

Identifying the Important Social Outcomes for Childhood Cancer Survivors: An e-Delphi Study Protocol

SUPPLEMENTARY FILE 1: PATIENT PARTICIPANT INFORMATION SHEET

UNDERSTANDING THE IMPORTANT SOCIAL OUTCOMES FOR CHILDHOOD CANCER SURVIVORS: AN E-DELPHI STUDY

PARTICIPANT INFORMATION SHEET FOR PATIENTS

We'd like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information. If there is anything that is not clear, or if you would like more information, please ask us.

What is the purpose of this study?

- This study will help identify the most important aspects of social health for adults who had cancer as a child.
- We think of social health as the parts of life, besides physical and mental health, that help adults who had cancer as a child to lead full, happy and satisfied lives.
- In the UK, more than 8 out of 10 children with cancer will survive. Some will have problems after their treatment.
- These can include problems with social health.
- Social health problems are important because they affect all areas of our lives.
- So far, we don't know what the most important areas are for people who had cancer as a child.
- It would be good to know this so that the best support can be given to survivors. Doing this will help survivors to lead the life they want as an adult.

Why have I been invited?

- You have been invited because you had cancer as a child or young person.
- This will mean you understand best how it affects your life in the long-term.
- We are also asking teachers, social workers, doctors and nurses to take part.
- In total, at least 40 people will be involved.

Do I have to take part?

- No. Taking part is voluntary.
- You can also stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have unless you specifically ask for it to be removed.
- If you do not take part or if you withdraw it will not affect your hospital care.

What will happen if I decide to take part?

- We will ask you to complete 3-5 online surveys over 4-5 months. The first survey will be in Spring 2022.
- It will take about 15-20 minutes to answer each survey.
- We will show you a list of possible aspects of social health and ask you whether they are important for adults who had cancer as a child and the general population.

- We will also ask you to let us know of any important areas we have missed.
- In the next survey, we will ask for your thoughts on a summary of the answers from the first round.
- All your answers are anonymous so other people will not know what you have said.

Who is organising, sponsoring and funding the study?

- A team at the University of Leeds is organising the study as part of their child cancer research alongside colleagues at Leeds Teaching Hospitals Trust.
- The University of Leeds is also the sponsor for this study.
- It is funded by Candlelighters charity who support children with cancer.

How confidential are my answers?

- All your answers are confidential.
- No-one else in the study will ever be able to see your answers. They are collected online using www.onlinesurvey.ac.uk.
- We will ask you for your email address and basic details like your age.
- Your answers and email address will be stored securely at the University of Leeds.
- We will delete your email address 12 months after the study closes.
- Your answers will be kept for 5 years after the end of the study.

Who has reviewed the study?

- All research is reviewed by an independent group of people called a Research Ethics Committee (REC) to protect you as a participant. This study has approval from the Health Research Authority (HRA) and the West of Scotland REC 4.

What happens at the end of the study?

- We will produce a report so that you can see the final results.
- We will write our report in a way that no-one can work out that you took part in the study.
- We may use direct quotes from the study in our report but they will also be anonymised so no-one could link them to you.
- We will publish this report and present it at conferences so that it can help other research teams.
- This study will also form part of a doctoral thesis.
- We hope that research based on these results will go on to help childhood cancer survivors live the best lives possible.

Where can I find out more about how my information is used if I take part?

- At www.hra.nhs.uk/information-about-patients/
- At <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf>. The University data protection officer can be contacted at dpo@leeds.ac.uk
- By sending the research team an email or ringing us using the contact details below.

What do I do now?

- If you would like to take part in the study or have any questions please contact us by:
 - Email: YSRCCYP@leeds.ac.uk
 - Phone or text: 07592285019
 - Scanning this QR code with your phone. It will send us an email from your email.



- After you get in touch we will contact you to make sure we have your email.
- We will then send out the link to the first survey via email with a reminder a week later.
- We will take consent before you start the first survey.
- Hopefully the study wouldn't cause any concerns for you but if you decide to take part and it does raise any issues then a member of the team will be available every day on 07592285019 or you could email us.

Thank you for considering to take part.