Methodological considerations for studies on cancer patient experiences of care using the SEER-CAHPS Data Resource

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April 2, 2019
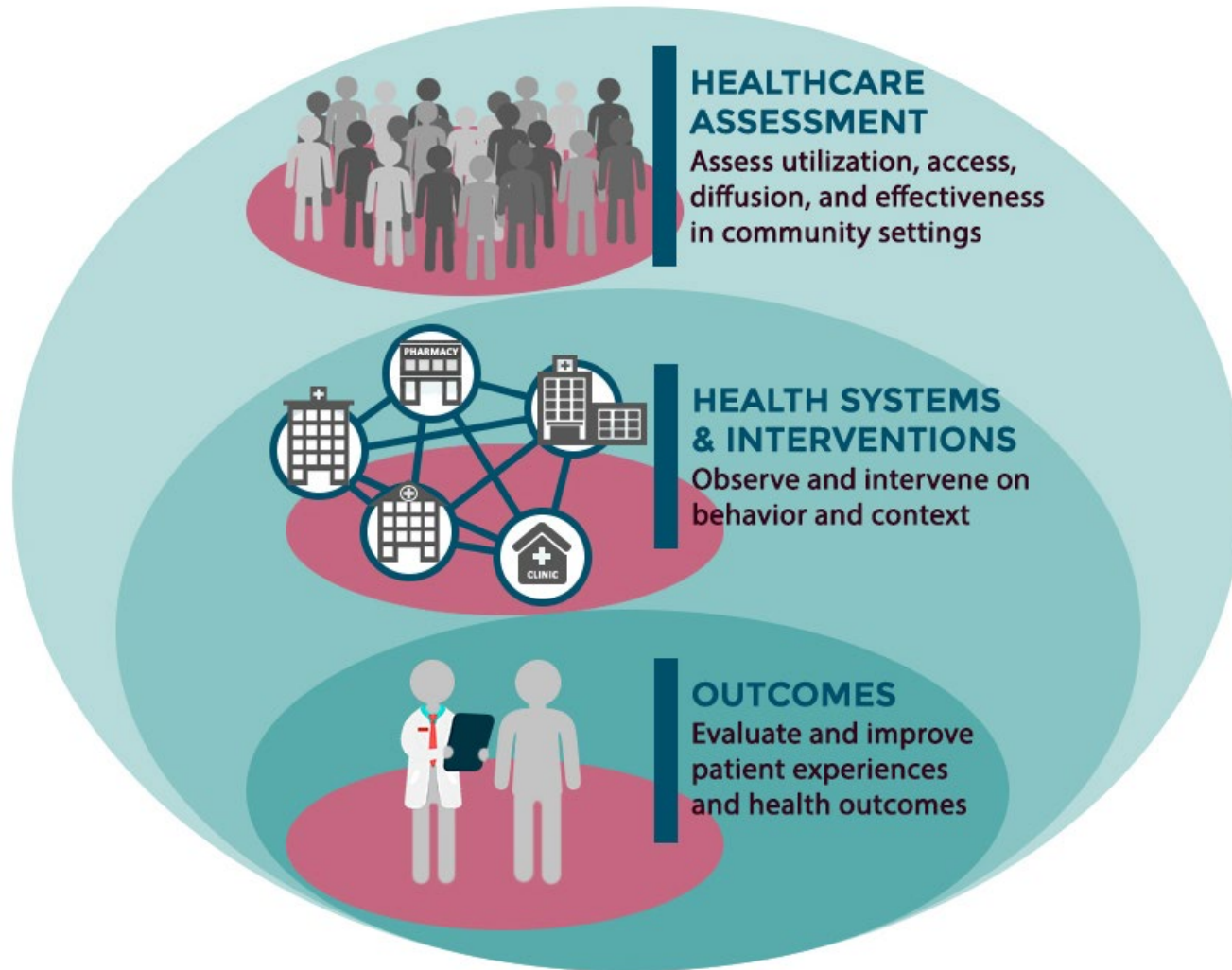
Today's webinar

- **SEER-CAHPS:** Surveillance, Epidemiology, and End Results Program-Consumer Assessment of Healthcare Providers and Systems

- The goal of today's webinar is to present methodological considerations for investigators interested in conducting research using the SEER-CAHPS linked data resource

HEALTHCARE DELIVERY RESEARCH PROGRAM
Advancing innovative research to improve the delivery of cancer-related care.

HEALTHCARE ASSESSMENT
Assess utilization, access, diffusion, and effectiveness in community settings

HEALTH SYSTEMS & INTERVENTIONS
Observe and intervene on behavior and context

OUTCOMES
Evaluate and improve patient experiences and health outcomes

Overview

- Background

- Purpose of SEER-CAHPS data resource

- Methodological discussions of each data source
  - SEER
  - CAHPS
  - Medicare Claims
  - SEER-CAHPS

- Q & A

Please refer to the SEER-CAHPS overview webinar for a more detailed introduction to the data resource

Presenters

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SEER-CAHPS Overview

Erin Kent

Importance of Patient Experiences

- Patient experiences are more than satisfaction

- Measurable, involves processes observable by patients

- Experiences are important for achieving:
    - Continuity of care
    - Strong patient-provider relationships
    - Better outcomes

SEER-CAHPS Linked Data Resource
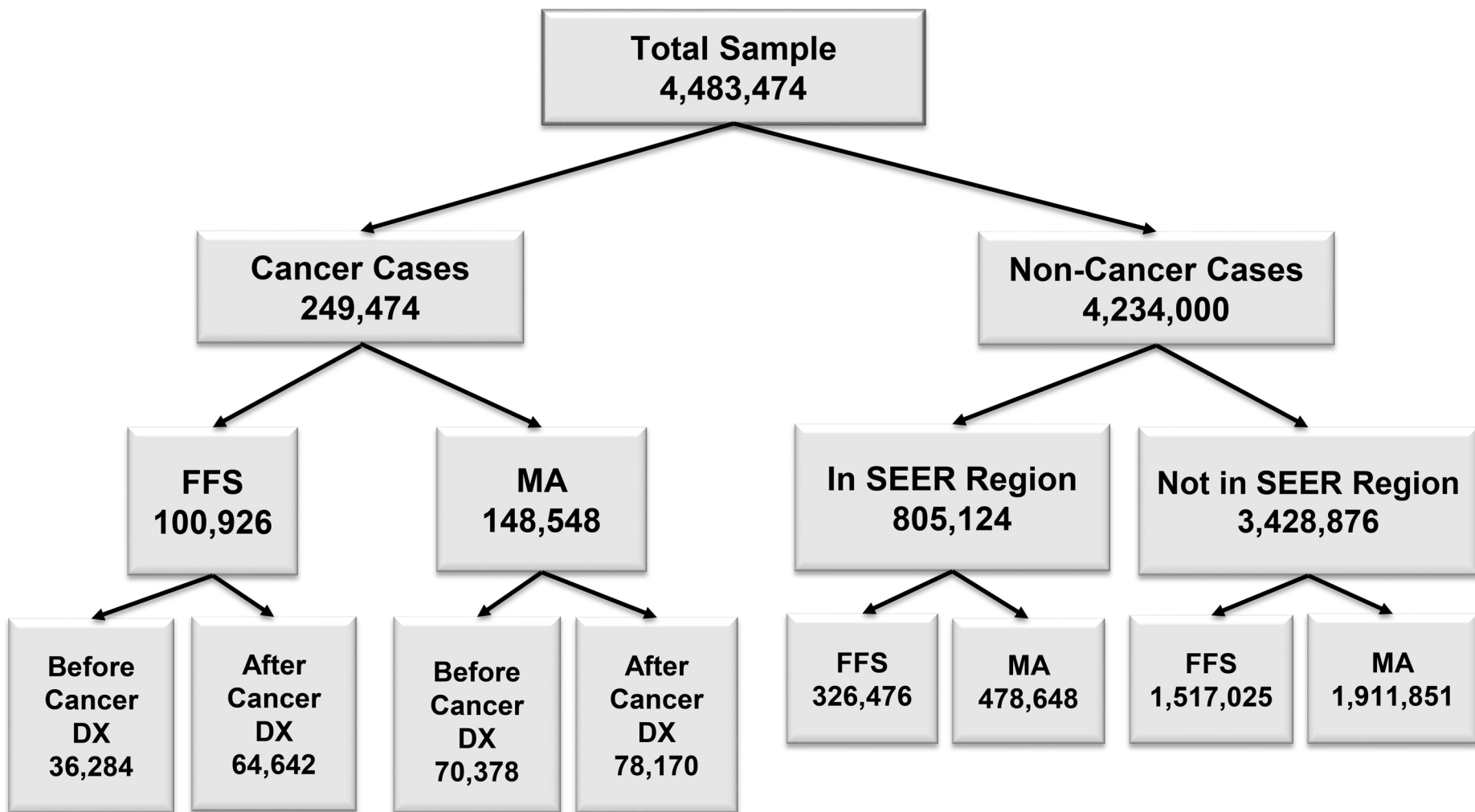
Linkage of three sources of data:

1. Cancer registry data: SEER: Surveillance, Epidemiology, and End Results Program

2. Patient-reported experiences with care: Medicare CAHPS® Survey: Consumer Assessment of Healthcare Providers and Systems Survey

   ▪ Medicare Advantage (MA), Prescription Drug Plan (PDP), & Fee-for-Service (FFS)

3. Medicare enrollment and claims for FFS beneficiaries

SEER
Cancer
Registry
Data

Medicare
FFS
Claims

Medicare
CAHPS
Surveys

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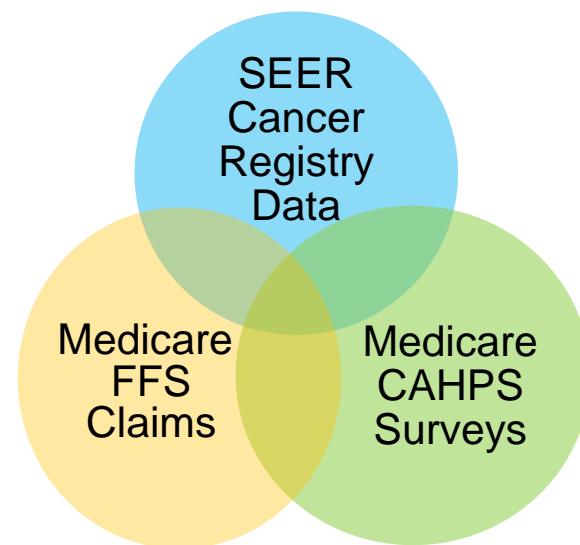
Purpose of SEER-CAHPS

- Provides a rich data resource on quality of care from the perspective of **cancer** patients

- Ability to examine Medicare beneficiaries' experiences with care along the cancer care continuum

- Provides an opportunity to examine associations between experiences of care and healthcare utilization or costs of care through use of Medicare FFS claims

Number of cancer and non-cancer survey respondents by SEER Region and Medicare Advantage vs Fee-for-Service

Total Sample
4,483,474

Cancer Cases
249,474

Non-Cancer Cases
4,234,000

FFS
100,926

MA
148,548

In SEER Region
805,124

Not in SEER Region
3,428,876

Before Cancer DX
36,284

After Cancer DX
64,642

Before Cancer DX
70,378

After Cancer DX
78,170

FFS
326,476

MA
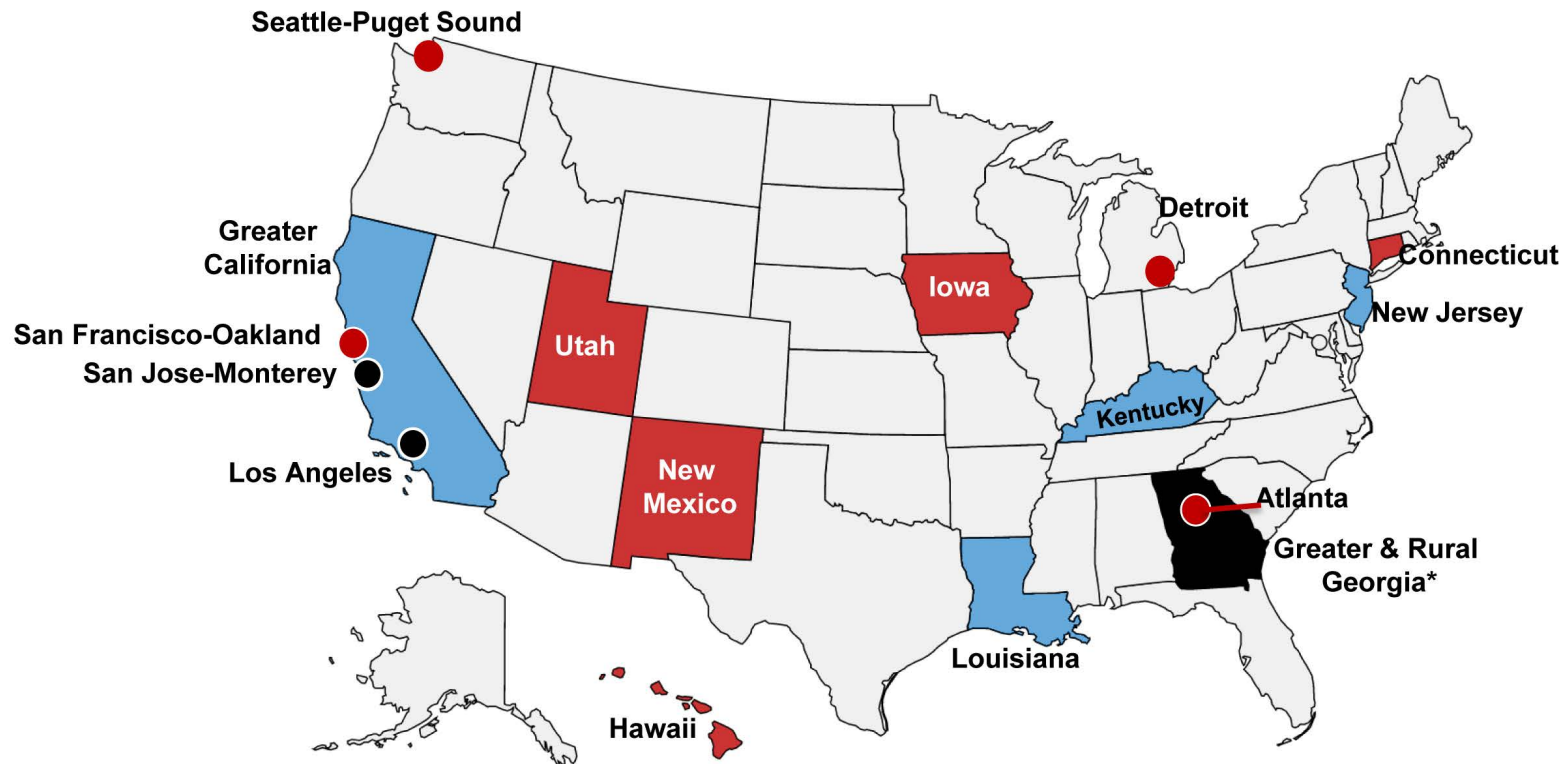478,648

FFS
1,517,025

MA
1,911,851

Note: some respondents have taken more than one survey, at different years. This figure reflects the first survey taken.

Methodological considerations: SEER

Lisa Lines

SEER Cancer Registry Data

Map of the United States showing SEER Cancer Registry locations:
- Seattle-Puget Sound (1973-1975 SEER)
- Greater California (2000 SEER Expansion)
- San Francisco-Oakland (1973-1975 SEER)
- San Jose-Monterey (1988-1999 SEER)
- Los Angeles (1988-1999 SEER)
- Utah (1973-1975 SEER)
- New Mexico (1973-1975 SEER)
- Hawaii (1973-1975 SEER)
- Iowa (1973-1975 SEER)
- Detroit (1973-1975 SEER)
- Kentucky (2000 SEER Expansion)
- Louisiana (2000 SEER Expansion)
- Connecticut (1973-1975 SEER)
- New Jersey (2000 SEER Expansion)
- Atlanta (1973-1975 SEER)
- Greater & Rural Georgia* (1988-1999 SEER)

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)

SEER Data Files and Documentation

- **Important documentation**

  - [Patient Entitlement and Diagnosis Summary File](#) (PEDSF)

    - Cancer cases diagnosed 1996-2013 (Unique ID: PHIC)

    - Data on each person's demographics, date & cause of death (if any), marital status, and location *at diagnosis*

    - Also has reason for Medicare entitlement, Medicare/dual eligibility and HMO [Medicare Advantage] enrollment *by month* (1996 – 2015)

  - SEER variables from the SEER file are described in [Appendix A: SEER Research Data Record Description](#)

  - [ZIP Code Census File Documentation](#)

  - [Census Tract File Documentation](#)

Primary Site

- Primary site ([code dictionary](#))
- SEER, NAACR (histrec), ICD-O-2, and ICD-10
  - Max of 10 sites or site combinations in your proposal
    - Head and neck = 1 site
    - Colon and rectal = 1 site
    - Lung and bronchus = 1 site
  - [Site-specific factors:](#)
    - ER/PR status, genetic information, Gleason score, WHO/ISUP grade
- Sample sizes
  - Single-site studies *possible* if there are big differences in your outcome measure
  - Power calculations are important

Clinical Information

Detailed clinical data available:

- First primary (firstprm1-firstprm10), sequence **(seq1-seq10)** and record # (rec01-rec*nn*): up to 10 dx per person

  - site1-site10

  - lat1-lat10

  - yrdx1-yrdx10

- Initial procedure indicators – surgery, radiation, lymph node removal/biopsy

- [Stage](#)

  - Extent of disease (EOD)

Extent of Disease Data
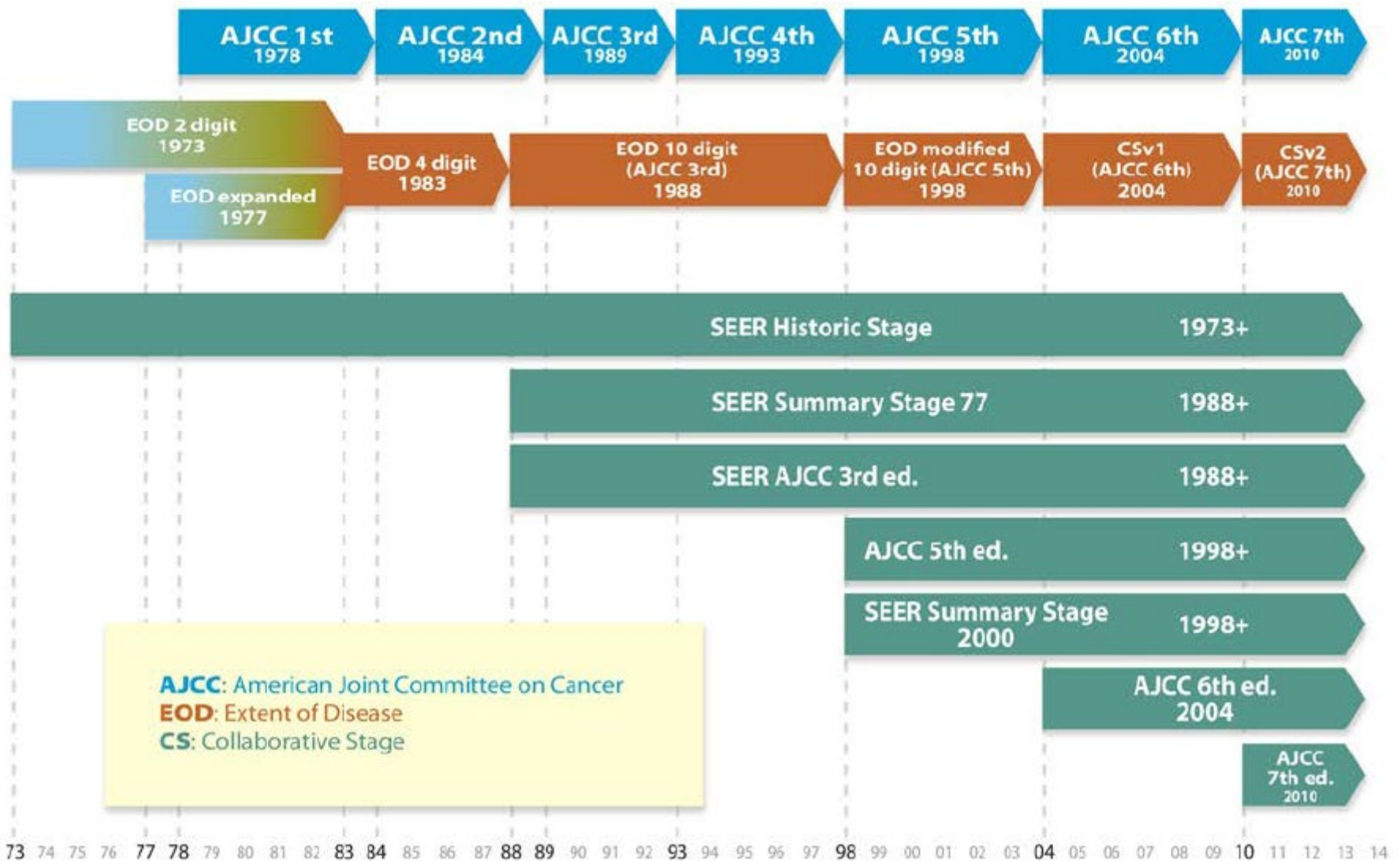
Pay Attention to the Source of Information

- Demographics

  - Medicare race/ethnicity:

    1 = White
    2 = Black
    3 = Other
    4 = Asian
    5 = Hispanic
    6 = N. Am. Native
    0 = Unknown

  - Race recodes

  - https://seer.cancer.gov/seerstat/variables/seer/race_ethnicity/

  - SEER race/ethnicity:

    01 = Caucasian
    11 = Caucasian, Spanish origin or surname
    02 = Black
    03 = American Indian/Alaska Native
    04 = Chinese
    05 = Japanese
    06 = Filipino
    07 = Hawaiian
    08 = Other Asian or Pac. Islander
    09 = Unknown
    12 = Other unspecified (1991+)

Methodological considerations: CAHPS

Sarah Gaillot

CAHPS Initiative

- CAHPS surveys follow scientific principles in survey design and development

- Surveys use standardized questions and data collection protocols to ensure that information can be compared across healthcare settings

Medicare CAHPS Surveys

- The Medicare CAHPS surveys have been rigorously developed and tested to reliably assess the experiences of beneficiaries who receive health care through:

  - FFS

  - MA

  - PDP

- Data allow objective and meaningful comparisons between MA and PDP contracts and with FFS on domains that are important to consumers

- Administered by CMS since 1997

Medicare CAHPS Surveys

Global Ratings	Composite Measures
Health Plan	Getting Needed Care
Health Care	Getting Care Quickly
Personal Doctor	Provider Communication
Specialist	Customer Service
Prescription Drug Plan	Getting Needed Prescription Drugs
	Care Coordination

Medicare CAHPS Implementation

- The FFS CAHPS and MA & PDP CAHPS surveys are administered annually to a large sample of Medicare beneficiaries using a mixed mode data collection protocol that includes two survey mailings and telephone follow-up of non-respondents to the mailed questionnaire

  - Approximately 275,000 FFS beneficiaries

  - Approximately 800 beneficiaries per MA contract

  - Approximately 1,500 beneficiaries per PDP contract

- Most items ask about experiences over the previous 6 months

  - Beneficiaries have to have been continuously enrolled in FFS or their MA/PDP contract for the previous 6 months to be eligible for sample

Methodological considerations: CAHPS

- Researchers need to consider:

  - Whether to include CAHPS data from FFS, MA, PDP, or some combination

    - Within MA, some beneficiaries are enrolled in MA-only contracts, while others are enrolled in MA-PD contracts

  - Which items are on which surveys, in which years

    - Item wording may have changed

    - Composites may have changed

    - Some older items have been removed in recent years because they had poor psychometric properties

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Publicly Accessible Data

  SEER-CAHPS Linked Data Resource

    The SEER-CAHPS Data File

      CAHPS Data Documentation

    SEER Program & Data

    SEER-Medicare Claims & Enrollment File Information

    SEER-CAHPS Flagged Custom Database in SEER*Stat – Sample Size Estimator

    Provider Files

    Participant Characteristics

🏠 ▸ Data, Tools, and Initiatives ▸ Publicly Accessible Data ▸ SEER-CAHPS Linked Data Resource ▸ The SEER-CAHPS Data File ▸ CAHPS Data Documentation

CAHPS Data Documentation

Here you will find details on items, variables, and composite variables on the Medicare CAHPS surveys, and differences across health plan survey type and survey years. Several variables were added to the CAHPS survey data file and are described in the Data Dictionary. The variable (*INSEER*) identifies CAHPS respondents who were found in the SEER file and were diagnosed with cancer between 1973 and 2013. Several variables were calculated to describe the timing of the survey relative to cancer diagnosis including the patient's cancer status at the time of the survey (*CA_STAT*). These variables can be used to select a subset of respondents or surveys based on pre/post-cancer diagnosis; for example, selecting number of cancers before survey equal to 0 (*NUMCABEF* = 0) will keep only surveys prior to any cancer diagnosis.

- ▸ Medicare CAHPS Data Dictionary:
  - ▸ MS Excel format (XLSX, 54 KB)
  - ▸ Portable Document Format:
    - ▸ 1997 – 2005 (PDF, 194 KB)
    - ▸ 2007 – 2015 (PDF, 217 KB)
- ▸ Changes in Medicare CAHPS Survey Items (PDF) ⧉
- ▸ SEER-CAHPS Details for Researchers:
  - ▸ MS Excel format (XLSX, 200 KB)
  - ▸ Portable Document Format:
    - ▸ Intro (PDF, 339 KB)
    - ▸ Global Rating (PDF, 102 KB)
    - ▸ About You (PDF, 682 KB)
    - ▸ Getting Care Quickly (PDF, 552 KB)
    - ▸ Getting Needed Care (PDF, 364 KB)
    - ▸ Doctor Communication (PDF, 356 KB)
    - ▸ Customer Service (PDF, 474 KB)
    - ▸ PDP Info (PDF, 330 KB)
    - ▸ Get Needed Rx (PDF, 447 KB)
    - ▸ Care Coordination (PDF, 301 KB)
    - ▸ Related (get care quickly) (PDF, 217 KB)

https://healthcaredelivery.cancer.gov/seer-cahps/aboutdata/documentation.html

Methodological considerations: CAHPS

- We strongly suggest:
  - Using existing CAHPS composites
  - [Reviewing CAHPS analytic guidance:](#)
    - Survey weights
    - Case-mix adjustment
    - Analytic approaches (e.g., linear mean scoring)

Case-mix Adjustment Guidance

- Case-mix adjustment helps to control for variability in patient experience ratings due to differing mixes of patient characteristics associated with patient experience scores

- Standard case-mix adjustment variables for Medicare CAHPS survey data include:

  - Education, general health status, mental health status, age, indicator of Medicaid dual eligibility, eligibility for low-income subsidy, proxy response status, Asian language survey response

- Inferences and interpretation of unadjusted CAHPS results are not appropriate

CAHPS Analytic Guidance

- Linear mean scoring is the preferred Medicare CAHPS scoring method, as it produces the most reliable estimates and the greatest statistical power

  - $Y = 100 * (X-a)/(b-a)$

    - Where Y is the transformed score, X is on the original numeric scale, a is the minimum possible value, b is the maximum possible value

  - Given that meaningful effect sizes can be small with Medicare CAHPS measures, adequate statistical power is a significant concern for analyses that are limited to subgroups of patients, as is the case with SEER-CAHPS data

https://healthcaredelivery.cancer.gov/seer-cahps/researchers/guidance.html

Medicare CAHPS Resources

- Review existing Medicare CAHPS literature:

  - https://ma-pdpcahps.org/globalassets/ma-pdp/home-page/bibliography.pdf

- More details about FFS CAHPS:

  - https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS/ffscahps.html

- More details about MA & PDP CAHPS:

  - https://ma-pdpcahps.org/

- More details about other CMS CAHPS surveys:

  - https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS/index.html

Methodological considerations: Medicare claims

Michael Halpern

Medicare Claims Data

Data include:

- **MEDPAR** (Medicare Provider Analysis and Review): inpatient hospital, skilled nursing facility, and rehabilitation facility claims

- **NCH** (Carrier Claims): Office-based provider and free-standing ambulatory care center claims

- **Outpatient claims:** institutional outpatient providers such as hospital-based outpatient care

- **HHA:** Home health care claims

- **Hospice** claims

- **DME:** Durable medical equipment claims

- **Patient encrypted ID** (phic): used to link different claims files

- **Part D** (prescription medication): data available in SEER-CAHPS for cancer cases only

Illustrative Case Study: Patterns of Care for Cancer Survivors

Cancer Survivorship Shared Care: care delivered by both oncologists and primary care providers (PCPs)

- Little information on outcomes, including patient experience of care, for survivors receiving shared care vs. oncologist-led or PCP-led care

Study Objective: Use SEER-CAHPS to examine association of survivorship pattern of care (shared, oncologist-led, PCP-led or other) with survivors' experience of care

Methodological Considerations in using Medicare Claims

Issue 1: Identifying the Population of Interest and Episode of Care.

- Survivorship care period often defined as starting one year following cancer diagnosis.

- Needed to select a cohort with SEER-CAHPS information during this survivorship care period.

  - CAHPS survey asks respondents to consider ratings for the **previous six months of care**.

- Also wanted to exclude individuals who are near end-of-life, when patterns of care and experience of care are likely to differ.

Identification of Cancer Survivors for SEER-CAHPS Survivorship Patterns of Care Study

- SEER-CAHPS Survivorship Patterns of Care Study included:
  - Individuals who responded to a Medicare CAHPS survey at least 18 months following cancer diagnosis.
    - CAHPS survey reflected experience of care for a period at least 12 months **after** diagnosis.
- Individuals enrolled in FFS Medicare Parts A and B at least 6 months before and 6 months after completing a CAHPS survey.
  - Ensured that claims data were available for a 12-month period of survivorship care and survivor lived for at least 6 months following survey completion.

Methodological Considerations in using Medicare Claims

Issue 2: Determining Physician Specialty.

Patterns of Survivorship Care Issue: Who is an oncologist?

- In Medicare claims data, unique ID number for each physician that cannot be linked to the actual person (encrypted IDs)

- Physician specialty can be linked to this encrypted IDs in Medicare claims data.

- However, many physicians have multiple specialties listed in their different Medicare claims.

Identifying Physician Specialty in Medicare Claims

- Developed rules to categorize physician specialty by looking at all Medicare claims for a physician across the 12 month study period:

  - Oncologist: physician with any E&M claim during the study period indicating specialty of hematology/oncology, medical oncology, surgical oncology, radiation oncology, hematology, gynecology/oncology, or urology (for prostate cancer survivors).

  - PCP: non-oncologists with any E&M claim during the study period indicating specialty of family practice, general medicine, general surgery, internal medicine, geriatric medicine, obstetrics/gynecology, or preventive medicine.

  - Other Specialty: all physicians not categorized as oncologists or PCPs.

Methodological Considerations in using Medicare Claims

Issue 3: Defining Patterns of Care.

Patterns of Survivorship Care Issue: How to define "Shared Care"?

- No uniform definition from previous research or guidelines.

- We wanted to use a data-driven definition of Shared Care, based on the care received by survivors during the 12-month study period.

  - Defined Shared Care to involve substantial contact with both oncologists and PCPs.

Categorization of Shared Care using Medicare Claims

Based on physician specialty from outpatient evaluation and management (E & M) Medicare claims during 12-month study window.

- Oncologist-led pattern of care: >60% of physician encounters with oncologists.

- PCP-led pattern of care: >60% of physician encounters with PCPs.

- Shared Care: population **not** in oncologist-led or PCP-led patterns of care who greater than the median proportion of outpatient visits with **both** oncologists and PCPs.

Medicare Claims Methodologic Considerations Summary Points

- Medicare claims data are detailed, voluminous, and can be overwhelming.

- Claims data are available only for individuals enrolled in Medicare Fee-for-Service (Parts A and B).

  - Analyses using claims data will exclude individuals in Medicare Advantage plans.

- Before starting analyses, need to develop approaches for identifying the population /episode of care and care patterns of interest.

  - May need to revise these approach once data analyses start.

- Information on Medicare claims available on SEER-CAHPS website at https://healthcaredelivery.cancer.gov/seer-cahps/medicare/claims.html

Methodological considerations: SEER-CAHPS

Erin Kent

Methodological considerations: timing of cohort selection

- SEER-CAHPS is a data linkage, not designed de novo around cancer experience

- Investigators are advised to consider the implications of their design with timing in mind
  - Timing of diagnosis, treatment, survey

- Questions to inform study design and goals:
  - Focus on cancer patients undergoing active treatment, survivorship, end-of-life?
  - Focus on individuals not yet diagnosed with cancer?
  - Comparisons between individuals with and without cancer?

Example 1: Urban/rural differences in patient experiences among cancer survivors

Examining Urban and Rural Differences in Perceived Timeliness of Care Among Cancer Patients: A SEER-CAHPS Study

Michelle A. Mollica, PhD, MPH, RN, OCN [1]; Kathryn E. Weaver, PhD [2]; Timothy S. McNeel, BA[3]; and Erin E. Kent, PhD[1]

Cohort selection: Colorectal, lung, prostate, breast (female) cancer survivors, MA and FFS

First primary cancer diagnosis 1998-2013	Survey ≤12 months post diagnosis

12 months

Example 2: Adherence to guideline-based follow-up care in colorectal cancer survivors

ORIGINAL PAPER

Examining colorectal cancer survivors' surveillance patterns and experiences of care: a SEER-CAHPS study

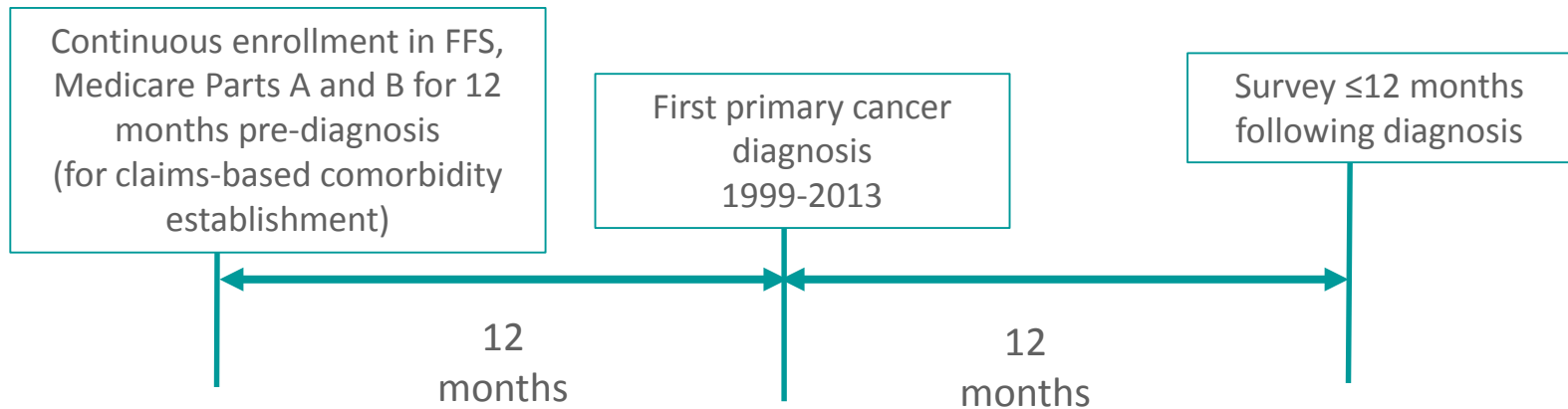Michelle A. Mollica[1] · Lindsey R. Enewold[1] · Lisa M. Lines[2] · Michael T. Halpern[2] ·
Jessica R. Schumacher[3] · Ron D. Hays[4] · James T. Gibson[5] · Nicola Schussler[5] ·
Erin E. Kent[1]

Cohort selection: Colorectal cancer survivors, FFS only

First primary colon or rectal adenocarcinoma cancer diagnosis 1999-2009

6 months after surgery

Observation period: guideline-based surveillance for recurrence (Office visit, CEA tests, colonoscopy, CT imaging) in months 7-42 following surgical resection

42 months after surgery
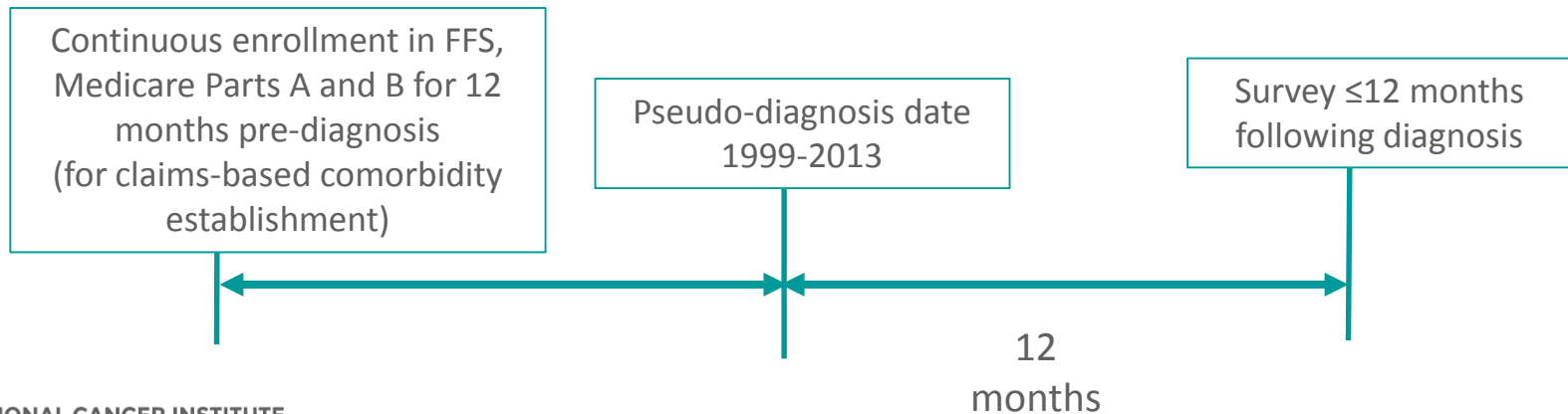
Survey ≤36 months after diagnosis
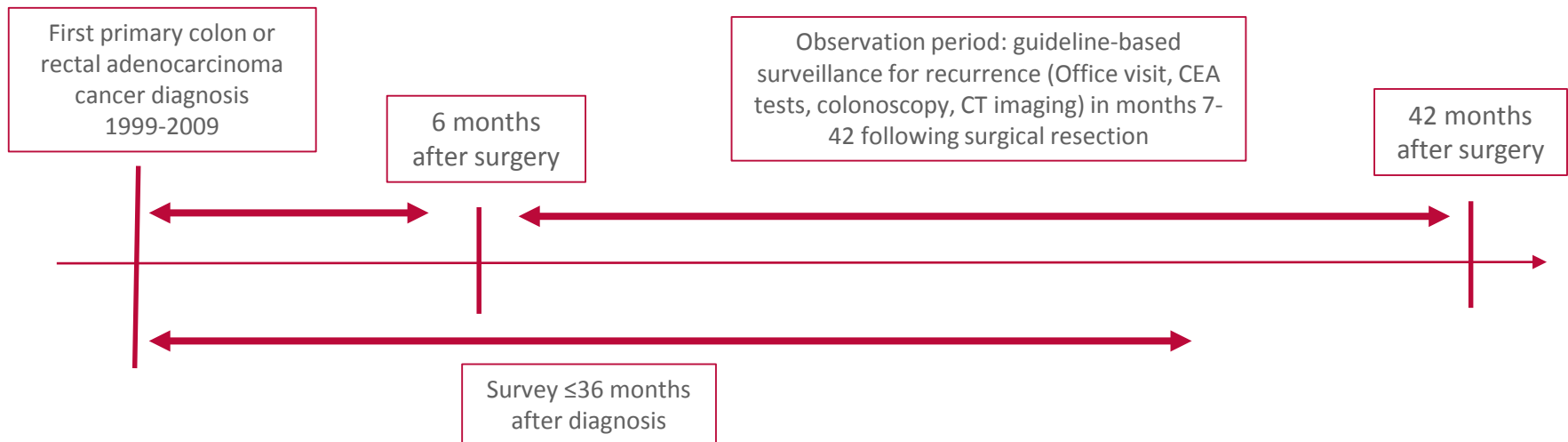
Example 3: Impact of activities of daily living (ADL) impairment on patient experience among individuals with and without cancer (hypothetical)

**Cohort selection: Cancer survivors (breast, prostate, colorectal, lung, heme)
FFS only**

Continuous enrollment in FFS, Medicare Parts A and B for 12 months pre-diagnosis
(for claims-based comorbidity establishment)

First primary cancer diagnosis
1999-2013

Survey ≤12 months following diagnosis

12 months

12 months

**Cohort selection: No history of cancer
FFS only**

Continuous enrollment in FFS, Medicare Parts A and B for 12 months pre-diagnosis
(for claims-based comorbidity establishment)

Pseudo-diagnosis date
1999-2013

Survey ≤12 months following diagnosis

12 months

Summary

NATIONAL CANCER INSTITUTE

SEER-CAHPS

- Resource to examine **cancer** patient experiences of care

- Includes > 240,000 individuals with a history of cancer

- Contains population-based cancer registry, Medicare CAHPS survey, and Medicare claims data

- Allows for comparisons of patient experiences between individuals with and without a cancer history

- Research questions can target associations between cancer patient experiences and health status, vital status, and healthcare utilization

SEER-CAHPS Partners

- National Cancer Institute (NCI) & SEER registries

- Centers for Medicare & Medicaid Services (CMS)

With technical assistance from:

- RTI International

- Information Management Services, Inc. (IMS)

- RAND Corporation, Harvard Medical School

For more information:
https://healthcaredelivery.cancer.gov/seer-cahps/

*News and announcements on the SEER-CAHPS data set and public launch: **SEER-CAHPS@list.nih.gov***

Additional questions or inquiries:
NCISEERCAHPS@mail.nih.gov