

What can we learn about case ascertainment from registries with high or low incidence ?

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BENIGN, BORDERLINE, & MALIGNANT BRAIN/CNS AND *IN SITU* BREAST CANCER REPORTING

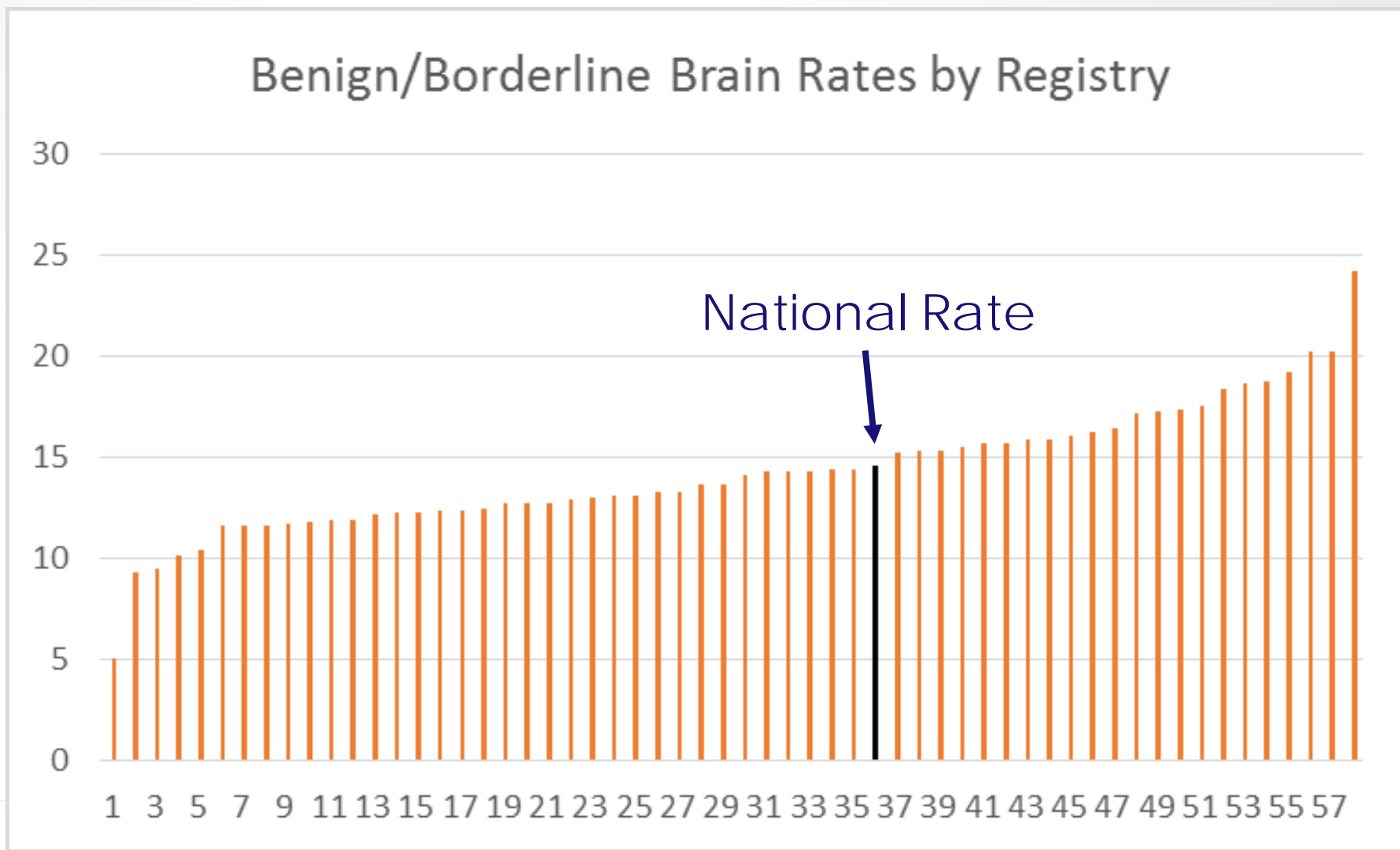
PRESENTATION OVERVIEW

- Context
- Pilot Project
 - Benign/Borderline Brain & *in situ* breast reporting
 - Registry Survey
 - Exploratory Analysis
- Conclusions
- Next steps

CONTEXT

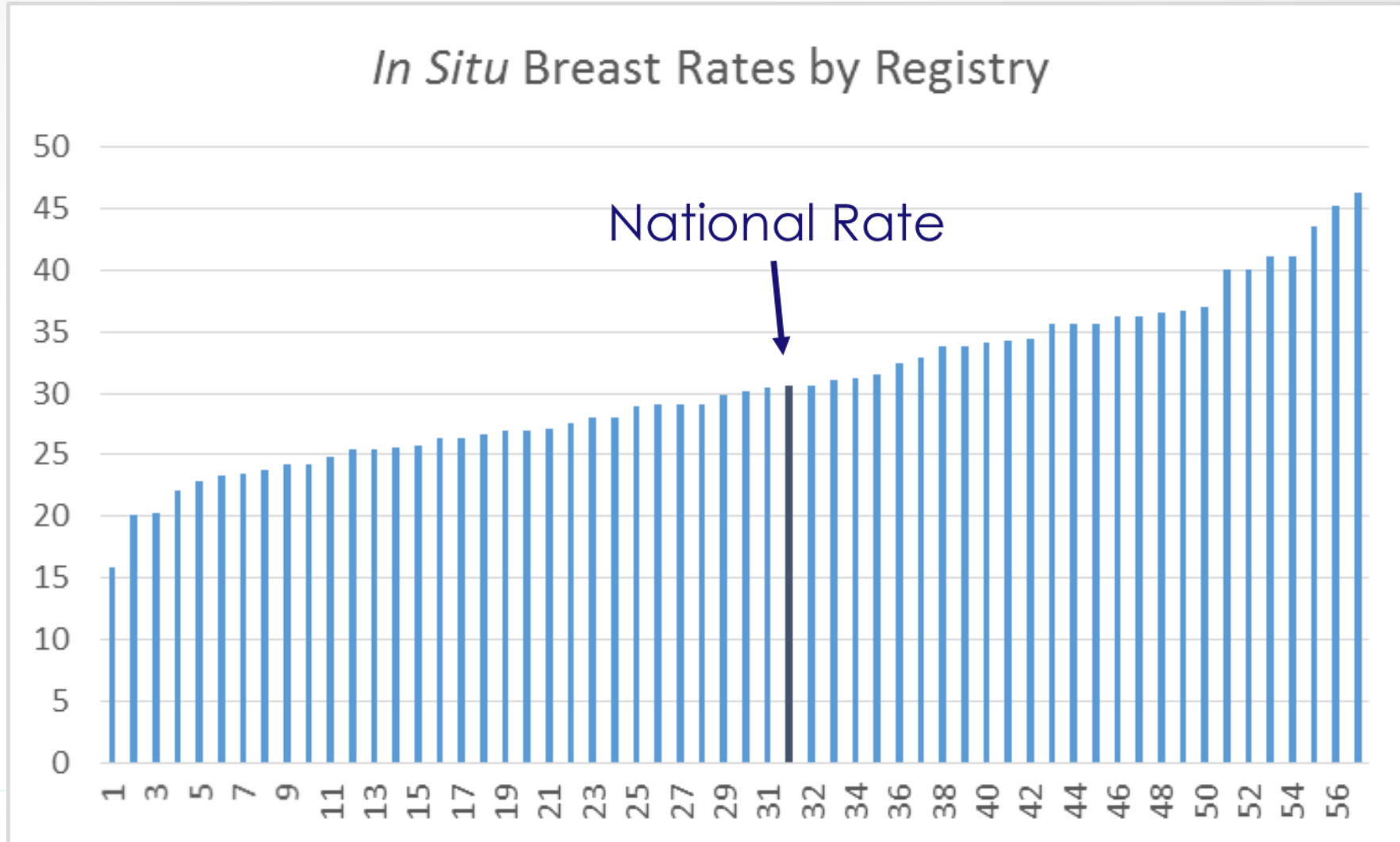
- Benign/Borderline brain tumors and *in situ* breast cancers historically have high degree of inter-registry variability in rates
- Does the variability have public health importance or is it spurious?
- Prior investigation indicates benign/borderline brain tumors variability driven by case completeness differences
- *In situ* breast cancers less clear
 - Potentially combination of screening & reporting

VARIABILITY OF BENIGN/BORDERLINE BRAIN TUMORS, 2007-2012; RANGE 5.1, 24.2





VARIABILITY OF *IN SITU* BREAST CANCERS, 2007-2012; RANGE 15.8, 46.3



CONTEXT

- Case finding and abstraction is increasingly complex
- Case completeness is tied to resources
 - Predominately funding
- Are there other intervention points?
 - Training, experience, methods

BACKGROUND (BRAIN)

- Benign & borderline brain tumors diagnosed in 2004 and after are reportable for cancer registries in the U.S.
- Data collection for these tumors is mandated by Public Law 107-260 - Benign Brain Tumor Cancer Registries Amendment Act
- Previous work documents underreporting

PREVIOUS WORK (BRAIN/CNS)

- 2009 NAACCR Annual Meeting
 - Marie-Jo Horner, Lynn Ries, Mary Potts: Benign Brain Reporting: Completeness and Quality Indicators
- 2011 NAACCR Annual Meeting
 - Dr. Bin Huang Presentation: Benign/Borderline Brain and ONS Tumors in the NAACCR Data
- 2013 NAACCR Annual Meeting / 2014 SEER Manager's In-Person Meeting
 - Dr. Li, Dr. Wu presentation: Are Benign and Borderline Brain Tumors Underreported?
- 2014 NAACCR Annual Meeting
 - Drs. Li and Wu poster: Improving Completeness of Benign Brain Tumor Reporting by a Linkage with Hospital Inpatient Discharge Data
- CBTRUS Report, 2007-2011 Journal of Registry Management, 40(1): 32-35, 2013
 - Incidence for non-malignants ranged from 8.67-19.51 across central cancer registries
 - McCarthy BJ, Kruchko C, Dolecek TA, The Impact of the Benign Tumor Cancer Registries Amendment Act (Public Law 107-260) on Non-malignant Brain and Central Nervous System Tumor Incidence Trends

CURRENT PILOT PROJECT OBJECTIVES

- Assess *in situ* breast cancers and benign/borderline brain tumors variability by registry
- Survey high and low incidence registries
 - Mutable differences in case ascertainment
 - training, operations
- Assess correlations with rates
 - Registry capacity, reporting facilities capacity, demographics, geography

SURVEY

- Incidence ranked by US registry
 - Ranked sum
 - Incidence of benign/borderline brain tumors & % benign/borderline brain of total brain tumors
 - Incidence of in situ breast cancers, % in situ of total known stage breast cancers, & % of unknown stage
- Benign/Borderline/Uncertain defined by CBTRUS
 - Site/histology specific
 - Updated 2012, expands SEER recode

SURVEY

- General and site specific questions
 - 15 general
 - 18 brain/cns specific
 - 14 breast specific
 - Qualitative & quantitative
- CBTRUS input
- Data Assessment Workgroup

SURVEY

- 24 registries total
 - 6 registries high; 6 low for each site
 - 4 overlapped; 20 unique registries
 - 2 overlapped with high BB/high *in situ*
 - 2 overlapped with high/low combos
- Survey Distribution
 - Call f/u with survey in email
 - Rationale
 - Voluntary
 - Total and question specific

SURVEY RESULTS

- 20 unique registries returned survey (100%)
- A few declined specific questions
 - Funding, % cases by facility type
- Follow-back is needed
 - Survey instrument needs some adjustment
 - “common” language
- Patterns identified
 - Both mutable and non-mutable
 - Clearer for brain

SURVEY RESULTS

- Does your central cancer registry (CCR) have a state law or practice which excludes the reporting of non-pathologically confirmed cancers? **No**
- Do you have a specific registrar assigned specific sites? **No**
- Do you have site specific protocols? **No (?)**
- Specific case ascertainment efforts? **Yes!**

SURVEY RESULTS

- Lower incidence for both sites
 - < % state funding
 - 100% Federal
 - < % electronic sources
 - Paper abstracting
 - Physician office, pathology labs, stand-alone radiation facilities
 - >% reporting from local hospitals
 - versus cancer centers

SURVEY RESULTS: BREAST

- No operations specific to *in situ* breast cancer rate
- Variability by facility
 - Most did not track facility variability
 - 1 registry stated variability not by facility but by facility location
 - County-level BRFSS screening rates
- No specific training or operation issues mentioned

SURVEY RESULTS: BRAIN

- Higher rates
 - History of collection prior to 2004
 - History of brain specific ascertainment training
 - 1 low registry had recent training
 - History of issue
 - Active case finding
 - Radiation facilities
 - Site-specific
 - AIM software synoptic software
 - Hospital discharge
 - Documented fewer case deletions during editing over time
 - Knowledge of issues; prior self assessment
 - Open ended questions—lists of potential barriers

SURVEY RESULTS: BRAIN (QUALITATIVE)

- Open ended questions: extensive lists of barriers
- High
 - Follow-back because brains are missed at facilities; delay-reporting (high)
 - Radiology only cases
 - Local hospitals; out of state centers
- Low
- “We don’t get credit for those cases”
 - “We have a back-log. We try to abstract all cases but if I have a malignant brain I will abstract that first.”
 - (low)

CORRELATIONS OVERVIEW

- Prior work indicates specific patient & tumor characteristics associated with underreporting for brain
 - Non-microscopically confirmed cases
 - Non-surgery cases underreported
 - Younger age
 - Specific subsites
- Want to assess facility & registry characteristics associated with rates of both sites
 - Promote survey results
 - Targeted training, discussions

CORRELATIONS: VARIABLES

- Facility capacity
 - # CoC approved programs
 - # NCI approved centers
 - # Pediatric Oncology Groups (brain only)
- Registry capacity
 - Funding: SEER versus non
 - Effort: pop size, pop density, geographic size
 - Certification
- Population risk
 - % poverty, % black, % minority, % rural
 - % mammography (breast)

CORRELATIONS RESULTS (BRAIN)

- No correlation
 - # CoC hospitals; # NCI centers; # Pedi Oncology Groups
 - Population size, Geographic area, Poverty, Rural
- Weak correlation
 - % non-Hispanic black +
- Moderate correlation
 - SEER registries +, Population Density +
- Strong correlation
 - NAACCR Certification +

CORRELATIONS RESULTS (BREAST)

- No correlation
 - Mammography rate (state)
 - **Invasive is correlated!**
 - # CoC hospitals, # NCI centers, SEER
 - Population size, % minority
- Weak correlation
 - % non-Hispanic black +
 - Geographic area -
- Moderate correlation
 - NAACCR Certification +, Pop density +
 - Poverty -, Rural - (screening access)
- Strong correlation
 - none

FUTURE DIRECTIONS

- Facility capacity important in survey
 - More specific measurement
 - % cases reported by CoC facilities versus # of facilities
- Revamp/shorten survey
 - Full membership
- Coordinate with CDC
 - Cost per case by registry
 - Performance Evaluation Instrument
 - Template for Hospital, Path, Physician Reporting

CONCLUSIONS

- Active case finding
 - Linkage, use electronic sources
 - Site Specific, code specific, patient discharge
 - Non-Hospital sources
 - Radiology
- *In situ* breast
 - Likely a combination of screening, demographics and case ascertainment
 - Less attention to completeness issues than for brain
 - Not correlated with mammography
 - Therefore, likely partially an ascertainment issue
- Brain
 - Active radiology case finding/hospital discharge
 - Site specific
 - AIM software

PUBLIC HEALTH RELEVANCE

- Collection ever more complex for all registries irrespective of funding level
- Important to determine specific methods that result in high levels of case ascertainment
- To effectively inform public health practice and research, we need to define and promulgate effective methods that can be adopted by all registries

THANK YOU

We would like to thank the participating registries

Questions?

