



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

PanCareSurFup

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Getting close to the end of the year, I hope you can enjoy the ninth and latest Bulletin focusing on PCSF and the wider world.

There are many interesting and exciting projects going on in parallel in the world of paediatric oncology in Europe at present, not least the impressive work by Riccardo Haupt and co-workers on the Survivorship Passport in the ENCCA project, with input from WP6 in PCSF and PanCare.

Work in the different Work packages in PCSF is progressing well and e.g. the cohort and case-control studies in WP 2-4 are getting off the ground in a good way. The Guidelines work in WP 6, much of it in collaboration with the International Guideline Harmonization Group is being quite productive and work on Transition and Models of Care is also progressing well. In fact, all our eight WPs are being kept busy!

I would like to wish you all a nice and relaxing holiday season.

All the best!

Lars Hjorth
Coordinator PanCareSurFup

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Latest developments in PanCareSurFup

Work Package 1

Data delivery of the data providers to Work Package 1 was a bit delayed, but all data providers succeeded in delivering their cohort data to WP1 so far. WP1 is continuing their work with regard to plausibility checks and gets back to the data providers in case of implausibilities.

Preliminary and prefinal cohort data were delivered to Work Packages 3-5. WP1 continues to check the data and updates the cohorts as soon as further input from the data providers arrives.

A Manuscript titled 'Survivorship after childhood cancer: PanCare: A European network to ensure optimal long-term care' was prepared in collaboration with WP8 and is under internal review at the current stage.

Work Package 3

This work package will study the incidence and risk factors of five different cardiac events (heart failure, ischemia, pericarditis, valvular disease and arrhythmia).

We are currently covering cardiac cases in the WP1 database for France, Italy (population based cohort), Hungary, the Netherlands, Slovenia and Switzerland. The United Kingdom will deliver their cardiac cases within the next 3 months. All data providers started data collection of chemotherapy and radiotherapy for the cardiac cases and as soon as the controls are selected can start with the data collection for them. We performed some preliminary analyses on a "preliminary cohort" (France, Hungary and the Netherlands). The cumulative incidence at 30 years of follow-up is 5,8%. This is more than 1 out of 20 childhood cancer survivor. We also checked if the different cohorts could be pooled, because the inclusion criteria are different between cohorts, and different methods of ascertainment and validation are used. We performed a competing risk regression analyses in which we put cohort as the only risk factor: cohort does not add any significance to the model if compared to the intercept. So despite all the differences, we think that they are homogenous enough to pool.

Work Package 6

WP6 Work Package 6 is making good progress with guideline development work, including both transition care and surveillance for several late toxicities. In addition, much collaborative activity is underway to support future guideline production and dissemination and to underpin implementation.

There is a great deal of ongoing guideline development work. Notable progress has been made by the WP6 Transition / Models of Care Topic subgroup which held a very successful working meeting in Amsterdam on 27 August to review progress on the group's systematic review of transition of childhood cancer survivors (CCS) as well as that of other children and adolescents with chronic health conditions. A unified definition of what constitutes transition was agreed by the group. Data on how transition has been performed and evaluated was summarised. Further work is being undertaken to finalise this summary, including information comparing different models of transition care. This will be completed in the next 3 months, allowing the development of recommendations to be incorporated in a series of guideline manuscripts written by the group over the next 6-9 months. The group has planned a systematic review of models of care for long-term follow-up of CCS which will complement and also be informed by the transition work. Our final piece of work will be to develop guidelines for health promotion in CCS, and we will start planning this at the PanCareSurFup meeting in Lucerne in October.

There has also been much progress in our ongoing collaborative work with the International Guideline Harmonisation Group (IGHG). The Cardiomyopathy guidelines, in which several WP6 members participated, has recently been accepted

for publication in the Lancet Oncology. The Female and Male Gonadotoxicity groups are both finalising their guideline recommendations and preparing manuscripts for publication. The Thyroid Secondary Cancer subgroup's systematic review is progressing well whilst the CNS Secondary Malignancy subgroup is recruiting members and planning its review. The next two Topics (Vasculopathy and Metabolic Syndrome) are being planned.

The WP6 Methodology subgroup has developed a strategy for developing evidence-based guidelines for the many smaller and relatively evidence-poor miscellaneous topics, and it is anticipated that guideline development work on these will start in late 2014. The joint WP6/7 Implementation and Feasibility subgroup has agreed its membership and remit and will hold a face-to-face meeting in Lucerne in October to plan collection of information about potential barriers to guideline implementation in European countries. The joint WP6/7 PLAIN Information subgroup has considered how guideline recommendations can be made more understandable for and accessible to survivors and their families, and is piloting this work on the IGHG Breast Cancer surveillance guidelines (as published in the Lancet Oncology in 2013).

PanCareSurFup Partners

In this edition of the Bulletin, the PanCareSurFup dissemination team interviews Dr. Lars Hjorth from Lund University in Sweden, the Coordinator of this project.

How is PanCareSurFup linked to the new EU research programme 'Horizon 2020'?

PanCareSurFup is not directly linked to Horizon 2020 as such. The individuals involved in PanCare are however constantly on the look-out for new projects and opportunities to promote and investigate survivorship issues. Our 'sister project' PanCareLIFE is an excellent example of such work. PanCare is involved in the draft stages of applications to Horizon 2020, but no future project is yet funded.

How will the project be made sustainable after its termination?

The legacy of PanCareSurFup will hopefully be multifold. The establishment of a virtual cohort of more than 115,000 childhood cancer patients in Europe should be the basis for new applications. The knowledge from the cohort and case-control studies as well as the work on late mortality should inform the paediatric oncology community further and be part of future strategies for both treatment and follow-up. The Guidelines on follow-up, including transition and models of care should help establish new centres for follow-up as well as help present institutions where care is given today.

Do you think that long-term follow up will feature among the in future National cancer plans?

I am certain that long-term follow-up must and will be part of any cancer plan worth its name. Rehabilitation is key to a good quality of survival and adequate long-term follow-up is an intrinsic part of this.

What are the synergies with other similar projects at the EU-level (e.g. ENCCA, Expo-R-Net, PanCareLife, etc.)?

In ENCCA, WP13 is focusing on Quality of survivorship with a special focus on medulloblastoma survivors and on the Survivorship passport. The Passport will be linked to Guidelines on follow-up that are produced by Work Package 6 in PanCareSurFup, in collaboration with the International Guideline Harmonization Group. In Work Package 7 of ExPO-r-Net, a virtual late-effects advisory centre for



PanCareSurFup meeting in Lucerne (Switzerland)

specific care needs of childhood cancer survivors will be set-up and the Survivorship passport and the Guidelines will be translated into multiple European languages. In PanCareLIFE, the risks of impairments in female fertility, in hearing and in quality of life will be evaluated, thereby complementing work in other projects.

Do you think that the controversial Data Protection Regulation may have an impact on the long-term monitoring of childhood cancer survivors?

Definitely so. I think it is in many ways misguided and looks for protection where it maybe not always is needed. If you ask our survivors and their families if they want research into survivorship being done, they will sometimes be very puzzled and even slightly irritated when they find out that we are not conducting research into as many things as possible. In some ways I think it is more unethical NOT to do research into survivorship issues. It is a moral obligation for us to know what our treatments do to a growing individual, both in the short and in the long term run.

Do you think that the Survivorship Passport initiative could be extended outside the European borders?

Baring issues related to translations and possibly into different cultural and perhaps religious differences, I see no reason why the Passport could not be used all over the world. It is definitely our ambition that as many survivors of childhood cancer as possible should be able to access the finished product. Sustainability of the electronic platform needs to be secured if any of this is to be made possible, both within and without of Europe.

After PanCareSurFup and PanCareLife, what are the missing aspects of late-effects research which should be covered by future projects?

Specific focus on the most vulnerable patients would be welcome, such as brain tumour survivors and survivors of allogeneic stem cell transplantation. Not only physical but also psychological and psycho-social aspects are in need of more knowledge and interventions to alleviate or prevent long-term consequences are needed very badly.

After several years of commitment in this field, how do you see the future of European survivors? Will they be able to access optimal care on the long term, no matter where they live?

I think we need to be positive and focus on things that are achievable. One step at a time will get us to where we want to go, but it will take time. As more and more knowledge and awareness on survivorship issues are spreading, the foundation for our work will hopefully become broader and broader. The catch-phrase sustainability is really what is needed if we are to progress as fast as we would like to.

Generally speaking, are people more aware about survival and late effects of childhood cancer?

I think they are to some extent, but since childhood cancer thankfully is rare, there are many who are not as well informed and there are areas and communities in our world where the lack of awareness is more prominent.

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

I am very happy and proud that the PanCare Network that many of us envisioned 10 years or more ago is healthy and well and the mother of two large EU-projects, PanCareSurFup and PanCareLIFE. We wanted something like this to happen but it turned out even better than we could have hoped for.



PanCare boat trip in Lucerne (Switzerland)

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