

## INFORMATION LEAFLET

### Survivorship after childhood cancer in Ireland – a national qualitative study.

The newly published National Cancer Strategy 2017-2026<sup>1</sup> has 52 recommendations. Recommendation 41 is focused on the requirement to conduct a National Cancer Survivorship Needs Assessment to ascertain the most suitable model of survivorship healthcare for use in Ireland. In order to achieve this recommendation, the National Cancer Control Programme (NCCP) wishes to establish what the major needs in cancer survivorship care are in Ireland. One of the distinct groups of interest is those who have survived after cancer in childhood.

**Aim:** To identify the major needs of adult survivors of childhood cancer from the perspective of patients and parents.

**Who should partake?** Anyone with an interest in the use or provision of cancer survivorship services, particularly those who have used services for survivorship or follow-up care after childhood cancer. This includes:

- Adults (over age 18) who had cancer in childhood, and who are not under active treatment for cancer
- Parents of children who had cancer within the past 20 years, and who are no longer under active treatment for cancer

**What does this entail for you?** This study comprises focus group interviews. You will be invited to participate in one focus group, which will last for about one hour. The focus groups aim to find out what services are available for patients who had cancer in childhood and who have completed their treatment. The focus groups also aim to find out the current needs of those patients/survivors.

**What about confidentiality?** The information you will give will be kept confidential. No personal details that might identify you will appear in the study report or associated publications.

**What about withdrawing?** You have the right to withdraw from the focus group discussions at any time, even if you initially agree to participate.

**What are the benefits of participating?** The results of this unique scoping exercise shall be used by the Department of Health, National Cancer Control Programme and Health Service Executive to inform the development and implementation of cancer survivorship services going forward. Thus, your opinions and perspectives are really important.

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<sup>1</sup> National Cancer Strategy 2017-2026. (2017) Government of Ireland: Dublin. Available at: <http://health.gov.ie/wp-content/uploads/2017/07/National-Cancer-Strategy-2017-2026.pdf>

**What risks are there to taking part?** The risks (if any) are considered minimal and ethical approval has been granted from the Clinical Research Ethics Committee of the Cork Teaching Hospitals. All information will be treated in the strictest confidence. Participation is voluntary. You will not be asked any personal details about your own treatment. The research findings will be presented in the report of the study, presentations, and publications, but anonymity of the person will be upheld.

**Contact details:**

Dr. Peter Barrett, National Cancer Control Programme. T: 01 8287187. E: [peterm.barrett@hse.ie](mailto:peterm.barrett@hse.ie)

Dr. Caitríona McCarthy, National Cancer Control Programme. T: 01 8281763. E:

[triona.mccarthy@cancercontrol.ie](mailto:triona.mccarthy@cancercontrol.ie)

**Thank you for taking the time to read this information leaflet.**