REGIONALA CANCERCENTRUM I SAMVERKAN

MANUAL

VERSION 1.0.2

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

2016-04-25

Contents

Manual version

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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

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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 halvåret 2016.

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, regardless of age at diagnosis, diagnosed with a sarcoma of the extremities and trunk wall according to the following criteria are included.
A sarcoma diagnosed at autopsy should not be included in the register; neither should a suspected but not confirmed sarcoma.

Soft tissue sarcomas

Histotypes	**SNOMED Codes**
Alveolar soft-part sarcoma	95813
Angiosarcoma*	91203
Clear cell sarcoma of soft tissue	90443
Desmoplastic small round cell tumor	88063
Epithelioid haemangioendothelioma	91303
Epithelioid sarcoma	88043

Extra-renal rhabdoid tumor	89633
Extraskeletal Ewing	92603
Extraskeletal mesenchymal chondrosarcoma	92203
Extraskeletal myxoid chondrosarcoma	92203
Extraskeletal osteosarcoma	91803
Fibrosarcoma	88103
Infantile fibrosarcoma	88143
Leiomyosarcoma	88903, 88913, 88963
Liposarcoma (not grade 1, see below**)	88503, 88513, 88523, 88533, 88543, 88583
Low-grade-fibromyxoma	88113
Malignant granular cell tumor	95803
Malignant ossyfying fibromyxoid tumour	88423
Malignant phyllodes tumour	90203
MPNST***	95403
Myxofibrosarcoma	88113
Other STS	88003
PEC-oma, malignant	87143
Rhabdomyosarcoma	89003, 89103, 89203, 89213
Solitary fibrous tumor	88151****, 88153
Synovial sarcoma	90403, 90413, 90423, 90433
Undifferentiated pleomorphic sarcoma/unclassified sarcomas (UPS)	88013, 88023, 88303

* Tumor site C44* may be included for soft tissue angiosarcomas (see below).

** Grade 1 liposarcomas (atypical lipomatous tumors) should not be included in the national quality register (see below).

*** MPNST is a soft tissue tumor in a peripheral nerve. The ICDO-3 C47*-codes should hence be used.

**** Solitary fibrous tumor (88151) should be included in the national quality register but not connected to the *Cancerregister* (see below)

Soft tissue sarcomas at the following sites should be registered:

C490 Head and neck (*may be registered, see below)*
C491 shoulder, upper arm, elbow, lower arm, hand
C492 thigh, knee, lower leg, foot
C495 gluteal, groin (*may be registered, see below)*
C496 upper trunk, lower trunk
C509 mamma
C44* if the tumor is an angiosarcoma 91203 *(may be registered, see below)*

MPNST tumor sites

C471 MPNST (95403) in shoulder, upper arm, elbow, lower arm, hand
C472 MPNST (95403) in thigh, knee, lower leg, foot

C475 MPNST (95403) in gluteal, groin (*may be registered, see below)*
C476 MPNST (95403) upper trunk, lower trunk

Bone sarcomas

Histotypes	**SNOMED codes**
Adamantinoma	92613, 93103
Angiosarcoma of bone	91203
Atypical cartilaginous tumor	To be defined
Benign giant cell tumor	92500*, 92501
Chondrosarcoma (grades I – III)	92203, 92433, 92213, 92423, 92403, 92313
Chordoma	93703
Clear cell chondrosarcoma	92423
Conventional osteosarcoma	91803, 91813, 91823
Dedifferentiated chondrosarcoma	92433
Epithelioid hemangioendothelioma	91333
Ewing sarcoma	92603
Leiomyosarcoma of bone	88903, 88913, 88963
Low-grade osteosarcoma	To be defined
Malignancy in giant cell tumor	92503
Mesenchymal chondrosarcoma	92403
Other osteosarcoma	91853, 91863, 91873, 91933, 91943
Other sarcoma of the bone	88003, 88123
Parosteal osteosarcoma	91923
Telangioectatic osteosarcoma.	91883
Undifferentiated high-grade pleomorphic sarcoma (UPS)	88503, 88023

* Benign giant cell tumors coded as 92500 should be included in the national quality register but not connected to the *Cancerregister* (see below)

Bone sarcomas at the following sites should be registered:
C400 scapula, humerus, radius, ulna,
C401 hand
C402 femur, tibia, fibula
C403 foot
C410 head and neck (*may be registered, see below)*
C412 Vertebra
C413 Rib, clavicle or sternum
C414 sacrum, pelvis not sacrum

Special tumor sites
No strictly cutaneous tumors (C44*) have to be registered in the national quality register but strictly cutaneous angiosarcomas *may* be registered by the physician. C44* should however

not be sought after in the *Cancerregistret* or used for control of the national quality registers completeness in comparison to the *Cancerregistret.*

Head and neck sarcomas, bone (C410) and soft tissue (C490), *may* be registered in the national quality register at the physician's discretion but it is not mandatory. To avoid erroneous inclusions these cases should not be sought after in the *Cancerregistret.* C410 and C495 should not be used in the control of the national quality registers completeness in comparison to the *Cancerregistret*.

Soft tisse sarcomas in the gluteal and groin area (ICD code for pelvic area C495) *may* be registered in the national quality register at the physician's discretion but it is not mandatory. The code C495 includes many tumors located within the pelvic area and therefore only selected cases with this site code should be included in this register. To avoid erroneous inclusions these cases should not be sought after in the *Cancerregistret.* C495 should not be used in the control of the national quality registers completeness in comparison to the *Cancerregistret*.

Special tumor types
Liposarcomas (soft tissue) grade 1, i.e. atypical lipomatous tumors 88501b, should not be registered in the national quality register.
Border line solitary fibrous tumor (88151) and benign giant cell tumors (coded as 92500 by the pathologist), should be included in the national quality register but NOT in the *Cancerregistret* (to the monitors: they should be saved without connect to a cancer register tumor). Benign solitary fibrous tumors (88150) should not be registered in either register.

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.

Incomplete
Online only. If variables are missing and the data cannot be found please check the incomplete box to avoid further inquiries. In such cases, please motivate why in the field for comments to the monitor (above the actual form).

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).

Arrival of the referral letter
Date when the referral letter *arrived* to the sarcoma center (or date of first contact using other type of communication).
PLEASE NOTE THAT THIS VARIABLE WILL BE ADDED DURING 2017.

Date of first visit
Date when the patients first visited the sarcoma center or was first discussed at a multidisciplinary treatment conference.

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.

Date of written pathological report for diagnosis
Date when the written pathological report of the diagnostic specimen was issued, either before or after referral to a center.
NOTE: In Norway this variable is called date of diagnosis, i.e. the date that the diagnosis was established (by pathologist).
PLEASE NOTE THAT THIS VARIABLE WILL BE ADDED DURING 2017.

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". Most often "Excision or surgery with histopathologic examination" (if a core biopsy and/or operation has been performed) or "Cytology" (if the diagnosis is based on fine needle aspiration only).

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 final histoype was assessed, most often the specimen from the first operation of the primary tumor. 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".

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).

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.

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".

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

Size unknown
When the size of the primary tumor cannot be assessed.

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).

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.

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).

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.

N-stage

N-stage for bone sarcomas, a mandatory variable for Swedish patients, part of the "Canceranmälan 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.

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".

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.

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).

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".

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

Size unknown
When the size of the primary tumor cannot be assessed.

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

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

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).

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.

N-stage

N-class for soft tissue sarcomas, a mandatory variable for Swedish patients, part of the "Canceranmälan 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.

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.

Treatment delay due to patient's choice
If the planned therapy has been postponed/delayed due to the patient's choice. Delay due to comorbidities should not be reported here.
PLEASE NOTE THAT THIS VARIABLE WILL BE ADDED 2017.

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 description of surgical procedure 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).

Shortest surgical margin (mm)
The reported shortest surgical margin in mm, except in unengaged fascia. Please leave empty if not assessed or intralesional margins.

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 written pathological report for the first surgery
Date when the written pathological report of the specimen from the first surgery was issued, either before or after referral to a center.
PLEASE NOTE THAT THIS VARIABLE WILL BE ADDED 2017.

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

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

Reported by
Automatically derived in online registration depending on the person reporting to INCA.
Name of the person filling in the follow up report in the INCA system.

Initiated by
Automatically derived in online registration depending who first reported the patient to the register.

Reporting hospital code
Automatically derived in online registration depending on the person reporting to INCA.
Filled in by monitor for cases reported on paper forms. Please contact the national monitor for further information.

Reporting clinic code
Automatically derived in online registration depending on the person reporting to INCA.
Filled in by monitor for cases reported on paper forms. Please contact the national monitor for further information.

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.

Reporting date
Date when the form is sent to RCC, automatically derived in online registration.

Follow up date
Date of the follow up visit/contact. Please note that the follow up date must be later than the date of diagnosis.

Status
Tumor status at the follow up visist/contact.
Please report no evidence of disease if the patient has no tumor recurrences (local or distant).
Please report persistent disease if the patient has any sign of tumor (local, distant or both) both if it is a new recurrence and if it is a persistent recurrence which has been previously reported.
Please report each tumor recurrence and disease free intervals to the register. If new recurrences/metastases are diagnosed after a tumor-free interval these should be registered as persistent disease. In the register the patient will be registered as being in remission and then having a recurrence (local or distant). This can be repeated if relevant. All FU's are registered.

If a previous tumor recurrence has been reported but no treatment of the recurrence a warning will be issued if no evidence of disease is reported.

Date of local recurrence
Date of diagnosis of a local recurrence, clinical or radiological. All local recurrences should be reported and will be registered in this variable. Multiple recurrences may be registered for each patient.

Date of distant metastasis
Date for diagnosis of distant metastases, clinical or radiological. All metastases occurring after metastases-free interval should be reported and will be registered in this variable. Multiple recurrences of distant metastases may be registered for each patient.

Site of distant metastasis
Site of the diagnosed distant metastasis. Please report ”Multiple” if distant metastases were diagnosed in more than one location during the specific follow-up period, i.e. from previous until current follow-up visit.

Date of information about recurrence
Date when the patient was informed about the new local recurrence / distant metastases diagnosed during current follow-up period.

Tumor size
Largest diameter of local tumor recurrence as assessed by radiological imaging or pathologic examination of the resected specimen, reported in cm.

Size unknown
When the size of the local recurrence cannot be assessed.

Surgery of local recurrence
Whether or not the patient was operated for the reported local tumor recurrence.

Local recurrence surgery date
Date of surgery of local recurrence; only activated if the previous variable reported that a surgery was performed.

Where the surgery of the local recurrence was performed
Whether the surgery for the reported local recurrence 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 of the primary tumor as well as to surgery of a local recurrence (if applicable).

Surgical procedure of the reported local recurrence
Local excision or amputation. The description of surgical procedure applies to first and last (if applicable) surgery as well as to surgery of a local recurrence (if applicable).

Surgical margin in the surgery of the reported local recurrence
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:
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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.

Other treatment of local recurrece

If the reported local recurrence has been treated with other/additional treatment to surgery. I.e. radiotherapy, medical antitumoral treatment, both or other type of treatment.

Treatment of distant metastasis

Check boxes which are activated if a distant metastasis is reported. If "none" is reported, no further treatment can be registered. Else, multiple treatment modalities may be reported (surgery of liver, lung or other metastasis, radiotherapy or medical antitumoral therapy).

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.

Cause of death

Dead from tumor If the patient dies with known metastases. If the patient dies with untreated primary tumor or local recurrence causing disabling disease. If the patient has known metastases (diagnosed within two years) but exact reason for death is not known cause of death will be re-coded as Death from tumor.

Dead with tumor If the patient dies with untreated primary tumor or local recurrence which does not cause disabling disease. If a patient with known metastatic disease dies of obviously unrelated cause (plane crash, murder etc.). Death from tumor should be used if in doubt for patients with generalized disease.

Without tumor No evidence of recurrent disease at death.

Unknown If the cause of death has not been able to establish.

Completeness of the register

A pre-defined check list for comparison of the national quality register to the *Cancerregistret* in Sweden is available for use by monitors in INCA. For further specifications, please contact the national support team at RCC Syd.