



AAVBC

AMERICAN ACADEMY OF VALUE BASED CARE

Small Intestine Cancer

Quick Reference Guide

2026

Table of Contents

1. CLINICAL SNAPSHOT	3
HCC/RAF V28 Mapping	3
2. RECOGNITION AND DIAGNOSIS	7
Diagnostic Tests Covered Under Medicare Part B (Older Adults, At-Risk Population)	8
Subtle Early Signs in Older Adults (>65)	9
Geriatric Risk Factors	10
Diagnostic Thresholds (NCCN Workup and AJCC TNM, 8th Edition)	11
Common Oversights	15
Key Differentials in Elderly	16
Comorbidity Screening	17
3. MEAT DOCUMENTATION ESSENTIALS	19
Clinical Documentation Elements	20
Reframing Common Documentation Shortcuts	21
4. TREATMENT AND REFERRAL QUICK GUIDE	22
Therapy Escalation Criteria	22
NCCN Small Bowel Adenocarcinoma–Aligned Treatment by Profile	23
Non-Pharmacologic Care and Supportive Interventions	25
Medication Safety and Key Interactions	26
When to Refer	28
Follow-Up Timing	28
Comorbidity Management — Primary Care Role	29
Cost-Smart Options	31
Patient Education and Adherence	32
Quality Metrics Tie-In	33
5. CODING REMINDERS AND CASE EXAMPLES	36
Coding Specificity	36
Annual Clinical Review and Confirmation	37
Good Documentation — EHR Tips	38
Brief Case Examples	38
REFERENCES	39

1 CLINICAL SNAPSHOT

Definition: Small intestine cancer (small bowel cancer) is a group of rare malignancies of the **duodenum, jejunum, and ileum**.¹ Although the small intestine makes up roughly **75%** of the length of the gastrointestinal tract, these tumors account for fewer than **3%** of GI neoplasms and about **0.6%** of all new US cancers.^{1,2} **Four histologies dominate** and each behaves, stages, and codes differently: **adenocarcinoma** (most common, typically duodenal),^{3,4} **neuroendocrine tumors** (NETs/carcinoids, most often ileal),¹ **gastrointestinal stromal tumors** (GIST), and **lymphoma**.⁵ The defining clinical problem is **diagnostic delay**: nonspecific symptoms mimic benign disease, so adenocarcinoma is delayed an average of **6-8 months** from symptom onset and small bowel NETs up to **36 months**.^{1,6}

ICD-10 Codes:

Small bowel adenocarcinoma is reported with anatomic-subsite codes: **C17.0** (duodenum), **C17.1** (jejunum), **C17.2** (ileum), **C17.3** (malignant Meckel diverticulum), **C17.8** (overlapping sites), and **C17.9** (small intestine, unspecified).⁷ **Histology drives code family**:^{3,7-10} neuroendocrine/carcinoid tumors use the **C7A.019** series (not **C17.x**), GIST uses **C49.A3**, and confirmed metastasis to the small bowel uses **C78.4**. The single most common coding error is defaulting to **C17.9** when pathology or imaging **has identified the subsite** → document the anatomic location **explicitly** (e.g., 'adenocarcinoma of the jejunum'). Code complications and surgical status separately **at every encounter**: malignant bowel obstruction (**K56.69**), cancer-related anemia (**D63.0**, not **D64.9** unspecified), and ileostomy status (**Z93.2**).⁷ Reserve **Z85.068** (personal history) only for **true remission with no active treatment**, surveillance, or complications; premature use during adjuvant therapy or watchful waiting **eliminates the active-malignancy picture entirely**.

Prevalence and Burden: The National Cancer Institute estimates approximately **14,450** new cases and **2,170** deaths from small intestine cancer in the US in 2026.¹¹ The global age-standardized incidence is about **0.60 per 100,000**, and incidence has been rising for both adenocarcinoma and NETs over the past two decades.² Median age at diagnosis is in the **6th decade**, with peak incidence in adults **60-79 years**.^{4,12} **Age itself confers risk**: the hazard ratio for adenocarcinoma is **3.12** (95% CI 1.33-7.31) in adults ≥65 versus 50-55 years, and increasing age is an independent predictor of mortality (**HR 1.1** per year).^{5,13} SEER data show a median survival of **11 months** in patients >60 versus **24 months** in those ≤60 ($p < 0.0001$).¹³

HCC/RAF V28 Mapping

ICD-10 CODE(S) ⁷	HCC CATEGORY (V28) ¹⁴	RAF (CNA) ^{*15}	DOCUMENTATION REQUIREMENT ^{3,7,8}
C17.0/C17.1/C17.2 Malignant neoplasm of duodenum/jejunum/ileum	HCC 22 Bladder/Colorectal/and Other Cancers	0.363	Active SBA confirmed by pathology; specify subsite (duodenum, jejunum, or ileum); document histologic subtype and AJCC 8th Edition stage ; for duodenum, distinguish from ampullary origin

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