REGIONALA CANCERCENTRUM I SAMVERKAN

Scandinavian Sarcoma Group 1979

MANUAL

THE NATIONAL QUALITY REGISTER FOR SARCOMAS OF THE EXTREMITIES AND TRUNK WALL

Contents

Manual version

Register version	Version	Date
	1.0.1/ RCC Syd	2015-01-20

Each variable is defined by its name (the same as the filed name on the form), thereafter a brief explanation of the variable is found. If a variable is mandatory for Swedish patients (optional for other countries) as part of the "Canceranmälan till cancerregistret" is specified here.

Alterations in the manual

Date	Variable	Alteration

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Nationella kvalitetsregistret för sarkom i extremiteter och bålvägg

Sarkom är en sällsynt grupp av tumörer med olika egenskaper. De utgör ungefär 1% av alla maligniteter och utgår från bind- och stödjevävnad. De drabbar personer i alla åldrar och kan sitta nästan i vilken del av kroppen som helst. De behandlas av läkare och annan vårdpersonal inom många olika specialiteter, vilka varierar beroende på typ av tumör och var den sitter. Antalet fall av sarkom är relativt konstant över tiden. Totalt insjuknar ca 300 patienter/år i Sverige varav 70 drabbas av skelettsarkom, ett 50-tal av buksarkom (viscerala och retroperitoneala sarkom) och resterande av mjukdelssarkom i extremiteter och bålvägg. Av de cancerformer som drabbar barn och ungdomar utgör sarkom ca 10% av alla fall.

Sarkomregistret är indelat i två delar; en för sarkom i extermiteter och bålvägg och en för intraabdominella och retroperitoneala sarkom. Anledningen till denna indelning är att tumörsjukdomarna kräver olika utredningar och behandlingar och därför är det intressant att följa olika parametrar.

Sarkomregistret startades av Skandinaviska sarkomgruppen (SSG) redan 1986 och en separat del viscerala och retroperitoneala sarkom startades 2008. Registren är fortfarande gemensamma inom Skandinavien. Båda delarna av det svenska nationella kvalitetsregistret för sarkom ligger från 2015 på INCA. Det finns en manual och en uppsättning blanketter för respektive register.

Syfte och mål

- att samla in tumör- och behandlingsrelaterad data om alla sarkom i Sverige
- att vara underlag för bedömning av resultat och följsamhet till nationella och internationella riktlinjer lokalt, regionalt och nationellt
- att utgöra underlag för förbättringsarbete och planering av sarkomverksamheten
- att möjliggöra utveckling och forskning kring sarkomsjukdomarna

Registrets innehåll

Det nationella kvalitetsregistret för sarkom i extremiteter och bålvägg har utgått från SSGs register och omfattar en del för anmälan av tumören (registration form), en del för behandling av primärtumören (treatment form) och en del för uppföljning av patienten som inkluderar behandling av eventuella lokalrecidiv eller fjärrmetastaser.
Det nationella kvalitetsregistret för sarkom i extremiteter och bålvägg utgör en del av det skandinaviska sarkomregistret och resterande del av manualen är därför gemensam med övriga länder och skriven på engelska.

OBS för det nationella kvalitetsregistret för sarkom i extremiteter och bålvägg är uppföljningsformuläret fortfarande under bearbetning. Det beräknas vara klart under första kvartalet 2015.

Background

The common registration of data allows for multicentric studies addressing treatment results and prognostic factors for local recurrence and survival in patients with soft tissue and bone sarcomas. Such studies are necessary to further define the best treatment for these patients. The close to 100% follow-up that is possible in Scandinavian countries makes our position unique.

Centralization of patients with bone and soft tissue sarcomas of the trunk wall and extremities has since long been practiced in Scandinavia. Visceral and retroperitoneal sarcomas have gathered great interest during later years due to novel techniques in the diagnosis and treatment of GIST, for more information see the manual on Registration of Visceral and Retroperitoneal Sarcomas.

The multidisciplinary diagnosis and treatment require close cooperation between the surgeon, the radiologist, the cytologist, the pathologist, gynecologist and the oncologist. Thus, centralization also of patients with visceral and retroperitoneal sarcomas is mandatory. The SSG Registry of soft tissue and bone tumors was initiated March 1, 1986. All Centers in Norway and Sweden participate in the Registry, as well as certain Centers in Denmark and Finland. The yearly accrual rate is approximately 250 soft tissue and 100 bone tumor patients.

The Register gives important information on how treatment of patients with musculoskeletal tumors is evolving in the Scandinavian countries. For example, important changes in referral pattern, preoperative diagnostic techniques, surgical margin and radiotherapy have been observed.

The Register has formed the basis for several theses regarding treatment and prognosis. In depth studies of patients reported to the Registry are important for quality assurance. An important facet of the Registry is the histopathological re-evaluation of diagnosis performed by the SSG Pathology Board.

The forms for registration of patients to the Central Register have been modified and the new forms have will be up for approval of the SSG working committee in May 2015. Reporting can be made online (currently only in Sweden, January 2015). The histopathological diagnoses are updated in accordance with the new WHO classification.

For guidelines regarding surgical, medical and oncological treatment we refer to ongoing SSG and collaborative study protocols. The guidelines for surgical treatment and radiotherapy provided in SSG XX are also applicable to soft tissue sarcoma patients who are not candidates for adjuvant chemotherapy.

Organization

The national board is responsible, in collaboration with the regional cancer centers in Sweden, for the creation, running and use of the register. The register is compared to the regional cancer registers to identify missing cases in the national registry for sarcomas in the

extremities and the trunk wall. Completions of missing registries are requested from reporting clinics. The data are collected annually at the Regional Cancer Centre South in Lund for statistical evaluation and inclusion in a national report.
From each region, a responsible physician at a sarcoma center is included in the national board (see http://www.cancercentrum.se/sv/Kvalitetsregister/Sarkom/). The chairman of the national board calls for meetings.

Registration

A patient diagnosed with a sarcoma of the extremities and trunk wall should be reported to the register and we recommend referral to a sarcoma center for final diagnosis and treatment. The forms for reporting a patient are the same within all of Sweden and the SSG. The registration form now includes all parameters needed for a *Canceranmälan* and it will function as such as well (in Sweden). The variables which are mandatory for a *Canceranmälan* are marked as such in the manual and they are optional when reporting patients from other countries.

The registration consists of two forms, one with basic tumor characteristics, referral pattern and performed diagnostic investigations and one for treatment of the primary tumor. When reporting a case online please note that *not all variables will be seen but only those appropriate to you prior selections*, i.e. if number of surgeries is reported as none then no data on type of surgery will be requested or if sarcoma type is reported to be a soft tissue sarcoma only variables applicable to this group of tumors will be shown.

Local recurrences or distant metastases found during follow up should be reported as such though using the follow up form, not as new sarcomas. If a patient is diagnosed with a second sarcoma, either related to previous treatment or a new primary sarcoma at another site, it should be reported to the register as a new tumor.

Inclusion criteria

All patients diagnosed, while alive, with a sarcoma of the extremities and trunk wall according to the following criteria: A sarcoma diagnosed at autopsy should not be included in the register, neither should a suspected but not confirmed sarcoma.

Included soft tissue sarcoma histotypes:
Fibrosarcoma, Undifferentiated/unclassified sarcomas (UPS), Myxofibrosarcoma, Liposarcoma, Leiomyosarcoma, Rhabdomyosarcoma, Solitary fibrous tumor, Synovial sarcoma, MPNST, Low-grade-fibromyxoma, Extraskeletal myxoid chondrosarcoma, Extraskeletal osteosarcoma, Malignant granular cell tumor, Alveolar soft-part sarcoma, Clear cell sarcoma of soft tissue, Epithelioid sarcoma, Extraskeletal Ewing, Other STS, Angiosarcoma, Desmoplastic small round cell tumor, Malignant phyllodes tumour, Epithelioid haemangioendothelioma, Extra-renal rhabdoid tumor, Extraskeletal mesenchymal chondrosarcoma, Malignant ossyfying fibromyxoid tumour, PEC-oma, malignant.

Included bone sarcoma histotypes:
Chondrosarcoma (grades I – III), Mesenchymal chondrosarcoma, Clear cell chondrosarcoma, Ewing sarcoma, Leiomyosarcoma of bone, Undifferentiated high-grade pleomorphic sarcoma (UPS), Malignancy in giant cell tumor, Chordoma, Other sarcoma of the bone, Benign giant cell tumor, Adamantinoma, Angiosarcoma of bone, Atypical cartilaginous tumor, Conventional osteosarcoma, Dedifferentiated chondrosarcoma, Epithelioid hemangioendothelioma, Parosteal osteosarcoma, Low-grade osteosarcoma, Other osteosarcoma, Telangioectatic osteosarcoma.

Presentation of and access to the register data

The register's national board is responsible for collection and presentation of data on a national level. An annual report will be presented in cooperation with the Regional Cancer Centre South in Lund at http://www.skane.se/webbplatser/regionalt-cancercentrum/ and http://www.cancercentrum.se/sv/INCA/.

Reporting clinics will have access to their own data. Regional data is accessed through each regional cancer center.

National data is accessed through the Regional Cancer Centre South in Lund after application. The application should define which data is requested and include a brief presentation of the project. It should be sent to the chairman of the national board and the head of the Regional Cancer Centre South.

To access Scandinavian data, the application should be sent to the chairman of the registers national board, the head of the Regional Cancer Centre South. And to the Scandinavian Sarcoma Group board for a review. The leading researcher should come from an active member institution and will be the first author of the publication. Before a decision is made by the board the research project will be evaluated by a group consisting of one representative from each Nordic country (two representatives from Sweden), in addition to the chairman of the central register. The members of the group will be suggested by the central register subcommittee and confirmed by the SSG board. This group will then present a proposal to the board. Authorship for pathology, imaging and translational research studies should be decided in the SSG board. All authors are expected to be involved actively in the manuscript writing, and must finally approve the version to be published.

Guidelines for completion of the forms

Registration form, general information.

Date of birth and country specific id number
The personal identity number (Sweden) or code number (other countries).

Name
The patient's name (unless it should not be reported due to national confidentiality laws).

Sex
The patient's sex.

Date of death
Date of death, automatically updated for Swedish patients. Updated in the file in Norway before transfer of the data to the register. Reported manually for other countries.

Reporting clinic/hospital/country
Automatically derived in online registration depending on the person reporting to INCA. Manually filled in on paper forms.

Responsible physician
Name of the physician responsible for the patient, the person reporting in INCA will be suggested as default but the name can be changed if needed.

Registration form, diagnosis.
Reporting date
Date when the report of the case was made (online registration only).

Referral date
Date when the referral letter to the sarcoma center was *written* (or first contact taken using other ways of communication).

Date of first visit
Date when the patients first visited the sarcoma center.

Date of diagnosis
Date when tissue suitable for microscopic diagnosis was **first** procured, either by needle biopsy, open biopsy or surgical treatment, before referral or at a center.
NOTE: In Norway this variable corresponds to the date the diagnosis was established (by pathologist), not the date the specimen was taken.

Date when the patient was first informed about the diagnosis
Date when the patient **first** was informed of the diagnosis.

Antecedents, several options
Previous cancer, chemo- or radiotherapy, cancer-related diseases, for example neurofibromatosis. More than one can be checked.

Referral pattern to sarcoma center
Local microscopic diagnosis or excision performed before referral to a sarcoma center or a center with a defined collaboration with a sarcoma center.
Not referred is used if the patient is identified from the sarcoma center, for example through a national cancer registry, but never referred.
Virgin implies referred with untouched lesion.
FNA implies referred after FNA.
Core biopsy implies to referral after core biopsy.
Excision implies any surgical procedure for primary tumor, e.g. open biopsy or partial or complete tumor excision. Patients referred after incision biopsy should be registered as referred after excision and the incisional biopsy registered as first surgery, not performed at center with R2 residual tumor.
Local recurrence implies not referred for primary tumor but only later for a local recurrence. Please note that patients referred with local recurrence or after development of metastatic disease should be registered in relation to the treatment of the primary tumor (if any) performed before referral, i.e. referral after excision or after local recurrence.

Preoperative diagnostic procedures performed before referral or at the sarcoma center
How the tumor diagnosis was made preoperatively, **either before referral or at the center.** More than one method can be checked. Note that intralesional or marginal excision is not classified as a diagnostic procedure but checked as "surgery for primary tumor" (see later). Check "none" for this variable if the surgery was done without any prior diagnostic morphology. "Incisional biopsy" is checked when less than 50% of tumor was removed. Incomplete removal of more than 50% of tumor is classified as "intralesional surgery".

Basis of diagnosis
The clinical and/or histopathological basis of the cancer diagnosis. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret".

Reporting pathology/cytology clinic
Name of the reporting pathology/cytology clinic. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret".

Specimen id number (PAD-number)
The id number (PAD-number) for the specimen from which the histoype was assessed. Year collected in a separate variable. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret".

Specimen id number, year
The year the tumor speciemen leading to a sarcoma diagnosis was taken. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret".

Sarcoma type
Type of sarcoma, i.e. soft tissue, bone sarcoma or benign giant cell tumor of bones. Controls the rest of the online reporting form (which variables the register will inquire about).
If benign giant cell tumor of bones is selected as sarcoma type the rest of the registration form will follow the main format for bone sarcomas although no inquiries about certain variables will be done, e.g. malignancy grade, side, ICDO3-code et cetera.

Registration form - Bone sarcoma and benign bone tumor (GCT):

Morphological diagnosis, histotype
Bone sarcoma morphological diagnosis. If a lesion cannot be classified it may be referred to other SSG pathologists for consultation.

Morphological diagnosis, free text (online only)
Morphological name of the tumor, derived automatically from morphological diagnosis for soft tissue or bone sarcomas. If "other type of sarcoma" is reported it should be defined here. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret".

IDCO3-code for bone sarcomas
ICD-O3-code for tumor location of bone sarcomas. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret".

Side (applicable for bilateral organs and body parts)
Primary tumor's location side. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret". Automatically derived as "Not applicable" for centrally located tumor sites (online only).

Site of primary tumor, free text
Free text for sarcoma location. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret". Automatically derived when from reported bone sarcoma primary tumor site and side when reporting online.

Primary tumor site
Where the primary bone tumor was situated.

Tumor location
Refers to whether the tumor is located within a compartment or not. A tumor that has eroded cortical bone but the periosteum is still intact is regarded as intraosseous.

Pathologic fracture at presentation
Whether there was a pathologic fracture at presentation.

Long bone
Where in a long bone, a bone sarcoma is located. Only activated when bone tumor site has been reported as one of the long bones (online only).

Size of primary tumor (cm)
Largest diameter as assessed by radiological imaging or pathologic examination of the resected specimen, reported in cm.

Malignancy grade: 4 grade scale
For bone sarcoma the Scandinavian 4-tier malignancy grade scale is used. Check "not applicable" if tumor always has the same grade of malignance (i.e. Classic osteosarcoma, Ewing/PNET or GCT).

Metastases at the time of the diagnosis of primary tumor
Refers to the diagnostic status of metastases at the time of diagnosis of the primary tumor. When metastasis is diagnosed within 30 days from diagnostic biopsy of primary tumor, the patient is considered to have metastasis at diagnosis of primary tumor. If the metastases are found later, please report them using the follow up form and report date and site of the metastases.
The N- and M-stage, mandatory variables for Swedish patients as part of the "Canceranmälan till cancerregistret", optional for others, are derived from this variable (online only).

T-stage
T-stage for bone sarcomas, a mandatory variable for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret". Automatically derived from tumor size and location (online only). T1 if size ≤8cm, T2 if size >8cm, T3 if discontinuous growth within the same bone, Tx if size is not determinable or primary tumor location is unclassified.

N-stage
N-stage for bone sarcomas, a mandatory variable for Swedish patients, part of the "Canderanmälan till cancerregistret". Automatically derived as N0 (no) if no metastasis diagnosis has been reported. Has to be filled in if metastasis at diagnosis has been reported. N1 if presence of regional lymph node metastases, N0 if none.

M-stage
M-stage for bone sarcomas, a mandatory variable for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret". Automatically derived as M0 (no) if no metastasis at diagnosis has been reported. Has to be filled in if metastasis at diagnosis has been reported. M1 if presence of distant metastases, M0 if none.

Registration form - Soft tissue sarcoma:

Morphological diagnosis, histotype
Soft tissue sarcoma morphological diagnosis. If a lesion cannot be classified it may be referred to other SSG pathologists for consultation. Please note that atypical lipomatous tumors/well differentiated liposarcomas on orthopedic locations should not be reported to the SSG register!

Morphological diagnosis, free text (online only)
Morphological name of the tumor, derived automatically from morphological diagnosis for soft tissue or bone sarcomas. If "other type of sarcoma" is reported it should be defined here. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret".

ICDO3-code for soft tissue sarcomas
ICD-O3-code for tumor location of soft tissue sarcomas. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret".

Side (applicable for bilateral organs and body parts)
Primary tumor's location side. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret". Automatically derived as "Not applicable" for centrally located tumor sites (online only).

Site of primary tumor, free text
Free text for sarcoma location. Mandatory for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret". Automatically derived when from reported soft tissue sarcoma primary tumor site and side (online only).

Primary tumor site
Where the primary soft tissue tumor was situated

Tumor location
Refers to whether the tumor is located within a compartment or not.
Cutaneous, strictly cutaneous tumors.
Subcutaneous, cutaneous tumors infiltrating the subcutaneous tissue or strictly subcutaneous tumors not invading the deep fascia.
Intramuscular tumors not engaging the muscle fascias without any invasive growth.
Extramuscular (deep), any deep tumor that originates or extends outside of a muscle is classified as extramuscular. Hence, a subcutaneous tumor with subfascial extension is classified as extramuscular.

Size of primary tumor (cm)
Largest diameter as assessed by radiological imaging or pathologic examination of the resected specimen, reported in cm.

Malignancy grade

For soft tissue sarcomas the French malignancy grade system (FNCLCC grade) is used. It is based in tumor differentiation, morphological diagnosis, mitotic count and necrosis.

Histological grade (FNCLCC):

Grade 1: total score 2, 3
Grade 2: total score 4, 5
Grade 3: total score 6, 7, and 8

Not applicable only applies to clear cell chondrosarcoma, chordoma, adamantinoma, atypical cartilaginous tumor, epithelioid hemangioendothelioma.
Not assessable: too limited amount of tumor tissue available to correctly assess grade.

Tumor differentiation:

Score 1: sarcomas closely resembling normal adult mesenchymal tissue
Score 2: sarcomas of certain histological type (e.g. myxoid liposarcoma, myxoid MFH)
Score 3: Embryonal and undifferentiated sarcomas, sarcomas of doubtful type, synovial sarcoma, osteosarcoma, PNET.
Tumor differentiation score of sarcomas in the French Federation of Cancer Centers Sarcoma Group System (*Modified from Guillou et al. 1997 and Rubin et al. 2006)*

Diagnosis Score

Well-differentiated liposarcoma (not recorded in the SSG)	1
Myxoid liposarcoma	2
Round cell liposarcoma	3
Pleomorphic liposarcoma	3
Dedifferentiated liposarcoma	3
Fibrosarcoma	2
Myxofibrosarcoma (myxoid MFH)	2
Typical storiform MFH (sarcoma, NOS)	3
Pleomorphic MFH (patternless pleomorphic sarcoma)	3
Giant cell and inflammatory MFH (pleomorphic sarcoma, NOS with giant cells or inflammatory cells)	3
Well-differentiated leiomyosarcoma	1
Conventional leiomyosarcoma	2
Poorly diff./epithelioid/pleomorphic leiomyosarcoma	3
Synovial sarcoma (bi- or monophasic and poorly differentiated)	3
Pleomorphic rhabdomyosarcoma	3
Mesenchymal chondrosarcoma	3
Extraskeletal osteosarcoma	3

Ewing´s sarcoma/PNET	3
Malignant rhabdoid tumor	3
Undifferentiated sarcoma	3

PNET= primitive neuroectodermal tumor; MFH= malignant fibrous histoocytoma
Note: Grading of malignant peripheral nerve sheath tumor, embryonal and alveolar rhabdomyosarcoma, angiosarcoma, extraskeletal myxoid chondrosarcoma, clear cell sarcoma and epithelioid sarcoma is not recommended.

Mitotic count:
Score 1: 0-9 mitoses per 10 HPF*
Score 2: 10-19 mitoses per 10 HPF*
Score 3: >20 mitoses per 10 HPF*
* A high power field (HPF) measures 0.1734 mm2. Standardized HPF should be used

Tumor necrosis*:*
Score 0: no necrosis
Score 1: <50% tumor necrosis
Score 2: >50% tumor necrosis

Metastases at the time of the diagnosis of primary tumor
Refers to the diagnostic status of metastases at the time of diagnosis of the primary tumor. When metastasis is diagnosed within 30 days from diagnostic biopsy of primary tumor, the patient is considered to have metastasis at diagnosis of primary tumor. If the metastases are found later, please report them using the follow up form and report date and site of the metastases.
The N- and M-stage, mandatory variables for Swedish patients, optional for others, as part of the "Canceranmälan till cancerregistret" are derived from this variable (online only).

T-stage
T-stage for soft tissue sarcomas, a mandatory variable for Swedish patients, optional for others, part of the "Canceranmälan till cancerregistret". Automatically derived from tumor size and location (online only).
T1a = cutaneous/subcutaneous, size <=5cm,
T1b = intramuscular/extramuscular deep, size <=5cm,
T2a = cutaneous/subcutaneous, size >5cm,
T2b = intramuscular/extramuscular deep, size >5cm,
TX = size not determinable or Tumor location Unclassified

N-stage
N-class for soft tissue sarcomas, a mandatory variable for Swedish patients, part of the "Canderanmälan till cancerregistret", optional for others. Automatically derived as N0 (no) if no metastasis diagnosis has been reported. Has to be filled in if metastasis at diagnosis has been reported. N1 if presence of regional lymph node metastases, N0 if none.

M-stage

M-stage for soft tissue sarcomas, a mandatory variable for Swedish patients, optional for others, part of the “Canceranmälan till cancerregistret”. Automatically derived as M0 (no) if no metastasis at diagnosis has been reported. Has to be filled in if metastasis at diagnosis has been reported. M1 if presence of distant metastases, M0 if none.

Treatment for primary tumor (bone and soft tissue sarcoma)

Treatment decided at multi-disciplinary tumor conference (MDT)
Whether or not the treatment was decided at a multidisciplinary tumor conference.

Assigned contact nurse
Whether or not the patient had an assigned contact nurse.

Date when the patient was informed about the initial treatment plan
Date when the patient was informed about the initial treatment plan. A later adjustment in the plan does not require change of this date.

Number of surgeries for primary tumor
Total number of operations performed to remove primary tumor, normally 1 or 2. If the patient was not operated, for example because of metastatic disease, check 0. If number of surgeries is reported to be none, no further inquiries about surgical parameters will be made (online only) Reporting physician determines if the surgery is for the primary tumor or a local recurrence.
If a patient is operated in a two stage procedure where the second procedure is only reconstructive then only the tumor resection date should be entered (one surgery).

Oncologic treatment given for primary tumor
Specify whether or not the patient has received oncological treatment for the primary tumor, radiotherapy, medical antitumor treatment or other (needs specification). More than one alternative may be reported.

Specification of other oncologic treatment given for primary tumor
Specify which other type of oncological treatment the patient has received, for example isolated limb perfusion or hyperthermic treatment.

Surgical treatment for primary tumor

Date of first surgery
Date of *first* surgery for the primary tumor. Note, if a date is entered more than 6 months after diagnosis of the tumor a warning will be shown to avoid typing errors. The reporting physician can ignore the warning.

Where the first and/or last surgery was performed
Whether the first surgery for the primary tumor was performed before referral (outside) or at the sarcoma center. The distinction between a surgery performed outside or at a sarcoma center applies to first and last (if applicable) surgery as well as to surgery of a local recurrence (if applicable).

Surgical procedure in first and/or last surgery
Local excision or amputation. The distinction between a surgery performed outside or at a sarcoma center applies to first and last (if applicable) surgery as well as to surgery of a local recurrence (if applicable).

Surgical margin in first and/or last surgery
As assessed at surgery and upon pathological macroscopic and microscopic examination. The most important margin is the *poorest* margin, i.e. the part of the specimen where the tissue coverage is poorest (qualitatively and quantitatively). In that area the pathologist should record the type of tissue (e.g. fat, connective tissue) and the thickness (mm) of issues covering the tumor.
The classification of surgical margins applies to first and last (if applicable) surgery as well as to surgery of a local recurrence (if applicable).

Two positive margins are defined:
Gross tumor left (R2)
The tumor is transected during the operation and macroscopic tumor tissue is left. This is reported by the surgeon.
Intralesional (R1)
Microscopic tumor tissue is seen at the resection border (reported by the pathologist) or leakage of fluid/tissue from the tumor into the wound occurs during surgery (reported by the surgeon).

Negative margins
Reported as R0, further specification needed (see below).

Assessed final margins on MDT (wide or marginal)
The distinction between a *marginal* and *wide* margin is made by the surgeon and is based on the combined information from surgery and histopathologic examination (as discussed on multi-disciplinary tumor conference). The pathologist decides whether the margin is negative (tumor-free). In case of a negative margin the pathologist reports the shortest distance (mm) between tumor and resection border in fat, muscle or loose areolar tissue in an area where there is no fascia between the tumor and the resection border.
Marginal
The closest margin is outside but near the tumor in one or more places (irrespective of how much healthy tissue is included elsewhere) or all around the tumor (shelling out). Microscopically the margin is negative all around the tumor (otherwise the margin is intralesional), but tumor cells may be only millimeters from the margin.
R0 Wide
There is a cuff of healthy tissue all around the tumor. Unengaged fascia is considered a cuff regardless of the thickness of tissue between tumor and the fascia. A cuff of fatty or muscular or loose areolar tissue must be minimum 10 mm thick as measured at the histopathologic examination to qualify for a wide margin.

Date of last surgery for primary tumor
Applies to patients operated two or more times of ***primary*** tumor. For example, in a patient referred to a sarcoma center for extended excision after marginal excision of a soft tissue tumor, details regarding the first procedure (outside) would be registered under the *first* operation, and the extended excision at the center under the *last* operation.
Please note that a warning will be shown if date of last surgery for primary tumor is more than 3 months after the first surgery (online only), this warning can be ignored.
Surgery performed for recurrence should be reported on Follow-up form.

Last surgery for primary tumor performed; Surgical procedure, last surgery; surgical margin, last surgery
See definitions above for first operation.

Type of reconstruction
Applies to both bone and soft tissue tumors.
Soft tissue reconstructions may be specified as Ot**her.**

No complications due to surgery for primary tumor
If a complication requiring re- operation within 30 days (not a planned reconstructive surgery) or a deep infection within 30 days has occurred. If neither of these complications has occurred check no complications.

Pathology of primary tumor

Mitotic rate, primary tumor
Mitotic count as reported by the pathologist.
<10 mitoses per 10 HPF*
10-19 mitoses per 10 HPF*
≥20 mitoses per 10 HPF*
* A high power field (HPF) measures 0.1734 mm^2. Standardized HPF should be used.

Primary tumor growth pattern (soft tissue sarcoma only)
Any presence of infiltrative peripheral growth pattern should be reported (also if the majority of the circumference shows a pushing pattern). If only pushing growth pattern is seen this is repoted. This data should be included in the histopathological report. If a lesion cannot be classified it may be referred another SSG pathologist.

Primary tumor vascular invasion (soft tissue sarcoma only)
Any presence of vascular invasion should be reported. This data should be included in the histopathological report. If a lesion cannot be classified it may be referred another SSG pathologist.

Necrosis in primary tumor (soft tissue sarcoma only)
Any presence of necrosis should be reported. This data should be included in the histopathological report. If a lesion cannot be classified it may be referred another SSG pathologist.

Necrosis percentage in primary tumor
Whether or not the percentage of necrosis in the tumor is below or above 50% as reported by the pathologist. This data should be included in the histopathological report.

Oncological treatment for primary tumor

Included in a clinical study
Whether or not the patient is included in a clinical study.

Treatment protocol
Specify which (ongoing) clinical study the patient is included in. If the study is not in the list enter the study´s name in "Other study" as free text.

Radiotherapy start date (primary tumor)
Date of radiotherapy start (primary tumor).

Dose/fraction
Radiotherapy dose/fraction.

Number of fractions
Number of fractions of radiotherapy.

Chemotherapy start date
Date of chemotherapy start.

If several variables are missing or not logical it can be explained here
If a case is missing many key variables please explain why briefly (i.e. not referred, charts lost...). This variable will be assessed by the register manager annually. Please keep the comment short, max 100 signs.

Follow up

This part of the register is not available online for the moment, it will be activated during spring 2015 (Sweden only). Paper forms are available.
Variables will be presented below when the online version of the follow up form is active.

Review form

This part of the register is not available online. However, it's variables will be described below when this part of the register is finished during spring 2015.

Completeness of the register

This part mainly concerns the Swedish part of the register. The list may of course also be used in other countries reporting to the register but please check with your national cancer registry if they have other requirements for checking the national completeness of the register.

In Sweden, the completeness of the register is calculated based on the reported cases to the register in relation to cases registered in the *Cancerregistret* with tumor sites and SNOMED codes as listed below. The quota is calculated and shows the completeness.

Codes for comparison to the *Cancerregistret*

ICD-0 code	SNOMED code
C490-C493 C496 C498-C499	M8001/1 M8001/3 – M8920/3 except 8832/3 and 8833/3 M9020/1 and M9020/3
C471-C472 C475-C476	M9040/3 – M9043/3 M9120/3 – M9261/3 except 9140/3 and 9124/3
C40* C41*	M9370/3 M9522/3 M9540/3 – M9581/3
C44	Only if SNOMED=91203

Please note that only SNOMED-codes ending in /3 should be sought after except for the first code, M8001/1.