



Master thesis

**Towards more standardized
diagnostic breast cancer care**

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Preface

This document contains my master's thesis, which is part of the completion of the Master's program in Health Sciences at the University of Twente. The research focuses on the diagnostic breast cancer care pathways in two hospitals, along with the experiences of staff and patients, in collaboration with the University of Twente. It was a challenge to combine the different methods in this research, from examining the care pathway on paper to observations and interviews. Without the invaluable assistance of the individuals involved in this research, this project would not have been possible.

First, I express my gratitude to my two supervisors for their support, patience, valuable tips, and understanding. Additionally, I extend special thanks to Caroline Bandel, who, despite her busy schedule, always made time to help me.

I would also like to acknowledge everyone at both hospitals who contributed to this research. Your hospitality, helpfulness and active engagement in exploring possibilities within the study were greatly appreciated. Furthermore, I am thankful for the opportunities I had to engage in conversations with various individuals within the hospital settings.

I hope you enjoy reading this thesis.

Abstract

Introduction

Standardizing diagnostic breast cancer care pathways is essential to ensure consistent care across high-quality hospitals. This research was designed to explore the variations and experiences in the diagnostic care for breast cancer at two hospitals in the Netherlands, underscoring the necessity for unified, standardized pathways. The study examined both the documented procedures and the real-world practices to pinpoint potential enhancements. The insights gained are intended to assist healthcare administrators in boosting the efficiency and efficacy of breast cancer diagnostics for increasing cooperation.

Method

This study utilized a qualitative descriptive design to investigate the diagnostic care pathways for breast cancer at two Dutch hospitals. Desk research, structured observations, and semi-structured interviews were employed to gather data. Data was compared with actual practices, and insights from both hospital employees and patients were gathered.

Results

Sufficient time for the diagnostic breast cancer care pathway is important according to hospital employees. They experience time constraints that affect patient care, for example due to decreasing shared decision-making. Second, patient satisfaction is generally positive, however clear communication is essential. Medical terminology often hinders patient understanding, affecting efficiency and patient involvement in the care process. Third, the involvement of Nurse Specialists in the diagnostic phase varies between the two hospitals. Their active participation is deemed beneficial for patient outcomes and process efficiency. Fourth, completing the anamnesis prior to the first consultation by the patient is favoured by both patients and healthcare providers. It allows for better recall and specific inquiries by patients, and saves time for healthcare providers to focus on other patient-related matters. Sixth, there are variations in the frequency of the Multidisciplinary Meeting (MDM) and involved cases. Where the MDM takes twice a week in Hospital 1 and Monday to Friday in Hospital 2. Finally, there is a variation in the methods for communicating the results of pathology on the biopsy between the two hospitals and the timeliness. Hospital 1 offers 36-hour diagnostics, where the results for both malignant and benign patients are discussed during a consultation. In Hospital 2, they conduct 24-hour diagnostics.

Conclusion

The diagnostic breast cancer care pathways in the two hospitals from this study, can be further standardized and integrated with increasing quality of care by taking an initial step by focusing on the following points: Key findings emphasize the importance of adequate time for healthcare providers, effective communication with patients, the active role of the Nurse Specialist in the diagnostic phase, possibilities for task delegations to a Breast Doctor, uniformity in preparing the MDM and the benefits of pre-filling the anamnesis.

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1. Introduction

Cancer is a leading cause of death worldwide, accounting for nearly 10 million deaths in 2022 [1]. The incidence of cancer is expected to rise from just under 20 million new cases per year in 2022 to 28 million new cases per year by 2040 [2]. Advances in early detection and treatment have led to improved survival rates, and as a result, the number of cancer survivors continues to increase [3]. However, cancer survivors often live with multiple health conditions or comorbidities, which can complicate their treatment and affect their quality of life [4,5]. Within this broader context of cancer, breast cancer holds significant prominence. Globally, breast cancer ranks as the most common cancer among women and stands as the third leading cause of cancer-related mortality per year among women [6]. Alongside cancer of the respiratory and digestive organs, breast cancer is the cancer with the highest death rates among women per year.

Breast cancer is notably prominent in the Netherlands, ranking within the top five countries with the highest incidence rate of 172.7 new cases per 100,000 women in 2022 [7]. This rate is surpassed only by Luxembourg, with the highest incidence rate of 189.6, while Bulgaria has the lowest at 88.3. These international variations can be attributed to differences in breast cancer screening, aging populations, and risk factors such as maternal age at first birth [8,9,10]. Notably, Dutch women tend to have their first child later in life, and the country has an aging population, both factors that increase breast cancer risk [9,10,11]. Despite a slight decrease in mortality from 3,245 cases in 2010 to 3,147 in 2022, the rate remains relatively high [12]. When it comes to survival, early diagnosis is crucial as the survival rate is strongly influenced by the stage of cancer at the time of diagnosis [13]. Transitioning from the incidence and risk factors of breast cancer, it is important to consider its significant impact on both individuals and society. At the individual level, breast cancer can lead to severe physical and emotional effects, including pain, fatigue, anxiety, and reduced quality of life [14,15]. At societal level, breast cancer places a heavy burden on healthcare systems due to the costs of diagnosis, treatment, and long-term care [16]. According to the National Institute for Public Health and the Environment (RIVM), breast cancer is the most expensive form of cancer with total costs of 812,7 million in 2019 in the Netherlands [17,18].

Given these different challenges, optimizing breast cancer care is crucial [19,20]. Care pathways are an established strategy to address issues as by standardizing care, reducing complexity, and limiting variation in care processes [21,22]. Standardized, evidence based care is crucial for efficient and secure patient care [23]. Because of the challenge of applying clinical guidelines in practice, due to, among other things, the complexity of these guidelines, care pathways provide clearer information for institutions to apply in practice [24]. These pathways are associated with improved patient outcomes, lower hospital costs, and positive effects on teams, such as better communication and collaboration [25,26,27,28]. Since breast cancer care is highly complex due to the involvement of different care providers throughout the entire process, it is not surprising that there has been significant growth in the adoption of care pathways in oncology [29]. Van Hove et al. (2014) concluded that the involvement of a multidisciplinary team and attention to professional and organizational aspects are essential for the success of breast cancer care pathways [30]. Success of care pathways can manifest itself in benefits for those involved in the care process, such as medical professionals and patients. It could lead to a better patients' outcomes, such as overall survival and quality of life [31]. Further, both the waiting times and the patient's length of stay in the hospital can be reduced [30,32]. Regarding medical professionals, a care pathway enhanced documentation among medical professionals [33].

Despite positive outcomes of care pathways, there are still opportunities for enhancement. Metsälä et al. (2022) mentioned the need for more patient-centeredness in the breast cancer care pathway [34]. The success of a breast cancer care pathway hinges on delivering the right content at a pace the patient can handle, especially at the beginning of the care and treatment process. Aftercare and the option for patients to maintain contact with healthcare staff after treatment are also crucial. Furthermore, the perspective of both patients and staff is essential when designing care pathways, as women's experiences differ from professionals' organizational perspectives. Addressing

information gaps before treatment and coordinating care to prevent service fragmentation are key areas for enhancement. Additionally, ensuring individualized attention and psychosocial support during treatment can significantly improve patient experiences and outcomes [35]. The increasing complexity of the Dutch healthcare system, driven by factors such as an aging population, comorbidity, and a shortage of healthcare providers, has necessitated enhanced collaboration among hospitals to sustain the quality of care [36]. This has led to a rise in the formation of networks and collaborations aimed at improving patient care and delivering quality healthcare for all individuals. Consequently, there is a growing demand for care pathways that transcend the boundaries of individual hospitals and care organizations. However, care pathways can exhibit variation across hospitals, due to differing implementation of guidelines. It is also recognized that adherence to the care pathway is not always achieved. Care pathways are designed to guide the treatment for 80% of patients, acknowledging that deviation may be necessary for complex patients who do not fit within the standard pathway or for patients with special wishes [24,37]. On the other hand, deviating from evidence-based guidelines can lead to quality deficiencies and suboptimal patient outcomes [38,39]. These variations underscore the need for more standardized care to ensure optimal practice and collaboration. To address this variety, The Netherlands Comprehensive Cancer Organization (IKNL) has introduced a model for Integrated Oncological Care Pathways (IOCP), accompanied by a related roadmap [40,41]. This model, grounded in process management and national guidelines, underscores the importance of standardized care and collaboration among healthcare entities.

Efforts are underway to move closer to standardization, with hospitals continually exploring strategies to enhance collaboration. An initiative by two hospitals in the Netherlands which jointly treat 600 to 800 breast cancer patients and numerous patients with benign abnormalities, aim to harmonize breast cancer care pathways in the future, taken into account the logistical possibilities per hospital. Both hospitals have different breast cancer care pathways, with varying processes and treatments. An initial step towards harmonization has been taken through a regional consultation with general practitioners for the implementation of a triage in the care domain for patients with a breast abnormality. While various studies exist in the literature regarding the evaluation of breast cancer care pathways, there appears to be no comprehensive study that considers both the procedural steps and the perspectives and experiences of hospital employees and patients within the breast cancer care pathway. Therefore, this qualitative study examines diagnostic breast cancer care pathways in the two mentioned hospitals, aiming to achieve the following objectives:

1. Gain insight into the specific steps and procedures currently followed in the breast cancer care pathways.
2. Gain insight into the extent to which actual practices in breast cancer care correspond to the documented care pathways.
3. Gain insight into the differences in processes and treatments within the breast cancer care pathways.
4. Gain insight into which indicators are currently considered important in breast cancer care pathways.
5. Gain insight into the perspectives of those involved in the breast cancer care pathway about which indicators they consider most important when assessing breast cancer care pathways.

In accordance with the aim of this study, the following research question has been formulated: *“How can the breast cancer diagnostic pathways of two different hospitals be combined into a more standardized care pathway, taking into account the perspectives of stakeholders and variations in processes?”*

2. Theory

2.1 Defining care pathways

Care pathways have already been used in the healthcare sector for more than 10 years. The reason that care pathways have been frequently used over the past decade is, that care pathways take the entire care chain as a starting point based on intensive and well-structured coordination between the various parties' care processes with the aim of efficiency, effectiveness and patient-centeredness within the improved care [40]. When it comes to the concept of care pathways, there are several synonyms in use: care paths, care plans, care maps, clinical pathways and critical pathways, protocols, guidelines, evidence-based care and multidisciplinary care [42,43]. Just as there are multiple terms, the definition also varies in different publications [43]. A frequently used definition of a care pathway based on the study of Rotter et al. (2010) [33]. Taking these criteria together, the following definition was formed: *"A care pathway is a structured plan involving one or more clinical professionals, based on protocols or algorithms and is evidence-based or based on practical guidelines to promote standardization of care for patients."* This definition focuses on structure and standardization, but the patient perspective is not involved while patient-centeredness is a crucial aspect of care pathway design [44,45]. This is more in line with the definition in the paper from Rotter et al. (2013), namely: *"A care pathway is a complex intervention for joint decision-making and the organization of care processes for a specific group of patients during a certain period"* [46]. This definition emphasizes the patient-centered approach and focuses on effective and coordinated care throughout the disease process. In this study the term 'breast cancer care pathway' will be used, because the care pathway specifically relates to breast cancer care in this study.

2.2. Guidelines Breast cancer care pathways

As mentioned in the Background section, IKNL presented a model for IOCP [48]. Based on this model, IKNL developed the format: Transmural breast cancer care pathway format. This format is, among other things, based on the national guidelines of the Federation of Medical Specialists [49]. In this breast cancer care pathway, the distinct phases of the pathway are clearly explained: Referral, diagnosis, treatment, aftercare and palliative care. In this paragraph, not all steps from the breast cancer care pathway will be discussed. This is due to the focus on the first part of the pathway in this study, so more information will be given about the process of referral and the associated diagnostic steps, see Figure 1 below. It is important to clarify that the steps outlined do not apply uniformly to all patients according to the care pathway, as will be elaborated in the subsequent sections of the Transmural format.

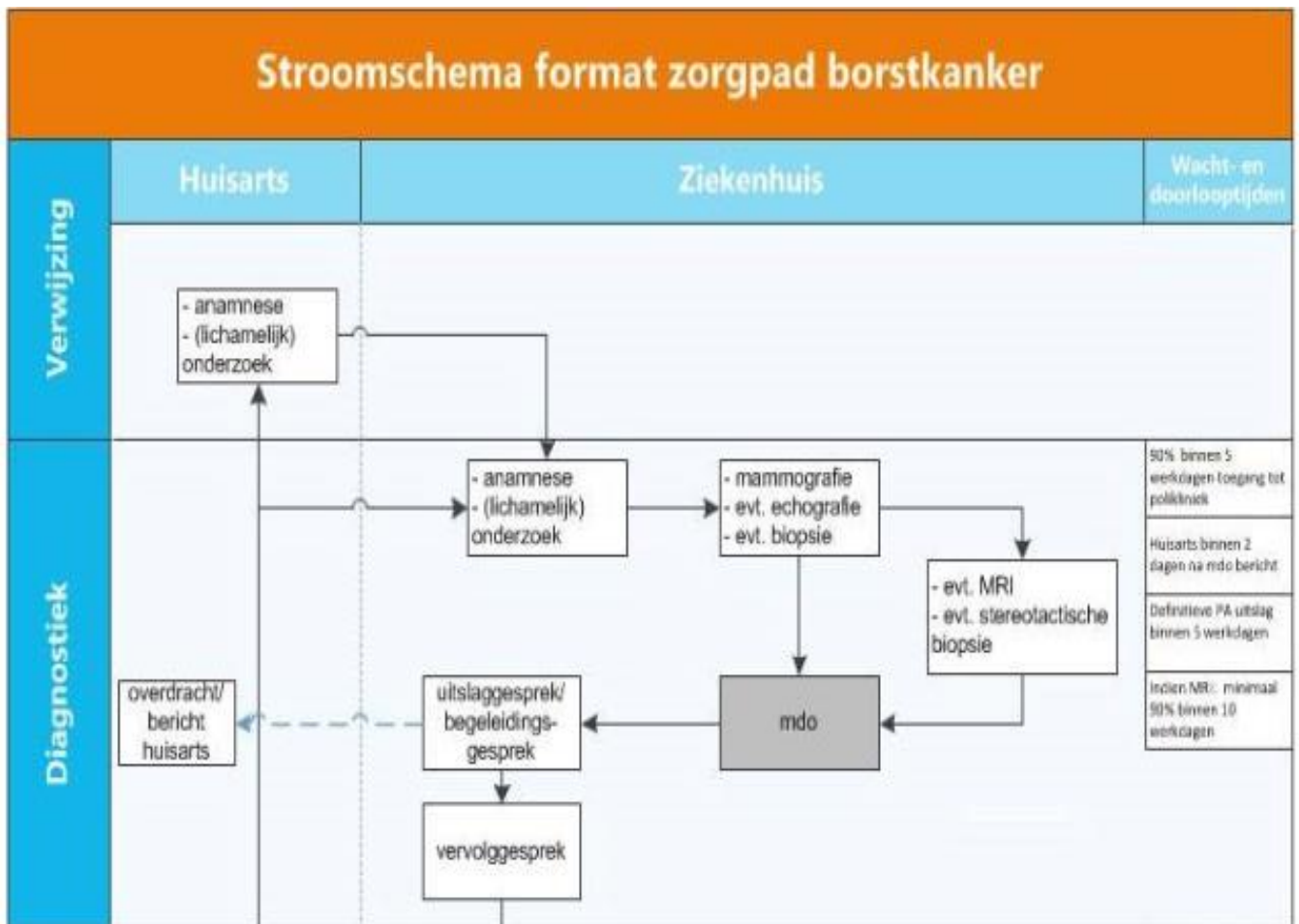


Figure 1. Flowchart Breast cancer care pathway format [47].

2.2.1 Referral

A patient can access the breast cancer care pathway through several ways. Firstly, the general practitioner (GP) may refer the patient if there are symptoms or suspicions related to breast cancer. Secondly, women aged 50 to 75 years can participate in the national breast cancer screening program. Abnormal mammography findings from the screening can lead to prompt referral to the breast clinic [49]. Additionally, a colleague specialist might also refer a patient for further evaluation. Thereafter, an appointment needs to be scheduled with the clinic's secretary for the first consultation [47].

2.2.2 Diagnosis

During the diagnostic phase of the breast cancer care pathway, patient involvement, in other terms shared decision-making is taken into account. This involves exploring treatment options and potential outcomes with the patient, and thoroughly discussing the patient's values and preferences.

First consultation in clinic

The first step within diagnosis is the patient visit to the Hospital or Breast Clinic for the first consultation. Here, comprehensive diagnostic procedures are undertaken. This includes reviewing the patient's medical history, conducting a physical examination, and performing imaging such as mammography or breast ultrasound. If any suspicious findings arise, additional investigations, such as axillary ultrasound, are promptly conducted. Genetic counselling is offered if relevant. If malignancy is suspected, a biopsy is promptly performed following the physical and imaging

evaluations. Also, geriatric screening and assessments for malnutrition risk are conducted, particularly for patients aged 70 or older. During this first consultation, information about the diagnostic process is conveyed to the patient through various channels: verbal, digital, and written. Diagnostic results, including mammography, ultrasound, and pathology reports, are communicated to the patient within a reasonable timeframe. Follow-up appointments are scheduled promptly, covering definitive biopsy results, additional diagnostic procedures if necessary, and imaging scans. The surgical assistant may refer the patient to a central hospital if required, ensuring pertinent information is transmitted effectively. If necessary, a patient is referred to a specialized clinic/hospital for further treatment. Throughout the diagnostic process, ongoing communication and involvement of the general practitioner remain integral. Biopsy results are expected to be available within 5 working days, and if further diagnostic procedures, such as stereotactic biopsies, are necessary, they should also be completed within the same timeframe.[47]

Multidisciplinary Meeting (MDM)

After the consultation in the clinic for imaging and other activities, the pre-operative MDM takes place. According to the format of the transmural breast cancer care pathway, the MDM must take place weekly following a standardized process of registration, discussion, and documentation [47]. The MDM is an organized meeting involving various healthcare providers, during which the diagnosis is discussed and treatment recommendations are formulated for patients. During the pre-operative MDM, 90% of patients with a breast carcinoma should be discussed. Throughout the discussion, various points are documented, including mammography/ultrasound results, pathology findings, outcomes of additional investigations, treatment goals (curative or palliative), treatment recommendations, potential trial options, and geriatric screening results if necessary. Further, it must be discussed who will be the main treating physician and case manager if changes occur after the MDM [47]. The multidisciplinary team should consist of a surgical oncologist, medical oncologist, radiologist, specialized nurse in mammacare, case manager, pathologist, radiation oncologist, and, if needed, a plastic surgeon, clinical geneticist, or geriatric nurse. This MDM is an important feature of a care pathway and is planned in advance on a regular basis [49,50]. With regard to documentation, there has been a national NABON standard for MDM reporting since 2018. This information standard for MDM reporting was necessary due to the frequent re-entry of the same patient data in the hospital, which increases the risk of errors and unnecessary administration. This standard is based on the national breast cancer guideline. Each hospital can supplement the standard in its own EPR (Electronic Patient Record) [51]. As previously mentioned, not all steps are mentioned, but it is useful to know that the MDM also takes place post-operatively.

Treatment advice

After the MDM, the patient should be informed with the diagnostic outcomes and treatment advice. During this consultation, several actions take place. The Surgeon informs the patient about the outcomes of various additional tests. Preferably, a Nurse should be present during the conversation, for example the one who also conducts the supportive follow-up conversation. The attending surgeon provides treatment advice that encompasses potential therapeutic interventions, treatment locales, and subsequent follow-up procedures, as deliberated during the MDM. The conversation further extends to the exploration of risks inherent to the proposed treatment options, such as malnutrition, and the possibility of participating in clinical trials. The patient is presented with the autonomy to select their preferred treatment plan, inclusive of the provision for seeking a second opinion if so desired. Throughout this discourse, the principle of shared decision-making is underscored, thereby ensuring the patient is afforded sufficient time for contemplation and

informed consent to their chosen course of treatment. After the results conversation, a supportive follow-up conversation is conducted with the patient by the Nurse. This conversation covers proposed treatments, informational materials, contact details for the care team or case manager, and guidance on psychosocial and paramedical support available during the care trajectory. The Nurse provides support and informs the patient about relevant patient associations and resources, such as the Netherlands Cancer Registry.[47]

2.3 Outcomes, shortcomings and success factors in breast cancer care

Improving the quality of healthcare requires a deep understanding of perceptions and experiences of both healthcare providers and patients, while breast cancer care pathways can provide different outcomes for patients and healthcare providers.

2.3.1 Patients

Various studies about breast cancer care pathways have shown valuable outcomes regarding patients, for example, the improvement in patients' quality of life [31]. These pathways have facilitated care provision by enabling the execution of evidence-based care at an appropriate time and specific care delivery that address patients' needs. Additionally, breast cancer care pathways have ensured that all care disciplines support each other through appropriate functionality. Hence, patients' physical, emotional, and psychosocial welfare has been enhanced at all stage of their cancer journey. Other research highlights the benefit of breast cancer care pathways in their ability to reduce waiting times and hospitalization [30,32]. As a result, standardized protocols and optimized and efficient workflows make it possible to attain diagnostic assessments, initiate treatment, and implement other supportive measures in a reduced amount of time than before while preventing unnecessary delays. In addition, care pathways encourage better documentation and interprofessional coordination, so the quality of care is improved while reducing the chance of mistakes and omissions [33]. In line with these findings, Gautam et al. (2018) and Colonna et al. (2018) [27,28] highlighted the cost-effectiveness of breast cancer care pathways. These pathways optimize resource utilization without compromising care quality, leading to significant cost savings while ensuring optimal patient outcomes. Transitioning to other outcomes, Van Dam et al. (2013) evaluated care pathways using various indicators [52]. Due to the implementation of the care pathway, the number of patients in the pathway increased and length of stay (LOS) reduced. In general, patient satisfaction increased, including for example, higher similarity of implementation of returning care, greater teamwork among care providers and decreased waiting times during hospital stays. Also, patients rely on informational moments or so-called touchpoints. These touchpoints are critical junctures in the patient's journey where they receive essential information that helps clarify their concerns and questions about the process. These could be moments of direct communication with healthcare providers, receiving test results, or even written materials or online resources provided at key stages of the pathway. These touchpoints not only help to resolve patient's worries and uncertainties but also contribute to their overall satisfaction with the care process.

2.3.2 Healthcare providers

In addition to patient experiences, studies on healthcare providers reveal both successes and shortcomings in the diagnostic breast cancer care pathway from their perspective [53]. A qualitative study, published in the Journal of Patient Experience, presented success factors including careful execution of sampling techniques and analyses in laboratory services, short waiting times, reliable and prompt reporting of results, and pleasant staff behaviour during mammography. On the other

hand, shortcomings involve failures in sample collection, -handling, and -storage, as well as unpleasant or unhelpful staff behaviours and long waiting times for appointments and results. For radiotherapy and treatment preparations, timely and adequate patient information is crucial, delivered at a pace that patients can absorb, especially at the beginning of the treatment process. Recognizing patient-related factors, such as their psychological and physical state, and fostering effective communication and collaboration during treatment, are critical for successful care pathways. Another study from Rotter et al. (2010) examined 27 articles about care pathways, ranging from breast cancer to diabetes and their effect on professional practice, patient outcomes, length of stay and hospital costs [33]. The overall results of this study indicate that clinical pathways have a significant impact on healthcare providers' professional practice. Numerous studies have demonstrated that care pathways lead to improved documentation in medical records, increased patient satisfaction, and enhanced quality measures [53,54]. Additionally, care pathway interventions, are associated with elements of case management and quality improvement programs, resulting in greater healthcare provider engagement in care pathway development and a more holistic approach to patient care [55,56]. The majority of studies in the literature on care pathways indicate a strong emphasis on evidence-informed development and implementation of care pathways. This suggests that healthcare providers actively tailor evidence to local contexts and identify gaps in evidence-based practices [57].

2.4 Integrative framework

Owing to the necessity for a more uniform definition of care pathways and integrative conceptual frameworks, Gartner et al. (2022) developed an Integrative Framework, offering a comprehensive view on care pathways [44]. This Integrative Framework was created through a combination of methods, including systematic review, concept analysis and bibliometric analysis. As a result, it provides an in-depth understanding of the complexity of care pathways and their impact on patient care. Figure 2, on the next page, shows all this visually: the central role of patients, the multidisciplinary approach, the focus on efficiency and the integration of information systems.

2.4.1 Construction of the framework

The framework consists of different layers of components. Beginning with antecedents, which are key factors for the successful implementation of care pathways, such as having a change management team and the importance of following guidelines for professional compliance [44,58]. These encompass elements such as access to reliable data, investments in electronic medical records, and approaches that focus on real patient care trajectories. The second layer, attributes consist of 28 subcategories grouped into seven attributes that should be considered in complex care pathway interventions. The framework places patients and their caregivers at the heart of the care pathway. This means that their experiences, needs and preferences form the basis for the design and implementation of care pathways. By promoting patient-centered care, hospitals can better respond to individual needs and improve the quality of care. Further, attributes include the positioning of professional actors, operational management, coordination structures, structural context, information systems and data management, and the emergence of the learning system. Information systems and data management including electronic health systems, data analytics, and information sharing between healthcare providers. Well-integrated systems facilitate care coordination and contribute to a seamless patient experience. The third layer, consequences, delineate the potential outcomes or results of the care pathway interventions. The last row, empirical referents, serve as measurable evidence of care pathway interventions, including outcomes and evidence that the application of the conceptual framework in healthcare

management aids. These referents could be Key Performance Indicators (KPIs), for example mortality rates and clinical outcomes. [44]

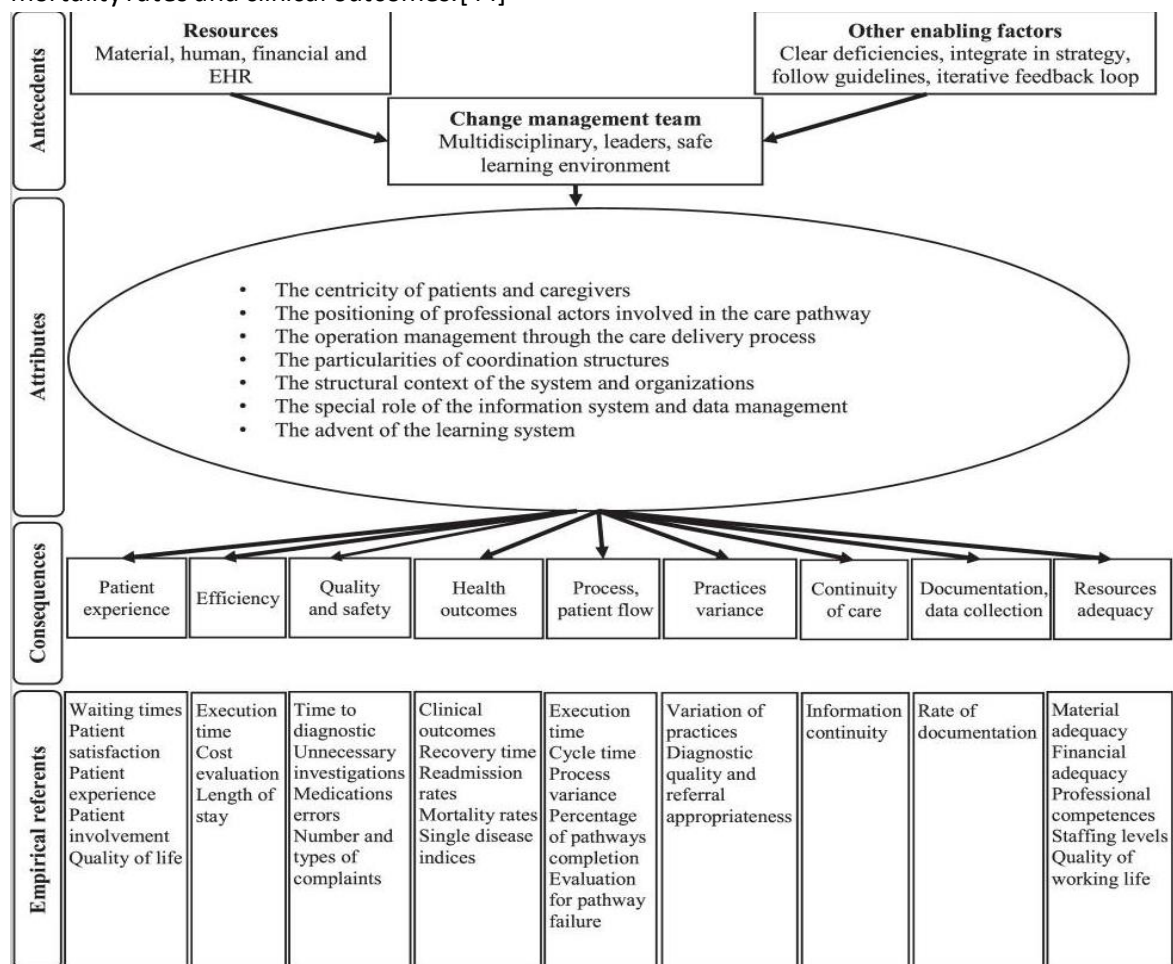


Figure 2. Integrative conceptual framework of care pathway [44].

2.4.2 Consequences and Empirical referents

The following section will provide a more comprehensive understanding of the last two rows, consequences and empirical referents. As can be seen in Figure 2, there are several themes of consequences and associated empirical referents. Although the consequences: quality and safety, efficiency, and process improvement were initially emphasized as primary objectives within literature, the prevailing themes often center around the impact on patient experience. Aspects like waiting times, patient satisfaction, and quality of life receive frequent attention, providing valuable insights into how patients perceive care and its effects on their well-being [44]. This is due to the significant influence of patient experience on satisfaction, treatment adherence and clinical effectiveness of the treatment. A positive experience correlates with improved treatment outcomes and a higher quality of life for patients [59]. By adopting a patient journey perspective, healthcare providers gain a better understanding of care pathways and their requirements. This approach assists in configuring pathways that consistently deliver high-quality care throughout the entire patient journey and especially at key touchpoints within the journey [60,61]. The concept of the patient journey encompasses the diverse interactions between patients and healthcare providers. Therefore, crafting an effective pathway involves optimizing these interactions to ensure a seamless and satisfactory patient experience [44].

2.4.3 Applicability in this study

The Integrative Framework for care pathways offers several advantages that underline its applicability in this study. The framework provides an in-depth understanding of the complexity of care pathways and their impact on patient care. Breast cancer care is highly complex, due to the wide range of diagnostic and therapeutic interventions, for that reason the framework is applicable. By analysing the components, insight can be gained into the factors that influence the success of care pathway implementation. Second, by evaluating the antecedents, attributes and consequences, care pathways can be optimized. This way, points for improvement can be identified and it can be determined which aspects are functioning well. Further, the framework emphasizes the central role of patients and their caregivers. By following this concept, care pathways can be designed that take into account individual needs and preferences. Finally, the framework focuses on efficiency and the integration of information systems. By implementing these aspects, waiting times can be reduced, flow improved, and the overall quality of care increased.[62] This framework has been employed during this research to identify and organize strengths and gaps from the information obtained (interviews and observations) in the results, as will be mentioned in the method in the following chapter.

3. Method

3.1 Study design

A qualitative descriptive study was undertaken to get insight into both diagnostic breast care pathways, their disparities and get an understanding in/into the experiences and opinions of patients and hospital staff about what is necessary in diagnostic breast cancer care. The strength of such an empirical research approach lies in its capacity to provide a deep and comprehensive understanding of the meanings and significance that individuals assign to actions, occurrences and relationships. Particularly in a qualitative design, this approach generates rich and detailed data, enabling an in-depth exploration of diagnostic breast care pathways. It allows for a nuanced understanding of the complexities and subtleties inherent in these pathways, as seen through the lens of those who experience them firsthand [63]. Moreover, the descriptive characteristic inherent in qualitative methodologies permits the researcher to construct a multifaceted, comprehensive depiction within a real-world context. In other words, the researcher is not just observing the surface level of the phenomenon, but can capture the complexity and totality of the situation in its natural setting. This results in a more authentic and comprehensive understanding of the diagnostic pathways, considering the numerous factors and dynamics at play. A broad view like this is crucial in providing insights that are grounded in the reality of the individuals' experiences, thereby enhancing the validity and applicability of the research findings [64]. Approval for this study has been granted by the ethics committee of the University of Twente, req. nr. 240275.

3.2 Study setting

The study setting comprises two prominent clinical hospitals in the Netherlands: The Breast Cancer Center East Netherlands (BON) from Ziekenhuisgroep Twente (ZGT) and the Medical Spectrum Twente (MST). Both hospitals are affiliated with Samenwerkende Topklinische opleidingsZiekenhuizen (STZ), an association of top clinical hospitals [65]. Membership in STZ is contingent upon meeting specific criteria, such as a robust foundation for innovation and scientific research. These hospitals collaborate to enhance patient care through professional training, innovation, and scientific research. The breast clinics within these hospitals are integral components of their respective surgery departments. Surgeons within these departments have a broad scope of practice, extending beyond breast cancer care to encompass patients with various other diagnoses.

3.3 Materials & Procedures

This study included desk research, structured observations, and semi-structured interviews. The combination of these methods for data collection of the diagnostic breast care pathway allows for methodological triangulation, in which it is evaluated to what extent the diagnostic breast care pathway corresponds to the actual practice. Despite the detailed information in the documented breast care pathway, only analyzing this documented pathway does not provide insight into the entire context of the various steps in the care pathway, nor does it shed light on its implementation. Individuals often perform actions and activities that are very habitual, so that they do not remember the specifics of what they did. Through observations, detailed information can be obtained by identifying best practices, points of intervention, and uncovering opportunities for process enhancement.[66]

3.3.1 Desk research

The study began with a comprehensive analysis of the documented care pathways, which were provided via E-mail by the Nurse Specialists from both hospitals. These care pathways were carefully studied by reviewing the detailed description, spanning several pages, to gain an in-depth understanding of the breast cancer care protocols used in each hospital. To reduce the complexity of

the care pathways and make them more accessible and understandable, the care pathways were translated into flowcharts using the Lucidchart website [67]. The flowchart included detailed information about the involved staff, waiting times/procedure durations, and actions taken. However, after examining the flowchart of the entire process, it became apparent how extensive it was. For this reason, the decision was made to focus on the initial part of the care pathway, specifically the diagnostic phase. The creation of the flowchart was a collaborative effort with relevant stakeholders to ensure a clear visualization of the care pathways as practiced in real-world settings. It became clear that the official times were missing per step in the documented, care pathway, these were checked with the nurse specialist of both hospitals. The amount of time planned for each step could not be deduced from the documented care pathways. These times have been checked with the Nursing Specialists. The transformed care pathways were then evaluated by Nurse Specialists from both hospitals and the Breast Nurse/Case Manager from Hospital 1, to ensure accuracy and relevance.

3.3.2 Observations

The first step involved an observation day without an observation schedule to gain a general overview and a clearer understanding of the care pathway in practice. However, in Hospital 2, this was not feasible due to difficulty in scheduling. Afterwards, structured participating observations were carried out, for both hospitals the observation schemes were designed prior to the observations. These structured observations ensured greater efficiency by providing clarity in advance on the aspects to be focused on during the observations, thereby ensuring consistency, as opposed to unstructured observations. It also enables an easier comparison of the results of both diagnostic breast care pathways. To evaluate whether the documented diagnostic breast cancer care pathways correspond in practice, the flowchart from desk research served as valuable input for the observation schedule. In addition, the framework of Gartner et al. (2022) served as input for focus points during the general observations, regarding coordination between healthcare providers, communication, patient involvement in treatment decisions, and registration/documentation of patient care [44]. All the steps in the care pathway were converted into structured observation schemes as shown in Appendix 1, A and B. The entire care path was included in the observation scheme, although the focus was on the diagnostic part. This was a conscious choice to obtain a clear view of the care pathway. Beyond the cohort of patients from the diagnostic pathway, there were also patients for follow-up and, among other things, the preoperative consultation. Before the observations were conducted, the schemes were subjected to an evaluation by the Nurse Specialists from both hospitals to ensure their relevance and completeness. The Nurse Specialist informed colleagues about the observation via e-mail, in Hospital 1. In Hospital 2, this was done by the secretary. Data collection for the observations lasted one day at Hospital 1 from 8:00 a.m. to 3:00 p.m. and one day at Hospital 2 from 7:45 a.m. to 2:00 p.m. At both hospitals, the focus was on the diagnostic part, although there were also patient appointments for other matters phases, such as the follow-up phase, at Hospital 1. This was not the case in Hospital 2. The observation schedule was printed and filled in with pen during the observations. For example, a check mark was placed if the action was correct and additional notes were made if something was not completely correct or if there were additions and times of the steps were recorded during observations. However, this was not fully recorded at Hospital 2 because pen and paper were not allowed in the consultation room.

3.3.3 Interviews

Semi-structured interviews are one of the most used methods in qualitative research and especially in health research. It provides direction by means of a flexible interview protocol, but it also allows to ask further questions to gain deeper information [68].

Focus group interviews

At both hospitals, a focus group interview was conducted with employees to enable utilization of group dynamics to stimulate discussion [69]. This makes a focus group more interactive and allows for a wider range of perspectives and ideas than with individual interviews. The focus group semi-structured interview schemes, were based on the outcomes of the observations. After the observations, differences emerged between both hospitals. These differences have been discussed with the various health employees involved in the diagnostic breast care pathway, such as the Surgeon and Nurse Specialist. This way, agreement was reached on which differences are considered relevant to include as topics in the focus group interview for discussion. Based on the differences between both hospitals the interview schemes were created, as can be seen in Appendices 3 and 4. For each topic, the situation was briefly described in the other hospital and questions were asked about it. The definition of the topics can be seen in Table 1.

Topic	Definition
Setting and communication	<i>Spatial layout of the department and what communication channels are used for communication with colleagues.</i>
First consultation	<i>The intake consultation in the hospital after referral [47].</i>
Multidisciplinary Meeting (MDM)	<i>A meeting in which various healthcare providers of the department come together to discuss the patients [47].</i>
Diagnosis	<i>The method by which the patient is informed of their diagnostic results, such as through a phone call or a consultation at the hospital to discuss the results of the tissue examination.</i>
Division of roles and responsibilities	<i>The division of roles and responsibilities of the employees involved in the breast cancer diagnostic pathway.</i>
Patient-centered care	<i>Care provision that is consistent with the values, needs, and desires of patients and is achieved when clinicians involve patients in healthcare discussions and decisions [70].</i>

Table 1. Focus group interview topics with definitions.

Prior to data collection, participants were sent an information letter by the secretary through e-mail to get informed consent, see Appendix 3A. It was asked to include employees who were not (extensively) spoken with during the observations, to incorporate diverse perspectives. After the first interview at Hospital 2, the interview schedule was adjusted based on feedback from the thesis supervisor and the course of the first interview. Additionally, certain questions were made more understandable as they were not direct enough. For example, the question 4.1 “*What do you think of the way the diagnosis is discussed with the patient at the other hospital during a consultation compared to mainly calling as done here?*” was changed to 5.1 “*What do you think of providing an additional option for the patient to receive the diagnosis over the phone?*” Furthermore, the order of the topics being asked has been altered to facilitate a smoother conversation. Notably, instead of asking about roles and responsibilities at the end, these questions were posed at the beginning of the interview. The objective and collective ambition of a care pathway is patient-centered care by fulfilling patient requirements and aspirations by continuous enhancing of patient experiences, patient outcomes, quality and safety, all while considering the practical and societal aspects of the system [44]. For this reason, the topic, patient-centered care pathways, was also included, to consider the view of health employees on this topic. In both hospitals, the participants were to some extent familiar with the way of working at both hospitals, varying in degree from one staff member to another. Participants included were those most involved in the diagnostic phase of the breast

cancer care pathway. Despite the fact that a Nurse Specialist's involvement begins at the follow-up stage in Hospital 2, their inclusion was deemed necessary, as their insights could potentially provide valuable contributions for future considerations.

Patient interviews and PREM

In contrast to hospital employees, patients were interviewed individually to collect information about their individual experiences in the diagnostic breast care pathway to offer detailed insights into patients' personal attitudes, views, and feelings [70]. The semi-structured interview scheme was based on the patient journey through the different steps in the diagnostic pathway from the flowchart. One identical interview scheme has been developed for both hospitals, see Appendix 2C. This scheme comprised questions on the following topics: Referral, Appointment planning and first appointment, Imaging examination, Results of imaging examination, Appointment after MDM, and Improvements. The interview scheme was reviewed by the thesis supervisor and the Nurse Specialist, Breast Care Nurse, and Surgeon. To assess the clarity and coherence of the questions and estimate the interview duration, a pilot test of the individual interview was conducted twice with a peer student. The selection of patients involved non-probability sampling. The date for patient interviews was determined in consultation with the Nurse Specialist, selecting a day with outpatient clinic visits. The focus was on patients who had been referred or were further along in the care pathway. Interviews were conducted in Hospital 1. Patients were approached after finishing their consultation by the Nurse Specialist or Breast Care Nurse to keep the threshold for participating low. If they were interested, they were provided with the information letter along with the informed consent form, allowing them time to review it. In case of agreement, they were escorted to a separate room by the Nurse Specialist or Breast Care Nurse to meet with the researcher, where additional information was provided, and informed consent was obtained. The idea was to interview approximately 10 patients per hospital or more until saturation occurred, so no new information was obtained. However, initially two patients were willing to participate in the interview at Hospital 1. For this reason, an additional morning was scheduled with the aim of interviewing more patients. Eventually, two more patients were interviewed. Interviews with patients at Hospital 2 were not approved by the hospital due to their concerns about the burden on the patients. For this reason, a recent Patient-Reported Experience Measure (PREM) from 2024 was utilized instead. In the PREM, there were both open and closed questions. It was a deliberate choice to only include the open questions to maintain consistency in the analysis process, by having the possibility to code the open question answers. The open questions were: 1. *"What aspects of our service at the hospital were executed well at the Breast Clinic?"* 2. *"What aspects can be improved at the Breast Clinic?"*

3.4 Analysis

3.4.1 Data from observations

The collected data from the observations was analysed by comparing the outcomes of both hospitals with each other within the diagnostic steps. Where similarities existed, they were disregarded to reduce complexity, and the focus was solely on points of divergence. Thus, the analysis concentrated purely on what emerged during those observational moments. Following the observations, both observation forms were thoroughly reviewed and all clear differences that were observed were summarized to create a clear overview. This overview was then discussed multiple times with employees from both hospitals to verify the accuracy of the information and determine whether the observed differences were actionable. This data served as input for the interview schedules. In addition, the data from the observations were also utilized for the augmentation and/or enhancement of the flowchart previously mentioned in 3.3.1 Desk research.

3.4.2 Data from interviews

Data collection in the form of interviews took place at the two hospitals. At the start of the interview, participants were able to introduce themselves. Audio was recorded with the researcher's mobile phone. To ensure objectivity of this study, the interviewer regularly summarized the answers during the interview, to avoid misinterpretations. The internal validity was guaranteed by documenting the collected data, by transcribing the audio recordings verbatim with the program Amberscript [71]. Access to Amberscript was obtained through the BMSlab of the University of Twente, where four hours for the focus group interviews and patient interviews were requested for transcription time. During transcribing, stop words and hesitations were omitted, because these had no added value for the analysis. After automatic transcription, each transcript was evaluated in Amberscript by listening to the full recording in slow motion. This made possible to evaluate whether sentences were correctly transcribed. The full transcript of the interview at Hospital 1 was sent by e-mail to an interview participant to verify whether the information was transcribed correctly to reduce misinterpretation from the researcher. After which a summary was sent to the Nurse Specialist at Hospital 1 and Coordinator of the tumor working group at Hospital 2 (see Appendix 4), to share the summary by e-mail with all participants of the interviews and other colleagues at the breast clinic with the question whether there were any additions to the given information. Eventually, four respondents provided feedback, including confusion about which hospital was being referred to, and some paragraphs were somewhat unclear. This feedback was addressed by identifying the hospitals as Hospital 1 and Hospital 2, and by providing more detailed descriptions for the unclear paragraphs. Data from the interviews were stored on a secure disk of the University of Twente, with a retention period of 10 years.

Data analysis was performed, after completing the interviews. The five steps for framework analysing from Krueger (1994) were followed [72]. This analysis was performed by using Atlas.ti [73]. During the analysis, it was important to keep the problem definition and research questions at hand, as these were the sources of the research. The first step was familiarization, by listening to the audio recording and reading the transcripts documented in Amberscript. Then, the transcripts were loaded in Atlas.ti. Data from the PREM does not contain audio, but written text, so this was retyped in Atlas.ti. During this first step, the general themes started to develop. The second step was identifying a thematic framework. Then, the subsequent step entailed the recognition of a thematic structure. This was achieved by noting down memos on the text margins, which were short phrases, or concepts that emerged from the text, thereby initiating the categorization process. During this phase, descriptive assertions were established and an examination of the data was conducted following the line of inquiry. In addition to inductive analysing, both interviews were also analysed deductively using the coding scheme as can be seen in Table 2. These codes were derived from the

topics of the interview scheme. The indicators from Gartner et al. (2022) were used by linking them to the topics from the interview [44]. The next step involved indexing, this consisted of filtering the data, highlighting, and sorting out quotations and making comparisons both within and across cases. Then, the fourth step, charting, entailed extracting the quotations from their original context and reorganizing them under the appropriate thematic categories that had been newly developed, or were already developed based on Table 2. According to Gartner's Framework, Execution time, Cost evaluation and Length of Stay are empirical referents of the consequence Efficiency. However, in this research, efficiency is seen as an overarching theme that recurs in the various sub-themes.

Gartner framework / Consequence	Empirical referent / Code	Definition
Efficiency	Efficiency	<i>The degree to which healthcare processes are performed with minimal waste of resources, time, and effort, while maintaining or improving the quality and effectiveness of care.</i>
Patient experience	Waiting time	<i>The time a patient waits between different phases of a care pathway, such as making an appointment, receiving treatment, or obtaining test results.</i>
	Quality of life	<i>The overall well-being status and satisfaction of an individual, including physical, psychological, social, and emotional aspects, related to their health condition and the impact of the care they receive.</i>
	Patient satisfaction	<i>The level of satisfaction and experience of patients with the care they have received, including aspects such as waiting times, communication with healthcare providers, treatment effectiveness, and overall care experience.</i>
	Patient experiences	<i>The specific interactions, events, and experiences that patients have during their care pathway, including positive and negative experiences with healthcare providers, treatments, and facilities.</i>
	Patient involvement	<i>The degree to which patients are involved in decision-making about their own care, including their ability to receive information, ask questions, express preferences, and collaborate with healthcare providers to develop joint treatment plans.</i>
Resource adequacy	Professional competences	<i>The skills, knowledge, experience, and competencies of healthcare providers necessary to deliver high-quality care and effectively address the needs of patients.</i>
	Staffing levels	<i>The amount of personnel available in a healthcare institution relative to the demand for care, including physicians, nurses, support staff, and administrative personnel.</i>
	Quality of working life	<i>The degree to which employees are satisfied with their work, work environment, workload, and work-life balance within a healthcare institution.</i>
Continuity of care	Information continuity	<i>The consistency and availability of patient information throughout the entire care pathway, including the transfer of information between different healthcare providers and departments.</i>
Documentation, data collection	Rate of documentation	<i>Information is recorded in a structured way in the medical file and is available to every professional involved in the care of the patient</i>

Table 2. Coding scheme as input for the analysis of focus-group interviews and patient interviews and PREM [45].

After these steps, the final step, analysis took place. This contained mapping and interpreting the data. Here, the task was to understand the individual quotations and see relationships between them. For the interpretation part, Krueger (1994) created seven criteria to use as headings for interpreting the coded data: words, context, internal consistency, frequency and extensiveness of comments, specificity of comments, intensity of comments and big ideas [72]. First, the actual words and their meaning that were used in the data were considered. Then, the context of the answers were considered, by examining the conditions or setting in which the responses were given. Understanding the context, provided deeper insights into why a particular response was given and helped in interpreting the data more accurately. Followed by how often a comment was made and how extensive they were. The criterium Intensity referred to the positive or negative load of the comments. According to Krueger (1994), Internal consistency refers to the extent to which different itmes intended to measue the same concept or phenomenon actually yield similar results [72]. In a focus-group case this means to what extent participants change in opinions. Further, with specificity it is meant that greater attention is placed on personal experiences rather than hypothetical scenarios. Finally, broader concepts were considered by looking at the overall themes or ideas that emerged from the data. Instead of focusing on individual responses or details, this step involved stepping back and looking at the larger patterns or trends in the data. It was about understanding the main ideas or concepts that the data was trying to convey.

4. Results

Desk research and observations

First, the results of the observations and desk research will be presented. Then, the results from the interviews with hospital employees will be described and last the results from interviews and the PREM with patients. These results will be presented chronologically based on the steps in the care pathway, including corresponding codes from Table 2 from the Framework of Gartner et al. (2022) [45]. The results will be described and supplemented by quotations from participants. The quotations are originally in Dutch and have been translated into English in the results section. For the original Dutch quotations, please refer to Appendix 5.

Observed action	Hospital 1	Hospital 2
Planning appointments	Secretary	Secretary
First appointment	Nurse Specialist or Surgeon	Breast Doctor or Surgeon
Radiology	Radiologist and Radiological laboratory technician	Radiologist and Radiological laboratory technician
In-clinic consultation outcome imaging	Nurse Specialist or Surgeon	Breast Doctor or Surgeon
Pre-operative MDM	Surgeon-Nurse Specialist-Breast Care Nurse-Radiologist-Nuclear Medicine Doctor-Radiation Therapist-Plastic Surgeon-Pathologist-Internal Medicine Oncologist-Secretary	Surgeon-Nurse Specialist-Breast Care Nurse-Radiologist- Nuclear Medicine Doctor-Radiation Therapist-Plastic Surgeon-Pathologist-Internal Medicine Oncologist-Breast Doctor-Secretary
Results MDM	Surgeon and Breast Care Nurse or Nurse Specialist	Surgeon and Breast Care Nurse
Appointment for emotional support and information about the procedures	Breast Care Nurse	Breast Care Nurse

Table 3. Actions and participants of the observations in both hospitals.

Observations were taken from specific actions and involved health employees shown in Table 3. Results of desk research and observations with employees and patients are integrated and presented chronologically based on the steps in the diagnostic breast cancer care pathway in Figure 3, on the next page. The outcomes from the observations showed that the documented diagnostic breast care pathway corresponds well in practice and the flowcharts are quite similar. The difference is mainly in nuanced matters and will be further discussed in the interview results. Most steps in the pathway were performed consistently according to the observations with the structured observation scheme. There was one detail that was incorrect in the documented care pathway of Hospital 2. This concerns the step mentioned in the observation form: Informing the patient with the diagnostic results after biopsy. In the documented care pathway, it was stated that an outpatient visit will take place to inform the patient, but the patient has the option to be phoned or to visit the clinic. Further, as far as measured, the official times, including preparation and administration, are being met within the standard. For that reason, the official planned times are shown in the flowcharts.

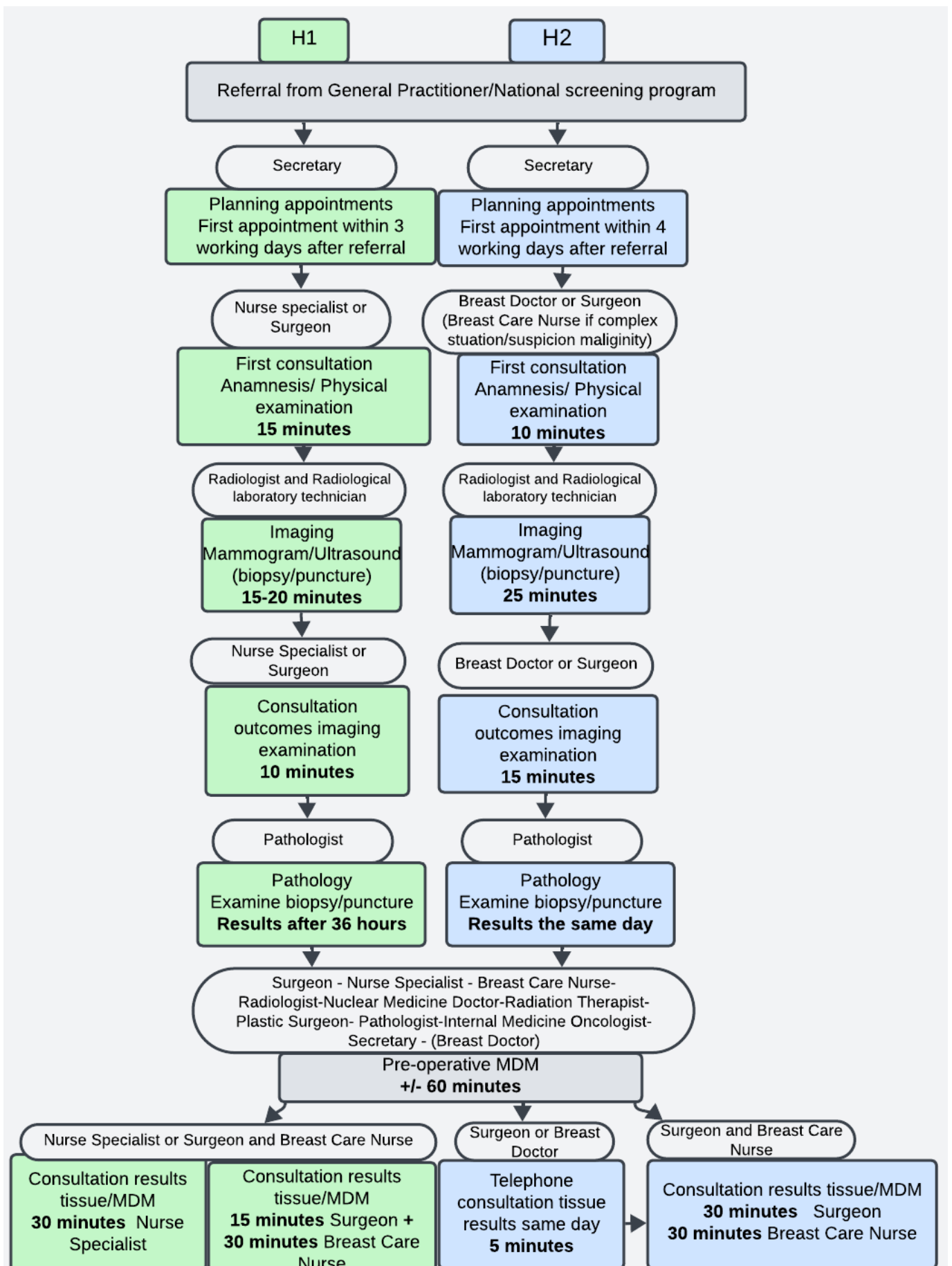


Figure 3. Flowcharts of the diagnostic breast care pathways of breast cancer in two different hospitals.

Interviews

Two group interviews were conducted face-to-face, one at Hospital 1 and one at Hospital 2. The participants are described in Table 4, where there is no H1 or H2 described, it signifies that the role description is identical in both hospitals. In contrast to Hospital 1, a Breast Doctor and Coordinator of the tumor working group were also participants in the group interview at Hospital 2, due to the extra position of a Breast Doctor in Hospital 2 and the Coordinator happened to be present at the hospital and asked if she could also attend the interview. The focus group interview at Hospital 1 lasted 58 minutes and lasted 45 minutes at Hospital 2, with the exclusion of the introduction time before the audio recording of approximately five minutes.

Participant	H1	H2	Role description
Surgeon	Yes	Yes	Informing patients about the process and responsible for surgery .
Nurse Specialist	Yes	Yes	H1: A specialized nurse who examines new patients and explains the treatment plan. H2: Not involved in the diagnostic part.
Secretary	Yes	Yes	H1: Receiving patients, taking care of scheduling and handling appointments and handling administrative matters. H2: Taking care of scheduling and handling appointments and handling administrative matters.
Breast Care Nurse	Yes	Yes	A nurse who also serves as a case manager and has a coordinating role through the pathway.
Breast Doctor	No	Yes	The title does not exist in the Dutch Healthcare Professionals Register (BIG register). However, the person performing the supportive tasks and consultations as a Breast Doctor must be registered with BIG.
Coordinator of the tumor working group	No	Yes	Policy advisor, responsible for acquiring new knowledge and sharing this knowledge when it comes to optimizing the quality of care for patients with breast cancer.

Table 4. Participants of the focus group interviews in the two hospitals.

4.1 Referral and planning appointments

Referral from the GP to the hospital takes place in the same way at both hospitals via the digital system, ZorgDomein [74]. ZorgDomein is a digital system that helps healthcare providers, such as general practitioners and physicians, to find, choose, and arrange care for patients. It is used to send referrals and requests for examinations digitally. With regard to the expected time frame to schedule an appointment at the outpatient clinic, in Figure 3 it can be seen that it should be within three working days of referral, at Hospital 1. In collaboration with the Nurse Specialist, a random sample of 10 patients from the HiX system was reviewed. At Hospital 2, the goal is within four working days, and the same process was carried out as in Hospital 1. In both hospitals, the first appointment was one day earlier or exactly the expected time frame.

Professional competences - Secretary and hostess

The breast clinic is part of the surgery department in both hospitals. At Hospital 1, the secretary is part of the oncological section and conducts all work for it. There are a few secretaries who are specifically responsible for breast care, but in general the secretary also sees other patients besides mamma patients. Administratively, secretaries play pivotal roles in managing patient information and facilitating smooth operations. At Hospital 1, secretaries greet patients at the desk, inputting important data from patient interactions into the system, and attending MDMs although they do not play an active role within the MDM. In contrast, at Hospital 2, there is a hostess, providing initial assistance to patients at the counter and a secretary specific for supporting administrative tasks. Here, the secretary is divided into four sections: gastrointestinal, trauma, vascular and breast and at the mamma clinic there are only mamma secretaries. Despite challenges such as staff shortages and furloughs, secretarial staff play an important role in coordinating care appointments and managing

the workload according to the respondents. Respondents highlight the impact of staff shortages on the efficiency of daily operations, with some days being more taxing than others. Nevertheless, the division of tasks within the secretariat is praised as being well organized according to the secretary and other respondents, contributing to a streamlined workflow for both medical employees and patients.

Quality of working life and Staffing levels - Workload

Respondents recognize the importance of a separate hostess function, especially when there is a large flow of patients who visit the outpatient clinic every day and increasing administrative tasks. Although there are different opinions about using a separate hostess, the potential is seen to reduce workload on the secretariat by distributing tasks more widely and improve the patient reception process in Hospital 1. The potential is especially seen during moments of staff shortage at the hospital. This way the secretary can perform administrative tasks separately from the desk where patients enter the clinic. When the secretary handles a wide variety of tasks and does not solely focus on one department, the workload tends to increase. The concept of a dedicated breast secretariat is perceived positively as a solution to alleviate the workload. For an efficient workflow, it is important that the secretaries have a clear division of tasks and carry out administrative tasks extensively. This saves time for the medical? specialistshospital employees and could lead to more efficient patient planning.

Respondent: *"The situation now is a bit exceptional to be honest. Today I was sitting here alone in the oncological secretariat. I had 70 calls in total. So, yes, all other tasks around those calls in terms of referral, planning etcetera remain uncompleted."*

Respondent: *"The secretaries are so well organized that I rarely have to do anything in the system itself."*

4.2 First consultation

Rate of documentation - Anamnesis

During the first consultation with the patient, an anamnesis is discussed. At Hospital 1, the anamnesis is asked during the consultation and answers are typed into the computer in the system HiX, by the Nurse Specialist. At Hospital 2, the patient receives the anamnesis form in advance from the general practitioner or from the hospital, fills it in themselves and hands it in to the hostess at the counter of the mamma clinic. The secretary types the information from the anamnesis into the system. During the first consultation, the medical history is briefly reviewed with the patient by the Breast Doctor or Surgeon. The discussion among participants highlights the possible advantages of simplifying patient admission procedures, especially through digital means, to reduce the administrative load on healthcare providers and promote patient-focused care. Participants pointed out the labour-intensive aspect of manual data input during consultations and showed excitement for pre-filled forms, which could enable healthcare professionals to concentrate more on patient engagement. Respondents also see the time saving component, because patients have already thought about the questions.

Respondent: *"Yes, ideally, when the secretary sends a consultation or an appointment to the patient, I would like the patient to receive a digital questionnaire, which is copied directly into the file. That could be the time saving."*

Respondent: *" Well, you have more time to focus on other matters. You can discuss things that do matter to the patient, namely: what to expect today, what do we do in which case and what fear does someone have? Those are the things you can address, that is what it is all about as far as I am concerned."*

Professional competences - Breast Doctor or Surgeon

In Hospital 2, the Breast Doctor or Surgeon conducts the initial consultation with patients, explains the steps in the diagnostic pathway and guides patients during and after the disease process. The role of the Breast Doctor does not exist in Hospital 1, as illustrated in Figure 3. Despite the lack of formal recognition of the title in the BIG register, the tasks associated with a Breast Doctor can be performed by BIG registered medical professionals, including both specialized and non-specialized doctors. The Breast Doctor carries out supporting activities for the surgeon. This suggests that the Breast Doctor serves as a kind of linking pin, bridging the roles and responsibilities of both a Nurse Specialist and a Surgeon. In case of a complex situation or suspicion of malignancy, the Breast Care Nurse is also involved in the initial consultation.

Respondent: *"The breast doctor is somewhat like a hybrid between a Nurse Specialist and a surgeon."*

Respondent: *"Breast doctor is not an official position. There are profile doctors who have a certain registration, but a breast doctor, we have created that term here. So you will not find a breast doctor in another hospital. But here at the outpatient clinic there is one breast doctor, I am the only one at the moment, who performs certain tasks."*

Professional competences - Nurse Specialist or Surgeon

In both hospitals a Nurse Specialist is involved in the breast cancer care pathway, but in Hospital 2 there is no involvement in the diagnosis. The Nurse Specialist plays a role there in the follow-up. The Nurse Specialist or Surgeon conducts the first consultation in Hospital 1. Respondents from Hospital 1, advocate for adherence to national standards, emphasizing the authority to independently establish treatment relationships with patients by the Nurse Specialist. It is seen as inefficient when the capacities of the Nurse Specialist are not utilized. Further, respondents in Hospital 2, see possibilities for the Nurse Specialist to conduct more standardized tasks. When it comes to task delegation, some respondents believe that the Surgeon should be in the lead, especially in complex cases and because they are the person who perform surgery if necessary. Others believe that the tasks of the Surgeon can be delegated to a Nurse Specialist, because they have the authority to do so.

Respondent: *"Discussing the results from diagnosis is something that could be considered as an option to perform here by the Nurse Specialists instead of the Surgeons alone."*

Breast Care Nurse Moment of involvement

The main difference between the two hospitals is the moment of involvement of the Breast Care Nurse in the diagnostic breast care pathway and the frequency of seeing the patient. In Hospital 1, the Breast Care Nurse is more involved after diagnosis for information about treatment and emotional support. However, when there is a suspicion of an abnormality or a complex situation, the Breast Care Nurse will be involved at the beginning of the diagnostic care pathway. In Hospital 2, the Breast Care Nurse is more involved from the start of the patient's care, by being present from the first consultation with the patient. As a result, the patient is also seen more often during the diagnostic care pathway. Having enough time for patients during consultations is mentioned as an important point.

Respondent: *"I do not think it is necessarily better there than here. It is different. I do think it is better in terms of time per consultation, but the number of times they see that patient, I do not know whether that is necessarily better."*

4.3 Imaging

In both hospitals, the imaging process begins immediately after the initial consultation on the same day. The process starts with a mammogram, followed by an ultrasound, and if necessary, a biopsy.

Both hospitals adhere to Magnetic Resonance Imaging (MRI) guidelines, with the need for an MRI discussed during the MDM. Hospital 1, is member of the Santeon collaboration of seven top clinical hospitals in the Netherlands. Within Santeon, they carefully considers the indications and number of MRIs performed, as they have found that many MRIs are not always necessary. If a biopsy is performed, it is discussed in the MDM. If there is a (pre)malignancy, during the MDM it is discussed whether there is an additional indication for an MRI. MRI is reserved for women at a very high risk. Reasons to perform an MRI after MDM include poorly or moderately assessable mammogram and the patient's wish for a breast-conserving operation. To reduce the chance of non-radical treatment, an MRI can be helpful and is often chosen to also be performed pre-operatively.

4.4 Consultation outcomes imaging examination

The consultation, which includes the discussion of imaging examination results, is on the same day following the initial consultation. This subsequent consultation will be conducted by the same healthcare professional(s) who were present during the initial consultation.

4.5 Pathology

The pathologist performs sections and assesses the biopsy for usability. Tissue material is collected at Hospital 1 on weekdays at 1:00 PM and transported to the laboratory adjacent to Hospital 2. Material is also collected at Hospital 2 on weekdays at 10:30 AM. Both hospitals rely on the same laboratory. Patients at Hospital 1 receive their results within 36 hours, while patients at Hospital 2 receive results within 24 hours on the same day. The speed of the PA results at both hospitals aligns with the Transmural breast cancer care pathway format [43]. At both hospitals, the PA result is known within 3 to 4 working days, which is within the standard of the format that describes this should be within 5 working days.

4.6 MDM

The frequency and scope of the MDM differs between the two hospitals. At Hospital 1, MDMs are held twice a week on Tuesday and Friday afternoon, each lasting an average of 60 minutes, depending on the number of patients discussed. Based on a sample concerning the number of patients at the pre-operative MDM by the Nurse Specialist of Hospital 1 over a period of 5 weeks, it was concluded that on average 9 to 10 patients are discussed at the pre-operative MDM. During the MDM, BIRADS one to two are not discussed, but they are discharged, and a policy letter is sent to the general practitioner. Meanwhile, at Hospital 2, MDMs are conducted daily, also lasting approximately 60 minutes. These meetings cover all patients, including those with BIRADS scores ranging from one to six from the preceding day or weekend. Patients with BIRADS scores of one and two are specifically discussed to ensure a second radiologist reviews the images for additional certainty before the patient is discharged. The content discussed during the MDMs is similar between the two hospitals. At both hospitals, discussions encompass the results of radiological and pathological examinations, imaging findings, and any required follow-up steps. It is noteworthy that at Hospital 1, patients from Thursday and Friday are discussed during Tuesday's MDM, whereas on Friday, patients from Monday to Wednesday are reviewed.

Respondents are generally satisfied with the frequency and execution of the MDM. However, respondents from Hospital 1 indicated that there is room for improvement in MDM preparation, especially regarding uniformity and accuracy. These respondents noted that the specialists in Hospital 2 better prepare the list of cases to be discussed, while the MDM forms are completed as standard, resulting in more consistent and complete reporting. With regard of the costs of the daily attendance of the multidisciplinary team, respondents noted that there are no associated costs during the MDM in Hospital 2, because the MDM takes place during lunch break. This is attributed to the timing of the MDM, which occurs during afternoon recess.

Respondent: "Yes, well, the frequency of the MDM daily is a lot every day and there are also patients that do not necessarily need to be discussed. I do think that it was always better prepared there. The specialist who is the chairman of the MDM checks the list the day before and fills it in better. So I think that's all just a bit brief here."

4.7 Consultation with results pathology/MDM

Diagnosis (Method of providing the patient with the diagnostic results)

At Hospital 1, the Nurse Specialist or the Surgeon with the Breast Care Nurse conducts a consultation in which the result of the pathology biopsy and MDM are discussed with the patient. At Hospital 2, patients choose their preference for how the results will be communicated. Patients may be phoned by the Surgeon or Breast Doctor at the end of the day with the results. This is always followed by an in-clinic consultation, one to two days later. Alternatively, the patient can choose for the in-clinic consultation with the Surgeon and Breast Care Nurse. According to the respondents from Hospital 2, most patients prefer the method of being called at the end of the day. Respondents typically suggest from their experiences that patients demonstrate enhanced information processing and engagement during in-person consultations when they have had the chance to process information at home in advance. Moreover, patients often express a need to be informed of their results to achieve a sense of tranquillity. However, respondents from Hospital 1 raise the question of whether this method might lead to patients having additional queries if results are initially shared over the phone. Furthermore, there is experience with the practice of communicating benign results to patients via phone calls prior to consultations at Hospital 1, however, this is not a standard procedure and respondents encounter such cases intermittently. Respondents express concerns that systematically identifying benign patients would require a significant amount of time and effort.

4.8 Setting and communication

Employees have their own room next to the waiting room for patients, in which employees work independently and receive patients in Hospital 1. This mainly concerns Nurse Specialists and Breast Care Nurses. The mamma clinic communicates informally through the Teams chat, e-mail, or in-person by visiting the colleagues room. Formal communication takes place through the system HiX. The secretary is located separately at the desk. In contrast, at Hospital 2, employees including the secretary work together in a back office outside of contact moments with patients, facilitating direct verbal communication with colleagues. In any case, the following employees are present: the Secretary, Surgeon, Breast Doctor and two Breast Care Nurses. Pathology and radiology can be reached by telephone, if necessary, in both hospitals.

Quality of working life - Cooperation

The physical setting of the workspace plays a pivotal role in fostering cooperation among healthcare providers. The shared back office in Hospital 2, where various team members including Secretaries, Breast Doctor, Breast Care Nurses, Nurse Specialist and Surgeons work together, is highlighted as a beneficial environment for teamwork. Respondents express appreciation for proximity, facilitating seamless communication and teamwork. This teamwork is viewed as instrumental in addressing challenges efficiently and ensuring the smooth operation of tasks. Despite some concerns about the practicalities of shared spaces, such as potential overcrowding, the consensus remains that the shared workspace positively impacts cooperation and overall effectiveness in healthcare delivery.

Respondent: "The physical setting of the workspace promotes strong teamwork. They all work closely together, with secretaries, doctors, nurses, surgeons, and trainees all in one space. This proximity allows for seamless communication and collaboration."

Quality of working life - Digital communication versus verbal communication

Communicating with colleagues via Teams is seen as the fastest way to communicate informally. However, healthcare providers who do not yet use Teams, do not necessarily see added value. Although Teams could be useful, preference is given to verbal communication.

Respondent: *"I don't think that chat will ever win over verbal communication."*

4.9 Barriers and opportunities

In this section, the barriers and opportunities from the focus-group interviews with hospital employees are described. The barriers and opportunities from the patient interviews and PREMs can be found in 4.10.

Barriers – Quality and safety, Quality of working life, Process and patient flow

In particular, surgeons face a scarcity of time throughout the entire diagnostic breast cancer care pathway. Respondents report feeling restricted by routine tasks and time constraints, which hampers their ability to deliver comprehensive care and engage in detailed discussions with patients. Existing routines and habits in both hospitals are seen as obstacles by the respondents, to the introduction of changes aimed at improving efficiency. Further Improving collaboration through a back office was mentioned, but this would require a complete renovation of Hospital 1, according to respondents.

Respondent: *"There is a lack of time for results discussions, biopsy results discussions, and discussing treatment plans for everyone, but especially the Surgeon."*

Opportunities – Process and patient flow, Quality of working life, Rate of documentation, Information continuity

Respondents recognize potential advantages of a more streamlined approach. In Hospital 1, the MDM takes place on Friday and a relatively large number of patients are scheduled for the outcome of the previous MDM. The workload is high that day and it is difficult to schedule patients here. Hospital employees, in specific the secretary, perceive the process of securing an available slot as a challenging endeavour, leading to the day being experienced as burdensome. With regard to pathology outcomes, there was also enthusiasm for the potential in rapid diagnostic phone calls with results and conducting anamnesis in advance. In Hospital 2, there is interest in involving the Nurse Specialist more in the entire process. Further, Hospital 1 indicated that it is important to work in a more uniform manner. This includes the complete maintenance of the electronic health systems by each healthcare provider and better preparation for the MDM, including consistent use of the standard MDM form. Hospital 2 uses a MDM form, designed by Chipsoft based on the Nabon protocols. Hospital 1 does not use the Nabon form due to the presence of the standard form in Hix. Employees of Hospital 1 see opportunities in the preparation for the MDM and maintaining the MDM form more consistently. When it comes to unambiguous communication, this is an important point according to the respondents from both hospitals. Occasionally, there is miscommunication with patients or misunderstandings due to the use of different terms by medical professionals.

4.10 Patient perspective

Patient interviews were conducted individually at Hospital 1 with four patients, lasting on average 11 minutes. The PREM from Hospital 2, contained 124 open responses regarding areas of improvement and 126 open responses regarding what is already going well.

Patient interviews

Patient satisfaction - Execution time, Information continuity,

Patients from Hospital 1 reported a number of positive experiences that contributed to a sense of support and trust. They appreciated the quick scheduling of their first and subsequent appointments,

which ensured they received the right care promptly, enhancing their confidence and reassurance. The clear and complete communication about the care pathway was highly valued. Each step was thoroughly explained, helping patients to better understand the treatment process and providing reassurance. This clarity and the accuracy of the information reinforced their trust in the treatment team. Patients also appreciated having sufficient time to ask questions and discuss concerns. The hospital employees took the time to listen, creating a sense that the patient's well-being was a priority. This contributed to patients feeling heard and appreciated. Patients mentioned, substantial emotional support was offered throughout the entire process, contributing to a feeling of safety and trust. Patients also preferred to be assisted by the same individual as much as possible throughout the care process. They found it comforting that multiple examinations could take place on the same day and that results were quickly available. Overall, the combination of efficient scheduling, clear communication, personal attention, and emotional support led to a positive patient experience. The patients felt involved in their treatment and appreciated the opportunity to ask questions and receive information.

Respondent: *"Results were received quickly and consultations were scheduled quickly and efficiently."*

Respondent: *"It was pleasant that multiple examinations could take place on the same day and the result followed quickly."*

Respondent: *"The communication was clear and complete, with extensive explanation about the procedures and sufficient time during consultations to ask questions and process information."*

Opportunities – Patient involvement, Waiting times

While patients were predominantly positive, patients also identified several points for improvement. The first point is about shared-decision making. Patients prefer to be guided through the decision-making process by healthcare professionals, recognizing their expertise, rather than having to make decisions independently. For example, a patient experienced difficulty in receiving information about survival rates and making decisions about treatment options, such as chemotherapy. When discussing options with the surgeon, who mentioned percentages, the patient felt overwhelmed and found it difficult to make a choice. However, upon receiving direct advice from the internist-oncologist to follow chemotherapy, the patient felt a sense of relief and certainty.

Respondent: *"I was seeking advice, as I had no prior knowledge or experience with chemotherapy. The surgeon presented me with various options and percentages related to chemotherapy, which I found overwhelming and difficult to comprehend. However, when I met with the oncologist, she straightforwardly recommended a specific type of chemotherapy. Upon hearing her advice, I felt relieved and no longer needed to ponder over the decision. After all, I realized that I lacked the expertise to make such a decision on my own."*

Another point for improvement concerned the waiting times between appointments. The long time? between appointments on the same day were found to be burdensome, and patients believed this process could be organized more efficiently. Patients also indicated that it is important that sensitive information, such as an unfavourable diagnosis, is communicated in a more empathetic and subtle way.

Respondent: *"It would be better if communication about the the cancer diagnoses were less direct and more sensitive, because the news hit like a bombshell."*

With regard to administrative procedures, patients were positive about the idea of completing the anamnesis in advance, which is not currently part of the general procedure at Hospital 1. Patients appreciated this idea to better remember details such as family history during the consultation. Also, three out of four patients indicated a positive view of being informed by phone about the pathology

results on biopsy, in order to process the news calmly at home before discussing further steps with the hospital employees.

PREM

Patient satisfaction – Waiting times, Continuity of care

Patients at Hospital 2 particularly appreciated the speed and efficiency of the care, as well as the clear and expert communication. A third of the patients emphasized how pleasant it was that examinations were handled quickly and that results were immediately available, reducing unnecessary uncertainty. The personal approach, kindness and empathy of the healthcare staff were also highly appreciated by nine patients. Patients felt heard and understood, which contributed to a feeling of safety and comfort. In addition, seven patients mentioned the professional and expert approach of the healthcare providers. This combination of speed, clear communication, personal attention and expertise ensured that the majority of patients were satisfied with their experience in Hospital 2.

Respondent: *“I found it very nice that there was an immediate result after the examinations and that you were well explained in advance what exactly would happen.”*

Respondent: *“It is very nice that as a patient you have a personal point of contact, the Nurse in the department. And it is nice that she arranges the appointments for you and takes care of you. The entire team I have dealt with is super caring, emphatic and appears very competent. All praise!”*

Respondent: *“Expertise and a very friendly and expert explanation. They have given me a lot of confidence.”*

Opportunities – Waiting times, Continuity of care

Although the majority of patients were very satisfied with their experience at Hospital 2, several points for improvement were mentioned that could further optimize patient care. One patient mentioned, that communication and mutual coordination could be better. Second, four patients suggested that the scheduling of appointments could be more efficient, especially when combining multiple appointments on one day to avoid long waiting times. The importance of quick and correct follow-up was also emphasized. Furthermore, one patient noted that communication about possibilities for mental support could be better.

Respondent: *“It was not very clear to me which waiting area I could take a seat in after being referred from one location to another. It would be nice if there was an employee near all waiting areas who you could ask if you are at the right place (I also saw an older couple struggling with this).”*

Respondent: *“Faster deployment of mental help in case of setbacks and opening the agendas of specialists further in the future (...).”*

5. Discussion

5.1 Main findings

The aim of this study was to explore the possibility of creating a more standardized diagnostic breast cancer care pathway by integrating practices of two different hospitals by understanding and considering the perspectives of various stakeholders involved in the process and also identifying and addressing variations in processes between the two hospitals. Based on these differences and the perspectives of patients and hospital employees, there are key variations and insights identified based on the framework in Figure 4, which are visible within the pink frame.

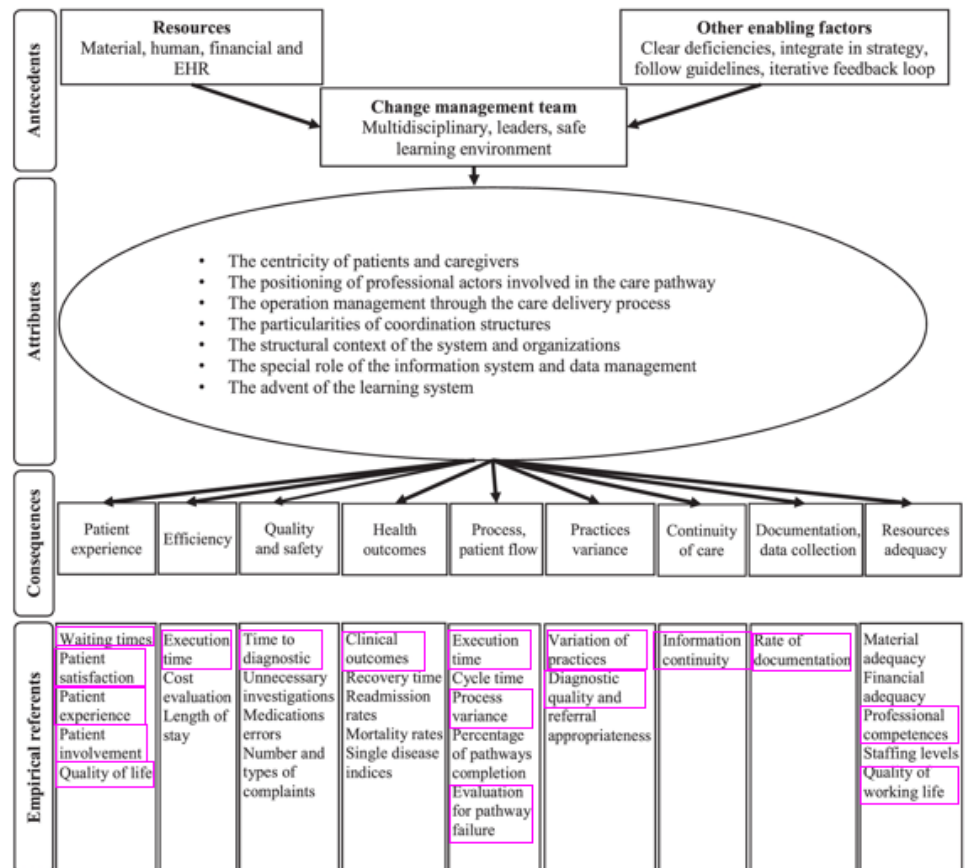


Figure 4. Integrative conceptual framework of care pathway [44].

General findings

The first general finding highlights the importance of allocating sufficient time for health employees. All employees experienced **time constraints**, which can hinder the integration of care pathways. This challenge is particularly pronounced for surgeons, due to their high workload and scheduled consultation times. When linking this result to Figure 4, time constraints could be associated within the entire framework. For instance, this issue might be increased due to staffing shortages. Consequently, it could negatively affect the quality of working life for employees. Moreover, in adherence to the care pathway can become a potential issue. Tsiga et al. (2013) found that increased time pressure due to high workload negatively affected adherence to guidelines [75]. While, adherence to guidelines is a key success factor of the implementation of care pathways [44]. In addition, physicians experienced more time constraints if they worked in large practices, which supports the finding from the hospitals that can be compared to a certain extent with large practices. It was found that, due to time constraints, medical specialists conducted less thorough clinical examinations [76], provided less advice to patients regarding lifestyle changes [75], and were not able to discuss the treatment plan with patients [77]. However, both studies were performed in a primary care setting making applicability to this study questionable. Balancing these demands is crucial for effective patient care, as sufficient time is necessary for both patient experiences by patient involvement in the form of shared-decision making as positive clinical outcomes [78]. While Maes-Carballo et al. (2021), concluded that lack of time and resources were identified as the biggest obstacle for patient involvement in the care pathway [78]. It might be worthwhile to explore the feasibility of allocating more time or task delegation. Analysing the specific activities of health

employees that consume the most time could inform potential solutions. In order to identify areas where time could be used more efficiently or where additional resources could be allocated to reduce time pressure. This way, areas can be identified where time utilization could be optimized or where additional resources might be allocated to alleviate time constraints. For instance, the introduction of a hostess in Hospital 1, could alleviate administrative burdens on secretaries. Another idea, mentioned by the specialists, could be the establishment of a specific breast clinic as mentioned by the respondents, where surgeons only see breast cancer patients. This could allow surgeons to focus their expertise and time more effectively, potentially reducing the time pressure they experience. No specific literature within the breast cancer setting that supports this statement was found. However, a study among radiologists concluded that in public hospital settings they experienced lower quality of working life with higher work stress, more burnout and lower job satisfaction compared to those in private practices [79]. Implying that the proposed idea of only seeing breast patients could reduce the workload. While this idea may be worth considering for the future, it would require a sufficient number of breast cancer patients to be feasible.

Secondly, **patient satisfaction** with the diagnostic breast cancer care pathway is largely positive. However, communication emerges as an important factor, as both patients and healthcare providers acknowledge that information does not always effectively reach patients. This is especially the case when using medical terminology. A study on patients' understanding of medical terminology in a breast clinic, concluded that 50% of could not correct questions regarding terminology correctly [80]. Therefore, patients and hospital employees emphasize the importance of **simple and unambiguous communication**. Since Figure 4 shows the centrality of patients, it is logical that if the focus on patients is lacking, there will be an impact on the indicators of all different consequences. Patients require clarity to understand information effectively and actively participate in shared decision-making, to prevent confusion and enhance patient satisfaction [81]. When patients and healthcare providers do not communicate in the same terms, patients may feel less involved in the decision-making process. This lack of communication contradicts the concept of patient-centered care. This aligns with literature, which mentioned that health employees often prioritize the organizational point of view when considering care pathways [34,82], and a qualitative study on patient experiences in public hospitals from Wong et al. (2020) confirms the difficulty in understanding information from medical specialists [81]. When Gartner's framework is linked to these findings, it can be recommended to create awareness among employees about communicating with patients [44], where effective communication between medical professionals and patients is essential for best practice breast cancer care [83], and patient satisfaction increases [84]. Since optimizing interactions between patients and healthcare providers is necessary for a seamless patient journey and satisfied patients [44].

Key findings

Respondents in both hospitals agree that the **Nurse Specialist should be actively involved in the diagnostic phase**, with the main reason of utilizing their authority and capabilities while they are independent practitioners. Moreover, efforts are underway to ensure more equitable distribution of their expertise by introducing own consultations led by the Nurse Specialist during the diagnostic phase in Hospital 2. This reflects what has been written in literature, about the growing international interest in expanding nursing practice, including Nurse Specialists, over the years with an essential role in cancer care and positive patient outcomes [85,86]. Nurse Specialists are authorized to independently establish a therapeutic relationship with patients [87], which benefits **patient-centered care**. Outcomes for both the entire process and specific patients can logically be influenced, including patient experiences, efficiency, health outcomes, and continuity of care, Figure 4. Since, patients are predominantly positive about the care provided by Nurse Specialists compared to other healthcare providers, for example by feeling safe and understood and high patient involvement [88,89]. Earlier, task delegation was mentioned as a potential solution to the time pressure experienced by healthcare providers. From this perspective, the Breast Doctor could be introduced as a role in Hospital 1. Considering these points collectively, it underscores the significance of

employing Nurse Specialists in diagnostic care. Initially, there were expectations of substantial differences between the two hospitals concerning Breast Care Nurses, based on employee discussions and colleague reports. However, this did not emerge from the study findings. Another key finding, is the positive attitude by both hospital employees and patients for **completing the anamnesis prior to the first consultation**. Firstly, patients can recall information more effectively and inquire about specific details covered in the anamnesis. Secondly, it saves time for healthcare providers, enabling them to address other patient-related matters during the initial appointment. A complete and correctly filled in anamnesis by gaining a comprehensive understanding by the medical professional is highly important for the quality of care [90]. and the general points that need to be addressed, including family history and specific complaints associated with breast related diseases. However, it is not specified whether the anamnesis should take place before or during the consultation [91]. Another interesting finding was, that in Hospital 1, the rate of documentation and adherence to workguidelines are lacking regarding the execution of the MDM. Specifically, they indicated that not all employees prepare the MDM sufficient enough and not in an uniform way. **Inefficiencies in MDMs** are often caused by lacking standardization of different aspects, like the representation of certain patients and the workflow of medical specialists [92,93] and the lack of patient information [94]. In a study from Brown et al. (2020), a standardized template led to more efficiency by decreasing time [95]. Consequently, patient outcomes can be positively influenced by even decreasing mortality [96]. The importance of documentation and data collection, is placed as a consequence in Gartner's framework. This can be interpreted as if peripheral issues for documentation are well organized, the level of documentation could also become better. Finally, this research found variation in **methods for communicating results of pathology results on the biopsy** between the two hospitals and the timeliness or time to diagnosis, see Figure 4. Hospital 1 offers 36-hour diagnostics, where the results for both malignant and benign patients are discussed during a consultation. While, in Hospital 2, they conduct 24-hour diagnostics. Here is an option for all patients to receive phone calls for both malignant and benign results. According to the patient experiences, they prefer fast diagnosis, this is in line with the Interviews with healthcare providers who indicated that 99% of patients prefer to be called the same day with diagnosis. Wright et al. (2002) suggests that clear and timely communication of results can enhance patient engagement and satisfaction, which aligns with the findings from Hospital 2 and the patient opinions [97]. In addition, Friedemann Smith et al. (2019), concluded that one-stop clinics reduce patient anxiety immediately after their appointment, however on the long term this led to more cases of depression than in a two-stop clinic [98]. This is also confirmed by Dey et al. (2002) [99].

5.2 New insights

These findings enhance the scientific understanding of breast cancer care by emphasizing practical challenges, such as time constraints and communication issues and suggesting potential solutions based on two hospitals. Emphasizing the significance of patient-centered care and streamlined clinical practices in enhancing outcomes and patient experiences throughout breast cancer diagnosis and treatment pathways. The use of the Framework of Gartner et al. (2022) has been meaningful in this study. Especially due to the complexity of comparing two hospitals, where the framework immediately identified important aspects such as specific "consequences and referents" and it prioritized the patient [44]. However, to a certain extent, it was challenging to link certain aspects to specific points in the framework because of the interconnectedness observed with other aspects within the framework. For example, There is overall coherence, which makes the framework comprehensive and quite intriguing. Modifications are necessary to address identified gaps and enhance its relevance to the specific challenges faced in breast cancer diagnostic care, for example by placing efficiency and communication within the attributes due to the importance over the different steps. However, when performing a study in which the indicators to focus on are very clear in advance, this framework may be less useful.

5.3 Strengths and limitations

The strength of this study lies in its triangulation of methods, allowing for a more thorough understanding of the care pathways, as each method provided a different perspective and form of data. Another strength is the engagement of both patients and hospital employees to ensure a wide range of perspectives. This diversity of viewpoints enriches the data and makes the findings more representative of the reality of the care pathways. Despite the strengths, there are also limitations. The study initially aimed for a mixed-method approach, including both qualitative and quantitative data analysis. However, due to time constraints, less emphasis was placed on the complete measurement of times and whether they correspond to practice. The time measurements were taken over a relatively small group and were not consistent in both hospitals, as not every step was observed equally often in both hospitals and sometimes, for example, more patients came for the first consultation. This makes the information less reliable. Further, only four patients were interviewed at Hospital 1, and no patients were interviewed at Hospital 2. Therefore, there is a lack of comprehensive results from patients, especially at Hospital 2 despite the use of the PREM. Another potential limitation arises from selection bias, patients who received a cancer diagnosis during the consultation before the individual interviews at Hospital 1, were not invited to participate. Excluding their perspectives could potentially affect the representativeness of the findings. However, the use of PREMs in Hospital 2 helped partially compensate for this bias by capturing broader patient experiences. In terms of generalizability, the study's focus on breast cancer care pathways within Dutch hospitals may limit the direct applicability of the findings to countries with differing healthcare systems or cultural contexts.

5.4 Future research

To enhance the objectivity, future research should focus on greater data inclusion, particularly involving more patients and quantitative data. Quantitative data can provide robust evidence across various indicators, such as waiting times, resource utilization, and patient outcomes. By comparing these aspects across different parts of the care pathway in various hospitals, inefficiencies can be identified and addressed. While this study was limited to samples from only 10 patients and a few observations, a larger-scale assessment is essential to validate the accuracy of the care pathway in practice. Leveraging existing registries, such as the NKR, over a specific time period can help determine whether the data aligns with the care pathway. If these registries lack comprehensive information, Electronic Patient Records (EPRs) become valuable sources for a patient's medical history, including diagnoses, treatments, and outcomes. EPR data is standardized across the healthcare system, facilitating easy comparison and analysis [100]. Additionally, future studies could conduct precise measurements across a larger cohort to verify whether the planned times for each step in the care pathway align with actual practice. While this study focused on the diagnostic phase, an overall comparison of other steps within the breast cancer care pathway would be interesting.

5.5 Practical implications

The outcomes of this study serve as valuable input for refining the diagnostic breast cancer care pathways in the two hospitals examined. By addressing specific areas highlighted in the results, these pathways can be further standardized, promoting higher quality of care and greater collaboration in the future. A summary of these specific recommendations for improvement can be found in Appendix 6. Additionally, other hospitals or healthcare institutions may find these outcomes relevant for evaluating the adequacy of their own care pathways.

5.6 Conclusion

This research has contributed to the literature on diagnostic breast cancer care pathways. While the diagnostic breast cancer care pathways of both hospitals exhibit substantial similarities, nuanced differences were noted that emphasized the need for attention when integrating care pathways. It can be concluded that the diagnostic breast cancer care pathways in the two hospitals from this study, can be further standardized and integrated by taking an initial step by focusing on the following points: Both hospitals should raise staff awareness about the importance of effective

patient communication by communicating in an understandable manner and with consistent use of terminology to increase efficiency en patient satisfaction. For Hospital 1 it is recommended to:

1. Consider appointing a Breast Doctor to manage workload and time constraints.
2. Ensure uniformity in staff practices by adhering strictly to standards and maintain up-to-date data.
3. Consistently use standardized MDM forms across all MDM staff to improve documentation quality and meeting efficiency.
4. Implement a pre-consultation anamnesis to enhance information recall and consultation efficiency.

On the other hand, for Hospital 2 it is recommended to empower the Nurse Specialists by allowing them to take a more leading role within the diagnostic breast cancer care pathway. These insights provide valuable guidelines for further standardization and improvement of diagnostic breast cancer care pathways. This integration could enhance efficiency by promoting equality for facilitating future collaboration.

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Appendices

Appendix 1 Observation scheme

Hospital 1

Date:

Start time:

End time:

Aim: Observe whether breast cancer care in practice corresponds to the documented care pathway.

General observations:

1. Coordination between healthcare providers
2. Communication between healthcare providers
3. Patient involvement in treatment decisions
4. Registration and documentation of patient care

End question: Are there discrepancies between the documented care path and practice, if so what are the differences from the care path in practice?

Fase Dia gnose	Geobserveerd e	Activiteit	Beoordeling
Verwijzing & Planning afspraken	EPD	<ul style="list-style-type: none"> ▪ Afspraak polikliniek <3 werkdagen na verwijzing 	Starttijd: - Eindtijd: Volgens zorgpad?
1 ^e afspraak VS/chirurg/A(N)IOS		<ul style="list-style-type: none"> ▪ Uitleg over gang van zaken door? ▪ Anamnese en lichamelijk onderzoek ▪ Aanvraag mammografie/echo/biopt door? Wel of niet gedaan? 	Starttijd: - Eindtijd: Volgens zorgpad?
Beeldvormend onderzoek		<ul style="list-style-type: none"> ▪ Uitleg procedure door? ▪ Beoordeling mammografie en echografie door radioloog 	Starttijd: - Eindtijd: Volgens zorgpad?
Fase Diagnose	Geobserveerd e	Activiteit	Beoordeling
2e moment VS/chirurg	Chirurg/VS EPD	<ul style="list-style-type: none"> ▪ Uitslag en vervolg bespreken met patiënt ▪ Op indicatie: MRI mammae / biopsie <5 werkdagen 	Starttijd: - Eindtijd: Volgens zorgpad?
Pathologie		<ul style="list-style-type: none"> ▪ Beoordeling biopt volgens PALGA protocol ▪ Uitslagen 36 uur na afnemen biopt bekend 	Starttijd: - Eindtijd: Volgens zorgpad?

Preoperatief MDO	Chirurg-oncol VS Mammavpgk Radioloog Nucleair gnsk Radioth oncol Internist onco Plastisch chir Patholoog	<ul style="list-style-type: none"> ▪ Bespreken uitslagen radiologisch onderzoek ▪ PA onderzoek en behandelplan 	Starttijd: - Eindtijd: Volgens zorgpad?
Afspraak chirurg+MCV/VS terugkoppeling MDO	VS of chirurg met mcv	<p>Terugkoppeling naar patiënt na MDO</p> <ul style="list-style-type: none"> ▪ Door wie? ▪ Advies over? ▪ Schriftelijk/mondeling? ▪ Duur afspraak: ▪ Procedure voor besluit over behandeling na communiceren van advies <p>Verwijzing naar internist-oncoloog indien NAC</p>	Starttijd: - Eindtijd: Volgens zorgpad?

Fase Behandeling	Geobserveerde	Activiteit	Beoordeling
NAC (indien nodig)			
Bespreken behandelplan internist & VS	Internist VS	<ul style="list-style-type: none"> ▪ Info over behandeling: Doel Volgorde Behandeling Werking Bijwerkingen Plannen: Intake, onderzoeken, start kuur <ul style="list-style-type: none"> ▪ Check of patiënt info over NAC heeft begrepen: Toediening, tijdsduur Uitleg trials Toelichting bereikbaarheid Screeningslijst voeding Info voer beweging tijdens chemo <ul style="list-style-type: none"> ▪ Inplannen kuren 	Starttijd: - Eindtijd: Volgens zorgpad?
Chemo op dagbehandeling	EPD	<ul style="list-style-type: none"> ▪ Start behandeling <5 weken na diagnose 	Starttijd: - Eindtijd: Volgens zorgpad?
Bezoek internist-oncoloog		<ul style="list-style-type: none"> ▪ Afhankelijk van kuren ▪ Wat wordt besproken? 	Starttijd: - Eindtijd: Volgens zorgpad?

Fase Behandeling	Geobserveerde	Activiteit	Beoordeling
Chirurgie		Of NAC+chirurgie(+aanvullend) Of Chirurgie(+aanvullend)	Starttijd: - Eindtijd: Volgens zorgpad?
Bespreken operatie	EPD	<ul style="list-style-type: none"> ▪ Na 2/3 deel van de kuren volgt responseevaluatie met MRI/echo. ▪ Daarna gesprek met chirurg en mcv voor bespreken van de operatie. ▪ Casemanager plant de OK en alles wat daarbij hoort en geeft de voorlichting 	Starttijd: - Eindtijd: Volgens zorgpad?
Medicatieverificatie POS/anesthesie		<ul style="list-style-type: none"> ▪ Patiënt bezoekt POS (preoperatieve screening) ▪ Invoeren gegevens van vragenlijst (waar?) ▪ Uitleg over anesthesie/pijn ▪ Indien nodig: plannen preoperatief diagnostisch onderzoek 	Starttijd: - Eindtijd: Volgens zorgpad?
Operatie			
Fase Behandeling	Geobserveerde	Activiteit	Beoordeling
Post MDO		<ul style="list-style-type: none"> ▪ PA (weefselonderzoek) bespreken ▪ Vaststellen vervolgleid 	Starttijd: - Eindtijd: Volgens zorgpad?
Bezoek mammapoli 7-10 dagen post-OK		<ul style="list-style-type: none"> ▪ Bespreken uitslag en behandelplan ▪ Indien nodig vervolplanning aanvullende behandeling (adjuvante radiotherapie of systeemtherapie) of meteen follow-up 	Starttijd: - Eindtijd: Volgens zorgpad?
Adjuvante radiotherapie			

Bezoek radiotherapeut oncoloog bij MST		<ul style="list-style-type: none"> ▪ Kennismaking, intake ▪ Toelichting doel, duur etc. ▪ Psychosociale screening op indicatie ▪ Therapie controle op indicatie 	Starttijd: - Eindtijd: Volgens zorgpad?
Start radiotherapie			
Controle		<ul style="list-style-type: none"> ▪ Bij primaire radiotherapie follow-up individualiseren ▪ Hoe? 	Starttijd: - Eindtijd: Volgens zorgpad?
Adjuvante systeemtherapie	Geobserveerde	Activiteit	Beoordeling
Bezoek internist oncoloog		<ul style="list-style-type: none"> ▪ Bespreken indicatie adjuvante chemo- etc. ▪ Bespreken evt. deelname wetenschappelijk onderzoek ▪ Anamnese en lichamelijk onderzoek ▪ Info over beleid/behandeling ▪ Plannen intake gesprek & start kuur 	Starttijd: - Eindtijd: Volgens zorgpad?
Consult VS oncologie of oncologie verpleegkundige		<ul style="list-style-type: none"> ▪ Indien adjuvante chemo: ▪ Check of patiënt over chemo heeft begrepen ▪ Plannen vervolgspraak (Zn) en plannen start 1^e kuur 	Starttijd: - Eindtijd: Volgens zorgpad?
Adjuvante chemo	EPD	Controle 5 jaar tijdens behandeling	Starttijd: - Eindtijd: Volgens zorgpad?
Bezoek internist oncoloog		<ul style="list-style-type: none"> ▪ Bespreken follow-up/afspraak volgende controle 	Starttijd: - Eindtijd: Volgens zorgpad?
Indien nodig Doelgerichte therapie of Endocriene therapie			

Follow-up		
Bij NAC	EPD	<ul style="list-style-type: none"> ▪ Controle chirurg 1e jaar daarna verpleegkundig specialist 1 x per jaar (per patiënt verschillend)
Bij adjuvante systeemtherapie	EPD	<ul style="list-style-type: none"> ▪ Labcontrole eenmalig internist
Bij endocriene therapie	EPD	<ul style="list-style-type: none"> ▪ Controle 5 jaar tijdens behandeling

B. Observation scheme Hospital 2

Date:

Start time:

End time:

Aim: Observe whether breast cancer care in practice corresponds to the documented care pathway.

General observations:

5. Coordination between healthcare providers
6. Communication between healthcare providers
7. Patient involvement in treatment decisions
8. Registration and documentation of patient care

End question: Are there discrepancies between the documented care path and practice, if so what are the differences from the care path in practice?

Fase Verwijzing	Geobserveerde	Activiteit	Beoordeling
Verwijzing & Planning afspraken	EPD	Afspraak plannen 1 ^e bezoek <4 werkdagen	Starttijd: - Eindtijd: Volgens zorgpad?

Fase Diagnose	Geobserveerde	Criteria / Activiteit	Beoordeling
1 ^e consult mamapoli	Chirurg of mammadokter/ Assistent	Anamnese Lichamelijk onderzoek Bespreken diagnostisch traject	Starttijd: - Eindtijd: Volgens zorgpad?
Radiologie	EPD Laborant radioloog	Mammografie (<3 werkdagen) /echografie/evt. biopt	Starttijd: - Eindtijd: Volgens zorgpad?
Pathologie	EPD Laborant patholoog	Indien nodig cytologisch en/of histologisch onderzoek (<24 uur)	Starttijd: - Eindtijd: Volgens zorgpad?
Uitslaggesprek na beeldvormend onderzoek	Chirurg of mammadokter MCV ook aanwezig vanaf BIRADS IV B EPD	Voorlopige uitslag van onderzoeken na radiologie Bespreken vervolgtraject Folders geven Emotionele ondersteuning en aanvullende info <3 weken doorlooptijd diagnostiek Eendagsdiagnostiek uitslag weefselonderzoek eind van de dag telefonisch	Starttijd: - Eindtijd: Volgens zorgpad?
MDO pre operatief	Chirurg Mammadokter	Bespreken: relevante patiëntgegevens lichamelijk onderzoek	Starttijd: - Eindtijd: Volgens zorgpad? Freq: dagelijks

	<p>MCV/casemanager Radioloog Radiotherapeut Internist oncoloog Plastisch chirurg op afroep Patholoog Secretaress e Consulent Klinisch geneticus op afroep EPD</p>	<p>uitslag mammografie uitslag echografie PA-uitslag uitslagen evt aanvullende onderzoeken behandeladvies evt indicatie mammaprint evt deelname aan wetenschappelijke studie</p> <p>Afspraak doorlooptijd PA uitslag max 10 werkdagen na OK</p>	<p>Patiënten die besproken worden: alle</p>
<p>2^e uitslaggesprek met patiënt, na biopt</p>			
<p>Polibezoek uitslaggesprek na biopt</p>	<p>Chirurg en MCV/casemanager</p>	<p>Patiënt bezoekt polikliniek chirurgie en krijgt van chirurg uitkomst MDO en onderzoeken te horen à uitleg behandelmogelijkheden etc</p>	<p>Starttijd: - Eindtijd: Volgens zorgpad?</p>
<p>Vervolggesprek door mammacare vpgk</p>	<p>MCV/casemanager</p>	<p>Begeleidingsgesprek na uitslag Geeft emotionele ondersteuning Geeft aanvullende informatie m.b.t. het vervolgtraject en regelt de vervolgafspraken Informeert over bereikbaarheid Navraag behoefte voorlichtingsvideo's Geeft voorlichtingsmateriaal mee +PIM en geeft uitleg op maat op papier of digitaal Geeft informatie over ondersteunende oncologische zorg</p>	<p>Starttijd: - Eindtijd: Volgens zorgpad?</p>
<p>Preoperatief consult plastische</p>	<p>Pastisch chirurg/VS plastisch</p>		<p>Starttijd: - Eindtijd: Volgens zorgpad?</p>

chirurgie op indicatie			
Gesprek pre chemo indien neoadjuvante behandeling	Radiotherapeut		Starttijd: - Eindtijd: Volgens zorgpad?
Preoperatief gesprek op indicatie	Radiotherapeut		Starttijd: - Eindtijd: Volgens zorgpad?
Preoperatief verpleegkundig mammaspreekuur	MCV/casemanager	Info over opnameprocedure en verpleegkundige activiteiten Schriftelijk/digitaal?	Starttijd: - Eindtijd: Volgens zorgpad?

Fase Operatieve behandeling	Geobserveerde	Activiteit	Beoordeling
POS/poliesthesie	Anesthesist / POS-medewerkers		Starttijd: - Eindtijd: Volgens zorgpad?
Opname verpleegafdeling	Afdelings-vpk Fysiotherapeut	Pre-operatieve voorbereiding	Starttijd: - Eindtijd: Volgens zorgpad?
Operatie	Chirurg Anesthesist		Starttijd: - Eindtijd: Volgens zorgpad?
Pathologie	Laborant en patholoog	Histologisch onderzoek	Starttijd: - Eindtijd: Volgens zorgpad?
Postoperatief verpleegafd.	Afdelings-vpk Chirurg MCV/casemanager Fysiotherapeut	Postoperatieve nazorg volgens protocol Controleert of alles geregeld is voor ontslag Evt. regelen thuiszorg Visite door arts-assistent Bezoek MCV	Starttijd: - Eindtijd: Volgens zorgpad?

	Evt. dietist	Bezoek fysiotherapeut (op maat gesneden consult)	
Ontslag	Afdelings- verpleegkundige/F ysiotherapeut EPD	Ontslaggerek volgens zkh-protocol, minimaal komt aan bod: Leefregels Informatie over bereikbaarheid hulpverleners Wat te doen bij complicaties Afspraak uitslag PA/controle BON 7-10 dagen na operatie	Starttijd: - Eindtijd: Volgens zorgpad?
MDO post operatief		Bespreken follow-up en eventuele aanvullende therapie	Starttijd: - Eindtijd: Volgens zorgpad?
Telefonisch consult na ontslag		3 ^e dag na ontslag	Starttijd: - Eindtijd: Volgens zorgpad?
Controlebezoek mammapoli 7- 10 dagen post- OK		Bespreken uitslag en behandelplan Indien nodig vervolgplanning aanvullende behandeling (adjuvante radiotherapie of systeemtherapie) of meteen follow-up	Starttijd: - Eindtijd: Volgens zorgpad?

Radiotherapie	Geobserveerde	Activiteiten	Beoordeling
Oproep patiënt	Secretariaat radiotherapie/ Radiotherapeut- oncoloog		Starttijd: - Eindtijd: Volgens zorgpad?
Intake/1 ^e consult	Radiotherapeut- oncoloog of Physician Assistant Chirurg blijft hoofdbehandelaar	Bespreken diagnose Lichamelijk onderzoek Bespreken behandelingsplan, en uitleg doel procedure en effecten van de behandeling Geef informatie over ondersteunende oncologische zorg (o.a. fysiotherapie, diëtiëk, werkbehoud, intimiteit/seksualiteit)	Starttijd: - Eindtijd: Volgens zorgpad?
Vorbereidingsafspraken	Secretariaat	A Afspraak CT- simulator voorafgegaan door een voorlichtingsgesprek met de bestralingsdeskundige (n.v.t. bij korte palliatieve series). Eventuele andere vorbereidingsafspraken (b.v. maken van bestralingsmasker) afhankelijk van de lokalisatie van het bestralingsgebied.	Starttijd: - Eindtijd: Volgens zorgpad?
Vorbereidingsactiviteiten	Bestralings desk. Radiotherapeut- oncoloog Secretariaat	Aftekenen bestralingsgebied m.b.v. de CT simulator Intekenen bestralingsgebied Planning (berekening) van de bestralingen. Vervolgafspraken voor de bestralingen worden gemaakt.	Starttijd: - Eindtijd: Volgens zorgpad?

		Verwijzer krijgen een brief van de voorgenomen bestralingen.	
Controlemoment en	Radiotherapeut-oncoloog of Physician Assistant Chirurg	Aftekenen bestralingsgebied m.b.v. de CT simulator Intekenen bestralingsgebied Planning (berekening) van de bestralingen. Vervolgafspraken voor de bestralingen worden gemaakt. Verwijzer krijgen een brief van de voorgenomen bestralingen.	Starttijd: - Eindtijd: Volgens zorgpad?

	Geobserveerde	Activiteiten	Beoordeling
(Neo-)Adjuvante systemische behandeling		Indien adjuvante chemo: Check of patient over chemo heeft begrepen Plannen vervolgafpraak (Zn) en plannen start 1 ^e kuur	Starttijd: - Eindtijd: Volgens zorgpad?
Gesprek mammavp gk aansluitend consult chirurg indien NAC	Mammacareverpleegkundige/casemanager	Medische activiteiten (patient informeren, lengte en gewicht meten etc. Plannen vervolgconsult(en) internist-oncoloog NAC start <5 weken vanaf diagnose Adjuvante chemo <5 weken na locale therapie	Starttijd: - Eindtijd: Volgens zorgpad?
Intake internist-oncoloog	Internist-oncoloog (hoofdbehandelaar)	Medische activiteiten: Licht de patiënt in over de uitslagen van onderzoeken die zijn verricht. Geeft beknopte informatie over therapie (aard, doel, duur bijwerkingen) Hartfunctie onderzoek op indicatie (ECG., MUGA).	Starttijd: - Eindtijd: Volgens zorgpad?

		<p>Meet lengte en gewicht Zet recepten in EPD (anti-emetica, chemotherapie / hormonale therapie / targeted therapie)</p> <p>Geef informatie over ondersteunende oncologische zorg</p>	
Voorlichtingsgesprek voor aanvang 1 ^e behandeling	Verpleegkundige oncologie dagbehandeling	Screening op ondervoeding, schriftelijke info etc.	Starttijd: - Eindtijd: Volgens zorgpad?
Na 1 ^e chemo en voorafgaand aan vervolgguren	Internist-oncoloog	<p>Medische activiteiten: Check toxiciteit ten gevolge van behandeling en past zo nodig behandelingschema/dosis aan Vraagt de patiënt naar algemeen welbevinden en beantwoordt eventuele vragen. Licht patiënt in over het labonderzoek voor aanvang volgende kuur</p>	Starttijd: - Eindtijd: Volgens zorgpad?
VS 3 maanden na laatste kuur	Verpleegkundig specialist oncologie	<p>Het dagelijks functioneren, psychisch functioneren en moeheid (kwaliteit van leven) Problemen op sociaal gebied Problemen van naasten Identiteitsproblemen Zingevingsvragen (spiritueel)</p>	Starttijd: - Eindtijd: Volgens zorgpad?

Follow-up	Geobserveerde	Activiteit	Beoordeling
Na 3 maand door mammacare vpg	EMCV/casemanager	Verpleegkundige activiteiten Bespreekt de lastmeter nadat patient deze heeft ingevuld en zet eventuele interventies uit Bespreekt de keuzehulp nazorg Geeft gelegenheid tot het stellen van vragen Geeft aanvullende informatie m.b.t. het nabehandelingstraject Geeft informatie over ondersteunende oncologische zorg	Starttijd: - Eindtijd: Volgens zorgpad?
Na 6 maand fysieke controle chirurg	Mammadokter of VS mammacare	Afnemen medische anamnese Uitvoeren lichamelijk onderzoek indien van toepassing	Starttijd: - Eindtijd: Volgens zorgpad?
Na 12 maand	chirurg en MCV/casemanager		Starttijd: - Eindtijd: Volgens zorgpad?
Na 18 maand	chirurg		Starttijd: - Eindtijd: Volgens zorgpad?

Appendix 2. Interview scheme

A. Focus-group interview H1

Focus-groep interview ziekenhuis 1

Introductie: Goedemiddag, mijn naam is Mèlen Tekirdag, master student Health Sciences aan de Universiteit Twente. Het doel van mijn onderzoek, is tot een aanbeveling komen hoe de twee diagnostische zorgpaden van het MST en ZGT meer gestandaardiseerd kunnen worden door te focussen op de verschillen tussen beide ziekenhuizen en de perspectieven van de verschillende betrokkenen. Het doel van het interview is, door vragen te laten beantwoorden en te discussiëren, wordt het duidelijk welke rol de zorgverlener heeft in het zorgpad, wat de ervaringen zijn binnen het zorgpad, welke factoren zorgverleners belangrijk vinden in het zorgpad borstkanker en waar kansen liggen ter verbetering.

Voor dit interview hebben jullie allemaal schriftelijk toestemming gegeven. De gegevens worden anoniem verwerkt en er bestaan geen foute antwoorden. Ook is er op ieder moment de mogelijkheid te stoppen. Vul elkaar aan mocht je het eens of oneens met de ander zijn.

Daarnaast vraag ik jullie toestemming te geven voor een audio-opname van het gesprek, zodat ik het later kan transcriberen en analyseren. Na transcriptie stuur ik jullie de tekst toe voor eventuele veranderingen, zoals aanvulling indien nodig. De audio-opname wordt opgeslagen in een veilige omgeving van de Universiteit Twente. Gaan jullie akkoord met deze voorwaarden?

Start audio opname: Vraag opnieuw toestemming voor de opname.

We hebben ongeveer een uur de tijd om de volgende onderwerpen te bespreken: Rol- en verantwoordelijkheidsverdeling, Communicatie, Eerste consult, MDO, Diagnose, Patiëntgerichte zorg. Ik zal bij elk onderwerp de situatie voorleggen van het andere ziekenhuis en vanuit daar de discussie starten. Tot slot eindig ik met een samenvatting om te controleren of ik de antwoorden goed heb begrepen. Zijn er nog vragen?

Openingsvraag: Kunt u kort aangeven wie u bent en wat is uw rol in de diagnostische fase van het zorgpad borstkanker?

1. Communicatie

- 1.1 Op welke manier verloopt de communicatie met collega's?
- 1.2 Zijn collega's op deze manier snel bereikbaar?

Bij het andere ziekenhuis zitten medewerkers van de mammapoli gezamenlijk in één ruimte met meerdere computers, met uitzondering van de mensen met spreekuur. Communicatie vindt direct plaats.

- 1.3 Hoe kijken jullie naar deze manier van werken en communiceren?
- 1.4 Welke mogelijke voordelen en uitdagingen ziet u in de communicatie bij het andere ziekenhuis?
- 1.5 Welke voordelen zien jullie in de manier waarop communicatie wordt georganiseerd binnen dit ziekenhuis?
- 1.6 Heeft de manier van communiceren een positief effect op patiënten en de zorg?
Zo ja, waaruit blijkt dat?

2. Rol- en verantwoordelijkheidsverdeling

Bij het andere ziekenhuis is de MCV net als hier de casemanager, de voornaamste rol is de zorg coördineren rondom de patiënt die de diagnose borstkanker krijgt. Dus het coördineren van alle afspraken en de MCV is het aanspreekpunt van zowel de arts als de patiënt vanaf het eerste moment. De chirurg of arts die de patiënt ziet gaat over het medisch inhoudelijke deel.

2.1 Wat is bij dit ziekenhuis de rol van de MCV in het diagnostische gedeelte?

VS heeft vooral een rol in de follow-up bij het andere ziekenhuis. Zij gaan wel een nieuwe VS opleiden om uiteindelijk ook zelfstandig spreekuren te doen en meer in de diagnose. De mammadokter neemt meer de rol over van hoe de VS bij dit ziekenhuis werkt. De mammadokter is geen beschermde titel, maar kan een basisarts zijn of een andere arts, kijkt breed en voert ondersteunend werk uit. De chirurg bespreekt zelf altijd het behandelplan en opties met de patiënt, hier kan de VS dat ook zelfstandig doen.

2.2 Hoe kijken jullie naar de invulling van de rol van de VS bij het andere ziekenhuis?

2.3 Hoe zit een gemiddelde dag van een secretaresse eruit?

2.4 Hoeveel secretaresses zijn er?

Bij het andere ziekenhuis zit de gastvrouw aan de balie voor het ontvangen van de patiënten. Verder zijn er verschillende secretaresses elk met een eigen taakverdeling. De secretaresses hebben een taakverdeling over de dag waarbij één gekoppeld is aan het intakespreekuur en daarmee aan het MDO en de administratie daarvan. De collega's die in de aparte ruimte zitten doen administratie van andere zaken die de rest van de dag doorkomen.

2.5 Hoe kijkt u naar de rol van de secretaresse bij het andere ziekenhuis?

3. Eerste Consult

Hier wordt tijdens het eerste consult de anamnese met de patiënt doorgenomen en door de VS in de computer getypt. Lichamelijk onderzoek vindt plaats en doorverwijzing voor mammografie/echo + punctie (indien nodig) Door wie: VS of chirurg

Bij het andere ziekenhuis wordt de anamnese vooraf door de patiënt ingevuld en deze wordt ingeleverd voor aanvang van het 1e bezoek. De anamnese wordt ingevuld in het systeem door de secretaresse als input voor het 1e consult. De anamnese wordt kort nagelopen, lichamelijk onderzoek wordt uitgevoerd. Informatie wordt op papier genoteerd door de mammadokter of chirurg. Het verschil zit in de afname van de anamnese en de betrokkene mammadokter of VS.

3.1 Wat vinden jullie van het vooraf laten invullen van een anamnese door de patiënt?

3.2 Wat vinden jullie van het afnemen van de anamnese tijdens het consult?

3.3 Zijn jullie van mening dat de invulling van het consult de patiënten ervaring en behandelingsuitkomst kan beïnvloeden als het gaat om de manier van afnemen van de anamnese en het gebruik van wel of geen computer?

Zo ja, hoe?

4. MDO

Er zijn verschillen in de frequentie en de besproken patiënten in het MDO van beide ziekenhuizen, hier vindt het MDO twee keer per week plaats en worden patiënten met BIRADS 3 t/m 6 besproken. De overige patiënten krijgen ontslag.

Bij het andere ziekenhuis vindt dagelijks het MDO plaats en worden alle patiënten besproken alhoewel het grootste gedeelte bestaat uit het bespreken van maligne patiënten en een klein gedeelte (circa 5 minuten) benigne. Voorheen vond het MDO 3 keer plaats, maar de MDO's werden te lang waardoor dagelijks de oplossing biedt.

4.1 Wat vinden jullie van de organisatie van het MDO in het andere ziekenhuis als het gaat om de frequentie?

4.2 Wat vinden jullie van het bespreken van alle patiënten tijdens het MDO?

- 4.3 Wat zijn de mogelijke voordelen van de verschillende benaderingen?
- 4.4 Wat zijn de mogelijke nadelen van de verschillende benaderingen?

5. Diagnose

Wat betreft de snelheid van de diagnose, kan er niets aan gedaan worden, maar wel de manier waarop de uitslag gebracht wordt. Bij het andere ziekenhuis is ééndagsdiagnostiek, mogelijk door PA-lab naast de afdeling. Dagelijks wordt om 10:30 materiaal meegenomen naar het lab waardoor patiënten die voor 10:30 behandeld zijn dezelfde dag de uitslag krijgen. Dit gebeurt aan het einde van de dag telefonisch door de chirurg. Zowel positieve als negatieve uitslagen. Mocht de patiënt liever een consult hebben i.p.v. bellen dan is dat ook mogelijk. Hier binnen 36 uur. Tijdens het 2e gesprek met de patiënt wordt de uitslag besproken door de VS of chirurg.

- 5.1 Wat vindt u van het geven van een extra beloptie aan de patiënt voor het krijgen van de uitslag?
- 5.2 Hoe ziet u idealiter de bespreking van resultaten met de patiënt?

6. Patiëntgerichte zorg

- 6.1 Worden prestatie indicatoren bijgehouden en besproken bij de mammapoli?
Zo ja, op welke uitkomsten wordt gemonitord?
Wordt daarop actie ondernomen?
Zo ja, zou u een voorbeeld kunnen geven?
- 6.2 Wat vindt u belangrijke factoren in de diagnostische fase?
- 6.3 Ziet u gebieden waarop het ZGT kan verbeteren om meer patiëntgerichte zorg te bieden in het diagnostische gedeelte van het borstkanker zorgpad?

7. Algemene vragen

- 7.2 Zien jullie mogelijkheden voor het integreren van jullie zorgpad met die van het andere ziekenhuis?
Zo ja, welke kansen?
Welke mogelijke barrières?
- 7.2 Welke lessen kunnen beide ziekenhuizen leren van elkaars situatie?
- 7.3 Zijn er verbeteringen die u voorstelt voor uw eigen ziekenhuis?
- 7.4 Zijn er andere aspecten van de diagnostische fase die u wil bespreken?
- 7.5 Heeft u nog opmerkingen of aanvullingen?

Conclusie: Algemene samenvatting (geef de respondent de gelegenheid om te reageren). Vraag of de respondent nog iets toe te voegen heeft. Benadruk nogmaals wat het doel van het interview was. Bedank de respondent voor deelname, geef aan dat u stopt met opnemen. Na gesprek, zonder audio-opname.

B. Focus-group interview H2

Focus-groep interview ziekenhuis 2

Introductie: Goedemiddag, mijn naam is Mèlen Tekirdag, master student Health Sciences aan de Universiteit Twente. Het doel van mijn onderzoek, is tot een aanbeveling komen hoe de twee diagnostische zorgpaden van het MST en ZGT meer gestandaardiseerd kunnen worden door te focussen op de verschillen tussen beide ziekenhuizen en de perspectieven van de verschillende betrokkenen. Het doel van het interview is, door vragen te laten beantwoorden en te discussiëren, wordt het duidelijk welke rol de zorgverlener heeft in het zorgpad, wat de ervaringen zijn binnen het zorgpad, welke factoren zorgverleners belangrijk vinden in het zorgpad borstkanker en waar kansen liggen ter verbetering.

Voor dit interview hebben jullie allemaal schriftelijk toestemming gegeven. De gegevens worden anoniem verwerkt en er bestaan geen foute antwoorden. Ook is er op ieder moment de mogelijkheid te stoppen. Vul elkaar aan mocht je het eens of oneens met de ander zijn.

Daarnaast vraag ik jullie toestemming te geven voor een audio-opname van het gesprek, zodat ik het later kan transcriberen en analyseren. Na transcriptie stuur ik jullie de tekst toe voor eventuele veranderingen, zoals aanvulling indien nodig. De audio-opname wordt opgeslagen in een veilige omgeving van de Universiteit Twente. Gaan jullie akkoord met deze voorwaarden?

Start audio opname: Vraag opnieuw toestemming voor de opname.

We hebben ongeveer een uur de tijd om de volgende onderwerpen te bespreken: Rol- en verantwoordelijkheidsverdeling, Setting en communicatie, Eerste consult, MDO, Diagnose, Patiëntgerichte zorg. Ik zal bij elk onderwerp de situatie voorleggen van het andere ziekenhuis en vanuit daar de discussie starten. Tot slot eindig ik met een samenvatting om te controleren of ik de antwoorden goed heb begrepen. Zijn er nog vragen?

Openingsvraag: Wie bent u en wat is uw rol in de diagnostische fase van het zorgpad borstkanker?

1. Fysieke indeling en communicatie

- 1.1 Hoe verloopt de communicatie met collega's in dit ziekenhuis?
- 1.2 Hoe ziet de fysieke indeling en organisatie van de ruimte eruit bij dit ziekenhuis?
- 1.3 Wat vinden jullie hiervan?
- 1.4 Hebben de fysieke indeling en manier van communiceren een positief effect op patiënten en de zorg?

Zo ja, waaruit blijkt dat?

Mammapoli bij het andere ziekenhuis maakt onderdeel uit van de chirurgie, de chirurg zit naast mamma patiënten ook andere patiënten/andere diagnoses. Alle medewerkers hebben een eigen kamer en de secretaresse werkt vanuit de balie. Communicatie vindt met name plaats via een online chat en telefonisch

- 1.5 Wat vinden jullie van deze manier van organisatie en communicatie?
- 1.6 Welke voordelen zien jullie in de manier waarop communicatie wordt georganiseerd binnen jullie team?
- 1.7 Welke mogelijke voordelen en uitdagingen zien jullie in de communicatie bij het andere ziekenhuis?

2. Eerste Consult

Hier wordt de anamnese vooraf door de patiënt ingevuld en in het systeem ingevoerd door de secretaresse als input voor het eerste consult. Tijdens het eerste consult wordt deze kort nagelopen, lichamelijk onderzoek wordt uitgevoerd. Informatie wordt op papier genoteerd door de mammapoli of chirurg.

Bij het andere ziekenhuis: Tijdens eerste consult wordt de anamnese mondeling met de patiënt doorgenomen en door de verpleegkundig specialist in de computer getypt. Lichamelijk onderzoek vindt plaats en doorverwijzing voor mammografie/echo + punctie (indien nodig) Door wie: VS of chirurg

2.1 Wat vinden jullie van deze aanpak?

2.2 Kan deze invulling van het consult de patiënten ervaring en behandelingsuitkomst beïnvloeden?

Zo ja, hoe?

3. MDO

3.1 Wat vinden jullie van de organisatie van het MDO in jullie ziekenhuis?

In het andere ziekenhuis:

Frequentie: dinsdag en vrijdag

Tijdsduur: Circa 60 minuten

Besproken patiënten: BIRADS 3 t/m 6.

MDO dinsdag: patiënten van donderdag en vrijdag

MDO vrijdag: patiënten van maandag t/m woensdag

BIRADS 0 t/m 2 wordt niet besproken tijdens het MDO, maar krijgen ontslag

Wat wordt er besproken: Uitslagen radiologisch en pathologisch onderzoek, radiobeelden en eventuele vervolgstappen

3.2 Wat vinden jullie van deze manier van organiseren?

3.3 Wat zijn mogelijke voordelen en nadelen van de verschillende benaderingen?

4. Diagnose

Klopt het volgende, bij dit ziekenhuis: ééndagsdiagnostiek, mogelijk door PA-lab naast de afdeling. Dagelijks wordt om 10:30 materiaal meegenomen naar het lab waardoor patiënten die voor 10:30 behandeld zijn dezelfde dag de uitslag krijgen. Dit gebeurt aan het einde van de dag telefonisch door de chirurg of mcv. Zowel positieve als negatieve uitslagen.

Het andere ziekenhuis: Binnen 36 uur. Dagelijks wordt om 13:00 materiaal meegenomen naar het PA lab, dus patiënten krijgen binnen 36 uur uitslag. Tijdens het 2e gesprek met de patiënt wordt de uitslag besproken door de VS of chirurg.

4.1 Wat vindt u van de manier waarop de uitslag met de patiënt besproken wordt bij het andere ziekenhuis tijdens een consult in tegenstelling tot bellen zoals hier vooral gedaan wordt?

4.2 Hoe zien jullie idealiter de bespreking van resultaten met de patiënt?

5. Rol- en verantwoordelijkheidsverdeling

Bij het andere ziekenhuis: MCV: Is de casemanager, coördineert alle afspraken en is het aanspreekpunt voor de patiënt. Geeft verpleegkundige voorlichting (preoperatief consult). Postoperatief afspraak chirurg/MCV

5.1 Hoe kijken jullie naar de rol van de MCV op deze manier?

In het andere ziekenhuis: VS: Geeft informatie aan de patiënt over het behandelplan. Vaak eerste en tweede afspraak met patiënt (eigen consult) uitslag onderzoek bespreken met de patiënt, anamnese afnemen, lichamelijk onderzoek. Bespreekt diagnose en behandelplan. Vult OK-formulieren in en regelt verwijzingen en medicatie. Opent en sluit zelfstandig de DBC.

5.2 En de VS?

Secretaresse heeft haar rol en verantwoordelijkheden al kort benoemd, ik zal de situatie bij het andere ziekenhuis ophelderen: Mammapoli is onderdeel van chirurgie. Secretaresse is onderdeel van de oncologie en doet alle werkzaamheden voor de gehele oncologie. Echter zijn er nog een aantal secretaresses die vooral mamma care verzorgen. Patiënten melden zich bij de secretaresse aan de balie.

5.3 Hoe kijken jullie naar de rol van de secretaresse bij het andere ziekenhuis met afwezigheid van een gastvrouw?

6. Patiëntgerichte zorg

6.1 Worden prestatie indicatoren bijgehouden en besproken bij de mammapoli?

Zo ja, op welke uitkomsten wordt gemonitord?

Wordt daarop actie ondernomen ?

6.2 Wat vinden jullie belangrijke factoren in de diagnostische fase?

6.3 Zien jullie gebieden waarop het ZGT kan verbeteren om meer patiëntgerichte zorg te bieden in het diagnostische gedeelte van het borstkanker zorgpad?

7. Algemene vragen

7.1 Zijn er andere aspecten van de diagnostische fase die jullie willen bespreken?

7.2 Welke lessen kunnen beide ziekenhuizen leren van elkaars situatie?

7.3 Zijn er verbeteringen die jullie voorstellen voor jullie eigen ziekenhuis?

7.4 Hebben jullie nog opmerkingen of aanvullingen?

Conclusie: Algemene samenvatting (geef de respondent de gelegenheid om te reageren). Vraag of de respondent nog iets toe te voegen heeft. Benadruk nogmaals wat het doel van het interview was. Bedank de respondent voor deelname, geef aan dat u stopt met opnemen. Na gesprek, zonder audio-opname.

C. Patients

Introductie: Goedemorgen/Goedemiddag, mijn naam is Mèlen Tekirdag, master student Health Sciences aan de Universiteit Twente. In dit onderzoek willen we duidelijk krijgen hoe patiënten en zorgverleners het diagnostische borstkanker zorgpad ervaren en welke factoren zij hierin belangrijk vinden. Voor dit interview dient u schriftelijk toestemming te geven. De gegevens worden anoniem verwerkt en er bestaan geen foute antwoorden. Ook is er op ieder moment de mogelijkheid te stoppen. Daarnaast vraag ik u toestemming te geven voor een audio-opname van het gesprek, zodat ik het later kan uittypen en analyseren. De audio-opname wordt opgeslagen in een veilige omgeving van de Universiteit Twente. Gaat u akkoord met deze voorwaarden?

Start audio opname: Vraag opnieuw toestemming voor de opname.

Interview structuur: Ik zal een aantal open en gesloten vragen stellen over de stappen in het diagnostische proces van de mammopoli. Als laatste wordt er afgesloten met een samenvatting om te controleren of ik de antwoorden goed heb begrepen.

1. Verwijzing

- 1.1 Kunt u kort iets vertellen over hoe het proces van verwijzing naar het ziekenhuis voor borstkankeronderzoek verliep?
- 1.2 Bij wie kon u terecht met vragen/ wie was uw belangrijkste aanspreekpunt tijdens het gehele proces?

2. Afspraakplanningen eerste afspraak

- 2.1 Hoe verliep het maken van de afspraak voor uw eerste consult?
- 2.2 Wat vond u van de wachttijd tot uw eerste consult?
- 2.3 Hoe verliep de eerste afspraak in het ziekenhuis?
- 2.4 Kon u de anamnese goed invullen?
- 2.5 Wat vond u van het lichamelijk onderzoek tijdens deze afspraak?
- 2.6 Werd u voldoende geïnformeerd over het verloop van het proces?

3. Beeldvormend onderzoek

- 3.1 Kunt u uw ervaring delen van het beeldvormend onderzoek?
- 3.2 Hoe voelde u zich tijdens het onderzoek en wat waren uw gedachten?

Indien van toepassing

4. Uitslag beeldvormend onderzoek

- 4.1 Hoe verliep het tweede consult op dezelfde dag, waarbij de uitslag van het beeldvormend onderzoek werd besproken?
- 4.2 Hoe heeft u deze informatie op dat moment ontvangen en verwerkt?
- 4.3 Was het voor u duidelijk wat u kon verwachten van het verdere proces?

Indien van toepassing

5. Uitslaggesprek na MDO

- 5.1 Hoe verliep het uitslaggesprek na het Multidisciplinair Overleg?
- 5.2 Hoe ontving u de uitslag?
- 5.3 Wat deed de uitslag met u?
- 5.4 Hoe heeft u gereageerd op de informatie die tijdens dit gesprek werd gegeven?
- 5.5 Hoe betrokken voelde u zich bij het besluitvormingsproces?
- 5.6 Werd er naar uw zorgen en vragen geluisterd?

6. **Verbetering**

6.1 Hoe tevreden bent u met de zorg die u heeft ontvangen tijdens het diagnostische proces?

6.2 Hoe tevreden bent u over de communicatie met de verschillende zorgverleners?

6.3 Als u iets zou kunnen veranderen aan de diagnostische fase, wat zou dat dan zijn? / Wat zijn verbeterpunten op basis van uw ervaringen?

7. **Reflectie en samenvatting:**

7.1 Zijn er nog andere onderwerpen die u wil bespreken?

7.2 Vraag of de patiënt nog iets wil toevoegen of benadrukken.

7.3 Bedank de patiënt voor zijn/haar deelname en sluit het interview af.

Conclusie: Algemene samenvatting (geef de respondent de gelegenheid om te reageren). Vraag of de respondent nog iets toe te voegen heeft. Benadruk nogmaals wat het doel van het interview was. Bedank de respondent voor deelname, geef aan dat u stopt met opnemen.

Appendix 3. Information letter and informed consent

A. Focus-groep interview employees

Diagnostische fase borstkanker zorgpad

Geachte heer/mevrouw,

Mijn naam is Mèlen Tekirdag en ik ben bezig met mijn afstudeeronderzoek voor de studie gezondheidswetenschappen aan de Universiteit Twente. Met deze informatiebrief wil ik u vragen of u wilt meedoen aan onderzoek bij twee ziekenhuizen.

Meedoen is vrijwillig. Voordat u de beslissing neemt, is het belangrijk om meer te weten te komen over het onderzoek. Lees deze informatiebrief rustig door. Als u dat fijn vindt kunt u het ook bespreken met uw partner, vrienden of familie.

1. Doelen achtergrond van het onderzoek

In beide ziekenhuizen zijn verschillende zorgpaden voor borstkanker aanwezig, waarbij de processen en behandelingen verschillend zijn. Het doel van beide centra is om deze zorgpaden op termijn zoveel mogelijk hetzelfde te krijgen, daarbij rekening houdend met de verschillen in mogelijkheden per ziekenhuis.

Dit start met het vergelijken van de zorgpaden in beide ziekenhuizen en in kaart brengen waar verschillen en overeenkomsten zitten. Vervolgens is het plan om daar waar verschillen te vinden zijn, hierover in gesprek te gaan om te kijken wat 'best practice' is. Dit onderzoek focust zich op de diagnostische fase, omdat het zorgpad erg uitgebreid is en de diagnostische fase al enige verschillen bevat tussen beide ziekenhuizen. In dit onderzoek worden interviews gehouden met de betrokkenen van het zorgpad om erachter te komen hoe zij de diagnostische fase hebben ervaren en welke factoren zij belangrijk vinden in deze fase.

2. Hoe wordt het onderzoek uitgevoerd?

Voor dit onderzoek wordt een groepsinterview gehouden met u en uw collega's. Het gaat om een groepsinterview met: de secretaresse, de chirurg, de mammacareverpleegkundige, de verpleegkundig specialist (en mammadokter). Dit gesprek zal maximaal 60 minuten duren. Ik zal dit gesprek opnemen, om het later nog een keer terug te kunnen luisteren.

3. Wat gebeurt er als u niet wenst deel te nemen aan dit onderzoek?

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen. Ook tijdens het onderzoek. U hoeft geen reden te geven waarom u niet mee wil doen of wil stoppen. Uw keuze heeft ook geen enkele invloed op uw zorg.

4. Wat gebeurt er met uw gegevens?

Het gesprek wordt opgenomen, zodat ik dit later nog een keer kan luisteren. Deze opname wordt opgeslagen binnen de beveiligde omgeving van de Universiteit Twente en zal direct verwijderd worden na afronding van de master thesis. Na de standaardtermijn van 10 jaar zullen de geanonimiseerde transcripten worden verwijderd. Alleen de onderzoeker en haar begeleiders hebben toegang tot deze gegevens. Alle gegevens worden anoniem gemaakt. Alle gegevens die herleidbaar zijn naar u worden verwijderd. Deze worden gedeeld met andere onderzoekers. De gegevens worden gebruikt voor het schrijven van

onder andere een wetenschappelijk rapport en een samenvatting.

5. Door wie is dit onderzoek goedgekeurd?

Dit onderzoek is beoordeeld en goedgekeurd door de ethische commissie van de faculteit BMS van de Universiteit van Twente

Contact: ethicscommissie-bms@utwente.nl

6. Wilt u verder nog iets weten?

Heeft u vragen of wilt u meedoen? Neem dan contact op met de onderzoeker of haar begeleider:

- Onderzoeker, M. Tekirdag: 06-81609887, m.tekirdag@student.utwente.nl

- Begeleider Jolanda van Hoeve: J.vanHoeve@iknl.nl

Wilt u meedoen?

Dan kan dit besproken worden met de collega die u deze mail gestuurd heeft. Bij deelname is het nodig dat u het toestemmingsformulier ondertekent. Deze kunt u alvast lezen in de bijlage. Het ondertekenen kan gebeuren tijdens het gesprek. De onderzoeker heeft dan het formulier bij zich dat u kunt ondertekenen.

Met vriendelijke groet,
Mèlen Tekirdag

Bijlage A: Toestemmingsformulier
Diagnostische fase borstkanker zorgpad

Versienummer 1, Datum: _____

Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn goed genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe. Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen met het onderzoek. Of om ermee te stoppen. Ik hoef dan niet te zeggen waarom ik wil stoppen. Ik geef de onderzoeker toestemming om audio opnames te maken van het interview, zodat deze door de onderzoeker teruggeluisterd kan worden. Ik geef toestemming om mijn gegevens te gebruiken, voor de doelen die in de informatiebrief staan. Ik geef toestemming om de anonieme onderzoeksgegevens van mij tot en met 10 jaar na afloop van dit onderzoek te bewaren. Ik wil meedoen aan dit onderzoek.

Mijn naam is (deelnemer):

Handtekening: Datum: __/__/__

Ik verklaar dat ik deze deelnemer volledig heb geïnformeerd over het genoemde onderzoek.

Naam onderzoeker (of diens vertegenwoordiger): Mèlen Tekirdag

Handtekening: Datum: __/__/__

B. Information letter and informed consent patients

Diagnostische fase borstkanker zorgpad

Geachte heer/mevrouw,

Mijn naam is Mèlen Tekirdag en ik ben bezig met mijn afstudeeronderzoek voor de studie gezondheidswetenschappen aan de Universiteit Twente.

Met deze informatiebrief wil ik u vragen of u wilt meedoen aan onderzoek bij twee ziekenhuizen.

Meedoen is vrijwillig. Voordat u de beslissing neemt, is het belangrijk om meer te weten te komen over het onderzoek.

1. Doelen achtergrond van het onderzoek

In beide ziekenhuizen zijn verschillende zorgpaden voor borstkanker aanwezig, waarbij de processen en behandelingen verschillend zijn. Het doel van beide centra is om deze zorgpaden op termijn zoveel mogelijk hetzelfde te krijgen, daarbij rekening houdend met de verschillen in mogelijkheden per ziekenhuis.

Dit start met het vergelijken van de zorgpaden in beide ziekenhuizen en in kaart brengen waar verschillen en overeenkomsten zitten. Vervolgens is het plan om daar waar verschillen te vinden zijn, hierover in gesprek te gaan om te kijken wat 'best practice' is. Dit onderzoek focust zich op de diagnostische fase, omdat het zorgpad erg uitgebreid is en de diagnostische fase al enige verschillen bevat tussen beide ziekenhuizen. In dit onderzoek worden interviews gehouden met de betrokkenen van het zorgpad om erachter te komen hoe zij de diagnostische fase hebben ervaren en welke factoren zij belangrijk vinden in deze fase.

2. Hoe wordt het onderzoek uitgevoerd?

Voor dit onderzoek wil ik kort met u een gesprek houden over uw ervaringen in het zorgpad, dit zal maximaal 20 minuten duren. Ik zal dit gesprek opnemen, om het later nog een keer terug te kunnen luisteren.

3. Wat gebeurt er als u niet wenst deel te nemen aan dit onderzoek?

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen. Ook tijdens het onderzoek. U hoeft geen reden te geven waarom u niet mee wil doen of wil stoppen. Uw keuze heeft ook geen enkele invloed op uw zorg.

4. Wat gebeurt er met uw gegevens?

Het gesprek wordt opgenomen, zodat ik dit later nog een keer kan luisteren. Deze opname wordt opgeslagen binnen de beveiligde omgeving van de Universiteit Twente en zal direct verwijderd worden na afronding van de master thesis. Na de standaardtermijn van 10 jaar zullen de geanonimiseerde transcripten worden verwijderd. Alleen de onderzoeker en haar begeleiders hebben toegang tot deze gegevens. Alle gegevens worden anoniem gemaakt. Alle gegevens die herleidbaar zijn naar u worden verwijderd. Deze worden gedeeld met andere onderzoekers. De gegevens worden gebruikt voor het schrijven van onder andere een wetenschappelijk rapport en een samenvatting.

5. Door wie is dit onderzoek goedgekeurd?

Dit onderzoek is beoordeeld en goedgekeurd door de ethische commissie van de faculteit BMS van de Universiteit van Twente

Contact: ethicscommissie-bms@utwente.nl

6. Wilt u verder nog iets weten?

Heeft u vragen of wilt u meedoen? Neem dan contact op met de onderzoeker of haar begeleider:

- Onderzoeker, M. Tekirdag: 06-81609887, m.tekirdag@student.utwente.nl

- Begeleider Jolanda van Hoeve: J.vanHoeve@iknl.nl

Wilt u meedoen?

Dan kan dit besproken worden met de collega die u deze mail gestuurd heeft. Bij deelname is het nodig dat u het toestemmingsformulier ondertekent. Deze kunt u alvast lezen in de bijlage. Het ondertekenen kan gebeuren tijdens het gesprek. De onderzoeker heeft dan het formulier bij zich dat u kunt ondertekenen.

Met vriendelijke groet,

Mèlen Tekirdag

Bijlage A: Toestemmingsformulier

Diagnostische fase borstkanker zorgpad

Versienummer 1, Datum: _____

Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn goed genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.

Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen met het onderzoek. Of om ermee te stoppen.

Ik hoef dan niet te zeggen waarom ik wil stoppen.

Ik geef de onderzoeker toestemming om audio opnames te maken van het interview, zodat deze door de onderzoeker teruggeluisterd kan worden.

Ik geef toestemming om mijn gegevens te gebruiken, voor de doelen die in de informatiebrief staan.

Ik geef toestemming om de anonieme onderzoeksgegevens van mij tot en met 10 jaar na afloop van dit onderzoek te bewaren.

Ik wil meedoen aan dit onderzoek.

Mijn naam is (deelnemer):

Handtekening: Datum: __/__/__

Ik verklaar dat ik deze deelnemer volledig heb geïnformeerd over het genoemde onderzoek.

Naam onderzoeker (of diens vertegenwoordiger): Mèlen Tekirdag

Handtekening: Datum: __/__/__

Appendix 4. Summary focus-group interview

A. H1

1. Communicatie

Bij het andere ziekenhuis zitten medewerkers van de mammapoli gezamenlijk in een backoffice met meerdere computers, met uitzondering van de mensen met spreekuur. Communicatie vindt direct plaats.

In dit ziekenhuis wordt veel gecommuniceerd via Teams. Het wordt gezien als het snelste middel, vooral voor zaken die niet direct betrekking hebben op patiënten. Verder, benadrukken een aantal respondenten het gemis van fysieke aanwezigheid in één ruimte voor directe samenwerking en overleg. Één respondent waardeert juist het samenwerken in één ruimte vanwege de directe interactie tussen verschillende disciplines, wat resulteert in een efficiëntere communicatie. Ook is er zo meer ruimte voor samenwerking. Een ander vindt werken zonder backoffice prima, zoals het nu is. Zo kan er rustig zelfstandig gewerkt worden, ook met het oog op de vele telefoontjes die gepleegd moeten worden. Over het algemeen tonen de respondenten verdeeldheid over de effectiviteit van fysieke nabijheid voor samenwerking, met sommigen die de voorkeur geven aan digitale communicatiemiddelen zoals Teams, terwijl anderen de voordelen van directe interactie benadrukken.

2. Rol- en verantwoordelijkheidsverdeling

MCV

De MCV vervult een cruciale rol, vooral als casemanager, in het coördineren van zorg voor patiënten, inclusief het plannen van afspraken en het bewaken van behandelingsdeadlines. Ze fungeren als het primaire aanspreekpunt voor zowel artsen als patiënten vanaf het begin. Tijdens consulten met chirurgen krijgen patiënten eerst medische informatie, waarna de verpleegkundigen extra tijd hebben om zaken te verduidelijken en aandacht te besteden aan sociale aspecten. In vergelijking met andere ziekenhuizen hebben deze verpleegkundigen meer tijd voor patiënten en consulten, wat als waardevol wordt beschouwd, vooral omdat chirurgen soms beperkte tijd hebben voor gesprekken. Dit verschil in tijdsbesteding kan van invloed zijn op de kwaliteit van zorg en communicatie met patiënten. Het verschil tussen beide ziekenhuizen zit daarin vooral, dat de MCV bij het andere ziekenhuis vanaf het begin al meer betrokken is dan hier.

VS en mammadokter (ZGT)

Over de rol van de VS komt naar voren dat in het andere ziekenhuis de VS momenteel geen rol heeft bij de diagnose, maar wel in de follow-up, met plannen om zelfspreekuren te gaan houden in de toekomst. Momenteel is daar een mammadokter, dit is een niet beschermd titel en kan uitgevoerd worden door verschillende personen (ANIOS, overige artsen). De mammadokter houdt zelfstandig spreekuren net zoals de VS in dit ziekenhuis. De mammadokter in het andere ziekenhuis en de VS hier hebben dus een vergelijkbare rol. Respondenten benadrukken dat zij de verdeling van taken over verschillende functies jammer vinden, omdat zij waarde hechten aan een continuüm van zorg. Desondanks erkennen zij dat de VS, op basis van haar juridische bevoegdheden, zelfstandig een behandelrelatie met patiënten kan aangaan. Dit wordt gezien als een efficiënte inzet van middelen, maar er wordt ook opgemerkt dat het verstandig is om in sommige gevallen de rol van de chirurg te behouden, met name bij langdurige behandeltrajecten. Dit alles benadrukt het belang van duidelijke afspraken en een heldere verdeling van verantwoordelijkheden binnen het zorgpad.

Secretaresse

Bij het andere ziekenhuis zit de gastvrouw aan de balie voor het ontvangen van de patiënten. Verder zijn er verschillende secretarissen elk met een eigen taakverdeling. De secretarissen hebben een taakverdeling over de dag waarbij één gekoppeld is aan het intakespreekuur en daarmee aan het

MDO en de administratie daarvan. De collega's die in de aparte ruimte zitten doen administratie van andere zaken die de rest van de dag doorkomen.

De respondenten bespreken de huidige uitdagingen rondom verwijzingen, planning en communicatie binnen het ziekenhuis. Ze erkennen dat de huidige werkwijze niet ideaal is, waarbij taken zoals verwijzingen, planning en communicatie efficiënter kunnen. Er wordt gesuggereerd dat een aparte gastvrouw mogelijk een oplossing kan bieden voor het ontvangen van patiënten en het doorverwijzen, waardoor de werkdruk op het secretariaat kan worden verlicht. Hoewel sommige artsen tegen dit idee zijn, zien anderen er wel potentie in, vooral als het ziekenhuis krap in personeel zit. Er wordt opgemerkt dat de implementatie van dergelijke veranderingen weerstand kan oproepen, maar dat het misschien de moeite waard is om de efficiëntie te verbeteren.

3. Eerste Consult

De respondenten bespreken de situatie in het andere ziekenhuis van het vooraf invullen van de anamnese door patiënten, waarbij de secretaresse deze gegevens in het systeem verwerkt. Er wordt opgemerkt dat dit proces in dit ziekenhuis momenteel nog niet volledig is geïmplementeerd vanwege beperkingen op het secretariaat en in afwachting van digitalisering. Hoewel het vooraf invullen van de anamnese de tijd die artsen aan deze taak besteden zou kunnen verminderen, merken ze op dat de huidige praktijk niet veel tijd kost. Idealiter zouden ze graag zien dat patiënten een digitale vragenlijst ontvangen die rechtstreeks in het dossier wordt opgenomen, wat tijdswinst zou opleveren.

4. MDO

Bij het andere ziekenhuis vindt dagelijks het MDO plaats in de pauze en alle patiënten van BIRADS 1 t/m 6 worden besproken alhoewel het grootste gedeelte bestaat uit het bespreken van maligne patiënten en een klein gedeelte (circa 5 minuten) benigne. Voorheen vond het MDO 3 keer plaats, maar de MDO's werden te lang waardoor dagelijkse MDO's de oplossing bieden.

De respondenten bespreken een gebrek aan uniformiteit bij het invullen van gegevens voor patiëntenadministratie, wat soms leidt tot verloren informatie. Ook vinden ze dat het MDO beter voorbereid zou kunnen worden, bijvoorbeeld door het allemaal op dezelfde manier te doen via een vast formulier bijvoorbeeld. Ze vinden het positief dat het MDO twee keer per week plaatsvindt in dit ziekenhuis, wat hen de kans geeft om belangrijke zaken te bespreken. Echter, ze ervaren soms beperkingen in de flexibiliteit van het MDO, zoals het ontbreken van specialisten bij bepaalde casussen. Ze merken op dat, hoewel het soms druk is op vrijdag, over het algemeen de tijd voor de MDO's redelijk uitkomt en er geen behoefte is aan een extra dag voor deze besprekingen.

5. Diagnose

Wat betreft de snelheid van de diagnose, kan er niets aan gedaan worden, maar wel de manier waarop de uitslag gebracht wordt. Bij het andere ziekenhuis is ééndagsdiagnostiek, mogelijk door PA-lab naast de afdeling. Dagelijks wordt om 10:30 materiaal meegenomen naar het lab waardoor patiënten die voor 10:30 behandeld zijn dezelfde dag de uitslag krijgen. Dit gebeurt aan het einde van de dag telefonisch door de chirurg. Zowel positieve als negatieve uitslagen. Mocht de patiënt liever een consult hebben i.p.v. bellen dan is dat ook mogelijk. Hier binnen 36 uur. Tijdens het 2e gesprek met de patiënt wordt de uitslag besproken door de VS of chirurg.

De respondenten bespreken hoe patiënten reageren op het ontvangen van medische resultaten en hoe verschillende benaderingen deze reacties beïnvloeden. Ze overwegen of directe communicatie van resultaten op locatie, met daarbij meteen de volgende stappen of behandelopties bespreken, angst kan verminderen. Ook wordt het concept van patiënten die vooraf toegang hebben tot hun medische dossiers besproken, wat vragen oproept over de timing van informatieverstrekking. Ten slotte wordt het idee geopperd om patiënten met benigne resultaten meteen telefonisch te

benaderen om geruststelling te bieden en onnodige ziekenhuisbezoeken te voorkomen, omdat er meestal een gebrekaan plekken zijn voor de afspraken (met name op vrijdag). Echter, er wordt gewezen op praktische uitdagingen bij de uitvoering van dit idee. Aan de andere kant, zal het bellen van patiënten met maligne resultaten wellicht juist veel vragen oproepen volgens één van de respondenten.

6. Patiëntgerichte zorg

De respondenten bespreken of prestatie-indicatoren worden bijgehouden voor de mammapoli. Ze noemen de NBCA en Santeon als bronnen voor het monitoren van prestaties en het vergelijken van resultaten tussen ziekenhuizen. Er wordt vermeld dat in het verleden kwartaalbijeenkomsten werden gehouden om prestaties te bespreken, maar het is onduidelijk of deze nog steeds plaatsvinden. Over het algemeen ervaren ze echter dat de planning goed verloopt, wat blijkt uit vergelijkingen met andere ziekenhuizen en toegangstijden die worden bijgehouden door de NBCA.

7. Algemene vragen

De respondenten bespreken de mogelijkheid om de zorgpaden te integreren en identificeren kansen en barrières. Ze wijzen op gebieden waar meer tijd nodig is, zoals uitslaggesprekken, bioptuitslagen, en het bespreken van behandelplannen. Er wordt gesuggereerd dat het diagnostische traject verstoord kan worden door andere patiënten buiten de mamma patiënten om, die door chirurgen worden gezien. Sommigen zijn het ermee eens dat de mammapoli mogelijk losgekoppeld moet worden van andere processen. Er wordt opgemerkt dat de zorgverleners meer tijd nodig hebben voor patiënten consulten, vooral nieuwe patiënten en na beeldvorming. De respondenten overwegen de mogelijkheid van dubbele tijd voor consulten en het verspreiden van patiënten over meerdere dagen om de druk op de vrijdagmiddag te verminderen. Er wordt erkend dat dit een verbeterpunt is, waarbij ook het tijdstip van het MDO wordt heroverwogen.

B. H2

1. Fysieke indeling en communicatie

In Ziekenhuis 1 hebben zorgverleners een eigen werkruimte, terwijl in Ziekenhuis 2 wordt samengewerkt in een backoffice buiten consulten om. Respondenten geven aan dat ze in deze gedeelde ruimte bij elkaar zitten, inclusief de secretaresse, chirurg, mammadokter, MCV en o.a. de ANIOS, afhankelijk van de spreekuren. Communicatie vindt daardoor direct plaats met elkaar. In Ziekenhuis 1 gebruiken medewerkers het programma Teams op de computer voor communicatie in hun eigen werkruimte met collega's.

2. Eerste Consult

De benadering die wordt beschreven voor het eerste consult als het gaat om de anamnese verschilt tussen beide ziekenhuizen. Bij Ziekenhuis 2 vult de patiënt het anamneseformulier van tevoren in, wat door het ziekenhuis personeel in het systeem wordt ingevoerd en vervolgens tijdens het consult wordt besproken en genoteerd. Dit wordt gezien als efficiënt, tijdbesparend. In Ziekenhuis 1 wordt over het algemeen de anamnese tijdens het consult direct met de patiënt afgenomen en meteen ingevoerd in de computer. Het lichamenlijk onderzoek en eventuele doorverwijzingen worden ook ter plekke uitgevoerd door de VS of chirurg in Ziekenhuis 1 en door de mammadokter of chirurg in Ziekenhuis 2.

Respondenten zijn over het algemeen positief over de efficiëntie van de laatstgenoemde aanpak. Ze benadrukken dat patiënten al over veel vragen hebben nagedacht, waardoor het proces wordt versneld. Bovendien wordt opgemerkt dat de anamnese gestandaardiseerd is en dat de zorgverleners, inclusief assistenten en chirurgen in opleiding, hiervoor worden getraind.

Over het algemeen wordt geconcludeerd dat het niet zozeer uitmaakt wie de anamnese uitvoert, zolang die persoon maar bekwaam is en enige ervaring heeft. Er wordt ook gesuggereerd dat verpleegkundig specialisten dit kunnen doen.

3. MDO

Het MDO vindt dagelijks plaats in Ziekenhuis 2, waar alle patiënten met BIRADS één tot en met zes worden besproken. In het andere ziekenhuis vindt het MDO tweemaal per week plaats, waarbij patiënten met BIRADS drie tot en met zes worden besproken en patiënten met BIRADS één tot en met twee direct ontslagen worden. Respondenten vinden de frequentie en de groep patiënten die bij dit ziekenhuis worden besproken passend, mede doordat het aantal patiënten bij eerdere MDO's (drie keer in de week) te groot was. Dit ziekenhuis heeft gekozen voor dagelijkse MDO's vanwege het grote aantal patiënten, waarbij de meeste tijd wordt besteed aan maligne gevallen. Er worden echter geen voordelen gezien in de aanpak van het andere ziekenhuis, omdat dit kan leiden tot een afname van aandacht en kwaliteit bij complexe gevallen, vooral als er onverwachte veranderingen in het casusvolume optreden.

4. Diagnose

Bij Ziekenhuis 1 wordt op werkdagen om 13:00 weefselmateriaal meegenomen naar het PA lab, dus patiënten krijgen binnen 36 uur uitslag van het weefselonderzoek. Tijdens het 2e gesprek met de patiënt wordt de uitslag besproken door de VS of chirurg. In dit ziekenhuis, Ziekenhuis 2, is de uitslag op dezelfde dag bekend. Dus 24 uren diagnostiek.

Er wordt benadrukt dat voldoende tijd erg belangrijk is. Respondent 6 benadrukt dat het lastig is om tijdens een kort consult gedeelde besluitvorming te bereiken. Dit werd gebaseerd op een ervaring in een ander ziekenhuis waarbij met de overstap naar gedeelde besluitvorming, de consulttijd verdubbelde. Dit komt doordat het proces van gedeelde besluitvorming, inclusief het bespreken van opties, patiëntvoorkeuren en gezamenlijke besluitvorming, tijd vergt. Verder werd aangegeven dat bij het bespreken van de uitslag met de patiënt, de voorkeur gaat naar de dokter die de patiënt heeft

gezien i.p.v. de VS. Als het gaat om het brengen van de uitslag, in de vorm van bellen of een fysiek consult, wordt bellen als de beste methode gezien. Dit, omdat patiënten zo het nieuws eerst zelf kunnen verwerken en bij het volgende consult op locatie de gegeven informatie goed op kunnen nemen waarbij emotie minder de overhand neemt.

5. Rol- en verantwoordelijkheidsverdeling

Bij het andere ziekenhuis: MCV: Is de casemanager, coördineert alle afspraken en is het aanspreekpunt voor de patiënt. Geeft verpleegkundige voorlichting (preoperatief consult). Postoperatief afspraak chirurg/MCV.

Bij dit ziekenhuis is de rol van de MCV vanaf het eerste moment cruciaal. Zodra een patiënt terugkomt na een eerste bezoeken er is een verdenking van een afwijking, worden we direct betrokken bij de opvang van de patiënt. De MCV zit erbij op de dag van het eerste bezoek of bij de volgende afspraak voor de uitslag. We zijn dus vanaf het begin betrokken bij de zorg voor de patiënt. Wat betreft het voornaamste aanspreekpunt, wij als MCV zijn het eerste contactpunt voor de patiënten. Als een patiënt vragen heeft, krijgen ze ons visitekaartje met ons telefoonnummer. Als we het antwoord niet weten, overleggen we met de chirurg of een andere collega. Tijdens de aanloop naar een operatie hebben we meestal geen expliciete hoofdbehandelaar, tenzij de situatie erg ingewikkeld wordt. In principe fungeren de MCV als het aanspreekpunt, de casemanagers die alles coördineren rondom de zorg van de patiënt. De chirurg of arts die de patiënt ziet, gaat over het medisch inhoudelijke deel. In het andere ziekenhuis: VS: Geeft informatie aan de patiënt over het behandelplan. Vaak eerste en tweede afspraak met patiënt (eigen consult) uitslag onderzoek bespreken met de patiënt, anamnese afnemen, lichamelijk onderzoek. Bespreekt diagnose en behandelplan. Vult OK-formulieren in en regelt verwijzingen en medicatie. Opent en sluit zelfstandig de DBC.

5.2 Hoe kijken jullie naar de rol van de verpleegkundig specialist (VS) op deze manier?

Er zijn verschillende perspectieven over het benoemen van een VS die taken uitvoert zoals het bespreken van het behandelplan met de patiënt, het afnemen van de anamnese en het regelen van verwijzingen en medicatie. De chirurg geeft aan de voorkeur te geven aan directe betrokkenheid bij besluitvorming en shared-decision making, terwijl een mammadokter benadrukt het belangrijk te vinden om de ingreep te bespreken met de persoon die deze uitvoert. De complexiteit van medische beslissingen wordt erkend en er wordt opgemerkt dat patiënten waarderen dat de lijntjes kort zijn en ze een vast aanspreekpunt hebben, maar ook contact met de specialist zelf. Er wordt besproken dat "mammadokter" geen officiële functie is, maar dat er wel een dokter is die specifieke taken uitvoert, en de rol van een verpleegkundig specialist wordt gezien als gelijkwaardig aan die van een mammadokter. De respondenten benadrukken het belang van herkenbaarheid en continuïteit van zorg, waarbij ze het belangrijk vinden om de patiënten te plannen bij dezelfde persoon bij zowel het eerste bezoek als in de follow-up.

Secretaresse heeft haar rol en verantwoordelijkheden al kort benoemd, ik zal de situatie bij het andere ziekenhuis ophelderen: Mammapolis is onderdeel van chirurgie. Secretaresse is onderdeel van de oncologie en doet alle werkzaamheden voor de gehele oncologie. Echter zijn er nog een aantal secretarissen die vooral mamma care verzorgen. Patiënten melden zich bij de secretaresse aan de balie.

5.3 Hoe kijken jullie naar de rol van de secretaresse bij het andere ziekenhuis met afwezigheid van een gastvrouw?

De taakverdeling binnen de poli wordt als efficiënt beschouwd, waarbij de gastvrouw en secretarissen verschillende rollen vervullen. De gastvrouw fungeert als aanspreekpunt. De secretarissen hebben diepgaande kennis van de poli en hebben specifieke taken, zoals het coördineren van afspraken. Deze taakverdeling wordt als effectief beschouwd, gezien de grote hoeveelheid patiënten die de poli dagelijks bezoeken.

6. Patiëntgerichte zorg

De Mammapoli houdt prestatie-indicatoren bij en bespreekt deze via tumorwerkgroepen, waarbij kwartaal- en jaarlijkse evaluaties plaatsvinden. Acties worden ondernomen op basis van de resultaten, zoals lopende verbeteracties voor doorlooptijden. Belangrijke factoren voor succes in de diagnostische fase zijn onder meer efficiënte communicatie en samenwerking, wat een positieve invloed heeft op de patiëntenzorg.

7. Afsluiting

Het team zal eind dit jaar een VS opleiden om taken over te nemen. Deze nieuwe specialist zou mogelijk meer gestandaardiseerde taken kunnen overnemen dan momenteel gebeurt. Respondent 6 benadrukt dat het trainen van iemand om intakes te doen een goed idee is, evenals het uitbreiden van de follow-up. De respondenten zijn over het algemeen tevreden met de gang van zaken in het ziekenhuis, maar erkennen dat er altijd ruimte is voor verbetering, met name op het gebied van tijd voor gedeelde besluitvorming met patiënten en interne communicatie.

Appendix 5. Quotations in Dutch

Original Dutch quotation	English translation
Focusgroep interviews	Focus group interviews
Respondent: <i>“De situatie is nu een beetje uitzonderlijk en heel eerlijk. Vandaag zat ik hier in mijn eentje op het secretariaat van de oncologische chirurgie. Ja, ik heb 70 belletjes gehad in totaal. Dus ja, alles wat daar verder nog bij komt kijken, qua afhandeling, qua verwijzing, qua planning, qua mail, ja, dat blijft gewoon liggen, daar doe ik tussendoor vis ik ergens nog wel eens wat uit, maar ja, dat is verre van ideaal.”</i>	Respondent: <i>“The situation now is a bit exceptional to be honest. Today I was sitting here alone in the oncological secretariat. I had 70 calls in total. So, yes, all other tasks around those calls in terms of referral, planning etcetera remain uncompleted.”</i>
Respondent: <i>“De secretaresses zijn hier zo goed geregeld, dat ik zelden iets in het systeem zelf hoeft te doen. Dat is voor mij als chirurg heel tijd efficiënt.”</i>	Respondent: <i>“The secretaries are so well organized that I rarely have to do anything in the system itself.”</i>
Respondent: <i>“De mammadokter is toch een beetje een kruising tussen een VS en chirurg.”</i>	Respondent: <i>“The breast doctor is somewhat like a hybrid between a Nurse Specialist and a surgeon.”</i>
Respondent: <i>“Mammadokter is geen officiële functie. Je hebt profiel artsen die hebben daar een bepaalde registratie voor, maar mammadokter, die term hebben we hier bedacht. Dus dat vind je in Den Lande niet. Maar hier op de poli is dus een dokter, ik de enige op dit moment, die bepaalde werkzaamheden verricht.”</i>	Respondent: <i>“Breast doctor is not an official position. There are profile doctors who have a certain registration, but a breast doctor, we have created that term here. So you will not find a breast doctor in another hospital. But here at the outpatient clinic there is one breast doctor, I am the only one at the moment, who performs certain tasks.”</i>
Respondent: <i>“Het is een optie om de resultaten van de diagnose te laten bespreken met de patiënt door de verpleegkundig specialist in plaats van de chirurg alleen hier.”</i>	Respondent: <i>“Discussing the results from diagnosis is something that could be considered as an option to perform here by the Nurse Specialists instead of the Surgeons alone.”</i>
Respondent: <i>“Ja, maar ik denk niet dat het daar persé beter is dan hier. Het is anders. Ik denk wel dat het qua tijd beter is, maar het aantal keer dat ze die patiënt zien ik weet niet of dat nou persé beter is.”</i>	Respondent: <i>“I do not think it is necessarily better there than here. It is different. I do think it is better in terms of time, but the number of times they see that patient, I do not know whether that is necessarily better.”</i>
Respondent: <i>“Ja, idealiter zou ik mooi vinden op het moment dat de secretaresse een consult of een afspraak stuurt naar de patiënt, dat de patiënt een digitale vragenlijst krijgt, die rechtstreeks over wordt genomen in het dossier. Hè, dus dat dat de tijdswinst zou kunnen zijn.”</i>	Respondent: <i>“Yes, ideally, when the secretary sends a consultation or an appointment to the patient, I would like the patient to receive a digital questionnaire, which is copied directly into the file. That could be the time saving.”</i>
Respondent: <i>“Naja je hebt meer tijd om in te gaan op andere zaken. Je kan ingaan op dingen die er wel toe doen voor de patiënt, namelijk: wat staat je te wachten vandaag, wat doen we in welk geval en wat voor angst heeft iemand? Dat zijn de dingen die je kunt adresseren daar gaat het wat mij betreft om.”</i>	Respondent: <i>“Well, you have more time to focus on other matters. You can discuss things that do matter to the patient, namely: what to expect today, what do we do in which case and what fear does someone have? Those are the things you can address, that is what it is all about as far as I am concerned.”</i>
Respondent: <i>“Ja, nou, ik vond iedere dag wel veel en er zijn ook dingen die inderdaad niet per se besproken hoeven worden. Ik vind wel dat het daar altijd beter werd voorbereid. De specialist die het MDO doet, die kijkt de dag van tevoren de lijst na en die vult het ook beter in. Dus ik vind dat hier nu allemaal net een beetje summier.”</i>	Respondent: <i>“Yes, well, the frequency of the MDM daily is a lot every day and there are also minor issues that do not necessarily need to be discussed. I do think that it was always better prepared there. The specialist who is the chairman of the MDM checks the list the day before and fills it in better. So I think that's all just a bit brief here.”</i>
Respondent: <i>“Dus je zit daar met secretaresse en de dokter en de verpleegkundige en de chirurg en ANIOS en poli zit je allemaal bij elkaar. Van daar uit ga je dingen doen, maar daar werkte je ook veel meer samen. Dus de mammacareverpleegkundige, die zag ook de nieuwe patiënten al met een vragenlijst die al even werd voorgelegd aan de patiënten. Dat werd dan ingevoerd en zo nou ja had je ook</i>	Respondent: <i>“The physical setting of the workspace promotes strong teamwork. They all work closely together, with secretaries, doctors, nurses, surgeons, and trainees all in one space. This proximity allows for seamless communication and collaboration.”</i>

<i>makkelijk even contact over de operatie, planning en dat soort dingen."</i>	
Respondent: <i>"Die chat gaat het toch nooit winnen van mondelinge communicatie denk ik."</i>	Respondent: <i>"I don't think that chat will ever win over verbal communication."</i>
Respondent: <i>"Er is een gebrek aan tijd voor resultaatbesprekingen, biopsieresultatenbesprekingen en het bespreken van behandelplannen voor iedereen, maar vooral voor de chirurg."</i>	Respondent: <i>"There is a lack of time for results discussions, biopsy results discussions, and discussing treatment plans for everyone, but especially the Surgeon."</i>
Interviews patiënten	Interviews patients
Respondent: <i>"De resultaten heb ik snel ontvangen en de afspraken werden snel en efficiënt ingepland."</i>	Respondent: <i>"Results were received quickly and consultations were scheduled quickly and efficiently."</i>
Respondent: <i>"Nou, ik kwam voor controle, ik heb eerder ook borstkanker gehad en ik kwam gewoon voor de controle om het jaar en dus mammografie gemaakt, een echo gemaakt en een punctie, biopt. Heel erg prettig dat dat gelijk in één keer hetzelfde moment kan, dezelfde dag."</i>	Respondent: <i>"It was pleasant that multiple examinations could take place on the same day and the result followed quickly."</i>
Respondent: <i>"De communicatie was duidelijk vanuit het personeel en volledig, met uitgebreide uitleg over de procedures en stappen die doorlopen zouden worden en voldoende tijd tijdens de afspraken om vragen te stellen en informatie te verwerken."</i>	Respondent: <i>"The communication was clear and complete, with extensive explanation about the procedures and sufficient time during consultations to ask questions and process information."</i>
Respondent: <i>"Ik wilde advies, chemo had ik geen verstand van, had ik nog nooit eerder gehad. Vorige keer was bestraling en operatie dus. Dat vond ik wel een lastig dingetje. De chirurg gaf cijfers en die gaf aan van dat ik dus zelf voor kon kiezen wat ik wou. Maar toen kwam ik bij, zeg maar de oncoloog internist en die zei: gaf gewoon als advies van nou ja, chemo, adviseer ik, dat zei ze letterlijk. Nou klaar. Toen hoefde ik niet meer na te denken van doe ik dat nog wel, doe ik dat nou niet. Want ja wat weet ik er nou van."</i>	Respondent: <i>"I was seeking advice, as I had no prior knowledge or experience with chemotherapy. The surgeon presented me with various options and percentages related to chemotherapy, which I found overwhelming and difficult to comprehend. However, when I met with the oncologist, she straightforwardly recommended a specific type of chemotherapy. Upon hearing her advice, I felt relieved and no longer needed to ponder over the decision. After all, I realized that I lacked the expertise to make such a decision on my own."</i>
Respondent: <i>"De arts zei, u heeft kanker, boem, zo bam. Ik schrok mij helemaal een ongeluk. Hij zei u kunt kiezen voor een amputatie, nog een klap in je gezicht. Er is bijna niks te zien aan de borst, iets subtieler was wel wenselijk geweest."</i>	Respondent: <i>"It would be better if communication about bad news were less direct and more sensitive, because the news hit like a bombshell."</i>
PREM H2	PREM H2
Respondent: <i>"Ik vond het heel fijn dat er gelijke uitslag was na de onderzoeken en dat je van te voren goed uitgelegd kreeg wat er precies zou gebeuren en in welke volgorde."</i>	Respondent: <i>"I found it very nice that there was an immediate result after the examinations and that you were well explained in advance what exactly would happen."</i>
Respondent: <i>"Heel fijn dat je als patient een persoonlijk aanspreekpunt hebt, de verpleegkundige op de afdeling. En fijn dat zij de afspraken voor je regelt en ontzorgt daarin. Het gehele team waar ik mee te maken heb gehad is super zorgzaam, empathisch en komt zeer bekwaam over. Alle lof!"</i>	Respondent: <i>"It is very nice that as a patient you have a personal point of contact, the Nurse in the department. And it is nice that she arranges the appointments for you and takes care of you. The entire team I have dealt with is super caring, emphatic and appears very competent. All praise!"</i>
Respondent: <i>"Deskundigheid en een zeer vriendelijk en deskundige uitleg. Ze hebben mij veel vertrouwen gegeven."</i>	Respondent: <i>"Expertise and a very friendly and expert explanation. They have given me a lot of confidence."</i>
Respondent: <i>"Het was me niet heel duidelijk in welke wachtruimte ik plaats kon nemen na van de ene naar de andere locatie verwezen te zijn. Het zou prettig zijn als in de buurt van alle wachtruimten een medewerker zou zijn waaraan je kunt vragen of je op de juiste plek bent (ik zag een ouder echtpaar hier ook mee struggelen)."</i>	Respondent: <i>"It was not very clear to me which waiting area I could take a seat in after being referred from one location to another. It would be nice if there was an employee near all waiting areas who you could ask if you are at the right place (I also saw an older couple struggling with this)."</i>
Respondent: <i>"Snellere inzet mentale hulp bij tegenslag. De agenda's van specialisten verder in de toekomst open zetten. Onbegrijpelijk dat dat niet kan. Ik ben bij de plastisch chirurg niet meer opgeroepen voor een consult en bij de (half)jaarlijkse controle voor CA ook niet opgeroepen. Kwalijk!"</i>	Respondent: <i>"Faster deployment of mental help in case of setbacks and opening the agendas of specialists further in the future. It is incomprehensible that this is not possible. I have no longer been called in for a consultation by the plastic surgeon and I have not been called in for the (semi-)annual check-up. Bad!"</i>

Appendix 6. Summary results

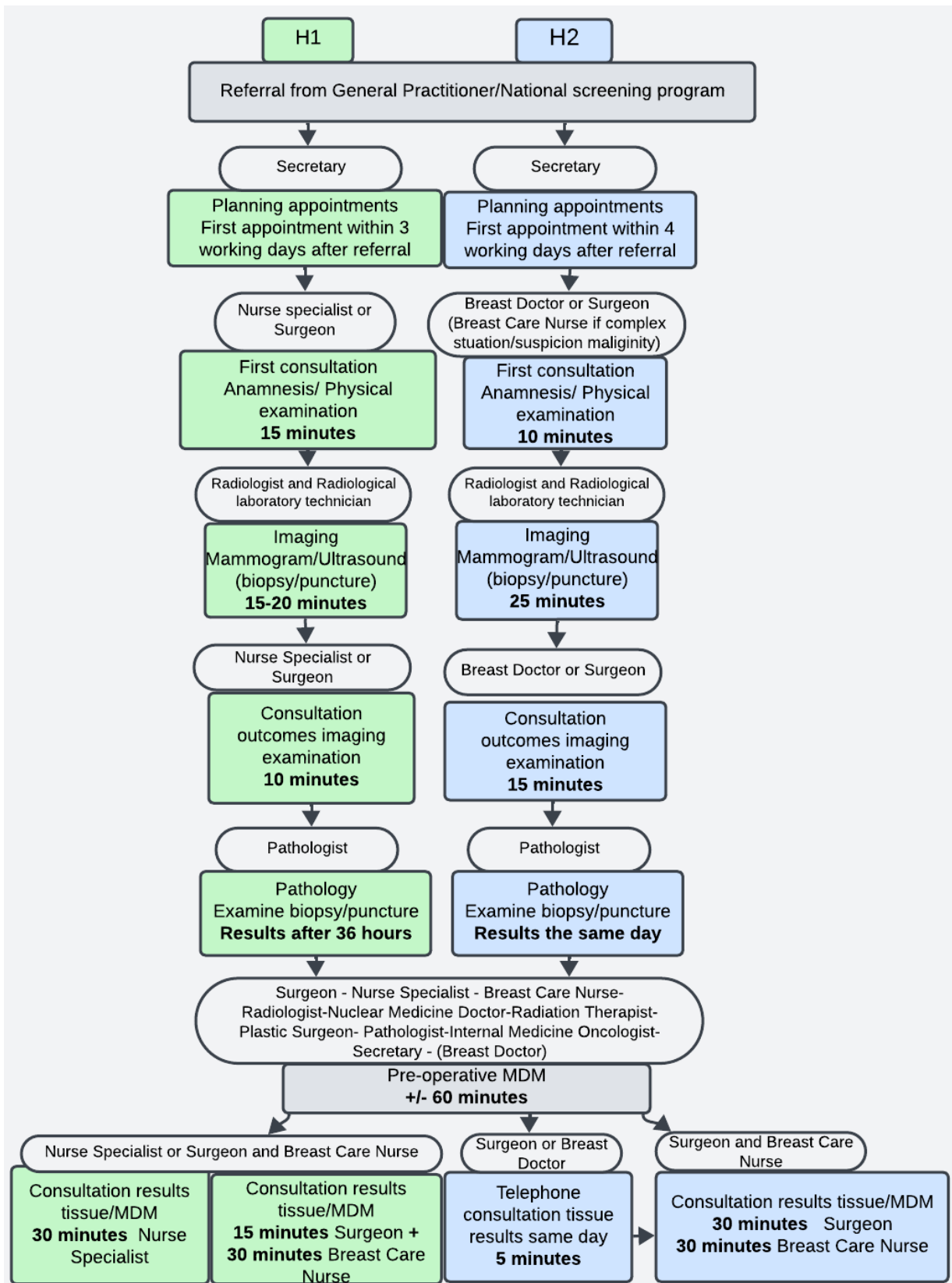


Figure 3. Flowcharts of the diagnostic breast care pathways of breast cancer in two different hospitals.

Research Objective: The aim of this study was to investigate the possibility of creating a more standardized diagnostic care pathway for breast cancer. The perspectives of various stakeholders were considered, and variations in processes between the two hospitals were identified. Based on the findings and perspectives of patients and hospital staff, several points were identified.

Research Question: “How can the breast cancer diagnostic pathways of two different hospitals be combined into a more standardized care pathway, taking into account the perspectives of stakeholders and variations in processes?”

General Findings:

1. Importance of Time Component

- **Finding:** Staff recognize the importance of sufficient time for patient interactions. However, time constraints, especially for surgeons with heavy workloads and due to established consultation times, hinder the effective integration of care pathways.
- **Recommendations:** Investigate the feasibility of allocating more time for staff or delegating tasks. Analyze specific activities that consume the most time to inform potential solutions, such as introducing a hostess to reduce administrative burdens. **H1:** Consider appointing a Breast Doctor to manage workload and time constraints.

2. Clear Communication:

- **Finding:** Communication is essential during the diagnostic process for breast cancer. Both patients and healthcare providers acknowledge that information often does not effectively reach patients, especially when medical terminology is used or colleagues use different terms when addressing the same patient. Patients indicate that this hinders their participation in shared decision-making, which is crucial for patient satisfaction.
- **Recommendation:** Raise awareness among staff about the importance of effective communication with patients, emphasizing simple and unambiguous terms to enhance patient satisfaction and engagement.

Specific Findings:

1. Role of Nurse Specialists:

- **Finding:** In H2, Nurse Specialists are currently not involved in the diagnostic phase, unlike H1, where they play an active role. Respondents in both hospitals recognize the importance of Nurse Specialist involvement during diagnostics.
- **Recommendation: H2:** Empower the Nurse Specialists by allowing them to take a more leading role within the diagnostic breast cancer care pathway to improve patient outcomes, efficiency, and continuity of care as patients prefer Nurse Specialists.

2. Completing Anamnesis:

- **Finding:** Both hospitals view completing anamnesis prior to the initial consultation positively, as it helps patients better remember information and saves time for healthcare providers.
- **Recommendation: H1:** Implement pre-consultation anamnesis to enhance information recall and consultation efficiency.

3. Multidisciplinary Meetings: (MDM):

- **Finding:** Both hospitals hold weekly MDM meetings that meet breast cancer care standards. However, H1 acknowledges the need for improvement in MDM preparation, focusing on uniformity and accuracy. H2 uses standardized MDM forms, resulting in consistent and comprehensive reporting.
- **Recommendation: H1:** Consistently use standardized MDM forms across all MDM staff to improve documentation quality and meeting efficiency. Ensure uniformity in staff practices by adhering to standards and maintaining up-to-date data.