

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

SUPPLEMENTARY FILE 2: ROUND 1 QUESTIONNAIRE, ALL PARTICIPANTS

WELCOME

Thank you for agreeing to take part in this study.

Firstly, we need to confirm that you have had information about the study and consent to be involved.

Please answer these questions to confirm that you have had information about the study and consent to take part.

- 1.1. I have read the participant information leaflet **yes/no**
- 1.2. I understand how my answers will be used **yes/no**
- 1.3. I consent for my email address to be stored securely at the University of Leeds for the purpose of this study **yes/no**
- 1.4. I consent to take part in this study **yes/no**

2. Please choose the participant group you fall into (**Click box leads to further question based on first box chosen**)
 - 2.1. Patient -> Leukaemia/Brain or spinal tumour/ Other cancer
-> Age 18-29years / >29 years
 - 2.2. Clinical-> Doctor/ nurse
 - 2.3. Social worker
 - 2.4. Teacher-> Primary/secondary
-> State/ Fee paying

3. We would like to collect some basic information that will help us to understand who is taking part in the study:
 - 3.1. Please choose one option that best describes your ethnic group or background: (**As per census ethnic groups**)
 - White: English, Welsh, Scottish, Northern Irish or British; Irish; Gypsy or Irish Traveller; Any other White background
 - Mixed or Multiple ethnic groups: White and Black Caribbean; White and Black African; White and Asian; Any other Mixed or Multiple ethnic background
 - Asian or Asian British: Indian; Pakistani; Bangladeshi; Chinese; Any other Asian background
 - Black, African, Caribbean or Black British: African; Caribbean; Any other Black, African or Caribbean background
 - Other ethnic group: Arab; Any other ethnic group
 - Prefer not to say
 - 3.2. Please choose one option that best describes your gender
 - Female
 - Male
 - Prefer to self-describe:
 - Prefer not to say

3.3. Please select your age bracket

- 18-24, 25-34, 35-44, 45-54, 55-64, 65+ & 'Prefer not to say'

- What is leading a good life for childhood cancer survivors?

Leading a good life is more than having good mental and physical health alone. There are other aspects of life that are needed to ensure happiness, satisfaction and a sense of fulfilment – allowing a person to be the most that they can be. We think of these as 'social health'.

We are interested in what you think these other things are for adults and which of them are the most important.

We are particularly interested in seeing whether you think they are the same for adults who had cancer as a child and adults in the general population.

All the responses we get will be brought together over the rounds of the project. We will use the results to target research in the important areas so that in the future we can provide the right support to survivors when they most need it.

- SCORING

Over the following pages, we are going to ask some questions about how important different things are for adults who had cancer as a child and the general, adult population.

Please rate each idea from 1 to 7.

1 is *NOT at all important* and 7 is *VERY important*.

In the text box below each idea, please write down any reasons for your rating. This will help us to understand your answers and prepare for the next round of questions.

We also want to know of any other ideas you have and will ask this at the end.

For each of the following questions there is an individual 7 point Likert scale for adults who had cancer as a child and for the general adult population with a free-text box under each when viewed on the survey host website: www.Onlinesurveys.ac.uk

4. Education

This section looks at whether education is or has been important.

- 4.1. How important is it to receive an education? This is being able to go to school, college and university for example.
- 4.2. How important is it to complete school up to age 18?
- 4.3. How important is being able to complete vocational training e.g. NVQs or apprenticeships?
- 4.4. How important is being able to complete higher education e.g. getting a degree at university or similar?
- 4.5. How important is it to have good school attendance as a child?
- 4.6. How important is it to achieve or have achieved good exam grades?
- 4.7. How important is it to have enjoyed school?

- 4.8. How important is it to have participated in extra-curricular activities such as sport or music clubs?

5. Independence and Autonomy

Next we're going to think about independence and autonomy.

- 5.1. How important is being able to live independently?
- 5.2. How important is it to have autonomy? This is a person being able to make their own decisions about how they want to live.
- 5.3. How important is being able to take on big responsibilities such as raising a child?

6. Work and Finances

This section looks at work and finances

- 6.1. How important is it to have financial stability? This is a person being in control of their day-to-day finances and having enough money to meet their needs including saving for retirement or emergencies.
- 6.2. How important is it to be able to save money for luxuries? These might include holidays abroad, meals out or a better car than necessary.
- 6.3. How important is it to have a job? This could be paid or unpaid.
- 6.4. How important is it to have a job that pays well enough to be independent and do the things a person wants to do?
- 6.5. How important is it to have job satisfaction? This means a person feeling content with their job and getting fulfilment from it.
- 6.6. How important is it to have a job that builds skills?
- 6.7. How important is it to be a homeowner? This means owning a home rather than renting. It could be with or without a mortgage.
- 6.8. How important is it to be doing as well or better financially compared to other people in the population?

7. Relationships

This section looks at relationships

- 7.1. How important is it to be connected to and have relationships with other people including family, friends, colleagues and romantic partners?
- 7.2. How important is it to have good family relationships?
- 7.3. How important is it to have good friendships?
- 7.4. How important is it to have good romantic relationships?
- 7.5. How important is it to have good relationships with colleagues at work?
- 7.6. How important is it to be able to communicate with government organisations, businesses or professionals?
- 7.7. How important is it to avoid social isolation? Social isolation is a lack of connections with or being cut off from other people? It can lead to loneliness.

8. Community Life

This section looks at being involved with the local community

- 8.1. How important is it to be involved with the local community?
- 8.2. How important is it to be able to take part in community leisure activities such as sports clubs or a local choir?
- 8.3. How important is it for adults to support those around them such as by volunteering or doing charity work? Being involved with a community because it's a good thing to do.
- 8.4. How important is it to be able to be involved in a religious or spiritual community if a person wishes?
- 8.5. How important is it to have a social identity? This means a feeling of belonging to a particular group.

9. Lifestyle

The last section looks at lifestyle.

- 9.1. How important is it to have good personal maintenance? This is a person being able to look after themselves in a way that maintains their health and ability to live independently. It includes areas like personal hygiene.
- 9.2. How important is being able to make positive lifestyle choices such as being able to exercise?
- 9.3. How important is it to be able to avoid risky behaviours which can impact health and well-being in the short and long term? This includes smoking and drug abuse.

10. What else is important?

You have worked through all of our suggestions for the social aspects of life that are needed to help adults who had cancer as a child lead a good life.

We are now interested in whether you have any other ideas of what these aspects might be. Is there anything we have missed?

In the box below, please add your comments about any other areas you think are important
Free text box

Thank you for completing the questionnaire
We will be in touch soon with the next round

END