This is the inaugural Annual Report Preview for the Musculoskeletal Tumor Registry (MsTR). Thank you to the MsTR Steering Committee, the Registry Oversight Committee, and the American Academy of Orthopaedic Surgeons (AAOS) for their contributions and leadership in bringing this Registry to fruition. This exciting and monumental effort reflects collaboration across institutions and subspecialty societies to collect data from across the United States, allowing improved appreciation of survivorship, patient-reported outcomes, and perioperative complications. With an infrastructure that can dovetail with the institutional databases common to many sarcoma centers, this ultimately allows for a streamlined organization of information to improve the quality of patient care.

Background and History
MsTR initially joined the AAOS Registry Program as a pilot project involving six institutions (Cleveland Clinic Foundation, Dartmouth-Hitchcock Medical Center, Johns Hopkins Medicine, Ohio State University-The James Cancer Hospital, Stanford Health Care-Stanford Hospital, and University of Iowa Hospital and Clinics). The pilot began in March 2018 and was supported by a grant from the Orthopaedic Research and Education Foundation (OREF) and Musculoskeletal Tumor Society (MSTS). This financial support was imperative to the later success in developing into the MsTR as it currently exists, allowing for the data elements that had been previously developed to be incorporated into an efficient “smartform” at each institution to allow centralized data collection within the registry framework of AAOS. Developing the smartform was the primary goal of the team involved in the pilot, establishing the means to satisfy the guiding principles of the MsTR.

In March 2020, AAOS approved MsTR's ascension from a pilot project to a full registry, allowing acceptance of other facilities to participate. MsTR was given representation on the AAOS Registry Oversight Committee (ROC) and formed a 10-person steering committee made up of dedicated orthopaedic oncologists, all of whom are members of AAOS and MSTS. This group is continuously and diligently working to shepherd MsTR through the critical first years of its existence with an emphasis on provider engagement, institutional enrollment, data accuracy and completeness, and financial sustainability (see Appendix A for a list of committee members).

The Registry currently consists of two modules, sarcoma and metastatic disease of bone, a combined spine tumor registry with the American Spine Registry® (ASR) (a collaborative registry between the American Association of Neurological Surgeons (AANS) and AAOS), and a clinical trial collaboration investigating the treatment of giant cell tumor of bone.

MsTR’s Guiding Principles Include

- Collect research-quality data
- Provide a flexible framework for future innovation
- Be of minimal burden to participating surgeons.
Sarcoma Module Overview

The initial goal for MsTR was to create a data collection module for patients with bone and soft-tissue sarcomas. Following MsTR’s mission, data elements were selected to facilitate improvements in all phases—diagnosis, treatment, surveillance—of management for future patients with spine, pelvic, and extremity tumors.

Data elements are grouped into three phase-of-care-specific domains: (see Appendix B for an overview)

1) **Disease and Treatment Summary**
   - Presentation, diagnosis, staging, and definitive management of a patient’s sarcoma

2) **Procedural Information**
   - Strategic and technical information relevant to the execution of a patient’s definitive surgical intervention

3) **Clinical Encounter**
   - Medical, surgical, or oncological adverse events related to a patient’s sarcoma or treatment

Data Collection Preview

As of August 2021, there were 21 facilities participating in MsTR. Contracted sites include both private and state-sponsored academic medical centers, large integrated private not-for-profit health systems, and a free-standing children’s hospital. Fifteen different states are represented, as detailed in the map below.
Patient Inclusion

To date, the AAOS Family of Registries (American Joint Replacement Registry (AJRR), Shoulder & Elbow Registry (SER), Fracture & Trauma Registry (FTR), and ASR) has focused upon procedural coding, extracting patient- and implant-related data for all patients undergoing procedures with pre-identified CPT codes. In contrast, MsTR is a diagnosis-based registry, where patients appropriate for inclusion are identified by their underlying ICD-10 diagnosis code. The registry accepts ICD-10 and CPT coding from 2016 to present. Due to the heterogeneity of sarcoma diagnoses, more than 60 unique ICD-10 codes are utilized to trigger registry inclusion. This approach is necessary in order to reflect the variety of procedural and anatomic the variety of procedural and anatomic sites that is common to the orthopaedic oncology practice.

A minimum of one ICD-10 diagnosis trigger code must be submitted for inclusion in the Registry. Any additional diagnosis codes will be accepted together with the primary trigger diagnosis. While procedure codes will also be accepted, suggested codes common to MsTR procedures are provided in the data specifications.

The ICD-10 and CPT coding tabs within the data specifications are intended for each institution's IT team. These tabs are used in writing the electronic queries to pull data from each institution's electronic health record (EHR) to ensure all eligible cases are submitted to MsTR.

Data Input

In an effort to reduce data entry burden and visual cognition fatigue for providers, each domain was built with attention to maximizing the use of conditional branching logic to streamline data entry. Conditional branching logic displays higher-level primary queries, and only displays secondary queries when an affirmative answer is given. Branching logic, combined with automated EHR data extraction, will provide a comprehensive summary of care and outcomes for patients with bone and soft-tissue sarcomas.

Following the initial engagement campaign, MsTR will soon deliver provider-facing dashboards. As for AJRR and SER, MsTR dashboards will feature registry-, institution-, and provider-level data output. These data will include demographic, disease-, and procedure-specific endpoints, facilitating practice summaries and providing MsTR users with federal quality reporting measures.

The following figures are examples of what may be included in the MsTR dashboards. They do not utilize real data.
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### Percent Complications

- Mechanical Failure: 9
- Soft Tissue Failure: 8
- Recurrence: 7
- Infection: 6
- Aseptic Loosening: 5

### Percent Local Recurrence

- Local Recurrence: 10%
- No Recurrence: 90%
- NR: 30%

### Linked Patient-Reported Outcome Measure (PROM) Assessment Summary

<table>
<thead>
<tr>
<th>PROM</th>
<th>Preop Assessments</th>
<th>% Linked Postop 3mo</th>
<th>% Linked Postop 12mo</th>
<th>% Achieved MCID 12mo</th>
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<td>MsTR PROM 4</td>
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<td>10</td>
<td>5</td>
<td>75</td>
</tr>
</tbody>
</table>
Quality Reporting Metrics

The AAOS Quality Resource Center includes Measures and Metrics related to quality reporting for the Merit-Based Incentive Payment System (MIPS) and Electronic Clinical Quality Measures (eCQM), Bundled Payments for Care Improvement Advanced (BPCI-A), The Joint Commission Advanced Certifications, as well as payer measures and registry metrics. All of the AAOS registries are eligible to be CMS-approved 2021 Qualified Clinical Data Registries (QCDR).

The AAOS Registry Program receives regular CMS data-sharing on its registry patients, creating a more robust database as patients may have part of their care at a non-AAOS registry site that is still captured by CMS. There are quality-related benefits for institutions and sites to participate in the MsTR as they have access to on-demand, practice-specific quality reports and dashboards. Longitudinal patient outcomes can be tracked and monitored with access to surveillance alerts for poorly performing prosthetic devices. The MsTR qualifies for reporting to many quality improvement programs such as MIPS, APMs (including BPCI-A) and the American Board of Orthopaedic Surgery Maintenance of Certification program. (ABOS MOC). Each site can compare their institutional data to national performance benchmarks.

Individual orthopaedic oncologists receive their data in personalized procedure, postop, and patient-reported outcome measures (PROMs) dashboards that provide national benchmarking and also quality for MOC credit from ABOS. With robust participation from MSTS surgeons, there will be large enough datasets to impact the value of care delivered to patients with musculoskeletal tumors. This is the critical imperative to join the MsTR with your colleagues!

On the Horizon

Metastatic Bone Disease

The initial iteration of MsTR revolved around bone and soft tissue sarcomas. Limiting the initial scope to this complex set of diseases allowed for a careful yet thorough incorporation of data elements for reliable and useful reporting on quality/safety and outcomes within the framework of the AAOS Registry Program. Unlike prior AAOS registries, which were predicated upon high-volume procedures, the MsTR developed as a diagnosis-based registry – establishing a novel avenue for registry development in orthopaedic surgery.

With the lessons learned regarding data input and extraction related to sarcomas, MsTR expanded with the Metastatic Bone Disease Module. The management of osseous metastases remains the largest societal impact that orthopaedic oncologic surgeons provide, affecting more than 100,000 patients each year. Efforts to collect and collate outcomes related to the various management options in these patients represents perhaps the greatest opportunity to advance this field. The Metastatic Bone Disease module provides a mechanism for understanding outcomes while minimizing provider manual data entry requirements.

Further coordination efforts together with orthopaedic and neurosurgery spine colleagues continue in the establishment of the Spine Tumor Module of the ASR, in order to optimize the evaluation in this highly complex area of interest.
Appendices
Appendix A: COMMITTEE MEMBERS

AAOS Registry Oversight Committee
William J. Maloney, MD, FAAOS
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AAOS Chief Operating Officer

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Kristy L. Weber, MD, FAAOS
University of Pennsylvania
## Appendix B: DATA ELEMENT OVERVIEW

Data elements include but are not limited to patient demographics, patient baseline and examination, tumor baseline, treatment and post-treatment, and surgery detail along with postoperative data (oncologic failure, surgery complication, vital status), and patient-reported outcomes as conveyed in applicable instruments. This page is a summary of the MsTR data elements and is not all inclusive.

### BASELINE

**Patient**
- Name (Last, First)
- Date of Birth
- Social Security Number
- Diagnosis (ICD-10, CPT)
- Gender
- Race/Ethnicity
- Height + Weight/Body Mass Index
- Payer Status

**Site of Service**
- Name and Address (TIN, NPI)

**Surgeon**
- Name (NPI)

### Surgical Intervention
- Procedure Type (ICD-10, CPT)
- Date of Surgery
- Implants
- Details Surrounding Surgery Type
- Comorbidities (ICD-10, CPT)

### Non-surgical Intervention
- Chemotherapy
- Radiation
- Clinical Trial

### Tumor Baseline
- Size
- Metastasis at Diagnosis
- Margins
- Tissue Type
- Biopsy Type

### ENCOUNTERS AND PATIENT-REPORTED OUTCOMES

**Encounters**
- Comorbidities (ICD-10, CPT)
- Hospital Admission
- Procedure (ICD-10, CPT)
- Diagnosis (ICD-10, CPT)
- Recurrence
- Chemotherapy
- Radiation

**Patient-reported Outcomes**
- PROMIS-10 Global
- VR-12
- MSTS
- TESS