Frequently Asked Questions

How can I access the ENCR protocol?

please follow this link to overview the guidelines: https://encr.eu/sites/default/files/inline-files/2021%20ECIS-IARC-EUROCARE%20call%20for%20data%20protocol_20210728.pdf

Is there a discrepancy regarding the recruitment of cases (study period) in page 6 vs. page 20,

For the three cancer types common in adolescents (osteosarcoma, Ewing sarcoma and rhabdomyosarcoma), are cases up to 19 years of age included in the project?

Yes, for osteosarcoma, Ewing sarcoma and rhabdomyosarcoma the cases eligible are 0-19 years of age (<20 years).

Do we fill the laterality field only if the neuroblastoma is found in the adrenal gland?

No, laterality field for neuroblastoma must be filled in any case.

If there is neuroblastoma found in right abdomen, then this should be recorded as right disease in the ?

Yes, it should be recorded as right laterality.

If there is neuroblastoma found in thorax, head, or spinal cord, what should it be recorded in the laterality field?

If the metastasis is in the same laterality as the primary site, no problem. If it has different laterality, then it must be marked as bilateral.

For patients with metastatic disease, i.e., right adrenal gland with metastases in liver, what should be recorded in the laterality field?

For patients with metastatic disease it is necessary to mark the laterality based on the laterality of the area affected by the metastasis. In the example, the laterality would be right.

There is a case with histopathology confirming Mesoblastic Nephroma (M-8960/1) with pulmonary metastases, while this is rare it is documented in the literature. In our registry we would register this as Nephroma NOS (M-8960/3). Should it be included in the BENCHISTA?

Regarding the coding (and hence whether the case should be included in BENCHISTA) – it needs to be considered a true “nephroblastoma” and not mesoblastic nephroma (which itself is a biologically heterogeneous entity and very much distinct from nephroblastoma). Assuming we all agree it should be coded M 8960/1, then it should be excluded from the BENCHISTA cohort.

I have an MRI report which states: a patient with high grade tumour in the proximal tibial metadiaphysis. The lesion extends into the subchondral region of the proximal tibia and into the knee joint. I think this would be localised tumour but because it has spread to the knee joint, I was unsure and need clarification as to whether this represents metastasis? There are no skip metastases present.

This would be localised. Invasion into the knee joint would be regarded as local extension of the tumour and not metastasis.

We have a doubt regarding inclusion/exclusion criteria of cases in the BENCHISTA study. Should we include children from foreign countries that are treated in our country’s hospitals? We are aware that the inclusion of these cases in our sample will bias our results on stage at diagnosis.

These cases usually represent more advanced stages of disease that, before accessing our national healthcare system, were assisted following clinical guidelines very different from those of our country.

We only want cases diagnosed in the resident population covered by each cancer registry, so please

What age limit do we use for each specific quality check indicator? Do we use age up to 20 years for bone tumors and up to 15 years for all other tumors? What about for the first indicator, DCO/autopsy among all cancer cases?

Yes, please use age up to 19 inclusive (i.e., <20) for Ewing sarcoma, osteosarcoma, and rhabdomyosarcoma and, age up to 14 (i.e.,

Just to make sure: the abdominal ultrasound in nephroblastoma is looking for the extent of tumour spread, as the primary site imaging has already been recorded as CT/MRI. So, I have not been recording this as positive when only the primary tumour was visible, with no extension into renal and inferior cava veins, liver or lymph nodes. Is this correct?

You need to record that an ultrasound was performed in column " " of the database file, however in the next column " " it should be recorded as negative if the imaging does not show any evidence of distant metastases.
In other words, this should only be recorded as positive for distant metastases seen on ultrasound such as liver metastases or gross peritoneal metastases.
It should not be recorded as positive if the only imaging evidence for metastases is in relation to enlarged lymph nodes (which need to be confirmed histologically after nephrectomy).

In medulloblastoma the SCCR always coded both ICD-10 and ICD-O-3 topography as C71.6 as "standard practice" for medulloblastoma. Should we go back and change the topography to C71.9 posterior fossa when this is the reported localization?

We recommend – whenever possible – to use the topographical code C71.6 which refers to the cerebellum.
The topography code for posterior fossa can be used but is classified under the general code C71.9 (brain, NOS) which means that we lose specificity. Of course, we agree that both terms are used in the context of medulloblastoma. As the primary location of the medulloblastoma is in almost all cases in the cerebellum, we would prefer use of the code C71.6.

Is immunohistochemical evidence enough to say the medulloblastoma belongs to the SHH subgroup when we have no molecular data?

Indeed it can be and can be diagnosed by GAB and YAP stains. For trials however requires 2 methods.

In a case where the initial report classifies the case as either M0 or M1, but later discharge reports say M0, can we assume there has been a negative CSF result? For medulloblastoma, we still seem to be missing a lot of reports from certain hospitals.

If the most recent hospital discharge report states M0, we must conclude that this has included all reports available to the clinical team and is therefore correct; probably meaning that the day 14 CSF has been done when it was not available the initial report.
Nevertheless, please ensure all quality checks