



Record ID	
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Visit

Date of posttreatment visit at 12-15 months after the end of gonadotoxic treatment

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*Min: 01-11-2023
Max: 31-12-2039*

Gonadotoxic treatment

Disease	<i>Final diagnosis, for which the fertility counselling is performed.</i>	<i>See annexed list with the disease list.</i>
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if → NOT LISTED	
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Start of gonadotoxic treatment		<i>Min: 01-01-2020 Max: 31-12-2039</i>
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End of gonadotoxic treatment		<i>Min: 01-01-2020 Max: 31-12-2039</i>
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Duration of gonadotoxic treatment	<i>Months</i>	<i>Automatic calculation of rounded number of months in REDCap.</i>
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Treatment protocol <i>(To be added by the organizers of the study.)</i>		<i>Numbered list from 1 to 99.</i>
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Have testicles been removed as part of cancer therapy?	<input type="checkbox"/> Yes <input type="checkbox"/> No
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if YES → How many testicles?	<input type="checkbox"/> ½ testicle <input type="checkbox"/> 1 testicle <input type="checkbox"/> 2 testicles
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A	<p>Agranulocytosis (D70) Anal carcinoma (C21) Anaemia - Aplastic (D60 – D61) Anaemia - Fanconi (D61.0) Angiosarcoma (C22.3)</p>	N	<p>Nasopharyngeal carcinoma (C11) Nebennierenkrebs → »Adrenocortical carcinoma« Nephritis / Glomerulonephritis (N05) Nephroblastoma → »Wilms' tumour« Non-Hodgkin lymphoma (C82 – C88)</p>
B	<p>Blasenmole → »Trophoblastic disease« Brain cancer:</p> <ul style="list-style-type: none"> ▪ Astrocytoma (C71.9) ▪ Ependymoma (C71.9) ▪ Glioblastoma (C71.9) ▪ Oligodendroglioma (C71.9) ▪ Medulloblastoma (C71.6) ▪ other (C71) <p>Breast cancer:</p> <ul style="list-style-type: none"> ▪ benign BRCA positive (Z15.01) ▪ hormone receptor positive (Z17.0) ▪ hormone receptor negative (Z17.1) ▪ hormone receptor status not known (Z17) ▪ other (C50) <p>Burkitt lymphoma (C83.7)</p>	O	<p>Osteosarcoma (C41.9) Ovary (C56):</p> <ul style="list-style-type: none"> ▪ borderline malignancy ▪ teratoma benign ▪ teratoma malignant ▪ other
C	<p>Cervix uteri carcinoma (C53) Chondrosarcoma (C41.9) Colitis ulcerosa → »Ulcerative colitis« Colon carcinoma (C18) Crohn disease (K50)</p>	P	<p>Pancreatic cancer (C25) Placenta cancer (C58.9; D39.2) → »Trophoblastic disease« Pleomorphic undifferentiated sarcoma → »Undifferentiated pleomorphic sarcoma« Polyarteritis nodosa (M30) Polychondritis (M94.8) Polymyositis (M33) Premature ovarian insufficiency (E28.3) Prostate cancer (C61)</p>
D	<p>Dermatomyositis (M33)</p>	R	<p>Rectal cancer (C20) Rectosigmoid junction cancer (C19) Renal cell carcinoma → »Kidney cancer« Rhabdomyosarcoma (C49.9) Rheumatoid arthritis (M05 – M06, M08)</p>
E	<p>Endometrial carcinoma (C54) Endometriosis (N80) Ewing sarcoma (C40-C41)</p>	S	<p>Schilddrüsenkrebs → »Thyroid cancer« Sharp syndrome → »Mixed connective tissue disease« Sickle cell disease (D57) Sigmakarzinom → »Colon carcinoma« Sjögren (Sicca) syndrome (M35) Stomach cancer (C16) Synovial sarcoma (C49.9) Systemic sclerosis (including: Scleroderma) (M34)</p>
F	<p>Fibrosarcoma (C49.9) Fragile X syndrome (Q99.2)</p>	T	<p>Takayasu arteritis (Aortic arch syndrome) (M31.4) Testicular cancer (C62):</p> <ul style="list-style-type: none"> ▪ seminoma ▪ non seminomatous germ cell tumour - teratoma ▪ non seminomatous germ cell tumour - embryonal carcinoma ▪ non seminomatous germ cell tumour - yolk sac carcinoma ▪ stromal tumour - Leydig cell tumour ▪ stromal tumour - Sertoli cell tumour ▪ other histological types <p>Thalassemia (D56) Thyroid cancer (C73) Transgender (F64) Trophoblastic disease (O01.9) Turner syndrome (Q96)</p>
G	<p>Galactosemia (E74.2) Germ cell tumour - extragonadal (ICD-O-3 M906-909)</p>	U	<p>Ulcerative colitis (K51) Undifferentiated pleomorphic sarcoma (C49)</p>
H	<p>Hodgkin lymphoma (C81)</p>	V	<p>Vasculitis limited to skin (L95) Vulva carcinoma (C51)</p>
I	<p>Immune thrombocytopenia (D69)</p>	W	<p>Wegener granulomatosis (M31.3) Wilms' tumour (Kidney cancer in children) (C64)</p>
K	<p>Keimzelltumor → »Germ cell tumour« Kidney cancer (C64)</p>	?	DISEASE NOT LISTED
L	<p>Leiomyosarcoma NOS (ICD-O-3 M8890/3) Leukaemia:</p> <ul style="list-style-type: none"> ▪ Leukaemia lymphoid - acute lymphoblastic (C91.0) ▪ Leukaemia lymphoid - chronic lymphocytic (C91) ▪ Leukaemia myeloid - acute (C92) ▪ Leukaemia myeloid - chronic (C92) ▪ Leukaemia - other forms (C91 - C95) <p>Liposarcoma (C49.9) Liver cancer (C22) Lung cancer (C34) Lupus erythematosus (L93)</p>		
M	<p>Malignant fibrous histiocytoma → »Undifferentiated pleomorphic sarcoma« Malignant nerve sheath tumour (C47.9) Melanoma (C43) Mesothelioma (C45) Mixed connective tissue disease (M35.1) Morbus Crohn → »Crohn disease« Myelodysplastic syndrome (D46) Multiple sclerosis (G35) Myositis (M60)</p>		



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Chemotherapy

Yes

if YES ➔ Protocol name (such as BEACOPPesc, CHOP, FEC, AC, etc.), medications given, dosage per cycle, number of cycles

No

Radiotherapy

Yes

if YES ➔ Protocol name, radiation field and applied dosage in case of pelvic radiation

No



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Immumotherapy

 Yes

if YES → Protocol name, type of antibodies or inhibitors, dosage plus any other relevant details

 No

Operation / Surgery

 Yes

if YES → Protocol name plus any other relevant details

 No

Other type of gonadotoxic treatment

 Yes

if YES → Protocol name plus any other relevant details

 No



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Disease status

Disease status	<input type="checkbox"/> Absence of tumor/disease (complete remission) <input type="checkbox"/> Some tumor mass/disease left (>50% reduction = partial remission) <input type="checkbox"/> Substantial tumor mass/disease left (≤50% reduction = no remission) <input type="checkbox"/> Relapse (reappearance of tumor/disease)
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Any important cancer treatment-related events, such as: further therapies, a second cancer, other diseases, etc.	<input type="checkbox"/> Yes <input type="checkbox"/> No
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if YES ➔ Please specify

Blood parameters

Date of blood test	<input style="width: 90%;" type="text"/>	<i>Min: 01-11-2023 Max: 31-12-2039</i>
Serum total testosterone concentration	<input style="width: 90%;" type="text"/>	<i>Number (one decimal place), suggested range: 0.0 - 2000.0</i>
Unit of the serum total testosterone value	<input type="checkbox"/> nmol/L <input type="checkbox"/> ng/dL <input type="checkbox"/> microgram/L	
Serum FSH concentration	<input style="width: 90%;" type="text"/>	<i>IU/L</i> <i>Number (one decimal place), suggested range: 0.0 - 160.0</i>
Serum LH concentration	<input style="width: 90%;" type="text"/>	<i>IU/L</i> <i>Number (one decimal place), suggested range: 0.0 - 12.0</i>



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Sperm parameters

Date of sperm analysis (first ejaculate)	<input style="width: 100%; height: 30px;" type="text"/>	Min: 01-11-2023 Max: 31-12-2039
Total sperm count in ejaculate	<input style="width: 100%; height: 30px;" type="text"/> 10^6	Number (one decimal place), suggested range: 0.0 - 928.0
Sperm concentration	<input style="width: 100%; height: 30px;" type="text"/> $10^6/mL$	Number (one decimal place), suggested range: 0.0 - 300.0
Total sperm progressive motility (WHO A+B)	<input style="width: 100%; height: 30px;" type="text"/> %	Integer, suggested range: 5 - 85
Proportion of sperm with normal morphology	<input style="width: 100%; height: 30px;" type="text"/> %	Integer, suggested range: 0 - 30 <i>If analysed in first ejaculate</i>

Legend:
 A = rapid progressive
 B = slow progressive
 C = non-progressive
 D = immotility

Fertility preservation measures

Type of fertility preservation measure performed	<input type="checkbox"/> None <input type="checkbox"/> Sperm freezing <input type="checkbox"/> Testicular tissue freezing
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Several items can be chosen.

Patient satisfaction

Is the patient satisfied with the decision to have undergone fertility preservation measures or not? Yes No

How satisfied is the patient with the <u>decision</u> to undergo or not to undergo fertility preservation measures?	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>
	0	1	2	3	4	5	6	7	8	9	10

How satisfied is the patient with the fertility preservation <u>counselling</u> before the gonadotoxic treatment?	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>
	0	1	2	3	4	5	6	7	8	9	10

Slider labels:
 0 = not applicable (N/A)
 1 = not satisfied at all
 10 = very satisfied



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Pregnancy outcomes USING fertility preservation measures

Was frozen material used to achieve pregnancy?	<input type="checkbox"/> Yes <input type="checkbox"/> No	if YES ➔	Total number of pregnancies achieved <u>after</u> the gonadotoxic treatment using their own previous frozen material	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> > 3
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1st Pregnancy	Frozen material	<input type="checkbox"/> Sperm freezing <input type="checkbox"/> Testicular tissue freezing <input type="checkbox"/> Unknown	
	Status	<input type="checkbox"/> Live birth <input type="checkbox"/> Ongoing pregnancy <input type="checkbox"/> Miscarriage - 1st trimester (< 14 weeks) <input type="checkbox"/> Miscarriage - 2nd trimester (< 22 weeks) <input type="checkbox"/> Stillbirth (≥ 22 weeks and weight ≥ 500 g) <input type="checkbox"/> Induced abortion <input type="checkbox"/> Ectopic pregnancy <input type="checkbox"/> Other	
if OTHER ➔ please specify			

2nd Pregnancy	Frozen material	<input type="checkbox"/> Sperm freezing <input type="checkbox"/> Testicular tissue freezing <input type="checkbox"/> Unknown	
	Status	<input type="checkbox"/> Live birth <input type="checkbox"/> Ongoing pregnancy <input type="checkbox"/> Miscarriage - 1st trimester (< 14 weeks) <input type="checkbox"/> Miscarriage - 2nd trimester (< 22 weeks) <input type="checkbox"/> Stillbirth (≥ 22 weeks and weight ≥ 500 g) <input type="checkbox"/> Induced abortion <input type="checkbox"/> Ectopic pregnancy <input type="checkbox"/> Other	
if OTHER ➔ please specify			



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Pregnancy outcomes USING fertility preservation measures

3rd Pregnancy	Frozen material	<input type="checkbox"/> Sperm freezing <input type="checkbox"/> Testicular tissue freezing <input type="checkbox"/> Unknown	
	Status	<input type="checkbox"/> Live birth <input type="checkbox"/> Ongoing pregnancy <input type="checkbox"/> Miscarriage - 1st trimester (< 14 weeks) <input type="checkbox"/> Miscarriage - 2nd trimester (< 22 weeks) <input type="checkbox"/> Stillbirth (≥ 22 weeks and weight ≥ 500 g) <input type="checkbox"/> Induced abortion <input type="checkbox"/> Ectopic pregnancy <input type="checkbox"/> Other	
	if OTHER → please specify		

4th Pregnancy	Frozen material	<input type="checkbox"/> Sperm freezing <input type="checkbox"/> Testicular tissue freezing <input type="checkbox"/> Unknown	
	Status	<input type="checkbox"/> Live birth <input type="checkbox"/> Ongoing pregnancy <input type="checkbox"/> Miscarriage - 1st trimester (< 14 weeks) <input type="checkbox"/> Miscarriage - 2nd trimester (< 22 weeks) <input type="checkbox"/> Stillbirth (≥ 22 weeks and weight ≥ 500 g) <input type="checkbox"/> Induced abortion <input type="checkbox"/> Ectopic pregnancy <input type="checkbox"/> Other	
	if OTHER → please specify		



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Pregnancy outcomes NOT USING their previous fertility preservation measures

Total number of pregnancies achieved <u>after</u> the gonadotoxic treatment <u>NOT</u> using their own previous frozen material	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> > 3
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0	Has the patient <u>tried to get pregnant</u> after the end of gonadotoxic treatment?	<input type="checkbox"/> Yes <input type="checkbox"/> No
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1st Pregnancy	Method	<input type="checkbox"/> Natural conception (sexual intercourse) <input type="checkbox"/> ART (Assisted Reproductive Technology) <input type="checkbox"/> Unknown	
	Status	<input type="checkbox"/> Live birth <input type="checkbox"/> Ongoing pregnancy <input type="checkbox"/> Miscarriage - 1st trimester (< 14 weeks) <input type="checkbox"/> Miscarriage - 2nd trimester (< 22 weeks) <input type="checkbox"/> Stillbirth (≥ 22 weeks and weight ≥ 500 g) <input type="checkbox"/> Induced abortion <input type="checkbox"/> Ectopic pregnancy <input type="checkbox"/> Other	
if OTHER ➔ please specify			

2nd Pregnancy	Method	<input type="checkbox"/> Natural conception (sexual intercourse) <input type="checkbox"/> ART (Assisted Reproductive Technology) <input type="checkbox"/> Unknown	
	Status	<input type="checkbox"/> Live birth <input type="checkbox"/> Ongoing pregnancy <input type="checkbox"/> Miscarriage - 1st trimester (< 14 weeks) <input type="checkbox"/> Miscarriage - 2nd trimester (< 22 weeks) <input type="checkbox"/> Stillbirth (≥ 22 weeks and weight ≥ 500 g) <input type="checkbox"/> Induced abortion <input type="checkbox"/> Ectopic pregnancy <input type="checkbox"/> Other	
if OTHER ➔ please specify			



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Pregnancy outcomes NOT USING their previous fertility preservation measures

3rd Pregnancy	Method	<input type="checkbox"/> Natural conception (sexual intercourse) <input type="checkbox"/> ART (Assisted Reproductive Technology) <input type="checkbox"/> Unknown	
	Status	<input type="checkbox"/> Live birth <input type="checkbox"/> Ongoing pregnancy <input type="checkbox"/> Miscarriage - 1st trimester (< 14 weeks) <input type="checkbox"/> Miscarriage - 2nd trimester (< 22 weeks) <input type="checkbox"/> Stillbirth (≥ 22 weeks and weight ≥ 500 g) <input type="checkbox"/> Induced abortion <input type="checkbox"/> Ectopic pregnancy <input type="checkbox"/> Other	
	if OTHER → please specify		

4th Pregnancy	Method	<input type="checkbox"/> Natural conception (sexual intercourse) <input type="checkbox"/> ART (Assisted Reproductive Technology) <input type="checkbox"/> Unknown	
	Status	<input type="checkbox"/> Live birth <input type="checkbox"/> Ongoing pregnancy <input type="checkbox"/> Miscarriage - 1st trimester (< 14 weeks) <input type="checkbox"/> Miscarriage - 2nd trimester (< 22 weeks) <input type="checkbox"/> Stillbirth (≥ 22 weeks and weight ≥ 500 g) <input type="checkbox"/> Induced abortion <input type="checkbox"/> Ectopic pregnancy <input type="checkbox"/> Other	
	if OTHER → please specify		



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WHOQOL-BREF

The World Health Organization Quality of Life Brief 26-item Version

English version

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WHO REFERENCE NUMBER: WHO/HIS/HSI Rev.2012.03



Instructions

This assessment asks how you feel about **your quality of life, health, or other areas of your life**. Please read each question, assess your feelings, and circle the number on the scale for each question **that gives the best answer for you**. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last 2 weeks**.

		Very poor	Poor	Neither poor nor good	Good	Very good
1 (G1)	<i>How would you rate your quality of life?</i>	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	<i>How satisfied are you with your health?</i>	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	<i>To what extent do you feel that (physical) pain prevents you from doing what you need to do?</i>	1	2	3	4	5
4 (F11.3)	<i>How much do you need any medical treatment to function in your daily life?</i>	1	2	3	4	5
5 (F4.1)	<i>How much do you enjoy life?</i>	1	2	3	4	5
6 (F24.2)	<i>To what extent do you feel your life to be meaningful?</i>	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7 (F5.3)	<i>How well are you able to concentrate?</i>	1	2	3	4	5
8 (F16.1)	<i>How safe do you feel in your daily life?</i>	1	2	3	4	5
9 (F22.1)	<i>How healthy is your physical environment?</i>	1	2	3	4	5



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The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	<i>Do you have enough energy for everyday life?</i>	1	2	3	4	5
11 (F7.1)	<i>Are you able to accept your bodily appearance?</i>	1	2	3	4	5
12 (F18.1)	<i>Have you enough money to meet your needs?</i>	1	2	3	4	5
13 (F20.1)	<i>How available to you is the information that you need in your day-to-day life?</i>	1	2	3	4	5
14 (F21.1)	<i>To what extent do you have the opportunity for leisure activities?</i>	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	<i>How well are you able to get around?</i>	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	<i>How satisfied are you with your sleep?</i>	1	2	3	4	5
17 (F10.3)	<i>How satisfied are you with your ability to perform your daily living activities?</i>	1	2	3	4	5
18 (F12.4)	<i>How satisfied are you with your capacity for work?</i>	1	2	3	4	5
19 (F6.3)	<i>How satisfied are you with yourself?</i>	1	2	3	4	5
20 (F13.3)	<i>How satisfied are you with your personal relationships?</i>	1	2	3	4	5
21 (F15.3)	<i>How satisfied are you with your sex life?</i>	1	2	3	4	5
22 (F14.4)	<i>How satisfied are you with the support you get from your friends?</i>	1	2	3	4	5
23 (F17.3)	<i>How satisfied are you with the conditions of your living place?</i>	1	2	3	4	5
24 (F19.3)	<i>How satisfied are you with your access to health services?</i>	1	2	3	4	5
25 (F23.3)	<i>How satisfied are you with your transport?</i>	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	<i>How often do you have negative feelings such as blue mood, despair, anxiety, depression?</i>	1	2	3	4	5

Thank you for your help!



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End Study Block I

Did the patient complete the first study block (12-15 months) according to the protocol?

<input type="checkbox"/> Yes
<input type="checkbox"/> No

if YES →	Completion date	
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if NO →	Reason for non-completion	<input type="checkbox"/> Patient withdrew consent <input type="checkbox"/> Patient was lost to follow-up <input type="checkbox"/> Patient died <input type="checkbox"/> Other reason
	End of study date	

*Min: 01-11-2023
Max: 31-12-2039*