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Governance & Oversight

Executive Board
The Executive Board (EB) is the main decision-making body of PanCareSurFup. It is chaired by the Project Coordinator, and includes one representative from each work package. The EB meets twice yearly.

General Assembly
The General Assembly (GA) meets twice yearly and comprises all participants. The GA is responsible for all major budgetary, management and scientific decisions.

Scientific & Ethical Advisory Board
The Scientific Advisory Board consists of experts in the area of research. It monitors the progress of the project and safeguards research quality. The board takes part in the annual consortium meetings. When appropriate, it consults the consortium through the Executive Board and makes recommendations intended to improve the project performance. Because of the collection, storage and handling of personal clinical data, PanCareSurFup has established an Ethical Advisory Board to address ethical, confidentiality and informed consent issues. The following individuals have agreed to serve:

- Dr Meriel Jenney, Department of Child Health, Cardiff and Vale NHS Trust, UK
- Dr Peter Inskip, Radiation Epidemiology Branch, National Cancer Institute, NIH, Bethesda, MD, USA
- Dr Jörn Beck, Heinrich Heine Klinik fuer Psychosomatik und Psychotherapie, Potsdam, Germany
- Dr Gerlind Bode, former CEO of the German umbrella organisation of all parent initiatives in Germany (German Childhood Cancer Foundation).

Dr. Meriel Jenney

Dr. Peter Inskip

Dr Jörn Beck

Dr. Gerlind Bode

What is the expected impact?

PanCareSurFup provides an unrivalled opportunity to: assess the extent of the burden of late effects among survivors of cancer in childhood and adolescence in Europe; update existing standardised clinical follow-up guidelines, provide evidence-based risk prediction, identify high risk groups for possible intervention studies to prevent or diagnose as early as possible adverse health outcomes, provide an evidence base for training health care professionals, focus health service resources on those most at risk and most likely to benefit from intervention, and to investigate health promotion initiatives. The health of long-term survivors of childhood cancer is both physical and psychosocial, and is best achieved through active partnerships between health-care providers and survivors and their families. PanCareSurFup uses current and emerging communication tools to reach the communities of interest, including conferences and workshops, for training and dissemination of these results, aiming for the widest possible involvement of existing EU childhood cancer bodies and survivor/parent groups, lay and professional, to ensure that health professionals receive appropriate training and information, that late complications are anticipated, prevented and treated optimally to ensure the best quality of life for survivors and their families.

The fragmented nature of health care delivery and follow-up and the diverse inter-relationships between providers and survivor/parent groups throughout Europe all probably contribute to sharply different survival rates across Europe. PanCareSurFup's approach is intended to lead to increased cooperation between treatment and advocacy groups, reduce disparities in survival and result in improved long-term outcomes for children and adolescents diagnosed with cancer in all regions of Europe.

Pancare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies
PanCareSurFup

SEVENTH FRAMEWORK PROGRAMME

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Pancare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies
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SEVENTH FRAMEWORK PROGRAMME

PanCareSurFup
PanCare Childhood & Adolescent Cancer Survivor Care & Follow-Up Studies
Synopsis

Medium sized collaborative project
Addressing Work Programme:
HEALTH.2010.2.4.1-7, Predicting long-term side effects to cancer therapy

Coordinator: Lars Hjorth, Lunds universitet, Sweden

Funded by the 7th Framework Programme (FP7) of the European Commission for 5 years, February 2011 to January 2016

Grant agreement no: 257505

PanCareSurFup: Executive Summary

Five-year survival after cancer during childhood or adolescence is now almost 80% in most developed countries. The growing numbers of survivors brings increasing concern about the long-term consequences of treatment to growing organs and tissues. As part of a pan-European network of professionals and survivors and their families, PanCareSurFup, a new FP7-funded project, will carry out a series of epidemiologic studies of the most serious complications of long-term survival. Sixteen European networks and institutions will follow about 80,000 survivors of childhood and adolescent cancer, making PanCareSurFup the largest study of its kind to date.

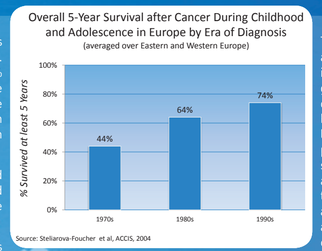
Over five years (2011 – 2016), PanCareSurFup will develop risk estimates for cardiac disease, second cancers and late mortality. A key component will be establishing the doses of radiotherapy to each organ, enabling tighter estimates of risk. These data, with results from other studies, will be the basis for establishing guidelines for follow-up in Europe, including suggestions for clinical networks to enable care to continue seamlessly from paediatric to adult settings. Finally, dissemination of the results will be achieved through conferences, workshops, newsletters and blogs, and partnerships with survivors and parents. PanCareSurFup's studies are intended to lead to increased cooperation between treatment and advocacy groups, reduce disparities in survival and improve outcomes for children and adolescents diagnosed with cancer in Europe.

What is PanCareSurFup?

PanCareSurFup, (PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies) is a 5-year research project, funded through the work programme "Health.2010.2.4.1-7, Predicting long-term side effects to cancer therapy", of the 7th Framework Programme (FP7) of the European Commission (*www.pancaresurfup.eu*). PanCare (in which PanCareSurFup is based) is a multidisciplinary pan-European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer (*www.pancare.eu*).

Why are we doing this project?

Survival after childhood cancer has improved substantially over recent decades. In developed countries, approximately 80% of children diagnosed with cancer survive for at least 5 years. However, across Europe there are gradients in survival, with Eastern Europe having lower survival rates than Western Europe.



Currently there are between 300,000 and 500,000 European survivors of childhood and adolescent cancer. This number will rise rapidly as treatments continue to improve.

Estimates place the number of young adults who are cancer survivors in Europe at 1 in 750. Unlike adult cancer, mostly diagnosed after 60 years of age, survivors of childhood cancer have all of their adult lives ahead of them. For them, late complications are a crucial issue.

Serious adverse effects

While aiming at and often succeeding in curing patients, treatment for childhood cancer may also damage healthy tissues and may leave long-lasting complications. Radiation, chemotherapy and surgery all play a part in the spectrum of late effects, as does the genetic make-up of the patient.

The most serious adverse effects are fatal. Considerable insights into treatment toxicity may be gained from detailed investigations of causes of death occurring beyond 5-year survival (so-called late mortality). Experience in previous studies has identified subsequent primary neoplasms and cardiotoxicity as two of the most serious and frequent adverse health outcomes which are related to previous exposure to chemotherapy and radiotherapy. PanCareSurFup intends to enroll approximately 80,000 survivors of childhood and adolescent cancer, making it the largest study of survival after childhood cancer to date.

Europe is especially well positioned to address these questions because of its history of cancer registration going back to the 1940s. The number of survivors who are aged beyond 40 years in individual countries is insufficient to satisfactorily estimate such risks, but combining data across Europe will provide an outstanding opportunity to address these questions.

What will PanCareSurFup do?

PanCareSurFup will assemble a database for the project by combining individual data from European cancer registries into a retrospective cohort of approximately 80,000 five-year survivors. For individual patients enrolled in case-control studies, PanCareSurFup will create estimates of the dose of radiation to each organ. PanCareSurFup will collect and store genetic material to make a DNA bank that will be the foundation for future genotypic analyses.

What are the major outcomes?

- Cohort-based risk assessments of all second malignancies, cardiac disease and late mortality, that is, deaths after 5 year from diagnosis
- Nested case-control-based risk assessments for cardiac disease, subsequent primary sarcomas and subsequent primary carcinomas
- Clinical follow-up guidelines for health care professionals, survivors and their families based on existing evidence and the results from this study, to include issues related to transition from a paediatric to an adult care environment.
- Dissemination of results from PanCareSurFup to health care providers and to survivors and their families; empower and educate survivors to promote healthier long-term living

How will PanCareSurFup do this?

The work of PanCareSurFup is accomplished within 8 Work Packages. Details of participants and the aims of each work package are provided below.

Work Package 1: Data collection and harmonisation

Work Package Leader: Desiree Grabow, University of Mainz, Germany

Work Package Members: Lars Hjorth, Stanislaw Garwicz, Leontien Kremer, Paola Pisani, Florent de Vathaire, Mike Hawkins, Eva Steliarova-Foucher, Edit Bardi, Riccardo Haupt, Julianne Byrne, Claudia Kuehni, Ruth Ladenstein.

WP1 will work towards an overview of the occurrence of subsequent primary neoplasms and survival in the population of five-year survivors of childhood or adolescent cancer; based on data collected in European population-based cancer registries. This task will be coordinated by the IARC (International Agency for Research on Cancer, Lyon, France). At the same time, WP1 will produce an overview of existing clinical and population-based registries across Europe that have the capacity to evaluate selected late effects in long term survivors. The resulting database will be the basis for studying cardiac diseases, subsequent primary neoplasms and late mortality in long-term survivors. Finally, WP1 will prepare a prospective pan-European information database to improve the availability of information on long-term survivors. The information database will consist of rules for collection, coding, storing and exchange of information relevant for future studies of new end-points.

Work Package 2: Radiation dosimetry

Work Package Leader: Florent de Vathaire, Institut Gustave Roussy, Paris

Work Package Members: Riccardo Haupt, Leontien Kremer, Desiree Grabow, Edit Bardi, Claudia Kuehni, Mike Hawkins, Lars Hjorth, Julianne Byrne,

WP2 will perform radiation therapy reconstruction and whole body dosimetry using original radiation therapy records obtained for each case and control who will contribute to studies of cardiac disease and subsequent primary neoplasm in WP3 and WP4. WP2 will estimate radiation doses received to the heart, and to the specific site of the subsequent primary neoplasm, as well as uncertainties in this estimate. Finally WP2 will produce a table of standardised dose estimation for organs at risk.

Work Package 3: Cardiac disease: cohort and nested case control study

Work Package Leader: Leontien Kremer, Emma Children's Hospital, Amsterdam

Work Package Members: Desiree Grabow, Florent de Vathaire, Mike Hawkins, Edit Bardi, Riccardo Haupt, Julianne Byrne, Claudia Kuehni, Gill Levitt, Paola Pisani.

Work Package 4: Subsequent primary neoplasms: cohort and nested case-control studies

Work Package Leader: Mike Hawkins, University of Birmingham, UK

Work Package Members: Desiree Grabow, Florent de Vathaire, Leontien Kremer, Mike Hawkins, Edit Bardi, Riccardo Haupt, Julianne Byrne, Claudia Kuehni, Paola Pisani, Lars Hjorth.

For the studies of WP3 and WP4, cohorts of survivors of childhood cancer and the underlying populations will be established by WP1. In the case of WP3, the occurrence of cardiac disease should have been systematically ascertained and validated. In the case of WP4, absolute risks of all types of subsequent primary neoplasm including sarcomas and carcinomas will be assessed through cohort analysis. Both WPs will undertake nested case-control studies to determine those aspects of radiotherapy and chemotherapy most strongly associated with increased risk for cardiac disease (WP3) and sarcomas and carcinomas as subsequent primary neoplasms (WP4). Biological material (blood or saliva) of cases and controls will be collected and stored for future DNA studies.

Work Package 5: Late mortality

Work Package Leader: Stanislaw Garwicz, University of Lund, Sweden

Work Package Members: Lars Hjorth, Desiree Grabow, Florent de Vathaire, Mike Hawkins, Edit Bardi, Riccardo Haupt, Julianne Byrne, Claudia Kuehni, Paola Pisani, Eva Steliarova-Foucher.

WP5 will establish a pan-European cohort of survivors within which all deaths occurring at least five years from diagnosis have been ascertained and for which an official cause of death is available, using the cohorts established by WP1. Based on these cohorts, WP5 will analyse total, gender-specific and cause-specific mortality; then, relate absolute and excess risk (compared to background population) of death from specific causes to gender, type of childhood cancer, age at diagnosis, period of cancer diagnosis and, in a subset of patients, type of treatment. WP5 will also validate the official causes of death through accessing death certificates, hospital records and autopsy reports in a sample of patients, assess the comparability and quality of causes of death recorded in different countries, and clarify, in those countries where mortality data and/or causes of death are not readily available, the reasons for the lack of information.

Work Package 6: Guidelines, long-term follow-up and transition

Work Package Leader: Rod Skinner, University of Newcastle, UK

Work Package Members: Lars Hjorth, Riccardo Haupt, Eva Frey, Leontien Kremer, Edit Bardi, Gill Levitt, Claudia Kuehni, Florent de Vathaire, Julianne Byrne, Momcilo Jankovic.

WP6 aims to provide an opportunity for equal access to long-term follow-up care across Europe by the development of guidelines for clinical practice for prevention, early detection and treatment of physical and psychosocial late adverse effects. WP6 will also organise strategies of long-term follow-up that will facilitate incorporation of the recommendations for follow-up in these clinical practice guidelines. Also assessed by WP6 will be transition care practices to optimise age-appropriate healthcare for those survivors who are approaching or have already reached adult age, including specific advice to address individual patient issues, so that survivors and their families can enjoy a healthier lifestyle.

Work Package 7: Dissemination and training

Work Package Leader: Momcilo Jankovic, University of Milan, Italy

Work Package Members: Julianne Byrne, Lars Hjorth, Ruth Ladenstein, Edit Bardi, Florent de Vathaire, Rod Skinner, Riccado Haupt, Leontien Kremer, Eva Frey, Paola Pisani,Gill Levitt, Desiree Grabow, Claudia Kuehni, Mike Hawkins, Eva Steliarova-Foucher.

WP7's dissemination and training group aims to add the results of its research projects and its guidelines group by working with stakeholders, both professionals and survivors and families, and other FP7 projects in order to disseminate information about PanCareSurFup to the general public and among health professionals and survivor/parent groups, and train health care professionals through conferences, workshops, booklets and web based information. WP7 will also establish partnerships between providers and survivor/parent groups to empower and educate survivors to be as informed as possible concerning their long-term risks. General dissemination of findings from PanCareSurFup to the general public will be achieved via media such as press releases, blogs, video webcasts. WP7 aims to provide better health care management of adverse effects from therapy, and to close the feed-back loop with collaborative groups conducting clinical trials.

Work Package 8: Management and coordination

Work Package Leader: Lars Hjorth, University of Lund, Sweden, Coordinator of PanCareSurFup

Work Package Members: Julianne Byrne, Elise Kvarnstrom (Project Manager).

Management of the scientific, financial and administrative aspects of PanCareSurFup in WP8 is achieved through overall research coordination by organising meetings, teleconferences and web-based interactions, using the newly created website *(www.pancaresurfup.eu)*. This will enable monitoring of work progress, evaluation of results, ensuring that all required reports and deliverables are completed in time and sent to the European Commission, as well as dissemination of information within the consortium, and development of strategies for external dissemination.