

Benign/Borderline Brain and ONS Tumors in the NAACCR Data

DURC Data Assessment Work Group

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History of Brain & ONS Tumor Surveillance

- 1992. Central Brain Tumor Registry of the United States (CBTRUS) was formed.
- 1996. National Coordinating Council on Cancer Surveillance (NCCCS) formed Brain Tumor Working Group (BTWG).
- 1998. BTWG forwarded 4 recommendations to the NCCCS.
- 2000. Dialogue between the clinical community and the surveillance community to standardize the site and histology definition.
- 2002. President signed public law 107-260, the benign brain tumor cancer registries amendment act.
- 2003. SEER and NAACCR agreed to report non-malignant brain tumors for cases diagnosed January 1, 2004 or later.

<http://training.seer.cancer.gov/brain/non-malignant/history/>

<http://www.naacr.org/LinkClick.aspx?fileticket=tm-wYbKcnlg%3D&tabid=95&mid=477>



Brain and ONS Tumor by Topography Codes

Reportable benign and borderline ONS tumor:

- Meninges (C70.0, C70.1, C70.9)
- Brain (C71.0- C71.9)
- Spinal cord, cranial nerves and other parts of ONS
 - Spinal Cord (C72.0), Cauda Equina (C72.1)
 - Cranial Nerves (C72.2-C72.5), Other ONS (C72.8, C72.9)
- Other endocrine glands and related structure
 - Pituitary Gland (C75.1), Craniopharyngeal Duct (C75.2)
 - Pineal Gland (C75.3)

<http://training.seer.cancer.gov/brain/non-malignant/reportable.html>

Data Collection of primary central nervous system tumors: NPCR training material. 2004

Study Objectives

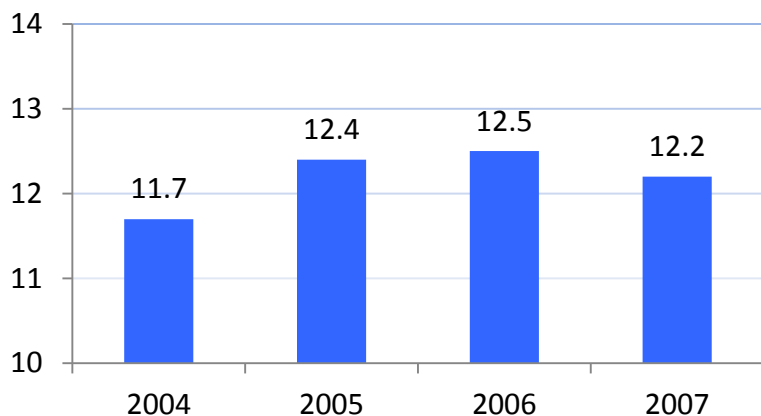
- Examine characteristics of the benign/borderline brain and ONS tumor data in the NAACCR Data
- Examine the completeness of the benign/borderline brain and ONS tumors by state
- Identify factors associated with completeness

Methods

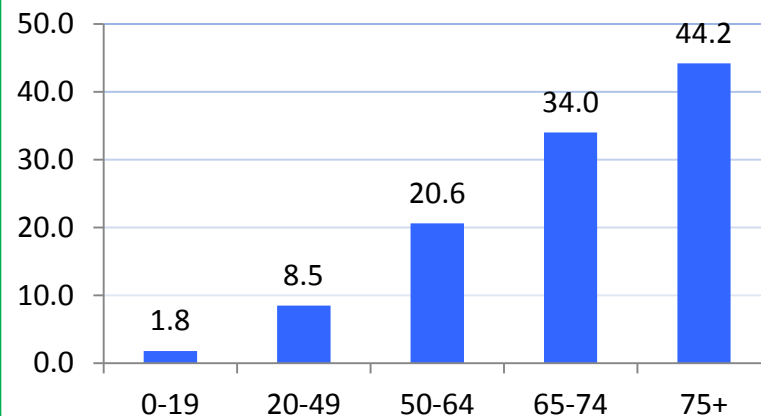
- 2004 – 2007 brain and ONS cases (including endocrine glands and related structures) from the CINA Deluxe data set 1995 – 2007
 - 48 states and regions in U.S.
 - Benign/Borderline brain and ONS tumor (N=141,414)
 - Invasive brain and ONS tumor (N=91,261)
 - DCO and autopsy cases included
- Variables examined
 - Race, gender, age at diagnosis, metro status, education and poverty status at county level, surgery status, diagnostic confirmation, type of reporting source
- Analytical methods
 - Age-adjusted rates, Pearson correlation, coefficient of variation (CV)
 - Multiple linear regression with rate ratio of benign/borderline vs. malignant as outcome variable

Age Adjusted Rates for Benign/Borderline

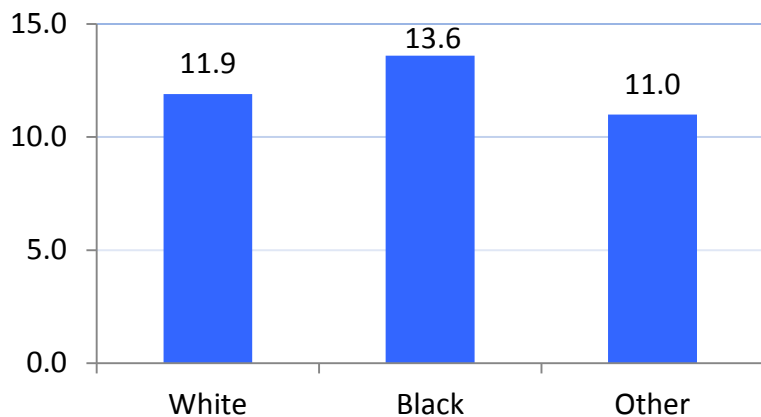
Age Adjusted Rates by Year of Diagnosis



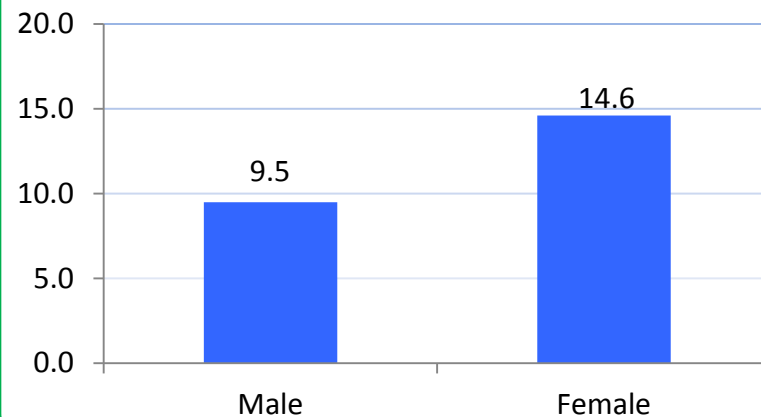
Age Adjusted Rates by Age Group



Age Adjusted Rates by Race

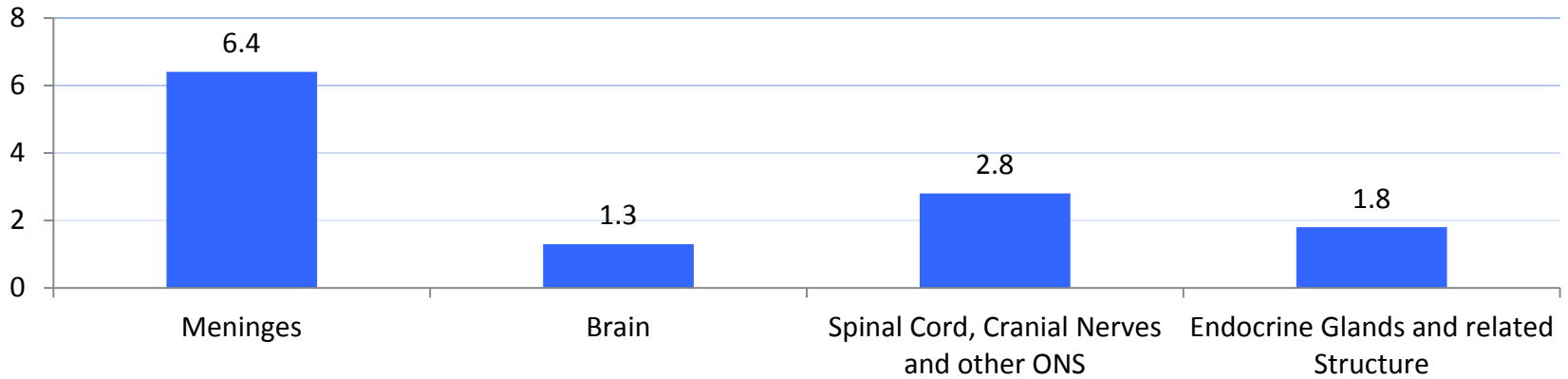


Age Adjusted Rates by Gender

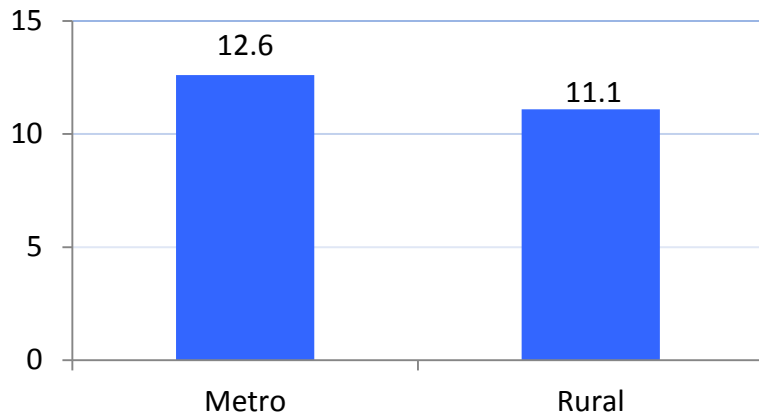


Age Adjusted Rates for Benign/Borderline (Cont.)

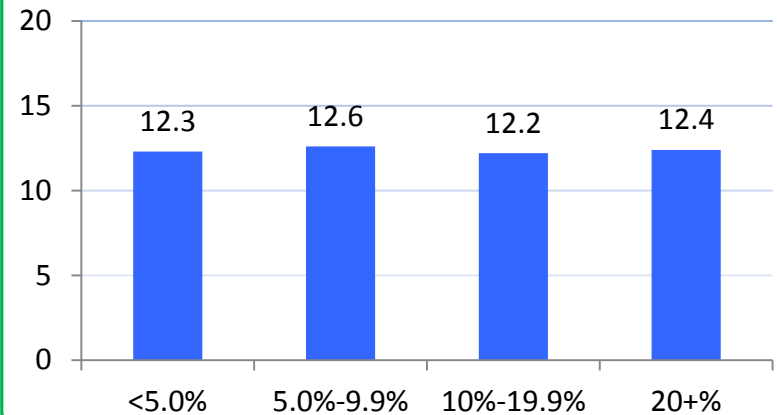
Age Adjusted Rates by Site Group



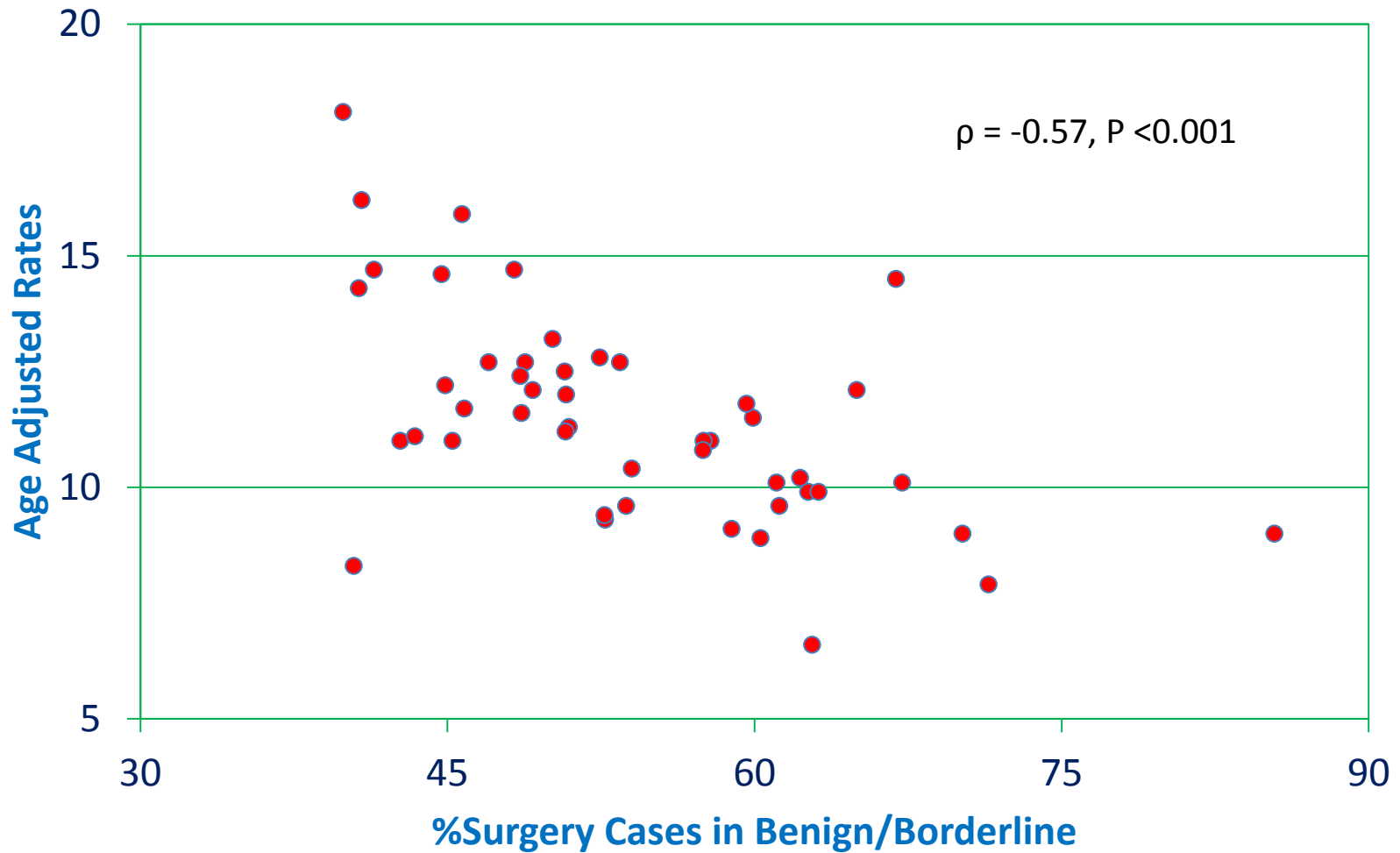
Age Adjusted Rates by Metro Status



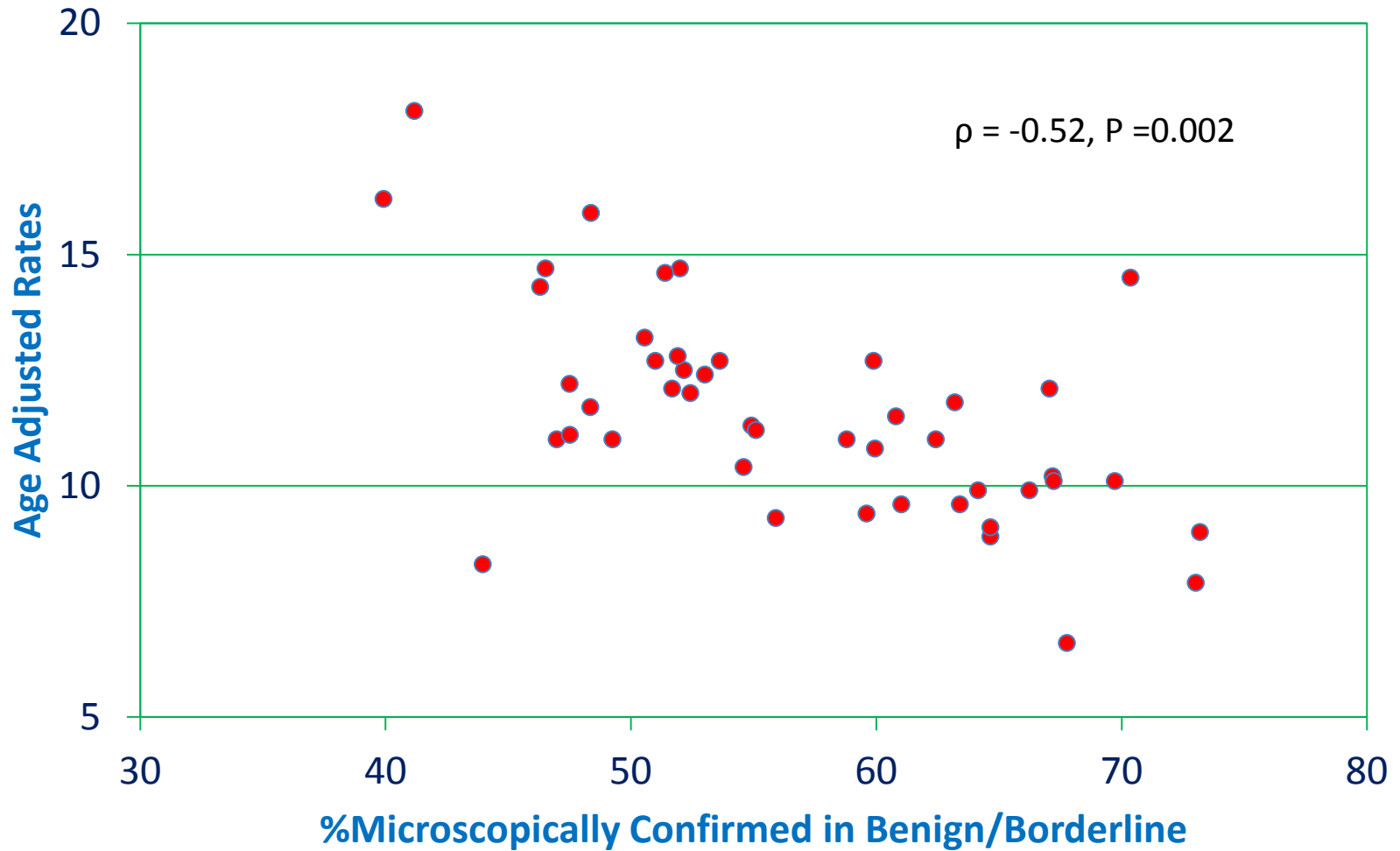
Age Adjusted Rates by Poverty Status



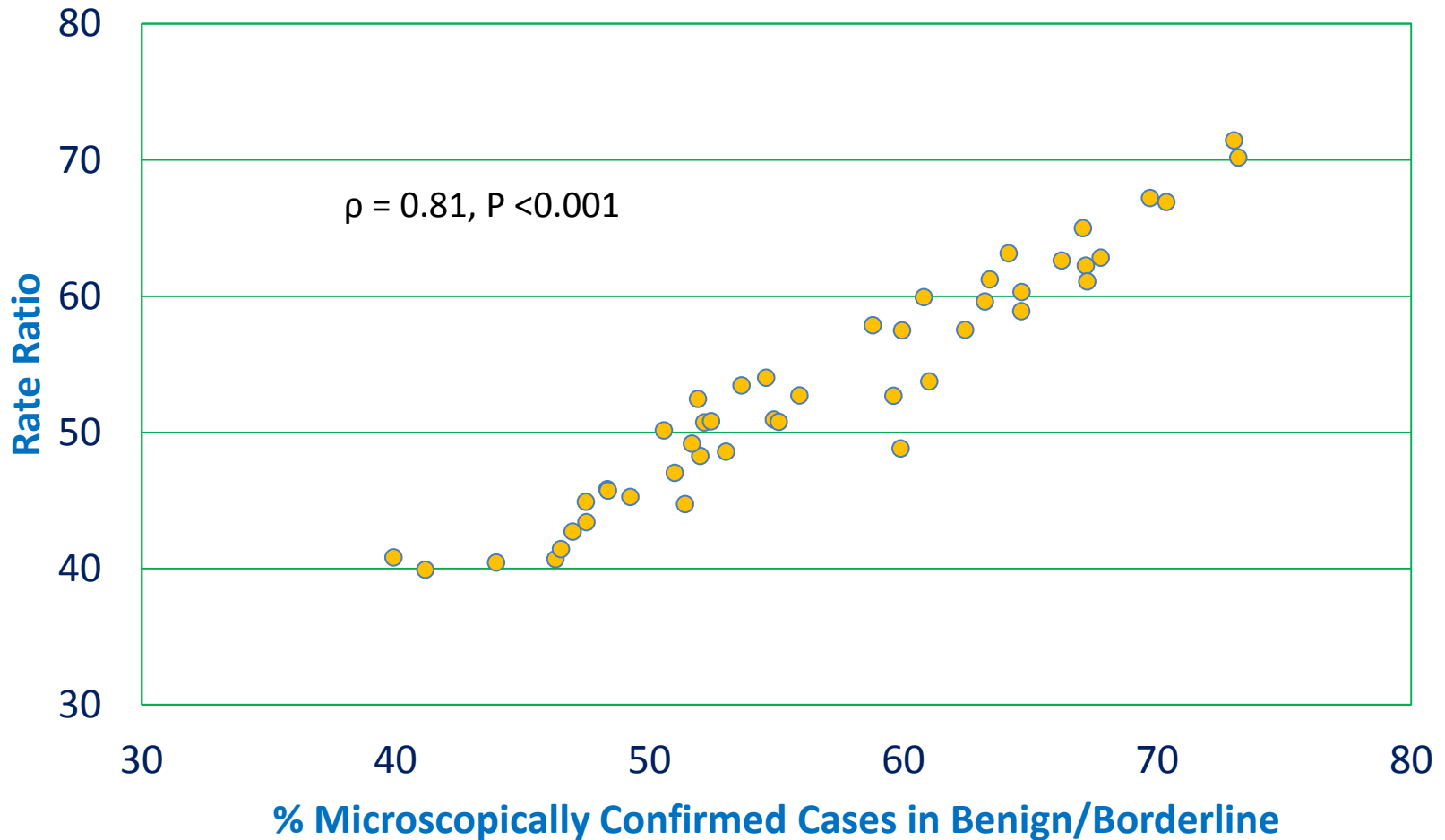
Rates for Benign/Borderline vs. % Surgery



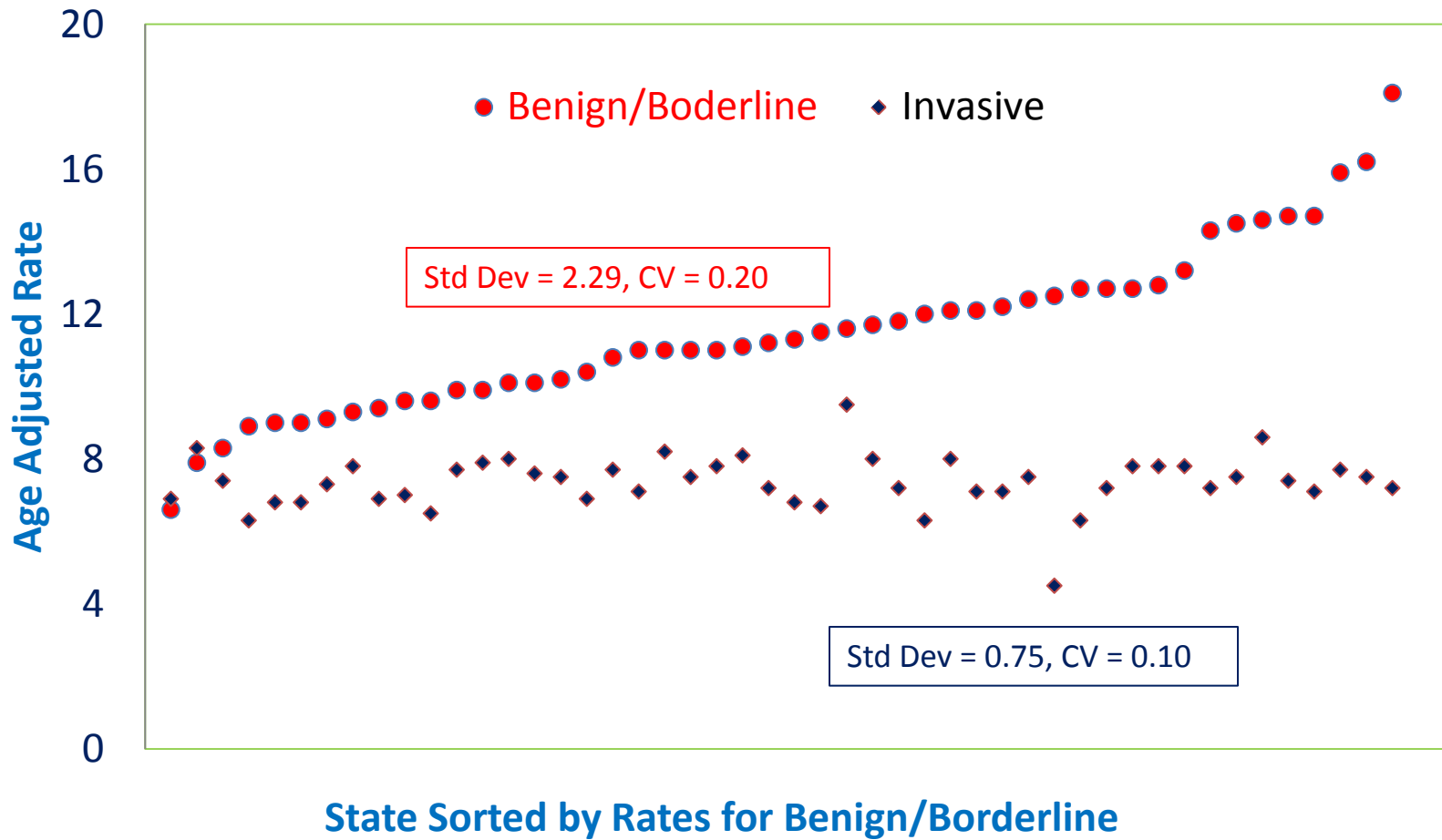
Rates for Benign/Borderline vs. % Microscopically Confirmed



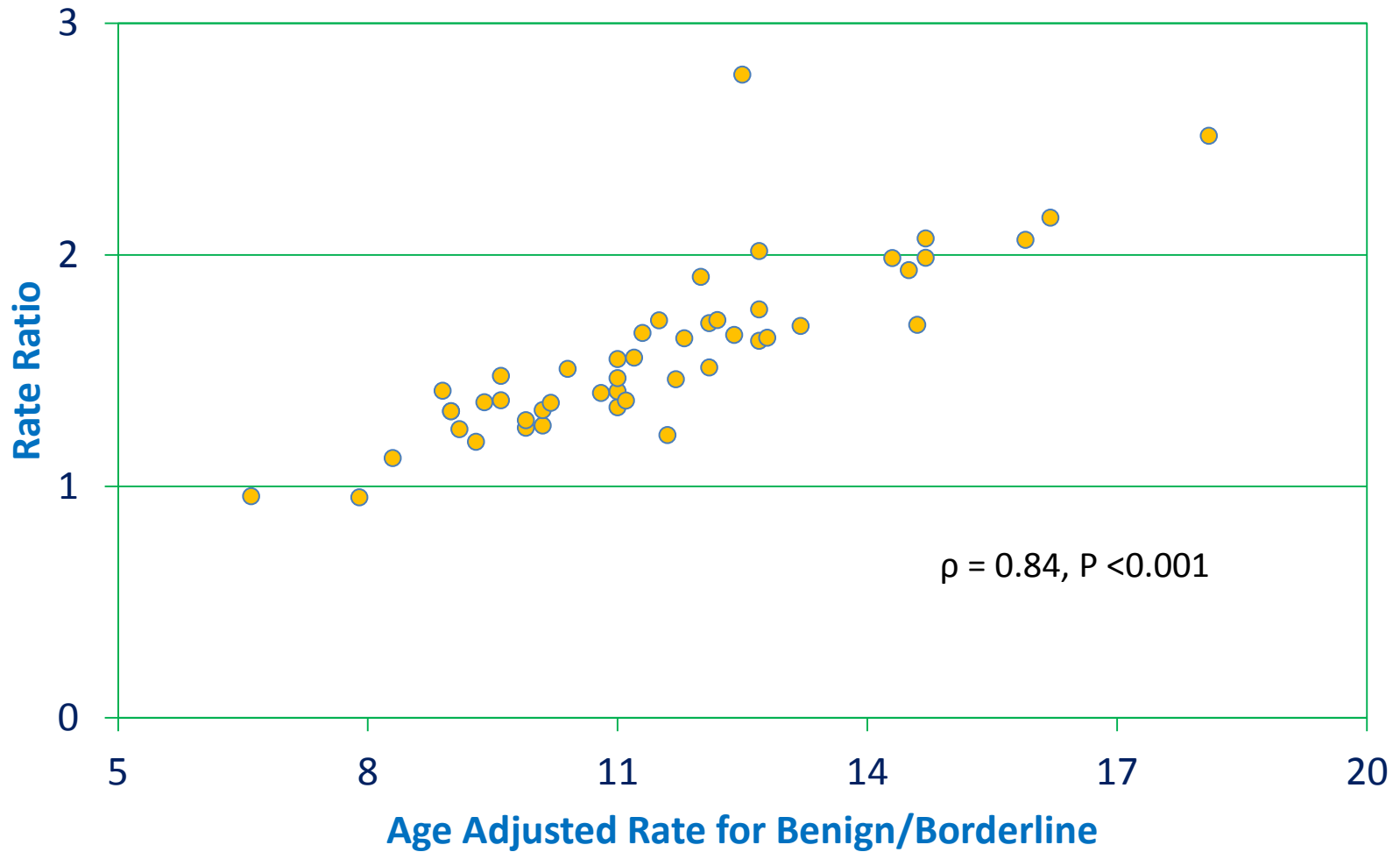
%Surgery vs. % Microscopically Confirmed in Benign/Borderline



Rates for Benign/Borderline and Malignant



Rate Ratio (Benign/Borderline vs. Malignant)



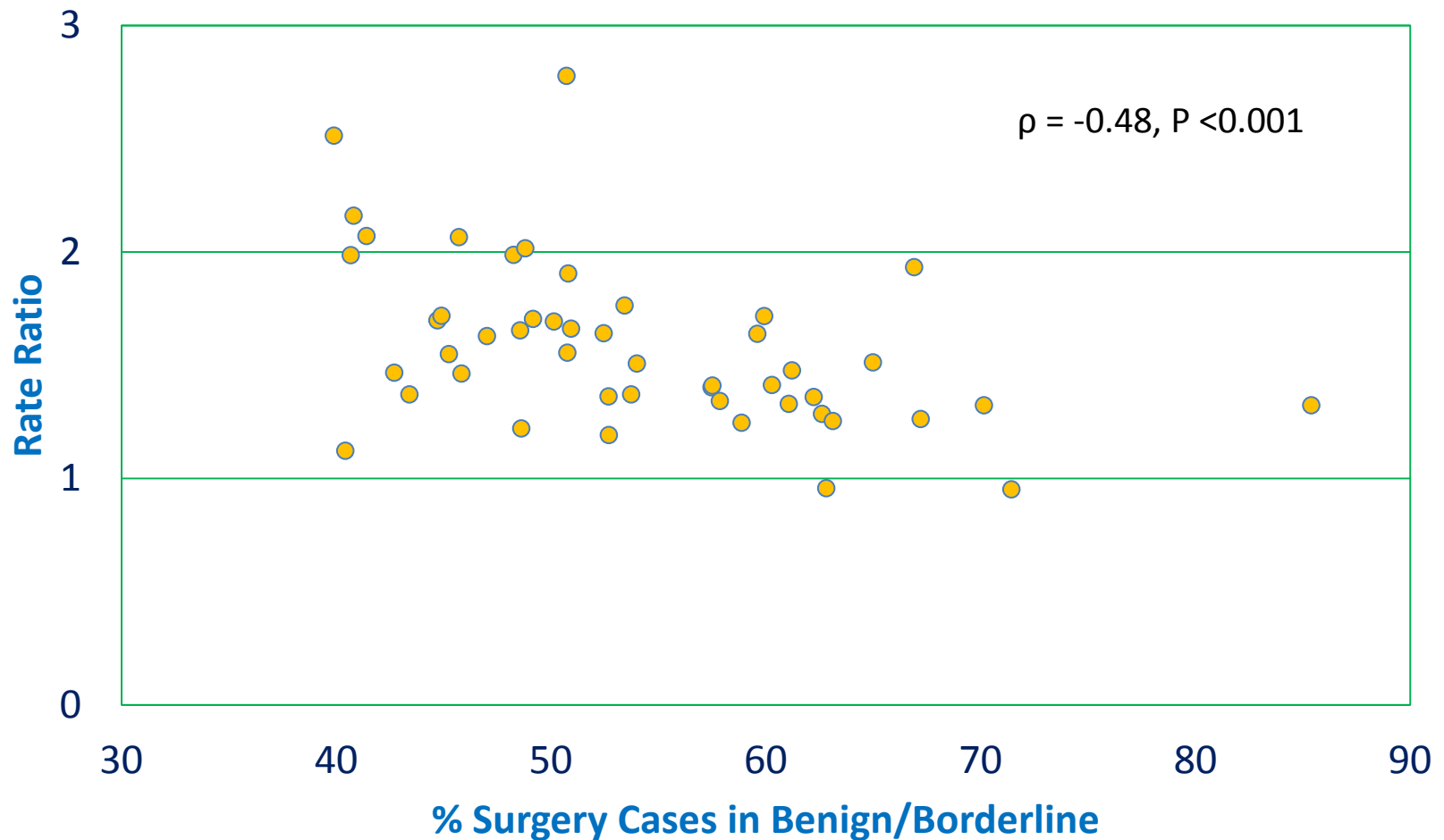
Completeness of Benign/Borderline Brain and ONS Data

- Compared to malignant brain and ONS tumor, much larger variation of rates for benign/borderline cases indicates possible quality issues.
- If rates for benign/borderline cases were as reliable as the rates for malignant cases, it is reasonable to expect the rate ratios between benign/borderline and malignant cases are stable.
- The substantially high correlation between rate ratio and rates for benign/borderline tumors suggests incomplete data in registries with low rate ratios.

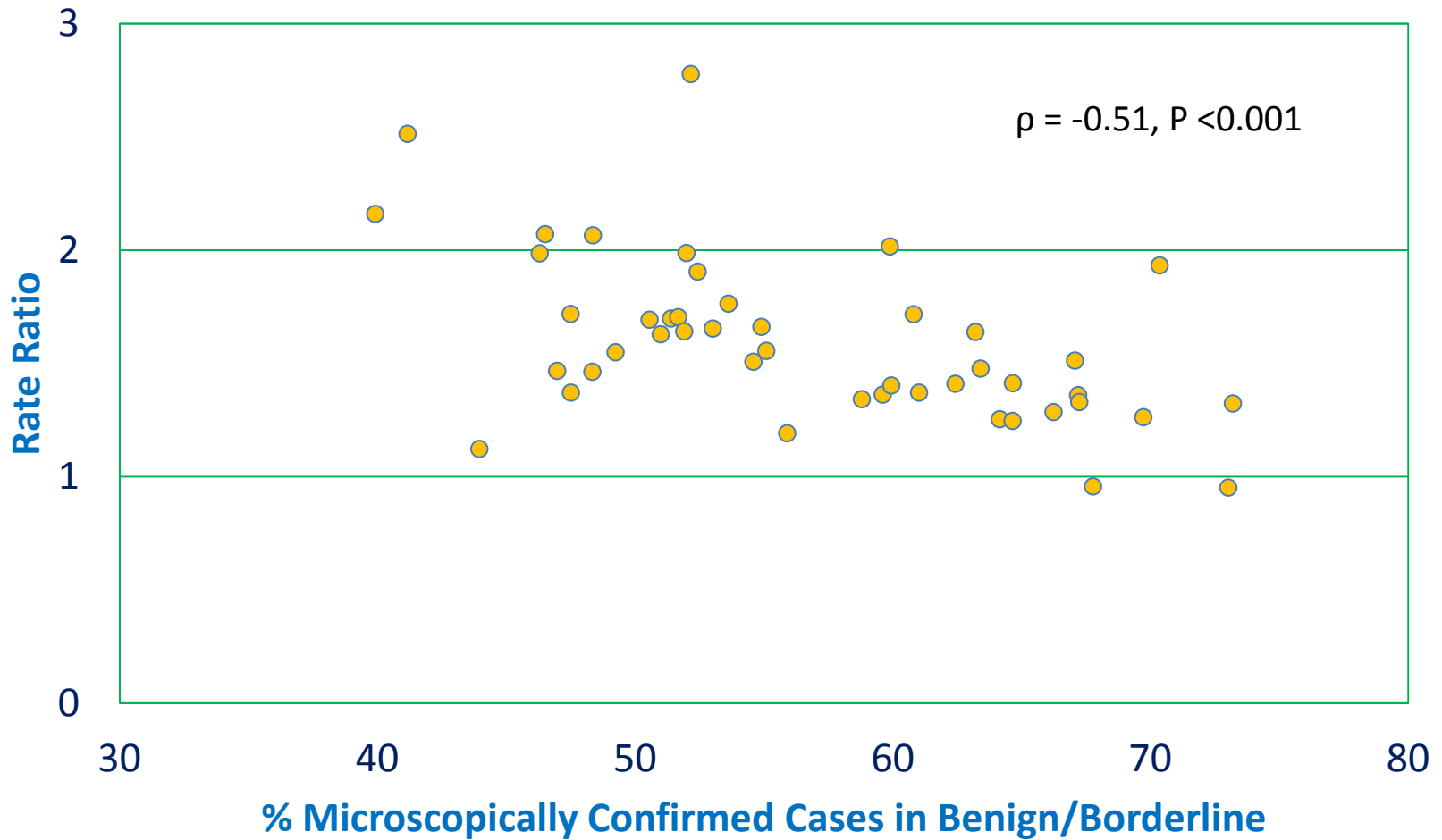
Benign/Borderline vs. Malignant

Characteristics	Benign/Borderline		Malignant	
	N	%	N	%
<i>Surgery Status</i>				
Surgery	72182	51.0%	57437	68.5%
No Surgery	63393	44.8%	30044	35.8%
Unknown	5839	4.1%	3780	4.5%
<i>Diagnostic Confirmation</i>				
Microscopical	80367	56.8%	71334	85.0%
Radiography	56477	39.9%	8614	10.3%
Lab/Visualization/clinic	1635	1.2%	565	0.7%
Unknown	2935	2.1%	3384	4.0%
<i>Reporting Source</i>				
Hospital	135662	95.9%	78306	93.3%
Radiation	1121	0.8%	506	0.6%
Lab/Office/Nursing	1507	1.1%	2223	2.6%
Autopsy/DC	3124	2.2%	2862	3.4%

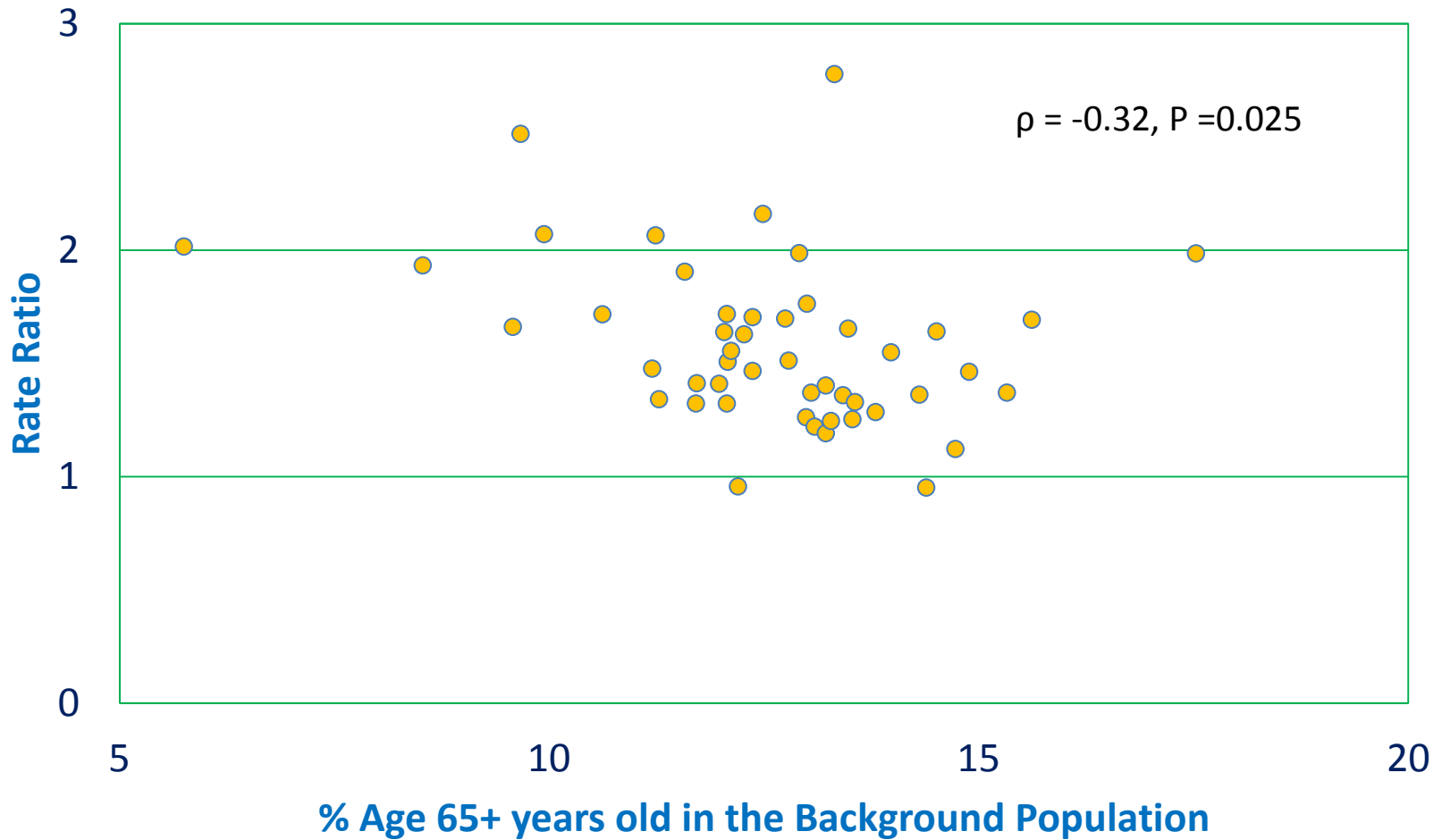
Rate Ratio vs. % Surgery in Benign/Borderline



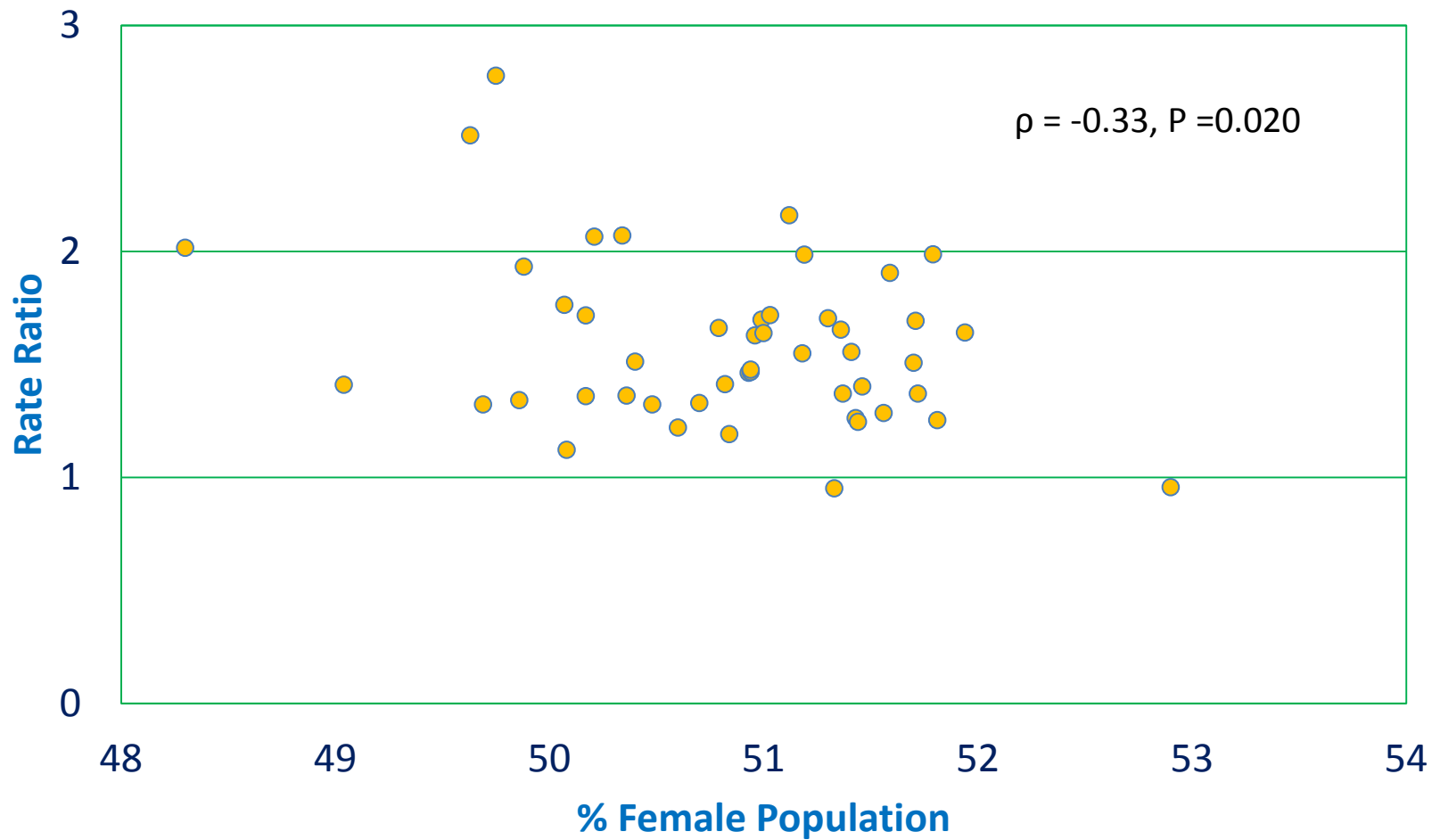
Rate Ratio vs. % Microscopically Confirmed in Benign/Borderline



Rate Ratio vs. % Age 65+ Old Population



Rate Ratio vs. % Female Population



Multiple Linear Regression Modeling Rate Ratio

Coefficient	Full Model		Reduced Model	
	Estimate(SE)	P value	Estimate(SE)	P value
%Microscopically Confirmed	-0.014(0.006)	0.030	-0.017 (0.004)	<0.001
%Age 65+	-0.053 (0.032)	0.099	-0.072 (0.021)	0.002
%Surgery	-0.005 (0.007)	0.489	$R^2 = 0.41,$ R^2 improve to 0.51 if dropping Hawaii	
%Reporting from Hospital	-0.011 (0.009)	0.289		
%Black	-0.000 (0.005)	0.981	% Microscopically Confirmed and % Surgery are interchangeable in the reduced model	
%Female	-0.094 (0.094)	0.323		

Summary

- Data has improved since year 2004.
- Incomplete data for benign/borderline brain and ONS tumors are likely found in the NAACCR data, especially for the state registries with low rate ratios and low rates for benign/borderline .
- % microscopically confirmed cases and %surgery cases are inversely correlated with the rates for benign/borderline brain and ONS tumors and rate ratios between benign/borderline and malignant brain and ONS tumors.
- % older population is also inversely correlated with the rate ratios between benign/borderline and malignant brain and ONS tumors.

Discussion

- Why data are missing?
 - It is new; registrars are still getting used to the process.
 - Lots cases are diagnosed through imaging.
 - Discharge diagnosis code may not be updated or accurate.
- How much data are missing?
 - Compared to the Colorado registry which has been collecting benign/borderline brain and ONS tumor much longer, some registries may have missed substantial amount of cases.
 - The real amount of missing cases are hard to estimate.
- What can we do to improve the data?
 - Use % microscopically confirmed or % surgery as part of quality check. Higher level of % microscopically confirmed or % surgery indicates possible issues.
 - Higher % of older population with a lower rate is a indication of incomplete data
 - Similar as E-Path, electronic radiology reporting system may improve the data quality

Thank you!

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