The final numbers are in! The central Data Centre in UMC-Mainz received information from over 14,000 survivors of childhood and adolescent cancer from our Data Providers in Germany, the Netherlands, France, Switzerland, the Czech Republic, the United Kingdom, Poland, Austria, Norway and Israel. This was well over our initial goal of 12,000 survivors, so a big thank you to all those involved, in particular the survivors for sharing their information! The team is hard at work analysing the information to help survivors.

We'll be sharing what we have learned during the project, focusing on fertility, hearing impairment and quality of life for survivors of childhood cancer at our Closing Conference on 26 October 2018 in Paris. The conference follow the PanCare network (www.pancare.eu) meeting and includes a joint PanCare - PanCareLIFE symposium.

The meeting is free and open to anyone, including survivors of childhood cancer, parents, policymakers, oncologists, physicians and researchers.

To register and for programme details, visit https://www.pancare.eu/en/meetings/registration/ and select Sessions 7, 8 and the PanCareLIFE Final Conference.

We hope to see you there!
PanCareLIFE in the German Press

On 21 June, members of the German press joined a tour of three EU projects in Mainz, which included PanCareLIFE. The tour was organised by the Regional Representation of the European Commission in Bonn. During an hour-long session, the impact of PanCareLIFE’s research into fertility and hearing impairment late effects in long-term survivors was described, as well as how our results can be used to inform the development of future diagnostics and therapies for young cancer patients. During the visit, survivors also talked about their lives after cancer. Following the tour, the EU projects featured in an article in Allgemeine Zeitung.

On 27 July, Deutschlandfunk Kultur spoke to cancer survivor Christine and PanCareLIFE coordinator Dr. Peter Kaatsch to learn more about the impact of European-funded research. Two EU-funded research projects by the PanCare network (PanCareLIFE, PanCareSurFup) to advance knowledge of late effects and advance survivorship care for childhood cancer survivors were highlighted. Both projects have collected large amounts of data, essential to studying late effects and to improving our knowledge to help survivors into adulthood.

Erice Statement on Survivorship Updated

It’s hard to believe it’s been over 10 years since the first Erice statement in 2016, which laid out 10 key points summarising the essential components of cure and care for childhood cancer survivors!

In November 2016, 65 pediatric cancer experts from 17 European countries and North America, including many members of the PanCareLIFE team, met in Erice as part of the semi-annual PanCare meeting to review the original statement. They have now published an updated version of the statement in the Journal of Cancer Survivorship (https://doi.org/10.1007/s11764-018-0701-0).

Publication on scientific basis of PanCareLIFE

The European Journal of Cancer has published our article PanCareLIFE: The scientific basis for a European project to improve long-term care regarding fertility, ototoxicity, and health related quality of life after cancer occurring among children and adolescents (103: 227 - 237 (2018)). In the publication, we describe our large pan-European cohort and planned studies of hearing loss, fertility impairment and quality of life. The overall aim of the studies is to look in-depth at these important late effects and to develop fertility preservation guidelines that will help patients and their families make informed decisions and contribute to their long-term well-being.

All our publications can be found at: http://www.pancarelife.eu/project/publications.
Meetings on Survivorship after Childhood Cancer

Over 100 people recently gathered in Dublin Castle Conference Centre for the “Survivorship after Childhood Cancer” public meeting. The event was jointly organised by the Boyne Research Institute (Drogheda, Ireland, and PanCareLIFE partner) and CanCare4Living, an Irish charity representing survivors and their families and friends. It was supported by the Irish Government’s National Cancer Control Programme (NCCP).

The event brought together survivors of childhood and adolescent cancer, their families and friends, as well as health care professionals, researchers and advocacy groups. A highlight was the keynote address by Dr. Heleen van der Pal, from the Princess Maxima Center (PMC) for Childhood Cancer in Utrecht, Netherlands (also a PanCareLIFE partner). Dr. van der Pal runs the survivorship clinic in PMC. She shared information and news of best practice in the care of childhood cancer survivors across Europe. The aim of this unique event was to explore the needs of survivors of childhood cancer, to hear from international experts and to discuss opportunities to improve services for the future.

PanCareLIFE was also represented by Dr. Gabriele Calaminus, Dr. Desiree Grabow, Prof. Dr. Thorsten Langer and Katja Baust at the first Survivor Day of the German Childhood Cancer Foundation (DKS) on 29 September 2018 in Cologne. In Germany, around 50,000 survivors are considered cured, and the DKS is committed to standing by patients during and long after treatment. The event celebrated that many former patients are doing well today, enjoying and celebrating their lives. At the same time, the event also offered information about life after cancer and reflected on how difficulties and long-term consequences can be successfully managed.

Publication on genetic variations and late toxicities

PanCareLIFE researchers recently published ‘The influence of genetic variation on late toxicities in childhood cancer survivors: A review,’ in Critical Reviews in Oncology/Hematology 126: 154-167 (2018). The study looked at whether genetic factors could explain the variation in a number of late effects. They looked at two late effects being studied by PanCareLIFE (hearing impairment, gonadal impairment), as well as bone mineral density impairment and metabolic syndrome. The review highlighted the importance of large cohorts and independent replication cohorts for future research to develop personalised treatment protocols, and the potential for international collaborations to enable genetic research into late effects.

All our publications can be found at: http://www.pancarelife.eu/project/publications.
Update on PanCareLIFE fertility preservation guidelines

There is a lot of scientific evidence about how to best help survivors of childhood cancer, but more is always being learned and it can be difficult for doctors to keep up with all the latest research. That is why we have clinical guidelines. Guidelines summarise the latest evidence and based on this, they provide recommendations to help healthcare professionals make the best choices for helping patients and their families.

Treatments for childhood cancer can affect whether survivors can have their own children or not when they become adults, but there are things that can be done to help preserve fertility. In PanCareLIFE, we focused on developing guidelines for fertility preservation. We evaluated the existing guidelines on fertility preservation from many countries, and found that they did not agree with each other. So, we created groups of experts from around the world to develop a set of guidelines that everyone can use.

We’re now in the final phase! Our experts have searched for the best evidence available - more than 1,000 scientific articles were checked and from these, more than a 100 were selected to be used for our guidelines. The international experts discussed the potential advantages/disadvantages and the costs of the fertility preservation procedures, as well as how to use them in different healthcare systems. Based on these discussions, we have created guidelines and recommendations. As a final step, patient representatives will review the guidelines before they are promoted globally to the healthcare community.

PanCareLIFE fertility protocol paper published

PanCareLIFE researchers recently published ‘Fertility Among Female Survivors of Childhood, Adolescent, and Young Adult Cancer: Protocol for Two Pan-European Studies’, in JMIR Res. Protoc. 7(9): e10824 (2018). The protocol paper described the methodology for our cohort and nested case-control studies. 10,964 survivors were invited to participate in the study, with 6,619 survivors providing data. From this cohort, a total of 450 cases and 882 controls were selected for the case-control study.

Both studies will provide detailed insight into the risk of fertility impairment for survivors. This will help clinicians to adequately counsel both girls and young women, who are about to start anticancer treatment, as well as adult female survivors about future parenthood and to refer them for fertility preservation, where needed, in a timely way.

All our publications can be found at: http://www.pancarelife.eu/project/publications.

PanCareLIFE Partners

This project has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under grant agreement No. 602030. The material presented and views expressed here are the responsibility of the author(s) only. The EU Commission takes no responsibility for any use made of the information set out.