

# GENERAL REPORT



## AYA PEER VISITS

Italy - Belgium - Netherlands



Co-funded by  
the European Union

Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.



**This General Report is developed  
in Work Package 4 under the umbrella  
of EU-CAYAS-NET, a project supported  
by the European Union's EU4Health  
program (grant agreement  
number 101056918).**

# TABLE OF CONTENTS

**2** Executive summary

**3** Introduction

**4** Objectives

**5** Outcomes

- Built environment
- Multidisciplinary teams and patient pathways
- Clinical trials
- Genetic counselling
- Nutrition and exercise training
- Fertility and sexual health
- Mental health and psycho-social support
- School and job

**9** Site-specific learnings

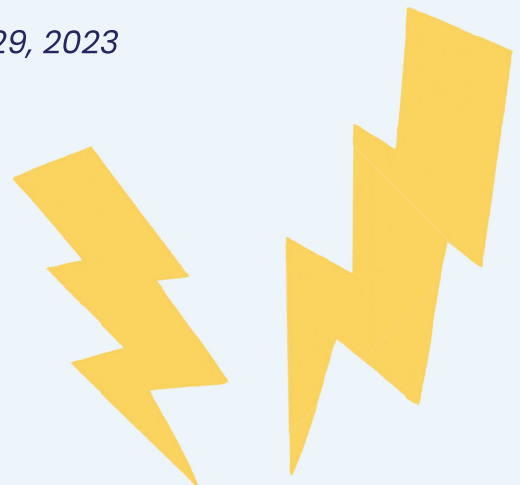
*Milan, Italy: May 15 – 18, 2023*

*Ghent, Belgium: July 12-16, 2023*

*Amsterdam, Netherlands: July 25-29, 2023*

**16** Conclusions

**17** Special thanks



# EXECUTIVE SUMMARY

EU-CAYAS-NET is a project supported by the European Union's EU4Health program (grant agreement number 101056918) that aims to enhance the quality of life for childhood, adolescent, and young adult people (AYA) afflicted by cancer. It does so by fostering meaningful social connections among those who have experienced cancer, along with professionals and stakeholders engaged in cancer care throughout the European Union.

Between May and July 2023, each of the three leading institutions in AYA cancer care across Europe (Milan, Italy; Ghent, Belgium; Amsterdam, Netherlands) was visited by 10-15 young people with lived experience. The aim was to understand how and why the systems operate well and what services might still be lacking. The overarching objective of the Work Package 4 (WP4) is to better understand how AYA care can be improved and transformed in the rest of Europe. The insights were gathered in the form of notes, as well as structured surveys, and semi-structured interviews with local patients and personnel. Analyses of the data were descriptive and triangulated with the members of the WP4.

Overall, the centres visited provide a comprehensive and holistic care to patients and their caregivers. Areas that could be further developed include educational and vocational assistance, palliative and end-of-life care, and dedicated support for minority groups. The knowledge and data gathered during Peer Visits did not only contribute to invaluable insights into how AYA cancer care operates in different countries, but also helped foster an international network of youth who will continue serving as ambassadors of AYA-related work. The results will directly inform the development of a position paper, inform policy recommendations, and enhance the work done by the rest of the Consortium.

# INTRODUCTION

Peer Visits are an innovative and creative form of research involving both observational and participatory aspects, where researchers (in our case, members of WP4 with lived experience) are able to be present on-site in order to observe and interact with healthcare professionals and other service providers. In particular, three types of data collection were used: naturalistic observation where the participants observed the hospital and care environment; participation in organised presentations, note-taking, and semi-structured interviews; and structured reporting, where the participants took the time to fill out a detailed online survey (via Qualtrics) where they reported their specific observations (see Peer Observation Form; POF). All participants were encouraged to submit their observations during the Peer Visit to minimise recall bias.

Peer Visits significantly contribute to enhancing the involvement of patients (so called PPI; Patient and Public Involvement) in work and research devoted to them. Patient advocates and representatives are instrumental to the success of EU-CAYAS-NET and have been actively involved from the very inception (writing of the grant proposal) through to the study management, data interpretation, as well as findings dissemination.

**Peer Visit methodology, selection criteria, structure, as well as the code of conduct for all participants have been described in further detail elsewhere (see Peer Visit as a Research Method in EU-CAYAS-NET).**



# OBJECTIVES

To date, AYA specialist services are limited to a few major centres across Western and Northern Europe. In order to advocate and raise awareness for the unique and distinct needs of AYAs with cancer, EU-CAYAS-NET aims to bring together diverse voices of experts, as well as young people living with and beyond cancer and outline the recommendations for minimum essential requirements for AYA cancer centres across the European Union and the UK.

**The overarching aim of the WP4 is to deliver a position paper on “Specialist AYA Units Minimum Standards across the EU”. In particular, the Peer Visits addressed the following objectives:**

**1**

Gather first-hand data from the patients who were treated in AYA-specialty centres, learn what works well and what does not.

**2**

Gather first-hand data from the healthcare professionals working with AYA patients, understand how the AYA-specific needs are met in their local settings.

**3**

Observe the workings of the AYA-specialty centers and report on the availability of services such as accessible care environment, psychosocial, educational or vocational support, financial or legal aid.

**4**

Gather first-hand data from the healthcare professionals working with AYA patients, understand how the AYA-specific needs are met in their local settings.



# OUTCOMES

Across the three sites, 30 participants representing 16 countries were present. The POF form was completed 13 times each for Italy and Belgium, and 12 times for the Netherlands. Longer qualitative responses were recorded for 30 participants. They included free-text answers asking about particular strengths, weaknesses, and major lessons relating to a specific visit.

The qualitative responses for each site were anonymously read and re-read, and the content was coded for any specific themes that could be discussed in this document. The following paragraphs provide descriptive summaries of the quantitative and short-answer responses to the POF. The final version was reviewed by participants from all different sites and revised in light of their feedback.

## 1. BUILT ENVIRONMENTS

An important part of recognizing and meeting AYA-specific needs is providing them with a care setting that is dedicated to them and age-appropriate. Across sites the settings were generally separate for the AYA patients and included private rooms, designated spaces for prayer or worship, kitchen, and cooking facilities, as well as play/common rooms, although the said settings were often embedded within pediatric wards. Across sites AYAs also had the ability to personalize their care settings by bringing their belongings such as beddings or other decorative items. Family and visitors were allowed and had the ability to stay overnight as well. Connectedness with members of staff and among patients was promoted through various activities, be it social or educational.

## 2. MULTIDISCIPLINARY TEAMS AND PATIENT PATHWAYS

All AYA centers that were visited by the participants employed a relatively multidisciplinary and holistic approach to care (see strengths and weaknesses of each site below). The personnel and programs acknowledged the psychosocial demands of illness, as well as more pragmatic needs of their patients and families, such as foreign language support. Collaboration between NGOs and external organisations and institutions was particularly pronounced in Belgium. The only aspect that was less commonly discussed and observed was palliative and end-of-life care.



### 3. CLINICAL TRIAL

Access to AYA-specific clinical trials is an area that needs more research and support. Provision of information related to the clinical trials is varied across the sites. In Italy it is not directly discussed with the patients, unless relevant or urgent in an individual case. In Belgium, patients are informed of a website with the clinical trial information, and in the Netherlands, the information is available on the major hospital sites, often discussed directly if the standard of care fails, with extensive efforts made so that AYAs are recruited into clinical trials where appropriate.

### 4. GENETIC COUNSELLING

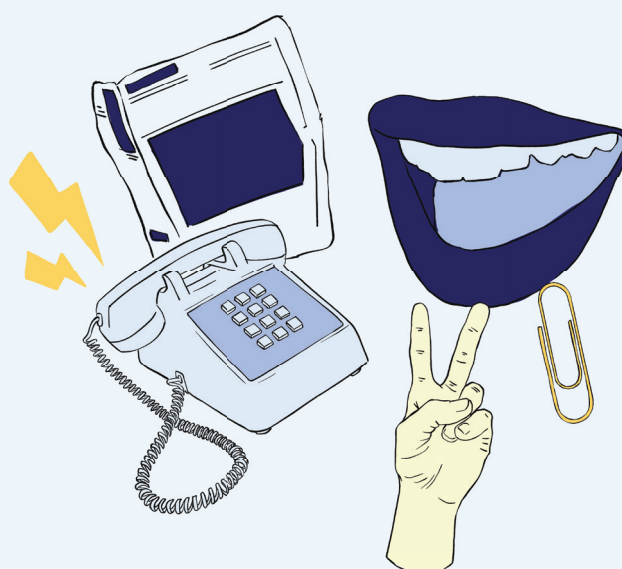
Genetic counselling was available to AYA patients, although not necessarily routinely performed. Genetic testing was also an elected option across sites.

### 5. NUTRITION AND EXERCISE TRAINING

Across all sites, most participants recorded that the meals for patients were carefully planned and adjusted for their nutritional needs. Nutritionists were available for consultation. In addition, AYA patients had ample access to exercise and physiotherapy support that had been age- and ability-tailored.

### 6. FERTILITY AND SEXUAL HEALTH

Fertility is an important topic for AYAs with cancer. Fertility specialists or referrals were common across sites; however, sexual health specialists were lacking. For the most part, fertility was discussed with patients and their families, and fertility preservation options were made available either on-site or by a referral to the specialist clinic. Topics regarding sexuality were less commonly discussed in formal settings but were addressed through creative means (e.g. peer-to-peer YouTube videos) or informal care settings (NGOs). More work would need to be done to better understand how fertility-related discussions occur in ethnically and culturally diverse patient populations. Fertility preservation services were covered by the national insurance plan, however, “hidden costs” sometimes weighed on the patients (e.g. storage payment).



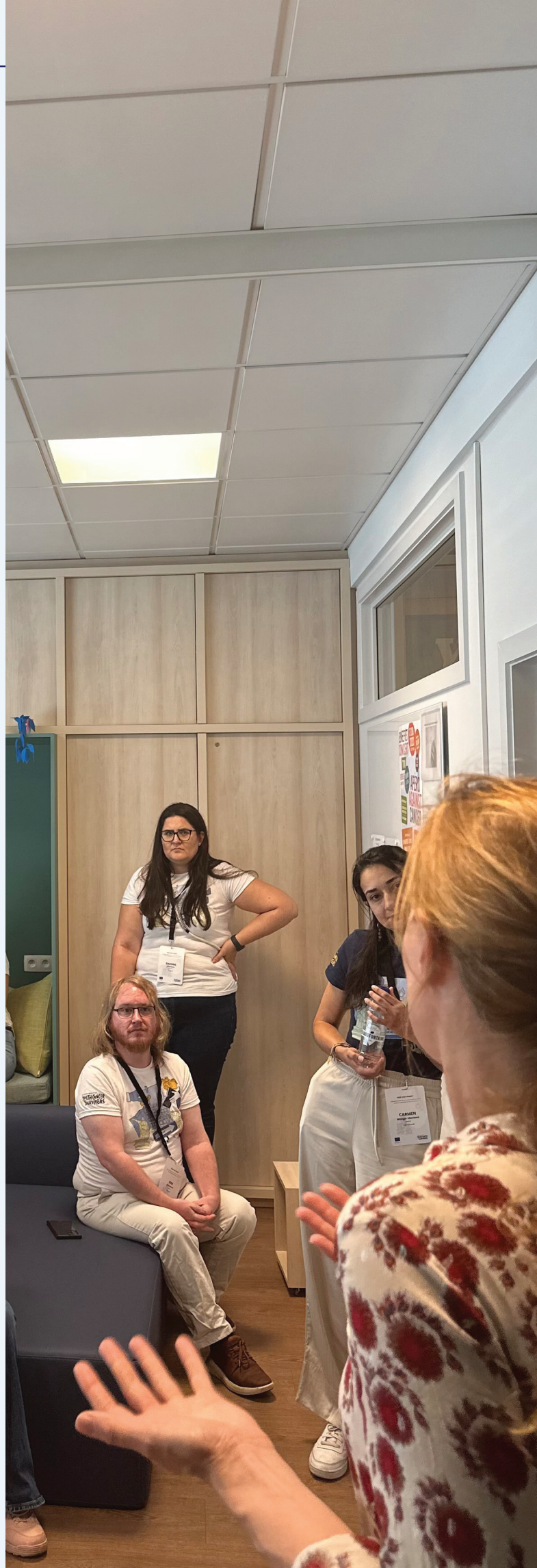


## 7. MENTAL HEALTH AND PSYCHO-SOCIAL SUPPORT

As part of providing holistic and multidisciplinary care, AYA-specialty centers also acknowledged the psycho-social and mental health needs of patients. Mostly, AYA units had a psychologist and a social worker that was made available to patients and their families on site, during and after treatment. Social needs were also met by integrating peer-to-peer support by engaging dedicated organisations working with young people. AYA coordinators or nurses offered a lot of non-medical support. The aspect that could have been improved is the provision of AYA-trained psychologists and counsellors, who are used to working with youth. More support could also be offered to AYAs who have their own families and children.

## 8. SCHOOL AND JOB

Across sites the settings and programs allowed for AYAs to receive support with their education, however, in large part the burden fell on the patients and their families to engage with the school, particularly for patients who were over the age of 18. Occasionally, social workers and NGOs were able to offer some support. The focus was primarily on educational aspects, and our findings highlighted a notable gap for the unemployed AYAs or those looking for help with returning to work



# ISTITUTO NAZIONALI DEI TUMORI

**MILAN, ITALY: MAY 15 – 18, 2023**

## STRENGTHS

- Overall, the care is very holistic and covers aspects of nutrition, fertility, exercise, education, and psycho-social issues,
- Patients form a cohesive group and have creative projects participation opportunities to engage them and the public,
- Gaming and gym spaces,
- Access and collaboration in other international projects (e.g., FORTE),
- Easy and direct patient access to healthcare professionals (i.e., phone/text communication),
- Pet therapy

## WEAKNESSES

- AYA spaces are also shared with the pediatric patients, overlooking some needs of older AYAs,
- The AYA care depends on the individual good-will and is not yet fully institutionalized or integrated into the system as a whole,
- Lack of written information and communication for AYA patients,
- Lack of structured, more robust transition into long-term follow up program,
- No existing group therapy for patients and/or caregivers, only informal meetings
- Lack of explicit support for patients with different sexual orientation than the norm,
- Lack of structured data collection, monitoring of patients (e.g., PROMs)
- Hard to exercise when in isolation.





# GHENT UNIVERSITY HOSPITAL

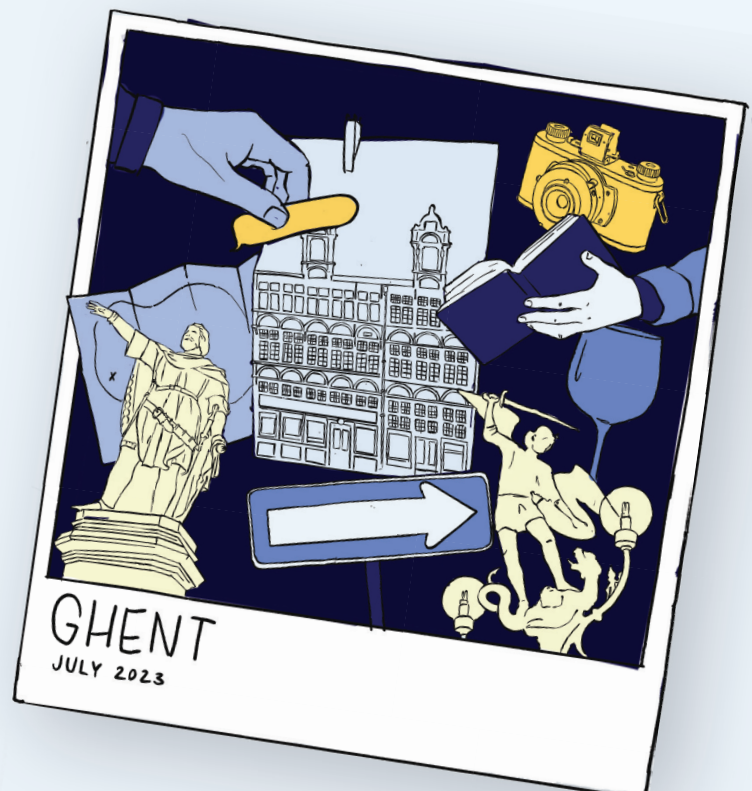
*GHENT, BELGIUM: JULY 12-16, 2023*

## STRENGTHS

- There is an AYA-dedicated team that also conducts research,
- The AYA care is very structured, and there is a large involvement of NGOs, supplementing the clinical care, resulting in a very good relationship between formal and informal care aspects,
- AYAs are included in the design of their spaces and services,
- The hospital provides AYA-specific training to the healthcare professionals,
- Availability of clear guidelines for AYA care,
- The Transition into long-term/post-treatment care is seamless and organized.

## WEAKNESSES

- A lot of the initiatives depend on private/grant/award funding, which makes AYA services hard to sustain.
- Services are holistic and include multidisciplinary teams but feel scattered as they are only sometimes present in the same ward, wing, or even hospital building.
- The focus is slightly more geared towards AYAs younger than 25 years; the need remains to include older AYAs.
- Lack of staff for the number of patients
- Lack of systematic support for diverse needs such as LGBTQ and migrant populations





# RADBOUD UNIVERSITY MEDICAL CENTER NETHERLAND CANCER INSTITUTE NOORDWEST ZIEKENHUISGROEP

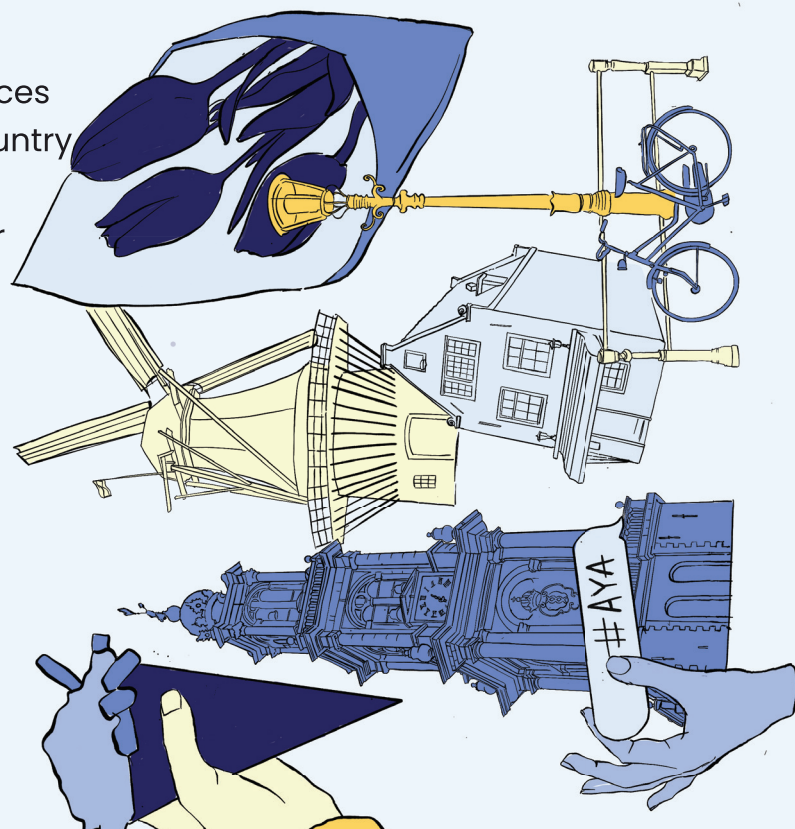
**THE NETHERLANDS: JULY 25-29, 2023**

## STRENGTHS

- Very cohesive collaboration within AYA services including individualised nutrition programmes and creative ways to address side effects, (e.g. pain management through the means of an arts' programme)
- NKI included research, which is beneficial for patients, as well as clinicians and academics
- Strong collaboration between care institutions and survivorship-focused organisations, allowing for a smoother transition into follow-up care
- Easy availability of nurses on site who are also trained in AYA-specific difficulties such as fertility and/or sexuality
- Harmonisation of the resources and curricula across the country
  - the majority of hospitals conform and employ similar standards, thus ensuring equal provision of care across the Netherlands

## WEAKNESSES

- Even though services are multidisciplinary, mental health aspects were not always emphasised or as well - integrated
- Materials and information primarily available in Dutch and thus less accessible to non-Dutch speakers
- In some places the rooms were single, which allows for greater privacy, they might also be more isolating
- AYA services are well developed, but the wards are not separate





## CONCLUSIONS

The European Network of Cancer Survivors (EU-CAYAS-NET), supported by the EU4Health program, embarked on an important endeavor to establish minimum standards of care for adolescents and young adults (AYA) with cancer across Europe. Through a series of Peer Visits to leading AYA cancer care institutions in Italy, Belgium, and the Netherlands, and carefully planned methods of observation and participation, we gathered invaluable insights.

Our findings highlight that AYA-specialty centers offer comprehensive and holistic care, focusing on the built environment, multidisciplinary teams, genetic counseling, clinical trials, nutrition, exercise training, fertility, mental health, and psycho-social support. However, some areas, such as support for diverse needs like LGBTQ and migrant populations, educational and vocational assistance require further development.

In conclusion, the Peer Visits proved an effective method to gather data and contributed to raising awareness of AYA initiatives and establishing an international network of patient advocates. The data collected will inform the writing of the position paper and policy recommendations and enhance the work of the EU-CAYAS-NET Consortium, ultimately striving to improve the quality of life for AYA cancer survivors throughout the European Union.





# SPECIAL THANKS TO

---



**Istituto Nazionale dei Tumori**

**Ghent University Hospital**

**The Netherlands Cancer  
Institute *in Amsterdam***

**The Northwest Hospital  
Groups *in Alkmaar***

**Radboudumc in Nijmegen**

**EUROPA DONNA –  
The European Breast  
Cancer Coalition**

**European School  
Of Oncology**

**Het Majin House**

**Kom op Tegen Kanker**

**Stichting Jongeren en Kanker**

**Stichting tegen Kanker**

**Andrea Ferrari**

**Anneke Eikelenboom**

**Chloe De Roo**

**Daan van der Meer**

**Danielle Roos**

**Els Van den Driessche**

**Eva Swart**

**Eveliëne Mantén-Horst**

**Fedro Peccatori**

**Felicia Lusing**

**Giulia Pareschi**

**Jeu de la Haye**

**Joanne Velzeboer**

**Johan de Munter**

**Karsten Vanden Wyngaert**

**Kim Messelink**

**Majin de Froidmont**

**Marco Chisari**

**Martha Swart**

**Martina Fontana**

**Marzia Zambon**

**Mathijs Hendriks**

**Milou Reuvers**

**Nathalie Belpame**

**Olga Husson**

**Paige Robinson**

**Pauline Engberts**

**Renske Fles**

**Sandra Biskanter-Baas**

**Silvie Janssen**

**Simone Hanebaum**

**Tanja Spanic**

**Tom Bootsma**

**Veerle Sey**

**William Guglielmo Zardo**

**Winette van der Graaf**

# SPECIAL THANKS TO

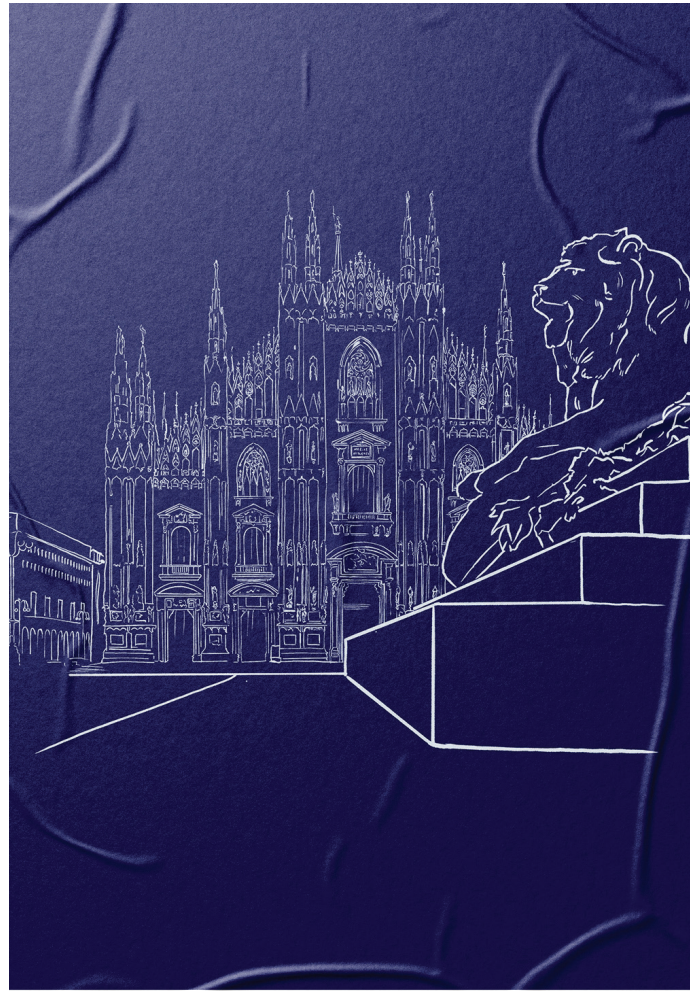
---



Ana Maria Totovina  
Andreas Christodoulou  
Anna-Elina Rahikainen  
Carmen Monge-Montero  
Colette Ryan  
Cristina Trifulescu  
Elena Arsenie-Constantinescu  
Erik Stureson  
Hannah Gsell  
Ioannis Akermanidis  
Iva Korović  
Katie Rizvi  
Lissandry Analia Acosta  
Madan Virgilia  
Magdalena Jaworska

Massimo Guglielmi  
Mihael Severinac  
Nataliia Hrad  
Nicola Unterecker  
Oriana Sousa  
Rebekah Lindores  
Sara Lassfolk  
Simona Hristova  
Sonia Silva  
Sophia Sleeman  
Tim Van Hoorenbeke  
Urška Kosir  
Varduhi Sargsyan  
Victor Girbu





# YOUTH CANCER EUROPE

The Peer Visit activities are delivered in Task 4.3.5 led by Youth Cancer Europe, a pan-European patient advocacy organisation with a community spanning more than 35 European countries.

To learn more, go to [youthcancereurope.org](https://youthcancereurope.org)  
or follow us on:



Youth Cancer Europe



Youth Cancer Europe



@youthcancereurope



@cancereurope

For more information about EU-CAYAS-NET project  
please visit [www.beatcancer.eu](https://www.beatcancer.eu)



@youthcancersurvivors

European Network of  
**YOUTH CANCER  
SURVIVORS**



Co-funded by  
the European Union

Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.