PAPER 30

Establishing Data Elements for the Musculoskeletal Tumor Registry Sarcoma Module

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Background: The Musculoskeletal Tumor Registry (MsTR) was introduced as a pilot program in 2018 through an effort supported by the Orthopaedic Research and Education Foundation (OREF) and the Musculoskeletal Tumor Society (MSTS) to improve data reporting and consistency across institutions for tertiary sarcoma programs. In 2020, MSTR was accepted as a full registry into the American Academy of Orthopaedic Surgeons (AAOS) Family of Registries, with the Sarcoma Module as its initial data capture tool. In the development of the MsTR, the MsTR Steering Committee was convened to establish consensus regarding standard data elements for collection. The pillars of the registry effort include 1) collection of research-quality data, 2) minimization of the burden of data entry to providers, and 3) utilization of a framework that allows for future modification. An important strategy used to fulfill these goals was to create “smartforms” within the electronic health record (EHR) with branching logic to collect the maximum amount of important data in the least intrusive possible manner.

Questions/Purposes: The current report describes the process and results from the consensus development for standardized data elements for the sarcoma module of the Musculoskeletal Tumor Registry, as well as clarifying inclusion criteria for MsTR.

Patients and Methods: A national panel of experts in musculoskeletal oncologic surgery was convened, including members of ten geographically distinct sarcoma centers. The MsTR Steering Committee panelists are all Fellows of the American Academy of Orthopaedic Surgeons (AAOS) and full members of the Musculoskeletal Tumor Society (MSTS) . A preliminary list of data elements was established, including demographic and procedural data, as outlined in the American Joint Replacement Registry (AJRR). The panel reviewed and refined data elements with consideration for clarity of element definition to optimize reliable and accurate reporting; verbal majority was required to establish consensus.

Results: The MsTR Steering Committee has approved patient inclusion criteria and data elements for the initial iteration of the MsTR Sarcoma Module. Patients with primary extremity sarcomas of the bone or soft tissues, or giant cell tumor of bone are eligible for inclusion. Data elements for collection are organized via branching logic to provide focus on relevant data. Selected data domains include: demographics, diagnosis and treatment, procedure and implants, histology, patient-reported outcomes, and follow-up and adverse outcomes.

Conclusions: The standard data elements for the introduction of the sarcoma module of the MsTR through consensus provide a template for international centers to coordinate data collection for collaboration and for benchmarking.