



September 2015

PanCareSurFup

PanCareSurFup Bulletin, Issue nr. 11

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

Dear Friends,

In the eleventh Bulletin you can read about the excellent and important work that some of our data managers in PanCareSurFup are doing. I hope and think you will agree with me that it is critical that this work is of the highest class and we are lucky to have Melanie Kaiser and David Winter, among others, as co-workers in our project.

PanCareSurFup very recently received a positive response from the Commission regarding our one year no-cost extension so now we can concentrate on delivering everything that we have promised and hopefully some additional outcomes that the extension will make possible. Our regular web meetings will continue to keep track of the progress for WP 2-5. From the guidelines work in WP 6 we hope to see the result of the work on male and female gonadal toxicity in the near future.

In WP 7, work is under way towards the European Conference in Brussels to be held May 23-24, 2016; please mark these dates in your calendars! Here we hope to disseminate and show much of the results from our project, and hopefully look to future work that is needed to improve the Survivorship of our former patients.

I would like to wish you all a continued warm and relaxing summer and hope to see many of you at the PanCareSurFup and PanCare meetings in Vienna in September.

With my very best regards!

Lars Hjorth
Coordinator PanCareSurFup



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Latest developments in PanCareSurFup

Work Package 7 – International Conference 2016

The dissemination Work Package is working to organise the PanCareSurFup International Conference in Brussels (Belgium) to be held on May 23-24, 2016. Please mark these dates in your calendar today, as this will be the most exciting meeting of our project, where all partners will be offered the opportunity to present the results achieved during the project duration, and in relation to the PanCareSurFup project as a concept.



Open Space Summit – Little People Romania

The NGO “Little People” from Romania organised on 20th December 2014 in Bucharest, Romania, a “Open Space Summit” for survivors and young patient advocates aged 17 to 31. Participants from 15 European nations (Bulgaria, Czech Republic, Greece, Hungary, Ireland, Italy, Lithuania, Moldova, Poland, Romania, Serbia, Slovenia, Spain, Sweden and the United Kingdom) took part in this very interesting event, whose focus was to assess the most urgent unmet needs that young people across Europe identify, and allow free discussion on various topics. The 17 breakout sessions led by the participants during the event resulted in a detailed report of all discussions, mainly concerning age appropriate and equally accessible cancer treatment across Europe, long-term follow up and quality of survivorship, as well as the political and regulatory representation of young people with cancer. Please contact “Youth Cancer Europe” (contact@youthcancereurope; katie@thelittlepeople.ro) for more information.

PanCareSurFup Partners

In this edition of the Bulletin, the PanCareSurFup dissemination team interviews two Data Managers for the PanCareSurFup project: Melanie Kaiser from the German Childhood Cancer Registry at the University of Mainz (Germany) and Dave Winter from the Centre for Childhood Cancer Survivor Studies at the University of Birmingham (UK).

What are the main tasks of a data manager in PanCareSurFup?

DW: At the Centre for Childhood Cancer Survivor Studies (CCCCS) at the University of Birmingham we have a cohort of almost 18,000 survivors of childhood cancer, diagnosed between 1940 and 1991 in the United Kingdom, who survived at least 5 years from diagnosis. We contribute to WP3 (cohort and nested case-control studies of cardiac disease), WP5 (late mortality) and WP4 (cohort and nested case-control studies of subsequent primary neoplasms - SPNs) – Prof Hawkins, Director of the CCCCCS, is the WP4 Work Package leader.

I am responsible for producing the UK cohorts and identifying the UK cases and controls.

I am also responsible for establishing, developing and maintaining a pan-European and web-based system for the collection of detailed radiotherapy charts for WP3 and WP4 (and onward transfer to WP2 in Paris); also, for the cases and controls in WP3 and WP4 treated with chemotherapy for their cancer, establishing, developing and maintaining a pan-European and web-based system for the coding of cumulative doses of individual chemotherapy drugs.

Together with Dr Raoul Reulen and Lieke Feijen I help identify the cases and controls for WP3 and WP4 and liaise with the data providers throughout Europe. It is important to confirm that the cases and controls which have been selected and distributed in the chemotherapy abstraction database application are consistent with each data provider's expectations. Every two weeks I lead part of a regular WP2-4 data collection web-conference to check with each individual data provider to WP3 and WP4 on issues including: case and control selection, provision of radiotherapy charts and abstraction of chemotherapy drug information.

MK: The main tasks of a Data Manager in PanCareSurFup differ quite a lot depending on the Work Package. In Work Package 1 (data collection and harmonisation) the main task is to unify the format of the data packages from the different countries, merge the data packages into a joint database and then prepare harmonised data for the other Work Packages. In order to achieve data of the highest quality possible, comprehensive plausibility checks are necessary. For this, good contact and active information exchange with the individual data providers and Work Package leaders are particularly important.

What are the most important datasets to assess the quality-of-life of a survivor and the health risks he/she may face?

DW: In the UK we sent a postal questionnaire to survivors aged 16 or older via their general practitioner – almost 15,000 questionnaires – and over 10,500 returned a questionnaire (over 70%). The extensive questionnaire asked about recent hospital experience, medications, medical conditions, surgery, fertility issues, pregnancy and family history. The benefit of contacting the study members directly is that we obtained a personal account of their quality of life and the problems they encountered. Using their responses on the questionnaire we can subsequently identify a range of adverse



Dave Winter



Melanie Kaiser

health outcomes that can then be validated with their general practitioners and hospitals. We also collected social and lifestyle outcomes including education and employment status, and smoking and alcohol consumption history. As our cohort is population-based we can compare these adverse health and social outcomes with national population statistics to identify excess risks. We also have access to the database of all hospital episodes in England (Hospital Episode Statistics) since 1997. The cohort is also linked to the UK National Health Service Central Registers so we are routinely notified of subsequent cancers and deaths from the population-based national cancer and death registries. I am responsible for the linkage of our cohort to the national cancer and death registries, as well as to the national hospital episode statistics database.

By using the questionnaire survey and undertaking record-linkage to these population-based datasets we can identify how our population differs from the general population, and provide an assessment of increased risk of a range of adverse health and social outcomes and what impact this is likely to have on the survivors themselves and the health services in the UK who will ultimately be responsible for future screening and possible treatment.

MK: I think the research projects such as PanCareSurFup and PanCareLife that have been carried out within the framework of the PanCare Network and the data these projects have collected are highly important for the quality of life and health risks of survivors.

Could you please describe what do you do in a typical day of work?

DW: Apart from the Data Management tasks I manage and support all of the network hardware and software requirements for the Centre for Childhood Cancer Survivor Studies. There are 4 senior research staff, 2 administrative staff, and 4 PhD students who require assistance with data and analysis. I have worked in cancer epidemiology for over 30 years so I have an extensive working knowledge of the cohort data and treatment record history. Consequently I am actively involved in the identification and validation of cardiac events and subsequent primary neoplasms, plus checking the availability and quality of treatment information for cases and controls.

MK: A typical days begins with me reading my emails so that I can see whether new data have arrived or whether there are questions regarding the data. Depending on the stage of the project, I then work on the database and data processing. The tasks are documented as necessary, and reports are generated for difference requests. All decisions that arise and further steps to be taken are discussed in regular meetings with Peter Kaatsch, who is the Work Package leader, and Desiree Grabow.

What are the main challenges of your daily work?

DW: There are always important deadlines to meet so the main challenge is to prioritise my workload daily. Not always easy!

MK: The biggest challenges are maintaining an overview of the work and treating all the data with the same level of care. Due to new information from the data providers and because of corrections that were/are necessary based on the plausibility checks, data processing was and is a continual task.

How are data collected and stored for this project?

DW: For the WP4 case-control study I have provided each of the data providers with an Access database, populated with cases and controls, to enable them to record the treatment history and chemotherapy given. This information is then exported back to us here in Birmingham and combined together into a SQL Server database. I am in the process of providing a similar database application for the WP3 data providers.



Dave Winter



Melanie Kaiser

For the WP3 and WP4 case-control studies in the UK the cases and controls are identified and stored in an Access/SQL server database. All sources of information we have here in the Centre are then checked to obtain a full record of the treatment history. If we are missing treatment we can identify the centres where treatment was given and then contact them to obtain the information.

MK: At the beginning of the project, all project partners agreed on a uniform list of data to be collected. The data providers collect these data together and send them in an encrypted form to a fileshare server in Mainz. Here in Mainz, the data are decrypted and imported into a regional database. The database is saved on a secured server.

What would you suggest to health centres/registries in order to have better quality data to analyse?

DW: This is an easy question to answer in principle, but one which requires considerable effort in practice; to validate the data with the best sources available. For example, we receive notifications of possible subsequent primary neoplasms from the national cancer registries and then write to general practitioners and hospital pathologists to obtain confirmatory reports. The diagnosis and date of diagnosis often changes between the cancer notification from the registries and the final histology reports.

MK: I can't say much about this point because I don't know enough about the structures and work processes in the individual countries, centres and registries. However we hope that the experience and intentions of PanCareSurFup, in particular the virtual database, have contributed to a general discussion on harmonised variable lists and good data structure. Basic data that are worth collection will hopefully be established as standard in the long run.

Are you also involved in the PanCareLife project?

DW: No, but we have recently established a cohort of 235,000 individuals who survived at least 5 years after diagnosis of cancer when aged 15 to 39 years, between 1941 and 2006 in England and Wales. I was responsible for establishing this cohort and ascertaining causes of death, subsequent primary neoplasms and adverse health outcomes through record linkage with national databases.

MK: Yes, I am also the data manager for Work Package 1 (data centre and biostatistical support) for the PanCareLife Project. But because the PanCareLife project is more complex compared to PanCareSurFup in terms of the data structure, we are a somewhat larger team. I am pleased that we can now use the experience we gathered in PanCareSurFup for the PanCareLife Project.

Do you exchange information with all PanCareSurFup Work Packages? With which PanCareSurFup partners do you liaise more in your daily work?

DW: We have web-conferences every two weeks and all the data providers to WP3 and WP4 are invited. These conferences are important to check on progress of data abstraction and the provision of the data to WP3 and WP4. Information and ideas are always exchanged at these conferences.

MK: We work the most closely with Work Packages 3, 4 and 5. These Work Packages contain the data from Mainz for their Work Package-specific studies. In addition to the colleagues from the previously mentioned Work Packages, we also maintain close contact with coordinator Lars Hjorth and, of course, also with the data providers.



Dave Winter

Please describe one of your proudest moments or an achievement you are particularly proud of.

DW: This is a difficult question to answer. Probably being involved in numerous studies over the years where the outcome of the research has made a real difference to survivors. For example, our group was one of the first to identify epipodophyllotoxins as a cause of subsequent leukaemia. More recently, we were among the first to identify that those survivors who receive direct abdominal radiotherapy have a significantly increased risk of bowel cancer. The actions taken following both of these findings may well have prevented some avoidable deaths among survivors.

MK: I am particularly happy about the good cooperation with the individual countries and that altogether we have managed to combine this large amount of data (> 100,000 datasets) so that goal-oriented research for survivors of childhood cancer can be carried out. I am proud that I have been able to have a data management role in this project.



For more information, please contact:

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This publication has received funding from the European Union's Seventh Framework Programme (FP7/2007-2013), project call HEALTH.2010.2.4.1-7, Predicting long-term side effects to cancer therapy, grant agreement n° 257505.