FertiTOX
Fertility after gonadotoxic treatments

Posttreatment 12-15 months

International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10)-WHO, Version for 2019-covid-expanded.

A

Agranulocytosis (D70)
Anal carcinoma (C21)
Anaemia - Aplastic (D60 – D61)
Anaemia - Fanconi (D61.0)
Angiosarcoma (C22.3)

B

Blasenmole ➜ **Trophoblastic disease**
Brain cancer:
- *Astrocytoma (C71.9)*
- *Ependymoma (C71.9)*
- *Glioblastoma (C71.9)*
- *Oligodendroglioma (C71.9)*
- *Medulloblastoma (C71.6)*
- *other (C71)*

Breast cancer:
- *benign BRCA positive (Z15.01)*
- *hormone receptor positive (Z17.0)*
- *hormone receptor negative (Z17.1)*
- *hormone receptor status not known (Z17)*
- *other (C50)*

Burkitt lymphoma (C83.7)

C

Cervix uteri carcinoma (C53)
Chondrosarcoma (C41.9)
Colitis ulcerosa ➜ **Ulcerative colitis**
Colon carcinoma (C18)
Crohn disease (K50)

D

Dermatomyositis (M33)

E

Endometrial carcinoma (C54)
Endometriosis (N80)
Ewing sarcoma (C40-C41)

F

Fibrosarcoma (C49.9)
Fragile X syndrome (Q99.2)

G

Galactosemia (E74.2)
Germ cell tumour - extragonadal (ICD-O-3 M906-909)

H

Hodgkin lymphoma (C81)

I

Immune thrombocytopenia (D69)

K

Keimzelltumor ➜ **Germ cell tumour**
Kidney cancer (C64)

L

Leiomyosarcoma NOS (ICD-O-3 M8890/3)
Leukaemia:
- *Leukaemia lymphoid - acute lymphoblastic (C91.0)*
- *Leukaemia lymphoid - chronic lymphocytic (C91)*
- *Leukaemia myeloid - acute (C92)*
- *Leukaemia myeloid - chronic (C92)*
- *Leukaemia - other forms (C91 - C95)*

Liposarcoma (C49.9)
Liver cancer (C22)
Lung cancer (C34)
Lupus erythematosus (L93)

M

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)

N

Nasopharyngeal carcinoma (C11)
Nebennierenkrebs ➜ **Adrenocortical carcinoma**
Nephritis / Glomerulonephritis (N05)
Nephroblastoma ➜ **Wilms' tumour**
Non-Hodgkin lymphoma (C82 – C88)

O

Osteosarcoma (C41.9)
Ovary (C56):
- *borderline malignancy*
- *teratoma benign*
- *teratoma malignant*
- *other*

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)

R

Rectal cancer (C20)
Rectosigmoid junction cancer (C19)
Renal cell carcinoma ➜ **Kidney cancer**
Rhabdomyosarcoma (C49.9)
Rheumatoid arthritis (M05 – M06, M08)

S

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)

T

Takayasu arteritis (Aortic arch syndrome) (M31.4)
Testicular cancer (C62):
- *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*

Thalassemia (D56)
Thyroid cancer (C73)
Transgender (F64)
Trophoblastic disease (O01.9)
Turner syndrome (Q96)

U

Ulcerative colitis (K51)
Undifferentiated pleomorphic sarcoma (C49)

V

Vasculitis limited to skin (L95)
Vulva carcinoma (C51)

W

Wegener granulomatosis (M31.3)
Wilms' tumour (Kidney cancer in children) (C64)

?

DISEASE NOT LISTED

Non-completion

Date of end of study	
Reason	○ Patient lost to follow-up ○ Patient withdrew consent ○ Death due to cancer disease, cancer therapy or cancer-related complications ○ Death due to other reasons, please specify: ○ Other reason:

WHOQOL-BREF

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

English version

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 two weeks.**

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

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	*How satisfied are you with your health?*	**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)	*To what extent do you feel that (physical) pain prevents you from doing what you need to do?*	**1**	**2**	**3**	**4**	**5**
4 (F11.3)	*How much do you need any medical treatment to function in your daily life?*	**1**	**2**	**3**	**4**	**5**
5 (F4.1)	*How much do you enjoy life?*	**1**	**2**	**3**	**4**	**5**
6 (F24.2)	*To what extent do you feel your life to be meaningful?*	**1**	**2**	**3**	**4**	**5**

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

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)	*Do you have enough energy for everyday life?*	1	2	3	4	5
11 (F7.1)	*Are you able to accept your bodily appearance?*	1	2	3	4	5
12 (F18.1)	*Have you enough money to meet your needs?*	1	2	3	4	5
13 (F20.1)	*How available to you is the information that you need in your day-to-day life?*	1	2	3	4	5
14 (F21.1)	*To what extent do you have the opportunity for leisure activities?*	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	*How well are you able to get around?*	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)	*How satisfied are you with your sleep?*	1	2	3	4	5
17 (F10.3)	*How satisfied are you with your ability to perform your daily living activities?*	1	2	3	4	5
18 (F12.4)	*How satisfied are you with your capacity for work?*	1	2	3	4	5
19 (F6.3)	*How satisfied are you with yourself?*	1	2	3	4	5
20 (F13.3)	*How satisfied are you with your personal relationships?*	1	2	3	4	5
21 (F15.3)	*How satisfied are you with your sex life?*	1	2	3	4	5
22 (F14.4)	*How satisfied are you with the support you get from your friends?*	1	2	3	4	5
23 (F17.3)	*How satisfied are you with the conditions of your living place?*	1	2	3	4	5
24 (F19.3)	*How satisfied are you with your access to health services?*	1	2	3	4	5
25 (F23.3)	*How satisfied are you with your transport?*	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)	*How often do you have negative feelings such as blue mood, despair, anxiety, depression?*	1	2	3	4	5

Thank you for your help!

12-15 months after the end of gonadotoxic treatment

Centre and city	
Date of 2nd visit	

Final diagnosis

Diagnosis (ICD-10)	*(Please see disease list with ICD-10 codes)*

Gonadotoxic treatment

Start date				
End date				
Treatment protocol	***Please email us the medical letter from oncology!***			
Removal of ovaries	○ None	○ ½ ovary	○ 1 ovary	○ 2 ovaries
Chemotherapy	○ Yes	○ No		
Radiotherapy	○ Yes	○ No		
Endocrine therapy	○ Yes	○ No		
Immunotherapy	○ Yes	○ No		
Surgery	○ Yes	○ No		
Other	○ Yes	○ No		

Disease

Status	○ **Complete remission** *(absence of disease)* ○ **Partial remission** *(> 50% reduction of disease)* ○ **No remission** *(≤ 50% reduction of disease)* ○ **Relapse** *(reappearance of disease)*	
Related events	○ Yes	○ No
Please specify	*(Such as further therapies, a second cancer, other diseases, etc.)*	

Contraception or HRT

Methods	○ **FSH reducing contraceptives** *(combined oral, transdermal, vaginal contraceptives or three month intra-cutaneous injections – DMPA)* ○ **Non-FSH reducing contraceptives** *(progesterone only, subcutaneous implants, any IUD)* ○ **HRT** *(hormone replacement therapy)* ○ **None of the above**

Gonadotoxic treatment – Protocol details

Chemotherapy	***Protocol name, medications, number of cycles, dosage details:***
Radiotherapy	***Protocol name, treatment field, dosage for pelvic irradiation:***
Endocrine therapy	***Protocol name, hormones, dosage details:***
Immunotherapy	***Protocol name, antibodies or inhibitors, dosage details:***
Surgery	***Protocol name and all other relevant details:***
Other	***Protocol name and all other relevant details:***

Posttreatment 12-15 months

REDCap Research Electronic Data Capture

Patient ID

Blood parameters

Date		
AMH		○ pmol/L ○ ng/mL ○ µg/L
FSH		IU/L
LH		IU/L
E2		○ pmol/L ○ ng/L ○ pg/mL

Menstrual cycle parameters

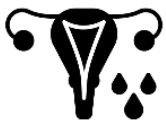
Menstrual cycle

- ○ **Regular** *(21-35 days)*
- ○ **Regular** *(due to hormones, such as oral contraceptives or HRT)*
- ○ **Irregular** *(oligomenorrhea, polymenorrhea, etc.)*
- ○ **Amenorrhea** *(due to premature ovarian insufficiency – POI)*
- ○ **Amenorrhea** *(due to pregnancy, breastfeeding, other hormone treatment, etc.)*
- ○ **Amenorrhea** *(due to endocrine therapy for cancer: GnRH, tamoxifen, AIs, etc.)*
- ○ **Amenorrhea** *(too young to assess, such as children and teenagers)*

In the last 3-6 months.

Day of menstrual cycle when blood test was taken

- ○ Day 1-5
- ○ After day 5
- ○ Cannot be specified (amenorrhea etc.)
- ○ Unknown



Fertility preservation measures

Type performed

- ○ None
- ○ GnRH analogues
- ○ Oocyte freezing
- ○ Zygote freezing
- ○ Embryo freezing
- ○ Ovarian tissue freezing
- ○ Transposition of the ovaries

Patient satisfaction

Is the patient satisfied with the <u>decision</u> 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?	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?	1	2	3	4	5	6	7	8	9	10

<u>Legend:</u>
***0** = not specified*
***1** = not satisfied at all*
***10** = very satisfied*

Pregnancies with use of frozen material

Frozen material used?			○ Yes ○ No
First	**Second**	**Third**	**Fourth**
○ Oocyte ○ Embryo ○ Ovarian tissue ○ Unknown	○ Oocyte ○ Embryo ○ Ovarian tissue ○ Unknown	○ Oocyte ○ Embryo ○ Ovarian tissue ○ Unknown	○ Oocyte ○ Embryo ○ Ovarian tissue ○ Unknown
○ Live birth ○ Ongoing pregnancy ○ Early miscarriage ○ Late miscarriage ○ Stillbirth ○ Induced abortion ○ Ectopic pregnancy ○ Other, specify:	○ Live birth ○ Ongoing pregnancy ○ Early miscarriage ○ Late miscarriage ○ Stillbirth ○ Induced abortion ○ Ectopic pregnancy ○ Other, specify,	○ Live birth ○ Ongoing pregnancy ○ Early miscarriage ○ Late miscarriage ○ Stillbirth ○ Induced abortion ○ Ectopic pregnancy ○ Other, specify:	○ Live birth ○ Ongoing pregnancy ○ Early miscarriage ○ Late miscarriage ○ Stillbirth ○ Induced abortion ○ Ectopic pregnancy ○ Other, specify:

Pregnancies without use of frozen material

Has the patient tried to get pregnant after the end of gonadotoxic treatment?			○ Yes ○ No
First	**Second**	**Third**	**Fourth**
○ Natural conception ○ ART ○ Unknown	○ Natural conception ○ ART ○ Unknown	○ Natural conception ○ ART ○ Unknown	○ Natural conception ○ ART ○ Unknown
○ Live birth ○ Ongoing pregnancy ○ Early miscarriage ○ Late miscarriage ○ Stillbirth ○ Induced abortion ○ Ectopic pregnancy ○ Other, specify:	○ Live birth ○ Ongoing pregnancy ○ Early miscarriage ○ Late miscarriage ○ Stillbirth ○ Induced abortion ○ Ectopic pregnancy ○ Other, specify:	○ Live birth ○ Ongoing pregnancy ○ Early miscarriage ○ Late miscarriage ○ Stillbirth ○ Induced abortion ○ Ectopic pregnancy ○ Other, specify:	○ Live birth ○ Ongoing pregnancy ○ Early miscarriage ○ Late miscarriage ○ Stillbirth ○ Induced abortion ○ Ectopic pregnancy ○ Other, specify: