

# SEER-MHOS: A Data Resource to Examine Cancer Health Outcomes

*Roxanne Jensen*

*Beth Gualtieri*

*Tanjina Shabu*

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**Roxanne E. Jensen, PhD**

Program Director,  
Outcomes Research  
Branch, Healthcare Delivery  
Research Program,  
Division of Cancer Control  
and Population Sciences,  
National Cancer Institute



**Beth Gualtieri, RN, BSN**

Medicare HOS Project  
Manager,  
Associate Director SR&A,  
Health Services Advisory  
Group



**Tanjina Shabu, MPH**

Senior Healthcare Analyst,  
Health Services Advisory  
Group

# Outline

- I. Background
- II. History of the Medicare Health Outcomes Survey
- III. SEER-MHOS Overview & Currently Available Data (including new linkages)
- IV. SEER-MHOS Survey Variables & Research Examples
- V. SEER-MHOS Data Application Process

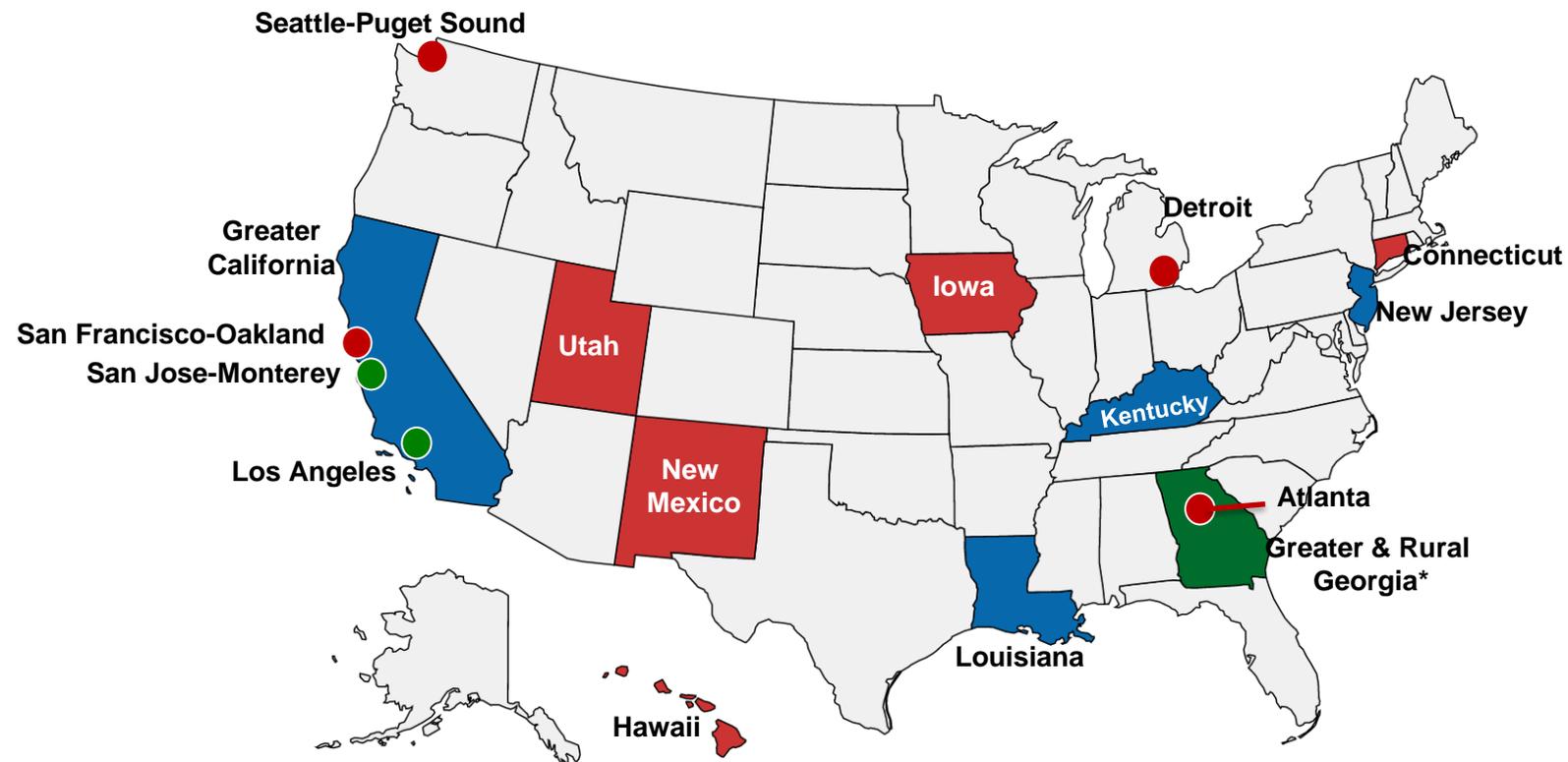
# Background

*Roxanne Jensen*

# Surveillance Epidemiology and End Results (SEER) Cancer Registry

- Comprehensive, population-based network of state and regional cancer registries across the United States
- Started in 1973, has grown and expanded over time, now covers 34.6% of the U.S. population
- SEER Cancer Registry Data includes:
  - Tumor Site
  - Cancer Stage at Diagnosis
  - Date of Diagnosis
  - Vital Status (updated with each new SEER-MHOS linkage)
  - Initial Treatment Information (e.g., Cancer Site-Specific Surgery Codes)

# SEER Cancer Registries Linked with MHOS



## SEER Registry Initiation Date

● 1973-1975 SEER ● 1988-1999 SEER ● 2000 SEER Expansion

\*Rural GA (data available since 1992) was added before Greater GA (data available since 2000)

# Medicare & Medicare Advantage

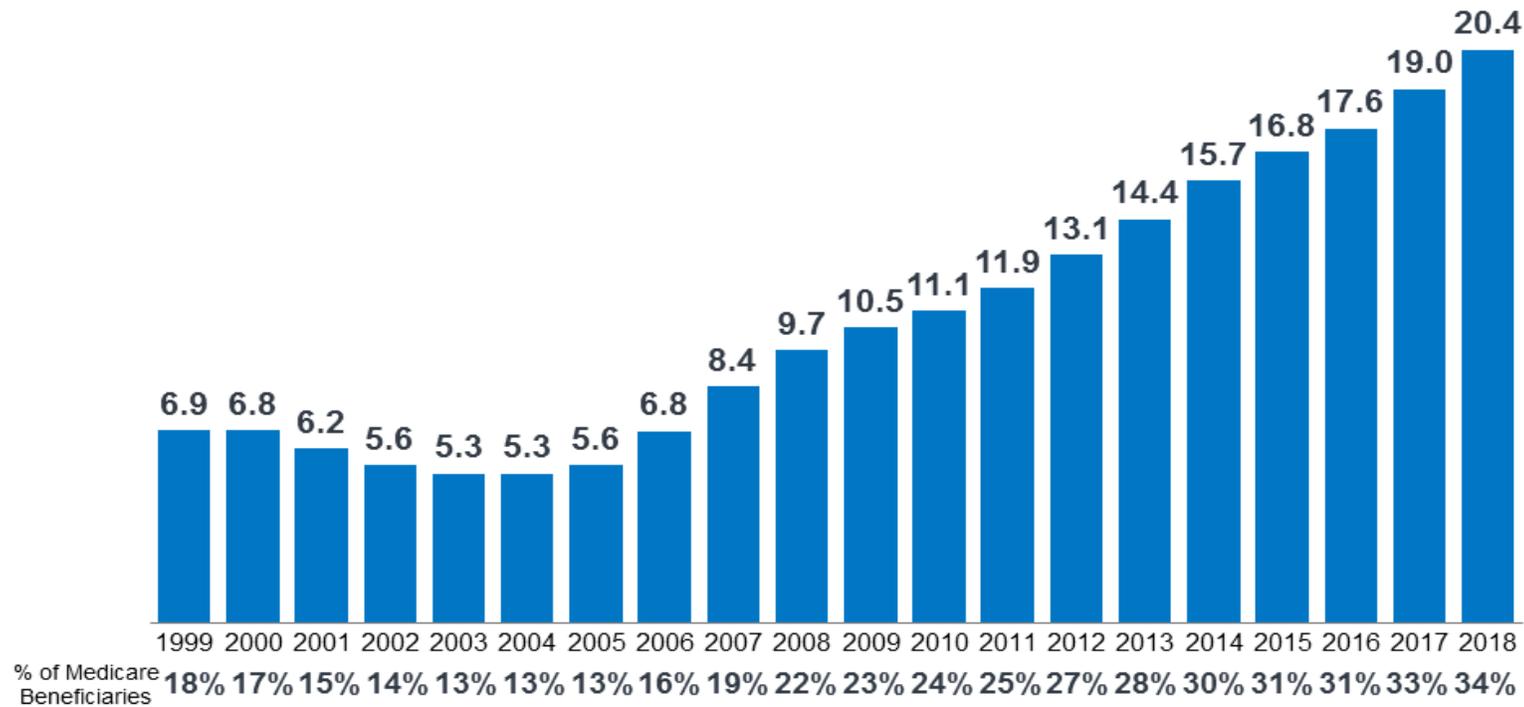
- Roughly 60 million beneficiaries are enrolled in Medicare as of 2018
- General Eligibility:
  - $\geq 65$  years or older
  - Younger people with disabilities
  - People with End Stage Renal Disease (permanent kidney failure requiring dialysis or transplant)
- Medicare Advantage:
  - Sometimes Called "Part C" or "MA Plans"
  - An "all in one" managed care alternative to traditional fee-for-service Medicare.
  - Offered by private companies approved by Medicare.
  - Over 20 million beneficiaries as 2018 (~34% of all Medicare beneficiaries)

# Medicare Advantage Enrollment Increasing



Figure 1

Total Medicare Advantage Enrollment, 1999-2018  
(in millions)



NOTE: Includes cost plans as well as Medicare Advantage plans. About 61 million people are enrolled in Medicare in 2018.  
SOURCE: Kaiser Family Foundation analysis of CMS Medicare Advantage enrollment files, 2008-2018, and MPR, 1999-2007; enrollment numbers from March of the respective year, with the exception of 2006, which is from April.



# History of the Medicare Health Outcomes Survey

*Beth Gualtieri*

# Medicare Health Outcomes Survey (MHOS)



First patient-reported health outcomes measure



Clinically meaningful data



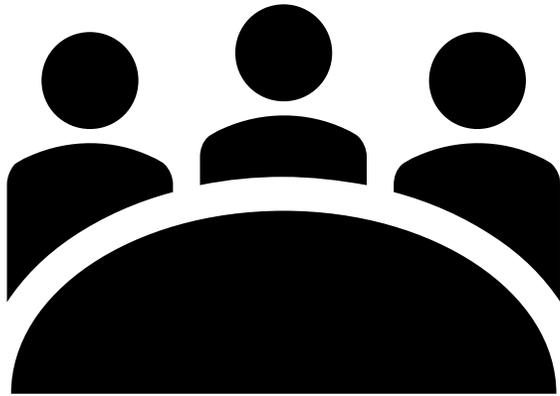
Measures physical and mental health



Medicare population in managed care

Medicare Plan Finder: <https://www.medicare.gov/find-a-plan>

# Development of the Medicare HOS



Technical Expert Panel convened



Health outcomes summarized using risk adjustment



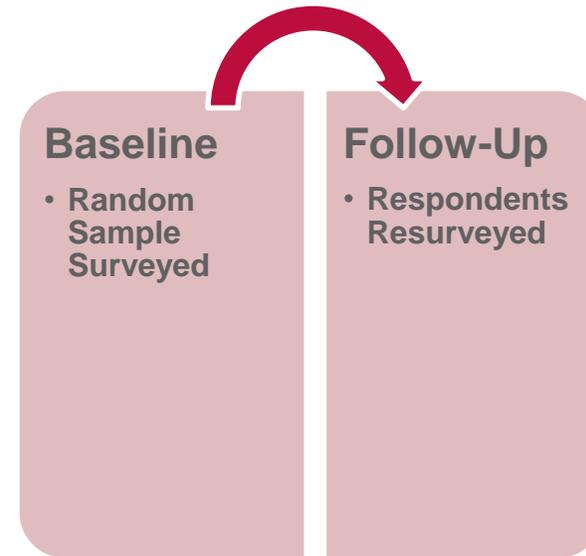
HEDIS® effectiveness of care measures included

# MHOS Sampling



## HOS Participants:

Medicare beneficiaries at least 18 years of age who are currently enrolled in an MA contract and reside in the U.S. or its territories



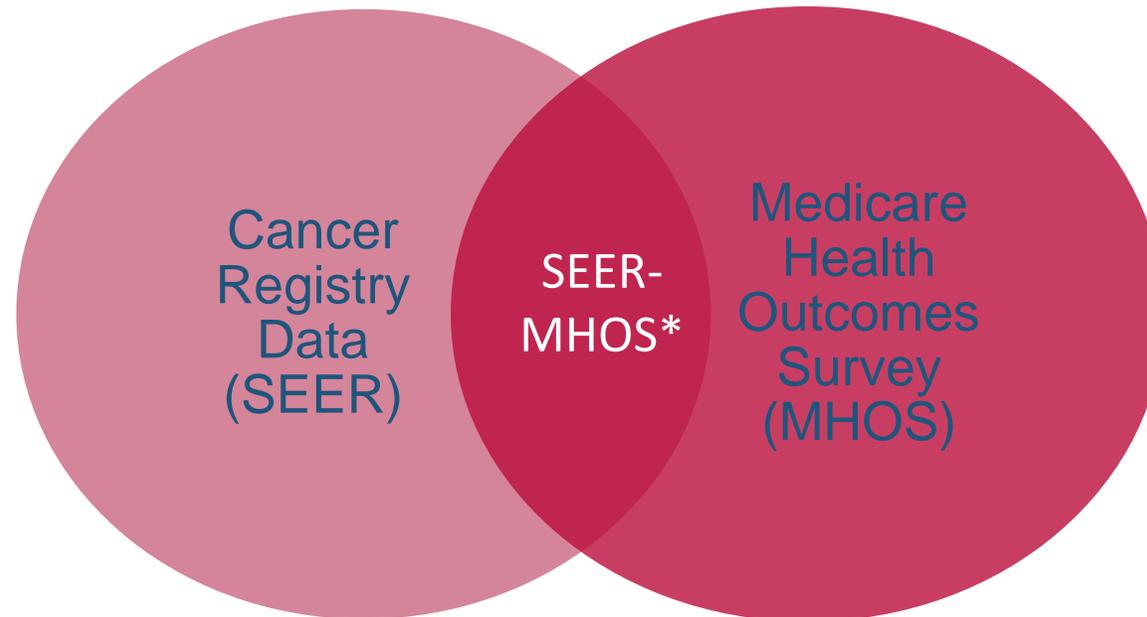
- <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/HOS/index.html>
- <https://www.hosonline.org>

# SEER-MHOS Overview & Available Data

*Roxanne Jensen*

# SEER-MHOS Data Resource

- SEER data represents cancer diagnoses between: 1973-2015
- MHOS Surveys from: 1998-2017 (Cohorts 1-18)
- Most recent data linkage: Spring 2019



\*Includes Non Cancer Cases from SEER Geographic Regions for cancer/non-cancer comparisons

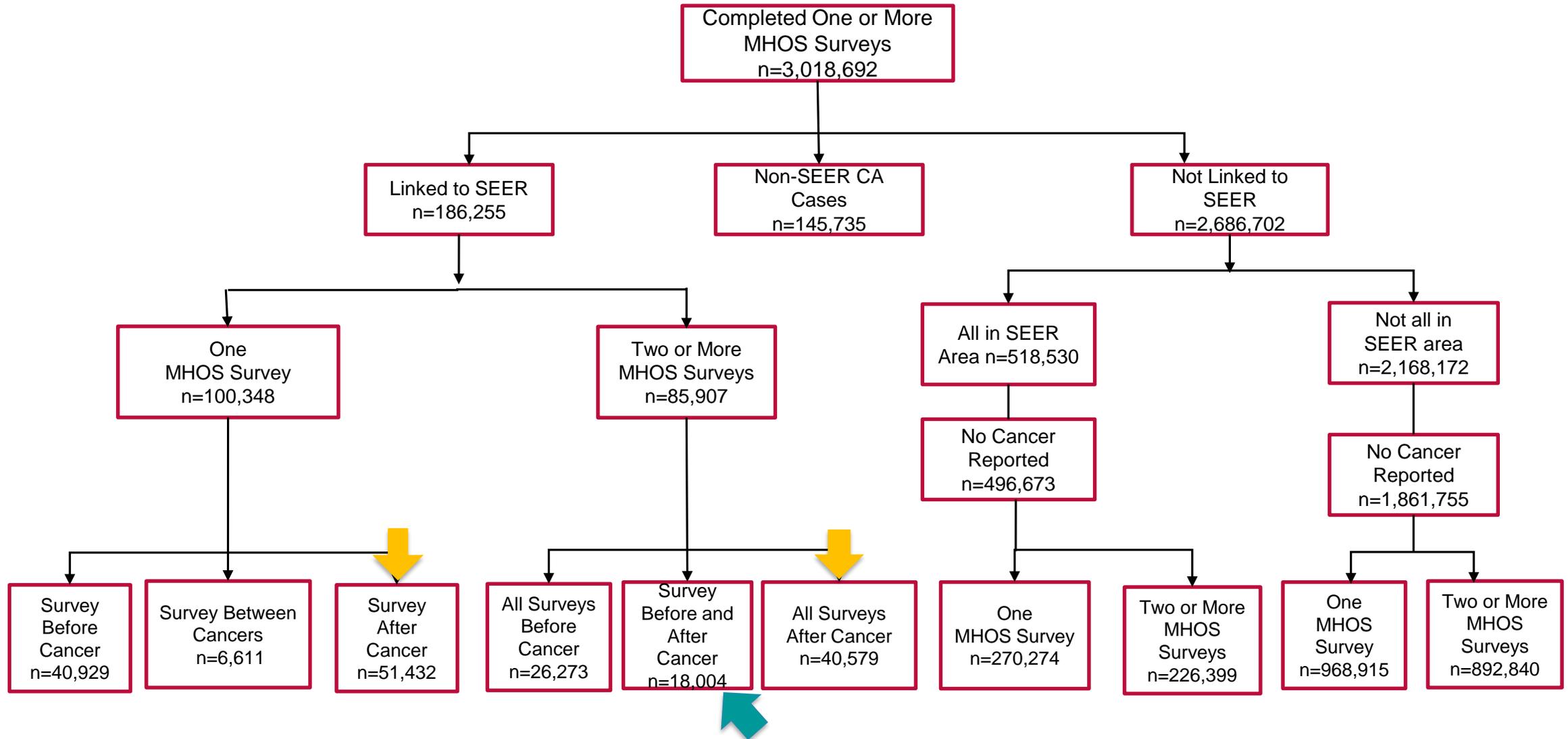
# SEER-MHOS Data Includes

- SEER Data Elements
- MHOS Survey Data Elements
  - Patient Reported Outcomes (PROs)
  - Demographic & Clinical Information
  - Healthcare Effectiveness Data and Information Set (HEDIS) Effectiveness of Care Quality Measures
    - Widely used set of performance measures
    - Developed and maintained by the National Committee for Quality Assurance (NCQA)



Part D Prescription Drug Claims

# Number of Individuals in SEER-MHOS 1998-2017, All Ages



For more detailed information on this flow diagram, see:

[https://healthcaresdelivery.cancer.gov/images/seer-mhos/number\\_of\\_patients\\_in\\_mhos.png](https://healthcaresdelivery.cancer.gov/images/seer-mhos/number_of_patients_in_mhos.png)

# SEER-MHOS: Most prevalent cancer types

First Cancer	Total Number of SEER linked patients	More than one survey		Survey before cancer diagnosis		Survey both before and after diagnosis		Survey after cancer diagnosis	
		N	%	N	%	N	%	N	%
Prostate	35,128	16,221	46.18	10,215	29.08	2,380	6.78	27,289	77.68
Breast	31,407	15,145	48.22	9,063	28.86	1,955	6.22	24,295	77.36
Colorectal	18,993	8,661	45.60	7,568	39.85	1,211	6.38	12,634	66.52
Lung and bronchial	14,880	5,836	39.22	11,400	76.61	854	5.74	4,329	29.09

<https://healthcaredelivery.cancer.gov/seer-cahps/aboutdata/diagnosis-ma.html>

# NEW: Part D Introduction and Overview

- Medicare Part D is a voluntary prescription drug benefit implemented in 2006
  - Part D prescription drug claims are available in SEER-MHOS from 2008 onward
  - Feasibility Report available upon request: [SEER-MHOS@hcqis.org](mailto:SEER-MHOS@hcqis.org)
-  Stay Tuned: Future webinar focused on Medicare Part D

# Strengths of SEER-MHOS

- ✓ Publicly accessible
- ✓ Large sample size for many cancer sites
- ✓ One of largest data sources on patient-reported outcomes among cancer patients in the U.S.
- ✓ Ability to look at change over a two-year period
- ✓ Can compare individuals with and without cancer

# Limitations of SEER-MHOS

- ✓ Data on certain therapies limited (no chemotherapy, hormone, or immunotherapy)
- ✓ No data on fee-for-service Medicare beneficiaries
- ✓ Only claims available are Medicare Part D
- ✓ Sample size limited in rare cancers
- ✓ Survey sampling frame not designed around time since diagnosis

# SEER-MHOS Survey Variables & Research Examples

*Roxanne Jensen*

# MHOS Survey Content: Patient-Reported Outcomes

- Health-Related Quality of Life (Mental & Physical)
  - SF-36 [1998-2005]
  - VR-12 [2006 – Current]
  - NOTE: NCI funded psychometric work to bridge/correct for response shifts for PCS/MCS and all 8 scales
- Activities of Daily Living
- Cancer-Relevant Symptoms: Depression, Pain

# MHOS Survey Content: HEDIS Effectiveness of Care

- Fall Risk Management
  - *A fall is when your body goes to the ground without being pushed. In the past 12 months, did you talk with your doctor or other health provider about falling or problems with balance or walking? (Yes/No/No Visit in Past 12 months)*
  - *Did you fall in the past 12 months? (Yes/No)*
- Management of Urinary Incontinence in Older Adults
  - *Many people experience leakage of urine, also called urinary incontinence. In the past six months, have you experienced leaking of urine? (Yes/No)*
- Osteoporosis Testing in Older Women
- Physical Activity in Older Adults

# MHOS Survey: Demographics & Clinical History

- Demographics

- Education
- Race / Ethnicity
- Language Spoken At Home [new 2015]



- Clinical

- Smoking History
- Comorbidities
- Body mass index
- Sleep History [new 2015]



# Example Research Questions

## ■ Health-Related Quality of Life (HRQOL)

- Do cancer patients with more comorbidities experience worse HRQOL or impairment to activities of daily living?
- Is overweight and/or obesity associated with worse HRQOL in older cancer patients?
- Is smoking associated with worse HRQOL in older cancer patients?

## ■ Health Disparities

- Do individuals in underserved groups, including racial/ethnic minorities and those living in areas with low socioeconomic resources report lower HRQOL?

## ■ Effectiveness of Care

- Do older individuals with cancer experience higher likelihood of falls? What is the association between fall risk management and cancer status?

# Highlights from Recent Publications: HRQOL before and after cancer

**Study Aim:** Determine if HRQOL reported before diagnosis is prognostic for overall survival for people d

**Sample:** Lung Cancer  
1998-2013, MHOS S  
(n=535)

## Conclusions:

- HRQOL is a predictor for overall survival

	Pre-diagnosis		Post-diagnosis		HRQOL changes	
	AHR-5 pt	95% CI	AHR-5 pt	95% CI	AHR-5 pt	95% CI
MCS	1.05	(0.98–1.11)	1.12	(1.06–1.16)*	1.10	(1.05–1.15)*
PCS	1.05	(0.98–1.10)	1.20	(1.14–1.26)*	1.11	(1.06–1.16)*
Physical function	1.07	(1.00–1.12)*	1.17	(1.12–1.22)*	1.10	(1.05–1.15)*
General health	1.02	(0.94–1.08)	1.12	(1.08–1.18)*	1.12	(1.07–1.17)*

	Pre-diagnosis		Post-diagnosis		HRQOL changes	
	AHR-5 pt	95% CI	AHR-5 pt	95% CI	AHR-5 pt	95% CI
MCS	1.05	(0.98–1.11)	1.12	(1.06–1.16)*	1.10	(1.05–1.15)*
PCS	1.05	(0.98–1.10)	1.20	(1.14–1.26)*	1.11	(1.06–1.16)*

AHR adjusted hazard ratios, 95% CI 95% confidence intervals

\* $p < 0.05$

Pinheiro LC, Reeve BBS. Investigating the prognostic ability of health-related quality of life on survival: a prospective cohort study of adults with lung cancer. Support Care Cancer. 2018 Nov;26(11):3925-3932. doi: 10.1007/s00520-018-4265-3. Epub 2018 May 18.

# Highlights from Recent Publications: Development and Testing of Deficit-Accumulation Frailty Index

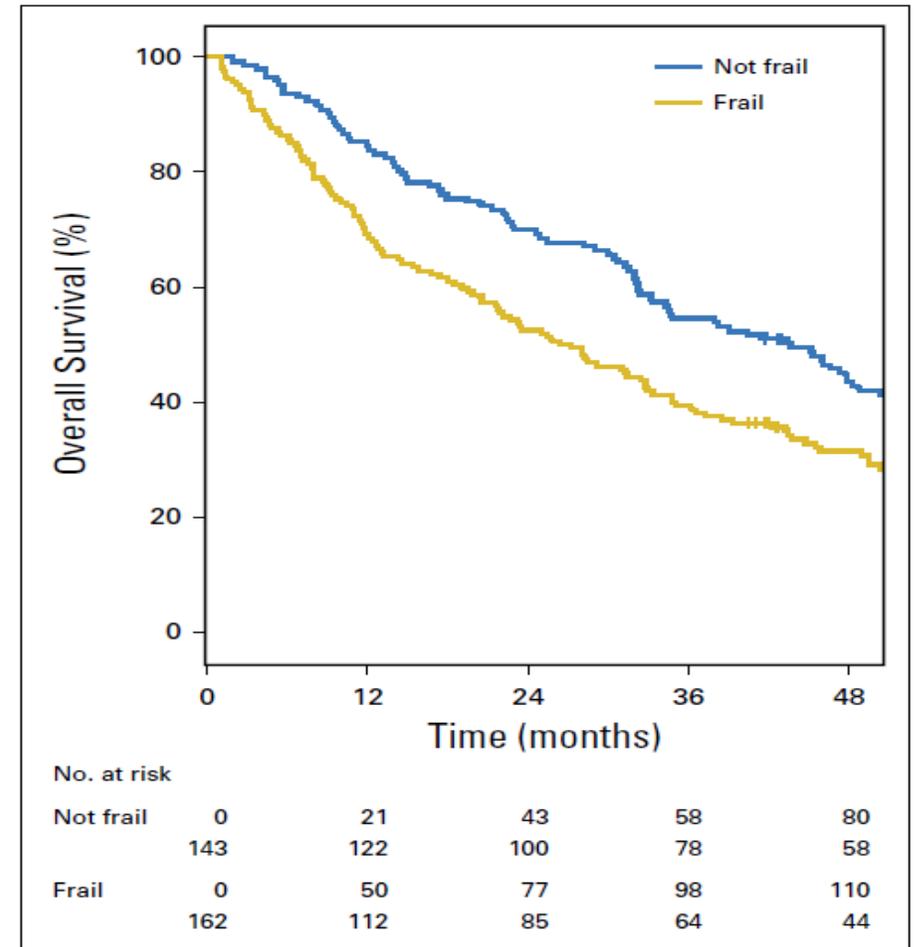
**Study Aim:** To develop and test a deficit accumulation frailty index

**Sample:** (1) Development: patients w/out Cancer (n=2,692,361) (2) Testing: Multiple Myeloma Dx within 1 year of one MHOS survey (n=305)

**Index:** 25 variables (incl. ADLs, Comorbid Conditions, MCS, PCS)

## Key Findings:

- Each 10% increase in the frailty index was associated with a 40% increased risk for death
- Fifty-three percent of patients with multiple myeloma were considered frail



Mian HS, Wildes TM, Fiala MA. Development of a Medicare Health Outcomes Survey Deficit-Accumulation Frailty Index and its Application to Older Patients with Newly-Diagnosed Multiple Myeloma JCO Clinical Cancer Informatics. Epub 2018 July 25.

# Highlights from Recent Publications: Quality of Care Study

**Study Aim:** Characterize older cancer survivors of cancer who report discussing physical activity with their healthcare provider.

## Sample:

- Breast, Colorectal, Prostate Cancer Dx
- MHOS survey  $\geq 2$  years after Dx (n=6,117)
- Mean Time From Dx (5.6 years)
- Visited Health Care provider within past year.

## Key Findings:

- About 50% of survivors report discussing physical activity with their providers

**Table 2**

Adjusted odds ratios (aOR) and 95% confidence intervals (CIs) of the likelihood to discuss physical activity (PA) with a healthcare provider among older cancer survivors.

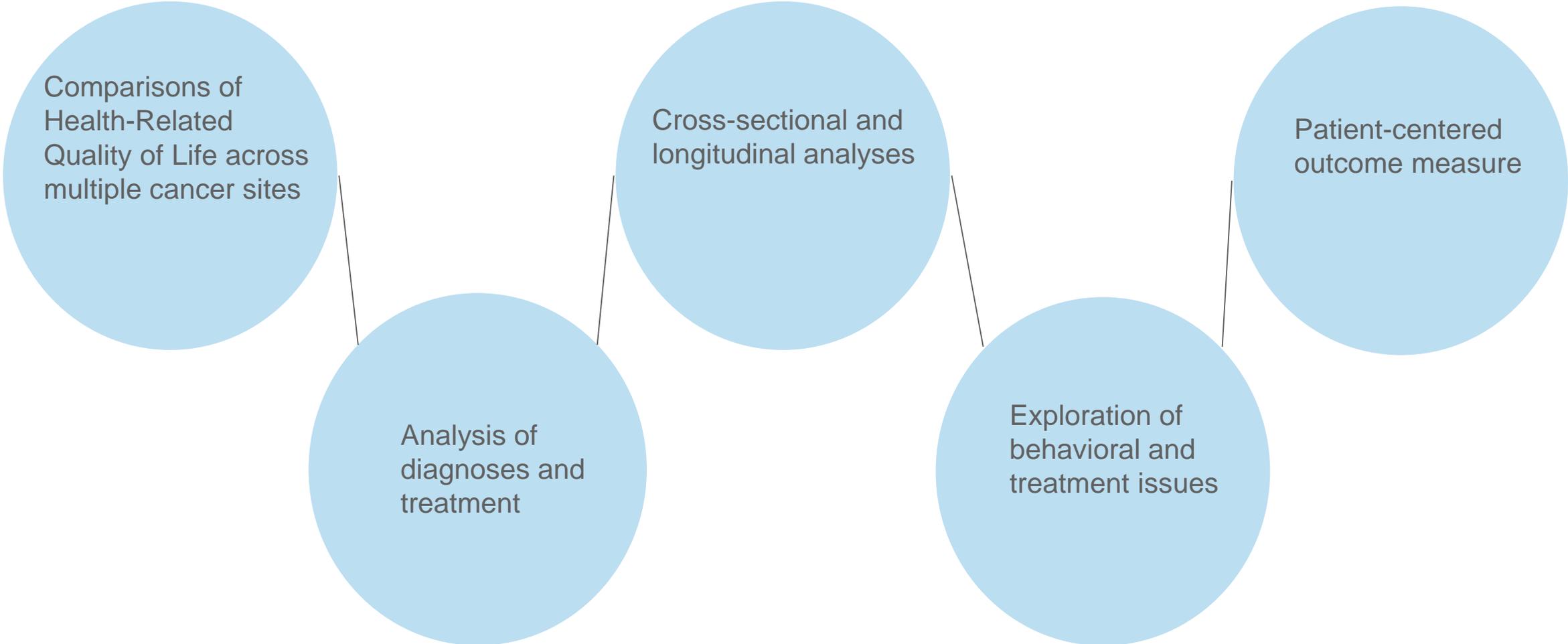
	aOR (95% CI)	p-value
<b>Cancer Site and Gender</b>		
Male, Prostate	Ref	
Female, Breast	0.93 (0.77–1.11)	0.41
Male, Colorectal	<b>0.68 (0.53–0.86)</b>	<b>0.001</b>
Female, Colorectal	0.85 (0.67–1.08)	0.179
<b>Body Mass Index (BMI)</b>		
Underweight (BMI < 20)	0.76 (0.58–1.00)	0.046
Normal (BMI 20–24)	Ref	
Overweight (BMI 25–29)	1.11 (0.97–1.26)	0.139
Obese (BMI 30–34)	<b>1.51 (1.27–1.80)</b>	<b>&lt; 0.001</b>
Morbid Obesity (BMI 35+)	1.23 (0.96–1.58)	0.103
<b>Comorbid Conditions</b>		
Hypertension (ref = no hypertension)	1.12 (0.99–1.26)	0.065
Cardiovascular disease (ref = no cardiovascular disease)	<b>1.46 (1.29–1.64)</b>	<b>&lt; 0.001</b>

Siembida EJ, Kent EE, Bellizzi KM, Smith AW. Healthcare providers' discussions of physical activity with older survivors of cancer: Potential missed opportunities for health promotion. J Geriatr Oncol.2019 May 20.pii: S1879-4068(18)30522-8.

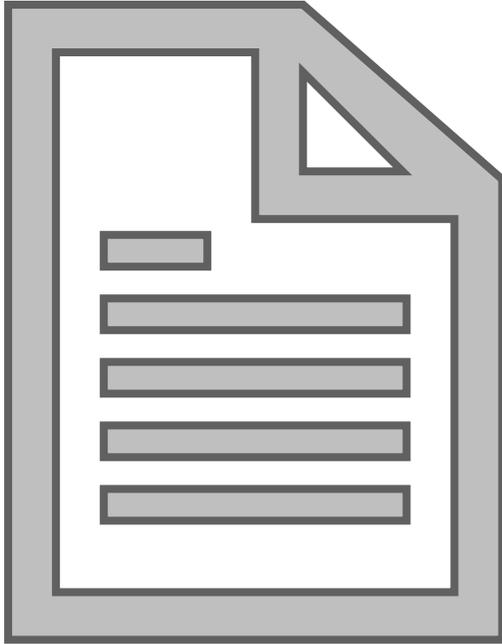
# SEER-MHOS Data Application Process

*Tanjina Shabu*

# What are the usages of SEER-MHOS Data?



# SEER-MHOS: How to apply for the data



- Required documents:
  - Cover letter
  - Application form
  - SEER-MHOS Data Use Agreement (DUA)
  - Institutional Review Board (IRB) approval
- All forms and applications can be found here:  
<https://healthcaredelivery.cancer.gov/seer-mhos/obtain/req.docs.html>
- The SEER-MHOS email is:  
[SEER-MHOS@hcqis.org](mailto:SEER-MHOS@hcqis.org)

# What is the approval process?



## NCI and SEER staff review each proposal to ensure:

- Feasibility and confidentiality of patients, providers, and institutions in SEER areas
- Alignment of proposed study purpose with the available SEER-MHOS data



## Internal Review Process

Usually takes 4-6 weeks upon receiving the completed proposals



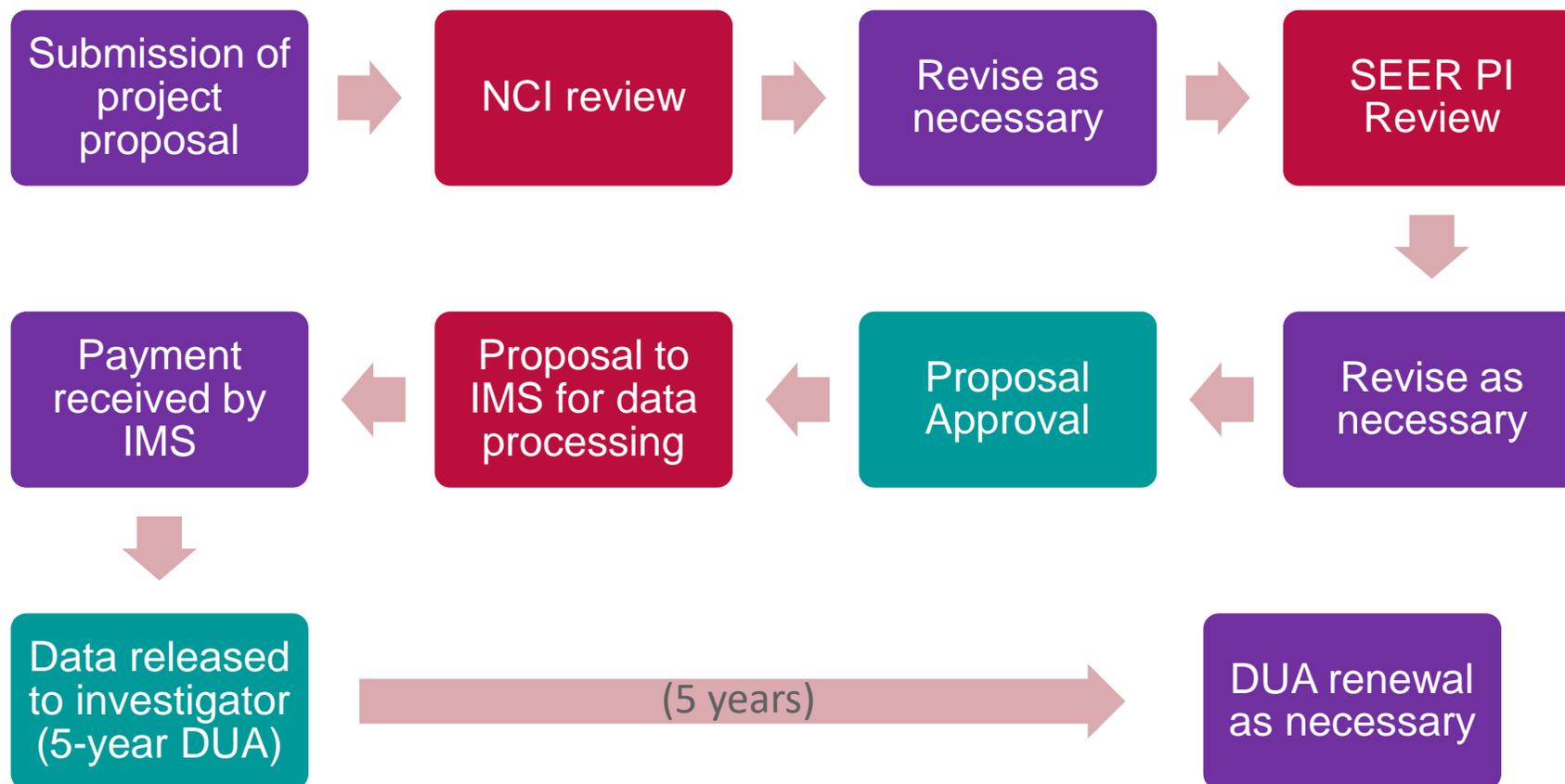
## Once data request has been approved

Investigators will receive an invoice for the costs of preparing the requested data files



# SEER-MHOS: Application process

- Applications require two levels of approval, and data requests generally take 4-6 weeks for review



# What to do after receiving SEER-MHOS data?

## Do:

- Abide by Data Use Agreement
- Use the data for the approved project only
- Store all media on which the SEER-MHOS data are delivered in a secure location, only accessible by you or appropriate designated staff
- Send all manuscripts (before submission) to SEER-MHOS contact for final clearance
- Include appropriate acknowledgments in all publications and presentations

## Don't:

- Provide the data to other researchers or institutions if they are not included in the research proposal
- Use the data for purposes other than described in the research proposal

# Summary

*Roxanne Jensen*



## **SEER-MHOS**

- Surveillance, Epidemiology, and End Results (SEER) cancer registry data linked to the Medicare Health Outcomes Survey (MHOS)
- MHOS examines health-related quality of life (HRQOL) among Medicare Advantage enrollees
- Linked data resource designed to provide an understanding of the HRQOL of cancer patients and survivors enrolled



**SEER Cancer Registry  
Data**



**Medicare Enrollment**



**Medicare Advantage  
Enrollees**



**Health-Related Quality  
of Life (MHOS) Survey  
Data**

**Visit the website**  
**[https://healthcaresdelivery.cancer.gov/  
seer-mhos/](https://healthcaresdelivery.cancer.gov/seer-mhos/)**

**Contact SEER-MHOS staff at**  
**[SEER-MHOS@hcqis.org](mailto:SEER-MHOS@hcqis.org)**