

ENTYAC NGO Survey Summary Report

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1. Introduction

This report presents a summary of findings from a survey conducted to map regional and national charities and NGOs working with Adolescents and Young Adults (AYA) affected by cancer across Europe.

2. Respondent Overview

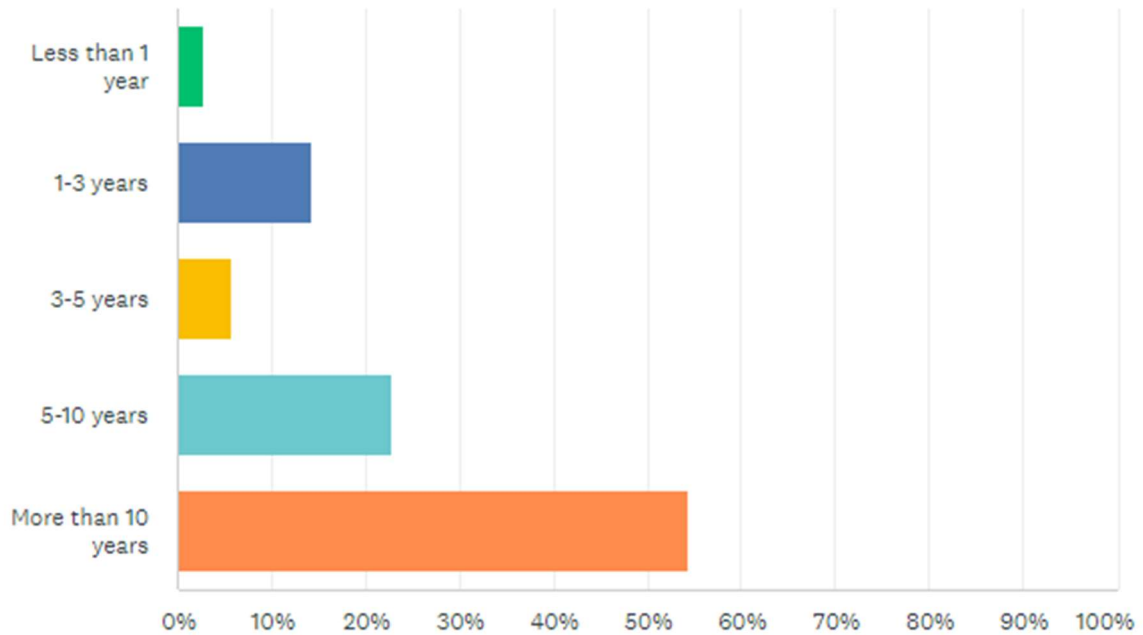
2.1 Participation

- **Total respondents: 37**
- **Countries represented: 15**

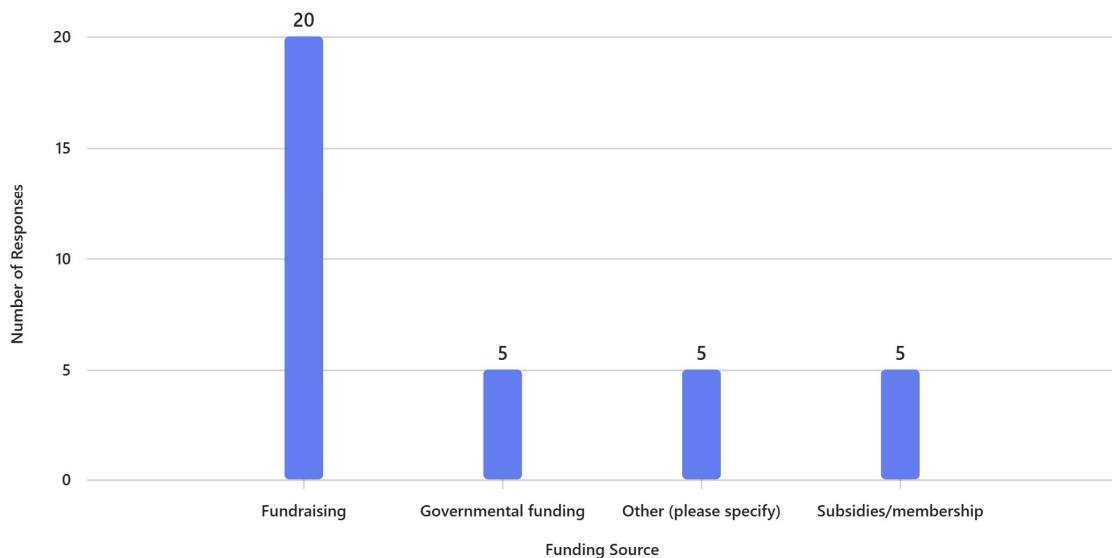
Country	No of responses
Austria	1
Belgium	6
Bosnia and Herzegovina	1
Bulgaria	1
Croatia	2
France	10
Germany	1
Ireland	4
North Macedonia	1
Portugal	1
Serbia	1
Slovenia	1
Switzerland	1
The Netherlands	2
United Kingdom	4

2.2 Organisational Profile

- 23% of organisations are **5–10 years old**; 54% are **over 10 years old**.



- 63% of organisations have **paid employees**.
- Primary funding sources: **fundraising activities**; only **14% receive government funding**.



- **NGOs work with several partners**, mainly with **hospitals, other NGOs, and universities**.
- **Operational scope:**
 - Local – 1
 - Regional – 6
 - National – 27

- European – 1

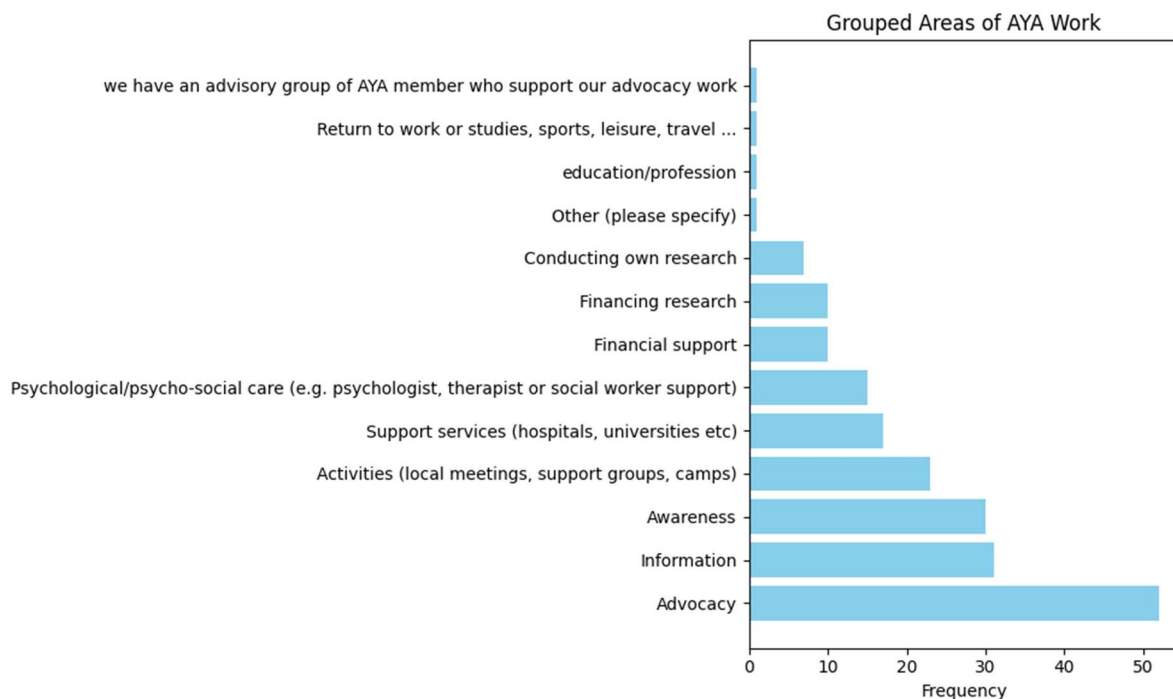
3. Organisational Focus

3.1 Target Population

- NGOs serve a wide **age range (0–39 years)**.
- 62% are aware of other AYA organisations within their country.

3.2 Primary Activity Areas – there are many areas the NGOs work in for AYA’s. The top categories in order are:

- **Advocacy**
- **Information giving**
- **Awareness**
- **Activities (local meetings, support groups)**
- **Support services (hospitals, universities)**
- **Psychological and psychosocial care**



4. Key Areas of Support for AYAs

NGOs address a range of AYA needs, ranked by frequency of focus:

1. Quality of life
2. Communication with peers and family
3. Education and employment reintegration
4. Psychosocial needs
5. Physical rehabilitation
6. Fertility preservation
7. Clinical studies and access to medicines
8. Sexuality and relationships
9. Financial needs
10. Socio-economic discrimination

Duration of support:

- Most organisations assist AYAs during **active treatment** and **follow-up**.
- About **half** provide **palliative care**.
- **Nine** organisations offer **lifelong support**.

Family involvement: Not all organisations work with family members, those that do primarily work with parents, some with siblings and less commonly with partners.

- Parents (23 NGOs)
- Siblings (16 NGOs)
- Partners (8 NGOs)

5. Patient Involvement in NGOs

5.1 Roles and Contributions

Many NGO's have patients who actively participate in their organisation through various roles:

- **Advisory & Strategic Roles:** board and steering group participation.
- **Peer Support:** providing psychosocial and emotional support.
- **Event Organisation:** facilitating support groups, camps, and hospital activities.
- **Advocacy & Awareness:** speaking at conferences, managing media outreach.

- **Content Creation:** storytelling and social media management.
- **Leadership Roles:** volunteers, ambassadors, or staff members.
- **Program Development:** designing transition and empowerment initiatives.

5.2 Common AYA Activities

1. Volunteering and Organizational Work

AYAs often volunteer, help with organizational tasks, and work within the association.

2. Peer-to-Peer Support

Providing emotional support, acting as buddies, and engaging in psychosocial support roles.

3. Event Organization

Organizing and participating in events such as regional support groups, summer camps, and awareness activities.

4. Advisory Roles

Serving on advisory boards, steering groups, and committees for advocacy and strategy.

6. Pressing Issues Identified. The most pressing issues for AYA's within the communities of the NGOs are summarised as:

1. Fertility and Reproductive Health

- Cost of fertility preservation and lack of coverage.
- Concerns about sexuality and reproductive choices.

2. Psychological and Emotional Well-being

- Insecurity, mental health challenges, and post-treatment struggles.
- Isolation exacerbated by the COVID-19 pandemic.

3. Social Reintegration and Quality of Life

- Difficulties re-entering education, work, and social life.
- Importance of peer support and empowerment.

4. Healthcare System Gaps

- Lack of dedicated AYA centers and age-appropriate care.

- Transition challenges between pediatric and adult care.

5. **Financial and Socioeconomic Barriers**

- Financial strain, employment issues, and access to insurance.

6. **Survivorship and Long-Term Care**

- Long-term effects of treatment and difficulty accessing specialists.

7. **Community and Identity**

- Limited recognition of AYAs as a distinct group in some regions.
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7. Organisational Challenges. The NGO's listed the following as the biggest hurdles to achieving the organisations objectives/goals (in order of most common obstacle):

1. Financial Constraints

- Difficulty in **raising enough money** and **generating donations**.
 - Lack of **core funding** and **financial support** for projects and staff.
 - Need for **alternative fundraising strategies**.
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2. Human Resource Challenges

- Heavy reliance on **volunteers** and lack of **professional staff**.
 - Issues with **volunteer time input** and **work overload**.
 - Need for **full-time employment** of active volunteers.
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3. Limited Collaboration and Networking

- Difficulty in **finding other non-profits** for collaboration.
 - Challenges in **building trust with medical teams** to access hospitals.
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4. Impact of COVID-19

- **Social distancing** and isolation reducing engagement.
- Disruption of **association activities** and peer support.

- Need to **relaunch positive dynamics** post-pandemic.
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5. Systemic and Structural Barriers

- **Political situation** and **slow government response**.
 - Extensive **government audits and conditions**.
 - Issues with **national health systems and legislation**.
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6. Awareness and Outreach

- Struggle to **make the association known**.
 - Difficulty in **reaching AYAs in hospitals** and engaging them post-treatment.
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7. Data and Research Gaps

- Lack of **national data on pediatric and AYA cancer**.
 - Limited **dedicated teams** and **psychological support** in many centers.
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8. AYA Empowerment and Governance

- Nearly **50% of NGOs** include AYAs in governance roles:
 - Board members (10)
 - Trustees
 - Vice Presidents
 - Patient Advisory Council members (3)
 - Steering group participants
- **34%** of NGOs provide **training** in advocacy and empowerment for AYAs involved in organisational activities.