of seven indicators were considered as outcome indicators, assuming that information provision and patient empowerment could be operationalized on a patients level. In the second list seven out of nine were outcome indicators with the same assumption.

Out of the insurers perspective, overall survival, irradicality, recurrence, long-term complications, recovery time and two additional indicators on treatments experience should be operationalized. The final two indicators were not clearly described during the interview but it was evident that at least two indicators should be including the patients experience of the treatment. In these sets tier one, two and three were operationalized and it included only outcome indicators, assuming that the ones that are not specified could be operationalized on a patients level.

In societal perspective, only based on literature and interviews with experts, overall survival, irradicality, recurrence, long-term complications, arm functionality and recovery time should be operationalized to describe value of breast cancer treatment on a societal perspective. Thus, tier one, two and three were operationalized in this final indicator set consisting only out of outcome indicators.

4.2 Discussion

This practical assignment was an explorative research based on the concept of value based healthcare to outcome indicators applicable for breast cancer treatment. The concepts of Porter on VBHC were used since these are considered as fundamental to value based healthcare and was used frequently in other scientific literature and initiatives to describe VBHC even further.

Twenty-five indicators were identified that could be used to describe value of breast cancer treatment. In patients perspective we identified seven indicators in breast cancer stage I and II and nine indicators in breast cancer stage III. In the insurers perspective seven indicators were chosen whereas six indicators were described in the societal perspective.

The results of the survey and interview were in line with the results based on literature and interview with experts and value based healthcare. Although, especially in patients perspective the relevance of some indicators differed from our expectations based on literature and experts interviews. Since the societal perspective was not verified in the target population, it was not possible to compare it to our expectations.

Design of conceptual framework

The framework was systematically designed according to our definition of quality that was based on recent literature. Due to the limited time available for this project, review of literature was semi-structured since not all identified literature was read. Although, the first conceptual framework was discussed with experts on completeness and was supplemented according their suggestions which benefits the internal validity of the framework. Additionally the motivation for determination, in the separated column, is only based on literature that was identified and inputs of experts which was affected by interpretation of the researcher. Another limitation was the inclusion of process indicators as we aimed at identifying a conceptual framework of outcome indicators. Finally the major limitation in designing the framework was the limited input of clinical experts and late identification of some interesting indicator sets. As operationalization of several indicators seemed not to correlate with clinical practice and indicators about screening and diagnostics were not included as these already existing indicators and their relevance was discovered too late.

Survey and interview

Conclusions in the insurers perspective based on the interview should be interpret with care since it was a non-structured interview with an employee that was not involved in the development of outcome indicators nor was he an expert on breast cancer. Therefore, confirmation bias might be present. It was included in the results and conclusions as it gave insight to the insurers way of thinking which was used to conclude to the final indicators that should be operationalized.

The survey towards patients perspective was designed in consultation with supervisors, an expert in designing surveys at University Twente, and two members of the breast cancer association for patients. In order to generalize our results, general aspects were included in the beginning of the survey. To prevent misleading results caused by compulsory choice between options in the closed questions, options of "I do not know" or "other" were included. In the third part, in which respondents had to choose between two quality aspects, this was still at risk. However reliability of the results is limited as only twenty-three breast cancer, relatively young, survivors that only represented breast cancer stage I, II and III, responded to the survey which caused selection bias.

Another limitation was the choice of the fifteen included indicators as these were mainly chosen in consultation with one of the members of the breast cancer association for patients and were based on the final conceptual framework. To be as thorough as possible the other aspects that were considered as relevant were included in another set of questions however no definite conclusions could be described since these aspects were no part of the priority part of the survey.. Finally the appropriateness of analysing the results according to breast cancer stage could be discussed as this information seemed not always be provided to patients in current practice.

Recommendations

Our first recommendation would be to set up meetings in which the different perspectives are represented to discuss the appropriateness, feasibility and operationalization of the indicators within the conceptual framework. Involving clinical experts, insurance companies or governmental committees, clinical project managers and patients or a patients association that could represent the patients should therefore be considered. Additionally it would be interesting to continue an explorative research on the insurers and societal perspective as it will allow conclusion towards possible indicator sets in these perspectives.

Secondly, further investigation on costs would be required to conclude on value in the different perspectives. For this, costs should be defined in each perspective in which all breast cancer treatment costs, i.e. homecare, physical therapy, mental care, should be included. As this would be a very ambitious aim it is recommended to start by calculation the costs of the breast cancer treatment within the institution as this is the most feasible.

This explorative research showed a first conceptual framework of (outcome) indicators towards breast cancer treatment. Other initiatives that were already developed or are still in development were already described within this report. However, as there is still no final framework or set of indicators that could be used to determine health outcomes in breast cancer treatment, this conceptual framework and results of the survey in breast cancer patients and survivors is of added value.

Therefore this framework could be used as a starting point for the NKI-AVL, to operationalize some of the indicators internally and start the discussion about the appropriateness of the indicators with medical experts and other stakeholders. This could contribute to the improvement of breast cancer treatment and the attractiveness of patients towards the hospital.

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Appendices

Appendices literature review

Appendix 1 – Study characteristics

Author	Year	Subtype size per subtype	Age	Study design	Enrolled	Clinical stage	Monitoring technique	Monitoring interval	Last monitoring to surgery (mean)	Neoadjuvant therapy	Response definition monitoring	pCR definition (category)	pCR rate	AUC (95% CI)	Sens, Spec, NPV, PPV, Accuracy	Setting imaging
Charehbili (33)	2014	HER2 – (194); ER+ (187); ER- (35)	Mean 49 years; postmeno pausal (88); premenop ausal (146)	Retrospec tively	July 2010 – April 2012	II and III; T1:2; T2: 128; T3/4: 92; N-: 99; N+:123	DCE MRI 1.5 and 3.0 T	Baseline and after three cycles	Median: 20 days	TAC with (107) or without (R) (115) zoledronic acid	RECIST 1.1; >30% decrease of tumour size	Miller-Payne grade 5; II	17%	0.55 (0.45-0.65)	37%, 87%, 22%, 93%, 45%	DCE-MRI; 1.5 and 3.0T
Chen (34)	2008	HER2+ (25);	Mean 51 years (32-77)	Retrospec tively	July 2003 – April 2006	II (19); III (18); IV (14)	DCE MRI 1.5 T	Baseline, at least 2 follow-up during NACT	6-90 days (38 days)	1 st line: AC. 2 nd line: TCaH (17); AbCaH (7); TCaH + AbCaAv (1)	>30% decrease of tumour size and cases in which no enhanced tissues were visible	No residual invasive cancer; no residual malignancy; DCIS present; II	76%	-	83%, 95%, 95%, 83%, 92%	Philips 1.5 T MRI; breast coil (4 channel); Injection of Gadodiamide after 5 scans without contrast; 12 postcontrast sets for axial, bilateral, dynamic imaging: slices: 4mm; FOV: 32-38; matrix size: 256 x 128; 42 sec per acquisition
		HER2- (26)	Mean 48 years						20-64 days (40 days)	1 st line: AC. 2 nd line: TCA (20); AbCaAv (6)			35%		53%, 89%, 50%, 90%, 65%	
Coudert (47)	2014	HER2+ (142)	48 (median); postmeno pausal (46); premenop ausal (96)	Prospecti ve	May 2010 – Oct 2012	T2;N0-N1 (104) T3N0-N1 (38)	FDG-PET	Baseline, after one cycle	+/- max 16 weeks (surgery after 19 weeks)	1 st line: TH ; 2 nd line: Responders: continue 1 st line therapy. Non-responders: Randomized in 2:1 additional bevacizumab or not	≥ 70% ΔSUVmax considered as responder	Chevallier grade 1 and 2 and sataloff classification TA and NA or NB; I	45%	--	37%, 86%, 54%, 76%, 60%	-, fasted 6h before PET; 90 min after injection; 2-5MGq/kg; Procubitus position, whole body scan and decubitis position; acquisition: 10 min;
		HER2+ / ER- (58)											62% (24/39)		40%, 83%, 69%, 60%, 67%	
		HER2+ / ER+ (84)											35% (19/55)		36%, 89%, 43%, 87%, 55%	
Gebhart (48)	2013	HER2+/HR- (43)	-	Prospecti ve	Jan 2008 – May 2010	Metabolic lymph nodes (52) and	FDG-PET/CT	Baseline, week 2 and 6	+/- max 20 weeks (surgery in 4 weeks after last	(R) Lapatinib or Trastuzumab or both. All	After 2 weeks ≥ 15% reduction of SUVmax;	Absence of invasive cancer in the breast; II	61%	-	After 2 weeks: 27%, 88%, 65%, 60%, 64%	GE / Philips or Siemen PET/CT; fasted 6h before injection; 3.7 – 7.4 MBq/kg; scan at least 50 min after

		HER2+ / HR+ (34)				distant lesions (9)			admission of paclitaxel	received paclitaxel	after 6 weeks $\geq 25\%$		18%		After 2 weeks: 38%, 71%, 20%, 86%, 44%	injection; same scanner and parameters in each institution
Groheux (42)	2012	TN(20)	-	Prospective	Enrolled within 30 months	II (9) and III (11)	FDG-PET/CT	Baseline, after two cycles	NS	EC-D (14) or SIM (6)	$\geq -42\%$ Δ SUVmax and $\geq -50\%$ Δ SUVmax	No evidence of residual invasive cancer in both breast tissue and lymph nodes; I	30%	Δ SUV = 0.88	With cut-off value - 42%: 64%, 100%, (with review manager: 55%, 100%, 75%)	Gemini XL PET/CT; fasted 6h before injection; scan 60 min after injection; 5MBq/kg; CT: 120 kV; 100mAs; 16 slices; 2 min per bed position
Groheux (37)	2013	ER+/HER2 - (64)	Mean: 52; postmenopausal (41); Premenopausal: (22)	Prospective	July 2007 to Oct 2011	T1(1), T2 (21), T3 (25), T4 (17); N0 (24), N1 (29), N2 (8), N3 (5)	FDG-PET/CT	Baseline, after two cycles	NS	EC-D	$\geq -38\%$ Δ SUVmax and $\geq -71\%$ Δ TLG	Sataloff scale: TA-TB; NA-NB-NC are considered as responder and partial responder; III	6%	Δ SUVmax 0.73; Δ SUVmean 0.67; Δ TLG 0.81	62%, 78% with review manager: 97%; 16%; -	Gemini XL Philips; fasted 6h before; scan 60 min after injection: 5MBq/kg; 2 min per bed position; \ CT:120 kV; 100mAs;
Groheux (45)	2013	HER2+ (30)	-	Retrospective	-	II (14) and III (16)	FDG-PET/CT	Baseline, after two cycles	NS	EC-D and trastuzumab	Reduction $\geq 62\%$ Δ SUVmax	No residual invasive disease in tumour and lymph nodes; I	53%	Δ SUVmax = 0.86	86%, 75%, -, 80%	Gemini XL PET/CT; fasted 6h before injection; scan 60 min after injection: 5MBq/kg; CT: 120 kV; 100 mAs; 2 min per bed position
Groheux (43)	2014	TN (50)	-	Prospective	Nov 2007 to Sept 2012	II (21) and III (29)	FDG-PET/CT	Baseline, after two cycles	NS	EC-D (20) or SIM (30)	$\geq -42\%$ Δ SUVmax and $\geq -50\%$ Δ SUVmax	No evidence of residual invasive cancer in breast tissues and lymph nodes; I	38%	Δ SUVmax 0.80 for EC-D and 0.86 for SIM	With cut-off value $\geq -42\%$ Δ SUVmax: 58%; 100%; 59%; 100%; 74%	Gemini XL PET/CT; Fasted 6h before injection; scan started after 60 min after injection; 5 MBq/kg; from mid-thigh to skull with arms raised; resolution (3D): 4x4x4 mm ³ CT: 16 slices; 120kV; 100 mAs; 2 min per position
Hatt (44)	2013	TN(13);	-	Retrospective	July 2007 - May 2009	II (24) and III (27)	FDG PET	Baseline, after two cycles	NS	EC-D and in HER2+ EC-D plus trastuzumab	Optimal cutoff values: Δ SUVmax: - 48% Δ SUVpeak: - 42%	Staloff scale: TA-B with NABC are considered as responder and partial responder; III	23%	No significant differences between AUCs for value based measurements and SUVs	-	Gemini XL Philips; fasted 6h before injection; 5 MBq/kg; after 60 min mid-thigh to skull with arms raised; resolution: 4x4x4; CT:

		ER+/HER2- (26)									ΔSUVmean: -30% ΔTLG: -56% ΔMATV: -42%		0%	ER+/HER2-: AUC values: ΔSUVmax: 0.88 ΔSUVpeak: 0.84 ΔSUVmean: 0.69 ΔTLG: 0.96 ΔMATV: 0.98		16 slices; 120kV; 100mAs;
		HER2+ (12)											33%	No significant differences between AUCs for value based measurements and SUVs		
Humbert (21)	2012	TN (25)	≤50 (61) and >50 (54); mean: 51 years	Prospective	-	T1-2(62) T3(42); N- (35); N+ (79)	FDG-PET	Baseline and just before second course NACT	Within four weeks after last course of NAC	FEC 100 (25); FEC 100 plus docetaxel (39); Docetaxel followed by Epirubicin and docetaxel (8) CEX (6); TH +/- carboplatin (37)	ΔSUVmax of -75%	Chevallier's classification grade 1 and 2; I	36%	-	No correlation between early metabolic and final pathological response	C-PET Plus scanner and Gemini GXL scanner; fasted 6h before injection of F-FDG; whole body scan 60 min after injection; 2 MBq/kg (C-PET) and 5MBq/kg (Gemini); Prone position started 80-90 min after administration
		ER+/HER2- (53)											1.9%		-	
		HER2+ (37)											37.8%		-, -, -, 76%	
Humbert (46)	2014	HER2+ (57) Majority ER positive	≤50 (36) and >50 (21); postmenopausal (21); premenopausal (35)	Prospective	Nov 2006 – Oct 2012	I and II (26), III (28)	FDG-PET CT	Baseline and after first course NAC	One month after last course of NAC	TH	ΔSUVmax ≥ 60%	ypT0/is and ypN0; I	44%	AUC: 0.70 (0.55-0.85)	83%, 52%, 84%, 50%, -	Gemini GXL and TF Philips; fasted 6 hours before injection: 5 MBq/kg (GXL) 3.5 MBq/kg (TP); brain to mid-thigh after 60 min; prone position after 90 min
Koolen (35)	2014	ER+/HER2- (50)	Median: 47 (range 25-68)	Retrospective	Since Sept 2008	T1 (9), T2 (66), T3 (24), T4 (8), N0 (18), N1 (61), N2	FDG-PET CT	Baseline, after one and three cycles and in HER2+: after three and 8	-	AC (53); CD(1); AC-CD(23); AC-CTC(4); PTC (26)	ΔSUVmax	Complete absence of residual tumour cells in the breast and axillary nodes; I	2%	After one cycle, AUC: 0.61 (0.37 – 0.86) After three cycles, AUC: 0.87 (0.69 – 1.00)	-	Gemini TF Philips, Fasted 6 h before injection; 180 – 240 MBq depending on BMI; scanning after +/- 70 min; Prone position, arms above

		HER2+ (26)				(2), N3 (26)		administratio ns					65%	After three administratio ns AUC 0.61 (0.33 – 0.89) After eight administratio ns: 0.59 (0.34-0.85)		head; 3.0 min per bed position; resolution: 2x2x2mm CT: low dose; 40mA s, 2 mm slices; Baseline PET/CT: whole body
		TN (31)											52%	After one cycle, AUC: 0.76 (0.55-0.96) After three cycles, AUC: 0.87(0.73 – 1.00)		
Koolen (36)	2013	ER+/HER 2- (45)	Median:47 (range: 25-68)	Retrospec tive	Since Sept 2008	T1 (8), T2 (59), T3 (24), T4 (7), N0 (14), N1 (57), N2(2), N3(25)	FDG-PET/CT	Baseline and after first course NACT	-	AC (48); AC-CTC (4); AC-CD (20); CD (1); PTC (25)	Change in FDG uptake	Complete absence of residual tumour cells at microscopy, irrespective of carcinoma insitu; II	11%	0.77 (0.68 – 0.87)	-	Gemini TF Philips, Fastes 6 h before injection; 180 – 240 MBq depending on BMI; scanning after +/- 70 min; Prone position, arms above head; 3.0 min per bed position; resolution: 2x2x2mm CT: low dose; 40mA s, 2 mm slices; Baseline PET/CT: whole body
		HER2+ (25)											68%	0.41 (0.16 – 0.67)		
		TN (25)											61%	0.85 (0.69 – 1.00)		
Loo (18)	2011	ER+/HER 2- (103)	Mean: 46 (range: 23-76)	Retrospec tive	Between 2000 - 2008	T1 (6), T2 (97), T3 (62), T4 (23) N0 (28), N1 (125), N3 (11), Nx (24)	DCE MRI 1.5T or 3.0T	Baseline and after three courses or eight administratio ns	-	AC (90); AC – CD (45); CD or AD (15); Trastuzumab based (38)	Change in largest diameter	Complete absence of residual tumour cells or small number of scattered cells at microscopy; II	7%	-	No association between residual tumour and change in largest diameter	Magnetom Vision scanner 1.5T; 3.0 T Philips Achieva scanner; prone position; breast coil; gadolinium (14ml/0.1mmol/kg); 5 series at 90s interval; FOV: 310 (1.5T); 360 (3.0T)
		HER2+ (38)											40%			
		TN (47)											34%			

															after NAC associated with change in largest diameter (p<0.001)	
Martoni (41)	2010	ER+/HER 2-: (16)	Median: 48 years (31-72)	Prospective	-	II (15), III (13), IV (6)	FDG-PET/CT	Baseline and after second and fourth cycle	Median: 24 days (11-52 days)	Anthracycline based and taxane based PCT	$\geq -50\%$ Δ SUVmax	Miller and Payne; 4 and 5 with NRG A and D; III	19%	-	38%, 100%, 27%, 100%, 50%	GE medical system; Discovery LS; Fasted 6h before scanning; scan after 60-70 min after injection; 5.3 MBq/kg; 4 min per bed position; CT: 120kV 60 mA. Slices 4 a 5 mm thick
		HER2+: (7)											14%		17%, 100%, 17%, 100%, 29%	
		TN (9)											33%		0%, 100%, 33%, -, 33%	
Rigter (40)	2013	ER+/HER 2- (246)	Median 48 (range 18-68)	Retrospectiveloo	Oct 2004 – March 2012	T1 (21), T2 (91), T3 (43) T4 (9); Na (49), Nb (40), Nc (50), Nd (98), Ne (9)	DCE MRI 1.5T or 3.0T	Baseline after three and six courses	-	6 x ddAC (164); 3 x ddAC – 3 x DC (82)	Difference in largest diameter	ypT0/is ypN0 /+(II) ypT0/is ypN0 and ypT0ypN0; I	7/24 6 = 3%	-	35%, 80%, 10%, 95%, 38%	Magnetom Vision scanner 1.5T; 3.0 T Philips Achieva scanner; prone position; breast coil; gadolinium (14ml/0.1mmol/kg); 5 series at 90s interval; FOV: 310 (1.5T); 360 (3.0T)
		Luminal B (30)											17%		40%, 100%, 25%, 100%, 50%	
Zucchini (38)	2013	ER+/HER 2- (31)	Median: 49 years	Prospective	July 2004 – March 2011	II (30) and III (23), IV (7)	FDG-PET CT	Baseline and after second PCT cycle	Median: 31 days (11-52 days)	6 x Anthracycline taxane regimen (9); 8 x Anthracycline taxane regimen (45) 4-8 x taxane and trastuzumab (6)	$\geq -50\%$ Δ SUVmax	Miller and Payne; TRG 4 and 5 with NRG A and D; III	16%	-	38%, 100%, 24%, 100%, -	GE medical system; Discovery LS; Fasted 6h before scanning; scan after 60-70 min after injection; 5.3 MBq/kg; 4 min per bed position; CT: 120kV 60 mA. Slices 4 a 5 mm thick
		HER2+ (14)											29%		20%, 100%, 33%, 100%, -	
		TN (15)											27%		0%, 100%, 27%, 0%, -	

Study characteristics of the included studies are presented. Abbreviations: R: Randomized; CI: Confidence Interval; NS: Not Specified; SUV: Standardized Uptake Value; pCR: pathologic complete response; AUC: Area Under Receiver Operating Curve; AC: doxorubicin and cyclophosphamide; CD: capecitabine and docetaxel; CTC: Cyclophosphamide, thiotepa, carboplatin; PTC: Paclitaxel, trastuzumab, carboplatin; TAC: Doxorubicin followed by cyclophosphamide and docetaxel; TCaH: Taxol, Carboplatin, Herceptin. AbCaH: Abraxane, carboplatin, Herceptin; AbCaAv: Abraxane, carboplatin, avastin; TCA: Taxol, Carboplatin; FEC: Fluorouracil, Epirubicin and cyclophosphamide; EC-D: epirubicin, cyclophosphamide followed by Docetaxel; SIM: epirubicin and cyclophosphamide (1200 mg/m²)

Appendix 2 - Results: Search strategy

Database PubMed**Time span** from January 2000 until March 2015**Search in** Title and abstract

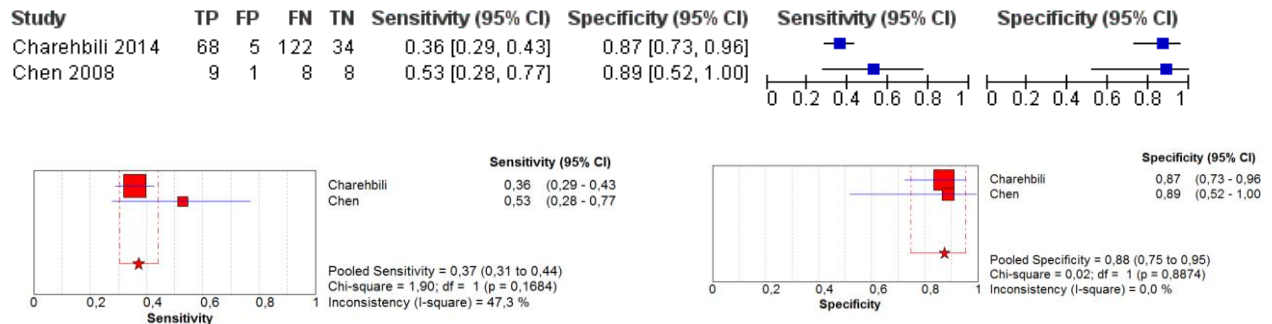
Category	Keywords
"Breast cancer"	breast neoplasms[mesh] OR breast neoplasm OR breast cancer OR breast tumour OR breast tumor OR breast malignan
"Imaging"	diagnostic imaging[mesh] OR imaging* OR MRI OR magnetic resonance imaging OR PET OR PET/CT OR PET-CT OR ultrasonograph* OR mammograph* OR PET/MRI OR PET-MRI OR positron emission tomograph* OR computed tomograph* OR image OR images
"Neo adjuvant therapy"	neoadjuvant therapy[mesh] OR preoperative therapy[MeSH] OR ((neoadjuvant therapy[mesh] OR neo-adjuvant OR neoadjuvant) AND (neoadjuvant therapy[mesh] OR preoperative therapy[MeSH] OR ((neoadjuvant therapy[mesh] OR neo-adjuvant OR neoadjuvant) AND (chemo OR chemotherap* OR chemo therap*))) OR ((pre-operative OR preoperative) AND (chemo OR chemotherap* OR chemo therap*))
"Outcome"	disease-free survival[mesh] OR surviv* OR survival rate[mesh] OR survival analysis[mesh] OR effective* OR cost-effective* OR treatment response* OR treatment outcome[mesh] OR complete pathologic response* OR complete pathological response* OR pathologic complete response* OR pathological complete response* OR pathologic response OR Ki67 OR Ki-67 OR MKI67
"Breast cancer subtype"	HER2 positive OR HER2/neu positive OR HER2neu positive OR HER2-neu positive OR non-luminal OR ((human epidermal growth factor receptor 2 OR receptor, erbB-2 [mesh] OR receptor, epidermal growth factor [mesh]) AND (positive)) OR (estrogen receptor-positive OR hormone receptor-positive OR estrogen receptor-positive OR oestrogen receptor-positive OR ER-positive OR hormone positive OR positive hormone receptor OR positive estrogen) OR Luminal OR triple negative OR TN OR TNBC OR ER-negative PR-negative HER2-negative OR basal-like OR basal like

Appendix 3 – Results: QUADAS criteria

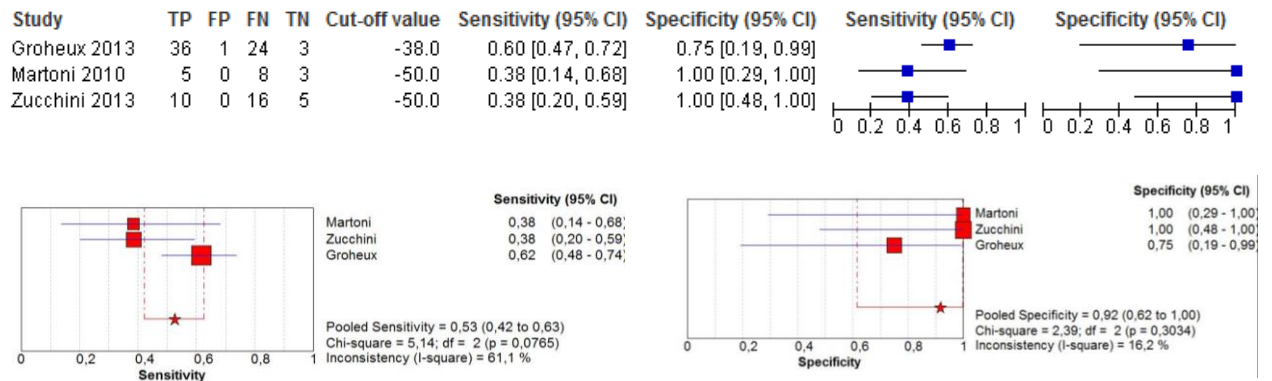
Author	Year	1. Representative spectrum of patients	2. Selection criteria clear	3. Reference standard reliable	4. Time interval between MRI/PET and pathology	5. Whole or random sample received verification	6. Same reference standard	7. Reference standard independent of the index test	8. Description execution of MRI/PET	9. Description execution of pathology	10. Interpretation of PET/MRI blinded from reference	11. Interpretation of reference blinded from MRI/PET	12. Same clinical data available	13. Uninterpretable test results reported	14. Withdrawals explains	Score (max = 14; yes = 1)
Charehbili	2014	yes	yes	yes	yes	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	yes	unclear	12
Chen	2008	yes	yes	yes	yes	yes, but not random	yes	yes	yes	yes	unclear	unclear	yes	unclear	unclear	10
Coudert	2014	yes	yes	yes	yes	yes, but not random	yes	yes	yes	yes	yes	yes	yes	yes	yes	14
Gebhart	2013	yes	yes	yes	yes	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	yes	yes	13
Gorheux	2013	yes	yes	yes	unclear	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	unclear	unclear	10
Groheux	2012	yes	yes	yes	unclear	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	unclear	unclear	10
Groheux	2013	yes	yes	yes	unclear	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	unclear	unclear	10
Groheux	2014	yes	yes	yes	unclear	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	unclear	unclear	10
Hatt	2013	yes	yes	yes	unclear	yes, but not random	yes	yes	yes	yes	unclear	unclear	yes	unclear	unclear	9
Humbert	2012	yes	yes	yes	yes	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	unclear	unclear	11
Humbert	2014b	yes	yes	yes	yes	yes, but not random	yes	yes	yes	yes	unclear	unclear	yes	yes	yes	12
Koolen	2014	yes	yes	yes	unclear	yes, but not random	yes	yes	yes	yes	unclear	unclear	yes	unclear	unclear	9
Koolen	2013	yes	yes	yes	unclear	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	yes	yes	12
Loo	2011	yes	yes	yes	unclear	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	unclear	unclear	10
Martoni	2010	yes	yes	yes	yes	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	unclear	unclear	11
Rigter	2013	yes	yes	yes	unclear	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	yes	unclear	11
Zucchini	2013	yes	yes	yes	yes	yes, but not random	yes	yes	yes	yes	yes	unclear	yes	unclear	unclear	11

Appendix 4 – Results: Meta analysis

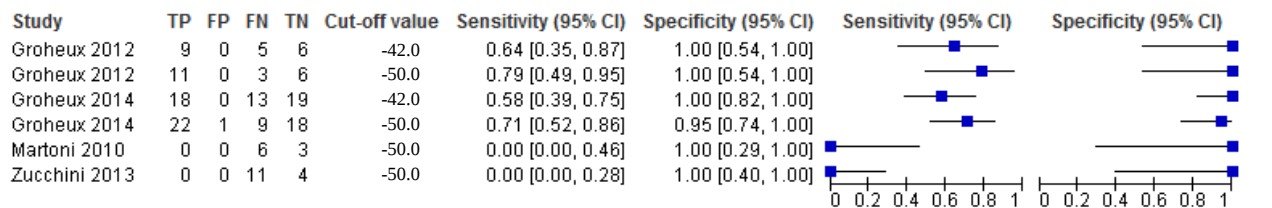
DCE MRI in HER2 negative; ER receptor status unknown



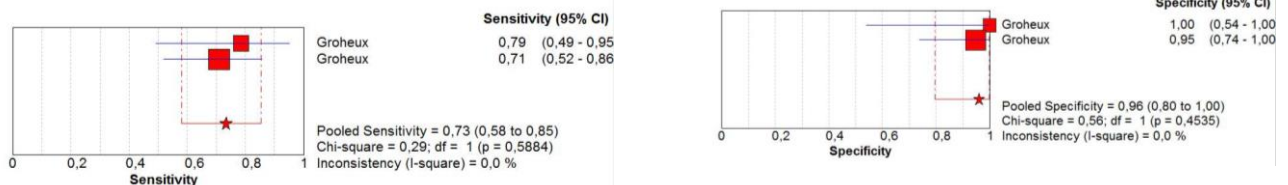
FDG-PET/CT in HER2 negative; ER positive



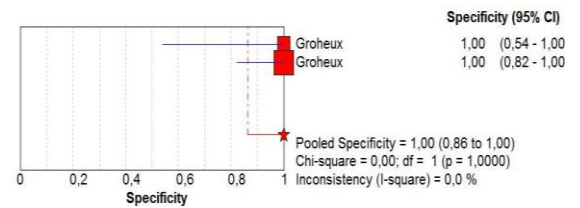
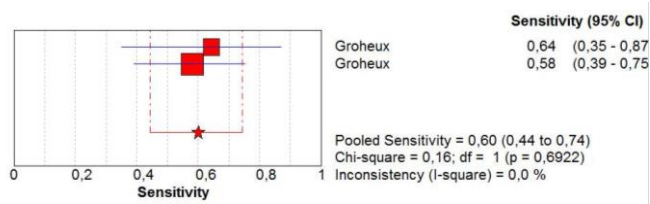
FDG-PET/CT in Triple negative



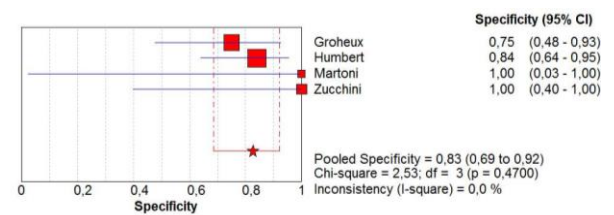
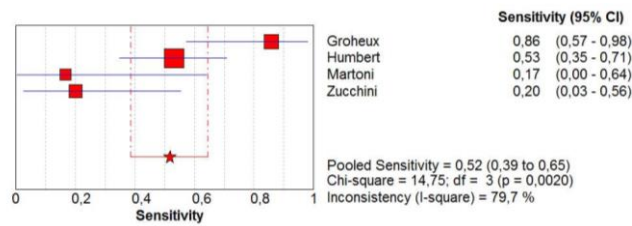
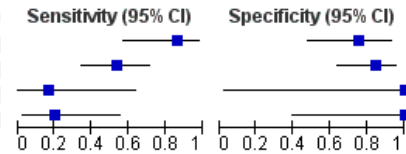
50% threshold



42% threshold

**FDG-PET/CT in HER2+ with unknown ER status**

Study	TP	FP	FN	TN	Cut-off value	Sensitivity (95% CI)	Specificity (95% CI)
Groheux 2013	12	4	2	12	-62.0	0.86 [0.57, 0.98]	0.75 [0.48, 0.93]
Humbert 2014	17	4	15	21	-60.0	0.53 [0.35, 0.71]	0.84 [0.64, 0.95]
Martoni 2010	1	0	5	1	-50.0	0.17 [0.00, 0.64]	1.00 [0.03, 1.00]
Zucchini 2013	2	0	8	4	-50.0	0.20 [0.03, 0.56]	1.00 [0.40, 1.00]



Appendices Value based healthcare assignment

Appendix 1 – Detailed description of quality indicators included in the survey

Algemeen

1	SURVIVAL
BESCHRIJVING	Borstkanker patiënten die na behandeling 2, 5, 10 jaar leven Een overlevingspercentage geeft een indicatie aan van het algemene succes of slagen van de aangeboden behandeling in het ziekenhuis. Mits gecorrigeerd wordt voor verschillende aspecten.
TYPE INDICATOR	Uitkomst
CATEGORIE	Survival
INDICATORENSET	–
TE	Ja
BENCHMARKEN	
FORMULE	Voor 2, 5 en 10 jaar: $\frac{\text{Aantal patiënten dat nog in leven is } x \text{ jaar na de behandeling}}{\text{Alle patiënten (mammacarcinoom of DCIS) invasief behandeld}}$ Deze informatie kan verkregen worden door de opkomst bij controle afspraken te registreren en anders contact te zoeken met de huisarts.
INCLUSIE	Mammacarcinoom en DCIS; T1–T4; anyN; M0
CASEMIX	Co morbiditeit, leeftijd, klinische status; histologie; subtype
2	IRRADICALITEIT
BESCHRIJVING	Het wordt als belastend ervaren wanneer na een borstsparende operatie alsnog tumorweefsel aanwezig is waarvoor behandeling nodig is. Een laag percentage betekent dus dat er weinig tweede operaties nodig zijn wat positief is voor de zwaartelast van de behandeling voor de patiënt en positief voor de efficiëntie van de behandeling. Deze uitkomst kan behaald worden door goede diagnose stelling en rapportage waardoor een goed operatieresultaat behaald wordt, het is ook mogelijk dat er meer weefsel wordt weggehaald dan nodig. Procesindicatoren als: "Markering bij diagnose" kunnen gebruikt worden om deze uitkomst beter te beschrijven.
TYPE INDICATOR	Uitkomstindicator
CATEGORIE	Survival
INDICATORENSET	NABON (indicator 20)
TE	Ja
BENCHMARKEN	
FORMULE	Per tijdseenheid: $\frac{\text{Aantal patiënten met tumorweefsel meer dan focaal aanwezig is in het resectievlak na een eerste lokale excisie van mammatumor}}{\text{Aantal patiënten met een eerste borstsparende operatie}}$ # patiënten waarbij markeringstechnieken werden gebruikt om zo nauwkeurig mogelijk de omvang van het tumorweefsel aan te geven / # het aantal patiënten dat werd gediagnostiseerd met beeldvormende technieken.
INCLUSIE	Primair invasief operabele mammacarcinoom met of zonder DCIS eerste sparende operatie
CASEMIX	Klinische status; Histologie; leeftijd, subtype

3

RECIDIEF

BESCHRIJVING	Optreden van een lokaal recidief in dezelfde borst na eerder behandeling van mammacarcinoom of DCIS na een bepaalde tijdsduur
	Een laag percentage betekent dat de behandeling dusdanig effectief is geweest dat het tumorweefsel met succes is behandeld. Een hoger percentage geeft aan dat dit niet het geval is. Dit kan beïnvloedt zijn doordat het ziekenhuis relatief gezien minder 'eenvoudig' te behandelen patiënten heeft, hier zal voor gecorrigeerd moeten worden. Ov
TYPE INDICATOR	Uitkomst
CATEGORIE	Survival
INDICATORENSET	NABON (indicator 23)
TE BENCHMARKEN	Ja
FORMULE	Per tijdsduur: $\frac{\text{Aantal patiënten met een lokaal of regionaal recidief als first event}}{\text{Alle patiënten (mammacarcinoom of DCIS) primair invasief behandeld}}$
INCLUSIE	Primair invasief mammacarcinoom en DCIS; T1–T4; anyN; M0
CASEMIX	Type behandeling; Leeftijd; Subtype; Klinische status; Histologie

X

VOLUME

BESCHRIJVING	Het aantal keren dat een operatie en/of behandeling wordt uitgevoerd. Norm 50 keer per jaar. Wanneer een behandeling vaker wordt uitgevoerd is het aannemelijk dat de specialisten en de organisatie meer ervaren is in een bepaalde handeling waardoor dit meestal leidt tot hogere kwaliteit.
TYPE INDICATOR	Process
CATEGORIE	x
INDICATORENSET	– , SONCOS (2015) stelt een volumenorm voor het aantal mammacarcinoom operaties: minstens 50 per jaar, gemiddeld over periode van 3 jaar.
TE BENCHMARKEN	Ja
FORMULE	$\text{Aantal uitvoeringen per specifieke behandelingsmethode per jaar}$
INCLUSIE	Borstsparende operatie, Volledige ablatie, Ablatie in combinatie met reconstructie, Okselklier dissectie, Bestraling, NACT
CASEMIX	Aantal nieuwe patiënten per jaar in het ziekenhuis,

Behandeling

23

PHYSICAL APPEARANCE

BESCHRIJVING	Patiëntentevredenheid na het ondergaan van een operatie al dan niet borstsparend. Het aantal borstbesparende operaties tov ablaties zegt niets over de kwaliteit van de behandeling. De patiëntentevredenheid na een operatie binnen een bepaald ziekenhuis kan hier meer informatie over geven. Van de patiëntentevredenheid tov alle chirurgische ingrepen wordt verwacht dat het een indicatie geeft hoe goed het ziekenhuis de wensen van de patiënt meeneemt en of het mogelijk is om een directe reconstructie uit te voeren. Uit verschillende kwaliteit van leven studies bleek namelijk dat hiervoor de Body Image Scale uitkomsten nagenoeg gelijk zijn als voor de borstsparende optie.
TYPE INDICATOR	Uitkomst

CATEGORIE	Degree of health
INDICATORENSET	– , BIS is ontwikkeld in samenwerking met EORTC
TE	Ja
BENCHMARKEN	
FORMULE	Body Image Scale (Hopwood, Fletcher, Lee, & Al Ghazal, 2001) is te gebruiken voor de gemiddelde tevredenheid na een contour besparende operatie (zowel borstsparend als directe reconstructie na ablatie). Gemiddelde body image scale bij patiënten met lokale behandeling waarbij uiteindelijk gesplitst kan worden in borstsparend operatie, directe reconstructie en volledige ablatie. Ook kan gekozen worden voor de vragen 39 – 42 uit QLQ-BR23 De volgende definities kunnen hierbij aanvullende informatie geven: - # patiënten met borstsparend operatie na neoadjuvante chemotherapie / # patiënten behandeld met neoadjuvante chemotherapie. - # Patiënten met directe reconstructie na ablatie / # patiënten met ablatie
INCLUSIE	Invasief operabele mammacarcinoom met of zonder DCIS eerste sparende operatie
CASEMIX	Leeftijd; Subtype; Klinische status; Histologie

4A LANGE TERMIJN EFFECTEN

BESCHRIJVING	De lange termijn effecten na behandeling van mammacarcinoom De lange termijn effecten hebben veel invloed op de kwaliteit van leven. Een kwalitatieve behandeling van borstkanker betekent dat deze na behandeling zo min mogelijk aanwezig zijn. Er kunnen verschillende lange termijn effecten gemeten worden: Hart en longsschade na bestraling of hartschade na behandeling met herceptin. Osteoporose na chemotherapie, plexopathie na bestraling
TYPE INDICATOR	Uitkomst
CATEGORIE	Survival
INDICATORENSET	–
TE	Ja
BENCHMARKEN	
FORMULE	Per tijdseenheid: # patiënten met hart schade na bestraling / # patiënten die werden bestraald # Patiënten met long schade na bestraling / # patiënten die werden bestraald # Patiënten met hart schade na Herceptin gebruik / # patiënten die werden behandeld met Herceptin # patiënten met Osteoporose na hormonale therapie / # patiënten behandeld met hormonale therapie # patiënten met plexopahtie / # patiënten die werden bestraald
INCLUSIE	Alle patiënten die behandeld werden met ofwel chemotherapie ofwel bestraling
CASEMIX	Subtype, Klinische status, Leeftijd

7

NEOADJUVANTE CHEMOTHERAPIE

BESCHRIJVING	Het starten van chemotherapie voordat een operatie plaatsvindt. Het starten van chemotherapie voordat een operatie gepland wordt geeft de patiënt tijd om na te denken over het type operatie. Wordt is voor de patiënt erg prettig omdat deze tijd krijgt om een goede doordachte keuze te maken. Daarnaast wordt de tumor kleiner gemaakt en zal de operatie vaker borstsparend uitgevoerd kunnen worden en is de operatie minder invasief.
TYPE INDICATOR	Uitkomst
CATEGORIE	Effectiveness
INDICATORENSET	NBCA lijst
TE BENCHMARKEN	Ja
FORMULE	$\frac{\text{Patiënten die zijn gestart met NACT in een jaar}}{\# \text{ Patiënten met T2 – T4 / N1 – N3 (grade IIB, IIIA, IIIC, IV) in een jaar}}$
INCLUSIE	Patiënten T2–T4 and N1–N3 (grade IIB, IIIa, IIIC, IV)
CASEMIX	Subtype, klinische status, leeftijd

10,11

PREVENTIE OVERBODIGE CHEMOTHERAPIE

BESCHRIJVING	Aantal patiënten dat adjuvante chemotherapie ontvangt Chemotherapie wordt het liefst vermeden als dit niet nodig is omdat dit veel bijeffecten heeft. Vanuit dat oogpunt is het vermijden van chemotherapie die niet nodig zou zijn kwalitatieve zorg. Op dit moment wordt in verschillende ziekenhuizen de mammaprint gebruikt om in kaart te brengen of adjuvante chemotherapie nodig is. Het percentage patiënten dat behandeld wordt met adjuvante chemotherapie zal hierdoor dan /ook beïnvloedt worden. Daarnaast bestaat natuurlijk de kans dat door een foute beoordeling geen chemotherpaie meer werd aangeboden, waar dat wel nodig werd. Het aantal recidieven in deze groep is dus ook relevant.
TYPE INDICATOR	Uitkomst
CATEGORIE	Effectiveness
INDICATORENSET	–
TE BENCHMARKEN	Ja
FORMULE	$\frac{\# \text{ patiënten behandeld met adjuvante chemotherapy in een jaar}}{\# \text{ patiënten met T2 of hoger en N1 – 3 in een jaar}}$ Om de gevonden uitkomsten goed uit te kunnen leggen: # patiënten die warden gescreend met mamma print in een jaar / # patiënten met T2 of hoger en N1–3 in een jaar # patiënten waarbij borstkanker opnieuw gevonden is binnen een half jaar / # patiënten met T2 of hoger en N1–3
INCLUSIE	borstkankerpatiënten met T2 of hoger en N1–3
CASEMIX	Subgroup, klinische status, leeftijd

19

FUNCTIONEREN ARM

BESCHRIJVING	De armfunctie na behandeling bij positief bevonden lymfeklieren De verminderde armfunctie, vaak door lymfeedeem, wordt als belastend ervaren door de patiënt (aldus kwaliteit van leven studies). Wanneer een okselklierdissectie voorkomen kan worden, door bijvoorbeeld de MARI procedure toe te passen, wordt verwacht dat de armfunctie minder sterk afneemt. Soms wordt ook besloten op
---------------------	--

TYPE INDICATOR
CATEGORIE
INDICATORENSET
TE
BENCHMARKEN
FORMULE

basis van een biopsie dat niet de gehele okselklier verwijderd hoeft te worden. Meest optimale behandeling is dus zo min symptomen na een behandeling van positieve lymfeklieren. Wel moet hierbij aandacht gegeven worden aan redicieven wanneer geen okselklierdissectie wordt uitgevoerd

Uitkomst

Degree of health

– , QLQ BR23

Ja, mits op een zelfde manier gemeten

- Diameter van de arm voor en na de behandeling
- Vragen 47 en 48 in de QLQ lijst BR23

Om de gevonden uitkomsten uit te kunnen diepen:

patiënten met een okselklierdissectie in het afgelopen jaar / patiënten met positieve lymfeklieren

patiënten waarbij de MARI procedure werd doorlopen in het afgelopen jaar / patiënten met positieve lymfeklieren

Patiënten waarbij alsnog de lymfeklieren positief bevonden werden / Patiënten met positieve lymfeklieren zonder okselklierdissectie tov aantal in alle patiënten met positieve lymfeklieren

INCLUSIE
CASEMIX

Patiënten met positieve lymfeklieren N1–3

Subtype, Age, Klinische status

Proces

16,17,18

INFORMATIE VOORZIENING

BESCHRIJVING

De mate waarin de patiënt vindt dat hij/zij werd geïnformeerd rondom de behandeling en de nazorg

Informatievoorziening is een belangrijk element in het kader van zelfmanagement. Het wordt als positief ervaren als de patiënt zelf het gevoel heeft voldoende informatie te krijgen waarop hij/zij een goede keuze kan maken mbt behandeling. De mate waarin de patiënt geïnformeerd is heeft dus een relatie met kwaliteit van zorg.

TYPE INDICATOR
CATEGORIE
INDICATORENSET
TE
BENCHMARKEN
FORMULE

Proces

Patient centeredness

CQI

Ja

De vragen uit de CQI lijst dienen hiervoor als meetinstrument:

- Kreeg u van de zorgverleners voldoende mondelinge informatie?
- Legden de zorgverleners u dingen op een begrijpelijke manier uit?
- Zijn de mogelijke behandelingen met u besproken?
- Zijn de mogelijke gevolgen van de eventuele behandelingen met u besproken?
- Kreeg u bij de afronding van de behandeling(en) in dit ziekenhuis informatie over eventuele klachten of gezondheidsproblemen waarop u moest letten?

Voor elke fase in het proces:

Vond u de hoeveelheid informatie een probleem?

Begreep u de schriftelijke informatie?

INCLUSIE

Alle borstkankerpatiënten die werden gezien in het ziekenhuis (benigne, maligne)

CASEMIX

-

X

SAMENWERKING MET ANDERE ZIEKENHUIZEN

BESCHRIJVING

De mate waarin wordt samengewerkt tussen verschillende ziekenhuizen/specialisten zowel internationaal als nationaal.

Het samenwerken tussen verschillende ziekenhuizen wordt gezien als kwalitatieve zorg omdat gebruik gemaakt kan worden van elkaars expertises. In het teken van de meest kwalitatieve zorg en meest patiënt gerichte zorg zou alles uit de kast getrokken moeten worden om de beste behandeling voor die patiënt aan te kunnen bieden. Goede samenwerking zou tot kwalitatievere zorg kunnen leiden.

TYPE INDICATOR

Proces

CATEGORIE

Patient centeredness

INDICATORENSET

-

TE BENCHMARKEN

Ja

FORMULE

$$\frac{\# \text{ onderzoeken per jaar in samenwerking met een ander ziekenhuis wordt uitgevoerd}}{\# \text{ onderzoeken dat in borstkankerszorg wordt uitgevoerd per jaar}}$$

$$\frac{\# \text{ patiënten dat per jaar voor verdere diagnostiek/behandeling wordt doorverwezen naar een ander ziekenhuis}}{\# \text{ aantal patiënten per jaar met benigne mammacarcinoom}}$$

INCLUSIE

CASEMIX

Alle borstkankerpatiënten die werden gezien in het ziekenhuis (benigne, maligne)

Specificeren naar benigne of maligne en diagnostiek of behandeling kan interessant zijn

Daarnaast: Subtype, klinische status en leeftijd

15

MOGELIJKHEID TOT MEEBESLISSEN

BESCHRIJVING

De patiënt heeft de mogelijkheid mee te beslissen / maakt zelf de keuze over het behandeltraject

Eigen regie en achter de gekozen behandeling staan is voor een patiënt erg van belang. Wanneer een ziekenhuis hier goed op scoort wordt dit voor een patiënt ervaren als kwalitatieve zorg.

TYPE INDICATOR

Proces

CATEGORIE

Patient centeredness

INDICATORENSET

CQI

TE BENCHMARKEN

Ja

FORMULE

Vanuit de CQI vragenlijst wordt dit bij de patiënt gevraagd:

- Kon u meebeslissen over uw behandelplan/behandelingen?

INCLUSIE

CASEMIX

Alle borstkankerpatiënten die werden gezien in het ziekenhuis (benigne, maligne)

-

5,6

WACHTTIJD

BESCHRIJVING

De tijd dat een patiënt moet wachten op een uitslag/behandeling/diagnose

Een kortere wachttijd wordt in relatie gebracht met hoge kwaliteit van zorg. Echter zal dit niet van een paar dagen afhangen. Wel is het van belang dat de patiënt zo snel mogelijk wordt behandeld of gediagnosticeerd. Dit heeft een positief effect op de ervaring van de patiënt en een beter klinisch resultaat.

TYPE INDICATOR

Proces

CATEGORIE

Timeliness

INDICATORENSET	NBCA
TE	Ja
BENCHMARKEN	
FORMULE	- Gemiddelde tijd vanaf de eerste afspraak tot aan de diagnose - Gemiddelde tijd van diagnose tot behandelplan - Gemiddelde tijd vanaf de diagnose tot neoadjuvante chemotherapie - Wachttijd tussen laatste gift neoadjuvante chemotherapie en operatie - Wachttijd tussen operatie of laatste dag chemotherapie en radiotherapie - Gemiddelde tijd vanaf diagnose tot operatie - Gemiddelde duur van chemotherapie
INCLUSIE	Alle borstkankerpatiënten die werden gezien in het ziekenhuis (benigne, maligne)
CASEMIX	Subtype, leeftijd, klinische status

13 AWARENESS AND APPLICATION OF SCIENTIFIC RESEARCH

BESCHRIJVING	Deelname aan wetenschappelijk onderzoek Om de zorg te verbeteren in de toekomst is deelname aan wetenschappelijk onderzoek nodig. Een ziekenhuis wordt dan kwalitatiever bevonden dan een ziekenhuis dat weinig aan onderzoek doet omdat onderzoek nodig is om op de hoogte te blijven en daarnaast worden behandelingsmogelijkheden geboden aan patiënten die in andere ziekenhuizen wellicht niet mogelijk zijn.
TYPE INDICATOR	Proces
CATEGORIE	effectiveness
INDICATORENSET	NABON
TE	Ja
BENCHMARKEN	
FORMULE	# patiënten dat deelneemt aan wetenschappelijke studies / # patiënten gediagnosticeerd met een invasief mammacarcinoom en/of een DCIS # Onderzoeken in borstkanker zorg die in Europese of internationale samenwerking zijn opgezet / # aantal onderzoek in borstkanker zorg
INCLUSIE	Patiënten met invasief mammacarcinoom en/of een DCIS
CASEMIX	–

24 RECOVERY TIME

BESCHRIJVING	De tijd die nodig is na de behandeling om te herstellen en de dagelijkse activiteiten weer op te pakken Als patiënten in ziekenhuis x sneller hersteld zijn dan in ziekenhuis y kan dit een indicatie zijn dat de zorg in ziekenhuis x effectiever is, dat er meer begeleiding is in de nazorg of dat de patiënten relatief fitter zijn. Voor dit laatste zal gecorrigeerd moeten worden. Voor een patiënt kan dit waardevolle informatie zijn omdat het tijdspad van het herstel veel invloed heeft op de kwaliteit van leven, ook financieel gezien.
TYPE INDICATOR	Outcome
CATEGORIE	Degree of health
INDICATORENSET	–
TE	Ja
BENCHMARKEN	
FORMULE	# patiënten dat na 6 maanden (controle moment) weer gestart is met werk of vergelijkbare bezigheden / # patiënten dat in het anamnese gesprek aangaf te werken.

INCLUSIE**CASEMIX**

patiënten dat na een jaar (controle moment) weer gestart is met werk of vergelijkbare bezigheden / # patiënten dat in het anamnese gesprek aangaf te werken.

Subtype, Leeftijd, Klinische status

Appendix 2 – Dutch online survey



Kwaliteit borstkankerzorg

Deze enquête is onderdeel van de afstudeeropdracht van Melanie Lindenberg voor de opleiding Gezondheidswetenschappen (Health Sciences) aan de Universiteit Twente. De afstudeeropdracht richt zich op het formuleren van aspecten die informatie kunnen geven, transparantie, over de kwaliteit van het borstkankerzorg proces.

Met deze korte enquête willen we in kaart brengen welke aspecten vanuit het oogpunt van de patiënt bijdragen aan kwaliteit van zorg. Dus de vraag: "Wat verstaat u onder kwalitatieve zorg of wat zou voor u kwalitatieve zorg zijn?" staat hierin centraal. Dit onderzoek is gestart omdat we in Nederland graag aspecten willen gaan meten zodat de kwaliteit van zorg (transparant) in kaart gebracht kan worden. Hiervoor is het van belang om te begrijpen wat vanuit het patiënten perspectief ervaren wordt als kwaliteit van zorg.

In de volgende vragenlijst worden eerst een aantal algemene vragen gesteld waarna een aantal vragen volgen over aspecten die volgens literatuur een verband hebben met kwaliteit van zorg.

De enquête zal ongeveer 10 minuten in beslag nemen.

Ik wil u alvast hartelijk danken voor uw deelname!-

Gebruik tijdens het invullen alleen de "verder" en "terug" knoppen binnen de enquête. De knoppen van het internetprogramma werken niet.
De informatie wordt vertrouwelijk behandeld.

Mocht u vragen of opmerkingen hebben: m.lindenberg@nki.nl / contact.melanielindenberg@gmail.com

Vriendelijke groet,
Melanie Lindenberg

* Required

Geslacht *

- ☐ Vrouw
☐ Man

Leeftijd *

- ☐ 18 - 29 jaar
☐ 30 - 39 jaar
☐ 40 - 49 jaar
☐ 50 - 59 jaar
☐ 60 jaar of ouder

Hoe lang is het geleden dat u bent behandeld in het ziekenhuis voor borstkanker *

Hierbij laten we bijvoorbeeld langdurige hormoontherapie buiten beschouwing

- ☐ Ik word nog behandeld
- ☐ Aantal weken
- ☐ Drie tot zes maanden
- ☐ Half jaar - jaar
- ☐ Langer dan een jaar

☐ Other:

De tumor die behandeld wordt of werd behandeld is in: *

- ☐ Stage I
- ☐ Stage II
- ☐ Stage III
- ☐ Stage IV
- ☐ Weet ik niet

Ik beschouw mijzelf als *

- ☐ Een borstkankerpatiënt
- ☐ Een borstkanker survivor / ervaringsdeskundige
- ☐ Other:

Mijn behandeling vindt of vond plaats in een *

- ☐ Regulier ziekenhuis (streek) (bijv. Slotervaart ziekenhuis, Groenehart ziekenhuis, Canisius Wilhelmina ziekenhuis)
- ☐ Academisch ziekenhuis (bijv. Universitair medisch centrum Utrecht, Academisch medisch centrum Amsterdam)
- ☐ Specialistisch ziekenhuis (bijv. Antoni van Leeuwenhoek, Daniël den Hoed)
- ☐ Weet ik niet

Continue »

 20% completed

Aspecten van kwaliteit

Hieronder volgen 15 aspecten die volgens literatuur in relatie staan met de kwaliteit van zorg binnen een ziekenhuis. We zijn benieuwd in hoeverre u deze aspecten in relatie vindt staan met kwaliteit. Op basis van welke informatie zou u bijvoorbeeld voor een bepaald ziekenhuis willen kiezen? Of wat vindt u belangrijke aspecten binnen het gehele borstkankerproces?

Hoe belangrijk zijn de volgende aspecten volgens u als we spreken over kwaliteit van zorg binnen een ziekenhuis?

Welke aspecten vindt u het belangrijkste met betrekking tot kwaliteit van zorg *

Kies maximaal 5 aspecten

- ☐ Aantal patiënten dat borstkanker overleeft
- ☐ Aantal patiënten dat een heroperatie ondergaat
- ☐ Aantal patiënten waarbij borstkanker terugkeert
- ☐ De informatie voorziening voor, tijdens en na de behandeling
- ☒ Mogelijkheid van meebeslissen tijdens het behandelproces
- ☐ Herstelperiode (tijd tussen diagnose/ziek zijn en weer aan het werk kunnen)
- ☐ Het cosmetische (uiterlijke) resultaat van de behandeling
- ☐ Het functioneren van de arm na de behandeling
- ☐ De kans op lange termijn complicaties (ongewenste effecten zoals bijvoorbeeld hart en/of longschade)
- ☐ Aantal keren dat een behandeling (operatie, chemokuur, diagnostiek) wordt uitgevoerd binnen een ziekenhuis (geeft mate van ervaring weer)
- ☐ Wachtijd tussen uitslag/diagnose en behandeling
- ☐ Als patiënt deel kunnen nemen aan wetenschappelijk onderzoek waardoor de behandeling bijvoorbeeld bestaat uit een nieuwe chemotherapie of zelfs een volledig nieuwe behandelmethode
- ☐ Het kunnen ontvangen van chemotherapie voor de operatie (neoadjuvante chemotherapie)
- ☐ Het voorkomen van overbodige chemotherapie b.v. door gebruik van mammaprint
- ☐ Mogelijkheid van directe reconstructie na volledige verwijdering van de borst (ablatie)
- ☐ Weet ik niet

Welke aspecten vindt u het minst belangrijk met betrekking tot kwaliteit van zorg in het ziekenhuis *

Kies maximaal 5 aspecten

- ☐ Aantal patiënten dat borstkanker overleeft
- ☐ Aantal patiënten dat een heroperatie ondergaat
- ☐ Aantal patiënten waarbij borstkanker terugkeert
- ☐ De informatie voorziening voor, tijdens en na de behandeling
- ☐ Mogelijkheid van meebeslissen tijdens het behandelproces
- ☐ Herstelperiode (tijd tussen diagnose/ziek zijn en weer aan het werk kunnen)
- ☐ Het cosmetische (uiterlijke) resultaat van de behandeling
- ☐ Het functioneren van de arm na de behandeling
- ☐ De kans op lange termijn complicaties (ongewenste effecten zoals bijvoorbeeld hart en/of longschade)
- ☐ Aantal keren dat een behandeling (operatie, chemokuur, diagnostiek) wordt uitgevoerd binnen een ziekenhuis (geeft mate van ervaring weer)
- ☐ Wachtijd tussen uitslag/diagnose en behandeling
- ☐ Als patiënt deel kunnen nemen aan wetenschappelijk onderzoek waardoor de behandeling bijvoorbeeld bestaat uit een nieuwe chemotherapie of zelfs een volledig nieuwe behandelmethode
- ☐ Het kunnen ontvangen van chemotherapie voor de operatie (neoadjuvante chemotherapie)
- ☐ Het voorkomen van overbodige chemotherapie b.v. door gebruik van mammaprint
- ☐ Mogelijkheid van directe reconstructie na volledige verwijdering van de borst (ablatie)
- ☐ Weet ik niet

« Back

Continue »

40% completed

Prioritering van aspecten

Met dit gedeelte willen we graag in kaart brengen welke aspecten het meest van belang zijn. We zetten hiervoor de aspecten uit het vorige overzicht per categorie tegenover elkaar.

Algemene ziekenhuis resultaten:

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Overlevingskans
- ☐ Kans op een heroperatie

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Overlevingskans
- ☐ Kans op het terugkeren van borstkanker

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Kans op een heroperatie
- ☐ Kans op het terugkeren van borstkanker

Resultaat van de behandeling

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Het cosmetische (uiterlijke) resultaat
- ☐ De kans op lange termijn complicaties (ongewenste effecten zoals bijvoorbeeld hart en/of longschade)

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Het cosmetische (uiterlijke) resultaat
- ☐ Het functioneren van de arm na de behandeling

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Het cosmetische (uiterlijke) resultaat
- ☐ Herstelperiode (tijd tussen diagnose/ziek zijn en weer aan de slag kunnen gaan)

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Het functioneren van de arm na de behandeling
- ☐ Herstelperiode (tijd tussen diagnose/ziek zijn en weer aan de slag kunnen gaan)

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ De kans op lange termijn complicaties (ongewenste effecten zoals bijvoorbeeld hart en/of longschade)
- ☐ Herstelperiode (tijd tussen diagnose/ziek zijn en weer aan de slag kunnen gaan)

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ De kans op lange termijn complicaties (ongewenste effecten zoals bijvoorbeeld hart en/of longschade)
- ☐ Het functioneren van de arm na de behandeling

Behandelaspecten

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Mogelijkheid tot neoadjuvante chemotherapie (chemotherapie voorafgaand aan de operatie)
- ☐ Het voorkomen van overbodige chemotherapie

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Mogelijkheid tot neoadjuvante chemotherapie (chemotherapie voorafgaand aan de operatie)
- ☐ Deel kunnen nemen aan wetenschappelijk onderzoek

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Mogelijkheid tot neoadjuvante chemotherapie (chemotherapie voorafgaand aan de operatie)
- ☐ Mogelijkheid tot directe reconstructie na ablatie (volledige verwijdering van de borst)

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Deel kunnen nemen aan wetenschappelijk onderzoek
- ☐ Mogelijkheid tot directe reconstructie na ablatie (volledige verwijdering van de borst)

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Deel kunnen nemen aan wetenschappelijk onderzoek
- ☐ Het voorkomen van overbodige chemotherapie

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Mogelijkheid tot directe reconstructie na ablatie (volledige verwijdering van de borst)
- ☐ Het voorkomen van overbodige chemotherapie

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Mogelijkheid tot directe reconstructie na ablatie (volledige verwijdering van de borst)
- ☐ Aantal behandelingen in dit gebied dat het ziekenhuis per jaar uitvoert (volume indicatoren)

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Mogelijkheid tot neoadjuvante chemotherapie (chemotherapie voorafgaand aan de operatie)
- ☐ Aantal behandelingen in dit gebied dat het ziekenhuis per jaar uitvoert (volume indicatoren)

Algemene ervaring van de behandeling

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Informatievoorziening
- ☐ Mogelijkheid tot meebeslissen

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Informatievoorziening
- ☐ Wachtijd tot behandeling

Als ik moet kiezen, vind ik het belangrijkste aspect mbt kwaliteit van zorg: *

- ☐ Mogelijkheid tot meebeslissen
- ☐ Wachtijd tot behandeling

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60% completed

Andere belangrijke aspecten?

Hieronder worden een aantal aspecten benoemd die mogelijk ook informatie geven over de kwaliteit van zorg.

Welke van de volgende aspecten zou u ook belangrijk achten als we het hebben over kwaliteit van het borstkankerproces? *

U mag meerdere aspecten aanvinken

- ☐ Korte termijn complicaties (ongewenste effecten zoals wondinfecties na de operatie)
- ☐ Betrokken artsen overleggen als team ten behoeve van de behandeling
- ☐ De mate van samenwerking tussen verschillende ziekenhuizen
- ☐ Het innovatieve karakter van een instelling bijvoorbeeld: het toepassen van wetenschappelijke onderzoeksresultaten
- ☐ Informatie gegeven over nazorg
- ☐ Informatie gegeven voor de behandeling over gevolgen t.a.v. vruchtbaarheid
- ☐ Mate van pijn na de behandeling
- ☐ Mate van vermoeidheid na de behandeling
- ☐ Mate van een verminderde eetlust na de behandeling
- ☐ Wachtijd op uitslagen van diagnostiek (scan uitslagen, bloeduitslagen etc.)
- ☐ Weet ik niet

Er werden verschillende aspecten aangegeven die in relatie zouden kunnen staan met kwaliteit van zorg. Heeft u nog andere aspecten die u van belang zou vinden mbt kwaliteit van zorg of wellicht aspecten waar u graag uw keuze voor het behandelend ziekenhuis op zou hebben gebaseerd? Zo ja, kunt u deze hier aangeven

Eventuele andere vragen en/of opmerkingen kunt u hier aan geven.

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Hartelijk dank!

Ik wil u heel hartelijk danken voor uw deelname, mocht u benieuwd zijn naar de resultaten, vul dan hieronder uw email adres in.

Ik wil graag op de hoogte worden gebracht van de resultaten (1 malige email) op dit email adres

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