

PAPER 29

Development Of The Metastatic Bone Disease Module Within The American Academy Of Orthopaedic Surgeons Musculoskeletal Tumor Registry

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Background: The American Academy of Orthopaedic Surgeons (AAOS) opened the Musculoskeletal Tumor Registry (MsTR) as the third member of its family of registries in 2020. Collection of data on primary bone and soft tissue sarcomas has been initiated with a Sarcoma Module. To date, there are 25 sites participating across 15 states. Metastatic bone disease (MBD) is far more common than sarcoma with concomitant greater societal health burden and costs. A second MsTR module is being developed to study the demographics, treatment, and outcomes of surgically treated MBD patients in the United States.

Questions/Purposes: The registry is designed to provide functional and quality-of-life outcome measures, in addition to oncologic end points. The MsTR leverages technology to minimize provider burden while maximizing accuracy and relevance. In furtherance of this purpose, we seek to answer the following: 1. What is the current status of development for the MBD module of the AAOS MsTR? 2. Can data abstraction technology be utilized to minimize data entry burden for surgeons participating in the registry? 3. Can early analysis of the initial participating site data inform the module development team as to which data elements are obtainable within the targets for completeness and accuracy?

Methods: Registry inclusion criteria consist of all patients with surgically treated MBD lesions of the extremities and pelvis at the participating institutions. A combination of ICD-10 and CPT codes are used to automatically identify patients for inclusion with subsequent confirmation by the local registry team. Baseline patient demographics, tumor characteristics, adjuvant treatments, procedural details, implants, adverse events, and outcome measures are then recorded. Automated data abstraction from the electronic health record (EHR) is utilized for the majority of variables. EHR “smartforms” with branching logic are used to minimize data entry burden of participating surgeons for variables which cannot be abstracted. Surgeon reported outcomes (MSTS upper and lower extremity scores) and patient reported outcomes (PROMIS global health, TESS upper and lower extremity) are included among the data elements. Our goal has been to capture 80% complete and accurate data in 80% of patients.

Results: A data dictionary containing over 250 unique data elements has been developed, and the data specification layout has been completed by the information technology staff at AAOS. Data elements amenable to abstraction have been defined, and draft smartforms with branching logic for elements requiring manual entry have been drafted. Platform launch is scheduled for mid-summer of 2022. We

anticipate data from this launch to be ready for presentation by November 2022. Completeness and accuracy of the early adopter site data will be analyzed and reported.

Conclusions: Aging of the population and improvements in systemic cancer therapy have dramatically increased the number of people living with MBD. Despite its major impact on patient suffering and societal costs, MBD is not discreetly studied in major national cancer registries such as the SEER program and National Cancer Database. The challenges overcome with the early successes of the MsTR sarcoma module are being applied to this more common yet frequently underappreciated problem. The registry is designed to help surgeons and institutions improve patient care through timely analysis of reliable and relevant data from surgically treated MBD patients at their institutions. Feedback from and acceptance by the broader orthopaedic oncology community is critical to the utility, application, and success of the MBD module. We plan to update the MSTs membership on the current status of the effort, answer questions regarding participation and logistics, and seek suggestions for ongoing improvement.