National Cancer Institute

REPORTING DELAY ADJUSTMENT ACROSS NAACCR REGISTRIES

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National Institutes of Health

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What is Reporting Delay?

- Registries report cases approximately 2 years after the end of specific diagnosis year.
- Cases are updates (added or deleted) in subsequent submissions

Reporting Delay Example through 2009 Submission

	Submission year										
Diagnosis Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
1997	32,741	33,460	33,793	33,958	33,917	33,968	33,881	33,914	33,941	33,955	33,965
1998		33,186	34,107	34,524	34,474	34,565	34,512	34,596	34,622	34,626	34,654
1999			34,061	34,978	35,071	35,234	35,202	35,279	35,317	35,315	35,329
2000				34,090	34,606	35,049	35,065	35,104	35,148	35,161	35,183
2001					34,640	35,293	35,758	35,845	35,952	35,976	36,003
2002						35,233	35,611	35,751	35,870	35,908	35,949
2003							34,899	35,214	35,382	35,442	35,499
2004								36,033	36,348	36,463	36,528
2005									35,670	36,095	36,226
2006										34,845	35,288
2007											36,503

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2007											36,503

- Even though delay adjustment factors are relatively small, the bias is largest for the most recent data points
  - Any small change in the recent rates is seen as a potential harbinger of the impact of cancer control activities
- Delay modeling is used to correct for under-reporting of the most recent years
  - By predicting case counts after a fixed number of years

Reporting Delay Example through 2009 Submission

	Submission Year										
Diagnosis Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
1997	2	3	4	5	6	7	8	9	10	11	12
1998		2	3	4	5	6	7	8	9	10	11
1999			2	3	4	5	6	7	8	9	10
2000				2	3	4	5	6	7	8	9
2001					2	3	4	5	6	7	8
2002						2	3	4	5	6	7
2003							2	3	4	5	6
2004								2	3	4	5
2005									2	3	4
2006										2	3
2007											2

Dark Green – Used to Produce Trends In Observed Rates

	Submission Year										
Diagnosis Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
1997	2	3	4	5	6	7	8	9	10	11	12
1998		2	3	4	5	6	7	8	9	10	11
1999			2	3	4	5	6	7	8	9	10
2000				2	3	4	5	6	7	8	9
2001					2	3	4	5	6	7	8
2002						2	3	4	5	6	7
2003							2	3	4	5	6
2004								2	3	4	5
2005									2	3	4
2006										2	3
2007											2

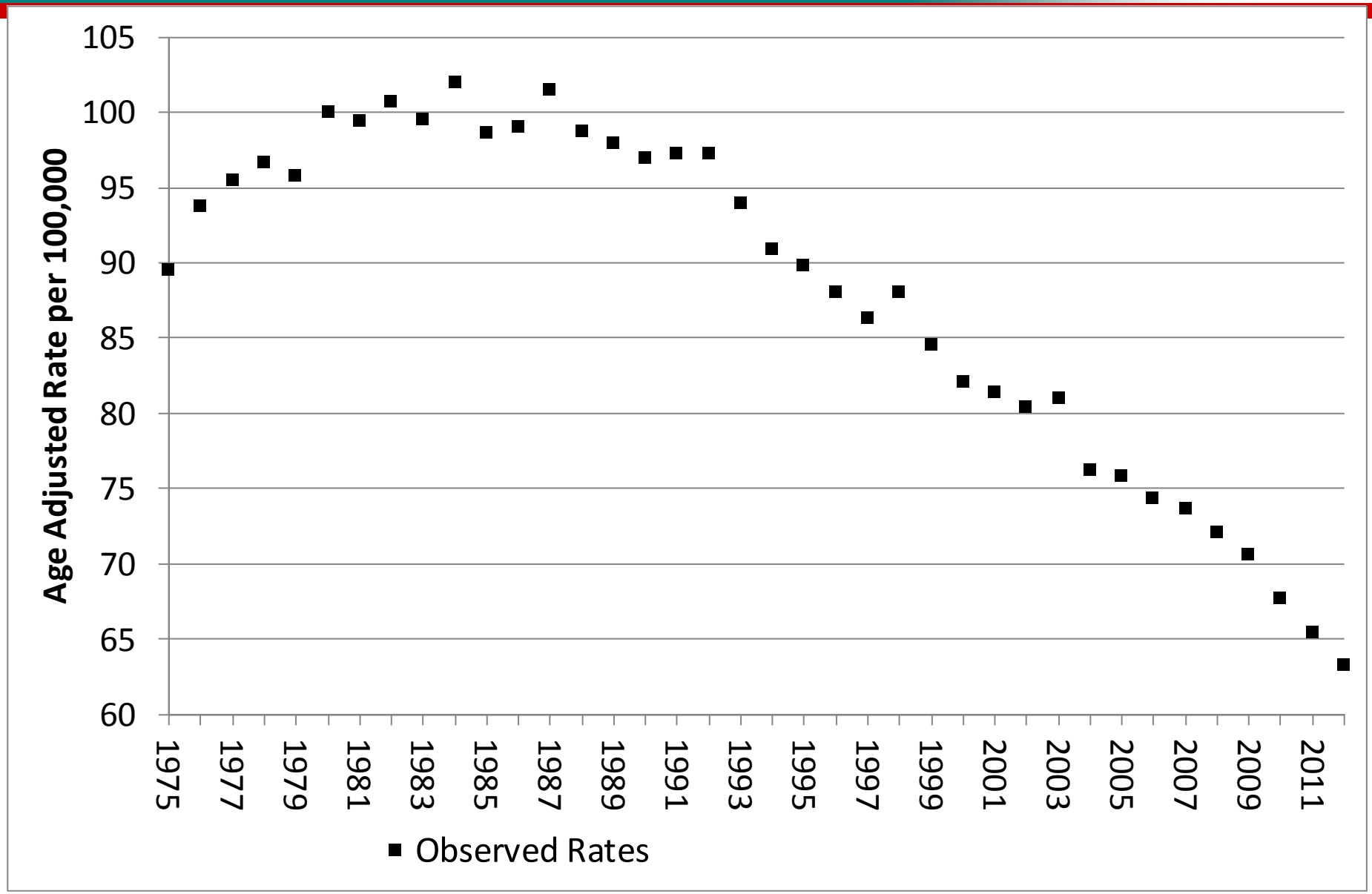
Purpose of Delay Modeling: Use the Data in Green to Project to the Yellow

	Submission Year																				
Diagnosis Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009										
1997	2	3	4	5	6	7	8	9	10	11	12										
1998		2	3	4	5	6	7	8	9	10	11	12									
1999			2	3	4	5	6	7	8	9	10	11	12								
2000				2	3	4	5	6	7	8	9	10	11	12							
2001					2	3	4	5	6	7	8	9	10	11	12						
2002						2	3	4	5	6	7	8	9	10	11	12					
2003							2	3	4	5	6	7	8	9	10	11	12				
2004								2	3	4	5	6	7	8	9	10	11	12			
2005									2	3	4	5	6	7	8	9	10	11	12		
2006										2	3	4	5	6	7	8	9	10	11	12	
2007											2	3	4	5	6	7	8	9	10	11	12

Purple – Used to Produce Trends in Delay Adjusted Rates

	Submission Year																				
Diagnosis Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009										
1997	2	3	4	5	6	7	8	9	10	11	12										
1998		2	3	4	5	6	7	8	9	10	11	12									
1999			2	3	4	5	6	7	8	9	10	11	12								
2000				2	3	4	5	6	7	8	9	10	11	12							
2001					2	3	4	5	6	7	8	9	10	11	12						
2002						2	3	4	5	6	7	8	9	10	11	12					
2003							2	3	4	5	6	7	8	9	10	11	12				
2004								2	3	4	5	6	7	8	9	10	11	12			
2005									2	3	4	5	6	7	8	9	10	11	12		
2006										2	3	4	5	6	7	8	9	10	11	12	
2007											2	3	4	5	6	7	8	9	10	11	12

Lung and Bronchus Cancer
SEER 9 Incidence for Males All Races



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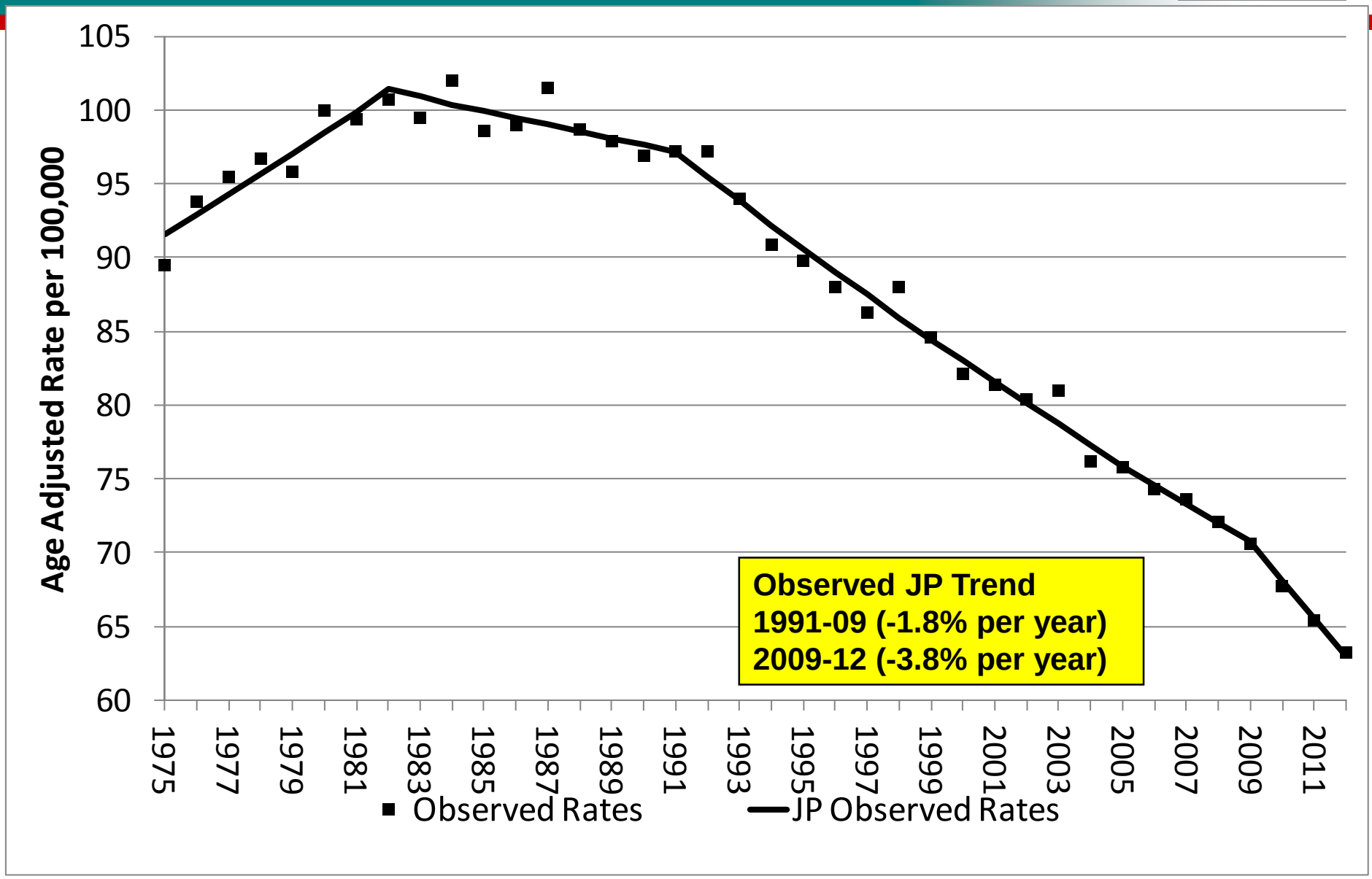

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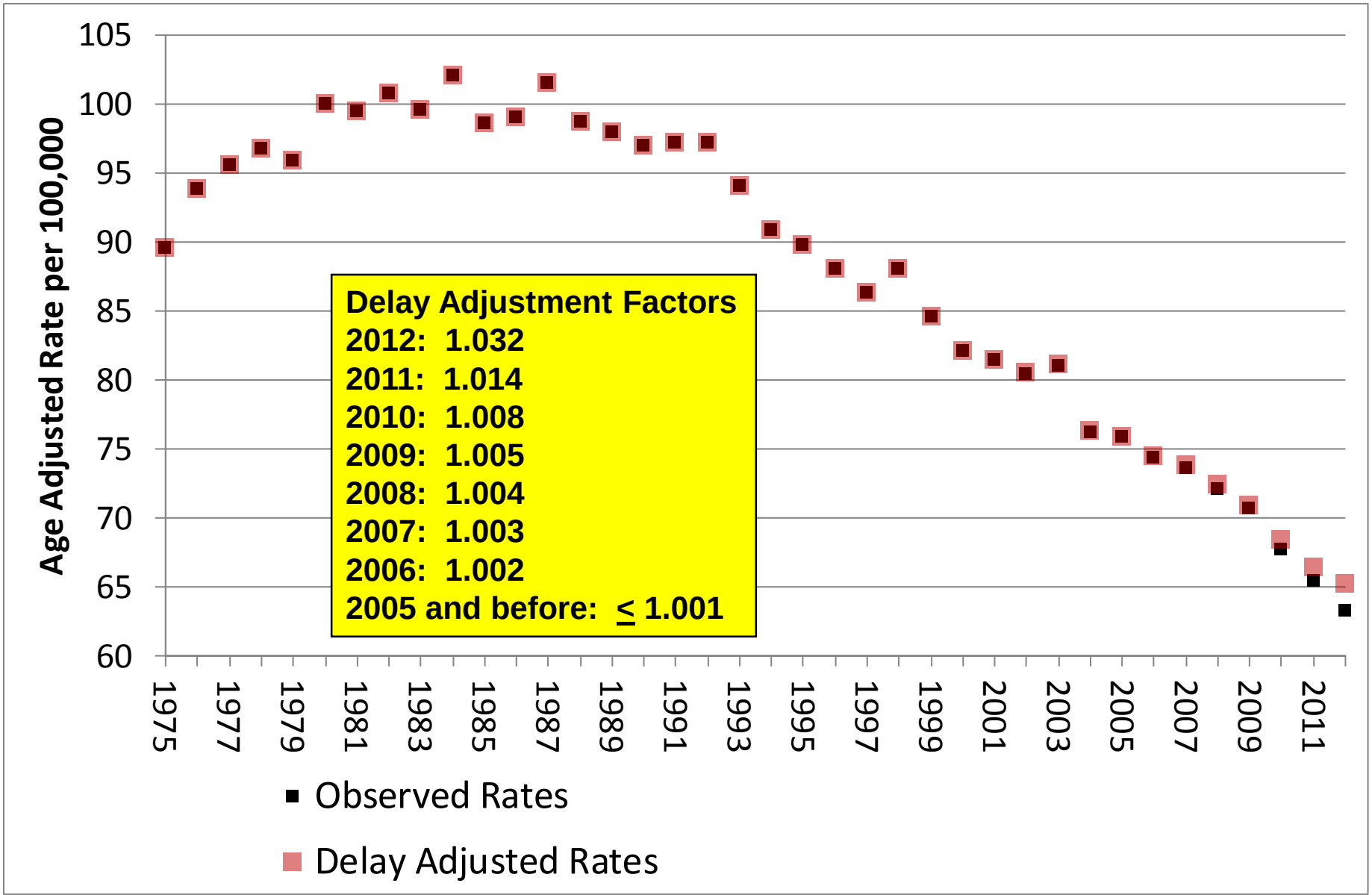

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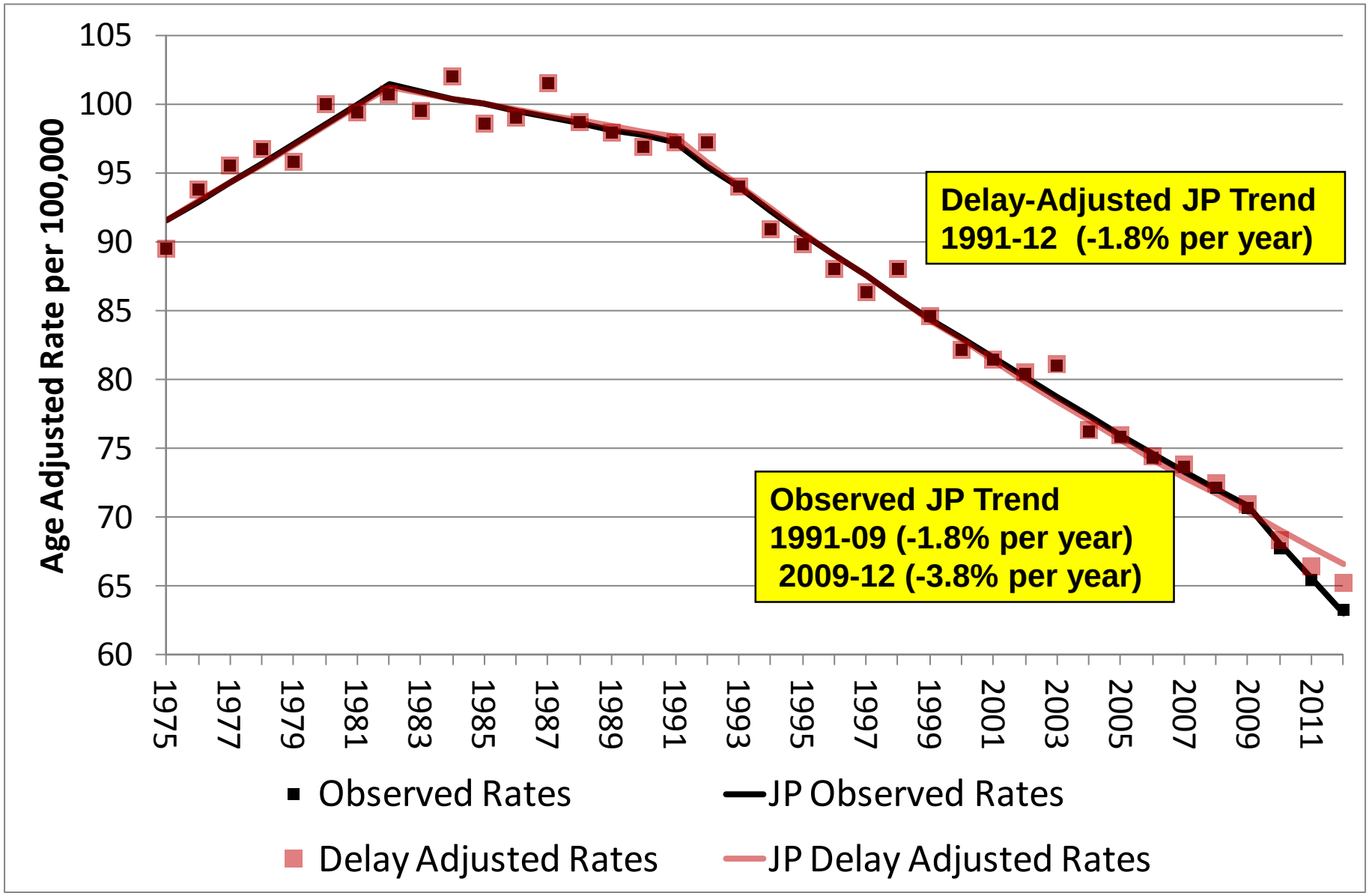

Cancer Statistics Review

- Since 2003 delay adjustment factors have been estimated for SEER 9 and SEER 13
  - Only reported for combination of gender (male, female) and races (all races, white, and black) for aggregation of registries in SEER 9 and SEER 13.

Cancer trends for SEER reported in Cancer Statistics Review

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SEER Observed Incidence, SEER Delay Adjusted Incidence and US Death Rates[a]
Cancer of the Prostate, by Race

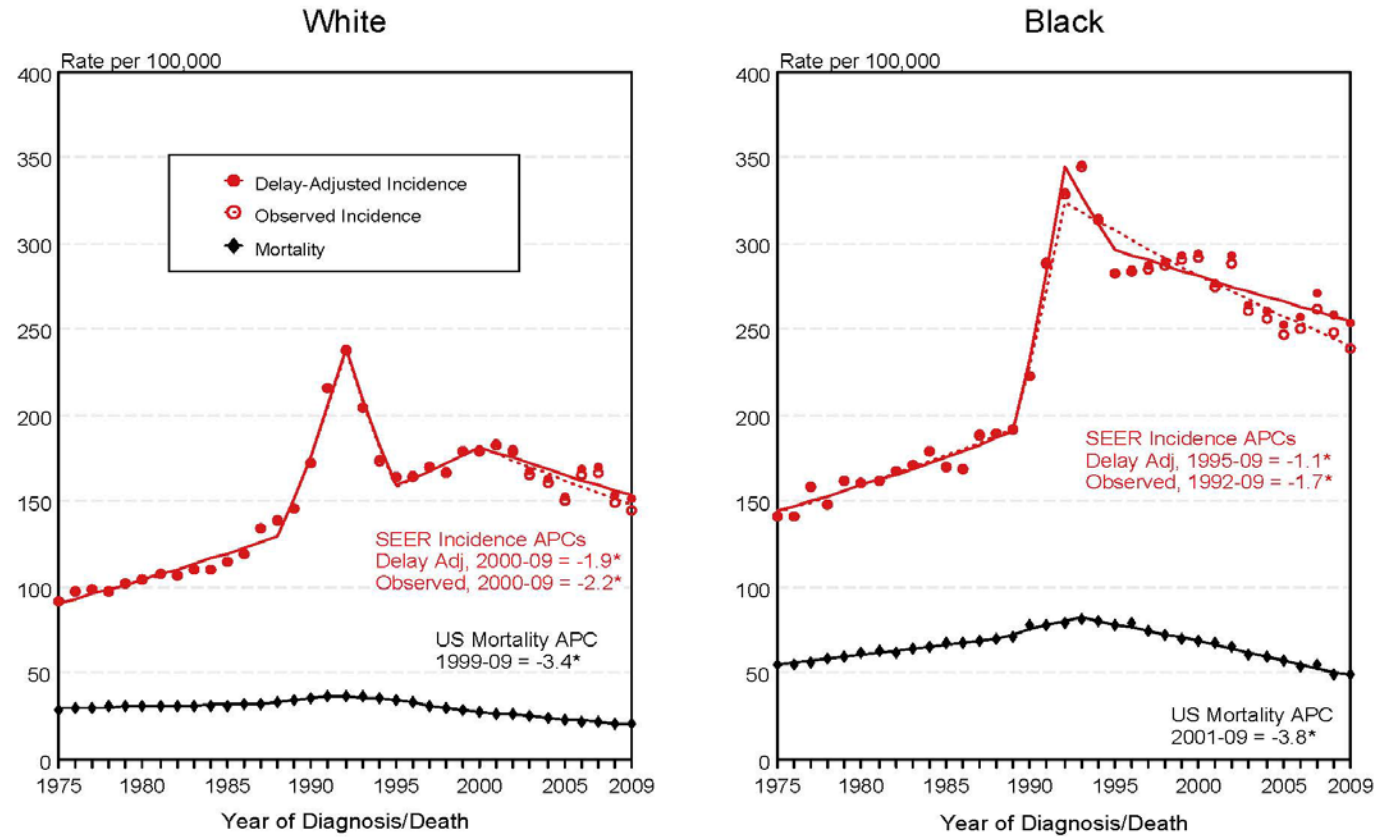


Figure 23.1

[a] Source: SEER 9 areas and US Mortality Files (National Center for Health Statistics, CDC).
Rates are age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1103).
Regression lines and APCs are calculated using the Joinpoint Regression Program Version 3.5, April 2011, National Cancer Institute.
The APC is the Annual Percent Change for the regression line segments. The APC shown on the graph is for the most recent trend.

* The APC is significantly different from zero ($p < 0.05$).

NAACCR

- Starting in 2015, for the first time, a joint effort by NCI, CDC, and the NAACCR was mounted to develop a unified approach for estimating and reporting delay-adjusted rates across all of the US and Canada
- In the future we want to facilitate delay adjustment for single registries or any combination of registries

of Registries Considered for Delay Adjustment

Total:

- 57 US registries
  - 4 states are divided into 9 sub-state registries
  - 46 state registries
  - District of Columbia
  - Puerto Rico
- 13 Canadian Registries

Three Overall Goals to Simplify and Standardize Delay Adjustment for NAACCR Registries

1. Delay adjustment factors should be adjusted to the same starting point for all registries

- SEER 9 is adjusted back to the 1983 submission but it is not possible to adjust NAACCR registries that far back
- Common starting point for many NAACCR registries is the 1999 submission (1997 diagnosis year)
  - Up to 17 years of reporting delay using the 2014 submission

Three Overall Goals (continued)

2. Produce delay factors (and standard errors) for every (or almost every) U.S. and Canadian registry
   - We would like NAACCR, NPCR, and SEER to use delay factors derived from a common set of models
   - Estimate delay factors by cancer site and registry as a function of diagnosis year, age group, race, and gender

Three Overall Goals (continued)

3. These factors should easily be “combinable” across any combination of the factors (cancer site, diagnosis year, registry, age group, race, and gender) so that the analyst can obtain delay adjusted incidence rates for any selected sub-group

Implementation: All registries use a single derived set of factors

Individual Delay Factors: race/gender/age/ dx year/cancer site/registry specific factors used to merge with cases in NAACCR, NPCR, or SEER databases

Composite Delay Factors: factors for any combination of race/gender/age/ dx year/cancer site/registry produced as a weighted average of individual factors using SEER*Stat

Statistical Modeling of Reporting Delay Run Centrally using NAACCR submission

Delay factors

Delay factors

Delay factors

merge the factors to the case data by race, sex, age, year, site, registry

NAACCR SEER*Stat

NPCR SEER*Stat

SEER SEER*Stat

Delay Adjustment Factor Releases

- 2015 release using Dec. 2014 NAACCR submission to develop factors
  - Developed at the registry level, but released with only aggregate identifiers (SEER9, SEER13, SEER18, US, Canada)
- 2016 release using Dec. 2015 NAACCR submission to develop factors
  - Developed at the registry level
  - Being used in Annual Report to the Nation
  - All race registry specific delay-adjusted rates included in CINA publication
  - SEER research data released with aggregated identifiers
  - SEER custom data available with registry identifiers

Overview of Major 2016 Changes

- Use data only from the 2004 submission/2002 diagnosis year rather than the 1999 submission/1997 diagnosis year

- A new (improved) statistical model with age, gender, and race effects

	Reporting Year																
Diagnosis Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
1997	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1998		2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1999			2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
2000				2	3	4	5	6	7	8	9	10	11	12	13	14	15
2001					2	3	4	5	6	7	8	9	10	11	12	13	14
2002						2	3	4	5	6	7	8	9	10	11	12	13
2003							2	3	4	5	6	7	8	9	10	11	12
2004								2	3	4	5	6	7	8	9	10	11
2005									2	3	4	5	6	7	8	9	10
2006										2	3	4	5	6	7	8	9
2007											2	3	4	5	6	7	8
2008												2	3	4	5	6	7
2009													2	3	4	5	6
2010														2	3	4	5
2011															2	3	4
2012																2	3
2013																	2

Rational for the Change in Data Used

- Early years are eliminated which tend to have longer reporting delays and more missing and aberrant data
- Little loss since delay times greater than 11 yielded few additional cases

Why a new statistical model?

- Old model: Unstable for some registries
  - Based on survival (cumulative distribution) type of modeling which is more sensitive to aberrant data
  - Old model had a gender and age effect, but all the factors for races were equal
- New model:
  - Based on a simpler form of model using individual ratios in multivariate regression
  - More stable, and so more individual registries can be included
    - From Dec. 2014 submission: 13 U.S and 6 Canadian registries excluded
    - From Dec. 2015 submission: 5 U.S. and 6 Canadian registries excluded

How does the new model work?

Ratios of delay time 3 and 2

$$r_{3/2} = y_{d=3}/y_{d=2}$$

Diagnosis Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
2002	2	3	4	5	6	7	8	9	10	11	12	13
2003		2	3	4	5	6	7	8	9	10	11	12
2004			2	3	4	5	6	7	8	9	10	11
2005				2	3	4	5	6	7	8	9	10
2006					2	3	4	5	6	7	8	9
2007						2	3	4	5	6	7	8
2008							2	3	4	5	6	7
2009								2	3	4	5	6
2010									2	3	4	5
2011										2	3	4
2012											2	3
2013												2

Ratios of delay time 4 and 3

$$r_{4/3} = y_{d=4}/y_{d=3}$$

Diagnosis Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
2002	2	3	4	5	6	7	8	9	10	11	12	13
2003		2	3	4	5	6	7	8	9	10	11	12
2004			2	3	4	5	6	7	8	9	10	11
2005				2	3	4	5	6	7	8	9	10
2006					2	3	4	5	6	7	8	9
2007						2	3	4	5	6	7	8
2008							2	3	4	5	6	7
2009								2	3	4	5	6
2010									2	3	4	5
2011										2	3	4
2012											2	3
												2

Ratios of delay time 5 and 4

$$r_{5/4} = y_{d=5}/y_{d=4}$$

Diagnosis Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
2002	2	3	4	5	6	7	8	9	10	11	12	13
2003		2	3	4	5	6	7	8	9	10	11	12
2004			2	3	4	5	6	7	8	9	10	11
2005				2	3	4	5	6	7	8	9	10
2006					2	3	4	5	6	7	8	9
2007						2	3	4	5	6	7	8
2008							2	3	4	5	6	7
2009								2	3	4	5	6
2010									2	3	4	5
2011										2	3	4
2012											2	3
2013												2

Ratios of delay time >5

$$r_{\frac{i}{i-1}} = \frac{y_{d=i}}{y_{d=i-1}}, i = 5,6,\ldots,11$$

Diagnosis Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
2002	2	3	4	5	6	7	8	9	10	11		
2003		2	3	4	5	6	7	8	9	10	11	
2004			2	3	4	5	6	7	8	9	10	11
2005				2	3	4	5	6	7	8	9	10
2006					2	3	4	5	6	7	8	9
2007						2	3	4	5	6	7	8
2008							2	3	4	5	6	7
2009								2	3	4	5	6
2010									2	3	4	5
2011										2	3	4
2012											2	3
2013												2

Four dependent variables

				r_{5+}					
Diagnosis Year	$r_{3/2}$	$r_{4/3}$	$r_{5/4}$	$r_{6/5}$	$r_{7/6}$	$r_{8/7}$	$r_{9/8}$	$r_{10/9}$	$r_{11/10}$
2002	y_{2005}/y_{2004}	y_{2006}/y_{2005}	y_{2007}/y_{2006}	y_{2008}/y_{2007}	y_{2009}/y_{2008}	y_{2010}/y_{2009}	y_{2011}/y_{2010}	y_{2012}/y_{2011}	y_{2013}/y_{2012}
2003	y_{2006}/y_{2005}	y_{2007}/y_{2006}	y_{2008}/y_{2007}	y_{2009}/y_{2008}	y_{2010}/y_{2009}	y_{2011}/y_{2010}	y_{2012}/y_{2011}	y_{2013}/y_{2012}	y_{2014}/y_{2013}
2004	y_{2007}/y_{2006}	y_{2008}/y_{2007}	y_{2009}/y_{2008}	y_{2010}/y_{2009}	y_{2011}/y_{2010}	y_{2012}/y_{2011}	y_{2013}/y_{2012}	y_{2014}/y_{2013}	y_{2015}/y_{2014}
2005	y_{2008}/y_{2007}	y_{2009}/y_{2008}	y_{2010}/y_{2009}	y_{2011}/y_{2010}	y_{2012}/y_{2011}	y_{2013}/y_{2012}	y_{2014}/y_{2013}	y_{2015}/y_{2014}	
2006	y_{2009}/y_{2008}	y_{2010}/y_{2009}	y_{2011}/y_{2010}	y_{2012}/y_{2011}	y_{2013}/y_{2012}	y_{2014}/y_{2013}	y_{2015}/y_{2014}		
2007	y_{2010}/y_{2009}	y_{2011}/y_{2010}	y_{2012}/y_{2011}	y_{2013}/y_{2012}	y_{2014}/y_{2013}	y_{2015}/y_{2014}			
2008	y_{2011}/y_{2010}	y_{2012}/y_{2011}	y_{2013}/y_{2012}	y_{2014}/y_{2013}	y_{2015}/y_{2014}				
2009	y_{2012}/y_{2011}	y_{2013}/y_{2012}	y_{2014}/y_{2013}	y_{2015}/y_{2014}					
2010	y_{2013}/y_{2012}	y_{2014}/y_{2013}	y_{2015}/y_{2014}						
2011	y_{2014}/y_{2013}	y_{2015}/y_{2014}							
2012	y_{2015}/y_{2014}								
2013									

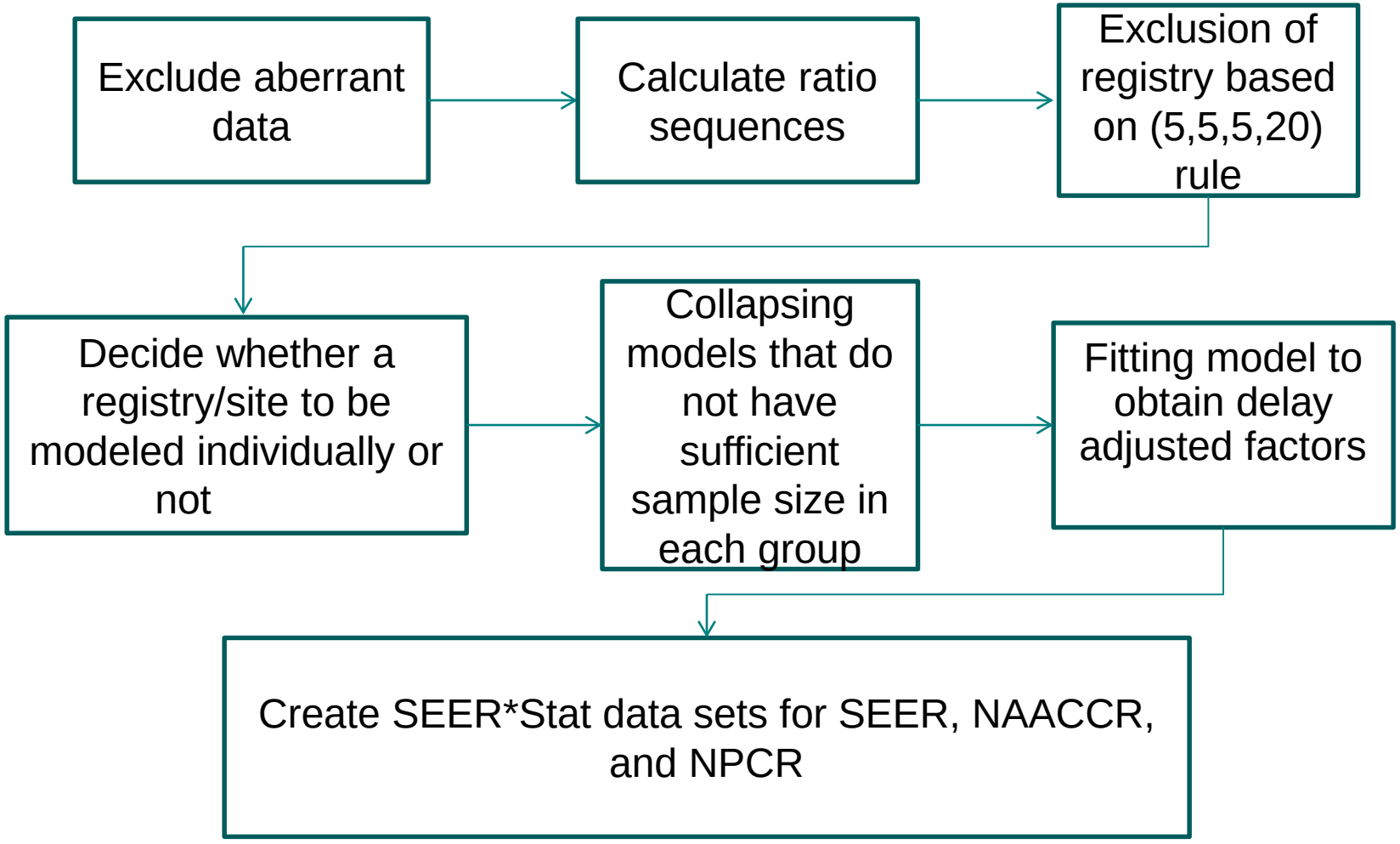
New Statistical Model

- Fit the 4 dependent variables $r_{3/2}, r_{4/3}, r_{5/4}$ and r_{5+}

  as a multivariate ANOVA using Proc Mixed in SAS

- where
  - Y = log(r),
  - X = covariates gender (male vs female), Age (<50, 50-64, 65+) and Race (White, Black, API)
- Derive the delay adjustment factors from the fitted model

Flow chart


Exclude aberrant data
Calculate ratio sequences
Exclusion of registry based on (5,5,5,20) rule
Decide whether a registry/site to be modeled individually or not
Collapsing models that do not have sufficient sample size in each group
Fitting model to obtain delay adjusted factors
Create SEER*Stat data sets for SEER, NAACCR, and NPCR

Modeling Cancer Sites/Registries with <50 Cases Per Year

- Form registry groups with similar site specific delay factors
  - Three approximately equal population groups based on empirical 5 year delay
- Use composite factors for registry/cancer site groups with <50 cases/year

Collapsing Data for Small Sample Sizes Prior to Statistical Testing for Gender, Age, and Race Effects

- Collapsing strata prior to testing for effects
  - Combine male and female if either male or female has average < 100 cases/year
  - Combine API with black, and API/black with white if the average is less than 100 cases/year
  - Collapse <50 with 50-64 and 65+ with 50-64 if average <100 cases/year
- Test for gender, race, and age effects ($p<.05$)

Results

SEER9, SEER 13, SEER18, US, and Canada 2013 Composite NAACCR-Based Delay Factors

	SEER 9	SEER 13	SEER 18	US	Canada
Cancer Site					
All Sites	1.028	1.029	1.033	1.045	1.024
Oral Cavity and Pharynx	1.023	1.027	1.032	1.045	1.015
Esophagus	1.016	1.017	1.020	1.029	1.016
Stomach	1.020	1.022	1.025	1.030	1.008
Colon and Rectum	1.018	1.019	1.022	1.032	1.014
Liver and Intrahepatic Bile Duct	1.049	1.057	1.056	1.054	1.092
Pancreas	1.029	1.031	1.034	1.038	1.035
Larynx	1.016	1.020	1.024	1.035	1.019
Lung and Bronchus	1.026	1.028	1.031	1.036	1.034
Melanoma of the Skin	1.031	1.032	1.037	1.062	1.014
Breast (female)	1.014	1.014	1.017	1.030	1.007
Cervix Uteri (female)	1.019	1.021	1.021	1.031	1.010

SEER9, SEER 13, SEER18, US, and Canada 2013 Composite NAACCR-Based Delay Factors

	SEER 9	SEER 13	SEER 18	US	Canada
Cancer Site					
Corpus and Uterus, NOS (female)	1.010	1.010	1.013	1.023	1.007
Ovary (female)	1.034	1.034	1.037	1.050	1.018
Prostate (male)	1.032	1.036	1.042	1.065	1.023
Testis (male)	1.015	1.017	1.021	1.030	1.006
Urinary Bladder	1.028	1.028	1.032	1.043	1.021
Kidney and Renal Pelvis	1.037	1.037	1.037	1.047	1.050
Brain and Other Nervous System	1.033	1.033	1.037	1.047	1.040
Thyroid	1.017	1.016	1.020	1.028	1.012
Hodgkin Lymphoma	1.020	1.019	1.024	1.035	1.014
Non-Hodgkin Lymphoma	1.034	1.033	1.040	1.055	1.017
Myeloma	1.104	1.106	1.115	1.141	1.063
Leukemia	1.144	1.135	1.139	1.157	1.117

Sample Registry Report Dec 2015 Submission Diagnosis year 2013

Data from NAACCR December 2015 Submission			United States (Total)			Sample Registry		
Site	**Sex**	**Race**	**Age-Adjusted Rate**	**Delay Age-Adjusted Rate**	**Composite Delay Factor**	**Age-Adjusted Rate**	**Delay Age-Adjusted Rate**	**Composite Delay Factor**
All Sites	Both Sexes	All Races	430.885	450.156	1.045	439.476	450.196	1.024
All Sites	Both Sexes	White	431.450	453.396	1.051	434.700	447.293	1.029
All Sites	Both Sexes	Black	436.791	464.480	1.063	447.444	465.529	1.040
All Sites	Both Sexes	Asian or Pacific Islander	279.548	298.998	1.070	258.004	268.072	1.039
All Sites	Male	All Races	468.132	491.429	1.050	509.491	522.567	1.026
All Sites	Male	White	463.284	490.989	1.060	493.166	509.713	1.034
All Sites	Male	Black	509.065	545.774	1.072	555.172	580.193	1.045
All Sites	Male	Asian or Pacific Islander	285.511	308.161	1.079	239.378	250.166	1.045
⋮								

Sample Registry Report Dec 2015 Submission Diagnosis years 2009-2013

Data from NAACCR December 2015 Submission		United States (Total)			Sample registry		
Site	**Sex**	**Age-Adjusted Rate**	**Delay Age-Adjusted Rate**	**Composite Delay Factor**	**Age-Adjusted Rate**	**Delay Age-Adjusted Rate**	**Composite Delay Factor**
All Sites	Both Sexes	448.058	457.488	1.021	454.634	460.223	1.012
All Sites	Male	500.030	511.433	1.023	541.973	548.346	1.012
All Sites	Female	411.825	419.765	1.019	391.555	396.608	1.013
Oral Cavity and Pharynx	Both Sexes	11.316	11.571	1.023	12.910	13.009	1.008
Oral Cavity and Pharynx	Male	17.052	17.445	1.023	19.814	19.985	1.009
Oral Cavity and Pharynx	Female	6.308	6.443	1.021	7.032	7.070	1.005
Stomach	Both Sexes	6.711	6.798	1.013	6.397	6.438	1.007
Stomach	Male	9.274	9.393	1.013	8.674	8.729	1.006

⋮

Four Delay Adjustment Factors per Tumor

- For each tumor, using NAACCR December submission produce delay factors for each combination:

	All races	Race-specific
All sites	X	X
Site-specific	X	X

- Cancer Site
  - Since not every cancer site is covered, we cannot have SEER*Stat weight individual sites specific factors to produce delay adjusted rates for All Sites. We need a separate All Sites factor
- Race
  - Separate all race and race specific factors are needed to account for the fact that some cases first come into the registry without a race designation, and assigned a race in later submissions
  - Race specific factors for Whites, Blacks, API
    - Working on factors for AI/AN (CHSDA counties only – not by registry) and Hispanics

Some Observations from the finding

- For US registries, in general, all races tend to have smaller delay factors then race-specific delay factors.
- Each case has an “all race” factor and a race-specific factor. If reporting “all race” statistics, the smaller all race delay adjustment factors should be used, while reporting rates for specific races, the larger race specific factors should used.

Some Observations from the finding

- Even though conceptually delay factors are estimated by cancer site registry, age group, gender, race, and delay time, because of collapsing of the data prior to modeling, or factors not reaching statistical significance, some of these factors may be identical.

Goal for the Next Year

Revise the models so they provide the proper balance of two opposing goals

Capture the unique patterns of reporting delay for each registry

Provide stable estimates that are not too noisy

2017 Specific Goals

- Revise the models so that racial/ethnic groups with smaller race specific counts can possibly have unique factors
  - In current model for smaller registries/rarer cancer sites B/API (or W/B/API) are pooled prior to analysis
- Produce factors at the registry level for White Non-Hispanic, Black Non-Hispanic, Hispanic, API
- Produce aggregate US factors for AI/AN for CHSDA counties
- Release race-specific registry-specific factors so registries can start to use delay adjustment in their individual registry reports

Thank you.