National Cancer Institute

Reporting Delay Adjustment for NAACCR Registries

Eric J.(Rocky) Feuer, Ph.D.
National Cancer Institute

NAACCR Plenary Session
Launching a New Era in Registry Operations
10-11:30 am June 18, 2015

Surveillance Research Program, NCI & IMS
NCI: Rocky Feuer, Huann-Sheng Chen, Doug Midthune
IMS: Martin Krapcho, Joe Zou, Steve Scoppa, Andy Lake, Danny Miller

NPCR, Division of Cancer Prevention and Control, CDC
CDC: Reda Wilson , Trevor Thompson, Jessica King
CDC Contractors: Kevin Zhang, Xing Dong

Delay Model Sub-Committee, NAACCR
Kevin Ward, Tom Tucker, Ron Dewar, Brenda Edwards, Frank Boscoe, Betsy Kohler

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health

What is Reporting Delay?

- Cases are reported approximately 2 years after the end of specific diagnosis year (e.g. NAACCR December 2014 submission reports cases diagnosed through 2012)
  - Cases are added and deleted in subsequent submissions
  - Delay modeling predicts case counts after a fixed number of years (e.g. after 12 years of delay) to correct for under-reporting of the most recent years

- Even though delay adjustment factors are relatively small, the bias is largest for the most recent data points
  - Most recent data points are considered most important because any small change is seen as a potential harbinger of the impact of cancer control activities

- In the past delay adjustment factors have been estimated for SEER 9 and SEER 13
  - Continuing to produce delay factors for groups of registries is not a sustainable long term solution because investigators want to combine registries in many different ways

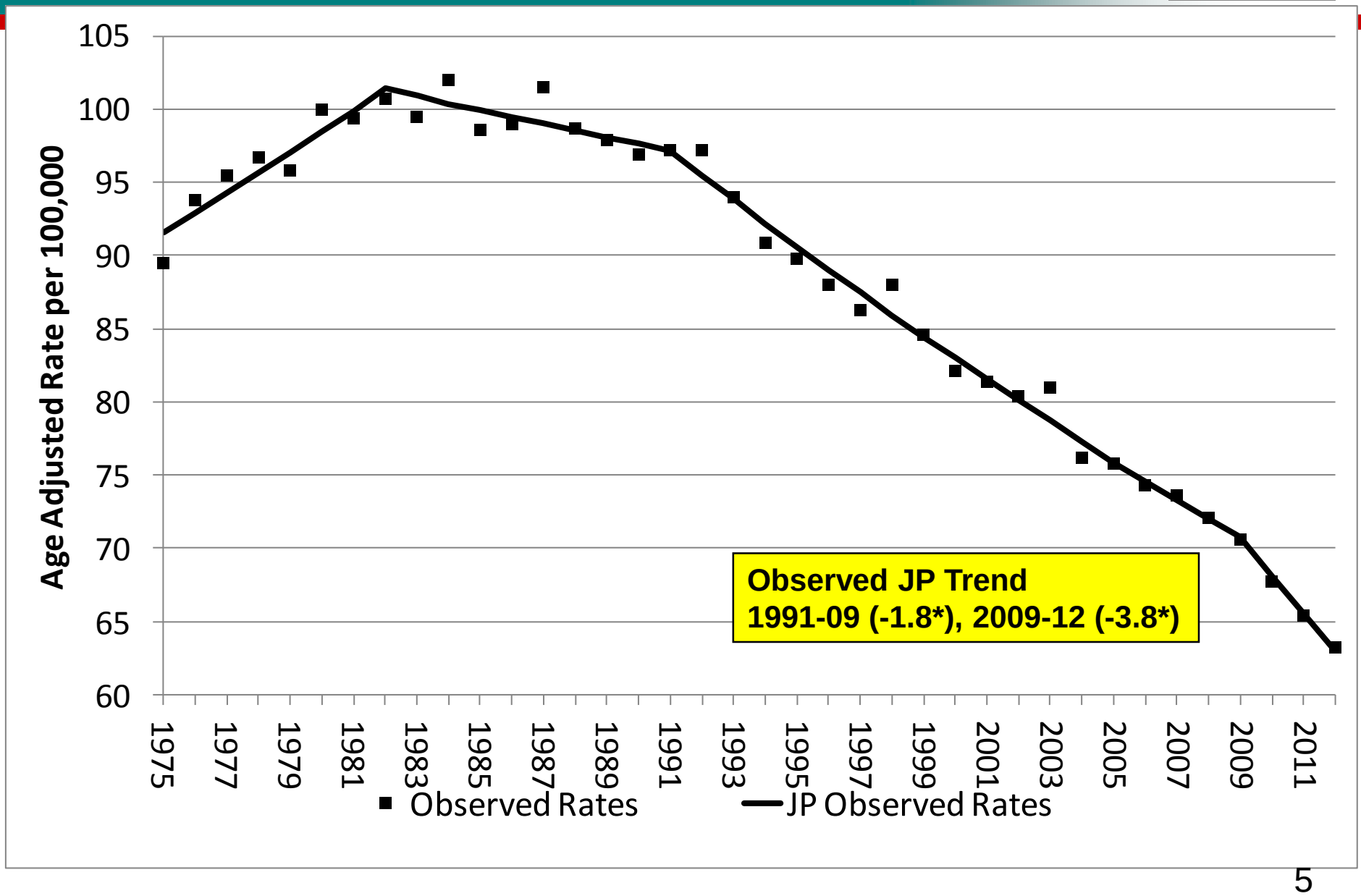
Reporting Delay Example through 2009 Submission

	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

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

Lung and Bronchus Cancer
SEER 9 Incidence for Males All Races



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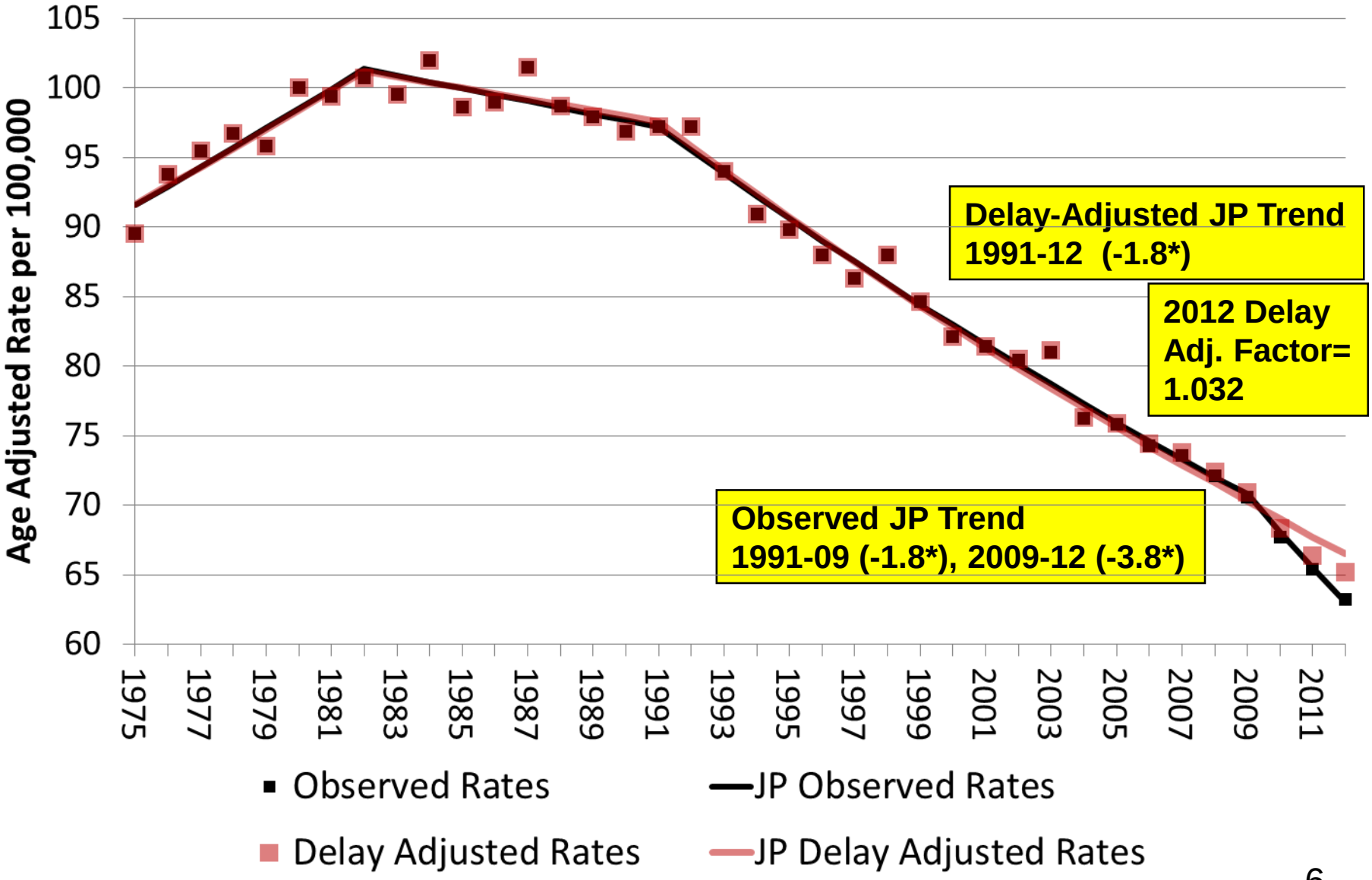


of Registries Considered for Delay Adjustment

Total:

- 56 US registries
  - 4 states are divided into 9 sub-state registries
  - 46 state registries
  - District of Columbia

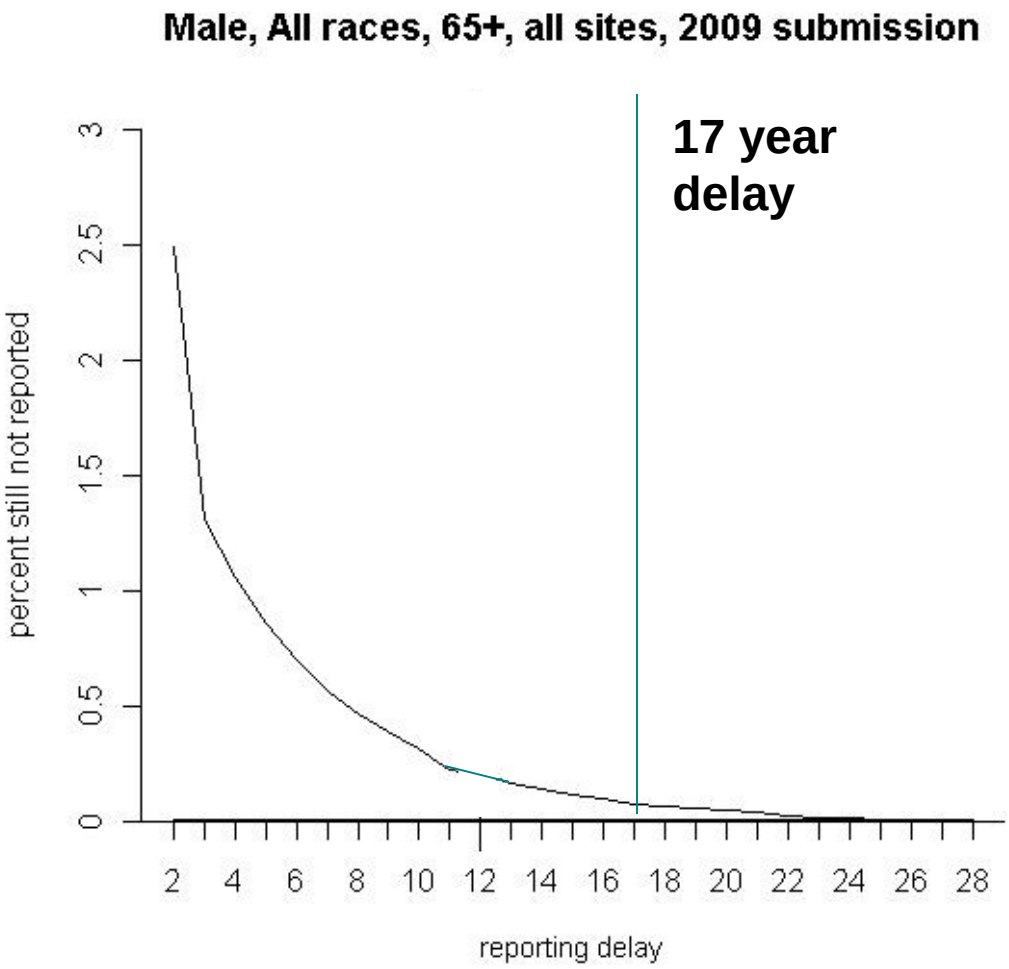
  {15 SEER funded (including NPCR co-funded) &
  41 solely NPCR funded}
- 13 Canadian Registries

Five Overall Goals to Simplify and Standardize Delay Adjustment for NAACCAR Registries

1. Delay adjustment factors should be adjusted to the same truncation 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)
  - # of years of reporting delay modeled will increase with each new submission
    - 15 years using 2012 submission
    - 16 years using 2013 submission
    - 17 years using 2014 submission

Percent of all cases still not reported after n submissions (SEER 9, 1981-2007 diagnosis years)

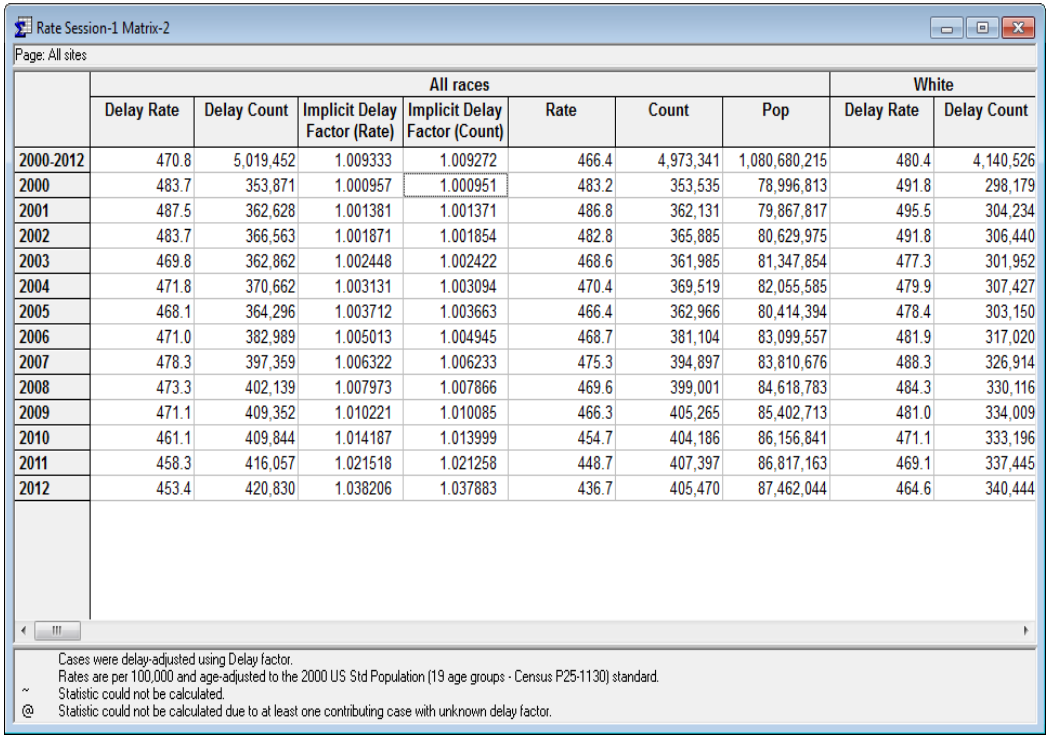


Overall Goals (continued)

2. Produce delay factors (and standard errors) for every (or almost every) U.S. registry
   - We would like NAACCR, NPCR, and SEER to use delay factors derived from a common set of models
   - Registries that do not have "enough" years of reporting or have reporting patterns that are difficult to model may be excluded
     - From 2014 submission: 12 U.S and 6 Canadian registries excluded
   - Estimate delay models for each registry and cancer site, unless the data are too sparse (average of less than 50 cases per year)
     - If the data are too sparse use groups of registries with similar delay

Overall Goals (continued)

3. These factors should easily be “combinable” across registries so that the analyst can obtain delay adjusted incidence rates using any combination of registries
   - Added delay adjustment to SEER*Stat



Rate Session-1 Matrix-2

Page: All sites

	All races							White	
	Delay Rate	Delay Count	Implicit Delay Factor (Rate)	Implicit Delay Factor (Count)	Rate	Count	Pop	Delay Rate	Delay Count
2000-2012	470.8	5,019,452	1.009333	1.009272	466.4	4,973,341	1,080,680,215	480.4	4,140,526
2000	483.7	353,871	1.000957	1.000951	483.2	353,535	78,996,813	491.8	298,179
2001	487.5	362,628	1.001381	1.001371	486.8	362,131	79,867,817	495.5	304,234
2002	483.7	366,563	1.001871	1.001854	482.8	365,885	80,629,975	491.8	306,440
2003	469.8	362,862	1.002448	1.002422	468.6	361,985	81,347,854	477.3	301,952
2004	471.8	370,662	1.003131	1.003094	470.4	369,519	82,055,585	479.9	307,427
2005	468.1	364,296	1.003712	1.003663	466.4	362,966	80,414,394	478.4	303,150
2006	471.0	382,989	1.005013	1.004945	468.7	381,104	83,099,557	481.9	317,020
2007	478.3	397,359	1.006322	1.006233	475.3	394,897	83,810,676	488.3	326,914
2008	473.3	402,139	1.007973	1.007866	469.6	399,001	84,618,783	484.3	330,116
2009	471.1	409,352	1.010221	1.010085	466.3	405,265	85,402,713	481.0	334,009
2010	461.1	409,844	1.014187	1.013999	454.7	404,186	86,156,841	471.1	333,196
2011	458.3	416,057	1.021518	1.021258	448.7	407,397	86,817,163	469.1	337,445
2012	453.4	420,830	1.038206	1.037883	436.7	405,470	87,462,044	464.6	340,444

Cases were delay-adjusted using Delay factor.
Rates are per 100,000 and age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1130) standard.
~ Statistic could not be calculated.
@ Statistic could not be calculated due to at least one contributing case with unknown delay factor.

Overall Goals (continued)

4. At deployment, abandon all previously developed delay adjustment factors, so there is a single agreed upon standard set of factors
   - E.g. eliminate use of old SEER9, SEER13 factors at the time of deployment

5. Allow (but do not necessarily encourage) analysis of delay adjusted rates by factors beyond what are included in delay models
   - E.g. delay adjusted rates by stage of disease

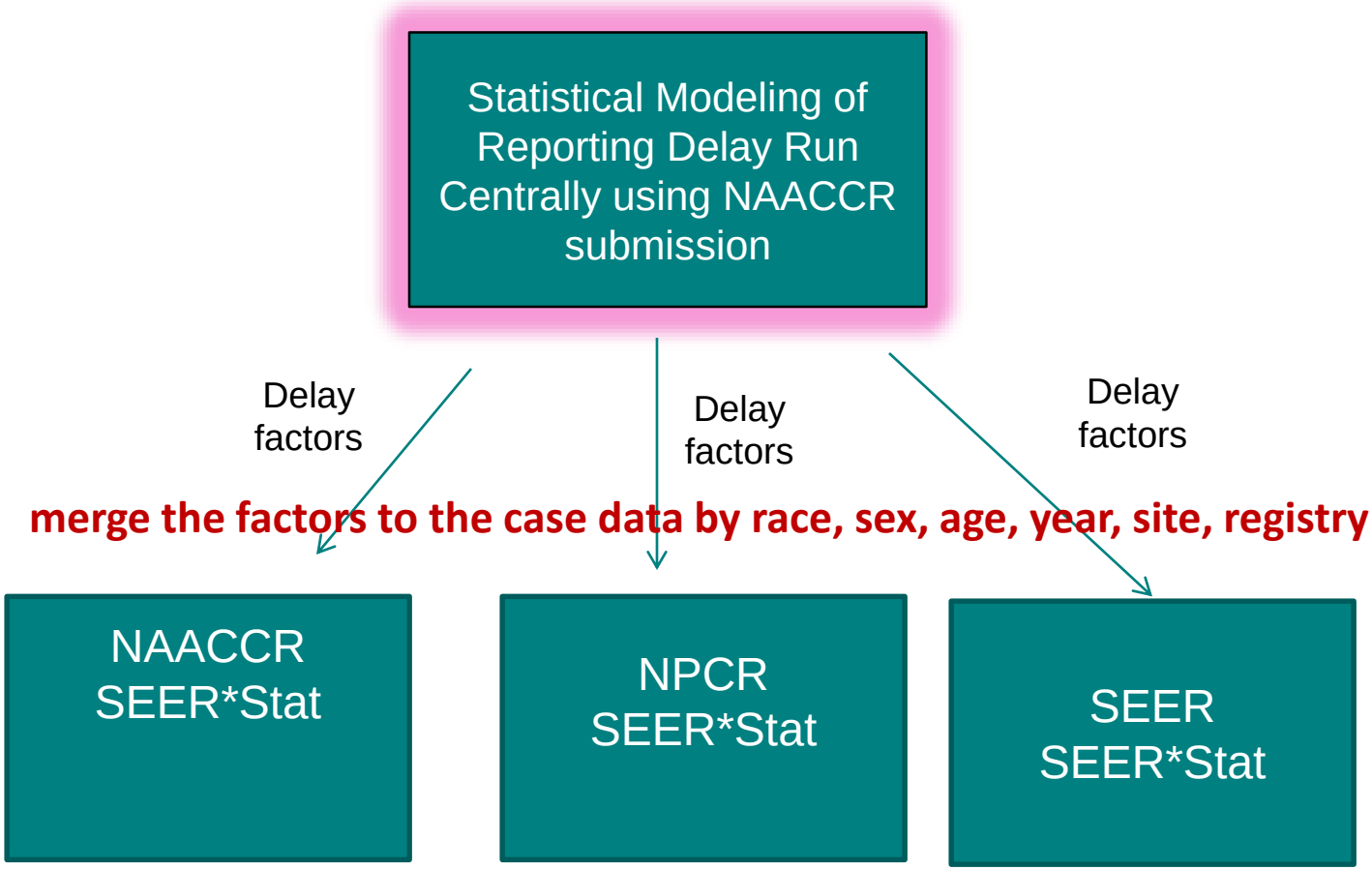
Four Delay Adjustment Factors per Tumor

- 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
  - Specific factors are needed to account for the fact that some cases are not assigned a race when they are first submitted, or race may be recoded
  - Produce race specific factors for Whites, Blacks, API
    - Not AI/AN (too sparse)

Implementation: All registries use a single derived set of factors



Philosophy for First Release of NAACCR-Based Delay Factors

- To be released and used for aggregation of registries only
  - SEER 9, SEER 13, SEER 18, US, Canada
  - SEER*Stat files with delay adjustment factors will not have individual registry identifiers
- Beta-test year for individual registry use
  - Individual registry factors are less stable and should NOT be used for any analyses or reporting (including state registry reports) this first year
  - Encourage feedback during 2015 so we can consider modifications for 2016 release (using December 2015 submission) that potentially allow delay adjustment for individual registries (or any group of registries)
  - We will be sending individual registry reports
- Reminder – Delay is not a quality measure

SEER9, SEER 13, SEEER18, US, and Canada 2012 Implicit NAACCR-Based Delay Factors

	SEER 9	SEER 13	SEER 18	US	Canada
Cancer Site					
All Sites	1.032	1.033	1.038	1.054	1.035
Oral Cavity and Pharynx	1.030	1.032	1.038	1.053	1.024
Esophagus	1.019	1.020	1.023	1.030	1.012
Stomach	1.022	1.022	1.025	1.031	1.019
Colon and Rectum	1.020	1.020	1.024	1.034	1.023
Liver and Intrahepatic Bile Duct	1.053	1.064	1.061	1.057	1.091
Pancreas	1.037	1.041	1.041	1.046	1.047
Larynx	1.021	1.022	1.027	1.041	1.016
Lung and Bronchus	1.032	1.033	1.036	1.043	1.038
Melanoma of the Skin	1.030	1.030	1.035	1.058	1.034
Breast (female)	1.017	1.017	1.022	1.042	1.019
Cervix Uteri (female)	1.020	1.020	1.025	1.039	1.030

SEER9, SEER 13, SEEER18, US, and Canada 2012 Implicit NAACCR-Based Delay Factors

	SEER 9	SEER 13	SEER 18	US	Canada
Cancer Site					
Corpus and Uterus, NOS (female)	1.012	1.012	1.016	1.028	1.012
Ovary (female)	1.042	1.040	1.043	1.061	1.039
Prostate (male)	1.038	1.042	1.050	1.082	1.029
Testis (male)	1.018	1.018	1.020	1.035	1.013
Urinary Bladder	1.032	1.031	1.036	1.052	1.021
Kidney and Renal Pelvis	1.037	1.037	1.042	1.054	1.057
Brain and Other Nervous System	1.038	1.040	1.043	1.057	1.019
Thyroid	1.023	1.021	1.027	1.036	1.032
Hodgkin Lymphoma	1.025	1.022	1.027	1.047	1.025
Non-Hodgkin Lymphoma	1.042	1.042	1.049	1.072	1.028
Myeloma	1.108	1.105	1.117	1.152	1.050
Leukemia	1.154	1.146	1.156	1.187	1.133

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

Upcoming Events

- Registry specific reports will be sent just after the meetings
  - Registry specific SEER*Stat files with delay adjustment factors will be available upon request
- July 23rd - 2pm ET
  - NAACCR webinar on using SEER*Stat to produce delay adjusted rates
- Working with Report to the Nation (RTN) team to consider NAACCR-based delay factors

Sample Registry Report Dec 2014 Submission

			Reference Implicit Delay Factors 2012		
Cancer Site	Sex	Race	United States	SEER 18	Registry xxxx Implicit Delay Factor 2012
All Sites	Both Sexes	All Races	1.054	1.033	1.088
All Sites	Both Sexes	White	1.065	1.041	1.099
All Sites	Both Sexes	Black	1.066	1.040	1.097
All Sites	Both Sexes	API	1.053	1.040	1.098
All Sites	Male	All Races	1.064	1.040	1.103
All Sites	Male	White	1.077	1.050	1.116
All Sites	Male	Black	1.077	1.049	1.113
All Sites	Male	API	1.066	1.051	1.115
All Sites	Female	All Races	1.046	1.026	1.073
All Sites	Female	White	1.053	1.031	1.082
All Sites	Female	Black	1.055	1.031	1.080
All Sites	Female	API	1.042	1.030	1.082
Oral Cavity and Pharynx	Both Sexes	All Races	1.053	1.032	1.108
Oral Cavity and Pharynx	Both Sexes	White	1.062	1.037	1.097
Oral Cavity and Pharynx	Both Sexes	Black	1.059	1.034	1.018
Oral Cavity and Pharynx	Both Sexes	API	1.045	1.032	1.069

Question?

- When they become available, would you find it useful to add delay adjusted rates and trends to your state registry reports?
  - (1) Absolutely – I love delay adjustment!
  - (2) Very Likely
  - (3) Somewhat Likely
  - (4) Not Sure
  - (5) Somewhat Unlikely
  - (6) Very Unlikely
  - (7) No way – this seems too complicated!