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MASTER THESIS

Women's Experiences from Breast Cancer Diagnosis to Neoadjuvant Chemotherapy at MST (CABRIO-Study)

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Abstract

Background
Breast cancer remains a prevalent and impactful disease affecting women globally. While surgery is the main treatment for early-stage breast cancer, neoadjuvant chemotherapy (NAC) involves administering chemotherapy before surgery. The period between diagnosis and the start of NAC, ideally within 5 weeks, is marked by emotional distress and anxiety. The short timeframe for decision-making adds pressure, raising questions about the feasibility of making well-informed choices. To understand these experiences, a multidisciplinary team has created and introduced a version 1 (V1) questionnaire. This study is a follow-up to a previous one, with an increased patient sample size and further development of the V1 questionnaire to make it more comprehensive.

Method
This monocenter study can be divided into two components. The first component is to describe what women go through before starting NAC at Medisch Spectrum Twente (MST). It involved a prospective quantitative study with an exploratory approach. This phase included data collection through the V1 questionnaire and a retrospective patient record analysis, where clinical and personal data were collected from electronic health records (EHRs). The combined data was used for statistical analysis to describe the experiences, focusing on their satisfaction and the time allocated for decision-making. Mann-Whitney-U, Cohen's d, and Fisher Exact tests were used to analyze age differences, measure effect sizes, and explore associations with variables such as employment status, education level, and partnership status.

The second component involved developing a version 2 (V2) questionnaire. Based on previous research and data analysis, it was found that the V1 questionnaire lacked specificity in identifying reasons for patient dissatisfaction. The V2 questionnaire was developed by the researcher based on the V1 questionnaire. The development of the V2 questionnaire also included literature review, patient feedback, and input from breast cancer care professionals.

Results
In the study, 15 more women were included, totaling 29 participants. Overall, patients were very satisfied with their care. However, seven patients expressed dissatisfaction with the time for decision-making before NAC. Higher education correlated statistically significant with higher satisfaction regarding information provision and decision-making time. Patients with grade 3 tumors were more likely to be satisfied with treatment information compared to grade 2 tumor patients. Other factors showed no significant impact on satisfaction.

The final V2 questionnaire is divided into 5 general questions about demographics, 14 likert scale questions about the treatment period, and 2 closing questions. Some key changes of the V2 questionnaire were: enhanced clarity, including answer categories (to stimulate the thoughts of participants), mandatory remarks (if someone disagrees, it should be mandatory to complete the subsequent question), follow-up consent for an interview and digitalization of the questionnaire. These changes were made to enhance the clarity, relevance, and comprehensiveness of the questionnaire.

Conclusion
In conclusion, this study aligns with previous research indicating that overall, patients are satisfied with their care, although the time between diagnosis and the start of NAC needs attention. The redesigned V2 questionnaire addresses the lacking specificity of the V1 questionnaire, by including additional options for patients to specify reasons for dissatisfaction. For future research, using the V2 questionnaire has the potential to provide deeper insights into the challenges faced by breast cancer patients during their NAC trajectory.

Introduction

Background

Breast cancer remains one of the most prevalent and impactful diseases affecting women globally. According to the World Health Organization (WHO), it is estimated that approximately 2.3 million new cases of breast cancer were diagnosed worldwide in 2020 alone [1]. In the Netherlands, breast cancer will affect approximately 1 in 7 women, with around 18,000 new cases annually [2, 3]. In addition to its physical toll, breast cancer often brings profound emotional and psychological challenges for affected individuals, significantly impacting their quality of life and well-being [4].

Surgery is the main treatment for early-stage breast cancer. Adjuvant therapies like chemotherapy may follow, aiming to eliminate any remaining cancer cells, thereby enhancing overall survival [5]. A different treatment option, neoadjuvant chemotherapy (NAC), involves administering chemotherapy before surgery. This approach aims to reduce tumor size, evaluate tumor sensitivity and enable less extensive surgery. This could lead to potential breast-conserving surgeries and provide clearer insight into a patient's prognosis by allowing clinicians to observe the tumor's response to treatment before surgery [6]. Breast cancer patients who are eligible for NAC typically include those with locally advanced breast cancer [7], triple-negative breast cancer, HER2-positive breast cancer, inflammatory breast cancer, or those who might benefit from tumor shrinkage to allow for breast conservation surgery [8]. Whether additional adjuvant chemotherapy is needed after NAC depends on the tumor response. The duration of NAC varies, lasting several weeks to months, depending on the number of cycles, dosage, and type of treatment, which can be influenced by factors such as the patient's overall health, tumor characteristics, and response to treatment. Surgery is typically performed after completing the treatment. Imaging tests like MRI may be used to evaluate tumor response, with partial or complete remission guiding decisions on the type of surgery needed, which can be either mastectomy or breast conserving surgery. Research shows that there is no significant difference in breast cancer mortality between patients receiving NAC and those receiving adjuvant chemotherapy [9]. This finding supports the safety of administering chemotherapy before surgery.

Based on the guidelines set in 2019 by the Dutch Health Inspectorate, the longest allowable interval between the biopsy and the start of NAC was 5 weeks [10]. While this 5-week interval is no longer mandatory, a quick throughput time is still preferred, as also mentioned in the indicator set of the NABON Breast Cancer Audit [11]. The time between diagnosis and the start of NAC represents an important phase in the cancer trajectory, marked by heightened emotional distress, anxiety, and anticipation of treatment effects [4]. Fertility treatments, such as in vitro fertilization or egg retrieval procedures, are among the factors that contribute to the complexity of the cancer trajectory within the 5-week timeframe, alongside genetic testing, additional imaging scans (MRI and PET-CT), plastic surgical considerations, and the need for additional biopsies [12]. The short timeframe for weighing the pros and cons, decision-making and starting treatment adds extra pressure, raising questions about the feasibility and desirability of making well-informed choices within this short timeframe.
Building a comprehensive questionnaire to better understand patient experiences is essential, as it provides insight into the specific challenges faced. While existing research by Poolen (2023) [13] has provided valuable insights into the experiences of 15 women by using the version 1 (V1) questionnaire, it showed dissatisfaction with the timeframe. However, the small patient sample size, lack of clarity, repetitive questions, and minimal feedback in the V1 questionnaire resulted in limited conclusions. This highlights the need to redesign the V1 questionnaire for a deeper understanding of these experiences.

The primary aim of this study is to investigate how women with breast cancer experience the period between diagnosis and the start of NAC within Medisch Spectrum Twente (MST), focusing on their satisfaction and the time allocated for decision-making, with an increased number of included patients. This study also introduces a redesigned questionnaire to even better investigate these experiences in the future.

Method

This monocenter study employs a both quantitative and qualitative research design to explore the experiences of women with breast cancer during the period between diagnosis and the start of NAC within MST. The focus was on patients with breast cancer who underwent NAC at MST in the years 2023 and 2024. The inclusion and exclusion criteria outlined in Table 1 were applied.

***Table 1** - Inclusion and exclusion criteria*

Inclusion criteria	***Exclusion criteria***
- Women diagnosed with breast cancer	- Individuals who do not have proficiency in the Dutch language
- Women between the ages of 18 and 70 years old	
- Women who underwent NAC	

NAC = Neoadjuvant chemotherapy

The study can be divided in two components. The first component is to describe what women go through before starting NAC. It involved a prospective quantitative study with an exploratory approach. This phase included data collection through V1 questionnaires and a retrospective patient record analysis, where clinical and personal data were collected from electronic health records (EHRs). The combined data was used for statistical analysis to describe the experiences.

The second component involved developing a version 2 (V2) questionnaire. The V2 questionnaire was developed by the researcher herself based on the V1 questionnaire, which was initially created by a multidisciplinary team. Additionally, observations were conducted in various departments, literature was reviewed [14-16], remarks from patients were analyzed and suggestions from the breast cancer team were included into its development. Suggestions from the breast cancer team were gathered through email and conversation. The V2 questionnaire concept was then reviewed by 10 diverse individuals, including healthcare providers and the public, covering various ages, education levels, and backgrounds. They provided feedback on question clarity, completion time, relevance, and coverage of important topics.

Data collection

For data collection, patients were enrolled during outpatient visits by the nurse specialist. They were informed about the CABRIO study and given necessary documents, including the patient information sheet, informed consent form, and the V1 questionnaire (appendix A (Dutch) and B (English)). Patients interested in participating in the study could return the filled-in paper questionnaire on their first chemotherapy day. This questionnaire, developed by the breast cancer treatment team at MST, comprises 13 Likert scale questions and an additional remarks field. It evaluates different components such as information completeness, presence of shared decision-making, desire for children and time between examinations. It also collects demographic details such as education level, living situation, and employment status.

Data from women who entered the study was also collected through a retrospective clinical record review. This method allowed for the examination of specific time frames, treatment regimens, and especially patient characteristics, such as age and tumor characteristics. These data were gathered from the hospital's electronic health record system, called Chipsoft HiX.

Data analysis

During the start of this study, additional patients had completed the V1 questionnaire and were added to the 15 patients previously analyzed by L. Poolen [13]. This resulted in one unified set for the subsequent analysis. The questionnaire data was summarized using the median, as well as the values representing the first and third quartiles. The Likert scale was recoded to provide a clearer distinction for the statistical analysis. Responses rated 1 through 3 (representing complete disagreement, disagreement, and neutral/no opinion) were categorized as dissatisfaction, whereas those rated 4 and

5 (representing agreement and complete agreement) were categorized as satisfaction. The results for each question were displayed using bar plots. A comparison between satisfied and dissatisfied patients was made to help identify areas for improvement. The Mann-Whitney-U test was used to assess age differences per question between satisfied and dissatisfied groups. The Cohen's d was then used to measure the effect sizes. The Fisher Exact test was used to explore variables such as employment status (paid work vs. other work situations), education level (low vs. high educated), partnership status (living with a partner vs. without), parental status (living with children vs. without), and cancer grade (grade 2 vs. grade 3). Additionally, relative risks associated with these variables were calculated to gain further understanding of their relationships.

R version 4.3.1 was used to perform statistical analysis.

Ethical considerations

The CABRIO study follows Good Clinical Practice (GCP) guidelines and ethical standards. Patients were informed orally and in writing, and provided written consent before participating. This was achieved through a “proefpersonen-informatieformulier” (PIF). Access to data complies with the “Algemene Verodening Gegevensbescherming” (AVG). This data is coded for privacy protection. The study is not subject to the “Wet Medisch-wetenschappelijk Onderzoek” (WMO) and follows the Dutch "Wet Geneeskundige Behandelovereenkomst" (WGBO). The study was approved by the hospital’s institutional review board.

Results

A total of 15 additional women were included in the CABRIO study. One participant withdrew from the study due to personal reasons, bringing the final number of participants in the analysis to 29. A summary of demographic variables and tumor characteristics is detailed in Table 2. These data were collected through clinical record reviews and V1 questionnaires. The average age of all patients is 48.5 (SD = 12.45). Additionally, 86% have a non-specific tumor type and 72% have a tumor at stage 2.

***Table 2** – Demographic variables and tumor characteristics retrieved from V1 questionnaires and records*

Characteristics	Total (N = 29)
Age (years), N (~%)	
≤ 40	8 (28)
41 – 50	11 (38)
51 – 60	5 (17)
> 60	5 (17)
Employment status, N (~%)	
Paid work	23 (79)
Retired	3 (10)
Unable to work	3 (10)
Living conditions, N (~%)	
Living alone	4 (14)
Living with kids	2 (7)
Living with partner	8 (28)
Living with partner and kids	15 (52)
Highest level of education, N (~%)	
LBO & MVO	7 (24)
MBO	9 (31)
HAVO	3 (10)
HBO & university	10 (34)
ER status, N (~%)	
Negative	16 (55)
Positive	13 (45)
PR status, N (~%)	
Negative	16 (55)
Positive	13 (45)
HER2 status, N (~%)	
Negative	20 (69)
Positive	9 (31)
Tumor grade, N (~%)	
Grade 2	10 (34)
Grade 3	19 (66)
Tumor type, N (~%)	
Lobular	3 (10)
NST	25 (86)
Other	1 (3)
Tumor stage, N (~%)	
Stage I	3 (10)
Stage II	21 (72)
Stage III	4 (14)
Stage IV	1 (3)

Translation to English: LBO (low vocational education); MVO (secundary education); MBO (secondary vocational education); HAVO (senior general secondary education); HBO (university of applied science). NST = nonspecific type

Questionnaire responses

The overall results of the V1 questionnaire, as shown in Table 3, indicate that for 11 out of 12 questions, at least 22 women were satisfied with the care they received. For 10 questions, the majority of responses were either “completely agree” or “agree”. In response to questions 8 and 11, disagreement indicates satisfaction. The majority responses for these questions were “completely disagree' (with

14 women completely disagreeing) and "neutral" (with 11 women choosing neutral), respectively (Appendix D, Figures D1-D12).

Out of 29 patients, 7 women were not satisfied with the time allocated for decision-making between tests and the start of chemotherapy (Q7). This was further highlighted in question 8, where also 7 out of 29 patients indicated they would have liked more time to decide. In the remarks field patients mainly stated that they felt a sense of urgency and a lack of sufficient options when starting their treatment (Appendix C). Question 11 also addressed timing concerns, reflecting the most dissatisfaction among the patients. Specifically, 11 patients expressed a neutral opinion, and 6 patients had a preference to start treatment even earlier.

Table 3 – Descriptive statistics of the results from the V1 questionnaire (Q1-Q12)

Questions		Median (Q1-Q3*)	Satisfied, N (%)
1.	The treatment team has fully informed me about my diagnosis of breast cancer.	5 (4.0 – 5.0)	28 (96.6)
2.	The treatment team has fully informed me about different treatment options.	4 (4.0 – 5.0)	22 (75.9)
3.	The treatment team has fully informed me about the risks and side effects of the various treatment options.	4 (4.0 – 5.0)	26 (89.7)
4.	The treatment team has involved me in making decisions about my treatment.	4 (4.0 – 5.0)	24 (82.8)
5.	The time between (imaging) tests and results was acceptable for me.	4 (4.0 – 5.0)	25 (86.2)
6.	The time between (imaging) tests and the start of chemotherapy was acceptable for me.	4 (4.0 – 5.0)	26 (89.7)
7.	I had sufficient time between the tests and the start of chemotherapy to make the right treatment decision.	4 (4.0 – 5.0)	22 (75.9)
8**.	I would have liked more time to decide on a treatment.	2 (1.0 – 2.0)	22 (75.9)
9.	There was sufficient time between the consultation at the oncologist and the start of chemotherapy.	4 (4.0 – 4.0)	25 (86.2)
10.	There was sufficient time between the consultation with the nurse specialist about NAC and the start of NAC.	4 (4.0 – 5.0)	25 (86.2)
11**.	I would have preferred to start the treatment sooner.	3 (2.0 – 3.0)	12 (41.4)
12.	The treatment team kept to the agreements made with me.	5 (4.0 – 5.0)	29 (100)

** Q1 and Q3 represent the first and third quartiles of the data, respectively. The higher the value, the more satisfied*
*** For questions 8 & 11 satisfied means "disagree". The lower the median value, the more satisfied*
NAC = Neoadjuvant chemotherapy

Of the patients included in the study, 8 individuals were under the age of 40. Among this subgroup, 4 participants responded positively when asked whether they felt they had enough time to consider their desire to have children within the context of their treatment decisions (see Table 4). Significantly, the remaining 4 participants did not provide a response to this question.

Table 4 - Descriptive statistics of the results from the V1 questionnaire (Q13)

Question		Median (Q1-Q3*)	Satisfied, N (%)
13.	I had sufficient time to think about my desire to have children	5 (4.0 – 5.0)	4 (100)

** Q1 and Q3 represent the first and third quartiles of the data, respectively*

Influence of demographics on participant satisfaction

Different demographic variables were analyzed to determine their influence on the responses to each question. Age was examined for its influence on patient satisfaction, considering that different age groups often have varying healthcare needs and expectations (Appendix D, Table D1). While some questions show small to medium effect sizes, none of the relationships are statistically significant.

The highest measured Cohen's d is 0.53 for Q5 "The time between (imaging) tests and results was acceptable for me". The mean age of this question for the satisfied group was 49.4 and the mean age for the dissatisfied group was 42.8.

In comparing satisfaction levels between high and low educated participants, two findings are significant (Appendix D, Table D2). Firstly, regarding the provision of information about risks and side effects (Q3), High educated patients exhibited a 1.43 times higher likelihood of satisfaction (RR = 0.70, p = 0.03). Similarly, when evaluating if there is enough time for treatment decision-making, high educated participants were 1.79 times more likely to express satisfaction (RR = 0.56, p = 0.03).

Despite no statistically significant influences being found between women with paid work and those in other work situations, the analysis revealed some trends (Appendix D, Table D3). For example, patients with paid work were 1.65 times more likely to be dissatisfied with the amount of time for treatment decision-making compared to those in other work situations (Q7).

Although the influence of living with a partner versus without also showed no significance (Appendix D, Table D4), results suggest that patients living with a partner were 1.65 times more likely to be dissatisfied with the amount of time available for making treatment decisions compared to those without a partner (Q7). Patients living with children showed a trend towards being 0.76 times more likely to express dissatisfaction with the amount of time provided between the nurse specialists and the start of NAC compared to those without children. (Q10), although this finding was also not statistically proven (Appendix D, Table D5).

The analysis between tumor grades 2 and 3 revealed one statistically significant difference (Appendix D, Table D6). Patients with grade 2 tumors were 0.56 times more likely to be satisfied with the information provided about treatment options compared to those with grade 3 tumors (Q2).

Development of the V2 questionnaire

The development of the V2 questionnaire was a structured process aimed at addressing the limitations and including feedback from the V1 questionnaire. Some important changes that have been made to the V2 questionnaire are shown in Table 5. These changes were made to enhance the clarity, relevance, and comprehensiveness of the questionnaire.

Table 5 - Change description from V1 to V2 questionnaire

Change description	
Enhanced Clarity	Some questions were changed to ensure that the questions are clearly understood by the participants. In the V1 questionnaire the interpretation of some questions might be different than the intent, like Q6: "the time between tests and the start of chemo was acceptable". It is unclear which tests are referred to and whether it is the first or last test.
Including answer categories	This is done to stimulate the thoughts of participants, provide guidance for their responses, and to encourage detailed feedback.
Combining questions	This is done to streamline the questionnaire and avoid redundancy, as the V1 contained numerous questions that were similar in nature.
Digitalization	It is highly recommended to turn the V2 questionnaire into a digital format. This makes it easier to access, analyze data, and ensure all questions are answered. A paper version should be provided for individuals who struggle with using online technology.
Mandatory subsequent questions	Out of 60 times someone was dissatisfied, they did not provide any remarks in 29 cases. Therefore, if someone (strongly) disagrees, it should be mandatory to complete the subsequent question or remarks field, ensuring input on how care could be improved.

Follow-up consent	Asking this question allows for the possibility of further engagement with participants, potentially through follow-up interviews, which can provide deeper insights and clarification on their responses.
Adding questions	Questions like “What is your age?” and “Have you previously been diagnosed with cancer” were added to make potential data analysis more efficient. The data no longer needs to be extracted from the EPD.
Change introduction	The introduction was modified to discourage the use of the answer, "Neutral," which was chosen 37 times in the V1 questionnaire, and encourage participants to provide feedback if they (strongly) disagree. It also encourages participants to share positive experiences and offer suggestions for further improvement.
Adding prompts	The V1 questionnaire sometimes only used the word ‘comments’ as a remarks field. Different prompts were added to the remarks fields in the V2 questionnaire to encourage detailed feedback, like: "How could we have increased your involvement & in which decision was your input not sufficiently considered?".

Throughout the development of the V2 questionnaire, the process was discussed multiple times with the breast cancer nurse specialist for continuous improvement. A final concept of the V2 questionnaire was distributed to a diverse range of 10 individuals, including health care providers and members of the general public, across different age groups, education levels, and backgrounds, ensuring broad representation. All individuals were instructed to comment on the clarity of the questions, share how much time they needed to finish the questionnaire, indicate if the questions made sense, and confirm if all important topics were included. Their input was used to adjust the questionnaire, clarify the wording, and adjust answer categories. No questions were removed. The final V2 questionnaire, comprising 5 general questions, 14 Likert scale questions about the treatment period, and 2 closing questions, is available in Appendix E.

Discussion & Conclusion

Conclusions of results

In this study, it was found that most patients are satisfied with the care they receive. However, seven patients expressed dissatisfaction with the time for decision-making before chemotherapy. Higher education correlated statistically significant with higher satisfaction regarding information provision and decision-making time. Patients with grade 2 tumors were statistically significant more likely to be satisfied with treatment information compared to grade 3 tumor patients. Other factors showed no significant impact on satisfaction. Based on previous research and data analysis, it was found that the V1 questionnaire lacked specificity in identifying reasons for patient dissatisfaction.

The time needed during the NAC trajectory varies significantly among patients. The results from Q11 highlight this variation, with diverse answers indicating that while some patients wanted more time to make decisions, others felt the process was too slow. This shows the varied needs and preferences among patients regarding treatment timelines. Other studies also confirm that decision making preferences are not static [17, 18].

Based on the responses to Q7 and Q8, it appears that not all patients are satisfied with the time given to make a treatment decision. The remarks field was only completed by a small number of patients, providing little information about why this time was too short. The V2 questionnaire will specify these options to give more insight into the difficulties and dilemmas patients face in their decision-making.

In comparing satisfaction levels between high and low educated participants, two significant findings were found. High educated patients were more likely to feel satisfied with both the information about risks and side effects, as well as the time allocated for treatment decision-making. No other studies were found that supported this finding, but these results suggest that the level of education could significantly influence how patients perceive the quality of their care. Healthcare providers should therefore adjust their communication and decision-making to better meet the needs of patients with different education levels. Investigating the use of digital decision aids, like the tools from ‘ZorgKeuzeLab [19]’ and ‘Predict Breast [20]’, could maybe provide a solution to this problem.
Furthermore, the analysis comparing tumor grades 2 and 3 discovered a statistically significant difference in patient satisfaction regarding the information provided about treatment options. Patients with grade 2 tumors were less likely to express dissatisfaction. This finding can not really be explained, since the grade alone does not determine the prognosis. Clinicians also do not recognize in practice that the grade influences satisfaction. With a larger study population in future research, this significant found may either be disproven or substantiated.
Age was also examined for its influence on patient satisfaction. While there were small to medium effect sizes for some questions, none of the relationships were statistically significant. This indicates that age did not significantly impact patient satisfaction in this study. However, the patient sample size was relatively small, with an average age of 48, and only 17% of participants were older than 60 years. This limited representation of older individuals in the study population may have contributed to the lack of significance found regarding age-related effects on patient satisfaction. Additionally, no significant findings were observed for the other variables.

Overall, this study aligns with L. Poolen's findings [12] regarding satisfaction levels. However, unlike the previous study, which initially included 15 participants, the larger sample size in this study has allowed for the identification of significant results that were not previously observed. The effect sizes of the significant findings showed minimal deviation compared to those reported by L. Poolen. This highlights the importance of a larger sample size in improving statistical power.

Strength & Limitations

The study uses both quantitative and qualitative methods to understand the experiences of women with breast cancer during NAC. This dual approach provides a thorough understanding of both patient

experiences and the medical processes involved. The study gathered feedback from patients through the V1 questionnaire and remarks fields, providing valuable insights into patient experiences and areas needing improvement. Another strong point of the study is that the researcher observed various types of examinations and consultations firsthand, interacting with patients and speaking with many breast cancer care professionals. This approach provided a deep understanding of the context, processes, and dynamics involved. These insights complemented the data analysis, literature review, and feedback from patients and medical professionals, which were crucial in developing the V2 questionnaire. Additionally, including a diverse range of 10 individuals (including health care providers and members of the general public) in the V2 questionnaire testing helped ensure that the tool is applicable and understandable across different demographics, enhancing its relevance and quality.

A limitation of the study is that the data entry process for the V1 questionnaires was done manually by the researcher, which could lead to mistakes. However, the upcoming administration of the V2 questionnaire online will address this issue, enhancing the objectivity and reliability of the data collection process. Additionally, the study encountered limitations due to its small sample size, with only 29 patients participating in the V1 questionnaire. This limited sample size might affect the analysis and make it harder to identify important patterns or relationships. Furthermore, some demographic variables are interrelated, like having children at home, employment status, and age, which can cause confounding. For example, if younger individuals are more likely to have children at home and also tend to have different employment statuses compared to older individuals, these factors may influence the outcome being studied (satisfaction levels). Including more patients is expected to stabilize the results and clarify whether they are significant or definitively not significant.

Conclusion

In conclusion, this study aligns with previous research indicating that overall, patients are satisfied with their care, although the time between diagnosis and NAC needs attention. The V1 questionnaire lacked specificity in identifying reasons for patient dissatisfaction. However, the revised V2 questionnaire addresses this by including additional options for patients to specify reasons for needing more or less time to make treatment decisions.

Recommendations future research

For future research, using the V2 questionnaire is essential, as it addresses the shortcomings of the V1 questionnaire and has the potential to provide deeper insights into the challenges faced by breast cancer patients. Additionally, increasing the sample size in subsequent studies can strengthen the reliability and validity of the results. This can be achieved by making the questionnaire available for all woman who undergo NAC and recommending completing it. Furthermore, the V2 questionnaire should be shared with other hospitals for wider use after being tested in MST Twente. This will enlarge the sample size and increase statistical power, allowing for more robust and reliable results.

Moreover, future research could involve patient interviews. Now, with the V2 questionnaire, patients are asked whether they are open to being approached for an interview. This approach would allow for a more in-depth exploration of patients' experiences throughout the NAC trajectory, particularly focusing on the time between diagnosis and treatment. The interview can also be used to learn more about the fertilization process for women who still want to have children and the time pressure involved in this process. This deeper understanding helps identify areas where improvements can be made to enhance patient outcomes.

Concluding, exploring the impact of digital tools, like ‘ZorgKeuzeLab’ or ‘PredictBreast’, on patient satisfaction and decision-making is highly recommended. Investigating the use of digital decision aids and online information portals can provide valuable insights, like the tools from ‘ZorgKeuzeLab’ and ‘Predict Breast’. It is advised to evaluate whether these tools improve the patient experience and decision-making process, especially for those who may need more time or information.

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Appendices

Appendix A – V1 Questionnaire (in Dutch)

CABRIO studie

Onderzoek naar de wensen en ervaringen van de borstkankerpatiënten in het neo-adjuvante traject

Mammacare

De vragenlijst: Bij de diagnose borstkanker, komt er veel op u af. Ook u is dat overkomen. Na de vele onderzoeken, en vaak ook vervolgonderzoeken, volgen verschillende keuzeopties. De tijd tussen diagnose en start behandeling is niet alleen spannend maar vaak ook complex. Wat is er mogelijk? Wat kan ik aan? Wat wil ik? Enz.

In de praktijk streven wij ernaar om maximaal 5 weken na het vaststellen van de diagnose te starten met de behandeling. Dit betekent dat een patiënt veel beslissingen moet nemen in een korte periode.

Als Centrum voor Mammacare zijn wij benieuwd naar uw ervaringen in de afgelopen weken. Met deze vragenlijst willen wij u vragen uw ervaringen in de afgelopen weken met ons te delen. Wij willen de zorg graag zo goed mogelijk toespitsen op uw wensen. Daarvoor hebben wij uw hulp nodig. Het invullen van de vragenlijst duurt ongeveer 10 minuten. Uw medewerking wordt zeer op prijs gesteld.

U kunt de vragen beantwoorden door het getal te omcirkelen dat het meest op u van toepassing is.

1=Helemaal mee oneens

2=Mee oneens

3=Neutraal / Geen mening

4=Mee eens

5=Helemaal mee eens.

Vragen over de behandelperiode

	Helemaal mee oneens	Mee oneens	Neutraal / Geen mening	Mee eens	Helemaal mee eens
1. Het behandelteam heeft mij volledig geïnformeerd over mijn diagnose borstkanker. Indien oneens: welke informatie heeft u gemist?	1	2	3	4	5
2. Het behandelteam heeft mij volledig geïnformeerd over de verschillende behandelingsmogelijkheden.	1	2	3	4	5

Indien oneens: welke informatie heeft u gemist?

3. Het behandelteam heeft mij volledig geïnformeerd over risico's en bijwerkingen van de diverse behandelingen.	1	2	3	4	5

Indien oneens: welke informatie heeft u gemist?

4. Het behandelteam heeft mij betrokken bij het nemen van beslissingen omtrent mijn behandelingen.	1	2	3	4	5

Indien oneens: Bij welke beslissing is er onvoldoende naar u geluisterd?

5. De tijd die tussen de onderzoeken en de uitslag van de onderzoeken zat, vond ik acceptabel.	1	2	3	4	5

Indien oneens: Op welke uitslag hebt u lang moeten wachten?

6. De tijd die tussen de onderzoeken en start chemotherapie zat, vond ik acceptabel.	1	2	3	4	5

Opmerkingen:

7. Ik heb voldoende tijd gehad tussen de onderzoeken en start chemotherapie om een juiste behandelkeuze te maken.	1	2	3	4	5

Opmerkingen:

8. Ik had graag meer tijd willen krijgen om te beslissen.	1	2	3	4	5

Opmerkingen:

9. Er zat voldoende tijd tussen het bezoek aan de internist-oncoloog en de start chemotherapie.	1	2	3	4	5

Opmerkingen:

10. Er zat voldoende tijd tussen de voorlichting door de verpleegkundig specialist / oncologie verpleegkundige over de chemotherapie en de start van de chemotherapie	1	2	3	4	5

Opmerkingen:

11. Ik had graag sneller willen starten met de behandeling.	1	2	3	4	5

Opmerkingen:

12. Het behandelteam hield zich aan de met mij gemaakte afspraken.	1	2	3	4	5

Opmerkingen:

De onderstaande vraag alleen beantwoorden indien u ten tijde van de diagnostiek een actieve kinderwens had.	Helemaal mee oneens	Mee oneens	Neutraal / Geen mening	Mee eens	Helemaal mee eens
13. Ik heb voldoende tijd gehad om na te denken over mijn actieve kinderwens.	1	2	3	4	5

Opmerkingen:

Algemene vragen

Hieronder willen wij u vragen nog een aantal algemene vragen te beantwoorden:

1. Wat is uw hoogst afgeronde (school)opleiding? (1 vakje aankruisen)
   - ☐ Basisschool
   - ☐ Lager Voortgezet Onderwijs (LAVO, VGLO)
   - ☐ Lager Beroepsonderwijs (LHNO, Huishoudschool, LTS, LDS)
   - ☐ Middelbaar Voortgezet Onderwijs (VMBO, MAVO, MMO, MULO)
   - ☐ Middelbaar Beroepsonderwijs (MEAO, MTS, MDGO)
   - ☐ Hoger Algemeen Voortgezet Onderwijs (HAVO)
   - ☐ Voorbereidend Wetenschappelijk Onderwijs (VWO, HBS, Atheneum, Gymnasium)
   - ☐ Hoger Beroepsonderwijs (HBO, HTS, HEAO)
   - ☐ Universiteit

2. Hoe is uw woonsituatie? (een vakje aankruisen)
   - ☐ Ik woon alleen
   - ☐ Ik woon alleen met een kind(eren)
   - ☐ Ik woon met een partner
   - ☐ Ik woon met een partner en kinderen
   - ☐ Ik woon met mijn ouders
   - ☐ Ik woon in een woongroep
   - ☐ Anders namelijk:……..

3. Hoe is uw werksituatie: (1 vakje aankruisen)
   - ☐ Betaald werk
   - ☐ Vrijwilligerswerk
   - ☐ Werkzoekende
   - ☐ Arbeidsongeschikt
   - ☐ Gepensioneerd
   - ☐ Studente
   - ☐ Anders, namelijk:……..

Opmerkingen:

Appendix B – V1 Questionnaire (in English)

1. **The treatment team has fully informed me about my diagnosis of breast cancer.**
   Remarks:
2. **The treatment team has fully informed me about different treatment options**.
   Remarks:
3. **The treatment team has fully informed me about the risks and side effects of the various treatment options.**
   Remarks:
4. **The treatment team has involved me in making decisions about my treatment.**
   Remarks:
5. **The time between (imaging) tests and the results was acceptable to me.**
   Remarks:
6. **The time between (imaging) tests and the start of chemotherapy was acceptable to me.**
   Remarks
7. **I had sufficient time between the tests and the start of chemotherapy to make the right treatment decision.**
   Remarks:
8. **I would have liked to have more time to decide on a treatment**
   Remarks:
9. **There was sufficient time between the consultation at the oncologist and the start of chemotherapy.**
   Remarks:
10. **There was sufficient time between the consultation with the nurse specialist about chemotherapy and the start of the chemotherapy.**
    Remarks:
11. **I would have preferred to start the treatment sooner**
    Remarks:
12. **The treatment team kept to the agreements made with me**
    Remarks:
13. **I had sufficient time to think about my desire to have children**
    Remarks:

General questions

1. **What is your highest completed level of education?**

Options: Primary education, lower secondary education, low vocational education, secondary education, secondary vocational education, senior general secondary education, university of applied sciences and university.

2. **What is your living situation?**

Options: Living alone, living alone with children, living with a partner, living with a partner and children, living with parents, living in a living community or different.

3. **What is your employment status?**

Options: paid work, volunteering, job seeker, unable to work, retired, student or different.

Remaining remarks: do you have remaining remarks about the period between your diagnosis and the start of the chemotherapy?

Appendix C – Remarks of Patients from V1 Questionnaire

1. **The treatment team has fully informed me about my diagnosis of breast cancer**

Nr of remarks	5
Remarks in writing (Dutch)	1. Heb niet echt wat gemist, maar dat de "bron" niet echt duidelijk is gevonden is lastig soms. Geeft toch een stukje angst en zoek dan naar geruststelling. Dat het vaker voorkomt en behandelbaar is. (2) 2. Dat denk ik. (5) 3. Ik ga ervan uit dat alles is verteld, de herneu2 informatie kwam volgens mij wel wat laat. (4) 4. Ik heb op 04-04-2023 pas alle scans gezien, informatie ontvangen en een update gekregen over de erfelijkheid, terwijl ik 7/4 al de eerste chemo ontvang. Hierdoor was het niet/nauwelijks mogelijk om een second opinion aan te vragen en was het mij niet duidelijk hoe groot de kans op terugkeer was. (Bij erfelijke borstkanker loop je groter risico op uitzaaiingen bij de eierstokken). (4) 5. Ik heb twijfels over mijn diagnose omdat men mij in een ander ziekenhuis een verkeerde diagnose gegeven heeft. (4)
Summary remarks	1. Missing source of information 2. Looking for more comfort 3. Trusting that professional has fully informed them 4. Not fully informed, late results, no time for second opinion 5. Doubts because of wrong diagnosis (other hospital)
Improvement of care	

2. **The treatment team has fully informed me about different treatment options**

Nr of remarks	8
Remarks in writing	1. Mogelijkheden niet echt over gehad. Ze vertelden over hoe het zou gaan. Wat de behandel manier is. Ik ga ervan uit dat zij het weten. (3) 2. Ik heb 1 optie gehoord, weet ook niet of er meer mogelijkheden zijn. Ik ga er vanuit dat dit het beste is. (3) 3. De informatie die gegeven werd was erg warrig en soms ook erg onduidelijk- dit lag ook aan het feit dat ik een bindweefselziekte heb, maar wanneer ik los van de bindweefselziekte om feitelijke statistieken vroeg bleef men er summier. Hierdoor is het voor mij erg moeilijk om gedegen afwegingen te maken en/of een risicoschatting te maken waarvoor ik bij bijvoorbeeld levenskwaliteit op ga offeren voor levensjaren. Als ik bijvoorbeeld me neuropathie en oedeem moet leren leven in ruil voor een kankervrij worden het een overmate levensverwachting, teloor ik toch echt voor fysiek ongemak in ruil voor meer tijd. (2) 4. Ik had niet echt het idee dat er echt iets te kiezen viel. (2) 5. Mogelijkheden zijn besproken, ik voel dat ik wel echt behandeld moet worden. (4) 6. Ik kreeg beetje met beetje dat er nog iets bij kwam. Eerst chemo en operatie, week later ook bestraling en later nog eens hormoonkuur en dat had ik niet verwacht. (3) 7. Eigenlijk alleen huidige mogelijkheid geadviseerd. (4) 8. Er is 1 behandelplan met mij besproken en deze volg ik (3)
Summary remarks	1. Only one option, trusting the professional to know best 2. Information was unclear and chaotic due to another illness. This makes decisions concerning quality of life difficult. 3. There was not really a choice to be made 4. Unexpected amount of treatments
Improvement of care	

3. **The treatment team has fully informed me about the risks and side effects of the various treatment options**

Nr of remarks	5

Remarks in writing	1. Ik ga ervan uit dat alles is verteld. (4) 2. Er werden wel risico's en bijwerkingen genoemd, maar er is geen onderzoek/literatuur voorhanden over EDS en kanker. Alhoewel ik een milde vorm van EDS heb, werd er soms extreem voorzichtig gedaan met het doen van uitspraken. Verder heb ik het idee dat het hele proces een soort van trial & error gaat worden waarbij er weer momenten zijn waarop gekeken wordt of de behandeling zinvol is gebleken. Dit maakt me wel redelijk onzeker. (2) 3. Ik heb niet alles opgenomen en zeker ook niet alle informatie kunnen onthouden, de periode van diagnose is erg intensief. (4) 4. Geen risico's en bijwerkingen (2) 5. Voornamelijk meest voorkomende bijwerkingen (4)
Summary remarks	1. Trusting the professional to have fully informed them 2. No information available for comorbidity. 3. Extremely careful with predictions/chances about treatment 4. Information overload, so not remembering everything 5. Diagnostic period is very intensive
Improvement of care	

4. **The treatment team has involved me in making decisions about my treatment**

Nr of remarks	5
Remarks in writing	1. Zie vraag 2. Ik vertrouw erop dat de beste behandelingen zijn gekozen. (4) 2. Even twijfelachtig tussen 4&5 omdat ik graag wil dat beide borsten worden afgezet. Dit heb ik in 2020 bij het verwijderen van mijn protheses aan dokter Rakhorst al gevraagd. Daar is toen niet naar geluisterd en nu heb ik borstkanker met uitzaaiingen. Al vanaf mijn 12e loop ik al bij artsen voor mijn borsten. Op mijn 15e heb ik protheses gekregen omdat dit mooier zou zijn. Op mijn 16e zijn de implantaten geplaatst. En sindsdien heb ik alleen pijn & ellende door mijn borsten gehad. Ik ben er klaar mee en wil ze niet meer. (4) 3. Ik had niet het idee dat er echt iets te kiezen viel. (2) 4. Uiteindelijk heb ik zelf de beslissing genomen. (5) 5. De gesprekken gingen erg snel. Ik was blij dat ik het had opgenomen. Arts gaf graag extra uitleg. (5)
Summary remarks	1. Trusting the professional to make the right decision for them 2. Was not heard in the past and now experiences the consequences 3. Able to make my own choices
Improvement of care	

5. **The time between (imaging) tests and the results was acceptable to me.**

Nr of remarks	7
Remarks in writing	1. Uitslag biopt duurde mij iets te lang waarschijnlijk ook doordat de afspraak verplaatst was. (4) 2. De uitslag van de biopten was vertraagd, kan gebeuren maar we waren al op weg naar de afspraak toen er gebeld werd afgebeld/verplaatst. (3) 3. Al met al duurde de onzekerheid lang doordat de PET-scan “mislukt” was. (3) 4. Alleen op het gen onderzoeken moesten we lang wachten. (4) 5. Na de oncoloog mocht gesprek verpleegkundige wel achteraan. Ik moest een week wachten. (4) 6. Op de uitslagen hoefden we niet lang te wachten, maar de onderzoeken wel. (4) 7. Ik vond het wachten op de MRI wel lang duren voordat ik aan de beurt was. (4)
Summary remarks	1. The biopsy results took a long time, and the appointment was rescheduled. 2. Late cancellation of appointment 3. Long period of uncertainty due to failed PET-scan 4. Long waiting times for MRI and other tests
Improvement of care	

6. **The time between (imaging) tests and the start of chemotherapy was acceptable to me.**

Nr of remarks	5
Remarks in writing	1. Ik vond het best lang duren, voor mijn gevoel. Maar er moest ook veel gebeuren. Als ik daarnaar kijk had het niet veel sneller gekund. (4) 2. De onderzoeken voor bijv het hart hadden eigenlijk eerder ingepland moeten worden evenals de terugkoppeling met de vaatchirurg over een PICC-lijn of Port a Cath- men wist bij de intake al van mijn EDS en ik heb dit zelf uit moeten zoeken. (4) 3. Had wel eerder gemogen, 5 weken is echt wel lang. (3) 4. Dit was ook mijn eigen keus een week later te starten, zodat ik niet in onze vakantie de tweede kuur te krijgen. (4) 5. Onderzoeken duurde lang. Jammer dat ik pet scan heb laten met de wetenschap dat deze tumoren niet goed zichtbaar zou zijn. Daarom de nap pet en ct scan. (2)
Summary remarks	1. It took a lot of time but there was probably no way to do it faster 2. Examinations and tests could have been planned earlier 3. Communication between departments could have been better, about port a Cath 4. Chemo may have started earlier
Improvement of care	

7. **I had sufficient time between the tests and the start of chemotherapy to make the right treatment decision.**

Nr of remarks	7
Remarks in writing	1. De keus was gemaakt en ik ga ervoor. (4) 2. Ik heb maar 1 keuze gehoord, ik ga ervan uit dat dat ook het beste is. 3. Geen second opinion aan kunnen vragen. Geen port a cath kunnen plaatsen alvorens chemo- onderzoeken waren rommelig ingepland/ checklist en casemanagement ontbrak. (1) 4. Ik had niet het idee dat er echt iets te kiezen viel. (2) 5. Diep van binnen twijfel ik nog over de behandelkeuze. Ik had het liefst langer gewacht maar dat voelt niet als een optie omdat de tumor groeit. (3) 6. Na de oncoloog mocht gesprek verpleegkundige wel achteraan. Ik moest een week wachten. (4) 7. Ging wel heel snel (3)
Summary remarks	1. There was only one option 3x 2. No time for second opinion 3. Doubts about choice of treatment 4. Wanting to wait longer but fearing negative impact on disease
Improvement of care	1. Advise to make a checklist for each patient

8. **I would have liked to have more time to decide on a treatment**

Nr of remarks	5
Remarks in writing	1. Eigenlijk hoefde ik nergens over te beslissen. (1) 2. Snel beginnen lijkt mij juist goed. (2) 3. Met name had ik graag een checklist willen krijgen waar ik aan moest denken, wat ik moest voorbereiden en zoo. Nu heb ik alles via vrienden en het internet moeten halen (zelfs over de port a cath en PICClijn). (1) 4. Ik had het liever willen uitstellen maar dit voelde niet als een optie omdat de tumor blijft groeien. (5) 5. Graag meer tijd maar ivm groei niet verstandig (2)
Summary remarks	1. There was not really a decision to make. 2. A fast start is beneficiary according to me 3. Postphoning has a negative impact on disease
Improvement of care	1. I would have liked a checklist with everything I needed to prepare for this

9. **There was sufficient time between the consultation at the oncologist and the start of chemotherapy.**

Nr of remarks	4
Remarks in writing	1. Wel genoeg tijd, maar door extra onderzoeken praktisch dagelijks in het ziekenhuis. (3) 2. Dit bezoek had wat mij betreft een week eerder gemogen (4) 3. Mocht sneller (2) 4. Weinig informatie ontvangen van internist over chemobehandeling, dus tijd tussen afspraak internist en start chemo voor mij niet relevant (3)
Summary remarks	1. There was enough time but many hospital visits 2. Could be faster
Improvement of care	

10. **There was sufficient time between the consultation with the nurse specialist with detailed information about chemotherapy and the start of the chemotherapy.**

Nr of remarks	2
Remarks in writing	1. Er zat maar 1 dag tussen. Dit was voor mij echter voldoende want ik wist dat komen zou en graag z.s.m. (4) 2. 24 uur zat ertussen (2)
Summary remarks	1. I knew it was needed, so I was prepared 2. I only had 24 hours to prepare
Improvement of care	

11. **I would have preferred to start the treatment sooner**

Nr of remarks	12
Remarks in writing	1. Ik had best sneller willen starten, maar zie ook zeker in dat dat lastig was met mijn diagnose en onderzoeken. Dus als ik erop "terugkijk" is het goed zo! Er is veel aan gedaan om z.s.m. onderzoeken te doen. Top. (4) 2. Kon niet sneller, wel gewild. (4) 3. Ik wil natuurlijk zsm starten, maar het is ook goed dat alles eerst goed is onderzocht. (3) 4. Ik had graag gestructureerder een plan van aanpak voor de onderzoeken en de voorbereidingsfase gehad. Daarnaast had ik graag gehad dat de PICClijn & Port a Cath gezien mijn EDS en het behandelplan proactief alvorens de chemo van start ging was aangeboden/ kon worden geplaatst. (3) 5. Ik voel dat de grootte van de tumor toeneemt, daarom zie ik het belang van een snelle behandeling in. (4) 6.Ik vond het erg fijn nog even met mijn gezin op vakantie te kunnen gaan en dat dit gesteund werd vanuit het ziekenhuis. (1) 7. Zo snel mogelijk als duidelijk is welke soort tumor en waar het zit (5) 8. Al met al prima (2) 9. Gaat nooit snel genoeg, maar 5 weken is erg snel. (1) 10. Er moest ook rekening gehouden worden met het fertilisatie traject. (3) 11. Ja, onderzoek en vele afspraken misschien bundelen of bijv uitstellen zoals afspraak bestralingsarts. (2) 12. Ik denk dat iedereen graag sneller wil starten met de diagnose kanker. (4)
Summary remarks	1. Wanted to start as soon as possible (3x) 2. A more structured plan for the examinations and preparationphase would be appreciated 3. The tumor is growing, so treatment as soon as possible 4. I felt supported by the hospital to go on a holiday with my family
Improvement of care	1. Making a structured plan for the preparation phase 2. Combining appointments

12. **The treatment team kept to the agreements made with me**

Nr of remarks	1
Remarks in writing	1. Tot op heden nog weinig met het gehele team te maken gehad. Toch vond ik het in Enschede wat zakelijker/ prettiger verlopen doordat de communicatie eenvoudig en concreet was. Ik heb veel afspraken ad hoc zelf ingepland op basis van uitval. (4)
Summary remarks	1. Not having seen the whole treatment team
Improvement of care	

13. **I had sufficient time to think about my desire to have children**

Nr of remarks	2
Remarks in writing	1. Je moet ook gewoon snel schakelen (5) 2. We hebben eerst nog een icsi traject gedaan voor we gaan starten met de chemo
Summary remarks	1. You have to switch gears fast 2. Did an icsi trajectory before chemo
Improvement of care	

14. **Other remarks:**

Nr of remarks	15
Remarks in writing	1. Het onzekere is het zwaarst. Mentaal. Dat wachten op bijv. de uitslag van de PET-scan. Zou niet weten hoe het anders moet, maar dat was wel een heftige week. 2. Het duurde vrij lang wanneer er plek was bij de internist. Dr Pleunis werkt volgens een bepaalde methode en de daarbij horende onderzoeken. Van mij had dit voor die tijd al wel ingepland mogen worden even als de afspraak met de verpleegkundig specialist waardoor je de laatste dagen voordat je begint erg druk bent. 3. Ik vind dat ik overal ontzettend goed opgevangen ben. Het traject is erg duidelijk uitgelegd maar wel met een menselijke ondertoon. En dat is ook erg belangrijk in deze al onzekere tijd. 4. Ik heb het idee dat alle afdelingen die betrokken zijn goed samenwerken en dat geeft vertrouwen in de behandeling. 5. Enigzins chaotisch, niet altijd helder en concreet, gene tijd voor second opinion, maar wel fijn dat ik snel geholpen werd gezien de agressie v/d tumor + uitzaaiingen. Denk dat een betere inventarisatie tijdens de intake (er was toen al voor 95% duidelijk dat het kanker met uitzaaiingen in de lymfe was, dus dat er wel hoogstwaarschijnlijk chemo zou volgen). Een efficiënter onderzoeksplan waarbij bezoek aan de cardio & vaatchirurg al in week 2/3 hadden kunnen worden ingepland. Had veel stress en onzekerheid gescheeld. 6. Topteam! Fijn dat ik met al mijn onzekerheden terecht kan bij internist /vpk specialist. Juiste voorlichting ook door vpk dagbehandeling/ start kuur. 7. Bij sommige onderzoeken (vooral MRI-scan en hartfilmpje ging de verpleegkundige ervan uit dat ik alles wel wist). Bij de MRI ben ik (voor mijn gevoel) onvoldoende voorbereid op hoe dat onderzoek ging. Ik heb het als een heel naar onderzoek ervaren. Dit had m.i. voorkomen kunnen worden door een betere voorbereiding op hoe het zou gaan. 8. Dat ik prima en snel geholpen ben 9. De begeleiding van het gehele team is zeer prettig. De uitleg is goed en iedereen neemt de tijd voor je. Dat is heel fijn, vooral als je ineens in deze situatie bent beland. 10. Dat we Oldenzaal als een fijn en rustig ziekenhuis hebben ervaren. 11. Ik vind iedereen vriendelijke, meelevend en behulpzaam 12. Nee, vond het allemaal keurig snel gaan maar wachten duurt altijd te lang haha. Vond het erg prettig dat de 1e onderzoeken in Oldenzaal allemaal tegelijk plaatsvinden en ook direct uitslag. 13. Iedereen is super lief en behulpzaam 14. Het probleem was gewoon dat mijn lichaam mij geen keus gaf. 15. Het ging wel heel snel, maar i.v.m. groei en uitzaaiing alleen maar goed dat het snel is gegaan.

	16. Ik heb de betrokkenheid, en de tijd die het behandelteam neemt tijden de afspraken als heel prettig ervaren.
Summary remarks	1. Waiting for biopsy results is mentally the most difficult period. 2. I had to wait a long time before the oncologist had time. 3. Some consultations such as with the nurse specialist could have been planned earlier on. 4. I was in good hands; the trajectory was clearly explained. 5. There was chaos, no clear explanation and no time for a second opinion. 6. A more efficient diagnostic plan with more anticipation would be beneficiary. 7. I was content that they could help me so fast. 8. I was able to discuss all my doubts with the oncologist and specialist nurse. 9. For some examinations it was expected that I knew how it would go, I would have liked better preparations (for example MRI). 10. I really liked that the first tests in Oldenzaal are all at the same time.
Improvement of care	1.Some consultations such as with the nurse specialist could have been planned earlier on. 2.A more efficient diagnostic plan with more anticipation would be beneficiary 3.Better preparations for examinations (with information etc.)

Appendix D – Tables and figures

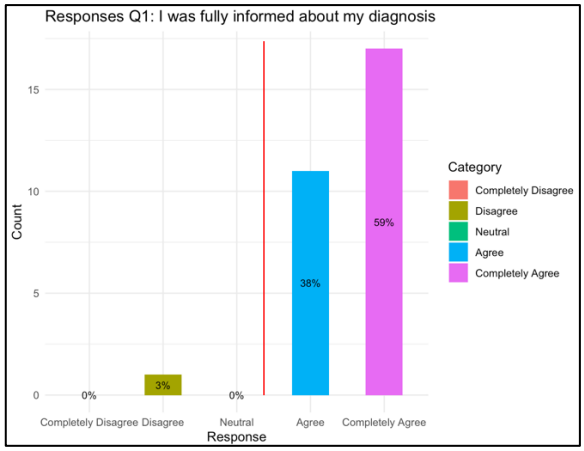

Figure D1: Responses to question 1 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

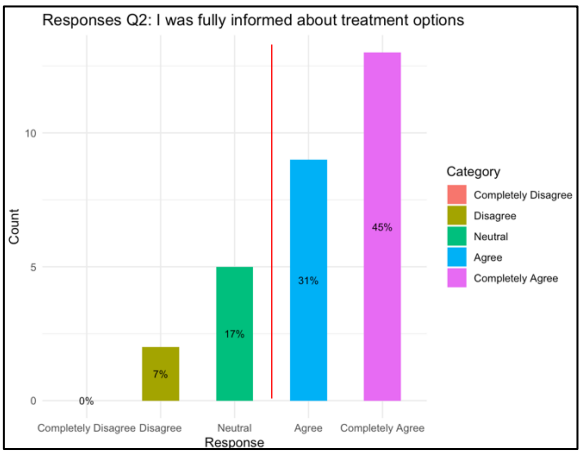

Figure D2: Responses to question 2 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

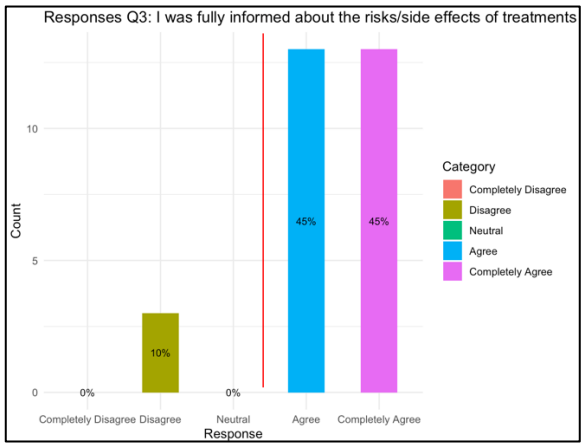

Figure D3: Responses to question 3 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

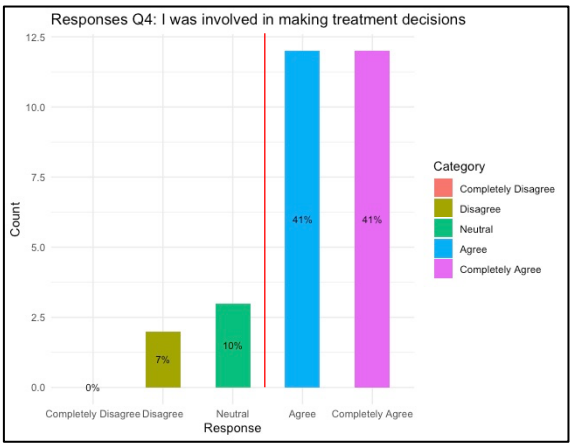

Figure D4: Responses to question 4 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

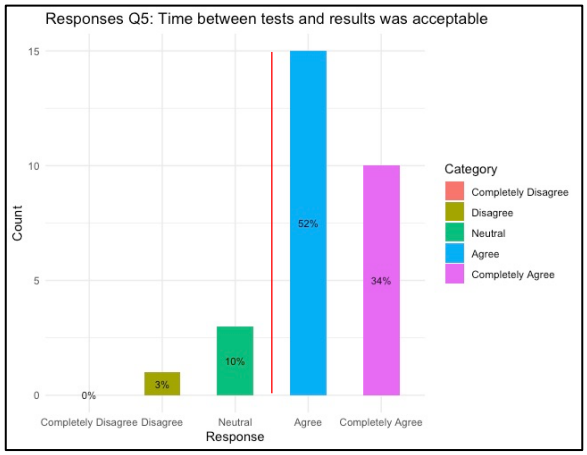

Figure D5: Responses to question 5 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

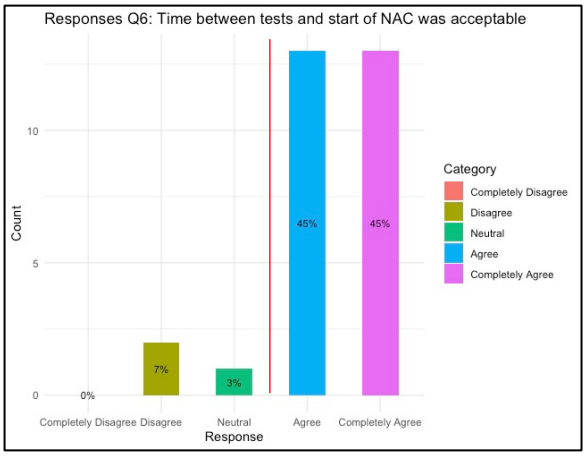

Figure D6: Responses to question 6 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

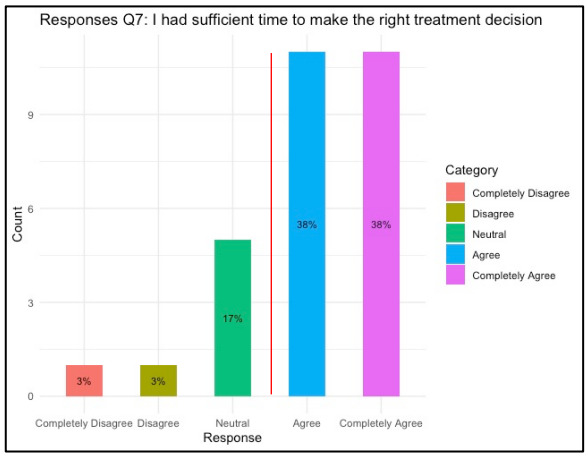

Figure D7: Responses to question 7 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

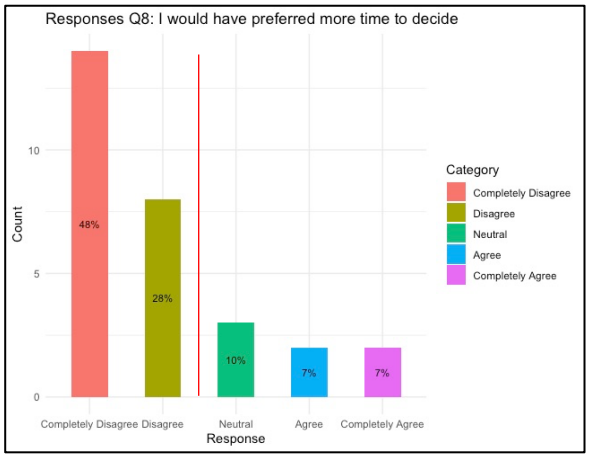

Figure D8: Responses to question 8 of the V1 questionnaire. The left side of the red line is coded as satisfied and the right side is coded as dissatisfied

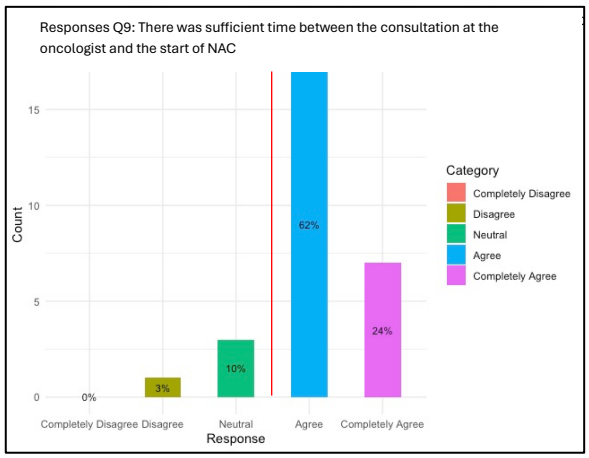

Figure D9: Responses to question 9 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

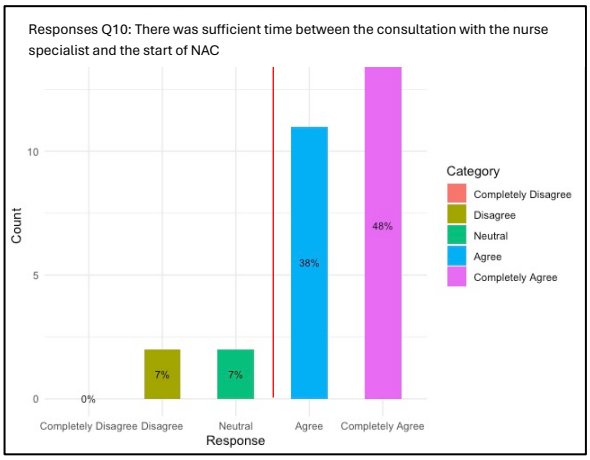

Figure D10: Responses to question 10 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

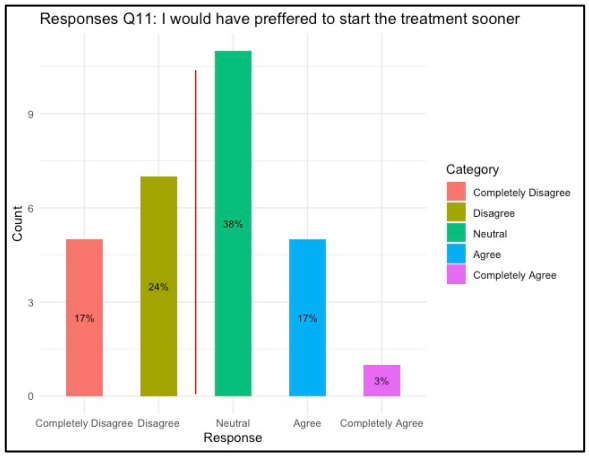

Figure D11: Responses to question 11 of the V1 questionnaire. The left side of the red line is coded as satisfied and the right side is coded as dissatisfied

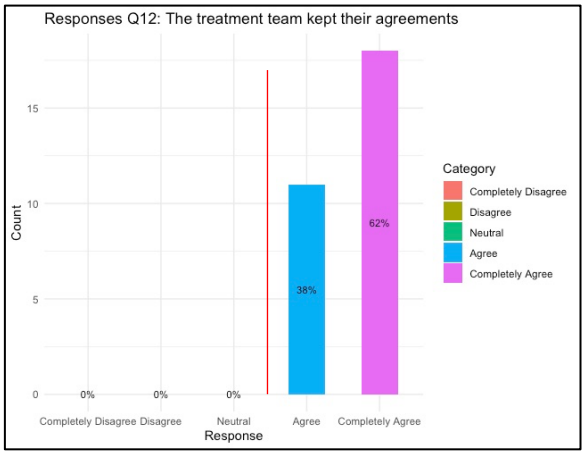

Figure D12: Responses to question 12 of the V1 questionnaire. The left side of the red line is coded as dissatisfied and the right side is coded as satisfied

Table D1: Relationship between age and satisfaction for 12 questions from the V1 questionnaire, N = 29

Relatioship between age and satisfaction (satisfied vs dissatisfied)		P value	Cohen's d	Mean age satisfied	Mean age dissatisfied
1.	Fully informed diagnosis	0.72	NA**	48.6	44.0
2.	Fully informed treatment options	0.65	0.24	49.2	46.1
3.	Fully informed risks & side effects	1.00	0.22	48.8	45.7
4.	Involved in treatment decision	0.86	0.01	48.5	48.4
5.	Acceptable waiting time test results	0.38	0.53	49.4	42.8
6.	Acceptable time between tests & NAC	1.00	0.16	48.7	46.7
7.	Enough time for treatment decision	0.40	-0.36*	47.4	51.9
8*.	Preffered more time for decision	0.46	-0.29*	47.6	51.3
9.	Enough time from oncologist to NAC	1.00	0.04	48.6	48.0
10.	Enough time from nurse specialist to NAC	0.68	0.30	49.0	45.3
11*.	Preferred starting treatment sooner	0.29	0.30	50.7	47.0
12.	Treatment team kept agreements	NA**	NA**	48.5	-

* Negative Cohen's d tells that the mean age of the satisfied group is lower than the dissatisfied group
** NA when only one or none of the participants are dissatisfied or there is not enough data to calculate
NAC = neoadjuvant chemotherapy

Table D2: Comparing satisfaction for high vs. low educated participants, N = 29

Comparing satisfaction (satisfied vs dissatisfied) for high vs. low educated participants		P value	Relative Risk	CI RR
1.	Fully informed diagnosis	1.00*	1.06	[0, NaN]*
2.	Fully informed treatment options	0.66	0.89	[0.15, 5.08]
3.	Fully informed risks & side effects	0.03	0.70	[0, NaN]*
4.	Involved in treatment decision	0.31	0.78	[0.11, 5.75]
5.	Acceptable waiting time test results	0.10	0.74	[0.07, 8.36]
6.	Acceptable time between tests & NAC	0.27	0.84	[0.07, 10.72]
7.	Enough time for treatment decision	0.03	0.56	[0.08, 3.81]
8*.	Preffered more time for decision	0.19	0.71	[0.12, 4.17]
9.	Enough time from oncologist to NAC	0.59	0.89	[0.11, 7.54]
10.	Enough time from nurse specialist to NAC	0.59	0.89	[0.11, 7.54]
11*.	Preferred starting treatment sooner	0.45	0.63	[0.12, 3.22]
12.	Treatment team kept agreements	1.00*	1.00*	[0, NaN]*

* P values of 1; relative risks of 1; upper bound confidence interval NaN means one of the quadrants of the contingency table is empty
CI = confidence interval
RR = relative risk
NAC = neoadjuvant chemotherapy

Table D3: Comparing satisfaction for paid work vs. other work situation, N = 29

Comparing satisfaction (satisfied vs dissatisfied) for paid work vs. other work situation		P value	Relative Risk	CI RR
1.	Fully informed diagnosis	1.00*	0.96	[0, NaN]*
2.	Fully informed treatment options	0.66	1.17	[0.16, 8.38]
3.	Fully informed risks & side effects	0.52	1.10	[0.08,14.62]
4.	Involved in treatment decision	0.55	0.78	[0, NaN]*
5.	Acceptable waiting time test results	0.55	0.83	[0, NaN]*
6.	Acceptable time between tests & NAC	1.00*	0.87	[0, NaN]*
7.	Enough time for treatment decision	0.13	1.65	[0.24, 11.38]
8*.	Preffered more time for decision	0.61	1.17	[0.16, 8.38]
9.	Enough time from oncologist to NAC	0.18	1.37	[0.15, 12.77]
10.	Enough time from nurse specialist to NAC	0.55	0.83	[0, NaN]*
11*.	Preferred starting treatment sooner	1.00*	1.30	[0.20, 8.61]
12.	Treatment team kept agreements	1.00*	1.00*	[0, NaN]*

* P values of 1; relative risks of 1; upper bound confidence interval NaN means one of the quadrants of the contingency table is empty
CI = confidence interval
RR = relative risk
NAC = neoadjuvant chemotherapy

Table D4: Comparing satisfaction for living with partner vs. without, N = 29

Comparing satisfaction (satisfied vs dissatisfied) for living with partner vs. without partner		P value	Relative Risk	CI RR
1.	Fully informed diagnosis	1.00*	0.96	[0, NaN]*
2.	Fully informed treatment options	0.13	1.65	[0.24, 11.38]
3.	Fully informed risks & side effects	0.10	1.43	[0.10,19.83]
4.	Involved in treatment decision	1.00*	0.99	[0.09, 10.96]
5.	Acceptable waiting time test results	0.55	0.83	[0, NaN]*
6.	Acceptable time between tests & NAC	1.00*	0.87	[0, NaN]*
7.	Enough time for treatment decision	0.13	1.65	[0.24, 11.38]
8*.	Preffered more time for decision	0.13	1.65	[0.24, 11.38]
9.	Enough time from oncologist to NAC	1.00*	1.04	[0.09, 12.29]
10.	Enough time from nurse specialist to NAC	0.55	0.83	[0, NaN]*
11*.	Preferred starting treatment sooner	0.35	2.87	[0.29, 28.55]
12.	Treatment team kept agreements	1.00*	1.00*	[0, NaN]*

* P values of 1; relative risks of 1; upper bound confidence interval NaN means one of the quadrants of the contingency table is empty
CI = confidence interval
RR = relative risk
NAC = neoadjuvant chemotherapy

Table D5: Comparing satisfaction for living with children vs. without, N = 29

Comparing satisfaction (satisfied vs dissatisfied) for living with children vs. without children		P value	Relative Risk	CI RR
1.	Fully informed diagnosis	1.00*	0.94	[0, NaN]*
2.	Fully informed treatment options	0.66	0.85	[0.13, 5.34]
3.	Fully informed risks & side effects	0.55	1.13	[0.09,14.14]
4.	Involved in treatment decision	1.00*	0.99	[0.14, 7.05]
5.	Acceptable waiting time test results	0.62	0.90	[0.08, 9.87]
6.	Acceptable time between tests & NAC	0.25	0.82	[0, NaN]*
7.	Enough time for treatment decision	1.00*	1.02	[0.18, 5.70]
8*.	Preffered more time for decision	0.40	1.24	[0.22, 6.97]
9.	Enough time from oncologist to NAC	0.62	0.90	[0.08, 9.87]
10.	Enough time from nurse specialist to NAC	0.12	0.76	[0, NaN]*
11*.	Preferred starting treatment sooner	0.70	1.41	[0.31, 6.53]
12.	Treatment team kept agreements	1.00*	1.00*	[0, NaN]*

* P values of 1; relative risks of 1; upper bound confidence interval NaN means one of the quadrants of the contingency table is empty
CI = confidence interval
RR = relative risk
NAC = neoadjuvant chemotherapy

Table D6: Comparing satisfaction for grade 2 vs. grade 3, N = 29

Comparing satisfaction (satisfied vs dissatisfied) for tumor grade 2 vs grade 3		P value	Relative Risk	CI RR
1.	Fully informed diagnosis	0.34	0.90	[0, NaN]*
2.	Fully informed treatment options	0.03	0.56	[0.08, 3.81]
3.	Fully informed risks & side effects	1.00*	1.01	[0.08,12.66]
4.	Involved in treatment decision	1.00*	0.95	[0.13, 6.88]
5.	Acceptable waiting time test results	0.59	0.89	[0.11, 7.54]
6.	Acceptable time between tests & NAC	1.00*	1.01	[0.08, 12.66]*
7.	Enough time for treatment decision	0.19	0.71	[0.12, 4.17]
8*.	Preffered more time for decision	0.66	0.89	[0.15, 5.08]
9.	Enough time from oncologist to NAC	0.59	0.89	[0.11, 7.54]
10.	Enough time from nurse specialist to NAC	0.27	1.27	[0, NaN]*
11*.	Preferred starting treatment sooner	1.00*	0.95	[0.20, 4.52]
12.	Treatment team kept agreements	1.00*	1.00*	[0, NaN]*

Appendix E – V2 Questionnaire (in Dutch)

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VRAGENLIJST

Bij de diagnose borstkanker komt er veel op u af. Na de vele onderzoeken, en vaak ook vervolgonderzoeken, volgen verschillende keuzeopties. De tijd tussen diagnose en start behandeling is niet alleen spannend maar vaak ook complex. Wat is er mogelijk? Wat kan ik aan? Wat wil ik? Enzovoorts.

In de praktijk streven wij ernaar om maximaal 5 weken na het vaststellen van de diagnose te starten met de behandeling. Dit betekent dat u veel beslissingen moet nemen in een korte periode.

Als Centrum voor Mammacare zijn wij benieuwd naar uw ervaringen in de afgelopen weken. Met deze vragenlijst willen wij u vragen uw ervaringen in de afgelopen weken met ons te delen. Wij willen de zorg graag zo goed mogelijk toespitsen op toekomstige patiënten. Daarvoor hebben wij uw hulp nodig. Het invullen van de vragenlijst duurt ongeveer 10 minuten. Uw medewerking wordt zeer op prijs gesteld.

De vragenlijst begint met algemene vragen. Daarna kunt u de vragen beantwoorden door het getal te kiezen dat het meest op u van toepassing is:

1 = Helemaal oneens
2 = Oneens
3 = Neutraal / Geen mening
4 = Eens
5 = Helemaal eens.

Gebruik 'Neutraal' alleen als u echt geen voorkeur of mening heeft. Als u bij een vraag aangeeft niet tevreden te zijn, verzoeken wij u vriendelijk om de bijhorende vervolgvraag in te vullen om ons te helpen begrijpen wat er verbeterd kan worden. U mag natuurlijk ook een opmerking achterlaten als u wel tevreden bent en u iets wil toelichten of adviseren.

Algemene vragen

1. Wat is uw leeftijd? *

2. Wat is uw woonsituatie? (één vakje aankruisen) *

- ◯ Ik woon alleen
- ◯ Ik woon alleen met kinderen
- ◯ Ik woon met mijn partner
- ◯ Ik woon met mijn partner en kinderen
- ◯ Ik woon bij mijn ouders
- ◯ Ik woon in een woongroep
- ◯ Anders, namelijk:

3. Wat is uw huidige werksituatie? (één vakje aankruisen) *

- ◯ Fulltime werkzaam
- ◯ Parttime werkzaam
- ◯ Arbeidsongeschikt
- ◯ Gepensioneerd
- ◯ Student
- ◯ Anders, namelijk: _____

4. Wat is uw hoogste afgeronde opleidingsniveau? (één vakje aankruisen) *

- ◯ Lagere school / basisonderwijs (bijv. LAVO, VGLO)
- ◯ Lager beroepsonderwijs (bijv. huishoudschool, LHNO, LTS, LDS)
- ◯ Middelbaar algemeen voortgezet onderwijs (bijv. VMBO, MAVO, MMO, MULO)
- ◯ Middelbaar beroepsonderwijs (bijv. MBO, MEAO, MTS, MDGO)
- ◯ Voortgezet algemeen onderwijs (bijv. HBS, MMS, HAVO, VWO, Gymnasium)
- ◯ Hoger beroepsonderwijs (bijv. HBO, HTS, HEAO) / universiteit

5. Heeft u vóór deze diagnose eerder de diagnose kanker gehad? *

- ◯ Ja
- ◯ Nee

Vragen over de behandelperiode

1. Het behandelteam heeft mij volledig geïnformeerd over mijn diagnose borstkanker. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: welke informatie ontbrak of was onduidelijk?

2. De informatie die door het behandelteam werd gegeven, was goed te begrijpen. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: wat begreep u niet en wat had u kunnen helpen om het beter te begrijpen?

3. Het behandelteam heeft mij volledig geïnformeerd over risico's en bijwerkingen van de diverse behandelingen. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: welke informatie ontbrak & hoe hadden wij u beter kunnen informeren?

4. Het behandelteam heeft mij voldoende informatie gegeven over het behandelplan neo-adjuvante chemotherapie. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: welke informatie ontbrak & hoe hadden wij u beter kunnen informeren?

5. Het behandelteam heeft met mij gesproken over verschillende behandelmogelijkheden (bijv. eerst opereren). *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: welke opties heeft u gehoord?

6. Ik voelde mij actief betrokken bij het maken van beslissingen over mijn behandelplan. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: hoe hadden wij uw betrokkenheid kunnen vergroten & bij welke beslissing is er onvoldoende naar u geluisterd?

7. Ik had genoeg tijd om mijn behandelkeuze te maken voordat ik met de chemotherapie begon. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: waardoor voelde het alsof u niet genoeg tijd had? (meerdere antwoorden mogelijk)

- ◯ Ik had onvoldoende informatie ontvangen
- ◯ Ik vond alle medische informatie en keuzes ingewikkeld
- ◯ Ik had veel last van emotionele stress en/of angst
- ◯ Ik had een 'second-opinion' gewild
- ◯ Anders, namelijk:

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8. Ik vond de tijd tussen de diagnose en de start van neo-adjuvante chemotherapie te kort. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: wat belemmerde een vroegtijdige start voor u? (meerdere antwoorden mogelijk)

- ◯ Ik vond dat er te veel onderzoeken en afspraken gepland stonden
- ◯ Ik had te weinig tijd om goed alle opties af te wegen en ik moest te snel beslissen
- ◯ Ik had tijd nodig om vruchtbaarheidsopties te overwegen
- ◯ Ik had tijd nodig om mij emotioneel voor te bereiden
- ◯ Anders, namelijk: _____

9. Van mij had de behandeling sneller mogen starten. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) eens: waarom vond u dat het sneller mocht? (meerdere antwoorden mogelijk)

- ◯ Ik was bezorgd over groei / uitzaaiing
- ◯ Ik voelde mij fysiek en emotioneel klaar
- ◯ Ik hoefde niet (lang) na te denken over deze behandelkeuze
- ◯ Anders, namelijk: _____

10. Ik vond dat ik lang moest wachten op onderzoeken (bijv. MRI, PET-scan, biopt, etc). *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: welke wachttijden vond u te lang en om hoeveel dagen ging het?

11. De tijd die tussen de onderzoeken en de uitslag van de onderzoeken zat, vond ik acceptabel. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: op welke uitslag heeft u lang moeten wachten?

12. Er zat voldoende tijd tussen de voorlichting door de verpleegkundig specialist / oncologie verpleegkundige over de chemotherapie en de start van de chemotherapie. *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: waarom had u onvoldoende tijd?

13. Het behandelteam hield zich aan de met mij gemaakte afspraken (bijvoorbeeld communicatie, tijdige ontvangst van testresultaten en naleving van geplande behandelingsdata). *

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: welke afspraken waren niet nagekomen?

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De onderstaande vraag alleen beantwoorden indien u nog een kinderwens heeft na de borstkanker behandeling:

14. Ik had genoeg tijd en informatie om mijn vruchtbaarheidsopties (invriezen van eicellen / embyo's) te overwegen voordat ik met de behandeling begon.

Helemaal oneens	Oneens	Neutraal	Eens	Helemaal eens
◯	◯	◯	◯	◯

Indien (helemaal) oneens: waar had u meer informatie over of tijd voor willen hebben?

Afsluitende vragen

1. Heeft u nog aanvullende opmerkingen of suggesties zodat wij onze zorg kunnen verbeteren?

2. Zouden wij u eventueel mogen benaderen voor een (telefonisch) interview? *

◯ Ja

◯ Nee

Eventuele opmerking:

Hartelijk dank voor uw medewerking.