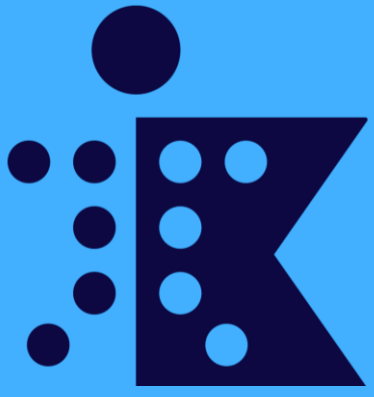
Syllabus



2026

Contents

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 'Pass it on'. An inspiring gathering for healthcare professionals about sharing or transferring knowledge. With a focus on permanent education as foundation for continuous quality improvement, in order to improve care.

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 "stress, pain and anxiety reduction" to 'AI in psychosocial care, a curse or a blessing".

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 an interview with Edward Nieuwenhuis, Chief Medical Officer at the Princess Máxima Center since early 2025. 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 February 5 and 6, 2026.

Kind regards,

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

Marc Bierings, Marc Vincent, Hans Merks and Natasja Dors

Schedule SKION & Shared care days

The program can be seen on the event website. Scan the QR code to see the program:

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 2020 and 2024, an average of 614 new primary diagnoses per year were registered. In 2024, the most recent complete registered year, 525 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 2020-2024. Figure 2 shows the average number of diagnoses, per ICCC-3 subclass, registered in the Basic Registry over the years 2020-2024.

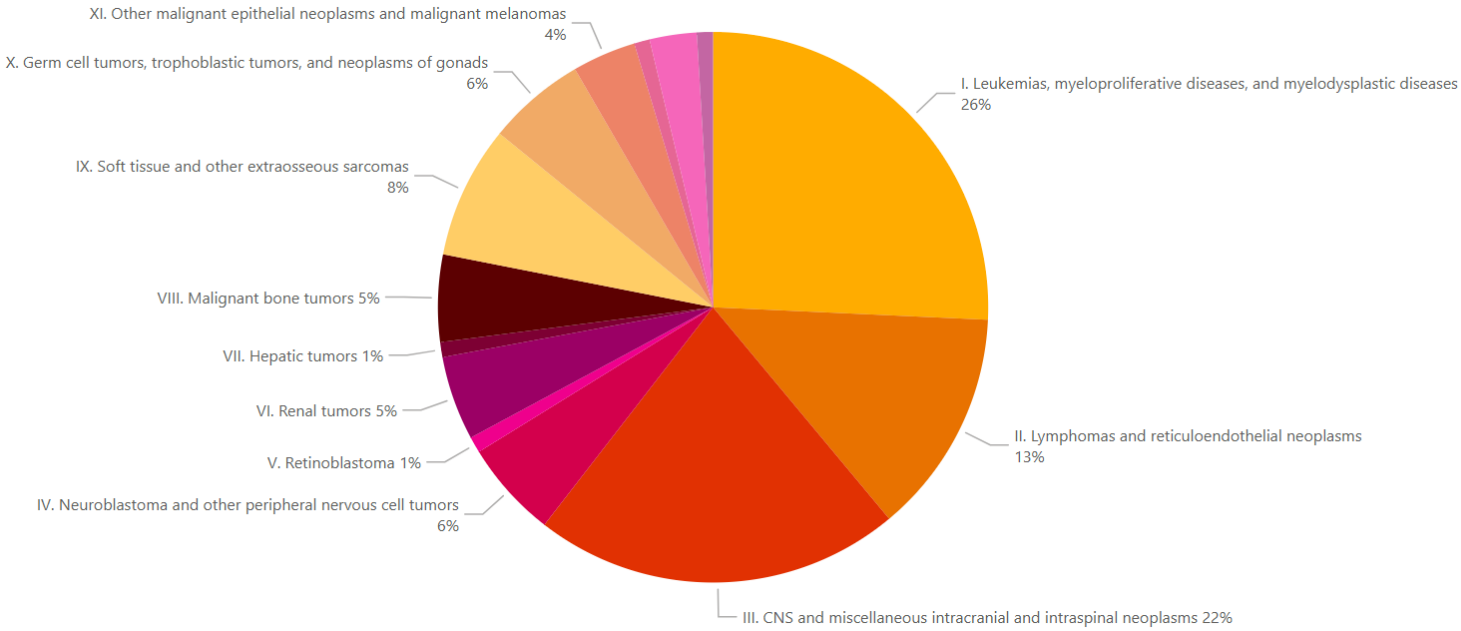


Figure 1. Distribution of diagnoses in the Basic Registry 2020-2024 broken down by ICCC-3 class (Prinses Máxima Centre, 2026).

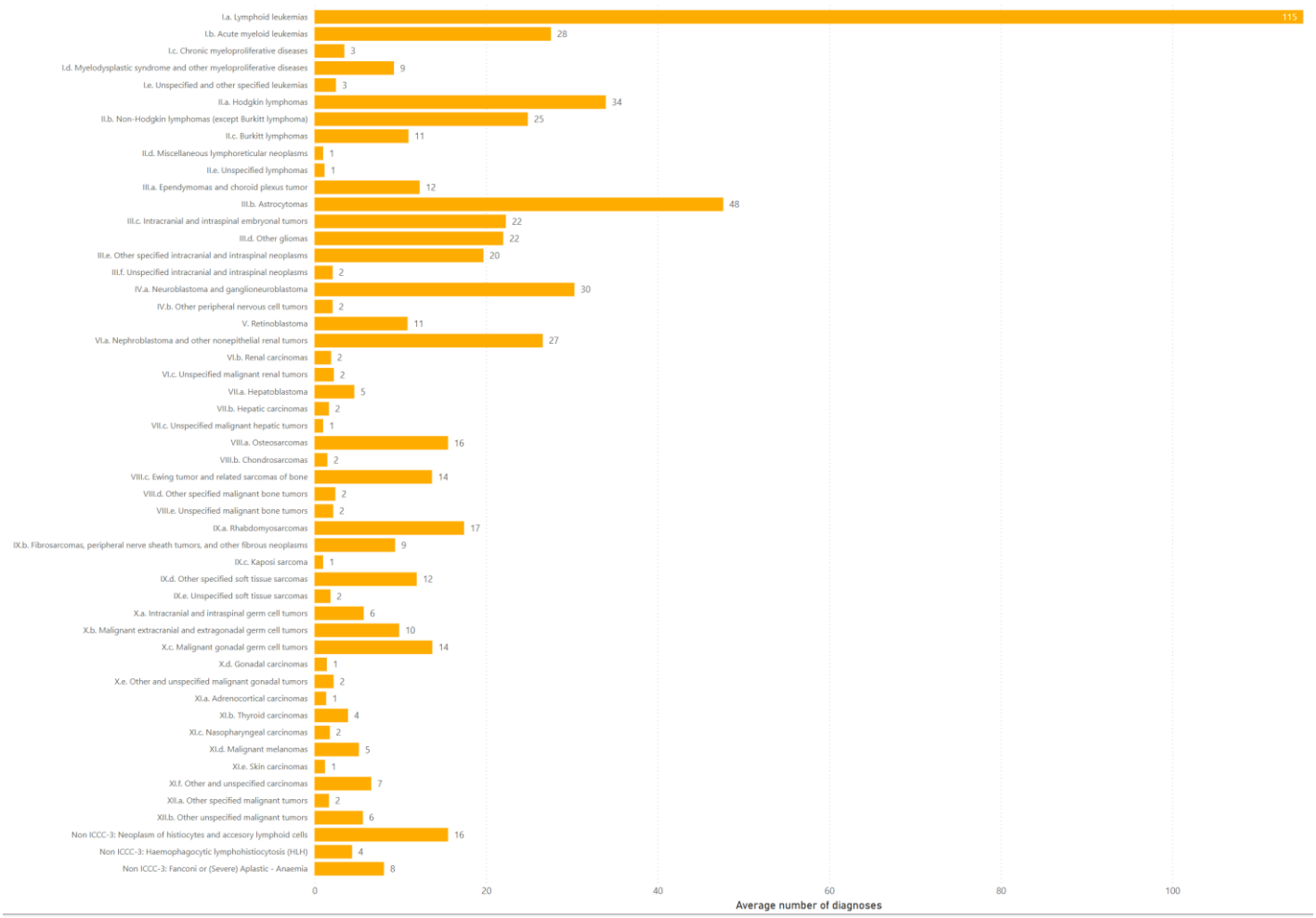


Figure 2. Average number of registered cases per year in the Basic Registry 2020-2024 broken down by ICCC-3 subclass (Prinses Máxima Centre, 2026).

More detail?
Scan the QR code

Guidelines

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 fort he 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 en 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 guideljne 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.

Diagnosis, treatment, and follow-up of patients with Fanconi anemia in the Netherlands (2025)
The guideline focuses on Fanconi anemia (FA). This is a rare condition in which DNA damage is more difficult to repair. This guideline follows the life stages of a patient with FA and guides healthcare provision during these different phases. The Utrecht team describes key considerations and procedures, with input from experts. By evaluating the practical application of this guideline, SKION aims to achieve optimal care for children with FA.

Management of childhood central nervous system incidentaloma (2025)
The guideline focuses on incidentalomas. These are lesions in the central nervous system that are suspicious for a neoplasm. The lesions are discovered incidentally on an MRI performed for other reasons. With the increasing use of MRI, incidental findings are becoming increasingly common. The aim of this guideline is to standardize the care of children with incidentalomas within the pediatric oncology setting. The recommendations from the guideline are being evaluated to improve care.

Treatment decisions and choice of systemic treatment for low-grade glioma in children (2025)
This guideline focuses on the treatment of low-grade gliomas (LGG). These are brain tumors that can occur anywhere in the central nervous system. Various treatment strategies are available for LGG in children, ranging from observation to surgery and/or systemic therapy. The guideline describes the indications and considerations for the use of various treatment modalities. The recommendations are being evaluated to improve the care of children with LGG.

Overview of guidelines

An overview of the various guidelines (per condition/area of interest) can be found on our website. Scan the QR-code below to see the guidelines.

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 Sharishna Krishnadath or Marilyn Diks, via richtlijnenkinderoncologie@prinsesmaximacentrum.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!

Evaluationdesk

Evaluation of guidelines is as important as the establishment of it. Current (international) studies focus in quality evaluation mainly on progress in research. The Princess Máxima Center 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 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 guidelines 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 (2024-2025)
- Fertility preservation in boys (2023-2025)
- Fertility preservation in girls (2024-2025)
- Glucarpidase (2025)
- Incidentaloma (2024-2025)
- JMML (2025)
- LGG (2024-2025)
- MDS (2025)
- Oral care (2025)
- Osteosarcoma (2024)
- SAA (2025)

Reach out to us if you have any questions about evaluating guidelines. You can contact us via richtlijnenkwaliteit@prinsesmaximacentrum.nl.

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.

- SIOP Ependymoma II
- SIOP HRMB
- ICC APL study 02
- Da Vincy Trial
- LOGGIC Core
- 5-ALA in children and adolescents
- ATRT01
- FASTigial
- MAKEI-V
- PNOC022 DMG
- Randomet
- LuDO-N
- FaR-RMS
- Umbrella
- HR-NBL2
- ML-DS 2018
- LBL2018
- CHIP-AML22
- APAL2020D - Venetoclax AML
- ALCL-VBL
- Interfant-21 - KWF 15388
- Pro-Teico
- IntReALL HR
- ALLTogether01
- LCH-IV
- EWOG SAA 2010

- EWOG MDS'06
- Fanconi Anemie
- The Drug Access Protocol
- FOCUS
- 7T MITCH
- LOGGIC Firefly-2 Europe
- Dabrafenib roll-over
- CIP
- Dulamp
- CO-IMPACT
- RELIVE
- SDM bottumoren
- PAVO studie - CCTL019A2205B
- LTF-304
- Pinocchio
- Pilot ademonderzoek
- INTERACT - Kika 429
- KinderOnconet
- LATER MetVasA - Kika 433
- Educational priorities
- VANISH
- Symptom ap/Approach
- Hercules – sponsor
- Follow-on study
- ERNIE (iBrain) - sponsor
- SIMBA - Kika 450
- QoL NEMO
- Testis biopsy/PRINCE

- FU poli botsarcomen
- FITco
- TRINGQS study - Kika 448
- EndoWatch-II - KWF 14984
- EthPOiB
- KiKa 416 Identify
- Belumosudil ROCKNROL1 EFC17757
- PROMIS II KiKa 449
- FU Sensory-2 – sponsor
- Astronaut study
- KOMPAS

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