



## **4 million euros awarded to EU project to improve long-term care for survivors of childhood and adolescent cancer**

The EU-funded project PanCareFollowUp ([pancarefollowup.eu](http://pancarefollowup.eu)) looks at how to best deliver survivorship care to survivors of childhood and adolescent cancer in Europe. Survival rates have improved over the last few decades but there is still a long way to go in long-term follow-up care for survivors of childhood cancer. This new focus in care and evaluation of care for survivors of childhood cancer is coordinated by Prof Leontine Kremer from the Princess Máxima Center for Pediatric Oncology in Utrecht, The Netherlands. Fourteen partners from 10 European countries (Austria, Belgium, Czech Republic, Denmark, Ireland, Italy, The Netherlands, Sweden, Switzerland, United Kingdom) will participate.

There are currently over 300,000 survivors of childhood and adolescent cancer across Europe, and this figure is expected to reach 500,000 by the year 2020. Thanks to better cancer treatments, more than 80% of children and adolescents in Europe who get cancer will now survive more than 5 years. However, cancer treatments are harsh and long-term effects mean that survivors require closer health monitoring compared to the average population. Despite increasing knowledge about health problems after childhood cancer, only a minority of adult childhood cancer survivors receive appropriate care.

PanCareFollowUp is therefore aiming at delivering care according to recently developed guidelines using an innovative model for person centred care that empowers survivors and supports self-management. The objectives of PanCareFollowUp are to:

- Develop the PanCareFollowUp Care intervention, based on state-of-the-art knowledge, summarised in guidelines, about what regular surveillance individual survivors need and how it can be best delivered using person-centred care approaches
- Test the PanCareFollowUp Care intervention in four countries (Belgium, Czech Republic, Italy and Sweden) in partnership with 800 survivors, measuring effectiveness, value and cost-effectiveness
- Test the feasibility of using the European Survivorship Passport in delivering the PanCareFollowUp Care intervention in Italy and explore the development of an App
- Develop the PanCareFollowUp Lifestyle intervention, a person-centred eHealth lifestyle intervention tailored to meet the individual needs of survivors
- Test the PanCareFollowUp Lifestyle intervention in the Netherlands in partnership with 60 survivors, looking at effectiveness, acceptability and feasibility
- Develop materials to support replication of the PanCareFollowUp Care and Lifestyle interventions in new countries across Europe in the future
- Widely disseminate and communicate the available research to survivors and their families, researchers, healthcare professionals, healthcare decision-makers and policy-makers

The aim to deliver better, person-centred survivorship care to European survivors of childhood and adolescent cancer should empower survivors and support self-management. Regular long-term follow-up aiming for prevention, early detection and intervention of late effects can indeed preserve or improve health. “It is important that every survivor of childhood cancer in Europe will be able to receive optimal survivorship care grounded on evidence-based guidelines and their own preferences”, said Professor Leontine Kremer (PanCare Project Coordinator). Dr Helena van der Pal (President of PanCare and late effect specialist) added “PanCareFollowUp will make a significant difference for survivors of childhood cancer across Europe. We will develop and implement a care intervention including new tools such as the survivorship care plan. This will enable health care providers and survivors to design the care that is needed”.

The kick-off meeting of 15 January 2019 in Amsterdam brought together PanCareFollowUp partners from across Europe to develop clear visions of their roles, start the activities to develop the interventions, and plan the studies. All partners reiterated their commitment to delivering the best survivorship care to survivors of childhood and adolescent cancer in Europe.



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