

Questionnaire prior to the surgery

The following pages include questions about your health in general, family history, living habits, possible use of hormonal agents and examinations so far. This questionnaire will take approximately 15 to 20 minutes to complete. We politely ask you to answer all questions as complete as possible.

Thank you very much!

General information

1. Date of filling in this questionnaire - - (dd-mm-yyyy)

2. Date of birth - - (dd-mm-yyyy)

3. In which country were you born?

4. In which country do you currently live?

5. In which country was your father born?

6. Is your father of Ashkenazi (Eastern European) Jewish descent?

Yes No I don't know

7. In which country was your mother born?

8. Is your mother of Ashkenazi (Eastern European) Jewish descent?

Yes No I don't know

9. What is your current marital status?

Married / living together

In a relationship, but not living together

Single and have never been married

Divorced

Widow

10. What is the highest grade or year of school you completed?

No schooling completed

Nursery school to 8th grade

- High school graduate, diploma or the equivalent (for example: GED)
- Trade / technical / vocational training
- Associate degree
- Bachelor's degree
- Master's degree
- Professional degree
- Doctorate degree
- Other, namely:

Questions about your gene mutation

11. In which gene do you have a mutation?

- BRCA1
- BRIP1
- BRCA2
- RAD51C
- BRCA 1 & 2
- RAD51D

12. When was this mutation diagnosed?

If you don't know the exact date, please try to estimate as precise as possible (for example, please fill in 01-04-2010 if you know it was discovered in the first half of 2010)

..... - - (dd-mm-yyyy)

Questions about previous cancers and its treatment

13. Have you ever been diagnosed with cancer?

- No *(please go to question 25)*
- Yes

14. What type of cancer did you have?

.....

15. Have you had breast cancer?

- No *(please go to question 25)*
- Yes

16. In which breast?
(multiple answers possible)

Left (please go to question 17)

Right (please go to question 18)

17. When was the diagnoses of breast cancer in you left breast?

... .. - - (dd-mm-yyyy)

18. When was the diagnoses of breast cancer in you right breast?

... .. - - (dd-mm-yyyy)

19. Did your breast cancer spread (metastasize) beyond its primary site?

No

Yes

20. Was your breast cancer Triple Negative (no receptors for female hormones)?

No

Yes

I don't know

21. How was your breast cancer treated?
(multiple answers possible)

Breast saving surgery

Breast amputation

Radiotherapy

Chemotherapy

Hormonal therapy

Please answer the next questions about all the therapies you might have had. If you did not have had that specific therapy, you can skip the question and leave it blank.

22. If you had chemotherapy, this was:

A single cure

Multiple cures

23. If you had hormonal therapy, you are now:

Already stopped

Still receiving hormones

24. If you had hormonal therapy, this was:

With Trastuzumab (label name: Herceptin)

Without Trastuzumab (label name: Herceptin)

I don't know

25. Have you had breast cancer screening prior to now? (for example mammography)

No

Yes

26. Did you have a preventive breast amputation?

No (please go to question 29)

Yes

27. Which breast has been removed preventively?

Left

Right

Both

28. Date you have had the preventive breast amputation (as precise as possible):

... .. - - (dd-mm-yyyy)

Questions about use of medicines

29. Do you currently use prescribed medication?

No (please go to question 31)

Yes

30. What prescribed medication do you use, what dosage and when did you start?
For example: microgynon, once per day 30ug, since 01-02-2014

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31. Do you use non-prescribed medication? (medicines you buy around the corner)

No *(please go to question 33)*

Yes

32. What non-prescribed medication do you use, what dosage and when did you start?
For example: paracetamol, three times per day 1000mg, since 01-02-2014

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33. Do you use any supplements or plant-based substances on a daily basis?

No *(please go to question 35)*

Yes

34. What supplements or substances do you use, what dosage and when did you start?
For example: fish oil drops, 1x per day 5 drops, since January 2019

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Familial history

The following questions are about diseases that may be present in your (biological) first degree family members. First degree family members include your mother, father, brother(s), sister(s) and children.

35. Does any of your first degree family members have had breast cancer?

No *(please go to question 38)*

Yes

36. Which family member(s) has had breast cancer?

(multiple answers possible)

Mother

Father

Sister 1

Sister 2

Sister 3

Sister 4

Sister 5

Sister 6

Brother

Daughter 1

Daughter 2

Daughter 3

37. Please describe who developed breast cancer at what age

For example: mother age 50, sister 1 age 32 and sister 2 age 36.

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38. Does any of your first degree family members have had ovarian cancer?

No (*please go to question 41*)

Yes

39. Which family member(s) has had ovarian cancer?

Mother

Sister 1

Sister 2

Sister 3

Sister 4

Daughter 1

Daughter 2

40. Please describe who developed ovarian cancer at what age

For example: mother age 60, sister 1 age 50.

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The following questions are about diseases that may be present in your (biological) second degree family members. Second degree family members include your grandmothers, grandfathers, aunts, uncles, nephews, nieces and half-brothers/half-sisters. PLEASE NOTICE: This is only about persons that are direct family, so no married family.

41. Does any of your second degree family members have had breast cancer?

No *(please go to question 44)*

Yes

42. Who of your second family members has had breast cancer?

Grandmother 1

Niece 1

Grandmother 2

Niece 2

Grandfather 1

Niece 3

Grandfather 2

Niece 4

Aunt 1

Nephew 1

Aunt 2

Nephew 2

Aunt 3

Half-sister 1

Aunt 4

Half-sister 2

Uncle 1

Half-brother 1

Uncle 2

Half-brother 2

43. Please describe who developed breast cancer at what age and how the person is connected to you

For example: grandmother age 50 connected via my mother; aunt age 50 connected via my mother

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44. Does any of your second degree family members have had ovarian cancer?

No *(please go to question 47)*

Yes

45. Who of your second family members has had ovarian cancer?

- | | |
|--|--|
| <input type="checkbox"/> Grandmother 1 | <input type="checkbox"/> Niece 1 |
| <input type="checkbox"/> Grandmother 2 | <input type="checkbox"/> Niece 2 |
| <input type="checkbox"/> Aunt 1 | <input type="checkbox"/> Niece 3 |
| <input type="checkbox"/> Aunt 2 | <input type="checkbox"/> Niece 4 |
| <input type="checkbox"/> Aunt 3 | <input type="checkbox"/> Half-sister 1 |
| <input type="checkbox"/> Aunt 4 | <input type="checkbox"/> Half-sister 2 |

46. Please describe who developed ovarian cancer at what age and how the person is connected to you

For example: grandmother age 50 connected via my mother; aunt age 50 connected via my mother

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Lifestyle

47. How tall are you? centimeters

48. What is your weight? kilograms

49. How much do you walk on average?

- Mostly in and around the house (less than 100 meters)
- A daily small walk (100 to 1000 meters)
- A good walk on regular basis (1 to 5 kilometers)
- Regularly long distance walk (more than 5 kilometers)

50. How often do you perform a moderate intensity work-out, for at least 30 minutes (for example brisk walking)?

- Never Three times a week

No

Yes (please go to question 57)

55. What is the reason for the lack of menstruation?

No menstruation because of an intra-uterine device or continuous use of 'the pill'

No menstruation because of use of other types of hormones (e.g. 'the shot' or hormones as a treatment for breast cancer)

No menstruation because it stopped naturally

No menstruation because of the removal of my uterus

No menstruation because of chemotherapy or radiotherapy

56. At what age did your menstruation stop naturally?

57. Have you ever used hormonal contraception?

No

Yes

For how many years have you used hormonal contraception?

58. Have you had hormonal therapy with female hormones?

No

Yes

What kind of hormonal therapy did you get?

Estrogens, used for years

Progesterone, used for years

Testosterone, used for years

I don't know, used for Years

59. Have you ever been pregnant?

No

Yes

Number of full-term pregnancies:

Number of miscarriages / not full-term pregnancies:

60. Have you ever been diagnosed with endometriosis?

Endometriosis is a disorder in which tissue similar to the tissue that forms the lining of your uterus grows outside of your uterine cavity

No

Yes

61. Have you ever had surgery on any of the female organs?

No (please go to question 64)

Yes

Namely:

Unilateral removal of the ovary

Unilateral removal of the Fallopian tube

Removal of the uterus

Sterilization

Other:

62. In case you have been sterilized, what method of sterilization was used?

Clips on the Fallopian tubes (Filshie clips)

Rings on the Fallopian tubes (Fallope ring)

Shut the Fallopian tubes by burning (bilateral electrocoagulation)

Removal of a part of the Fallopian tubes (Pomeroy / Uchida method)

Other:

63. At what age have you been sterilized?years

Ovarian cancer screening

The following questions are about examinations you might have had, to examine whether you might have ovarian cancer.

64. Have you received screening for ovarian cancer prior to now?

No (please go to question 88)

Yes

What type of screening did you have?

(Transvaginal) ultrasound (please go to question 65)

CA-125 (tumormarker in blood) (please go to question 71)

Internal pelvic exam (vaginal toucher) (please go to question 78)

Other, namely:..... (for example CT-scan, MRI-scan or CEA) (please go to question 83)

65. How often do you receive this ultrasound?

- Monthly Every five years
 Twice per year Every ten years
 Once per year Had this once
 Every two years

66. If you have had this ultrasound more than one time, how often did you receive this ultrasound, in total?

..... times

67. Have any of the (transvaginal) ultrasounds been abnormal?
(multiple answers possible)

- No, everything was normal (please go to question 70)
 Yes, the uterus showed abnormalities (please go to question 70)
 Yes, the ovaries showed abnormalities

68. When was the last abnormal ultrasound (of the ovaries)?

... .. - - (dd-mm-yyyy)

69. After your last abnormal ultrasound (of the ovaries), did you have a follow-up ultrasound?

- No
 Yes

70. What was the plan after the last ultrasound?

- Follow-up test: blood sample (please mark 'CA-125' in question 64 as well and answer the corresponding questions)
 Follow-up test: imaging
 Another ultrasound was planned
 No further testing

71. How often is CA-125 checked?

- | | |
|--|---|
| <input type="checkbox"/> Monthly | <input type="checkbox"/> Every five years |
| <input type="checkbox"/> Twice per year | <input type="checkbox"/> Every ten years |
| <input type="checkbox"/> Once per year | <input type="checkbox"/> Had this once |
| <input type="checkbox"/> Every two years | |

72. How often is CA-125 checked in total? times

73. What was your (latest) value of CA-125?

- The value was within the range of normal (*please go to question 78*)
- The value was too high

74. If you know the highest value of CA-125, what was it?U/ml

75. When was the highest value of CA-125 measured?

..... - - (dd-mm-yyy)

76. How often was your value of CA-125 too high?times

77. What was the plan after your CA-125 was too high?

- Follow-up test: ultrasound (*please mark (transvaginal) ultrasound in question 64 as well and answer the corresponding questions*)
- Another measurement of CA-125
- No follow-up
- Other, namely:.....

78. How often did you have an internal pelvic exam (vaginal toucher)?

- | | |
|--|---|
| <input type="checkbox"/> Monthly | <input type="checkbox"/> Every five years |
| <input type="checkbox"/> Twice per year | <input type="checkbox"/> Every ten years |
| <input type="checkbox"/> Once per year | <input type="checkbox"/> Had this once |
| <input type="checkbox"/> Every two years | |

79. How often did you have this internal pelvic exam (vaginal toucher) in total?

..... times

80. Has this internal pelvic exam (vaginal toucher) ever been abnormal?

- Yes, this might be because of abnormal ovaries
- Yes, but this has nothing to do with my ovaries (*please go to question 82*)
- No, everything was normal (*please go to question 82*)

81. What was the plan after this abnormal internal pelvic exam ?

- Follow-up test: ultrasound (*please mark (transvaginal) ultrasound in question 64 as well and answer the corresponding questions*)
- Follow/up test: blood sample t of CA-125 (*please mark 'CA-125' in question 64 as well and answer the corresponding questions*)
- Another appointment was made for an internal pelvic exam
- No follow/up

82. For what reason do you have internal pelvic exams (vaginal toucher)?

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83. How often do you have the other type of screening (for example a CT-scan, MRI-scan or CEA)?

- | | |
|--|---|
| <input type="checkbox"/> Monthly | <input type="checkbox"/> Every five years |
| <input type="checkbox"/> Twice per year | <input type="checkbox"/> Every ten years |
| <input type="checkbox"/> Once per year | <input type="checkbox"/> Had this once |
| <input type="checkbox"/> Every two years | |

84. How often did you have this other type of screening in total?

..... times

85. Has this other type of screening ever been abnormal?

- No
- Yes

86. What abnormalities were found during this other type of screening?

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87. What was the plan after this abnormal other type of screening?

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88. Have you had a (transvaginal) ultrasound within the last six months?

No (*please go to question 93*)

Yes

89. Have abnormalities been found during this last (transvaginal) ultrasound?

No, everything was normal (*please go to question 93*)

Yes, the uterus showed abnormalities (*please go to question 93*)

Yes, the ovaries showed abnormalities

90. What was the plan after this abnormal last ultrasound (of the ovaries)?

Follow-up test: blood sample (CA-125)

Follow-up test: imaging (*please go to question 93*)

Another ultrasound was planned (*please go to question 93*)

No follow-up (*please go to question 93*)

Other, namely: (*please go to question 93*)

91. What was your value of CA-125?

The value was within the range of normal (*please go to question 78*)

The value was too high

92. If you know the highest value of CA-125, what was it?U/ml

Choice of preventive treatment

93. Can you indicate at what age you have planned to remove your tubes and ovaries before you heard about this investigation?

- Yes, at age: years
- No, I did not have any thoughts about that yet
- No, I don't know what age I had in mind

94. What treatment do you choose, after having enough information and time for consideration?

- The standard strategy: simultaneous removal of the tubes and ovaries at the currently advised age (*please go to question 96*)
- The innovative strategy: first removal of the tubes and afterwards removal of the ovaries approximately 5 years after the currently advised age
- The innovative strategy: first removal of the tubes only, but the removal of the ovaries within the currently advised age

95. At what age, do you think, you want to get your ovaries removed?

This question is only used to get an idea of the expected delay, you are absolutely not tied to this entered age!

..... years

96. What considerations were important to you for your choice?

At '1' please write down the most decisive consideration. You can document multiple answers if you like

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2.

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4.

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97. What methods (except surgery) have you applied yourself to minimize the risk of getting (ovarian) cancer?

- Eating healthy
- Working out
- Maintaining healthy weight
- No smoking
- No usage of alcoholics
- No usage of drugs
- Undergo screenings
- Other: