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YARN

European Youth Cancer Network

Project number: 101219053



Just as **yarn is made of individual threads woven together**, the European Youth Cancer Network (YARN) connects the voices, stories and strengths of young people across Europe affected by cancer.



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Glossary

- **Beneficiaries:** Organisations that receive EU funding under the Grant Agreement and are responsible for delivering parts of the work plan and reporting to the EU.
- **Associated Partners:** Organisations involved in YARN activities that support delivery and outreach but do not receive EU funding through the Grant Agreement.
- **Affiliated Entity:** An entity with a formal link to a Beneficiary that may carry out tasks and incur costs under the Grant Agreement, according to EU rules.
- **Work Package (WP):** A major ‘block’ of work in the project, grouping activities and outputs under a shared theme (for example mental health, long-term follow-up, EDI).
- **Milestone (MS):** A key achievement point in the project showing that an important step or phase has been completed.
- **Deliverable (D):** A concrete output that must be produced and submitted to the EU, such as a report, guideline, toolkit, curriculum, or resource.
- **Youth Cancer Council (YCC):** A pan-European advisory group of 100 young people with lived experience of cancer that contributes to decision-making, consultation, and co-design across YARN.
- **Peer support:** Support between people with shared lived experience, often through one-to-one or group connections.
- **Peer visits:** Structured visits where partners exchange practice and learn from each other’s approaches, supporting implementation and quality improvement.
- **Certification system:** A structured approach to recognising and encouraging inclusive practice using agreed criteria.
- **Impact study / impact assessment:** An evaluation that looks at what changed because of YARN, such as collaboration, knowledge exchange, and the effects of the Network.
- **Digital platform:** The online hub that hosts multilingual resources and interactive features and supports peer connections (beatcancer.eu).
- **Long-term follow-up (LTFU):** Ongoing care and monitoring after cancer treatment, focused on late effects, wellbeing, and long-term outcomes.
- **Transition of care:** Planned support when moving between services or life stages (for example from paediatric to adult healthcare).
- **Late effects:** Effects that can occur months or years after treatment (physical, psychological, cognitive, or social).
- **Shared decision-making:** A way of making healthcare decisions where people and healthcare professionals work together, using evidence and lived experience preferences.
- **Psychosocial care:** Support for psychological and social needs, including mental health, wellbeing, relationships, and practical life issues.

Abbreviations

- **AYA** – Adolescents and Young Adults
- **CAYA** – Children, Adolescents and Young Adults

- **D** – Deliverable
- **EDI** – Equity, Diversity and Inclusion
- **EU** – European Union
- **EU4Health** – European Union health programme
- **HaDEA** – European Health and Digital Executive Agency
- **LTFU** – Long-term follow-up
- **MS** – Milestone
- **OACCUs** – Optimal Care in Cancer Care Units (predecessor EU project referenced in YARN materials)
- **WP** – Work Package
- **YARN** – European Youth Cancer Network
- **YCC** – Youth Cancer Council

Project Summary

The European Youth Cancer Network (YARN) project focuses on peer support, social networking, and digital tools to improve access to reliable information, particularly for young people facing relapse, metastatic cancer, and treatment side effects. The project also assesses the role of social connections in the emotional well-being of young people affected by cancer.

An impact study evaluates the effects of the EU action grant on Beneficiaries and Partners, with a focus on collaboration, knowledge exchange, and synergies with other EU-funded initiatives.

At the core of YARN is the Youth Cancer Council, a pan-European advisory group made up of 100 young people with lived experience of cancer. The Council plays an active role in decision-making, consultation, and design across the entire project, ensuring that youth voices shape both project outputs and longer-term systems.

Key areas of focus include:

- Peer support and social networking
- Mental health and psychosocial standards
- Education and career reintegration
- Relapse, metastatic cancer, and late effects
- Healthy lifestyles and personalised rehabilitation
- Long-term follow-up and transition of care
- Equality, diversity and inclusion (EDI) in healthcare and patient organisations

YARN specifically delivers:

- Frameworks for EDI certification in healthcare and patient organisations
- Personalised tools for long-term follow-up and end-of-life planning
- Evidence-based standards for mental health and shared decision-making
- Training of both youth advocates and healthcare professionals
- Public awareness campaigns through festivals, media, and influencer engagement

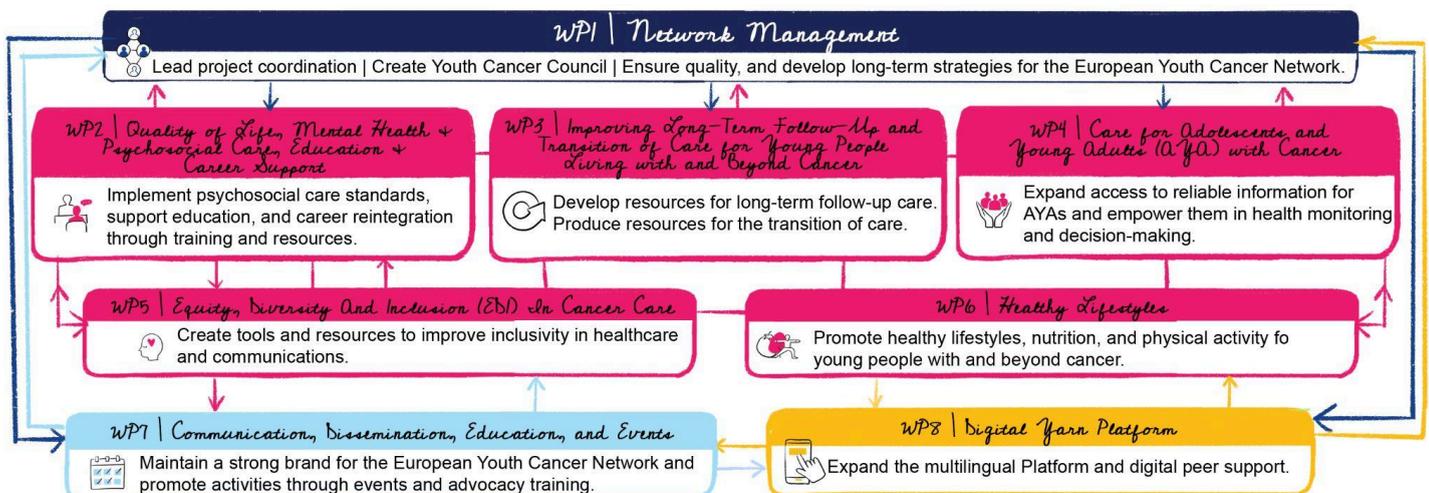
How the work plan is structured

The YARN work plan is organised into eight interconnected Work Packages (WPs) that together deliver the project's objectives.

WP1 focuses on managing and growing the Network and ensuring that the Youth Cancer Council plays a central role in decision-making.

WPs 2 to 6 deliver thematic content: psychosocial and career support (WP2), long-term follow-up and transition of care (WP3), resources on side effects, relapse, and metastatic cancer (WP4), equity, diversity, and inclusion (WP5), and healthy lifestyles (WP6).

WP7 amplifies these outputs through communication, dissemination, education, and advocacy, while WP8 provides the digital platform that hosts resources, supports peer connections, and ensures long-term sustainability.



WP1 – Network Management

WP1 manages and coordinates the project, ensures timely delivery of milestones and deliverables, and guarantees compliance with EU reporting requirements. It sets up and engages the Youth Cancer Council, conducts quality assessments, explores long-term sustainability strategies, and evaluates the impact of the Network and social connections.

Milestones and Deliverables:

- Establishment and operation of the Youth Cancer Council
- Quality assessment framework for the Network
- Sustainability and synergies report for the European Youth Cancer Network
- Impact assessment of the EU Network Action Grant

WP2 – Quality of Life, Mental Health & Psychosocial Care, Education & Career Support

WP2 disseminates and implements the Joint Standard of Psychosocial and Mental Health Care for children, adolescents, and young adults with cancer across Europe, while supporting education and career reintegration.

Milestones and Deliverables:

- Online curriculum for psychosocial and mental health care
- Psychoeducational resources addressing high-demand topics
- Peer visits supporting implementation of the Joint Standard
- Education and career support training programme and evaluation

WP3 – Long-Term Follow-Up and Transition of Care

WP3 develops resources and evidence-based guidelines for long-term follow-up and transition of care, implemented and evaluated in best-practice centres.

Milestones and Deliverables:

- Comprehensive long-term follow-up resources
- Evidence-based guideline on communication and shared decision-making
- Transition of care resources
- Pilot implementation and evaluation report from best-practice centres

WP4 – AYA Cancer Care, Side Effects, Relapse and Metastatic Cancer

WP4 improves access to accurate, multilingual information for adolescents and young adults with cancer, their families, and caregivers.

Milestones and Deliverables:

- Multilingual information resources on treatment side effects
- Resources addressing relapse and metastatic cancer
- AYA Cancer Symposia (Slovenia and Portugal)
- Analysis of synergies with EU Horizon and EU4Health projects

WP5 – Equity, Diversity and Inclusion (EDI) in Cancer Care

WP5 develops tools and resources to enhance inclusivity across healthcare settings, patient organisations, and communication activities, embedding EDI principles across YARN.

Milestones and Deliverables:

- Inclusivity Checklist and Certification System for healthcare settings
- Six online EDI training modules
- EDI Self-Assessment Tool for patient organisations
- Guidelines for inclusive events
- Project-wide Inclusivity Report

WP6 – Healthy Lifestyles

WP6 promotes healthy lifestyles and quality of life through physical activity, nutrition, and mental well-being.

Milestones and Deliverables:

- Standardised protocols for measuring quality of life and physical fitness
- Personalised exercise programmes and recommendation guidelines
- Integration of the OACCU Network Toolbox into the platform
- Six healthy lifestyle workshops
- Healthy Lifestyles Bootcamp

WP7 – Communication, Dissemination, Education and Events

WP7 ensures visibility, dissemination, and policy impact through campaigns, events, and advocacy, while training patient advocates through the ACE Academy.

Milestones and Deliverables:

- Project branding and dissemination plan
- At least three Europe-wide communication campaigns reaching 50 million people
- High-visibility events at congresses and public venues
- ACE Academy training at least 100 patient advocates

WP8 – Digital YARN Platform

WP8 maintains and expands the digital platform beatcancer.eu, hosting multilingual resources and peer-support tools, ensuring accessibility and long-term sustainability.

Milestones and Deliverables:

- Multilingual digital resource library
- Expanded interactive and peer-support features
- Accessibility-focused platform redesign
- Digital sustainability and EU project synergies strategy

Project coordination and contacts

The European Youth Cancer Network (YARN) is coordinated by **Youth Cancer Europe**.

For general information about the project, please contact:

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YARN Project Coordinator

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For questions related specifically to the **Youth Cancer Council**, including participation and activities, please contact:

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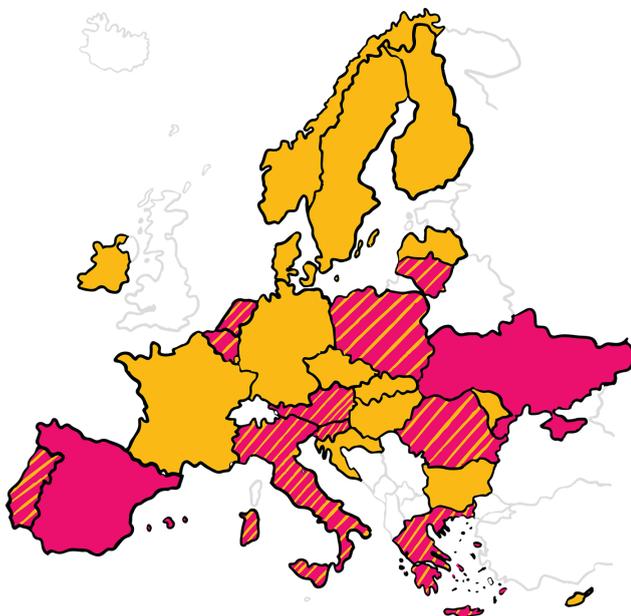
Participating Organisations

Beneficiaries

1. Youth Cancer Europe
2. Childhood Cancer International - Europe
3. Lithuanian Cancer Patient Coalition
4. Centro Internazionale per la Promozione dell'Educazione e lo Sviluppo ETS
5. Portuguese Cancer League
6. University of Cádiz
7. Europa Donna Slovensko Združenje Za Boj Proti Raku Dojk
8. Babeş-Bolyai University
9. European Regional and Local Health Authorities
10. Princess Máxima Center
11. Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer
12. Medical University of Vienna
13. Fundacja na Ratunek Dzieciom z Chorobą Nowotworową
14. Hellenic Cancer Society
15. European Society for Paediatric Oncology
16. European Oncology Nursing Society
17. Inspiration Family Charity Foundation
18. European Cancer Organisation
19. Fundació Privada Per A La Recerca I La Docència Sant Joan De Déu
- 19b. Hospital Sant Joan de Déu (Affiliated Entity)

Associated Partners

- AUSTRIA** • Survivors Österreich - Kinder - Krebs - Überlebenden - Initiative
- BELGIUM** • Kom op tegen Kanker
- BULGARIA** • Foundation Gold
- CROATIA** • Kriješnica - udruga za pomoć djeci i obiteljima suočenim s malignim bolestima
- REPUBLIC OF CYPRUS** • Pagkyprios Syndesmos Karkinopathos Kai Filon 1986
- CZECH REPUBLIC** • Společne k usmevu, z.s.
- DENMARK** • Region Midtjylland
- FINLAND** • Svenska Cancerförbundet
• Suomen Syöpäpotilaiden ry
- FRANCE** • On Est Là
• European Network Of Medical Residents In Public Health
- GERMANY** • Deutsche Leukämie-Forschungshilfe - Aktion für krebskranke Kinder e.V |
- GREECE** • Karkinaki - Enimerosi Gia Ton Karkino Stin Paidiki Kai Efiviki Ilikia
• "Kyttao" Panhellenic Organisation Of Childhood and Adolescent Cancer Survivors
- HUNGARY** • Magyar Gyermekonkológiai Hálózat
• Érintettek Egyesület
- IRELAND** • YouCan Cancer Support Network Ireland
• Childhood Cancer Foundation
• CanTeen Ireland
- ITALY** • Lega Italiana Per La Lotta Contro I Tumori - Sezione Provinciale di Palermo
- LATVIA** • Latvian Association of Oncology Patient Organizations OncoAlliance
- LITHUANIA** • Onkologines Ligos Paliesto Jaunimo Asociacija
- LUXEMBURG** • Survivors Lëtzebuerg
- NETHERLANDS** • Erasmus Universitair Medisch Centrum Rotterdam
- POLAND** • Fundacja Pani Ani - Psychoterapeutyczna Rehabilitacja Dzieci Chorych Onkologicznie
• Marzena Wieczorek-Przybyło M-Powered
• Fundacja Urszuli Smok "Podaruj Życie" Ośrodek Pomocy Osobom z Chorobami Krwi i Nowotworami
• Uniwersytet Medyczny W Lublinie
- PORTUGAL** • ACREDITAR - Associação de pais e amigos de crianças com cancro
• Instituto Portugues De Oncologia De Lisboa Francisco Gentil EPE
• Unidade Local De Saude De Coimbra EPE
- ROMANIA** • Asociația Little People Romania
- SLOVAKIA** • Detom s rakovinou, n. o.
- SLOVENIA** • Foundation Little Knight
- SWEDEN** • Ung Cancer
- REPUBLIC OF MOLDOVA** • Viata Fara Leucemie, Asociatie Obsteasca
• Asociatia Obsteasca Filiala din Republica Moldova a Asociatiei Little People Romania
- NORWAY** • Ung Kreft
• Universitetet i Oslo



 19 Beneficiaries + 1 Affiliated Entity from 11 EU Member States and Ukraine

 39 Associated Partners from 24 EU Member States + Republic of Moldova and Norway

 10 Countries with both Beneficiaries and Associated Partners

