

Comparative Effectiveness Research

CDC National Program of Cancer Registries

Christie Ehemann, PhD

NAACCR 6/2012

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Acknowledgements

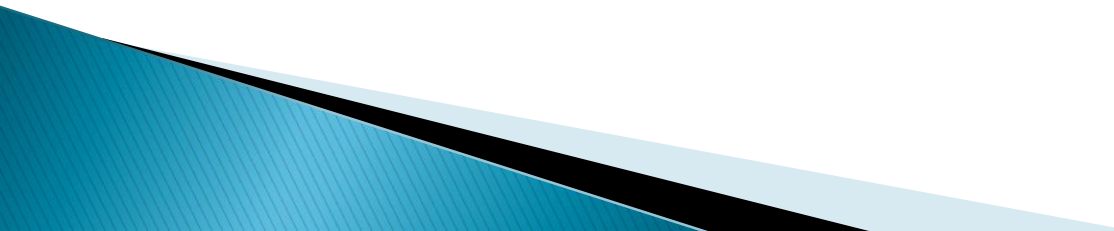
- ▶ CDC – Fran Michaud, Dave Butterworth, Linda Mulvihill, Joan Phillips, Castine Verrill, Sandy Jones
- ▶ ICF – Kevin Zhang, Syvella Kirby, Aliza Fink
- ▶ **Specialized Registries (many others in each registry not listed individually)**
 - Alaska – Lynn Reaume
 - California – Janet Bates
 - Colorado – Randi Rycroft
 - Florida – Jill MacKinnon
 - Idaho – Chris Johnson
 - Louisiana – Vivien Chen
 - New Hampshire – Judith Rees
 - North Carolina – Chandrika Rao
 - Rhode Island – David Rousseau
 - Texas – Melanie Williams

What is Comparative Effectiveness Research?

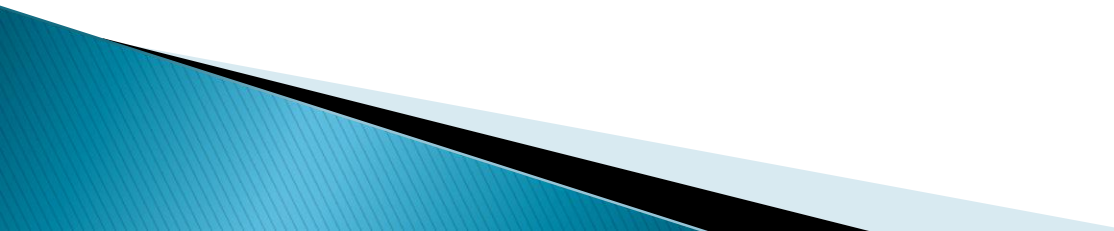
- ▶ 2009 IOM Report – “Initial National Priorities for Comparative Effectiveness Research (CER)”.
- ▶ “CER ...compares the benefits and harms of alternative methods to prevent, diagnose, treat and monitor a clinical condition, or to improve the delivery of care. “

Institute of Medicine Report Brief, *Initial National Priorities for Comparative Effectiveness Research*, June 2009. For more information visit www.iom.edu/cerpriorities

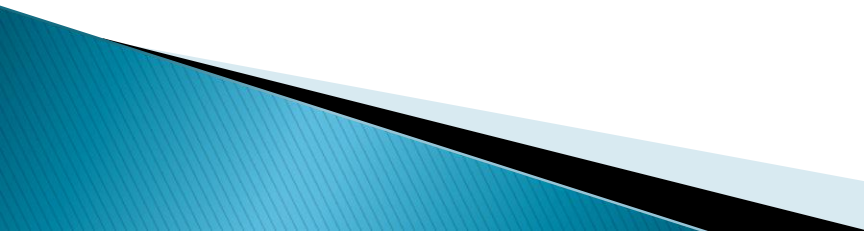
HHS and Comparative Effectiveness Research

- ▶ HHS interested in building data infrastructure
 - ▶ Requested a proposal from CDC for National Program of Cancer Registries project
 - ▶ Multiple levels of review and revisions
 - ▶ Funded by American Recovery and Reinvestment Act (ARRA) via Agency for Health Care Quality and Research (AHRQ).
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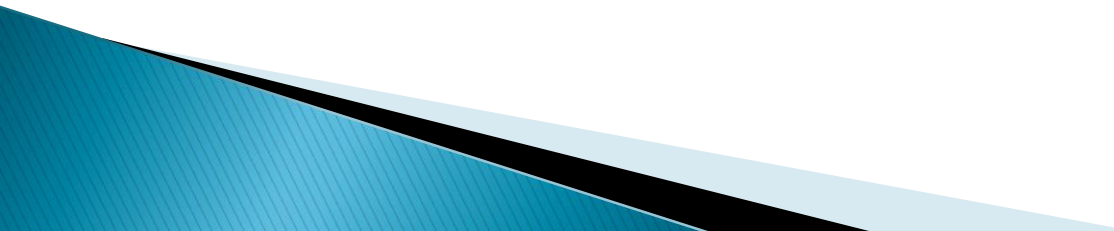
CER Project Provides An Opportunity for Cancer Registries to:

- ❑ Develop new sustainable methods for rapid data collection and the expansion of data items collected through linkages and electronic reporting.
 - ❑ Develop new capacity for innovative public health applications of cancer registries.
 - ❑ Develop datasets for researchers to address as many CER-related research questions as possible.
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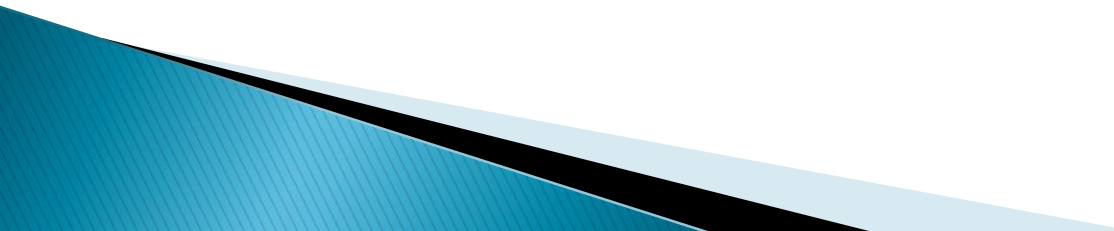
Specific CER Questions Developed in Concert with AHRQ

- ▶ Are colorectal cancer patients tested for KRAS and are the results used appropriately to determine treatment? What impact does KRAS testing have on 2–3 year survival among colorectal cancer patients?
 - ▶ Are rectal cancer patients receiving radiotherapy and what is the timing of radiotherapy? Are disparities apparent in the appropriate neo–adjuvant use of radiotherapy among these patients?
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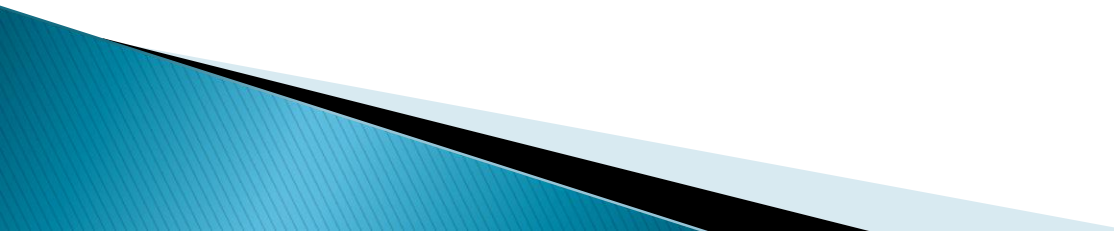
CER Questions Developed in Concert with AHRQ

- ▶ Are women with breast cancer being tested appropriately for HER2, progesterone receptor (PR2), and estrogen receptor (ER) status and treated appropriately?
 - ▶ Are chronic myeloid leukemia patients being tested for the BCR–ABL2 gene and receiving appropriate treatment according to those results?
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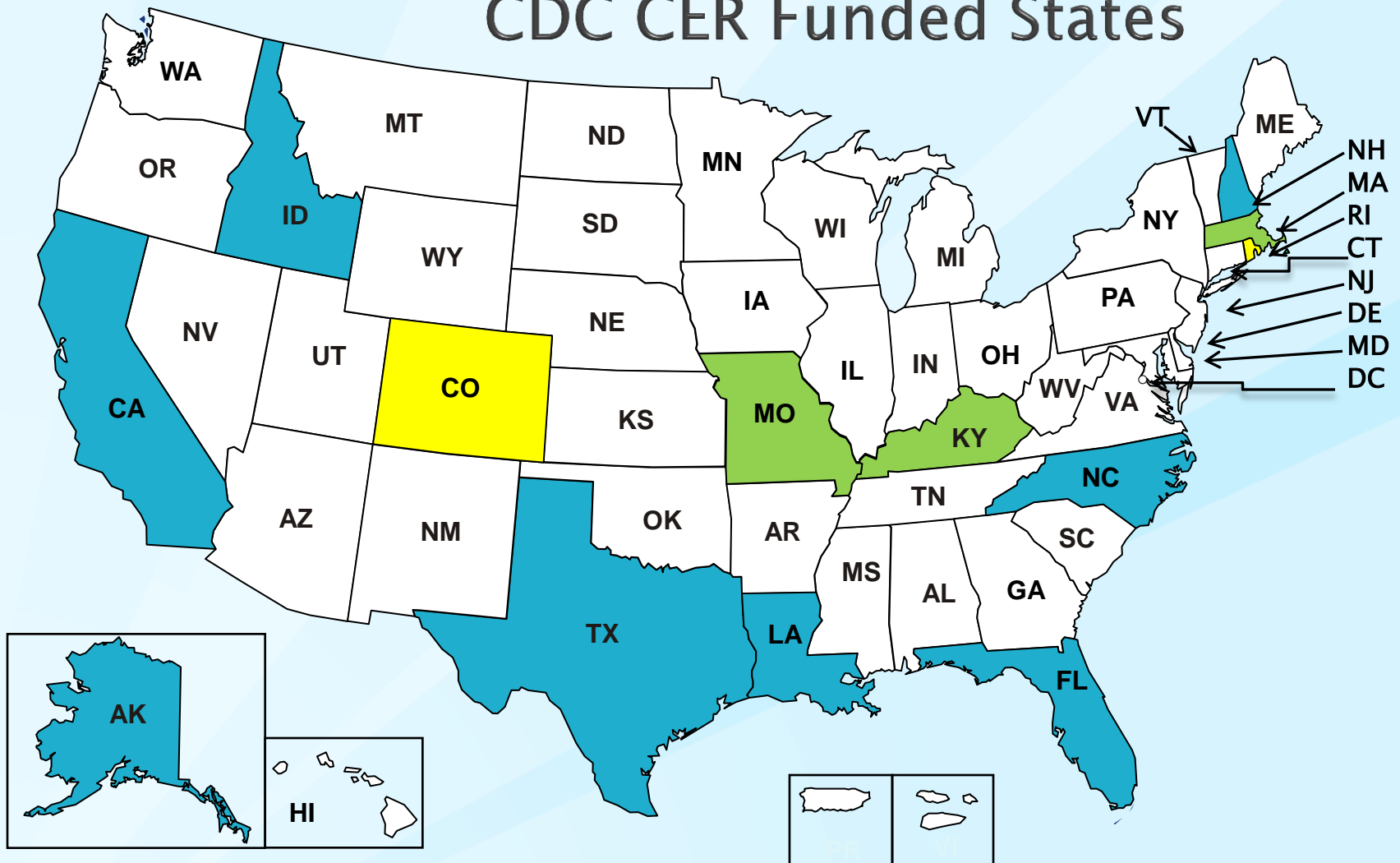
Project Details

- ▶ \$20 Million – obligated in FY10
 - Approx. 80% of funding for registries
 - ▶ Task order contract with ICF Macro
 - NPCR registries as sub-contractors
 - 10 Specialized Registries – expanded data collection
 - 3 special projects
 - ▶ Project Length: May 2010 – Sept. 2013
 - ▶ Cancer diagnoses for 2011
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Project Details

- ▶ Submission of data: January 2013
 - ▶ Data will be available to researchers through the NCHS Research Data Centers: Summer 2013
 - ▶ Future updates to RDC dataset expected – linkages to NDI for example
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CDC CER Funded States



Blue: Specialized Registry (8) YELLOW: Specialized Registry and Special Project (2)
GREEN: Special Project Only (3)



Special Projects

- ▶ Develop methods and pilot projects for innovative uses of cancer registries for effective interventions post-cancer diagnosis (Colorado, Massachusetts)
 - ▶ Develop innovative methods to increase the completeness and quality of race/ethnicity data (Rhode Island, Missouri)
 - ▶ Develop methods for reporting from non-hospital settings using Electronic Medical Records (Kentucky, Missouri)
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Data Collection within Specialized Registries

- ▶ Capture additional or higher quality data:
 - Cancer staging
 - Biomarkers
 - KRAS, HER2, ER and PR status, and BCR-ABL2
 - Race/ethnicity, place of birth
 - Co-morbid conditions
 - Smoking history
 - Height, weight, occupation, vital status
 - Census tract or block characteristics
 - poverty, education, availability of healthcare professionals
 - Linkage with the National Breast and Cervical Cancer Early Detection Program

Detailed Treatment – Breast, Colon, Rectum, Chronic Myeloid Leukemia only

□ Treatment

- focus on specific regimens for colorectal and breast cancer and chronic myeloid leukemia

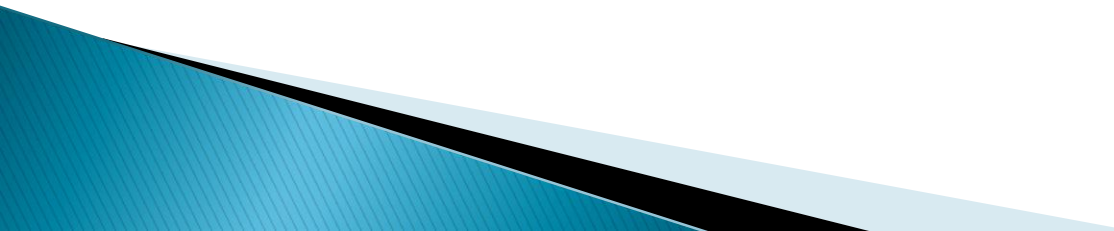
• Radiotherapy

□ Chemotherapy dosages

- Height & Weight at or near diagnosis
- Dosage
- Dates
- Completion Status

□ Subsequent Treatment (*As available*)

Process

- ▶ Guidance Documents
 - Data Dictionary for CER-specific data items
 - EDITS metafile
 - Consolidation Logic
 - ▶ Software Modifications
 - 5 central registry software vendors
 - 11 hospital reporting software vendors
 - 5 non-hospital reporting software vendors
 - ▶ Information Sharing Portal
 - ▶ Quarterly reports from registries
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Status Overview

Milestone	# of states
Began 2011 Case Ascertainment	10
Began CER-specific data collection	10
Conducted CSv2 trainings	9
Increased electronic reporting	
Hospitals	4
Treatment Centers	5
Physician Offices	5
Laboratories	7
Increased non-hospital reporting	
Treatment Centers	2
Physician Offices	4
Laboratories	3

Data Linkage

Data Source	Assessing Feasibility	Preparing for Linkage	Conducting Linkage
Vital Statistics	0	9	1
Socio-economic	0	10	0
NBCCEDP	0	5	5
Hospital Discharge	2	4	1
Health Insurance			
Medicaid	2	3	2
Other	2	1	0

Notes:

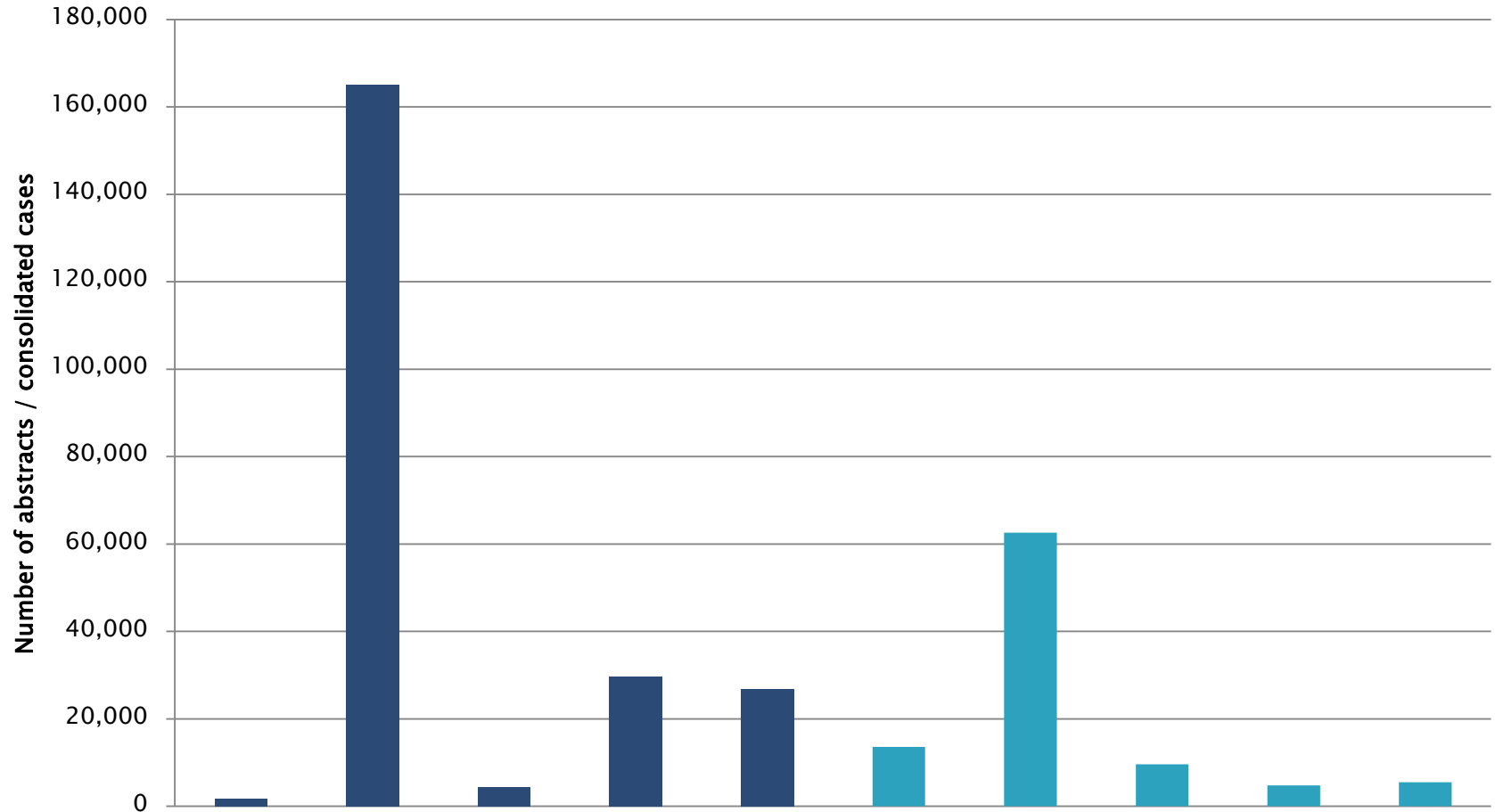
Assessing Feasibility: States are determining whether they can obtain access to required data sets within project time frame.

Preparing for Linkage: States have approval to obtain data sets, waiting for 2011 cancer data to be ready or additional data to be available. In many cases, have conducted linkage with previous year's data.

Conducting Linkage: Linking at least some of 2011 cases to data sets.

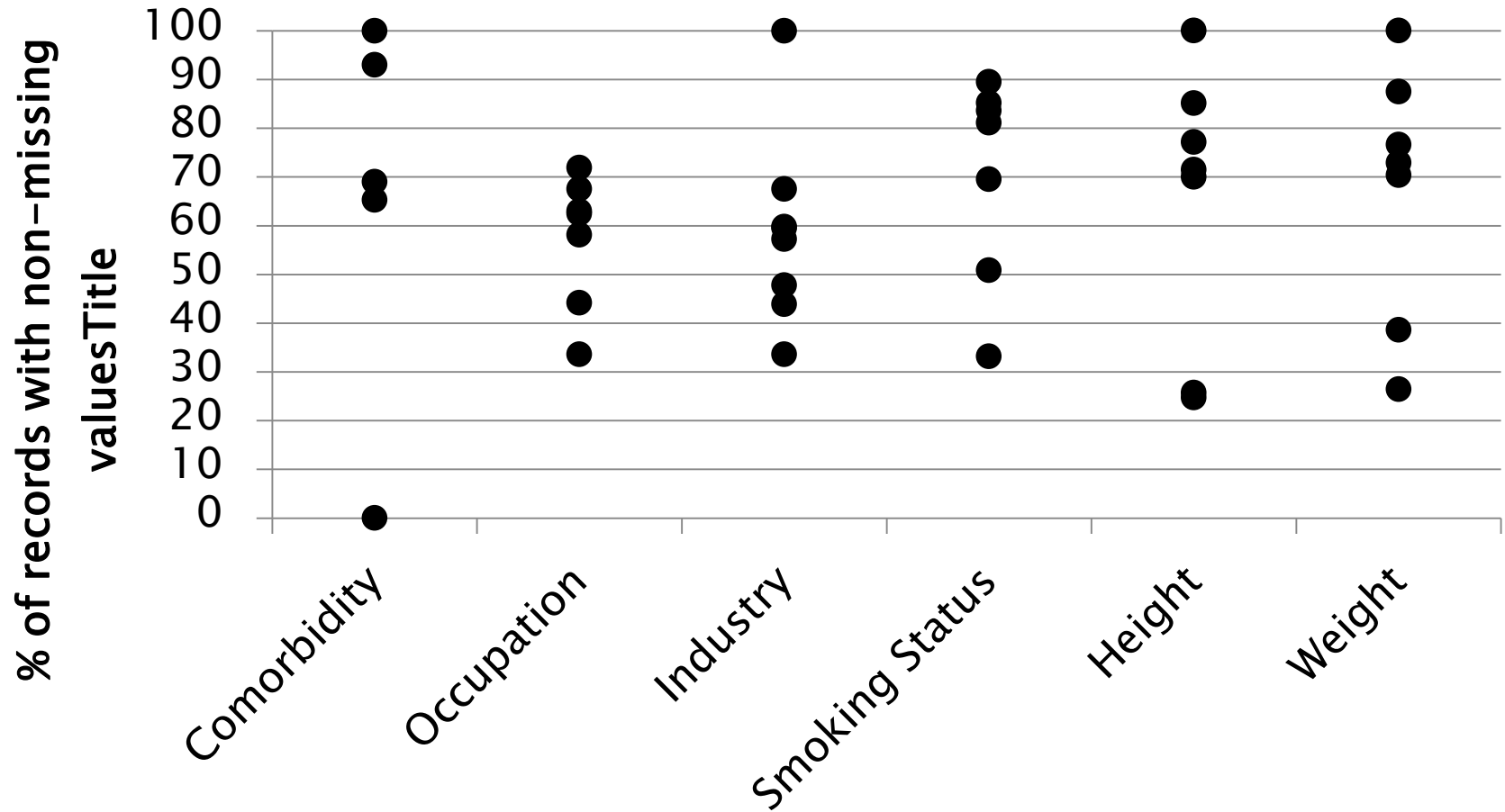
All CER-specialized registries will be linking their data with Nielsen-Claritas datasets which include socio-economic, demographic and other contextual data.

Case Ascertainment

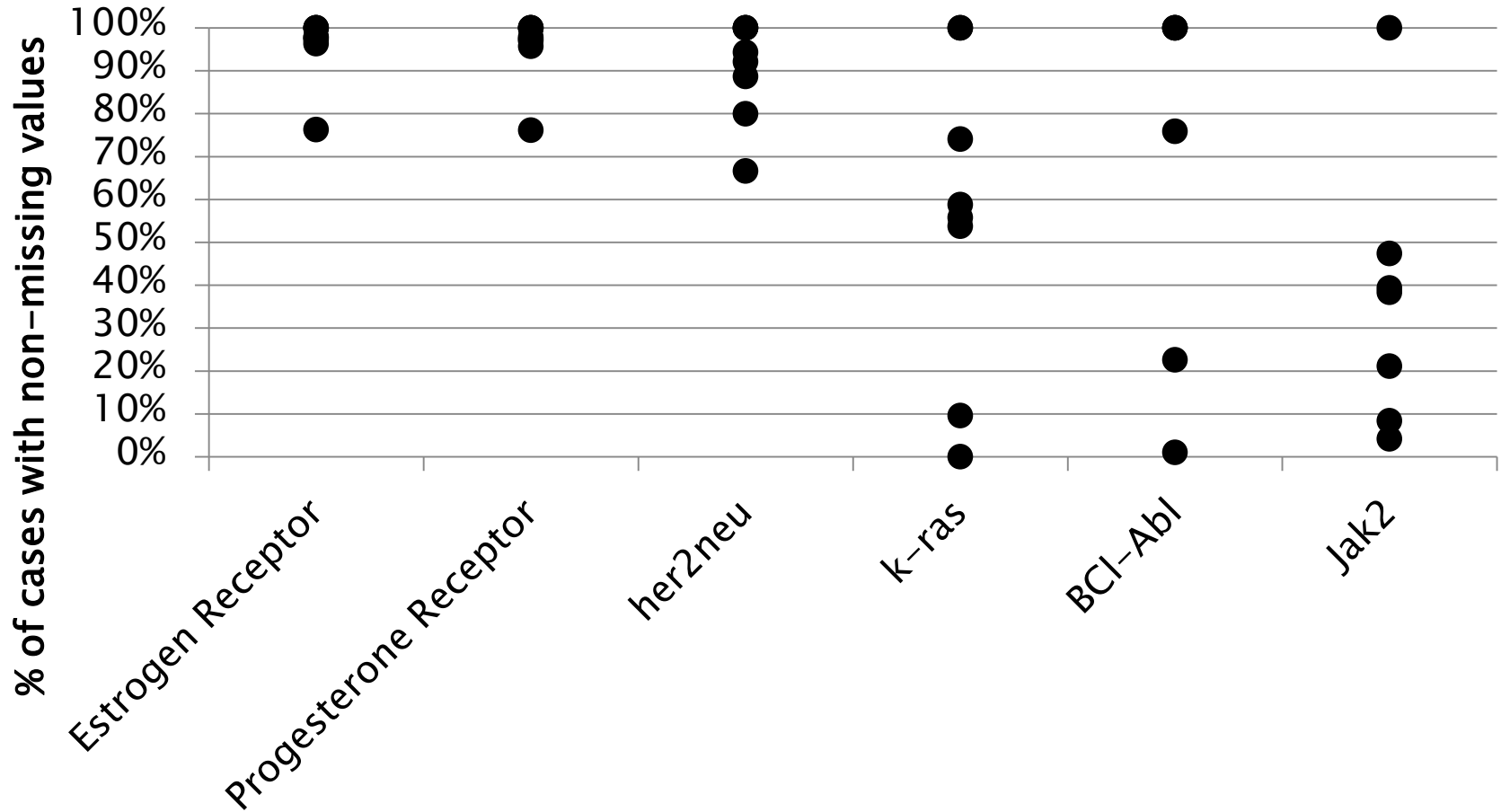


For those providing reports on consolidated cases (light blue) the estimated completeness ranges from 44% to 88% with an average of 66%.

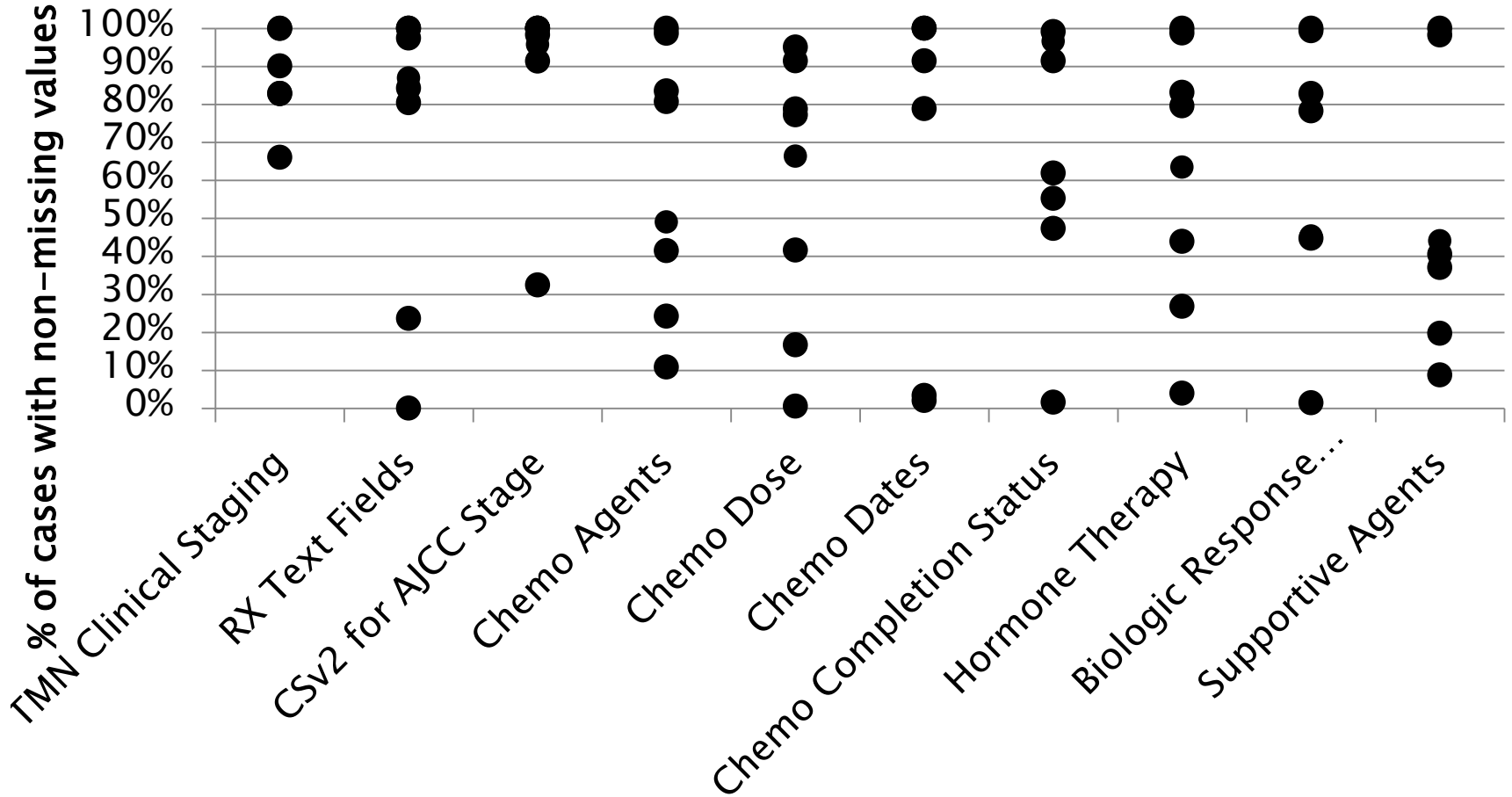
Targeted Variables




Site-Specific Factors



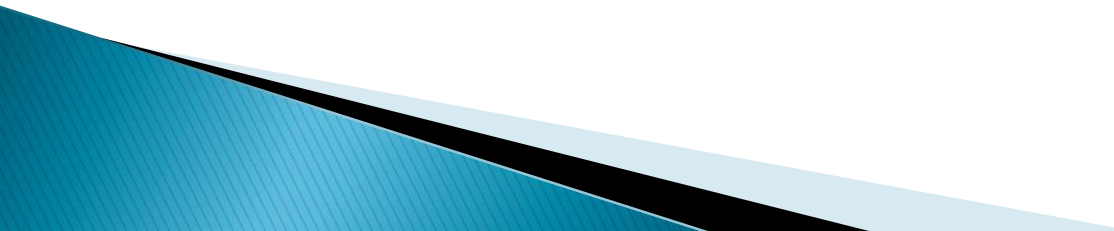
Staging and Treatment Variables



Future of CER

- ▶ Learn from experience
 - Costs and resources involved
 - Availability/access to data
 - Future requests
 - ▶ Sustainability
 - Data linkages planned to continue with data submission to CDC
 - Electronic reporting and utilization of electronic medical records
 - ▶ Transfer of knowledge and experience
 - Mentoring of NPCR registries
 - ▶ Continued development of Specialized Registries
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Challenges

- ▶ Locating information in a variety of health records–unfamiliar territory
 - ▶ Calculating dosage and cycles
 - ▶ Access to private oncology offices
 - ▶ Collecting additional fields=time
 - ▶ Electronic vs. paper health records
- 



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This project is supported through ARRA funding for Comparative Effectiveness Research.

The findings and conclusions in this presentation are those of the presenter, and do not necessarily represent the official position of the Centers for Disease Control and Prevention

CDC Specialized Registries

Core data collection in CER Specialized Registries collecting cancer diagnosed in 2011 (10 States).

Alaska, California, Colorado, Florida, Idaho, Louisiana, New Hampshire, North Carolina, Rhode Island and Texas

Special Projects (5 States) activities vary by project regarding timing of data collection and other project activities