



Department  
of Health

# The impact of the “presumed alive” follow-up method on survival rates by race/ethnicity and national origin in New York

Maria J. Schymura  
Francis P. Boscoe  
Baozhen Qiao  
Xiuling Zhang

NAACCR Annual Conference, Charlotte, NC  
June 18, 2015

# Background

- The “presumed alive” method is being increasingly used
  - NPCR; U.S. Cancer Statistics
  - NAACCR
  - NYSCR
- Pinheiro et al showed that for API and Hispanics the “presumed alive” method overestimates survival
  - 0.9-6.2 percentage points among Hispanics
  - 0.4-2.7 percentage points among API
  - Overestimation is worse for cancer sites with poorer survival

## Background – cont.

- NYSCR does not conduct active follow-up
- NYSCR includes a high proportion of Hispanics and API
- What do the survival rates for Hispanics and API look like in the NYSCR?



# Methods

1. Compared 5-year observed age-adjusted survival by race/ethnicity in NY to SEER18
  - Cases diagnosed 2000-2008, followed through 12/31/2012
  - Presumed alive method used for NY
  - Active follow-up method used for SEER18
  - Sites examined:
    - Favorable survival sites: colorectal, female breast, prostate
    - Poor survival sites: lung & bronchus, esophagus, gallbladder, liver & intrahepatic bile duct, pancreas, and stomach
  - Comparisons conducted by birth place and stage at diagnosis

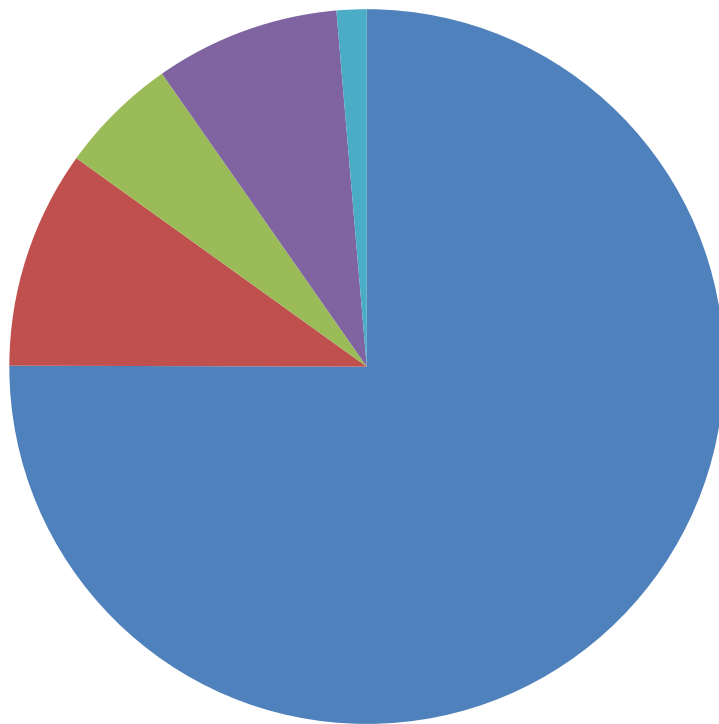
## Methods – cont'd.

2. Examined percent alive distribution in NY by race/ethnicity, social security # (present, missing), birth place (US, non-US, unknown), and age (<65, 65+)
  - Cases diagnosed 2000-2008, followed through 12/31/2012
3. Examined birth place distribution in NY for unlikely survivors
  - dx 2000-2007 at distant stage with a cancer site of poor survival and alive 5 or more years after dx

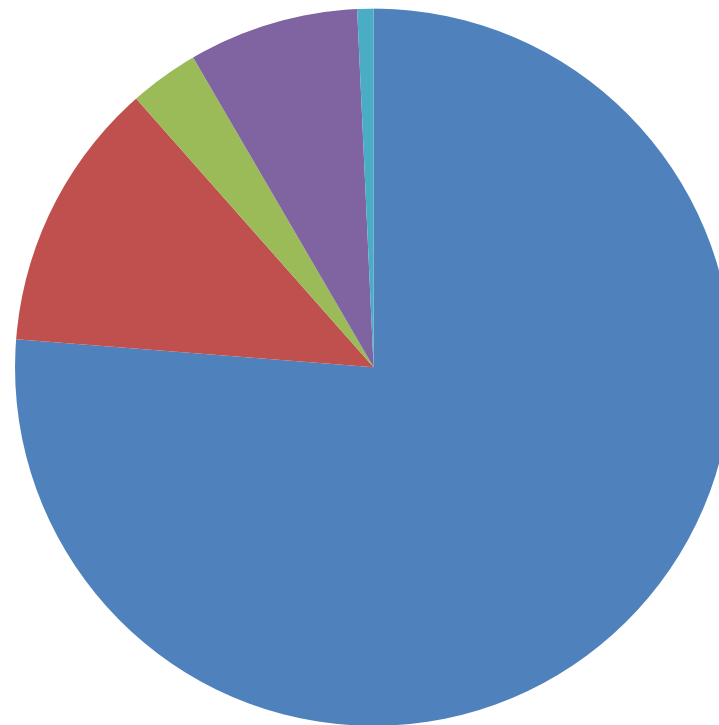
Note: In all analyses - all racial groups (whites, blacks, API) exclude Hispanics

# Race/Ethnicity Distribution of Cancer Cases Diagnosed 2000-2008, SEER18 and NYSCR

**SEER18**



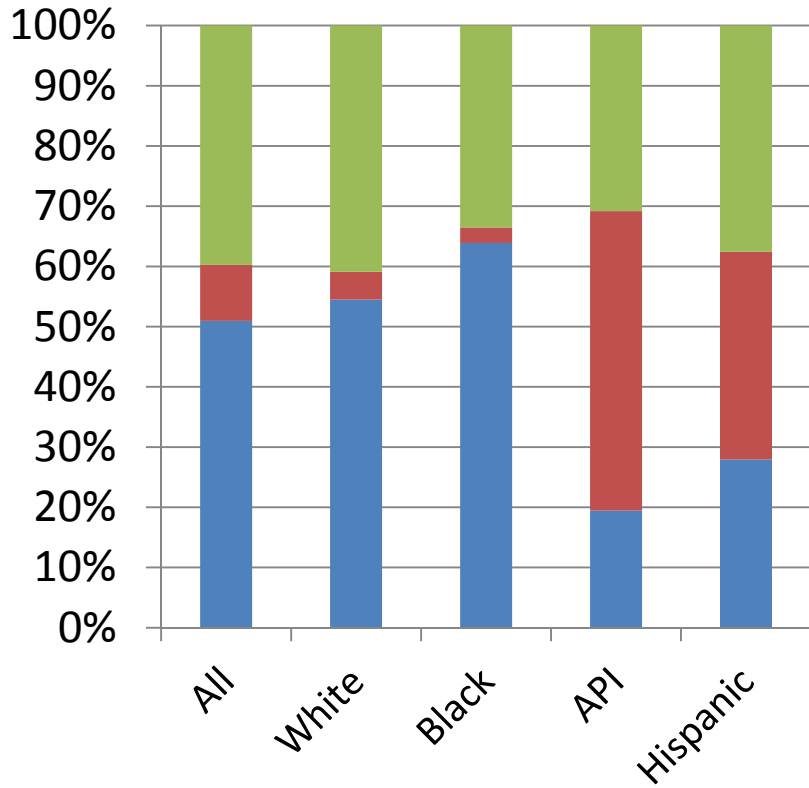
**NYSCR**



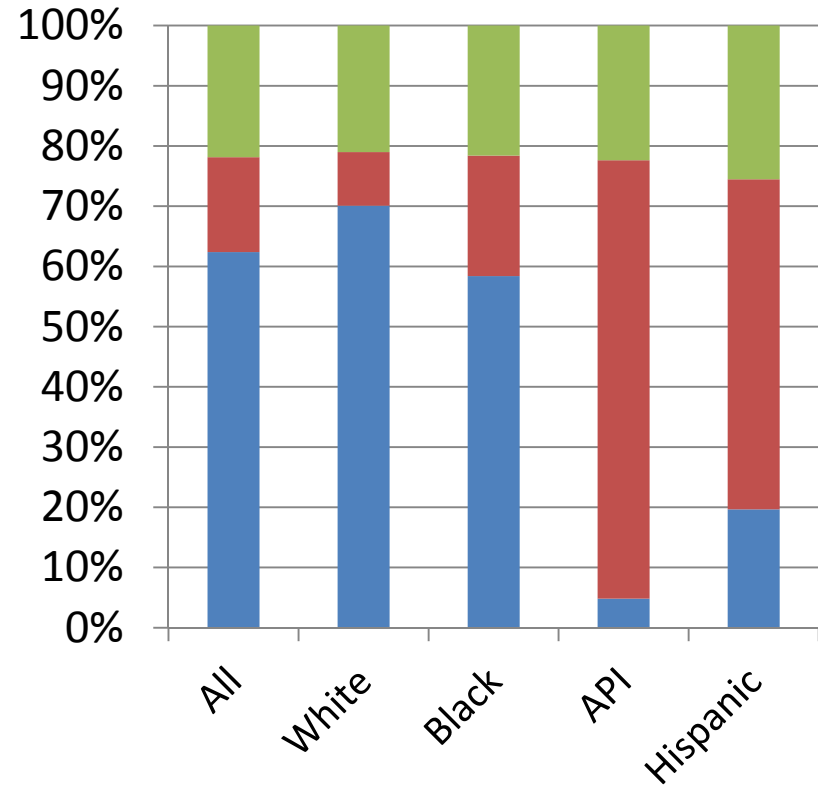
- White
- Black
- API
- Hispanic
- Other

# Birth Place Distribution of Cancer Cases Diagnosed 2000-2008, SEER18 and NYSCR, by Race/Ethnicity

## SEER18



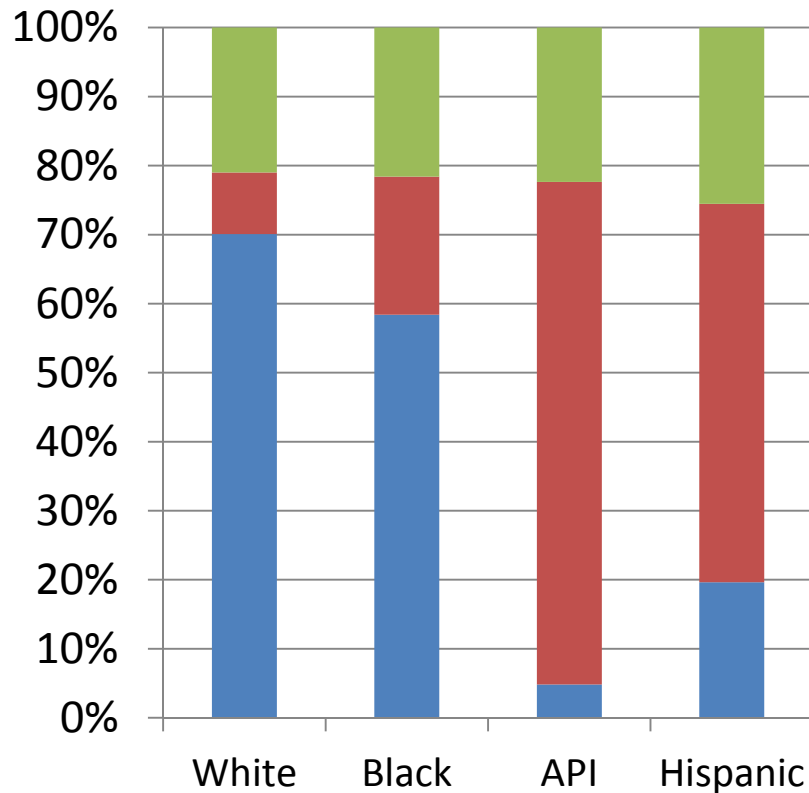
## NYSCR



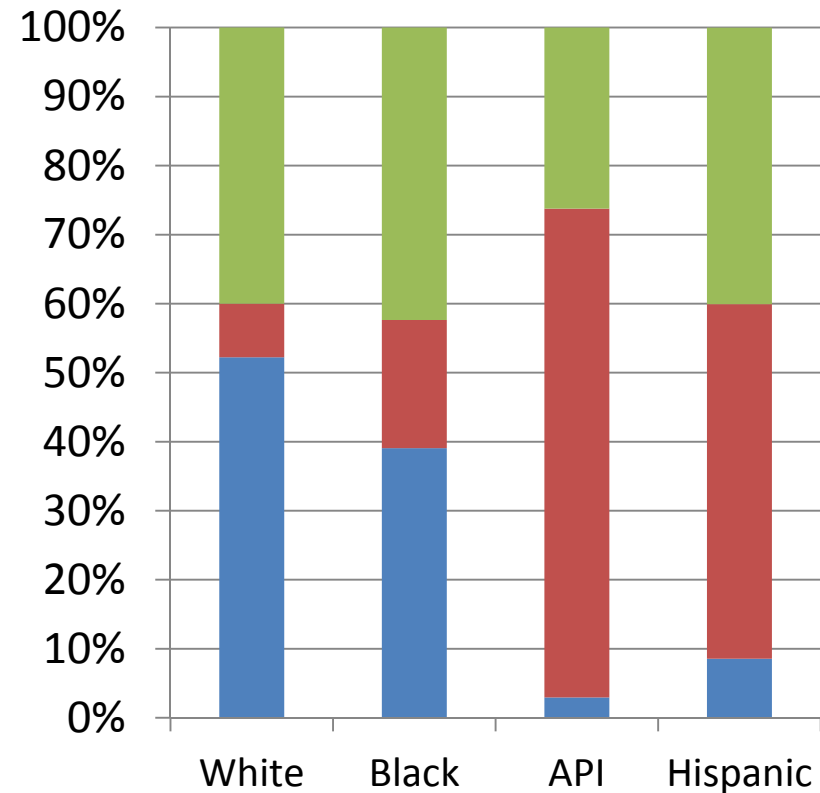
■ US     
 ■ non-US     
 ■ Unknown

# NYSCR Birth Place Distribution With and Without Information from the Death Certificate, 2000-2008 Diagnoses, by Race/Ethnicity

## With Death Information



## Without Death Information



■ US     
 ■ non-US     
 ■ Unknown



# Age-Adjusted Observed 5-Year Survival, Cases Diagnosed 2000-2008, by Race/Ethnicity, NYSCR and SEER18

Cancer Sites	Race/Ethnicity	NYSCR Survival	SEER18 Survival	Difference
<b>Favorable Survival Sites</b>	All	74.1%	73.7%	0.4%
	White	75.1%	74.7%	0.4%
	Black	68.5%	65.9%	2.6%
	API	77.4%	76.2%	1.2%
	Hispanic	74.2%	73.6%	0.6%
<b>Poor Survival Sites</b>	All	17.6%	14.0%	3.6%
	White	17.1%	14.2%	2.9%
	Black	14.1%	10.7%	3.4%
	API	29.9%	18.0%	11.9%
	Hispanic	20.0%	13.8%	6.2%

# Age-Adjusted Observed 5-Year Survival, Cases Diagnosed 2000-2008, by Race/Ethnicity, NYSCR and SEER18

Cancer Sites	Race/Ethnicity	NYSCR Survival	SEER18 Survival	Difference
<b>Favorable Survival Sites</b>	All	74.1%	73.7%	0.4%
	White	75.1%	74.7%	0.4%
	Black	68.5%	65.9%	2.6%
	API	77.4%	76.2%	1.2%
	Hispanic	74.2%	73.6%	0.6%
<b>Poor Survival Sites</b>	All	17.6%	14.0%	3.6%
	White	17.1%	14.2%	2.9%
	Black	14.1%	10.7%	3.4%
	API	29.9%	18.0%	11.9%
	Hispanic	20.0%	13.8%	6.2%

**Difference = 12.8%**

**Difference = 3.8%**

## Possible Sources of Bias that Contribute to the “Apparent” API and Hispanic Survival Advantage

- Linkage issues
  - Inaccurate or missing SSNs
  - Surname transcription errors
  - Less variability in surnames among Chinese, Korean, and Vietnamese populations
- Ill patients returning to home country before death (“salmon bias”)
- “Medical tourism”

# Age-Adjusted Observed 5-Year Survival, Cases Diagnosed 2000-2008, Born in the US, by Race/Ethnicity, NYSCR and SEER18

Cancer Sites	Race/Ethnicity	NYSCR Survival	SEER18 Survival	Difference
<b>Favorable Survival Sites</b>	All	65.1%	60.5%	4.6%
	White	67.2%	61.5%	5.7%
	Black	54.3%	52.8%	1.5%
	API	69.7%	72.1%	-2.4%
	Hispanic	52.1%	64.7%	-12.6%
<b>Poor Survival Sites</b>	All	11.8%	8.8%	3.0%
	White	12.6%	8.9%	3.7%
	Black	8.5%	6.9%	1.6%
	API	16.3%	13.5%	2.8%
	Hispanic	7.6%	10.3%	-2.7%

Difference =3.7%    Difference=4.6%

# Percent Alive Distribution

# Contribution of Missing SSN to API vs. White Difference in Percent Alive

% Alive (White) = 45.8%

% Alive (API) = 57.9%

Difference in % Alive (API-White) = 57.9% - 45.8% = 12.1%

Population	Proportion of Cases		Population	% Alive	
	With SSN	Missing SSN		With SSN	Missing SSN
White	99.6%	0.4%	White	45.7%	84.3%
API	94.3%	5.7%	API	56.6%	78.3%

Population	Contribution to % Alive	
	With SSN	Missing SSN
White	45.5%	0.3%
API	53.4%	4.5%



= 57.9%

# Contribution of Missing SSN to API vs. White Difference in Percent Alive

% Alive (White) = 45.8%      % Alive (API) = 57.9%

Difference in % Alive (API-White) = 57.9% - 45.8% = **12.1%**

Population	Proportion of Cases		Population	% Alive	
	With SSN	Missing SSN		With SSN	Missing SSN
White	99.58%	0.42%	White	45.65%	84.32%
API	94.25%	5.75%	API	56.64%	78.31%

Population	Contribution to % Alive	
	With SSN	Missing SSN
White	45.5%	0.3%
API	53.4%	4.5%



<b>Difference</b>	<b>7.9%</b>	<b>4.2%</b>	<b>12.1%</b>
-------------------	-------------	-------------	--------------

# Contribution of SSN, Birth Place, and Age to Percent Alive by Race/Ethnicity

Factor		% Alive			
		White	Black	API	Hispanic
		45.8%	44.2%	57.9%	52.8%
		Contribution of Factor to % Alive			
SSN	Not missing	45.5%	42.2%	53.4%	49.2%
	Missing	0.3%	2.0%	4.5%	3.6%
Birth Place*	U.S.	23.5%	15.6%	2.5%	12.8%
	Non-U.S.	3.3%	9.7%	38.8%	16.9%
	Unknown	19.0%	18.9%	16.6%	23.1%
Age	<65	26.7%	29.1%	40.6%	36.1%
	≥65	19.2%	15.1%	17.3%	16.7%

\*Puerto Rico included with U.S.



# Contribution of SSN, Birth Place, and Age to Race/Ethnicity Differences in the Percent Alive

White=Referent

Factor		Difference in % Alive		
		Black	API	Hispanic
		-1.6%	12.1%	7.0%
		Contribution of Factor to Difference in % Alive		
SSN	Not missing	-3.3%	7.9%	3.8%
	Missing	1.6%	4.2%	3.2%
Birth Place*	U.S.	-8.0%	-21.0%	-10.7%
	Non-U.S.	6.4%	35.5%	13.6%
	Unknown	-0.0%	-2.4%	4.1%
Age	<65	2.4%	13.9%	9.4%
	≥65	-4.0%	-1.9%	-2.4%

\*Puerto Rico included with US

# Unlikely Survivors

## Comparison of Birth Place Distribution, Unlikely Survivors vs. All Cases Diagnosed 2000-2007

<b>Birth Place</b>	<b>Unlikely Survivors</b>	<b>All Cases dx 2000-2007</b>	<b>Ratio</b>
United States	34.76%	62.38%	0.56
Puerto Rico	0.85%	1.54%	0.55
Haiti	1.39%	0.49%	2.83
Dominican Republic	2.88%	0.84%	3.43
Jamaica	2.08%	0.76%	2.74
Other Caribbean Islands	1.39%	0.72%	1.93
Columbia	1.23%	0.26%	4.72
Ecuador	1.39%	0.27%	5.14
Italy	0.96%	1.29%	0.74
Poland	1.28%	0.51%	2.51
Philippines	1.07%	0.25%	4.27
China	5.45%	1.11%	4.91
Korea	0.96%	0.26%	3.70
All Other Countries	16.60%	6.43%	2.58
Unknown	26.64%	21.87%	1.22

# The Main Issues Contributing to the Survival Advantage in New York

## 1. Salmon bias

- Some cases on registry have text including the intent to return to home country
- Many examples of individuals who “should” have died who have not been heard of for many years – no registry reports, no Medicaid or Medicare claims, no hospitalizations, not in LexisNexis

## 2. “Medical Tourism”

- Above-board medical tourism not so much of an issue because usually reported as such
  - Though sometimes with a NY address corresponding to the hospital, its international services office, or extended-stay apartments it manages
- Much more difficult to identify individuals from other countries who seek care through emergency room or short-term Medicaid enrollment
  - Also face this issue with residents of other states (poster #05 by X. Zhang)

# The Main Issues Contributing to the Survival Advantage in New York – cont'd.

## 3. Generous Medicaid Program

- Medicaid is for NY residents
- Medicaid for the treatment of an emergency medical condition may be provided to eligible temporary non-immigrants and undocumented aliens
  - The physician determines whether treatment for cancer meets the definition of an emergency medical condition
- NYSCR is counting some people who were never NY residents
- We will be working with our Medicaid program to get a better handle on identifying these individuals

## Conclusion re the “Presumed Alive Method”

- Clearly does not work in NY for API, Hispanics, and to a lesser extent blacks
  - API and Hispanics represent almost 11% of our cases
  - Blacks represent 12.2%
- Is also an issue for foreign born whites but their contribution to the white survival rate is smaller
- Although survival rate looks “reasonable” for total and white population, does not mean it’s accurate
- One of the main reasons for looking at survival is to examine survival differences
- We will try to incorporate some additional follow-up
  - Implementation will depend on resources and access
- These issues are not unique to New York

# Acknowledgement

This work was funded in part by CDC's Cooperative Agreement U58DP003879 awarded to the New York State Department of Health. The contents are solely the responsibility of the New York State Department of Health and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

**Contact Information:**

Maria J. Schymura, Ph.D

[maria.schymura@health.ny.gov](mailto:maria.schymura@health.ny.gov)

New York State Cancer Registry



**Questions?**

**Thank you!**