

INTRODUCTION

- Diagnostic strategies, management paradigms, and clinical outcomes of patients with neuroendocrine tumors (NETs) are diverse and poorly characterized.
- The National Comprehensive Cancer Network (NCCN) created a comprehensive longitudinal database to characterize patients treated for NETs at seven participating institutions.
- The primary aim of this analysis is to report preliminary results for the initial screening of NET patients for possible inclusion into this database.

METHODS

- The NCCN Oncology Outcomes Database was queried to identify patients presenting to one of seven NCCN member institutions with a pathologically confirmed newly or previously diagnosed NET.
- Newly diagnosed patients presented to an NCCN institution within 120 days following initial diagnosis. Previously diagnosed patients presented more than 120 days after diagnosis.
- Institutional IRB approval was obtained at all participating institutions:
 - The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
 - Dana-Farber Cancer Institute
 - The University of Texas MD Anderson Cancer Center
 - UCSF Helen Diller Family Comprehensive Cancer Center
 - The Ohio State University Comprehensive Cancer Center - James Cancer Center and Solove Research Institute
 - Robert H. Lurie Comprehensive Cancer Center of Northwestern University
 - H. Lee Moffitt Cancer Center and Research Institute
- The study population consisted of patients presenting with eligible histologies between January 2004 and December 2007 (n=2,798).

Figure 1: Cohort Eligibility Criteria

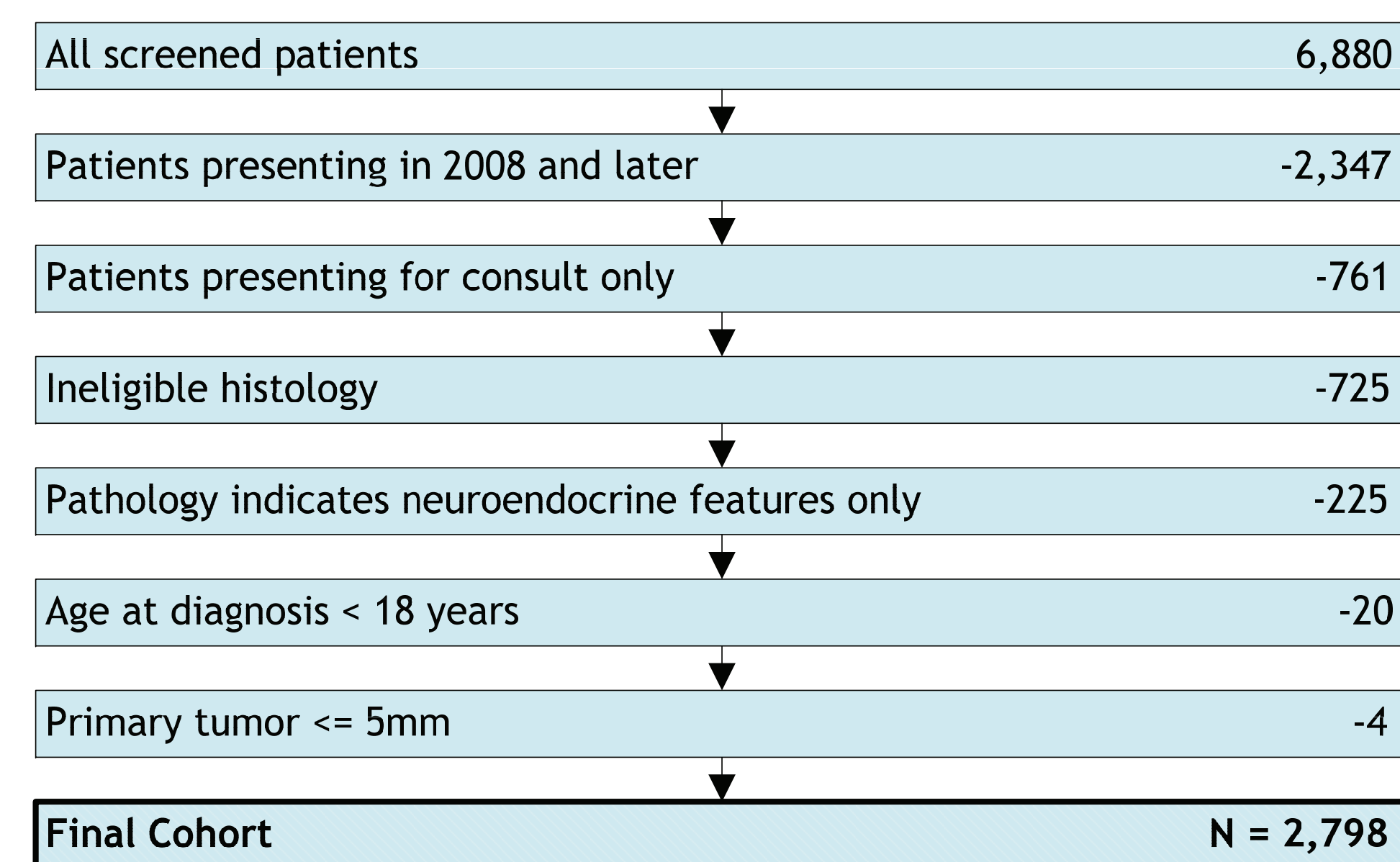


Table 1: Baseline Characteristics (N=2,798)

Age at Diagnosis (yrs)	N	%
18 to 44	513	18%
45 to 49	288	10%
50 to 54	399	14%
55 to 59	410	15%
60 to 64	363	13%
65 to 69	347	13%
70+	478	17%
Median = 56 (SD=14)		
Gender	N	%
Male	1,319	47%
Female	1,479	53%
Race	N	%
Caucasian	2,399	86%
African American	210	8%
Asian	63	2%
Other	73	3%
Unknown	53	1%
Hispanic Ethnicity	N	%
No	2295	82%
Yes	127	5%
Unknown	376	13%
Tumor type	N	%
Carcinoid (any primary tumor site)	1,476	53%
Pancreatic NET	716	26%
NET of unknown primary	242	8%
Poorly differentiated extra-pulmonary NET	88	3%
Paraganglioma	87	3%
Pheochromocytoma	83	3%
Goblet cell/Adenocarcinoid/Composite carcinoid	34	1%
Small/large cell NET (non-lung)	65	2%
Other	7	<1%

RESULTS

Figure 2: Newly and Previously Diagnosed by Institution

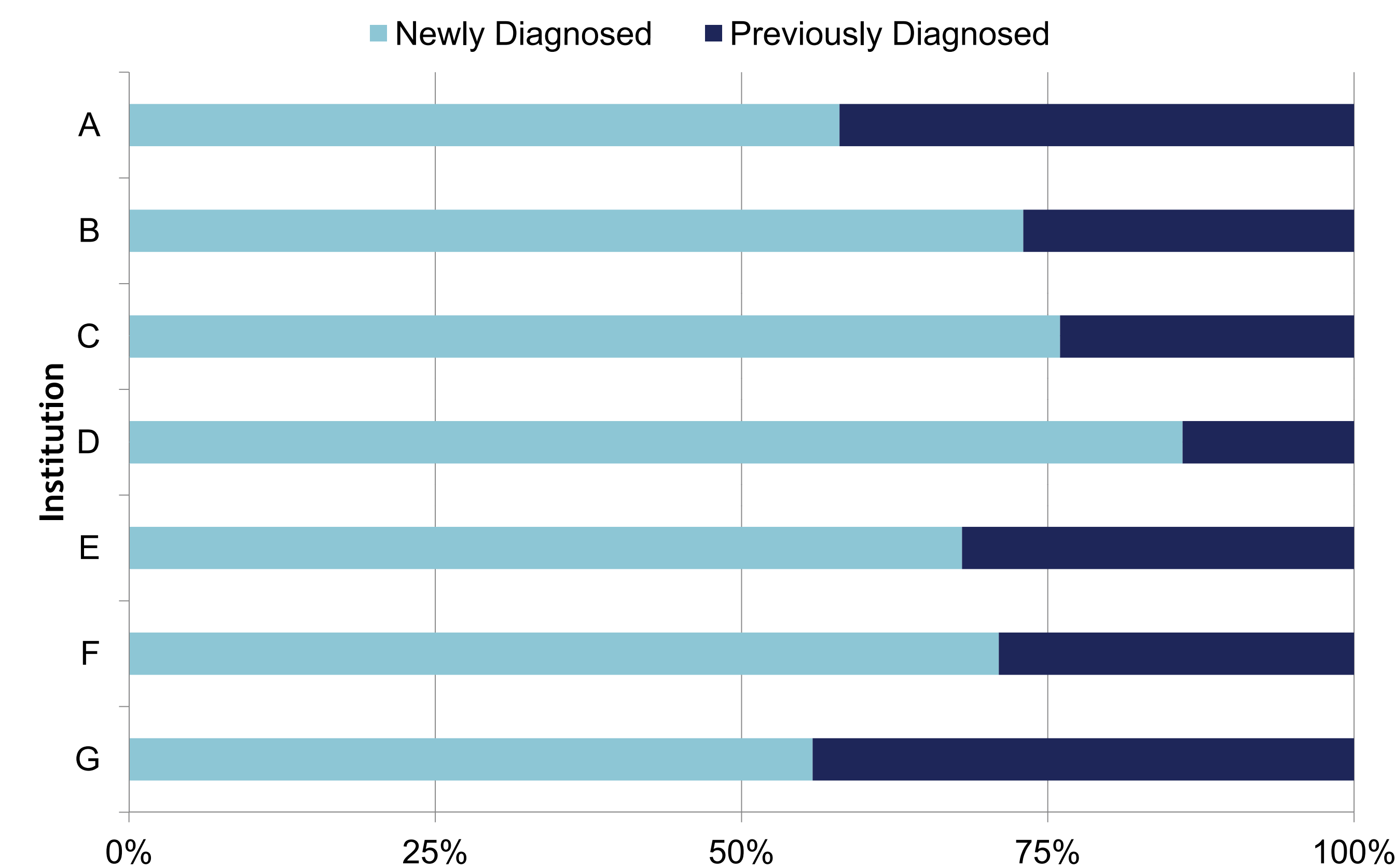
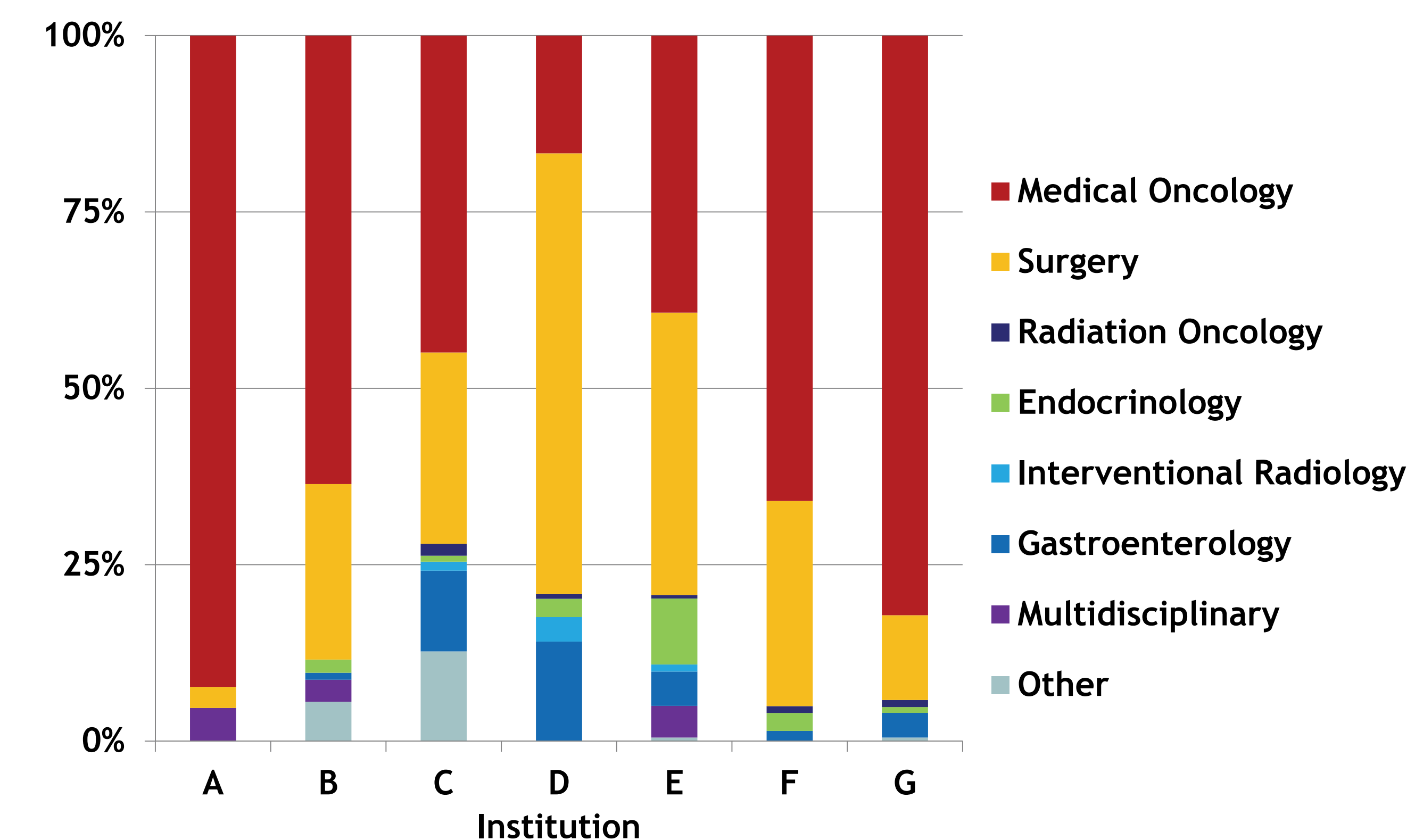


Figure 3: Institutional Referral Patterns: Point of Entry



Note: Figure 3 excludes 7 patients with unknown point of entry.

- Distribution of age, gender, race, ethnicity and tumor type is reported in Table 1.
- Patient distribution by year of presentation was: 2004 (18%), 2005 (25%), 2006 (27%) and 2007 (30%).
- The majority of patients who presented to NCCN institutions were newly diagnosed (Figure 2).
- 30% of patients were diagnosed with NET before presenting to the NCCN institution. Among these patients, the median time between initial NET diagnosis and presentation to the NCCN institution was 2 years (SD=6).
- Institutional differences exist in point of entry, defined as the specialty clinic where eligible patients first present to the institution (Figure 3).
 - Patients initially presented for treatment to medical oncology at the majority of participating NCCN institutions.
 - A significant percentage of patients also initially presented to surgery at many of the centers.
 - A slightly higher proportion of carcinoid patients initially presented to medical oncology, whereas slightly more pNET patients initially presented to surgical oncology (data not shown).

DISCUSSION

- This large NCCN NET Outcomes Database provides a robust platform to characterize this rare disease and its treatment with actual patient data, and includes longitudinal follow-up.
- NCCN institutions reflected markedly variable point of entry for neuroendocrine tumor treatment.
- Further study is needed to characterize the differences in point of entry by NET histology.

CONCLUSIONS

- The baseline demographic and clinical characteristics of NET patients in this new database are consistent with those previously reported in population-based registries.
- This is the first analysis of data from the NCCN NET Outcomes Database and was limited to the data collected at initial screening. For future analyses, the full NCCN NET database containing comprehensive data on diagnosis, staging, treatment, and clinical outcomes for this rare disease, will be utilized.



NANETS 2012 Abstract: Scan QR code to view poster online.

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