

Participant Initials

Participant ID

 –

Completion Date

 2 **0**
DD MM YYYY

Surveillance **A**fter **E**xtremity Tumor Surger**Y** (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

☐ French

☐ Korean

☐ Spanish

☐ Cantonese

☐ German

☐ Mandarin

☐ Urdu

☐ Dutch

☐ Hindi

☐ Portuguese

☐ Vietnamese

☐ English

☐ Italian

☐ Russian

☐ Other (specify): _____

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6. What is your marital status?

☐ **Single** ☐ **Separated** ☐ **Divorced** ☐ **Common Law** ☐ **Married** ☐ **Widowed**

7. What is your highest level of education?

<input type="checkbox"/> Did Not Complete High School	<input type="checkbox"/> High School Diploma
<input type="checkbox"/> College/Trade Diploma	<input type="checkbox"/> Undergraduate Degree
<input type="checkbox"/> Masters Degree	<input type="checkbox"/> Doctorate Degree
<input type="checkbox"/> Professional Degree	<input type="checkbox"/> Other (specify):

8. Are you currently employed?

☐ **Yes** → If yes, what is your current occupation? _____

☐ **No** → If no, please specify why:

<input type="checkbox"/> Retired	<input type="checkbox"/> Homemaker
<input type="checkbox"/> Student	<input type="checkbox"/> Unemployed
<input type="checkbox"/> Doctor's Advice/Disability	<input type="checkbox"/> Other (specify):

9. Do you have a medical history of any of the following diseases?

Please select ALL that apply.

<input type="checkbox"/> None	<input type="checkbox"/> Diabetes (Type I)	<input type="checkbox"/> Inflammatory Bowel Disease	<input type="checkbox"/> Peripheral Vascular Disease
<input type="checkbox"/> Addiction	<input type="checkbox"/> Diabetes (Type II)	<input type="checkbox"/> Kidney Transplant	<input type="checkbox"/> Psychoses
<input type="checkbox"/> AIDS/HIV	<input type="checkbox"/> Heart Disease	<input type="checkbox"/> Liver Failure	<input type="checkbox"/> Pulmonary Circulation Disorder
<input type="checkbox"/> Anemia	<input type="checkbox"/> Hepatitis	<input type="checkbox"/> Neurological Disorders	<input type="checkbox"/> Renal Failure
<input type="checkbox"/> Cardiac Arrhythmia	<input type="checkbox"/> Hypertension	<input type="checkbox"/> Obesity	<input type="checkbox"/> Rheumatoid Arthritis
<input type="checkbox"/> Chronic Pulmonary Disease	<input type="checkbox"/> Hyperthyroidism	<input type="checkbox"/> Osteoarthritis	<input type="checkbox"/> Systemic Lupus Erythematosus
<input type="checkbox"/> Depression	<input type="checkbox"/> Hypothyroidism	<input type="checkbox"/> Osteoporosis	<input type="checkbox"/> 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**.*

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 – **PLEASE COMPLETE THIS PAGE IF YOU LIVE IN CANADA OR THE USA.**

13. What is your yearly household income before taxes?

- | | |
|--|--|
| <input type="checkbox"/> Less than \$20,000 | <input type="checkbox"/> \$60,000 to \$79,999 |
| <input type="checkbox"/> \$20,000 to \$39,999 | <input type="checkbox"/> \$80,000 to \$99,999 |
| <input type="checkbox"/> \$40,000 to \$59,999 | <input type="checkbox"/> \$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:
- | | |
|--|--|
| <input type="checkbox"/> Employer-Provided Insurance | <input type="checkbox"/> Military/Veteran |
| <input type="checkbox"/> Personally-Purchased Insurance | <input type="checkbox"/> 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:
- | | |
|--|--|
| <input type="checkbox"/> Employer-Provided Insurance | <input type="checkbox"/> Medicaid |
| <input type="checkbox"/> Personally-Purchased Insurance | <input type="checkbox"/> Military/Veteran |
| <input type="checkbox"/> Medicare | <input type="checkbox"/> Other (specify): _____ |

*Please proceed to **Part B** on **Page 5**.*

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PLEASE COMPLETE THIS PAGE IF YOU LIVE IN THE **NETHERLANDS** OR **SPAIN**.

13. What is your yearly household income before taxes?

- | | |
|--|--|
| <input type="checkbox"/> Less than €14,500 | <input type="checkbox"/> €43,500 to €57,999 |
| <input type="checkbox"/> €14,500 to €28,999 | <input type="checkbox"/> €58,000 to €71,999 |
| <input type="checkbox"/> €29,000 to €43,499 | <input type="checkbox"/> €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:

- | | |
|--|--|
| <input type="checkbox"/> Employer-Provided Insurance | <input type="checkbox"/> Military/Veteran |
| <input type="checkbox"/> Personally-Purchased Insurance | <input type="checkbox"/> Other (specify): _____ |

Please proceed to **Part B** on **Page 5**.

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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?

- | | |
|--|--|
| <input type="checkbox"/> Chondrosarcoma | <input type="checkbox"/> Ewing's sarcoma |
| <input type="checkbox"/> Fibrosarcoma | <input type="checkbox"/> Fibrous histiocytoma |
| <input type="checkbox"/> Giant cell tumor of bone | <input type="checkbox"/> Leiomyosarcoma |
| <input type="checkbox"/> Liposarcoma | <input type="checkbox"/> Non-osteogenic sarcoma of bone |
| <input type="checkbox"/> Osteosarcoma | <input type="checkbox"/> Rhabdomyosarcoma |
| <input type="checkbox"/> Synovial sarcoma | <input type="checkbox"/> Other (specify): _____ |
| <input type="checkbox"/> Not Sure | |

16. Where is your cancer located?

- | | |
|--|--|
| <input type="checkbox"/> Arm | <input type="checkbox"/> Leg |
| <input type="checkbox"/> Not Sure | <input type="checkbox"/> Other (specify): _____ |

17. When were you diagnosed with cancer?

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
DD		MM		YYYY			

18. How long have you been a cancer patient at the center where you are for your current treatment?

- | | | | |
|------------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 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.

- | | |
|---|--|
| <input type="checkbox"/> Chemotherapy | <input type="checkbox"/> Radiation therapy |
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Other (specify): _____ |

20. How many times have you seen your orthopaedic oncologist (cancer surgeon)?

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 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?

- | | | | | |
|---------------------------------|----------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Less Than
30 Minutes | 30 - 59
Minutes | 1 - 1.5
Hours | 1.5 - 2
Hours | Over 2
Hours |

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 – 22. How do you *typically* travel to the hospital for a cancer appointment?

- | | |
|---|---|
| <input type="checkbox"/> Public Transit | <input type="checkbox"/> Personal Vehicle |
| <input type="checkbox"/> Taxi | <input type="checkbox"/> Bicycle |
| <input type="checkbox"/> Foot | <input type="checkbox"/> Hospital Transportation |
| <input type="checkbox"/> Relative/Friend's Vehicle | <input type="checkbox"/> Other (specify): _____ |

23. Who is your primary caregiver?

A primary caregiver is the person who assumes the most responsibility in caring for your health and wellbeing.

- | | |
|--|--|
| <input type="checkbox"/> Myself | <input type="checkbox"/> Spouse/Partner |
| <input type="checkbox"/> Parent | <input type="checkbox"/> Sibling |
| <input type="checkbox"/> Child | <input type="checkbox"/> Grandchild |
| <input type="checkbox"/> Friend | <input type="checkbox"/> 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.

- | | | | | |
|--------------------------|--------------------------|---------------------------------------|--------------------------|------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 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?
- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 1 | 2 | 3 | Over 3 |

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

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 0 | 1 | 2 | 3 | Over 3 |

27. I have a good understanding of clinical research.

- | | | | | |
|--------------------------|--------------------------|---------------------------------------|--------------------------|------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 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.

- | | | | | |
|--------------------------|--------------------------|---------------------------------------|--------------------------|------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Strongly Agree | Agree | Neither Agree
Nor Disagree | Disagree | Strongly
Disagree |

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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**

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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**

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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**

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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**☐ **Sibling**☐ **Friend**☐ **Family Physician**☐ **Parent**☐ **Child**☐ **Grandchild**☐ **Other (specify):** _____

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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**☐ **Literature (books/journals)**☐ **Hospital Resources**☐ **Patient Support Group(s)**☐ **Other Organization (specify):**☐ **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.**☐ **F. I believe the results from the study could benefit other patients in the future.**☐ **B. I want to contribute to scientific research.**☐ **G. I believe that I would be monitored more closely as part of this study.**☐ **C. I believe that the quality of care I receive would be better as part of this study.**☐ **H. My family is keen for me to participate.**☐ **D. I trust the doctor treating me.**☐ **I. I think my cancer will get worse unless I participate in this study.**☐ **E. I believe that the benefits of participating would outweigh any negative side-effects.**☐ **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.**☐ **F. I have concerns about the additional radiation exposure from CT scans.**☐ **B. I do not want to contribute to scientific research.**☐ **G. My family is not keen for me to participate.**☐ **C. I believe that the quality of care I receive would be inferior to what I would receive if I did not participate.**☐ **H. I believe that this study would cause issues with my insurance coverage.**☐ **D. I do not trust the doctor treating me.**☐ **I. I do not believe that I can currently cope with the additional requirements of a research study.**☐ **E. I have concerns about possibly being followed less intensively in this study.**☐ **J. I had a negative experience in a previous research study.**☐ **K. Other (specify):** _____

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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!