

# European Network of Youth Cancer Survivors

The network of survivors for survivors.

Mag.a Carina Schneider, CCI Europe

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# Über das Projekt



- EU-CAYAS-NET ist ein von Patient-Advocates geleitetes, EUgefördertes Projekt, mit dem Ziel, das European Youth Cancer Survivors Network zu etablieren, eine der Flaggschiff-Initiativen im Europäischen Krebsplan.
- EU-CAYAS-NET vereint führende Organisationen und Institutionen im Bereich der Kinder- und Jungen Erwachsenen Onkologie aus 18 Europäischen Ländern.
- Existierende Ressourcen warden zusammengetragen, um basierend darauf neue Guidelinese, Empfehlungen, Positions-Papiere und Toolkits zu entwickeln, damit Survivors national und international damit für ihre Rechte eintreten und gesundheitspolitische Änderungen anstoßen können.

#### 2 Beneficiaries & Assoziierte Partner



Beneficiaris (& Affiliierte Entitäten)



#### Assoziierte Partner























## Überblick





9 Beneficieris (& Affiliated Entities)















MEDIZINISCHE PINTAIL

Associated Partners

& Inclusion

& Sustainability

#### Selected Outcomes



Standards & Guidelines Psychosocial Follow-Up Care Standard

Transition Guideline



**Ambassadors & Events** 

Ambassadors from 27 MS **National Policy Events** 



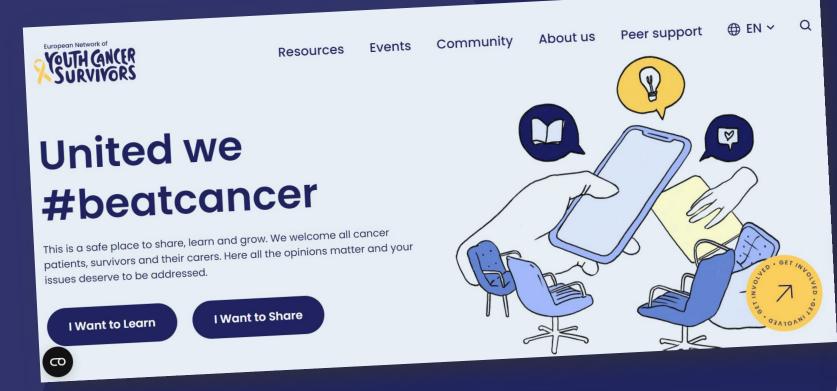
Toolkits & Train-the-Trainer **Education & Career Support EDI** 



**Position Papers** 

Specialist AYA Units Minimum Standard

Importance of LTFU Care





#### 6 Learnings aus der Antragsphase

Patient Involvement

Definieren des Projekts gemeinsam mit Patient:innen Organisationen

Konsortium Set-Up

Breite Erfahrung, breite Involviertheit -> erleichtert Querverbindungen zu laufenden Projekten

Kompakt und:

Weniger ist mehr
-> Dein Zukunfts-Ich wird es dir danken!

 Unbezahlbar: Projekt Management Support  Specific Action Level Indicators, Zielgrößen usw.:

Stimmen Angaben zu Zielgrößen überall überein?

Achtung:

Funding Rate – Special Utility gegeben?

Nix für schwache Nerven:

Die EU4Health Budget-Tabelle

· Reiseplanung:

**Unit Costs** 

### 7 Selected Evaluation Results

The proposal is clearly aligned with the themes and priorities of the Call. The overall objectives are well defined, relevant and well structured.

Multiple EU partners are involved, with several partners representing European - wide organizations with wide reach in terms of patients and Multiple EU partners are involved, with several partners representing European - wide organizations with wide reach in terms of patients and Multiple EU partners are involved, with several partners representing European - wide organizations with wide reach in terms of patients and activities. This provides the proposal with a strong EU dimension. There is clear potential also for non-EU patients/care providers to access the proposed platform and other envisaged results.

The Consortium is very strong and offers relevant expertise in a wide range of disciplines. It includes several very large umbrella organizations combination of complementarities and geographical coverage.

The proposal offers good potential for wide dissemination of results, especially as this is envisaged to be propelled by the AYAs involved in the proposal. However, the proposal does not include a fully developed dissemination strategy. The tasks within WP6 specify that a number of "highly visible public events" will be organized, yet limited quantifiable indicators with specific targets are provided for these events.

The issue of sustainability is discussed in general in the proposal, but the sustainability plan is not fully developed.

#### 8 Sustainability

# Gewisse Eckpunkte im Antrag mitdenken

- Projekt Outcomes so gestalten, dass sie möglichst breit für die Patient:innen-Zielgruppe zugänglich sein werden
- Gibt es andere Projekte mit ähnlichen Zielen?
   Synergien möglich?

#### **Kostengünstige Tools**

- Wartungsaufwand?
- Z. B.- EU-CAYAS-NET Platform: Interacive Hub via integriertem Discord

#### Open Access Publikationen, Lay-Summaries, Nutzung von Multi-Media Tools

- Position Papers, Versorgungsstandards
- Webinars
- Educational Videos
- Train-the-Trainer Programme: Multiplikator:innen

#### Nationale Implementierung mitdenken

- Zusammenarbeit HCPs & Patient Organisations
- Toolkits, Policy Recommendations
- Netzwerkarbeit: Assoziierte Parnter laufend miteinbinden

SURVIVORS

European Network of

SURVIVORS

Danke!





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