

Do We All Call It the Same: An Inter-Rater Reliability Analysis of Musculoskeletal Tumor Registry Data Elements

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INTRODUCTION: The Musculoskeletal Tumor Registry (MsTR) is part of the AAOS Family of Registries, designed to capture critical data to understand clinical outcomes and patient-reported outcomes for patients undergoing treatment for musculoskeletal malignancies. The initial Sarcoma Module affords a level of detail regarding the nature of the disease and treatment not previously seen outside of single-institutional databases. However, the utility of the Musculoskeletal Tumor Registry (MsTR) in providing research quality data is dependent upon ensuring reliable and accurate data entry. In order to assess data integrity, the current analysis aims to: 1) understand data elements for which MSTs members do not have consensus regarding how best to code into the registry, and 2) to develop a data dictionary to advise as to how registry coding should be performed.

METHODS:

A series of Qualtrics surveys were conducted of MsTR Steering Committee Members and MsTR users to identify data elements for which uncertainty may exist as to the optimal registry coding. Once these were compiled, a survey was completed by 60 MSTs members involving the data entry for 35 clinical vignettes related to the areas of question. Consensus was defined as at least 90% agreement. A modified Delphi method was utilized to establish a consensus on a data dictionary to inform uniform guidance as to how registry elements should be coded in otherwise ambiguous clinical scenarios.

RESULTS: The MsTR member survey highlighted areas of inconsistency or confusion, particularly for 1) the range of percent necrosis on histopathology, 2) defining the longitudinal location of the tumor along the compartment, and 3) the appropriate categorization of tumor depth when the tumor was situated along the superficial aspect of the fascia, without invasion deep to the fascia.

DISCUSSION AND CONCLUSION: Through a series of surveys and consensus meeting, the MsTR Steering Committee has utilized a modified Delphi approach to identify data elements for which inter-rater reliability of data element entry was a concern. This allowed for the development of a data dictionary to allow for consistency of coding between institutions contributing to the registry. This effort, and similar ones in the future, aim to optimize the accuracy, reliability, and utility of the MsTR in providing reproducible, research-quality data for this highly complex patient population.

Areas of Strong Consensus (High Agreement $\geq 90\%$)

- **Percent Necrosis:**
 - 50% necrosis: coded as 50%
 - Complete necrosis: coded as 100%
 - No appreciable treatment effect: coded as 0%
- **Laterality:**
 - Right forearm: clear consensus (one outlier)
 - Sternum: midline
 - Left rhomboid: majority coded with laterality
- **Bone vs. Soft Tissue:**
 - One outlier, but broad consensus overall
- **Longitudinal Tumor Location:**
 - Intertrochanteric femur: proximal
- **Tumor Depth:**
 - Superficial DFSP: superficial
 - Liposarcoma in vastus lateralis: deep
- **Compartment Status:**
 - Liposarcoma in vastus lateralis: intracompartmental
- **Tumor Size (6.5 x 5.0 x 4.5 cm):**
 - All correctly coded greatest dimension
- **Eligibility after Unplanned Excision:**
 - Consensus to include in MsTR

Areas Without Initial Consensus

1. **Estimated Necrosis Described as a Range (e.g., 80-90% necrosis)**
 - **Data Dictionary Recommendation:** Define as the average of the range
2. **Longitudinal Location within the Compartment**
 - Difficulties with some instances determining whether proximal/distal or midshaft
 - **Data Dictionary Recommendation:** Define according to AO definitions
3. **Tumor Depth**
 - Myxofibrosarcoma along superficial aspect of fascia lata
 - **Data Dictionary Recommendation:** Fascia is considered "deep", and superficial is defined as whatever is not deep.
4. **Compartment Status**
 - High disagreement on superficial DFSP and myxofibrosarcoma cases
 - **Data Dictionary Recommendation:** Define compartments using Enneking's original definitions
5. **Method of Biopsy if Presentation is After Unplanned Excision**
 - High disagreement in responses
 - **Data Dictionary Recommendation:** Add a category for "Unplanned Excision"
6. **For Patients with Known Metastatic Disease Who Return with Progression of Disease, is that a Complication?**
 - Highly Mixed responses (21 Yes, 37 No)
 - **Data Dictionary Recommendation:** Plurality indicates that this should not be coded as an oncologic "complication".
7. **How to Enter Final Surgical Margins if Final Margins are Wide, but only after Intraoperative Re-Excision for Positive Frozen Section**
 - **Data Dictionary Recommendation:** Utilize surgeon and pathologist judgment