

Patient- reported outcome surveillance in older cancer survivors: Using the SEER-MHOS linked data resource

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Disclosures

No relationships to disclose.

Acknowledgments

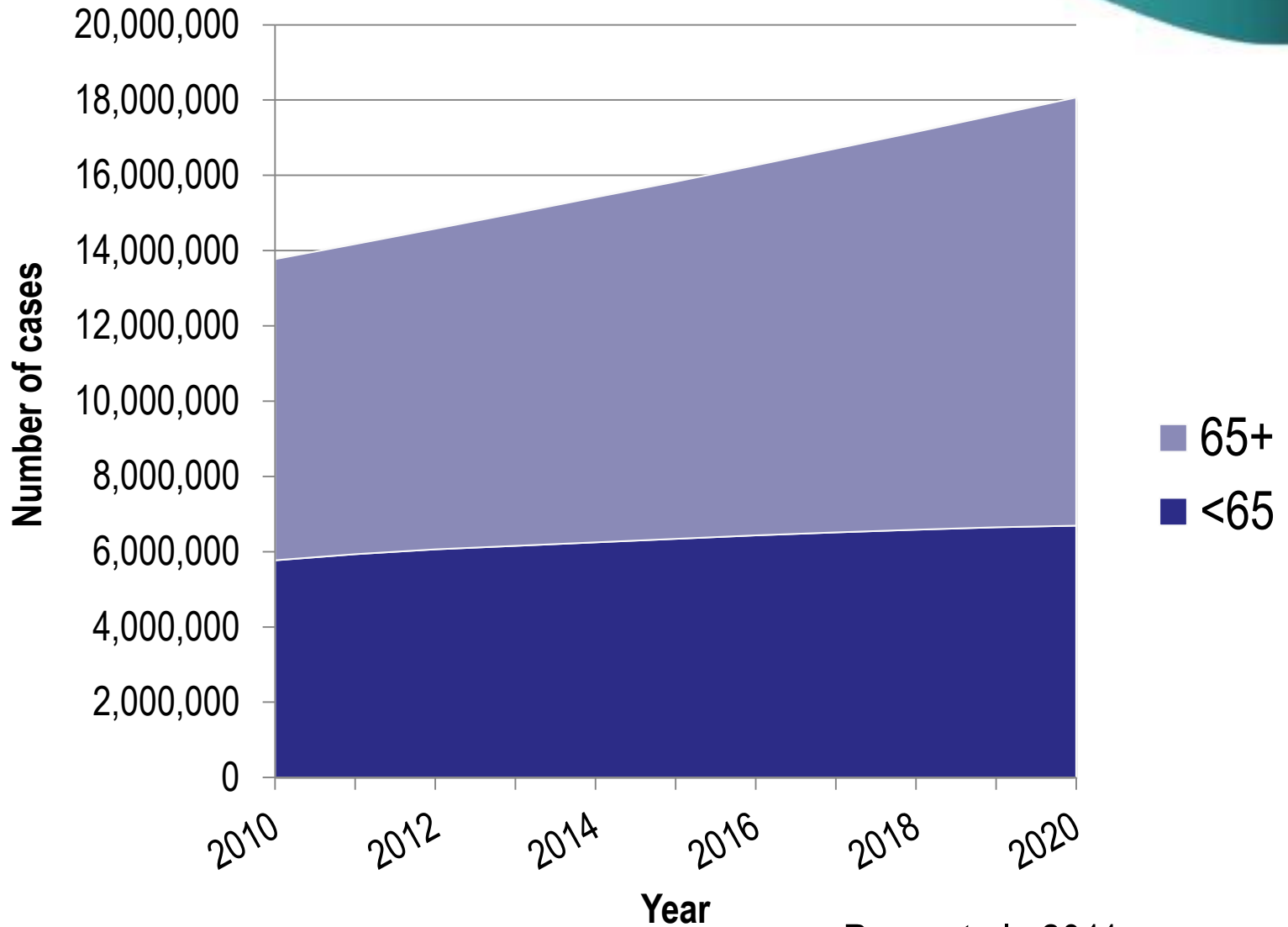
- **Anita Ambs, MPH**
Food and Drug Administration,
Center for Tobacco Products
- **Steven Clauser, PhD**
Patient-Centered Outcomes Research Institute



Cancer in older adults

- **Adults 65 years account for approximately 60% of all cancer diagnoses**
- **43% of older adults with cancer diagnoses survive more than 10 years**
 - 17% survive more than 20 years from initial diagnosis
- **With more effective therapies and earlier detection, the number of older cancer survivors will grow**
 - Limited research that on the health related quality of life (HRQOL) of older cancer survivors

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.

Medicare Health Outcomes Survey

**Medicare
Health Outcomes
Survey**

HEDIS 2007
HEALTH PLAN EMPLOYER DATA & INFORMATION SET

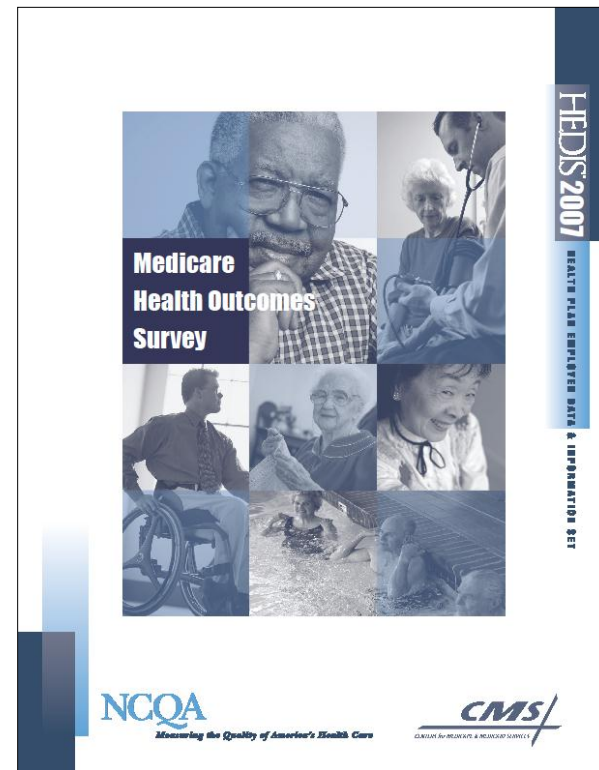
NCQA
Measuring the Quality of America's Health Care

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES

Surveillance Epidemiology and End Results (SEER) Cancer Registries

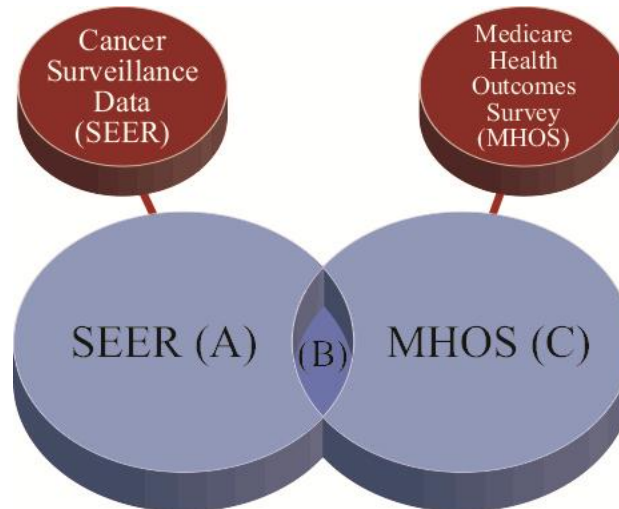


SEER-MHOS Data Linkage



SEER-MHOS Data Linkage

- Linkage of cancer registry data (SEER) to patient-reported measures from the Medicare Health Outcome Survey (MHOS)
- Linked data are the records of individuals in both the SEER (through 2009) and MHOS data sets, plus all additional MHOS data for the years 1998-2011

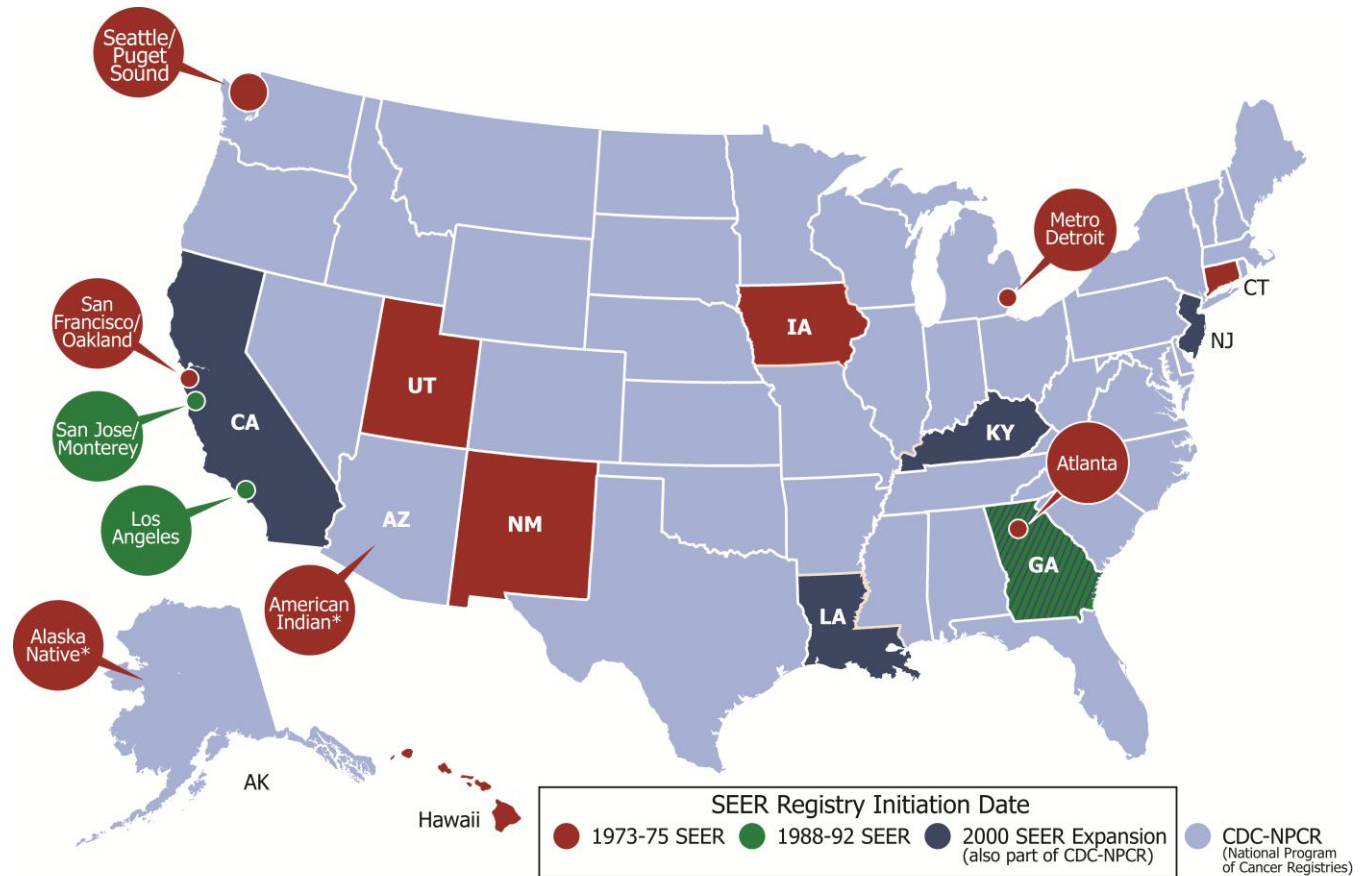


1998-2011 SEER-MHOS Linkage = (B) + (C)

Goals of SEER-MHOS

- Create an ongoing dataset for use by NCI, CMS, and external investigators
- Collect valid and reliable data on PROs that may be used to promote research and policy:
 - Outcomes Research and Surveillance
 - Health Plan Quality Improvement
 - Eg. Star Ratings Program

SEER Program Coverage



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

Variables available in SEER-MHOS

SEER Variables

- Cancer incidence and survival
- Month/year of diagnosis, site of cancer, histology, grade, and stage
- Initial surgical and radiation treatment within 12 months of diagnosis
- Follow-up vital status
- Demographics

Variables available in SEER-MHOS

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MHOS Variables

- HRQOL: SF 36 v2, VR 12
- Activities of daily living
- Comorbidities
- Depressive symptoms
- Number of unhealthy days
- Health behaviors: Smoking
- HEDIS effectiveness of care measures
 - Urinary incontinence
 - Physical activity management
 - Bone Density Scanning
 - Fall risk management
- Demographics

Health-Related Quality of Life (HRQOL): SF-36 Scales

Scale	Description
Physical Component Summary (PCS)	Summary measure, includes: PF, RP, BP, VT, SF, RE, MH and GH
Physical functioning (PF)	10 questions on how health limits performance of physical activities.
Role-physical (RP)	4 questions on the extent to which the physical health limits work/usual activities
Bodily pain (BP)	2 questions on severity of pain and extent to which pain interferes
General health (GH)	5 questions on current health status, susceptibility to disease, and expectations for health in the future.
Mental Component Summary (MCS)	Summary measure, includes: MH, RE, SF, VT, GH, BP, RP, and PF.
Vitality (VT)	4 questions on energy and fatigue
Social functioning (SF)	2 questions on limitations in normal social functioning due to health
Mental Health (MH)	5 questions on mental health dimensions.
Role-emotional (RE)	3 questions on whether emotional problems have interfered with work/usual activities

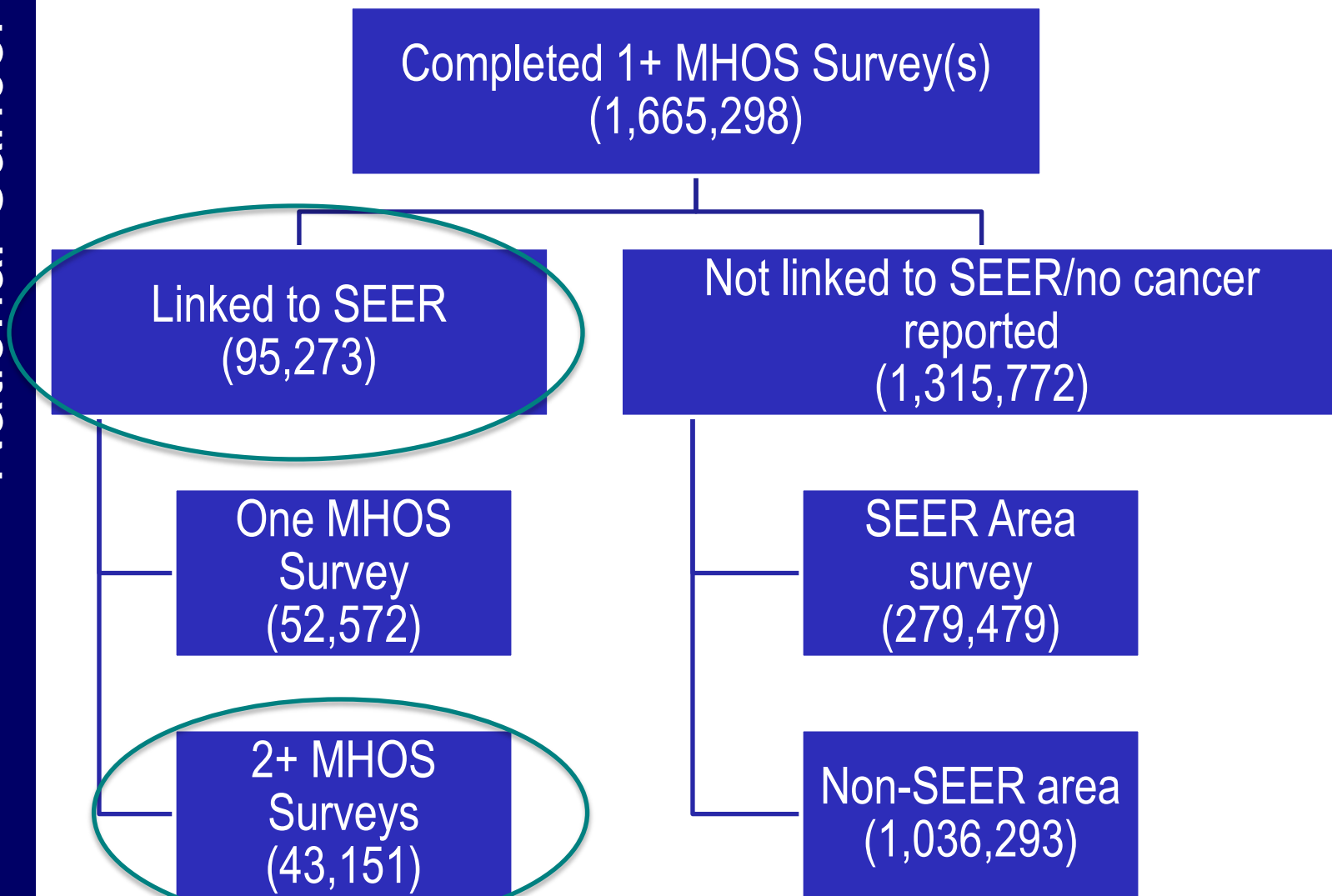
MHOS 2.0: Switch from SF-36 to VR-12 in 2006

VR-12:

- Shorter, 14-question survey
- Reduces respondent burden and survey costs while producing results similar to 36-item survey
- Developed, tested, and implemented by Veterans Administration in multiple studies
- Validated conversion formulas allow comparisons with earlier 36-item survey
- In progress: mapping 8 scales from SF-36 to VR-12



Number of SEER-MHOS Participants



Number of SEER-MHOS Respondents Age 65+ by First Cancer Site, 1998-2009

First Cancer	Total # of linked Patients (N)	Baseline Survey (N)	Baseline and Follow-up Surveys (N)	Survey Before and Survey after Dx (N)
Prostate	19,727	19,598	8,657	1,352
Breast	16,388	16,264	7,679	992
Colorectal	11,127	11,061	4,839	698
Lung and bronchus	7,823	7,756	2,728	434
Gynecological Cancers	5,171	5,134	2,351	201
Bladder	4,757	4,723	2,028	330
Melanomas -- skin	4,338	4,302	2,032	283
Kidney and Renal pelvis	1,874	1,859	784	150
Non-Hodgkin's lymphomas - nodal	1,893	1,877	775	119
Stomach	1,029	1,026	366	53
Pancreas	1,294	1,284	427	47

Strengths

- 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

Limitations

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

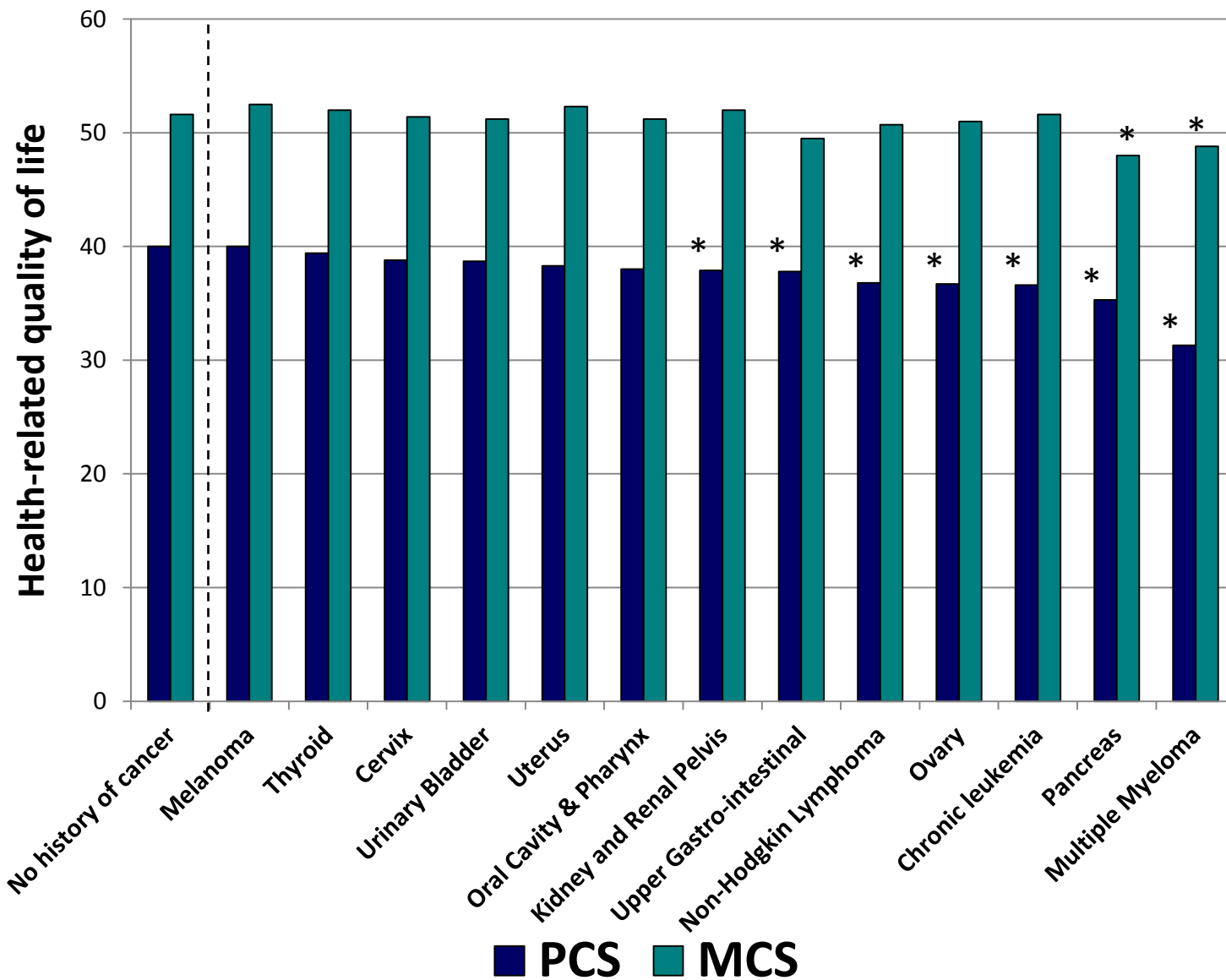


SEER-MHOS Public Use Data Resource

The data were made available to the public by application in 2008. Since then:

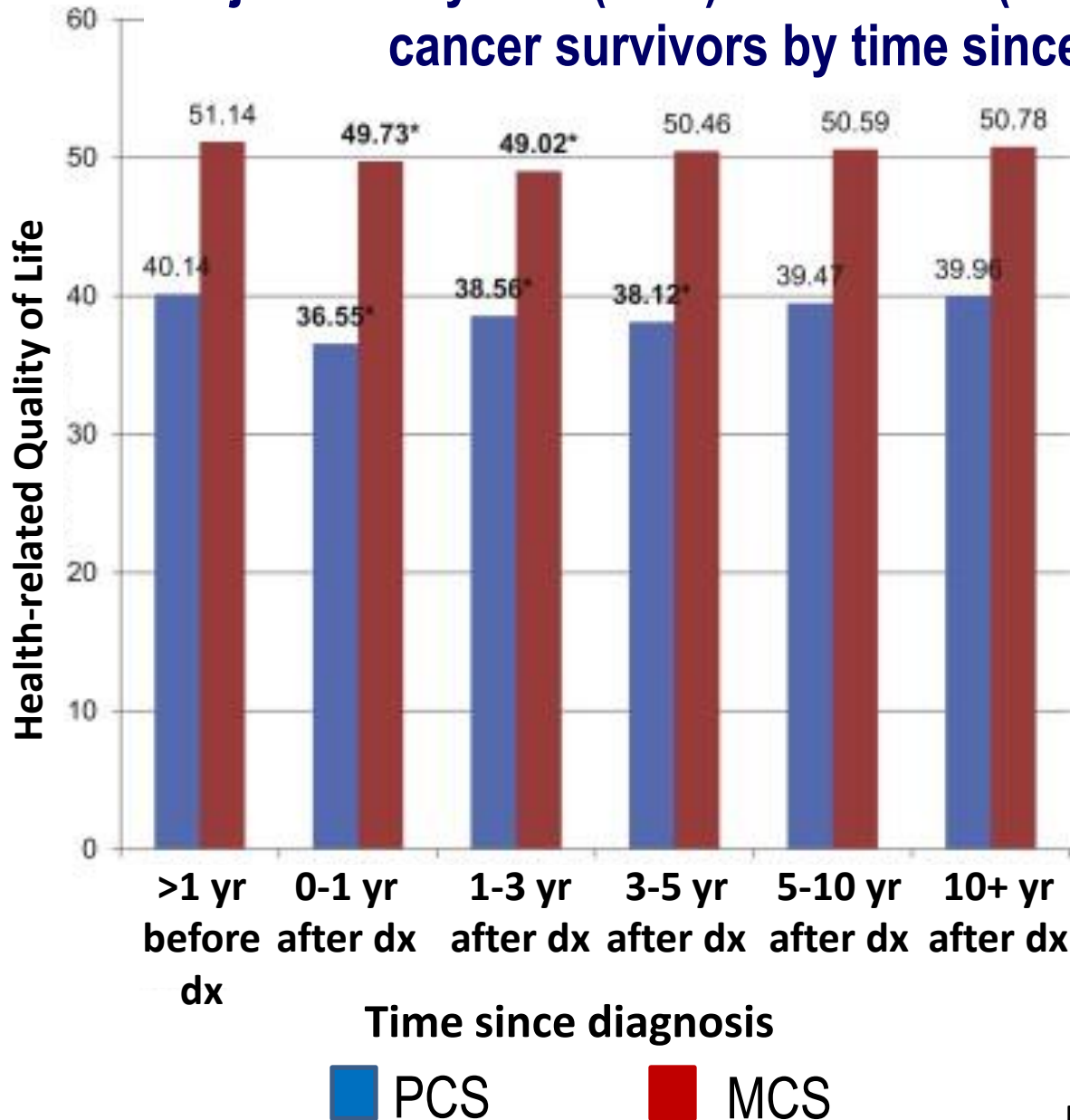
- 19 data use agreements
- 16 publications

Adjusted Physical (PCS) and Mental (MCS) scores



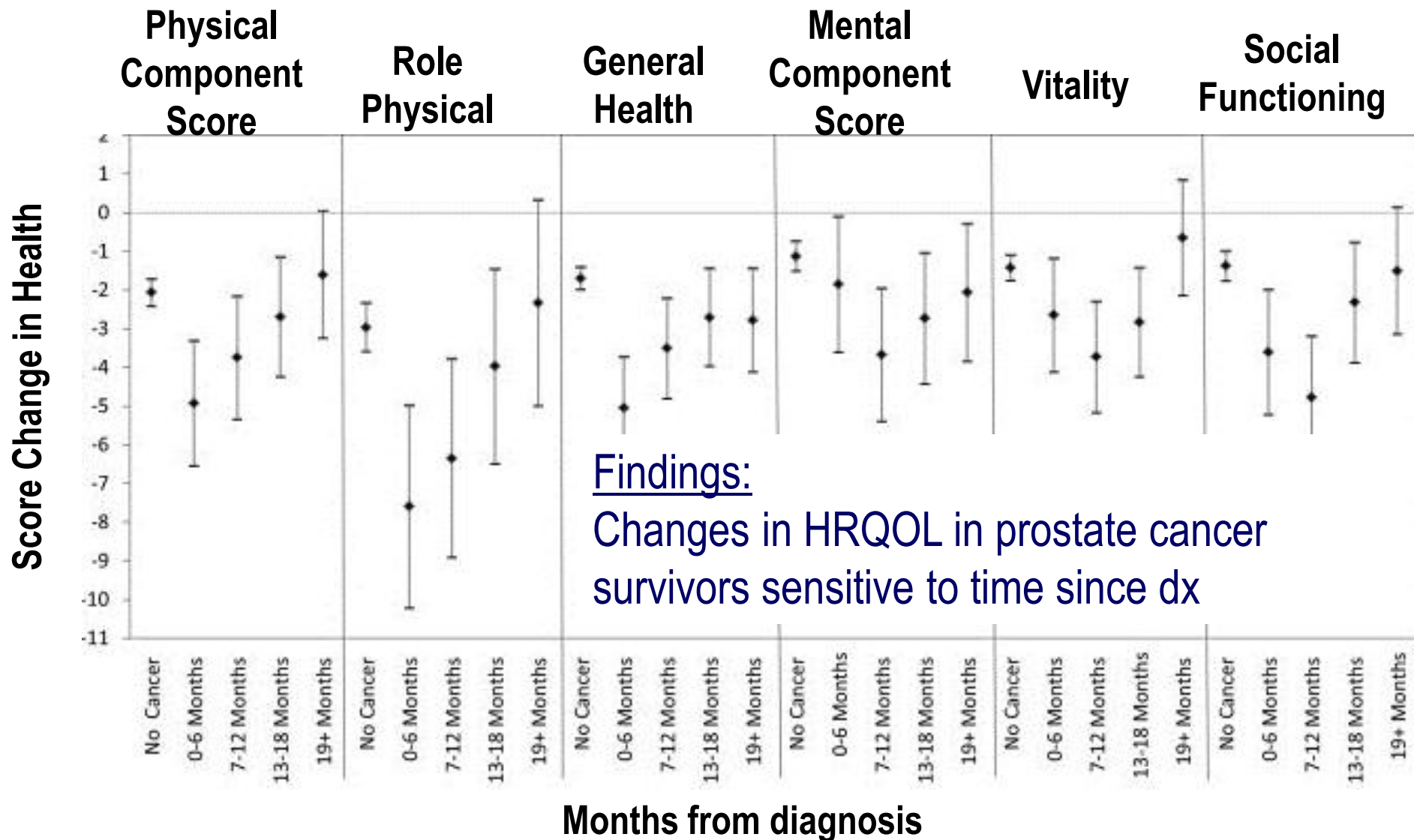
Findings:
 PCS lower in survivors of certain cancers, particularly multiple myeloma and pancreatic cancer

Adjusted Physical (PCS) and Mental (MCS) scores in bladder cancer survivors by time since diagnosis

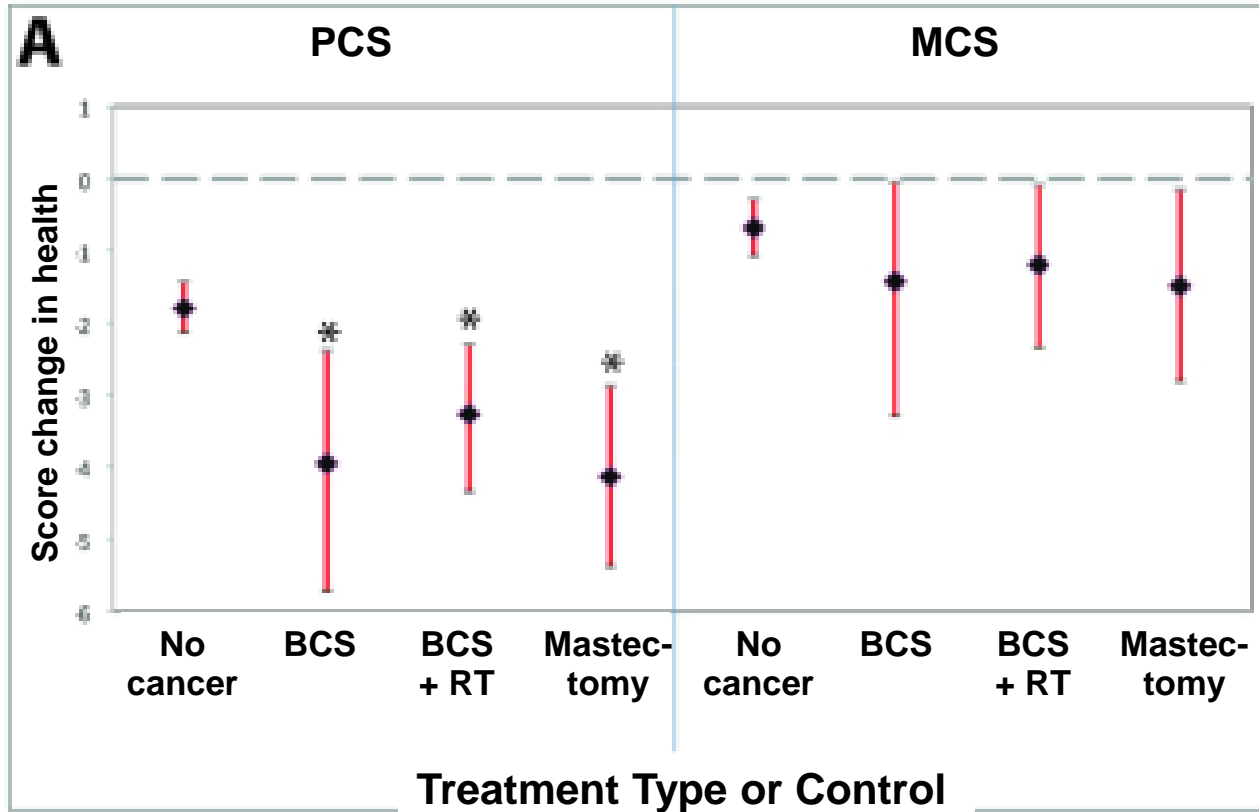


Findings:
PCS lower in bladder cancer survivors, persisting up to 10 years after diagnosis

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

Additional Findings

- **HRQOL in colorectal cancer patients –**
Quach et al., 2014, *Cancer*
 - Declines in physical HRQOL
 - Greatest decrements in recently diagnosed and those with stage III and IV
 - Greater odds of major depressive disorder than controls
- **Differences in HRQOL among prostate, breast, colorectal cancer across racial/ethnic groups -**
Pinheiro et al., In Review
 - Pre-dx, non-Hispanic Whites better HRQOL than minorities
 - Post-dx, some gaps in HRQOL across racial/ethnic groups narrowed

Sample research questions using SEER-MHOS data

1. How has HRQOL and other patient reported outcomes among older cancer patients changed over time?
2. What types of comorbidities occur among older patients with specific types of cancer?
3. How does functional status predict mortality and survival among older cancer patients and survivors?
4. Has the Medicare Star Ratings program affect enrollment/retention of cancer patients in MAOs, and if so, does this differ from older individuals w/o cancer?
5. Are there regional, geographic, and/or health plan effects on the health status of cancer patients/survivors in MAOs?

Accessing SEER-MHOS

<http://outcomes.cancer.gov/surveys/seer-mhos/obtain/>

The screenshot shows the National Cancer Institute website. The header includes the NCI logo and the text "National Cancer Institute U.S. National Institutes of Health | www.cancer.gov". Below the header is a navigation bar with "Outcomes Research" and "Cancer Control and Population Sciences". A search bar is visible on the right. The main content area is titled "Overview of the Process for Obtaining the Data". It contains several paragraphs of text explaining the availability of SEER-MHOS data, confidentiality concerns, and the process of obtaining data. A sidebar on the left contains links such as "Cancer Control and Population Sciences Home", "Applied Research Home", "Outcomes Research Home", "SEER-MHOS Linked Database Home", "Obtaining the SEER-MHOS Data", "Overview of the Process for Obtaining the Data", "Required Documents & Instructions for Submitting Requests", "Proposal Review Process", and "Cost of Acquiring the SEER-MHOS Data". At the bottom of the page, there is a footer with "Last modified: 21 Dec 2010" and a row of logos including the NCI logo, the USA.gov logo, and other organizational logos.

1. Send e-mail to: SEER-MHOS@hcqis.org
2. Use the MHOS flag in SEER*Stat to determine sample sizes of individuals with specific cancers, just released.
3. Come to the NCI Booth tomorrow (Tues) 1:30-2:30pm to talk with me about SEER-MHOS research ideas!

SEER-MHOS Partners:



National Cancer Institute (NCI)



Centers for Medicare & Medicaid Services (CMS)

With technical assistance from:



– Health Services Advisory Group (HSAG)



– Information Management Services, Inc. (IMS)

Coming soon... SEER-CAHPS

- Data linkage between SEER and the Consumer Assessment of Healthcare Providers and Systems (SEER-CAHPS)
- CAHPS data exists for both MA and Fee-for-Service (FFS)
- Linkage contains SEER cancer registry data, responses to the CAHPS survey, and Medicare Claims data (FFS only)

SEER-CAHPS: Priority research questions

- Do perceptions of care differ among Medicare beneficiaries with and without cancer?
- To what extent do cancer patients' care experiences vary by racial and ethnic groups?
- Do patients' care experiences vary by increasing chronic illness burden?
- How are patients' care experiences associated with health care utilization at the end of life?
- Do cancer patients' care experiences vary by time since diagnosis?

***When performance is measured,
performance improves. When
performance is measured and
reported back, the rate of
improvement accelerates.***

-Pearson's Law



Thank you

MHOS Administration Timeline

- Each spring, a random sample of Medicare beneficiaries is drawn and surveyed from each MAO with a minimum of 500 enrollees
- Two years later, the baseline respondents are surveyed again (i.e., follow up measurement).
- *Cohort 1* was surveyed in 1998 and was resurveyed in 2000, etc.
- 1998-2006: MAO baseline sample size was one thousand; 2007-sample size increased to twelve hundred.
- 1998-2008, members required to be continuously enrolled in their MAO for 6 months; 2009 restriction waived.
- 1998-2009, beneficiaries with End Stage Renal Disease (ESRD) were excluded. Effective 2010, those with ESRD are no longer excluded.