Questionnaire

Name:

Patient ID number

Date:

Guide:

How to fill in the questionnaire:

1) Use a pen

2) Please, read every question and all the categories of answer to that question before you answer. Pay attention that sometimes you may tick off more than one box. If more than one tick off is allowed, it will be listed as follows: "(Please tick off more than one box if relevant)". Tick off the statement most in harmony with your opinion. If you make a mistake or change your mind, fill out the whole wrong box and tick off the new box.

3) Some questions are easier than others to answer. If you are in doubt, tick off the box most appropriate for you. If there are questions you are not able to or do not want to answer, then please continue to the next question.

4) Please, fill in the questionnaire according to how ***you have been feeling about yourself during the past week***.

In this questionnaire we understand pain as just something hurting. We do not distinguish between pain and something hurting.

The questionnaire is divided into the following groups of questions:

- General
- Questions regarding pain
- Questions regarding sensory disturbances or discomfort
- Questions regarding swelling and heaviness (lymph edema)
- Questions regarding restriction of function

DBCG – PROTON TRIAL

DANISH BREAST CANCER COOPERATIVE GROUP

PATIENT FORM

MORBIDITY, BIS

Name – Patient ID ___ - ___ - ___ - ____ Day Month Year No.	Hospital
Years after RT: 0 1 2 3 4 5 10	Date ______ ddmmyy

Patient reported morbidity

	None	Sometimes	Often	Always
Pain, breast / chest wall				

	None	Sometimes, mild	Often, mild	Opiod need
Analgesics because of pain in breast / chest wall				

	None	Slight	Moderate	Severe
Sensibility changes, breast / chest wall				

	High confidence	Feels less confidence, less feminine	Lack of confidence, avoids mirrors	Ashamed of body
Body image				

	No	Yes
Dresses differently, e.g. prefers looser fitting clothing		

Body Image Scale

	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?				
Have you felt less physically attractive as a result of your disease or treatment?				
Have you been dissatisfied with your appearance when dressed?				
Have you been feeling less feminine/masculine as a result of your disease or treatment?				
Did you find it difficult to look at yourself naked?				
Have you been feeling less sexually attractive as a result of your disease or treatment?				
Did you avoid people because of the way you felt about your appearance?				
Have you been feeling the treatment has left your body less whole?				
Have you felt dissatisfied with your body?				
Have you been dissatisfied with the appearance of your scar?				

	Poor	Fair	Good	Excellent
How satisfied are you with the overall result of your treated breast?				
How satisfied are you with the overall result of your treated breast compared to the other breast? (Only relevant after breast conserving surgery.)				

	No	Yes
Have you had lipo injection in your treated breast / chest wall since last follow up visit?		
Have you had lipo injection in your opposite breast since last follow up visit?		

April 2020

DBCG – PROTON TRIAL

DANISH BREAST CANCER COOPERATIVE GROUP

PATIENT FORM

QUESTIONNAIRE

Name – Patient ID	Hospital
___ - ___ - ___ - ____ Day Month Year No.	
Years after RT: 0 1 2 3 4 5 10	Date ______ ddmmyy

	Right-handed	Left-handed
1. Are you right-handed or left-handed?		

Questions regarding pain

In this questionnaire we define ”breast area” as either the operated breast or the area from which the breast was removed.

	No	Yes
2. Do you have pain in the area of the breast, armpit, side of the body or the arm on the side where you had surgery? If ”No”, please proceed to question 12 (next page).		
3. If “Yes”, where do you have pain? (Please, tick yes or no for each area)		
Area of the breast		
The side of the body		
Armpit		
Arm		

	0	1	2	3	4	5	6	7	8	9	10
4. If you have pain in the **area of the breast**, how strong on average is the pain? (0 is no pain and 10 is the worst pain imaginable)											

	(Almost) every day	1-3 days a week	More rarely
5. If you have pain in the area of the breast, how often do you have this pain?			

	0	1	2	3	4	5	6	7	8	9	10
6. If you have pain on the **side of the body**, how strong on average is the pain?											

	(Almost) every day	1-3 days a week	More rarely
7. If you have pain on the side of the body, how often do you have this pain?			

	0	1	2	3	4	5	6	7	8	9	10
8. If you have pain in the **armpit**, how strong on average is the pain?											

	(Almost) every day	1-3 days a week	More rarely
9. If you have pain in the armpit, how often do you have this pain?			

	0	1	2	3	4	5	6	7	8	9	10
10. If you have pain in the **arm**, how strong on average is the pain?											

	(Almost) every day	1-3 days a week	More rarely
11. If you have pain in the arm, how often do you have this pain?			

Patient ID	Day	Month	Year	No.
	☐☐ -	☐☐ -	☐☐ -	☐☐☐☐

Questions regarding sensory disturbances or discomfort

	No	Yes
12. Do you have sensory disturbances or discomfort in the area of the breast, armpit, side of the body or the arm on the side where you had surgery? If ”No”, please proceed to question 14.		
13. If ”Yes”, where do you have sensory disturbances or discomfort? (Please, tick yes or no for each area)		
Area of the breast		
The side of the body		
Armpit		
Arm		

Questions regarding swelling and heaviness (lymphedema)

	No						Yes				
14. Does the armpit, the arm or the back of the hand, on the side where you had surgery, sometimes or always feel swollen or heavy? If ”No”, please proceed to question 19.											
15. If ”Yes”, where do you feel the armpit, arm or back of the hand is swollen or heavy? (Please, tick yes or no for each area)											
Back of the hand											
Forearm											
Upper arm											
Armpit											
	0	1	2	3	4	5	6	7	8	9	10
16. How severe are the swellings/sensation of heaviness of your armpit and/or upper arm? (0 is no swellings/sensation of heaviness and 10 is the worst imaginable swellings/sensation of heaviness)											
17. How severe are the swellings/sensation of heaviness of your forearm and/or back of your hand?											
	(Almost) every day				1-3 days a week				More rarely		
18. How often does the swellings/sensation of heaviness occur?											

Questions regarding restriction of function

How do you manage the following activities compared with before your treatment for breast cancer?
(Select “Not relevant” for activities you do not perform.)

	The same way as before	The same way as before, but with difficulties/slower and/or more tired afterwards	The same way as before, but with more pain afterwards	In another way than before, for example using the other arm/both hands	Not relevant
19. Washing hair					
20. Brushing teeth					
21. Taking a bra off/on					
22. Carrying shopping bags					
23. Lifting above the height of shoulders					
24. Cleaning floors					

In the following we would like to ask questions related to heart disease and risk of heart disease.

The following is a list of activities that people often do during the week. Although for some people with several medical problems it is difficult to determine what it is that limits them, please go over the activities listed below and indicate how much limitation you have had due to **chest pain, chest tightness or angina** **over the past 4 weeks**.

Place an X in one box on each line (please, omit to place an X between 2 boxes)

	Have you ever had a heart disease?						
	No	Yes	No answer				
25	->Go to 26						
If yes at 25	Activity	Extremely limited	Quite a bit limited	Moderately limited	Slightly limited	Not at all limited	Limited for other reasons or did not do the activity
25a	Walking indoors on the level ground						
25b	Gardening, vacuuming or carrying groceries						
25c	Lifting or moving heavy objects (e.g. furniture, children)						
	Over the past 4 weeks, on average, how many times have you had **chest pain, chest tightness or angina**?						
	I have had **chest pain, chest tightness or angina….**						
		4 or more times per day	1-3 times per day	3 or more times per week, but not every day	1-2 times per week	Less than once a week	None over the past 4 weeks
25d							
	Over the past 4 weeks, on average, how many times have you had to take nitroglycerin (nitroglycerin tablets or spray) for your **chest pain, chest tightness or angina**?						
		4 or more times per day	1-3 times per day	3 or more times per week, but not every day	1-2 times per week	Less than once a week	None over the past 4 weeks
25e							

	Over the past 4 weeks, how much has your **chest pain, chest tightness or angina** limited your enjoyment of life?						
		It has **extremely** limited my enjoyment of life	It has limited my enjoyment of life **quite a bit**	It has **moderately** limited my enjoyment of life	It has **slightly** limited my enjoyment of life	It has **not** limited my enjoyment of life at all	
25f							
	If you had to spend the rest of your life with your **chest pain, chest tightness or angina** the way it is right now, how would you feel about this?						
		Not satisfied at all	Mostly dissatisfied	Somewhat satisfied	Mostly satisfied	Completely satisfied	
25g							
	Do you have chest pain, chest tightness or angina at stress, activity and/or when being cold?						
	No	Yes	No answer				
26	->Go to 30						
If yes at 26	How often?						
	Few times per year	Few times per months	Few times per weeks				
27							
If yes at 26	Are the symptoms relieved by rest?						
	No	Yes	No answer				
28							
If yes at 26	Do the symptoms last less than 15 minutes?						
	No	Yes	No answer				
29							
	Have your mother or sisters at age less than 65 years, or your father or brothers at age less than 55 years had a myocardial infarction or bypass surgery of the heart?						
	No	Yes	No answer				
30							
	Are you being treated for diabetes?						
	No	Yes	No answer				
31							
	Are you being treated for high cholesterol?						
	No	Yes	No answer				
32							
	Are you being treated for high blood pressure?						
	No	Yes	No answer				
33							