

Myositis (M60)

# Posttreatment 12-15 months



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

internat	ional Statistical Classification of Diseases and Related Health P	robiems 10th	kevision (ICD-10)-WHO, version for 2019-covia-expanaea.
A	Agranulocytosis (D70) Anal carcinoma (C21) Anaemia - Aplastic (D60 – D61) Anaemia - Fanconi (D61.0) Angiosarcoma (C22.3)	N	Nasopharyngeal carcinoma (C11)  Nebennierenkrebs → Adrenocortical carcinoma  Nephritis / Glomerulonephritis (N05)  Nephroblastoma → Wilms' tumour  Non-Hodgkin lymphoma (C82 – C88)
	Blasenmole → Trophoblastic disease  Brain cancer:  ■ Astrocytoma (C71.9)  ■ Ependymoma (C71.9)  ■ Glioblastoma (C71.9)  ■ Oligodendroglioma (C71.9)	0	Osteosarcoma (C41.9) Ovary (C56):  • borderline malignancy  • teratoma benign  • teratoma malignant  • other
В	<ul> <li>Medulloblastoma (C71.6)</li> <li>other (C71)</li> <li>Breast cancer:</li> <li>benign BRCA positive (Z15.01)</li> <li>hormone receptor positive (Z17.0)</li> <li>hormone receptor negative (Z17.1)</li> <li>hormone receptor status not known (Z17)</li> <li>other (C50)</li> <li>Burkitt lymphoma (C83.7)</li> </ul>	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)
С	Cervix uteri carcinoma (C53) Chondrosarcoma (C41.9) Colitis ulcerosa → Ulcerative colitis Colon carcinoma (C18) Crohn disease (K50)	R	Rectal cancer (C20) Rectosigmoid junction cancer (C19) Renal cell carcinoma → Kidney cancer Rhabdomyosarcoma (C49.9) Rheumatoid arthritis (M05 – M06, M08)
D	Dermatomyositis (M33)		Schilddrüsenkrebs → Thyroid cancer
E	Endometrial carcinoma (C54) Endometriosis (N80) Ewing sarcoma (C40-C41)	S	Sharp syndrome → Mixed connective tissue disease Sickle cell disease (D57) Sigmakarzinom → Colon carcinoma
F	Fibrosarcoma (C49.9) Fragile X syndrome (Q99.2)		Sjögren (Sicca) syndrome (M35) Stomach cancer (C16) Synovial sarcoma (C49.9)
G	Galactosemia (E74.2) Germ cell tumour - extragonadal (ICD-O-3 M906-909)		Systemic sclerosis (including: Scleroderma) (M34)  Takayasu arteritis (Aortic arch syndrome) (M31.4)
Н	Hodgkin lymphoma (C81)		Testicular cancer (C62):  seminoma
I	Immune thrombocytopenia (D69)		<ul> <li>non seminomatous germ cell tumour - teratoma</li> <li>non seminomatous germ cell tumour - embryonal</li> </ul>
K	Keimzelltumor → Germ cell tumour Kidney cancer (C64)		carcinoma ■ non seminomatous germ cell tumour - yolk sac carcinoma
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)	Т	<ul> <li>stromal tumour - Leydig cell tumour</li> <li>stromal tumour - Sertoli cell tumour</li> <li>other histological types</li> <li>Thalassemia (D56)</li> <li>Thyroid cancer (C73)</li> <li>Transgender (F64)</li> <li>Trophoblastic disease (O01.9)</li> <li>Turner syndrome (Q96)</li> </ul>
	Liver cancer (C22) Lung cancer (C34) Lunus on thematocus (L92)	U	Ulcerative colitis (K51) Undifferentiated pleomorphic sarcoma (C49)
	Lupus erythematosus (L93)  Malignant fibrous histiocytoma → Undifferentiated	V	Vasculitis limited to skin (L95) Vulva carcinoma (C51)
	pleomorphic sarcoma Malignant nerve sheath tumour (C47.9) Melanoma (C43)	W	Wegener granulomatosis (M31.3) Wilms' tumour (Kidney cancer in children) (C64)
M	Mesothelioma (C45) Mixed connective tissue disease (M35.1) Morbus Crohn → Crohn disease Myelodysplastic syndrome (D46) Multiple sclerosis (G35)	?	DISEASE NOT LISTED

Version: September 2025 Page 1 of 8







**Patient ID** 

Non-completion							
Date of end of study							
Reason	<ul> <li>Patient lost to follow-up</li> <li>Patient withdrew consent</li> <li>Death due to cancer disease, cancer therapy or cancer-related complications</li> <li>Death due to other reasons, please specify:</li> <li>Other reason:</li> </ul>						

Version: September 2025 Page **2** of **8** 







**Patient ID** 

### **WHOQOL-BREF**



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

Granted permission for WHO copyrighted material; request number: **393701** 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
<b>1</b>	How would you rate your quality of life?	1	2	3	4	5

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
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
<b>3</b> (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
<b>4</b> (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
<b>5</b> (F4.1)	How much do you enjoy life?	1	2	3	4	5
<b>6</b> (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
<b>7</b> (F5.3)	How well are you able to concentrate?	1	2	3	4	5
<b>8</b> (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
<b>9</b> (F22.1)	How healthy is your physical environment?	1	2	3	4	5

Version: September 2025 Page 3 of 8







**Patient ID** 

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
<b>10</b> (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
<b>11</b> (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
<b>12</b> (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
<b>13</b> (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
<b>15</b> (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
<b>16</b> (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
<b>17</b> (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
<b>18</b> (F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
<b>19</b> (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
<b>20</b> (F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
<b>21</b> (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
<b>22</b> (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
<b>23</b> (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
<b>24</b> (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
<b>25</b> (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
<b>26</b> (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Version: September 2025 Page 4 of 8





REDCap	)
Research Electronic Data Capture	

**Patient ID** 

12-15 months	after the end o	of gonadotoxic	treatment		
Centre and city					
Date of 2 <sup>nd</sup> visit					
Final diagnosis	5				
Diagnosis (ICD-10)			(Please see di.	sease list with ICD-10 codes)	
Gonadotoxic t	reatment				
Start date					
End date					
Treatment protocol	Please email us the m	edical letter from oncol	ogy!		
Removal of testicles	o None	o ½ testicle	o 1 testicle	o 2 testicles	
Chemotherapy	o Yes		o No		
Radiotherapy	o Yes		o No		
Endocrine therapy	o Yes		o No		
Immunotherapy	o Yes		o No		
Surgery	o Yes		o No		
Other	o Yes		o No		
Disease					
Status	<ul> <li>Complete remission (absence of disease)</li> <li>Partial remission (&gt; 50% reduction of disease)</li> <li>No remission (≤ 50% reduction of disease)</li> <li>Relapse (reappearance of disease)</li> </ul>				
Related events	o Yes		o No		
Please specify		(Such (	as further therapies, a second	cancer, other diseases, etc.)	

Version: September 2025 Page **5** of **8** 





REDCar	O
Research Electronic Data Capture	

**Patient ID** 

Gonadotoxic trea	tment – 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:

Version: September 2025 Page **6** of **8** 





REDCar	<b>O</b>
Research Electronic Data Capture	

**Patient ID** 

Blood parame	ters											
Date												
Testosterone		o nmol/L o ng/dL o μg/L									Z.	\$
FSH		IU/L								•	<b>/~</b>	
LH		IU/L										
Sperm parame	eters											
Date		Intervalle de temp	s entre	le dernie	er éjacul	ation et	la colle	cte du s	perme :	idéalen	nent 3 à	7 jours.
Total sperm count		10 <sup>6</sup>										
Sperm concentration		10 <sup>6</sup> /mL									(8	(m)
Progressive motility		% (WHO A+B)			<u> </u>							
Normal morphology		%								U.		
Fertility preservation measures												
Type performed	<ul><li>None</li><li>Sperm freezing</li><li>Testicular tissue freezing</li></ul>	zing										
Patient satisfaction												
	d with the <u>decision</u> to have ertility preservation meas	_		Yes No								
How satisfied is the patient with the <u>decision</u> to undergo not to undergo fertility preservation measure		_	1	2	3	4	5	6	7	8	9	10
How satisfied is the patient with the fertility preservation counselling before the gonadotoxic treatment?		1	2	3	4	5	6	7	8	9	10	
										i <mark>end:</mark> not sp	ecified	

1 = not satisfied at all

**10** = very satisfied

Version: September 2025 Page **7** of **8** 







**Patient ID** 



Pregnancies with use of frozen material							
Frozen material used?			<ul><li>Yes</li><li>No</li></ul>				
First	Second	Third	Fourth				
<ul><li>Sperm</li><li>Testicular tissue</li><li>Unknown</li></ul>	<ul><li>Sperm</li><li>Testicular tissue</li><li>Unknown</li></ul>	<ul><li>Sperm</li><li>Testicular tissue</li><li>Unknown</li></ul>	<ul><li>Sperm</li><li>Testicular tissue</li><li>Unknown</li></ul>				
<ul> <li>Live birth</li> <li>Ongoing pregnancy</li> <li>Early miscarriage</li> <li>Late miscarriage</li> <li>Stillbirth</li> <li>Induced abortion</li> <li>Ectopic pregnancy</li> <li>Other, specify:</li> </ul>	<ul> <li>Live birth</li> <li>Ongoing pregnancy</li> <li>Early miscarriage</li> <li>Late miscarriage</li> <li>Stillbirth</li> <li>Induced abortion</li> <li>Ectopic pregnancy</li> <li>Other, specify,</li> </ul>	<ul> <li>Live birth</li> <li>Ongoing pregnancy</li> <li>Early miscarriage</li> <li>Late miscarriage</li> <li>Stillbirth</li> <li>Induced abortion</li> <li>Ectopic pregnancy</li> <li>Other, specify:</li> </ul>	<ul> <li>Live birth</li> <li>Ongoing pregnancy</li> <li>Early miscarriage</li> <li>Late miscarriage</li> <li>Stillbirth</li> <li>Induced abortion</li> <li>Ectopic pregnancy</li> <li>Other, specify:</li> </ul>				



Pregnancies without use of frozen material						
Has the	<ul><li>Yes</li><li>No</li></ul>					
First	Second	Third	Fourth			
<ul> <li>Natural conception</li> </ul>	<ul> <li>Natural conception</li> </ul>	<ul> <li>Natural conception</li> </ul>	<ul> <li>Natural conception</li> </ul>			
o ART	o ART	o ART	o ART			
<ul><li>Unknown</li></ul>	<ul><li>Unknown</li></ul>	<ul><li>Unknown</li></ul>	<ul><li>Unknown</li></ul>			
<ul><li>Live birth</li></ul>	<ul> <li>Live birth</li> </ul>	o Live birth	o Live birth			
<ul> <li>Ongoing pregnancy</li> </ul>	<ul> <li>Ongoing pregnancy</li> </ul>	<ul> <li>Ongoing pregnancy</li> </ul>	<ul> <li>Ongoing pregnancy</li> </ul>			
<ul> <li>Early miscarriage</li> </ul>	<ul> <li>Early miscarriage</li> </ul>	<ul> <li>Early miscarriage</li> </ul>	<ul> <li>Early miscarriage</li> </ul>			
<ul> <li>Late miscarriage</li> </ul>	<ul> <li>Late miscarriage</li> </ul>	<ul> <li>Late miscarriage</li> </ul>	<ul> <li>Late miscarriage</li> </ul>			
<ul> <li>Stillbirth</li> </ul>	<ul> <li>Stillbirth</li> </ul>	<ul> <li>Stillbirth</li> </ul>	<ul> <li>Stillbirth</li> </ul>			
<ul> <li>Induced abortion</li> </ul>	<ul> <li>Induced abortion</li> </ul>	<ul> <li>Induced abortion</li> </ul>	<ul> <li>Induced abortion</li> </ul>			
<ul> <li>Ectopic pregnancy</li> </ul>	<ul> <li>Ectopic pregnancy</li> </ul>	<ul> <li>Ectopic pregnancy</li> </ul>	<ul> <li>Ectopic pregnancy</li> </ul>			
<ul><li>Other, specify:</li></ul>	<ul><li>Other, specify:</li></ul>	<ul><li>Other, specify:</li></ul>	<ul><li>Other, specify:</li></ul>			

Version: September 2025 Page 8 of 8