

Peer Visit to the Princess Máxima Center

24 & 25 May 2023,
Utrecht



Welcome to the Princess Máxima Center!



This Peer Visit is organized by:



EU-CAYAS-NET

Peer Visit to the Princess Máxima Center

Introduction

Welcome to the Princess Máxima Center in Utrecht! We hope you will have a nice stay and want to thank you in advance for your time and effort during this Peer Visit. Your contribution to this Peer Visit is very valuable to us. We've designed a two-day programme that enables you to observe and ask questions about how the long-term follow-up (LTFU) care is organized, provided to CAYA cancer survivors and how transition from child-centered to adult-oriented healthcare systems is organized within the Princess Máxima Center. We appreciate all your additional questions and comments, therefore please don't hesitate to write them down in the Peer Observation Form or in your personal notebook. What can you expect in the next two days? Find out below!

Registration

Registration for the Peer Visit takes place during the lunch (12:30 – 13:30) on the 24th of May.

Questions?

Do you need any assistance or help during the Peer Visit or do you have a question regarding the programme, filling in the Peer Observation Form, accommodation or dinner? Please contact the following persons:

Peer Visit Day 1:

Cherine Mathot +31 6 16202438 / cherine.mathot@pancare.eu or
Jeroen te Dorsthorst +31 6 45295634 / info@pancare.eu

Peer Visit Day 2:

Jikke Warms +31 6 39109326 / J.Warms-2@prinsesmaximacenter.nl or
Jaap den Hartogh +31 6 34277204 / J.G.denHartogh@prinsesmaximacentrum.nl



Information locations & travel instructions

Traveling from Schiphol Airport to Hotel Crowne Plaza – Catharijne Esplanade 13, Utrecht:

Hotel: [Crowne Plaza Hotel](#) + 31-30-2377100. The hotel entrance is located within the Hoog Catharijne Shopping Centre, located between the old city and the central train station. During the check-in into the hotel you will receive two public transport day-tickets which can be used for traveling by bus or tram. This ticket cannot be used for the train, for example to Schiphol Airport on day 2.

Accommodation

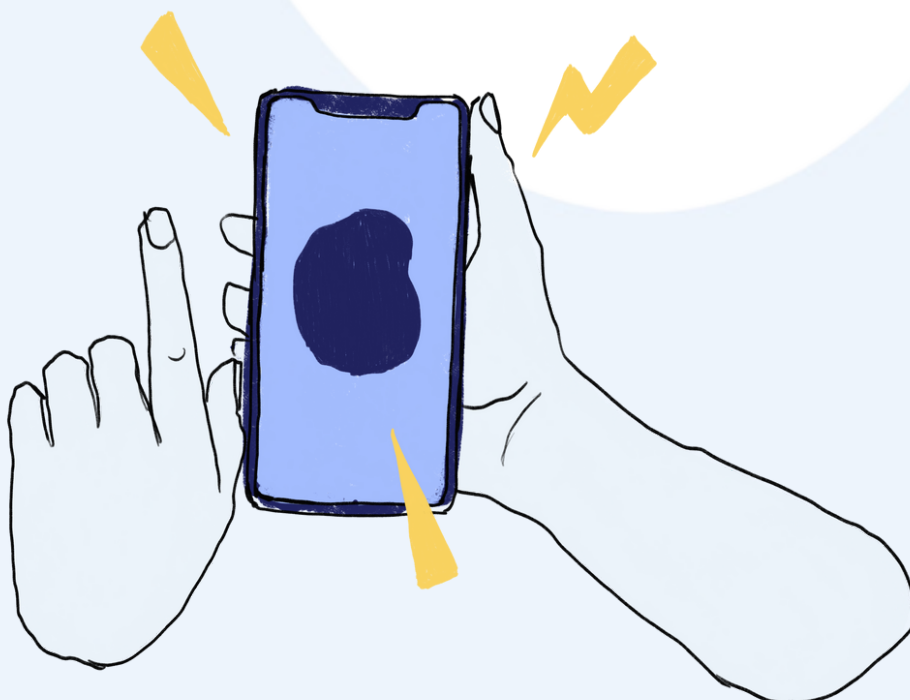
Your accommodation for the night(s) was booked directly by CCI Europe. CCI Europe pays bed and breakfast. Any other expenses (including mini bar, and any food and beverages outside of organised meals charged to the room by participants, must be paid by the participants themselves.

Public transport from Schiphol Airport to the hotel

- Train from Schiphol Airport to Utrecht Central Station (35 mins travel time)
- The Utrecht Central Station is a 5 minute walk from the hotel. From the train station you will walk into Hoog Catharijne Shopping Mall and from there you can follow the directions on the black sign boards towards our hotel. They will guide you to our hotel.
- If you need travel by bus, take the city Bus from Utrecht Central Station which departs at side of the 'Jaarbeurs' (e.g. bus 4 or bus 8) or regional Bus (e.g. 74) to bus stop 'Vredenburg'
- From the bus stop 'Vredenburg' to the Crown Plaza Hotel it is a 3 minute walk, please consult Google Maps

Traveling by car

Complimentary Daily Self-Parking is not available. Valet Parking is not available. Off-site parking at 2 minutes walking distance is available at a fee via Interparking. Pre-reserve parking at a discounted rate via parkerencentrumutrecht.nl/locaties-in-de-omgeving/parkeren-bij-crowne-plaza/. GPS address 'Daalsesingel'. Main entrance address: Daalsesingel, 3511 LC Utrecht. Exit the P5 parking garage via the escalators into Shopping Mall Hoog Catharijne. The entrance of the hotel is located directly opposite the exit of the P5 parking garage.



EU-CAYAS-NET Peer Visit to the Princess Máxima Center

Wednesday 24th of May

Introduction Long-Term Follow-up (LTFU) Care

Research into late effects and the translation of findings into approaches for long-term follow-up (LTFU) have been funded by EU and national initiatives in many EU countries, as well as largely voluntary international collaborations such as the International Harmonization Guideline Group (IGHG). Evidence-based clinical practice guidelines, developed by the International Late Effects of Childhood Cancer Guideline Harmonization Group and within European Union-funded PanCare projects (PanCareSurFup, PanCareLIFE, PanCareFollowUp, PanCareSurPass), are available to inform effective surveillance strategies for late adverse effects.

In addition, a survivorship care plan including a summary of cancer treatment and personalized recommendations for LTFU-care is endorsed as an important tool to increase knowledge and empowerment of survivors, oncologists and primary care providers. However, more action is needed to better inform survivors, their families and healthcare professionals about late effects and to ensure agreed standards of care for LTFU-care are not only agreed but actually implemented across Europe.

Despite the availability of guidelines, their use is inconsistent across Europe. Long-term follow-up (LTFU) care, although endorsed, is not available for the majority of adult survivors of childhood, adolescence and young adult (CAYA) cancer. Barriers to implementation include lack of time, knowledge, personnel and funding. Sustainable solutions are urgently needed to address the needs of CAYA cancer survivors to improve the quality of life and reduce the burden of late effects on survivors, health care systems and society.

During the three Peer Visits in Utrecht (Princess Máxima Center), Barcelona (Hospital Sant Joan de Déu) and Vienna (Medical University Vienna) the aim is to gain deeper and valuable insights into how in these hospitals LTFU care is organized, who is involved in the LTFU care and how healthcare professionals are educated. Furthermore we take a close look at how CAYA cancer survivors are informed about their treatment history, late effects and to what extent personalized care is provided to CAYA cancer survivor

Topics LTFU care

During day 1 of the Peer Visit the following topics regarding LTFU care will be covered:

- Organization of LTFU care
- Who is involved in LTFU care
- Training and education of LTFU-health care professionals
- LTFU care content
- Personalized care and shared decision making
- Information provided to CAYA cancer survivors

Practical information

Traveling to the Princess Máxima Center

On this day we will travel together with you. Cherine Mathot from PanCare (+31 6 16202438) will be guiding the Peer Visit participants from Hotel Crowne Plaza to the Princess Máxima Center. Please meet her at 11.15 hours at the lobby of the hotel.

The address of the Princess Máxima Center is Heidelberglaan 25, Utrecht

Public transport

The Princess Máxima Center is located opposite the Wilhelmina Children's Hospital (WKZ) in the Utrecht Science Park and is easily accessible by public transport.

- Walk from the hotel to Utrecht Central Station (5 minutes walking, please consult google maps)
- From Utrecht Central Station, tram 22 stops at the Princess Máxima Center.
- You get off at the second to last stop WKZ/Máxima, opposite the entrance of our center.
- Bus 28 also stops here.
- Visitors who go by car can park in P+R Utrecht Science Park can take tram 22 or bus 28 to the Máxima (one stop, journey takes 1 minute).

Location within the Princess Máxima Center

When you enter the Princess Máxima Center, you will be led to an elevator which is located at the end of the hallway on your left. Here you find someone of the organisation who will take you to the 6th floor. *Please note: the elevator only works with a badge, so you cannot go up and down on your own.* Please follow the sign 'kleine zaal' which will lead you in the right direction to attend the Peer Visit Programme.

Dinner

Please note that at the end of Day 1 we will travel together from the Princess Máxima Center to the restaurant. We meet at the entrance of the hospital at 18.30 hours.

Traveling with public transport

- From the Princess Máxima Center take tram 21, 22, or 23 to tram stop 'Vaartsche Rijn'.
- From this tram stop it is a 6 minutes walk to the restaurant, please consult Google Maps.

Traveling by car

It is a 15 minutes drive (depending on traffic) from the Princess Máxima Center to the restaurant. Please note that the restaurant has a parking lot (free parking).

Traveling from restaurant LE:EN back to the Crowne Plaza Hotel

- From the restaurant walk 3 minutes to bus stop 'Tolsteegplantsoen' (please consult google maps)
- Take bus number 8 to bus stop 'Vredenburg'
- From bus stop 'Vredenburg' it is a 3 minute walk to the Crowne Plaza Hotel (please consult Google maps). Please note the entrance of the hotel is inside Hoog Catherijne Shopping Centre.

Programme day 1: LTFU

12.30 – 13.30 **Lunch**

13.30 – 14.30 **Plenary session**

Welcome & introduction

Cherine Mathot, Jaap den Hartogh, Jeroen te Dorsthorst, Jikke Wams

General aspects about the Princess Máxima Center

Wouter Kollen

General aspects about the LTFU care clinic

Rianne Koopman

14:30 – 15.00 **Coffee break**

15:00 – 15:30 **Deep dive into LTFU care**

Introduction by PanCare

Helena van der Pal, Jeroen te Dorsthorst and Cherine Mathot

Pitches

Rianne Koopman, LTFU-specialist

Alied van der Aa, LTFU-psychologist

Herma Vermeulen, Nurse Specialist

Cherine Mathot, Survivor

Willemijn Plieger, Parent



15.30 – 17.15 **Round table sessions**

Find your table and ask anything you like!

17.15 – 17.25 **Break**

17.25 **Plenary closing session**

17.30 **Guided tour**

18.00 **Gather at entrance & travel to restaurant**

19.00 **Dinner at restaurant LE:EN**

EU-CAYAS-NET Peer Visit to the Princess Máxima Center

Thursday 25th of May

Introduction Transition

Transition of childhood and adolescent cancer survivors: An active, planned, coordinated, comprehensive, multidisciplinary process to enable childhood and adolescent cancer survivors to effectively and harmoniously transfer from child-centered to adult-oriented healthcare systems. The transition of care process should be flexible, developmentally appropriate and consider the medical, psychosocial, educational and vocational needs of survivors, their families and care-givers, and promote a healthy lifestyle and self management. Transition from follow-up care to long term survivorship care (5 years after diagnosis) as transition timepoints can be flexible.

Topics LTFU care

During day 2 of the Peer Visit the following topics regarding 'transition' will be covered:

Organization of care

- Patient pathways
- Multidisciplinary team
- Personalized care and shared decision making
- Resources
- Education health care professionals

Content of care

- Mental health & psychosocial support
- Lifestyle & self management
- Education & employment
- Insurance, finances, legal assistance
- Fertility and sexual health

Practical information

Traveling from Crowne Plaza to the Princess Máxima Center

Please check-out of the hotel in the morning. Your luggage can be safely stored at the Princess Máxima Center.

Public transport

The Princess Máxima Center is located opposite the Wilhelmina Children's Hospital (WKZ) in the Utrecht Science Park and is easily accessible by public transport.

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- You get off at the second to last stop WKZ/Máxima, opposite the entrance of our center.
- Bus 28 also stops here.
- Visitors who park in P+R Utrecht Science Park can take tram 22 or bus 28 to the Máxima (one stop, journey takes 1 minute).

Traveling from the Princess Máxima Center to Schiphol Airport

- It takes approximately 1,5 hours to travel from the Princess Máxima Center to Schiphol Airport.
- Please be mindful of check-in times at the airport and adjust your travels accordingly
- Take the tram to Utrecht Central Station (e.g. tram number 20)
- Take the train from Utrecht Central Station to Schiphol Airport. Your public transport ticket is not applicable for train use, please purchase a train ticket.

Programme day 2: Transition

8:30 – 9:00 **Registration**

9:00 – 10:00 **Plenary session**

Welcome & introduction

Jaap den Hartogh & Jikke Wams

Transition explained

Andrica de Vries (paediatric oncologist) & Herma Vermeulen (nurse practitioner)

Martha Grootenhuis (head of Psychology department) & Alied van der Aa (late effects psychologist)

Annemiek Kuijer (parent representative) & Dewi Jill van den Heuvel (survivor representative)

Q&A

10:00 – 10:30 **Break**

10:30 – 12:30 **Open Space Session about transition**

Led by Ismay de Beijer (PhD-candidate & open space expert)

12:30 – 12:45 **Closing session**

12.45 – 13.30 **Lunch**



Peer Observation Form Instructions

Below you will find the Peer Observation Form, which we ask you to fill in during the Peer Visit. Please read the following instructions carefully. You can choose to fill out the paper version of Peer Observation form or the digital version. When filling out the paper version of the Peer Observation Form it would be of great help if your handwriting is clear and readable in order for an effective analysis to be carried out afterwards. If writing down the answers poses difficulties for you and filling out the form digitally is not possible either, please let us know. We would like to emphasize that the filled out Peer Observation Form remains anonymous. We also kindly request to not mention any names/persons you have received information from in order to fill in the Peer Observation Form.

- Read through all the questions beforehand to get an idea of what you can pay attention to during the two days.
- There is a set of questions for Day 1 LFTU care and for Day 2 Transition.
- Please note that there is also a set of general questions to be answered at the end of the Peer Observation Form.
- You are welcome to write down any additional questions or answer options, observations and notes.
- You as a Peer Visit Participant remain anonymous when filling the Peer Observation Form. We kindly ask you to not write down any names/persons when having received information in order to fill out the Peer Observation Form.

How to use the Peer Observation Form?

The Peer Observation is meant to be used to guide conversations, to help formulate questions and to provide a structure for documenting observations during peer visits to oncology centers serving childhood and adolescent patients across Europe. Answers might be gathered through various activities during peer visits, such as:

- Interactive guided tours at the collaborating institution
- One-on-one interviews with healthcare providers (doctors, nurses and other HCP), patients, or members of the hospital management team
- Round table-sessions
- (External) meetings with stakeholders or other NGOs that support the collaborating institution
- Informal meetings with local young people living with and beyond cancer and/or their families who were treated in the visited institution

This Peer Observation Form consists of three parts:

- 1.Observation Long term Follow-Up care
- 2.Observation Transition
- 3.Observation General hospital aspects

List of abbreviations / Explanation of terms

AYA: Adolescent and young adult

CCS: childhood cancer survivor

QOL: quality of life

LTFU: long-term follow-up

Survivors: those who were diagnosed with cancer at the age of being a child, adolescent or a young adult and are alive 5-years after the treatment

LFTU care: long term follow-up care for survivors

LFTU care clinic: special department for long-term follow-up care for survivors

Room to use your creativity



European Network of
**YOUTH CANCER
SURVIVORS**



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