



November 2013

# PanCareSurFup

## PanCareSurFup Bulletin, Issue nr. 3

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

Dear project partners,

We are delighted to present to you the latest edition of the **PanCareSurFup** Bulletin. Our project is the first one aiming to provide every childhood cancer survivor in Europe with better access to care and better long-term health, by carrying out pan-European studies into the complications of long-term survival.

Last October, the PanCare and PanCareSurFup meeting 2013 in Amsterdam, right after the European Cancer Congress, has been a success, both in terms of participation and partners' commitment. You can see in this Bulletin issue some pictures from the event.

In this issue we are interviewing Dr. Rod Skinner, leader of PanCareSurFup Work Package 6 on Guidelines, long-term follow-up and transition. Rod is a Consultant and Honorary Clinical Senior Lecturer at the Great North Children's Hospital and Royal Victoria Infirmary in Newcastle upon Tyne, UK and at the Northern Institute for Cancer Research of the University of Newcastle (one of the strongest groups in paediatric and haematological cancer research in Europe). In particular, Dr. Skinner investigates some of the most severe and/or life-changing toxicities that may occur in survivors of childhood malignancy, providing a basis for counselling long-term survivors and for planning clinical follow-up.

Within PanCareSurFup, Rod's work focuses on the Clinical Practice Guidelines for prevention, early detection and treatment of physical and psychosocial late adverse effects of childhood cancer. In order to provide equal opportunities to all European survivors, the Work Package is also developing guidelines for long-term follow-up including transition care practices for those survivors who are approaching or have already reached adult age. The Work Package is holding detailed discussions with the International Guideline Harmonisation Group (IGHG) to plan the guideline topics that will be addressed over the next 12 months, and approaching individuals to join and lead the individual guideline groups.



Riccardo Haupt, Elaine Sugden and Lars Hjorth,  
PanCareSurFup Project Coordinator



Sabine Karner and Anita Kienesberger from  
ICCCPO

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## Latest developments in PanCareSurFup

### Work Package 2

This month PanCareSurFup Work Package 2 did not receive any technical records and therefore did not perform any new dose-reconstruction. During this period, WP2 partners re-organised the internal structure of the dosimetry data base. During this monthly period, this Work Package also progressed in the development of user-friendly interface aiming to export detailed dosimetry results (voxel coordinates, tissue characteristics, and per voxel..) from DICOM-RT to the SAS® software.

### Work Package 5

The call for data collection regarding late mortality was sent by Work Package 1 on 30 January 2012 to 8 data providers: France, Hungary, Italy, the Netherlands, the Nordic Countries (Sweden, Norway, Finland, Denmark, Iceland), Slovenia, Switzerland, and UK. Protocol of data requirements was prepared together with WP1 and ready as deliverable 5.1 on 31 July 2012. In order to prepare Milestone 5.1 "Availability of information on vital status and cause of death in different European countries", a questionnaire was answered by all data providers and the summary placed for internal use at the PanCareSurFup website. A modified questionnaire was sent to all PanCare members and answers were received from additional 10 countries. It is planned to prepare (together with WP1) the publication "Investigating late mortality in childhood cancer survivors in Europe: legal, structural, and methodological aspects". At present time most data providers delivered their cohorts to Mainz.

### Work Package 6

WP6 partners remain keen to hear from anybody who is interested in contributing to their work on guidelines (please contact [roderick.skinner@ncl.ac.uk](mailto:roderick.skinner@ncl.ac.uk)). The ongoing work on male and female gonadotoxicity is making good progress and both guidelines are expected to be finalised in the first part of 2014. The WP6 guidelines on transition of care should be completed during 2014 as well. Partners are creating two new sub-groups, in order to consider important issues that affect how the guidelines are written and how they are disseminated and implemented. The 'Information Sub-Group' will consider how appropriate information is conveyed to survivors, their families and non-specialist health carers once a particular guideline has been written (particularly important for those guideline topics where less evidence is available and guideline recommendations depend more on expert opinion). This sub-group will consider how much and what sort of information WP6 should provide, and will also consider future projects that may arise from this work. The 'Implementation and Feasibility Sub-Group' will identify solutions to the potential difficulties some European countries may have about the implementation of the guidelines. Potential leaders for both these sub-groups have been contacted, and WP6 partners aim to start web conferences for both groups before the end of 2013.



Project partners at the last PanCareSurFup meeting in Amsterdam



Gisela Michel and Mike Hawkins



Leike Feijen and Julianne Byrne



Project partners at the last PanCareSurFup meeting in Amsterdam



# PanCareSurFup Partners

The project's dissemination team interviews the leader of Work Package 6, Prof. Rod Skinner from the Northern Institute for Cancer Research, Great North Children's Hospital and Royal Victoria Infirmary, University of Newcastle (UK).

## Can you describe how you got involved in PanCareSurFup?

I was one of the founding members of PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer) at its inaugural meeting in Lund in March 2008. Since 2003 Lars Hjorth, PanCareSurFup's Coordinator, and I had talked about the idea of developing a European network of health professionals and scientists involved in the long-term follow-up care of survivors of childhood cancer, and we were also very keen to involve survivors and their families. Lars and I then talked to Riccardo Haupt, who had succeeded to Momcilo Jankovic as Chair of the [IBFM Early and Late Toxicity Education Committee \(ELTEC\)](#). As ELTEC Chair, Riccardo organised the workshop between paediatric oncologists, epidemiologists, nurses, survivors, and their families from which the influential "Erice statement" was written (*Eur J Cancer* 2007; 43: 1778–1780). Riccardo then invited us to the next ELTEC meeting in Budapest in November 2007: discussion at that meeting made it clear that there was a lot of enthusiasm for a European network to both undertake research to reduce the risk of late adverse effects of treatment for childhood cancer and develop ways of improving the long-term care of survivors. The three of us planned the first meeting which Lars hosted in Lund in March 2008, at which our overall aims were agreed. Lars kindly agreed to lead our new organisation and the name PanCare was chosen. These were hugely exciting times! From the very first meeting of PanCare, it was agreed that a vital element of improving care would be to develop evidence-based guidelines for long-term follow-up that would help survivors in all European countries, and I was asked to lead on this strand of our work. When we started planning PanCareSurFup in 2009, we designed a coherent proposal that included both large-scale epidemiological research and evidence-based guideline development. We saw both of these aspects as ways of improving care by generating high-quality research and then using this and other evidence to produce guidelines based on a rigorous scientific process rather than expert opinion. The framework of this proposal was written during the 4th PanCare meeting which I hosted in Newcastle in October 2009.



Rod Skinner

## How can a former childhood cancer patient explain to any new doctor/GP his/her clinical history and challenges he/she may face?

It can be extremely hard for childhood cancer survivors (CCS) to explain their illness and its treatment. Although parents often become expert in their child's disease and care, this doesn't always happen and the survivor him/herself may not know anywhere near as much especially if they were too young or ill to understand. Furthermore, childhood cancer is (fortunately) very rare so most doctors, including primary care doctors and GPs, have very little or no experience of it. So CCS frequently struggle to explain everything to their new doctor who may in turn have little or no real understanding of their experiences and, most importantly, of their future health and psychosocial risks and challenges. All healthcare professionals involved in the care of children with cancer, and especially long-term survivors, have an important responsibility to inform them and their carers about their illness and treatment in understandable and meaningful terms.

### **How does the “Survivorship Passport” project integrate the guidelines you are developing within your Work Package?**

The “Survivorship Passport” is being developed under Riccardo Haupt’s leadership in WP13.2 of the ENCCA project. In addition to the important basic information on the survivor’s former cancer diagnosis and treatment, it will include the recommendations from our guidelines that are relevant to each individual CCS. Some of these will be important and therefore included for all survivors (for example, recommendations about health promotion), whilst others will be relevant for only certain groups of CCS depending mainly on the particular treatment that they received. The Passport software will import the correct recommendations for each CCS. These recommendations will then provide important information for each survivor and their non-specialist health carers about their possible future health risks and ways in which these can be reduced.

### **Do these Guidelines include the psychological and social consequences after having suffered from childhood cancer?**

Yes, we are planning to include information and recommendations about psychological and social problems that some survivors may experience. In addition, we are already developing guidelines about the way in which health professionals care for survivors in the long-term. These include the very important step of transitioning them and their care to age-appropriate facilities and healthcare teams when they enter adulthood. We also plan to write guidelines about how survivors (and their families) can take general steps to improve their future health, for example by understanding more about the value of regular exercise.

### **How do national healthcare systems take into account the adverse events that can affect former cancer patients?**

This varies enormously between different European countries, and even between different centres within individual countries. However, it would be fair to say that in most countries and centres it relies mainly on systems developed by the individual teams and health carers that carried out the child’s initial treatment. Obviously the way in which survivors receive long-term care, and what is included in this care, will also vary depending on the type of health care system in their country and what facilities are available. In addition, it may depend on how health care is funded, and this may be a major problem for some countries. There is an important role for research and data collection that will help each country to understand more about the needs of their own survivors, and for guidelines that will highlight what is recommended to provide the best possible long-term care for all survivors in each European country.

### **How do you deal with the issue of late effects’ prevention, early detection and treatment in the United Kingdom?**

We are relatively fortunate in the UK since we have a long tradition of clinical interest and research into the late consequences of treatment for childhood cancer. The Late Effects Group (currently chaired by Dr Helen Jenkinson from Birmingham) of the Children’s Cancer and Leukaemia Group (CCLG) has played a major role in much of this work and has produced a practice statement to guide the long-term care of CCS. In addition, the British Childhood Cancer Survivor Study (BCCSS), described by Prof Mike Hawkins in [last month’s Bulletin](#), continues to provide a wealth of information to guide our efforts to prevent late adverse events and to design ways of detecting them early at a time when we can take steps to reduce their impact. More recently, the National Cancer Survivorship Initiative (NCSI) has helped both paediatric and adult teams to design more effective and efficient ways of caring



*Left to right, Rod Skinner, Lars Hjorth, Momcilo Jankovic (PanCare and PanCareSurFup member)  
Front row, Riccardo Haupt (at PanCare/  
PanCareSurFup meeting, Genoa 2013)*

for all cancer survivors, and these are still being improved and implemented. All paediatric haematology / oncology centres are now required to have a late effects multidisciplinary team meeting and most run regular clinics for long-term survivors. Survivorship has become a very high-profile issue for survivor and family organisations as well as for the individuals involved and the health service.

### **Describe your typical working day**

First and foremost I am a children's leukaemia doctor but my major interest is in late effects and long-term follow-up, and my involvement in PanCare and PanCareSurFup means that I have a hugely stimulating job with no two days ever being the same. 80% of my time is spent looking after children during and after their chemotherapy or bone marrow transplant treatment. The other 20% is spent on developing guidelines for PanCareSurFup and on related research projects. I work closely with a large number of European colleagues in PanCareSurFup Work Package 6 (Guidelines, long-term follow-up and transition) and many other international collaborators in the International Late Effects of Childhood Cancer Guideline Harmonization Group. This is all with a common aim to produce evidence-based guidelines that will improve the long-term follow-up of CCS across all European countries and indeed the whole world. I am very grateful to my European colleagues and to Morven Brown, our research assistant in Newcastle, for helping me to keep the work on course!

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

My long-term follow-up clinics are amongst the most challenging part of my job, but it is immensely rewarding to see long-term survivors grow up and make their way in the world, especially when you know that without treatment they would not have survived. This makes me feel so lucky that I have been working in this field over the last 25 years when we have made such tremendous progress in curing children with cancer and leukaemia but witnessing some of their struggles against late adverse effects reminds me that we still have a lot of work to do before the job is finished.



Left to right, Rod Skinner, Lars Hjorth and Riccardo Haupt (PanCare meeting, Mainz, 2010)

### **For more information, please contact:**

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