MASTER THESIS

Factors related to women's recurrence risk perceptions after treatment for invasive breast cancer and the influence of these recurrence risk perceptions on worries and self-examination behavior

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# UNIVERSITY OF TWENTE.

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### Abstract

#### Background

The burden of follow-up care after breast cancer is rising due to improved survival rates. Follow-up care of breast cancer consists of after care and post-treatment surveillance. Even though factors influencing the risk for recurrences are known, post-treatment surveillance is the same for all patients. There is a growing demand for personalized post-treatment surveillance, which could be guided by implementation of the INFLUENCE nomogram that estimates patients' recurrence risk and can aid clinical decision-making. Adequate communication between healthcare professionals and patients about their recurrence risk is vital for patients to understand their personal risk and make informed decisions. Although the best way to communicate a patient's recurrence risk is unknown, different recurrence risk types might influence how individuals perceive and use it. There is a growing need to improve women's understanding of their recurrence risk. This paper aims to get an insight in the specific factors underlying recurrence risk perception types and the influence of these perceptions on worries and self-examination behavior.

### Method

For this study, a subset of baseline data collected in the SHOUT-BC study was used. In the SHOUT-BC study, women participated who faced the decision for post-treatment surveillance about one year after treatment. Data was collected by means of online questionnaires. The measures included women's recurrence risk perception types (absolute risk, risk appraisal, and comparative risk), cure beliefs, personal control over recurrence, cancer worry, worry about post-treatment diagnostic test results, nervousness prior to appointments or examinations, breast self-examination, and demographic characteristics. Regression models with odds ratios and 95% confidence intervals were developed to detect factors associated with the different recurrence risk perceptions and determine the influence of these perceptions on worries and self-examination behavior.

#### Results

Among 245 women, 52.5% estimated their risk of recurrence reasonably accurate. Most women had high levels of cancer worry (73.9%), were sometimes nervous prior to appointments or examinations (38.4%), worried about post-treatment diagnostic test results sometimes (52.2%) and examined their breasts sometimes (49.0%). Women who had stronger beliefs about their breast cancer being cured were more likely to report low absolute and comparative recurrence risk estimates (OR = 0.91, 95% CI = 0.84-0.99; OR = 0.83, 95% CI = 0.79-0.91, respectively). Occupationally disabled women were more likely to appraise their recurrence risk high than women who have a paid job (OR = 9.10, 95% CI = 1.43-57.7, p = 0.02). Women who appraised their recurrence risk higher: had higher levels of cancer worry (OR = 2.21, 95% CI = 1.40-3.48), worried more often about post-treatment diagnostic test results (OR = 1.80, 95% CI = 1.25-2.61), and examined their breasts more often (OR = 1.55, 95% CI = 1.09-2.22).

### Conclusions

Higher perceived recurrence risk was related to higher levels of cancer worry, more worry about post-treatment diagnostic test results, and more frequent breast self-examination. Considering that the recurrence risk appraisal was most predictive of worries and self-examination behavior and that the absolute risk and risk appraisal were not strongly related, our study recommends using not only absolute risks but also the recurrence risk appraisal (terms of high and low), when communicating recurrence risks with patients. In addition, we suggest presenting women their comparative risk so that they understand why they receive more or fewer surveillances than others. It may be helpful to assist survivors in accessing appropriate and available support for their cancer worry. The findings of this study can be used to develop interventions aimed at effective recurrence risk communication while using the INFLUENCE nomogram, so that patients better comprehend their recurrence risk and can make an informed shared decision regarding personalized post-treatment surveillance.

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### Introduction

In the Netherlands, the incidence rate of invasive breast cancer has almost doubled since 1989 and appears to be leveling off in recent years to 15,000 diagnoses per year (1). Survival rates have improved due to increased early detection and improved treatment modalities (2-4). Consequently, the prevalence and the number of breast cancer patients receiving follow-up care after curative treatment have increased (5). Follow-up care for breast cancer consists of aftercare and post-treatment surveillance (6). Aftercare consists of providing information and support for psychosocial complaints and detecting and guiding the direct or late consequences of the breast cancer after treatment. Post-treatment surveillance includes imaging and physical examinations with the purpose of early detecting locoregional recurrences (LRR) and second primary breast cancer (SPBC) to improve survival (7). Detection of distant metastasis is no primary aim of post-treatment surveillance because an early treatment start does not prolong survival (6, 8).

Approximately 4% of the women treated for invasive breast cancer will develop LRR and 5% will be diagnosed with SPBC within 10 years after primary diagnosis (9). The risk of developing LRR or SPBC is influenced by several factors including age, tumor size, histological grade, vascular invasion, multifocality, hormone receptor status, surgery type, and treatment of the primary tumor (5). Although the risk factors are known, all breast cancer survivors are followed clinically for imaging and physical examinations at least five years after treatment in the Netherlands (6). Research showed that many recurrences are detected by women themselves in between surveillance visits or after the follow-up period (10). Surveillance visits can provide reassurance, but they can also cause anxiety in patients (11). Additionally, false-positive tests and subsequent invasive biopsies create unnecessary costs and disutility (9, 12). These limitations, together with the increasing number of breast cancer survivors, may cause a shortage in healthcare capacity. Hence, there is a growing demand for personalized post-treatment surveillance based on the individual risk of recurrence, to optimize the provision of care in the context of scarce resources (13, 14). Personalized post-treatment surveillance could be guided by implementation and continuous development of the INFLUENCE nomogram, which estimates patients' recurrence risk and can aid clinical decision making (5, 13, 15).

To get towards high-quality personalized post-treatment surveillance, patients should be included in the decision-making process (13, 14). Shared decision-making about surveillance is only effective if patients understand their recurrence risk (5, 16, 17). However, risk communication can be challenging, especially for women with lower health literacy, lower numeracy skills, or anxiety (17, 18). Healthcare professionals can use different methods to communicate risks, for example by using words or numbers, and showing graphs. Although the best way to communicate results of the nomogram is unknown, it is important to consider that the way in which information is presented or framed by healthcare professionals influences how individuals perceive and use it (19, 20). For example, providing information as comparative risk measure (i.e., personal risk compared to other patients) appeared to lead to more risk-avoidant behavior than providing information in an absolute incidence rate form (19). Nevertheless, women's misunderstanding of their recurrence risk may have consequences for decision-making about surveillance and can affect worries and behaviors (21-23). Overestimation of the recurrence risk has been associated with anxiety, cancer worry, and hypervigilance about symptoms leading to a worse quality of life (24, 25). Moreover, it might influence patient's preferences for more extensive treatment or post-treatment surveillance than necessary (26, 27). On the other hand, underestimation could result in less adherence to posttreatment imaging and physical examinations, resulting in underdiagnoses of cancer recurrences (17, 28, 29). Either way, adequate communication between healthcare professionals and patients about

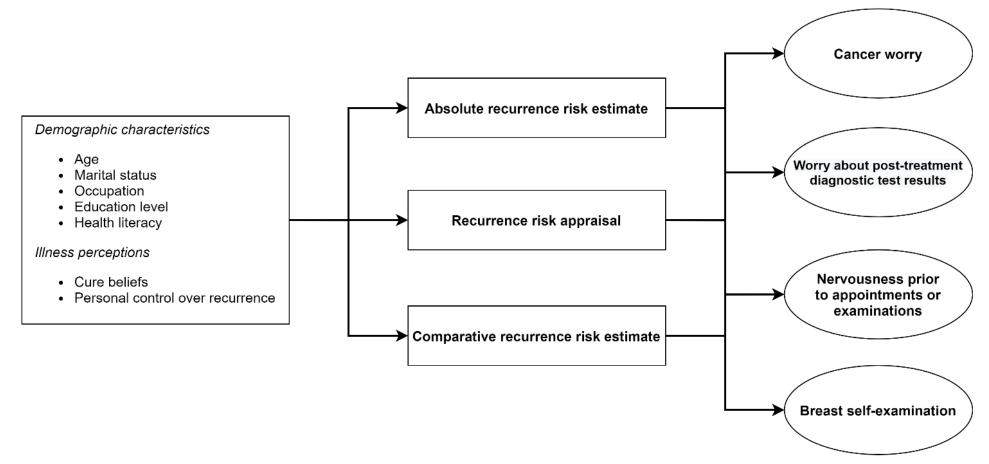
their recurrence risk is vital for patients to understand their risk and make informed decisions together with their healthcare professionals (17, 30).

Several studies sought to find out how women shape their recurrence risk perceptions to provide a foundation for effective interventions to improve risk communication. Perceived recurrence risk was associated with anxiety, health literacy, fear of recurrence, personal control perceptions, and social support (24, 25, 31-36). However, most studies included women with ductal carcinoma in situ (DCIS) in their study population and there may be differences in risk perceptions between women with DCIS and invasive breast cancer, because invasive breast cancer is a more serious disease than DCIS. Besides, some studies defined recurrence as either LRR, SPBC, or metastases, while post-treatment surveillance is mainly focused on detecting LRR and SPBC (22, 25, 31-33, 36). Contradictory findings were found regarding the risk estimates of women and studies operationalized recurrence risks in different ways, yet it is unknown which type is most effective for risk communication and which risk is the best predictor of worries and behavior. Because there are different methods of operationalizing and communicating recurrence risks, it is important to investigate the influence that different framing types might have on the patient (37).

There is an urgent need for adequate recurrence risk communication to support implementation of personalized post-treatment surveillance. Insight into the specific factors underlying different recurrence risk perception types and the influence of these perceptions on worries and self-examination behavior is critical to the development of interventions that improve women's understanding. Therefore, the first objective of this study is to detect factors affecting different types of recurrence risk perceptions (absolute risk, risk appraisal, and comparative risk). Secondly, this study aims to determine the influence of these different recurrence risk perceptions on cancer worry, worry about post-treatment diagnostic test results, nervousness prior to appointments or examinations, and breast self-examination.

### Conceptual framework

Based on literature research, a conceptual framework has been developed (Figure 1). Age, marital status, occupation, education level, and health literacy will be included as demographic characteristics and cure beliefs and personal control over recurrence as illness perceptions. We expect that age, health literacy, cure beliefs, and personal control over recurrence affect women's recurrence risk perceptions. We will measure the recurrence risk perception of women using three recurrence risk types: absolute recurrence risk (expressed in odds like '1 in 1000' and '1 in 5'), recurrence risk appraisal (expressed in terms of low and high), and comparative recurrence risk (expressed in terms of lower, higher or the same as other breast cancer survivors). We anticipate that older women perceive the recurrence risk types lower than younger women, because young women are at increased risk of recurrence (12). Another expectation, based on literature research, is that women with lower health literacy perceive the recurrence risks higher. Furthermore, we expect that women who believe that their breast cancer is cured, and women who think that their actions have control over the breast cancer recurring, perceive their recurrence risks lower. Marital status, occupation, and education level will be included as control variables. Regarding our second objective, we anticipate that women who perceive their recurrence risks higher to: have higher levels of cancer worry (i.e., fear of recurrence), worry more about post-treatment diagnostic test results (for instance mammogram, MRI, and ultrasound), be more nervous prior to appointments or examinations, and be more inclined to self-examine their breasts to look for physical signs of cancer.



*Figure 1* Conceptual framework showing the relationships between demographic characteristics, illness perceptions, recurrence risk perception types, and worries and self-examination behavior

### Methods

### Study population

This study used a subset of the baseline data of the SHOUT-BC study (SHared decision-making supported by OUTcome information regarding Breast Cancer follow-up). The SHOUT-BC study started in November 2019 and investigates the implementation and effects of shared decision-making supported by outcome data about personalized post-treatment surveillance. Women aged 18 years or older and facing the decision for the organization of post-treatment surveillance after receiving treatment for invasive breast cancer in a Santeon<sup>1</sup> hospital were eligible for participation. Informed consent, access to and experience with electronic devices with an internet connection, and an ability to understand the Dutch language in speech and writing were required for participation. Male breast cancer patients were excluded from this study. Further, women were excluded if they were diagnosed with non-invasive breast cancer (DCIS), received palliative treatment, received neoadjuvant therapy, developed recurrence, or had dementia.

### Data collection

Women attending a Santeon hospital for their first surveillance consultation about one year after surgery were informed about participating in the study by their healthcare professional. Participants received information about the study, both verbally and in writing. All materials were sent in Dutch. Participation was voluntary and the participants were informed that they could withdraw from participation at any time without stating any reason. Eligible individuals were asked to provide written consent. Women received an online questionnaire directly after the consultation, in which the decision for the organization of post-treatment surveillance was made by the patient and their healthcare professional. Only participants who completed the questionnaire fully during the period of November 2019 to February 2021 were included in this study. The study was approved by every medical ethical commission of each participating Santeon hospital.

### Questionnaire design

The questionnaire consisted of validated measures when available and, when necessary, new measures where developed. The original questionnaire was divided into several sections of which illness representations and concerns, perceived risk of recurrence, and demographic characteristics were used in this sub-study. The exact wording of the questions and answering options can be found in Appendix A and measures specific to this sub-study are listed below.

### Measures

**Health literacy** was assessed with the Set of Brief Screening Questions (SBSQ) (38). The SBSQ consists of three statements on a five-point Likert scale. Two items had a scale ranging from never to always and one question had a scale ranging from not at all to extremely. The answers were added and averaged to create one score. A score of two or higher indicated adequate health literacy. For the assessment of **illness perceptions** two domains of the Revised Illness Perceptions Questionnaire for breast cancer survivors (IPQ-BCS) were used (39). The two domains consist of eight questions, four about **cure beliefs** (i.e., whether women believe that their breast cancer is cured) and four about **personal control over recurrence** (i.e., whether women think that they have control over the cancer recurring). All questions were measured on a five-point Likert scale ranging from strongly disagree to strongly agree. Scores were calculated separately for each domain by adding up the answers, after

<sup>&</sup>lt;sup>1</sup> Santeon is a cooperative association of seven Dutch teaching hospitals

reversing the scores on three items. Total scores ranged from 0 to 16, with higher scores indicating that women had stronger beliefs that their breast cancer is cured, or that they thought their actions had an effect on the breast cancer recurring. The questionnaire also collected demographic characteristics including age, marital status, occupation, and education level.

#### Recurrence risk perception types

Recurrence risk perceptions were assessed using a self-administered three-item questionnaire including two questions regarding perceived personal risk, and one item assessing comparative risk. We defined recurrence as LRR or SPBC. The first item measured the **absolute recurrence risk estimate** by asking *"How high do you estimate your risk of breast cancer recurrence in the same or the other breast?"*. Participants were asked to choose one of the following odds: 1 in 1000, 1 in 100, 1 in 50, 1 in 25, 1 in 10, or 1 in 5. We considered 1 in 1000 as underestimation, 1 in 10, and 1 in 5 as overestimation, and the other odds as reasonably accurate estimation. The next item measured the *recurrence risk appraisal* by asking *"How do you rate your risk of breast cancer recurrence in the same or the other breast?"*. Participants were asked to appraise their risk of breast cancer recurrence in the same or the other breast?". Participants were asked to appraise their risk of breast cancer recurrence in the same or the other breast?". Participants were asked to appraise their risk of breast cancer recurrence in the same or the other breast?". Participants were asked to appraise their risk of breast cancer recurrence on a five-point Likert scale ranging from very low to very high. The comparative recurrence risk estimate was measured by asking *"How do you rate your personal risk of breast cancer recurrence, compared to the average risk of women who have had breast cancer?"*. The comparative risk was assessed on a five-point Likert scale ranging from much lower to much higher.

#### Worries and self-examination behavior

Cancer worry was measured with the six-item Cancer Worry Scale (CWS) which is an appropriate instrument to detect fear of recurrence in breast cancer survivors (40). An example of one of the items is "How often have you thought about your own chances of developing breast cancer?". All items were scored on a four-point Likert scale ranging from never to almost always. Total scores ranged from 6 to 24 with higher scores indicating more cancer worry (i.e., fear of recurrence). Scores of 12 or higher indicate that patients had high levels of cancer worry (40). Worry about posttreatment diagnostic test results was measured with one item of the Cancer-Related Health Worries Scale (CRHWS) (41). The statement "I worry about the results of diagnostic tests (for instance the mammogram, MRI, and ultrasound) that will be performed during post-treatment surveillance", was measured on a five-point Likert scale ranging from not at all to all the time. Nervousness prior to appointments or examinations was measured with one item of the Fear of Progression Questionnaire (FoP-Q) (42). The statement "I am nervous prior to doctor's appointments or examinations", was measured on a five-point Likert scale ranging from not at all to all the time. Breast self-examination was measured with one item of the Fear of Cancer Recurrence (FCR7) questionnaire (43). The statement "I examine my body for signs of cancer", was measured on a fivepoint Likert scale ranging from not at all to all the time.

### Data analysis

Patients who failed to complete the questionnaire were excluded from the data analysis. Descriptive statistics were used to characterize the participants according to age, marital status, occupation, education level, and health literacy. We performed univariate analysis to identify whether demographic and illness perceptions were associated with women's absolute recurrence risk estimate, recurrence risk appraisal, and comparative recurrence risk estimate. Stepwise ordinal logistic regression analyses were employed to determine which recurrence risk perception (absolute risk, risk appraisal, or comparative risk) could be best predicted. Preliminary analyses were conducted to ensure no violation of assumptions of multicollinearity and proportional odds. All variables were entered in blocks, one representing the demographic characteristics (initial model)

and one representing the illness perceptions (final model). Odds ratios (OR) and 95% confidence intervals (CI) were reported, with *p*-values  $\leq$  0.05 considered statistically significant. Nagelkerke's *R*-square ( $R^2$ ) was calculated to determine the proportion of variance explained by the regression models.

We explored correlations between worries and self-examination behavior. Next, univariate analysis was performed to ascertain associations between the recurrence risk perceptions and cancer worry, worry about post-treatment diagnostic test results, nervousness prior to appointments or examination, and breast self-examination, and to determine which recurrence risk perception was most predictive of worries and self-examination behavior. Then, we developed multivariable logistic regression models to determine whether worries and self-examination behavior were influenced by the recurrence risk perception types. A binary logistic regression model was developed for cancer worry whereas ordinal logistic regression models were developed for worry about post-treatment diagnostic test results, nervousness prior to appointments or examinations, and breast self-examination. Preliminary analyses were conducted to ensure no violation of assumptions of multicollinearity, linearity (in binary logistic regression), and proportional odds (in ordinal logistic regression). ORs with 95% CI and Nagelkerke's *R*<sup>2</sup> were reported for all models.

All statistical analyses were performed using IBM SPSS Statistics (version 27).

### Results

### Sample description

Overall, 245 of 266 participants (92.1%) fully completed the SHOUT-BC baseline questionnaire. Table 1 shows demographic characteristics of the study cohort. The mean age of the participants was 61.8 (SD = 10.1). Most reported being married or having a partner (74.7%) and having a paid job (44.5%). Further, the level of education among the participants was fairly even distributed in low (36.3%), moderate (26.5%), and high (37.1%). The mean health literacy of the participants was 3.59 (SD = 0.5), and almost all women (99.2%) had adequate health literacy (scores of two or higher).

Characteristic	Ν	%	Mean (SD)	Min-max
Age			61.8 (10.1)	31-85
Marital status				
Divorced	12	4.9		
Widowed	22	9.0		
Single	28	11.4		
Married/partnered	183	74.7		
Occupation				
Study	1	0.4		
Occupationally disabled	4	1.6		
Voluntary work	8	3.3		
Home management	50	20.4		
Retired	73	29.8		
Paid job	109	44.5		
Education level				
Low	89	36.3		
Moderate	65	26.5		
High	91	37.1		
Health literacy			3.59 (0.5)	1-4

 Table 1 Demographic characteristics of the study cohort (N = 245)

SD = standard deviation

### Illness perceptions

Approximately 42% of the women believed that their breast cancer is cured (scores of 12 or higher). A minority of the participants (13.9%) believed that their actions have an effect on the breast cancer recurring (scores of 12 or higher).

### *Recurrence risk perception types*

Table 2 provides an overview of women's answers on the recurrence risk types. Concerning the **absolute recurrence risk estimate**, 34.3% of the participants underestimated their risk of recurrence (1 in 1000), 13.5% overestimated (1 in 10 or 1 in 5), and 52.5% estimated reasonably accurate (1 in 100, 1 in 50 or 1 in 25). With regard to the **recurrence risk appraisal**, most women (46.5%) assessed their recurrence risk as not low and not high, about 40% considered it as (very) low, and about 10% considered it as (very) high. The majority (56.7%) assessed their **comparative recurrence risk** comparable to other women treated for invasive breast cancer. Of the remaining women, about half considered their own risk as higher, and the other half considered their own risk as lower than that of other women.

Recurrence risk perception type	Ν	%
Absolute recurrence risk estimate		
1 in 1000	84	34.3
1 in 100	74	30.2
1 in 50	40	16.3
1 in 25	14	5.7
1 in 10	24	9.8
1 in 5	9	3.7
Recurrence risk appraisal		
Very low	32	13.1
Low	72	29.4
Not low/not high	114	46.5
High	25	10.2
Very high	2	0.8
Comparative recurrence risk estimate		
Much lower	15	6.1
Lower	38	15.5
The same	139	56.7
Higher	52	21.2
Much higher	1	0.4

**Table 2** Recurrence risk perception types of the study cohort (N = 245)

We developed cross-tabulations and scatterplots of the recurrence risk perception types to explore the consistency. Appendix B provides an overview of these cross-tabulations and scatterplots. As can be seen from Figure 2, women have different conceptions of what is a low and high risk. Some women estimated their risk 1 in 100 and appraised it as very low, while others appraised it as high. Moreover, some women estimated their risk 1 in 5 and appraised it as very high or high, while others appraised it as very low or low. These results indicate that the absolute recurrence risk estimate and recurrence risk appraisal were not strongly related.

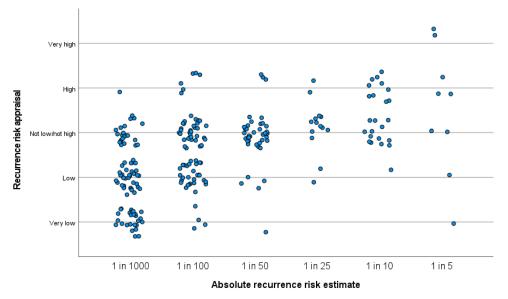


Figure 2 Scatterplot of recurrence risk appraisal and absolute recurrence risk estimate

#### Worries and self-examination behavior

Table 3 provides an overview of women's worries and self-examination behavior. The majority of the participants (73.9%) had high levels of cancer worry. Most women (52.2%) worried sometimes about the results of post-treatment diagnostic tests. Moreover, 38.4% responded that they were nervous prior to appointments or examinations sometimes. As can be seen from the table, 49% of the women sometimes examined their breasts and 2.9% did this excessively (i.e., all the time).

A strong positive correlation was observed between worry about post-treatment diagnostic test results and nervousness prior to appointments or examinations (r = 0.70, p < 0.01). Moderate positive correlations were observed between worry about post-treatment diagnostic test results and cancer worry (r = 0.51, p < 0.01), and nervousness prior to appointments or examinations and cancer worry (r = 0.50, p < 0.01). Besides, weak correlations were observed between cancer worry and breast self-examination (r = 0.27, p < 0.01), worry about post-treatment diagnostic test results and breast self-examination (r = 0.16, p < 0.05), and nervousness prior appointments or examinations and breast self-examination (r = 0.17, p < 0.01).

Worry or self-examination behavior	Ν	%
Cancer worry		
Low levels (<12)	64	26.1
High levels (≥12)	181	73.9
Worry about post-treatment diagnostic test results		
Not at all	12	4.9
Rarely	54	22.0
Sometimes	128	52.2
Regularly	44	18.0
All the time	7	2.9
Nervousness prior to appointments or examinations		
Not at all	29	11.8
Rarely	49	20.0
Sometimes	94	38.4
Regularly	53	21.6
All the time	20	8.2
Breast self-examination		
Not at all	19	7.8
Rarely	34	13.9
Sometimes	120	49.0
Regularly	65	26.5
All the time	7	2.9

 Table 3 Worries and self-examination behavior of the study cohort (N = 245)

### Factors affecting women's recurrence risk perceptions

Univariate analysis was conducted to examine the associations between the person-related background variables (demographics and illness perceptions) and the recurrence risk perception types. Table 4 shows odds ratio (OR) estimates from this analysis. Cure beliefs were associated with all three recurrence risk perception types. Besides, an association between health literacy and the absolute recurrence risk was revealed. Women who are occupationally disabled were more likely to appraise their recurrence risk high than women with a paid job. And widowed women assessed their comparative recurrence risk lower than women who are married or live together.

		Absolute R	R		RR appraisa		C	omparative	RR
	OR	95% CI	р	OR	95% CI	р	OR	95% CI	р
Age	0.99	0.97 - 1.01	0.31	0.99	0.97 - 1.02	0.52	0.98	0.96 - 1.01	0.16
Marital status [Divorced]	2.37	0.84 - 6.63	0.10	1.01	0.34 - 3.01	0.99	1.40	0.49 - 4.01	0.53
Marital status [Widowed]	1.11	0.51 - 2.40	0.79	0.53	0.25 - 1.13	0.10	0.43	0.19 - 0.99	0.05
Marital status [Single]	0.99	0.49 - 2.00	0.98	0.59	0.28 - 1.23	0.16	0.83	0.38 - 1.80	0.63
Marital status [Married/partnered]	1			1			1		
Occupation [Study]	0.00	-	1.00	2.89	0.10 - 81.2	0.53	0.88	0.03 - 26.2	0.94
Occupation [Occupationally disabled]	2.48	0.48 - 12.9	0.28	10.2	1.66 - 62.6	0.01	2.16	0.28 - 16.8	0.46
Occupation [Voluntary work]	0.85	0.21 - 3.40	0.81	2.02	0.45 - 8.94	0.36	0.59	0.15 - 2.32	0.45
Occupation [Home managment]	0.82	0.45 - 1.51	0.52	1.50	0.81 - 2.80	0.20	0.88	0.47 - 1.66	0.70
Occupation [Retired]	0.74	0.43 - 1.26	0.26	0.98	0.57 - 1.70	0.95	0.73	0.41 - 1.30	0.29
Occupation [Paid job]	1			1			1		
Education level [Low]	1.14	0.67 - 1.95	0.63	1.35	0.78 - 2.31	0.28	0.73	0.42 - 1.30	0.28
Education level [Moderate]	1.01	0.58 - 1.77	0.98	1.60	0.88 - 2.90	0.12	1.25	0.68 - 2.30	0.47
Education level [High]	1			1			1		
Health literacy	0.62	0.39 - 0.96	0.03	0.72	0.45 - 1.15	0.16	0.80	0.49 - 1.29	0.36
Cure beliefs	0.92	0.86 - 1.00	0.04	0.92	0.85 - 1.00	0.05	0.84	0.78 - 0.92	0.00
Personal control over recurrence	1.06	0.99 - 1.13	0.10	1.01	0.95 - 1.08	0.72	0.97	0.91 - 1.04	0.37

Table 4 Univariate analysis of the effect of demographics and illness perceptions on the recurrence risk perceptions

RR = recurrence risk

We performed stepwise logistic regression for each recurrence risk perception type (Table 5). Table 5 indicates that the demographic characteristics accounted for 5-7% of the variance in the recurrence risk perception types. When illness perceptions were added, the model explained 8%, 9%, and 13% of the variance in absolute recurrence risk, recurrence risk appraisal, and comparative recurrence risk, respectively. These findings show that based on demographics the recurrence risk appraisal could be best predicted, whereas based on demographic and illness perceptions the comparative recurrence risk could be best predicted. Initially, health literacy was associated with the absolute recurrence risk estimate (OR = 0.60, 95% CI = 0.37-0.98, p = 0.04), but it did not retain its significance in the final model. In the final regression models, cure beliefs appeared to be related to the absolute and comparative recurrence risk estimate. Women who had stronger beliefs that their breast cancer is cured were more likely to report low absolute recurrence risk estimates (OR = 0.91, 95% CI = 0.84-0.99, p = 0.02), and comparative recurrence risk estimates (OR = 0.83, 95% CI = 0.79-0.91, p < 0.01). Additionally, women who are occupationally disabled were more likely to appraise their recurrence risk high than women who have a paid job (OR = 9.10, 95% CI = 1.43-57.7, p = 0.02).

**Table 5** Stepwise logistic regression analysis of the effect of demographics and illness perceptions on the recurrence riskperceptions

	Initial ma	Initial model		nodel	1	Initial mod	el		Final mode	1	Initial model				Final mode	el
	Absolute	RR	Absol	ute RR		RR apprais	al	RR appraisal		с	Comparative RR			omparative	e RR	
	OR 95% CI	р	OR 95%	CI p	OR	95% CI	р	OR	95% CI	р	OR	95% CI	р	OR	95% CI	р
Age	0.99 0.96-1.0	2 0.52	0.99 0.96	1.02 0.53	0.99	0.96-1.03	0.72	0.99	0.96-1.03	0.68	0.99	0.96-1.03	0.80	0.99	0.96-1.03	0.76
Marital status [Divorced]	2.12 0.73-6.1	2 0.17	2.45 0.73	6.12 0.17	1.02	0.33-3.12	0.98	1.15	0.37-3.57	0.81	1.52	0.52-4.44	0.45	2.41	0.79-7.32	0.12
Marital status [Widowed]	1.31 0.58-2.9	5 0.52	1.45 0.64	3.31 0.52	0.58	0.26-1.31	0.20	0.62	0.27-1.40	0.25	0.48	0.20-1.15	0.10	0.49	0.20-1.20	0.12
Marital status [Single]	0.93 0.46-1.8	9 0.84	1.00 0.48	2.08 0.84	0.65	0.31-1.37	0.26	0.69	0.32-1.48	0.35	0.82	0.38-1.80	0.62	1.04	0.47-2.23	0.93
Marital status [Married/partnered]	1.00 .		1.00 .		1.00			1.00			1.00			1.00		
Occupation [Study]	0.00 -	1.00	0.00 -	1.00	2.74	0.09-81.9	0.56	3.23	0.11-98.0	0.50	1.27	0.04-40.6	0.89	1.73	0.05-61.0	0.76
Occupation [Occupationally disabled]	2.43 0.45-13	0 0.30	2.15 0.39	12.0 0.38	9.14	1.51-55.2	0.02	9.10	1.43-57.7	0.02	2.03	0.26-16.0	0.50	3.03	0.40-22.9	0.28
Occupation [Voluntary work]	1.05 0.25-4.3	1 0.95	0.96 0.23	4.09 0.96	2.20	0.50-9.68	0.30	1.95	0.43-8.94	0.39	0.66	0.16-2.74	0.57	0.37	0.09-1.57	0.18
Occupation [Home managment]	0.78 0.40-1.5	3 0.48	0.76 0.38	1.51 0.43	1.39	0.70-2.75	0.35	1.35	0.68-2.70	0.40	0.98	0.49-1.96	0.95	0.82	0.40-1.68	0.59
Occupation [Retired]	0.77 0.38-1.5	6 0.47	0.77 0.38	1.58 0.48	1.04	0.50-2.16	0.92	1.05	0.50-2.19	0.90	0.87	0.41-1.85	0.72	0.87	0.41-1.88	0.73
Occupation [Paid job]	1.00 .		1.00 .		1.00			1.00			1.00			1.00		
Education level [Low]	1.06 0.58-1.9	5 0.85	1.24 0.66	2.30 0.50	1.20	0.65-2.23	0.56	1.32	0.70-2.48	0.39	0.66	0.34-1.25	0.20	0.72	0.37-1.46	0.34
Education level [Moderate]	1.01 0.55-1.8	5 0.97	1.13 0.61	2.08 0.70	1.52	0.80-2.86	0.20	1.61	0.84-3.09	0.15	1.17	0.61-2.23	0.65	1.21	0.62-2.37	0.59
Education level [High]	1.00 .		1.00 .		1.00			1.00			1.00			1.00		
Health literacy	0.60 0.37-0.9	8 0.04	0.66 0.40	1.07 0.09	0.72	0.43-1.20	0.20	0.74	0.45-1.23	0.25	0.72	0.43-1.23	0.23	0.74	0.44-1.26	0.27
Cure beliefs			0.91 0.84	0.99 0.02				0.93	0.85-1.00	0.06				0.83	0.76-0.91	0.00
Personal control over recurrence			1.05 0.98	1.12 0.21				1.02	0.95-1.09	0.65				0.95	0.88-1.03	0.20
R2	0.05		0.	08		0.07			0.09			0.05			0.13	

Influence of recurrence risk perceptions on worries and self-examination behavior

Results from the univariate analysis revealed significant relationships between each recurrence risk perception type and cancer worry, worry about post-treatment diagnostic test results, and nervousness prior to appointments or examinations (Table 6). Regarding breast self-examination, there was only a significant association with the recurrence risk appraisal. As can be seen from Table 6, the recurrence risk appraisal explained most of the variance in worries and self-examination behavior.

Table 6 Univariate analysis of the effect of the recurrence risk perceptions on worries and self-examination behavior

		Cancer worry				Worry about post-treatment diagnostic test results			Nervousness prior appointments or examinations			Breast self-examination				
	OR	95% CI	р	R2	OR	95% CI	p	R2	OR	95% CI	р	R2	OR	95% CI	p	R2
Absolute RR	1.54	1.19-1.98	0.00	0.08	1.35	1.13-1.62	0.00	0.05	1.28	1.08-1.51	0.00	0.04	1.16	0.98-1.37	0.09	0.01
RR appraisal	2.74	1.88-3.99	0.00	0.18	2.21	1.64-2.99	0.00	0.12	1.60	1.22-2.11	0.00	0.05	1.16	1.20-2.11	0.00	0.05
Comparative RR	2.05	1.41-2.98	0.00	0.09	1.91	1.39-2.62	0.00	0.07	1.54	1.14-2.07	0.01	0.04	1.29	0.96-1.73	0.09	0.01

RR = recurrence risk

The results of the multivariable regression analysis are shown in Table 7. Cancer worry could be predicted for 19% with the three types of recurrence risk perception. Women who appraised their recurrence risk higher were more likely to: have high levels of cancer worry (OR = 2.21, 95% CI = 1.40-3.48, p < 0.01), worry more about post-treatment diagnostic test results (OR = 1.80, 95% CI = 1.25-2.61, p < 0.01), and examine their breasts more often (OR = 1.55, 95% CI = 1.09-2.22, p = 0.02).

	Cancer worry				Worry about post- treatment diagnostic test results			rvousness p pointments examinatior	s or	Breast self- examination		
	OR	95% CI	р	OR	95% CI	р	OR	95% CI	р	OR	95% CI	p
Absolute RR	1.13	0.86-1.49	0.39	1.09	0.89-1.34	0.42	1.14	0.94-1.38	0.20	1.01	0.83-1.22	0.92
RR appraisal	2.21	1.40-3.48	0.00	1.80	1.25-2.61	0.00	1.30	0.93-1.84	0.13	1.55	1.09-2.22	0.02
Comparative RR	1.36	0.89-2.07	0.16	1.39	0.98-1.97	0.07	1.28	0.92-1.79	0.14	1.03	0.74-1.44	0.85
<u>R2</u>		0.19			0.14			0.07			0.05	

**Table 7** Multivariable regression analysis of the effect of the recurrence risk perceptions on worries and self-examination behavior

RR = recurrence risk

### Discussion

This study enabled a better understanding of factors affecting recurrence risk perception types and the influence of these perceptions on cancer worry, worry about post-treatment diagnostic test results, nervousness prior to appointments and examinations, and breast self-examination among women treated for invasive breast cancer. The most important findings are that a higher recurrence risk appraisal (expressed in terms of high and low) was associated with higher levels of cancer worry, more worry about post-treatment diagnostic test results, and more frequent breast self-examination. Also, the recurrence risk appraisal explained most of the variance in worries and self-examination behavior.

The association between the recurrence risk appraisal and cancer worry is in accord with previous studies that showed women who perceived they were at higher risk of developing a recurrence to have greater fear of recurrence and higher levels of worry (33, 36). Our study revealed a moderate positive correlation between cancer worry and worry about post-treatment diagnostic test results. It seems likely that women who appraised their recurrence risk high also had high levels of cancer worry and therefore worried more often about post-treatment diagnostic test results because recurrences are discussed then. These findings reflect those of an earlier study that found an association between worries about recurrences and worries about future diagnostic tests (41). In our study, nearly three quarters of the women had scores of 12 or higher on the Cancer Worry Scale, indicating high levels of anxiety. This is higher than proportions found in previous studies (44, 45). A possible explanation for the high levels of cancer worry might be related to the Coronavirus disease 2019 (COVID-19) pandemic which took place during this study. Research among breast cancer patients has shown that specific stressors related to the pandemic were associated with higher levels of anxiety, depressive symptoms, and fear of cancer recurrence (46). Moreover, routine checkups, mammograms, and other examinations have been canceled or postponed as a consequence of COVID-19, which may have caused more worry about future diagnostic test results (47).

Our study recommends to not solely use the absolute risk (i.e., odds) when communicating recurrence risks from the INFLUENCE nomogram to patients, but also focus on the recurrence risk appraisal (expressed in terms of high and low) since it turned out that the recurrence risk appraisal was most predictive of worries and self-examination behavior. Moreover, earlier research has shown that people with lower numeracy skills have problems understanding and applying mathematical concepts, and that the advantages of using verbal terms for risk communicating are that they are easy to use and may better capture emotions (48, 49). We further suggest presenting women their risk compared to the average risk in women treated for invasive breast cancer, so that women understand why they receive more or fewer post-treatment surveillances than other breast cancer survivors. Besides, it may be helpful to assist patients in accessing appropriate and available support for their cancer worry nearing the end of treatment since fear of recurrence may affect quality of life and daily activities negatively (50). Additionally, we recommend investigating the effects of the COVID-19 pandemic among breast cancer survivors to identify long-term outcomes concerning detection of recurrences, cancer worry, and adherence to post-treatment surveillance, as canceling surveillances may have negative consequences.

One of the issues emerging from our findings is that the absolute recurrence risk and recurrence risk appraisal were not strongly related i.e., women had different conceptions of what odds are low and high. Considering the inconsistency between the absolute recurrence risk estimate and the recurrence risk appraisal, it might have been too difficult for women to interpret the absolute

recurrence risk using odds like '1 in 1000'. This supports our recommendation to communicate recurrence risks not only by using numbers but also words. An alternative approach to measure women's absolute recurrence risk perception could be providing a numeric probability scale ranging from 0-100% (51). This should reduce thinking about uncertain events in verbal terms.

Another finding was that women who appraised their recurrence risk high were more likely to examine their breasts more often. Cancer worry and breast self-examination were also positively correlated. This is in line with earlier studies that revealed an association between hypervigilance about symptoms and overestimation of the recurrence risk (33, 52, 53). When women are hypervigilant about symptoms, they might examine their breasts more often to look for physical signs of breast cancer. Another study showed that women who experience greater fear of recurrence would be more likely to check their bodies for signs or symptoms of cancer (54). To develop a full picture of these relationships, additional studies will be needed that explore hypervigilance about symptoms. Moreover, additional studies should investigate if women who were hypervigilant were more likely to visit their healthcare professional in between follow-up visits or to detect recurrences by themselves. Breast self-examination is a relatively simple low-cost method that can be performed by women themselves in addition to their mammography with the purpose of early detecting tumors. However, it may lead to more breast biopsies and diagnoses of benign lesions and thereby expose women to unnecessary anxiety and medical investigation, which in turn could lead to continued excessive breast self-examination (55, 56). Thus, it is important that the positive benefits of performing breast self-examination and appropriate frequency are mentioned by healthcare professionals.

Women who are occupationally disabled were more likely to appraise their recurrence risk high than women who have a paid job. Research showed that cancer survivors experience problems such as anxiety, fatigue, pain, and depression which may cause impairments that diminish social functioning including the retention of employment (57). A possible explanation for our finding might be that women who were occupationally disabled had a severe form of invasive breast cancer causing them to be unable to work, and because of the severeness their risk of recurrence is also higher. Another possible explanation might be that women are so anxious that they are unfit for work, and because they are so fearful that the cancer will return they estimate their recurrence risk higher. Further research should be performed to investigate the reason behind the disability to work so that conclusions can be drawn.

The current study revealed associations between cure beliefs and the recurrence risk perception types. It seems likely that women who believed that their breast cancer is cured (i.e., that there are no cancer cells left in the body), report lower recurrence risks because the risk of developing new tumors is lower when the breast cancer is cured. However, this result has not previously been reported in existing literature.

Although personal control perceptions have been found to be associated with recurrence risk perceptions (35), this study has been unable to demonstrate this relationship. It seems possible that these results are due to the low percentage of participants (13.9%) who believed they have personal control over recurrence. In another study among breast cancer survivors, 89% perceived that they could control cancer recurrence through lifestyle, diet, and exercise (58). In our study, most participants (73.5%) who believed that their actions had effect on the cancer recurring had high levels of cancer worry, so the discrepancy with existing literature might be related to this. Additionally, we expected that older women perceive the recurrence risk types lower because their risk is lower. Younger women are at greatest risk for recurrence, but they often fall into a different

category because many have a genetic component to the development of breast cancer and second primary tumors, and therefore follow-up for these women is organized differently (59). The results of our study might be related to the fact that only four patients in this study were aged <40 years old and women with a genetic component were excluded from the study population.

We also expected that women with lower health literacy perceive the recurrence risk types higher as been described in previous work (34). Although, the average health literacy in our study population was very high (i.e., 99.2% was classified as having an adequate health literacy). This is interesting since the latest data from Nivel showed that 28.8% of the Dutch adult population have insufficient or limited health literacy skills (60). It is possible that women who participated in our study had to complete consent forms which could have been too complicated for women with lower health literacy, causing them not to participate.

Lastly, women's recurrence risk perceptions were not significantly associated with nervousness prior to appointments or examinations. This may be partly explained by the fact that the question evaluated how often women were nervous prior to appointments or examinations in general, not specifically about post-treatment surveillance. In the future, this question should therefore be adapted so that it measures nervousness prior to post-treatment appointments or examinations specifically.

Our study highlights the importance of effective recurrence risk communication by using numbers and words, so that women are better able to comprehend their risk and to prevent inaccurate recurrence risk perceptions and consequently high levels of cancer worry, more worry about posttreatment diagnostic test results, and excessive breast self-examination. The upcoming challenge is to use the specific factors underlying the type of recurrence risk perceptions to develop effective communication techniques that improve women's understanding. A better understanding will also benefit healthcare professionals in providing information necessary for shared decision-making. Further studies should include women's treatment and tumor characteristics to develop a full picture of factors associated with women's recurrence risk perceptions. Moreover, the perceptions of healthcare professionals could be investigated.

#### Strengths and limitations

A strength of this study is the use of data from women treated in seven different hospitals spread over the country. The findings reported here shed new light on the recurrence risk perceptions and associated factors of women treated for invasive breast cancer. Since patients were not excluded based on treatment type and invasive breast cancer is most common, the results therefore apply to a large group. To our knowledge, our study is the first to explore the influence of different recurrence risk types on worries and self-examination behavior, thereby contributing to new knowledge. However, there are some potential limitations that should be noted. The design of this study was cross-sectional so the above findings must be interpreted with caution since the relationships might be bidirectional. Besides, caution is necessary when generalizing these findings to other breast cancer survivors not treated in a Santeon hospital. Since communication about recurrence risks may differ per hospital, women's recurrence risk perceptions and the associated factors also may differ.

### Conclusion

The first aim of this research was to detect factors affecting women's absolute recurrence risk estimate (expressed in odds), recurrence risk appraisal (expressed in terms of high and low), and comparative recurrence risk estimate (expressed in terms of higher, lower or the same as other women) after treatment for invasive breast cancer. Cure beliefs were found to be associated with the absolute and comparative recurrence risk estimates. Occupationally disabled women were more likely to appraise their recurrence risk high than women with a paid job. Other demographic characteristics and personal control over recurrence were not significantly associated with the types of recurrence risk. The second aim of this study was to investigate the influence of these recurrence risk perceptions on worries and self-examination behavior. Higher perceived recurrence risk was related to higher levels of cancer worry, more worry about post-treatment diagnostic test results, and more frequent breast self-examination. Considering that the recurrence risk appraisal was most predictive of worries and self-examination behavior, and the inconsistency between the absolute risk and risk appraisal, our study recommends using not only absolute risks when communicating but also the recurrence risk appraisal. Additionally, we suggest presenting women their risk compared to the average risk in women treated for invasive breast cancer, so that women understand why they receive more or fewer surveillances than other survivors. Considering the high levels of cancer worry, it may be helpful to offer patients appropriate support in managing their cancer worry nearing the end of treatment. The findings of this study can be used to develop interventions aimed at effective recurrence risk communication while using the INFLUENCE nomogram, to personalize post-treatment surveillance.

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# Appendix A: Questionnaire

Algemene	vragen
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1. In welk jaar bent u geboren?
2. Wat is uw burgerlijke staat?
Alleenstaand
Samenwonend/ gehuwd
Gescheiden
Weduwe
Anders, nl.:
3. Waaruit bestaan momenteel uw <u>voornaamste</u> dagelijkse bezigheden?
Betaalde baan, voor uur per week (al dan niet in Ziektewet)
WAO/ arbeidsongeschikt
AOW/ VUT/ Pensioen
Vrijwilligerswerk/ onbetaalde baan
Huishoudelijke taken
Volgen van studie/ opleiding
Anders, nl.:
4. Wat is uw hoogst <u>voltooide</u> opleiding?
Geen opleiding (lager onderwijs: niet afgemaakt)
Lager onderwijs (basisschool, speciaal basisonderwijs)
Lager of voorbereidend beroepsonderwijs (zoals LTS, LEAO, LHNO, VMBO)
Middelbaar algemeen voortgezet onderwijs (zoals MAVO, (M)ULO, MBO-kort, VMBO-t)
Middelbaar beroepsonderwijs en beroepsbegeleidend onderwijs (zoals MBO-lang, MTS, MEAO, BOL, BBL, INAS)
Hoger algemeen en voorbereidend wetenschappelijk onderwijs (zoals HAVO, VWO, Atheneum, Gymnasium, HBS, MMS)
Hoger beroepsonderwijs (zoals HBO, HTS, HEAO, HBO-V, kandidaats wetenschappelijk onderwijs)
Wetenschappelijk onderwijs (universiteit)
Anders, nl.:

		Nooit	Af en toe	Soms	Vaak	Altijd
5.	Hoe vaak wordt u door iemand					
	geholpen met het lezen van brieven of folders van uw huisarts of van het					
	ziekenhuis?	Helemaal	Een klein	Een beetje	Nogal	Heel erg
		niet zeker	beetje zeker	zeker	zeker	zeker
6.	Hoe zeker bent u ervan dat u medische formulieren zelf goed					
	invult?	<b>.</b>				
7.	Vindt u het moeilijk om meer te	Nooit	Af en toe	Soms	Vaak	Altijd
	weten te komen over uw gezondheid, omdat u geschreven informatie niet					

goed begrijpt? Zo ja, hoe vaak is dat?

#### Gedachten over uw ziekte

We zijn benieuwd hoe u denkt over uw ziekte en behandeling. Kruis alstublieft aan in hoeverre elke uitspraak van toepassing is. Er zijn geen goede of foute antwoorden. Het gaat om uw ervaring.

	Helemaal	Mee	Niet mee	Mee	Helemaal
	mee	oneens	eens of	eens	mee eens
	oneens		oneens		
1. Door mijn behandeling is mijn					
borstkanker genezen.					
2. Ik heb geen borstkanker meer.					
3. Mijn borstkanker is genezen.					
4. Ik zie mijzelf nog steeds als					
borstkankerpatiënt.					
5. Er zijn dingen die ik kan doen om te					
voorkomen dat de borstkanker					
terugkomt.					
6. Wat ik doe, is van invloed op het wel of					
niet terugkomen van mijn borstkanker.					
7. Ik kan zelf niets doen tegen het risico					
dat de borstkanker terugkomt.					
8. Wat ik doe, heeft geen effect op het					
risico dat de borstkanker terugkomt.					

#### Zorgen over uw ziekte

De volgende vragen gaan over mogelijke zorgen die mensen na de diagnose en behandeling kunnen hebben. Geef alstublieft voor elk van de vragen aan hoe vaak u tijdens **de afgelopen maand** deze zorgen heeft gehad.

	Nooit	Zelden	Soms	Bijna
				altijd
1. Hoe vaak heeft u gedacht aan uw kans op				
het (opnieuw) krijgen van borstkanker?				
2. Zijn deze gedachten van invloed geweest op				
uw stemming?				
3. Hebben deze gedachten u belemmerd bij het				
uitvoeren van uw dagelijkse activiteiten?				
4. Bent u bezorgd over de mogelijkheid dat u				
ooit (opnieuw) borstkanker krijgt?				
5. Hoe vaak maakt u zich zorgen over het				
(opnieuw) krijgen van borstkanker?				
6. Zijn deze zorgen een probleem voor u?				

Beantwoord de volgende vragen door per vraag <u>één vakje</u> aan te vinken ...

	Nooit	Zelden	Soms	Vaak	Heel vaak
lk onderzoek mijn lichaam op tekenen van					
kanker.					
Ik maak me zorgen over de uitslag van					
diagnostische tests (bijv. de					
mammografie, MRI of echografie) die					
worden uitgevoerd tijdens de nacontrole.					
Ik ben zenuwachtig voorafgaand aan					
afspraken met mijn arts of voorafgaand					
aan periodieke nacontroles.					

# Appendix B: Cross-tabulations and scatterplots recurrence risk

### perceptions

 Table B1 Cross-tabulation recurrence risk appraisal and absolute recurrence risk estimate

		Absolute recurrrence risk estimate						
		1 in 1000	1 in 100	1 in 50	1 in 25	1 in 10	1 in 5	Total
Recurrence risk appraisal	Very low	26	4	1	0	0	1	32
	Low	35	29	4	2	1	1	72
	Not high/not low	22	35	32	10	13	2	114
	High	1	6	3	2	10	3	25
	Very high	0	0	0	0	0	2	2
	Total	84	74	40	14	24	9	245

Table B2 Cross-tabulation recurrence risk appraisal and comparative recurrence risk estimate

		Comparative recurrence risk estimate						
		Much lower	Lower	The same	Higher	Much higher	Total	
Recurrence risk appraisal	Very low	10	7	13	2	0	32	
	Low	4	19	41	8	0	72	
	Not high/not low	1	12	74	27	0	114	
	High	0	0	10	15	0	25	
	Very high	0	0	1	0	1	2	
	Total	15	38	139	52	1	245	

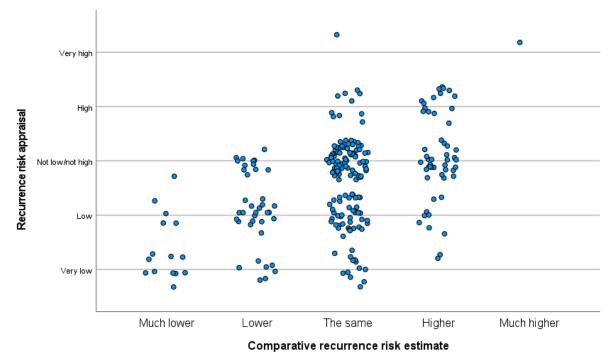
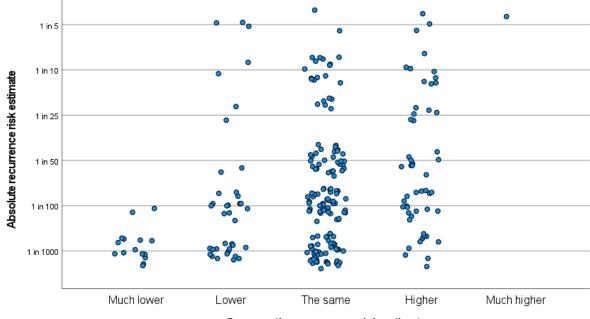


Figure B1 Scatterplot of recurrence risk appraisal and comparative recurrence risk estimate

		Comparative recurrence risk estimate						
		Much lower	Lower	The same	Higher	Much higher	Tota	
Absolute recurrence risk estimate	1 in 1000	13	16	45	10	0	84	
	1 in 100	2	13	43	16	0	74	
	1 in 50	0	2	29	9	0	40	
	1 in 25	0	2	6	6	0	14	
	1 in 10	0	2	14	8	0	24	
	1 in 5	0	3	2	3	1	9	
	Total	15	38	139	52	1	245	





Comparative recurrence risk estimate

Figure B2 Scatterplot of absolute recurrence risk estimate and comparative recurrence risk estimate