



PanCare Childhood and Adolescent Cancer
Survivor Care and Follow-up Studies

PanCareSurFup

December 2013

PanCareSurFup Bulletin, Issue nr. 4

PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies

Dear project partners,

We are glad to present to you the latest edition of the PanCareSurFup Bulletin. PanCareSurFup is the first project aiming to provide every childhood cancer survivor in Europe with better access to care and better quality of life, by carrying out pan-European studies into the complications of long-term survival. In this edition you will find a very interesting interview with PanCareSurFup partners, Dr. Desirée Grabow and Dr. Peter Kaatsch, together with some pictures from a recent awareness-raising event that took place on a cruise boat in Italy (you can read more in Bulletin nr. 1).

Both scientists come from the University Medical Centre of Mainz (UMC-Mainz), Germany, which includes the Institute of Medical Biostatistics, Epidemiology and Informatics (IMBEI), where the German Childhood Cancer Registry (GCCR) is located. With more than 50,000 registered patients, the GCCR is the most comprehensive childhood cancer registry worldwide: it is member of the International Association of Cancer Registries (IARC) and the European Network of Cancer Registries (ENCR), and participates in a couple of EU-funded projects (e.g. ACCIS and EURO CARE). The GCCR conducts epidemiological projects on childhood cancer (e.g. on aetiology, second tumours); as the GCCR is located at the IMBEI, it benefits additionally from in-house methodological expertise in medical informatics, biostatistics and epidemiology.

University lecturer Dr. Peter Kaatsch was trained in Medical Informatics, is an epidemiologist and head of the GCCR. He is member of the PanCare Board, of the Automated Childhood Cancer Information System (ACCIS) Scientific Committee, and of the Advisory Board of the German Society of Paediatric Oncologists (GPOH). His research fields are childhood cancer epidemiology, population-based cancer registration, late effects, and standards in medical informatics. He is the Coordinator of a new EU-funded project (PanCareLIFE), and in this project he is also leading the Work Package "Data centre and Biostatistical Support", similar to the one led in PanCareSurFup.



Entertainment shows of Italian artists on the boat

Dr. Desiree Grabow holds a doctoral degree in epidemiology. At the GCCR, she is responsible for long-term surveillance (conducting epidemiological studies, comprising patient contact, constructing logistics). She is Work Package 1 Leader in PanCareSurFup. In the new project, PanCareLIFE, she will assist in project management and in the Work Package “Data centre and Biostatistical Support”.

The PanCareSurFup Work Package 1 “Databases and Harmonisation” (WP1) has 4 main objectives:

- 1** to establish a retrospective pan-European cohort of long-term survivors of childhood and adolescent cancer, for whom the occurrence of at least one of the endpoints: cardiac disease, second primary tumours and late mortality has been or can be ascertained and validated;
- 2** to provide harmonized datasets for the analyses to be performed in WP3 (on cardiac events), WP4 (on second cancer), and WP5 (on late mortality);
- 3** to systematically evaluate the availability of data on long-term survivors of childhood cancer in existing European databases;
- 4** to construct a virtual pan-European database of late effects (storing data characteristics that could be provided by population-based registries and clinical data sources) to enable future access to data on late effects in a timely fashion.



Welcoming participants to this high-level event



All aboard for research against leukaemia

Latest developments in PanCareSurFup

Work Package 1

Last month WP1 has received the last in a series of extra-large data sets (comprising more than 10,000 individuals). This means that WP1 is now able to run all standard plausibility checks over the whole material, i.e. a cohort of more than 80,000 individuals. The last month was also characterized by updating ICD-codes in data sets where previously some out-of-date codes have been used. After the recent report to the Ethical and Scientific Advisory Board, WP1 now has an overview of which additional (updated) data are expected, from which data providers and at which date, and is happy to better plan our strategy for the next weeks and months.

Work Package 3

WP3 is the cardiac work package. This Work Package will study the incidence and risk factors of five different cardiac events (heart failure, ischemia, pericarditis, valvular disease and arrhythmia). The cardiac outcome will be collected by France, Hungary, Italy, the Netherlands, Slovenia, Switzerland and the United Kingdom. Both a cohort and case-control study will be conducted. For the case-control study, also the treatment data and confounding and risk factors will be collected for all the cases and controls.

To ensure consistency between countries in validating a cardiac event, a validation method is developed and tested; this is described in the WP3 manual (which is on the website). Also, in collaboration with WP4, a data collection course has been given. This course was about collecting the cases, controls, treatment data (chemotherapy and radiotherapy) and confounding and risk factors.

Slovenia finished identifying and validating the cardiac cases, while the other countries are well underway. The collection of the treatment data has been finished in several countries, and is undergoing in some other countries.

Work Package 8

Following the General Assembly in Amsterdam, the Consortium put together an updated report to the Ethical and Scientific Advisory Board (ESAB), clarifying some outstanding issues. The response from the ESAB is forthcoming. All partners with a claim of more than 370,000€ up until January 31 are preparing an audit to produce a Financial statement to accompany the official financial report. All partners are also continuing to prepare the second report for the European Commission. The Project Coordinator Lars Hjorth took part as a guest at the successful kick-off meeting of PanCareLIFE in Mainz last 11-13 November. The next **PanCareSurFup General Assembly** will take place on 14-15 May 2014 in Wroclaw, Poland.

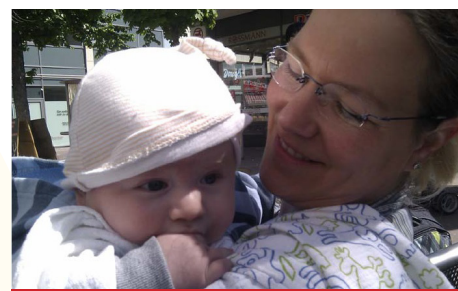
[Download the brochure in different languages](#)
[More information on project partners](#)

PanCareSurFup Partners

The project's dissemination team interviews the Leaders of PanCareSurFup Work Package 1, Dr. Peter Kaatsch and Dr. Desiree Grabow, from the University Medical Centre of Mainz, Germany.

Can you describe how you got involved in PanCareSurFup?

The former PanCare steering group (Lars Hjorth, Rod Skinner, and Riccardo Haupt) met for the first time in 2007; the following year, they invited some potential future members to the foundation of PanCare in Lund. As a representative of the German Childhood Cancer Registry (GCCR), Desiree Grabow became one of the founding members of PanCare and, since then, the GCCR has been involved in every PanCare meeting, including hosting the 6th meeting in Mainz in September 2010. One essential part of these meetings was the task of defining the most important late effects after childhood and adolescent cancer, in order to form a group of experts devoted to late effects issues and set up a first proposal, the PanCareSurFup proposal. In the PanCareSurFup project, Desiree Grabow became the Leader of WP1 but, since her maternity leave the head of the GCCR, Dr. Peter Kaatsch is now replacing her.



Dr. Desirée Grabow with her new-born baby

Work Package 1 aims to create a pan-European database of the survival and the occurrence of late effects in childhood cancer patients. This is an immense task: how are your WP partners working towards this goal?

As far as those data exist or can be collected in a 5-year period (from the start of the project in 2011), all partners agreed to provide national retrospective as well as prospective data on a set of common late effects to the PanCareSurFup consortium. Those common late effects are late mortality, second primary neoplasms, and cardiovascular adverse events. WP1 will harmonize those data and gain experience about its quality and quantity in the course of the project. By acquiring this knowledge, we hope to define how and which data should be collected in an "ideal world", a common standard which could be then used at the national level and enable stakeholders to easily pool late effects' data at the European level. Gaining all the information about the provider of the data, accessing rules, formats, coding rules, standardization procedures, imputation rules, etc. will enable us to set up new databases for future projects in a shorter time.

Why is harmonization of epidemiological studies so important? How can PanCareSurFup ensure that the evaluation of late-effects in the future can be improved?

Harmonization and standardization are essential to compare national results between countries. Some late effects are unusual, but important, so an international approach is needed in order to enlarge the sample size. This approach can only be successful if data are collected with the same common standards to allow comparability. PanCareSurFup collected the largest dataset on late effects in Europe, and perhaps globally. The experience gained in establishing this dataset will be applied to developing standard approaches, which will be used in the future to set up other large pan-European studies.

Why were cardiac diseases, subsequent neoplasms and late mortality chosen as areas to focus upon in PanCareSurFup?

Subsequent neoplasms and cardiac disease were chosen as they are among the most severe late effects - they are all life threatening - and as most European countries are already assessing them. Late mortality (deaths occurring more than five years after diagnosis) have been insufficiently studied. A European approach was urgently necessary, as cardiac-related late effects, subsequent neoplasms and late mortality have an immense impact on treatment strategies, after-care strategies and public health.

What have been the main challenges to date?

The main challenge is to develop a “common language” and, therefore, a “common understanding”. This is related to communication with both data providers and Work Package Leaders. We have worked to clarify deadlines for the last data delivery, including updates, to resolve misunderstandings on what WP Leaders are expected to deliver; to figure out exactly the deadline for the other Leaders to have their data; to discuss with WP Leaders the best procedures for data harmonization.

Describe your typical working day.

My (Peter’s) typical working day is to work as the head of the GCCR (i.e. responsible for my staff, for routine registry work, for writing papers, for teaching, for responding to inquiries from scientists, cooperating partners or private persons concerned, like parents and survivors). Since I am also the interim WP1 Leader in PanCareSurFup and a Board member of PanCare, I have to combine this routine job with teleconferences, data management (with major support from Melanie Kaiser) and additional organizational issues. At present, Desirée is enjoying her maternal leave after having delivered her second child and, therefore, her typical day is to take care of her two little children, being with her family and supporting the PanCareSurFup work whenever she can, but soon she will join again the PanCareSurFup team in Mainz, in order to bring forward the work done by WP1.

What do you love most about your job?

We enjoy getting to know new colleagues and friends, all working towards the same objective. As a team, it gives us great satisfaction to know that our work will contribute to the overall goal of reducing late effects of anticancer therapy, so that childhood cancer survivors will get the care they need for a better quality-of-life and will be able to live a life comparable to that of peer groups of their age.



Prof. Peter Kaatsch from the Mainz University

Are there synergies with the other Work Packages? How do you see this synergies continuing, beyond the life of this EU project?

From our point of view, one of the most relevant synergy for all data providers is the use of the baseline variables' list, which was defined by the WP Leaders (WP1 to 5) through a series of teleconferences. Much effort was done on the definition and standardization of baseline variables, to fix a minimum set of variables which every partner needs to provide to the project. Our wish is that this list will be further developed beyond this project as a set of minimum standards for future projects, e.g. PanCareLIFE. The more countries will reach these standards (and maybe be able to extend data collection, e.g. to include details of therapy), the better studies on late effects after childhood and adolescence cancer will be generated.

Why is coordinating this data collection across Europe so important? In your opinion, how will this impact on the lives of future survivors?

The coordination and harmonization of data collection is fundamental to reach a common standard within our European network. This standardisation will help improving the quality of data and help to answer late effects' related questions, which can only be answered at the European level due to the sample size and quality of the data. The perception and dissemination of our results will help to improve healthcare, not only the one needed by former childhood cancer patients but also by newly diagnosed, treated and cured children and adolescents.

Why do you consider this project to be sustained?

PanCareSurFup will help to answer a set of questions related to the three main life threatening late effects. But more questions related to these late effects will emerge, and further late effects need to be studied (the next are defined in the new project PanCareLIFE: ototoxicity, fertility, and health-related quality-of-life). With the development of new therapies, some late effects can be reduced but, in principle, other late effects could appear more frequently: therefore, further studies need to be set up to answer these and all the other upcoming questions. A European-wide network like PanCare is an optimal basis to deal with these challenges.

Describe one of your proudest moments/an achievement you are particularly proud of.

We are very satisfied, our job in WP1 was so well-received by our fellow colleagues. Thereupon we were asked not only to be responsible of a comparable Work Package in PanCareLIFE, but also to coordinate the whole new project. We are very glad today to work with some of the same excellent partners in both projects (PanCareSurFup and PanCareLIFE) and every step (small or large) that we are currently taking goes in the direction to reach the above mentioned goal (what do we love most) and improves our satisfaction.



Prof. Peter Kaatsch and Dr. Desirée Grabow

For more information, please contact:

PanCareSurFup, Work Package 7 'Dissemination'
c/o Lars Hjorth, Coordinator, PanCareSurFup, lars.hjorth@skane.se
Elise Witthoff, Project Manager, elise.witthoff@med.lu.se
Momcilo Jankovic, WP Leader, m.jankovic@hsgerardo.org