




# What do women at high risk of breast cancer request of a patient education day? Focus interviews with women before and after deciding about prophylactic interventions

Anne Katrine Hartmann Søby<sup>1</sup>  | Christina Maar Andersen<sup>1</sup>  | Camilla Bille<sup>2</sup>  |  
Birgitta Fahnø Larsen<sup>2</sup> | Lene Nyhøj Heidemann<sup>2</sup> | Rachel Adelberg Johansen<sup>2</sup> |  
Helle Timm<sup>3</sup>  | Kirsten Kaya Roessler<sup>1</sup> 

<sup>1</sup>Department of Psychology, University of Southern Denmark, Odense, Denmark

<sup>2</sup>Department of Plastic Surgery, Odense University Hospital, Odense, Denmark

<sup>3</sup>National Institute of Public Health, University of Southern Denmark, Odense, Denmark

## Correspondence

Anne Katrine Hartmann Søby, Department of Psychology, University of Southern Denmark, Odense, Denmark.

Email: [akpoulsen@health.sdu.dk](mailto:akpoulsen@health.sdu.dk)

## Abstract

**Objective:** At a Danish Hospital, we wished to establish a co-designed patient education day about prophylactic interventions for women at high risk of developing breast cancer. However, knowledge is lacking on the women's acceptability and requests for content. The objective of this study is to gain knowledge about the acceptability and requests of the content of a patient education day among women at high risk of breast cancer considering prophylactic mastectomy.

**Methods:** A user panel consisting of patients and health care professionals developed an interview guide for two focus interviews with two groups of women at high risk of breast cancer; one group had received a prophylactic mastectomy and one group considered it. Thematic analysis was used to explore the participants' acceptability and requests for content.

**Results:** Meaningful content was knowledge about prophylactic interventions, how to share knowledge with partners and children, and talking to equals in a safe forum. Not all participants wished to discuss own surgery in a group setting.

**Conclusion:** An education day is an acceptable and supportive format for gaining knowledge about surgery, but since some topics may be vulnerable to discuss in a group setting to some women, we suggest the education day as a valuable supplement to the individual consultations.

## KEYWORDS

breast neoplasms, decision making, heredity, patient education as topic, prophylactic mastectomy, qualitative research

## 1 | INTRODUCTION

Data collection was conducted by the Department of Plastic Surgery, Odense University Hospital.

Breast cancer is the most common cancer diagnosis among women (Globocan, 2020b) with a cumulative lifetime risk of 10% among

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Western European women (Globocan, 2020a). Five to 10% of all breast cancer cases are thought to be genetically disposed, and in these cases, the risk can be up to 87% (American Cancer Society [ACS], 2022; Kuchenbaecker et al., 2017).

Being informed of having an increased risk of breast cancer evokes distress, questions regarding consequences for the future, and experiences of loss of control for many women, which can be worsened by experiences from close family members' course of and death from breast cancer (Kwiatkowski et al., 2016; Taylor et al., 1991). Young women, facing identity issues, the onset of romantic relationships and reproduction, are particularly vulnerable (Hoskins et al., 2008; McKinnon et al., 2007). Health care systems often lack support in this regard (St-Pierre et al., 2018).

In Denmark, women with a cumulative lifetime risk of breast cancer of  $\geq 30\%$  are offered risk-reducing surgery or yearly check-ups (Terkelsen et al., 2019). A breast cancer risk-reducing surgery is a bilateral prophylactic mastectomy (preventive surgical removal of both breasts) with the possibility of breast reconstruction and/or oophorectomy (removal of the ovaries) (Gerdes et al., 2016). Yearly check-ups can include MRI, mammography, clinical examination and ultrasound imaging (Gerdes et al., 2016).

To decide for risk-reducing surgery or yearly check-ups is a challenging and complex process (Glasse et al., 2016; Howard et al., 2009; St-Pierre et al., 2018). The acquisition and processing of accurate information are necessary conditions for the women to make an appropriate decision (Padamsee et al., 2017). The decision concerns both health, length of life, reproduction, being able to breastfeed and the change of body image, hormonal level and looks. Many request and appreciate professional counselling on how to talk to children about inherited genetic conditions (Metcalfe et al., 2008). Concerns about children's emotions related to being at high risk of breast cancer can be decisive as to whether the women choose surgery (Padamsee et al., 2017). While some women are motivated to receive prophylactic surgery out of fear of abandoning their children if they die from breast cancer, others decline surgery, because it might cause their children to worry (Padamsee et al., 2017).

Though many women receive several consultations before deciding, they often experience a lack of knowledge and health care support (Glasse et al., 2016; Gottlieb & Wachala, 2007; Stan et al., 2013; Thewes et al., 2003). Some might have chosen not to receive prophylactic surgery, had they known about the possible complications (Padamsee et al., 2017). Many women request additional knowledge about cancer genetics and discussions with equals (Thewes et al., 2003).

Evidence suggests that a group-based patient education day about preventive interventions as a supplement to individual counselling can be both cost-effective, in terms of less time spent per patient and increased adherence to treatment, as well as socially supportive, for example, in processing the new situation (Calzone et al., 2005; Dunkel-Schetter, 1984; Gottlieb & Wachala, 2007; Karp et al., 1999; McKinnon et al., 2007; Montazeri et al., 2001; Ridge et al., 2009; St-Pierre et al., 2018). Ridge et al. (2009) found that though most participants preferred individual to group genetic counselling, the level of

patient satisfaction was similar in group and individual genetic counselling. Similarly, Calzone et al. (2005) found that participants were equally satisfied with either individual or group education and counselling before genetic testing and that significantly more time was spent per patient in individual sessions compared to group education (Calzone et al., 2005). McKinnon et al. (2007) detected lifestyle changes, increased cancer screening, initiated chemoprevention and planned or completed preventative surgery among the participants in an intervention providing education and psychosocial support following genetic testing. Karp et al. (1999) found that participants in a 1-year follow-up reported gaining new perspectives and a realisation of the seriousness and complexity of their situation, as well as feeling more confident in their decisions from participating in a support group for women at high risk of developing breast cancer considering prophylactic mastectomy.

To offer women at high risk of breast cancer support to decide whether to accept prophylactic mastectomy or not, the author group, consisting of nurses, surgeons and psychologists, wished to develop a patient education day at the hospital.

Since research suggests that an inductive approach from the women's own perspectives may enlighten processes important for the women's decisions and offer new potential approaches to prophylactic treatment (Padamsee et al., 2017), we decided to co-design the patient education day (Voorberg et al., 2014). Co-design is a participatory approach in which the creativity and knowledge of the health care professionals and the affected women are brought together in the design development process (Jessup et al., 2018; Sanders & Stappers, 2008). In this qualitative study the co-design consisted of a user panel and focus interviews. A user panel is a group interview, in which the participants inspire each other to identify themes for the following interview (Center for Patientinddragelse [CPI], 2022). By engaging patients in the user panel, we could draw on both the patients and health care professionals' experiences in the development of the interview guide for the focus interviews.

The objective of this study is to gain knowledge of the acceptability and requests for content of a patient education day at a Danish hospital for women at high risk of breast cancer considering a prophylactic mastectomy. This knowledge will inform the development of a co-designed patient education day aiming to support women in the decision of whether to receive a prophylactic mastectomy.

The research question of this study is:

- What is the acceptability and what are the requests for content of a group education day among women at high risk of breast cancer considering a prophylactic mastectomy?

## 2 | METHODS

To gain knowledge of the women's acceptability and requests for content of a patient education day in a co-design, we conducted two semi-structured focus interviews with a phenomenological approach.

The research team consisted of one consultant (MD), one surgeon, two nurses and three psychologists (one MD, one PhD). All were female. All three psychologists were occupied by research in health psychology. One had experiences with working with breast cancer patients and their families. The consultant, surgeon and nurses were working in the outpatient clinic with the treatment of the participating women.

Two former and two present patients were invited to a user panel with the four staff members from the outpatient clinic to develop an interview guide for two focus interviews. In the selection of participants for the user panel, we attached importance to the patients' cognitive and communicative competencies and the staffs' interest in and knowledge about the group of patients. All participants for the user panel and focus interviews were recruited face to face by convenience sampling when seen by the consultant in the outpatient clinic.

Two groups of women were invited for the focus interviews: (1) women considering a prophylactic mastectomy (non-operative group: N1–N5) and (2) women who had received prophylactic mastectomy (post-operative group: P1–P5). Twelve women were invited, whereof two declined. The interviews were conducted in the outpatient clinic by the user panel and lasted for approximately 1 h each and were audio recorded and transcribed verbatim. Transcripts were not returned to the women for corrections or comments. The two groups were chosen to provide knowledge of the requests of women considering surgery and retrospective experiences from women who had received surgery.

Focus interviews were chosen to facilitate social interaction, comparison of experiences, individual understandings and freedom of speech among the participants (Halkier, 2020). Thus, the setting of a focus interview assimilated the situation of a patient education day. This gave the participants an experience of talking to equals about their predisposition (to breast cancer) and the interviewees an impression of the dynamics this facilitated. Identical interview guides with open questions (e.g., 'How does the optimal education day look from your perspective?', 'What is essential to know concerning check-ups versus surgery?') were used in the two groups, aiming for an explorative study (see Appendix A).

The three psychologists, who did not take part in the focus interviews, analysed data with an inductive descriptive approach (Thorne et al., 1997). A thematic analysis was used to identify common themes in the interviews (Braun & Clarke, 2006). Braun and Clarke's (2006) six phases of conducting a thematic analysis were followed: After having read through the data material several times (1), one psychologist generated initial codes (2) and searched for common themes (3), resulting in nine initial themes. Hereafter, the data set was reviewed to modify the themes and secure that they were in line with the data. Further data extracts fitting into the themes were searched for, and the themes were expanded and subsequently reduced by the three in collaboration (4). The four final themes were defined and named (5), and the findings were written up (6) (Braun & Clarke, 2006). The analysis was conducted in Microsoft Word, and no other software was used. No feedback from the participants was requested.

### 3 | FINDINGS

The five participants in the non-operative group (N1–N5) were women aged 25–48 who considered receiving a prophylactic mastectomy. The five participants in the post-operative group (P1–P5) were women aged 28–46 who had received prophylactic mastectomy. All participants had a high risk of breast cancer. Two participants in the post-operative group had suffered from breast cancer, and one participant in the non-operative group had suffered from ovarian cancer (see Table A1).

The analysis resulted in four themes: 'Theme 1: Knowledge about risks and complications', 'Theme 2: Help to share knowledge with important others', 'Theme 3: Knowledge from former patients' and 'Theme 4: Group versus individual session'. In themes with differences between the groups, this is highlighted in the text (see Table A2 for an outline).

#### 3.1 | Theme 1: Knowledge about risks and complications

Knowledge about the course before and after surgery was comforting to the participants. They appreciated to receive a lot of and accurate knowledge in direct contact with a professional, rather than from a leaflet or recorded material. Relevant themes were what to expect of life after surgery, recommendations of exercises for recovery, possible complications and pros and cons of surgery.

To the non-operative participants, the participation of a physiotherapist was valuable, as was an insight in life after surgery, including pictures of reconstructed breasts. The knowledge that the breasts might not look pretty immediately after surgery, but that this will change over time, was important:

N2: If you are only thinking: 'Well, no breasts end up ugly after this [surgery]' [...] then, if you come out, and it bleeds and there's drain, I mean, then you go, 'F\*\*\*! That's not what I ordered!' So, of course, you should not put up the worst-case scenario, but I just do not believe it's of any use to cut out all the ugly stuff.

Hence, the participants preferred not to be withheld potentially frightening knowledge.

The consequences of surgery versus yearly check-ups were important to the post-operative participants:

P4: Have it pitted against each other, so you know the risks of scanning, and if it e.g., will be pointed out: 'well, you cannot breastfeed [after the surgery] [...] and if you would like to have more children, then you should probably wait a while [with having the surgery]. But if you do not care if they are breastfed or given a bottle, well ...' Like, to set it up like that, but let it be your own choice.

Hence, the question about surgery to prevent breast cancer relates not only to the participants' future health and looks but also to their ability to reproduce and breastfeed.

The post-operative participants would have preferred to be informed about the length of the course of surgery. With this preparation, they believed they had experienced less shock and disappointments:

P2: Because I thought 'Cool, now I'm going in to have a new pair of breasts'. And now it's been one year since we started, right? And I still have at least half of a year before I'm done. I wasn't prepared at all that it would be such a lengthy project.

This and the above-mentioned quotations highlight the importance of health care professionals to explain what to expect of the surgery to the women.

### 3.2 | Theme 2: Help to share knowledge with important others

Communication with family members about being at high risk of breast cancer concerned the participants. They expressed a request for support on how to share this knowledge with their close relatives, especially children. Participants in both groups had experiences with family members going through a similar surgery when treated for breast cancer, which made a great impression on them and their children. All tried to involve partners by sharing knowledge with them.

Many of the non-operative participants were considering how to inform children about being at high risk of breast cancer. They were uncertain about how much information their children could handle and worried about causing distress. Experiences regarding family members going through a similar surgery influenced how the participants expected children to react to the surgery:

N4: My mom just had surgery, and she chose to have her breasts completely removed. And it all went really well. But she [my daughter] became so [...] upset, so I dare not think about how she'll react when it's me. And actually, I do not know how to deal with it. [...] I need help with that.

Thus, help with communication was requested.

The participation of a nurse who could inform about practical circumstances about surgery would empower the non-operative participants to inform their relatives. A participant was met with fear by her partner and requested information that could reassure him:

N2: I [...] have a boyfriend who almost believes that I'm close to dying every time I go to the hospital. [...] It would be nice to tell him that when I come back, I'll be hooked up to some drains, and that's not because I

was close to dying at the operating table, but they are supposed to be there.

Information on the surgery can thus be used to comfort relatives. However, the non-operative participants did not wish to bring partners, since they expected the participation of relatives would hinder disclosure:

N2: I would feel really uncomfortable being there if there were other husbands present and we should talk about these things.

Some issues the women were not comfortable discussing in the presence of partners.

The post-operative participants were more open to bring relatives and discerned between content when deciding for or against. They all agreed that it would be very helpful in the part concerning information about surgery and treatment:

P4: They're also left with thoughts and questions that you might not have thought about yourself at all.

Thus, relatives can help ask for elaboration of relevant issues.

The post-operative participants who had not brought relatives to individual meetings at the hospital regretted this. Those who brought relatives considered this a good experience, since the relatives could also help navigate in the information provided which could otherwise be overwhelming.

However, like the non-operative participants, the post-operative participants preferred to participate without relatives in the part of the day that was about socialising and exchanging experiences.

Hence, help with communication with relatives about being at high risk of breast cancer and prophylactic surgery, and the possibility for relatives to participate in the knowledge-part of the education day was requested.

### 3.3 | Theme 3: Knowledge from former patients

Both groups believed that meeting former patients and other women who considered surgery could support their decision making.

Since most of the participants knew of no or few other women at high risk of developing breast cancer, the decision-making process could be rather lonely. To cope with this, they searched for communities with equals on social media. They expressed concerns that knowledge given in these communities could be of varying accuracy. They expected a reasonable and successful case presentation at the hospital to be more trustworthy and considered it helpful to be able to ask questions.

P2: I think it would be a huge advantage, as you have all these questions. And I know there are some health care professionals who can answer [these questions],

but it just is not the same as someone who has actually been through it.

While the participants considered knowledge from a former patient in addition to knowledge from the healthcare professionals useful, they expressed a wish not to be presented to women who received unsuccessful surgery, as they feared that this would sway them to decline surgery.

### 3.4 | Theme 4: Group versus individual session

The groups disagreed on the relevancy of the themes receiving genetic counselling, opportunity to give birth in the future, own feelings and talking to the family about being at high risk of breast cancer on the education day. The non-operative group did not feel comfortable discussing these topics on an education day, while the post-operative group found it highly relevant.

The non-operative participants preferred talking about genetic composition and considerations about reproduction in an individual setting, since they considered these as private matters. Nevertheless, meeting equals at the interview session made the non-operative participants talk about issues they had never put into words before. Hence, the group situation facilitated a talk about topics that were both vulnerable and difficult to talk about elsewhere. The non-operative participants stated the importance of agreeing upon confidentiality and of articulating their differences in the group—that not one surgery fits all. It was important to them that all participants were in the same process of decision making so that they could relate. The non-operative participants who had not suffered from breast cancer were worried about hurting the participants who had suffered from breast cancer with their questions and hence preferred to separate these two groups of participants.

The post-operative participants were generally more open to discuss other issues than surgery, especially emotional and gynaecological issues.

Hence, some themes are vulnerable to discuss on the education day and should be addressed with care.

## 4 | DISCUSSION

In this study, we investigated the acceptability and requests of content of an education day among women at high risk of breast cancer.

The main findings show that knowledge about prophylactic surgery and help on how to share knowledge about being at high risk of breast cancer and the potential prophylactic mastectomy with partners and children was requested. Talking to equals made the decision process less lonely and supported the participants.

Our findings support prior findings showing that the women require extensive knowledge about their status and the prophylactic interventions (Thewes et al., 2003). Theme 1 pointed out the importance of the health care professionals to explain to the women what

to expect of the surgery. In a busy clinic, this can be hastened. The same knowledge is often given to many patients, and time can be saved by giving this knowledge in a group setting (Calzone et al., 2005). In addition, Themes 3 and 4 support prior findings showing that many women at high risk of breast cancer wish for discussions with equals (Thewes et al., 2003). An education day at the hospital can accommodate this and make the decision process about surgery less lonely, threatening and easier to overcome (Heap, 2005; Taylor et al., 1991). However, in Theme 4, we saw that some women may not wish to discuss their own potential surgery in a group setting. This is in line with previous research (Ridge et al., 2009), and we thus suggest the patient education day as a supplement to individual consultations. If knowledge about surgery is given on the education day, this can save time to explaining what to expect of the surgery in the individual consultation. This will also offer the women time to consider their situation, wishes and needs between the education day and a consecutive individual consultation.

Theme 2 indicates an interest in partners participating on the education day. Since prior findings suggest that adequate information heightens partners' ability to support the women and lead to enhanced psychological support and emotional well-being in the couple (Rowland & Metcalfe, 2014), an involvement of partners can support both the partners and the women. We found that some women were more comfortable with group discussions without partners and hence suggest inviting partners for the part of the day concerning knowledge but not the experience-sharing part of the education day. This is to facilitate an open discussion among the women.

Supporting previous research (Metcalfe et al., 2008), Theme 2 also presented a request for counselling on how to inform children about being at high risk of breast cancer and prophylactic surgery. Hence, information from a health care professional about how to share this knowledge with children is relevant.

This qualitative, inductive study from the perspectives of the women themselves has offered an understanding of the participants' acceptability and requests of content of a patient education day. The collaboration between nurses, surgeons and patients in co-designing and conducting the present study ensured the interests and knowledge of all concerned to be put into play. This will likely increase the quality, user acceptance and effectiveness of the patient education day (De Vito Dabbs et al., 2009; Sanders & Stappers, 2008).

The perspectives from the two groups of participants (non-operative and post-operative) gives a valuable insight into what content is relevant during the process of decision and surgery. The non-operative participants contributed with what is requested when deciding whether to go through surgery. The post-operative participants contributed with what they missed during their process of decision and surgery. This combination gives an extensive knowledge about what is relevant content in a patient education day.

The focus interviews facilitated discussions and sharing of opinions among the participants (Hughes & DuMont, 1993). A risk of focus interviews is that they can silence individual voices of dissent (Kitzinger, 1995), which may have happened without the interviewers noticing. Further, the setting in the outpatient clinic may have made

the participants more reserved or disempowered than had the interviews been conducted on neutral ground (Tong et al., 2007). The limited number of participants puts a limitation to the variety of perspectives presented, and using convenience sampling, we may have failed to capture important perspectives from affected women difficult to reach (Elder & Miller, 1995). The interviews were not pilot tested, and repeat interviews were not carried out. Hence, we cannot assure to have reached a saturation of data. However, the broad age span of the participants secures a variety of perspectives and makes them representable of the patient population in the clinic. Feedback on our findings from the participants might have refined or nuanced our results further and ensured that the women's meanings and perspectives were represented (Tong et al., 2007).

In all, our findings add valuable knowledge to the field of support to women at high risk of breast cancer. We have illuminated processes important to the women's decisions about prophylactic mastectomy that are previously unstudied and offered new potential approaches for designing prophylactic-supportive interventions (Padamsee et al., 2017). This will support not only the affected women but also the families surrounding them. Involving patients in the creation of the study secures the content of the study to be relevant to our population. Further focus and individual interviews may help to nuance our findings. The method can be used in other specialties to create valuable and nuanced knowledge on how to support patients.

## 5 | CONCLUSION

In this study, we found that to women at high risk of breast cancer, knowledge about their possibilities of prophylactic interventions, how to share knowledge with partners and children and talking to equals in a safe forum is meaningful content of a patient education day when deciding whether to receive a prophylactic mastectomy or not. An education day is an acceptable format for gaining knowledge about surgery, but since some topics may be vulnerable to discuss in a group setting for some women, we suggest the education day as a valuable supplement to the individual consultations. This study has informed the development of a patient education day at a Danish Hospital.

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### CONFLICT OF INTEREST

We have no conflicts of interest to disclose.

### ANONYMITY STATEMENT

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

### DATA AVAILABILITY STATEMENT

To ensure the anonymity of the participants, research data are not shared.

### ORCID

Anne Katrine Hartmann Søby  <https://orcid.org/0000-0002-1310-0196>

Christina Maar Andersen  <https://orcid.org/0000-0001-8008-6729>

Camilla Bille  <https://orcid.org/0000-0002-7727-462X>

Helle Timm  <https://orcid.org/0000-0003-1388-1794>

Kirsten Kaya Roessler  <https://orcid.org/0000-0001-6605-7999>

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## APPENDIX A: INTERVIEW GUIDE FOR PATIENTS AT HIGH RISK OF DEVELOPING BREAST CANCER (TRANSLATED FROM DANISH)

### Purpose

To qualify education and information for an education day for patients at high risk of developing breast cancer, so the patients feel well-informed and comfortable with deciding on treatment (course).

### Issue

Which factors are essential for patients to have clarified before they make their decision about treatment (course)?

### Procedure

#### Briefing

Purpose of interview and why we record it.

Potential questions from informants before the interview.

Confidentiality and anonymity.

Research questions	Interview questions	Further questions
What do the patients think is essential content on a patient education day?	<p>When being at high risk of developing breast cancer what would be important for you to discuss on an education day?</p> <p>How does the optimal education day look from your perspective?</p> <ul style="list-style-type: none"> <li>- What will it take for you to emerge stronger from there</li> <li>- What should the format be?</li> <li>- What do you think about the variation between information and discussions in workshops?</li> <li>- How many should participate?</li> <li>- Who should participate? Professionals/relatives?</li> <li>- How long should it last?</li> </ul>	<p>What topics?</p> <p>If there was one thing you would like to know more about, what would it be?</p> <p>What should be prioritised—what is the most important to you?</p> <p>Which profit could it yield?</p> <p>And why that number? Pros and cons.</p>
What is relevant for the patient to know before and after surgery?	<p>What is the most important for you to know?</p> <ul style="list-style-type: none"> <li>- Before?</li> <li>- After surgery?</li> </ul> <p>What do you think about seeing photos of other patients—before and after photos?</p> <ul style="list-style-type: none"> <li>- What do you need to know about different surgery techniques/possibilities?</li> <li>- Is it essential for you to know something about complications concerning surgeries?</li> <li>- What do you need to know about check-ups?</li> </ul>	<p>Elaborate</p> <p>What worries you the most?</p> <p>Is there anything you have missed (if you received surgery)?</p> <p>If it is important, then why?</p> <p>If you received surgery?</p> <p>If you did not receive surgery?</p>
How does it impact the patient's life to be at high risk of developing breast cancer?	<p>How does it affect your life and life quality to be at high risk of developing breast cancer?</p> <p>What does it mean for you to know that you ... ?</p> <p>What is essential to know concerning check-ups versus surgery?</p>	<p>Concerning your family?</p> <p>Concerning you, your job and other people?</p> <p>Your self-image, self-worth and self-confidence?</p> <p>What do check-ups mean?</p> <p>How often are you checked?</p>
Can a high-risk patient benefit from a mentee?	<p>Could you imagine benefitting from talking to a fellow patient that had received surgery?</p> <ul style="list-style-type: none"> <li>- What could be the pros and cons?</li> </ul>	<p>In that case:</p> <p>When?</p> <p>Why?</p>
How important is knowledge about genetics to the patient with a high risk of developing breast cancer?	<p>Is it important to raise genetic issues on an education day?</p> <p>What is important in that regard?</p>	<p>Why? Or why not?</p> <p>Risk in general?</p> <p>Ovary/breast cancer?</p> <p>Heredity?</p> <p>Pregnancy?</p>



**TABLE A1** Characteristics of women at high risk of breast cancer in the focus groups

Non-operative group	Post-operative group (had a prophylactic mastectomy)
N1: 46 years old Has suffered from ovarian cancer	P1: 46 years old Has not suffered from cancer
N2: 25 years old Has not suffered from cancer	P2: 44 years old Has not suffered from cancer
N3: 37 years old Has not suffered from cancer	P3: 39 years old Has suffered from breast cancer
N4: 48 years old Has not suffered from cancer	P4: 28 years old Has not suffered from cancer
N5: 27 years old Has not suffered from cancer	P5: 38 years old Has suffered from breast cancer
Patient representative co-interviewer	Patient representative co-interviewer

**TABLE A2** Overview of themes

General assumptions		Non-operative group's assumptions	Post-operative group's assumptions
Theme	Content	Content	Content
Theme 1: Knowledge about risks and complications	All knowledge is valuable. Especially: <ul style="list-style-type: none"> <li>• Pros and cons of surgery</li> <li>• Possible complications</li> <li>• Life after surgery</li> <li>• Accurate and face to face information about the course of surgery ahead of it</li> </ul>	Especially pre–post pictures	Especially knowledge on: <ul style="list-style-type: none"> <li>• Length of course of surgery</li> <li>• Consequences of surgery or yearly check-ups</li> </ul>
Theme 2: Help to share knowledge with important others	Need of help with how and what to tell	Need of help with: <ul style="list-style-type: none"> <li>• How &amp; what to share with children</li> <li>• Pass-on-information about surgery</li> </ul> No wish to bring partners.	Helpful to bring relatives to the information-part of the patient education day
Theme 3: Knowledge from former patients	Meeting others in the same situation could be supportive. Preference for presentation of a woman who received a successful prophylactic mastectomy.		
Theme 4: Discussion of sensitive topics	Sensitive topics: <ul style="list-style-type: none"> <li>• Genetic counselling</li> <li>• Talking to family about being at high risk</li> <li>• Opportunity to give birth in future</li> <li>• Own feelings</li> </ul>	Genetics, future children and partners are private issues.	Open to discuss matters not related to surgery.

*Debriefing*

Summary of main points that have emerged.

Ask informants if there is more to add before ending.

Thank you for participation.