

INTRODUCTION

Due to high incidence of pediatric cancers in New Hampshire, the New Hampshire State Cancer Registry (NHSCR) partook in a three-part childhood cancer project to evaluate the accuracy and quality of pediatric cancer data and reporting.

A **recoding audit** was performed to review records for all patients aged <20 years at diagnosis, assess data quality, and identify problems in data collection and interpretation.

Non-hospital affiliated clinics that employ **pediatricians were surveyed** regarding history in diagnosing, treating, and/or referrals of pediatric cancer patients. This helped us understand if there is a reliable path for cases to be reported to the NHSCR and understand referral patterns of pediatricians outside the hospital system.

We focused on the quality of, and relationship between, **insurance status and stage of cancer** at time of diagnosis among pediatric cancer patients to assess missing data for insurance, stage, and other factors that may be affected by insurance status.

METHODS

RECODING AUDIT. Independent Certified Tumor Registrars reviewed 2036 records for the period 1986-2020 for all patients aged <20 years at diagnosis within NHSCR.

PEDIATRICIAN SURVEYS. A list of licensed physicians was obtained from the state Board of Medicine. A questionnaire to explore trends in pediatric cancer incidence, reporting, and referral patterns was presented by phone or fax.

INSURANCE STATUS & STAGE. We assessed missing data for insurance, stage, and other factors that may be affected by insurance status (e.g., treatment and age at diagnosis) for New Hampshire residents aged 0-19, diagnosed 2009-2018.

RESULTS

RECODING AUDIT

Table 1. Forty-seven Data Items Reviewed

NAACCR #	Data Item	NAACCR #	Data Item
220	Sex	1231	RX Date—Hormone Flag#
230	Age at Diagnosis	1240	RX Date BRM
380	Sequence Number--Ctr	1241	RX Date — BRM Flag#
390	Date of Diagnosis	1250	Rx Date Other
400	Primary Site	1251	RX Date — Other Flag#
410	Laterality	1270	Date of 1st Course RX—CoC
440,3843,3844	Grade	1271	Date of 1st Crs RX—CoC Flag#
490	Diagnostic Confirmation	1290	RX Summary Surgery Primary Site
522	Histologic Type ICD-O-3	1292	RX Summary Scope Regional Lymph Node Surgery
523	Behavior Code ICD-O-3	1294	RX Summary Surgery Other Regional/Distant
759,3020,764	SEER Summary Stage	1340	Reason No Surgery
780,2800,756	Tumor Size	1380	RxSumm—Surg/Rad Seq
820	Regional Nodes Positive	1380	RX Summ--Surg/Rad Seq
830	Regional Nodes Examined	1390	RX Summary Chemotherapy
1200	Date of Surgery Primary Site	1400	RX Summary Hormone
1201	RX Date — Surgery Flag#	1410	RX Summary Biological Response Modifier
1210	RX Date Radiation	1420	RX Summary Other
1211	RX Date—Radiation Flag#	1570	Radiation Regional RX Modality
1220	RX Date Chemotherapy	1639	RX Summ--Systemic/Surg Sequence
1221	RX Date—Chemo Flag#	1639	RxSumm—Systemic/Sur Seq
1230	RX Date Hormone	3250	RX Summary Transplant/Endocrine

Table 2. Data Items With the Most Differences

Data Item	# Differences	% in Agreement
Laterality	27	98.7
Grade	19	99.1
SEER Summary Stage	50	97.5
Total	96	

Majority of differences were in coding Stage, Laterality, and Grade.

Remaining data items were at least 99.5% accurate.

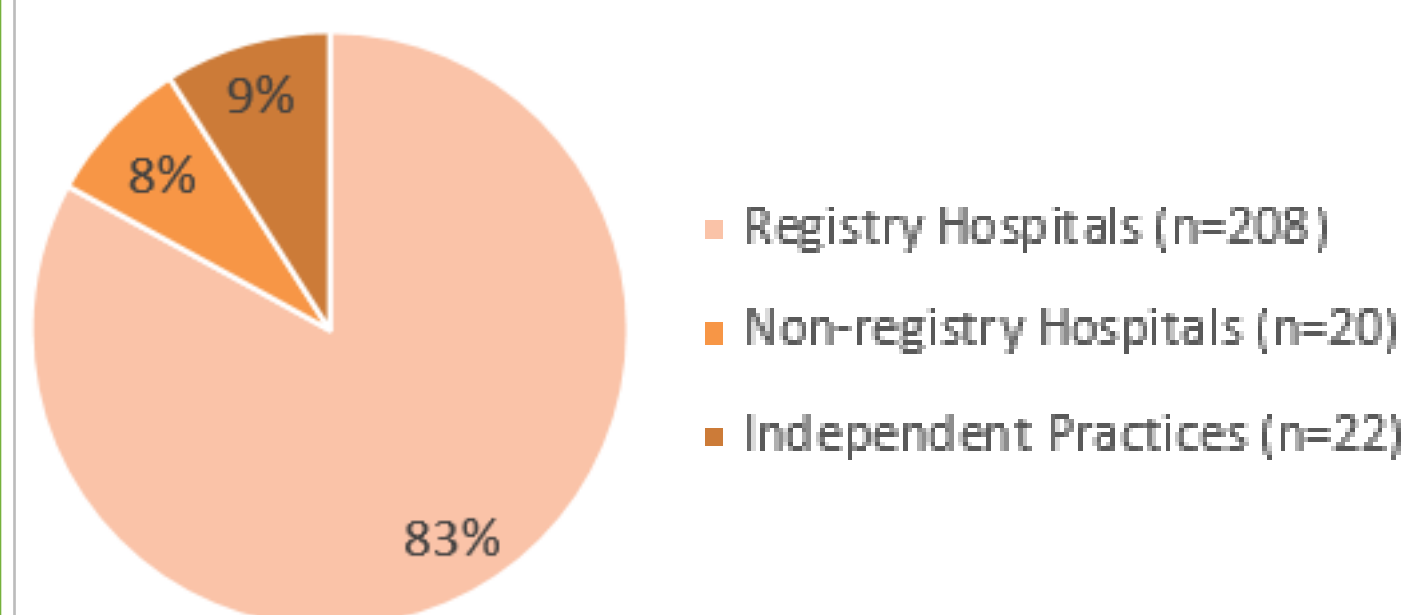
Table 3. Summary of NH Childhood Cancer Recoding Audit and Findings

a. Number Cases Reviewed	2036
b. Number Data Items Per Case Reviewed	47
c. Total Number of Data Items (a*b)	95692
d. Number of Differences	154
Accuracy Rate	99.8%

Accuracy Rate (%) = (c-d)/c

PEDIATRICIAN SURVEYS

Figure 1. New Hampshire Pediatricians by Affiliation Type (n=250)



Majority of NH pediatricians are affiliated with a registry hospital (n=208) or a non-registry hospital (n=20), and any cancers would be picked up through NHSCR's usual mechanisms.

228 of 250 pediatricians were affiliated with an organization that had a mechanism to report, including cancer registry hospitals and non-cancer registry hospitals.

22 pediatricians working from 13 independent practices did not appear to be affiliated with NH hospitals. Five of 13 non-hospital affiliated clinics responded by the conclusion of the study despite several attempts to reach them by phone and/or fax.

Most clinics demonstrated uniformity in their answers. They were aware of the state law requiring the reporting of cancer cases to the NHSCR, had never diagnosed cancer in a pediatric patient, and would refer a pediatric patient suspected of having cancer for both workup and treatment to either their local hospitals or a more specialized regional hospital.

INSURANCE STATUS & STAGE

Figure 2. Characteristics of New Hampshire Childhood Cancer Cases, 2009-2018 (n=682)

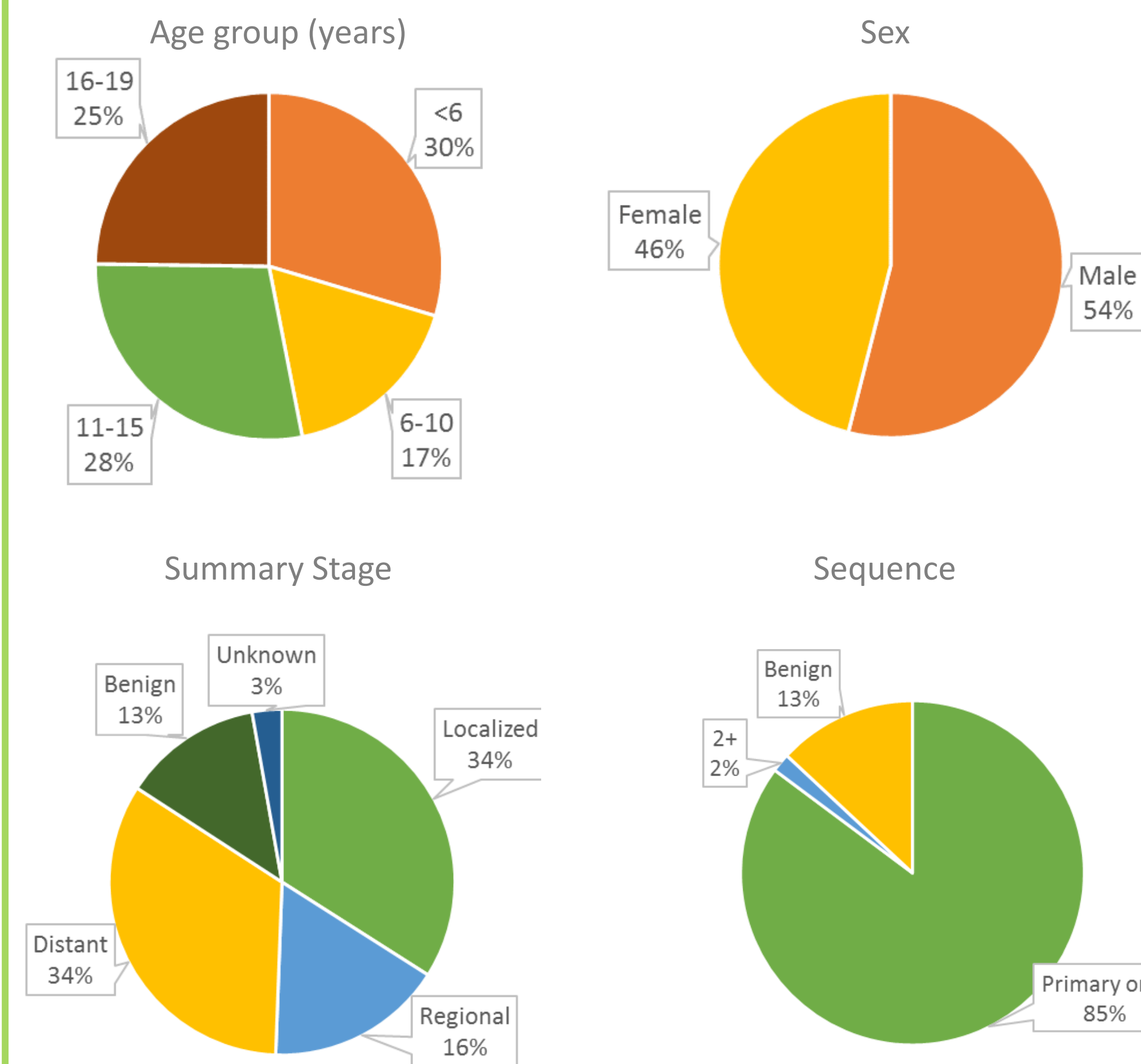
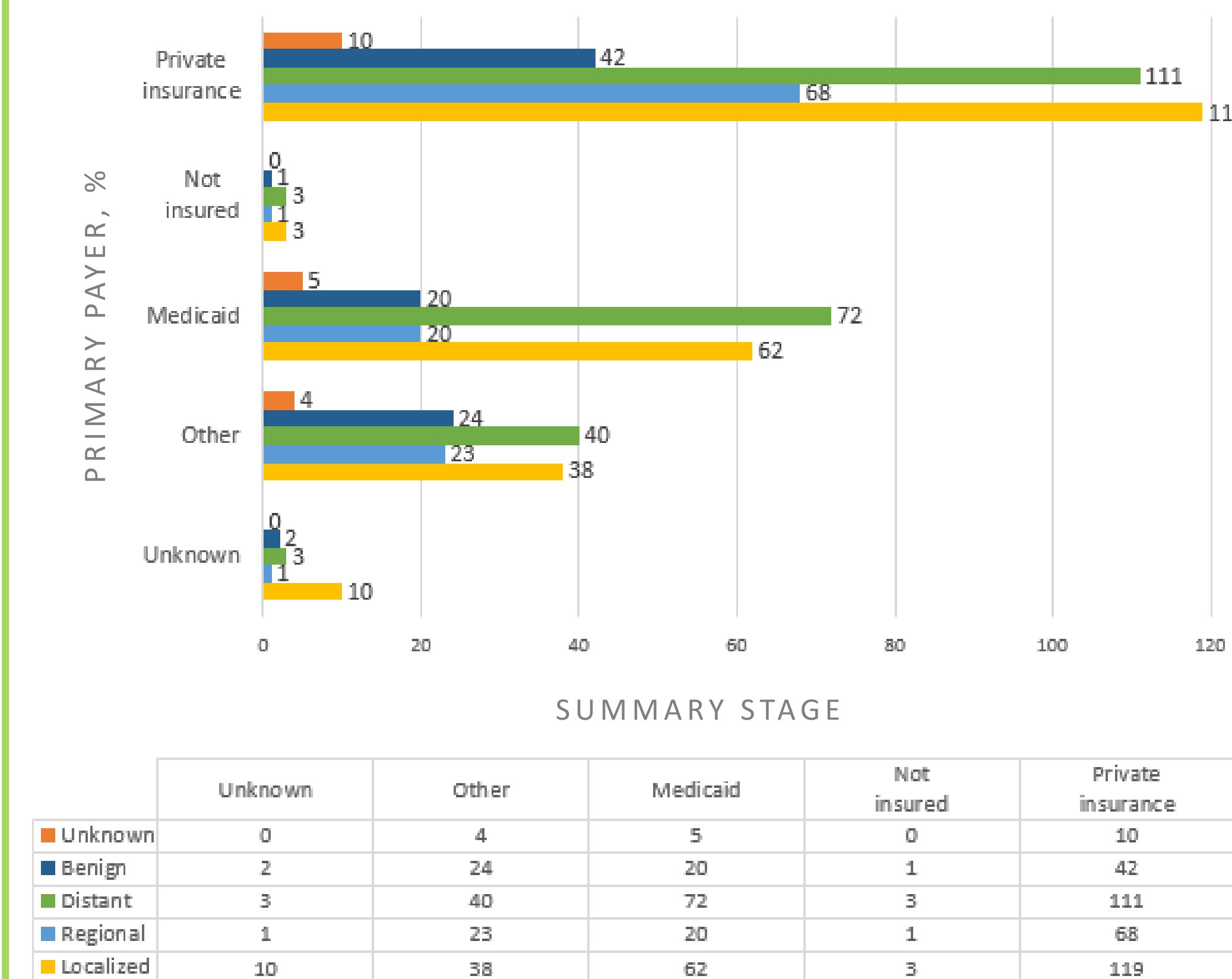


Figure 3. Stage at Diagnosis for New Hampshire Childhood Cancers, 2009-2018 (n=682)



DISCUSSION

RECODING AUDIT. Overall, the accuracy rate was very high (99.8%) for NHSCR childhood cancer data.

The most common errors were reported back to hospital registrars. In addition to understanding that the data were of very high quality, this audit also allowed the whole NHSCR database from 1986 onwards to be reviewed and corrected for all childhood cancers.

PEDIATRICIAN SURVEYS. Given that pediatricians employed by a non-hospital affiliated clinic represent less than 10% of all pediatricians in the state and based on the self-reported referral patterns to hospitals with registries, as well as the low incidence of cases seen by these pediatricians, it seems likely that pediatric cancer is adequately reported in New Hampshire when patients are initially diagnosed by independent clinics. We continue to reach out to clinics that did not respond in the timeframe of this study, since non-responders seem to be at highest risk of noncompliance with reporting.

INSURANCE STATUS & STAGE. The data quality review is being assessed to determine next steps.

ACKNOWLEDGEMENTS

The NHSCR is supported by the Centers for Disease Control (CDC) and Prevention's National Program of Cancer Registries (NPCR) through cooperative agreement NU58DP006298 awarded to the New Hampshire Department of Health and Human Services, Division of Public Health Services, Bureau of Disease Control and Health Statistics, Health Statistics and Data Management Section. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC or NH DHHS.

We thank the New Hampshire Drinking Water and Groundwater Trust Fund for funding these projects.