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Structured Chart Abstraction Improves Progression Ascertainment in a Neuroendocrine Neoplasm Registry: A Quality Improvement Initiative

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BACKGROUND

Accurate progression documentation is essential for cancer registry quality reporting and outcomes research. We identified a documentation gap in which standard NAACCR recurrence fields failed to capture progression events in patients with neuroendocrine neoplasms (NENs). We implemented a quality improvement (QI) initiative to standardize progression ascertainment and inform registry redesign.

METHODS

We conducted a QI project using our institutional NEN registry at a CoC-accredited community cancer center. Registry records for 481 patients diagnosed from 2018–2025 were audited to establish baseline progression documentation. WHO-aligned differentiation class was chart-abstracted for 386 patients. A standardized abstraction workflow was developed, incorporating reviewer training, predefined abstraction criteria, and structured review of oncology notes, imaging reports, and tumor board records.

RESULTS

Baseline audit revealed 325 of 481 patients (67.6%) coded 'never disease-free,' reflecting metastatic presentation, and 146 patients (30.4%) coded disease-free with zero disease-free survival — the field was effectively uncoded. Standard registry captured 7 progression events (1.5%); chart abstraction identified 76 (19.7%) — 13-fold improvement. Despite this gain, 103 deceased NEC patients had no documented progression date, identifying a persistent workflow gap. The improved dataset enabled stratified PFS analysis: NEC median time to progression 4.0 months versus 6.8 months for NET/WD (log-rank p=0.023).

Table 1. Standard Registry vs. Chart-Abstracted PFS Completeness

Finding	Standard Registry	Chart Abstraction	Result
PFS events captured	7/481 (1.5%)	76/386 (19.7%)	13× improvement
Coded 'never disease-free'	325 (67.6%)	N/A	Structural mismatch
Disease-free; 0-mo DFS	146 (30.4%)	N/A	Field effectively uncoded
Deceased NEC, no progression	—	103 patients	Residual workflow gap

NEC median TTP	Not estimable	4.0 months	—
NET/WD median TTP	Not estimable	6.8 months†	p=0.023

NEC=neuroendocrine carcinoma; NET/WD=well-differentiated NET; TTP=time to progression. Log-rank p=0.023, NEC n=197 vs. NET/WD n=166. †Heavy censoring in the NET subgroup limits precision of the 6.8-month estimate.

CONCLUSIONS

This QI initiative identified a critical registry workflow failure in NEN progression documentation. Standardized chart abstraction increased event capture 13-fold and enabled PFS analyses not previously possible from standard registry fields. However, absent progression data in 103 deceased NEC patients demonstrate that retrospective abstraction cannot serve as a long-term solution. These findings directly informed redesign of our institutional registry workflow, with implementation of prospective, point-of-care progression documentation to support quality reporting and clinical research.

ABSTRACT ID #36663