Surveillance AFter Extremity Tumor SurgerY (SAFETY) Protocol Study

PATIENT QUESTIONNAIRE

Thank you for agreeing to complete this questionnaire. Your responses will help orthopaedic oncology researchers better understand whether sarcoma patients are willing to participate in research evaluating different post-operative follow-up schedules. This questionnaire should take you approximately 15 minutes to complete. A participant ID number will be assigned to track completion of the questionnaires. A master list linking the ID number will be maintained during the data collection phase. Once all questionnaires from each round have been received, the list will be destroyed and your responses will be anonymized.

Some of the questions may be uncomfortable for you to answer. However, we ask that you try your best in answering all of the questions. Your participation is important to us and those whom may benefit from this research.

Part A: DEMOGRAPHICS
This section asks a few basic questions to let us know a little bit more about you.

1. What is your age?
   ___________ years

2. What is your gender?
   ☐ Male
   ☐ Female
   ☐ Other (specify):

3. What is your race/ethnicity?
   ☐ Caucasian
   ☐ Native/Aboriginal
   ☐ African/Caribbean
   ☐ East Asian
   ☐ Hispanic/Latino
   ☐ South Asian
   ☐ Middle Eastern
   ☐ Other (specify):
   ☐ Mixed (specify):

4. Where do you live?
   ☐ Canada
   ☐ Spain
   ☐ Netherlands
   ☐ USA
   ☐ Other (specify):

5. What is your first language?
   ☐ Arabic
   ☐ Korean
   ☐ Spanish
   ☐ Cantonese
   ☐ Mandarin
   ☐ Urdu
   ☐ Dutch
   ☐ Portuguese
   ☐ Vietnamese
   ☐ English
   ☐ Russian
   ☐ Other (specify):
6. What is your marital status?
- Single
- Separated
- Divorced
- Common Law
- Married
- Widowed

7. What is your highest level of education?
- Did Not Complete High School
- High School Diploma
- College/Trade Diploma
- Undergraduate Degree
- Masters Degree
- Doctorate Degree
- Professional Degree
- Other (specify): ________________

8. Are you currently employed?
- Yes → If yes, what is your current occupation? ________________
- No → If no, please specify why:
  - Retired
  - Homemaker
  - Student
  - Unemployed
  - Doctor’s Advice/Disability
  - Other (specify): ________________

9. Do you have a medical history of any of the following diseases?  
*Please select ALL that apply.*
- None
- Diabetes (Type I)
- Inflammatory Bowel Disease
- Peripheral Vascular Disease
- Diabetes (Type II)
- Kidney Transplant
- Psychoses
- AIDS/HIV
- Heart Disease
- Liver Failure
- Pulmonary Circulation Disorder
- Anemia
- Hepatitis
- Neurological Disorders
- Renal Failure
- Cardiac Arrhythmia
- Hypertension
- Rheumatoid Arthritis
- Chronic Pulmonary Disease
- Hyperthyroidism
- Systemic Lupus Erythematosus
- Depression
- Hypothyroidism
- Osteoarthritis
- Other (specify): ________________

10. Do you smoke?
- Never
- Former Smoker
- Current Smoker

11. Do you routinely use recreational drugs?
- Never
- Former User
- Current User

12. How much alcohol do you drink on a weekly basis?  
  _____ Drinks/Week

*If you live in Canada or the USA, please proceed to Page 3.  
If you live in the Netherlands or Spain, please proceed to Page 4.*
13. What is your yearly household income before taxes?

☐ Less than $20,000
☐ $20,000 to $39,999
☐ $40,000 to $59,999
☐ $60,000 to $79,999
☐ $80,000 to $99,999
☐ $100,000+

14. Please answer 14A if you live in Canada. Please answer 14B if you live in the USA.

(A) For Canadian patients, do you have any additional medical insurance coverage outside of your provincial health insurance plan?

☐ No
☐ Yes ➔ If yes, please indicate what type of additional medical insurance coverage:
☐ Employer-Provided Insurance
☐ Military/Veteran
☐ Personally-Purchased Insurance
☐ Other (specify): ______________________

(B) For American patients, do you have medical insurance coverage?

☐ No
☐ Yes ➔ If yes, please indicate what type of additional medical insurance coverage:
☐ Employer-Provided Insurance
☐ Medicaid
☐ Personally-Purchased Insurance
☐ Military/Veteran
☐ Medicare
☐ Other (specify): ______________________

Please proceed to Part B on Page 5.
13. What is your yearly household income before taxes?

☐ Less than €14,500
☐ €14,500 to €28,999
☐ €29,000 to €43,499
☐ €43,500 to €57,999
☐ €58,000 to €71,999
☐ €72,000+

14. Do you have any additional medical insurance coverage outside of your state health insurance plan?

☐ No
☐ Yes ➔ If yes, please indicate what type of additional medical insurance coverage:
   ☐ Employer-Provided Insurance
   ☐ Military/Veteran
   ☐ Personally-Purchased Insurance
   ☐ Other (specify): __________________________

*Please proceed to Part B on Page 5.*
Part B: CANCER HISTORY
This section asks questions about your cancer and cancer treatment. If you have been diagnosed with more than one cancer, please answer the following questions considering only the cancer you are in clinic for today.

15. What type of cancer do you have?
- [ ] Chondrosarcoma
- [ ] Ewing's sarcoma
- [ ] Fibrosarcoma
- [ ] Fibrous histiocytoma
- [ ] Giant cell tumor of bone
- [ ] Leiomyosarcoma
- [ ] Liposarcoma
- [ ] Non-osteogenic sarcoma of bone
- [ ] Osteosarcoma
- [ ] Rhabdomyosarcoma
- [ ] Synovial sarcoma
- [ ] Other (specify): ______________________
- [ ] Not Sure

16. Where is your cancer located?
- [ ] Arm
- [ ] Leg
- [ ] Not Sure
- [ ] Other (specify): ______________________

17. When were you diagnosed with cancer?
[ ] DD [ ] MM [ ] YYYY

18. How long have you been a cancer patient at the center where you are for your current treatment?
- [ ] Less Than 2 Weeks
- [ ] 2 - 4 Weeks
- [ ] 1 - 6 Months
- [ ] Over 6 Months

19. How has your cancer been treated so far?
Please select ALL that apply.
- [ ] Chemotherapy
- [ ] Radiation therapy
- [ ] Physiotherapy
- [ ] Other (specify): ______________________

20. How many times have you seen your orthopaedic oncologist (cancer surgeon)?
- [ ] First Visit
- [ ] Once Before
- [ ] 2 - 3 Times
- [ ] Over 3 Times

21. How long does it typically take you get from home to the hospital for a cancer appointment?
- [ ] Less Than 30 Minutes
- [ ] 30 - 59 Minutes
- [ ] 1 - 1.5 Hours
- [ ] 1.5 - 2 Hours
- [ ] Over 2 Hours
22. How do you typically travel to the hospital for a cancer appointment?

- Public Transit
- Taxi
- Foot
- Relative/Friend’s Vehicle
- Personal Vehicle
- Bicycle
- Hospital Transportation
- Other (specify): ________________

23. Who is your primary caregiver?

- Myself
- Spouse/Partner
- Parent
- Child
- Grandchild
- Friend
- Sibling
- Other (specify): ________________

Part C: IMPORTANCE OF CANCER RESEARCH

This section asks questions about your previous participation in research and your opinion on cancer research. For each opinion question, please rate your level agreement with each statement.

24. I am interested in participating in clinical research related to my cancer.

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree

25. Have you previously participated in any other research studies?

- No
- Yes ➔ If yes, how many other research studies have you previously participated in?

- 1
- 2
- 3
- Over 3

26. How many different research studies have been discussed with you over the course of your cancer treatment?

- 0
- 1
- 2
- 3
- Over 3

27. I have a good understanding of clinical research.

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree

28. Some clinical research determines by chance what treatment a patient receives (randomization). I am comfortable with being randomly assigned (randomized) to receive a treatment.

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
29. Cancer research will help doctors better understand and treat cancer.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree Nor Disagree
- [ ] Disagree
- [ ] Strongly Disagree

30. The primary reason cancer research is done is to improve the treatment of *future* cancer patients.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree Nor Disagree
- [ ] Disagree
- [ ] Strongly Disagree

31. I will not directly benefit from participating in cancer research.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree Nor Disagree
- [ ] Disagree
- [ ] Strongly Disagree

32. Patients who participate in research studies should be told the results when the study is complete.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree Nor Disagree
- [ ] Disagree
- [ ] Strongly Disagree

**Part D: FINANCIAL BURDEN OF CANCER CARE**

This section asks questions about some of the costs you may have incurred as a result of your cancer treatment and whether they are a financial burden to you. A financial burden is any cost or fee that is difficult to pay.

33. Are transportation and travel expenses incurred due to your cancer care paid by you/your family?

Some examples of transportation and travel expenses include costs from gas, tolls, parking, taxis, and public transportation fares.

- [ ] No
- [ ] Yes ➔ If yes, please indicate how much of a financial burden these costs are to you:

  - [ ] Unmanageable Burden
  - [ ] Significant Burden
  - [ ] Somewhat of a Burden
  - [ ] Slight Burden
  - [ ] No Burden

34. Are accommodation and meal expenses incurred due to your cancer care paid by you/your family?

Some examples of accommodation and meal expenses include costs from hotel stays and meals at restaurants.

- [ ] No
- [ ] Yes ➔ If yes, please indicate how much of a financial burden these costs are to you:

  - [ ] Unmanageable Burden
  - [ ] Significant Burden
  - [ ] Somewhat of a Burden
  - [ ] Slight Burden
  - [ ] No Burden
35. Are family and living expenses incurred due to your cancer paid by you/your family?
   Some examples of family and living expenses include costs related to running your household, childcare, and housekeeping.
   ☐ No
   ☐ Yes ➔ If yes, please indicate how much of a financial burden these costs are to you:
     ☐ Unmanageable Burden
     ☐ Significant Burden
     ☐ Somewhat of a Burden
     ☐ Slight Burden
     ☐ No Burden

36. Are caregiving expenses incurred due to your cancer care paid by you/your family?
   Some examples of caregiving expenses include costs from hiring a person to prepare meals or drive you to appointments, extended nursing care, homecare, and personal support workers.
   ☐ No
   ☐ Yes ➔ If yes, please indicate how much of a financial burden these costs are to you:
     ☐ Unmanageable Burden
     ☐ Significant Burden
     ☐ Somewhat of a Burden
     ☐ Slight Burden
     ☐ No Burden

37. Have you experienced a loss of your own wages due to your cancer care?
   ☐ Not Applicable ➔ I was not employed prior to my cancer diagnosis.
   ☐ No
   ☐ Yes ➔ If yes, please indicate how much of a financial burden this loss of income is to you:
     ☐ Unmanageable Burden
     ☐ Significant Burden
     ☐ Somewhat of a Burden
     ☐ Slight Burden
     ☐ No Burden

38. Has your primary caregiver experienced a loss of wages due to your cancer care?
   ☐ Not Applicable ➔ My primary caregiver was not employed prior to my cancer diagnosis.
   ☐ No
   ☐ Yes ➔ If yes, please indicate how much of a financial burden this loss of income is to your primary caregiver:
     ☐ Unmanageable Burden
     ☐ Significant Burden
     ☐ Somewhat of a Burden
     ☐ Slight Burden
     ☐ No Burden

Part E: LOGISTICAL BURDEN OF CANCER CARE
This section asks questions about some of the tasks you may have to manage as a result of your cancer treatment and whether they are a logistical burden to you. A logistical burden is any task that involves the coordination of many details or people that is difficult to manage.

39. I find that coordinating frequent medical appointments for my cancer care is a logistical burden.
   ☐ No
   ☐ Yes ➔ If yes, please indicate how much of a logistical burden coordinating medical appointments is to you:
     ☐ Unmanageable Burden
     ☐ Significant Burden
     ☐ Somewhat of a Burden
     ☐ Slight Burden
     ☐ No Burden
40. I find that completing and submitting paperwork related to my cancer care is a logistical burden.
   - [ ] Not Applicable  ➔ I do not have any additional paperwork to complete related to my cancer care.
   - [ ] No
   - [ ] Yes  ➔ If yes, please indicate how much of a logistical burden completing additional paperwork is to you:
     - [ ] Unmanageable Burden
     - [ ] Significant Burden
     - [ ] Somewhat of a Burden
     - [ ] Slight Burden
     - [ ] No Burden

41. I find that processing medical bills related to my cancer care is a logistical burden.
   - [ ] Not Applicable  ➔ I do not have any additional medical bills related to my cancer care.
   - [ ] No
   - [ ] Yes  ➔ If yes, please indicate how much of a logistical burden processing additional medical bills is to you:
     - [ ] Unmanageable Burden
     - [ ] Significant Burden
     - [ ] Somewhat of a Burden
     - [ ] Slight Burden
     - [ ] No Burden

42. I find that arranging for time off work to attend medical appointments for my cancer care is a logistical burden.
   - [ ] Not Applicable  ➔ I am not currently employed.
   - [ ] No
   - [ ] Yes  ➔ If yes, please indicate how much of a logistical burden arranging for time off work is to you:
     - [ ] Unmanageable Burden
     - [ ] Significant Burden
     - [ ] Somewhat of a Burden
     - [ ] Slight Burden
     - [ ] No Burden

43. I find that arranging childcare to attend medical appointments for my cancer care is a logistical burden.
   - [ ] Not Applicable  ➔ I do not have children OR I do not have children that currently require childcare.
   - [ ] No
   - [ ] Yes  ➔ If yes, please indicate how much of a logistical burden arranging childcare is to you:
     - [ ] Unmanageable Burden
     - [ ] Significant Burden
     - [ ] Somewhat of a Burden
     - [ ] Slight Burden
     - [ ] No Burden

Part F: THE SAFETY TRIAL

Please review the Patient Information Sheet for the SAFETY Trial before answering the following questions. For questions asking your opinion, please rate your level of agreement with each statement.

44. The post-operative follow-up schedule described below is standard care for my type of cancer.

   For the first two years after your surgery, your doctor will see you every three months to see if the tumor will grow back where you had your surgery or in your lungs. After that, your doctor will see you for the same reasons every six months for three years. At five years after surgery, your doctor will see you once a year. You will have a CT scan of your lungs for the first two years. Otherwise, you will only have a chest x-ray at each visit.

   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Neither Agree Nor Disagree
   - [ ] Disagree
   - [ ] Strongly Disagree
45. The post-operative follow-up schedule described above has been scientifically proven to be the best for my type of cancer.

☐ Strongly Agree  ☐ Agree  ☐ Neither Agree Nor Disagree  ☐ Disagree  ☐ Strongly Disagree

46. Compared with the standard follow-up schedule, none of the other study follow-up schedules carry any additional risks or discomforts.

☐ Strongly Agree  ☐ Agree  ☐ Neither Agree Nor Disagree  ☐ Disagree  ☐ Strongly Disagree

47. I have concerns about being followed by my orthopaedic oncologist less frequently.

☐ Strongly Agree  ☐ Agree  ☐ Neither Agree Nor Disagree  ☐ Disagree  ☐ Strongly Disagree

48. I have concerns about my exposure to radiation from additional CT scans or x-rays.

☐ Strongly Agree  ☐ Agree  ☐ Neither Agree Nor Disagree  ☐ Disagree  ☐ Strongly Disagree

49. I have concerns that CT scans will miss any cancer nodules that weren’t detected on a chest x-ray.

☐ Strongly Agree  ☐ Agree  ☐ Neither Agree Nor Disagree  ☐ Disagree  ☐ Strongly Disagree

50. Compared with the standard follow-up schedule, fewer follow-up appointments would ease the financial burden of my cancer care.

☐ Strongly Agree  ☐ Agree  ☐ Neither Agree Nor Disagree  ☐ Disagree  ☐ Strongly Disagree

51. Compared with the standard follow-up schedule, fewer follow-up appointments would ease the logistical burden of my cancer care.

☐ Strongly Agree  ☐ Agree  ☐ Neither Agree Nor Disagree  ☐ Disagree  ☐ Strongly Disagree

52. Would you discuss this research study with anyone before deciding to / not to participate in this study?

☐ No

☐ Yes → If yes, please specify who:

☐ Spouse/Partner  ☐ Parent
☐ Sibling  ☐ Child
☐ Friend  ☐ Grandchild
☐ Family Physician  ☐ Other (specify):  __________________________
53. Would you search for any additional information before deciding to / not to participate in this study?

☐ No

☐ Yes   ➔ If yes, please specify where:

☐ Internet

☐ Hospital Resources

☐ Other Organization (specify):

☐ Literature (books/journals)

☐ Patient Support Group(s)

☐ Other (specify): ______________________

54. Would you participate in the SAFETY trial?

☐ Yes

☐ No

55. My decision to / not to participate in this research study was easy.

☐ Strongly Agree

☐ Agree

☐ Neither Agree Nor Disagree

☐ Disagree

☐ Strongly Disagree

56. Please answer 56A if you would participate in the SAFETY trial. Please answer 56B if you would not participate in the SAFETY Trial.

(A) Why would you agree to participate in this research study?

Please select ALL that apply.

☐ A. I believe that the study offers the best treatment available.

☐ B. I want to contribute to scientific research.

☐ C. I believe that the quality of care I receive would be better as part of this study.

☐ D. I trust the doctor treating me.

☐ E. I believe that the benefits of participating would outweigh any negative side-effects.

☐ F. I believe the results from the study could benefit other patients in the future.

☐ G. I believe that I would be monitored more closely as part of this study.

☐ H. My family is keen for me to participate.

☐ I. I think my cancer will get worse unless I participate in this study.

☐ J. I had a positive experience in a previous research study.

☐ K. Other (specify): ______________________

(B) Why would you choose not to participate in this research study?

Please select ALL that apply.

☐ A. I do not believe that the study offers the best treatment available.

☐ B. I do not want to contribute to scientific research.

☐ C. I believe that the quality of care I receive would be inferior to what I would receive if I did not participate.

☐ D. I do not trust the doctor treating me.

☐ E. I have concerns about possibly being followed less intensively in this study.

☐ F. I have concerns about the additional radiation exposure from CT scans.

☐ G. My family is not keen for me to participate.

☐ H. I believe that this study would cause issues with my insurance coverage.

☐ I. I do not believe that I can currently cope with the additional requirements of a research study.

☐ J. I had a negative experience in a previous research study.

☐ K. Other (specify): ______________________
Participant Initials

Participant ID

57. Which of the reasons above was the most important reason for you deciding to / not to participate in the SAFETY trial?

58. Additional Comments: ___________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Thank you for completing this questionnaire!