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"Specialist AYA Units Minimum Standards" position paper

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"Specialist AYA Units Minimum Standards" position paper

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1 Executive Summary

To meet the goals outlined in Europe's Beating Cancer Plan, which emphasized the specific needs of young individuals dealing with cancer, the EU-CAYAS-NET consortium received funding from the European Union's EU4Health program (grant number 101056918). This project, initiated in September 2022, involves 9 Beneficiaries (& Affiliated Entities) and 28 Associated Partners from 18 countries. The primary objective of EU-CAYAS-NET is to improve the care provided to children, adolescents, and young adults (CAYAs) with cancer by establishing valuable connections among patients, survivors, healthcare professionals, and various stakeholders throughout the European Union. As part of the project's goals, a patient-driven initiative is underway to create recommendations aimed at achieving minimum standards of care across cancer treatment facilities in Europe.

In 2022, over 150,000 young people aged 15-39 were diagnosed with cancer in Europe, yet many face limited access to specialised oncology services, especially outside major urban centres. The EU-CAYAS-NET consortium aims to enhance cancer care for young people by connecting patients, survivors, healthcare professionals, and stakeholders across Europe. This initiative focuses on developing recommendations for uniform care standards to ensure all young cancer patients receive adequate and holistic treatment. This position paper emphasises the need for policymakers and healthcare professionals to prioritise the unique needs of adolescents and young adults (AYA) with cancer.

This document describes the actions that resulted in the "Specialist AYA Units Minimum Standards" position paper, available on the EU-CAYAS-NET Platform.¹

2 Introduction & Background

Work Package (WP) 4 developed the "Specialist AYA Units Minimum Standards" position paper (D4.1) drawing on Peer Visit study reports and roundtable discussions.

The mission behind this deliverable is to actively contribute to the development of good practices for AYA patients with cancer. For this reason, Peer Visits were conducted to identify and share best practice and identify gaps in current practice. During the Peer Visits, the participants were introduced to the local context and successful practices through dynamic forms of peer learning designed to stimulate interaction, collaborative learning and solution-building. Peer Visits resulted in valuable feedback to the host institution and actionable takeaways for peers to support AYA initiatives in their home-countries.

WP4 also contributed to WP2 of the project, which had the objective, 'To develop network Platform content related to the following healthy survivorship themes, which have been identified by survivors and from the literature as priority areas: AYA Care'.

On 08 February 2023, in Brussels, the WP4 Working Group delivered a training event for participants involved in the Peer Visits for WP3 and WP4. A total of 64 individuals attended, representing various roles: participants for Peer Visits (20 for WP3 and 30 for WP4), speakers and facilitators (9 for WP3 and 1 for WP4), and organising team members (2 for WP4 and 2 Observers). A workshop session was held where participants' ideas and contributions were recorded. All suggestions on the draft

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<https://beatcancer.eu/resources/quality-of-life/guidelines/recommendation-and-implementation-roadmap-for-minimum-standards-of-specialist-adolescentand-young-adult-aya-cancer-care-units-position-paper/>

materials for Peer Visit research activities were reviewed, and necessary changes were implemented. Additionally, the Working Group from WP5 contributed by developing the Equality, Diversity, and Inclusion criteria, as well as “Safeguarding and Wellbeing guidelines” for the Peer Visit methodology, with a focus on Participants Inclusion criteria.

3 Approach

3.1 Selection of the WP4 Working Group

Selection of the WP4 Working Group was made based on the needs of expertise fields for each task. The invitation to take part in the Working Group was open to all Beneficiaries and to all Associated Partners. The Working Group had 2 co-leaders and 25 members from 13 countries. The WG had weekly meetings on Zoom. Each member worked on task(s) where they had expertise and wanted to contribute. The tasks were divided into sub-tasks and they were aligned with deadlines mentioned in the internal Gantt chart of the project.

Working group members involved in specific tasks had regular meetings organised by task leaders and agreed upon by group members. Internal communication occurred through email, Slack, and the EU-CAYAS-NET Discord Platform. Working documents were stored in the shared folder on the project shared Drive. Participants of the Working Group employed by Beneficiaries followed their guidelines for tracking their contributions. Associated Partners were welcomed to contribute without additional remuneration.

WP4 was co-lead by Elena Arsenie-Constantinescu (Romania) and Ana Maria Țoțovîă (Romania). The Working Group consisted of Ana-Ecaterina Amărieuței (Romania), Andrea Ruano Flores (Spain), Ania Buchacz (Poland), Begonya Nafria (Spain), Carme Monge-Montero (Netherlands), Colette Ryan (Ireland), Cristina Trifulescu (Romania), Daliana Rodica Vigu (Romania), Elena Torou (Greece), Giorgia Manuzi (Belgium), Hilda Piroska Hajdu (Romania), Katie Rizvi (Hungary), Magdalena Jaworska (Poland), Marius Covaci (Romania), Oriana de Sousa (Portugal), Samira Essiaf (Belgium), Sophia Sleeman (Netherlands), Sonia Silva (Portugal), Tim Van Hoorebeke (Belgium), Tiago Costa (Portugal), Ulrike Leiss (Austria), Urska Kosir (Slovenia), Varduhi Sargsyan (Armenia), Victor Gîrbu (Moldova), Victor Royo (Spain).

3.2 Literature review and Desktop Research

In preparation for the work in WP4, which includes Patient Public Involvement (PPI), qualitative interviews, and a Delphi process, a thorough review of existing academic and grey literature was conducted to gather information and evidence relevant to the services and needs of AYAs. 30 articles were screened and systematically reviewed for information related to AYA care. Based on the extracted information, the Working Group developed an extensive list of relevant items. The resulting Participant Observation Form (POF) was used by members of the PPI groups attending the Peer Visits.

3.3 Peer Visit as Research Method in EU-CAYAS-NET

Starting from M2 and continuing until M6, a thorough search and review of current guidelines and best practices was carried out. The discoveries from this effort proved valuable in formulating the Peer Visit methodology. The Working Group continuously assessed and refined this methodology until the WP4 position paper (D4.1) was finalised and published.

By M6, the methodology for Peer Visits and associated training materials, such as the Peer Visit Training Agenda, draft Peer Observation Form, and Training presentations were created. The

document outlining the methodology, titled "Peer Visit as Research Method in EU-CAYAS-NET", underwent multiple reviews by 13 members actively participating in the WP4 Working Group. Both interim and final versions of the materials were shared on the project shared Drive. Additionally, the methodology group defined participant inclusion criteria and a selection process, giving preference to Network Ambassadors.

3.4 Training for Peer Visit participants

In M6 (February 2023), Youth Cancer Europe (YCE) organised and led a training session 'Peer Visit as a research method in EU-CAYAS-NET' for young cancer survivors and invited representatives of other stakeholder groups identified in WP3 and WP4. The training consisted of a one-day face-to-face meeting, preparing participants for their role as Peer Observers.

For this Peer Visit Training, 116 individuals expressed their interest in participating. From these applications, YCE selected 30 participants specifically for WP4 visits (10 per visit), while WP3 partners chose 20 participants for the WP3 visits on the topic of Quality of Life. The criteria and selection process for participant inclusion were detailed in the document 'Peer Visit as Research Method in EU-CAYAS-NET'.²

During the period from M4 to M6, the following logistical arrangements were made. 48 hotels were contacted, received responses from 34 and the coordinators of the project identified 12 hotels available for the training, and the hotel chosen was in the best location (relative to the hospital, airport), and had the best value for money offer. Preparation of the materials and the development and printing of the surveys, agendas, badges, and other necessary items for the event took place one month ahead of the event. These efforts ensured the smooth preparation and execution of the training sessions, and a detailed agenda can be found in **Appendix 1** and **Appendix 2**. A video about the Training was also created and posted to YouTube.³

3.5 Peer visits in 3 countries to 5 healthcare institutions

The WP4 Peer Visits took place in Italy, Belgium, and the Netherlands, selected for their diverse AYA initiatives. With nearly a decade of experience in developing AYA care, the Netherlands stands as a leading example in Europe. Belgium, as a neighbouring country, began initiatives in 2016 to learn from good practices and incorporate them into its own policies and structures. Italy has recognized AYA care as a priority and is taking initial steps in further development. This range of settings offered us the opportunity to observe AYA care delivery in three different stages: beginner, advanced, and expert.

The success of the Peer Visits was ensured in three well-planned stages:

1. Preparation for the Peer Visits (M2-M8, October 2022 to April 2023)
 - a. Selection of participants (M4-M5, December 2022 to January 2023)
 - b. Training of participants (M6, February 2023)
2. Peer Visits in the countries of the collaborating member institutions (M9-M11, May 2023 to July 2023)
3. Peer Visit feedback and reporting (M9-M13, May 2023 to September 2023)

In March 2023 (M7), the task leaders of WP4 distributed an Expression of Interest form to the WP4 participants of the Peer Visit training. This form was used to gather participants' location preferences

² <https://beatcancer.eu/wp-content/uploads/2024/07/4.2.1.5-Peer-Visit-as-Research-Method.pdf>

³ <https://www.youtube.com/watch?v=oby1YOxrCDc>

for the upcoming Peer Visits. Based on the preferences indicated by the participants, selections were made, and 10 participants were assigned to each of the planned visits in Italy, Belgium, and the Netherlands. WP4 peer visitors were 30 patient representatives from at least 15 Member States (10 patients per visit), including Network Ambassadors described in WP1, as well as healthcare professionals and representatives of other stakeholder groups. The peer reports and knowledge gained during the visits were shared with the network and made available on the Platform and provided the foundation for the Specialist AYA Units Minimum Standards document.

The concept of Peer Visits is rooted in observational and participatory research, where researchers (in our case, members of specific working groups in WP4) were able to observe healthcare professionals and other service providers in their natural environment. Three types of observation were used:

- naturalistic observation where the working group members (called peer visit researchers) observed the environment where the healthcare professionals work,
- participatory observation where the researchers conducted interviews, took notes and photographs, and
- structured observation, where the researchers observed specific aspects about AYA care, long term follow up of late effects and transition from pediatric to adult oncology care, filling in a structured report card (i.e. POF developed as part of the Peer Visit training).

3.5.1 Peer Visit research activities

1. Interactive guided tours at the collaborating institution.
2. One-on-one interviews with healthcare personnel (doctors, nurses, and others), patients, or members of the hospital management team employed open-ended questions.
3. Round table discussions in an 'open space' setting, for easier data-analysis with written output.
4. Focus group discussions based on open-ended questions.
5. External meetings with stakeholders or other non-governmental organisations (NGOs) that support the collaborating institution or AYA care policies.
6. External, informal meeting with local young people living with, and beyond cancer. Safeguarding and wellbeing principles were observed and individual permissions sought before recording any interaction.
7. Feedback and debriefing session.

Following each Peer Visit, participants submitted written reports outlining their learning outcomes based on the POF. Based on the participants' POFs, the final General Report was written by WP4 and Task Leaders. The General Report was shared at the M18 General Assembly, at other meetings of the European Network of Youth Cancer Survivors, with Network Ambassadors and on the Platform.

3.5.2 Peer observation form (POF)

The Peer Observation Form was developed in M4 - M5 (**Appendix 3**). It was completed by Peer Visit participants individually after each visit. A draft of the form was presented at the Peer Visit Training event, and then finalised based on feedback from the training and other internal reviews. In M9, the Peer Observation Form was used on the first Peer Visit in Italy.

3.5.3 Logistics of the Peer Visits

Accommodation, room hire, food, travel, and other logistical arrangements acquisitions and bookings were the responsibility of the WP4 leaders. Arrangements were made according to the needs of the activities and the needs of the participants in the countries where Peer Visits were taking place. The Working Group in collaboration with YCE and CCI Europe, prepared, printed, and branded the Peer Visit materials.

Task leaders started early discussions with host institutions to agree on possible visiting timeframes, as well as secure the support of institutional management. For each Peer Visit there was a dedicated contact person per institution who handled communication between the EU-CAYAS-NET Peer Visit coordinators and the receiving hospital.

3.5.4 Peer Visit Italy

The first Peer Visit was held in Milan, Italy, from 14 – 18 May 2023 (M9). The visit was hosted by Dr. Andrea Ferrari at the Pediatric Oncology Unit of the Istituto Nazionale Tumori. The focus of the visit was on Adolescent and Young Adult (AYA) care. The agenda of the peer visit can be found in **Appendix 4**.

Schedule and Activities can be found here: <https://beatcancer.eu/event/aya-care-peer-visit-milan/>

This visit provided valuable insights into AYA care practices and facilitated the sharing of knowledge and experiences among participants, contributing to the overall goals of the Peer Visits.

3.5.5 Peer Visit Belgium

The second Peer Visit was held in Ghent, Belgium, from 12 – 16 July 2023 (M11). Johan de Munter (Nurse Manager Cancer Center, University Hospital Ghent & Past-President, European Oncology Nursing Society) hosted this visit at Ghent University Hospital. The visit aimed to observe the newly implemented procedures in AYA care and experience cultural activities with AYA survivors. The agenda of the peer visit can be found in **Appendix 5**.

Schedule and Activities can be found here: <https://beatcancer.eu/event/aya-care-peer-visit-ghent/>

This visit provided participants with a comprehensive understanding of the new procedures and support systems in place for AYA care at Ghent University Hospital, as well as the cultural and financial aspects related to AYA patient support.

3.5.6 Peer Visit Netherlands

The third Peer Visit was held in Amsterdam, the Netherlands, from 25 – 29 July 2023 (M11). The visit was hosted by Dr. Eveliene Manten-Horst (director Dutch AYA Carenetwork), and participants visited three hospitals (Radboud University Medical Center, Netherlands Cancer Institute and Noordwest Ziekenhuisgroep) that are part of the National AYA Network. The agenda of the peer visit can be found in **Appendix 6**.

Schedule and Activities can be found here: <https://beatcancer.eu/event/aya-care-peer-visit-amsterdam/>

This visit allowed participants to observe and understand the comprehensive care and support systems for AYA patients across different hospitals in the Netherlands, facilitating knowledge exchange and best practice sharing.

A video about the Peer Visits was posted to YouTube.⁴

⁴ https://www.youtube.com/watch?v=3_-ZyX4j4k

3.6 General Report on the Findings of Peer Visits

The process of drafting the overall report on the WP4 Peer Visits began in M9, following the completion of the first Peer Visit. Researchers from the WP4 Working Group collected data from the Peer Visits, using the Peer Observation Forms completed by participants, throughout the subsequent visits in M11.

The Report drafting and review process was as follows:

- Data Collection:
 - After each Peer Visit, participants completed POFs, which were collected by WP4 Working Group members.
 - Data from all three Peer Visits (Italy, Belgium, and the Netherlands) was collected by the end of M12.
- Draft Report Preparation:
 - Researchers started drafting the overall report on the Peer Visits immediately after the first visit in M9.
 - As the data from the subsequent visits was collected, it was integrated into the draft report.
- Review and Feedback:
 - By the end of M12, a draft report was compiled and shared with all WP4 WG members for their input and feedback.
 - The WP4 WG members reviewed the draft, providing suggestions and additional insights.
- Finalisation:
 - YCE compiled the feedback and integrated the suggestions to finalise the report.
- Dissemination:
 - The completed General Report was presented and disseminated during the EU-CAYAS-NET meetings.
- Network Ambassadors:
 - The report was shared with Network Ambassadors to inform them of the findings and recommendations.
- Platform Accessibility:
 - The report⁵ was made accessible on the Platform by M14 to ensure broad accessibility and transparency.

This comprehensive process ensured that the final report was thorough, well-reviewed, and widely disseminated, providing valuable insights and recommendations from the Peer Visits.

⁵ <https://beatcancer.eu/wp-content/uploads/2023/11/General-Information-AYA-Care-Document.pdf>

3.7 Delphi Process

A modified online Delphi process presented the topics that emerged from the literature review, Peer Visits, and qualitative responses. Two subsequent rounds outlined services and topics, which were rated on the scale of importance (Round 1) and ranked for priority (Round 2). The survey was distributed via consortium channels and mailing lists to the major stakeholders: AYAs and healthcare professionals. The goal was to reach a consensus on what the priorities should be when implementing AYA cancer care in different settings across Europe. This iterative process sought to highlight what patients, survivors and healthcare professionals deem most important and relevant for AYA care, and observe where their respective expert opinions diverged. All the relevant materials are posted on the project OSF page.⁶

3.8 Multistakeholder Online Roundtable on AYA cancer care

The AYA Online Roundtable, held on 11 December 2023 (M16) by SIOP Europe with the support of YCE, served as a platform for discussing key issues pertaining to AYA cancer care. The discussion was led and moderated by Katie Rizvi, executive director of YCE and Prof. Daniel Stark, Professor of Teenage and Young Adult Cancer Research, Leeds Institute of Medical Research. The panel consisted of 14 individuals with lived experience and/or healthcare professionals.

Discussion points included:

1. Financial and Infrastructural Barriers:
 - Identifying financial and infrastructural obstacles hindering the improvement of AYA services.
2. Criteria for Health Policy Decisions:
 - Discussing potential criteria for health policy decisions that Member States could consider to enhance AYA cancer care.
3. Necessary Structures and Key Processes:
 - Identifying essential structures and processes required to bring about positive changes in key outcomes for AYA cancer patients.
4. Measurement of Development:
 - Exploring methods to measure the development of clinical structures, key processes, and core outcomes for AYA cancer patients across Europe.

SIOP Europe compiled a report⁷ summarising the key takeaways and discussions from the AYA Online Roundtable. The report served as a foundation for developing the Position Paper in Task 4.6, outlining key recommendations and strategies to improve AYA cancer care. The insights and recommendations generated from the AYA Online Roundtable, as documented in the final report, will contribute to ongoing efforts aimed at enhancing AYA cancer care policies and practices across Europe.

4 Results

4.1 Key Performance Indicators for WP4

The following Key Performance Indicators were achieved:

⁶ <https://osf.io/k4vdi/>

⁷ <https://beatcancer.eu/resources/quality-of-life/report/minimum-standards-of-care-for-adolescents/>

- 1 AYA – specific working group by M3,
- 50 young cancer survivors from at least 15 countries participating in Peer Visit methodology training (to support Peer Visit activities in WP3 & WP4) by M6,
- 3 separate WP4 peer visits with at least 10 participants per visit (target = 30 from 15 countries) by M11,
- 1 General Report by M12,
- 1 Online Roundtable Meeting by M14, and
- 1 Specialist AYA Units Minimum Standards position paper by M22.

4.2 Specialist AYA Units Minimum Standards Position Paper

Youth cancer survivors from the patient communities of YCE, CCI Europe, and patient representatives of the project's Associated Partners led the development of the Specialist AYA Units Minimum Standards position paper. This effort benefited from the combined expertise of various stakeholders, including healthcare professionals, who provided valuable insights. SIOP Europe, PMC, AMU, and FJD/HSJD all contributed their perspectives.

The Specialist AYA Units Minimum Standards Position Paper⁸ was shared with the network and made accessible on the Platform, during a dedicated online meeting of the EU Network of Youth Cancer Survivors, focusing on AYA care. The Position Paper is also published also on the Platform in 8 languages⁹ and was distributed to all Network Ambassadors. Additionally, the Standards document will be advocated for at the local level through national activities outlined in WP6.

The most important output of WP4 is the recommendations for developing comprehensive AYA Services in Clinical Settings - A Checklist for Minimum Standards of Care, along with an

⁸ Recommendation and Implementation Roadmap for Minimum Standards of Specialist Adolescent and Young Adult (AYA) Cancer Care Units” Position Paper
<https://beatcancer.eu/resources/quality-of-life/guidelines/recommendation-and-implementation-roadmap-for-minimum-standards-of-specialist-adolescentand-young-adult-aya-cancer-care-units-position-paper/>

⁹German:

https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper_German.pdf

French:

https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper_French.pdf

Lithuanian:

https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper_Lithuanian.pdf

Spanish:

https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper_Spanish.pdf

Dutch:

https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper_Dutch.pdf

Italian:

https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper_Italian.pdf

Serbo-Croatian:

https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper_Serbo-Croatian.pdf

Implementation Roadmap.¹⁰ Developing comprehensive AYA services in clinical settings is essential to meet the unique needs of young cancer patients. The checklist provides a guide to establishing minimum standards of care, ensuring a supportive and inclusive environment for AYAs.

Age-Appropriate Built Environment

- ✓ **Environment:** AYA patients should be treated in departments with other patients of similar age.
- ✓ **Social Spaces:** Provide dedicated social spaces for AYAs to spend time with peers and friends.
- ✓ **Connectivity:** Ensure access to computers and Wi-Fi.
- ✓ **Control and Comfort:** Allow AYAs to control and personalise their hospital environment (e.g., bringing their own objects, clothing, and bedding, and controlling the room temperature). Ensure a private closet is available for each patient.

Clinical Care Organisation and Patient Pathways

- ✓ **AYA Multidisciplinary Team:** Establish a team comprising medical oncologists, haematologists, radiation oncologists, surgical oncologists, nurses, social workers, psychologists, and other specialists trained in AYA care. This team should include experts in palliative care, reproductive and sexual health, nutrition, physical therapy, occupational therapy, and mental well-being.
- ✓ **Case Management:** Include a dedicated AYA coordinator to oversee patient care and transitions.
- ✓ **Trained Professionals:** Ensure healthcare professionals are specifically trained and have access to ongoing education to address the unique needs of AYA patients.
- ✓ **Clinical Trials:** Encourage participation in clinical trials and research focused on AYA populations. Provide accessible, easily understood information about clinical trials and facilitate AYA participation in clinical and translational research.
- ✓ **Genetic Counselling:** Integrate genetic testing and counselling into patient care.
- ✓ **Digital Records Access:** Provide unrestricted digital access to patient records.
- ✓ **Second Opinions:** Facilitate access to second opinions for treatment options.
- ✓ **Supportive Care:** Ensure access to palliative care, pain management, and symptom control.

¹⁰

<https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper-2.pdf>

- ✓ **Reproductive Health:** Include fertility specialists in the multidisciplinary team to offer counselling and treatment options for fertility preservation and reproductive planning before, during, and after cancer treatment. Utilise decision-aid tools for fertility preservation and family planning.
- ✓ **Sexual Health:** Provide access to professionals who offer therapy and support for sexual health concerns, changes in sexual function, and intimacy issues.
- ✓ **Mental Wellbeing:** Include specially trained mental health counsellors, psychologists, psychotherapists, and psychiatrists in the multidisciplinary team to provide mental health assessments, psychological support, therapy for patients and their families, and management of psychiatric symptoms during and after cancer treatment.
- ✓ **Nutrition:** Provide access to a certified nutritionist and offer either kitchen facilities or involve patients in hospital menu planning and meal options if a kitchen is unavailable.
- ✓ **Exercise Training and Physical Rehabilitation:** Promote access to physical activity and sport-related activities. Include exercise specialists and physiotherapists or physical therapists who specialise in oncology rehabilitation in the multidisciplinary team.
- ✓ **Late Effects Surveillance and Long-Term Follow-Up Care:** Provide each patient with a survivorship care plan that addresses long-term follow-up, late effects, and ongoing health needs. Ensure a seamless transition to long-term follow-up care.
- ✓ **Facilitated Care Pathways:** Facilitate smooth transitions from paediatric to adult care services. Use technology to enhance communication and coordination of care.

Support Services

- ✓ **Education and Career Support:** Provide support for patients to continue or return to education during and after treatment. Offer career counselling and resources to help patients plan and pursue their professional goals.
- ✓ **Family and Social Support:** Offer support services for families, including counselling and support groups.
- ✓ **Childcare Support:** Provide free childcare for AYA parents attending the clinic for treatment.
- ✓ **Housing Support:** Offer free or low-cost housing on-site or near the hospital.
- ✓ **Transportation Support:** Assist patients with getting reimbursements or free transportation to the treatment site.
- ✓ **Insurance, Finances, and Legal Assistance:** Ensure a dedicated social worker is available to assist with financial and legal issues and provide access to legal assistance.

Make all services and care settings inclusive and accessible

Ensure that all services and care settings prioritise inclusivity and accessibility. This involves offering interpretation and translation services, utilising pictograms, and providing easily understandable information for neurodiverse patients, among other supports. These resources must be readily available without patients needing to request them. Facilities should be designed to accommodate those with limited mobility and consider neurodiversity by including calm and quiet areas. Moreover, inclusive amenities like gender-neutral toilets should be provided, along with a multi-faith prayer or worship area to meet the diverse spiritual needs of all patients. These are just a few examples of how services and care settings can ensure inclusivity and accessibility for everyone they serve.

More information on improving equity, diversity and inclusion in cancer services and providing culturally sensitive care is available from WP5 (Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe, available on the Platform).

This checklist highlights essential items to consider when developing AYA services in clinical settings. Our recommendations provide a roadmap to achieving fully operational and improved care for all AYA units across Europe, ensuring a supportive and inclusive environment for young cancer patients.

5 Impact & Conclusion

Impact of the AYA care activities during the project has been achieved by hosting a webinar to discuss recommendations with 72 participants and 12 speakers (cancer survivors, patient advocates, HCP and stakeholders) from 29 European and outside Europe countries within the AYA cancer care ecosystem. The recommendations and implementation of the Minimum Standards of Specialist AYA Cancer Care Units were shared on a live webinar on Facebook.¹¹ One week later, the webinar was uploaded on YouTube¹² and the Position Paper was published on the Platform,¹³ with translations to additional languages added thereafter. In the closing months of the project, the Position paper will be disseminated on every social media platform of the Project (Facebook, Instagram) and on YCE's website and social media platforms. All the other Beneficiaries will also share AYA care outputs from the project, position paper being available in more than 8 languages. Additionally, the project's reach and engagement have been further amplified through dissemination on Discord. Furthermore, the recommendations will be discussed at the closing event with the participation of 175 cancer survivors, patient advocates, and multiple stakeholders in the AYA cancer care ecosystem from 34 European countries.

The position paper presented in this report resulted from a mixed-method and interdisciplinary approach, integrating insights from Adolescents and Young Adults, healthcare providers, researchers, and other stakeholders. It calls on policymakers, healthcare professionals, and advocacy groups to prioritise the specific needs of AYAs, ensuring they have access to high-quality care that addresses all aspects of their health and well-being. The impact that we hope is to improve the well-being of thousands of young Europeans, fulfilling, among others, the vision of Europe's Beating Cancer Plan.

¹¹ <https://beatcancer.eu/event/webinar-specialist-adolescent-and-young-adults-units-minimum-standard/>

¹² <https://www.youtube.com/watch?v=P-CjOwc9KMo>

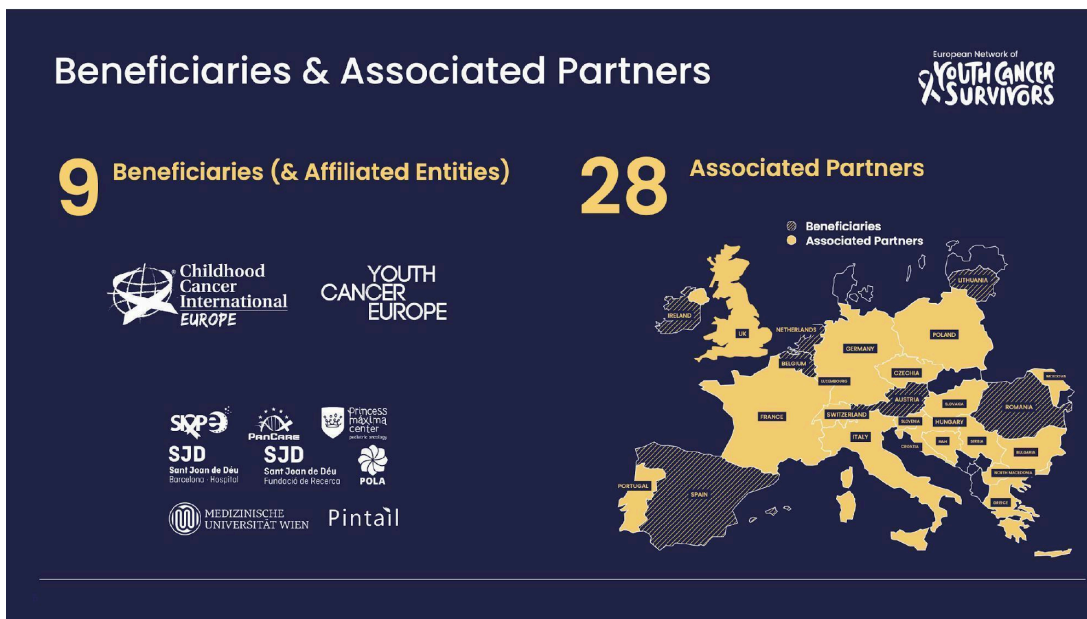
¹³

<https://beatcancer.eu/wp-content/uploads/2024/07/Minimum-Standards-of-Specialist-Adolescent-and-Young-Adult-AYA-Cancer-Care-Units-Position-Paper-2.pdf>

The recommendations for AYA cancer patients have the potential to significantly improve their clinical outcomes, mental health, and quality of life. By addressing the unique needs of this age group, these guidelines can help ensure that AYAs patients receive the holistic and specialised care they require.

6. Appendices

Appendix 1. EU-CAYAS-NET Peer Visit Training, Training Materials



28 Associated Partners

European Network of
YOUTH CANCER SURVIVORS

Project participants

Beneficiaries (BEN)

- Will establish the European Network of Youth Cancer Survivors
- Will work throughout project on implementation of project plan
- Will coordinate events & meetings
- Will produce content, develop & deliver trainings, materials, toolkits etc.
- Will receive dedicated budget in order to implement the project

Associated Partners (AP)

- Can join the Network of Youth Cancer Survivors
- Can participate in and actively contribute to project meetings & events
- Can review and provide feedback
- Can share existing materials
- Will not receive dedicated budget, but participation in some activities will be covered by BEN

The European Network of Youth Cancer Survivors

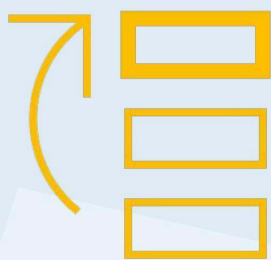
A 24-month project that started in September 2022



To improve the quality of life of children, adolescents and young adults living with & beyond cancer

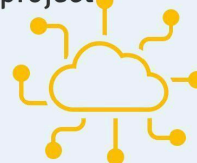


The European Network of Youth Cancer Survivors



by designing and developing a
network Platform

- to facilitate social networking
- provide peer support
- have a virtual co-working space
- repository of relevant content created during the project



The European Network of Youth Cancer Survivors

The project addresses

- ✓ Quality of Life (QoL)
- ✓ Adolescent and Young Adult (AYA) Care
- ✓ Equality, Diversity and Inclusion (EDI)



The European Network of Youth Cancer Survivors

- ✓ Peer visits
- ✓ Meetings
- ✓ Trainings
- ✓ Virtual coworking
- ✓ Social media campaigns
- ✓ Webinars
- ✓ Policy recommendations
- ✓ Policy events
- ✓ National and international networking events



6 Work Packages

1

Management

WPI establishes and manages the EU Network of Youth Cancer Survivors



2

Platform

Knowledge centre, platform for social networking & peer-support; virtual co-working space



3

Quality of life

Focus on late effects and long term follow up, on transition from paediatric to adult care, on education and career support & mental health, psychosocial care



6 Work Packages

4

AYA care

Focus on AYA with cancer as a distinct and specific group, focus on peer visits and peer visit training



5

Equality, diversity & inclusion

Research & policy recommendations, policy event + EDI training toolkit



6

Communication and events

Highly visible network events & sustainability planning



SELECTED OUTCOMES

 **Standards & Guidelines**


- Psychosocial follow-up care standard
- Transition guideline

 **Position Papers**

- **Specialist AYA Units Minimum Standards**
- Importance of LTFU care

 **Toolkits & Train-the-Trainer**

- Education & career support
- **EDI training toolkit**

 **Events**

- Launch Event
- **Peer visits**
- **Peer Visit Training**
- **EDI Training**
- European & National Policy events
- **Closing Event**

European Network of
**YOUTH CANCER
SURVIVORS**

EU-CAYAS-NET

Peer Visit as Research Method

Training event
8 February 2023, Brussels

Why PEER VISITS?

- ✓ LOCAL CONTEXT
- ✓ SHARE BEST PRACTICE
- ✓ PEER LEARNING
- ✓ INTERACTION
- ✓ COLLABORATIVE LEARNING
- ✓ SOLUTION-BUILDING
- ✓ TWO-WAY EXPERIENCE



The concept of PEER VISITS is rooted in **observational** and participatory research

Observational research

- ✓ Observation research is a **qualitative** research technique where researchers observe participants' ongoing behaviour in a natural situation.
- ✓ Sometimes the researcher will **insert themselves** into the environment, and other times, the researcher will **not intervene** in the setting
- ✓ researchers can capture **data** on what participants **do** as opposed to what they **say they do**.



The concept of PEER VISITS is rooted in observational and **participatory** research

Participatory research

- PR can be defined as an **umbrella term** for research designs, methods, and frameworks that use **systematic inquiry in direct collaboration with those affected by the issue being studied for the purpose of action or change** (Cargo & Mercer, 2008)
- PR engages those who are not necessarily trained in research but belong to /or represent the interests of the people who are the focus of the research. (Vaughn, L. M., & Jacquez, F. 2020)

WHO ARE THE RESEARCHERS?

- Participants** selected by the Working Groups of WP3 and WP4



Leading principles:

1. The working groups of WP3 and WP4 will employ **purposive sampling** to assure representation of diverse voices and youth cancer communities. *Equality, Diversity and Inclusion (EDI) principles*
2. To ensure a wide geographic representation, the key performance indicators of EU-CAYAS-NET ask for Peer Visit participants from **at least 15 EU Member States**. [18+4]
3. Priority consideration will be given to **Network Ambassadors** selected in T1.6 [Ambassador Programme] Participation will be entirely voluntary.
4. In WP4 on-site participation in Peer Visits is going to be offered to **young people with lived experience** of cancer. Other stakeholders might join the research activity online if and when appropriate.
5. In WP3 on-site participation is offered to **multiple stakeholders**.

Equality, Diversity and Inclusion (EDI)

Everyone involved in the EU-CAYAS-NET project values Equality, Diversity and Inclusion. The Working Group of Work Packages included in the project will promote a culture of inclusion and an environment that works for everyone. For us to deliver work that is fit-for-purpose, each member will seek to understand the challenges and barriers faced by vulnerable and marginalized cancer patients and survivors in order to eliminate discrimination. We're embedding EDI in every area of work because we recognise the value of diversity of thought, expertise, background and experience. These qualities will be reflected when selecting participants for peer visits in WP3 and WP4.

European Network of Youth Cancer Survivors

WHAT WILL RESEARCHERS DO?

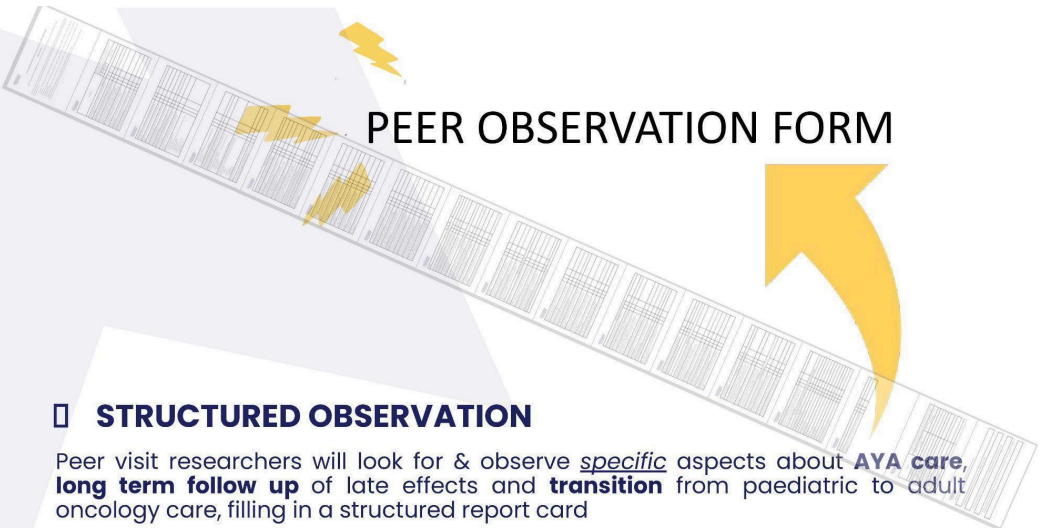
Interact with

- service **users** and
- service **providers**

Observe

- patients
- healthcare professionals
- other service providers
 - in their natural environment*

European Network of Youth Cancer Survivors



PEER OBSERVATION FORM

□ STRUCTURED OBSERVATION

Peer visit researchers will look for & observe *specific* aspects about **AYA care, long term follow up** of late effects and **transition** from paediatric to adult oncology care, filling in a structured report card

European Network of Youth Cancer Survivors

□ NATURALISTIC OBSERVATION

Peer visit researchers will observe the environment where patients receive treatment and where the healthcare professionals are working



□ PARTICIPATORY OBSERVATION

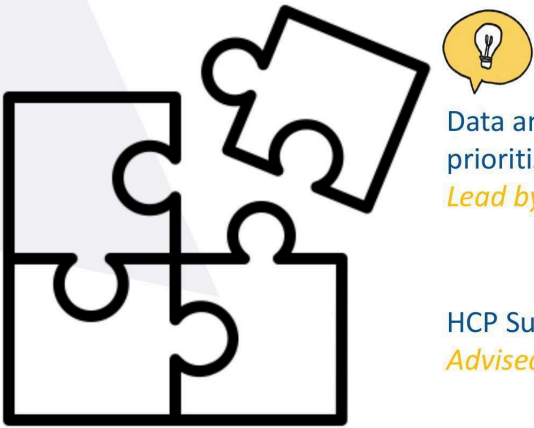
Peer visit researchers will conduct interviews, lead focus groups, ask questions, speak with observed participants, take notes and photographs

□ STRUCTURED OBSERVATION

Peer visit researchers will look for & observe *specific* aspects about **AYA care, long term follow up** of late effects and **transition** from paediatric to adult oncology care, filling in a structured report card

European Network of Youth Cancer Survivors

Research, for the purpose of action



Desktop research
Lead by AYA

Peer visits
Lead by AYA

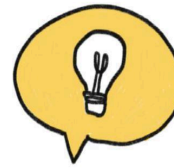
Data analysis and prioritisation
Lead by AYA

HCP Survey
Advised by AYA

European Network of Youth Cancer Survivors

Safeguarding and wellbeing

- We recognise that our work involves and serves those who are part of a vulnerable population: young people diagnosed with cancer. There are many safeguarding procedures already in place as the EU-CAYAS-NET project coordinator and its beneficiaries are organisations that have vast expertise in supporting children and young people diagnosed with cancer. We'll handle safeguarding issues, reports, and disclosures with care and sensitivity, according to **procedures** created by our lead organisations.
- In addition, all research activities directly related to the Peer Visits in WP4 are undergoing further review by the ethical committee at the University of Oxford (R84173/RE001).



European Network of Youth Cancer Survivors

Possible research activities of Peer

Visits

- **Interactive guided tours** at the collaborating institution will allow interaction with various hospital personnel as well as cancer patients receiving care at the visited department – wherever appropriate. Photo and videography permissions as well as consent to be visited will be sought from institutions, as well as individual vulnerable young people, prior to recording any interaction.

DOs	DON'Ts	Safeguarding/Wellbeing
<ul style="list-style-type: none"> • Interact • Ask questions • Smile • Greet people • Follow guide • Be curious • Express appreciation 	<ul style="list-style-type: none"> • Interact • Ask questions • Be intrusive • Enter where you're not invited • Express pity and other unhelpful emotions 	<ul style="list-style-type: none"> • Consideration for the privacy, dignity and expressed preference, including consent (or the lack of it) of visited patients • Consideration of triggers, trauma and resurfacing emotions of peer visit participants • Health and safety considerations [COVID]

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European Network of Youth Cancer Survivors

Possible research activities of Peer

Visits

- **One-on-one interviews** with healthcare personnel (doctors, nurses and other HCP), patients, or members of the hospital management team will employ open-ended questions. The interviews, **if and when appropriate and applicable**, will be audio recorded, informed consent will be sought. Upon agreement, demographic information will also be recorded

DOs	DON'Ts	Safeguarding/Wellbeing
<ul style="list-style-type: none"> • Select interviewers • Use pre-established interview questions • Respect the time for them to talk • Provide feedback of the results • Provide a good environment for the interview 	<ul style="list-style-type: none"> • Interrogate (or express hostility) • Interrupt the speaker • Let your own experience lead the conversation 	<ul style="list-style-type: none"> • Respect the interviewed • Don't push on topics that they are not comfortable to talk • Psychologist in the room • Be flexible and be aware off the feeling of the patients • Provide the interview with the patients in their native language

25

European Network of Youth Cancer Survivors

Possible research activities of Peer

Visits

- **Round table discussions** in an 'open space' setting, for easier data-analysis with written output.

DOs	DON'Ts	Safeguarding/Wellbeing
<ul style="list-style-type: none"> • Prepare the topics of conversation • Add your input • Summarise the discussion 	<ul style="list-style-type: none"> • Have long speeches • Forget the program 	<ul style="list-style-type: none"> • Respect others input • Create a good environment

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Possible research activities of Peer

Visits

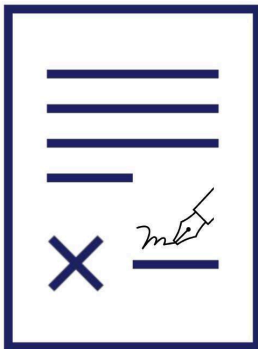
- **Focus group discussions** based on open-ended questions. The focus groups will be audio and video recorded, informed consent will be sought. Upon agreement, demographic and medical information will be recorded (if applicable)

DOs	DON'Ts	Safeguarding/Wellbeing
<ul style="list-style-type: none"> • Select participants • Use pre-established interview questions • Respect the time for them to talk • Provide feedback of the results • Provide a good environment for the interview 	<ul style="list-style-type: none"> • Interrogate (or express hostility) • Interrupt the speaker • Let your own experience lead the conversation 	<ul style="list-style-type: none"> • Respect the interviewed • Don't push on topics that they are not comfortable to talk • Psychologist in the room • Be flexible and be aware off the feeling of the patients • Provide the interview with the patients in their native language

27

European Network of Youth Cancer Survivors

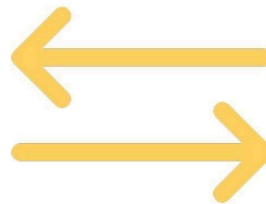
Guiding Principles and Code of Conduct



- ✓ Each peer visit researcher will have to sign it
- ✓ Each WP responsible for the final version that applies to their PV activity
- ✓ Each WP leader organisation ultimately responsible for the peer visit group's activities
- ✓ Individuals can be expelled from peer visit activities for violating the Code of Conduct agreement [Final decision: PV activity task leader(s)]

European Network of Youth Cancer Survivors

What's in it for me?





Why The Netherlands, Belgium and Italy

With almost 10 year experience in the AYA care development The Netherlands is one of the leading examples in Europe.

Belgium as a neighbouring country started initiatives in 2016 to learn about the good practices and integrate them within their own policies and structures.

Italy has identified AYA care as a priority and is taking the first steps in further development.

This variety will provide us the chance to visit 3 countries in three different stages of AYA care delivery: beginner – advanced – expert.



Appendix 2. EU-CAYAS-NET Peer Visit Training, Agenda

EU-CAYAS-NET Peer Visit as Research Method Training Event

February 8th, 2023
NH Collection Brussels Centre,
Boulevard Adolphe Max, 7, Brussels
Room Namur

- 9:30 **EU-CAYAS-NET overview & introductions**
Carina Schneider, Elena Arsenie-Constantinescu, Ana Totovina, Urska Kosir, Katie Rizvi
- 10:00 **Peer Visit as observational research method in EU-CAYAS-NET**
The role of peer visit researchers in EU-CAYAS-NET
Guiding principles and code of conduct for Peer Visits
Katie Rizvi - based on materials produced by the working group of WP4
- 11:00 Coffee break
- 11:20 Group photo
- 11:30 **Reporting Procedures**
Elena Arsenie-Constantinescu, Ana Totovina
- 11:45 **The current European landscape**
National AYA cancer policies and programmes – *Ana Amariutei*
National transition programmes in place – *Jikke Wams*
National LTFU programmes in the EU – *Jeroen te Dorsthorst*
- 12:30 *15 mins buffer*
- 13:00 Lunch in the Rooftop Restaurant
- 14:30 **Breakout session**
Adolescent and Young Adult (AYA) care in oncology – *WP4, Room Namur*
Transition from paediatric to adult services & long term follow up –
WP3, Room Charleroi
- 16:00 Coffee Break
- 16:30 **Breakout session continued**
- 18:00 **Regroup Room Namur. Close of training event**
- 19:30 *Dinner in restaurant La Rose Blanche (address: Grand Place 11)*



Co-funded by the European Union (Grant Agreement No. 101056918). Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or EU4Health. Neither the European Union nor the granting authority can be held responsible for them.



Appendix 3. EU-CAYAS-NET Peer Visit Training, Final POF

European Network of Youth Cancer Survivors (EU-CAYAS-NET)

PEER VISITS

Peer Observation Form - DRAFT (example for the AYA Care topic. Separate forms to be developed for each topic)

This form is meant to be used to guide conversations, to help formulate questions and to provide a structure for recording observations during peer visits to oncology centres serving AYA patients across Europe. Answers might be gathered through various activities during peer visits, such as:

- Interactive guided tours at the collaborating institution (allowing interaction between patients, healthcare professionals and peer observers)
- One-on-one interviews with healthcare personnel (doctors, nurses and other HCPs), patients, or members of the hospital management team
- Single-session focus group led by WP4 researchers with AYA patients in the host institution (for other work packages: focus groups in general)
- External meetings with stakeholders or other NGOs that support the collaborating institution
- External, informal meetings with local young people living with and beyond cancer who were treated in the visited institution



Observation Questions

1. Built environment	2
2. Multidisciplinary team, patient pathways	7
3. Genetic counselling	9
4. Research and clinical trials	9
5. Nutrition and exercise training	10
6. Fertility and sexual health	11
7. Mental health & psychosocial support	12
8. School and job	14

Interview Questions

1. Built environment	15
2. Multidisciplinary team, patient pathways	17
3. Genetic counselling	22
4. Research and clinical trials	22
5. Nutrition and exercise training	25
6. Fertility and sexual health	26
7. Mental health & psychosocial support	27
8. School and job	29
9. Insurance, finances and legal assistance	31
10. Housing and transport	32

Abbreviations:

1. AYA - Adolescent and Young Adult
2. HCP- HealthCare Provider
3. NGO- Non-Governmental

Observation Questions	Please answer whether the service is available (or if the activity takes place) at the institution you are visiting: YES or NO. If something is partially provided or it is unclear whether it is provided please mark it in the third column. Please mark your observations in the last column. If something is not applicable, please note under the Observation section.			Observations
	Yes	No	Partially /unclear	
Built environment				
1. Are AYA patients provided with dedicated, AYA-specific inpatient and day-care facilities (like TV room, gym, game room)? Please add examples of the day-care facilities you can observe, in the Observation column.				
2. Are AYA patients sharing the space with other patients of similar age?				
3. Does the clinic provide specific AYA access to a private room or area where AYA patients and their carers (and/or healthcare providers, including for eg. mental health professionals) can talk in conditions of adequate privacy?				

2

	Yes	No	Partially /unclear	Observations
4. Are there gender neutral toilets available (other than gender neutral disabled toilets)?				
5. Are there designated areas for prayer and worship appropriate for all religions?				
6. Do AYA cancer patients have access to computer resources, TV and games, and unlimited internet?				
7. Do AYA patients or their carers have access to facilities where they can prepare and cook food?				
8. Were young people generally involved in creating the hospital's food and menu choices?				
9. Do AYA patients have access to a space that combines and balances the clinical area with a homely zone that promotes choice, control and privacy? Please add a detailed answer in the Observation column.				

3

	Yes	No	Partially /unclear	Observations
<p>10. Do AYA patients have access to:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Private bathrooms <input type="checkbox"/> Private bedrooms same sex / gender accommodation / rooms with soundproof walls <input type="checkbox"/> Temperature control <input type="checkbox"/> Lighting control <input type="checkbox"/> Visitor's bed <input type="checkbox"/> Therapy area <input type="checkbox"/> Careers and patients lounge <input type="checkbox"/> Personal closet space <input type="checkbox"/> Large windows that facilitate connection between patient and the outside world <input type="checkbox"/> Accessible outside / garden space? <p>Please check the box and give a more detailed answer in the Observation column, if needed.</p>				
<p>11. Is the AYA environment open to friends and family visiting?</p> <p>12. Is the culture welcoming and warm?</p>				
<p>13. Does the AYA clinic provide activities that allow patients to reduce boredom and engage with each other?</p>				

4

	Yes	No	Partially /unclear	Observations
<p>14. Are AYA patients able to personalise their environment / private rooms to create a preferred space?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Ability to bring in personal objects - photograph frames / personal objects on shelves <input type="checkbox"/> Use own bedding <input type="checkbox"/> Boards to place cards / personal messages <p>Please check the box and give a more detailed answer in the Observation column, if needed.</p>				
<p>15. Overall, does the AYA clinic / department accommodate the AYA specific needs and lifestyles of different AYA patients promoting key benefits such as the following?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Control <input type="checkbox"/> Comfort <input type="checkbox"/> Stimulation <input type="checkbox"/> Personalisation <input type="checkbox"/> Connectedness <p>Please check the box and give a more detailed answer in the Observation column, if needed.</p>				

5

	Yes	No	Partially /unclear	Observations
16. Is the clinical space accessible to those with mobility related disabilities (eg. step free)?				
17. Is there an accessible toilet and are the facilities within it up to the correct standard (eg. does the emergency cord reach the floor)?				

6

Multidisciplinary team, patient pathways				
	Yes	No	Partially /unclear	Observations
1. Is there an on-site, dedicated, age-appropriate facility for end-of-life care, ensuring the AYA patient's comfort and dignity?				
2. Does the clinic have language support services, such as interpretation or translation, available for AYA patients who are non-native speakers of the predominant language?				
3. Does the clinic have AYA physician champions / named physicians that work in each specialty area to align their team's practice and processes with the specific needs of AYA?				
4. Do AYA cancer patients have access to age-based unmet needs screening and psychological assessment measures?				

7



	Yes	No	Partially /unclear	Observations
5. Is the clinic collaborating with regional and national AYA cancer organisations?				
6. Did you as an AYA patient have the option to choose where to be treated - were you able to have both specialist services for your cancer and AYA services available?				

8



Genetic counselling				
	Yes	No	Partially /unclear	Observations
1. Do AYA cancer patients have access to genetic counselling if required?				
2. Do AYA cancer patients have access to genetic testing within the clinic?				

Clinical trials				
	Yes	No	Partially /unclear	Observations
1. Are AYA cancer patients aware / informed of clinical trials?				
2. Are they offered the opportunity to access appropriate clinical trials, or are any AYA patients within the hospital participants in clinical trials?				

9

Nutrition and exercise training				
	Yes	No	Partially /unclear	Observations
1. Are the meals of the patients properly adjusted to their need for food?				
2. Do the patients have access to a nutritionist, if they need it?				
3. Do AYA patients have access to sport-related activities such as physical exercise, including yoga and/or breathing exercises?				
4. Are HCPs able to provide information on age-tailored exercise and sport classes?				
5. Is physiotherapy or/and holistic approaches support available?				

10

Fertility and sexual health				
	Yes	No	Partially /unclear	Observations
1. Within the AYA clinic / department are there fertility and sexual health specialists available on site?				
2. If services are not available on site, are patients able to access external fertility counselling and is this process streamlined?				
3. Are AYA patients provided with access to sexual health specialists who can provide counsel on intimacy and sexuality after diagnosis?				

11

Mental health & psychosocial support				
	Yes	No	Partially /unclear	Observations
1. Do AYA cancer patients have access to on-site or online psychological counselling and / or psychotherapy?				
2. Do AYA cancer carers have access to on-site or online psychological counselling and / or psychotherapy?				
3. Is there a dedicated, AYA coordinator for psycho-social support services? Please add a detailed answer in the Observation column, if it is an NGO embedded or a hospital psych department.				
4. Is the clinic providing AYA patients with assessments that evaluate social and cognitive functioning, as well as health-literacy?				
5. Are AYA provided with screening tools and regular assessments that allow for rapid and timely mental health and social support interventions?				

12

	Yes	No	Partially /unclear	Observations
6. Do AYA patients have access to peer support through organised meetings within the clinic?				
7. Are AYA patients able to attend informal meetings and activities that reduce their feeling of isolation?				
8. Does the clinic provide childcare for AYA outpatients with children?				
9. Does this clinic have peer-navigators for AYA patients?				

13

School and job				
	Yes	No	Partially /unclear	Observations
1. Is there a dedicated support program or coordinator within the clinic to assist AYA patients with education and employment related needs?				
2. Are AYA patients provided with assistance in completing education and/or gaining employment?				

14

Interview Questions	Please answer with detailed observation We encourage you to add as many details as you can.
	Answer
Built environment	
1. What AYA ages is the clinic providing care for? Please note the age range.	
2. How do doctors approach communication with AYA patients considering their age?	
3. Are AYA patients able to access clinical spaces associated with their gender identity rather than their sex registered at birth if they wish?	
4. Are AYA patients allowed romantic partners visiting or staying overnight as carers? Including diverse relationships such as LGBTQI+, interracial, cross-religious, etc	

15



5. If food is provided, are there options to accommodate those with dietary restrictions (eg. religious or allergy)?	
6. How were young people involved in the hospital's food and menu choices?	
7. How were AYA patients / survivors involved in designing the AYA department / space?	
8. Is any artwork within the clinic selected for the AYA population and was it chosen by AYA cancer patients?	
9. Are AYA patients able to snack and access foods when they wish?	

16



Multidisciplinary team, patient pathways	
1. Do AYA patients have access to multidisciplinary care provided by an extended group of AYA specialists bringing together expertise in paediatric and in adult cancer care?	
2. Do HCPs have accreditation in the specific skills (or other documented training) required for working with the AYA population?	
3. Are AYA specialists attending ongoing training and educational opportunities as specialist AYA professionals?	
4. Are AYA patients provided with onsite pain-management, symptom-management and non-curative care services that are age specific and are available 24/7?	

17



5. Does the clinic / department have a system of regular outcomes measurement in place to evaluate the care provided to the AYA cancer patients? / Is the AYA cancer care programme assessed by others to identify ways to improve?	
6. Are HCPs trained in LGBTIQ+ awareness and supportive care?	
7. Are HCPs trained in ethnicity and cultural awareness & supportive care?	
8. Are HCPs trained in disability (incl. neurodiversity) awareness & supportive care?	
9. Are AYA HCPs trained for the optimal delivery of cancer care and are they trained for direct patient contact specifically relating to age-appropriate communication?	
10. Are AYA HCPs having regular meetings set in place in order to ensure all the cases are discussed and updated accordingly?	
11. Are young people with lived experience invited to the Ethical Board of the hospital / clinic?	

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12. Are there other ways AYA patients / AYA cancer survivors can contribute to and give feedback on the clinical work of the hospital and the management of the clinic?	
13. Are AYA patients and survivors feeling welcome and able to contribute with their voice to help make the services and research right for their community?	
14. Are clinical teams managing the care pathway of AYA patients connecting regularly with youth organisations in order to receive support and guidance?	
15. Is the clinical service collaborating with regional and national AYA cancer organisations, or other NGOs? Please add some examples of organisations or NGOs in the Observation column.	
16. Are AYA patients provided with continuity of care? How are they prepared for transition to adult services and any life-long survivors' care?	
17. Are transition programmes put in place in order for childhood patients to transition to AYA or adult services?	

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<p>18. How are AYA cancer patients provided with a treatment and care summary after their treatment is complete? Is it electronic? Is it available to all AYA? When is it available by (how long after treatment ends)?</p>	
<p>19. Who has access to the treatment summary record and how? Is this electronically available in order for it to be stored, maintained, accessible and updated when needed?</p>	
<p>20. Is there a Long Term Follow Up service within the hospital after cancer? Is it adapted to AYA patients'?</p>	
<p>21. How is communication maintained between departments for those patients with comorbidities/ under the care of other non-oncological services? Including patients under the care of mental health pathways.</p>	
<p>22. What services are in place for transgender patients receiving gender affirming hormone therapies?</p>	

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<p>23. Which written resources are available for AYA patients from diverse backgrounds (such as LGBTIQ+ and refugee populations, racial, ethnic or religious minorities?) What work is done to optimise their cultural sensitivity?</p>	
<p>24. How are AYA patients from refugee or migrant populations given information about their rights and access to healthcare services, including those available through government or non-government organisations?</p>	
<p>25. Is the clinic collaborating with community organisations, advocacy groups, and other relevant stakeholders to ensure that the needs of AYA patients from refugee or migrant populations are met and addressed in a holistic manner?</p>	

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Genetic counselling	
1. Are the costs for genetic testing covered by the clinic or reimbursed by the state?	
2. Are AYA patients and their families provided with information and support in making informed decisions about treatment options after genetic testing (if indicated)?	

Research and clinical trials	
1. How are AYA cancer patients informed of clinical trials. How are they supported to access appropriate clinical trials in other services?	
2. How many AYA patients are seen each year in the clinical service? How many AYA are participants in clinical trials in any one year?	

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3. Can you describe the portfolio of clinical trials accessible in this cancer service? Is it inclusive of each of the more common AYA cancer types?	
4. How many trials have age-restricted entry criteria that do not include all AYA? Which national or international clinical trial groups is the centre formally affiliated with?	
5. Which national or international clinical trial groups is the centre formally affiliated with?	
6. Are HCPs within the clinic carrying out their own research (as chief or principal investigator) that contributes knowledge relevant for the AYA population? Have they published work recently within the service, in the peer-reviewed medical literature?	
7. Is the clinic collecting data related to AYA experience and treatment outcomes?	
8. Are the researchers supporting or coordinating the collection, utilisation, and analyses of biospecimens with the purpose of improving AYA medical care and biological knowledge?	

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9. Is the AYA cancer research programme within the clinic banking data for translational research to aid in the progress of knowledge of the AYA population?	
10. Is the community of HCPs and researchers aware and actively participating in multi-site international research to further develop evidence-based practice for AYAs?	
11. Are the HCPs within the clinic raising awareness regarding the need to increase participation of AYAs in clinical trials?	
12. Is the clinic providing lay language information about the potential benefits and risks of participating in clinical trials to AYA patients?	



Nutrition and exercise training	
1. How are HCPs providing nutritional advice that is tailored to AYA cancer patients?	
2. If dietary advice cannot be provided within the AYA clinic are patients able to receive dietary and nutrition counselling outside of the department? Is this process streamlined?	
3. If HCPs are not able to provide this within the multidisciplinary team – is there a service through which patients can be signposted to physical health professionals and programmes?	

Fertility and sexual health	
1. How are AYA cancer patients made aware of fertility risks and fertility preservation options? Is fertility and fertility preservation discussed with every single AYA patient?	
2. What is the cash cost of fertility counselling for an AYA patient?	
3. Are HCPs or the clinic collaborating with advocacy groups to increase government support for fertility preservation / assisted fertility options for fertility-impaired long-term cancer survivors?	
4. Are fertility specialist and sexual health specialist consultations available for young people <i>after</i> their treatment is finished and are these services free for them?	
5. Are HCPs discussing sex and fertility preservation with AYA who are identified as LGBTIQ+?	

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6. Are HCPs discussing sex and fertility preservation with AYA who are identified as having a disability, including learning disabilities?	
7. Are HCPs discussing sex and fertility preservation with AYA from all ethnicities and cultures?	

Mental health & psychosocial support	
1. Is the clinic providing AYA patients with assessments that evaluate social and cognitive functioning, as well as health-literacy?	
2. Are AYA provided with screening tools and regular assessments that allow for rapid and timely mental health and social support interventions?	
3. Do AYA cancer patients and carers have access to on-site or online psychological counselling and / or psychotherapy?	

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<p>4. Is <i>specialist</i> mental health support available for AYA patients, including also those from minority communities (eg. LGBTQ+, disabled, ethnically diverse, migrant and refugee populations)? Please state which options are available and if they vary in frequency or barriers to entry when compared to mainstream support (eg. time of day and cost).</p>	
<p>5. Upon treatment completion are young people provided with rehabilitation services that address physical, psychosocial, occupational and educational aspects?</p>	
<p>6. Are AYA patients able to discuss and able to access programmes that help them manage body image issues encountered after treatment?</p>	

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School and job	
<p>1. Are AYA patients screened for support needs in education or employment?</p>	
<p>2. Are the patients screened at different stages, such as:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Diagnosis <input type="checkbox"/> During treatment, <input type="checkbox"/> End of definitive treatment, <input type="checkbox"/> During LTFU, <input type="checkbox"/> Relapse <p>Please check the box and give a more detailed answer in the Answer column, if needed.</p>	
<p>3. Are HCPs or social workers liaising with teachers, tutors, and educational institutions to ensure education can continue whilst undergoing treatment?</p>	
<p>4. Are HCPs assisting AYAs in arranging special considerations for exams & assessed work?</p>	

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5. Are HCPs assisting AYAs in recognising and requesting reasonable adjustments they're entitled to in the workplace?	
6. Are HCPs or support / psychosocial workers within the clinic trained in advising and assisting AYA patients in navigating the complexities of educational and employment laws, policies, and support systems?	
7. Are AYA patients sign-posted to specific support services for educational and vocational support?	

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Insurance, finances and legal assistance	
1. Are AYA patients (including those from refugee, migrant and minority populations) provided with support for navigating complex and potentially unfamiliar healthcare systems, including information about insurance, costs, and billing, financial aid and available government support as well as their rights and legal matters?	
2. Are AYA patients sign-posted to specific support services for financial & legal support?	
3. Does the clinic have measures in place to ensure that the data collected from AYA patients is kept confidential and protected in accordance with ethical and legal guidelines? (Including basic data such as names, phone numbers or photos of patients that might sometimes be overlooked?)	

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Housing and transport	
1. Are AYA patients assessed by their HCPs on whether they would still be able to live independently or not during / after cancer treatment?	
2. Are support workers within the AYA clinic / department ensuring that patients do not have financial issues that prevent them from keeping their accommodation?	
3. Do AYA have access to financial assistance for covering transportation costs? (Does this include outpatients as well?)	
4. Are HCPs and support workers within the AYA clinic trained to understand and address any possible unique housing and transportation needs of refugee and migrant populations?	
5. Are AYA provided with relevant information if their diagnosis or treatment will impact their current housing needs (for ex need for grab rails, ramps, etc) and if local councils provide support for that and/or if government support is available for such needs?	

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Does this clinic provide written resources for AYA patients on the following topics				
	Yes	No	Partially /unclear	Observations
Stress management and mental health support				
Relationships and family dynamics				
How to talk about their cancer diagnosis				
Available peer support				
Continued education				
Managing work				
Smoking				
Alcohol consumption				
Drug awareness				

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Nutrition				
Fertility, sexuality and sexual health				
Physical exercise during and after cancer treatment				
Legal support				
Financial aid				
Tumour - and treatment specific, plain language information about disease management				
Are the resources age-appropriate and especially designed for the care of AYAs?				
Do you have a place where the resources and data shared are stored, and how?				
Are there other information leaflets tailored to AYA needs?				

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Category	Please note here if different participants had different responses to the items assessed above, especially if the different participants' perspectives were notably contrary.	
	Healthcare personnel / Healthcare institution	AYA patients / AYA advocacy or peer support group
Built environment		
Multidisciplinary team, patient pathways		
Genetic counselling		
Research and clinical trials		
Fertility and sexual health		
Mental health & psychosocial support		
School and job		
Insurance, finances, and legal assistance		
Housing and transport		
Written resources		

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1. What are some particular strengths of AYA Care in the institution you visited?

2. What are the particular weaknesses of AYA Care (if any) in the institution you visited?

3. What overall impressions do you have about AYA Care in the collaborating institution/ country after this peer visit?

4. Are there any specifics you've learned on this peer visit that you think you could advocate for, or any learnings you could pass on to decision-makers in your home-country?

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Here are five questions about your personal experience as a patient. They are not mandatory to be completed, but it will help us for the conclusion of the Peer Visit.

1. Can you identify and briefly describe, from a patients' perspective, factors that help as well as hinder young people's abilities to cope with cancer, the treatment, and all of the associated challenges?

2. Can you identify and briefly describe components of cancer resources that young patients would find most relevant and useful?

3. In thinking of the resources that you listed above, at what point during the illness would they be most useful (e.g. psychological support at the time of diagnosis)?

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4. What are some of the things you have learned about the healthcare system and navigating it during your cancer care?

5. How do you perceive the use of technology in your care, and why?

Appendix 4. EU-CAYAS-NET Peer Visit in Milan, Agenda

Air Hotel Milano Linate, Via Francesco Baracca, 2, Milano
Istituto Nazionale dei Tumori, Via Giacomo Venezian, 1, Milano

EU-CAYAS-NET Peer Visit in Milan, Italy May 14-18, 2023

SUNDAY 14

19:00 **Networking Dinner** (*Via Francesco Baracca, 2*)

MONDAY 15

10:00 **Welcome to Istituto Nazionale dei Tumori (INT)**

Meeting with Massimo at the entrance of INT (*Via Giacomo Venezian, 1*)

10:30 **AYA Care in Italy, Milan (INT, The Youth Project, National and International programs, Psychosocial support, Spirituality)**

Meeting with Dr. Andrea Ferrari, youth project staff, and a group of patients in Room F floor -1 (*Via Giacomo Venezian, 1*)

13:00 **Lunch** (*La Mongolfiera, Via Giovanni da Milano, 4*)

14:30 **Guided tour of the paediatric department** (*Via Giacomo Venezian, 1*)

15:30 **Fertility prevention and ART in AYA with cancer**

Room F floor -1 (*Via Giacomo Venezian, 1*)

19:00 **Networking Dinner** (*Viaggi Nel Gusto, Via Edmondo de Amicis*)



TUESDAY 16

10:00 **Second PV day – Opening**

Meeting with Massimo at the entrance of INT (*Via Giacomo Venezian, 1*)

10:30 **AYA Epidemiology, Genetics and CT Participation**

Room F floor -1 (*Via Giacomo Venezian, 1*)

13:00 **Lunch** (*Route 66 American Diner, Viale Romagna, 23*)

14:30 **Sport programs for AYA and guided tour of the sport and recovery area** (*Via Giacomo Venezian, 1*)

15:30 **Visit the outpatient service** (*Via Giacomo Venezian, 1*)

19:00 **Networking Dinner** (*Le Jardin au Bord du Lac, Via Circonvallazione Idroscalo, 51*)

WEDNESDAY 17

9:00 **Fertility and Procreation for AYA**

Meeting with Fedro Alessandro Peccatori, Director of the Fertility and Procreation Unit within the Division of Gynecologic Oncology at the European Institute of Oncology (*Via Beatrice D'Este, 37*)




12:00 **Breast Cancer in AYA**

Meeting with Marzia Zambon, Executive Director of EUROPA DONNA – The European Breast Cancer Coalition (*Piazza Amendola, 3*)

15:00 **Lunch** (*Roadhouse Meatery, Piazza Tre Torri c/o*)

16:30 **Filling in the Peer Observation Form** (*Via Francesco Baracca, 2*)

20:00 **Networking Dinner** (*Pino in Duomo, Via Silvio Pellico, 4*)

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European Network of
YOUTH CANCER SURVIVORS



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Appendix 5 .EU-CAYAS-NET Peer Visit in Ghent, Agenda

AGENDA

EU-CAYAS-NET – Peer visit Ghent, Belgium

Ghent University Hospital - Corneel Heymanslaan 10, 9000 Gent

Wednesday, July 12th

18:30 - 19:00 Welcome and Registration at [Residence Inn by Marriott Ghent](#)

19:00 - Networking Dinner at the hotel

Thursday, July 13th

06:30– 9:00 Breakfast at [Residence Inn by Marriott Ghent](#)

09:30 – 09 :45 Meeting and Welcome at [Ghent University Hospital](#)

09:45 – 10:30 Introduction meeting EU-CAYAS-NET (room Hoof)

10:30 – 11:30 Guided tour in UZ Ghent AYA care – part 1 (**AYA spaces / wellness area**)

11:30 – 11:45 Coffee/tea break

11:50 – 12:15 Meeting with national stakeholder “Stichting tegen Kanker”

12:15 – 12:30 Guided tour in UZ Ghent AYA care – part 2 (**Revalidation service**)

12:30 – 13:30 Lunch in the catering building

13:30 – 14:30 Guided tour in UZ Ghent AYA care – part 3 (**De Lieving**)

14:30 – 15:30 Focus group(s)/round table/interviews AYA care experts

15:30 – 16:15 Guided tour in UZ Ghent part 4 (**Haematology / Den Allée**)

16:15 – 16:45 Meeting with national stakeholder “Kom op Tegen Kanker”

16:45 – 17:00 Meeting with Medical coordinator UZ Ghent cancer center

17:00 – Closing

19:00 – Networking Dinner at [De Rechters](#)

Friday, July 14th

06:30 – 8:45 Breakfast at [Residence Inn by Marriott Ghent](#)

09:00 – 10:30 Welcome & visit [Het Majin Huis](#)

10:30 – 10:45 Coffee/tea break

10:45 – 12:00 Focus group(s)/round table/interviews AYA care intern/extern stakeholders

12:00 – 12:30 Transport break

12:30 – 13 :30 Lunch in Restaurant “de Slechtvalk” UZ Ghent

13:30 – 14:30 Meeting with Fertility service (meeting room Elaut, entrance 71, Route 723)

14:30 – 15:00 Coffee/tea break

15:00 – 16:20 Closing meeting EU-CAYAS-NET & farewell

19:00 – Networking Dinner at [Feestzaal Madonna](#)

Saturday, July 15th

07:00 – 09:00 Breakfast at [Residence Inn by Marriott Ghent](#)

09:15 - 13:00 Session for completing the POF

14:00 – 15:30 Lunch at [Greenway Ghent](#)

15:30 – 18:30 Cultural activities in Ghent

19:00 – Networking dinner at [50 fifty](#)

Sunday, July 16th

Farewell and departure for everyone

Appendix 6. EU-CAYAS-NET Peer Visit in Netherlands, Agenda

AGENDA **EU-CAYAS-NET – Peer visit Amsterdam, Netherlands**

Tuesday, July 25th

18:30 - 19:00 Welcome and Registration at [Dutch Design Hotel Artemis](#)
 19:00 Networking dinner at the hotel

Wednesday, July 26th

07:45 Meet in lobby hotel
 08:00 - 10:00 [Travel](#) from hotel Amsterdam to Radboudumc Nijmegen
 10:30 - 10:50 Welcome at AYA lounge [Radboudumc](#)
 10:50 - 11:10 History and organization Dutch AYA 'Young & Cancer' Care Network
 11:10 - 11:40 AYA outpatient clinic Radboudumc
 11:10 - 11:40 Working in co-creation with AYAs
 12:00 - 13:00 Special lunch, presented in AYA lounge
 13:00 - 13:30 Fertility preservation
 13:30 - 15:00 Guided tour(s) of hospital
 15:00 - 16:00 Q&A session
 18:00 Networking dinner in Nijmegen
 20:00 [Travel](#) back to Amsterdam

Thursday, July 27th

09:10 Meet in lobby hotel
 09:30 - 09:50 Travel (walk) from hotel to NKI hospital
 10:00 - 10:10 Welcome at [The Netherlands Cancer Institute \(NKI\)](#)
 10:10 - 10:45 Research morning - Part 1
 10:45 - 11:00 Q&A and Coffee break
 11:00 - 11:30 Research morning - Part 2
 11:30 - 11:45 Q&A and Coffee break
 11:45 - 12:00 Research morning - Part 3
 12:00 - 14:00 Lunch nearby hospital
 14:00 - 14:15 Introductions AYA care NKI/AVL
 14:15 - 15:00 Interactive 'surprise' session
 15:00 - 16:00 Guided tour(s) of hospital
 16:00 - 17:00 Q&A session
 19:00 Networking dinner

Friday, July 28th

08:00 Meet in lobby hotel
 08:15 - 10:00 [Travel](#) from hotel Amsterdam to [NWZ Alkmaar](#)
 10:00 - 10:15 Welcome at [Noordwest Ziekenhuisgroep locatie Alkmaar](#)
 10:15 - 11:00 Introduction AYA care NWZ
 11:00 - 12:00 Guided tour(s) of NWZ Alkmaar
 12:00 - 13:00 Lunch at hospital
 13:00 - 15:00 [Travel](#) back to the hotel
 15:00 - 18:00 POF Session at hotel
 20:00 Networking dinner

Saturday, July 29th

Farewell and departure for everyone