NAACCR Summer Forum

June 15-17, 2021

LOS ANGELES COUNTY Cancer Surveillance Program

Are Non-Pathologically Diagnosed Cancers Underreported?

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Los Angeles Cancer Surveillance Program, USA

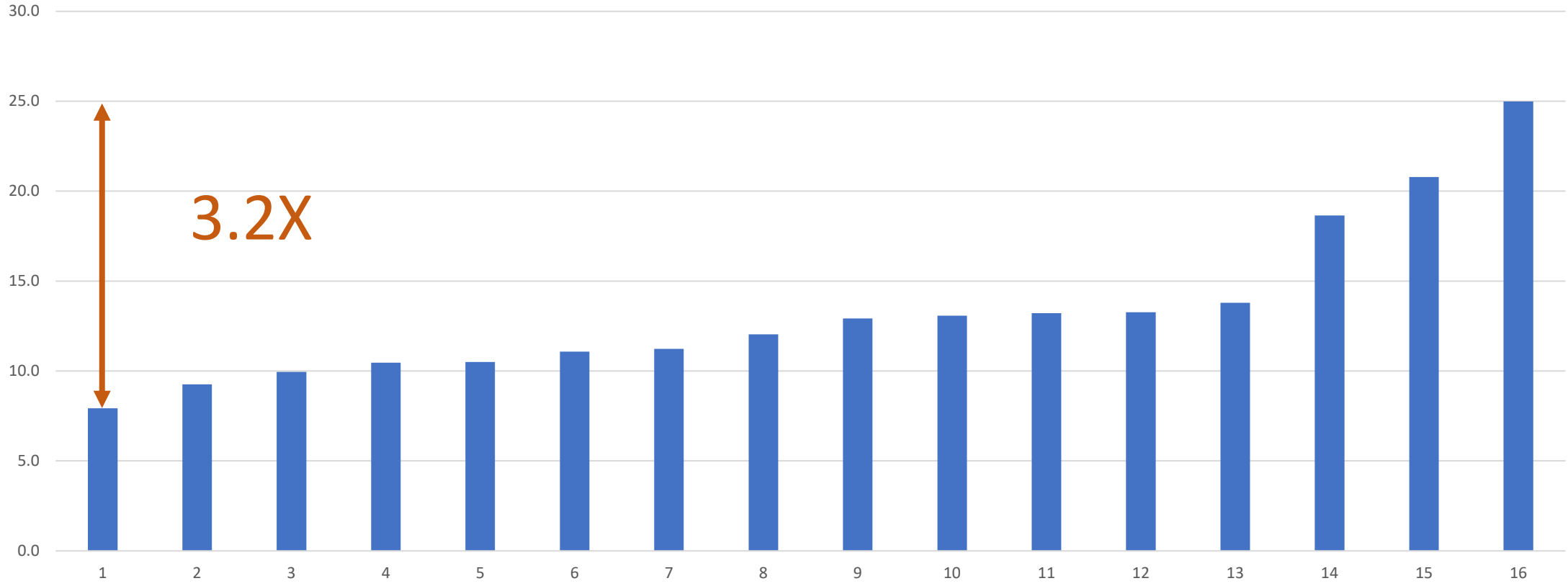
Dennis Deapen, JuanJuan Zhang, Tina Xu, Andrea Sipin-Baliwas, Amie Hwang, Lihua Liu, Diana Withrow

Analysis by NCI Division of Cancer Epidemiology and Genetics: Selected Brain Tumor Trends

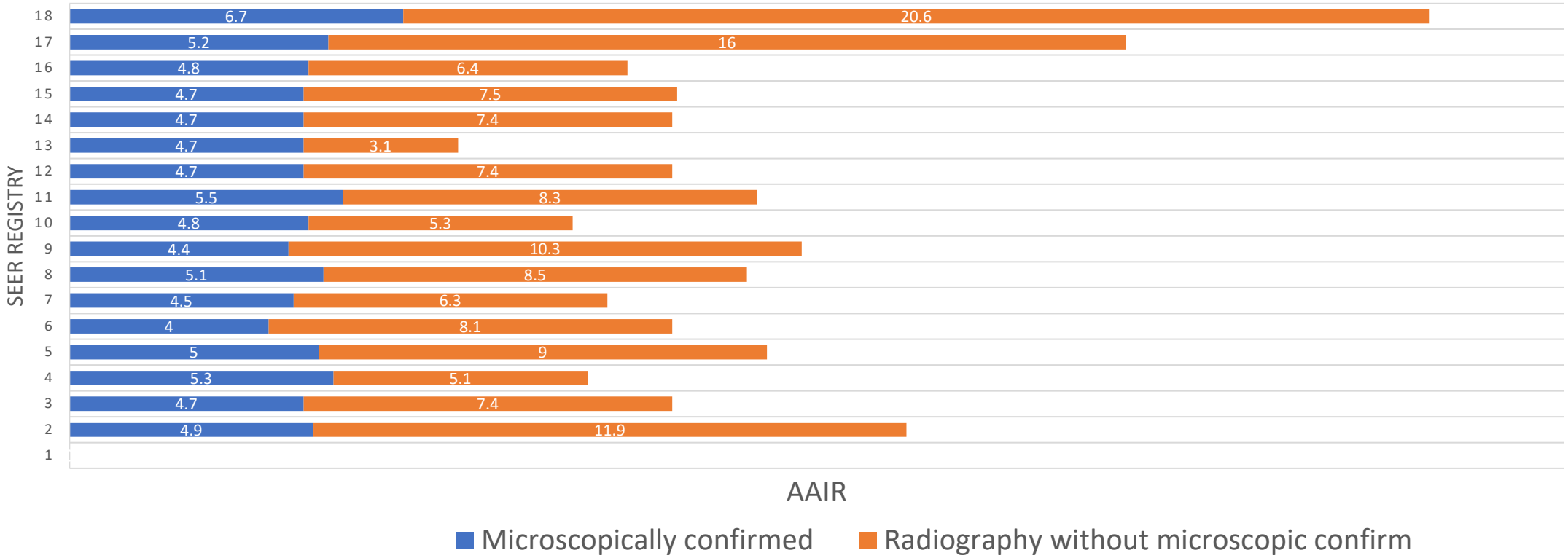
- Incidence rate secular trends, SEER data 2014-2016
- Observed large incidence rate variation of non-malignant meningioma between registries

Withrow DR, Devesa S, Deapen D, Petkov V, van Dyke A, Adamo P, Armstrong TS, Gilbert MR, Linet M. Non-malignant meningioma and vestibular schwannoma incidence trends in the United States, 2004-2017. (In press)

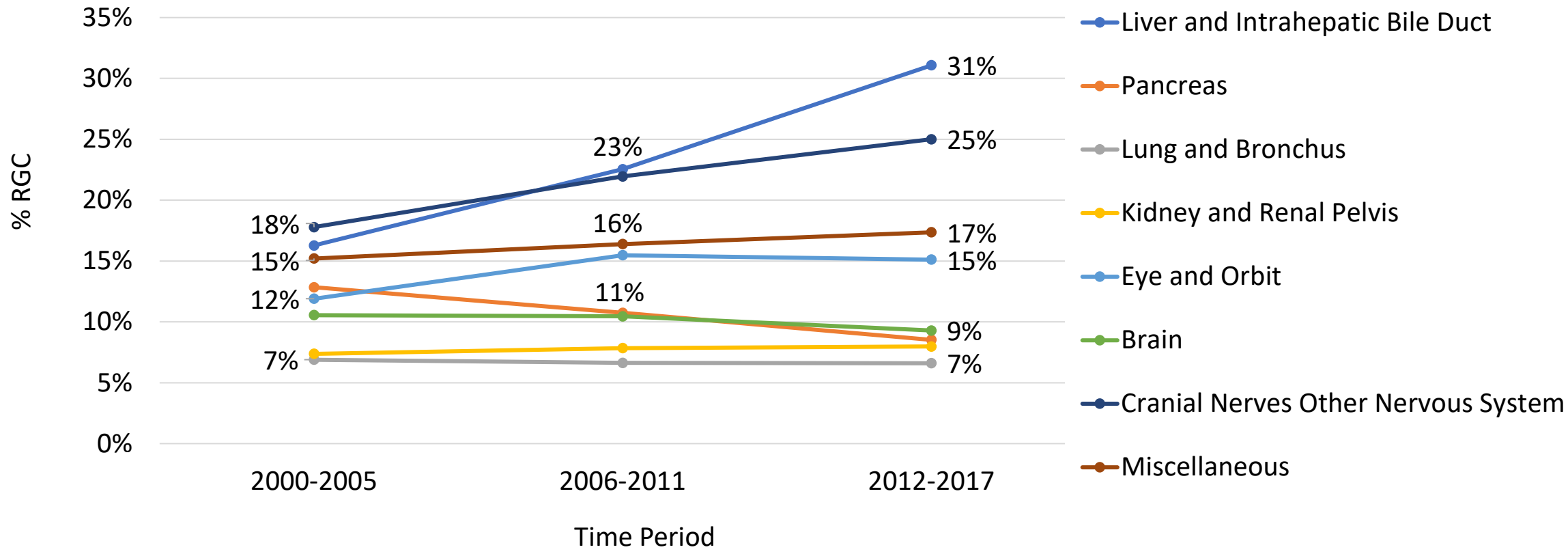
Non-malignant Meningioma Rates (per 100,000 person years) by Registry, Ages 20+, 2016, SEER 18.



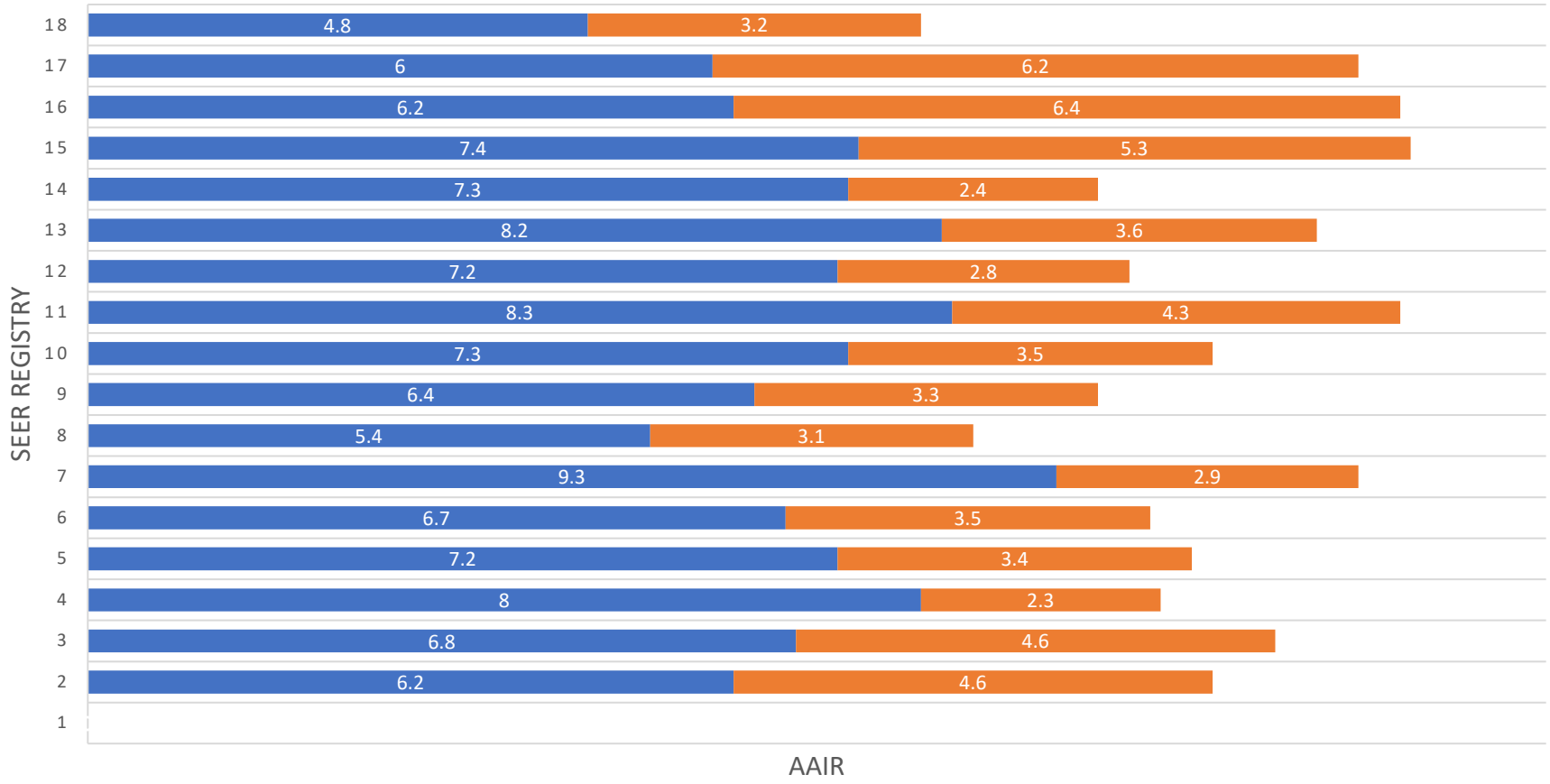
Non-malignant Meningioma AAIR by Diagnostic Confirmation, 2014-2018, Ages 20+, SEER 18



Malignant Cancers with Percent Radiographically Confirmed >5%, Age 20+, 2000-2017, SEER 18



Liver and Intrahepatic Bile Duct AAIR by Diagnostic Confirmation, Age 20+, 2014-2018

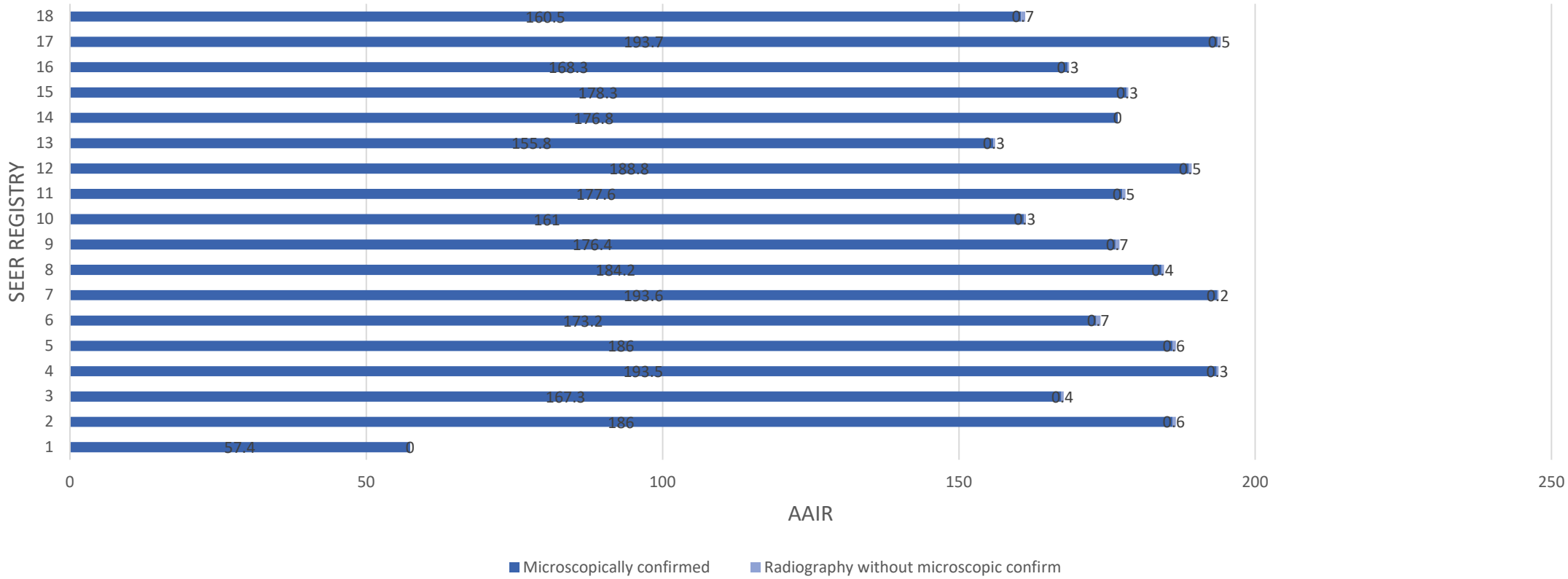


Radiographically Confirmed Rate Range: 16.6-50.1(3.0X)

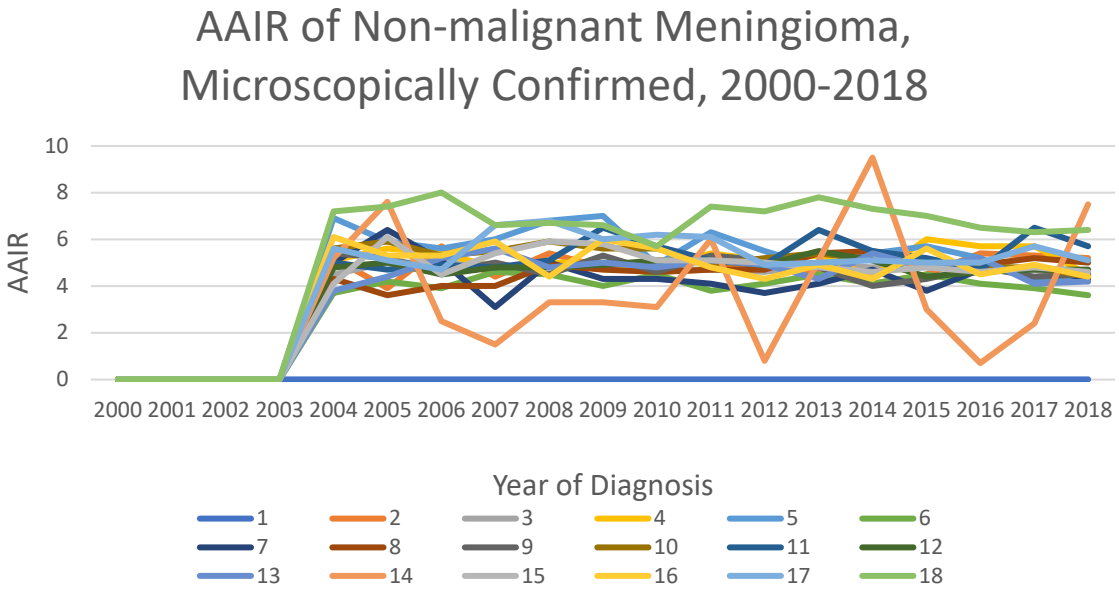
Other Cancers with >5% Radiographic Dx

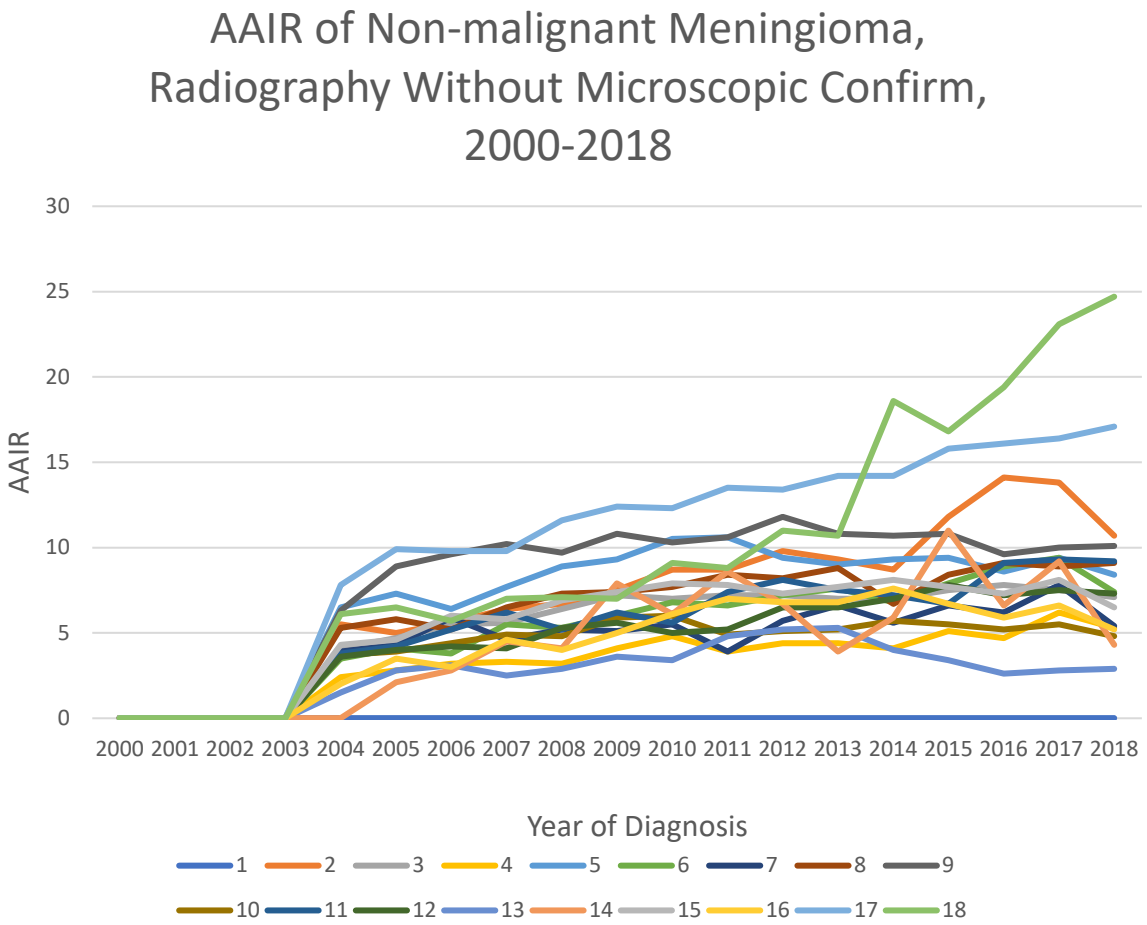
- Brain – little registry variation in radiographic incidence
- Cranial Nerves Other Nervous System – very small numbers
- Eve and Orbit – very small numbers, larger registry variation
- Kidney and Renal Pelvis – radiographic is small proportion of all
- Lung and Bronchus – radiographic is small proportion of all, large registry variation
- Pancreas – little registry variation

Breast Cancer AAIR by Diagnostic Confirmation, Age 20+, 2014-2018

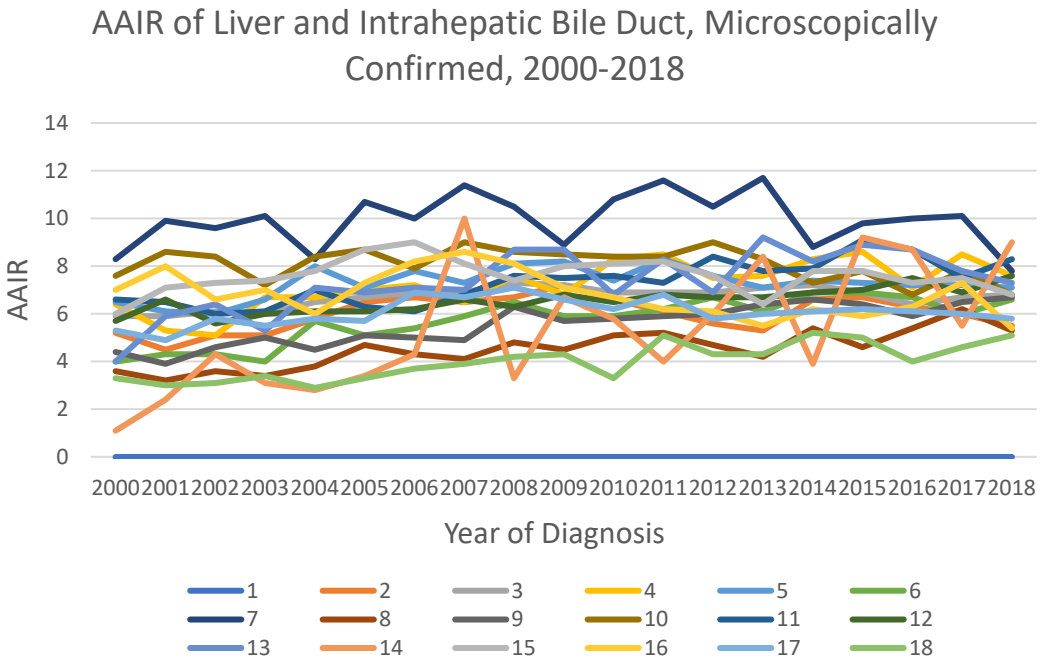


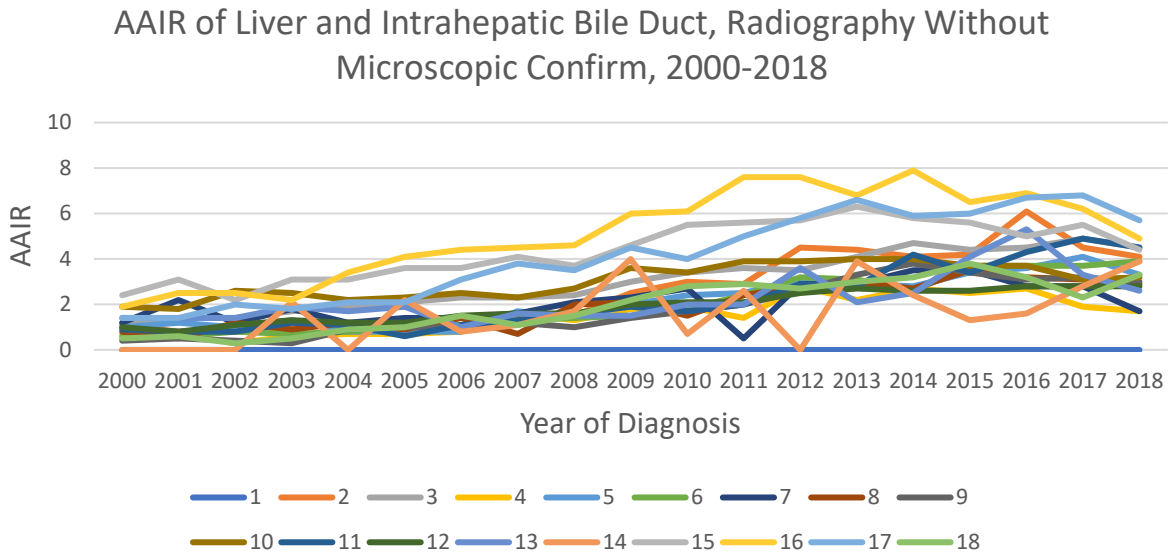
Non-malignant Meningioma Diagnostic Confirmation Trends by Registry 2000-2018, SEER 18



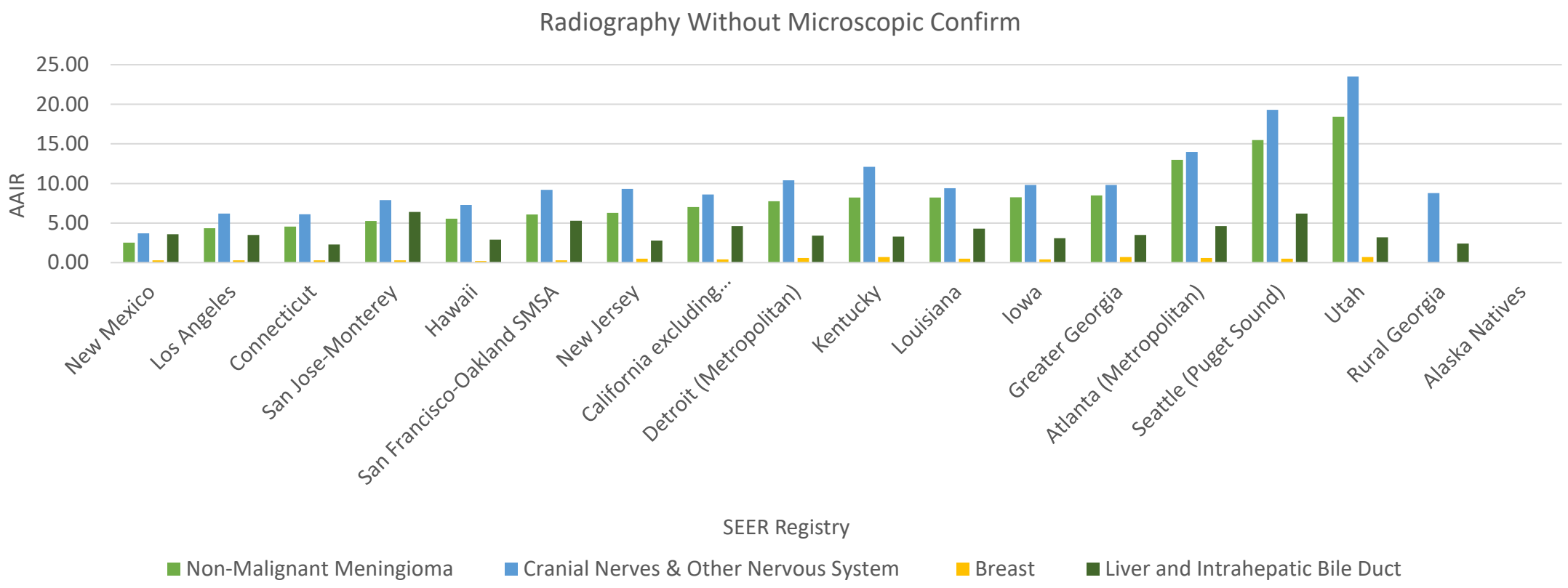


Liver and Intrahepatic Bile Duct Diagnostic Confirmation Trends by Registry 2000-2018, SEER 18

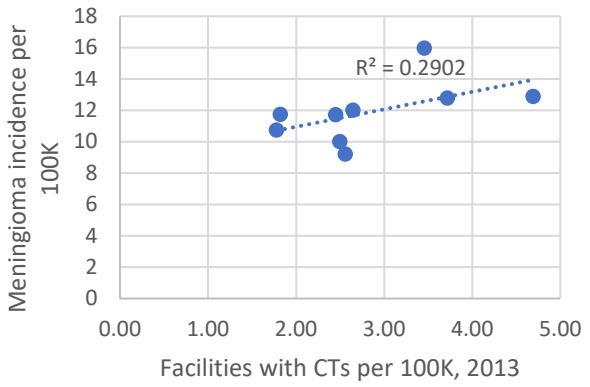


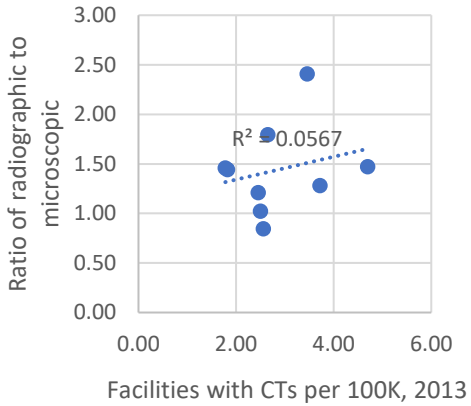


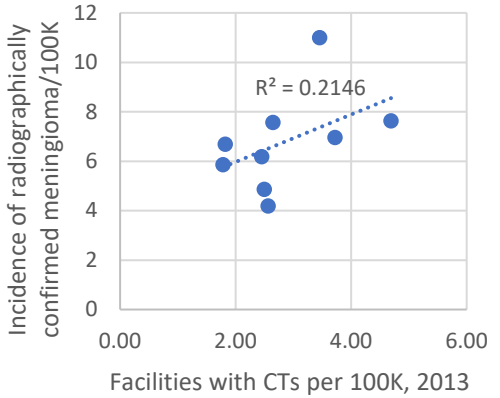
AAIR Radiographically Diagnosed Cancers, 2014-2018, SEER 18 by Registry and Site

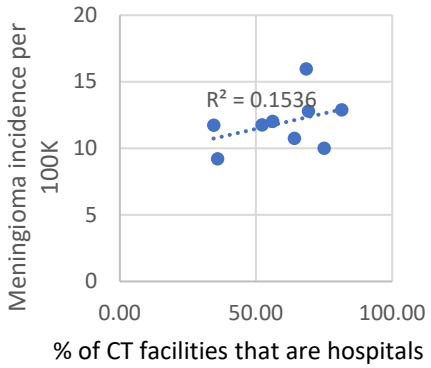


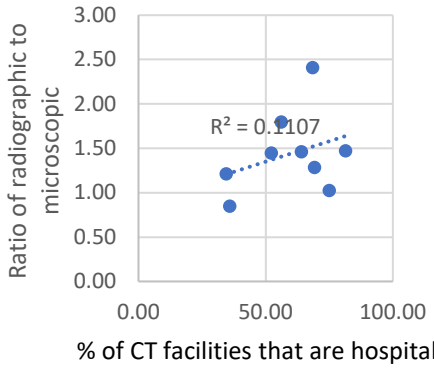
Non-malignant meningioma and CT, SEER 17 (exc. Utah), 2012-2014

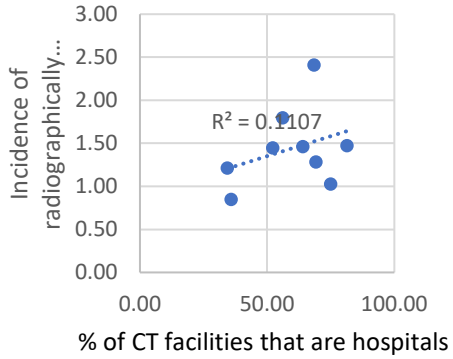












Conclusions & Next Steps

- Non-malignant meningioma rates vary widely between SEER registries
- The largest variation is observed among radiographically-confirmed rates
- Further assessment should be conducted to document reasons for the variation including availability of imaging centers and completeness of reporting
- Seek additional data on prevalence of imaging centers
- Similar variations may exist to a lesser extent for other cancers
- SEER may wish to assess validity of current non-malignant meningioma incidence rates
- Non SEER registries may wish to review variation in radiographically-confirmed rates

Acknowledgments

Support from:

- SEER
- California Cancer Registry
- Los Angeles Cancer Surveillance Program
  - JuanJaun Zhang, Tina Xu, Andrea Sipin-Baliwas, Amie Hwang, Lihua Liu
- NCI Division of Cancer Epidemiology and Genetics
  - Diana Withrow, Susan Devesa, Valentina Petkov, Alison van Dyke, Peggy Adamo, Armstrong TS, Mark Gilbert, Martha Linet

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Bias introduced by relying on incomplete electronic pathology reporting for rapid case ascertainment in patient contact studies

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New York State Cancer Registry
Co-authors: Jovanka N. Harrison, PhD; Maria J. Schymura, PhD

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Background

- Researchers often are interested in contacting and enrolling patients in studies as soon as possible after diagnosis
- Electronic pathology reports (ePath) can be used to identify cases soon after diagnosis, but incomplete ePath reporting can introduce issues:
  - Relying on ePath can introduce bias if the patient populations differ for facilities with and without ePath
  - The percent of cases reported by ePath may differ by cancer site

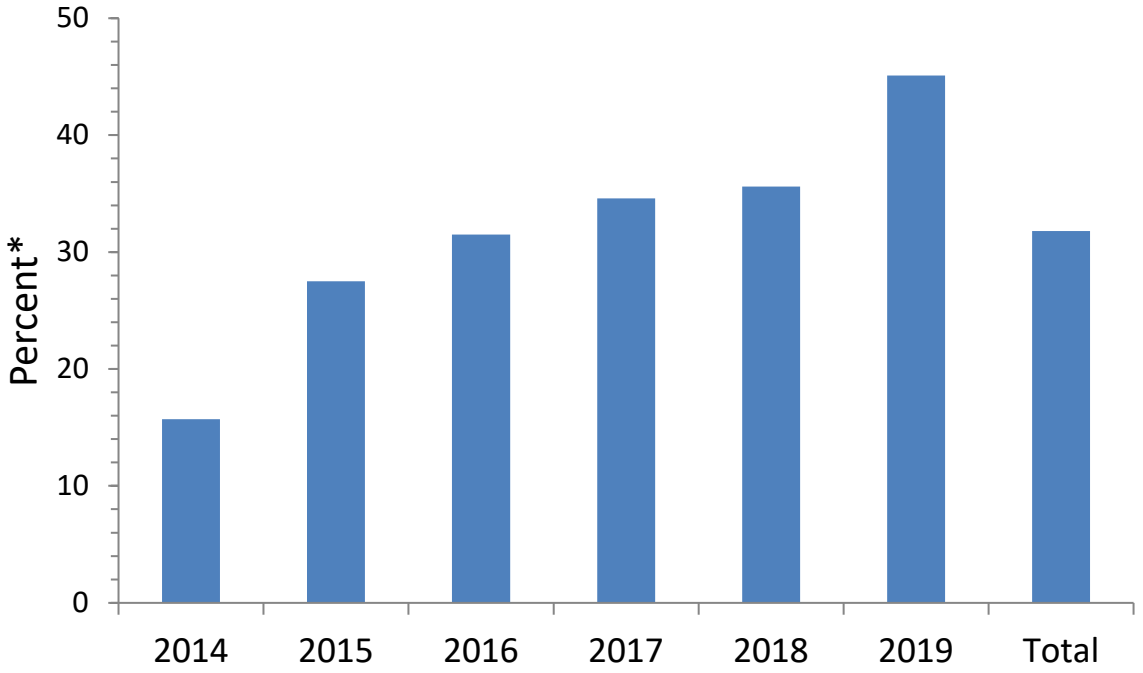
Purpose

- Examine changes over time in the percent of cases reported to the New York State Cancer Registry (NYSCR) by ePath within three months after diagnosis
- Examine characteristics of recent cases reported by ePath vs. those not reported by ePath
- Assess differences by cancer site in:
  - ePath reporting
  - Patient characteristics by ePath status

Methods

- Retrieved data on first malignant cancers diagnosed in NYS residents ages 18 and older in 2014-2019
- Categorized ePath status based on receipt of an HL7 report within three months after diagnosis
- Assessed differences in case characteristics by ePath status using chi-square and t-tests
- Categorized primary site based on SEER site group and repeated analyses for common cancer sites
- Analyses conducted in SAS 9.4

Results: ePath Reporting by Diagnosis Year



*Percent reported by ePath within three months after diagnosis

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Results: Case Characteristics by ePath Reporting Status Within Three Months After Diagnosis, 2017-2019

Characteristic	ePath	No ePath	*P*-value*
Female, %	54.5	48.0	<0.0001
Race/ethnicity, %			<0.0001
Non-Hispanic White	69.1	64.8	
Non-Hispanic Black	11.9	14.4	
Non-Hispanic API	5.9	6.7	
Hispanic	10.4	12.7	
Other/missing	2.7	1.6	
Resident of NYC/Long Island, %	49.5	53.8	<0.0001

**P*-value from chi-square test

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Results: Case Characteristics by ePath Reporting Status Within Three Months After Diagnosis, 2017-2019 (Cont'd)

Characteristic	ePath	No ePath	*P*-value*
Marital Status, %			<0.0001
Single	19.4	22.4	
Married	53.7	50.8	
Divorced/separated	9.6	9.8	
Widowed	9.2	11.5	
Other/unknown	8.1	5.5	
Age, mean (standard deviation)	62.5 (13.8)	64.6 (14.3)	<0.0001
Not known to have died, %	84.3	76.2	<0.0001

*_P_-value from chi-square test for categorical variables and t-test for age

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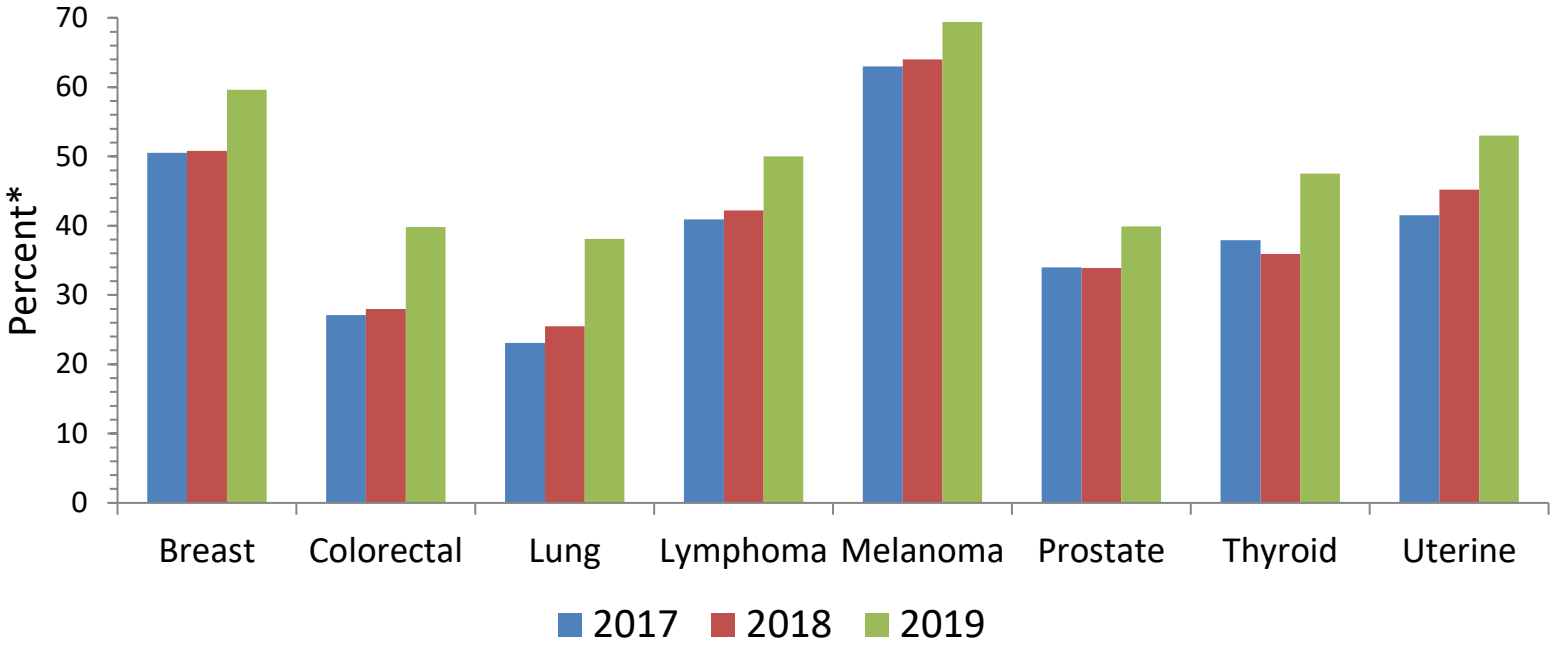
Results: ePath Reporting by Cancer Site and Diagnosis Year, 2017-2019



*Percent reported by ePath within three months after diagnosis

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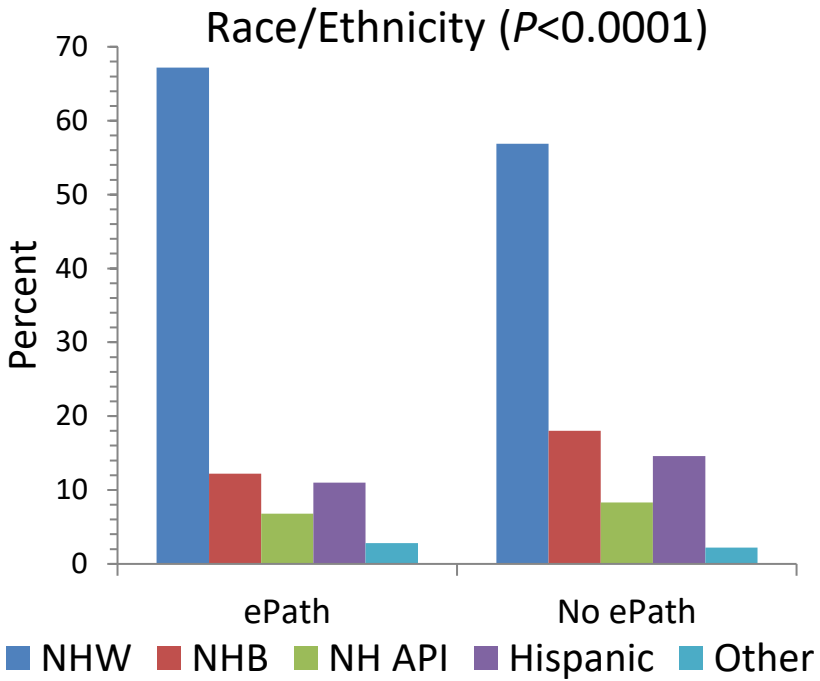
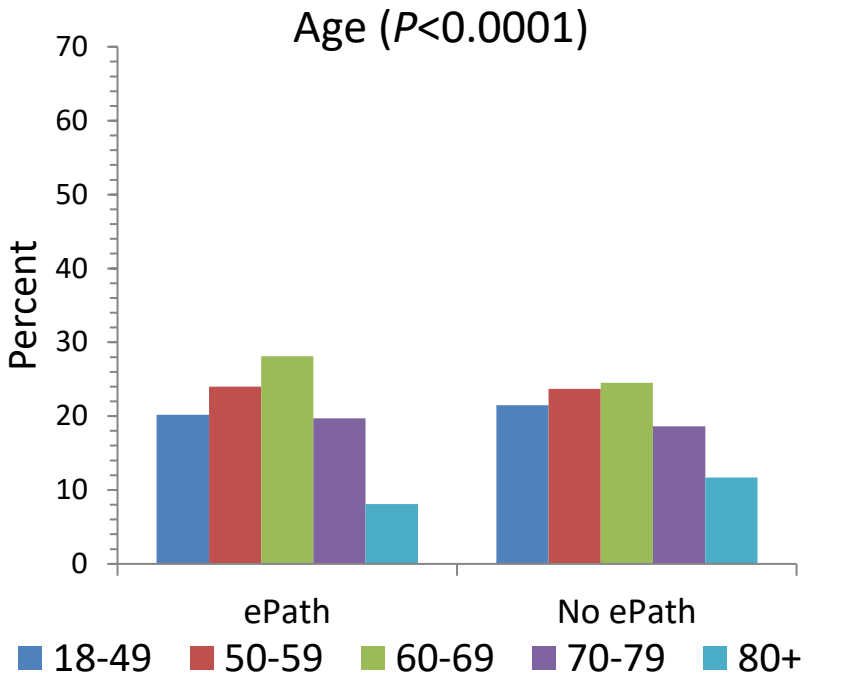
Results: Case Characteristics by ePath Reporting Status Within Three Months After Diagnosis, Breast Cancer, 2019





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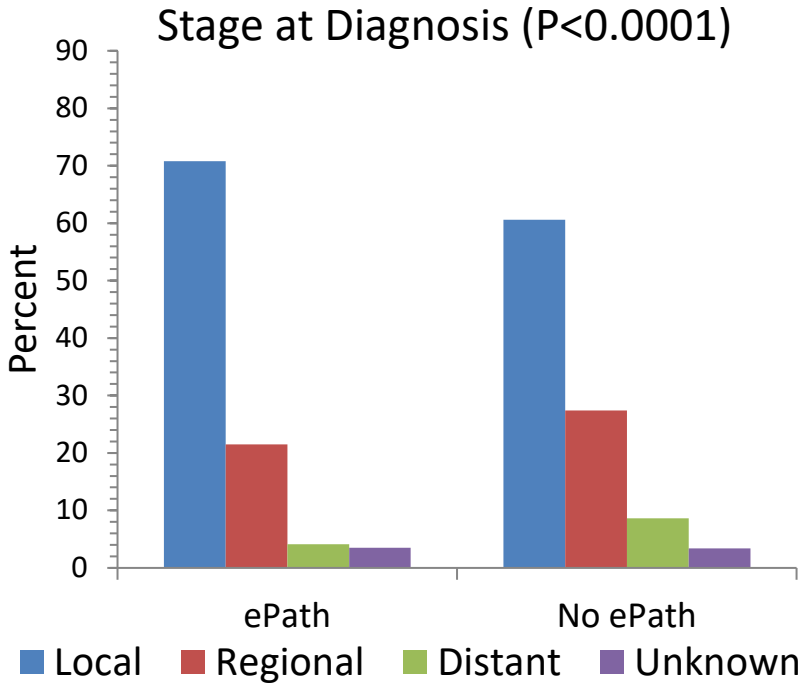
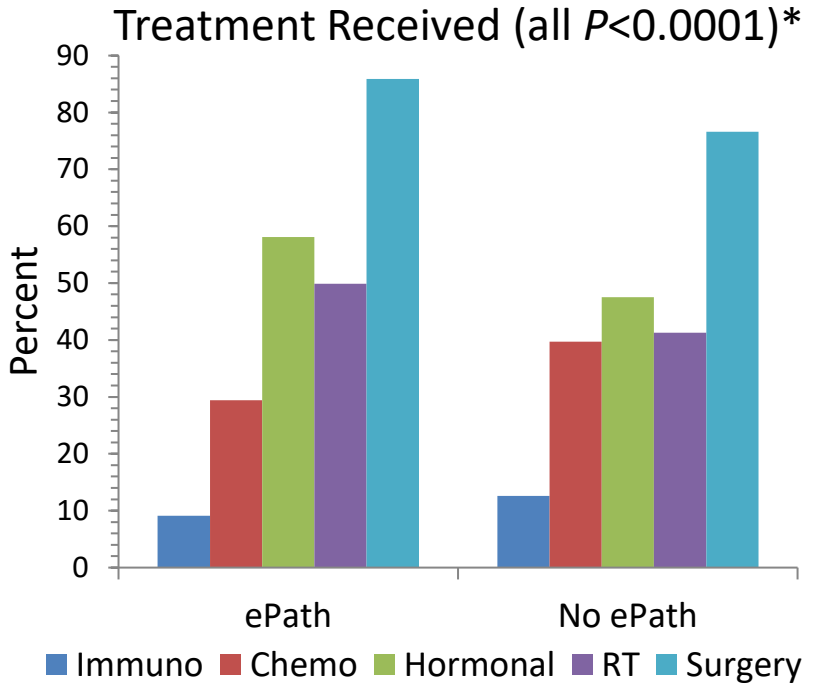
Results: Case Characteristics by ePath Reporting Status Within Three Months After Diagnosis, Breast Cancer, 2019





*Received during initial therapy; categories are not mutually exclusive

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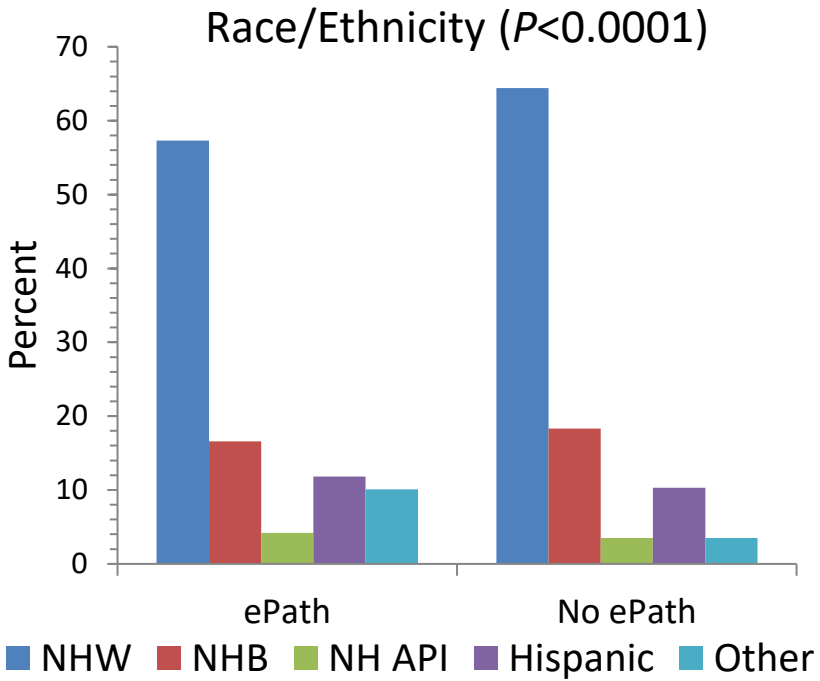
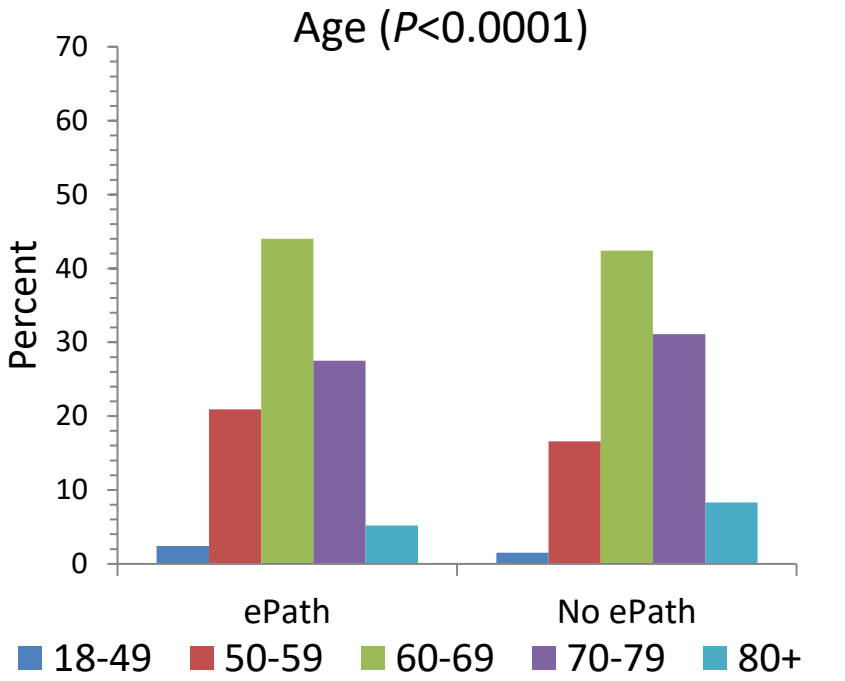
Results: Case Characteristics by ePath Reporting Status Within Three Months After Diagnosis, Prostate Cancer, 2019





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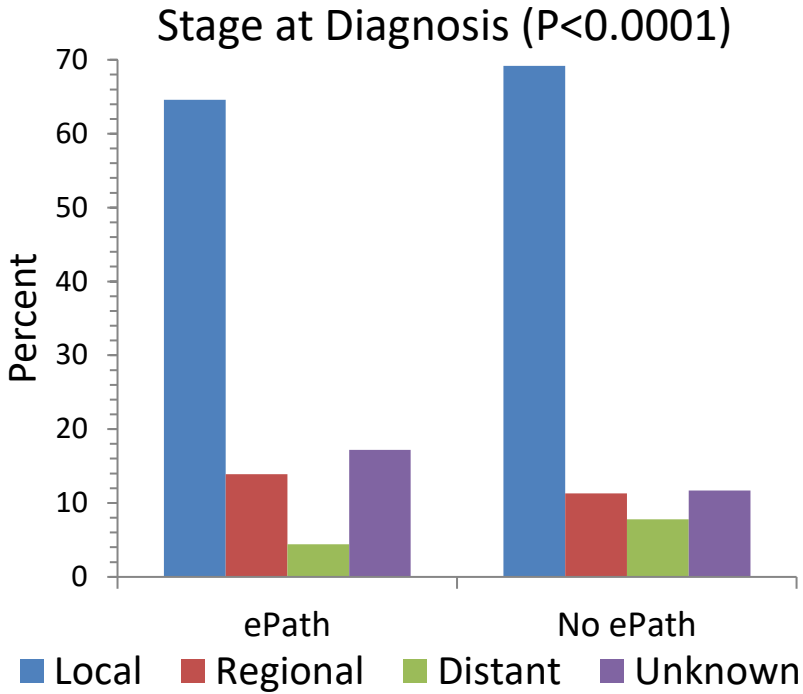
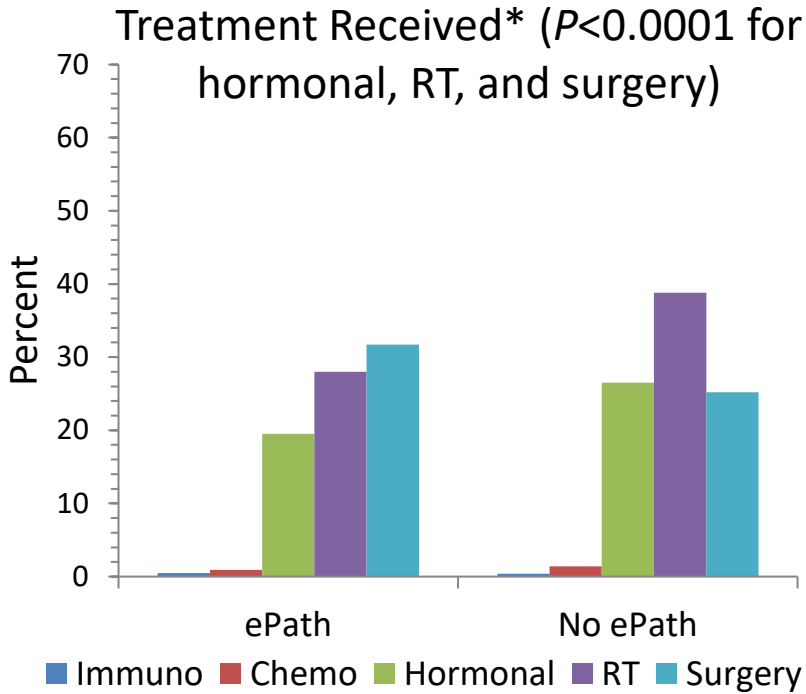
Results: Case Characteristics by ePath Reporting Status Within Three Months After Diagnosis, Prostate Cancer, 2019





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Summary

- ePath reporting has increased over time in New York State, with approximately 45% of cases reported by ePath in 2019
- Demographic and clinical characteristics differ by ePath reporting status, both overall and by cancer site
- Completeness of ePath reporting varies by cancer site
  - A higher proportion of melanomas and breast cancers were reported by ePath
  - Lung and prostate cancers were less likely to be reported by ePath

Summary

- Relying on incomplete ePath reporting for rapid case ascertainment will introduce selection bias in the study sample for research studies
  - Bias will be lower as additional facilities acquire ePath reporting capability
  - Differences by cancer site
  - Decreased accessibility of software used for ePath reporting will make rapid case ascertainment for research studies more challenging

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Electronic pathology laboratory reports: How can central cancer registries get the biggest bang for the buck?

April A. Austin
New York State Cancer Registry

Co-authors: Jovanka N. Harrison; Colleen G. Sherman; Maria J. Schymura

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NYSCR Operations Related to Laboratory Reports

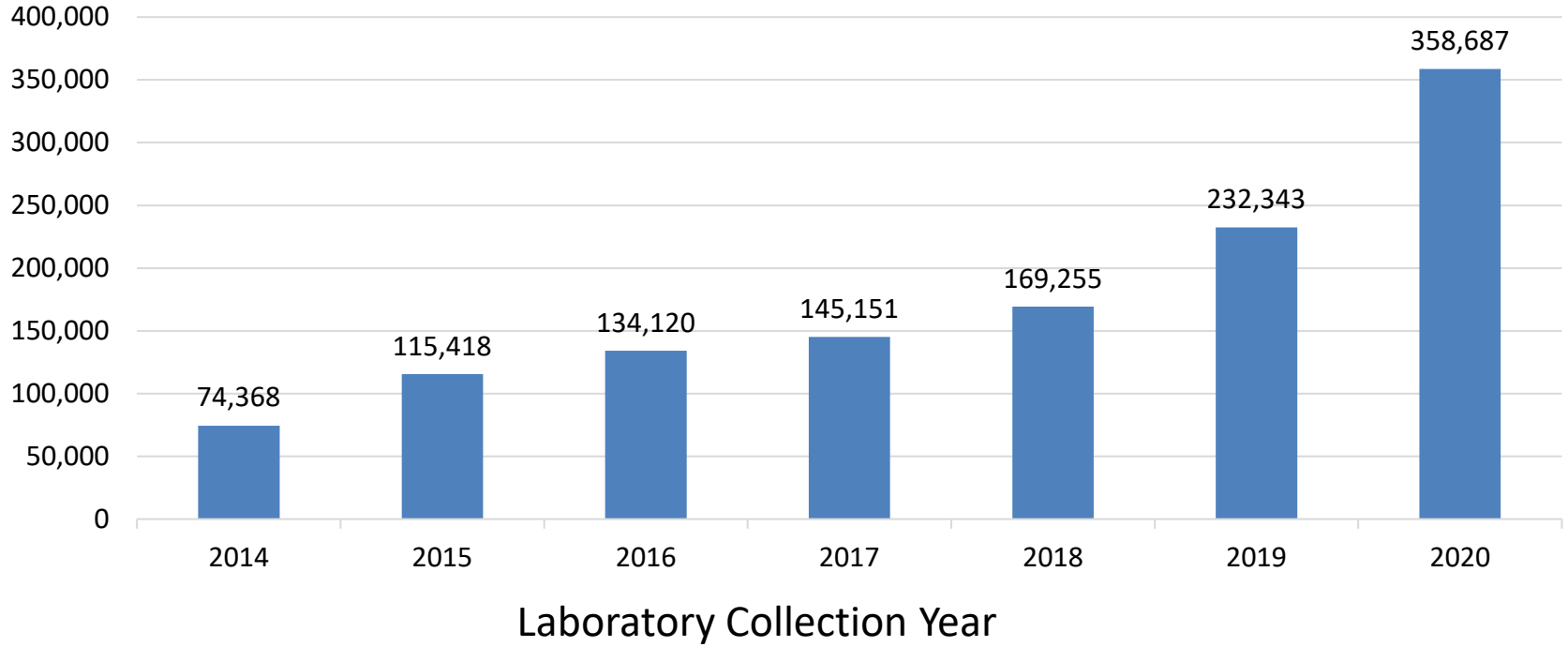
Pathology Laboratory Reporting

- The NYSCR has implemented and maintained a successful laboratory reporting program since the early 2000s.
- At the end of 2020, 158 laboratories were onboarded for transmitting data using:
  - HL7 (n = 75)
  - ASCII (n = 3)
  - Web entry (n = 80).
- Independent or affiliated with hospitals/physician offices; located in NY or outside NY.

Hospital Pathology Laboratory Reporting

- More recent successes include implementing reporting from hospital pathology laboratories using the Inspirata (formerly AIM) software for filtering and transmission of pathology records.
- Through 2020: 49 hospital laboratories as part of 14 hospital organizations.
- 2021: 2 large organizations, one with12 hospitals.

Number of Lab Records* by Collection Year



*All lab records regardless of screening status/results, auto or manual, as of 3/2021

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Physician Reporting to the NYSCR

- Unsolicited (*de novo*) case reporting
  - Average of 6,000 cases for each diagnosis year.
  - Primarily dermatology, urology, small hematology/oncology practices independent of hospitals.

- Solicited cases through laboratory followback requests
  - Lab records that appear reportable or potentially reportable (auditable) for which we do not have an abstract (AFLs = Abstract facility leads).
  - About 6,500 requests annually.
  - Yields about 2,500 case reports and 60% resolution.

Laboratory Followback Requests to Hospitals - a Pilot Project

Methods

- Reviewed lab reports and the frequencies of ordering facility name/address and managing provider address that correspond to facilities.
- Queried our database and created case lists for facility CTRs (December 1, 2020).
- Facilities reported cases or provided feedback as to why the case was not reportable.

Methods

- 44 Facilities were provided information about 3,212 AFLs related to 2019 laboratory records.
- Range per facility: 7 to 638 (median = 30).

# AFLs	# Facilities
< 25	19
25 -100	15
101-199	7
200-638	3

- 1,081 (~30%) were coded to heme histology (9590+).

Results

Assessment	N	%
Total	3,212	
Abstracted by facility	1,615	50.3
Abstract received from another source	121	3.8
Already reported, not matched	98	3.1
Already reported, now metastatic	63	2.0
Not reportable - primary site is skin BCC/SCC	52	1.6
Not reportable - heme diagnostic assessment	370	11.5
Not reportable - screened as auditable	219	6.8
Not reportable - screened as reportable	226	7.0
Not reportable - slide consult only, not diagnosed in NY	20	0.6
No patient found	109	3.4
Lab examination only (i.e., class of case 43)	319	9.9

The Upside

- Among these 3,000+, the Registry is following back to individual physicians for only 428 (13.3%) case reports. Reduces burden on both the Registry and physicians.
- Abstracts from facility CTRs contain higher quality information and always preferred.
- The facility has information about the final diagnosis that cannot always be ascertained from pathology reports.
- Might be of assistance for facilities lagging in reporting.

The Downside

- Reviewing case lists and providing feedback about non-reportable cases may be a burden to facility reporters.
- Timing needs to be considered with other registry operational processes to reduce burden on our partners in facilities.

Challenges and Collaboration

Challenges

- Increasing number of hospital reports
  - Many (30% of our pilot project) are not reported because they don't represent new or reportable conditions (e.g., metastasis, skin BCC/SCC, ruled out diagnosis) but we lack that information.
- Manual pathology screening is labor intensive
  - Twice the volume of raw records in 2020 compared to 2018.
  - Business rules that help remove records from the workflow are extremely helpful (e.g., deduplication, non-NY).
  - Natural Language Processing (NLP) – will help immensely.

Challenges

Lab reports are extremely heterogeneous

- Varying transmission formats and various laboratory information systems (LIS) contain different data fields/completeness/interpretation.
- Differing specimen types (i.e., solid tumor biopsies, bone marrow biopsies, blood, fine needle aspirates, urine) require decision rules for assessing reportability from the central registry perspective.
- Diagnostic workups for hematopoietic conditions yield multiple reports and often clinical confirmation is lacking.
- Genetic testing, immunohistochemical stains, tumor markers: increasing in number; include a variety of techniques/methods and interpretation requires expertise.

Conclusion

- NYSCR has made great strides in collecting laboratory reports and in conducting followback to improve our data completeness.
- The increasing number of pathology reports adds unquestionable value to our data.
- The increasing number of pathology reports adds undeniable burden to our resources.
- How can we find solutions for efficiently managing and effectively using pathology laboratory data?

Collaboration

Through collaboration we can consider the potential for uniform decisions/business rules for handling the records, technical solutions for processing needs, and an appropriate level of effort to this work.

We welcome opportunities to share our experiences and to learn from other central registries. I invite conversations and can be contacted at: April.Austin@health.ny.gov

Acknowledgements

All operational teams at the NYSCR work extremely hard on management of laboratory reports and we continue to identify areas to improve processes and data quality.

Special thanks to Rebecca Grant of our Field Services Unit for performing the review and assessment of facility response and feedback.

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