NAACCR Data Quality Indicators

NAACCR 2011-2012 Webinar Series June 14, 2012

NAACCR

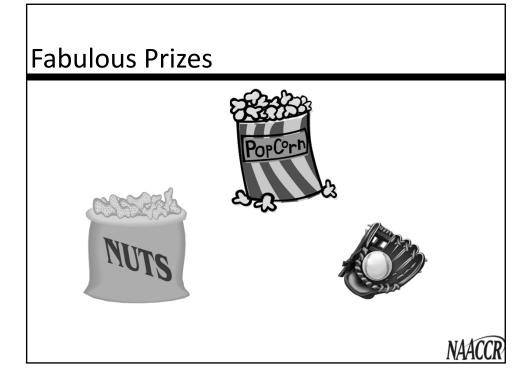
Q&A

 Please submit all questions concerning webinar content through the Q&A panel.

Reminder:

- If you have participants watching this webinar at your site, please collect their names and emails.
 - We will be distributing a Q&A document in about one week. This document will fully answer questions asked during the webinar and will contain any corrections that we may discover after the webinar.

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Agenda

- NAACCR Data Quality Reports
 - Glenn Copeland, Director of the Michigan Cancer Surveillance Program, CINA Chair
- Evaluation of NAACCR Survival Data
 - Hannah K Weir, PhD, Division of Cancer Prevention and Control Centers for Disease Prevention and Control
 - Chris J Johnson, MS Cancer Data Registry of Idaho
- Stage data profile
 - Brad Wohler, Florida Cancer Data System, Manager, Statistical Analysis
- Factors associated with unknown stage prostate cancer
 - Maria Schymura, PhD, Director New York State Cancer Registry

NAACCR Data Quality Reports

Using NAACCR DQI Reports to Assess Submitted Call for Data

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Objectives

- Explain Data Quality Indicators Report
 - What does the DQI include
 - Why they are generated
 - What they can tell you
- Review New DQI Analytical Summary
 - Introduced this year
 - Explanation of statistics and presentation

General Information

- Annual Call-for-Data submissions are analyzed
 - Assess submission for data problems
- NAACCR Certification
 - Determines Certification
- CINA Editorial
 - Inclusion in CINA Combined

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Confidentiality

- IMS Receives the data submissions
 - Responsible for data file assessments
 - Designs and Produces DQI reports for NAACCR
 - Provides DQI to Certification and CINA Committees only
- Reports by registry are privileged
 - Available to committee members only
 - To be used to carry out committee duties

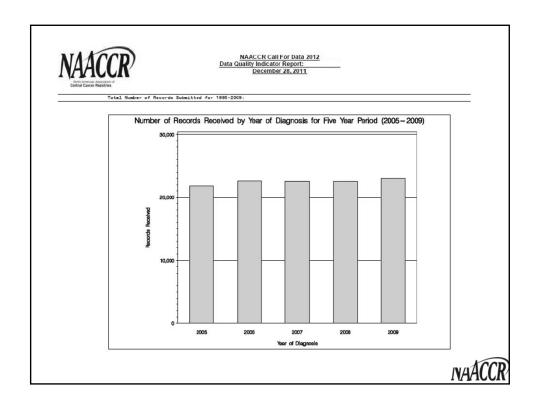
Provided to Submitting Registry

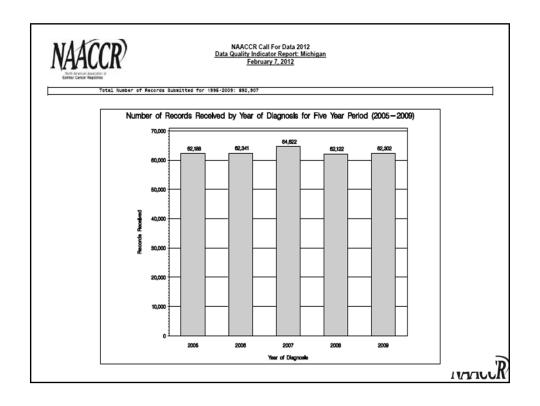
- Shared with each submitting registry
 - Provides summary data used by NAACCR committees
 - Delineates certification and inclusion measures
 - Offers tool for registry to review their data

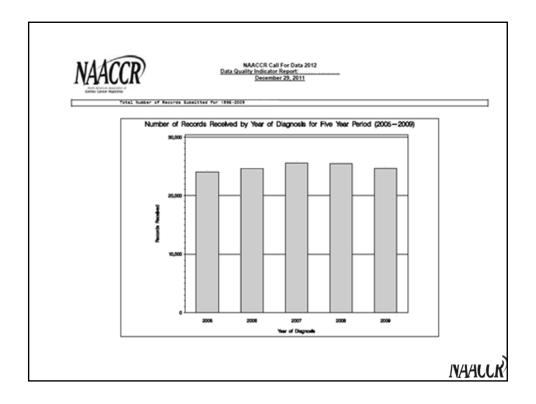
NAACCR

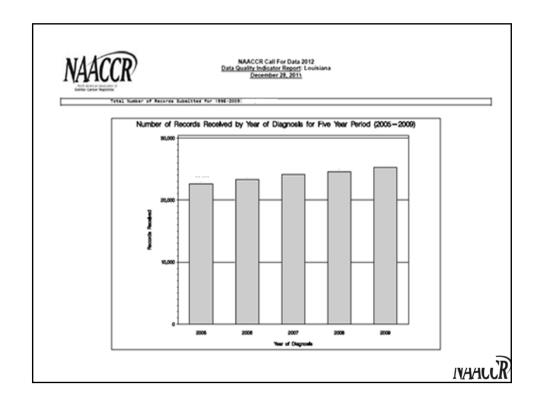
DQI Contents

- Series of tables by year of diagnosis
- Incidence counts by year and by site
- Certification and inclusion criteria
- Field Specific tables of submitted variables by year









Inclusion Criteria Information

Percent Unknown Sex, Race, County, Age and Percent DCO by Year of Diagnosis (Malignant Only)

Year of		Sex			Race			County			Age		Re	porting S	ource
Diagnosis	Unk	Valid	% Unk	Unk	Valid	% Unk	Unk	Valid	% Unk	Unk	Valid	% Unk	DCO	Other	% DCO
2005	11	53,934	0.02	1,201	52,744	2.23	1,235	52,710	2.29	5	53,940	0.01	672	53,273	1.25
2008	9	54,388	0.02	1,313	53,084	2.41	1,258	53,139	2.31	9	54,388	0.02	998	53,399	1.83
2007	32	56,537	0.08	1,402	55,167	2.48	1,160	55,409	2.05	2	56,567	0.00	682	55,887	1.21
2008	47	53,843	0.09	1,300	52,590	2.41	1,087	52,823	1.98	2	53,888	0.00	952	52,938	1.77
2009	41	53,489	0.08	1,105	52,425	2.06	880	52,540	1.85	0	53,530	0.00	693	52,837	1.29

Inclusion Criteria Information

Percent Unknown Sex, Race, County, Age and Percent DCO by Year of Diagnosis (Malignant Only)

Year of		Sex			Race			County	!		Age		Reg	oorting S	ource
Diagnosis	Unk	Valid	% Unk	DCO	Other	% DCO									
	0	34,389	0.00	373	34,016	1.08	0	34,389	0.00	0	34,389	0.00	595	33,794	1.73
	0	35,128	0.00	224	34,904	0.64	1	35,127	0.00	0	35,128	0.00	998	34,130	2.84
	0	36,884	0.00	449	36,435	1.22	1	36,883	0.00	0	36,884	0.00	198	36,686	0.54
	0	36,641	0.00	329	36,312	0.90	5	36,636	0.01	0	36,641	0.00	1,174	35,467	3.20
	1	35,465	0.00	360	35,106	1.02	4	35,462	0.01	1	35,465	0.00	2,015	33,451	5.68

Screening Item Details

- Code Distributions
- Illegal/Inappropriate
- IHS Link
- Cancer Sequence
- Pre 2004 Benign
- Blank and Unknown %
- Trends in Unknowns
- Edit Override Usage

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Spot Incorrect – Nonstandard Coding

Description	2007	2008	20
	64,622	62,122	62,3
0	0	3	
9	1	0	
30	0	1	
43	0	0	
45	0	0	
91	1	1	
115	0	0	
145	0	0	
223	2	0	
224	0	0	
226	0	0	
641	0	0	
999	27	43	
Inv. State unable to identify cnty	39	43	
Unknown	1,212	1,092	1,0
Valid County	63,340	60,939	61,1

Processing Assessments – IHS Link

Description	1995	1996	1997	1998	1999	2000	
	52,966	53,833	54,993	56,407	58,047	59,306	
Record sent for linkage, IHS match	80	83	105	105	111	106	
Record sent for linkage, no IHS match	52,886	53,750	54,888	56,302	57,936	59,200	
	2001	2002	2003	2004	2005	2006	
	59,808	61,149	61,393	61,430	62,188	62,341	
Record sent for linkage, IHS match	118	139	146	143	137	148	
Record sent for linkage, no IHS match	59,690	61,010	61,247	61,287	62,051	62,193	
	2007	2008	2009				Total
	64,622	62,122	62,302				892,907
Record sent for linkage, IHS match	122	137	182				1,862
Record sent for linkage, no IHS match	64,500	61.985	62,120				891,045
	/	. ,	,				,



Data Quality Priorities - Derived Stage

Description	2003	2004	2005	2006	2007	2008	2009
	61,393	61,430	62,188	62,341	64,622	62,122	62,302
IS	0	7,765	8,070	7,774	7,885	8,059	8,503
L	0	20,160	21,087	21,979	25,102	23,716	24,165
RE	0	3,452	3,665	3,839	4,008	3,840	3,836
RN	0	3,444	3,450	3,702	3,824	3,842	3,838
RE+RN	0	2,028	2,150	2,316	2,282	2,261	2,300
RNOS	0	83	101	246	556	527	525
D	0	9,646	11,031	11,607	12,924	11,960	12,099
NA	0	1,443	1,502	1,410	1,461	1,428	1.536
U	0	13,409	11,132	9,468	6,580	6,489	5,499
Blank	61.393	0	0	0	0	0	1



Issues

- Registry Specific
- Lacks Comparisons
- Missing effects of other factors
 - Population changes

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Needed Something Better

- Statistical relevance
- Rates and proportions
- Easy to compare across registries

CINA Submission Summary Report

- Summary of total records used in CINA.
- "Fit For Use" Criteria
- Frequency distributions and bar charts
- Compare counts across submissions
- Box and whisker plots.

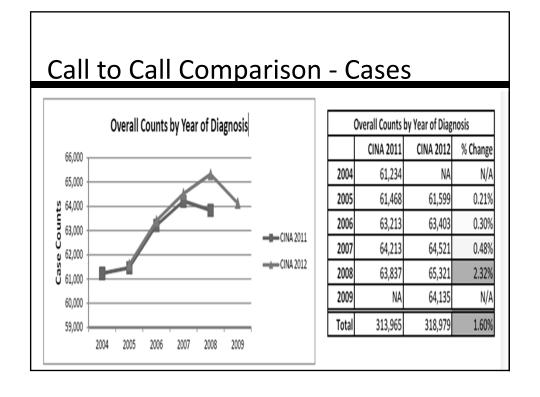


Cases Received/Cases Included in CINA

Summary of Data Received for the 2012 NAACCR Call For Data by Year of Diagnosis

Total Case Records Received (1995-2009)	892,907
Case Exclusions for 1995-2009 (In Order of	of Exclusion)
Invalid Year, State Code, County Code = 998	19,547
In-situ, Benign, Borderline Malignant (1995-2009)	77,975
Year of Diagnosis not 2005-2009	519,359
Invalid Site, Missing Age, Non-Male/Female Cases	354
Total Cases Excluded	617,235
Cases Included for CINA 2005-20	009
Malignant Cases (Inc. In situ Bladder)	265,899
In Situ Breast Cases	9,773
Total Cases Included in CINA	275,672

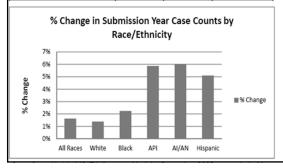
Data Quality Inclusion Criteria Data Quality Indicators (2005-2009) 2005 2006 2007 2008 2009 Completeness of Case Ascertainment 106.5 104.6 106.3 100.9 97.4 0.0 0.0 0.0 0.0 0.0 Missing Age 0.0 0.0 0.0 0.0 Missing Sex 0.0 1.7 2.1 2.2 1.9 Missing Race 1.8 0.1 0.2 0.9 1.2 0.6 Missing County Death Certificate Cases Only (DCO) 1.2 1.7 1.1 1.7 1.2 Passing Edits 100.0 100.0 100.0 100.0 100.0 Duplicate case reports per 1,000 records: 0.80 Meets the Inclusion Criteria for Combined Volume?

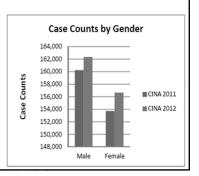


Call to Call Comparison - Race

Counts by Race*/Ethnicity						
	CINA 2011	CINA 2012	% Change			
All Races	313,965	318,979	1.60%			
White	261,943	265,536	1.37%			
Black	41,373	42,290	2.22%			
Asian or Pacific Islander	6,002	6,353	5.85%			
Am. Indian/Alaska Native	183	194	6.01%			
Hispanic	15,268	16,042	5.07%			

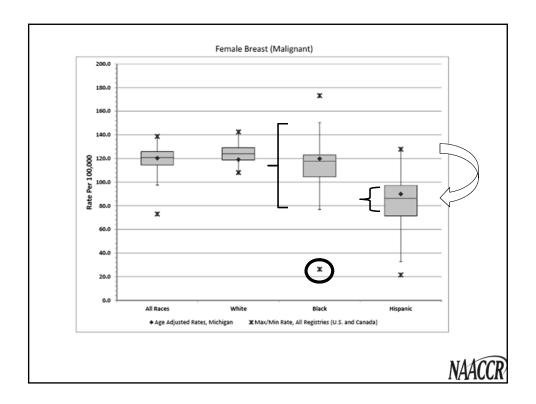
Case Counts by Gender						
	CINA 2011	CINA 2012	% Change			
Male	160,250	162,335	1.30%			
Female	153,715	156,644	1.91%			
Total	313,965	318,979	1.60%			





Relative Rates – Box and Whisker Plots

- Intended to provide a quick comparative look
- Displays the distribution of rates for all registries
 - Identifies the Median
 - Identifies the interquartile range
 - Shows maximum values
 - Identifies registry rate within the overall distribution
- Displays rates by race/ethnicity by sex
 - All cancers, lung, colorectal, breast, prostate



Companion Data Table

	All races	White**	Black**	Hispanic**
Rate	120.3	119.0	119.8	89.9
Count	34,967	29,591	4,283	500
Rate Percentile	49.2%	30.9%	54.5%	56.3%

Note: ~ indicates no data available; ^ indicates fewer than 6 cases; shading indicates rate is outside 25-75% Percentile Range (IQR)

Rate Statistics For All Submitting Registries (U.S. and Canada)						
All races	White**	Black**	Hispanic**			
114.5 - 125.8	118.7 - 129.1	104.5 - 122.9	71.4 - 97.2			
73.0 - 138.7	108.1 - 142.5	26.3 - 173.2	21.5 - 127.8			
120.8	124.0	117.7	86.2			
125.8 <- 138.7	129.1 <- 142.5	122.9 <- 150.5	97.2 <- 127.8			
97.6 -< 114.5	108.1 -< 118.7	76.9 -< 104.5	32.7 -< 71.4			
	All races 114.5 - 125.8 73.0 - 138.7 120.8 125.8 <- 138.7	All races White** 114.5 - 125.8 118.7 - 129.1 73.0 - 138.7 108.1 - 142.5 120.8 124.0 125.8 <- 138.7 129.1 <- 142.5	All races White** Black** 114.5 - 125.8 118.7 - 129.1 104.5 - 122.9 73.0 - 138.7 108.1 - 142.5 26.3 - 173.2 120.8 124.0 117.7 125.8 <- 138.7			

^{*}Rates are per 100,000 population and are age-adjusted by five-year age groups to the 2000 U.S. standard population based on single years of age.

Issues	or	prob	lems:
133463	O1	PIOD	101113.

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jhofferkamp@naaccr.org

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Please submit questions through the Q&A Panel

QUESTIONS?

Evaluation of NAACCR Survival Data June 14, 2012

Chris J Johnson, MS Cancer Data Registry of Idaho Boise, ID

Hannah K Weir, PhD Division of Cancer Prevention and Control Centers for Disease Prevention and Control Atlanta, GA

And the NAACCR Survival Analysis Workgroup (SAWG)

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NAACCR Survival Analysis Workgroup Members

Name	State, Province or Agency
Deb Hurley	SC (co-chair)
Chris Johnson	ID (co-chair)
Glenn Copeland	MI
Larry Ellison	Stat Cam
Monique N. Hernandez, Ph.D.	FL
Bin Huang	KY
Angela Mariotto	NCI
Zoran Miladinovic	Stat Can
Cyllene Morris	CA
Xiaoling Niu	NJ
Arti Parikh-Patel	CA
Paulo S. Pinheiro, MD PhD	NV
Trevor Thompson	CDC
Donna Turner	MB
Baozhen Qiao	NY
Zhenguo Qiu	AB
Kevin Ward	GA
Hannah Weir	CDC
Reda Wilson	CDC
Brad Wohler	FL
Kevin Zhang	MACRO



Overview

- What is population-based survival and how is It used?
- Data evaluation
- Putting it all together
- Next steps

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What is Population-Based Survival

- Measures survival achieved in the population regardless of age, race, stage of disease, access to health care, etc.
- Can be used to:
 - Target and monitor cancer control and health policy initiatives
 - Evaluate the effectiveness of healthcare delivery (measure of cancer system performance)

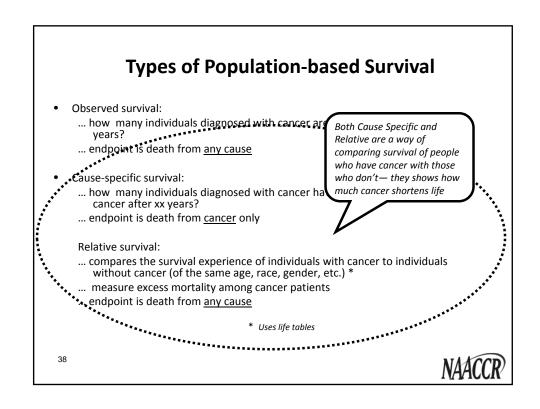


Innovative Uses of Survival Data

- Compare survival by geographic area, race, ethnicity, SES, etc.
- Estimate the number of avoidable deaths within a specified time period if there were no disparities
- Estimate the population "cure" fraction
- Estimate "current" survival using period analysis

EUROCARE: Survival of Cancer Patients in Europe http://www.eurocare.it/





Advantages and Disadvantage of Relative vs. Cause Specific Survival

	Advantages	Disadvantages
Relative	Relies on fact of death not cause of death	Life tables may not be available for all populations
Cause Specific	Not limited to populations with life tables	Death Certificates may not be reliable (e.g., may be coded to site of mets or recurrence)

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Overview

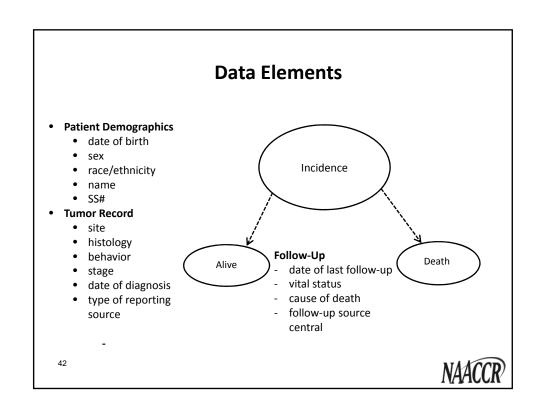
- What is population-based survival and how is It used?
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Data

- CINA (1995-2008) 2010 data submission
- First year requested follow-up data
- Excluded Canadian data due to coding of vital status variable
- Registries
 - SEER: CA (LA, SF), Detroit, HI, IA, KY, LA, NJ, NM, UT, Seattle
 - NPCR: remaining states
 - 2 NPCR state cancer registries not included





Evaluation Criteria

CONCORD

• Coleman MP and CONCORD Working Group. Cancer survival in five continents: a worldwide population-based study (CONCORD). Lancet Oncology. 2008 Aug;9(8):730-56.

EUROCARE

 De Angelis R and EUROCARE Working Group. The EUROCARE-4 database on cancer survival in Europe: data standardization, quality control and methods of statistical analysis. European J Cancer. 2009 Apr;45(6):909-30.

C-SPAN (Cancer Survival and Prevalence Analytic Network) in Canada

• C-SPAN Data Quality Assessment Protocol for Survival Analysis

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Evaluation Criteria

- % Sex, Age or Race Unknown
- % DCO/Autopsy
- % Vital status Unknown
- % Edi Errors
- % MV
- % Missing Cause of Death
- % Multiple Primaries
- % Alive with 0 Survival Time
- % Death within 1 Month of Diagnosis
- % Dead 0 Survival Time not reported by DCO/Autopsy



The Foundation for Population-Based Survival



The validity of population-based survival comparisons is clearly dependent on the validity of the incidence data. Berrino, 2003

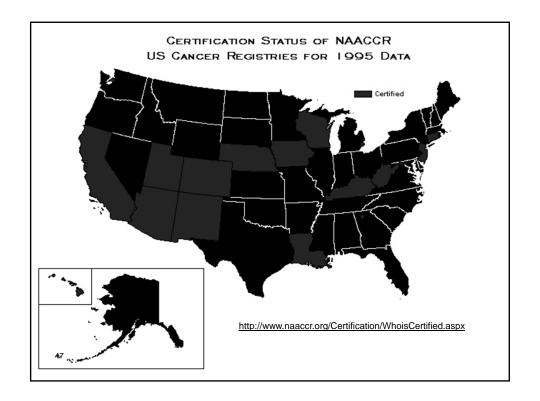
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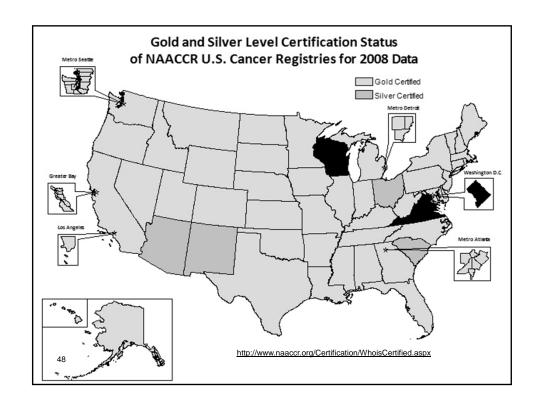


Factors that Impact Incidence

- NAACCR Certification
 - Completeness of case ascertainment
 - DCO/ autopsy
 - Missing critical information (age, sex, race)
 - Edits
 - Duplicates







Factors that Impact Incidence

- NAACCR Certification
 - Completeness of case ascertainment
 - DCO/ autopsy
 - Missing critical information (age, sex, race)
 - Edits
 - Duplicates
- Population Coverage
 - 1995 19 US registries NAACCR Certified
 - 2008 53 US registries Certified

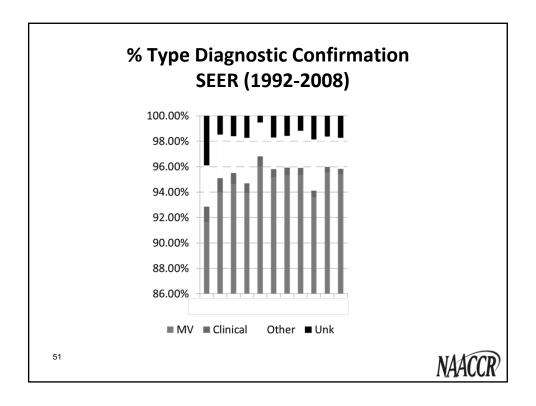
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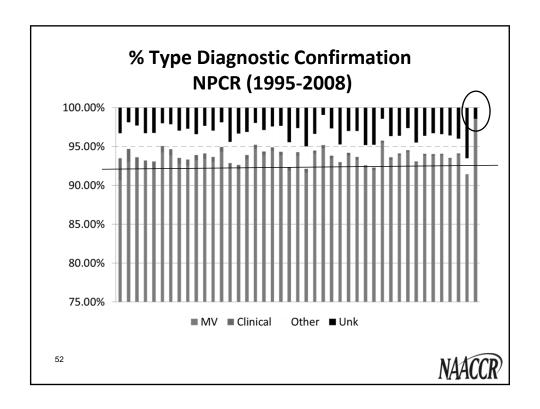


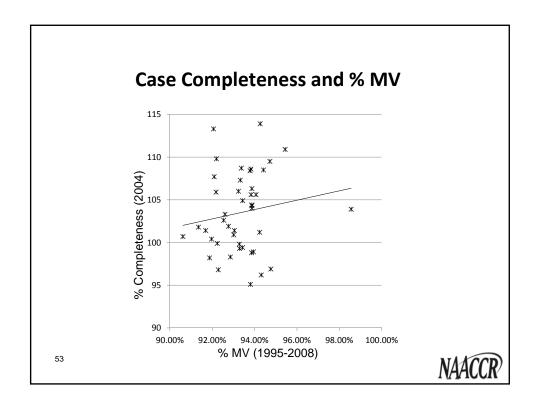
Factors that Impact Incidence

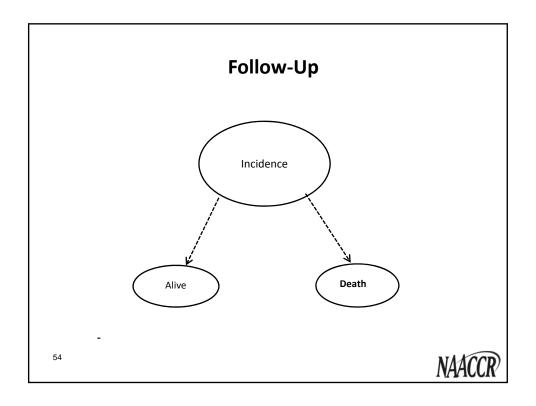
- NAACCR Certification
- Completeness of Case Ascertainment
 - Clinical vs. Microscopically Verified (MV)











Demographic Variables

- Variable: Name (last, first), Sex, Date of birth, Social Security No (SS#)
- Critical for enhancing race/ethnicity, follow-up information through linkage
- Results from Melissa Jim IHS linkage project

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% Missing - Linkage Variables Birth SS# First Sex Last Date Name Name SEER - range 0.00-3.93 0.00-0.09 0.00-0.02 0.00-0.00-< 0.00 < 0.00 - No. states 7/10 4/10 3/10 1/10 3/10 w/missing NPCR - range 0.00-2.58 0.00-0.07 0.00-0.03 0.00-0.00-< 0.02 < 0.02 30/41 21/41 22/41 - No. states 9/10 15/41 w/missing Source: M Jim, IHS linkage data, variable years of diagnosis

Follow-Up Variables: Inter-Field and Intra-Record Edits

Data Variables and Edits

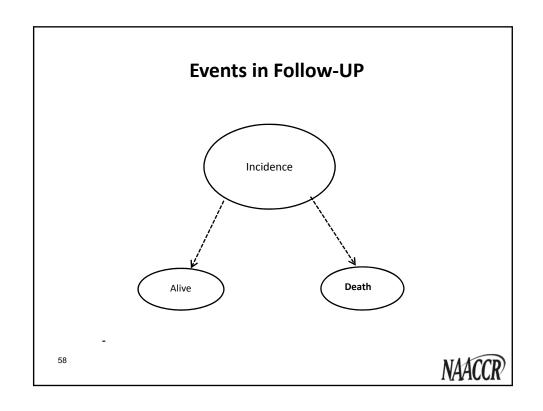
- Date of last contact
- Vital status
- Cause of death
- ICD revision number
- Follow-up source central
- Types of reporting source

All NPCR and SEER registries reported <1% edit errors for any individual edits

Age, Histologic Type, COD, ICDO3 (SEER IF43)
Cause of Death (SEER COD)
Date of Last Contract (Vivinne) ate of Last Contact (NAACCR DATEEDIT) late of Last Contact Flag (NAACCR)
late of Last Contact, Date Flag(NAACCR) ollow-Up Source Central, Vital Status (NPCR Type of Report Srce(DC/AO), COD (SEER IF09)
Type of Report Srce(DC/AO), Diag Conf (SEER IF05 Type of Reporting Source (SEER RPRTSRC) erify date of follow-up same on all records for a patient (SEER IRO8)

Verify vital status same on all records for a patient (SEER IR10)





Vital Status

 All NPCR and SEER registries reported <1% missing vital status information

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Follow-Up Requirements

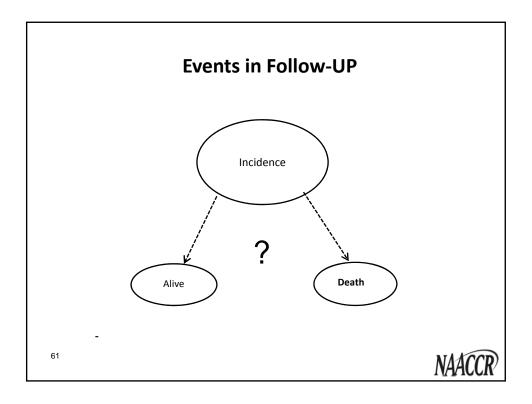
Alive Status

- SEER Program requires all SEER registries to follow alive patients
 - 95% patients have last contact date within 18 months of the annual date of submission
- NPCR registries are not required to follow patients

Death Staus

- All Registries conduct death clearance with state DC
- SEER and NPCR provide support for registries to link with the National Death Index and the Social Security Death Index

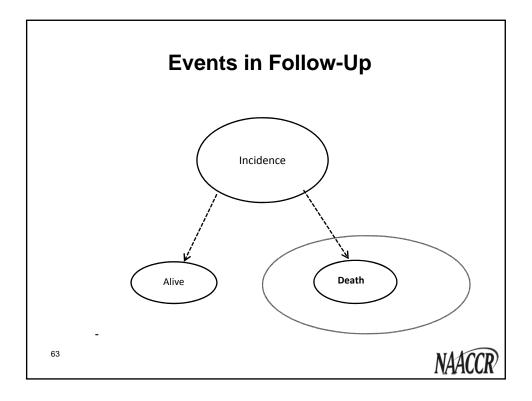




Immediately Lost to Follow UP Alive

- SEER 11 database (not CINA)
- 1992-2006
- Information obtained from SEER survival session
- Alive with "0" survival time
- Contribute no follow-up information
- Survival time could be 0-<1 months
- <1% survival time = 0 months (range 0.1- 0.3%)</p>





The Importance of Death Ascertainment

Johnson CJ, Weir HK, Yin D, Niu X. *The impact of patient follow-up on population-based survival rates.* J Registry Manag. 2010 Fall;37(3):86-103.

OBJECTIVE: designed to measure the impact of variation in patient follow-up on survival statistics.

METHODS: SEER data used to construct datasets simulated scenarios of complete (SEER), incomplete, and no follow-up (NPCR) of alive patients; and complete and incomplete death ascertainment.

CONCLUSIONS:

- Complete death ascertainment important for producing accurate cancer survival statistics, and
- Ascertainment of deaths only should generally be sufficient for survival analysis.



Full Dates vs. Partial Dates

Date of Birth

Age at diagnosis needed for Life Tables

Date of diagnosis

Survival interval

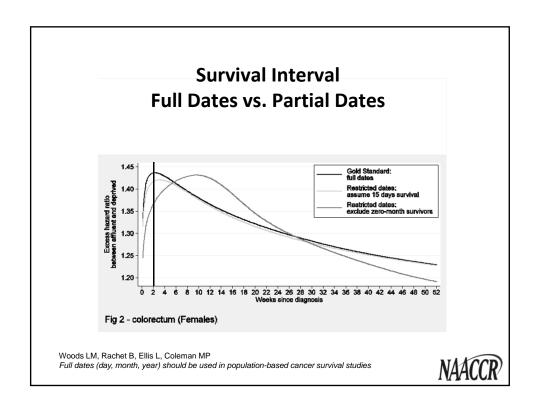
Date of last contact

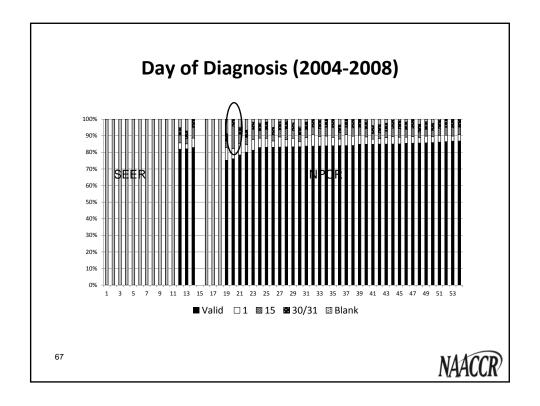
SEER Program uses month and year

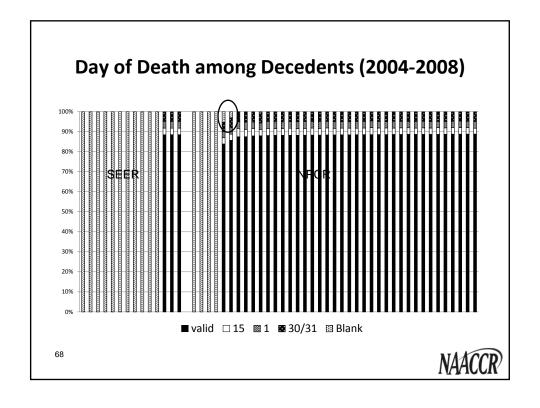
Example: Patient diagnosed April 2000 and dies May 2000 . Survival interval could be $1-60\,$ days

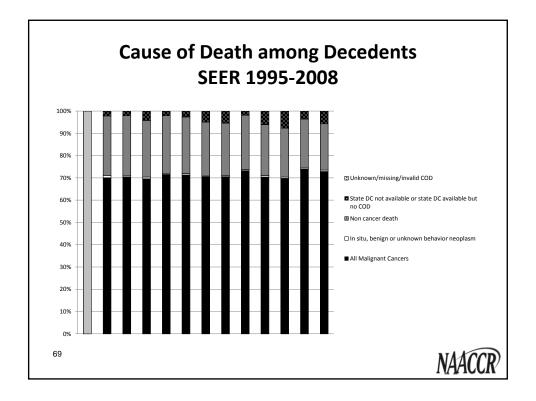
NAACCR / NPCR uses month, day and year

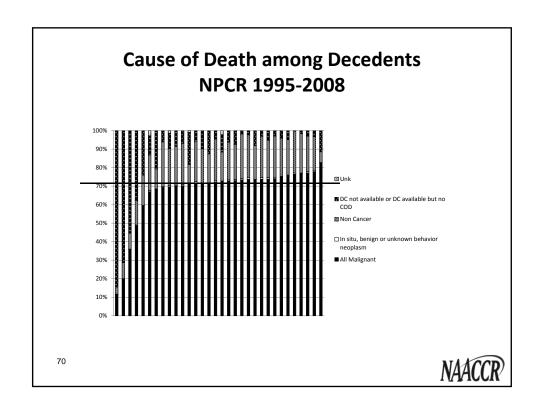


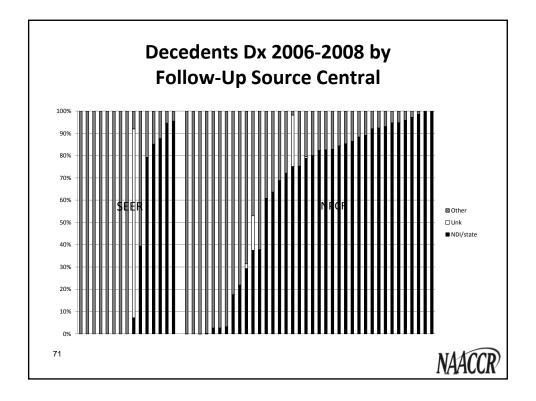








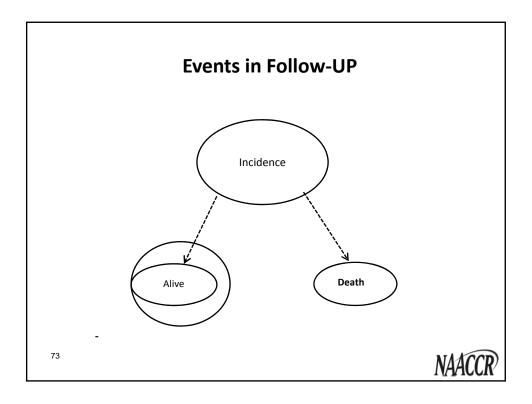




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- Data evaluation
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Follow-Up Requirements

Alive Status

- SEER Program requires all SEER registries to follow alive patients
 - 95% patients have last contact date within 18 months of the annual date of submission
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Follow-Up Requirements

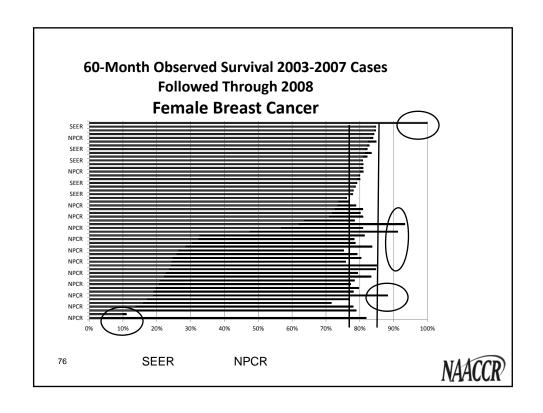
Alive Status

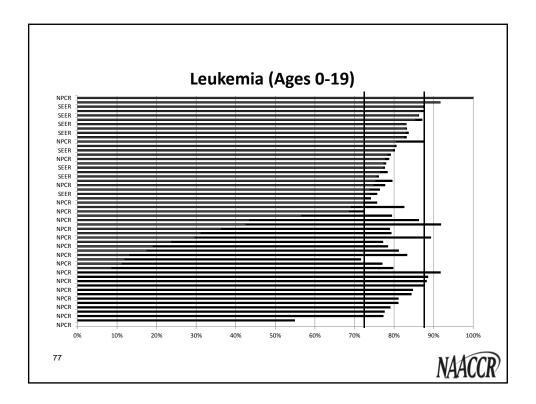
- SEER Program requires all SEER registries to follow alive patients
 - 95% patients have last contact date within 18 months of the annual date of submission
- NPCR registries are not required to follow patients
 - impute follow-up date to be the end of study (e.g., 12/31/08)

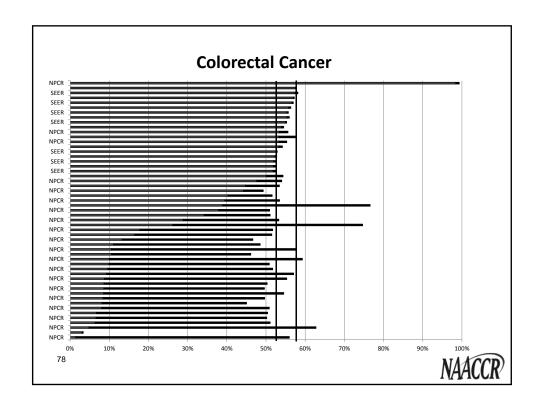
Death Staus

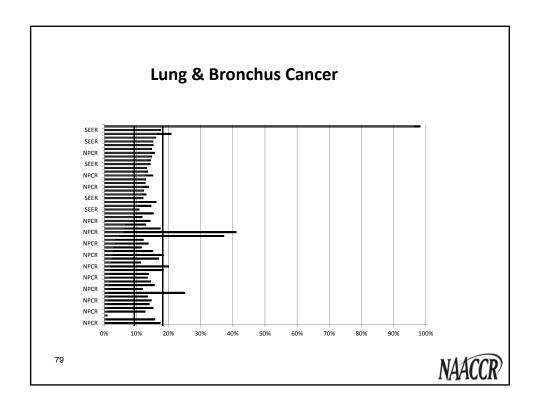
- All Registries conduct death clearance with state DC
- SEER and NPCR provide support for registries to link with the National Death Index and the Social Security Death Index

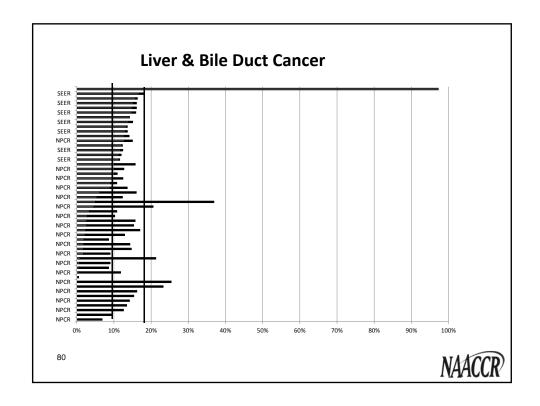


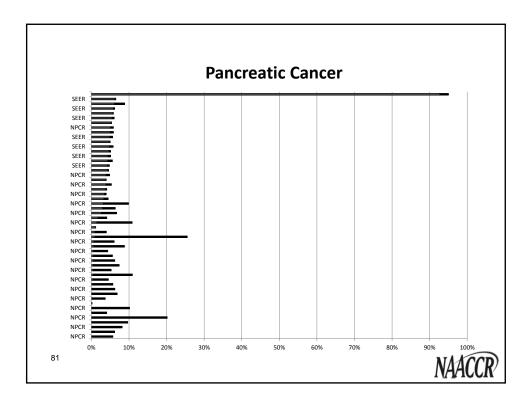












Overview

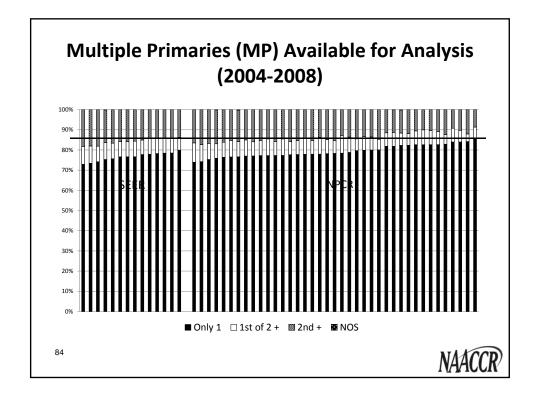
- What is population-based survival and how is It used?
- Data evaluation
- Putting it all together
- Next steps

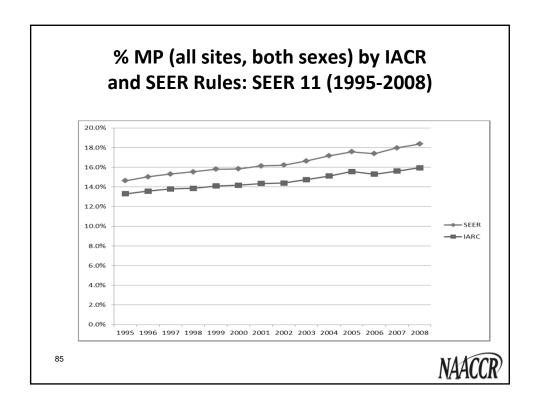


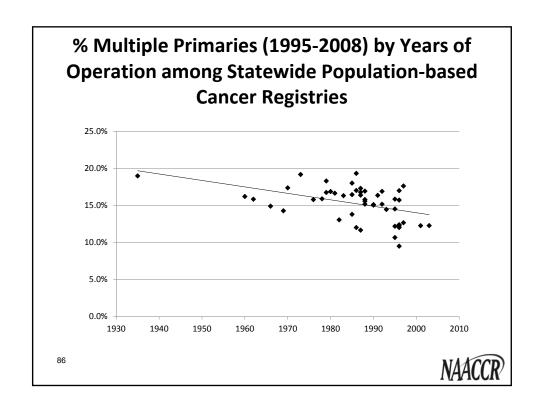
What to do with Multiple Primaries in Survival

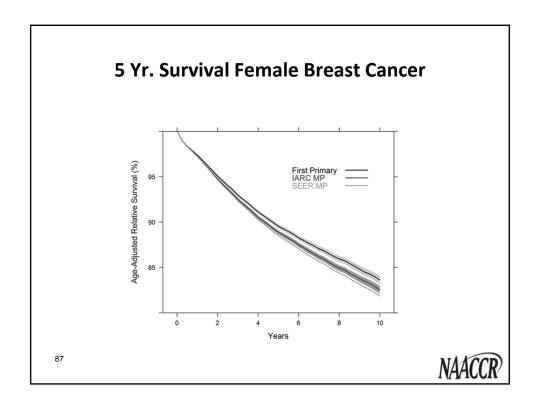
- Background: Historic use of first cancers only in survival
- Objective:
 - Compare first cancers vs. all cancers
 - Evaluate the impact of SEER and IACR MP rules on survival
- Methods and Materials: SEER data, SEER MP rules and IACR MP rules

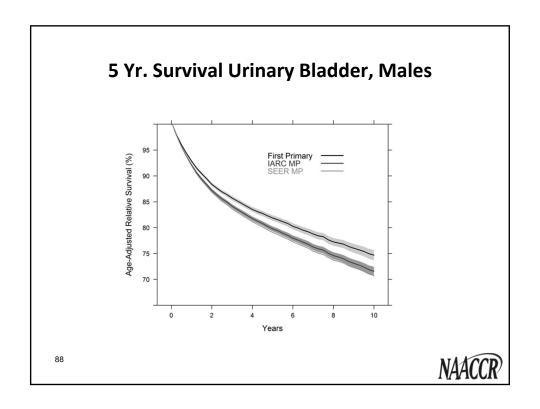












What to do with Multiple Primaries in Survival

- Background: Historic use of first cancers only in survival
- Objective:
 - Compare first cancers vs. all cancers
 - Evaluate the impact of SEER and IACR MP rules on survival
- Methods and Materials: SEER data, SEER MP rules and IACR MP rules
- Results:
 - First cancers only excludes a large and increasing number of cancers
 - First cancer only survival higher than survival using all primaries (SEER or IACR MP rules)
 - Using all cancers, survival with SEER MP lower than IACR MP for female breast and urinary bladder (males) cancer
- Conclusion:
 - NAACCR registries should include all primary cancers in comparative survival studies using IACR MP rules

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Overview

- What is population-based survival and how is It used?
- Data evaluation
- · Putting it all together
- Next steps



Next Steps

- Deceased with 0 survival time (and not a DCO/AO case)
 - E.g., Physician only reporting source, follow up source central (State or NDI). These events are <u>included</u> in analysis whereas DCO/AO cases are <u>excluded</u>
- Immortal cases
- Survival using full dates SEER*Stat enhancement
- State specific life tables available in 2012
- Participation in CONCORD Study

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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.



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Maria Schymura, PhD, Director New York State Cancer Registry	
FACTORS ASSOCIATED WITH	
UNKNOWN STAGE PROSTATE CANCER	
	NAACCR

Please submit all questions through the Q&A panel

QUESTIONS?

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Coming up!

- 7/12/12
 - ICD-10-CM and Cancer Surveillance
- 8/2/12
 - Collecting Cancer Data: Hematopoietics

And the winners of the fabulous prizes are....

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