

European Network for Teenagers and Young Adults with Cancer Meeting

Newsletter from the Leadership Group (January – December 2021)

Dear All,

We hope this message find you well in these continued unusual and difficult times.

Would you like to feature any of your work in this newsletter in future?... if so, let us know

Following our virtual meeting on 19 February 2021, the leadership group consisting of Marie Balsat (FR), Ivana Bozovic (RS), Anna Castleton (UK), Johan De Munter (BE), Andrea Ferrari (IT), Ashley Gamble (UK), Anita Kienesberger (AT), Assia Konsoulova-Kirova (BG), Katie Rizvi (RO), Carina Schneider (AT), Dan Stark (UK), and Josef Vormoor (NL), have met on several occasions to discuss upcoming initiatives and activities that were suggested during the meeting in Brussels.

The key objective is to rebuild a network function across professional disciplines, consumers, charities and national groups to focus upon AYA cancer care and improving their outcomes across Europe, with the aim of widening the set of people who are aware and making use of the ongoing European collaborations in AYA cancer care and to widen the team of people and organisations who can play a part in ongoing and future collaborations in AYA cancer care

Please find below an update on the activities undertaken so far:

Survey 1 - HCPs

The purpose of this initiative was to survey the state of development in terms of providing age-specific care across Europe to TYA. Endorsed by SIOPE, ESMO, EONS and EHA, the survey aimed to understand the challenges and their geographical and cultural distribution (the data), the engagement with stakeholders, and to map progress sequentially. The plan is to repeat the survey every couple of years to distribution channels such as national and international society members (SIOPE, ESMO, EONS, EHA), the haematology community (EHA, EBMT), ERN PaedCan members, and perhaps some others. This survey aims to reach individuals, specifically HCPs, and not organisations. The survey closed on 15 July and we have received 377 responses from 60 countries. The analysis is in progress and we will share the results when we can!

Survey 2 - NGOs

The purpose of the second survey is to reach NGOs, charities, not for profit organisations and parent/patient organisations, in different countries in order to engage the widest possible range of NGOs and other organisations that have a stake in AYA activities. The survey content will relate to the professional survey so that sensible but limited comparisons can be carried out.

This survey is currently ongoing and analysis will start in March 2022. If you know of NGOs, send them the survey link: <https://www.surveymonkey.co.uk/r/ENTYACNGOs>

Common position statement/paper

A short, broad editorial was drafted, expressing our wish to work in this very broad manner, to engage actively with all of paediatric and adult oncology organisations, adult haematology, nursing, NGOs, and parents/survivors. The purpose of this editorial is to make the position of the group clear and to invite others to join this initiative.

The paper was published in April 2021 and is available here:

<https://www.liebertpub.com/doi/abs/10.1089/jayao.2021.0028>

EU consultations/policy

The group has explored possible channels to influence policy and will draft a policy statement with endorsement of SIOPE, EONS, ESMO and CCI-Europe, now that the position paper is published. We have been engaged in developing EU-level messages about AYA with cancer, and promoting those with policy-makers such as in the Cancer Plan.

Stakeholders

We are in the process of confirming formal agreements with SIOPE, ESMO, EONS, EHA, CCI, Youth Cancer Europe and others in order to ensure optimal collaboration and buy-in to the network. We've had requests from several other groups who wish to be part of this initiative. The structure of the network requires further thought, to make sure all stakeholders are included and the network runs effectively. If you know of a local, regional or national organisation specifically committed to AYA cancer care, do ask them to contact d.p.stark@leeds.ac.uk.

Next steps

We are working on a proposal to organize an ENTYAC Research and Service Development conference in 2022, with the objective of sharing ongoing and recent AYA research, as well as to identify new collaborative projects.

We very much look forward to continuing our fruitful collaboration with the aim of better addressing the specific needs of teenagers and young adults with cancer.

Should you have any further questions, please don't hesitate to contact us.

Sincerely,

Dan Stark, on behalf of the ENTYAC Leadership Group