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Position Paper

The PanCareSurFup consortium: research and guidelines to improve lives for survivors of childhood cancer

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Abstract ***Background:*** Second malignant neoplasms and cardiotoxicity are among the most serious and frequent adverse health outcomes experienced by childhood and adolescent cancer survivors (CCSs) and contribute significantly to their increased risk of premature mortality. Owing to differences in health-care systems, language and culture across the continent, Europe has had limited success in establishing multi-country collaborations needed to assemble the numbers of survivors required to clarify the health issues arising after successful cancer treatment. PanCareSurFup (PCSF) is the first pan-European project to evaluate some of the serious long-term health risks faced by survivors. This article sets out the overall rationale, methods and preliminary results of PCSF.

Methods: The PCSF consortium pooled data from 13 cancer registries and hospitals in 12 European countries to evaluate subsequent primary malignancies, cardiac disease and late mortality in survivors diagnosed between ages 0 and 20 years. In addition, PCSF integrated radiation dosimetry to sites of second malignancies and to the heart, developed evidence-based guidelines for long-term care and for transition services, and disseminated results to survivors and the public.

Results: We identified 115,596 individuals diagnosed with cancer, of whom 83,333 were 5-year survivors and diagnosed from 1940 to 2011. This single data set forms the basis for cohort analyses of subsequent malignancies, cardiac disease and late mortality and case–control studies of subsequent malignancies and cardiac disease in 5-year survivors.

Conclusions: PCSF delivered specific estimates of risk and comprehensive guidelines to help survivors and care-givers. The expected benefit is to provide every European CCS with improved access to care and better long-term health.

1. Introduction

Survival after childhood cancer continues to improve, and currently 80% of children diagnosed in developed countries survive for at least 5 years [1]. As estimated, 300,000 EU citizens are alive and cured from childhood cancer [2], and their numbers will increase with advancing therapies. However, the toxicities of cancer