AAOS
American Academy of Orthopaedic Surgeons

Musculoskeletal Tumor Registry
Improving Orthopaedic Care Through Data

How Surgeons Can Improve Musculoskeletal Oncology Care Through Registry Data

February 15, 2024

Musculoskeletal Tumor Society MSTS EST. 1977

registry insights

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MsTR | Purpose & Guiding Principles

The purpose of the Musculoskeletal Tumor Registry (MsTR) is to provide a centralized record of patient, tumor, treatment, and outcomes data on musculoskeletal neoplasia in the pelvis, spine, and extremities. The registry will focus on extremity sarcoma and metastatic disease of bone; MsTR is **diagnosis based** rather than procedure based.

The data will be of research quality and allow for investigation into the natural history of disease, risk factors, quality and delivery of care, oncologic and reconstructive outcomes, prognosis, function, and patient quality-of-life.

Registry design should facilitate maximum participation by AAOS and MSTS members with clear goals to minimize the burden of data entry, capture a comprehensive set of relevant information, and to maintain flexibility for future modification as needed.

MsTR | Mission Focused

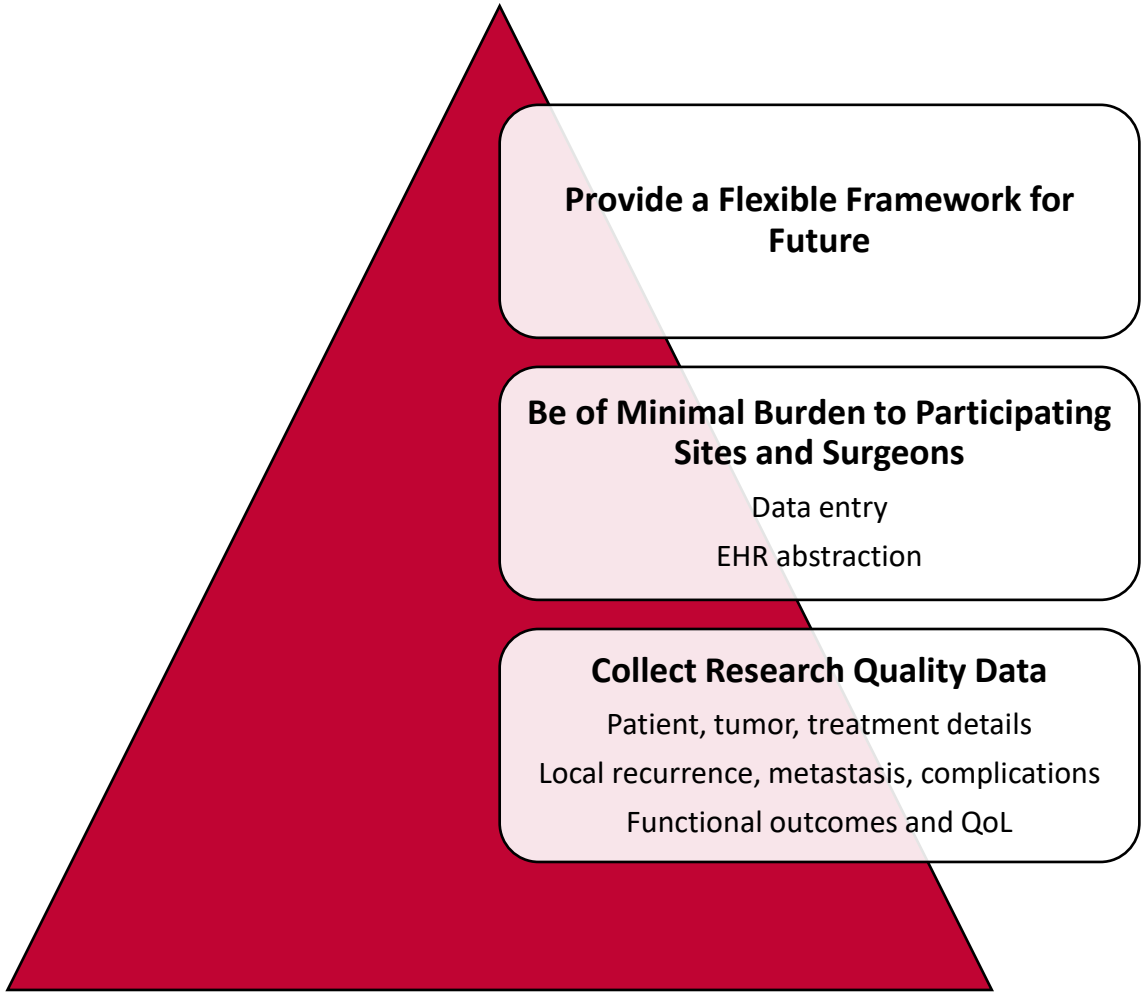
The commitment to build the MsT Registry is driven by the Academy's mission to provide the highest quality of musculoskeletal care. The volume of MsT procedures compared to other subspecialities is low, but the registry will contribute directly to providing data to support the current gap in research for MsT to improve care for this in need patient population.

Sarcoma

- Cancer of extremities
  - Bone and soft tissue
- Affects all ages
- Difficult to treat and cure
  - >75 subtypes
- Difficult to study
  - <1% of cancer (rare)
  - <1% of research funding

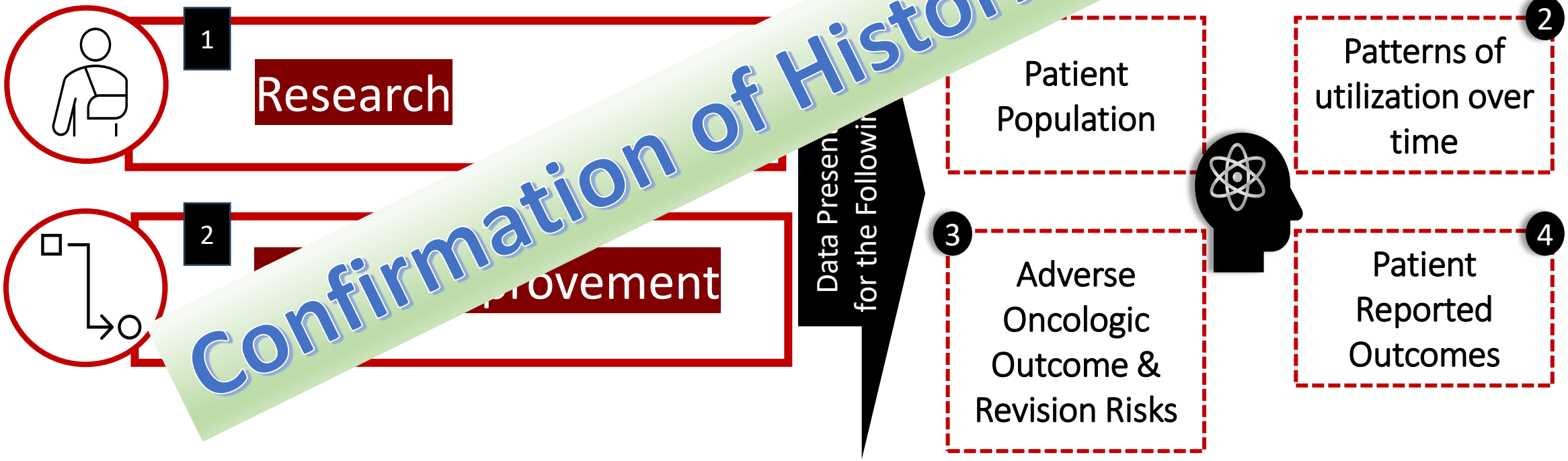
Not developed to be financially viable – designed to advance an underserved area of orthopaedics

MsTR | Guiding Pillars



Registries| Design Concepts

A patient registry is a systematic collection of data on pati… …ics, procedures, devices used, and outcomes for a well-d… …patients to inform clinical decisio…



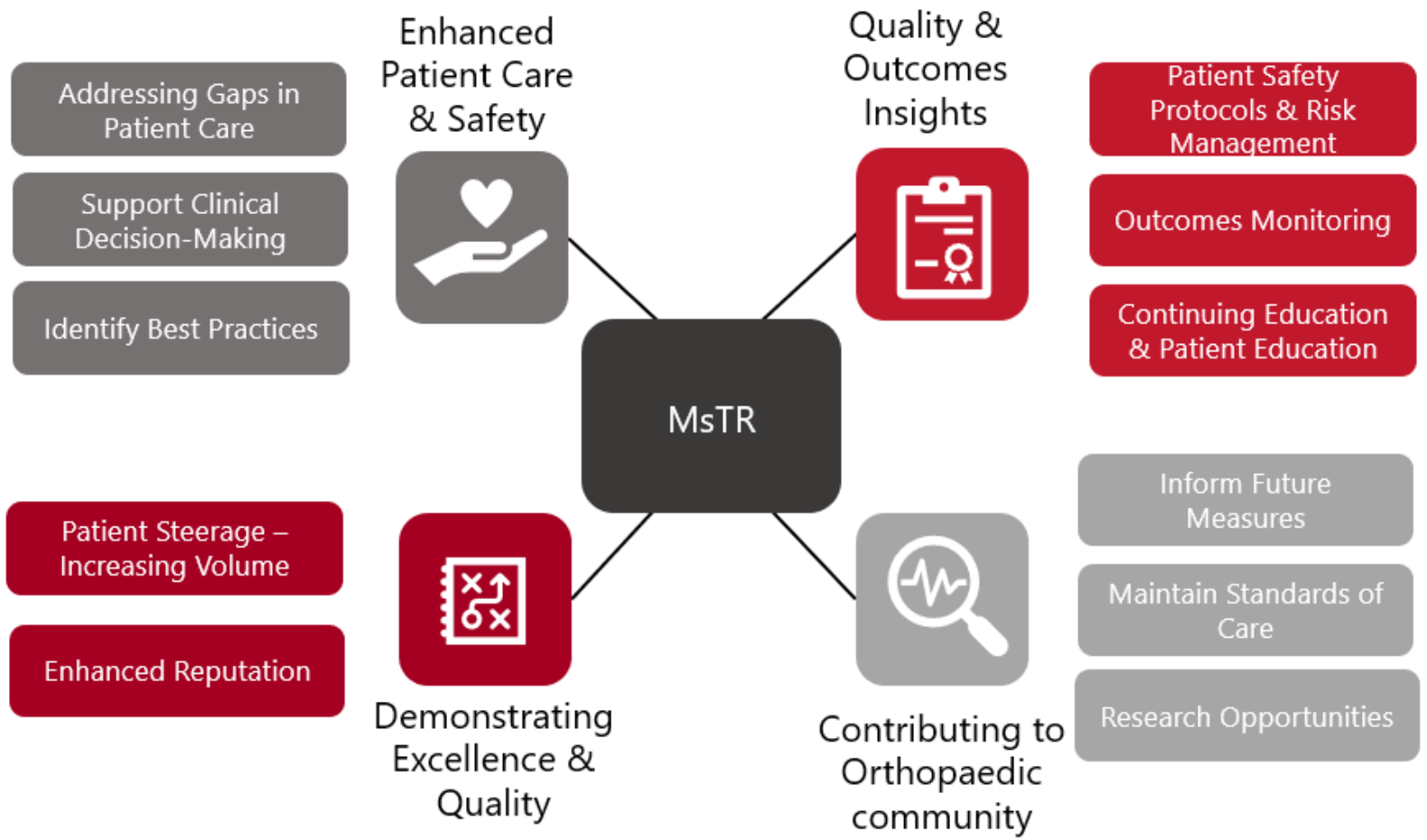
Confirmation of Historical Mantra

Arthroplasty registries around the world: valuable sources of hip implant revision risk data - PMC (nih.gov)

MsTR | Participation Benefits

Understanding Effects of Treatment Decisions

"Centralization" to MDT Sarcoma Teams



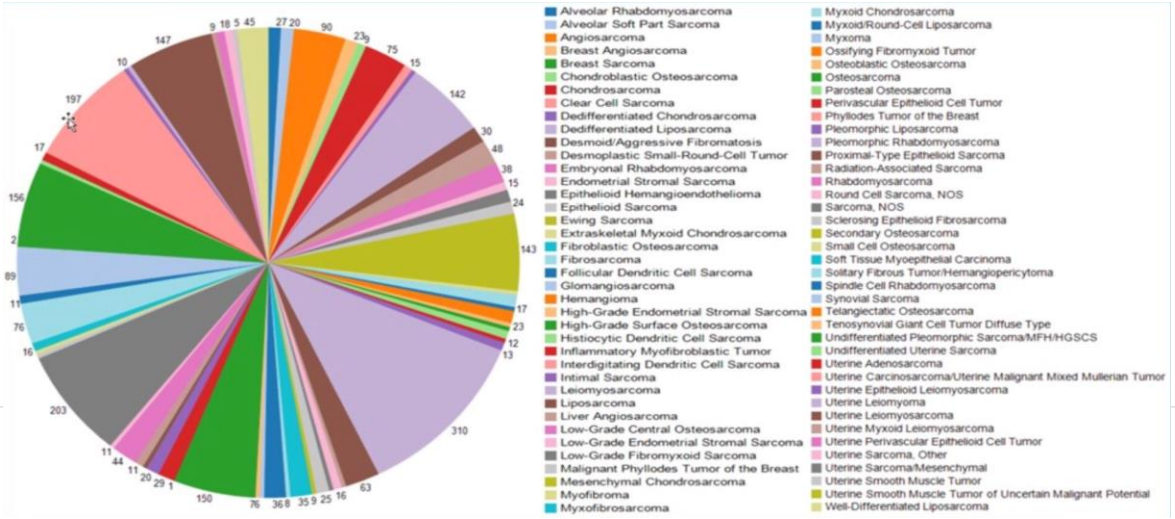
Making Research Real for Patients and Docs

Cooperative Efforts Improve "Power" in a Shorter Amount of Time

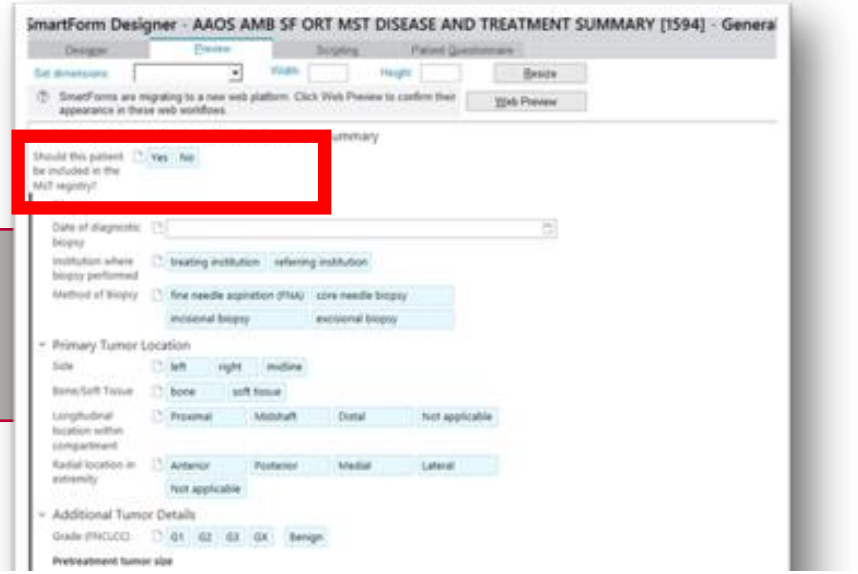
MsTR | Differentiators

Diagnosis Based Registry

- Patients appropriate for inclusion are identified by their underlying ICD-10 DX code
- More than 60 unique ICD-10 codes are utilized to trigger registry inclusion



MsTR | Differentiators



Provider Entered Elements

- Not easily extracted from EHR
- Value add for research quality data

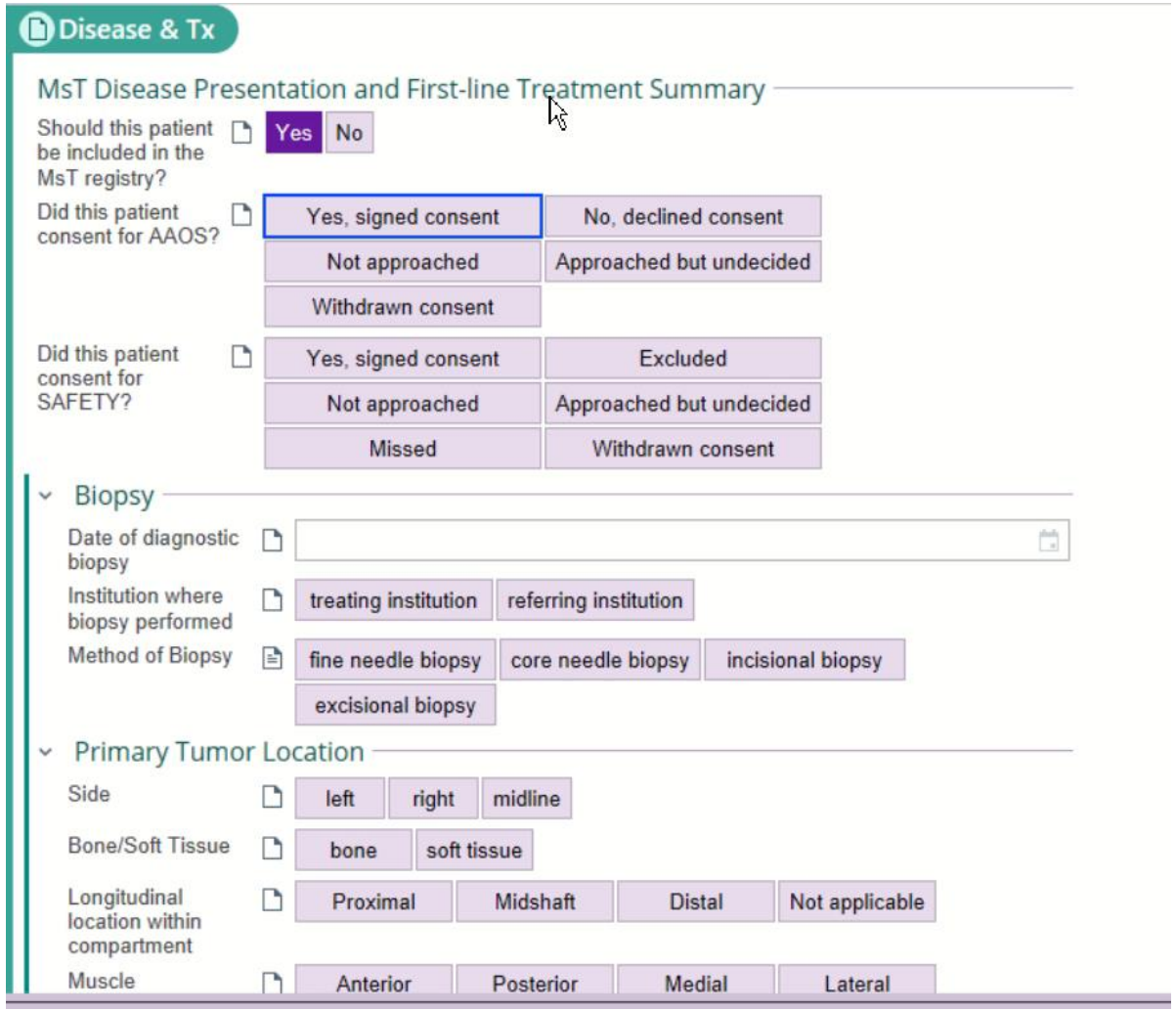
Registry Participation Requirements

- SmartForm Utilization – validated by surgeon clicking on confirmation box to trigger inclusion
- Exploring additional standardized data collection methods

SmartForm | Development

- Allows provider to collect historical information
- Patient level Smart Data Elements (SDE)
- Record Complete selection
  - Causes larger font “Record Complete” to display at top of form
- Utopia → Note generation from form completion

75 sec



MsTR | Data Element Overview

PATIENT

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

SURGICAL INTERVENTION

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

NON-SURGICAL INTERVENTION

Chemotherapy
Radiation
Clinical Trial

1 TUMOR BASELINE

Size
Metastasis at Diagnosis
Margins
Tissue Type
Biopsy Type

2 ENCOUNTERS

Hospital Admission
Procedure (ICD-10, CPT)
Diagnosis (ICD-10)
Recurrence

3 PROs

PROMIS-10 Global or VR-12
MSTS
TESS

MsTR | Data Element Sources

Abstracted from EHR

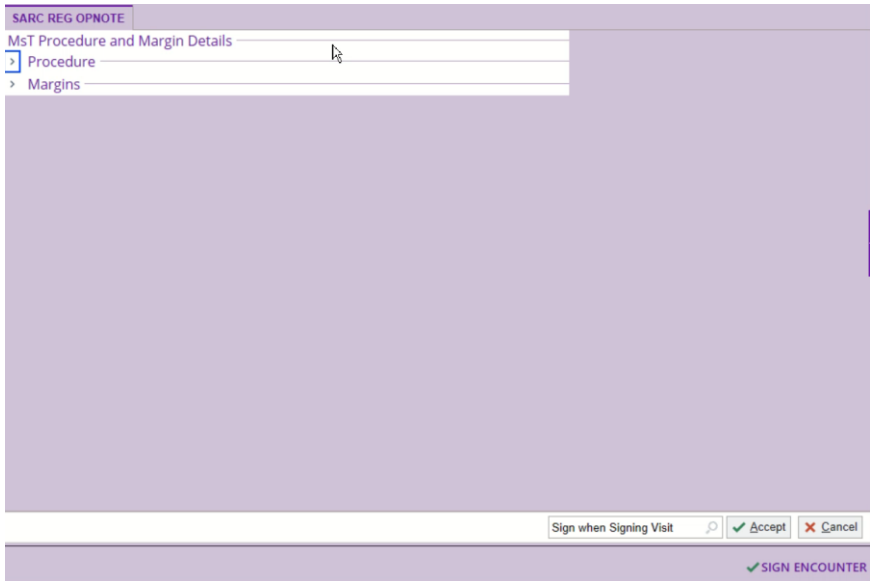
- Patient demographics
- Treatment & procedure dates
- Diagnosis codes
- Manufacturers and implants

Entered by Practitioner

- Tumor details
  Location, size, histology, stage
- Treatment details
  Systemic therapy, radiation, reconstruction
- Complications

What is a SmartForm?

- SmartForms capture detailed procedure-specific information.
- Go beyond traditional ICD-10 and CPT coding.
- Include tailored data elements for patient presentation, procedure, approach, tissue observations, and complications.
- SmartForms use branching logic to gather additional clinically relevant details as data points are provided.

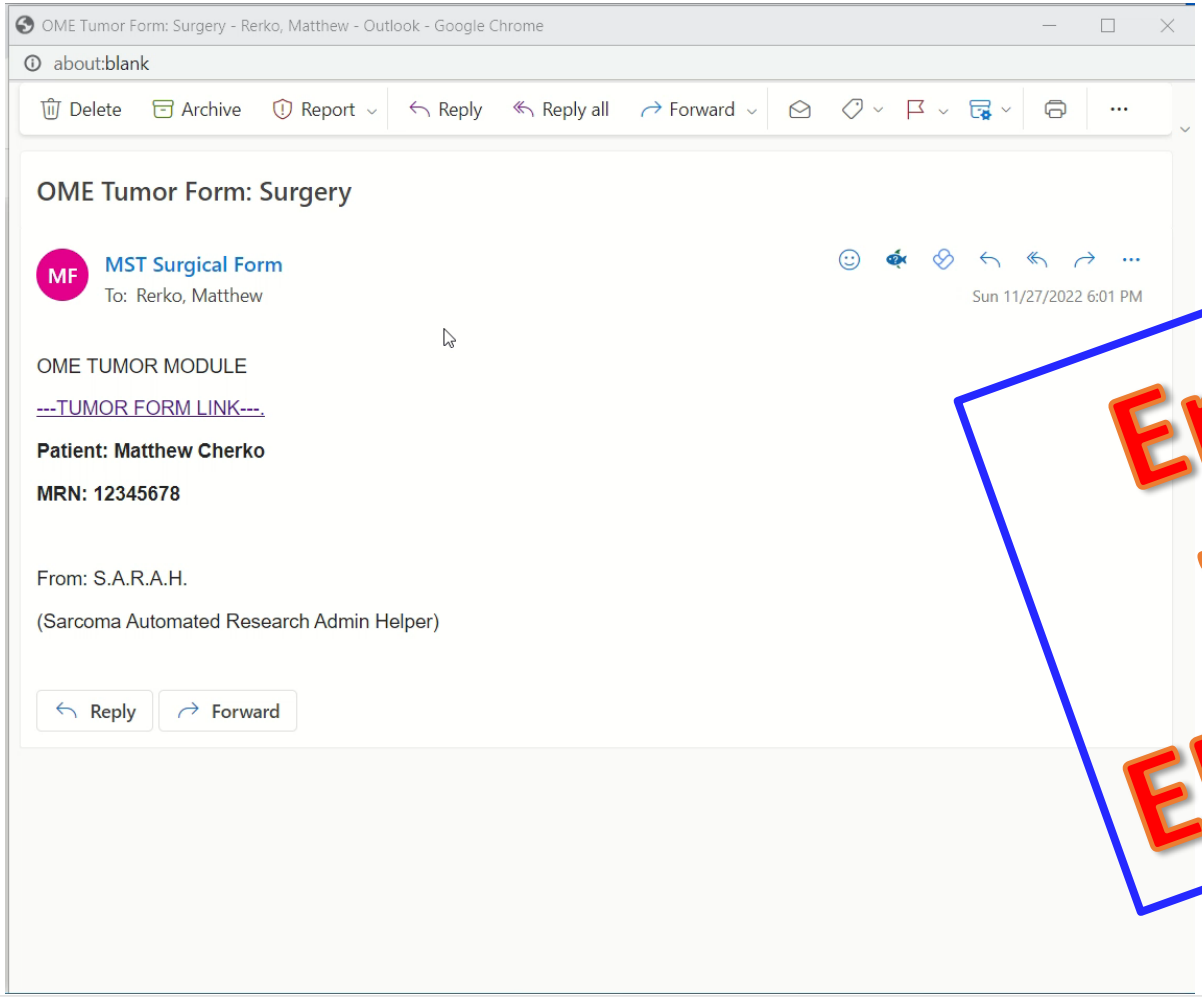


Value of Smartforms for Data Capture

Streamlined and Standardized Data Entry

- Standard EMR released elements → Acknowledged need to expand
- SmartForms allow for conditional branching logic format to better facilitate ease of data entry while minimizing clinician burden.
- UIowa pre-built conditional forms to allow for instant implementation within user environments.
- Provides institutions with a means to centralize data collection within the registry framework of AAOS

Creative Alternatives For Data Capture?



Email Link?
Text Link?
EMR Agnostic?

MsTR | Putting the Data to Work

Gender and Age Distribution

Collecting fundamental information such as age and gender distribution is foundational to sarcoma research, as it provides valuable insights into demographic patterns and disease prevalence. This data helps pinpoint the age groups and genders most affected by sarcomas, facilitating the development of precise screening and diagnostic strategies. Moreover, it unveils trends like age-related variations in incidence rates and gender-specific susceptibility to particular sarcoma subtypes, which in turn inform treatment strategies customized to specific patient populations. Additionally, the data on age and gender aids in making informed decisions about resource allocation and underscores the significance of early detection initiatives for high-risk groups.

Figure 1 Gender Distribution
Graph represent data collected through standard demographic reporting methods extracted from EHRs.

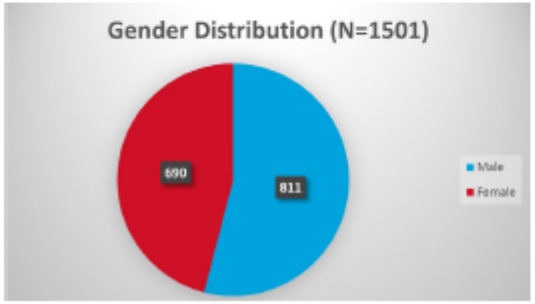
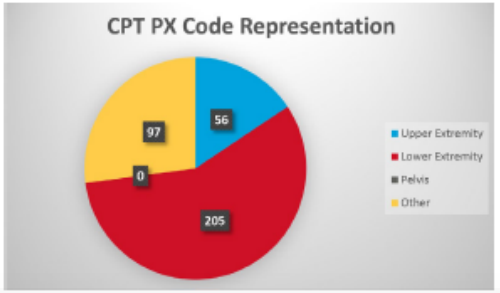


Figure 2 Age Distribution
Graph represent data collected through standard demographic reporting methods extracted from EHRs.

CPT PX Code Representation

Collecting CPT codes are critical in sarcoma research, enabling standardized documentation for evaluating treatment effectiveness and informing guidelines.

Figure 3 CPT PX Code Representation
Please note that this graph is not a complete representation of the entire dataset, as sites can submit any CPT or ICD-10 codes. The graph displays CPT codes that align with the MsTR Data Specifications as a general guideline for relevant procedures.



Manufacturer Report

Manufacturer reports and comprehensive component data is vital in informing sarcoma care. This information can enable researchers to evaluate treatment effectiveness, assess device safety, and support quality improvement efforts. Additionally, these details can support resource allocation decisions and the customization of patient care plans based on extremity-specific needs. It can also contribute to advancements in implants through trend analysis and enhance patient education regarding surgical devices.

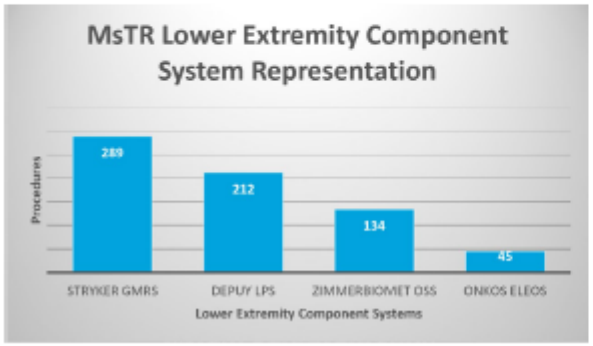


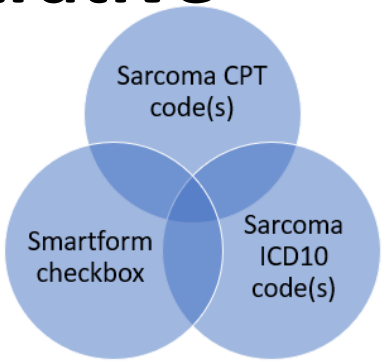
Figure 4 Manufacturer Report
This graph specifically represents the number of procedures submitted with lower extremity component systems for endoprosthetic reconstructions. It does not include cases submitted with upper extremity component systems or procedures lacking component information.

MsTR | Participation Strategies

☹ **No SmartForm, Purely Administrative Submission**

😕 **Partial SmartForm Completion and Administrative Submission**

☺ **Comprehensive Data Submission**



The variety of data submission methods in the MsTR presents both opportunities and challenges for data interpretation. While diversifying data sources enriches the Registry, it also complicates interpretation due to the lack of standardization, hindering direct comparisons. Initial data analysis lends itself to adaptation of a comprehensive data submission, whereby SmartForm data is required.

MsTR | Impact on Registry Data

✓ Comprehensive data submissions with SmartForms enhance data quality

- SmartForms capture essential clinical details accurately
- Provides a more comprehensive understanding of patient cases
- Enables healthcare providers to gain valuable treatment insights
- Facilitates evidence-based decision-making
- Supports refinement of treatment strategies

Ultimately improves patient care and outcomes in musculoskeletal oncology

QUESTIONS?

MsTR | Background

Through collaboration with the Musculoskeletal Tumor Society (MSTS), MsTR is the third subspecialty registry to be incorporated into the AAOS family of registries.

The wide-spread rollout of the MsT Registry allows surgeons to combine data about rare bone and soft tissue tumors from sites around the country, thereby potentially answering treatment and outcome questions that are otherwise unable to be answered due to the rarity of the disease.

The MsTR feedback and dashboards will help clinicians and health systems track function, complications, and outcomes in patients treated for these sarcomas with the potential to expand to metastatic bone disease and other musculoskeletal tumors in the future.