Peer Visit as Research Method in EU-CAYAS-NET

Description of Methodology - Draft

Developed under Task 4.2 in Work Package 4: AYA Care

CONTENTS

INTRODUCTION

The **EU Network of Youth Cancer Survivors (EU-CAYAS-NET)** is a project co-funded by the European Union's EU4Health under grant agreement number *101056918* that promises to improve the quality of life of childhood, adolescent and young adult cancer survivors through meaningful social networking among individuals with lived experience of cancer, as well as social and health professionals active in cancer prevention and care across the European Union. The network will bring together a wide spectrum of stakeholders and create an online Platform to support the promotion of targeted actions and initiatives, covering areas which are of demonstrated benefit to the quality of life of young people affected by cancer. The focus will be on three themes identified by young people with lived experience throughout Europe:

1) **Quality of Life** *(in Work Package 3 - WP3*),
2) **Adolescent and Young Adult Cancer Care** (*in Work Package 4 - WP4*),
3) **Equity, Diversity and Inclusion** *(in Work Package 5 - WP5)*.

Young people living with cancer and beyond will lead a collaborative approach involving diverse stakeholders to identify targeted actions and initiatives to be promoted via the network and Platform. Activities will include Peer Visits, meetings, training, virtual co-working, social media campaigns, webinars, policy recommendations/events and other national/international policy events. Activities will build on previous and on-going initiatives, such as European Reference Networks (ERN) PaedCan and Horizon 2020/Horizon Europe projects. The project will help deliver on Europe's Beating Cancer Plan Flagship initiatives such as the "Knowledge Centre on Cancer" and "EU Network of National Comprehensive Cancer Centres". EU-CAYAS-NET will also address many objectives of the EU4Health programme, including health promotion and reduced disease burden, reducing health inequalities and improving access to care, improving patient/survivor rights, and more.

In addition to delivering an EU-wide digital Platform informed by research as well as stakeholder engagement, EU-CAYAS-NET will also directly contribute to reducing health inequalities, improving access to care and resources, and promoting young patients' and survivors' rights.

THE AIM OF THIS DOCUMENT

The overarching aim and deliverable of Work Package 4 (WP4) is the co-creation of the *"Specialist AYA Units Minimum Standards"* position paper. To this end, the working group of WP4 will undertake desktop research, Peer Visits, and a round table with healthcare professionals to inform the writing of the position paper.

This document, developed as part of Task 4.2, focuses on **describing the Peer Visits as a research method** for EU-CAYAS-NET Task 3.4.2, Task 3.5.8 and Task 4.3 and will provide the **framework** for:

- Participant selection criteria,
- Selection process for both participants (patients, survivors, healthcare professionals, social workers, Representatives of other stakeholder groups) and collaborating institutions,
- Peer visit preparation and communication with local stakeholders and members of the AYA cancer care ecosystem in the target countries,

- Conducting Peer Visits with the Inclusion of additional Network Ambassadors and an extended number of participants who will be invited to participate online through real-time, live streaming solutions
- Analytical approach.

This document will serve as foundation and guidance for the development of training materials foreseen to be used in M6 of the project, Peer Visit training event for all participants who will be conducting Peer Visits in Tasks T3.4.2, T3.5.8 and T4.3.

HOW THIS DOCUMENT WAS CREATED

This document was drafted by task 4.2.1 (”Develop Peer Visit methodology for this project”) group members by researching existing guidelines and best practices. The first round of consultations and edits were done by all stakeholders and interested parties within WP4. The final version was accepted by the full working group of WP4.

PEER VISITS AS RESEARCH METHOD IN EU-CAYAS-NET

I. WHY PEER VISITS?

The concept of Peer Visits is rooted in observational and participatory research, where researchers (in our case, members of specific working groups in WP3 and WP4 of the project) are able to observe healthcare professionals and other service providers in their natural environment. Three types of observation will be used: naturalistic observation where the working group members (from now on: *peer visit researchers*) will observe the environment where the healthcare professionals are working; participatory observation where the researchers will conduct interviews, take notes and photographs; and structured observation, where the researchers will 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. (This report card will be referred to as *Peer Observation Form* later on in this document.)

Peer Visits are also expected to result in valuable feedback to the collaborating institution, as well as actionable takeaways for researchers (in our case peers, that is members of specific working groups in WP3 and WP4 of the project who might be young people with lived experience or healthcare providers, etc) to support AYA initiatives in their home-countries.

This form of peer learning is designed to stimulate interaction, collaborative learning and solution-building.

Successful Peer Visits will rely on **three, well-planned stages**:

1. Preparation for the Peer Visits *(M2-M8, October 2022 to April 2023 in WP3 & WP4)*
    a. Selection of participants *(M4-M5, December 2022 to January 2023 in WP3 & WP4)*
    b. Training of participants *(M6, February 2023)*
2. Peer Visits in the country of the collaborating member institution *(M9-M11, May 2023 to July 2023 in WP3 & WP4)*
3. Peer Visit feedback and reporting *(M9-M13, May 2023 to September 2023 in WP3 & WP4)*

The follow-up & dissemination of results is equally important but it’s not the subject of this document and the description of methodology. Within the context of the EU-CAYAS-NET project throughout months 18 - 24 there will be a Position Paper prepared on the need for LTFU care and one on Mental Health & Psychosocial Care after CAYA cancer in WP3. In WP4 between M14-M24, October 2023 to August 2024, there will be an online RoundTable with further discussions on AYA care, which, together with the findings of the Peer Visits will inform a Position Paper about “Specialist AYA Units Minimum Standards”.

II. PARTICIPANT INCLUSION CRITERIA AND SELECTION PROCESS

A total of 50 participants (20 participants to support WP3 and 30 participants to support WP4) will participate in a “**Peer visit as research method in EU-CAYAS-NET"** training session at M6 of the project (February, 2023). Participants will have been selected by the Working Groups of WP3 and WP4 respectively.

1. **Leading principles:**
    1. The working groups of WP3 and WP4 will employ purposive sampling to assure representation of diverse voices and youth cancer communities. The selection will respect *Equality, Diversity and Inclusion (EDI)* principles (such as considering diverse geographic representation, gender, educational status, health status and disability, etc. See below for more information) and the working groups commit to *safeguarding and wellbeing* during the training and Peer Visits (for more information please see highlighted text box below).
    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.
    3. Priority consideration will be given to Network Ambassadors selected in T1.6 [Ambassador Programme] of EU-CAYAS-NET.
    4. Participation will be entirely voluntary.
    5. In WP4 on-site participation in Peer Visits is going to be offered to young people with lived experience of cancer. Other stakeholders (in this sense not referred to as “peers”) might join the research activity online or through other innovative methods employed by the working group. In WP3 on-site participation is offered to multiple stakeholders.

2. **Inclusion criteria for the Training event and Peer Visits:**
    - **Participating as a “Young people with lived experience”:**
        a. At least 18 years old
        b. Diagnosis of primary cancer before/at the age of 39 years
        c. Diagnosis of primary cancer was at least 2 years ago
        d. Interested in any one of the specific research topics of WP3 and WP4
            - Adolescent and young adult care settings in oncology
            - Long-term follow up of childhood cancer survivors
            - Transition from paediatric to adult oncology care
        e. Able to understand primarily English language
        f. Able to travel (participants who need carers or assistance to travel will also be considered)
        g. Available to attend the Peer Visit training event in M6 (February, 2023), as well as available to attend a topic-specific 3-day Peer Visit to one of the identified institutions in M9-M11 (May-July, 2023).
        h. Able to understand the undertakings of this research and their rights and responsibilities (such as participating in training and Peer Visit, respecting code of conduct, adhering to principles and committing to complete Peer Visit report after the activity)
        i. Able to provide informed consent.

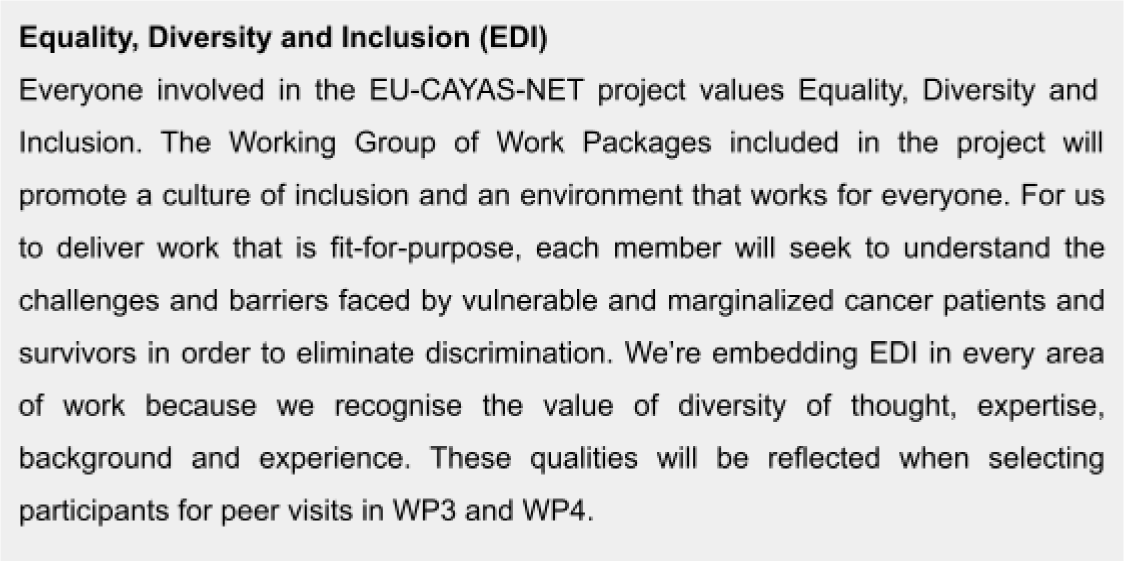
    - **Participating as a ”Parent or Carer”:**

    a. Parent of child, adolescent, or young adult (CAYA) patient(s) or survivors diagnosed before/at the age of 39
    b. The diagnosis of primary cancer of the child was at least 2 years ago
    c. Interested in any one of the specific research topics of WP3 and WP4
        - Adolescent and young adult care settings in oncology
        - Long-term follow up of childhood cancer survivors
        - Transition from paediatric to adult oncology care
    d. Able to understand primarily English language
    e. Able to travel (participants who need carers or assistance to travel will also be considered)
    f. Available to attend the Peer Visit training event in M6 (February, 2023), as well as available to attend a topic-specific 3-day Peer Visit to one of the identified institutions in M9-M11 (May-July, 2023).
    g. Able to understand the undertakings of this research and their rights and responsibilities (such as participating in training and Peer Visit, respecting code of conduct, adhering to principles and committing to complete Peer Visit report after the activity)
    h. Able to provide informed consent.

- **Participating as a ”Health Care Professional”:**
    a. Medical doctor, Nurse, or Psychosocial professional working in the field of CAYA cancer/ CAYA cancer survivorship care (cancer patients diagnosed before the age of 39)
    b. Interested in any one of the specific research topics of WP3 and WP4
        - Adolescent and young adult care settings in oncology
        - Long-term follow up of childhood cancer survivors
        - Transition from paediatric to adult oncology care
    c. Able to understand primarily English language
    d. Able to travel (participants who need carers or assistance to travel will also be considered)
    e. Available to attend the Peer Visit training event in M6 (February, 2023), as well as available to attend a topic-specific 3-day Peer Visit to one of the identified institutions in M9-M11 (May-July, 2023).
    f. Able to understand the undertakings of this research and their rights and responsibilities (such as participating in training and Peer Visit, respecting code of conduct, adhering to principles and committing to complete Peer Visit report after the activity)
    g. Able to provide informed consent.

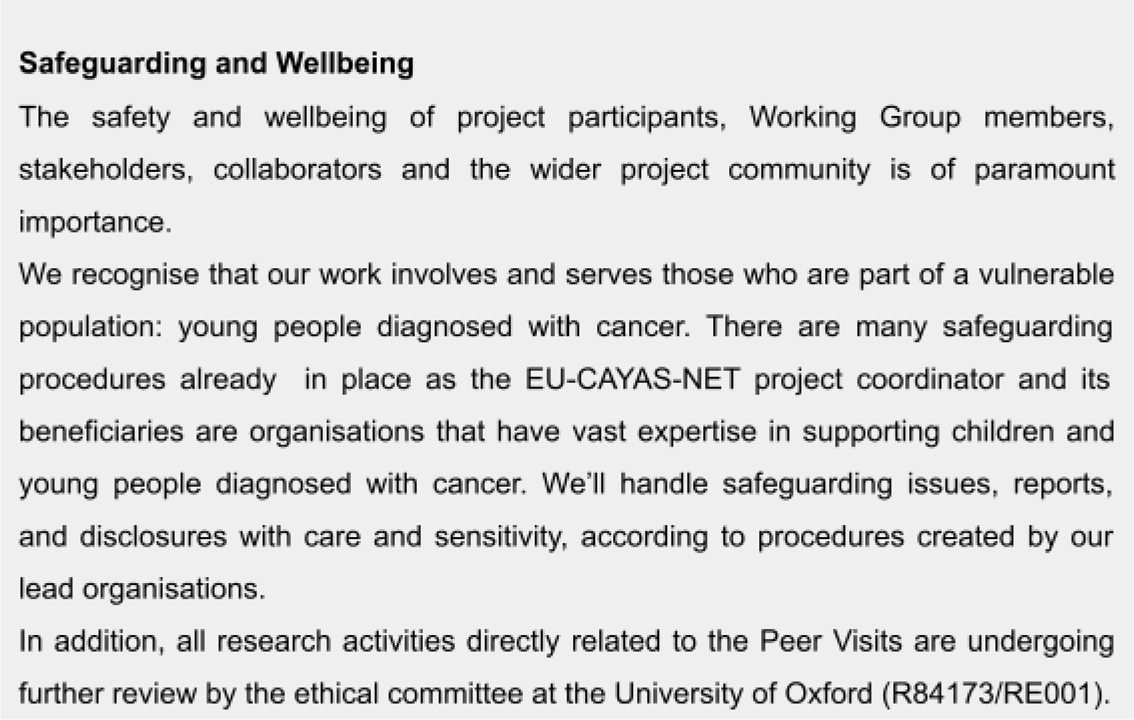
3. **Selection process:**
    a. The WP3 and WP4 working groups will invite members to register their expression of interest through online forms, via emails.

b. The WP3 and WP4 working groups will evaluate expression of interest registrations on the above Leading Principles (point 1), as well as considering the Inclusion Criteria (point 2).
c. Work Package leaders of WP3 and WP4 are ultimately responsible for making sure that the results of the selection process are sensitively communicated in a timely manner, to all applicants.



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.



Safeguarding and Wellbeing

The safety and wellbeing of project participants, Working Group members, stakeholders, collaborators and the wider project community is of paramount importance.

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 are undergoing further review by the ethical committee at the University of Oxford (R84173/RE001).

III. PREPARING THE PEER VISIT PARTICIPANTS

In M6 (February, 2023) Youth Cancer Europe will organise and lead a **"Peer Visit as research method in EU-CAYAS-NET'"** training session for young cancer survivors and invited representatives of other stakeholder groups identified in WP3 and WP4.

The training will consist of a one-day face-to-face meeting, preparing participants for their role as Peer-observers. The training will:

1. Set expectations and describe the aim of Peer Visits.
2. Describe the expected activities that will take place during Peer Visits, including an estimated time table and draft agenda.
3. Discuss principles of safeguarding and wellbeing of both the project participants as well as the vulnerable populations that will be observed
4. Will provide an overview of EU-wide legislative provisions and policies, as well as known national programmes in the specific research topics of WP3 (LTFU and Transition) and WP4 (AYA Care)
5. Will introduce each topic and the currently available research publications in topic-specific sub-groups and will agree, together with participants on the specific research questions through a collaborative priority-setting process
6. Will showcase a draft report form and seek input on final reporting format
7. Will facilitate learning of basic observational, interviewing and report writing skills

Peer Visit research activities are based on active and effective listening, observing and questioning. Some of the research activities that participants will be prepared for are the following:

1. 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.
2. 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.
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. 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).
5. External meetings with stakeholders or other 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 will be observed and individual permissions sought before recording any interaction.
7. Feedback and debriefing session.

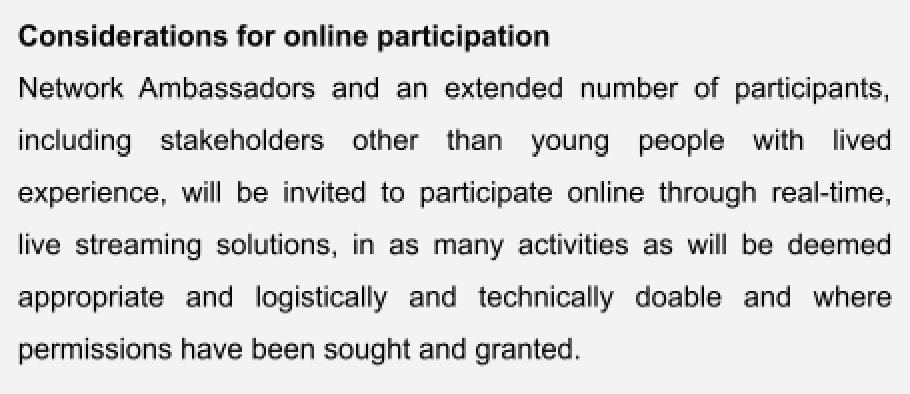
IV. PREPARING THE COLLABORATING INSTITUTIONS

Participants are introduced to the local context and successful practices through dynamic forms of peer learning designed to stimulate interaction, collaborative learning and solution-building. The collaborating host institution of such Peer Visits would need to be willing to:

- Grant permission to Peer Visit participants to observe activities or procedures carried out in the cancer institute
- Involve personnel that understands and speaks English (alternatively, provide interpreters to translate and aid in the communication of the participants and hospital personnel and or cancer patients)
- Provide practical and technical support throughout the Peer Visit
- Help the participants to understand the local clinical care practice and policies on AYA treatment
- Plan and help organising the Peer Visit
- Prepare the agenda (or make recommendations for the agenda)
- Propose institution-based speakers and identify healthcare professionals willing to assist the Peer Visits
- Identify AYA healthcare professionals willing to participate in semi-structured individual interviews

Work package and task leaders are recommended to start early discussions with host institutions to agree on possible visiting **timeframes**, as well as secure the **support of institutional management**. It is recommended that for each Peer Visit there should be one dedicated **contact person** per institution who will handle communication between the EU-CAYAS-NET Peer Visit coordinators and the receiving hospital.
Collaboration agreements and media waivers with the host institutions, as well as research participation **consent** with individuals need to be sought early on and draft documents circulated (and if possible, final versions signed off by all concerned) ahead of a visit taking place.

Accommodation, room hire, food, travel, etc acquisitions & bookings are the responsibility of WP leaders CCI-E (WP3) and YCE (WP4) and will be made according to the needs of the activities and the needs of the participants in the countries where Peer Visits will take place. Preparing Peer Visits materials, printing, branding is going to be realised by the working group with the collaboration of YCE and CCI.



Considerations for online participation

Network Ambassadors and an extended number of participants, including stakeholders other than young people with lived experience, will be invited to participate online through real-time, live streaming solutions, in as many activities as will be deemed appropriate and logistically and technically doable and where permissions have been sought and granted.

V. PEER VISIT FEEDBACK AND REPORTING

Following each Peer Visit, participants will be expected to provide a written report with the learning outcomes based on a template provided during the training. This will be done via Survey Platform accessible through the link provided to participants upon their visit. Based on the participants' reports, final General reports will be written by Work Package and Task Leaders. The General report will be shared with the General Assembly, at meetings of the EU Network of Youth Cancer Survivors, with Network Ambassadors and on the Platform.

VI. OVERVIEW OF ROLES AND RESPONSIBILITIES

All Associated Partners (AP) and Beneficiaries (BEN) of the EU-CAYAS-NET consortium are invited to participate in planning Peer Visits, preparing the methodology and training materials (including the effective participation to training/Peer Visits). The opportunity to attend the Peer Visits is given to an extended number of participants (with priority for Network Ambassadors) by live-streaming of Peer Visits. The roles and responsibilities of the different stakeholders are included below:

Roles and responsibilities of Beneficiaries (BEN)

- Will work throughout the project length on the implementation of the training and organisation of the Peer Visits
- Will coordinate events & meetings included in the task and subtask for planning Peer Visits and preparing the methodology and training materials
- Will produce content, develop & deliver training, materials, toolkits etc.

Roles and responsibilities of Associated Partners (AP)

- Encouraged to join the Network of Youth Cancer Survivors
- Encouraged to participate in and actively contribute to project meetings & events about planning Peer Visits and preparing the methodology and training materials
- Can review and provide feedback about the Peer Visit Methodology

Roles and responsibilities of the WP4 leaders

- Researching into existing guidelines, published literature and best practices across EU
- Creating the Peer Visit methodology
- Creating training materials & preparing training event
- Developing selection criteria for the participants of the Peer Visits
- Recruiting participants for training and Peer Visits
- Preparing the visit agenda in collaboration with the Institutions of the collaborating countries
- Supervising the process of the visit
- Assuring that the agenda is implemented
- Scheduling and monitoring of the Peer Visits
- Helping the participants to fill up the reports
- Collecting the reports from the participants
- Draft the report according to the participants input

- Assuring the process of follow-up & dissemination of the Peer Visits' outcome

Roles and responsibilities of participants (researchers)

- Participate in the training in person in February 2023, Belgium, or if unable, confirm the reading and assimilation of all training materials made available by the organisers after the event
- Observe and learn throughout the visit in the collaborating institution
- Participate in focus group with peers
- Complete an anonymous individual report based on the experience during Peer Visit
- Provide any additional feedback during the feedback sessions

VII. RISK MANAGEMENT

Risk	WP	Proposed risk-mitigation measures
Network fails to collaborate effectively (low likelihood, high impact)	WP4 is included	Beneficiaries involved in the network have a history of successful collaboration with each other and with the stakeholders they represent (including Associated Partners), and the activities of the project are well aligned with their strategic priorities, making the likelihood of the risk low. To mitigate the risk, the Management Team will maintain regular contact with all beneficiaries and associated partners to identify any issues at an early point. The consortium will have monthly conference calls to facilitate communication and will aim to resolve any conflicts by consensus.
Youth cancer survivors lack skills in successful report writing, impacting the final position paper that would then lack sufficient patient input. (Low likelihood, high impact)	Only WP4	The project foresees targeted training for young cancer survivors participating in the activities, preparing them with the skills and competence to engage in the Peer Visits and use guidelines and templates for reporting. Their input

		will be consolidated by an experienced patient advocate, with deep understanding of the context, making sure that all contributions will be valued and feed directly into the publication preparation process.
Data confidentiality breaches (Low likelihood, high impact)		All procedures where personal and sensitive information will be collected will be reviewed and approved by the university research ethics committee. Consent will be sought and participants will be made aware of the possibility to decline participation. Aims will be clearly outlined and data collected via secure survey Platform LimeSurvey that is GDPR compliant. No IP addresses will be stored and only anonymized data will be made ready for use in the analyses.

ABBREVIATIONS

AYA - Adolescent and Young Adult

CCI-E - Childhood Cancer International, Europe

EDI - Equity, Diversity and Inclusion

ERN - European Reference Networks

EU-CAYAS-NET - The European Network of Youth Cancer Survivors

GDPR - General Data Protection Regulation

LE - Late Effects

LTFU - Long-Term Follow-Up

M - Month

WP - Work Package

WP3 - EU-CAYAS-NET Work Package on Quality of Life

WP4 - EU-CAYAS-NET Work Package on Adolescent and Young Adult Cancer Care

WP5 - EU-CAYAS-NET Work Package on Equity, Diversity and Inclusion

YCE - Youth Cancer Europe

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