

Women's Experiences with Deciding on Neoadjuvant Systemic Therapy for Operable Breast Cancer: A Qualitative Study

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ABSTRACT

Objective: We explored, qualitatively, in a sample of Australian early-stage breast cancer patients eligible for neoadjuvant systemic therapy (NAST): (i) their understanding of the choice of having NAST; (ii) when and with whom the decision on NAST was made; and (iii) strategies used by patients to facilitate their decision on NAST. **Methods:** A sub-sample of patients participating in a larger intervention trial took part in this study. A total of 24 semi-structured phone interviews were analyzed using framework analysis. **Results:** A number of women perceived they were not offered a treatment choice. Most patients reported that the decision on NAST was made during or shortly after the initial consultation with their doctor. Women facilitated decision-making by reducing deciding factors and “claiming” the decision. Most women reported that they made the final

decision, although they did not feel actively involved in the decision-making process. **Conclusions:** When deciding on NAST, patient-centered care is not always delivered to patients. Clinicians should emphasize to patients that they have a treatment choice, explain the preference-sensitive nature of deciding on NAST and highlight that patients should be involved in this treatment decision. Providing patients with appropriate time and tailored take-home information might facilitate patient decision-making. Process-orientated research is needed to adequately examine patient involvement in complex treatment decisions.

Key words: Breast cancer, doctor–patient-communication, neoadjuvant systemic therapy, neoplasm, patient decision-making, qualitative research, treatment choice

Introduction

Patient-centered decision-making implies that patients are offered a treatment choice, are enabled to participate

in the decision-making process and that patients have the final say regarding their treatment decisions.^[1,2] This has

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been shown to increase patients' understanding of their treatment options, improve patients' satisfaction with their care and their overall quality of life.^[3-5] Clinicians have been encouraged to help patients become involved in deciding on their treatment, to the extent they desire.^[6] However, treatment decision-making can be challenging. Treatment choices are increasingly involving differing outcomes, such as efficacy and toxicity, which may be valued differently by different patients.^[7,8] Such "preference-sensitive" decisions often add complexity and uncertainty at a time when patients are likely to be distressed from the initial cancer diagnosis.

A potentially difficult "preference-sensitive" decision is the choice as to whether to receive neoadjuvant systemic therapy (NAST) or not. Early-stage breast cancer patients with larger operable or highly proliferative disease may be offered this option. It involves the receipt of chemotherapy or endocrine therapy before cancer-removing surgery. Based on the current prospective randomized data of 3,946 patients with operable breast cancer, survival rates and disease progression are equivalent for NAST compared to upfront surgery, regardless of cancer type.^[9] However, the impacts of the two options are different. Some patients may value NAST due to a higher chance of breast conserving surgery rather than mastectomy.^[10] NAST also allows a better understanding of tumor response and biology. This can facilitate prognostication,^[9,11] and might decrease patients' anxiety associated with their cancer.^[12,13] However, some patients may prefer having upfront surgery as they fear that their cancer could get worse while receiving NAST, and thus wish to have the tumor surgically removed as soon as possible.^[14]

Adequate patient involvement in such difficult treatment decisions it is not always applied in clinical practice.^[15,16] Elwyn *et al.*, have argued that the specific underlying issues that militate against the adoption of adequate patient involvement, are still under-investigated.^[17] To guide the development and implementation of appropriate decision support for cancer patients, we need to better understand how patients make difficult treatment decisions and what we can do to adequately support them when deciding on their treatment.^[18]

This paper reports a qualitative analysis of phone interviews conducted as part of a prospective, single-arm pre- and post-trial. The trial aimed at evaluating a decision aid which has been designed to help women decide on NAST. We explored, qualitatively, in a sample of early-stage breast cancer patients eligible for NAST: (i) their understanding of their treatment choice; (ii) when and with whom their decision on NAST was made; and (iii) strategies used by patients to facilitate this decision. Another analysis focusing

on women's use and perceived benefit of the decision aid is currently in press.

Methods

Setting and sample

A purposeful sample of 24 patients attending breast cancer treatment centers in New South Wales and Victoria, Australia. Recruitment continued until data saturation (no new themes in three consecutive interviews) was achieved.

Inclusion and exclusion criteria

Patients were eligible for this study if, at the time of enrolment, they (i) were female; (ii) were aged ≥ 18 years; (iii) had a histological diagnosis of operable invasive breast cancer; (iv) were considered for NAST as a treatment option with curative intent; (v) were willing and able to access the trial information through the internet and complete a phone interview. Patients were excluded if: (i) < 3 months duration of NAST was planned; (ii) they had a hearing or another impairment or insufficient English language skills for participation in a phone interview; (iii) they had inflammatory, metastatic, or inoperable breast cancer; (iv) they were considered by the treating investigator to have a medical or psychiatric condition precluding informed consent; and (v) they were unable to be contacted via telephone.

Ethics approval and consent to participate

This study was developed and conducted in accordance with the tenets of the Declaration of Helsinki and principles of Good Clinical Practice. All participants provided voluntary informed consent to join the study, which had been approved by the regional research ethics committee (approval number: 14/12/10/4.05) and conducted according to local site governance processes.

Recruitment

The treating clinician identified all eligible patients attending their clinic for a consultation, introduced the larger intervention trial and obtained written consent to be contacted by the Australia and New Zealand Breast Cancer Trials Group for study registration. Consenting patients were emailed a link with access to the trial information letter and online consent form for the larger intervention trial, which gave participants the option to opt out of a follow-up telephone interview. Patients who consented to a telephone interview were contacted via phone by a researcher to schedule the interview.

Data collection

All interviews were conducted by one researcher who has been trained extensively in qualitative research methods.

Participants were informed that the interviews would be audiorecorded and transcribed but that their information would remain de-identified. They were asked to tell how they made their decision on NAST, in the way they preferred, without interruption from the interviewer. This narrative was followed by semi-structured questions about the information provided to patients, their information seeking behavior, the decision-making process and psychological concerns (for questions in each domain of the question guideline please see Appendix 1). At the end of the interview, patients were given the option to provide additional comments. The questions were informed by a previous study and discussions among the research team.^[14] Participants were asked as many questions as needed to gain the required information, with prompting used to elicit topics not spontaneously spoken about by patients.

Statistical analysis

Interviews were transcribed verbatim. Transcripts were checked for accuracy by one researcher and analyzed using framework analysis.^[19] According to Gale *et al.*, the framework analysis approach belongs to a broad family of qualitative data analysis methods often related to as “thematic analysis” or “qualitative content analysis.” As suggested by these approaches, we aimed to draw both descriptive and explanatory conclusions from the data which were clustered around themes.^[19] Conclusions drawn from the data were double checked by another researcher. Disagreement was resolved by discussions between all members of the research team. The transcripts were read line by line, and their content was examined, compared, and categorized to apply a paraphrase or label (a “code”) that describes what was interpreted in the passage as important. “Open coding” took place, i.e. anything was coded that could have been relevant from as many different perspectives as possible.^[19] Codes were then grouped to start the development of more complex categories. An analytical framework was developed based on key categories and data were assigned to the codes and categories in the framework.^[20] An iterative approach was followed with newly developed and existing codes and categories constantly being compared with each other and revised if necessary.^[21] This enabled us to develop interpretive concepts that describe or explain aspects of the data (i.e. themes).^[19]

The coding process was accompanied by writing analytical memos to help document the research process and preliminary findings. This approach to qualitative data analysis provided a systematic model for mapping and interpreting the data and was thus considered appropriate to develop a profound understanding of patients’ decision-making experiences.^[19] Demographics are presented using appropriate summary statistics.

Results

Patients were interviewed between February 2016 and February 2017. Fifty-nine patients consented to participate in the trial, 30 (51%) consented to be interviewed and 24 (41%) were available for an interview, by which time saturation was achieved. The median time since diagnosis was 91 days (interquartile range = 49,169). Participants’ median age was 51 (standard deviation [SD] = 7.3), [Table 1]. The results are organized around three themes: (1) patients’ perceptions of being provided with a treatment choice; (2) decision-making in a situation of perceived emergency; and (3) strategies used to facilitate decision-making.

Patients’ perceptions of being provided with a treatment choice

Many patients did not feel that they had a choice of whether or not to receive NAST. This was for three main reasons. First, some women perceived that they were not offered a treatment choice at all. They felt that their doctor provided them with a treatment plan without discussing alternative options. This did not allow women to participate in the decision-making process. However, due to the power imbalance between doctor and patient, women accepted their doctor’s treatment choice.

“She (=the surgeon) said, you’re going to have chemo anyway, so let’s have it first. Shrink the tumour, and yeah – that was very simple. We didn’t even discuss other options at all. She made the decision. (...) I heard that it usually goes, surgery first, then chemo. When I told her I want to

Table 1: Patient characteristics (n=24)

Characteristics	Patients, n (%)
Age (years), mean (SD)	51 (7.3)
Marital status	
<i>De facto</i>	4 (17)
Married	17 (71)
Single	3 (13)
Education	
Secondary school	4 (17)
Vocational	3 (13)
University	17 (71)
Lymph nodes involved	
Yes	10 (42)
No	14 (58)
Treatment decision	
Neoadjuvant	21 (88)
Adjuvant	3 (13)
Surgery	
Mastectomy only	10 (42)
Breast conserving surgery only	13 (54)
Both	1 (4.1)

SD: Standard deviation

have surgery first, then chemo, she said, that's not going to happen, and then I said, okay, you know best; and that was all." (P8)

Second, even when perceived to be offered a treatment choice, many women did not feel that they had a say in the treatment decision. They reported that the decision was strongly guided by their doctors. Doctors were seen to have a preference for the "best" treatment choice and were perceived to have guided the decision-making process both in an explicit way (i.e. providing a treatment recommendation) and in an implicit way (i.e. implying a preferred treatment option through the way in which options were presented to patients). All women followed their doctors' treatment advice. Some women felt that they were "in their doctors' hands" (P2) and that they could only participate in the decision-making process if they were agreeing with their doctors' treatment recommendation. In these instances, decision-making on NAST was predominantly characterized by clinicians' disclosure and explanation of information, rather than being a patient-centered process which involves joint participation between doctor and patient.

"Ultimately they both (=the surgeon and the oncologist) heavily heavily heavily recommended that I make this decision that favours what they decided. So whether it's – they gave me the information which was pretty hard to say no to. Whether they made the decision and then decided to convince me that it was the best option, or whether I was just – you know I go with the experts. (...) I suppose I did make the decision, but it was after some pretty heavy pressuring." (P 16)

"It was pretty much this is what we recommend. He (=the oncologist) did present it as you have a choice but all of the advice led down that path (=to have NAST)." (P 21)

Third, some women struggled with comprehending and accepting the preference-sensitive nature of the decision on NAST. Although survival outcomes are equivalent for NAST and upfront surgery, women found it hard to understand that their preferences needed to be involved in the decision-making process to determine the "best" treatment choice. These women perceived the decision on NAST as a no-win-situation. They felt that no matter which option they chose, it would not lead to a perceived gain, given that survival benefits are similar for NAST or upfront surgery, and given that they would have chemotherapy anyway. Some women experienced the decision-making process as a burden, rather than a chance to make a treatment decision in line with their individual preferences.

"Either way wasn't really going to make any difference. I guess I felt by doing it beforehand (=chemotherapy before surgery), I'm not disadvantaging myself (.) It seems that

the results and so on are the same, or there doesn't seem to be much in difference." (P 12)

"Unfortunately it's such a grey area that there are pros and cons to both sides. So you're like shit, there's no obvious answer at the end." (P 22)

Decision-making in a situation of perceived emergency

Many women felt that the decision on NAST needed to be made quickly and perceived to be in an emergency situation which required urgent action to prevent a worsening of their cancer. The majority of patients reported that the decision was made during or shortly after the initial consultation with their doctor. A mean of 5 days (SD = 4.6) elapsed between study consent and treatment decision. A number of women reported having little time between the consultations with their medical specialists during which their treatment options were discussed. Some women noted the limited amount of time they had with their doctors during these consultations. Many women felt rushed when deciding on NAST which did not allow them to comprehend and weigh-up the information provided to them and make a considerate treatment decision.

"It was all really quite quick for me. I only found out in the morning and (was) then at the doctor's the same day, both the breast surgeon and the oncologist. So there wasn't very much down time for me. (...) So I was straight into, okay, you've been diagnosed, and straight into acting on it straight away."(P 5)

"Because when you are in a surgeon appointment, it's only a limited amount of time. Like it's specific to, boom, boom, boom, the things that have to be dealt with." (P 17)

A number of women felt a loss of control over the situation in which the decision was made. They were overwhelmed by the fear associated with their diagnosis and the potential treatment outcomes. Many patients reported a lack of medical expertise and did not feel capable of taking an active role in the decision-making process. A number of women perceived the lack of information as a "vicious circle" as it did not allow them to ask further questions which might have helped overcome their perceived lack of understanding. Some women felt that it was their responsibility to escape this "vicious circle" by seeking additional decision support.

"Obviously it was overwhelming because it's not something that you obviously hope on anybody." (P 5)

"Maybe I would have wanted to know more about prognosis and survival rates, but, if I wanted to know more, I should have asked more."(P 8)

Most women made the decision with their doctors and their support persons and perceived them to be the most important information sources for deciding on NAST. Some women reported to have appreciated if their doctor

suggested a treatment plan and offered to change the course of treatment at any time. These women perceived that the “right” treatment choice was determined by treatment success. Having the option to change the treatment plan if NAST was considered unsuccessful seemed to help women feel more satisfied with their decision.

“Yeah, like I really didn’t know either way, so – but I was happy with the decision that was made knowing that at any time we could stop the chemo and have surgery if they felt the cancer was progressing or wasn’t reacting or – yeah, if there were any other signs going on.” (P 2)

Strategies used to facilitate decision-making

Women used a number of strategies to facilitate decision-making on NAST. The most commonly used strategies included: (i) reducing deciding factors; (ii) “claiming” the decision; and (iii) using additional information. These strategies are described below.

Most women did not contemplate over the variety of potential reasons for or against having NAST. They seemed to base their decision on one or two key factors which they perceived as most important to them, at the time when the decision was made, such as having breast conserving surgery, rather than a mastectomy, or having a treatment that would affect the whole body, not just the breast. The reasons why women decided for or against NAST did not only relate to the medical effectiveness of the treatment options available to them. Some women decided on NAST based on their personal circumstances or on what they considered emotionally “bearable.” For example, some women made the decision on NAST based on their family commitments or the fear associated with their cancer. This highlights that when deciding on NAST, the “right” treatment choice depends heavily on patients’ individual preferences and needs.

“So if it doesn’t affect the prognosis and/or the percentages of survival, and it does help you in other words in a few ways, in that the cancer can be reduced in size which means that the operation is not such a major one. Number one (1). Number two (2), if the cancer does reduce in size, they know that the chemo actually works.” (P 16)

“I suppose in the back of your mind you’re thinking because as it’s (=the chemotherapy) blasting the whole body and even if it is somewhere in my body, you can only hope that it has been blasted by this chemotherapy.” (P 4)

“I think the main clincher with me was finally feeling the size of the lump after the dressing’s come down and everything. Then just thinking that I couldn’t cope with that (=not getting the tumour removed immediately) and not knowing if it was going to get bigger or spread.” (P 9)

“I thought, well, I would rather get the chemo out of the way first because we’ve also got something coming up later in the year and I didn’t want to be going through chemo

when that happened. Our daughter’s wedding is in the middle of the year, so that’s why I was happy to do the chemo first.” (P 7)

Most women described the decision-making process in the passive voice. Although they did not seem to play an active role in deciding on NAST, most women reported that they made the final decision and thus “claimed” the decision. In these instances, patients’ perceived involvement in the decision-making process differed from their perceived involvement in the final decision.

“I guess it was my decision at the end of the day but I was really just guided by what the doctors were saying.” (P 2)

“I guess you sign the paper and you say I’m making the decision but I do think that definitely the surgeon and the oncologist had both said this is what we would recommend.” (P 21)

Women used additional written information, such as the decision aid that was part of the larger trial, to confirm their decisions on NAST, rather than changing them. (An in-depth qualitative analysis of the use and perceived benefit of the decision aid is presented in another article which is currently in press). Using additional information helped women supplement the information provided by their doctors and reassure that their treatment choice was not solely determined by their doctors’ opinion, but based on women’s individual circumstances and preferences. Some women reported that using additional information helped them comprehend that they had a treatment choice and thus enabled them to better understand the preference-sensitive nature of the decision on NAST.

“Then she (=the breast surgeon) said, we’ve got this trial which is a decision tool. Would you be interested in being part of that? I said, yes that would be good, because I’d like to make sure that the decision that I am making is not being influenced by my healthcare practitioners who were telling me what they thought was better. So this helped me confirm that the decision that we were making together was the right decision.” (P 13)

“As I went away and started reading the literature in between sessions, it suddenly dawned on me that this is actually a choice. I could choose.” (P 23)

Women who used additional information in between the consultation with their surgeon and their medical oncologist appreciated having sufficient time to make sense of the information provided by their doctors. It helped them better cope with the perceived emergency of the situation and feel more involved in deciding on NAST.

“I think it was important to speak to the surgeon and get his view on it all, but I think it was also very helpful to have the written information that was in the decision aid so I could sit and read that at my own pace.” (P 17)

Discussion

Our data suggest that preference-sensitive decision-making in the context of NAST can be difficult for patients. Some did not feel that they were offered a treatment choice or received a strong treatment recommendation. This is in line with previous studies. Ziebland *et al.*, analyzed pancreatic cancer patients' perceptions of treatment decision-making and found that doctors were often perceived to have presented surgery as the obvious course of action, rather than offering a treatment choice patients could have been involved in.^[22] It is possible that the treatment recommendations of some clinicians may be at odds with patients' values.^[23,24] Clinicians should emphasize that patients have a treatment choice and make it clear that patients can be involved in decision-making. This could be done by offering to explain the available evidence to patients, help patients comprehend the risks and benefits of their options, check for patients' understanding, and ask patients about their preferences for information provision and decision-making.^[25] A patient-centered approach towards medical decision-making could help patients consider "what matters most to them" and facilitate their involvement in treatment decisions.^[26,27] This is important as there is evidence to suggest that patients make decisions regarding their cancer care not only based on statistical risk assessment but based on a broad range of experiential factors, including family history of cancer or information sought from their personal network of family and friends.^[28,29]

The patients in our study felt that the decision on NAST needed to be made quickly. Many felt overwhelmed by their diagnosis and treatment options which is in line with previous studies on other cancer treatment decisions.^[27,30,31] It is vital to provide patients with appropriate time to consider their options and make sense of the information presented to them. Where possible, clinicians should emphasize to patients that it is usually safe to consider their options for a few days before making a decision. Offering the second consultation may be a strategy worthy of investigation to help improve patients' understanding of their options and their participation in decision-making.^[26] Furthermore, providing additional written information for patients to review at home could take the pressure off having to provide and receive all required information within the consultation. This could counteract patients' feeling of being overwhelmed and allow for considered decision-making which might reduce patients' decisional regret.^[32,33]

A patient-centered approach towards medical decision-making might also reduce costs to the healthcare system as there is evidence to suggest that patient-centered communication might be associated with better recovery

from discomfort, better emotional health, and fewer diagnostic tests and referrals.^[34,35] A recent Cochrane review on interventions to support patient involvement in decision-making indicated that consultations that involved such interventions were on average only 2.5 min longer (median: 2.55 min).^[36] Patient-centered communication about treatment decisions patients have to make soon after their diagnosis might also lead to more succinct treatment discussions later in patients' care trajectory.^[37] As a consequence, emphasizing that patients have a treatment choice and involving patients in treatment decision-making could ultimately lead to more efficient and effective patient care.

"Claiming" the decision to maintain cognitive consonance and the need for process-orientated research.

Many women reported having made the final decision on NAST, although they did not feel that they had been actively involved in the decision-making process. Festinger's Theory of Cognitive Dissonance may help explain why this occurred. This theory suggests that people strive to achieve a state of harmony by maintaining consistency between their beliefs, values and behaviors, to avoid psychological discomfort.^[38] It might be that patients perceived to have made the final decision, although they did not feel that they played an active role in the decision-making process to align their behavior with their understanding of the situation. It is likely that women perceived an obligation for being involved in their own healthcare decisions, as it is the patients who have to manage the consequences of treatment decisions.^[2] In line with the premise of cognitive dissonance theory, it might be that this strategy of "claiming" the final decision helps patients maintain cognitive consonance and thus psychological comfort by protecting themselves from any distress they may experience as a result of their views not aligning with their behavior.

Decision-making is a dynamic process where patients' preferences and needs might change.^[39] When measuring patients' decision-making preferences and experiences, researchers should focus on the decision-making process rather than patients' perceptions of the final decision. However, many instruments in this area, including the widely used Control Preferences Scale, focus on patients' views about the final decision rather than the process of decision-making.^[40] Such measures can be misleading as patients are often unaware that decisions need to be made and do not feel that they should have participated in them.^[41] Process-orientated measures might help better understand patient involvement in treatment decisions by examining different components of the decision-making process.^[26,41,42]

This is likely to increase the progress in the research and the implementation of patient-centered care.

Limitations

The study findings are not intended to be numerically representative. They rather provide in-depth insights into how women decided on NAST. As such, we avoided a potentially misleading numerical description of our results. We conducted phone interviews which might be a less productive mode of data collection than face-to-face interviews.^[43,44] However, evidence is lacking on whether phone interviews produce lower quality data.^[45-47] Also, patients might feel more relaxed and able to disclose sensitive information when being interviewed on the phone, in the comfort of their homes and without having to face the interviewer.^[45] Furthermore, there is evidence to suggest that rearranging a phone interview by calling back at a more convenient time for the interviewee might cause study participants less embarrassment and difficulty than rearranging a face-to-face interview.^[43] This was considered to be of particular importance for this study as many women asked to rearrange the interview because they felt too unwell to do the interview, or because they had to attend the clinic. As a consequence, it was assumed that conducting phone interviews, rather than face-to-face interviews would reduce research-related burden on patients. Some women participated in the interview months after deciding on NAST (median time between study consent and interview: 102 days). This introduces the possibility of recall bias that could lead to inaccurate narratives.^[48] Also, most study participants were well-educated and younger. Older women and those with lower levels of education might have different experiences with deciding on NAST.^[49] Clinicians' communication skills and styles may have influenced how women decided on NAST. For example, clinicians' skills in communicating risks might have had an impact on patients' understanding of their options.^[50,51] As we do not have recordings of the consultations where the decision on NAST was discussed, we do not know how clinicians' communication skills and styles may have influenced patient decision-making.

Conclusion

Although the patients in this study presumably had a choice between two equally effective treatment regimes, a number of women felt overwhelmed and believed that they were not offered a treatment choice. Clinicians should emphasize to patients that they have a treatment choice, explain the preference-sensitive nature of NAST and highlight that patients should be involved in this decision, to the extent they desire. Strategies to support patient involvement in deciding on NAST might include

providing patients with appropriate time and further written information to consider at home. Where possible and reasonable, clinicians should emphasize to patients that it is usually safe to take a few days to consider their options before a decision is made. Also, many of the study participants "claimed" the decision and reported having made the final decision, although they did not feel actively involved in deciding on NAST. Process-orientated research is warranted to examine changes in patients' preferences and experiences with making cancer treatment decisions.

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Conflicts of interest

There are no conflicts of interest.

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Appendix 1 – Questions in each domain of the question guideline

Questions on information provided to patients included asking patients (i) where they got information to help them make a decision about whether to have chemotherapy before surgery; (ii) which of these information sources they found most useful; (iii) what exactly the information was that helped them make the decision; (iv) whether they felt they were given enough information to allow them to make a decision; (v) if they felt they were not given enough information, what other information they would like to have received; and (vi) how they would like information presented to them (written, face-to-face, online).

Questions regarding the decision-making process and psychological concerns included asking patients (i) who made the decision in the end; (ii) what was difficult about making the decision; (iii) how certain they were about the decision at the time when they made the decision; (iv) how certain they were now that they made the right decision; and (v) if their certainty has changed, why it has changed. Patients were further asked whether (vi) they do or did worry that their cancer would get worse whilst having chemotherapy; (vii) what period during chemotherapy and surgery they found most difficult, mentally and physically; and (viii) whether they worried that their cancer would come back.

Questions regarding other factors which might have influenced patients' decisions included asking patients whether and if so, how the following factors influenced their decision: (i) having breast conserving surgery (lumpectomy); (ii) being able to know whether the cancer responded to chemotherapy; (iii) having treatment sooner for the whole body, not just for the breast; (iv) being involved in a clinical trial (and whether their doctor talked to them about this); (v) their ability to have children in the future. Patients were further asked whether (vi) they were aware that breast cancer can be inherited in the family and whether that was relevant to their decision; (vii) what other issues they considered when making the decision, such as financial or logistic issues; and (viii) whether they have considered having a breast reconstruction.