

Contributing to Childhood Cancer Survivorship in Europe: current programmes, emerging trends and furthering the agenda

Katrin Scheinemann

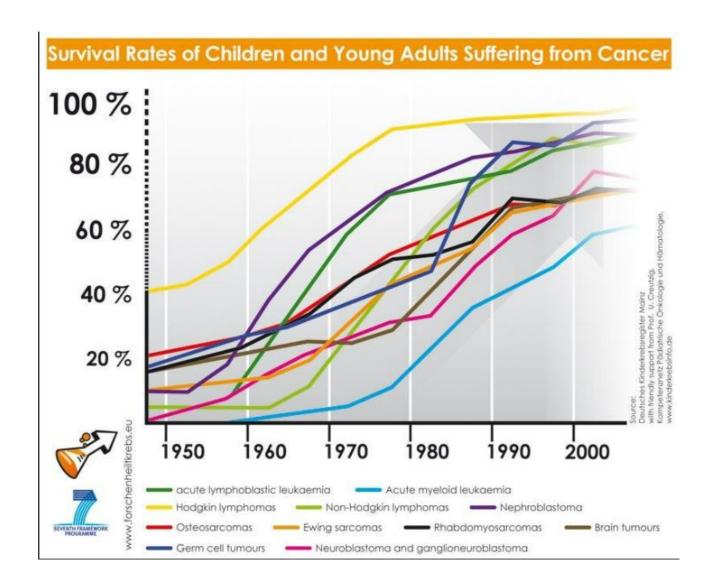
Elevating childhood cancer survivorship: from SIOP Europe Strategy to Europe's Beating

Cancer Plan and EU4Health





Childhood cancer – a success story







- 1. 80 % survival at five years in highly developed European countries, but differences between European countries and worldwide
- 2. Currently more than 300'000 survivors of childhood and adolscent cancer within Europe, but huge differences in survivorship care across Europe
- 3. At least two-thirds of survivors have early-or late-occuring complications due to their treatments and disease, around 25 % even sever or life-threatening
- 4. By 2030, anticipation of around 750'000 pediatric and adolescent cancer survivors in Europe

- 1. Standardized surveillance guidelines for late-occurring side effects of childhood cancers
- 2. Organized health care transition (pediatric to adult) as a standard of care across Europe
- 3. Survivorship follow-up care plans, infra(structures) & interoperable IT tools including a Survivorship Passport and integration of patient-reported outcomes to facilitate an appropriate life-long informed care model allowing childhood cancer survivors to live their life at its best potential
- 4. The facilitation of prospective long-term follow-up of novel therapies against childhood cancer for these growing and developing individuals

THANK YOU FOR YOUR ATTENTION





13th Edition

International Childhood Cancer Day (ICCD) 2023

8 February 2023 13:00 to 15:00 CET

Brussels, Belgium







Contributing to Childhood Cancer Survivorship in Europe: current programmes, emerging trends and furthering the agenda

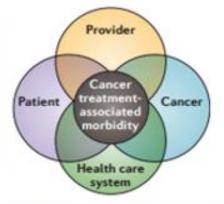
Katrin Scheinemann

Research priorities in childhood cancer survivorship





- * Survivorship education or training
- * Survivorship experience
- * Practice style
- Perceptions regarding preventive care
- * Access to survivorship resources
- * Knowledge or access to individual survivor health history
- Age at treatment and attained age
- * Sex, race or ethnicity
- Familial or genetic factors
- * Pre- or co-morbid conditions
- * Health behaviours
- Cognitive or developmental status
- * Health knowledge
- * Health risk perceptions
- * Self-efficacy
- * Insurance or health care access



- Histology or involved sites
- . Biology or response
- Treatment
- * Surgery
- Chemotherapy
- Radiotherapy
- * Transplantation
- * Transfusion
- * Treatment events

- * Financing and payment policies
- * Organization and affiliation of providers
- . Data systems and information sharing
- * Models of survivorship care
- Insurance coverage and benefits supporting survivorship care (especially preventive and psychosocial services)
- * Community resources
- . Survivorship advocacy activity

Figure 3 | Inter-relationships. This figure shows patient-, cancer-, health care system- and providerrelated issues that affect cancer treatment-associated morbidity among the long-term survivors of childhood and adolescent cancer.

NATURE REVIEWS CANCER

VOLUME 14 JANUARY 2014





Survivorship research – areas mainly covered

1. Cohort studies in different countries

- Long term survival
- Morbidity
- Mortality
- Specific long term side effects of surgery, radiotherapy and chemotherapy
- 2. Evidence based guidelines on follow up
- 3. Models of care for survivorship
- 4. Survivorship follow up care plans
- 5. Implementation of survivorship research in up front clinical trials to minimize long term sequelae





Survivorship research – future directions

- 1. Risk models
- 2. Interventions to prevent or minimize long term sequelae
- Follow up and long term side effects of novel therapies like immunotherapy, targeted therapy etc.
- 4. Not yet covered ares of long term sequelae like mental health, psychosocial outcome, fertility issues, vocational outcomes, insurance issues, independent living etc.
- 5. Stronger involvement of survivors and families as well as other stakeholders



THANK YOU FOR YOUR ATTENTION





13th Edition

International Childhood Cancer Day (ICCD) 2023

8 February 2023 13:00 to 15:00 CET

Brussels, Belgium



