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## Survivorship after childhood cancer: PanCare: A European Network to promote optimal long-term care

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### Abstract

Survival after childhood cancer has improved substantially over recent decades. Although cancer in childhood is rare increasingly effective treatments have led to a growing number of long-term survivors. It is estimated that there are between 300,000 and 500,000 childhood cancer survivors in Europe. Such good survival prospects raise important questions relating to late effects of treatment for cancer. Research has shown that the majority will suffer adverse health outcomes and premature mortality compared with the general population. While chronic health conditions are common among childhood cancer survivors, each specific type of late effect is very rare. Long-term effects must be considered particularly when addressing complex multimodality treatments, and taking into account the interaction between aspects of treatment and genotype. The PanCare Network was set up across Europe in order to effectively answer many of these questions and thereby improve the care and quality of life of survivors.

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#### Conflict of interest statement

None declared.

The need for a structured long-term follow-up system after childhood cancer has been recognised for some time and strategies for implementation have been developed, first nationally and then trans-nationally, across Europe. Since its first meeting in Lund in 2008, the goal of the PanCare Network has been to coordinate and implement these strategies to ensure that every European survivor of childhood and adolescent cancer receives optimal long-term care. This paper will outline the structure and work of the PanCare Network, including the results of several European surveys, the start of two EU-funded projects and interactions with relevant stakeholders and related projects.

## Keywords

Childhood cancer; Survivorship; Long-term care; Long-term follow-up; Late effects

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## 1 Introduction

Survival after childhood cancer has improved substantially over recent decades. Although cancer in childhood is rare increasingly effective treatments have led to a growing number of long term survivors. This improvement in survival means that one in 1000 individuals in the general population of developed countries is a survivor of childhood cancer [1]. Research has shown that a significant proportion will suffer adverse health outcomes including premature mortality compared with the general population. While chronic health conditions are common among childhood cancer survivors, each specific type of late effect is very rare. Over the last two decades there have been many studies addressing the risks of specific late effects in relation to aspects of previous anti-cancer treatment but they have been hampered by the ability to recruit adequate numbers of survivors. It is estimated that there are between 300,000 and 500,000 childhood cancer survivors in Europe [2]. Such good survival prospects raise important questions relating to late effects of treatment for cancer, particularly when addressing complex multimodality treatments, and taking into account the interaction between aspects of treatment and genotype. By forming a Network across Europe we may be able to effectively answer many of the questions and from the answers improve the holistic care of all survivors.

Childhood cancer survivors deserve an effective structured long-term follow-up system to maximise their quality of life. For many years national groups have been working on special guidelines and recommendations in long-term follow-up; strategies for implementation have been developed, first nationally and then trans-nationally, across Europe [3–8]. This formed the basis for the networking and collaboration leading to the formation of PanCare in Europe. Since the first meeting in Lund, the goal of the PanCare Network has been to implement these strategies to ensure that every European survivor of childhood and adolescent cancer receives optimal long-term care. This paper will outline the PanCare Network, our mission statement and the first step towards achieving our ambitions.

## 2 The PanCare network

### 2.1 Aims and organisational structure

In March 2008 PanCare – the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer – was founded in Lund, Sweden, at a meeting attended by 26 representatives from 13 European countries ([www.pancare.eu](http://www.pancare.eu)). PanCare's name and mission statement were agreed at the meeting and have remained as follows:

PanCare is a multidisciplinary pan-European Network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer. Most European countries are represented. PanCare is working to achieve equity of access to care for childhood cancer survivors across Europe, to perform collaborative research and to act as a resource of research based information concerning all late side-effects of cancer treatment. An important aim of PanCare is to work with the European Community to increase awareness and research about childhood cancer survivors. The long-term strategic aim of PanCare is to ensure that every European survivor of childhood and adolescent cancer receives optimal long-term care.

The first Executive Committee consisted of Lars Hjorth (Lund, Sweden), Riccardo Haupt (Genoa, Italy) and Roderick Skinner (Newcastle, UK). The PanCare Network meets twice yearly (for upcoming meetings, see [www.pancare.eu](http://www.pancare.eu)).

PanCare's philosophy is based on the Erice statement, which was formulated at an international meeting held in Erice, Sicily, in 2006. It defines cure and care of long-term survivors of childhood cancer as the starting point of our work [9]. Among other things, the Network works towards the objective of ensuring optimal long-term care by:

- Identifying international best practices of long-term care, and supporting these practices.
- Developing methods to achieve equal access to care.
- Promoting and collaborating with and supporting the research into the late effects of cancer and its treatment.
- Developing, disseminating and applying guidelines for the care of survivors.
- Creating awareness and knowledge about survival after childhood and adolescent cancer within Europe.
- Interacting on survivorship issues with other stakeholders.

The Network consists of the *PanCare Board*, a group of 15 elected members representing various constituencies and stakeholders (e.g. survivors and parents, paediatric oncology, medical and clinical oncology, nurses, epidemiology, cancer registration and psychology). Regular telephone conferences of the Board and biannual face-to-face meetings coordinate the work. In autumn 2013 PanCare became a legal entity (a Society) under Dutch law. Founding members were the 15 current Board members. In the spring of 2014, PanCare was granted charitable status in the Netherlands.

*Executive Board* members (as of 2014) are Lars Hjorth as Chairperson, Helena van der Pal (Amsterdam, Netherlands) as Honorary Secretary and Julianne Byrne (Drogheda, Ireland) as Honorary Treasurer. A *General Assembly* is held at least once a year bringing together individuals who are PanCare members, and guests. Members of the Society are eligible to vote at the General Assembly. There are *Committees* responsible for different aspects, e.g. for Dissemination (Newsletter; Website), for Membership and Election issues and more recently for matters relating to Fundraising, Advocacy and Research. *Working groups* concerning the scientific content of the Network are in place for particular issues relating to specific late effects, such as Ototoxicity, Fertility, Quality of life and Leisure and Employment. Since the early days of the Network, dissemination of PanCare's activities has been achieved via the PanCare Newsletter and the website ([www.pancare.eu](http://www.pancare.eu)).

## 2.2 PanCare surveys

Early in its development PanCare decided to develop a number of research projects that require external funding. As background to these applications the Network launched a series of questionnaire surveys to gain a greater understanding of the infrastructure for research in Europe. Five questionnaire-based surveys were conducted between 2008 and 2010 and are summarised below. A sixth survey enquiring into the fertility preservation practices of European paediatric haemato-oncologists was recently published [10]. Over time, the number of recipients of the surveys has varied due to an increasing number of PanCare members. The respondents to these surveys came mostly from within the PanCare network which may introduce a possible bias in the results and the relatively low response rate calls for careful interpretation of the results.

**2.2.1 Survey 1: The European PanCare cohort of long-term survivors after childhood cancer – a survey to establish European databases which could be accessed for further research**—PanCare members were asked to respond to a purpose-built web-based questionnaire in 2008. Twenty-six members from 16 European countries indicated that over 118,000 subjects were registered; of these, approximately 80,000 were followed and approximately 10,000 were deceased. These subjects resided on 26 databases in 17 hospitals, five population based cancer registries and four late effects Networks, with a regional ( $n = 12$ ) or national ( $n = 14$ ) catchment area. Most databases included regular follow-up and collected basic information, indicating that the infrastructure exists within Europe ready for assembly into a large pan-European research Network. This research Network went on to become the PanCareSurFup consortium ([www.pancaresurfup.eu](http://www.pancaresurfup.eu)).

For the purpose of both cohort and case-control studies to be conducted within the framework of research projects on late effects, especially cardiac adverse events, second primary neoplasms and late mortality (only cohort study), the institutions were asked whether they were able to go back to the treating centres to collect details about chemotherapy and radiotherapy. Furthermore, the questionnaire determined whether it was possible to contact the survivors directly and additionally whether they were willing to provide DNA for genotyping [11].

### **2.2.2 Survey 2: Follow-up care after childhood cancer in Europe: a pilot study**

The second survey assessed the nature and barriers to implementation of follow-up programs. Of 64 clinicians surveyed, 26 responded, representing 14 countries. These 26 Follow-up clinics cared for a median of 380 survivors with a wide range of diagnoses. Nineteen were situated within a paediatric hospital or ward; the rest were in an adult cancer centre or in an out-patient clinic. Most clinics started follow-up at the end of treatment; some started when survivors became adults (16–18 years). Duration of follow-up and ability to provide transition varied: Seven ended follow-up at age 20, five at age 30 and 10 clinics followed survivors for as long as they requested. Eighteen clinics discharged survivors: most of them to general practitioners and some to adult follow-up clinics or to adult oncologists.

Cardiac problems, second malignant neoplasms, fertility and psychological problems were evaluated by almost all clinics. Barriers encountered in follow-up programmes were both related to the provider and the survivor: e.g. lack of dedicated time for providers, lack of funding, patients' and colleagues' lack of knowledge, distance to clinic, and inability to locate survivors [12].

Two larger scale funded surveys supported the findings [13,14].

### **2.2.3 Survey 3: Transition programmes in Europe for adult long-term survivors**

The third survey was intended to determine the number of transition programmes in Europe and to obtain the views of clinicians on models of follow-up care. A questionnaire was sent to 64 PanCare clinicians representing 19 European countries; of these, 26 replies were received from 14 countries. Results showed that 15 centres have special programmes for adult survivors within the paediatric institution; nine centres have transition and adult follow-up programmes in place; a few centres have adult follow-up only. All programmes were headed by a paediatric oncologist. In terms of satisfaction, most respondents ( $n = 16$ ) were content with the current state of affairs. Most ( $n = 20$ ) estimated that 10–30% of survivors were lost to follow-up at the point of transition to adult programmes. Obstacles to adequate transition included insufficient financial support ( $n = 13$ ), lack of experienced and specialised staff ( $n = 13$ ), lack of available clinical space ( $n = 10$ ) and lack of interest from adult clinicians ( $n = 3$ ).

Most respondents preferred a professional team that included different specialists for medical and psychosocial problems ( $n = 16$ ), involvement of a paediatric oncologist ( $n = 14$ ) and general practitioners ( $n = 10$ ), education programmes for survivors ( $n = 14$ ), for general practitioners ( $n = 12$ ) and for paediatric oncologists ( $n = 9$ ) and guidelines to assist in setting up and running transition programmes ( $n = 20$ ).

Because of the many models for transition to adult care evident across Europe the EU funded PanCareSurFup project (see below) included a specific objective within the Guidelines Work Package (WP6) concerning the development of guidelines for establishing transition care [15].

### **2.2.4 Survey 4: Expectations of parents and survivor groups**

The purpose of the fourth survey was to determine what survivor and parent groups expect from health care

providers. PanCare members completed one questionnaire each about Survivor and Parent Groups, responding on behalf of either their country (a 'combined' response) or their centre (allowing analysis of diversity within country). Thirty-two questionnaires were returned from 16 European countries. Only four PanCare responders stated that their country/unit had no Parent or Survivor Groups. Fifteen responders had links with Parent Groups, five with Survivor Groups and eight with combined Parent/Survivor Groups. The responders knew the aims of and received support from these groups, but only 16 knew what Survivor/Parent Groups expected from health care providers.

Respondents indicated that Survivor/Parent groups provided help integrating survivors and their families back into their lives: with organising meetings and camps for survivors and families, or weekends for parents; with facilitating contact between survivors and coordinating activities of different associations; with information about possible treatment-related late effects; with assistance in seeking improvements needed to achieve optimal health and psychosocial care for survivors. Some survivors groups provide financial/logistic support for meetings of health care professionals.

The responses suggested that access to and support from Survivor/Parent Groups varies across Europe or within individual countries [16].

### **2.2.5 Survey 5: Guidelines for long-term follow-up care for European**

**survivors of childhood and adolescent cancer**—The fifth survey consisted of a structured questionnaire sent to 78 PanCare members, representing 19 countries. We asked about the use, origin, development, intention and evaluation of long-term follow-up guidelines. Responses were received from 16 out of the 19 European countries, representing a total of 21 centres. Long-term follow-up guidelines were used by 18 centres in 14 countries, of which eight used guidelines originating in another country.

Thirteen centres were involved in developing long-term follow-up guidelines. The majority of guideline development teams were multidisciplinary, involving more than 10 representatives from paediatric oncology, radiation oncology, psychology, adult specialties, nursing as well as survivors and families. Of nine countries that had developed and used long-term follow-up guidelines in more than 50% of centres, only three described their guidelines as recommendations derived from evidence-based literature review. Most guidelines had been written after 2000, and all had plans for future updates. No long-term follow-up guidelines had been audited to determine if and how they had been implemented. This limited survey indicated the need for an updated and critically appraised set of guidelines to facilitate harmonisation of long-term follow-up care within Europe [17].

### **2.2.6 Survey 6: Fertility preservation practices among European paediatric**

**onco-haematologists**—The sixth survey identified 198 institutions in Europe that provided haemato-oncology treatment to children. A questionnaire was sent to assess their usual practices around fertility preservation. Representatives of 68 institutions responded. Pre-treatment fertility counselling was offered by 64 institutions and performed mostly by a paediatric onco-haematologist and in about one third by a team. About half of the institutions lacked guidelines for fertility preservation. All 64 centres offered sperm banking;



eight offered testicular tissue cryopreservation for pre-pubertal boys. For females, the possibility of preserving ovarian tissue was offered by 40 institutions. While most recommended sperm cryopreservation, many also recommended technologies for other purposes whose efficacy has not been shown. This urgent need for evidence-based European guidelines for fertility preservation to help survivors deal with the stressful topic of fertility contributed to the formation of the PanCareLIFE consortium (see below) [10].

### 3 EU funded projects following PanCare networking and surveys

At the conclusion of these surveys it had become clear that European centres, if collaborating, would have the capacity to carry out extensive, broad-based, comprehensive and detailed studies of risks to health in long-term survivors of childhood and adolescent cancer. Allied to this conclusion, it was evident that the current fragmentation and lack of networking between countries and clinics across Europe was hindering the development and implementation of long-term follow-up guidelines. In turn, this had led to a situation where the structures for follow-up are few and varied, and not evidence-based. In short, there is inequality across Europe in the ability to deliver optimal long-term follow-up care to survivors.

The PanCare Network decided to work towards research designed to

- Evaluate the long-term risks of certain life-threatening risks emanating from treatment of the primary malignancy.
- Develop evidence-based guidelines to guide clinical practice.
- Provide education and dissemination of this information to survivors and clinicians.
- Establish best practice guidelines for transition programmes, models of care and health promotion.

The outcome of this work has been the establishment of two five-year collaborative EU-funded projects. These are PanCareSurFup (Grant Agreement Number 257505) and PanCareLIFE (Grant Agreement Number 602030), both described below. Table 1 compares the two projects.

Noteworthy are also the EU-funded Network of Excellence called ENCCA (Grant Agreement Number 261474) and the European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment called ExPO-r-Net (Grant Agreement Number 20131207), in which members of the PanCare Network are participating actively. Both projects are also described below.

#### 3.1 PanCare childhood and adolescent cancer survivor care and follow-up studies (PanCareSurFup; start date 1st February 2011)

PanCareSurFup will, through cooperation with existing registries and databases, collect data on the risks of complications of cancer treatments to create a retrospective European cohort of more than 115,000 former childhood cancer patients. Through the use of radiation dosimetry, doses of radiotherapy to each organ will be established, enabling tighter estimates

of risk to these organs to be used in the case-control studies. PanCareSurFup will through cohort and case-control studies develop risk estimates for various aspects of cardiac disease, subsequent primary neoplasms (principally second sarcomas and second adult-type carcinomas) and late mortality ([www.pancaresurfup.eu](http://www.pancaresurfup.eu)). These data, with results from other studies, will be the basis for establishing guidelines for follow-up in Europe, including suggestions for clinical Networks to enable care to continue seamlessly from paediatric to adult settings (transition) and suggest different models for this follow-up care. Since global cooperation is essential to produce robust and reliable results, the guidelines work is in part being performed together with the International Guidelines Harmonisation Group [18]. Finally, dissemination of the results will be achieved through conferences, workshops, newsletters and blogs, as well as partnerships with survivors and parents. PanCareSurFup's studies will increase cooperation between treatment and advocacy groups, reduce disparities in survival and improve outcomes for children and adolescents diagnosed with cancer in Europe.

Within PanCareSurFup and within the PanCare Network new ideas were born to put together a second consortium to investigate non-life-threatening, but still serious late effects, resulting in the PanCareLIFE project.

### **3.2 PanCare studies in fertility and ototoxicity to improve quality of life after cancer during childhood, adolescence and young adulthood (PanCareLIFE; start date 1st November 2013)**

PanCareLIFE will evaluate the risks of impairments in female fertility, in hearing and in quality of life ([www.pancarelife.eu](http://www.pancarelife.eu)). It will also develop guidelines for fertility preservation, and will disseminate widely the results from this project. These topics were chosen since there were existing working groups in PanCare where collaboration and mutual scientific interests already had come together.

The goal of PanCareLIFE is that survivors of cancer diagnosed before age 25 years should enjoy the same quality of life and opportunities as their peers who have not had cancer. Using observational studies and molecular genetic investigations PanCareLIFE will through 12,000 well-characterised childhood cancer survivors investigate genetic and non-genetic factors that impact on the risk of fertility and hearing impairment (ototoxicity), and will assess health-related quality of life. Information from PanCareLIFE's studies will be incorporated into new guidelines for fertility preservation.

PanCareLIFE will advance the state-of-the-art in survivorship studies by evaluation of large cohorts with observational and genetic tools that will provide better knowledge of individual risk factors. Survivors can then be stratified into groups benefitting from personalised, evidence-based, care; future patients may expect effective therapies to have less severe side-effects, and plans for a seamless transition to long-term follow-up care can be made. These approaches will result in better quality of life for survivors of cancer diagnosed at a young age.



### **3.3 European network for cancer research in children and adolescents (ENCCA; start date 1st January 2011)**

The ENCCA network aims to establish a durable, European virtual institute where clinical and translational research in childhood and adolescent cancers will define and implement an integrated research strategy ([www.encca.eu](http://www.encca.eu)). By bringing together existing informal paediatric and adolescent oncology clinical trial groups, ENCCA will integrate all relevant stakeholders, their expertise and viewpoints to ensure that the project is all-encompassing while remaining patient-centred. In ENCCA's Work package 13 a Survivorship Passport is produced and the Health Tracker system is tested to monitor quality of life.

### **3.4 European expert paediatric oncology reference network for diagnostics and treatment (ExPO-r-Net; start date 1st March 2014)**

This DG SANCO-funded three-year project aims to pilot the idea of Reference Networks within the concept of cross-border health care in Europe ([www.expornet.eu](http://www.expornet.eu)). Work package 7 will set up a virtual Network of late effect experts in Europe and also translate Guidelines from PanCareSurFup and a Survivorship Passport from ENCCA into multiple European languages. Much of the work will be performed by members from both PanCare and SIOP-Europe.

## **4 Partnering with parent and survivor organisations/groups**

Partnership with parent and survivor organisations is essential to achieve the aims of promoting/ensuring optimal long-term care for survivors within the European countries. Childhood Cancer International – CCI (formerly ICCCP, the International Confederation of Childhood Cancer Parents Organizations, [www.icccpo.org](http://www.icccpo.org)) is part of or is a partner in EU-funded projects like PanCareSurFup, PanCareLIFE, ENCCA and ExPO-r-Net, where CCI members are cooperating with physicians on several levels, e.g. the implementation of the European Standards of Care, the Survivorship Passport and long-term follow-up guidelines [19]. CCI members have also played an important part in the PanCare Network since its inception. Furthermore, CCI strives to provide information to survivors and parents by dissemination and training.

## **5 Future work**

Challenges for children and adolescents with cancer and the need for improvement of follow-up of survivors are described elsewhere [19,20]. With the establishment of PanCare an interdisciplinary Network of experts in the field was created which continues to address challenges faced by long-term survivors of childhood cancer arising from successful treatment of their primary disease. The PanCare Network will together with international collaborators and groups continue to lead the way by initiating new studies on late effects of cancer therapy, and provide guidance for clinicians and families in the form of evidence-based guidelines for follow-up and for transition to adult care [14,18]. As the PanCare Network unites researchers, clinicians and parents and survivors it will continue to enhance the quality of life of survivors in many different ways. Challenging areas of work lie ahead. Primary prevention of late complications by avoiding potentially harmful drugs should be a

goal for everyone working with childhood cancer patients. If this is not possible, other strategies to prevent or ameliorate late complications should be sought after. Ethical aspects to this work as well as data protection issues must be taken into account and rigorous efforts must be made to ensure the highest possible quality of the data collected across different regions and countries within Europe.

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Table 1

Comparative summary of the two EU-funded sister projects arising from the PanCare Network.

	<b>PanCareSurFup: PanCare childhood and adolescent cancer survivor care and follow-up studies</b>	<b>PanCareLIFE: PanCare studies in fertility and ototoxicity to improve quality of life after cancer during childhood, adolescence and young adulthood</b>
Main focus	Cardiotoxicity, second primary neoplasms, late mortality, guidelines for long-term follow-up and transition and models of care	Fertility, ototoxicity, health-related quality of life – combined with genetics
Participants (countries)	16 Partners from 11 countries (Austria, Belgium, France, Germany, Hungary, Ireland, Italy, Netherlands, Sweden, Switzerland, UK)	15 Partners from eight countries (Czech Republic, Denmark, France, Germany, Ireland, Italy, Netherlands, Switzerland)
Work packages	<p>1: Data collection and harmonisation (D. Grabow, Mainz, Germany)</p> <p>2: Radiation dosimetry (F. de Vathaire, Paris, France)</p> <p>3: Cardiac disease: cohort and nested case-control study (L. Kremer, Amsterdam, Netherlands)</p> <p>4: Subsequent primary neoplasms: cohort and nested case-control studies (M. Hawkins, Birmingham, UK)</p> <p>5: Late mortality (S. Garwicz, Lund, Sweden)</p> <p>6: Guidelines, long-term follow-up and transition (R. Skinner, Newcastle, UK)</p> <p>7: Dissemination and Training (M. Jankovic, Monza, Italy)</p> <p>8: Management and coordination (L. Hjorth, Lund, Sweden)</p>	<p>1: Data centre and biostatistical support (P. Kaatsch, Mainz, Germany)</p> <p>2: Fertility preservation guidelines (L. Kremer, Amsterdam, Netherlands)</p> <p>3: Female fertility impairment (E. van Dulmen-den Broeder, Amsterdam, Netherlands)</p> <p>4: Genetics of fertility impairment &amp; hearing loss (M. van den Heuvel-Eibrink, Utrecht, Netherlands)</p> <p>5: Ototoxicity (T. Langer, Lilbeck, Germany)</p> <p>6: Health-related quality of life (G. Calaminus, Münster, Germany)</p> <p>7: Dissemination and exploitation (C. Clissmann, Dublin, Ireland)</p> <p>8: Project management (P. Kaatsch, Mainz, Germany)</p>
Start of 5-year project	February 2011	November 2013
Coordinator	L. Hjorth (Lund, Sweden)	P. Kaatsch (Mainz, Germany), Coordinator; J. Byrne (Drogheda, Ireland), Research Manager; C. Clissmann (Dublin, Ireland), Administrative Manager
Project Manager	E. Withoff/H. Linge (Lund, Sweden)	D. Grabow (Mainz, Germany), H. Campbell (Drogheda, Ireland), K. O'Brien (Dublin, Ireland)
Ethical (both projects) and scientific (PCSF only) advisory board	J.D. Beck (Erlangen, Germany), G. Bode (Bonn, Germany), P. Inskip (Washington, US), M. Jenney (Cardiff, UK)	L.E. Knudsen, (Copenhagen, Denmark), N.W. Paul, (Mainz, Germany)
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