

## **The Under-Reporting of GISTs (Gastrointestinal Stromal Tumors)**

According to standard setters, GISTs are only reportable when found to be malignant. While that rule has not changed, pathologists rarely document these tumors as being outright malignant making it increasingly difficult for registrars to determine a malignancy status solely based on a pathology report. Pathologists prefer to use the NCCN's "Risk Stratification" of Primary GISTs by mitotic index, tumor size and site which yields either a low, moderate or high risk declaration of aggressive behavior and/or malignant potential. As a result, many GISTs are marked as nonreportable leading to a national under-reporting of malignant GISTs. In an effort to collect more accurate data that truly reflects the malignant status of these tumor **further chart investigation is needed** by the registrar to determine the correct reportability status of GISTs.

Because pathologists generally do not categorize these tumors as either benign or malignant, the determination of a GIST's malignant status and resultant treatment is typically made by the clinician using ALL available *clinical AND pathological* findings. **As a result, Gastrointestinal Stromal Tumors have been added to the ICD-10-CM Casefinding lists effective 10/1/2016.** Therefore, **follow back on GIST cases is imperative before a nonreportable status can be recorded with certainty.**

Registrars need to look for the following:

- a clinician's **statement of malignancy**
  - Surgery may be the only treatment needed especially for small, lower mitotic index GISTs.
  - Please keep in mind that surgical pathology reports which state either moderate or high risk of aggressive behavior and/or malignant potential OR state (GIST) tumor extension or invasion *without a statement of malignancy* are **not sufficient to confirm malignancy on their own.**
    - For example, a GIST stated to extend to the pancreas or invade into the muscularis propria; pericolonic fat tissue; or thru the gastric wall to the serosal surface cannot be considered malignant 89fdi`1. Borderline GISTs can extend and invade but do not metastasize.
- patient is being treated as if the GIST was malignant with:
  - **chemotherapy agents** such as Gleevec (targeted tyrosine kinase inhibitor [TKI] therapy), Sutent (anti-angiogenesis therapy) or Stivarga (TKI approved in 2013 for later stage GIST that cannot be surgically removed and when both Gleevec and Sutent did not work or caused severe side effects) OR
  - **radiation**
- **Obvious distant metastases**, such as liver mets **OR nodal metastases** as seen on diagnostic scans or based on biopsy results.

Working together we can all ensure that malignant GISTs are being accurately reported in Louisiana.

References: SEER SINC questions 20091021, 20100014, 20140088, 20150027; NCCN GIST Treatment guidelines; PDQ GIST Treatment Health Professional Version: <https://www.cancer.gov/types/soft-tissue-sarcoma/hp/gist-treatment-pdq>; Cancer.net: <http://www.cancer.net/cancer-types/gastrointestinal-stromal-tumor-gist/treatment-options>.