

## Rare Cancer Incidence Trends in North Carolina

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### Introduction

The purpose of this report is to examine the most recent incidence trends of rare cancers in North Carolina. Rare cancers, as defined by World Trade Center Health Program, include: adrenal/endocrine glands, anus/anal canal, bone/articular cartilage, breast among men, gallbladder/biliary tract, brain/other parts of central nervous system, pancreas, penis/testis, placenta, small intestine, thymus, female genital system, etc.<sup>1</sup> These cancers were listed as rare because the age-adjusted incidence rates were lower than 15 cases per 100,000 per year.<sup>2</sup> Even though they are called rare cancers, they collectively accounted for 25 percent of all tumors among adults aged 20 and older.<sup>2</sup> However, rare cancers in this report only include the following sites: pancreas, male breast, adrenal/other endocrine glands, and malignant neuroendocrine neoplasms. These sites were selected due to increasing incident cases during the last 10 years.

### Data and Definitions

The most current incidence data from the North Carolina Central Cancer Registry was used. Except for yearly incidence trend (data from diagnosis years 2004 to 2013), data from the latest five years of diagnosis, between 2009 and 2013, were employed in the analysis.

Pancreatic cancer was defined by ICD-O site codes C250-C259. Male breast cancer was defined by ICD-O site codes C500-C509. Adrenal/other endocrine cancers were defined by ICD-O site codes C739, C740-C749 or C750-C759. Malignant neuroendocrine neoplasms were defined by histology codes 8246, 8013, 8247, 8041 or 8574.

Age groups were based on age at diagnosis and divided into three groups: 1) 0–49, 2) 50–64 and 3) 65 and older.

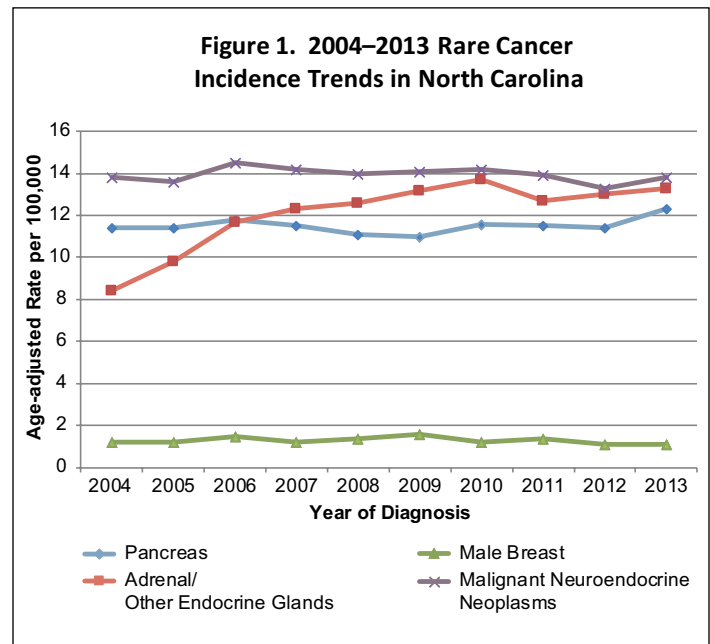
Type of insurance coverage was categorized into four groups based on the variable, primary payer at diagnosis: 1) private insurance, 2) government (Medicare, Medicaid, and Military), 3) uninsured and 4) unknown.

### Results

#### Overall Trend

Figure 1 shows the the age-adjusted rates for rare cancers between 2004 and 2013. Only adrenal/other endocrine cancers have been steadily increasing, from 8.4 per 100,000 in 2004 to 13.3 per 100,000 in 2013 while the rates for other rare cancers remained stable during the period.

Table 1 shows that the incidence rates were highest among those over 65 years old between 2009 and 2013 (see Table 1).



#### Incidence Trend by Site

##### PANCREAS:

Table 2 shows that the age-adjusted rates for non-Hispanic African Americans were higher (14.8 per 100,000) than both non-Hispanic whites (10.9 per 100,000) and Hispanics (8.9 per 100,000). Within each race/ethnicity, the incidence was higher among white males (12.9 per 100,000) than white females (9.3 per 100,000). Similar trend was observed among non-Hispanic African Americans (males: 16.3 per 100,000; females: 13.5 per 100,000).

Higher proportions of African Americans were diagnosed with pancreatic cancer at distant stage (48.4%) than whites (46.6%) between 2009 and 2013 (see Figure 2).

**Table 1. 2009–2013 Rare Cancer Incidence in North Carolina by Age Groups Per 100,000 Population**

	00 to 49		50 to 64		65+	
	Cases	Rate	Cases	Rate	Cases	Rate
Pancreas	352	1.1	1,881	20.4	3,914	60.5
Adrenal/Other Endocrine Glands	3,012	9.3	2,077	22.6	1,553	24.0
Male Breast	34	0.2	91	2.1	174	6.3
Malignant Neuroendocrine Neoplasms	476	1.5	2,566	27.9	4,452	68.8

Higher proportions of individuals with no insurance were diagnosed at distant stage (56.0%) than those with health coverage (private: 52.5%, government: 48.0%) (see Table 3).

**ADRENAL/OTHER ENDOCRINE GLANDS:**

The age-adjusted incidence was the highest among non-Hispanic whites (14.4 per 100,000). Within each race/ethnicity, higher incidence was observed among females than males (see Table 2).

Higher proportions of African Americans were diagnosed at localized stage (77.2%) than whites (69.8%).

Higher proportions of uninsured individuals were diagnosed at later stages (regional and distant: 37.4%) than those with health coverage (private: 27.8%, government: 26.5%) (see Table 3).

**MALE BREAST:**

Similar to pancreatic cancer, the 2009–2013 age-adjusted rates for non-Hispanic African Americans were higher (1.7 per 100,000) than both non-Hispanic whites (1.2 per 100,000). However, there were too few cases for male breast cancer among Hispanics for the analysis.

Again, higher proportions of African Americans were diagnosed at distant stage (7.7%, vs. whites: 3.0%).

Higher proportions of individuals with government coverage were diagnosed at late stages (regional and distant: 54% vs. private: 41.5%).

**MALIGNANT NEUROENDOCRINE NEOPLASMS:**

The age-adjusted incidence rate for malignant neuroendocrine neoplasms was the highest among non-Hispanic

whites (14.9 per 100,000). It was higher than that of non-Hispanic African Americans (10.8 per 100,000) as well as Hispanics (7.4 per 100,000). Within each race/ethnicity, the incidence was higher among males than females (see Table 2).

No significant differences between races were observed at the stage of diagnosis.

Higher proportions of individuals with no insurance were diagnosed at distant stage (66.2%) of malignant neuroendocrine neoplasms than those with private (60.2%) or government (59.6%) coverage (see Table 3).

**Discussion**

The report illustrated a mixed picture for rare cancer incidence in North Carolina. While non-Hispanic African Americans were more likely to be diagnosed with pancreatic and male breast cancers at later stages, non-Hispanic whites were more affected by adrenal/other endocrine cancer and malignant neuroendocrine neoplasms. Having health coverage was highly associated with the early diagnosis of pancreatic cancer, adrenal/other endocrine cancer and malignant neuroendocrine neoplasms. Limitations of this report include the use of data up to 2013 and incomplete data in primary payer at diagnosis. Further research is needed

**Table 2. 2009-2013 Rare Cancer Incidence by Race/Ethnicity in North Carolina Per 100,000 Population Age-adjusted to the U.S. 2000 Census**

	Pancreas		Adrenal/Other Endocrine Glands		Male Breast		Malignant Neuroendocrine Neoplasms	
	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate
	White Non-Hispanic Males	2,386	12.9	1,402	8.1	228	1.2	3,330
White Non-Hispanic Females	2,149	9.3	3,678	20.5	NA	NA	2,914	12.9
Non-Hispanic Whites	4,535	10.9	5,080	14.4	228	1.2	6,244	14.9
Non-Hispanic African American Males	641	16.3	199	4.5	65	1.7	549	13.8
Non-Hispanic African American Females	726	13.5	821	14.6	NA	NA	496	8.9
Non-Hispanic African Americans	1,367	14.8	1,020	10.1	65	1.7	1,045	10.8
Hispanic Males	46	8.6	70	5.5	*	*	38	7.8
Hispanic Females	60	9.4	223	15.8	NA	NA	52	7.6
Hispanics	106	8.9	293	10.2	*	*	90	7.4

Produced by the North Carolina Central Cancer Registry, 06/2016

Numbers are subject to change as files are updated.

Cases may not sum to totals due to unknown or other values.

\* Counts fewer than five are suppressed.

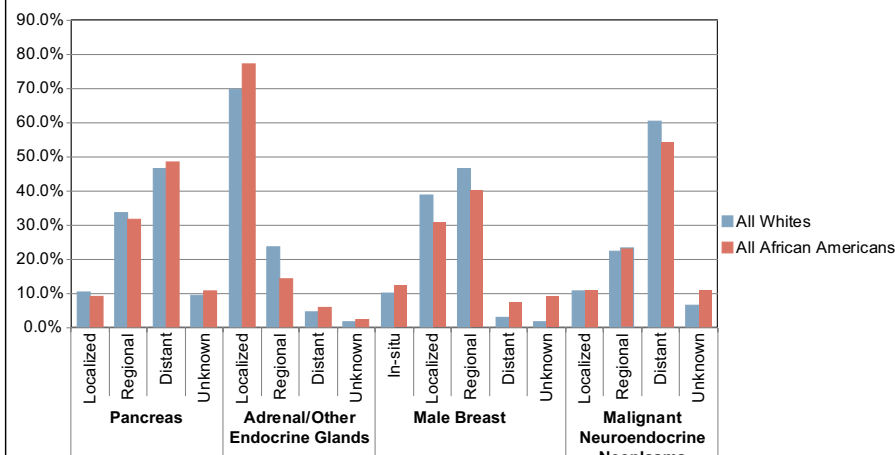
Rates based on counts fewer than 16 are unstable. Use with caution.

Cancers of the urinary bladder and female breast include in situ cases.

Hispanic ethnicity is independent of race. Hispanic ethnicity is determined by self-report and the National Hispanic Identification Algorithm ([www.naacr.org/LinkClick.aspx?fileticket=iTvqgbzLrx81%3d&tabid=118&mid=458](http://www.naacr.org/LinkClick.aspx?fileticket=iTvqgbzLrx81%3d&tabid=118&mid=458)).

Vintage 2013 bridged-race postcensal population estimates were obtained from the National Center for Health Statistics ([www.cdc.gov/nchs/nvss/bridged\\_race/data\\_documentation.htm#vintage2013](http://www.cdc.gov/nchs/nvss/bridged_race/data_documentation.htm#vintage2013)).

**Figure 2. 2009–2013 Rare Cancer Incidence at Stage of Diagnosis by Race in North Carolina**



to investigate if expanded health coverage through the enactment of Affordable Care Act in 2014<sup>3</sup> improved the access to cancer care in North Carolina.

### References

- Howard, J. Rare Cancers: WTC Health Program, Monitoring and Treatment. [www.cdc.gov/wtc/pdfs/WTCHP\\_PP\\_RareCancers05052014.pdf](http://www.cdc.gov/wtc/pdfs/WTCHP_PP_RareCancers05052014.pdf).
- Greenlee RT, Goodman MT, Lynch CF, Platz CE, Havener LA and Howe HL. The Occurrence of Rare Cancers in US Adults, 1995–2004. Public Health Reports. 2010;125:28–43.
- Affordable Care Act. <https://www.medicaid.gov/affordablecareact/affordable-care-act.html>.

**Table 3. 2009–2013 Rare Cancer Incidence by Stage and Insurance Type in North Carolina**

Site	Stage	Private Insurance	Government	Uninsured	Unknown	Overall
Pancreas	Localized	8.1%	11.7%	5.8%	5.0%	10.0%
	Regional	37.6%	35.1%	33.0%	9.3%	33.1%
	Distant	52.5%	48.0%	56.0%	25.0%	47.1%
	Unknown	1.8%	5.2%	5.2%	60.7%	9.8%
Adrenal/Other Endocrine Glands	Localized	71.2%	71.4%	61.8%	47.8%	70.4%
	Regional	24.9%	18.9%	29.4%	24.8%	22.9%
	Distant	2.9%	7.6%	8.0%	5.7%	4.9%
	Unknown	0.9%	2.1%	0.8%	21.7%	1.9%
Male Breast	In-situ	16.0%	7.5%	28.6%	0.0%	10.4%
	Localized	39.4%	36.4%	42.9%	36.4%	37.5%
	Regional	38.3%	49.7%	28.6%	27.3%	44.8%
	Distant	3.2%	4.3%	0.0%	9.1%	4.0%
	Unknown	3.2%	2.1%	0.0%	27.3%	3.3%
Malignant Neuroendocrine Neoplasms	Localized	11.2%	10.8%	10.4%	7.8%	10.7%
	Regional	22.5%	23.2%	18.8%	14.8%	22.6%
	Distant	60.2%	59.6%	66.2%	46.3%	59.5%
	Unknown	6.1%	6.5%	4.6%	31.1%	7.2%

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