

Syllabus



2024

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Preface

In the Netherlands, pediatric oncology care has been successfully concentrated, integrating care and research for children with cancer in a unique way. This has been made possible in part by cooperation with the Shared care hospitals, working together every day to provide the best possible care for children with cancer and their families.

This successful collaboration forms the basis for the SKION & Shared care days, the platform where professionals in pediatric oncology come together to exchange valuable knowledge, share experiences and attend inspiring workshops. We also dive into the latest developments in clinical trials and other innovations within our field.

This year's theme is 'Balancing'. Here we focus on dealing with dilemmas and issues in healthcare; a topic that touches both the heart and mind of healthcare professionals. It is like navigating through a complex maze where every turn is a choice between conflicting values. Let's explore this fascinating topic together!

Program

1. Overview of studies and guidelines

First, we present an overview of studies and guidelines for hemato-oncology, quality of life, neuro-oncology, solid tumors and immunotherapy. The goal is to make this information accessible to a broader audience within oncology care.

2. Workshops

During the workshops we cover topics relevant to all professionals in the Princess Máxima Center, the Shared care centers and beyond. This year we are offering several workshops ranging from "prevention of nausea" to "nutrition vision" and a workshop on grief-balancing between different cultures.

We realize that it can be challenging to fit time into your busy schedules, while the need for interdisciplinary knowledge and education remains high. Therefore, we have asked the four disciplines within pediatric oncology - hemato-oncology, neuro-oncology, solid tumors and quality of life - to put together an exciting and comprehensive program over two days. Visitors to the SKION & Shared care days will be updated on all relevant developments within pediatric oncology in the Netherlands and abroad.

Don't miss out: We conclude the official program on the first day with a walking dinner and a special theater performance by our colleagues and theater group BINT – highly recommended!

With this program we hope to offer you a varied and exciting experience with plenty of room for your active participation. We look forward to welcoming you on November 28 and 29, 2024.

Kind regards,

On behalf of the committee of the SKION & Shared Care days,

Marc Bierings, Marc Vincent, Hans Merks, Natasja Dors and Renske Karens

Schedule SKION & Shared care days – November 28

08:30 - 09:00	Walk-in		
09:00 - 09:30	Welcome Marc Vincent		
09:30 - 10:15	Metro Map SKION Sharishna Krishnadath Wim Tissing		
10:15 - 10:45	Break		
10:45 - 12:15	Update hemato-oncology	10:45 - 12:15	Workshop: Nausea prevention Aeltsje Brinksma, Els Haverkate, Marianne van de Wetering, Eveline Vos & Muriël Bakker Workshop: Sustainability in healthcare and in practice in the Princess Máxima Center Joost Bennekens Workshop: Effective techniques for stress, pain and anxiety reduction Brieke Hampsink & Richard Kop Care follows the patient: continuing the search to the best place of care Natascha Kok
12:15 - 13:30	Lunch break		
13:30 - 15:00	Update neuro-oncology	13:30 - 15:00	Workshop: AI in action: trust and application in tomorrow's healthcare Judith Von Reeken Workshop: Nausea prevention Aeltsje Brinksma, Els Haverkate, Marianne van de Wetering, Eveline Vos & Muriel Bakker Workshop: Shared Decision Making in children prior to malignant bone tumour surgery Kiki Blom & Peter Bekkering Workshop: Vision on nutrition Nina van der Linden
15:00 - 15:30	Break		
15:30 - 16:45	Preperations theatre performance (no meeting in the Auditorium)	15:30 - 16:45	Workshop: Mindfulness work-life balance Kees van de Ven & Rianne Maille Workshop: Acupuncture Miranda Dierselhuis & Djien Liem Workshop: A child with cancer in motion, what can you do? Team physiotherapy Prinses Máxima Centrum

National Shared Care Commission

Network meeting: Dietetics

Guided tour Princess Máxima Center

16:45 - 17:00 Walk-in theatre performance

**17:00 - 18:00 Theatre performance
'Hoogvliegers'**

18:00 - 19:30 Walking dinner

Schedule SKION & Shared care days – November 29

08:30 - 09:00	Walk-in		
09:00 - 09:15	Welcome Natasja Dors		
09:15 - 10:45	Update solid tumours	9:15 - 10:30	<p>Workshop: To include or not include a patient? Charlotte van Aart, Miranda Dierselhuis & Ilse Stolte</p> <p>Workshop: If no agreement is reached about treatment Babet Drenth & Florian van Woerden</p> <p>Workshop: Escaperoom acute paediatric oncology Bianca van Rossum, Jan Loeffen, Indra Morsing, Richard Kop & Stephanie Janssen</p> <p>Workshop: Balancing under pressure, each in their own place Loes Everts & Jacqueline 't Spijker</p> <p>Workshop: 3D printing of tablets Rogier Lange</p> <p>Network meeting: Communication</p>
10:30 - 11:15	Break		
11:15 - 12:45	Update quality of life	11:15 - 12:30	<p>Workshop: Grief - balancing between different cultures Saïda Aoulad Baktit</p> <p>Workshop: Listening Elise Steenbergen & Caroline Lavell</p> <p>Workshop: Escaperoom acute paediatric oncology Bianca van Rossum, Jan Loeffen, Indra Morsing, Richard Kop & Stephanie Janssen</p> <p>Workshop: Balancing under pressure, each in their own place Loes Everts & Jacqueline 't Spijker</p> <p>Workshop: AI in action: trust and application in tomorrow's healthcare Myrthe Buser</p>
12:30 - 13:30	Lunch break		

13:30 - 14:45 Network care

13:30 - 14:45 **Workshop: Grief - balancing between different cultures**
Saïda Aoulad Baktit

Workshop: Effective techniques for stress, pain and anxiety reduction
Brieke Hampsink & Richard Kop

Workshop: Escaperoom acute paediatric oncology
Bianca van Rossum, Jan Loeffen, Indra Morsing, Richard Kop & Stephanie Janssen

Workshop: Mindfulness | work-life balance
Kees van de Ven & Rianne Maille

Network meeting: NVK
Annelies van Mavinkurve

Tour Princess Máxima Center

14:45 - 15:15 Break

15:15 - 16:15 **Key speaker Maryse Spapens**

16:15 - 16:30 **Conclusion**

16:30 - 18:00 **Networking drinks**

Basic registry

Since 2003, all children between the ages of 0 and 18 with a (pre-)malignant condition are registered in the Basic Registry. Between 2019 and 2023, an average of 601 new primary diagnoses per year were registered. In 2023, the most recent complete year, 579 new primary diagnoses were registered.

Figure 1 shows the distribution of diagnoses, defined per ICCC-3 main class, registered in the Basic Registry over the years 2019-2023. Figure 2 shows the average number of diagnoses, per ICCC-3 subclass, registered in the Basic Registry over the years 2019-2023.



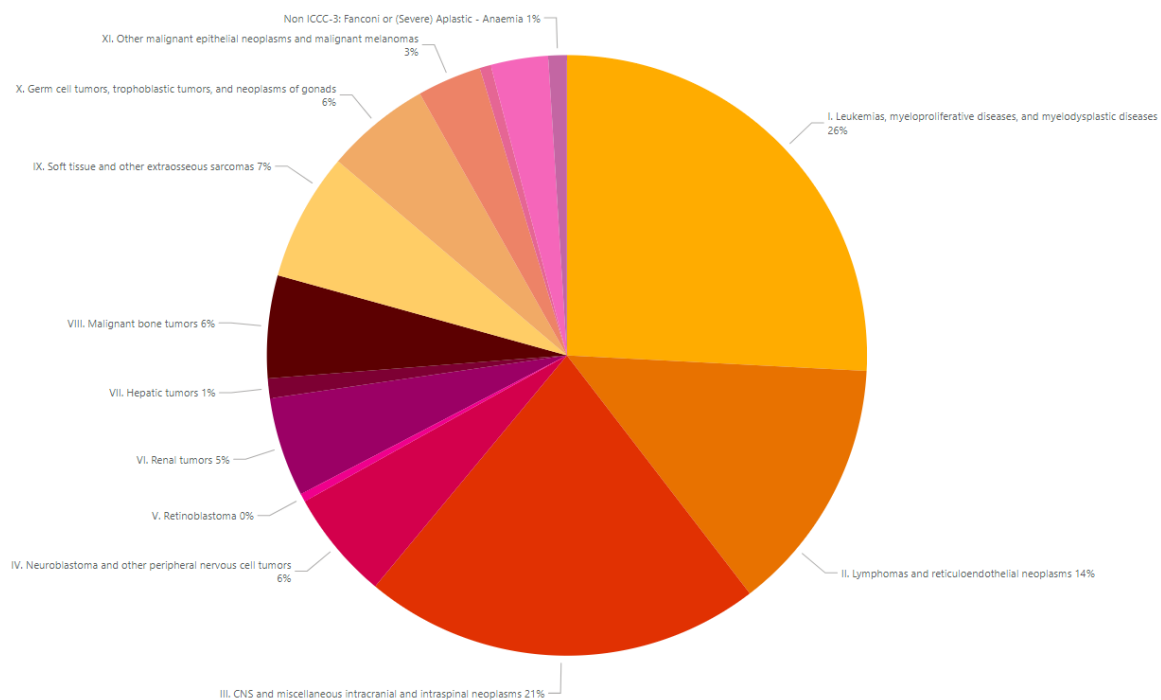


Figure 1. Distribution of diagnoses in the Basic Registry 2019-2023 broken down by ICCC-3 class (Prinses Máxima Centre, 2024).

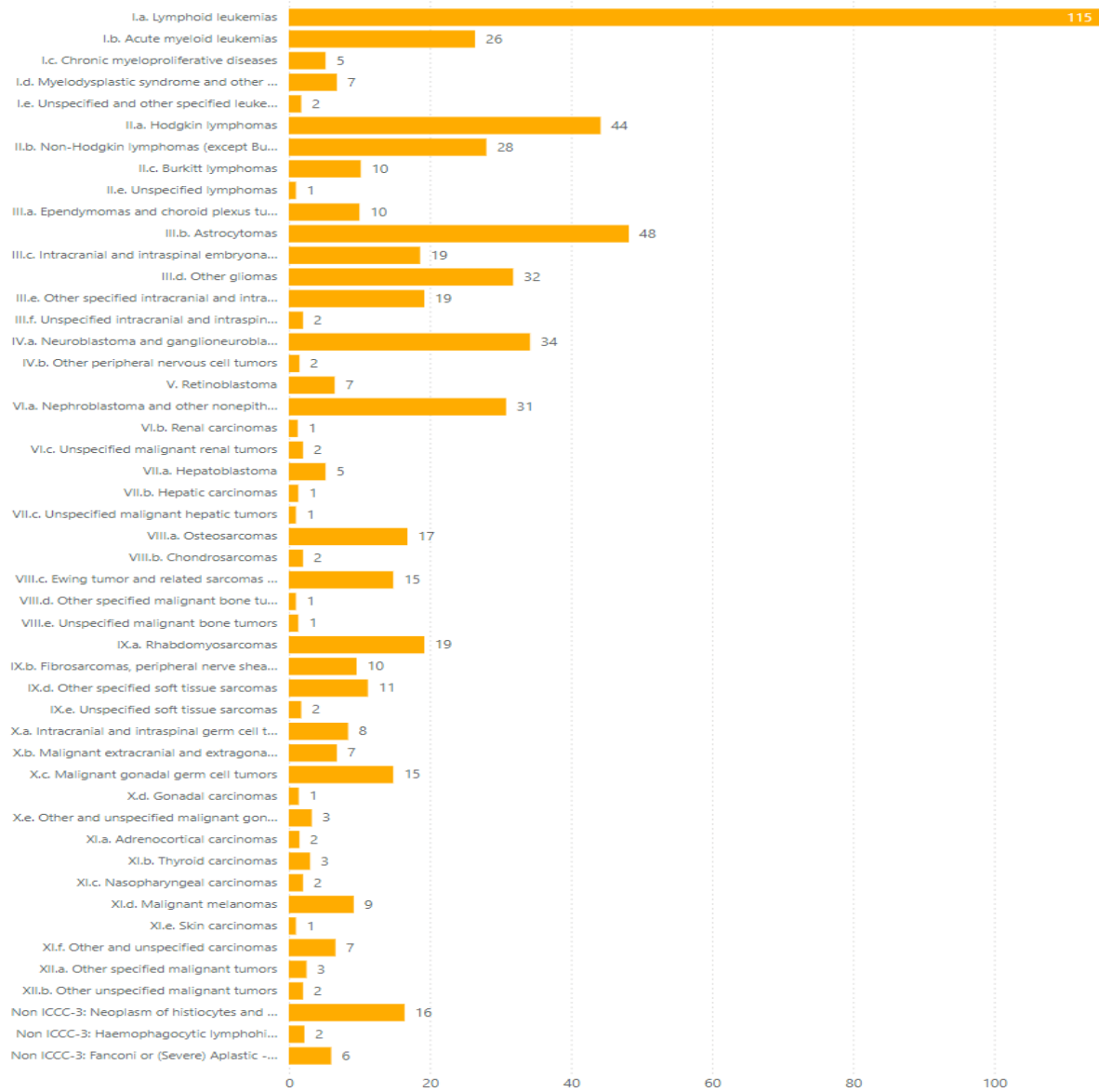


Figure 2. Average number of registered cases per year in the Basic Registry 2019-2023 broken down by ICCC-3 subclass (Prinses Máxima Centre, 2024).

More detail?

Go to http://tiny.cc/SKION_BR_Visual

Guidelines

SKION's mission is to promote the quality of diagnosis, treatment and follow-up of children and adolescents with cancer. One of our main tasks is to objectively monitor the quality of standard care by authorizing national guidelines and evaluating existing guidelines. To achieve our mission, guidelines and evaluation of healthcare are very important.

To establish and evaluate guidelines, the SKION Raad has been established. This is a council consisting of 29 multidisciplinary professionals working in pediatric oncology. The council's tasks include advising on the establishment of guidelines. Once approved, these guidelines are published online and apply as national guidelines.

For an up-to-date overview of national guidelines in pediatric oncology, please visit the [SKION website](#). Documents on guideline development and guideline review can also be found on [the SKION website](#).

Guidance for the process of guideline development by SKION

A core task of SKION is to establish national guidelines for diagnosis, treatment and follow-up. In practice, this means that SKION provides process guidance to healthcare professionals during guideline development.

SKION understands the challenges healthcare professionals in pediatric oncology face when writing guidelines. Our structured approach and clear steps are designed to support healthcare professionals and make their work easier. SKION has offered support in streamlining the guideline development process since 2024. This reduces the time and effort required to achieve effective practice and speeds up the process from concept to publication.

Types of guidance

We offer various types of process guidance, tailored to the specific needs of healthcare professionals. For example, we can perform an **assessment** of existing (international) guidelines, identifying which elements are missing in order to evaluate the guideline and convert it into a SKION guideline. This saves time for healthcare professionals and enables them to work in a goal-oriented way. This assessment can also be combined with process guidance, so that healthcare professionals not only gain insight into what they need to do, but also receive support in an efficient approach. We recently performed an assessment for the guidelines osteosarcoma and Fanconi anemia. Both guidelines will be updated based on the findings and monitored annually. This periodic review provides insight into the compliance, impact and quality of the guidelines and allows us to make any improvements so that they remain in line with the latest scientific development and the needs of both healthcare professionals and patients.

In addition, we provide **full process support** from start to finish. This is currently happening, for example, in the drafting of the liver tumor guideline. This support includes regular meetings with the guideline authors, in which we evaluate progress, discuss bottlenecks and determine follow-up steps together using the SKION formats. This frequent coordination allows us to identify obstacles in a timely manner and adjust the process where necessary. By doing so, we not only create clarity about the steps to be taken, but also ensure that the entire process keeps moving in the right direction. This contributes to the smooth development and publication of new guidelines. The process for the liver tumor guideline started about five months ago and the guideline authors expect to submit it soon.

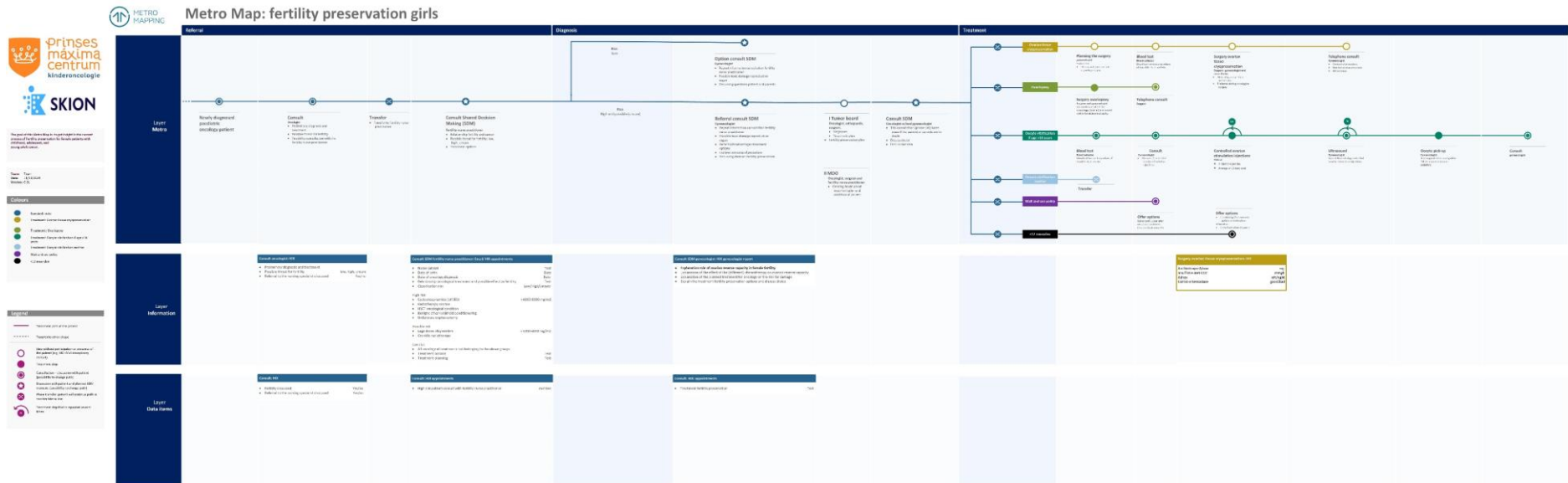
Finally, there is the option for **process guidance with the support of the Metro Map**. The Metro Map is an important tool in our process guidance. It is a design method for mapping the healthcare pathway. This visual representation of the pathway is created together with the healthcare professionals and provides a clear overview of the different steps in the care process, from diagnosis to follow-up. This contributes to the guideline drafting process by providing a unified frame of reference, which helps to identify and prioritize elements to be included in the guideline. In addition, two essential components are added to the Metro Map during the guideline drafting process. The first concerns the information recorded by the healthcare professional in the electronic patient record, among others. The second component involves data evaluation points. These stem from guideline recommendations and are needed to evaluate a guideline. The Metro Map "Fertility preservation girls" is shown on page 12 (enlarge the page to read the details).

Clearly defining information points will make it easier to find healthcare data, simplifying guideline evaluation. Evaluation and revision of guidelines are essential components of promoting quality of care. Revision can be based on the conclusions of the evaluation, new insights from the literature or findings from practice.

Are you interested in writing a guideline?

Are you considering writing a guideline, but don't know where/how to start? Feel free to contact us at bureauskion@skion.nl.

In an exploratory meeting we will explore the possibilities together and discuss which form of support is appropriate. We are happy to help you in this process!



*Click [here](#) to see the MetroMap full screen.

Evaluationdesk

The evaluation of guidelines is one of SKION's core work activities. Current (international) studies focus in quality evaluation mainly on progress in research. SKION goes a step further by involving, in addition to research, clinical practice as well as registered care (care data) in the evaluation of a guideline. Based on predefined criteria, measurements can be performed on anonymized and aggregated data that contribute to evaluating the quality of a guideline. The SKION evaluation desk supports professionals in formulating evaluable guidelines. These are guidelines in which compliance, effect and quality can be defined using healthcare data.

Together with healthcare professionals (i.e. the authors of a guideline) evaluation indicators are determined for each guideline and an inventory is made of the system in which the required information is registered. This already happens in the development phase of a guideline. The indicators relate to specific quality aspects. These aspects focus primarily on the question whether provided care is in accordance with established agreements (adherence and deviation) and what the effect of a guideline is on a specific patient population (outcome).

After a guideline has been authorised, the data from various healthcare information system is collected. The collected data is then analysed by the clinical data scientists and translated into an evaluation report. Together with the authors of the guideline, the results are explained and interpreted. What do they mean? Are the results as expected? At this point, points of improvement are determined, after which the cycle starts all over.

Below some examples of guidelines in which the evaluation desk was involved lately:

- Febrile neutropenia (2024)
- Fertility preservation in boys (2023)
- Fertility preservation in girls (2024)
- Incidentaloma (2024)
- Osteosarcoma (2024)

Results of the first 10 guidelines (among the above) are expected at the end of 2024, by means of a baseline measurement. This baseline measurement maps the current situation, the inventory forms the starting point of the improvement process. At the beginning of 2025, these results will be discussed with the involved healthcare professionals (the authors / guideline working group).

Reach out to us if you have any questions about evaluating guidelines. You can contact us via bureauskion@skion.nl or visit the SKION office located in the Prinses Máxima Centre (room number 6-4 W1).

SKION-approved guidelines since 2021

In 2021, a standard was developed for assessing and establishing SKION guidelines. (i.e. national guidelines in paediatric oncology). Below you can find an overview of the SKION-guidelines that have been approved since 2021.

Treatment guideline: symptomatic radiation necrosis of the central nervous system in children by using Bevacizumab (2021)

[The guideline](#) describes the treatment of symptomatic radiation necrosis in the central nervous system of children as a result of radiotherapy. Radiotherapy is an important part of the treatment of most brain tumours in children. A severe complication of radiotherapy is radiation-induced brain necrosis (RBN). RBN occurs after radiotherapy has been completed, usually months or sometimes even years later. The guideline describes recommendations for the use of Bevacizumab in the treatment RBN in children.

Treatment guideline acute GvHD in paediatric SCT patients (2021)

[The guideline](#) describes the treatment of acute graft-versus-host disease (GvHD) occurring after allogeneic stem cell transplantation (SCT). It classically presents in the first months after allogeneic SCT and manifests in one or more of the following three organ systems: skin, liver and digestive tract. First-line treatment consists of immunosuppression. However, this guidelines focuses on second-line treatment, when steroids don not work (sufficiently). The guideline was developed to provide uniform and unambiguous advice on the second-line treatment of acute GvHD and to evaluate the recommended treatment options for this rare condition. The guideline was developed by both Dutch paediatric allo-SCT centres, LUMC and Princess Máxima Centre.

Guideline use of Glucarpidase in high-dose methotrexate-induced acute kidney insufficiency resulting in delayed methotrexate clearance (2022)

[The guideline](#) focuses on the treatment of patients with a delayed methotrexate clearance due to high-dose methotrexate (HDMTX)-induced acute kidney insufficiency. Treatment with HDMTX is an important part of the treatment of paediatric oncology patients in hemato-oncology, solid oncology as well as neuro-oncology. A serious complication of the treatment with HDMTX is acute kidney insufficiency (AKI), leading to delayed MTX clearance ('MTX intoxication'). Untreated HDMTX intoxication is a serious, potentially life-threatening condition, given the side effect profile of MTX (e.g. severe bone marrow suppression, mucositis, diarrhoea, hepatotoxicity). To prevent this, the guidelines recommends the use of Glucarpidase as antidote.

Severe aplastic anaemia (2022)

[The guideline](#) is based on the European EWOG SAA guideline and includes recommendations for diagnosis and treatment of SAA. Aplastic anaemia (AA) is defined as pancytopenia in combination with a hypo cellular bone marrow. The bone marrow is often characterized by replacement of healthy marrow cells by fat tissue, as well as lymphocytosis. SAA and hypoplastic myelodysplasia have been notoriously difficult to distinguish. Therefore, treatment should be weighed involving experienced diagnostic experts, and doctors experienced in both chemotherapy/immunosuppressive therapy and stem cell transplantation. The guideline was developed by the M4C bone marrow failure and myelodysplasia in collaboration with the diagnostic lab, the stem cell transplantation unit and the Trial and Data Centre of the Princess Máxima Centre for paediatric oncology.

Palliative care for children (2022)

[The guideline](#) is a revision of the 2013 guideline and is intended for all healthcare providers who deal with children in the palliative phase (including in paediatric oncology). The aim of the guideline is to improve care for children in the palliative phase by formulating recommendations aimed at organisation of care, decision making, communication and coordination, psychosocial care, mourning and aftercare and symptom control. The guideline consists of sixteen sub-guidelines, every sub-guideline contains separate recommendations for a specific part of the care for children in the palliative phase. The guideline is developed by experts in the field of palliative care (in paediatric oncology), guideline development and patient representatives. In addition, professionals with additional expertise were involved in the development of the sub-guidelines.

Oral care for children with chemo and/or radiotherapy or with reduced immune functions (2022)

[The guideline](#) includes recommendations for preventive and curative treatment of mucositis in children undergoing chemotherapy and/or radiotherapy or children with reduced immune functions. The guideline was developed by researchers and healthcare professionals working at the Princess Máxima Centre, in collaboration with dentists and dental hygienists from the Wilhelmina Children's Hospital and (representatives) of parents.

Isavuconazol for the treatment of fungal infections (2022)

[The guideline](#) includes recommendations for the use of Isavuconazol as second-line drug in the treatment of and as prophylaxis for fungal infections in children. The guideline is developed under supervision of the M4C Supportive Care, part of the department Quality of Life of the Princess Máxima Centre.

Follow-up after childhood cancer, more than 5 years after diagnosis (2023)

[The guideline](#) is an update of the SKION LATER guideline (2010) and is focused on care for survivors of childhood cancer who are in remission for more than 5 years after diagnosis. The guideline is intended for survivors of childhood cancer and their care providers who are involved in the follow-up. This LATER guideline was developed by a project group from the Princess Máxima Centre, in collaboration with healthcare providers from the outpatient clinic LATER RadboudUMC and LUMC. In addition, feedback was requested from two delegates from Vereniging Kinderkanker Nederland (i.e. the Dutch patient and parent association). The availability of a national guideline will enable healthcare professionals to provide high quality of care to all survivors of childhood cancer in the Netherlands.

Fertility preservation in boys with cancer (2023)

[The guideline](#) is developed for fertility preservation in male patients <25 years of age, in children, adolescents and young adults. The recommendations in the guideline include the assessment of the risk of fertility disorders and the provision of available methods for fertility preservation. For groups at high risk of reduced fertility, the steps for fertility preservation are described. This guideline on fertility preservation will, hence, contribute to a better quality of life. The recommendations were proposed by the EU-funded research project PanCareLIFE in collaboration with the International Guideline Harmonisation Group (IGHG) on late effects of childhood cancer.

Fertility preservation in girls with cancer (2024)

[The guideline](#) is developed for fertility preservation in female patients <25 years of age, in children, adolescents and young adults. The recommendations in the guideline include the assessment of the risk of fertility disorders and the provision of available methods for fertility preservation. For groups at high risk of reduced fertility, the steps for fertility preservation are described. This guideline on fertility preservation will, hence, contribute to a better quality of life. The recommendations were proposed by the EU-funded research project PanCareLIFE in collaboration with the International Guideline Harmonisation Group (IGHG) on late effects of childhood cancer.

Febrile neutropenia (2024)

[The guideline](#) is developed to optimize the treatment of children with febrile neutropenia. Fever during neutropenia (febrile neutropenia) is one of the most common side effects of the treatment of children with cancer. It can be a manifestation of an infection in children being treated for cancer. When not treated properly/adequately, a child can suffer from (serious) consequences of a bacterial sepsis, such as prolonged hospital stay, ICU admission or even death. The guidelines includes recommendations for both starting and stopping antibiotics. The implementation of the recommendations in practice will be evaluated using evaluation indicators. In this way, we can further improve the treatment of children with febrile neutropenia in the future.

Studies

An overview of current studies within paediatric oncology is shown below. More detailed information about each study is shown in the appendix of this syllabus, available on [our website](#).

- 5-ALA in children and adolescents
- ALCL-VBL
- ALL SCTped FORUM 2012
- ALLTogether01
- EsPhALL2017 COGAALL1631
- TDC KWF Caterpillar
- APAL2020D - Venetoclax AML
- VACCinATE
- ATRT01
- Fanconi Anemie
- Da Vinci Trial
- Randomet
- EWOG MDS'06
- LuDO-N
- EWOG SAA 2010
- FaR-RMS
- iCML-Ped
- VERITAS
- PHITT
- MAKEI-V
- LCH-IV
- HR-NBL2
- Umbrella
- NB-SCI
- CHIP-AML22
- PNOC022 DMG
- HIT-HGG-2013

- SIOP PNET 5 MB
- LOGGIC Core
- SIOP Ependymoma II
- IntReALL SR
- SIOP HRMB
- Euronet C2
- ICC APL study 02
- ML-DS 2018
- LBL2018
- Pro-Teico
- IntReALL HR
- NIVO-ALCL
- Interfant-21
- FU poli botsarcomen
- Near Infrared
- Testis biopsy/PRINCE
- QoL NEMO
- QoL Thyrodynamics
- Sensory-2
- Parel
- ENERGICE
- QoL Early
- Micado-2
- EndoWatch-I - KWF 14984
- HAPPYthalamus
- SIMBA - Kika 450
- LATER IZP
- Follow-on study
- CONTACT/Optimaliseren diagnosegesprek
- BSI prediction - VIKinG

- Symptom ap/Approach - sponsor
- Watch Us Move
- VANISH
- Educational priorities
- LATER MetVasA - Kika 433
- KinderOnconet
- Pilot ademonderzoek
- SPACE
- OpKoersOnline
- PrediCT
- Pinocchio
- LTF-304
- ALD 104
- PAVO studie - CCTL019A2205B
- SDM bottumoren
- RELIVE
- PanCareSurPass WP1
- DIAMONDS
- - Dulamp
- CIP
- Dabrafenib roll-over
- LOGGIC Firefly-2 Europe
- 7T MITCH
- PanCareFollowUp
- AML slaap studie
- NOPHO-DBH AML 2012
- ALL 11 222
- RM-493-040 Setmelanotide
- FOCUS
- The Drug Access Protocol



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