

Table 1: Characteristics of the focus group participants

Criterion	Target group	
	Previvors	Survivors
Total number (n)	9	10
Medium age [range] (years)	41,1 [27-53]	45,6 [27-56]
Gene test result		
<i>BRCA1</i> mutation (n)	6	8
<i>BRCA2</i> mutation (n)	3	1
<i>BRCA1 and BRCA2</i> mutation (n)	0	1
Genetic test result received [range] (months ago)	7,5 [4-15]	30 [4-156]
History of breast cancer		
Individuals with one breast cancer (n)	not applicable	5
Individuals with more than one breast cancer (n)	not applicable	5
Therapeutic surgery: breast-conserving (n of breasts)	not applicable	10
Therapeutic surgery: mastectomy (n of breasts)	not applicable	4
Therapeutic surgery: not specified (n of breasts)	not applicable	1
Preventive measures taken - breast cancer		
Intensified breast cancer screening (n)	3	3
Risk-reducing mastectomy (n)	4	4
- With breast reconstruction (n)	4	4
- Without breast reconstruction (n)	0	0
Preventive measures planned - breast cancer		
Intensified breast cancer screening (n)	2	1
Risk-reducing mastectomy definitely planned (n)	0	0
Considering risk-reducing mastectomy (n)	3	1
Definitely no risk-reducing mastectomy (n)	2	0
Preventive measures taken - ovarian cancer		
Risk-reducing bilateral salpingo-oophorectomy (n)	4	6
Preventive measures planned - ovarian cancer		
Risk-reducing bilateral salpingo-oophorectomy definitely planned (n)	3	2
Considering risk-reducing salpingo-oophorectomy (n)	0	1
Other		
Currently no further planning (n)	1	1
Planning not specified / not applicable (n)	1	3
Family history of breast and/or ovarian cancer		
Yes (n)	9	4
No (n)	0	3
Not specified / not applicable (n)	0	3
Family planning		
Completed / has own children (n)	7	not specified
Not completed / has childbearing preferences (n)	2	not specified

Table 2: Basic results of the focus group discussions with previvors and survivors

Focus group discussions	Topic	Basic results
With previvors (n=9)	General impression	<ul style="list-style-type: none"> • Highly positive to the DA overall. • High, but suitable level, most of the information is well explained and comprehensible.
	Beneficial aspects	<ul style="list-style-type: none"> • Information in detail compiled in one medium, of a suitable level; makes it possible to delve deeper into certain topics. • Detailed information especially on mutations, risks, risk-reducing breast surgery. • Integrated overview tables and fact boxes. • Worksheets for comparing the options and establishing values. • Integrated glossary.
	Aspects to add, delete, or change	<ul style="list-style-type: none"> • To clarify that the mutation should be acknowledged a stress factor, even though not having cancer. • To address positive and negative consequences of the options. • To change the sections for clarifying values in the worksheets from box ticking to free-form notes to formulate own thoughts. • To present personal testimonies.¹ • To integrate photos of genuine breast surgery results.²
	Specific needs	<ul style="list-style-type: none"> • More information on the consequences of risk-reducing salpingo-oophorectomy (e.g. loss of fertility, hormone replacement therapy, adverse effects). • More information on the various procedures for risk-reducing breast surgeries and the procedure following the operation (e.g. stay in the clinic, duration of recovery). • More psychological aspects.
With survivors (n=10)	General impression	<ul style="list-style-type: none"> • Positive response to the DA overall.
	Beneficial aspects	<ul style="list-style-type: none"> • Information in detail compiled in one medium; makes it possible to delve deeper into certain topics. • Comprehensive information, especially on breast surgery and reconstruction. • Worksheets for comparing the options and establishing values.
	Aspects to add, delete, or change	<ul style="list-style-type: none"> • To make certain sections more precise and comprehensible. • To handle breast cancer self-examination as an important topic. • To change the sections for clarifying values in the worksheets from box ticking to free-form notes to formulate own thoughts. • To integrate summary boxes at the end of each chapter. • To integrate photos of genuine breast surgery results.²
	Specific needs	<ul style="list-style-type: none"> • More information on the first breast cancer on the already affected side: biochemical parameters, therapy of the first breast cancer including surgery, radiotherapy, medical therapy (anti-hormonal, anti-growth receptor, chemotherapy), risk of recurrence on the affected side. • More information on the procedure following the various breast surgeries (e.g. stay in the clinic, duration of recovery), breast reconstruction, and symmetry following contralateral mastectomy of the opposite side. • More information on the consequences of risk-reducing salpingo-oophorectomy. • More information on the intensified breast screening and aftercare programme.

¹Personal testimonies were not included due to the lack of evidence for their benefits and their potential to cloud a person's judgement [66]. ²Photos of genuine breast surgery results were not provided for liability reasons.