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

Instructions on how to fill in the notification form

General instructions

The notification form contains three different pages: Diagnosis, Course of Disease and Clinical Follow-up.

- Fill out one notification form per patient:
  - If you are **notifying a case for the first time**, choose Diagnosis.
  - If you are notifying an event such as a **relapse, progression, new distant metastasis or transformation**, choose Course of Disease. Include any new therapeutic information, which took place after the event.
  - If you are adding information regarding **new or additional therapies, follow-up consultations and late effects** that do not depend on a relapse, progression, new distant metastasis or transformation or if you want to **notify the death of a patient**, choose Clinical Follow-Up.
- Any fields and pages which are not relevant can be skipped.
- We do not want you to do redundant work. Information that is already mentioned in the reports attached does not need to be filled in again. But please fill in the sections "Date of patient information", "Filled out by" and "General patient information".
- Please save the file as a PDF document and/or print it out.
- Attach the appropriate reports and consent forms and send your notification.

Diagnosis

Date of patient information	Indicate the date in which the patient and/or the family were informed about the childhood cancer registry and the registration of their data. This is not necessary if the patient died before they could be informed.
Hospital / Institute	Name of your hospital.
Clinic / Unit	Name of your unity (e.g. *pediatric oncology*).
GLN number	For notifications from individual doctors in a practice: Indicate your Global Location Number. For further information, please consult GS1 Switzerland (https://www.gs1.ch/).
Institute number (BER number)	Indicate your Business and Enterprise Register Number (Legal Enterprise Unit (Entity ID) or Local Unit (Local ID)). For further information, please consult the Business and Enterprise Register (www.bfs.admin.ch/bfs/en/home/registers/enterprise-register/business-enterprise-register.html).

Filled out by (Name, address, phone number)	Your name, address and phone number.

General patient information	Indicate the AHVN13 number, family name, first name(s), complete address, date of birth, sex and contact language of the patient.
Diagnosis information	
Diagnosis date	Day, month and year of the diagnosis (e.g. the date in which the diagnostic biopsy sample was collected).
Diagnosis in text	Diagnosis in text form (e.g. *Osteosarcoma*).
Diagnosis group	Select the corresponding ICCC3 diagnosis group as listed (if known) (e.g. **Malignant bone tumours**).
Predispositions, prior diseases & comorbidities	Any pre-existing medical conditions in text form and their respective ICD 10 codes (if known): • **Predispositions**: conditions, which are present at birth that predispose to the development of cancer (e.g. *Trisomy 21* or *neurofibromatosis*). • **Prior diseases:** non-inherited conditions that either predispose to the development of cancer or are relevant to treatment decisions or possible late effects (e.g. *HIV* or *hearing loss diagnosed before* any ototoxic *chemotherapy*). • **Comorbidities**: diseases present at the time of the cancer diagnosis that may affect patient treatment and/or survival (e.g. *diabetes*).
Treatment information	
Treatment	Treatment in text form (e.g. *surgery, neoadjuvant chemotherapy and radiotherapy*).
CHOP treatment code (if known)	Please indicate the corresponding code of the Schweizerische Operationsklassifikation (if known). For further information, please consult: www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/nomenklaturen/medkk.html
Treatment start date	Start day, month and year of the therapy (e.g. *16 March 2020*).
Treating institution (if different from above)	Indicate a second treating institution (if applicable).
Treatment goal	Select the goal of the treatment as listed (e.g. **Curative**).
Basis of treatment decision	Select the basis of the therapeutic decision as listed (e.g. **Tumour board**) and attach a copy of the tumour board report.
Study information	
Study patient	Select the corresponding option as listed (e.g. **yes if the patient was enrolled in a clinical trial or register**).

Treated according to protocol	Select the corresponding option as listed (e.g. **yes if the patient was treated according to a clinical trial protocol whether enrolled in the study or not**).

Study protocol	Select the name of the study protocol as listed (e.g. **COSS**).
Study comments	Further comments regarding the study (e.g *standard arm*).
Please attach following reports if available	Select and attach any appropriate reports and consent forms.
Other comments	Any other comments.

Course of Disease

Hospital / Institute	Name of your hospital.
Clinic / Unit	Name of your unity (e.g. *pediatric oncology*).
GLN number	For notifications from individual doctors in a practice: Indicate your Global Location Number. For further information, please consult GS1 Switzerland (https://www.gs1.ch/).
Institute number (BER number)	Indicate your Business and Enterprise Register Number (Legal Enterprise Unit (Entity ID) or Local Unit (Local ID)). For further information, please consult the Business and Enterprise Register (www.bfs.admin.ch/bfs/en/home/registers/enterprise-register/business-enterprise-register.html).
Filled out by (Name, address, phone number)	Your name, address and phone number.
General patient information	Indicate the AHVN13 number, family name, first name(s), complete address, date of birth and sex of the patient.
Course of disease	**Any of the following events:** • **Progression**: Locoregional new findings without disease free intermission (locoregional refers to the same or adjacent site of the original tumour or the regional lymph nodes). • **Metastasis** : New finding at a site distant to the primary tumour, i.e. metachronous metastasis. Either with or without disease free intermission. • **Relapse**: Locoregional new findings after a period of documented disease free intermission or remission without detectable tumour. • **Transformation**: The development of one ICD-O M term into another (for example, the change of a haematopoetic or lymphoid neoplasm from chronic to acute phase).
New event	Select the corresponding option as listed (e.g. **Relapse**).
Date of event	Day, month and year of the event (e.g. *21 November 2020*).
New treatment information	**Include any treatment that was administered after the event.**

CHOP treatment code (if known)	Please indicate the corresponding code of the Schweizerische Operationsklassifikation (if known). For further information, please consult: www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/nomenklaturen/medkk.html
Treatment	Treatment in text form (e.g. *radiotherapy*).
Treatment start date	Start day, month and year of the therapy (e.g. *21 November 2020*).
Treatment goal	Select the goal of the treatment as listed (e.g. **Palliative**).
Basis of treatment decision	Select the basis of the therapeutic decision as listed (e.g. **Tumour board**) and attach a copy of the tumour board report.
New study information	**Include any study in which the patient was enrolled, or treated according to after the event.**
Study patient	Select the corresponding option as listed (e.g. **yes if the patient was enrolled in a clinical trial or register**).
Treated according to protocol	Select the corresponding option as listed (e.g. **yes if the patient was treated according to a clinical trial protocol whether enrolled in the study or not**).
Study protocol	Select the name of the study protocol as listed (e.g. **COSS**).
Study comments	Further comments regarding the study.
Please attach following reports if available	Select and attach any appropriate reports and consent forms.
Other comments	Any other comments.

Clinical Follow-Up

Hospital / Institute	Name of your hospital.
Clinic / Unit	Name of your unity (e.g. *pediatric oncology*).
GLN number	For notifications from individual doctors in a practice: Indicate your Global Location Number. For further information, please consult GS1 Switzerland (https://www.gs1.ch/).
Institute number (BER number)	Indicate your Business and Enterprise Register Number (Legal Enterprise Unit (Entity ID) or Local Unit (Local ID)). For further information, please consult the Business and Enterprise Register (www.bfs.admin.ch/bfs/en/home/registers/enterprise-register/business-enterprise-register.html).
Filled out by (Name, address, phone number)	Your name, address and phone number.
General patient information	Indicate the AHVN13 number, family name, first name(s), complete address, date of birth and sex of the patient.
Clinical Follow-Up	
Type of event	Select the corresponding option as listed (e.g. **Notification of death**).

Date of event	Day, month and year of the event (e.g. *28 December 2021*).
Therapy status in text	Select the corresponding option as listed (e.g. **Dead**).
Late Effects	
Date of diagnosis	Day, month and year of the diagnosis (e.g. *5 December 2020*).
ICD 10 code (if known)	Indicate the corresponding ICD 10 code (if known). For further information, please consult: www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/nomenklaturen/medkk.html
Diagnosis in text	Diagnosis in text form (e.g. *Bilateral ototoxic hearing loss*).
Additional treatment information	
CHOP treatment code (if known)	Please indicate the corresponding code of the Schweizerische Operationsklassifikation (if known). For further information, please consult: www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/nomenklaturen/medkk.html
Treatment	Treatment in text form (e.g. *radiotherapy*).
Treatment start date	Start day, month and year of the therapy (e.g. *20 August 2021*).
Treatment goal	Select the goal of the treatment as listed (e.g. **Palliative**).
Basis of treatment decision	Select the basis of the therapeutic decision as listed (e.g. **Tumour board**) and attach a copy of the tumour board report.
New study information	
Study patient	Select the corresponding option as listed (e.g. **yes if the patient was enrolled in a clinical trial or register**).
Treated according to protocol	Select the corresponding option as listed (e.g. **yes if the patient was treated according to a clinical trial protocol whether enrolled in the study or not**).
Study protocol	Select the name of the study protocol as listed (e.g. **COSS**).
Study comments	Further comments regarding the study.
Please attach following reports if available	Select and attach the appropriate reports and consent forms.
Other comments	Any other comments.