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

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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

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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:
  - ≥ 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 81 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

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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.hosonline.org](https://www.hosonline.org)
SEER-MHOS Overview & Available Data

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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

Completed One or More MHOS Surveys  
n=3,018,692

Linked to SEER  
n=186,255

Non-SEER CA Cases  
n=145,735

Not Linked to SEER  
n=2,686,702

One MHOS Survey  
n=100,348

Survey Before Cancer  
n=40,929

Survey Between Cancers  
n=6,611

Survey After Cancer  
n=51,432

Two or More MHOS Surveys  
n=85,907

Survey Before Cancer  
n=26,273

Survey After Cancer  
n=18,004

All Surveys Before and After Cancer  
n=40,579

All Surveys Before Cancer  
n=270,274

All Surveys After Cancer  
n=226,399

One MHOS Survey  
n=968,915

Two or More MHOS Surveys  
n=892,840

No Cancer Reported  
n=496,673

All in SEER Area  
n=518,530

No Cancer Reported  
n=1,861,755

Not all in SEER area  
n=2,168,172

For more detailed information on this flow diagram, see:  
## SEER-MHOS: Most prevalent cancer types

<table>
<thead>
<tr>
<th>First Cancer</th>
<th>Total Number of SEER linked patients</th>
<th>More than one survey</th>
<th>Survey before cancer diagnosis</th>
<th>Survey both before and after diagnosis</th>
<th>Survey after cancer diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Prostate</td>
<td>35,128</td>
<td>16,221</td>
<td>46.18</td>
<td>10,215</td>
<td>29.08</td>
</tr>
<tr>
<td>Breast</td>
<td>31,407</td>
<td>15,145</td>
<td>48.22</td>
<td>9,063</td>
<td>28.86</td>
</tr>
<tr>
<td>Colorectal</td>
<td>18,993</td>
<td>8,661</td>
<td>45.60</td>
<td>7,568</td>
<td>39.85</td>
</tr>
<tr>
<td>Lung and bronchial</td>
<td>14,880</td>
<td>5,836</td>
<td>39.22</td>
<td>11,400</td>
<td>76.61</td>
</tr>
</tbody>
</table>

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

➤ 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
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 diagnosed with lung cancer.

**Sample:** Lung Cancer Diagnosis between 1998-2013, MHOS Survey Pre/Post Dx (n=535)

**Conclusions:**
- HRQOL is a predictor for overall survival
- Post-diagnosis HRQOL and HRQOL change models were most associated with Overall Survival

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.
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 ≥ 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

SEER-MHOS Data Application Process

Tanjina Shabu
What are the usages of SEER-MHOS Data?

- Comparisons of Health-Related Quality of Life across multiple cancer sites
- Analysis of diagnoses and treatment
- Cross-sectional and longitudinal analyses
- Exploration of behavioral and treatment issues
- Patient-centered outcome measure
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](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

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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
Visit the website
https://healthcaredelivery.cancer.gov/seer-mhos/

Contact SEER-MHOS staff at
SEER-MHOS@hcqis.org