

# Research on cancer patient-reported outcomes: opportunities using the SEER-MHOS & SEER-CAHPS cancer registry-survey linkages

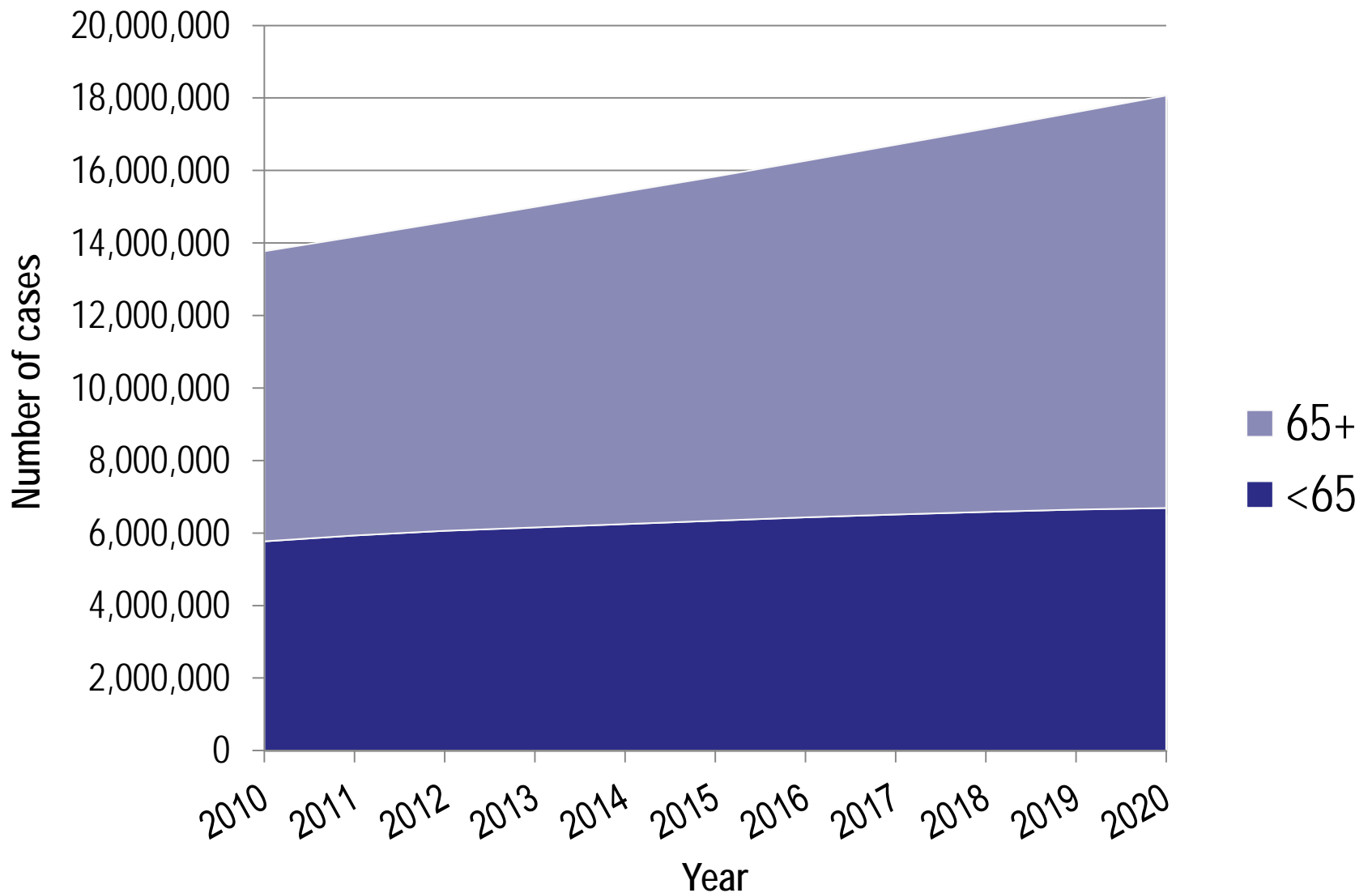
DCCPS New Grantee Workshop  
November 5, 2015

For more information, contact:

Erin Kent, PhD

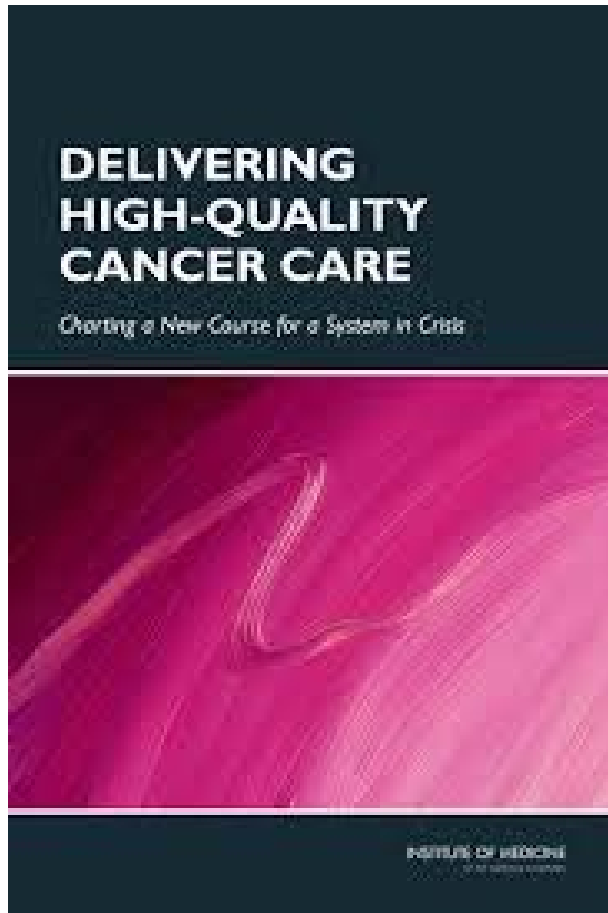
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# U.S. cancer prevalence



Parry et al., 2011

# PRO surveillance and quality improvement



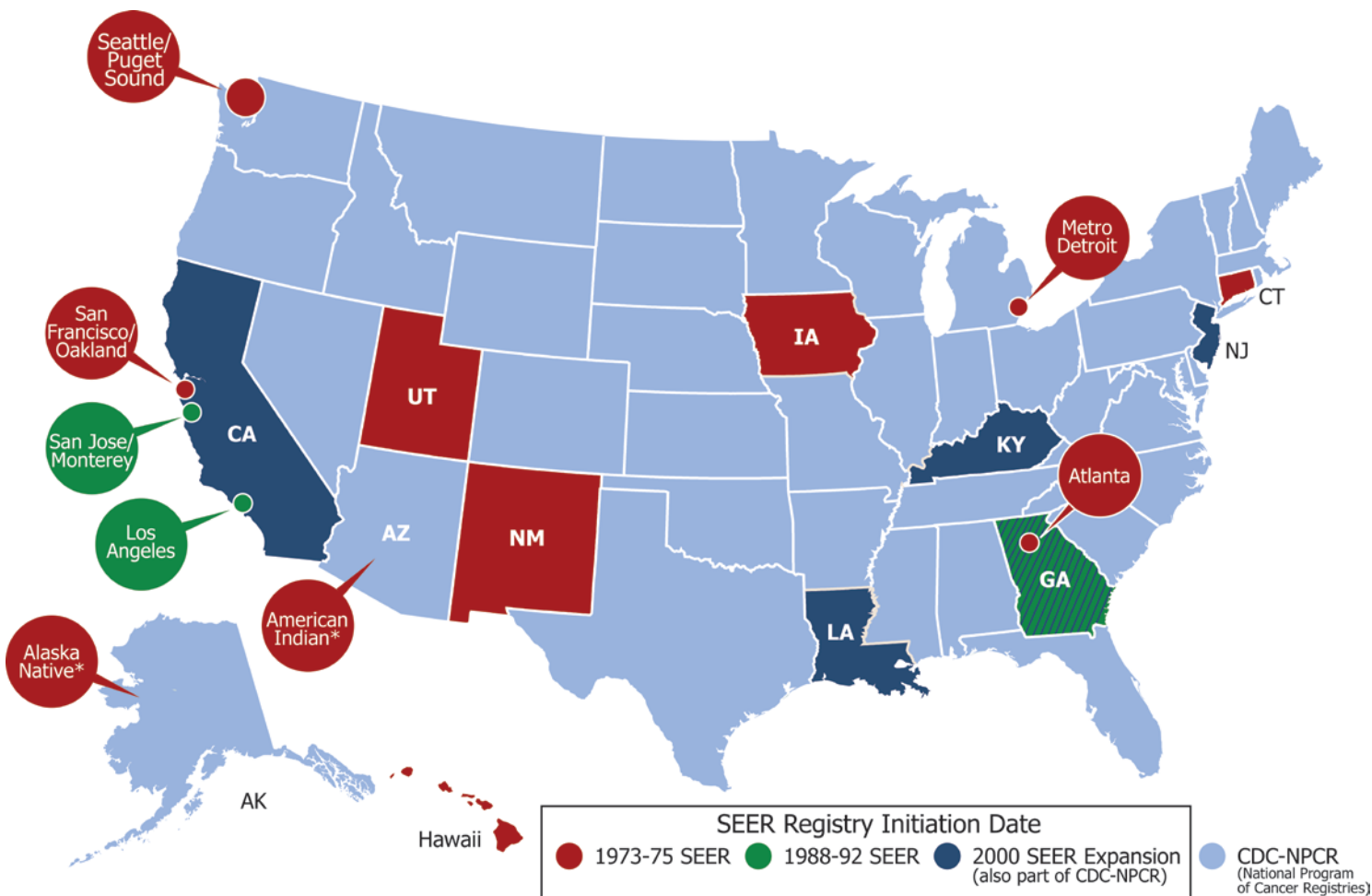
## Recommendation 8: Quality Measurement

- Goal: *Develop a national quality reporting program for cancer care as part of a learning health care system.*

# Cancer registry–linkages for patient-reported outcome surveillance

- Surveillance, Epidemiology, and End Results (SEER) Program national cancer registry program data linkages with CMS-led surveys
  1. Medicare Health Outcomes Survey (MHOS)
  2. Consumer Assessment of Healthcare Providers and Systems (CAHPS)

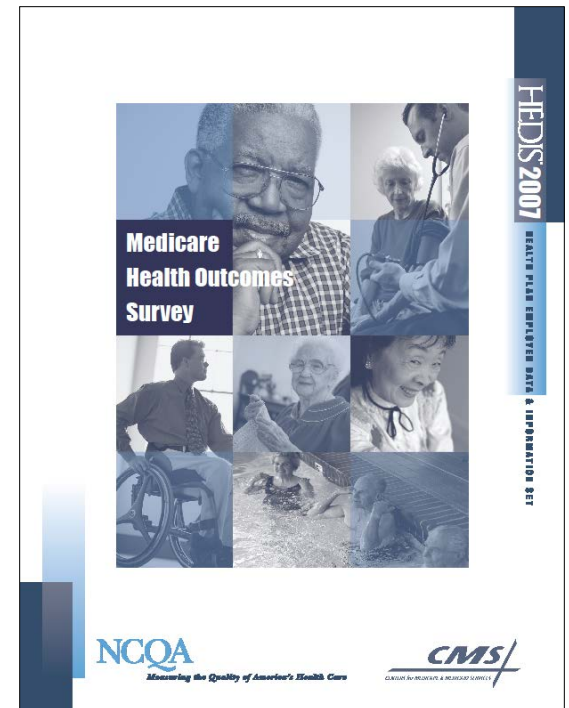
# SEER Program Coverage



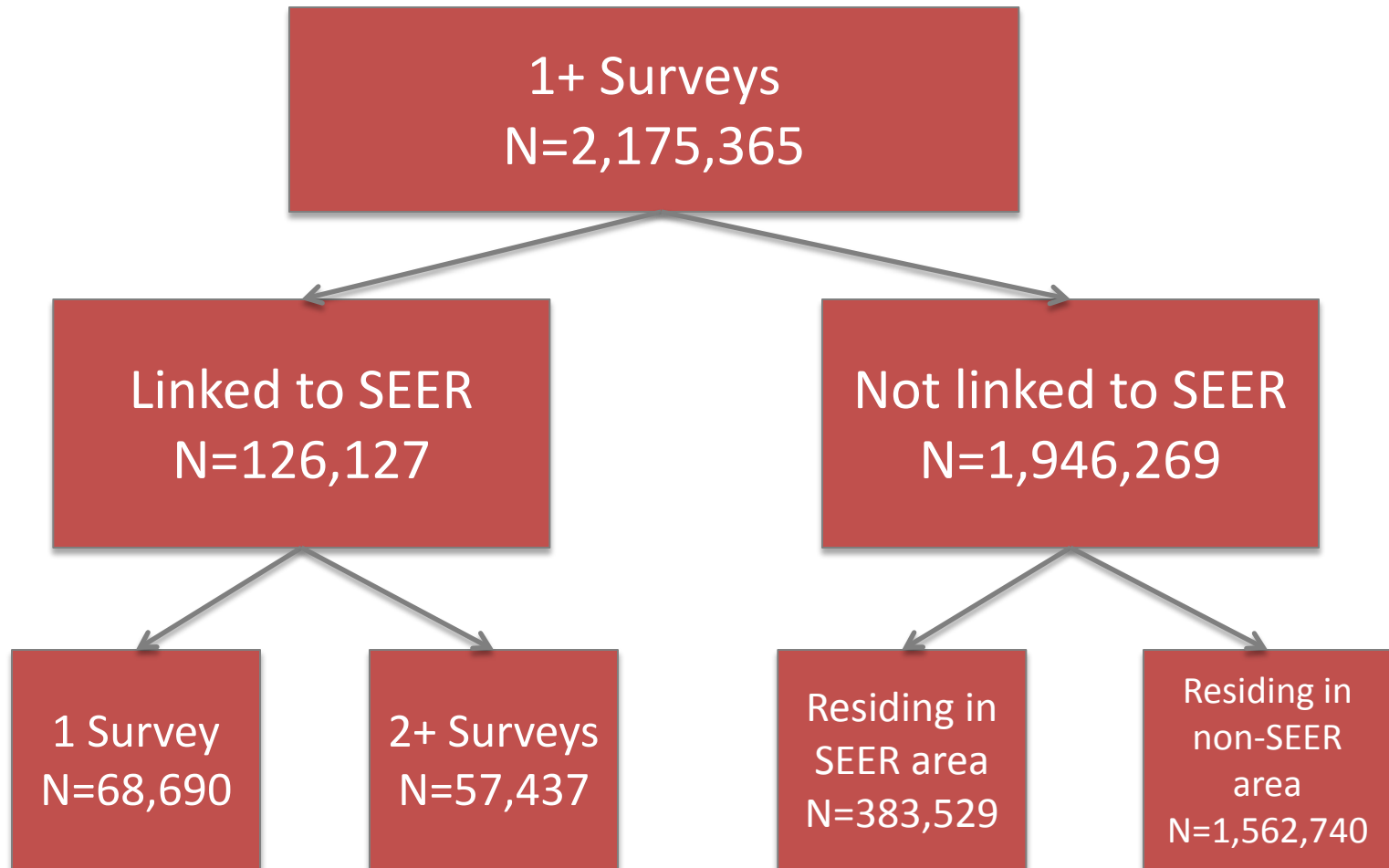
\*Alaska Native and Arizona American Indian are not part of SEER-MHOS.

# SEER-MHOS Description

- Linkage of cancer registry data (SEER) to patient-reported measures from the Centers for Medicare Medicare & Medicaid Services Health Outcome Survey (MHOS)
- Linked data are the records of individuals in both the SEER (1973-2011) and MHOS data sets, plus all additional MHOS data for the years 1998-2013



# Number of participants in SEER-MHOS from the 2015 linkage

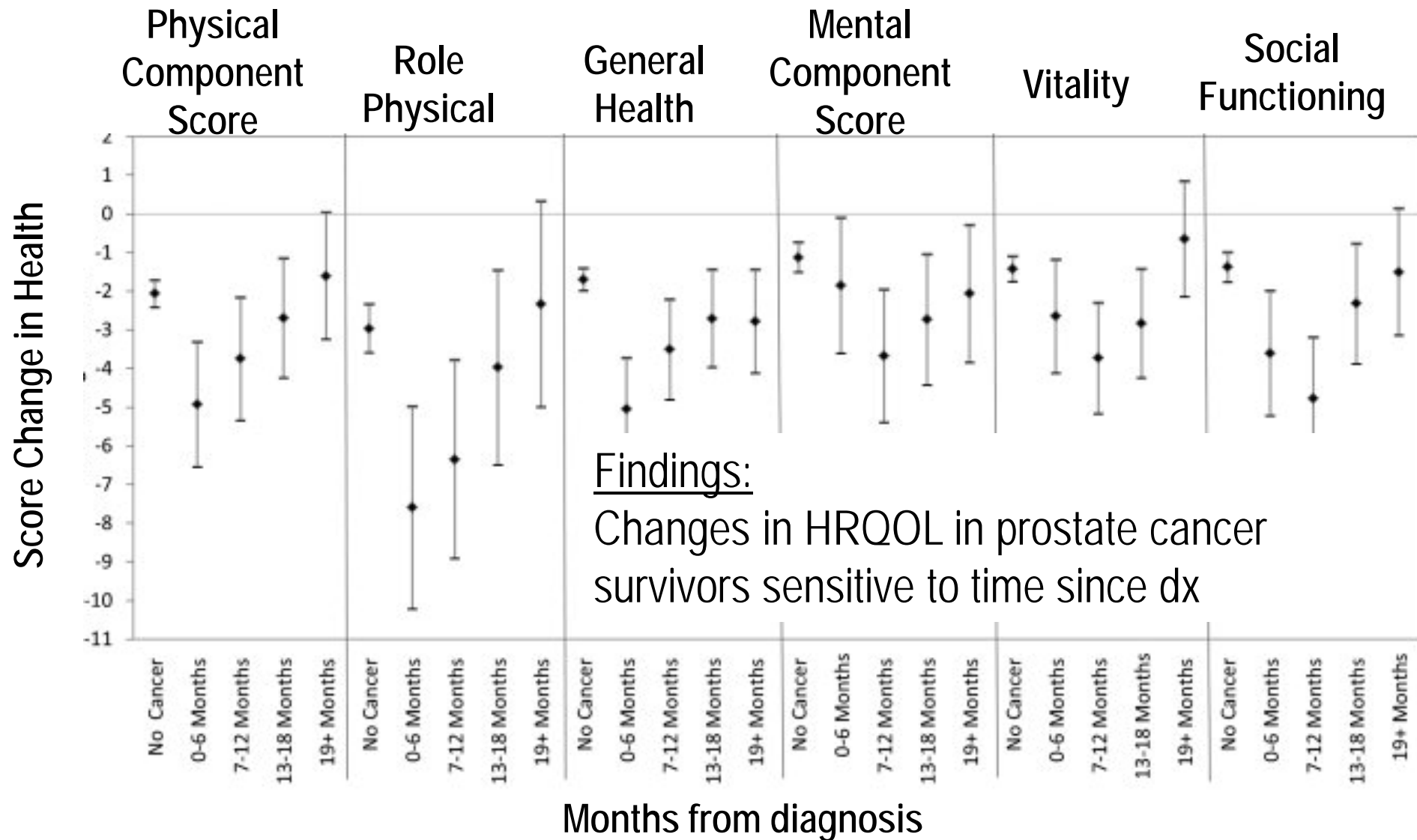


## SEER-MHOS Respondents Age 65+ by (Selected) First Cancer Site, 1998-2011

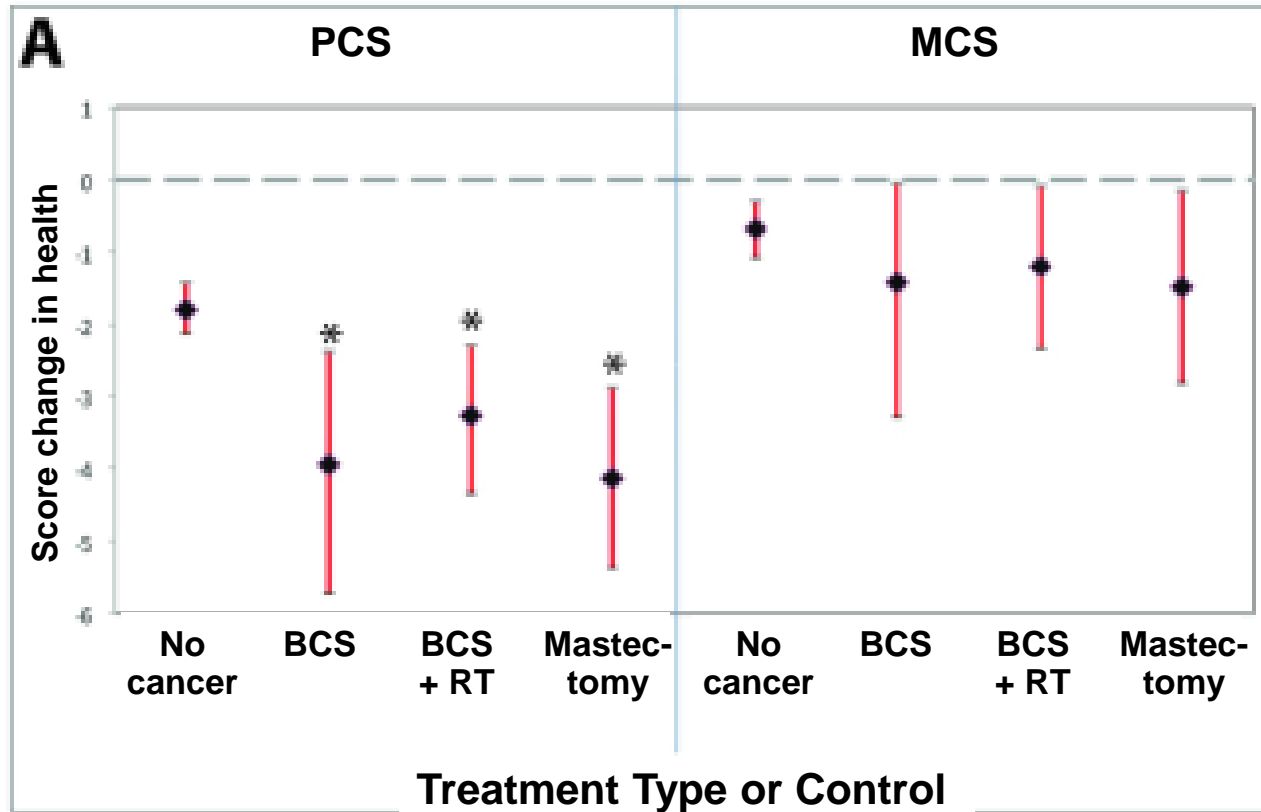
First Cancer	Total # of linked Patients (N)	Baseline Survey (N)	Baseline and Follow-up Surveys (N)	Survey Before and Survey after Dx (N)
Prostate	25,424	25,253	11,192	1,732
Breast	21,470	21,299	10,040	1,331
Colorectal	13,989	13,904	6,052	899
Lung and bronchus	10,060	9,973	3,588	588
Ovary	1,294	1,286	547	64
Uterus	3,993	3,961	1,877	184
Bladder	6,148	6,102	2,637	434
Melanomas -- skin	5,983	5,934	2,816	415
Head and neck	3,010	2,986	1,278	180
Kidney/Renal	2,524	2,508	1,077	203
NHL-nodal	3,702	3,670	1,608	261
Stomach	1,365	1,357	501	71
Pancreas	1,691	1,680	567	67



# Changes in HRQOL among prostate cancer survivors by time since dx



## Changes in HRQOL among breast cancer survivors by treatment type



Findings:  
Greater PCS declines in health among women with breast cancer than controls, across treatment types

# Strengths & Limitations: SEER-MHOS

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- Adequate sample sizes for many cancer sites
- Ability to look at change over a two-year period
- Compare individuals with and without cancer
- One of largest data sources on PROs of older adults with cancer

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- Linkage is limited to select SEER registry areas
- SEER treatment data limited to first few months of therapy
- No data on non-Medicare populations
- Survey sampling frame not designed around time since diagnosis



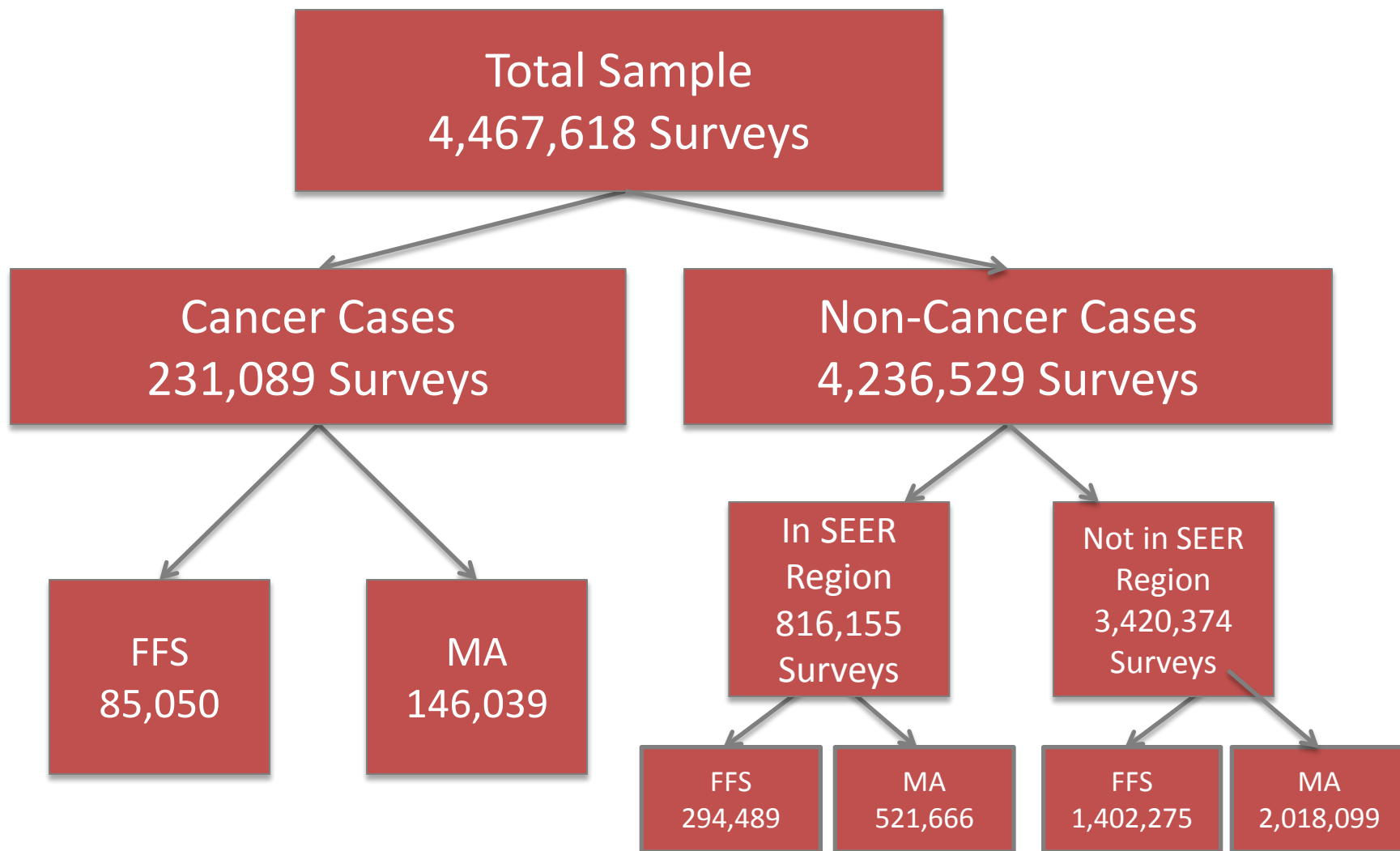
# SEER-MHOS: Obtaining Data

- Publicly available for a fee as of December, 2010. Researchers may submit applications and data use agreements at:  
<http://healthcaredelivery.cancer.gov/seer-mhos/>
- Applications require two levels of approval, and data requests generally take 4-6 weeks for review, manuscripts require NCI clearance
- SEER\*Stat users: request access to custom database with MHOS flags for advanced sample size estimates
- Over 40 DUAs and 19 publications to date

# SEER-CAHPS: Description

- SEER-CAHPS links patient-reported information from the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Medicare Survey with clinical information from NCI's SEER cancer registry program.
- Assesses patient experiences with the following:
  - Doctor communication
  - Getting needed care
  - Getting care quickly
  - Health plan customer service
  - Care coordination
- Includes Medicare Advantage and Medicare Fee-for-Service (FFS) patients
  - Can be linked with Medicare claims (FFS only)

# Number of participants in SEER-CAHPS from the 2015 linkage



## SEER-CAHPS: Managed Care

First Cancer	Total	Survey before cancer diagnosis	Survey <2 y after dx	Survey 3-5 y after dx	Survey 3-5 y after dx
Prostate	24,551	8,114	4,076	4,076	5,165
Breast	22,668	7,110	3,216	3,216	4,158
Colorectal	13,538	6,057	1,896	1,896	1,903
Lung and bronchus	11,617	8,917	1,331	1,331	467
Ovary	1,414	686	174	174	142
Uterus	3,901	1,037	463	463	653
Bladder	6,298	3,037	915	915	804
Melanomas (skin)	6,962	2,863	990	990	1,034
Head and neck	6,358	2,954	883	883	801
Kidney/Renal	2,877	1,427	417	417	350
NHL-nodal	4,271	2,294	580	580	492
Leukemia	2,379	1,497	303	303	211
Stomach	1,414	931	196	196	101
Pancreas	2,019	1,835	112	112	20

## SEER-CAHPS: Fee-for-Service

First Cancer	Total	Survey before cancer diagnosis	Survey <2 y after dx	Survey 3-5 y after dx	Survey 3-5 y after dx
Prostate	16,464	3,746	2,795	3,078	4,103
Breast	15,440	3,429	2,104	2,457	3,349
Colorectal	8,195	2,543	1,350	1,237	1,532
Lung and bronchus	6,420	4,142	992	550	474
Ovary	919	307	138	108	134
Uterus	2,753	540	349	346	526
Bladder	3,992	1,363	680	628	706
Melanomas (skin)	5,134	1,371	848	854	1,009
Head and neck	4,530	1,600	713	717	717
Kidney/Renal	1,964	745	330	290	347
NHL-nodal	2,773	1,030	470	444	468
Leukemia	1,596	714	253	214	253
Stomach	759	415	111	74	95
Pancreas	1,007	828	107	34	23



# Unveiling SEER-CAHPS®: A New Data Resource for Quality of Care Research

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Chawla et al., 2015, JGIM

# Strengths & Limitations: SEER-CAHPS

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- Adequate sample sizes for many cancer sites
- Compare individuals with and without cancer
- Ability to link patient experiences with health care utilization
- Ability to compare patient experiences across health plan type

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- Linkage is limited to select SEER registry areas
- SEER treatment data limited to first few months of therapy
- No data on non-Medicare populations
- No claims on MA
- Survey sampling frame not designed around time since diagnosis



# SEER-CAHPS: Obtaining Data

- Not yet publicly available, but coming soon (fall/winter 2016).
- Process will be similar to SEER-MHOS and SEER-Medicare:  
<http://healthcaredelivery.cancer.gov/seermedicare/>
- Contact Erin Kent ([Erin.Kent@nih.gov](mailto:Erin.Kent@nih.gov)) for more information



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