



Dear patient,

we are very happy about your participation in our interventionstudy. With that, you help us to learn more about patients and parents knowledge and attitude about possible late effects of cancer treatment.

Please take some time to answer a few questions for us. Your answers will be stored and evaluated without any conclusions on your person.

Thank you very much for your support!

I_Patient_1

Data provider ID:

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Patients ID:

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Date of questionnaire completion:

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Personal Data

1

Are you a boy or a girl?

Boy Girl

When were you born?

Please indicate the month and the year, in which you were born.

Month: Year:

To which nationality do you belong to?

2

Did anyone discuss with you the possible late effects of cancer treatment before treatment started?

	Yes	No	Don't know
Heart problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Second malignancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Impaired hearing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of hair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Growths problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hormonal problems, including fertility impairment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental impairment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, specify:	<input type="text"/>		

If yes, with whom you have talked about this?

- Physician
 Nurse
 Any other

If yes, did you have to ask for information on this topic yourself?

- Yes No

3

Did anyone discuss with you the possible prophylactic measures to preserve your fertility before treatment started?

- Yes No Don't know

If yes, with whom you have talked about this?

- Physician
 Nurse
 Other

If yes, did you have to ask for information on this topic yourself?

- Yes No

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Was the flyer on fertility risks and prophylactic measures handed out to you?

- Yes No Don't know

If yes, did you read the flyer?

- Yes No Don't know

If yes, please enter how you feel informed by the flyer on fertility risks and prophylactic measures.

Not at all 1 2 3 4 5 Completely
informed informed

5

You are treated with several types of chemotherapy and maybe also with radiotherapy. How do you estimate the risk of this treatment for an impairment of your fertility?

Please tick only one possibility.

- High risk Medium risk Low risk

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What risk factors for infertility do you know?

Tick all you know

- Radiation
- Total body irradiation
- Cranial irradiation
- Irradiation of the chest
- Pelvic irradiation
- Chemotherapy
- Therapy with busulfan
- Therapy with procarbazine
- Therapy with antibiotics
- Surgery
- Brain surgery
- Pelvic surgery
- Underlying cancer disease
- Age at treatment
- Prepubertal
- Postpubertal



If you are a girl... (otherwise continue with question 13)

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What signs for fertility do you know?

Tick all you know

- Body hair changes
- Breast size changes
- Maturation of follicles in the ovaries
- Hormone changes
- Clear skin
- Solid finger nails
- Menstruation

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Which form of hormone replacement therapy do you know?

Tick all you know

- Fertility stimulation with growth hormones
- Oestrogen can be administered in tablet form or by transdermal patch
- Replacement treatment with LH and FSH

9

What possibilities of artificial insemination are there?

Tick all you know.

- Egg cells are fertilized with sex hormones
- Sperm cells fertilize egg cells in a test tube
- A single sperm cell is injected directly into an egg cell

10

What fertility-preserving measures do you know?

Tick all you know.

- Freezing of ovarian tissue (Cryopreservation)
- Freezing of egg cells (Cryopreservation)
- Cortisone therapy
- Transposition of the ovaries

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Which of the fertility-preserving measures can be applied before puberty?

Tick all you know

- Freezing of ovarian tissue (Cryopreservation)
- Freezing of egg cells (Cryopreservation)
- Cortisone therapy
- Transposition of the ovaries

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Did you already use fertility-preserving methods?

- Yes No Don't know

If yes, which one?



If you are a boy... (otherwise continue with question 19)

13

What signs for fertility do you know?

Tick all you know.

- Body hair changes
- Testicular size changes
- Change of voice
- Hormone changes
- Clear skin
- Solid finger nails
- Ejaculation

14

Which kind of hormone replacement therapy do you know?

Tick all you know.

- Fertility stimulation with growth hormones
- Testosterone can be administered by transdermal patch, gel or injection
- Replacement treatment with LH and FSH

15

What are the possibilities of artificial insemination?

Tick all you know.

- Egg cells are fertilized with sex hormones
- Sperm cells fertilize egg cells in a test tube
- A single sperm cell is injected directly into an egg cell

16

What fertility-preserving measures do you know?

Tick all you know.

- Freezing of testicular tissue (Cryopreservation)
- Freezing of sperm cells (Cryopreservation)
- Cortisone therapy
- Stimulation of testicles with LH and FSH

17

Which of the fertility-preserving measures can be applied before puberty?

Tick all you know

- Freezing of testicular tissue (Cryopreservation)
- Freezing of sperm cells (Cryopreservation)
- Cortisone therapy
- Stimulation of testicles with LH and FSH

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Did you already use fertility-preserving methods?

- Yes No Don't know

If yes, which one?

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Where did you mainly get your information about fertility risks and preservation methods?

Please tick one or more which you think was/were the most important

- From the conversation with the attending physician
- From the flyer
- From the internet
- From books / magazines / newspapers
- From the media (television, radio)

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Please rate the following statement:

"I feel sufficiently informed by the given information to make a decision for me."

Strongly disagree

Tend to disagree

Partly agree, partly disagree

Tend to agree

Totally agree

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How strongly do you wish to be able to have own children?

- I don't have such a wish
- A little
- Fairly
- Greatly

22

Please tell us to what extent each of the following statements applies to you, thinking about your own children.

	Not at all	A little	Medio-cre	Fairly	Greatly
I am afraid that any child I may have would be more likely to have cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am afraid that my own cancer may come back.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about my fertility.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm concerned about fertility-preserving measures side effects.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Do you plan to make use of fertility-preserving methods?

- Yes No

If yes, why?

You can choose more than one answer

- I have a high risk of infertility due to treatment
- In order to have the additional opportunity to get own children.
- To have own children has a high priority in our family.
- Other reason, specify: _____

If no, why not?

You can choose more than one answer

- I have a low risk of infertility due to treatment.
- I do not want to intervene in the natural course of reproduction.
- Access to the egg puncture through the still intact hymen (vaginal flap) is not acceptable for me.
- I am afraid that my own cancer may come back.
- I am afraid that any child I may have would be more likely to have cancer.
- The costs of the freezing and storage of egg or sperm cells are too high for us.
- The costs of the artificial insemination are too high for us.
- I'm too young to think about having children.
- Insufficient success rate of artificial insemination.
- Unforeseeable side effects of artificial insemination.
- Other reason, specify: _____

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Have you already or do you plan to make a fertility test?

- Yes, I have already made a fertility test
- Yes, I plan to make a fertility test
- No

The following questions are designed to assess your data better

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Are you still going to school?

- Yes No

If yes, on which school do you go?

- Primary school (Key stages 1 and 2)
- Secondary school (Key stages 3 and 4)
- School sixth form, sixth form college, further education college
- Special school (SEN)
- Other, specify

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If you no longer go to school, what degree have you achieved?

- School ended without completion
- GCSE or equivalent
- AS-Level, A-Level or equivalent
- University, undergraduate level: BA, BSc or equivalent
- Other school degree, e.g. from abroad
- Other, specify

And what you are doing now?

- Apprenticeship or youth training course
- Study
- Employed/working
- Internship / Vocational preparation offers
- Unemployed
- Other, specify

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To which denomination do you belong?

Please indicate here.

- None