

Appendix III Questions e-survey 'Evaluation of TGCT on daily living'

Non-validated questions

Question		Answer options
1	What is your email address?	Open question, <i>optional</i>
2	What is your gender?	Male Female
3	What is your year of birth?	Open question
4	In which country do you live?	Open question
5	What is your employment status?	Employed Self-employed Unemployed Student Retired Other, specify _____
6	Please specify employment status	Full time paid employment Part-time paid employment, due to TGCT Part-time paid employment, due to other reasons No paid employment due to TGCT No paid employment due to TGCT but receiving disability aid paid by the government No paid employment due to other reasons Retired due to TGCT Retired due to other reasons
7	Do you have any auto-immune diseases (e.g. rheumatoid arthritis, SLE, Diabetes Mellitus type I?)	No Yes, please specify disease _____
8	Do you have any auto-immunes disease s in the family?	No Yes, please specify disease _____
9	At which age were you first diagnosed with TGCT?	Open question
10	Where is TGCT localized?	Knee Hip Ankle Foot Shoulder Elbow Wrist Hand Other, please specify _____
11	Did you experience trauma and/or surgery at location of TGCT prior to diagnosis (e.g. fracture, (repetitive) sprain, rupture)?	No Yes, I experienced trauma, but no previous surgery at location of TGCT [please specify trauma] _____ Yes, I experienced surgery, but no trauma at location of TGCT [please specify surgery] _____ Yes, I experienced trauma at location of TGCT prior to diagnosis and underwent surgery at location of TGCT [please specify trauma and surgery] _____
12	Which type of TGCT is diagnosed?	Localized (giant cell tumor tendon sheath) Diffuse (previous PVNS) Soft tissue Unknown
13	What were your <u>initial</u> symptoms? [<i>more answer-options possible</i>]	None Pain Stiffness Swelling Limited range of motion Other, specify _____
14	What are your <u>current</u> symptoms? [<i>more answer-options possible</i>]	None Pain Stiffness Swelling Limited range of motion Other, specify _____
15	How many GP (General Practitioner) visits due to TGCT did you have? [<i>estimation</i>] [<i>please put 99 when unknown</i>]	Open question

1 6	How many Orthopedic surgeon visits due to TGCT did you have? <i>[estimation] [please put 99 when unknown]</i>	Open question
1 7	Which initial surgery did you have?	I did not have any surgery Arthroscopy (<i>small surgical incisions</i>) Open synovectomy (one-stage) (<i>large surgical incisions</i>) Combined/two-staged synovectomy (<i>at least two surgical incisions</i>) Total joint replacement/(tumor)prosthesis Amputation Other, specify _____
1 8	How many <u>years</u> ago did the initial surgery take place? <i>[If surgery took place less than a year ago, fill in 0]</i>	Open question
1 9	Which adjuvant treatment did you have?	Nothing Radiotherapy 90-Yttrium Systemic Cryosurgery Other, specify _____
2 0	How many <u>weeks</u> in rehabilitation/physical therapy did you have? <i>[If you did not have any rehabilitation/physical therapy, fill in 0]</i>	Open question
2 1	Which additional/second surgery did you have?	I did not have any surgery Arthroscopy (<i>small surgical incisions</i>) Open synovectomy (one-stage) (<i>large surgical incisions</i>) Combined/two-staged synovectomy (<i>at least two surgical incisions</i>) Total joint replacement/(tumor)prosthesis Amputation Other, specify _____
2 2	How many <u>years</u> ago did additional/second surgery take place? <i>[If surgery took place less than a year ago, fill in 0]</i>	Open question
2 3	What is the total number of surgeries you have had?	1 surgery 2 surgeries 3 surgeries 4 surgeries 5 surgeries 5+ surgeries
2 4	Did you experience any recurrences of TGCT?	No Yes
2 5	After how many <u>years</u> did recurrence of TGCT take place? <i>[If recurrence took place less than a year ago, fill in 0]</i>	Open question
2 6	Did you have a joint replacement?	No Yes
2 7	How long was the in hospital <u>follow-up</u> period (controls in order to monitor TGCT)? <i>[years] [If follow-up was less than a year ago, fill in 0]</i>	Open question
2 8	Were you TGCT free at final follow-up?	I did not have my final follow-up yet No Yes
2 9	Are you currently able to perform sports?	No Yes, once a week Yes, two times a week Yes, three times a week Yes, four times or more per week
3 0	Which sport(s) do/did you perform? <i>[If you do not perform sports, please put X]</i>	Open question
3 1	Space for questions/suggestions/notes from the participant	Open question, <i>optional</i>

Validated questionnaire I: EQ-5D-5L Health Questionnaire

Under each heading, please tick the ONE box that best describes your health TODAY.

Question	Answer options
Mobility	I have no problems in walking about I have slight problems in walking about I have moderate problems in walking about I have severe problems in walking about I am unable to walk about
Self-care	I have no problems washing or dressing myself I have slight problems washing or dressing myself I have moderate problems washing or dressing myself I have severe problems washing or dressing myself I am unable to wash or dress myself
Usual activities (e.g. work, study, housework, family or leisure activities)	I have no problems doing my usual activities I have slight problems doing my usual activities I have moderate problems doing my usual activities I have severe problems doing my usual activities I am unable to do my usual activities
Pain/discomfort	I have no pain or discomfort I have slight pain or discomfort I have moderate pain or discomfort I have severe pain or discomfort I have extreme pain or discomfort
Anxiety/depression	I am not anxious or depressed I am slightly anxious or depressed I am moderately anxious or depressed I am severely anxious or depressed I am extremely anxious or depressed
We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100; <ul style="list-style-type: none"> • 100 means the best health you can imagine; • 0 means the worst health you can imagine. Please write the number for your health today.	Open question (0-100)

Validated questionnaire II: Visual Analogue Scale (VAS) for worst pain/stiffness in last 24 hours

Question	Answer options
<p>Worst pain over the last 24 hours</p> <p>Please rate your pain by choosing the one number that best describes your pain at its worst in the last 24 hours;</p> <ul style="list-style-type: none">• 0 means no pain;• 10 means pain as bad as you can imagine.	0-10
<p>Worst stiffness over the last 24 hours</p> <p>Please rate your pain by choosing the one number that best describes your stiffness at its worst in the last 24 hours;</p> <ul style="list-style-type: none">• 0 means no stiffness;• 10 means stiffness as bad as you can imagine.	0-10

Validated questionnaire III: Patient-Reported Outcomes Measurement Information System-Physical Functioning (PROMIS-PF); upper- and lower extremity short forms

Upper extremity

Please respond to each item by marking one box per row.

Question	Answer options
PFB34: Are you able to change a light bulb overhead?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFA16r1: Are you able to dress yourself, including tying shoelaces and buttoning up your clothes?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFB54: Does your health now limit you in going OUTSIDE the home, for example to shop or visit a doctor's office?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFA4: Does your health now limit you in doing heavy work around the house like scrubbing floors, or lifting or moving heavy furniture?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFA12: Are you able to push open a heavy door?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFB28r1: Are you able to lift 10 pounds (5 kg) above your shoulder?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFA14r1: Are you able to carry a heavy object (over 10 pounds/5 kg)?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFB1: Does your health now limit you in doing moderate work around the house like vacuuming, sweeping floors or carrying in groceries?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFA5: Does your health now limit you in lifting of carrying groceries?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFA42: Are you able to carry a laundry basket up a flight of stairs?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do
PFA13: Are you able to exercise for an hour?	Without any difficulty With a little difficulty With some difficulty With much difficulty Unable to do

Lower extremity

Please respond to each item by marking one box per row.

Question	Answer options
PFA23: Are you able to go for a walk of at least 15 minutes?	Without any difficulty With a little difficulty

	<p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA16r1: Are you able to dress yourself, including tying shoelaces and buttoning up your clothes?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFB54: Does your health now limit you in going OUTSIDE the home, for example to shop or visit a doctor's office?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA4: Does your health now limit you in doing heavy work around the house like scrubbing floors, or lifting or moving heavy furniture?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA12: Are you able to push open a heavy door?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA14r1: Are you able to carry a heavy object (over 10 pounds/5 kg)?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFB1: Does your health now limit you in doing moderate work around the house like vacuuming, sweeping floors or carrying in groceries?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA5: Does your health now limit you in lifting of carrying groceries?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA21: Are you able to go up and down stairs at a normal pace?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA42: Are you able to carry a laundry basket up a flight of stairs?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA10: Are you able to stand for one hour?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA3: Does your health now limit you in bending, kneeling or stooping?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>
PFA13: Are you able to exercise for an hour?	<p>Without any difficulty</p> <p>With a little difficulty</p> <p>With some difficulty</p> <p>With much difficulty</p> <p>Unable to do</p>

Validated questionnaire IV: SF-12

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Answer each question by choosing just ONE answer. If you are unsure how to answer a question, please give the best answer you can.

Question	Answer options
In general, would you say your health is ...	Excellent Very good Good Fair Poor
Health and daily activities The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf?	Yes, limited a lot Yes, limited a little No, not limited at all
Health and daily activities The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? Climbing several flights of stairs?	Yes, limited a lot Yes, limited a little No, not limited at all
Physical health During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? Accomplished less than you would like.	No Yes
Physical health During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? Were limited in the kind of work or other activities.	No Yes
Emotional health Accomplished less than you would like.	No Yes
Emotional health Didn't do work or other activities as carefully as usual.	No Yes
During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)	Not at all A little bit Moderately Quite a bit Extremely
Feelings Have you felt calm and peaceful?	All of the time Most of the time A good bit of the time Some of the time A little of the time None of the time
Feelings Did you have a lot of energy?	All of the time Most of the time A good bit of the time Some of the time A little of the time None of the time
Feelings Have you felt downhearted and blue?	All of the time Most of the time A good bit of the time Some of the time A little of the time None of the time
During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?	All of the time Most of the time Some of the time A little of the time None of the time