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## **Cancer and sexual health: The continuum of care**

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**Appendix 2.**  
**Questionnaire chapter 2**

**Questionnaire (translated from Dutch)**

**Part 1: demographics**

- Male
- Female

1. What is your age? \_\_\_\_\_ years

2. Which type of cancer did / do you have?

- Breast
- Prostate
- Gastro-intestinal
- Gynaecology
- Bladder and kidney
- Head neck
- Skin
- Male external genitalia
- Endocrinology
- Haematology
- Lung
- Bone
- Other: \_\_\_\_\_

3. Which stage of cancer do you have/had?

- Local disease
- Metastatic disease
- I don't know

4. How long ago were you diagnosed with cancer?

- Less than 2 ago
- 3 – 5 years ago
- 6 – 10 years ago
- More than 10 years ago
- I don't know

5. Which treatment did you received? (*multiple answers possible*)

- None
- Surgery
- External radiotherapy
- Internal radiotherapy
- Hormonal therapy
- Chemotherapy
- Immunotherapy
- Stem-cell therapy
- Other: \_\_\_\_\_

6. Did you actively search for information about intimacy and sexuality? *(multiple answers possible)*

- No
- Yes

7. Where did you search for information about intimacy and sexuality? (open question; not required)

8. Are you satisfied with the information about intimacy and sexuality you found?

- Yes
- No

9. Why were(n't) you satisfied with the information? (open question; not required)

10. What kind of information regarding intimacy and sexuality do you prefer?

- I don't have a need for information now
- Practical tips
- Experiences from others
- Contact with other cancer patients
- Practical information (prevalence and cause of sexuality issues)
- A referral to a professional
- Information for partners
- Information for care providers
- Information video's
- Other:.....

11. Did your intimacy or sexuality change due to the diagnosis cancer?

- No, it did not change
- Yes, it became better
- Yes, it became worse

12. As a result of cancer, what kind of changes in sexuality or intimacy did you experience?

- Physical changes
- Psychological changes
- Changes self-image
- Other:\_\_\_\_\_

13. Which physical sexuality problems did you experience? *(multiple answers possible)*

- I do not experience physical problems
- Pain during sexual intercourse
- Erection problems
- Dry mouth
- Lubrication problems
- Hormonal changes
- Fatigue
- Incontinence of urine or defecation
- Problems with ejaculation
- Unable to ejaculate
- Other:\_\_\_\_\_

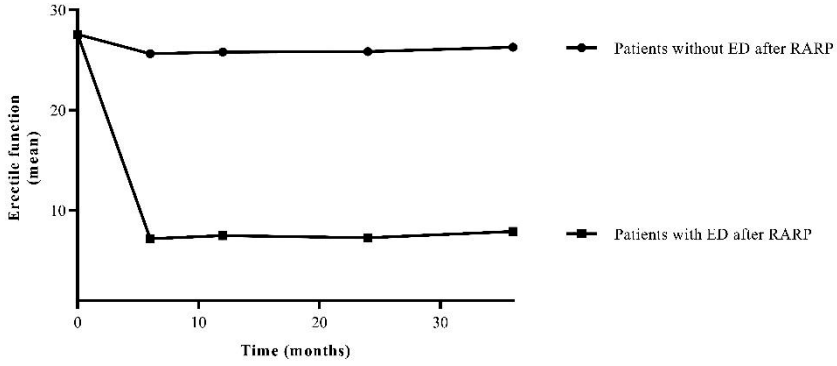
14. Which other intimacy or sexuality problems did you experience?
- I do not experience other problems
  - I do not experience problems, but had to get used to the changes in sexuality
  - No sexual arousal
  - No sexual desire
  - I am afraid to have sexual intercourse
  - The character of my sexual relationship have changed a lot
  - No sex drive
  - My self-image has changed
  - I feel deformed
  - I think my partner experience difficulties with my changed body
  - I think my partner do not have sexual desire
  - I am afraid to approach my partner
  - Other: \_\_\_\_\_
15. How do you deal with sexuality and intimacy problems?
- I do nothing (skip question 17)
  - I do not experience problems
  - I discuss the problems with my (sexual) partner
  - I discuss the problems with friends
  - I discuss the problems with other patients
  - I discuss the problems with my healthcare provider
  - I seek for professional help by a sexologist/psychologist
  - I used medication
  - I used an aid
  - I searched for information via internet
  - I searched for information via a patient organization
  - Other: \_\_\_\_\_
16. What did help you to improve intimacy and sexuality, and why? (open question, not required)
17. Why did you choose to do nothing?
- I accepted the situation and I am fine with it
  - I accepted the situation, but I am not fine with it
  - I am afraid to hurt my partner, so I do not talk about the sexuality problems
  - I do not dare to discuss my problems with anyone
  - I do not think there is a solution
  - I do not know where I can go for help
  - I do not feel comfortable to discuss my problems with my health care provider
  - The treatment I want is not covered by my health care insurance
  - Survival is more important at this moment
  - I thought, it was part of it
  - Other: \_\_\_\_\_
18. Could you explain why nothing helped you? (open question, not required)

19. You find some statements below. Choice one of the following answers by each statement.
- Totally disagree
  - Disagree
  - Agree
  - Totally agree
  - Not applicable
  - I don't know
- a. I am satisfied with my sex life
  - b. It is easy for me to discuss my thoughts and feelings about sex with my (sexual) partner
  - c. I do not have sexual desire anymore due to the cancer
  - d. Intimacy between me and my partner was better before the cancer
  - e. My sex life was better before the cancer
  - f. I have learned to deal with changes in sexuality
20. What do you recommend to other cancer patients with regard to (discussing) intimacy and sexuality? (open question, not required)
21. What do you recommend to partners of cancer patients with regard to (discussing) intimacy and sexuality? (open question, not required)
22. What do you recommend to health care providers with regard to discussing intimacy and sexuality?
- My health care provider should initiate the discussing about sexuality
  - My health care provider should provide information systematically
  - My health care provider should involve my partner when discussing sexuality
  - My health care provider should provide an referral to another specialist/sexologist in an approachable manner
  - Other: \_\_\_\_\_
23. What do you want to know about sexuality (after cancer), but never dared to ask?

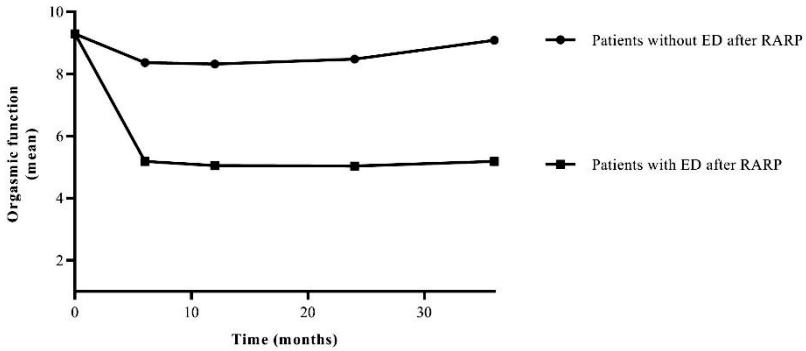
**Questions about your relationship state**

24. Do you have a relationship?
- No (skip question 26 and 27)
  - Yes
  - I do not want to answer this question
25. Did you have the relationship already **before** you were diagnosed with cancer?
- Yes
  - No
26. Partner of patients with cancer might suffer from intimacy and sexuality problems as well. Therefore, we would like to send a similar questionnaire the partners as well. May we approach your partner?
- No
  - Yes
27. Do you have additional comments? (not required)
-

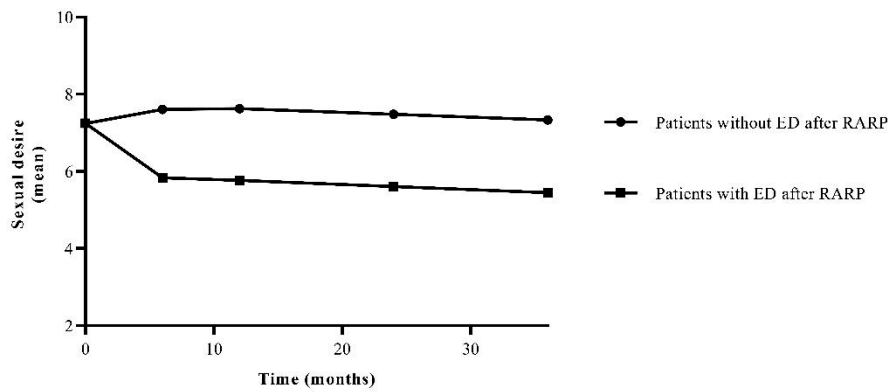
Appendix 3.  
Supplementary information (SI) chapter 3



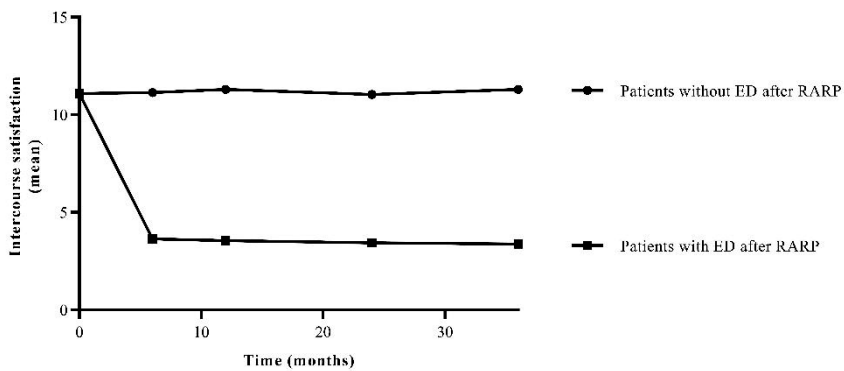
SI Figure 1: Erectile function score (range 1-30) (subdomain of IIEF-15)



SI Figure 2: Orgasmic function score (range 1-10) (subdomain of IIEF-15)



SI Figure 3: Sexual desire score (range 2-10) (subdomain of IIEF-15)



SI Figure 4: Intercourse satisfaction score (range 0-15) (subdomain of IIEF-15)



**Appendix 4.**  
**Questionnaire chapter 4**

**Questionnaire (translated from Dutch)**

**Part 1: demographics**

1. What is your gender?
  - Male
  - Female
  
2. What is your age? \_\_\_\_\_ years
  
3. Which type of cancer did / do your partner have/had?
  - Breast
  - Prostate
  - Gastro-intestinal
  - Gynaecology
  - Bladder and kidney
  - Head neck
  - Skin
  - Male external genitalia
  - Endocrinology
  - Haematology
  - Lung
  - Bone
  - Other: \_\_\_\_\_
  
4. Which stage of cancer did / do your partner have/had?
  - Local disease
  - Metastatic disease
  - I don't know
  
5. How long ago was your partner diagnosed with cancer?
  - Less than 2 ago
  - 3 – 5 years ago
  - 6 – 10 years ago
  - More than 10 years ago
  - I don't know
  
6. Which treatment did your partner received? (*multiple answers possible*)
  - None
  - Surgery
  - External radiotherapy
  - Internal radiotherapy
  - Hormonal therapy
  - Chemotherapy
  - Immunotherapy
  - Stem-cell therapy
  - Other: \_\_\_\_\_

7. Did you actively search for information about intimacy and sexuality after cancer? (*multiple answers possible*)

- No
- Yes

8. Are you satisfied with the information about intimacy and sexuality you found?

- Yes
- No

9. Where did you search for information about intimacy and sexuality? (open question; not required)

10. Why were(n't) you satisfied with the information? (open question; not required)

11. What kind of information regarding intimacy and sexuality do you prefer?

- I don't have a need for information now
- Practical tips
- Experiences from others
- Contact with other cancer patients
- Practical information (prevalence and cause of sexuality issues)
- A referral to a professional
- Information for partners
- Information for care providers
- Information videos
- Other:.....

12. Did your intimacy or sexuality in your relationship change due to the cancer of your partner?

- No, it did not change
- Yes, it became better
- Yes, it became worse

13. As a result of cancer, what kind of changes in sexuality or intimacy did you experience?

- Physical changes
- Psychological changes
- Both physical and psychological changes
- Changes in self-image
- Other:\_\_\_\_\_

14. Which physical sexuality problems did you experience? (*multiple answers possible*)

- We did not experience physical problems
- My partner experiences pain during sexual intercourse
- My partner experiences erection problems
- My partner experiences a dry mouth
- My partner experiences lubrication problems
- My partner experiences hormonal changes
- My partner is too fatigue to have sexual intercourse
- I am too fatigue to have sexual intercourse
- My partner has incontinence of urine or defecation
- My partners experiences problems with ejaculation
- My partner is unable to ejaculate
- Other:\_\_\_\_\_

15. Which other intimacy or sexuality problems did you experience?
- I do not experience other problems
  - I do not experience problems, but have to get used the changes in sexuality
  - My partner do not have sexual arousal
  - I have no sexual desire
  - My partner has no sexual desire
  - I think my partner is too afraid to have sexual intercourse
  - The character of our sexual relationship has changed a lot
  - I have no sex drive
  - The self-image of my partner has changed
  - My partner thinks he/she is deformed
  - I experience difficulties with the changed body of my partner
  - I think my partner do not have sexual desire
  - I am afraid to force my partner
  - Other: \_\_\_\_\_

16. How do you deal with sexuality and intimacy problems?
- I do nothing (skip question 17)
  - I do not experience problems
  - I discuss the problems with my (sexual) partner
  - I discuss the problems with friends
  - I discuss the problems with other patients
  - I discuss the problems with my health care provider
  - I seek for professional help by a sexologist/psychologist
  - I used medication
  - I used an aid
  - I searched for information via internet
  - I searched for information via a patient organization
  - Other: \_\_\_\_\_

17. What did help you to improve intimacy and sexuality, and why? (open question, not required)

18. Why did you choose to do nothing?
- I accepted the situation and I am fine with it
  - I accepted the situation, but I am not fine with it
  - I am afraid to hurt my partner, so I do not talk about the sexuality problems
  - I do not dare to discuss my problems with anyone
  - I do not think there is a solution
  - I do not know where I can go for help
  - I do not feel comfortable to discuss my problems with my health care provider
  - The treatment I want is not covered by my health care insurance
  - Survival is more important at this moment
  - I thought, it was part of it
  - Other: \_\_\_\_\_

19. Tell in your own words why nothing did help you? (open question, not required)

20. You find some statements below. Choice one of the following answers by each statement.

- Totally disagree
- Disagree
- Agree
- Totally agree

- Not applicable
- I don't know
- 
- g. I am satisfied with my sex life
- h. I am comfortable to discuss my thoughts and feelings about sex with my (sexual) partner
- i. I do not have sexual desire due to the cancer of my partner
- j. Intimacy between me and my partner was better before the cancer
- k. My sex life was better before the cancer
- l. I have learned to deal with my changed sexuality

21. What do you recommend to others people dealing with cancer with regard to discussing intimacy and sexuality? (open question, not required)

22. What do you recommend to partners of cancer patients with regard to discussing intimacy and sexuality? (open question, not required)

23. What do you recommend to health care provider with regard to discussing intimacy and sexuality?

- My health care provider should initiate the discussing about sexuality
- My health care provider should provide information systematically
- My health care provider should involve my partner when discussing sexuality
- My health care provider should provide an referral to another specialist/sexologist in an approachable manner
- Other: \_\_\_\_\_

24. What do you want to know about sexuality (after cancer), but never dared to ask?

**Appendix 5.**  
**Questionnaire chapter 5, part 1**

*Questionnaire patient (translated from Dutch)*

Choose the most suitable answer. Thank you in advance for your effort.

**Part 1: demographics**

1. What is your age? \_\_\_\_\_ years
2. What is your ethnicity?  
 Dutch  
 Other: \_\_\_\_\_
3. What is your marital status?  
 Single  
 In a relationship, living together  
 In a relationship, not living together  
 Married  
 Widowed  
 Other: \_\_\_\_\_
4. If you are in a relationship, for how long?  
 ....years
5. Level of education?  
 Elementary school  
 Middle school  
 High school  
 College  
 University  
 Other:.....
6. Are you currently employed?  
 Yes  
 No, I am in between jobs  
 No, not able to work due to my illness  
 No, I am retired  
 Other: \_\_\_\_\_

**Part 2: Diagnosis and treatment**

7. Which stage of breast cancer do you have/had?  
 A premalign stage (ductal carcinoma in situ)  
 Breastcancer only in the breast itself  
 With metastasis in the axilla(s)  
 With metastasis elsewhere in the body
8. How long ago were you diagnosed with breast cancer?

- 0 – 3 months ago
- 3 – 6 months ago
- 6 months – 1 year ago
- 1 – 2 years ago
- more than 2 ago

9. Which surgical treatments did you underwent? (*multiple answers possible*)

- No operation
- Breast conserving surgery
- Mastectomie, without construction of the breast
- Mastectomie, with direct construction of the breast
- Mastectomie, with secondary reconstruction of the breast
- Mastectomie of both breasts, without construction
- Mastectomie of both breasts, without direct construction
- Mastectomie of both breasts, without secondary construction
- Axillary lymph node dissection, one side
- Axillary lymph node dissection, both sides

10. Did you receive, besides surgery, other treatments? (*multiple answers possible*)

- No
- Radiotherapy after the operation
- Radiotherapy during the operation
- Chemotherapy before surgery
- Chemotherapy after surgery
- Endocrine therapy
- Immunotherapy (Herceptin)

11. To what extent were you concerned about your health when you heard the diagnosis breast cancer?

- No concerns
- Some concerns
- Many concerns
- Grave concerns

12. Have your concerns changes **after** treatment?

- Yes, my concerns are increased
- Yes, my concerns are declined
- No, my concerns didn't change
- No, I had no concerns

13. If you are breast cancer-free, are you afraid that the breast cancer may come back?

- Inapplicable
- Not afraid
- A bit afraid
- Afraid
- Very afraid

**Part 3: Your experience about intimacy and sexuality after disease**

14. Were you sexually active **before** the diagnosis breast cancer?

- Yes
- No

15. Did you experience complaints in intimacy or sexuality before the diagnosis breastcancer?

- Yes, **go to question 16**
- No, **go to question 18**

16. Which intimacy or sexuality complaints did you have? *(multiple answers possible)*
- Fatigue
  - Feel uncertain about my appearance
  - Less intimacy with my partner
  - No enjoying sex anymore
  - No sex drive
  - Difficulties with orgasms
  - Pain during intercourse
  - Insufficient lubrication
  - Other: \_\_\_\_\_
17. Did the intimacy or sexuality complaints changes **after** the diagnosis of breast cancer?
- No, complaints didn't change
  - Yes, complaints have disappeared
  - Yes, complaints have declined
  - Yes, complaints have increased
  - Yes, complaints have changed
18. Are you **after** treatment sexually active?
- Yes
  - No
19. Did you experience new complaints with regard to intimacy or sexuality due though the breast cancer or the treatment?
- Yes, **go to question 20**
  - No, **go to question 25**
20. Which complaints did you experience? *(multiple answers possible)*
- Fatigue
  - Feel uncertain about my appearance
  - Feel uncertain about changes body image
  - Less intimacy with my partner
  - No enjoying sex anymore
  - No sex drive
  - Difficulties with orgasms
  - Pain during intercourse
  - Insufficient lubrication
  - Menopausal complaints
  - Other: \_\_\_\_\_
21. On a scale of 0-10, in which amount did you suffer from these complaints?  
0 means no suffering, 10 means a lot of suffering  
Grade: .....
22. Did one of your therapists ever offered you help for these complaints?
- Yes, by advising tools (for example lubricant)
  - Yes, by tips on other forms of intimacy
  - Yes, other: \_\_\_\_\_
  - No, **go to question 25**
23. Were you satisfied with the help you were offered?
- Yes
  - No
24. Are you referred, by your therapist, for your sexual of intimacy complaints?

- Yes, to: \_\_\_\_\_ (for example other specialist or sexologist)
- No, but I would have wanted a referral
- No, I had no need of a referral Nee, ik had daar geen behoefte aan

**Part 4: Information about intimacy and sexuality**

25. Did you need information about possible intimacy or sexuality complaints due to breast cancer and treatment?
- Yes
  - No
26. Did you at some point receive any information about intimacy and sexuality and possible complaints due to treatment?
- Yes, **go to question 27**
  - No, **go to question 31**
27. At what stage did you receive the information about intimacy and sexuality? (*multiple answers possible*)
- At the same time as the diagnosis breast cancer
  - Before chemotherapy before surgery
  - Before the operation
  - After the operation
  - Before the additional treatment\*
  - During the additional treatment
  - At the end of all treatments
  - Other: \_\_\_\_\_

*\*With additional treatment is meant chemotherapy, radiotherapy and/or endocrine therapy*

28. Did you have to ask for information about intimacy or sexuality?
- Yes, I had to ask for this information by myself
  - No, the care provider gave the information from
  - No, it was clear to me where I could find information (for example a flyer or on the web)
29. Who gave you the information about intimacy and sexuality? (*multiple answers possible*)
- General practitioner
  - Surgeon
  - Nurse on the breast cancer outpatient clinic
  - Oncologist
  - Radiotherapist
  - Plastic surgeon
  - Psychologist
  - Sexologist
  - Social worker
  - Someone else: \_\_\_\_\_
30. How did you receive information about intimacy and sexuality? (*multiple answers possible*)
- Patient flyer
  - Via other (breast) cancer patients
  - By an information moment for patients with breast cancer
  - By Dutch Breast cancer Society (Borstkankervereniging Nederland)
  - By Dutch Cancer Society (KWF Kankerbestrijding)
  - By a web page about breast cancer and sexuality



- In a conversation with a healthcare professional
- Other: \_\_\_\_\_
31. Did you actively searched for information about intimacy and sexuality? *(multiple answers possible)*
- No, I didn't searched for information
- Yes, on the internet
- Yes, via Dutch Breast cancer Society (Borstkankervereniging Nederland)
- Yes, Dutch Cancer Society (KWF Kankerbestrijding)
- Yes, Via other (breast) cancer patients
- Yes, via family or friends
- Other: \_\_\_\_\_
32. Are you satisfied with the information about intimacy and sexuality?
- Yes, **go to question 34**
- No, **go to question 33**
- Inapplicable, **go to question 34**
33. What could have been better about the information? *(multiple answers possible)*
- The amount was insufficient
- The information was too general, it was not about my situation
- The content of the information was incorrect
- The moment of the information was too late
- The moment of informatie was too early
- I have asked for information, but I didn't receive any
- The healthcare professional should have given me the information
- I have no need for information
- Other: \_\_\_\_\_
34. What is, according to you, the best way of receiving information about intimacy and sexuality? *(multiple answers possible)*
- Patient flyer
- Via an application on a tablet or phone (E-health)
- By a web page about breast cancer and sexuality
- By Dutch Breast cancer Society (Borstkankervereniging Nederland)
- By Dutch Cancer Society (KWF Kankerbestrijding)
- By a patient forum on the internet
- By a group meeting with other patients lead by a healthcare professionals
- In a conversation with other (breast) cancer patients
- In a conversation with a healthcare professional
- None, I have no need for information
- Other: \_\_\_\_\_
35. At which moment, during treatment, would you prefer to receive information about intimacy and sexuality? *(multiple answers possible)*
- At the same time as the diagnosis breast cancer
- Before chemotherapy before surgery
- Before the operation
- After the operation
- Before the additional treatment\*
- During the additional treatment
- At the end of all treatments
- Other: \_\_\_\_\_

*\*With additional treatment is meant chemotherapy, radiotherapy and/or endocrine therapy*

**Part 5: Discussing intimacy and sexuality with a healthcare professional**

36. Who should, according to you, initiate the discussing about intimacy and sexuality?
- Me
  - My partner
  - General practitioner
  - Surgeon
  - Nurse on the breast cancer outpatient clinic
  - Oncologist
  - Radiotherapist
  - Plastic surgeon
  - I don't want to discuss the subject
  - Other: \_\_\_\_\_
37. With which health care professional would you prefer discussing intimacy and sexuality? (*multiple answers possible*)
- General practitioner
  - Surgeon
  - Nurse on the breast cancer outpatient clinic
  - Oncologist
  - Radiotherapist
  - Plastic surgeon
  - Psychologist
  - Sexologist
  - Social worker
  - I don't want to discuss the subject with a health care professional
  - Other: \_\_\_\_\_
38. What was for you a reason **not** to start a conversation about intimacy and sexuality with a health care professional? (*multiple answers possible*)
- Inapplicable, I did ask my questions about intimacy and sexuality
  - I have no need
  - A feeling of shame
  - Intimacy and sexuality are private
  - I am too sick for discussing intimacy and sexuality
  - There is nothing to do about it
  - Intimacy and sexuality are no priority
  - I would rather discuss this subject with my partner
  - I don't have a partner
  - The health care professional is too busy
  - The health care provider didn't initiate the discussion
  - The health care professional was not open for discussing this subject
  - The health care professionals is a man
  - The age of the health care professional
  - This subject doesn't belong to a health care professional
  - Lack of privacy, I was with my partner
  - Lack of privacy, I was with friends/family
  - Lack of privacy, due to other health care professionals (for example an intern)
  - Other: \_\_\_\_\_
39. Statement: Every breast cancer patient should offered a conversation about intimacy and sexuality, **before treatment.**
- Agree

- Disagree  
 I don't know
40. Statement: : Every breast cancer patient should offered a conversation about intimacy and sexuality, **during treatment.**
- Agree  
 Disagree  
 I don't know
41. Statement: : Every breast cancer patient should offered a conversation about intimacy and sexuality, **after treatment.**
- Agree  
 Disagree  
 I don't know
42. At which state of treatment would you prefer to talk about intimacy and sexuality? (*multiple answers possible*)
- At the same time as the diagnosis breast cancer  
 Before chemotherapy before surgery  
 Before the operation  
 After the operation  
 Before the additional treatment\*  
 During the additional treatment  
 At the end of all treatments  
 I don't want to discuss the subject  
 Other: \_\_\_\_\_

*Results of this research*

43. Would you prefer a meeting with other patients on intimacy and sexuality after breast cancer? The results of this research will be discussed anonymously.
- Yes  
 No
44. In response to this research, we are willing to invite patients for an individual conversation about intimacy and sexuality. Might we invite you for a conversation?
- Yes  
 No

**Part 6: Questions about your relationship**

**If you didn't have a partner at time of breast cancer or treatment, then you completed the questionnaire.**

45. I have a relationship with a:
- Man  
 Woman
46. Did you have a relationship **before** you were diagnosed with breast cancer?
- Yes, **go to question 48**  
 No, **go to question 52**
47. Did the **diagnosis breast cancer** had an impact on the quality of the relationship with your partner?
- Yes, the quality increased  
 Yes, the quality declined  
 Yes, my relationship is broken  
 No, the quality didn't change

48. Did **body changes** as a result of the breast cancer treatment had an impact on the quality of the relationship with your partner?
- Yes, the quality increased
  - Yes, the quality declined
  - Yes, my relationship is broken
  - No, the quality didn't change
  - No, my body didn't change
49. Did new complaints on intimacy or sexuality had an impact on the quality of the relationship with your partner?
- No impact
  - Negative impact
  - Positive impact
  - Inapplicable, I don't had any complaints
50. Did you discuss possible effects of the breast cancer treatment on intimacy and sexuality with your partner?
- Yes
  - No, but I would have liked to discuss it
  - No, no need to
51. Is it important to you that your partner is present when discussing the subject intimacy and sexuality with a healthcare professional?
- Yes
  - No
52. Statement: The partner of every breast cancer patient should be offered a conversation about intimacy and sexuality.
- Agree
  - Disagree
  - I don't know
53. How would your partner support you with possible complaints in the area of intimacy and sexuality? *(multiple answers possible)*
- By exerting as few pressure as possible on sexuality
  - To talk about sexuality
  - To reassure me when a sexual attempt contact fails
  - By not losing intimacy
  - To be involved as much as possible with my sexual complaints
  - By discovering intimacy and sexuality in another way I don't know
  - Inapplicable, I don't had any complaints
  - Other: \_\_\_\_\_
54. How do you plan to support your partner with possible complaints in the area of intimacy and sexuality? *(multiple answers possible)*
- To talk about sexuality
  - By not losing intimacy
  - To involve my partner as much as possible by my sexual complaints
  - By discovering intimacy and sexuality in another way
  - Inapplicable, I don't had any complaints
  - I don't know
  - Other: \_\_\_\_\_
55. Would you have liked to receive professional help with complaints on intimacy or sexuality?

- Yes
- No
- Inapplicable, I don't had any complaints

56. Please check the box which is most applicable to you

	Totally disagree	Disagree	Neutral	Agree	Totally agree
1. My partner and I can talk well about our mutual feelings					
2. I often take the time to listen to my partner					
3. My partner and I can discuss everything					
4. We try to resolve disagreements with a calm conversation					
5. Disagreements often lead to an argument					
6. My partner tend to boss me					
7. I would like to have sex more often with my partner					
8. My partner and I can talk easily about our sexual desires and needs					
9. I am satisfied with our sex life					
10. I have a good relationship with my partner					
11. I am felling annoyed with my partner					
12. I am happy with my partner					

**Thank you for participating in this research.**

You can return the questionnaire to attached envelope (no stamp required).

**Appendix 6.**

**Questionnaire chapter 5, part 2**

**Questionnaire partner (translated from Dutch)**

Choose the most suitable answer. Thank you in advance for your effort.

**Part 1: demographics**

1. What is your age? \_\_\_\_\_ years
2. What is your ethnicity?  
 Dutch  
 Other: \_\_\_\_\_
3. What is your gender?  
 Male  
 Female
4. Level of education?  
 Elementary school  
 Middle school  
 High school  
 College  
 University  
 Other:.....
5. Are you currently employed?  
 Yes  
 No, I am in between jobs  
 No, not able to work due to my illness  
 No, I am retired  
 Other: \_\_\_\_\_

**Part 2: Diagnosis and treatment**

6. Did you already have a relationship **before** she was diagnosed with breast cancer?  
 Yes, **go to question 7**  
 No, **go to question 11**
7. To what extent were you concerned about your health when you heard the diagnosis breast cancer?  
 No concerns  
 Some concerns  
 Many concerns  
 Grave concerns
8. Have your concerns changes **after** treatment?  
 Yes, my concerns are increased  
 Yes, my concerns are declined  
 No, my concerns didn't change  
 No, I had no concerns
9. Did the **diagnosis breast cancer** had an impact on the quality of the relationship with your partner?  
 Yes, the quality increased  
 Yes, the quality declined

- Yes, my relationship is broken
  - No, the quality didn't change
10. Did **body changes** as a result of the breast cancer treatment had an impact on the quality of the relationship with your partner?
- Yes, the quality increased
  - Yes, the quality declined
  - Yes, my relationship is broken
  - No, the quality didn't change
  - No, my body didn't change
11. If your partner is breast cancer-free, are you afraid that the breast cancer may come back?
- Inapplicable
  - Not afraid
  - A bit afraid
  - Afraid
  - Very afraid

**Part 3: Your experience about intimacy and sexuality after disease**

12. Did you discuss possible effects of the breast cancer treatment on intimacy and sexuality with your partner?
- Yes
  - No, but I would have liked to discuss it
  - No, no need to
13. Did you experience complaints in intimacy or sexuality before the diagnosis breastcancer?
- Yes, **go to question 14**
  - No, **go to question 17**
14. Did new complaints on intimacy or sexuality had an impact on the quality of the relationship with your partner?
- No impact
  - Negative impact
  - Positive impact
  - Inapplicable, I don't had any complaints
15. On a scale of 0-10, in which amount did you suffer from these complaints?  
0 means no suffering, 10 means a lot of suffering  
Grade: .....
16. To what extent did you find it difficult to handle changes in intimacy and sexuality within your relationship?
- No difficulties
  - A little difficult
  - Difficult
  - Very difficult
  -

**Part 4: Information about intimacy and sexuality**

17. Did you need information about possible intimacy or sexuality complaints due to breast cancer and treatment?

- Yes
- No

18. Did you at some point receive any information about intimacy and sexuality and possible complaints due to treatment of your partner?

- Yes, **go to question 19**
- No, **go to question 23**

19. At what stage did you receive the information about intimacy and sexuality? (*multiple answers possible*)

- At the same time as the diagnosis breast cancer
- Before chemotherapy before surgery
- Before the operation
- After the operation
- Before the additional treatment\*
- During the additional treatment
- At the end of all treatments
- Other: \_\_\_\_\_

20. Did you have to ask for information about intimacy or sexuality?

- Yes, I had to ask for this information by myself
- No, the care provider gave the information from
- No, it was clear to me where I could find information (for example a flyer or on the web)

21. Who gave you the information about intimacy and sexuality? (*multiple answers possible*)

- General practitioner
- Surgeon
- Nurse on the breast cancer outpatient clinic
- Oncologist
- Radiotherapist
- Plastic surgeon
- Psychologist
- Sexologist
- Social worker
- Someone else: \_\_\_\_\_

22. How did you receive information about intimacy and sexuality? (*multiple answers possible*)

- Patient flyer
- Via other (breast) cancer patients
- By an information moment for patients with breast cancer
- By Dutch Breast cancer Society (Borstkankervereniging Nederland)
- By Dutch Cancer Society (KWF Kankerbestrijding)
- By a web page about breast cancer and sexuality
- In a conversation with a healthcare professional
- Other: \_\_\_\_\_

23. Did you actively searched for information about intimacy and sexuality? (*multiple answers possible*)

- No, I didn't searched for information
- Yes, on the internet
- Yes, via Dutch Breast cancer Society (Borstkankervereniging Nederland)
- Yes, Dutch Cancer Society (KWF Kankerbestrijding)
- Yes, Via other (breast) cancer patients
- Yes, via family or friends
- Other: \_\_\_\_\_



24. Are you satisfied with the information about intimacy and sexuality?
- Yes, **go to question 26**
  - No, **go to question 25**
  - Inapplicable, **go to question 26**
25. What could have been better about the information? (*multiple answers possible*)
- The amount was insufficient
  - The information was too general, it was not about my situation
  - The content of the information was incorrect
  - The moment of the information was too late
  - The moment of information was too early
  - I have asked for information, but I didn't receive any
  - The healthcare professional should have given me the information
  - I have no need for information
  - Other: \_\_\_\_\_
26. What is, according to you, the best way of receiving information about intimacy and sexuality?  
(*multiple answers possible*)
- Patient flyer
  - Via an application on a tablet or phone (E-health)
  - By a web page about breast cancer and sexuality
  - By Dutch Breast cancer Society (Borstkankervereniging Nederland)
  - By Dutch Cancer Society (KWF Kankerbestrijding)
  - By a patient forum on the internet
  - By a group meeting with other patients lead by a healthcare professionals
  - In a conversation with other (breast) cancer patients
  - In a conversation with a healthcare professional
  - None, I have no need for information
  - Other: \_\_\_\_\_
27. At which moment, during treatment, would you prefer to receive information about intimacy and sexuality? (*multiple answers possible*)
- At the same time as the diagnosis breast cancer
  - Before chemotherapy before surgery
  - Before the operation
  - After the operation
  - Before the additional treatment\*
  - During the additional treatment
  - At the end of all treatments
  - Other: \_\_\_\_\_

**Part 5: Discussing intimacy and sexuality with a healthcare professional**

28. Is it important to you that you are present when the subject intimacy and sexuality is discussed by a healthcare professional?
- Yes
  - No
29. Statement: **The partner** of every breast cancer patient should be offered a conversation about intimacy and sexuality.
- Agree
  - Disagree

I don't know

30. With which health care professional would you prefer discussing intimacy and sexuality? (*multiple answers possible*)

- General practitioner
- Surgeon
- Nurse on the breast cancer outpatient clinic
- Oncologist
- Radiotherapist
- Plastic surgeon
- Psychologist
- Sexologist
- Social worker
- I don't want to discuss the subject with a health care professional
- Other: \_\_\_\_\_

31. At which state of treatment would you prefer to talk about intimacy and sexuality? (*multiple answers possible*)

- At the same time as the diagnosis breast cancer
- Before chemotherapy before surgery
- Before the operation
- After the operation
- Before the additional treatment\*
- During the additional treatment
- At the end of all treatments
- I don't want to discuss the subject
- Other: \_\_\_\_\_

32. Would you have liked to receive professional help with complaints on intimacy or sexuality?

- Yes
- No
- Inapplicable, I don't had any complaints

#### **Part 6: Questions about your relationship**

33. How would your partner support you with possible complaints in the area of intimacy and sexuality? (*multiple answers possible*)

- By exerting as few pressure as possible on sexuality
- To talk about sexuality
- To reassure me when a sexual attempt Door gerust te stellen als een poging tot seksueel contact fails
- By not losing intimacy
- To be involved as much as possible with my sexual complaints
- By discovering intimacy and sexuality in another way I don't know
- Inapplicable, I don't had any complaints
- Other: \_\_\_\_\_

34. How do you plan to support your partner with possible complaints in the area of intimacy and sexuality? (*multiple answers possible*)

- To talk about sexuality
- By not losing intimacy
- To involve my partner as much as possible by my sexual complaints

- By discovering intimacy and sexuality in another way
- Inapplicable, I don't had any complaints
- I don't know
- Other: \_\_\_\_\_

35. Please check the box which is most applicable to you

	Totally disagree	Disagree	Neutral	Agree	Totally agree
1. My partner and I can talk well about our mutual feelings					
2. I often take the time to listen to my partner					
3. My partner and I can discuss everything					
4. We try to resolve disagreements with a calm conversation					
5. Disagreements often lead to an argument					
6. My partner tend to boss me					
7. I would like to have sex more often with my partner					
8. My partner and I can talk easily about our sexual desires and needs					
9. I am satisfied with our sex life					
10. I have a good relationship with my partner					
11. I am felling annoyed with my partner					
12. I am happy with my partner					

36. Would you prefer a meeting with other patients on intimacy and sexuality after breast cancer? The results of this research will be discussed anonymously.

- Yes
- No

37. In response to this research, we are willing to invite patients for an individual conversation about intimacy and sexuality. Might we invite you for a conversation?

- Yes
- No

If you answered 'yes' to question 36 or 37, you might fill in you contact details. It might take a while before we will contact you. You always can decide not to participate later on.

Name/address/email

**Thank you for participating in this research.**

You can return the questionnaire to attached envelope (no stamp required).

**Appendix 7. Questionnaire chapter 6**

**Questionnaire medical oncologists (translated from Dutch).**

*Demographics*

1. What is your gender? M/F
2. What is your age? . . . . . years
3. What is your function?
  - Oncologist
  - Haematologist
  - Oncologist-in-training (resident)
  - Haematologist-in-training (resident)
4. What is/are your area(s) of specialization?
  - Breast
  - Colorectal
  - Gynaecology
  - Hematology
  - Head and neck
  - Dermatology
  - Lung
  - Lymphoma
  - Nephro- and urology
  - Neuro-endocrine
  - Sarcoma
  - Palliative care
  - Other:.....
5. Where do you work?
  - Academic hospital
  - District general teaching hospital
  - District general hospital
  - Cancer institute
  - Academic and district general teaching hospital or district general hospital
6. How long do you practice as an oncologist?
  - < 1 year
  - 1-2 year
  - 3-5 year
  - 6-10 year
  - 11-15 year
  - > 15 year

*Sexual function*
7. In your current workplace, which percentage of the patients do you estimate to experience changed sexual function due to therapy \_\_\_\_\_ %

8. How often do you discuss the sexual function of the patient?

- Never / almost never
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Almost always / always

9. During the informing of patients about the possible consequences of therapy (informed consent), do you also inform about the possible consequences on sexual functioning?

- Never / almost never
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Almost always / always

10. How often do you believe the oncology nurse discusses sexual function with patients?

- Never / almost never
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Almost always / always

11. Who has the responsibility for discussing sexual function? (multiple answers possible)

- The patient has to raise the subject by itself.
- The partner of the patient
- Oncologist
- Oncology nurse
- General practitioner
- Social work
- Psychologist
- Physical therapist
- Other: .....

If you never discuss sexual function, go to question 22.

12. If you discuss sexual function, with which patients would you do so? (multiple answers possible)

Patients with:

- Breast tumours
- Colorectal tumours
- Gynaecology tumours
- Hematology tumours
- Head and neck tumours
- Skin tumours
- Lung tumours
- Lymphoma
- Nephrologic tumours
- Neuro-endocrine tumours
- Urologic tumours
- Sarcoma
- Palliative care
- Independent of tumour type
- I don't discuss sexual function
- Other:.....

13. With which type of treatment patients do you discuss sexual function? (multiple answers possible)

- Treatment with intent to cure.
- Life-prolonging treatment.
- Palliative treatment.
- Other:.....

14. Could you please denote in the subsequent table how often you discuss sexual function with patients from the mentioned age categories?

	Never	Rarely	Regularly	Often
16-35 year				
36-50 year				
51-65 year				
66-75 year				
76 year and older				

15. Which percentage of your patients did you refer in the past year to a physician or other professional for support of sexual problems or for answering question concerning sexual function? \_\_\_\_\_%

16. How often present patients sexual functioning complaints spontaneously?

- Never/ rarely
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Often/ always

17. How often do you make sure that sexual function is discussed with a new patient?

- Never/ rarely
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Often/ always

18. How much knowledge do you possess on sexual dysfunction resulting from cancer treatment?

- No knowledge at all
- Not so much knowledge
- Some knowledge
- Sufficient knowledge
- A lot of knowledge

19. In which way do you discuss the subject? (multiple answers possible)

- I don't ask for it but I tell something about it.
- Patient raises the subject
- Addressing possible sexual side effects
- Closed questions

- Open questions
- Ask if the patient has questions about it
- Use a sense of humour
- I hardly or never discuss the subject.

20. If you discuss sexual functioning, what do you ask a female patient? (multiple answers possible)

- Fatigue
- Fear
- Not being able to enjoy
- Decreased libido
- Insufficient lubrication
- Dyspareunia
- Reaching an orgasm
- Insecurity due to changed self-concept
- Insecurity due to changed appearance
- Menopause symptoms
- Sexual abuse
- Other:.....

21. What do you ask a male patient? (multiple answers possible)

- Fatigue
- Fear
- Not being able to enjoy
- Decreased libido
- Erectile dysfunction
- Reaching an orgasm
- Insecurity due to changed self-concept
- Insecurity due to changed appearance
- Sexual abuse
- Other:.....

22. Do you discuss sexual function during follow-up?

- Never/ rarely
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Often/ always

23. Do you ever describe phosphodiesterase inhibitor (Viagra or Cialis) to patients with erectile dysfunction?

- Never/ rarely
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Often/ always

24. Is in your department sufficient information on sexual function available to provide the patient with?

- Yes
- No
- I don't know

25. If you discuss sexual function, do you ask for the sexual orientation of the patient? (Homosexual, lesbienne, bisexual?)

- Never/ rarely
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Often/ always

26. If you discuss sexual function, do you discuss concerns on ‘contagiousness’ of cancer during intercourse? (i.e. meaning the transmittance of cancer during intercourse; in case of for example testis-, penis- or cervix tumours)

- Never/ rarely
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Often/ always

27. Are problems on sexual function of the patients discussed during the multidisciplinary meetings?

- Yes
- No

28. Is it from your department or from a protocol an obligation to discuss sexual function at any time?

- Yes
- No
- I don’t know

29. Is it from your department clear who is responsible to discuss sexual function with the patient?

- Yes
- No
- I don’t know

30. If you discuss sexual function, do you discuss the possible transmitting of chemotherapy agents to the partner during intercourse?

- Never/ rarely
- In fewer than half of the cases
- In half of the cases
- In more than half of the cases
- Often/ always

31. In the subsequent table are reasons that possibly keep you from discussing sexual function with your patients. To which extent do you agree with the statements? Please circle one square per statement.

	<b>Totally disagree</b>	<b>Disagree</b>	<b>Partly agree/partly disagree</b>	<b>Agree</b>	<b>Totally agree</b>
Lack of time					
Lack of knowledge					
Lack of training					
It is someone else’s task					



Patient is not ready to discussing sexual health					
Surviving is more important					
Concerned about causing the patient discomfort					
Reasons related to culture/religion					
Reasons related to language/ethnicity					
Age difference between you and patient					
Afraid to offend the patient					
Sexuality is not a patient's concern					
Not relevant for all type of cancers					
Patient is the opposite gender					
No angle or motive for asking					
Embarrassment					
Advanced age of the patient					
Sexuality is a private matter					
I feel uncomfortable					
Patient is too ill					
Patient is the same gender					
Patient doesn't bring up the subject					
No confidence in treatment for sexual dysfunction					
Sexuality is not a matter of life or death					

Colleagues think it is inappropriate if I discuss SF with patients					
Presence of a third party					

32. The oncologist carries responsibility for discussing sexual function with patients.

- Totally agree
- Agree
- Disagree
- Totally disagree
- I don't know

33. The oncology nurse carries responsibility for discussing sexual function with patients.

- Totally agree
- Agree
- Disagree
- Totally disagree
- I don't know

34. Do you think it is important to screen for sexual concerns of cancer patients?

- Very important
- Important
- Rather important
- Slightly important
- Not important

35. With which patients do you believe sexual function should be discussed at least once? (multiple answers possible)

Patients with:

- Breast tumours
- Colorectal tumours
- Gynaecology tumours
- Hematology tumours
- Head and neck tumours
- Skin tumours
- Lung tumours
- Lymphoma
- Nephrologic tumours
- Neuro-endocrine tumours
- Urologic tumours
- Sarcoma
- Palliative care
- Independent of tumour type
- I believe discussing sexual function is not necessary.
- Other:.....

36. Do you believe there is enough attention for sexual problems and counselling during the current oncology training?

- Yes
- No

37. Do you feel the need to extend your knowledge on discussing sexual function with your patients?

- Yes
- No

*(Questions on fertility assessment were located in this area but have been removed in this Appendix as they have not been used for this research proposal)*

**Thank you very much for participating!**

## Appendix 8.

### Questionnaire chapter 7, part 1

#### Questionnaire AYAs (translated from Dutch).

##### Part 1: Demographics

1. What is your age? \_\_\_\_\_ years
2. What is your gender?
  - Male
  - Female
3. Are you in a relationship?
  - No, I am single, continue with question 5
  - Yes, living apart, continue with question 4
  - Yes, living together, continue with question 4
  - Yes, married, continue with question 4
  - Other, \_\_\_\_\_
4. If you are in a relationship, for how long? \_\_\_\_\_ years
5. Do you have children?
  - Yes
  - No
6. What is your highest level of education?
  - None/primary education
  - Lower vocational education (VMBO/MAVO/LBO)
  - Intermediate vocational education (MBO)
  - Higher secondary education (HAVO/VWO)
  - Higher education (HBO/WO)
7. Do you have a job?
  - Yes, \_\_\_\_\_ hours per week (average)
  - No, job seeking
  - No, not possible due to illness
  - No, I am a student
  - Other, \_\_\_\_\_

##### Part 2: Diagnosis and treatment

8. What type of cancer do/did you have?
  - Brain cancer
  - Breast cancer
  - Colorectal cancer
  - Gynaecological cancer
  - Hematological cancer
  - Sarcoma
  - Skin cancer
  - Testicular cancer
  - Thyroid cancer
  - Other, \_\_\_\_\_
9. How long ago did you receive your diagnosis?
  - 0-3 months
  - 3-6 months

- 6 months - 1 year
- 1-2 years
- 2-4 years
- 5-10 years
- >10 years

10. How old were you when you received your diagnosis? \_\_\_\_\_ years

11. What treatments did you undergo? (*multiple answers possible*)

- Chemotherapy
- Hormonal therapy
- Immunotherapy
- Operation
- Radiotherapy
- Other, \_\_\_\_\_

**Part 3: Perception of intimacy and sexuality**

12. Did your disease or treatment have a negative influence on your sexuality?

- Yes, continue with question 13
- No, continue with question 15

13. Which of the items below has (temporarily) influenced your sexuality? (*multiple answers possible*)

- Difficulty with orgasm
- Emotional lability
- Erectile dysfunction
- Fatigue
- Fear around sex
- Fertility issues
- Less sexual desire
- Lower lubrication
- No more pleasure from sex
- Pain during intercourse
- Scared to disappoint partner
- Self-uncertainty due to changed appearance
- Self-uncertainty due to changed self-image
- Other, \_\_\_\_\_

14. Do you find it difficult to deal with changes around your sexuality?

- Not difficult
- Slightly difficult
- Difficult
- Very difficult

**Part 4: Provided information on intimacy and sexuality**

15. Do you find it important that good information is available about the possible effects of the treatment on sexuality?

- Important
- Not important
- Impartial

16. Did you ever receive information from a health care professional about the effects of the disease and treatment on sexuality?

- Yes
- No, continue with question 23

17. At what moment did you receive this information? (*multiple answers possible*)

- At the moment of diagnosis
- During treatment
- After treatment
- During follow-up

18. Did you have to ask for this information yourself?

- Yes, I had to ask for this information myself
- No, the health care professional provided me with this information
- No, it was clear to me where to find this information (for example in a folder or on the internet)

19. Which health care professional provided you with the information about intimacy and sexuality? (*multiple answers possible*)

- Physician
- Nurse practitioner
- Nurse in the department
- Psychologist
- Sexologist
- Social worker
- Other, \_\_\_\_\_

20. How did you receive information about intimacy and sexuality? (*multiple answers possible*)

- Via a conversation with a health care professional
- Via leaflets
- Via fellow AYAs
- Via an organised meeting at the hospital
- Via a general website
- Via the AYA website/'Young and Cancer' platform
- Via social media
- Other, \_\_\_\_\_

21. Were your parents present when you received information about intimacy and sexuality?

- Yes
- No, continue with question 23

22. If your parents were present, what did you think of that?

- Uncomfortable
- Annoying
- No problem
- Reassuring
- Easy
- Fine

23. Did you ever actively search for information? (*multiple answers possible*)

- No, I did not search for information
- Yes, directly via the AYA website ([www.aya4net.nl](http://www.aya4net.nl))
- Yes, directly via the website [www.kankerenseks.nl](http://www.kankerenseks.nl)
- Yes, via social media
- Yes, via fellow AYAs
- Yes, via family/friends/acquaintances
- Other, \_\_\_\_\_

24. What could be improved about the information on intimacy and sexuality? (*multiple answers possible*)
- Nothing, I was satisfied with the information
  - The amount of information did not suffice
  - The information was too general, it was not about my situation
  - The content of the information was wrong
  - The moment of information supply was too late
  - The moment of information supply was too early
  - I asked for information, but did not receive any
  - The health care professional should have provided me with the information
  - Other, \_\_\_\_\_
25. What is, in your opinion, the best way to receive information on intimacy and sexuality? (*multiple answers possible*)
- Via leaflets
  - Via a website
  - Via (online) videos
  - Via an online forum or blog
  - Via group sessions with fellow AYAs, guided by a psychologist
  - Via an app
  - Via social media - cross out which you would not use:
  - Facebook, Instagram, Pinterest, Twitter
  - Via a conversation with fellow AYAs
  - Via a conversation with a health care professional
  - I do not need information
  - Other, \_\_\_\_\_
26. What/which moment(s) would, in your opinion, be most suited to receive information about the effects of the disease and treatment on intimacy and sexuality? (*multiple answers possible*)
- Before treatment
  - During treatment
  - After treatment
  - 3 months after treatment
  - 6 months after treatment
  - 9 months after treatment
  - 1 year after treatment
  - Other, \_\_\_\_\_

**Part 5: Addressing intimacy and sexuality with the health care professional**

27. Has the subject of intimacy and sexuality sufficiently been discussed by the health care professional?
- Yes
  - No, but I have/had the need to talk about it
  - No, but I do/did not have the need to talk about it
28. Who is, in your opinion, most suited to discuss intimacy and sexuality with?
- My partner
  - Physician
  - Nurse practitioner
  - Nurse in the department
  - Psychologist
  - Sexologist
  - Social worker
  - I rather discuss it anonymously
  - Other, \_\_\_\_\_

29. If intimacy and sexuality were not discussed, what was the reason you did not initiate the conversation with the health care professional yourself? (*multiple answers possible*)

- N/A, I did initiate the conversation
- I do not want to talk about it
- Feeling of shame
- Intimacy and sexuality is private
- I am too sick to discuss intimacy and sexuality
- Nothing can be done about it
- Intimacy and sexuality are not my priority
- I rather discuss it with my partner
- I do not have a partner
- The health care professional is too busy
- The health care professional does not initiate the conversation
- The health care professional does not seem open to this
- The health care professional is from the opposite gender
- The age of the health care professional
- This is no task for the health care professional
- Lack of privacy, my partner was present during the conversation
- Lack of privacy, my parents were present during the conversation
- Lack of privacy, other health care professionals were present during the conversation
- Other, \_\_\_\_\_

30. Are you satisfied with the information you received on the items below?

Information on..	Satisfied	Impartial	Dissatisfied	Not received
Consequences of treatment on sexuality				
Where to find relevant information				
How to deal with sexual issues				
Which health care professional to approach in case questions occur				
Professional help with sexual issues				
Sexual tools				
Information for partners				
<i>Other suggestions:</i>				

31. For which of the items below do you find the availability of information important?

Information on..	Important	Impartial	Not important
Consequences of treatment on sexuality			
Where to find relevant information			
How to deal with sexual issues			
Which health care professional to approach in case questions occur			
Professional help with sexual issues			
Sexual tools			
Information for partners			
<i>Other suggestions:</i>			

#### Part 6: Relationships

32. Are you currently in a relationship?

- Yes, continue with question 35
- No, continue with question 33



33. Does the disease have an impact on starting a new relationship?
- Yes
  - No
  - I don't know
34. Do problems or uncertainty with fertility have an impact on starting a new relationship?
- Yes
  - No
  - I don't know

*If you did not have a partner at the moment of diagnosis or during treatment, you are now finished with the questionnaire.*

35. Were you in a relationship at the moment of diagnosis?
- Yes, continue with question 36
  - No, continue with question 38
36. Did sexual problems, as a result of the diagnosis or treatment, influence your relationship with your partner?
- No influence
  - Negative influence
  - Positive influence
  - N/A, I do not experience sexual problems
37. Have you discussed possible effects of the cancer treatment on intimacy and sexuality with your partner?
- Yes
  - No, because \_\_\_\_\_
  - No, there is no need of
38. Do you find it important to have your partner present when discussing intimacy and sexuality with a health care professional?
- Yes
  - No
  - I don't know
39. Is there enough information about intimacy and sexuality available for partners?
- Yes
  - No
  - I don't know

**Thank you very much for participating!**

You can find more information on this subject via <https://sickandsex.nl>

**Appendix 9.**

**Questionnaire chapter 7, part 2**

**Questionnaire healthcare professionals (translated from Dutch).**

**Part 1: Demographics**

1. What is your gender?

- Male
- Female

2. What is your age? \_\_\_\_\_ years

3. What is your function?

- Medical specialist
- Oncologist/internist-in-training (resident)
- Nurse specialized in AYA care
- Nurse practitioner
- Oncology nurse
- Social worker
- Other, \_\_\_\_\_

4. Time of practice in the area of oncology, including your education?

- 0-11 months
- 1-2 years
- 3-5 years
- 6-10 years
- 11-15 years
- >15 years

5. Where do you work? (*multiple answers possible*)

- Academic hospital
- General teaching hospital
- District general hospital
- Independent extramural practice
- Extramural group practice
- Other, \_\_\_\_\_

6. Did you follow a course/training on sexuality in AYAs or oncology patients in general?

- Yes, specifically for AYAs
- Yes, on cancer and sexuality in general
- No

**Part 2: The discussion of sexuality with AYAs**

7. How often do you discuss sexuality with a new AYA?

- Never
- In less than half of the cases
- In half of the cases
- In more than half of the cases
- Always

8. How often do you discuss sexuality with an AYA during follow-up?

- Never
- In less than half of the cases
- In half of the cases
- In more than half of the cases
- Always

9. Can you mark in the table below how often you discuss sexuality in the following age categories:

	Never	In less than half of the cases	In half of the cases	In more than half of the cases	Always
18 years					
19 – 25 years					
25 – 30 years					
> 30 years					

10. Can you mark in the table below how often you discuss sexuality with:

	Never	In less than half of the cases	In half of the cases	In more than half of the cases	Always
Male patients					
Female patients					

11. Can you mark in the table below how often you discuss sexuality in the following AYA subgroups:

	Never	In less than half of the cases	In half of the cases	In more than half of the cases	Always	N/A, I don't see these patients
Brain cancer						
Breast cancer						
Colorectal cancer						
Gynaecological cancer						
Hematological cancer						
Sarcoma						
Skin cancer						
Testicular cancer						

Thyroid cancer						
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12. Can you mark in the table below how often you discuss sexuality with patients:

	Never	In less than half of the cases	In half of the cases	In more than half of the cases	Always
In curative setting					
In palliative setting					
In terminal setting					

13. Do AYAs present sexual questions or complaints on their own initiative?

- Never
- In less than half of the cases
- In half of the cases
- In more than half of the cases
- Always

14. If you discuss sexuality with an AYA, how do you do this?

- I do not/rarely discuss sexuality
- I discuss this during the first consult
- I discuss this during a follow-up consult
- I make a separate appointment
- Someone else from the treatment team usually discusses this
- I refer someone
- Other, \_\_\_\_\_

15. If you discuss sexuality, how often do you discuss this when the AYAs' parents are present?

- I do not/rarely discuss sexuality
- Never
- In less than half of the cases
- In half of the cases
- In more than half of the cases
- Always

16. Do you find it important to have the partner present when discussing sexuality?

- Yes, I always ask the partner to attend the conversation
- I leave the choice with the patient and/or partner
- No, I prefer to discuss this separately with the patient
- No, I do not/rarely discuss sexuality
- Other, \_\_\_\_\_

17. Do you discuss the influence of the disease on the relationship between the AYA and partner?

- Never
- In less than half of the cases
- In half of the cases
- In more than half of the cases
- Always

18. If you discuss sexual functioning with a **man**, what do you discuss? *(multiple answers possible)*

- Difficulty with orgasm
- Emotional lability
- Erectile dysfunction
- Fatigue
- Fear around sex
- Hormonal changes
- Less sexual desire
- No more pleasure from sex
- Pain during intercourse
- Self-uncertainty due to changed appearance
- Self-uncertainty due to changed self-image
- Side-effects of medication
- Other, \_\_\_\_\_

19. If you discuss sexual functioning with a **woman**, what do you discuss? *(multiple answers possible)*

- Difficulty with orgasm
- Emotional lability
- Fatigue
- Fear around sex
- Hormonal changes
- Less sexual desire
- Lower lubrication
- No more pleasure from sex
- Pain during intercourse
- Self-uncertainty due to changed appearance
- Self-uncertainty due to changed self-image
- Side-effects of medication
- Other, \_\_\_\_\_

20. The list below shows a number of reasons that may prevent you from discussing sexuality with patients. To which extent do you agree with the statements? Please mark one square per statement.

	Totally disagree	Disagree	Partly agree/partly disagree	Agree	Totally agree
Lack of time					
Lack of knowledge					
Lack of training					
It's someone else's task					
AYA is not ready to discuss sexuality					
Sexuality is not a patient's concern					
AYA is too ill					

Reasons related to culture/religion					
Reasons related to language/ethnicity					
AYA's parents are present					
AYA's partner is present					
Age difference between you and AYA					
Sexuality is a private matter					
Presence of a third party					
AYA is the opposite gender					
I feel uncomfortable					
Afraid to offend the AYA					
Not feeling a connection with the AYA					
No angle or reason for asking					
AYA doesn't bring up the subject					
AYA doesn't have a partner					
No resources to refer the AYA					
My workplace is not quiet					

21. Is there a protocol from your centre where the discussion of sexuality is included?

- Yes
- No
- I don't know

22. Is it from your department clear who is responsible for discussing sexuality with the AYA?

- Yes, namely \_\_\_\_\_
- No
- I don't know

23. Is in your current workspace sufficient information available on sexuality to provide the AYA with?
- Yes
  - No
24. Which percentage of the AYAs did you refer in the past year to a physician or other health care professional for support of sexual problems? \_\_\_\_\_ %
25. If you refer an AYA for support of sexual problems, to whom do you refer them?
- I never refer an AYA
  - Oncologist/head practitioner
  - Urologist
  - Gynaecologist
  - Sexologist
  - Psychologist
  - Nurse
  - General practitioner
  - Other, \_\_\_\_\_

**Part 3: Knowledge about sexual changes due to treatment**

26. Do you think it is important to discuss the influence of treatment on sexuality?
- Very important
  - Important
  - Slightly important
  - Not important
27. Has the subject of sexuality in AYAs been addressed during your education?
- Yes
  - No
28. Has the subject of sexuality ever been discussed during in-service training?
- Never
  - Rarely
  - Regularly
  - Often
29. To which extent do you possess sufficient knowledge to be able to discuss sexuality with an AYA?
- No knowledge at all
  - Not so much knowledge
  - Some knowledge
  - Sufficient knowledge
  - A lot of knowledge
30. Do you feel capable to discuss sexuality with AYAs?
- Yes
  - No
30. Do you feel the need to extent your knowledge on discussing sexuality with AYAs?
- Yes
  - No
31. What could be helpful to discuss sexuality with AYAs? (*multiple answers possible*)

- Training to improve skills on discussing sexuality
- Leaflets about sexuality to give to the AYA
- A short line with department of sexology for easy referral
- Clear guidelines or protocols on which health care professional discusses sexuality
- More time with the patient
- Quiet workplace
- Other, \_\_\_\_\_

**Part 4: Opinion on discussing sexuality**

32. Who has, in your opinion, the responsibility for discussing sexuality? (*multiple answers possible*)

- The AYA
- Partner of the AYA
- Head practitioner/medical specialist
- Nurse specialized in AYA care
- Social worker
- Radiotherapist
- General practitioner
- Sexologist
- Psychologist
- Other, \_\_\_\_\_

33. Do you think it is important to inform AYAs about potential sexual dysfunction due to treatment?

- Very important
- Important
- Slightly important
- Not important

34. Do you think it is important to screen AYAs for sexual dysfunction?

- Very important
- Important
- Slightly important
- Not important

35. How often do you discuss fertility with AYAs?

- Never
- In less than half of the cases
- In half of the cases
- In more than half of the cases
- Always

36. To which extend do you possess sufficient knowledge to be able to discuss fertility with an AYA?

- No knowledge at all
- Not so much knowledge
- Some knowledge
- Sufficient knowledge
- A lot of knowledge

37. Has the subject of fertility in AYAs been addressed during your education?

- Yes
- No



38. Do you feel capable to discuss fertility with AYAs?

Yes

No

**Thank you very much for participating!**

You can find more information on this subject via <https://sickandsex.nl>

**Appendix 10. Supplementary to chapter 8: Table S1**

**TABLE S1** Semi-structured interview questions used for interviews with participants

<b>Number</b>	<b>Question</b>
1	I want to start this interview with the question of what oral information provision on intimacy and sexuality for AYA patients currently looks like in your practice?
2	Ideally, what should oral information provision on intimacy and sexuality for AYA patients in your opinion looks like in the future?
3	What gaps or barriers do you currently notice in oral information provision and how could these ideally be solved?
4	Literature shows barriers in communication about intimacy and sexuality as well, like ... (lack of knowledge/experience having the conversation, lack of resources/referrals for patients, low priority, presence of parents/family, patients discomfort, clinicians discomfort, time and a lack of rapport/longitudinal relationship), how could these ideally be solved?
5	Ideally, who should discuss the topic intimacy and sexuality with AYA patients?
6	When should the topic intimacy and sexuality ideally be discussed with AYA patients?
7	In terms of content, what should ideally be discussed with AYA patients in the topic intimacy and sexuality?
8	How does education material on intimacy and sexuality for AYA patients currently looks like in your practice?
9	Do you feel a certain need in education material around intimacy and sexuality for AYAs?
10	Ideally, what should information material on intimacy and sexuality for AYA patients in your opinion looks like in the future?
11	In terms of content, what should the information material on intimacy and sexuality ideally contain for AYAs?

## Appendix 11. Supplementary to chapter 9: S1

Search in PubMed. Search date: 11 October 2019. Limitations: English language.

(neoplasms[majr] OR "Cancer Survivors"[majr] OR cancer\*[ti] OR adenoma\*[ti] OR adenocarcinom\*[ti] OR anticarcinogen\*[ti] OR antitumour\*[ti] OR blastoma\*[ti] OR carcinogen\*[ti] OR carcinom\*[ti] OR carcinosarcoma\*[ti] OR chordoma\*[ti] OR germinoma\*[ti] OR gonadoblastoma\*[ti] OR hepatoblastoma\*[ti] OR hodgkin disease[ti] OR hodgkin's disease[ti] OR hodgkins disease[ti] OR leukemia\*[ti] OR lymphangioma\*[ti] OR lymphangiomyoma\*[ti] OR lymphangiosarcoma\*[ti] OR lymphom\*[ti] OR malignan\*[ti] OR maligne[ti] OR malignes[ti] OR melanom\*[ti] OR meningioma\*[ti] OR mesenchymoma\*[ti] OR mesonephroma\*[ti] OR metasta\*[ti] OR neoplas\*[ti] OR neuroma\*[ti] OR nscic[ti] OR oncogen\*[ti] OR oncolog\*[ti] OR paraneoplastic[ti] OR plasmacytoma\*[ti] OR precancerous[ti] OR sarcoma\*[ti] OR teratocarcinoma\*[ti] OR teratoma\*[ti] OR tumor[ti] OR tumors[ti] OR tumour\*[ti]) AND ("Sexual Dysfunctions, Psychological"[majr] OR "Sexual Behavior"[majr] OR "Sexual Partners"[majr] OR "Sexual Dysfunction, Physiological"[majr] OR "Sexual Health"[majr] OR "Orgasm"[majr] OR "Coitus"[majr] OR sex[ti] OR sexual\*[ti] OR orgasm[ti] OR orgasms[ti] OR erection[ti] OR erections[ti] OR erectile[ti] OR coitus[ti] OR intercourse[ti] OR "Sex Education"[majr] OR "Sex Counseling"[majr]) AND ("Education"[majr] OR educat\*[ti] OR workshop\*[ti] OR train[ti] OR training\*[ti] OR trained[ti] OR program[ti] OR programs[ti] OR teach[ti] OR taught[ti] OR teaching[ti] OR intervention\*[ti] OR course[ti] OR courses[ti] OR "Learning"[majr] OR learn[ti] OR learned[ti] OR learning[ti] OR knowledge[ti] OR "Role Playing"[majr] OR role play\*[ti] OR quality improve\*[tw] OR "improving quality"[tw] OR "improving the quality" [tw] OR supportive car\*[tw] OR support car\*[tw] OR physician discussion\*[tw] OR physicians discussion\*[tw] OR physician's discussion\*[tw] OR (quality[ti] AND improv\*[ti])) AND (English[lang] OR Dutch[lang])

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**Appendix 12. Supplementary to chapter 9: S2**

Assessment of risk of bias in individual studies according to the JBI -MAStARI Critical appraisal checklist

JBI -MASARI Critical appraisal checklist (items 1-13) for randomized Controlled Trials	Kim (2014)	JBI -MAStARI Critical appraisal checklist for Quasi-Experimental Studies (items 1-9).	Jonsdottir (2016)	Wang (2015)	Reese (2019)	Afiyanti (2016)	Hordern (2009)	Grondhuis (2019)
1. Was true randomization used for assignment of participants to treatment groups?	Y	1. Is it clear in the study what the cause is and what the effect?	Y	Y	Y	Y	Y	Y
2. Was allocation to treatment groups concealed?	Y	2. Were the participants included in any comparisons similar?	Y	Y	Y	Y	Y	N
3. Were treatment groups similar at baseline?	Y	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Y	Y	Y	Y	Y	Y
4. Were participants blind to treatment assignment?	N	4. Was there a control group?	N	N	N	N	N	N
5. Were those delivering treatment blind to treatment assignment?	N	5. Were there multiple measurements of the outcome both pre- and post- the intervention/exposure?	Y	Y	Y	Y	Y	Y

Continuation S2

6. Were outcomes assessors blind to treatment assignment?	N	6. Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analyzed?	Follow-up incomplete, although adequately described and analyzed	Y	Follow-up incomplete, although adequately described and analyzed	Y	Follow-up incomplete, although adequately analyzed	Y	Follow-up incomplete, although adequately analyzed
7. Were treatment groups treated identically other than the intervention of interest?	Y	7. Were the outcomes of participants included in any comparisons measured in the same way?	Y	Y	Y	Y	Y	Y	Y
8. Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analyzed?	Y	8. Were outcomes measured in a reliable way?	Y	Y	Y	Y	Y	Y	Y
9. Were participants analyzed in the groups to which they were randomized?	Y	9. Was appropriate statistical analysis applied?	Y	Y	Y	N	Y	Y	Y
10. Were outcomes measured in the same way for treatment groups?	Y								

Continuation **S2**

- |   |   |
|---|---|
| 11. Were outcomes measured in a reliable way?   | Y |
| 12. Was appropriate statistical analysis used?  | Y |
| 13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial? | Y |
-

