

# **EUROPEAN NETWORK FOR TEENAGERS AND YOUNG ADULTS WITH CANCER (ENTYAC)**

## **TERMS OF REFERENCE**

### **1. Background**

The aims of ENTYAC are to become a working engine, that delivers interdisciplinary projects based upon bringing together strategic and direction-forming input, to and from the widest possible range of existing networks and groups with a stake in cancer in Teenagers and Young Adults. Therefore ENTYAC relates to both children and adults living with and after cancer and their care, and to care for a wide range of specific cancers (including haematological and solid tumours). Affiliated membership includes the organisations in the most recent addendum, but also (and uniquely) a very wide range of professional, patient and non-governmental organisations to improve outcomes for AYA and bring AYA issues onto the political agenda.

All of these initiatives together aim to bring the adult oncology, paediatric oncology, haematology, AYA specialists, nursing, psychology and social work, wider clinical and charitable sector communities and patient organisations together across Europe. That wider co-operation, sharing of ideas and perspectives and engaging organisations with many backgrounds, as well as healthcare professionals and researchers who are not part of a formal organisation, will be the main role of ENTYAC, which will act as a network not a more formal organisation.

A small leadership group with various stakeholders from multiple backgrounds and varied geographical distribution, was convened in March 2020 and has established several specific initial goals to be achieved together as ENTYAC.

### **2. Remit of the ENTYAC**

The key objective of ENTYAC is to rebuild a network function across professional disciplines, consumers, charities, carer, parent and patient advocacy groups, and national groups to focus upon AYA cancer care and improving their outcomes across Europe. This can

- widen the shared understanding of perspectives, priorities, projects and progress in AYA cancer care.
- widen the set of people who are aware and making use of the ongoing European collaborations in AYA cancer care
- widen the team of people and organisations who can play a part in ongoing and future collaborations in AYA cancer care

ENTYAC has made formal agreements with other organisations, and will build such agreements with others, in order to ensure optimal collaboration and buy-in to the network.

ENTYAC is active in the following areas:

- Surveying the state of development in terms of providing age-specific care across Europe to AYA.
- Surveying NGOs and parent/patient organisations in different countries in order to

obtain a catalogue of NGOs and other organisations that have a stake in AYA activities.

- Promoting the sharing of AYA-focussed work across organisations and to and from individuals.
- Publishing a common position paper expressing ENTYAC's goal of engaging actively with all of paediatric and adult oncology organisations, adult haematology, nursing, NGOs, and patients/carers/parents/survivors.
- Participating in EU consultations and policy activities.

### **3. Constitution of ENTYAC**

The ENTYAC will be composed of:

1. Leadership Group:
  - a. 1 Chair
  - b. Up to 12 other Members, including the chair-elect and the past chair.
2. Members:
  - a. Existing national AYA Groups
  - b. Stakeholder organisations
  - c. Dedicated working groups of scientific societies
  - d. Function-specific partners
  - e. Individuals not part of the groups above

The Chair, Chair-Elect, Past-Chair and Leadership Group members will oversee the activities of ENTYAC. Decisions that are not agreed by consensus will be passed based on a majority vote of the leadership group, who will use consultation with the overall membership when required.

The term of the Steering Group Members is 4 years. Terms are not renewable but a chair or steering group member may re-apply.

To guarantee continuity, the term of the Chair is 3 years. the Chair will also serve for 1 year as Chair-Elect, and 1 year as Past-Chair on the Leadership Group.

The chair-elect will be appointed by consensus in the Leadership Group.

The ENTYAC Leadership Group will guarantee optimal communication and interaction with the ENTYAC members.

### **4. Membership Requirements**

Membership should consist of stakeholders with an active interest in AYA cancer care.

Currently, ENTYAC is composed as follows:

Leadership Group:

- Inaugural Chair: Dan Stark (UK)
- Members: 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), and Josef Vormoor (NL).

- Chair: to be appointed by consensus in the Leadership Group.
- Leadership Group Members: to be elected among ENTYAC Members through nomination, if necessary supported via electronic voting coordinated by SIOPE office.
- Members will be able to apply to the lead for administration including a statement of their planned contribution and curriculum vitae. Each will be discussed with the chair, chair elect and past chair within one month of receipt, and by the leadership group at their next planned meeting (or sooner if the chairs wish)

## **5. Meetings**

The ENTYAC Leadership Group will meet 3-4 times per year or as needed. The entire network will meet annually.

## **6. Funding**

The ENTYAC currently has no funding stream, therefore any expenses incurred by the members of the Group will need to be met by their own institutions or their own funds.

## **7. Administrative Support**

The SIOPE office will provide administrative support to the ENTYAC for a limited time, after which administrative support will be transferred to another member organisation.

## **8. Reporting guidelines**

ENTYAC will have a bi-directional flow of information between the network leadership group and the boards and structures of each of the international membership organisations (see addendum) that are formally taking part. ENTYAC will seek to use whatever route to share its activities that those organisations prefer. Minutes will be available on the SIOPE website (while SIOPE leads the provision of the secretariat) and so will be freely available to the membership.

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[In a separate document]

### **Addendum**

Organisations that are formally affiliated of ENTYAC

ESMO  
ESMO/SIOPE AYA Working Group  
EHA  
ESTRO  
EONS  
Other SIOPE Europe Working Groups