International Sarcoma Registry Minimal Dataset Data Dictionary
September 10, 2025

This data dictionary is an explanation for the minimal dataset of the International Sarcoma Registry. This should be used as a guideline for data collection, and we have provided examples for specific scenarios. There may be instances of regional variation for some data elements, but we encourage everyone to remain as close to the suggestions as possible and to remain internally consistent. Accurate and complete data collection will allow for informative and meaningful collaborative research projects in the future.

1. **Is this a primary (non-recurrent) sarcoma?**
    a. **Yes**
    b. **No**

This data element is meant to ensure that a patient meets inclusion criteria for the registry by having a new diagnosis of sarcoma that was not previously treated with curative intent. This is a sarcoma registry primarily, but we also record sarcoma-adjacent benign entities (atypical cartilaginous tumors, atypical lipomatous tumors, giant cell tumors, aggressive fibromatosis/desmoid tumors, and Langerhans cell histiocytosis). Patients with a non-curative attempt at treatment or a previous inadequate excision prior to referral (a “whoops” procedure) are still eligible for inclusion in the registry.

Examples:

A patient referred after a needle biopsy confirming a synovial sarcoma: “Yes.”

A patient referred with a local recurrence 3 years after an osteosarcoma was previously excised and given chemotherapy: “No.”

A patient with an unrecognized leiomyosarcoma excised by a non-oncologic surgeon with positive margins who was referred 4 weeks after excision: “Yes”

2. **Name of treating institution**

This is the name of the hospital, institution, or healthcare system where the patient was treated. It should include additional details (such as location/city) if multiple hospitals exist with similar names (as in a chain of hospitals).

3. **Country/state of treating institution**

This question records the details of the country and state/province/region where the patient was treated.

4. **Patient name and/or unique ID**

A specific patient identifier that will allow for identification and referencing of the patient’s medical record. This is meant to be only for the institution/provider managing the registry at their site primarily for the benefit of quality improvement and patient safety. This identifier will

not be used or shared in any future collaborative studies, which will used de-identified data. However, it is important to identify the patient internally so that their medical record may be assessed to obtain additional information needed for future research questions, additional treatment details, outcome assessment, and auditing for data accuracy and completeness. The identifier need not be consistent across institutions (but should be consistent within each institution) and each contributing center can decide how best to record this information.

Examples:

Social security number
Medical record number or unique health ID
First and last name

5. **Patient date of birth (YYYY-MM-DD)**

This is the date of birth of the patient recorded in the format YYYY-MM-DD.

6. **Patient sex**
    a. **Male**
    b. **Female**
    c. **Nonbinary**

This records the sex of the patient. "Nonbinary" can refer to anyone who does not fit into the traditional categories of male or female.

7. **Patient zip code or city/region of residence**

This item aims to identify the patient's geographic location at the time of diagnosis, with a unique identifier for monitoring and analyzing the geographical distribution of cases. This unique identifier may vary by center but is an essential element for regional analysis and mapping access to treatment.

Examples:

Brazil: BR12345/Sao Paulo/Brazil/04567-000

US: Zip code 52246

8. **Date of diagnosis (YYYY-MM-DD)**

Ideally this will be the date that the pathology report was finalized. This is not the date when the sarcoma was first suspected on imaging or clinical presentation, but rather the date of a confirmatory histologic report after a biopsy or surgical resection. Alternatively, the date that the biopsy was performed can also be used.

Examples:

A core needle biopsy was performed on August 20, 2025 and reported as synovial sarcoma on August 25, 2025. The date of diagnosis is 2025-08-25. Reporting the date that the biopsy was performed (2025-08-20) is also acceptable.

A prior attempt at excision on July 15, 2025 reported a tumor of unknown malignant potential with positive margins, and a subsequent re-excision on August 13, 2025 established a diagnosis of myxofibrosarcoma from a pathology report dated August 24, 2025. The date of diagnosis is acceptable as either 2025-08-13 (date of re-resection) or 2025-08-24 (date of final pathology report).

9. **Unplanned excision prior to referral ("whoops" procedure)?**
    a. **Yes**
    b. **No**

A "whoops" procedure is an inappropriate excision of an unrecognized sarcoma prior to referral to a sarcoma specialist. It refers to an incomplete non-oncologic resection and applies to both bone and soft tissue tumors. It can be determined from medical records or surgical notes. It does not include biopsies done at an outside center prior to referral

Examples:

A tumor was thought to be a lipoma and was removed by a general surgeon with a final report of leiomyosarcoma with positive margins: "Yes"

A patient had an incisional biopsy done at an outside hospital through a small incision without contamination: "No"

A patient had an incomplete excision where the tumor was removed in pieces and with palpable residual disease: "Yes"

10. **Tumor side**
    a. **Left**
    b. **Right**
    c. **Midline**

This refers to the side of the body where the tumor is located. Tumors of the axial skeleton or paraspinous muscles are midline

Examples:

Soft tissue sarcoma of the right triceps muscle: "Right"

Osteosarcoma of the left pedicle of L3: "Midline"

11. **Bone or soft tissue type and location**
    a. **Bone**
        i. **Upper extremity**
            1. **Scapula**

2. Clavicle
3. Humerus
4. Radius
5. Ulna
6. Carpus
7. Metacarpals
8. Phalanges

ii. Lower extremity

1. Pelvis (select all that apply)
    a. Zone 1
    b. Zone 2
    c. Zone 3
    d. Sacrum
2. Femur
3. Patella
4. Tibia
5. Fibula
6. Hindfoot
7. Midfoot
8. Forefoot

iii. Axial

1. Cervical spine
2. Thoracic spine
3. Lumbar spine
4. Sacrum/coccyx
5. Sternum
6. Ribs

b. Soft tissue

i. Upper extremity

1. Axilla
2. Shoulder
3. Arm
4. Elbow
5. Forearm
6. Wrist
7. Hand

ii. Lower extremity

1. Gluteal
2. Pelvis
3. Thigh
4. Knee
5. Popliteal fossa
6. Leg
7. Ankle
8. Foot

iii. Axial

1. Trunk and chest wall
2. Flank and abdominal wall
3. Paraspinal – cervical
4. Paraspinal – thoracic
5. Paraspinal – lumbar

This refers to the specific anatomical location of the tumor which is essential for anatomic and statistical classification. This will allow comparisons of tumors that occur in the same bone or site in the extremity and will be important for surgical details and functional outcomes. There are more specific choices under the larger categories of "bone" or "soft tissue." The wording of the specific location should be exactly as written and preferably with a drop-down menu to avoid spelling errors and inconsistency in labeling. In some cases, it may be difficult to determine whether the primary tumor is bone with an exophytic soft tissue extension or a soft tissue tumor with bone erosion, but every effort should be made to classify correctly into bone or soft tissue based upon the origin of the tumor. Pelvic tumors have an additional level of detail to choose all affected zones.

Examples:

A 15-cm soft tissue sarcoma centered in the pectoralis major and minor with erosion into a rib – "Soft tissue," "Axial," "Trunk and chest wall."

An osteosarcoma involving the iliac wing and acetabulum – "Bone," "Lower extremity," "Pelvis," "Zones 1, 2."

12. Longitudinal location (select all that apply)
- **a. Proximal**
- **b. Middle**
- **c. Distal**
- **d. Not applicable**

This element exists to distinguish proximity to joints, neurovascular structures, and muscle origins and insertions. It is applicable only to long and short bones of the extremities; tumors in the axial skeleton are "not applicable." Use the AO classification (based on Heim's system of squares) dividing long and short bones into proximal, middle, or distal thirds based on overall length of the bone.

Examples:

A distal femoral osteosarcoma spanning the middle and distal thirds: "Middle" and "Distal."

An osteosarcoma in the thoracic vertebra: "Not applicable."

A myxofibrosarcoma of the anterior knee which was coded as "Knee" for question 11 (type and location): "Not applicable."

13. Bone or soft tissue histology
- **a. Bone**
  - **i. Giant cell tumor**
  - **ii. Ewing family**
  - **iii. Chondrosarcoma/ACT**
    1. **Atypical cartilaginous tumor**
    2. **Conventional**
    3. **Secondary**

4. Periosteal/juxtacortical
5. Mesenchymal
6. Clear cell
7. Dedifferentiated

iv. Osteosarcoma
1. Conventional
2. Surface
    a. Parosteal
    b. Periosteal
    c. High-grade surface
3. Telangiectatic
4. Small cell
5. Low-grade central

v. Chordoma

vi. Other
1. Fibrosarcoma
2. Angiosarcoma
3. Adamantinoma
4. Synovial sarcoma
5. Hemangioendothelioma
6. Leiomyosarcoma
7. Solitary fibrous tumor of bone
8. Langerhans cell histiocytosis
9. Sarcoma, not otherwise specified, not fusion-related
10. Other fusion-related sarcoma

b. Soft tissue

i. Fibrous tumors
1. Myxofibrosarcoma
2. Solitary fibrous tumor
3. Inflammatory myofibroblastic tumor
4. Fibromyxoid sarcoma
5. Dermatofibrosarcoma protuberans
    a. Fibrosarcomatous transformation
    b. No fibrosarcomatous transformation
6. Giant cell fibroblastoma
7. Myofibroblastic sarcoma
8. Sclerosing epithelioid sarcoma
9. Angiomatoid fibrous histiocytoma
10. Aggressive fibromatosis/Desmoid tumor

ii. Liposarcoma
1. ALT/WDLS
2. Myxoid liposarcoma
3. Dedifferentiated liposarcoma
4. Pleomorphic liposarcoma
5. Sclerosing liposarcoma
6. Myxoid pleomorphic liposarcoma

iii. Uncertain differentiation
1. Extraskeletal osteosarcoma
2. Extraskeletal myxoid chondrosarcoma
3. Epithelioid sarcoma
4. Alveolar soft parts sarcoma

5. **Clear cell sarcoma**
6. **Plexiform fibrohistiocytic tumor**
7. **Benign, Diffuse type tenosynovial giant cell tumor**
8. **Malignant tenosynovial giant cell tumor**
9. **Giant cell tumor of soft tissue**
10. **Angiomatoid fibrous histiocytoma**
11. **Malignant ossifying fibromyxoid tumor**
12. **Myoepithelial carcinoma**
13. **Hemosiderotic fibrolipomatous tumor**
14. **Malignant phosphaturic mesenchymal tumor**
15. **Extrarenal rhabdoid tumor**
16. **Ewing family of tumors**
17. **Desmoplastic small round cell tumor**
18. **PEComa**
19. **Sarcoma, not otherwise specified, not fusion-related**
20. **Other fusion-related sarcoma**

iv. **Synovial sarcoma**

v. **Vascular sarcoma**
   1. **Angiosarcoma**
   2. **Kaposi sarcoma**
   3. **Pseudomyogenic hemangioendothelioma**
   4. **Epithelioid hemangioendothelioma**
   5. **Malignant glomus tumor**
   6. **Intimal sarcoma**

vi. **Leiomyosarcoma**

vii. **Neural sarcoma**
   1. **Malignant peripheral nerve sheath tumor**
   2. **Melanotic schwannoma**
   3. **Malignant perineuroma**
   4. **Malignant granular cell tumor**

viii. **Rhabdomyosarcoma**
   1. **Embryonal**
   2. **Pleomorphic**
   3. **Alveolar**
   4. **Spindle cell**

ix. **Undifferentiated sarcoma**
   1. **Undifferentiated pleomorphic sarcoma**
   2. **Undifferentiated round cell sarcoma**
   3. **Undifferentiated spindle cell sarcoma**
   4. **Undifferentiated epithelioid sarcoma**

The histology is separated by bone or soft tissue and is primarily based on the World Heath Organization 2020 classification. This encompasses the most commonly occurring subtypes and nomenclature applied in real-world diagnostic practice and institutional expertise. It serves as a critical variable for diagnosis classification and downstream analysis. We have two categories for sarcomas that do not clearly fit a current classification: “sarcoma, not otherwise specified, not fusion-related” and “other fusion-related sarcoma.” These can be used when the situation warrants but only when the sarcoma does not clearly fit in another defined category.

Examples:

A secondary chondrosarcoma in a patient with multiple hereditary exostosis: "Bone," "Chondrosarcoma/ACT," "Secondary."

A soft tissue tumor signed out descriptively as a EWSR1-rearranged spindle cell sarcoma: "Soft tissue," "Uncertain differentiation," "Other fusion-related sarcoma."

14. Grade

- **a. Benign**
- **b. Grade 1**
- **c. Grade 2**
- **d. Grade 3**
- **e. Grade X**

This variable records tumor grading on a 3-point scale for soft tissue sarcoma according to the FNCLCC system, which assesses differentiation, mitotic rate, and necrosis to infer biologic aggressiveness. For bone sarcomas, grading depends on the subtype: chondrosarcomas are graded histologically from grade 1-3 based on cellularity and atypia; Ewing sarcomas are generally considered high-grade without formal grading; osteosarcomas include both high-grade and low-grade forms, which are graded according to specific histologic criteria. Benign tumors are classified as a distinct category, while cases with undetermined grade are designated as "Grade X." These categories guide clinical assessment, prognosis, and treatment decisions.

Examples:

A solitary fibrous tumor determined to be low-risk: "Grade 1"

An atypical cartilaginous tumor or atypical lipomatous tumor: "Benign"

An intermediate-grade extraskeletal myxoid chondrosarcoma: "Grade 2"

15. Tumor size in greatest dimension

- **a. <=5 cm**
- **b. >5 and <=10 cm**
- **c. >10 and <=15 cm**
- **d. >15 cm**
- **e. Not applicable**

This documents the largest dimension of the tumor as measured on a pretreatment MRI. Tumor size is a key prognostic factor in both soft tissue and bone sarcomas, influencing staging, recurrence risk, and treatment planning. Cases where size is not accessible, not known, or not recorded can be coded as "Not applicable."

Examples:

A UPS that is 12x8x7 cm on pre-treatment MRI: ">10 and <=15 cm."

A tumor that was incompletely excised with positive margins, no preoperative imaging, and no reliable documentation of tumor size: "Not applicable."

16. **Tumor depth (select all that apply)**
    a. **Superficial**
    b. **Deep**

This data element records the anatomical depth of the tumor relative to the investing fascia and surrounding structures. Tumors are classified as “superficial” when located above the muscle fascia or periosteum. Superficial tumors can be adjacent to and abut the fascia or periosteum, but they should not be intimately involved with the fascia or periosteum. “Deep” tumors will involve the muscle fascia, periosteum, or any deeper structures. Tumor depth was previously important in staging systems and remains important with clinical decision-making and reconstructive options.

Examples:

A leiomyosarcoma located in the skin and subcutaneous fat. It abuts, but does not involve, the fascia focally but clearly originated in the subcutaneous tissue: “Superficial.”

A myxofibrosarcoma that has contrast enhancement along the muscle fascia of the thigh with subcutaneous extension: “Deep” and “Superficial.”

17. **Metastasis at diagnosis (choose all that apply)**
    a. **Yes, lung**
    b. **Yes, other than lung**
    c. **No**

This parameter documents the presence and location of distant metastases at the time of initial diagnosis. Metastatic involvement is recorded as “lung,” “other than lung,” or “no metastasis,” with multiple selections allowed if applicable. Lung metastases are the most frequent in sarcoma, while “other than lung” includes any other sites including bone (distant and skip metastasis), lymph nodes, liver, brain, and all other sites. Identifying metastatic spread at diagnosis is essential for accurate staging, prognostic assessment, and guiding treatment strategies. This field is meant to capture the metastatic status only at the time of the initial diagnosis of their tumor. Do not revise this field if the patient develops metastasis after the initial treatment course.

Examples:

A patient is diagnosed with a localized UPS. On the 6-month surveillance chest imaging there is evidence of pulmonary metastatic disease. Since there were no metastasis at diagnosis: “No.”

A patient with an osteosarcoma also has multiple pulmonary lesions consistent in appearance with metastasis and lymph nodes that are mildly enlarged but not clearly metastatic: “Yes, lung”

18. **Treatment intention at diagnosis**
    a. **Curative**
    b. **Palliative**

This variable indicates the primary therapeutic goal established at the time of diagnosis. Treatment intention is categorized as curative, aiming for complete eradication of the tumor, or palliative, focused on symptom relief and quality of life without the expectation of cure. The rationale behind this data element is to distinguish patients with no reasonable chance of cure and an inherently worse prognosis from patients that present with a goal of cancer eradication. "Curative" intent can still apply to a patient who has metastatic disease at diagnosis if the treating team feels that all sites of disease can be addressed definitively. A "palliative" intervention has a primary focus on preserving function, limiting complications, and cancer control for as long as possible.
This field refers to the treatment plan at presentation when the diagnosis was first made, after biopsy, staging, and multidisciplinary team discussion. Do not revise this value if there is a change in treatment intent that occurs later in the disease course (e.g. if curative treatment becomes no longer possible due to progression).

Example:

A patient was initially planned for curative surgery as the soft tissue sarcoma was localized on initial imaging. On a surveillance CT 6 months after surgery, diffuse metastases were found and the patient was starting on palliative chemotherapy: "Curative."

A patient presented with a UPS and multiple, bilateral lung metastases and was treated with radiation, wide margin surgical excision, and immunotherapy: "Palliative."

A patient presented with a UPS and two ipsilateral lung metastases and was treated with radiation, wide margin surgical excision, and pulmonary metastasectomy: "Curative"

A patient presented with widely metastatic synovial sarcoma and a pathologic fracture through a femoral metastasis. The patient elected for comfort cares and a femoral nail was placed for pain control and improved mobility: "Palliative"

19. Surgery type
- **a. Limb salvage**
- **b. Rotationplasty**
- **c. Amputation**
- **d. None**

This entry is to record, in general terms, the operation performed and is divided simply into limb salvage, rotationplasty, or amputation. If patient is treated with non-surgical management, like definitive radiotherapy in case of Ewing sarcoma, then chose "None."

20. Date of surgery (YYYY-MM-DD)
- **a. Enter date**
- **b. None**

If a patient had a surgical procedure, enter the date of the operation (YYYY-MM-DD). This should be the date of the definitive resection that resulted in the final histologic margins.

Examples:

A patient had an incomplete excision on July 21, 2025 and a tumor bed re-excision on August 18, 2025: "2025-08-18"

A patient had an initial excision on August 5, 2025 by the treating orthopaedic oncologist. The margins were positive, so a repeat excision was performed on August 20, 2025: "2025-08-20"

21. **Final margins**
    a. **Wide (R0, >=1 mm, no residual tumor)**
    b. **Marginal (R0, <1 mm)**
    c. **Microscopic positive (R1)**
    d. **Macroscopic positive (R2)**
    e. **Intralesional curettage**
    f. **Not applicable – no definitive resection**

The data for margins is informed by the Enneking and Residual Tumor ("R") Classification Systems. The R classification was adopted into the 3rd edition of the AJCC Manual for Staging of Cancer. It is based on the macroscopic and microscopic assessment of the surgical resection margin. The margin is categorized as grossly positive (R2), microscopically positive (R1), or microscopically negative (R0), meaning that no tumor cells are seen at the inked margin with a microscope. The Enneking classification was described in 1980 and categorized as wide (histologically non-reactive normal tissue at margin), marginal (pseudocapsule present at margin), and intralesional (tumor present at margin). The margin should be reported as the closest margin (e.g. if a margin is 99% wide, but 1% microscopically positive, the final margin is "microscopic positive [R1]").

Wide (R0, >=1 mm, no residual tumor) – represents a complete resection with no tumor or reactive tissue at the closest resection margin. This is often referred to as a "clean" or "negative" margin. It is defined as a distance from closest tumor of at least 1mm. This is also the margin that should be used after a tumor bed re-excision that does not demonstrate any residual tumor.

Marginal (R0, <1 mm) – represents a complete resection with a negative margin, but with the closest margin as less than 1 mm away from the tumor.

Microscopic positive (R1) – indicates the presence of microscopic residual tumor at the resection margin, meaning cancer cells are found under the microscope but not visible to the naked eye. Defined as a microscopic margin that has tumor at the periphery.

Macroscopic positive (R2) – Signifies macroscopic residual tumor, meaning that gross (visible) disease remains after the procedure. This could represent a debulking procedure done for palliation.

Intralesional curettage – This is when a formal en bloc resection is not attempted, but there is an intentional effort to remove all visible disease. This may be seen in a benign or low-grade tumor such as a giant cell tumor of bone or atypical cartilaginous tumor.

Examples:

A soft tissue sarcoma is treated with preoperative radiation and surgical excision. The sciatic nerve must be peeled from the tumor with a small layer of epineurium. The margins are

reported as negative, but tumor is within 1 mm of the edge of the specimen: "Marginal (R0, <1mm)."

A myxofibrosarcoma is removed and the pathology report states that, although the tumor was removed en bloc, there is microscopic extension of tumor cells from the main specimen and involves the lateral margin: "Microscopic positive (R1)."

A Ewing sarcoma of the clavicle is treated with neoadjuvant chemotherapy prior to surgical resection. The pathology report documents 72% necrosis and 2 mm margins: "Wide (R0, >=1 mm, no residual tumor)."

A giant cell tumor of the distal radius is treated with curettage and cementation. The final pathology report confirms the diagnosis: "Intralesional curettage."

22. Intraoperative contamination

- **a. Yes**
- **b. No**

This data element explores whether or not the tumor was entered during the operation. It is a different question than the final surgical margins, as it is possible to recognize intraoperative contamination and complete the resection with a wider margin. However, given the uncertainty on the consequences of intraoperative spillage, it is important to record both the final histologic margins from the pathology report, but also whether there was contamination intraoperatively. Intraoperative contamination can be a positive frozen section, cutting into the tumor, spilling the tumor contents during removal, or operating on a fungating tumor.

Examples:

A soft tissue sarcoma is fungating through the skin at the time of clinical presentation. The tumor is later removed en bloc but the fungating mass is exposed to the operative field through the skin erosion: "Yes."

During a tumor resection a plane is developed that enters the edge of the tumor. The surgeon immediately recognizes this and backs out to take a wider margin of normal tissue and closes the area that was entered: "Yes."

23. Systemic agents

- **a. Yes**
  - **i. Neoadjuvant (preoperative) only**
  - **ii. Adjuvant (postoperative) only**
  - **iii. Both neoadjuvant and adjuvant**
  - **iv. Definitive (no surgical resection)**
- **b. No**

This question generally records whether a patient was given anti-cancer systemic agent(s) (chemotherapy, immunotherapy, monoclonal antibody, etc) as part of the initial course of treatment. <u>This does not include agents started later in treatment.</u>

Examples:

A patient with osteosarcoma is treated with neoadjuvant and adjuvant MAP chemotherapy: "Both neoadjuvant and adjuvant."

A patient with a soft tissue sarcoma is treated with radiation and surgical resection. Nine months later, the patient develops lung metastases and is started on systemic therapy: "No."

24. Radiation therapy

- **a. Yes (select all that apply)**
  - **i. Neoadjuvant (preoperative)**
  - **ii. Adjuvant (postoperative)**
  - **iii. Intraoperative**
  - **iv. Definitive (no surgical resection)**
- **b. No**

This element is the description of timing of any modality of radiation treatment for the patient (e.g. external beam, proton, carbon ion, brachytherapy, intensity-modulated, etc). This does not include radiation therapy given later in treatment.

Examples:

A patient was treated with 50 Gy of radiation prior to resection of a soft tissue sarcoma: "Neoadjuvant (preoperative)."

A patient with Ewing sarcoma of the lumbar spine was treated with definitive radiation and no surgical resection: "Definitive (no surgical resection)."

A patient with a solitary fibrous tumor was treated with a wide surgical resection without adjuvant treatment. 8 months after the resection, the patient developed a lung metastasis adjacent to the heart that was targeted with focused external beam radiation: "No."

25. Record complete

- **a. Yes**
- **b. No**

This data element can be useful for internally tracking whether each question has been answered for a patient entry into the registry. Others have found that marking a file as "Record complete" is an effective and efficient means to signal that this record does not need to be opened or revised. Conversely, entering "No" may help flag a record that needs to be revisited after some baseline data has been entered, but not all data elements are known. This question may also be used for internal and external auditing for data completeness and accuracy.

Example

A patient record is partially entered, but the margins cannot be completed because the pathology report is not yet available at the time of data entry: "No."