

Assessing ability of cancer registries to collect data for comparative research on childhood cancer survivorship

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Background: Information collected by population-based cancer registries is crucial for estimating cancer burden indicators and planning cancer control policies. Within the Cancer Risk in Childhood Cancer Survivors (CRICCS) study we aimed to assess the ability of registries to collect data needed to conduct comparative studies of childhood cancer prevalence and risk of second primary neoplasms among survivors of childhood cancer.

Methods: We developed an online questionnaire using the Research Electronic Data Capture (REDCap) tool to enquire about data collected on stage, therapy, predisposing characteristics, and follow-up. We also asked about the willingness of registries to provide data for central analyses. The questionnaire was made available on the IARC Registries Portal in July 2021 to 548 registries. The registries received 2 reminders to complete the questionnaire. We summarised the data collected until 27th June 2022.

Results: Overall, 141 registries completed the questionnaire. Responding registries were from Europe (n=56), Asia (n=32), Latin America (n=28), North America (n=11), Africa (n=8), and Oceania (n=6). Sixteen registries were paediatric and 37 had national coverage. The earliest complete incidence year was 1944 and the latest was 2021. The average registration period was 27 years; 19 registries covered less than 10 years. Among 141 registries, subsequent primary neoplasms were recorded in 135 (96%) and follow-up data in 113 of them. Stage was collected in 112 (79%) registries, treatment in 75 (53%) and predisposing characteristics in 18 (13%) registries. Information on both stage and treatment was collected in 72 (51%) registries, however only 15 (11%) collected information on stage, treatment, and predisposing characteristics. Overall, 129 registries agreed to provide data for the CRICCS study.

Discussion and Conclusion: Population-based cancer registries can collect relevant data for studying childhood cancer survivors and the corresponding cancer burden. The CRICCS collaboration will boost the potential of registries in addressing survivorship issues.

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