International Guideline Harmonization Group
for Late Effects of Childhood Cancer

Information letter for participation in the COVID-19 questionnaire study:

Provider perspective on implementing survivorship care in times of COVID-19.

Introduction

Dear sir/madam,

Hereby we invite you to participate in our questionnaire study. Participation is voluntary. If you decide to participate in this study, completion of the questionnaire automatically provides consent to collection, storage and usage of your responses.

Before you decide to participate, we would like to inform you about the planned research. Please read this information carefully. If you have any questions, please contact the study coordinator and/or independent clinician. Contact details can be found at the end of this letter.

1. **General information**

This questionnaire study is part of a global collaborative effort. Soon after the outbreak of COVID-19, medical researchers within the International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG) combined forces to gain insight about how the pandemic has affected survivors of childhood cancer and survivorship care clinicians.

Adequate survivorship care is of great importance to maintain and/or improve quality of life (QoL) of survivors. Hence, continuation of long-term follow-up (LTFU) service delivery during this pandemic is crucial. With this questionnaire, we aim to learn how the outbreak of COVID-19 has affected survivorship care and how it can best be implemented under the current circumstances. This study will also form the basis for future IGHG guideline development.

2. **Research objectives**

The goals of this questionnaire study are to describe LTFU services offered by childhood cancer institutions at an international level and to describe how the outbreak of COVID-19 has affected the delivery of LTFU services over time. Additionally, we would like to gain insight about the personal impact of this pandemic on survivorship clinicians.

3. **Background**

Over the last decades, childhood cancer treatments have improved, causing 5-year survival rates to steadily increase since the 1970s from 40% to 80%. However, cancer and its

treatment predispose childhood cancer survivors to greater risk of physical and psychosocial health problems later in life. These problems include secondary neoplasms and organ dysfunction, as well as lower school performance, unemployment due to disability and lower income. On average, childhood cancer survivors experience lower quality of life (QoL), excess morbidity and even premature death compared to sibling and non-cancer control populations.

To optimize outcomes of survivors and their families, many childhood cancer institutions offer long-term follow-up (LTFU) services. These services have a strong focus on education of childhood cancer survivors and prevention of late effects, as well as early detection and timely intervention when problems do occur. In order to maintain or improve their health and mental wellbeing, it is paramount that childhood cancer survivors receive appropriate survivorship care that is tailored to their individual health needs.

However, due to the current outbreak of COVID-19, the World Health Organization (WHO) has reported a severe disruption of health services at a global level. It is to be expected that the current COVID-19 outbreak has also greatly impacted survivorship care. Disruption of the delivery of LTFU services may negatively affect the health and emotional wellbeing of childhood cancer survivors. Additionally, the COVID-19 outbreak may not only affect how LTFU services are currently provided, but also future methods of survivorship care.

4. **What it means to participate in this study**

If you decide to participate, you will be asked to fill out a questionnaire. Completing the questionnaire will take approximately 10 minutes of your time. The questionnaire will address the LTFU services offered by your institution and how COVID-19 has changed the delivery of these services. Furthermore, questions are included that help us understand how you have personally been affected by this pandemic. Your answers are anonymous and will be analyzed in the Princess Máxima Center (the Netherlands). You are free to decline to respond to any personal questions that make you feel uncomfortable.

5. **You have decided to participate: next steps**

In the email you find a link to the questionnaire. Completing the questionnaire automatically provides consent to collection, storage and usage of your responses.

6. **Possible (dis)advantages**

Before you decide to participate in this study, it is important that you consider possible (dis)advantages. You will not directly benefit from participating in this study. However, your participation could contribute to more knowledge on how to implement survivorship care in times of COVID-19.

7. **If you do not want to participate or want to retract your response**

Participation in this study is voluntary. If you have decided to participate and entered the questionnaire, you are still free to decide otherwise and not submit your response. When you

have already submitted your response, however, it is no longer possible to withdraw from the study; your response is anonymous and cannot be retracted.

8. End of the study

The study is finalized when a sufficient amount of responses is collected. We aim to collect responses for a duration of 4 weeks, but this period may be extended if necessary. After data analysis, the study coordinator will inform you on the most important results. We anticipate that we can report to you 2-4 months after your participation.

9. Data usage and storage

For this study we will collect, analyze and store your answers to the questionnaire. As mentioned previously, the questionnaire is **anonymous** and you will not be asked to fill out any personal details such as your name, address and/or birth date. If you do not want your response to be used in this study, you cannot participate.

The handling of your data complies with the General Data Protection Regulation (GDPR). Responses to the questionnaire will be collected by the study coordinator. To separate individual responses, the date and time of questionnaire completion will be used. All responses will be stored in a folder that is only accessible by the principle investigator and study coordinator. In addition, a password will be used to prevent unauthorized access. Data will be stored until 5 years after the publication of the research paper.

Access to your data
Some persons and organizations could gain access to your data at the research site (Princess Máxima Center, the Netherlands). This is necessary to verify whether the study has been performed according to good research practices. Persons and organizations that could gain access to your data are:

- Safety committee who monitors this study
- National and international supervisory authorities, e.g., the Health and Youth Care Inspectorate
- Researchers within the research group

They will be asked to handle your data discreetly. We ask you for your permission to make your data accessible to the persons and organizations named above.

If you have any questions or complaints before or during the study about how your data are processed, you can contact the data protection officer of the Princess Máxima Center (fg@prinsesmaximacentrum.nl).

10. Contact details

If you have any questions or comments, you can contact:

- Selina van den Oever, study coordinator. Email: s.r.vandenoever-2@prinsesmaximacentrum.nl

If you have doubts about participating in this study, you can also direct your question(s) at an independent clinician who is not involved in this research, yet is an expert in this field:

- Dr. Wouter Kollen. Email: w.j.w.kollen@prinsesmaximacentrum.nl

If you have any questions before or during the study that you would rather not direct at the researchers, feel free to contact the independent clinician as well.

11. Your written consent

The questionnaire will be open for responses for a minimum of 4 weeks. After 2 weeks, you will receive reminder by email.

If you decide to participate in the questionnaire, you consent to the collection, storage and usage of your responses. Participation in this study confirms that you understood the information provided in this letter and consent to participation in this study.

Best wishes, on behalf of the IGHG COVID-19 working group,

Selina van den Oever (MSc)