

SOP: Tumor conferences via the Clinical Patient Management System (CPMS) of the European Reference Network PaedCan (ERNPaedCan) for children with CNS tumors

1. Aim and background

SIOPE-E-BTG members have been invited by the ERNPaedCan coordinator (Ruth Ladenstein, Vienna), to run a virtual Tumor-board for children with CNS tumors, aiming to enhance activities of ERN PaedCan members already engaged in cross-border healthcare advisory functions. In these tumor boards, experts will offer access to expertise and knowledge of multidisciplinary teams to institutions from widening countries in the EU, so that children with brain tumors receive the best advice for diagnostic assessments and treatment.

Healthcare providers who are members of ERNs are connected through a dedicated IT platform (Clinical Patient Management System, CPMS) with link-anonymized data transfer and a viewer which accepts images DICOM-format), through which consultations are handled using a variety of telemedicine tools.

CPMS is a web-based application provided by the European Commission DG SANTÉ, that supports the networks between specialized experts and healthcare providers taking care of patients with rare or low prevalence complex diseases. It allows virtual consultation across national borders, so that expertise can travel to the patient, instead of the other way around.

In this EU-funded pilot phase from September 2022 to August 2023, consultations will be offered for 2 cases per week during a regular time-slot (proof of concept). Consultations are provided free of charge for the local centers who request consultations.

The HIT-MED team from University Medical Center Hamburg-Eppendorf (S. Rutkowski, M. Mynarek) has agreed to coordinate the tumor boards. Images will be demonstrated by an experienced neuroradiologist (B. Bison, HIT neuroradiology reference center, Augsburg, Germany). Expertise from the SIOPE-BTG panelists (B. Pizer, K. Scheinemann) and the respective SIOPE-BTG working groups (tumor- and discipline groups) will be integrated wherever appropriate and feasible.

Participation of the attending physician from the local institution will be mandatory.

2. Technical prerequisites for participating centers

To create a CPMS account you need to first create an EU Login ([here](#)). Please see the “CPMS Registration Guide” sent via e-mail and find [FAQ](#) on how to perform the necessary steps and submit your request for activation. Once you have submitted your request, your account will be activated within 24h. If you are a guest and require an account, please contact the support team via email at sante-ern-cpms-itsupport@ec.europa.eu.

In case you have questions how to register and access the platform, please refer to the [User Guide](#) or contact the ERN PaedCan CPMS Helpdesk at cpmshelpdesk@paedcan.ern-net.eu.

You can log in to the CPMS ERN [here](#).

3. Process Workflow

3.1 Informed consent

Prior to requesting a tumor conference via CPMS, the patient or his guardian are required to give their consent on sharing patient-sensitive data with involved ERN CPMS panel members. The informed consent forms can be found in your language on CPMS under “Help and Support” > “CPMS Consent forms”

3.2 Requesting a consultation via the CPMS tumor conference

3.2.1 Contacting coordinator and case preparation

1. Contact the PaedCan brain tumor coordinator via ERNPaedCan@uke.de containing the following information on the case:
 - Age and gender
 - Histopathological diagnosis (please indicate if second opinion/central review has been performed)
 - Molecular diagnosis (when available e.g. methylation profiling result, DNA- or RNA-sequencing)
 - Initial staging: degree of resection (R0 –R4), metastatic staging (M0-M3) in MRI and CSF
 - Previous treatment (e.g. date of resection, chemotherapy)
 - Further information specific to the case (e.g. Germline mutation analysis, secondary malignancy)
 - Previous presentation in the tumor board (if yes, please report “Nickname” used in CPMS)
 - Reason for inquiry

These data will only be used to decide if discussion in the CPMS-board is possible. Therefore, please do not submit detailed information at this stage.

2. The coordinator will give you a response with further questions and inform you if the patient will be discussed, with the date and time of the tumor board. Please confirm the date of the meeting via ERNPaedCan@uke.de
3. Register patient on CPMS ERN and provide the following information/materials by latest 1 day prior to the tumor board:
 - All necessary patient information under “consultation form”
 - Upload MRI images and other relevant medical reports/results regarding the case under the “medical documents” in “consultation form”

4. The PaedCan brain tumor coordinator will organize a panel meeting with required members of the ERN.
5. On the day of the meeting: A member of the local institution will present the case to the panel members.
6. After the discussion, a final report will be issued by the UKE team under “contributions & outcome”

In case of technical or organizational issues, please see section 2.