

(Central Registry) Recipe for Success: We couldn't do it without YOU!



**MOKA Regional Cancer Registrars Meeting
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Acknowledgments

- Thanks to:
 - My co-author, Chester Schmaltz
 - Other MCR-ARC staff members
 - Nancy Cole, CTR, Operations Manager
 - Nancy Role, CTR, new Ops Manager
 - CTRs and other registrars/staff of reporting facilities across the state
 - Staff from the other CCRs with which we have data exchange agreements (and their reporting facilities)

Objectives

- Describe/explain:
 - Importance of facilities' tumor registrars to central cancer registry (CCR) activities
 - Relevance of interstate data exchange
 - Next-of-kin requests (primarily Energy Employees Compensation Act)
 - 2014 report on breast cancer survival in Missouri

Objectives (cont'd)

- Describe/explain:
 - Use of data visualization software to increase awareness/improve understanding of cancer incidence and behavioral risk factors
 - Challenges facing CCRs

Background

- Timely, complete, & accurate cancer data are needed for
 - Public health surveillance,
 - Research, and
 - Variety of other purposes
- Without the diligent work of certified tumor registrars (CTRs) and other reporting facility staff, CCRs would be severely limited in their ability to meet these needs

Background (cont'd)

- All U.S. and Canadian CCRs are members of the National Association of Central Cancer Registries (NAACCR)
- U.S. CCRs follow standards set by:
 - CDC National Program of Cancer Registries (NPCR)
 - National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) program
 - NAACCR

Background: CCR Funding

- All 4 MOKA CCRs are funded in part by CDC-NPCR
- Oklahoma's Cherokee Nation Registry is supported in part by NCI-SEER
 - Covers self-reported American Indians in the 14-county Cherokee Nation Tribal Jurisdictional Service Area (CNTJSA) in northeast OK



CCR Certification

- CCR data quality (2014 certification for cases diagnosed in 2011)
 - Missouri: Currently **Gold**
 - Oklahoma: Currently **Silver**
 - Gold in 2012 for 2009 cases
 - Kansas: Currently **Gold**
 - Arkansas
 - Gold in 2011 for 2008 cases

Hospital v. Central Registries

- Both types of registries play an important role in cancer surveillance and research
 - Hospital
 - Detailed tumor/treatment/comorbidity information
 - Very timely
 - Active follow-up of survivorship (CoC)
 - Central
 - Fewer details, less timely
 - Population-based
 - Consolidated from multiple sources
 - Incidence rates and trends

Limitation of CCRs

- The majority of NPCR-funded CCRs only collect 1st course treatment
 - Summary treatment information
 - No comorbidities
- This limits the ability to:
 - Evaluate outcomes
 - Conduct comparative effectiveness research

Importance of Facilities' Tumor Registrars to CCR Activities

- Without facility registrars, CCR staff couldn't function!
- CCRs critically rely on reporters for:
 - Dedication
 - Desire for continuous quality improvement
 - Timely submission of reportable cases
 - Response to death clearance requests
 - Willingness to participate in cancer inquiries, special projects

Relevance of Interstate Data Exchange

- Identify unreported cases (or obtain additional information)
 - Patient diagnosed &/or treated in another state
- Missouri currently has case sharing agreements with 19 other states
 - Including OK, KS & AR + remaining 5 border states & 11 other states
- Particularly important for states
 - With major population centers on/near the border
 - Whose residents have homes in 2 states
 - Whose residents travel out-of-state for diagnosis/treatment

Interstate Data Exchange (cont'd)

- Same NAACCR data exchange layout used by all states
 - Consolidated record, not abstract-level data
 - Limited # of data elements, text
 - Receiving registry must rely on quality of data from sending registry
- So, it isn't just the state that a facility-based registrar works in that benefits from quality work, other states benefit

Interstate Data Exchange (cont'd)

- Potential case-sharing opportunity
 - A patient (local resident at time of dx) may later die while a resident of another state
 - That other state may be erroneously reporting a DCO incidence case
 - Notifying other states' CCRs of patients who die while residents of their state (but not when diagnosed) may be able to reduce these extra DCOs
 - Encouraged by NPCR in making use of NDI results
 - Not currently conducted by Missouri

Next-of-Kin Requests

- “During the period of the Cold War, thousands of workers were employed in the nation's atomic weapons programs. The work was dangerous and consequently many workers may have been exposed to radioactive and toxic substances.”
 - <http://www.id.doe.gov/eeoicpa.htm>

Next-of-Kin Requests (cont'd)

- To ensure fairness & equity to nuclear workers, congress passed the Energy Employees Occupational Illness Compensation Program (EEOICP)
 - Administered by the Department of Labor
 - Since 2001, compensation paid out to employees of the DOE, contractors and subcontractors, **& to certain survivors of such individuals**

Next-of-Kin Requests (cont'd)

- MCR-ARC responds to requests for verification of a tumor diagnosis:
 - Next-of-kin must provide documentary evidence (e.g., requestor's driver's license, marriage certificate, death certificate, will)
 - The resulting letter is used by a next-of-kin as evidence for a compensation claim
 - A CCR is uniquely situated as an effective and efficient location for these types of verification
 - Years after exposure/diagnosis, CCR records may be only ones that survive

Next-of-Kin Requests (cont'd)

- DOE claims not only source of request:
 - Survivor wants information
 - Patient may want to see own record
- Clearly, having accurate and complete information reported by tumor registrars is critically important for compensation claims or to provide information to individual or family

Breast & Cervical Cancer Survival in Missouri

- Like many NPCR-funded CCRs, MCR-ARC has considered itself an incidence-only registry (inadequate survivorship information)
 - Tracking survivorship is important for fully assessing the burden of cancer and comparing, *e.g.*, treatment outcomes, survivorship by age group, race/ethnicity, etc.
- Recently MCR-ARC has embarked on becoming a survival registry

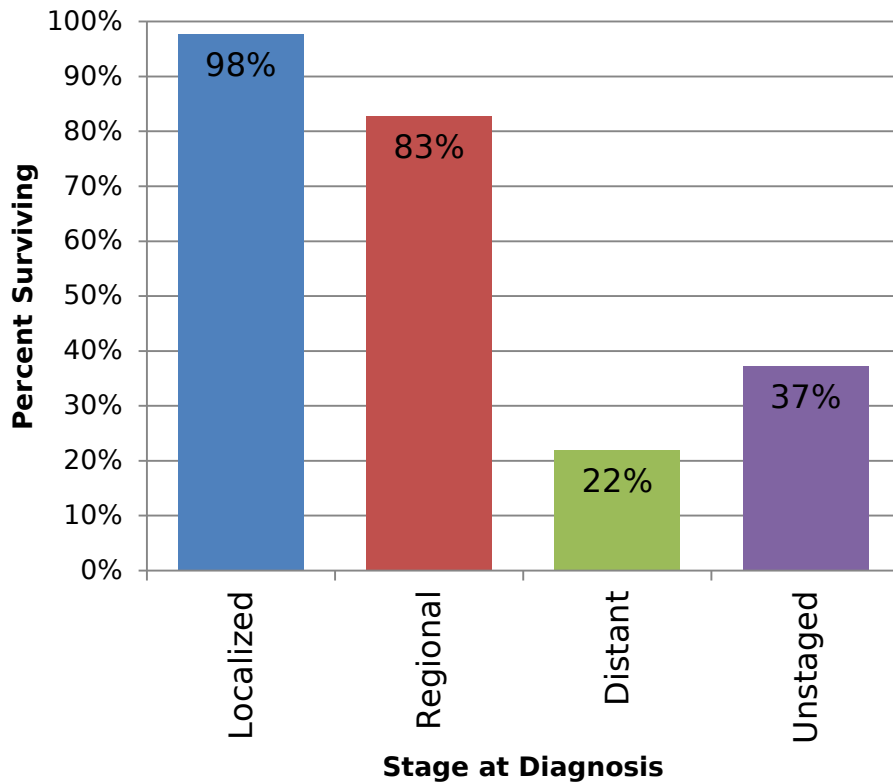
Breast & Cervical Cancer Survival in Missouri (cont'd)

- Active follow-up
 - Expensive
 - Perhaps unnecessary
- Passive follow-up
 - Database linkage
 - State Death Certificate (DC) file
 - Social Security Death Index (SSDI)
 - National Center for Health Statistics' (NCHS') **National Death Index (NDI)**
 - May be sufficient for complete ascertainment of survival information

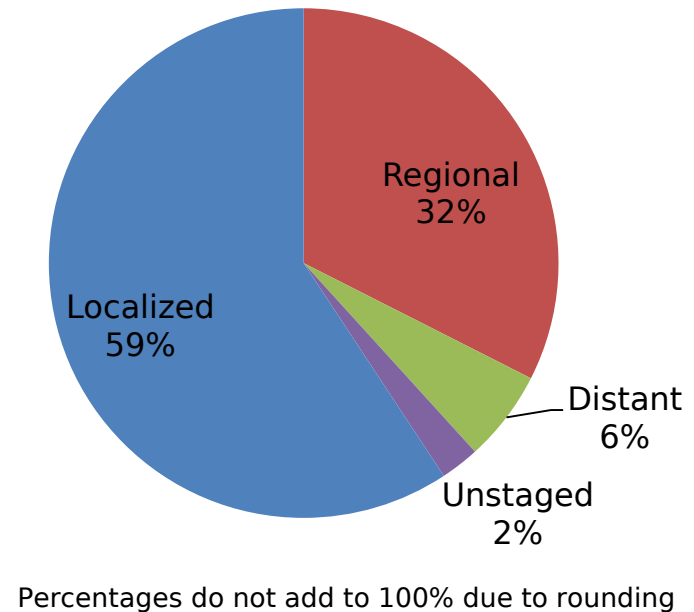
Breast & Cervical Cancer Survival in Missouri (cont'd)

Female Breast Cancer, 2004-2010

5-Year Relative Survival

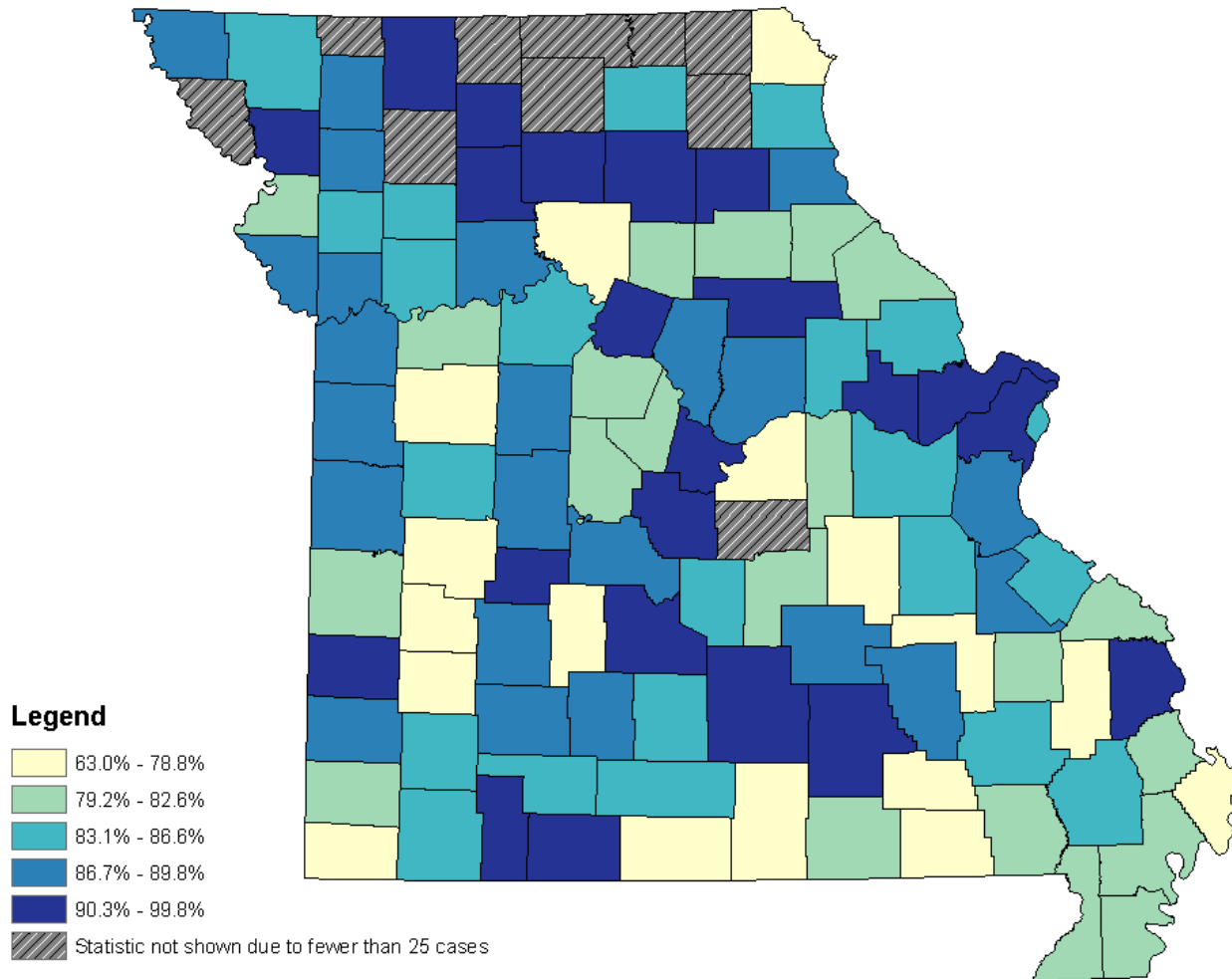


Distribution of Stage at Diagnosis



Breast & Cervical Cancer Survival in Missouri (cont'd)

Female Breast Cancer among Whites: 5-Year Relative Survival, 2004-2010



Breast & Cervical Cancer Survival in Missouri (cont'd)

- Release of follow-up information to *reporting sources*
 - State DC file: depends on state statutes & regulations
 - In Missouri: **No** re-release to reporting sources
 - Other states may differ?
 - SSDI: Public information
 - Fact & date of death, but cause is not in the SSDI
 - NDI: Fact & date of death (**not cause**)
 - But cause of death is re-releasable to *researchers* for studies after formal review and approval

Breast & Cervical Cancer Survival in Missouri (cont'd)

- The final report is under review
 - NDI linkage funded by DHSS's Comprehensive Cancer Program
 - Must be approved by DHSS before release
 - Missouri Cancer Consortium requested information on survival
 - DHSS's Show Me Healthy Women (MO's BCCCP Program) also interested

Data Visualization

- MCR-ARC makes incidence data directly available to the public through two main sources
- **1** - Missouri Information for Community Assessment (MICA) website
 - Interactive system that allows users to create tables
 - Current 2014 data (complete cases diagnosed 1996-2011) at:
 - <http://health.mo.gov/data/mica/CancerMICA/index2014.html>
 - MICA also has other data (births, hospitalizations, behavioral risks, *etc.*)
 - <http://health.mo.gov/data/mica/MICA/>
 - Some users may prefer, and benefit from, having the data plotted rather than in tables

Data Visualization (cont'd)

- **2** - Interactive mapping software
 - More intuitive means of disseminating information that can be easily understood
 - Currently focuses on major types of cancer plotted at the county level

Data Visualization (cont'd)

Age-adjusted Invasive Cancer Incidence Rate : All Sites : 2011

Experimental dashboard with InstantAtlas county cancer profile feature

Sources: MCR-ARC 2014DB (Complete 1996-2011 cases); US Combined (2010); 2013 NAACCR Call For Data, December 2012



Select Cancer Site

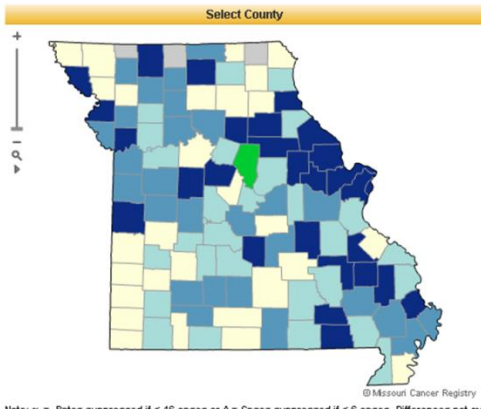
- Age-adjusted Invasive Cancer Incidence Rate
 - All Sites
 - Female Breast
 - Cervix
 - Colon and Rectum
 - Corpus and Uterus, NOS
 - Lung and Bronchus
 - Prostate
 - Urinary Bladder

County	Age-adjusted Rate	Number of Cases
Adair	418.3	104
Andrew	326.2	70
Atchison	270.2	24
Audrain	468.2	144
Barry	389.4	186
Barton	322.4	52
Bates	509.6	113
Benton	449.4	147
Bollinger	487	73
Boone	459.1	650
State / US	Rate	Cases
Missouri State	436.6	30179
US (2010)	447.8	--

Legend

- Counties
- 162.7 - 382.2
- 382.3 - 418.5
- 418.6 - 463.4
- 463.5 - 594.2
- ~

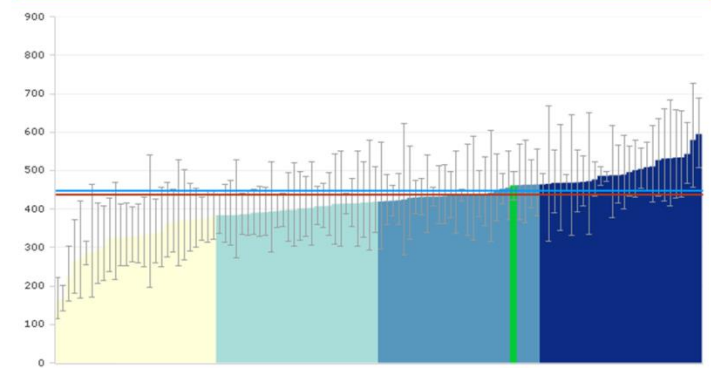
Select Quartile



Note: ~ = Rates suppressed if < 16 cases or ^ = Cases suppressed if < 6 cases. Differences not measured if < 16 cases

Missouri Cancer Registry and Research Center

County Rankings with 95% confidence intervals



Indicator	Period	Rate	Lowest	Selected County Cancer Profile (Major sites)	Highest
All Sites	2011	459.1	162.7		594.2
Female Breast	2006-2011	133.9	55.3		186.7
Cervix	1996-2011	5.8	5.8		20.8
Colon and Rectum	2006-2011	37.7	30.8		69.6
Corpus and Uterus, NOS	1996-2011	27.2	12.4		37.2
Lung and Bronchus	2009-2011	66.7	37.1		127.1
Prostate	2006-2011	156.6	61.6		188.8
Urinary Bladder	1996-2011	18.5	8.9		26.7

Boone

Statistically significant difference from the state rate: higher (red dot), lower (green dot), no difference (yellow dot)

Missouri state average | U.S. Combined (2010)

Quartile 1 | Quartiles 2-3 | Quartile 4

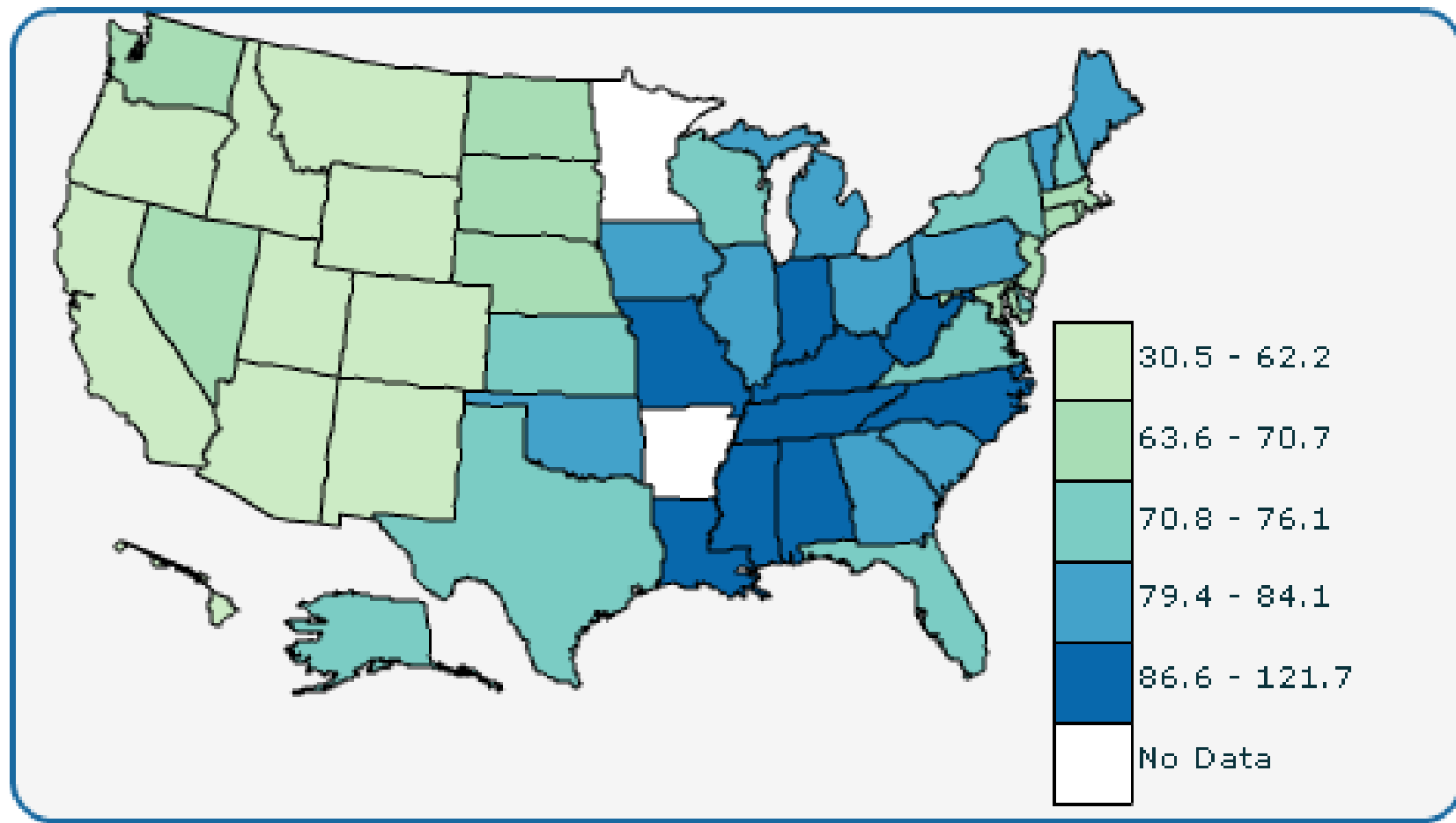
Help

This project supported in part by cooperative agreement between Centers for Disease Control and Prevention (CDC) and Missouri Department of Health and Senior Services (DHSS) (U58/DP003924-02) and Surveillance Contract between DHSS and University of Missouri.

Other displays of MO data

- MCR-ARC also reports data to national sources (CDC-NPCR & NAACCR) which releases MO incidence with other states
 - NPCR: <http://apps.nccd.cdc.gov/uscs/>
 - NAACCR: <http://www.cancer-rates.info/naaccr/>
- National incidence data is in turn reported to the International Agency for Research on Cancer (IARC)
 - <http://www-dep.iarc.fr/>

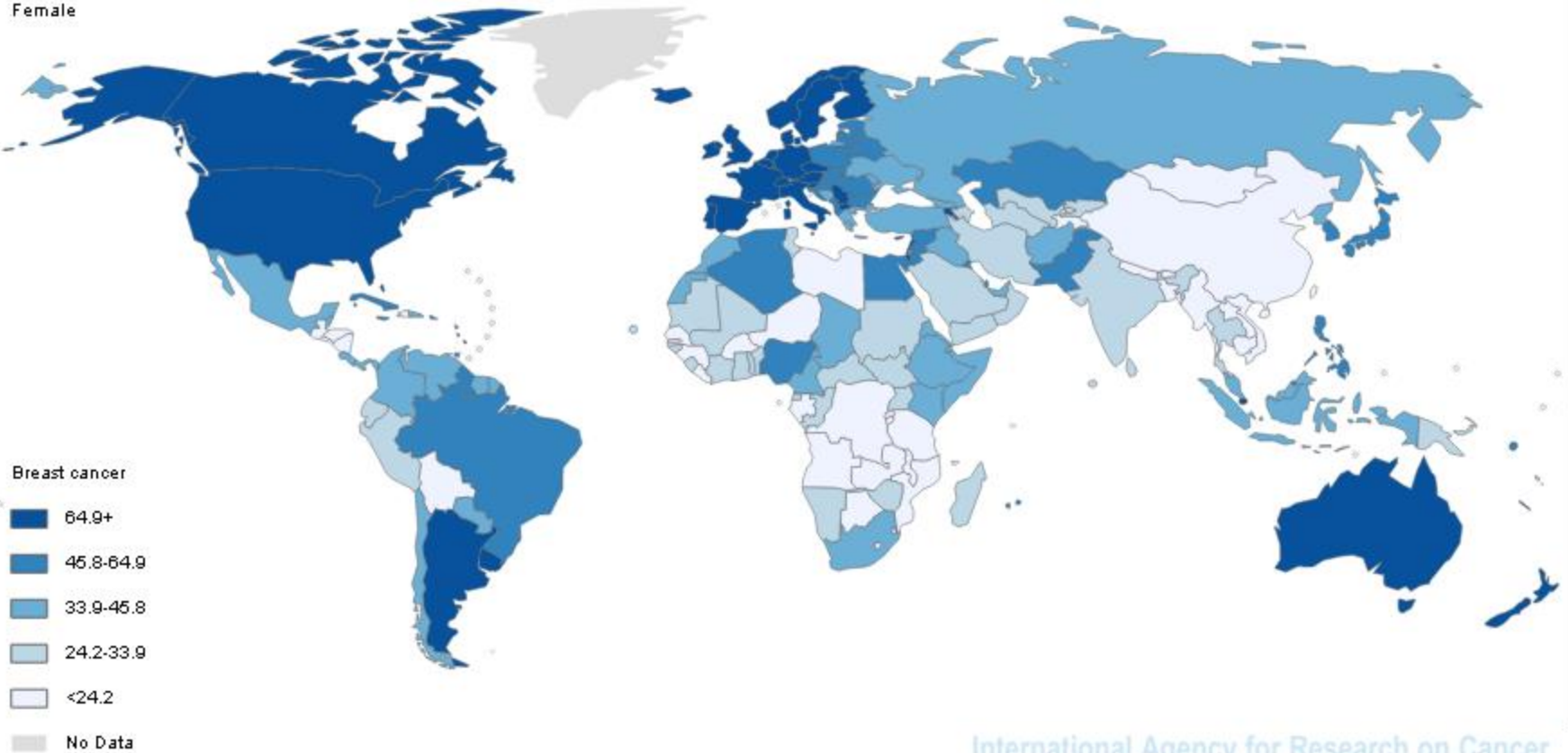
National Incidence of Male Lung & Bronchus Cancer



Global Incidence of Female Breast Cancer

Incidence ASR

Female



International Agency for Research on Cancer



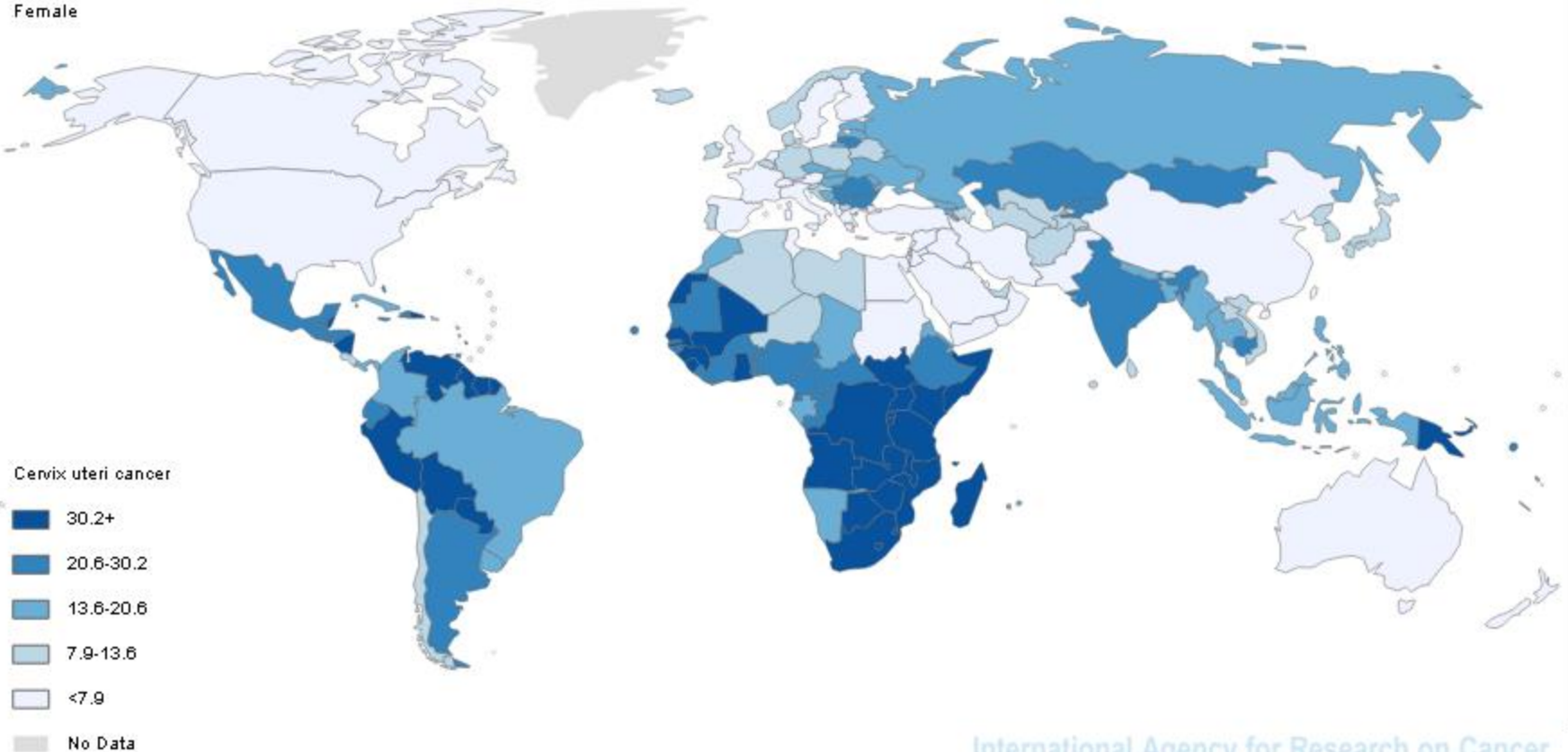
Source: GLOBOCAN 2012 (IARC)

Note, case selection criteria and age-standardization differs from that often used by US registries

Global Incidence of Cervix Uteri Cancer

Incidence ASR

Female



Source: GLOBOCAN 2012 (IARC)

International Agency for Research on Cancer



Note, case selection criteria and age-standardization differs from that often used by US registries

Challenges CCRs Face

- Changes in medical practice & health care delivery have increased the incidence of cancers being diagnosed/treated outside a hospital setting
 - Time-consuming and expensive to obtain many of these cases
 - Cases diagnosed & treated in physician office most expensive & difficult to obtain

Challenges: Changes in Reporting (Cont'd)

- Complete surveillance of some cancers may be particularly affected by diagnosis/treatment outside of the hospital setting, *e.g.*,
 - Leukemia
 - Lymphoma
 - Melanoma skin cancer
 - Prostate cancer
 - *In situ* & localized breast cancer
 - Localized cervical & colorectal cancers

Challenges: C/PO Reporting

- Cases treated entirely within a physician office setting present a potential challenge for CCRs
 - Relatively large number of C/POs
 - Lack of trained tumor registrars to prepare abstracts
- EHRs offer some hope of capturing these cases

Challenges Facility-based & CCR Registries Face

- Increasing complexity of cancer registration
- Shortage of CTRs
- Aging workforce
- Reductions in funding
- Facility closures
- Facility mergers

Summary

- Different levels of cancer incidence data systems:
 - Local
 - State
 - National
 - International
- All rely on the dedication and desire for continuous quality improvement of tumor registrars

Conclusions

- Virtually all aspects of CCR activities depend critically on experienced tumor registrars abstracting cases
- Nearly all aspects of the work Chester and I do depends on the work of facility registrars and CCR CTRs and database administrators.

Acknowledgments

- MCR-ARC data collection activities are supported by a Cooperative Agreement between the Missouri Department of Health and Senior Services (DHSS) and the CDC and a Surveillance Contract between DHSS and the University of Missouri (#U58/DP003924-02/03)
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Questions?

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