

## **ISR VARIABILITY IN PRESENTATION WORKPLAN**

### **Hypothesis/Question:**

There are regional differences in tumor size, presence of metastasis, and attempted excisions prior to referral in patients with bone and soft tissue sarcoma.

### **Background:**

Sarcoma affects patients globally and there is substantial variability in access, technology, treatment options, and willingness to seek specialty care. Providers agree that early referral is important for expeditious diagnosis and initiation of treatment, which should lead to more effective management of cancer.

The International Sarcoma Registry (ISR) is a novel effort with the support of the 5 multi-national sarcoma professional societies (ISOLS, MSTS, EMSOS, SLATME, APMSTS) and represents the majority of the world's sarcoma specialists. This provides a unique opportunity to focus on questions of international importance and provides the ability to determine regional differences.

Several factors would give insight into variability into referral patterns. Specifically, tumor size and presence of metastasis may be a surrogate for delays in diagnosis. Comparison of the percentage of patients presenting with inappropriate attempts at excision prior to presentation to a sarcoma specialist (i.e. a "whoops procedure") would demonstrate areas where access is suboptimal and efforts for improvement justified. A global comparison could help providers, administrators, and policy makers compare their institutions to others and make informed decisions about educational efforts and resource distribution.

### **Study design:**

- 1) Patients
  - a) Patients of all ages with bone and soft tissue sarcoma
- 2) Data
  - a) Collection through the ISR Minimal Dataset (MDS)
    - i) Each individual collects through their preferred method
  - b) Collect prospectively for 1 year (1/1/26-12/31/26)
  - c) Submit through a de-identified REDCap survey link to report summary data so as to negate the risk of loss of confidentiality for patients
    - i) Name and institution (for authorship)
    - ii) Global region
    - iii) Total number of patients
    - iv) Bone, soft tissue
    - v) Histology
    - vi) Location (Upper extremity, lower extremity, axial)
    - vii) Grade

- viii) Depth
  - ix) Size in maximal dimension
  - x) Presentation with metastasis
  - xi) Whoops procedures
- 3) Analyses
- a) Descriptive statistics by region (continent, LMIC, country, etc)
    - i) % whoops procedures
    - ii) % with metastasis
    - iii) % of various sizes
- 4) Outstanding issues
- a) Participant commitments
  - b) Study distribution by QR code
  - c) Confirm no need for IRB or data transfer agreements