



**Dear parents and guardians,**

we are very happy about your participation in our intervention study. 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\_Parents\_1

Data provider ID: 

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Parents ID: 

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Date of questionnaire completion: 

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## Personal Data

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### Who is answering the questionnaire?

- Biological mother
- Biological father
- Other female legal guardian (e.g. step, adoptive or foster mother)
- Other male legal guardian (e.g. step, adoptive or foster father)

### 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?

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### 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"/>
Others, 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

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

- Yes       No       Don't know

**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

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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 informed      1      2      3      4      5      Completely informed

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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**Your child is treated with several types of chemotherapy and maybe also with radiotherapy. How do you estimate the risk of this treatment for a fertility impairment of your child?**

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 your child is 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 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

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**What possibilities of artificial insemination are there?**

Tick all you know

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

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**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 your child already use fertility-preserving methods?**

- Yes       No       Don't know

**If yes, which one?**



**If your child is a boy... (otherwise continue with question 19)**

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**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

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**Which form of hormone replacement 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 possibilities are there for artificial insemination?**

Tick all you know

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

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**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

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**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 your child 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 on 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 information given, to make a decision with my child.“*

- Strongly disagree      Tend to disagree      Partly agree, partly disagree      Tend to agree      Totally agree
- 

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**How strongly do you wish for your child that she/he is able to have children of her/his own?**

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

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

	Not at all	A little	Medi-ocre	Fairly	Greatly
I'm afraid that any child my child may has, would be more likely to have cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm afraid that the cancer of my child may come back.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm concerned about my child's 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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**Have you recommended your child to have a fertility testing?**

- Yes       No

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**Have you recommended your child to use fertility-preserving methods?**

- Yes       No

**If yes, why?**

You can choose more than one answer

- My child has a high risk of infertility due to treatment.
- In order to have the additional opportunity for my child 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

- My child has a low risk of infertility due to treatment.
- We 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.
- I am afraid that the cancer of my child may come back
- I am afraid that any child my child 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 artificial insemination are too high for us.
- My child is too young to think about having children.
- Insufficient success rate of artificial insemination.
- Unforeseeable side effects of artificial insemination.
- Other reason, specify:

## The following questions are designed to assess your data better

Please keep in mind, that in the following questions persons called „mother“ or „father“ can also be those who take this role for the child, e.g. the partner of the mother or the partner of the father.

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### What is the highest educational/vocational qualification you have?

Please answer for both parents.

	Mother	Father
<u>Postsecondary and tertiary qualification</u> University/CNAA Bachelor Degree, Teaching qualification, Higher degree, Graduate member of prof. institute, Doctorate	<input type="radio"/>	<input type="radio"/>
<u>Postsecondary below bachelor's level</u> NVQ levels 4 and 5, Foundation degree, Diploma in higher education, RSA higher diploma, HNC/HND, BTEC higher etc, Nursing qualification,	<input type="radio"/>	<input type="radio"/>
<u>University entry qualification</u> AS level or equivalent, A level or equivalent, higher or equivalent, Scottish 6th year certificate (CSYS), Access qualification	<input type="radio"/>	<input type="radio"/>
<u>Upper secondary qualification without university access</u> O level, GCSE grade A-C or equivalent (5 or more), BTEC/SCOTVEC first or general diploma, BTEC/SCOTVEC national, City and Guilds craft, City and Guilds advanced craft, RSA diploma, RSA advanced diploma or certificate, GNVQ intermediate and advanced, NVQ/SVQ levels 2 and 3, Traditional Apprenticeship, Modern apprenticeship, OND/ONC	<input type="radio"/>	<input type="radio"/>
<u>Lower secondary qualification</u> CSE below grade 1, GCSE below grade C, O level, GCSE grade A-C or equivalent (less than 5), Entry Level qualification, Basic Skills qualification, Key Skills qualification, YT/YTP certificate, City and Guilds other, RSA other, SCOTVEC modules or equivalent, BTEC first or general certificate, GNVQ/GSVQ foundation level, NVQ/SVQ level 1 or equivalent	<input type="radio"/>	<input type="radio"/>
Other, specify <input type="text"/>	<input type="radio"/>	<input type="radio"/>
No formal qualification	<input type="radio"/>	<input type="radio"/>
Other school degree, e.g. from abroad	<input type="radio"/>	<input type="radio"/>
No qualification yet	<input type="radio"/>	<input type="radio"/>

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**Which of the following information on occupational activity applies to you currently?** Please answer for both parents.

Currently...	Mother	Father
...Unemployed	<input type="radio"/>	<input type="radio"/>
...Fully employed/working	<input type="radio"/>	<input type="radio"/>
...Part-time or hourly basis working	<input type="radio"/>	<input type="radio"/>
...Temporary exemption (e.g. parental leave)	<input type="radio"/>	<input type="radio"/>
...Not working (retired, student)	<input type="radio"/>	<input type="radio"/>
...Trainee, e.g. apprentice	<input type="radio"/>	<input type="radio"/>

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**What is the average monthly household income, i.e. the net income, which all household members have together after deduction of taxes and social security?** (Including the parental benefit and child allowances)

- |   |   |
|---|---|
| <input type="radio"/> Under 400 £               | <input type="radio"/> 1,600 up to under 1,800 £ |
| <input type="radio"/> 400 up to under 600 £     | <input type="radio"/> 1,800 up to under 2,000 £ |
| <input type="radio"/> 600 up to under 800 £     | <input type="radio"/> 2,000 up to under 2,500 £ |
| <input type="radio"/> 800 up to under 1,000 £   | <input type="radio"/> 2,500 up to under 3,200 £ |
| <input type="radio"/> 1,000 up to under 1,200 £ | <input type="radio"/> 3,200 up to under 4,000 £ |
| <input type="radio"/> 1,200 up to under 1,400 £ | <input type="radio"/> 4,000 up to under 5,000 £ |
| <input type="radio"/> 1,400 up to under 1,600 £ | <input type="radio"/> 5,000 £ and more          |

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**How many persons live, reside and operate economically together in your household, including yourself?**

Please think also about all children living in your household

Persons altogether:

 

**And how many persons of these are under 18 years of age?**

Children < 18 years:

 

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**To which denomination do you belong?**

Please answer for both parents.

Mother:

None

Father

None

**Thank you for participation!**