Kinderkrebsregister
Registre du cancer de l'enfant
Registro dei tumori pediatrici
Childhood Cancer Registry

UNIVERSITÄT BERN

Instructions for completing the registration form

General information

The registration form contains two pages to be fill in.
The white fields are filled in for all declarations, the coloured fields only for the corresponding declarations, e.g. for the evolution of the disease.

All white fields, including the corresponding blue field.

Evolution of the disease

Date of event ☐ New event ☐ Relapse ☐ Progression ☐ Metastases

Complete one declaration form per patient:

- If you are reporting a case for the first time, select First report and enter the details of the diagnosis and treatment
- If you want to report information about new or additional therapies, the current course of the disease, an event such as a relapse, progression, metastases, transformation or if you want to report the death of a patient, then select Follow-up treatment/course of disease.
- If you want to add information on late effects, select Late effects.

Important. The date of the patient information must always be filled in for a first report.

Please save the file as a PDF document and/or print it out, attach the relevant reports and consent forms and send us your declaration.

General patient information (white field)

Date of patient information	Indicate the date on which the patient and/or family were informed that the case had been reported to the register.
Hospital / Institute	Indicate your hospital
Clinic / department	Indicate your department (e.g. paediatric oncology).
Filled in by (name)	Indicate your name
E-mail	Enter your e-mail address
General patient details	Enter the patient's surname, first name(s), address, date of birth, gender and 13-digit AHV number.

First declaration

Information on first diagnosis (yellow field)

Date of first diagnosis	Indicate the day, month and year of diagnosis (e.g. the date the biopsy was taken).
Diagnosis	Indicate the diagnosis in text form (e.g. osteosarcoma).
Metastases	Tick whether or not metastases are present.
Location	Indicate the location of the tumour.
Tumour predisposition	Indicate in text form the conditions already present and their ICD 10 codes (if known). Conditions present at birth that favour the development of cancer (e.g. trisomy 21 or RB1 mutations).

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Treatment information (yellow field)

Start of treatment	Indicate the day, month and year of the start of treatment (e.g. 16 March 2024).
Purpose of treatment	Tick whether the treatment is curative or palliative
Date of tumour board with therapy decision	Name the day, month and year of the planned/conducted tumour board with therapy decision
Treatment	Select an element (e.g. surgical therapy; radiotherapy etc.)
Comment	Free text field for comments regarding the treatment

Follow-up treatment/course of disease

Progression of treatment (blue field)

Start of the therapy change	Name the day, month and year of the start of the therapy change (e.g. 25 September 2024)
Purpose of treatment	Tick whether the treatment is curative or palliative
Treatment	Select an element (e.g. surgical therapy, neoadjuvant chemotherapy or radiotherapy)
Comment	Free text field for comments regarding the treatment

Evolution of the disease (blue field)

Date of event	Name the day, month and year of the event (e.g. 21 November 2024)
New event	Tick whether the event is a recurrence, progression or metastasis

Follow-up details (blue field)

Type of event	Tick whether the notification is a follow-up, therapy or death
Date of event	Name the day, month and year of the event (e.g. 28 December 2024)
Remission status	Select the appropriate option listed (e.g. Partial Remission)
Additional information on treatment	Free text field for additional information on treatment (e.g. radiotherapy)

Late effects

Late effects (green field)

Diagnosis date	State the day, month and year of the diagnoses (e.g. 5 December 2025)
Diagnostic specification	State the diagnosis in text form (e.g. Bilateral ototoxic hearing loss)
Comment	Free text field for comments regarding late effects

General information

Study information (blank field)

Treatment according to protocol	Tick whether the patient is being treated according to protocol
Study patient	Tick whether the patient has participated in a study or not
Study protocol	Indicate the name of the study protocol (e.g. COSS).
Regime / arm	Free text field to record which study arm or regimen the patient is in
Comment on the study	Free text field for entering further information regarding the study

Reports attached (blank field)

If available, please attach the following reports	Select the appropriate reports and consent forms and attach them.

Thank you for your support!