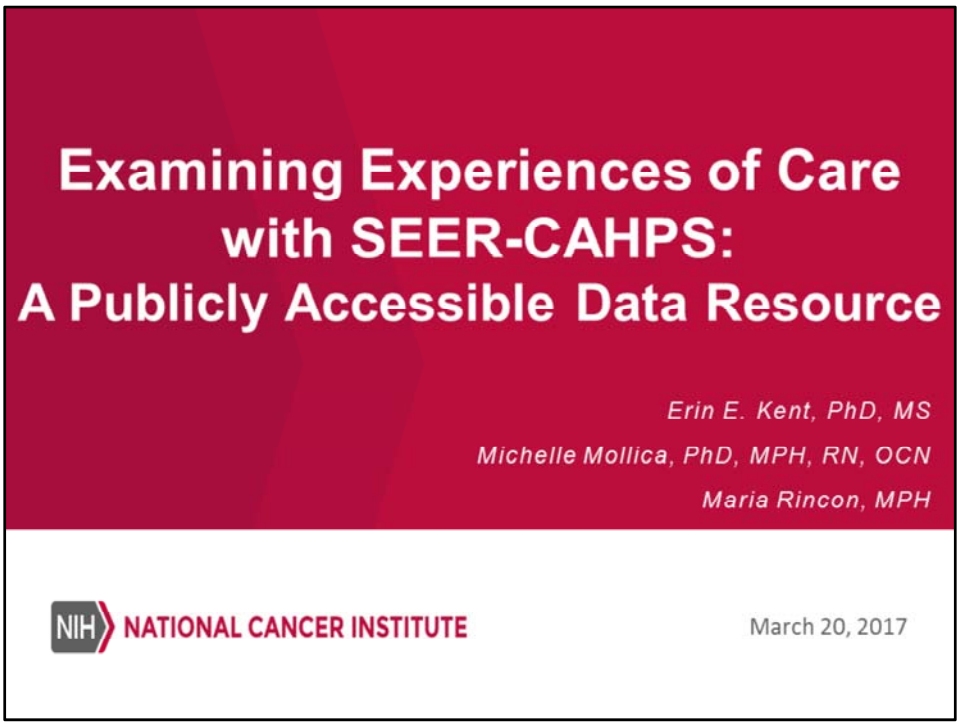
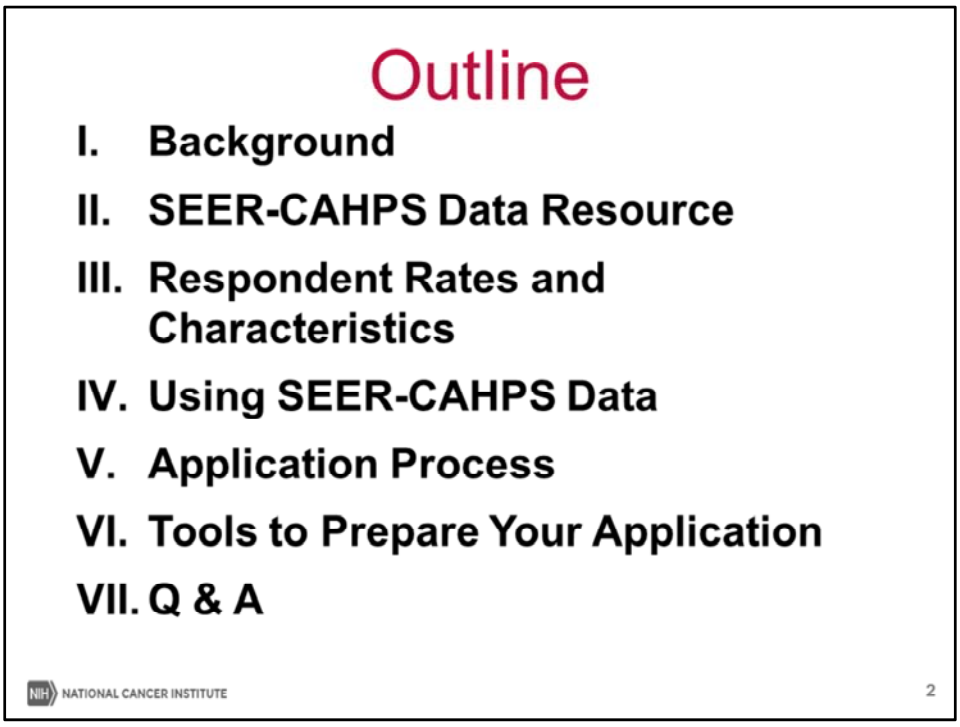


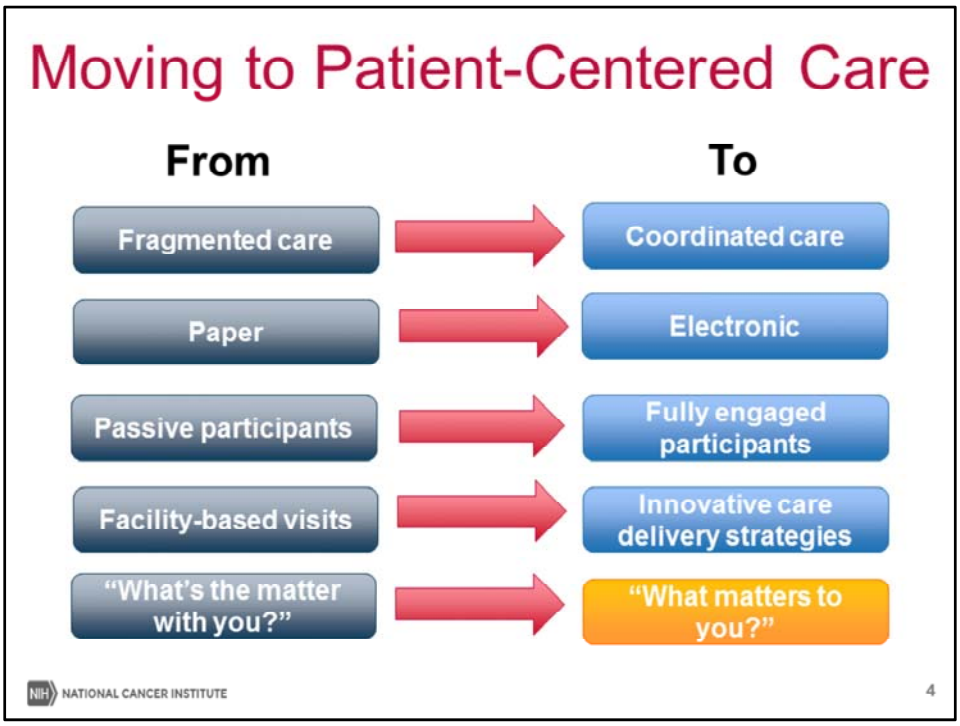
My name is Michelle Mollica, and I'm please to welcome you to our webinar today, entitled: Examining experiences of care with SEER-CAHPS: A Publicly Accessible Data Resource. I am joined by my colleagues, Dr. Erin Kent and Maria Rincon.



During this webinar, we will provide you with a background about the importance of patient experiences, describe a newly accessible linked data resource called SEER-CAHPS, including the components of the linkage, as well as respondent rates and characteristics. We will provide an overview of potential uses/applications of this resource, and the application process to obtain the data. We will also then describe some tools to help prepare your application.

Finally, we will be taking your questions, which will also help populate our frequently asked questions section on the SEER-CAHPs website. If you have questions at any time, please submit them through the chat function in WebEx. A final note that we are recording the presentation portion of this webinar, and this recording will be on our website for future reference.

We first would like to provide you with a background on the importance of patient experiences.



The world of healthcare delivery, as many of you know, is dynamic and ever-changing. Healthcare is moving from disease-centered care to more patient-centered care.

There has been a shift from fragmented care, with patients seeing multiple types of healthcare providers, to a more coordinated system of care. Ultimately, we are moving towards a world where patients have a voice and are fully engaged as partners in the healthcare process.

There are an emerging number of innovative care delivery strategies, designed to coordinate care, and utilizing EHRs. Respect for patients should be an integral part of that care. In fact, the US Institute of Medicine defines patient-centered care as: "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions."

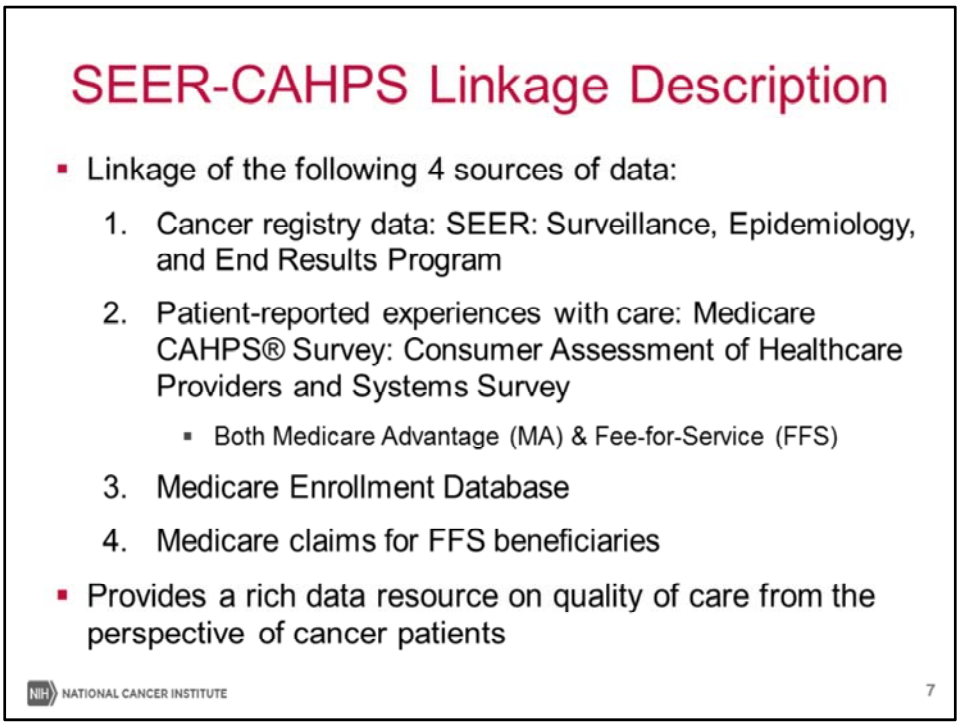
In essence, patient centered care is moving from what's the matter with you, to what matters TO you?

Cancer care delivery is particularly complex, with multimodality treatment, diverse treatment settings, multiple stakeholders, and interdisciplinary team-based care.

With this move to patient-centered care has been an increasing amount of importance placed on the voice of the patients, including patient experiences, which are distinct from patient satisfaction. Patient experiences emphasize reports of measurable components of care, involving processes observable by patients. Valid surveys of patient experience provide important information to patients and providers, and are useful for focusing on care quality and improvement efforts.

Positive patient experiences are important for achieving continuity of care, strong patient-provider relationships and trust, as well as improved health outcomes.

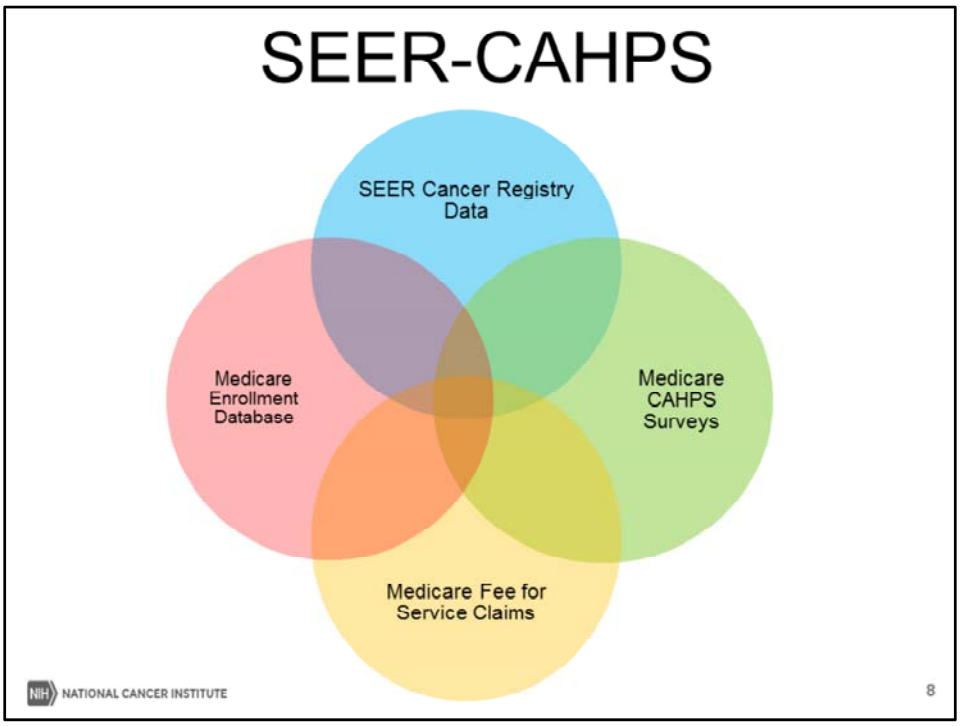
One new way that we can explore cancer patient experiences is through a new publicly accessible linked data resource, called SEER-CAHPS.



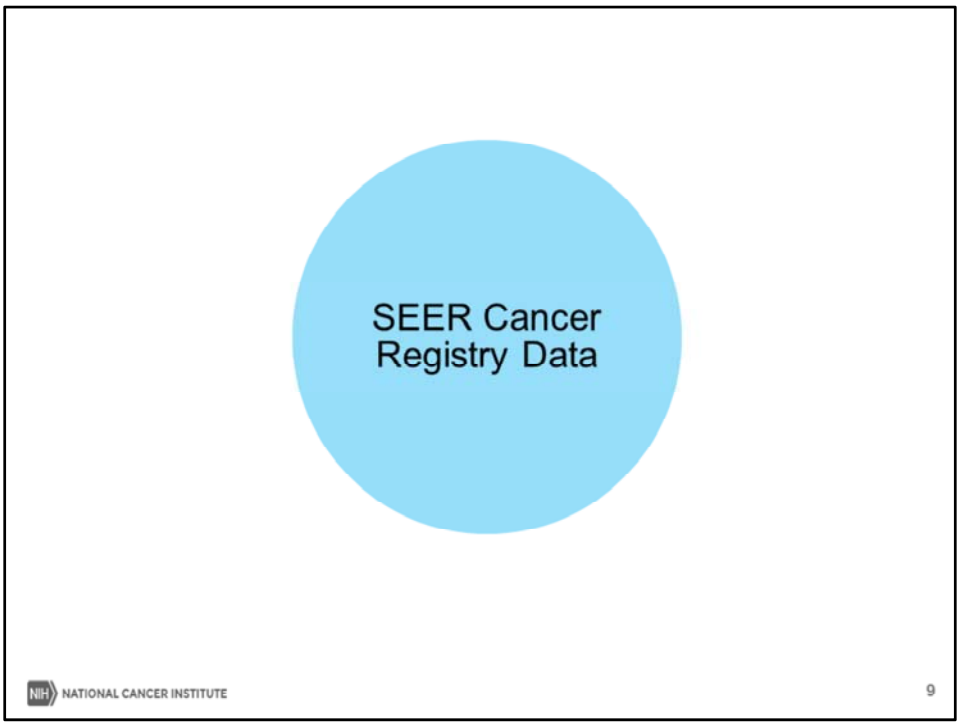
SEER-CAHPS is a linkage of 4 sources of data:

1. The Surveillance, Epidemiology, and End Results Program (known as SEER)
2. The Medicare Consumer Assessment of Healthcare Providers and Systems Survey (the Medicare CAHPS survey), which provides patient-reported experiences of care for both Medicare Advantage and Fee-for-Service Medicare beneficiaries
3. The Medicare Enrollment Database and,
4. Medicare claims for FFS beneficiaries

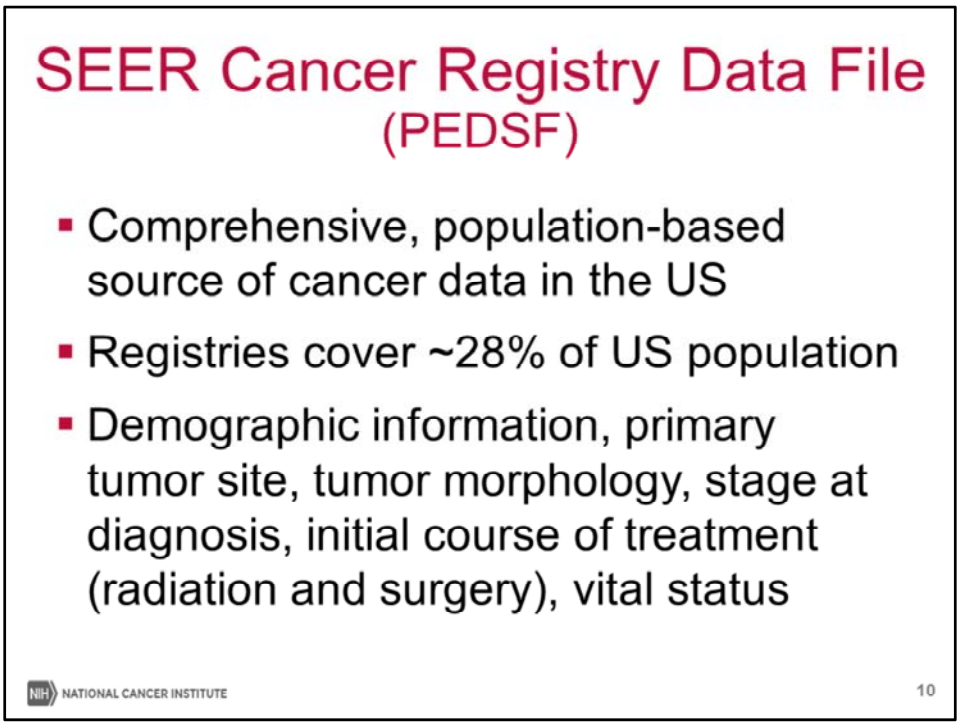
SEER-CAHPS provides a rich data resource on quality of care from the perspective of cancer patients.



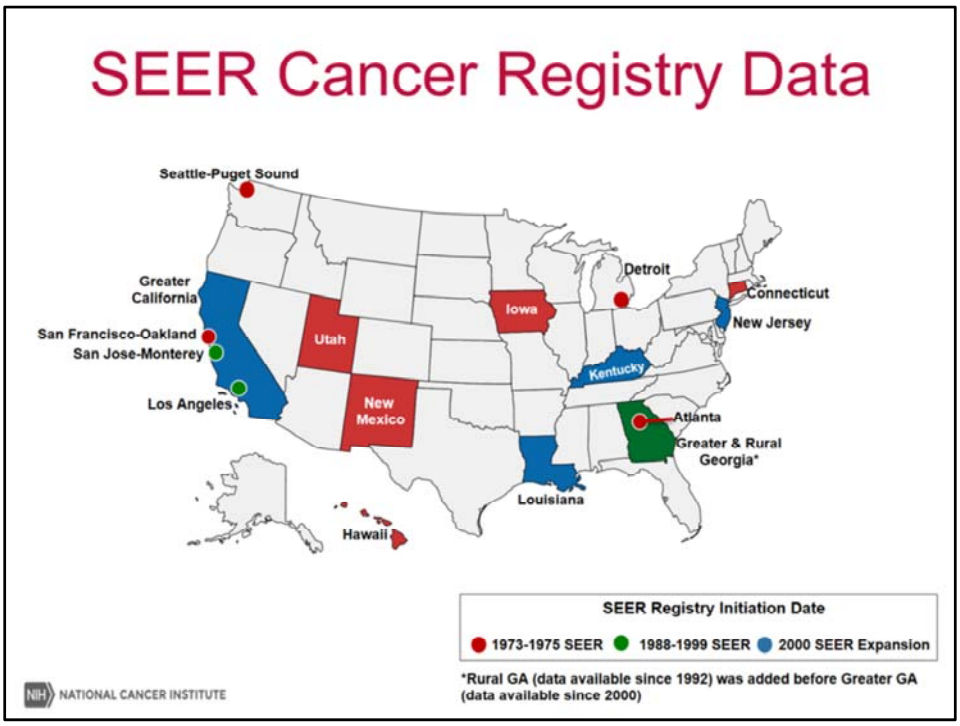
We will now go in the different sources of data that make up SEER-CAHPS. For those familiar with SEER-Medicare, we want to point out that the sampling frame of SEER-CAHPS is not just the addition of the CAHPS survey to the SEER-Medicare linkage. Rather, this sampling frame is based off of the CAHPS survey.



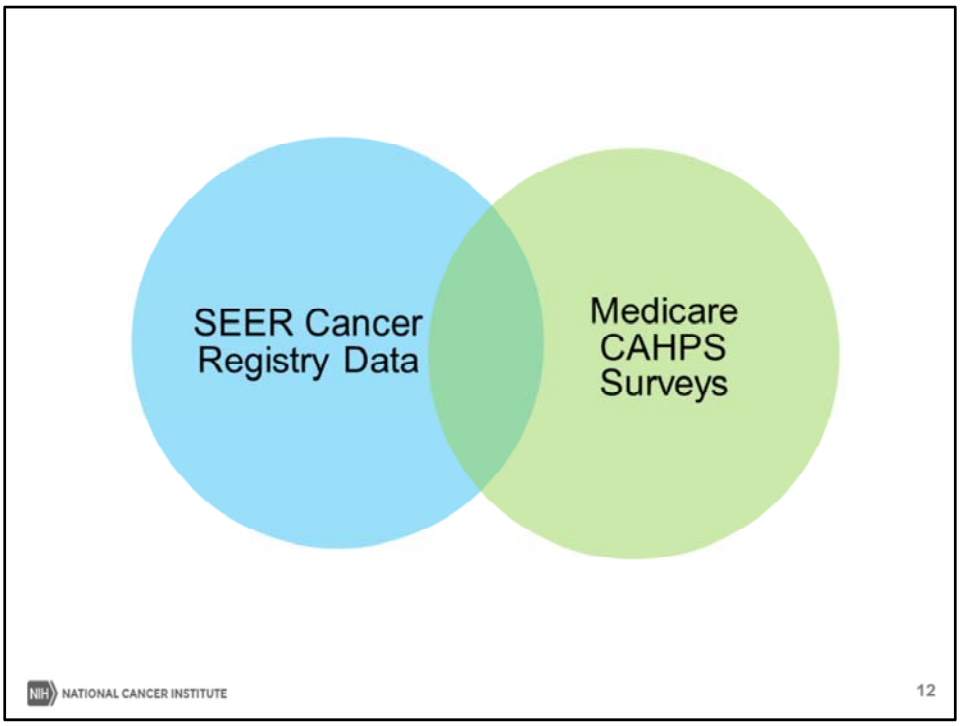
First, I will provide an overview of the SEER Cancer registry data.



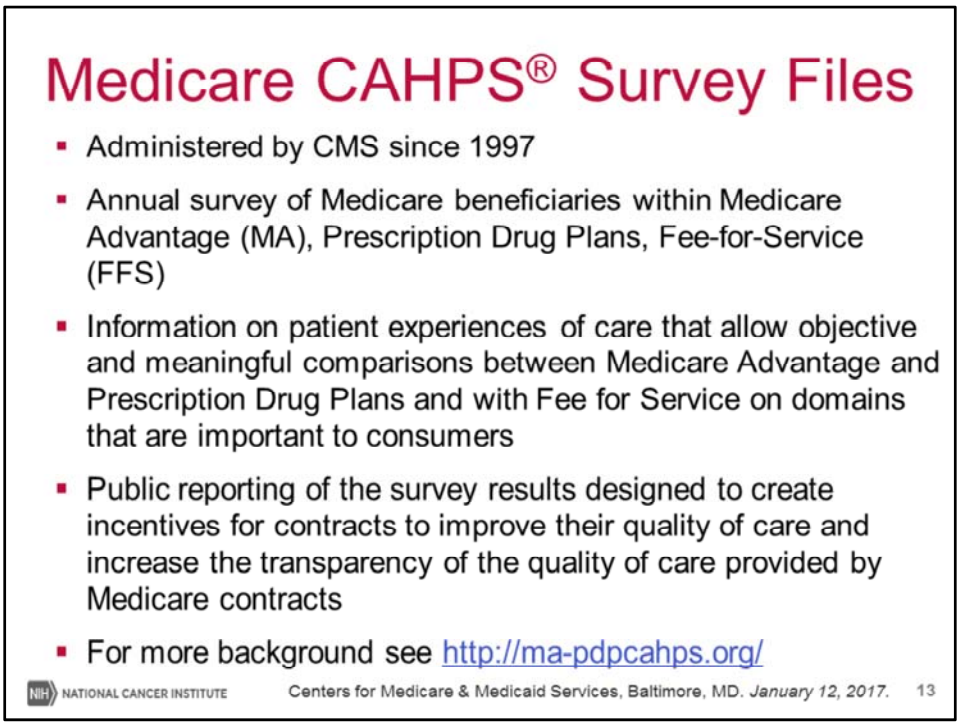
The SEER Cancer Registry Data File, known as PEDSF, is a comprehensive population-based source of cancer data in the US. The cancer registries represented in SEER cover roughly 28% of the US population. SEER contains demographic information, and cancer information such as primary tumor site and morphology, cancer stage at diagnosis, and initial course of treatment (radiation and surgery). It is important to note that the SEER data in SEER-CAHPS does have vital status over time, to enable researchers to perform a survival analysis.



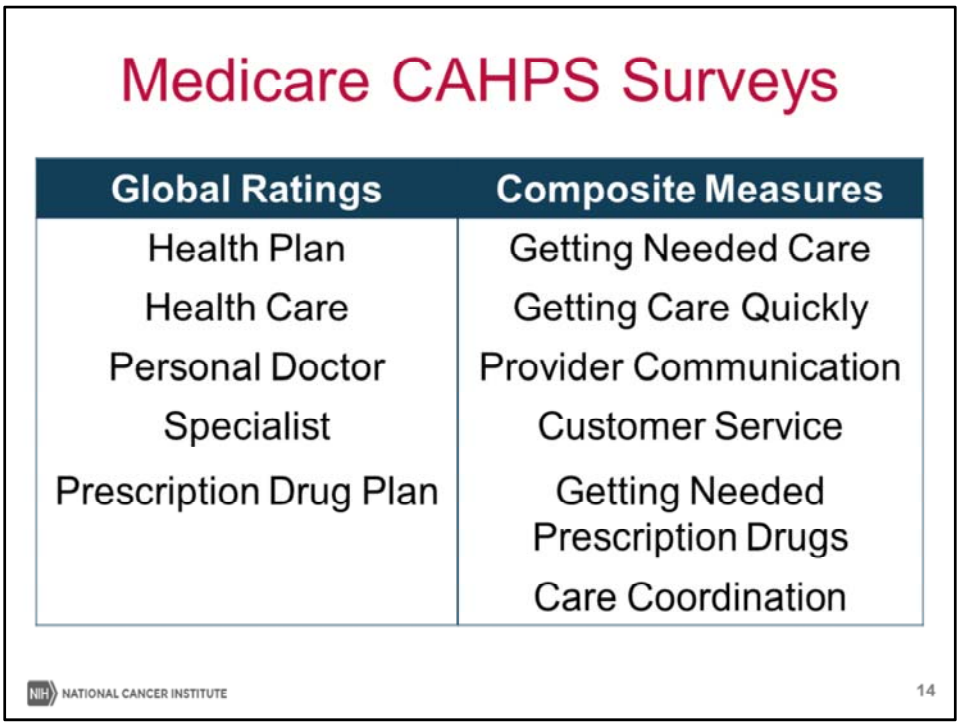
This map shows you the registries included in SEER-CAHPS. SEER-CAHPS does not include the Alaska Native and Arizona American Indian registries.



I will now provide an overview of the Medicare CAHPS survey.



The Medicare CAHPS survey, which provides information on patient experiences, has been administered by CMS since 1997. Public reporting of the survey results are designed to create incentives for contracts to improve their quality of care and increase the transparency of the quality of care provided by Medicare contracts.

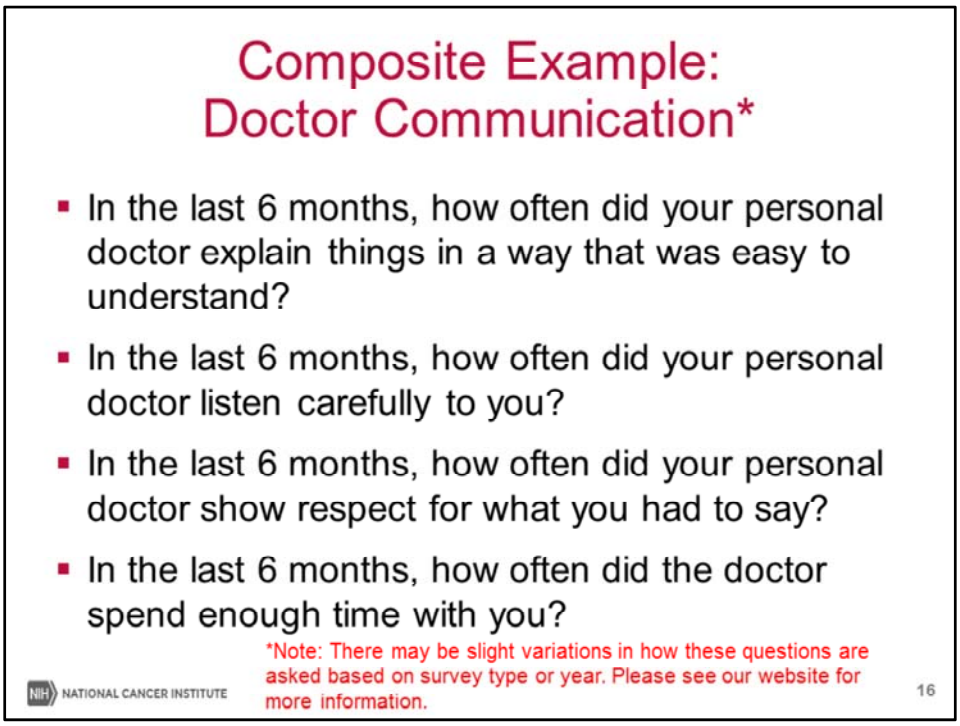


Within the CAHPS survey, there are global ratings of care components, as well as composite measures of specific aspects of care. I will go through each of these in the next slides.

Global ratings ask the patient a single item question for each of the following components of care.

The example question reads, *Using any number from 0 to 10, where 0 is the worst **health care** possible and 10 is the best **health care** possible, what number would you use to rate all your **health care** in the last 6 months?*
This question is asked for health plan, health care, personal doctor, specialist, as well as prescription drug plan for select health plan types.

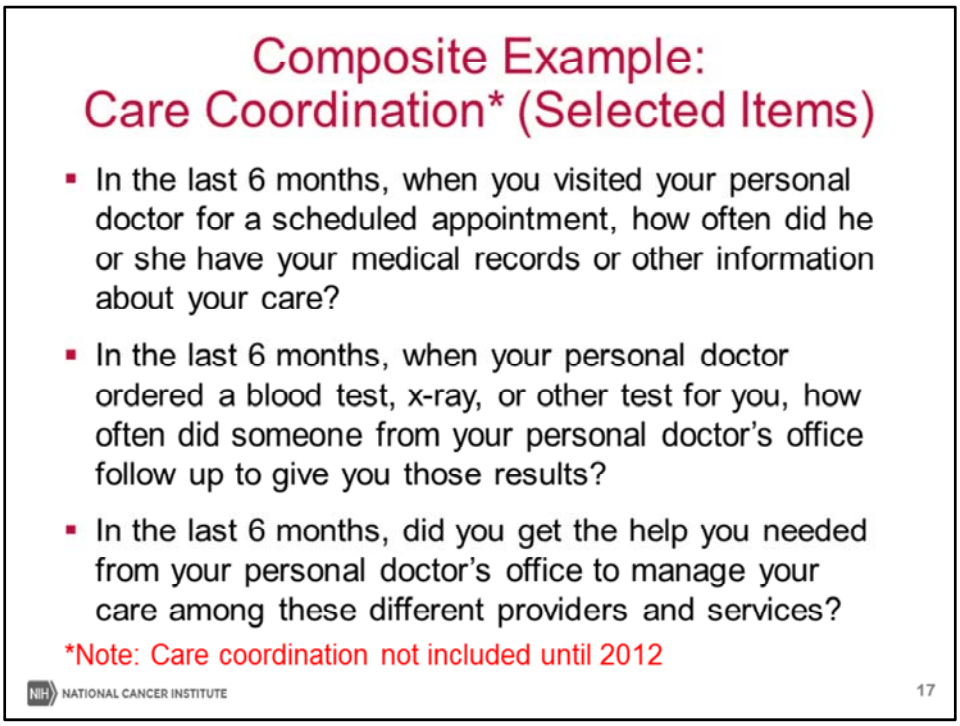
It is important to note many responses to the items in CAHPS are positively skewed, indicating the potential for ceiling effects.



We also have CAHPS composites, representing specific components of care.
In the interest of time, we will only show you items from two of the composites to give you a flavor of the types of questions that are asked. It's important to note that exact phrasing of these items changes over time, however we do have documentation reflecting these changes over time so that researchers can utilize multiple years of survey data when appropriate.

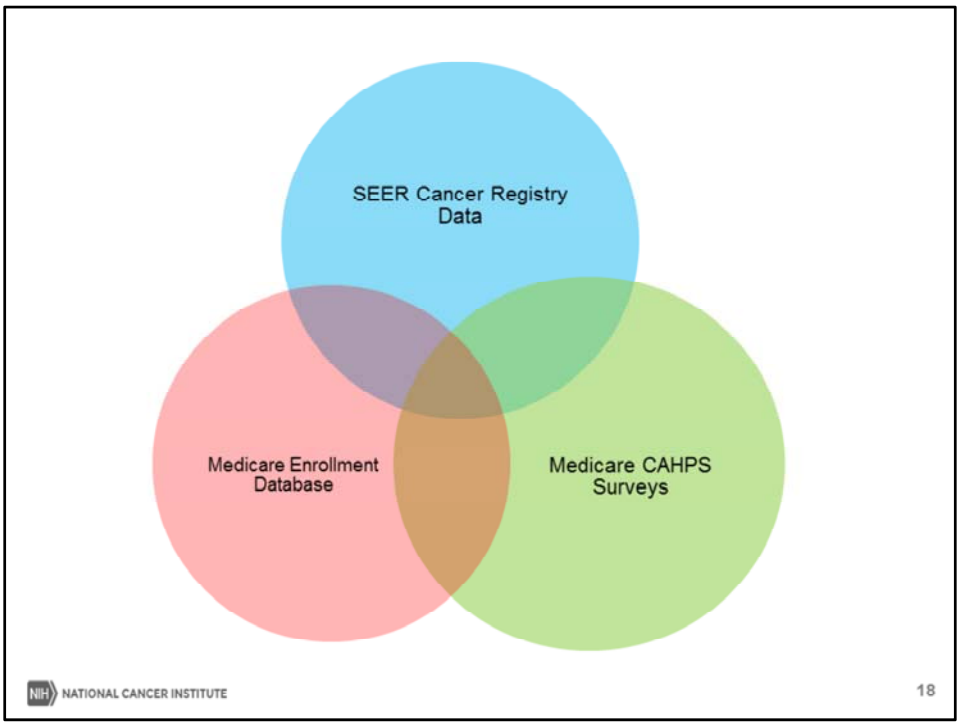
In response to the following questions, respondents choose from options of : (never, sometimes, usually, always) higher scores, indicate more positive assessments of health professionals, etc. These composites are then linearly combined and transformed to a 0-100 scale.

- How often did your personal doctor explain things in a way that was easy to understand?
- How often did your personal doctor listen carefully to you?
- How often did he/she show respect for what you had to say?
- How often did the doctor spend enough time with you?

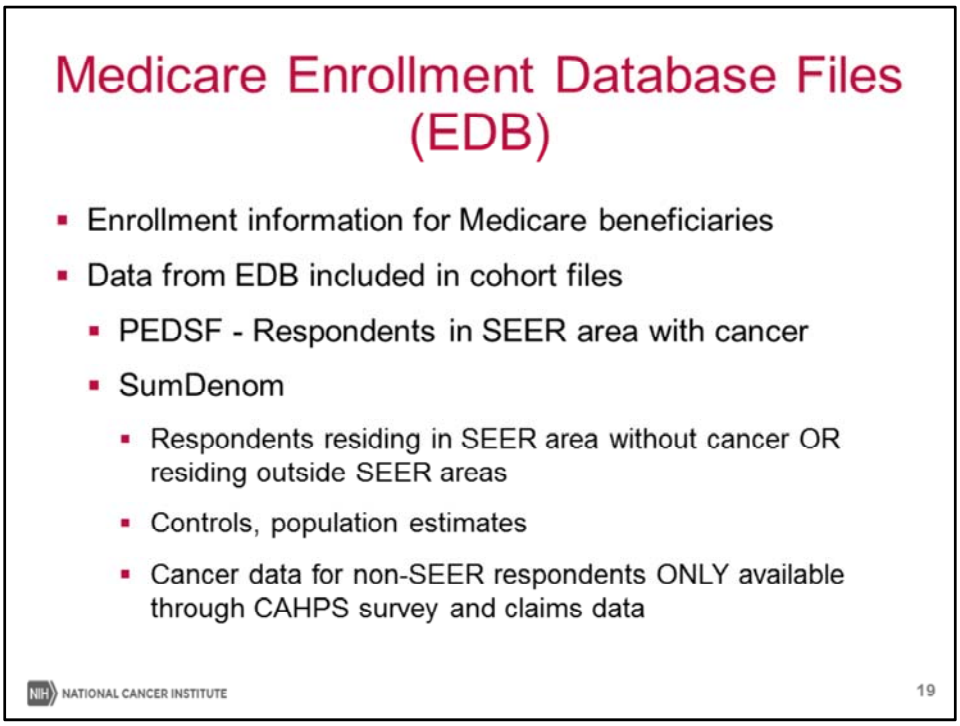


Finally, Care coordination, a composite which was not added until 2012, includes items such as:

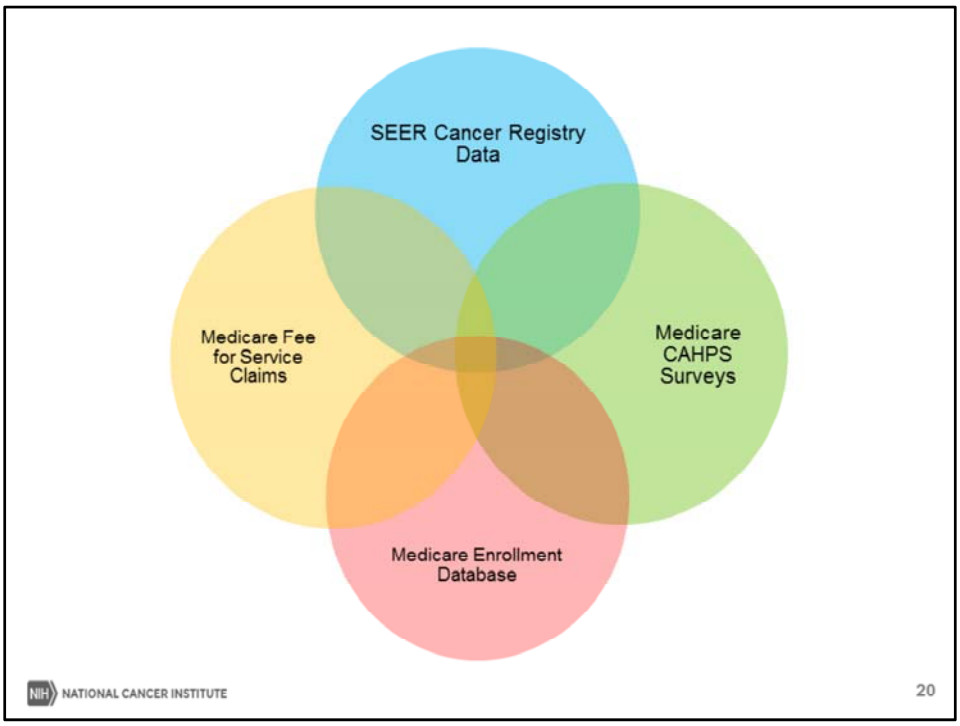
- When you visited your personal doctor, how often did he/she have your medical records or other information about your care?
- When your personal doctor ordered a blood test/x-ray/other test for you, how often did someone from your personal doctor's office follow up to give you those results?
- How often did you get those results as soon as you needed them?
- How often did you and your personal doctor talk about all the prescription medicines you were taking?
- Did you get the help you needed from your personal doctor's office to manage your care among these different provides and services?
- How often did your personal doctor seem informed and up-to-date about the care you got from specialists?



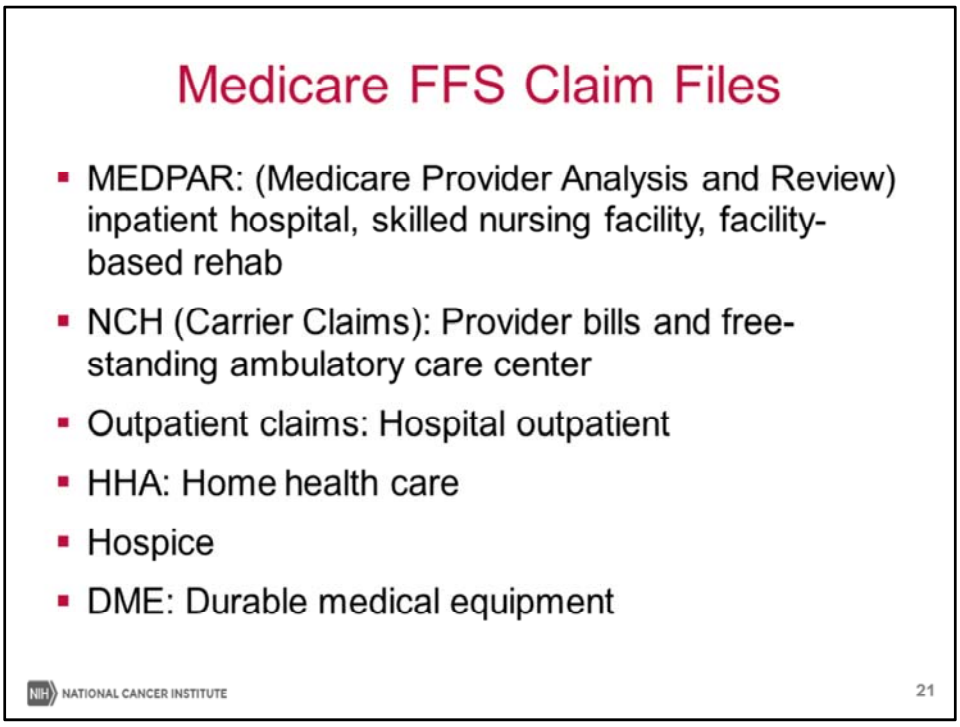
We will now provide an overview of the Medicare Enrollment Database.



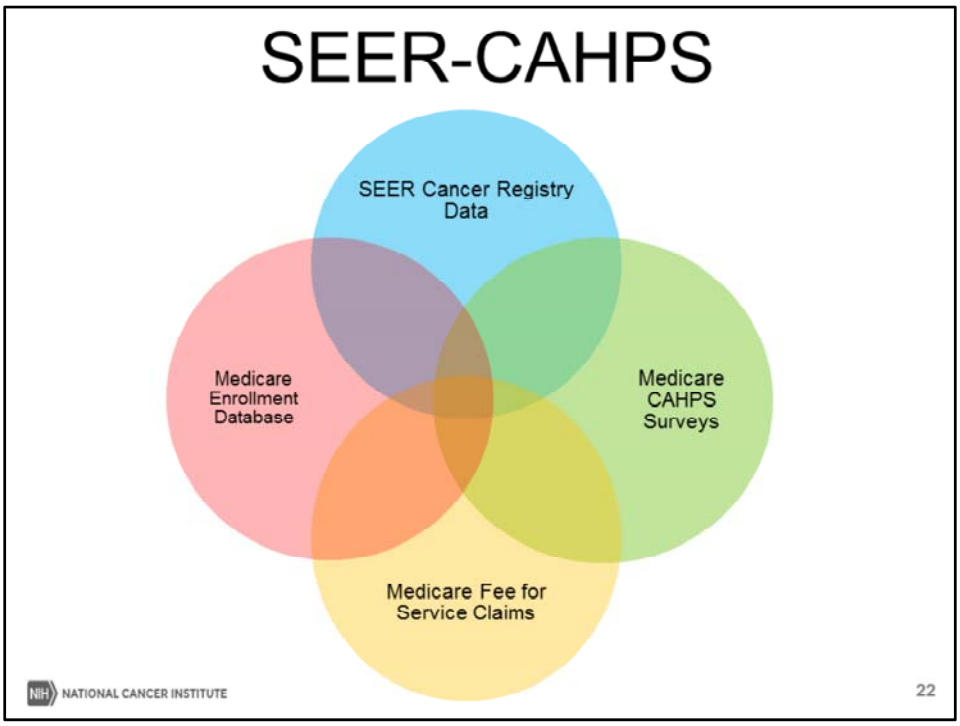
- Enrollment information of each Medicare recipient found in SEER-CAHPS (cancer and non-cancer respondents)



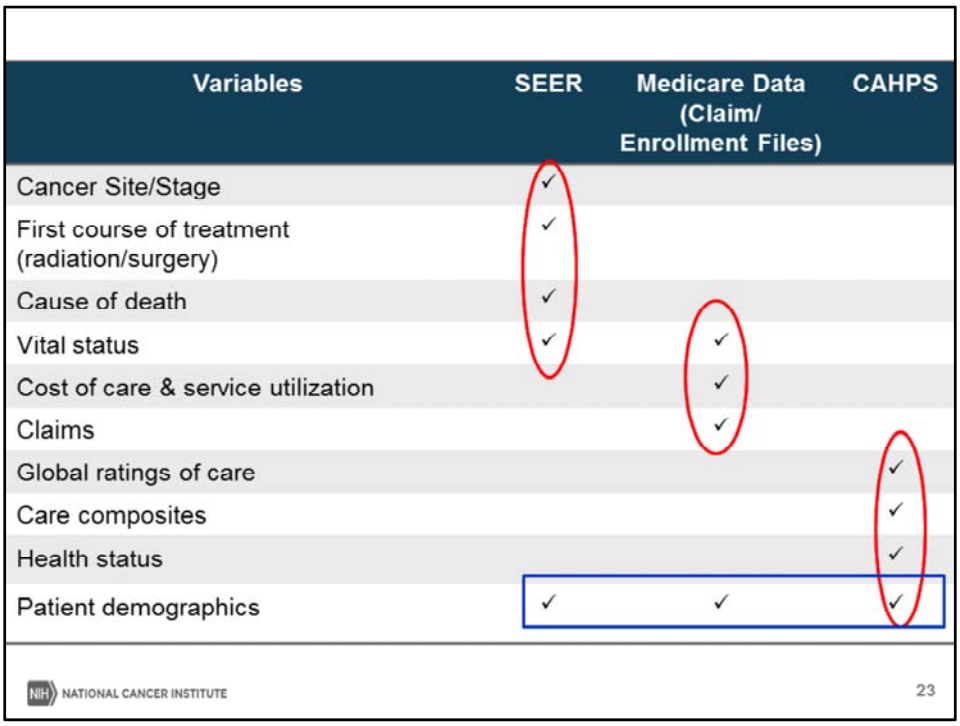
SEER-CAHPS also includes Medicare claims for Fee-for-Service claims.



Similar to SEER-Medicare, SEER-CAHPS contains the follow claims files for FFS beneficiaries:
- MEDPAR, which includes inpatient hospital, SNF, and facility-based rehab claims
- NCH, which is also known as carrier claims, and provides claims for providers and free-standing ambulatory care centers
The claims files also include outpatient claims, home health care hospice, and durable medical equipment, or DME.



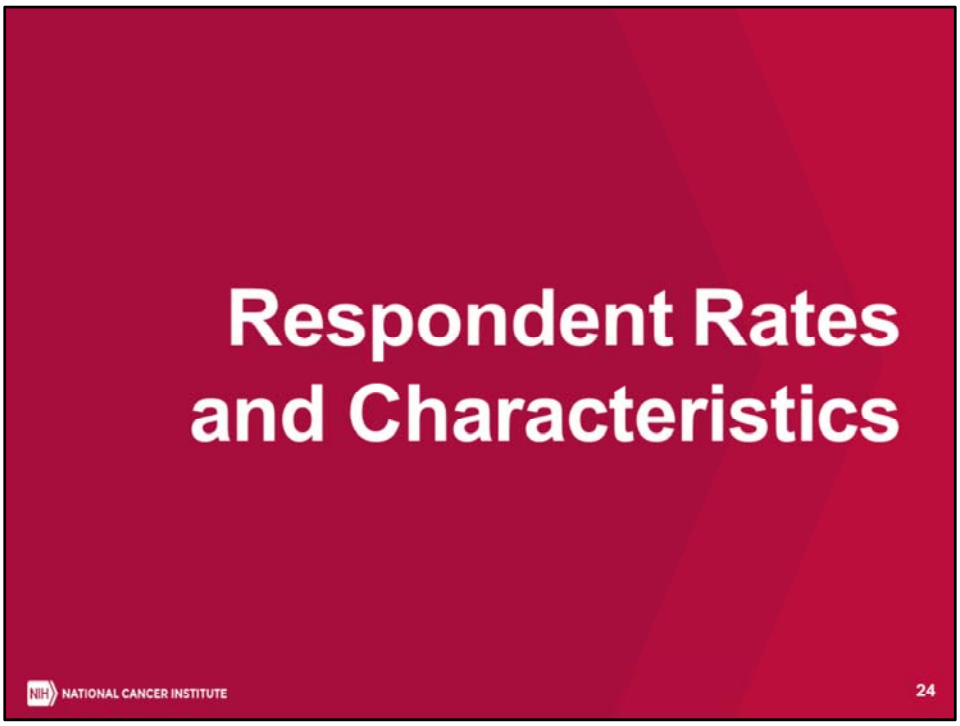
Together, these 4 data sources make up SEER-CAHPS.



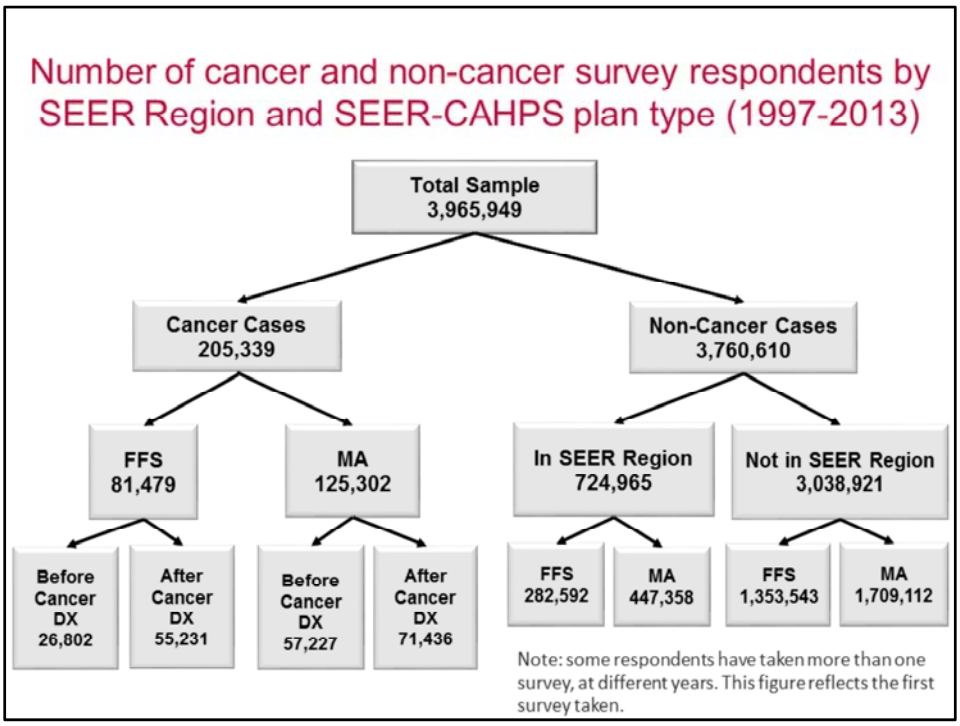
Variables	SEER	Medicare Data (Claim/ Enrollment Files)	CAHPS
Cancer Site/Stage	✓		
First course of treatment (radiation/surgery)	✓		
Cause of death	✓		
Vital status	✓	✓	
Cost of care & service utilization		✓	
Claims		✓	
Global ratings of care			✓
Care composites			✓
Health status			✓
Patient demographics	✓	✓	✓

This table demonstrates the different types of variables available in the SEER-CAHPS resource.

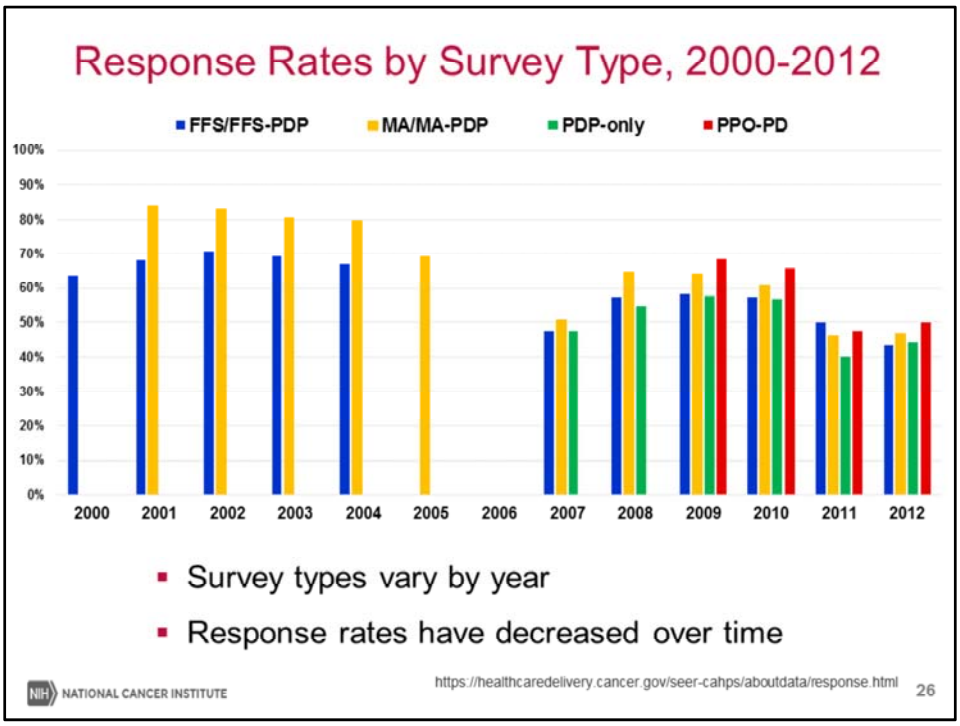
You can see that SEER provides cancer information, as well as cause of death, Medicare Data provides enrollment for all Medicare beneficiaries, and Claims for FFS beneficiaries, and the CAHPS survey data provides global ratings of care, care composites, and health status. It is also important to note that patient demographics are available in each of the data resources included in SEER-CAHPS.



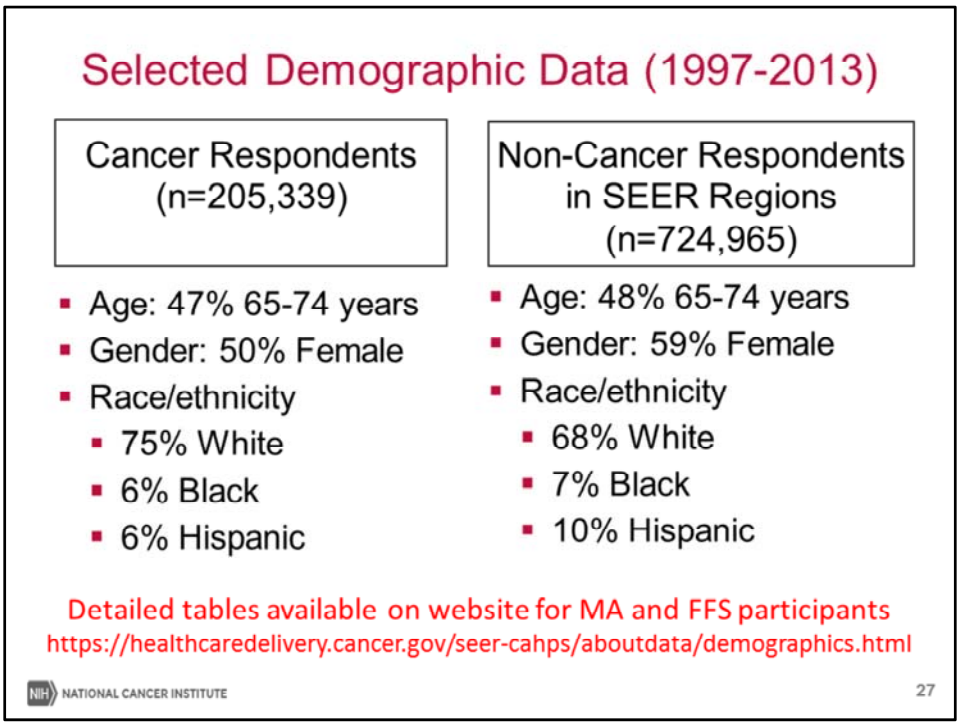
We will next give you an overview of the respondent rates and characteristics of the respondents in SEER-CAHPS.



This flowchart depicts the cancer and non-cancer survey respondents that make up the total sample in SEER-CAHPS. You can see that we have over 200,000 respondents with a history of cancer, and over 3.7 million survey respondents who do not have a history of cancer. It's important to note that some respondents have taken more than one survey in different years. This flowchart reflects the first survey taken.



Her you see the response rates of the CAHPS surveys by year of administration. You should notice a few things from this graph: First, the types of surveys vary by year, with an increasing number of types of surveys administered after 2007. Second, there were no surveys administered in 2006, and third, response rates have decreased over time.



While we have detailed demographic data available on our website for both Medicare Advantage and Fee for Service participants, we wanted to give you some brief information regarding our demographics for the respondents. You can see that almost half of both cancer and non-cancer respondents are between 65 and 74 years of age. In addition, while roughly half of the cancer respondents are female, we have slightly higher proportion of females in the non-cancer respondent groups. SEER-CAHPS contains 75% white respondents with a diagnosis of cancer, and about 68% white in those without a history of cancer.

Again, please see the detailed demographic tables for more variables of interest.

Number of Individuals in SEER-CAHPS: MA

Selected most prevalent cancer types

First cancer	Total Number of SEER linked patients	Before first diagnosis		Post-Diagnosis: Time between first survey and first diagnosis							
				Within 2 years		Within 3-5 years		Within 6-10 years		11+ years	
		N	%	N	%	N	%	N	%	N	%
Prostate	24,551	8,114	33.0	4,076	16.6	4,059	16.5	5,165	21.0	3,137	12.8
Breast	22,668	7,110	31.4	3,216	14.2	2,939	13.0	4,158	18.3	5,245	23.1
Colorectal	13,538	6,057	44.7	1,896	14.0	1,556	11.5	1,903	14.1	2,126	15.7
Lung and bronchial	11,617	8,917	76.8	1,331	11.5	567	4.9	467	4.0	335	2.9

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

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This table shows the number of individuals for selected cancer types. The top row shows the breakdown of time between first survey and first cancer diagnosis for all cancers. You can see that, depending on your research question, we have data on the time between diagnosis to first survey. For example, for prostate cancer, there are approximately 8,000 respondents who took their first CAHPs survey before their first cancer diagnosis, and a little over 4,000 respondents who completed a CAHPS survey within 2 years post cancer diagnosis. This information is extremely useful in designing your cohort selection criteria based on your research question.

Number of Individuals in SEER-CAHPS: FFS

Selected most prevalent cancer types

First cancer	Total Number of SEER linked patients	Before first diagnosis		Post-Diagnosis: Time between first survey and first diagnosis							
				Within 2 years		Within 3-5 years		Within 6-10 years		11+ years	
		N	%	N	%	N	%	N	%	N	%
Prostate	16,464	3,746	22.8	2,795	17.0	3,078	18.7	4,103	24.9	2,742	16.7
Breast	15,440	3,429	22.2	2,104	13.6	2,457	15.9	3,349	21.7	4,101	26.6
Colorectal	8,195	2,543	31.0	1,350	16.5	1,237	15.1	1,532	18.7	1,533	18.7
Lung and bronchial	6,420	4,142	64.5	992	15.5	559	8.6	474	7.4	262	4.1

https://healthcaredelivery.ca

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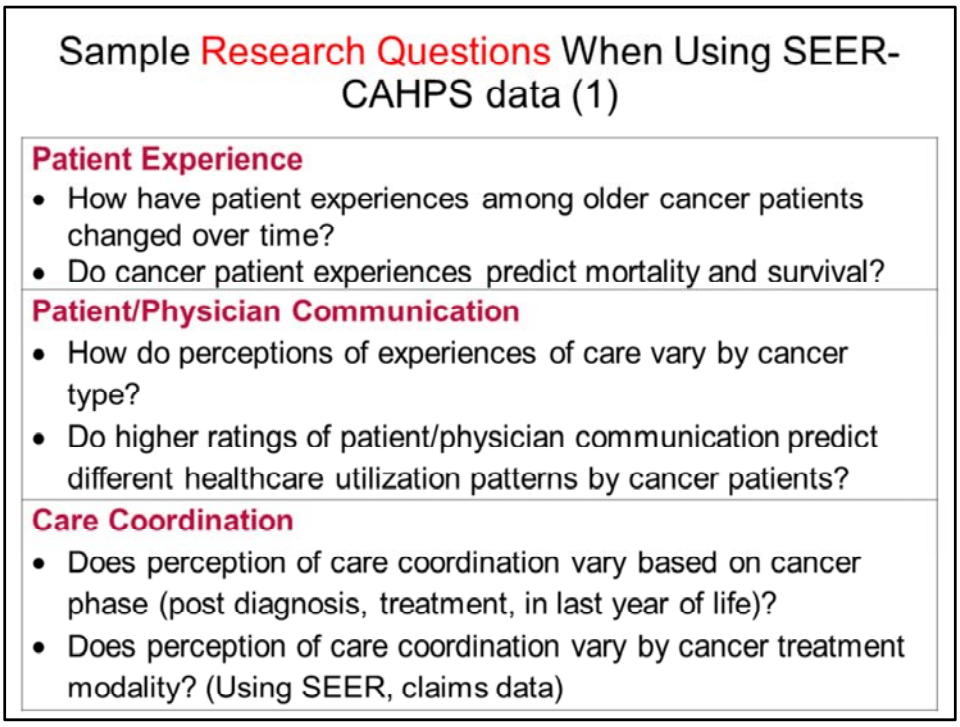
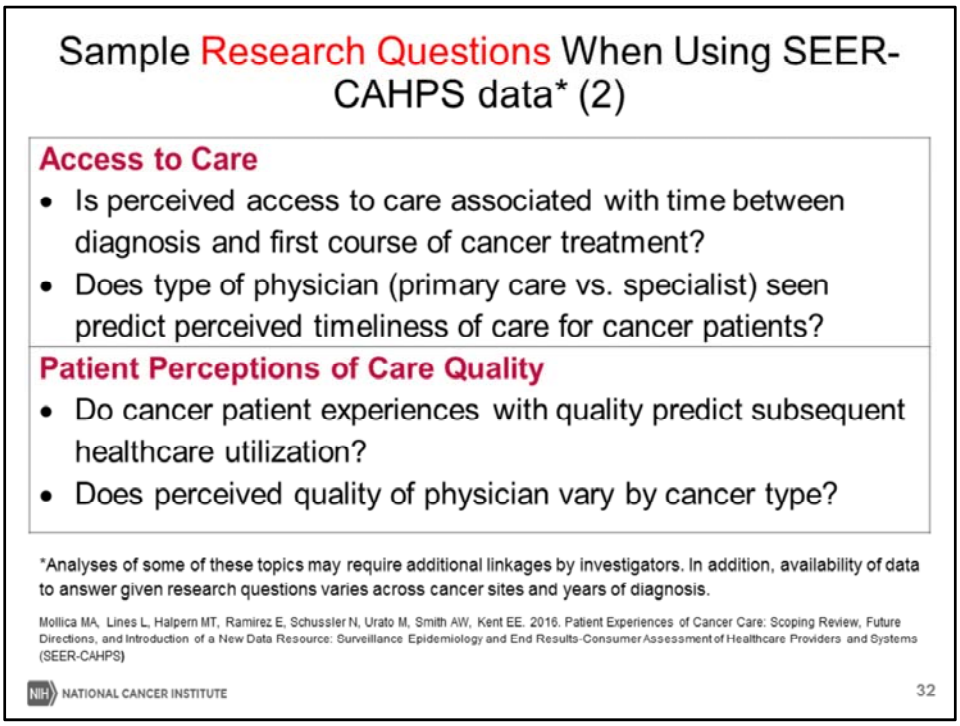
We also have this data for FFS patients, as you can see here.

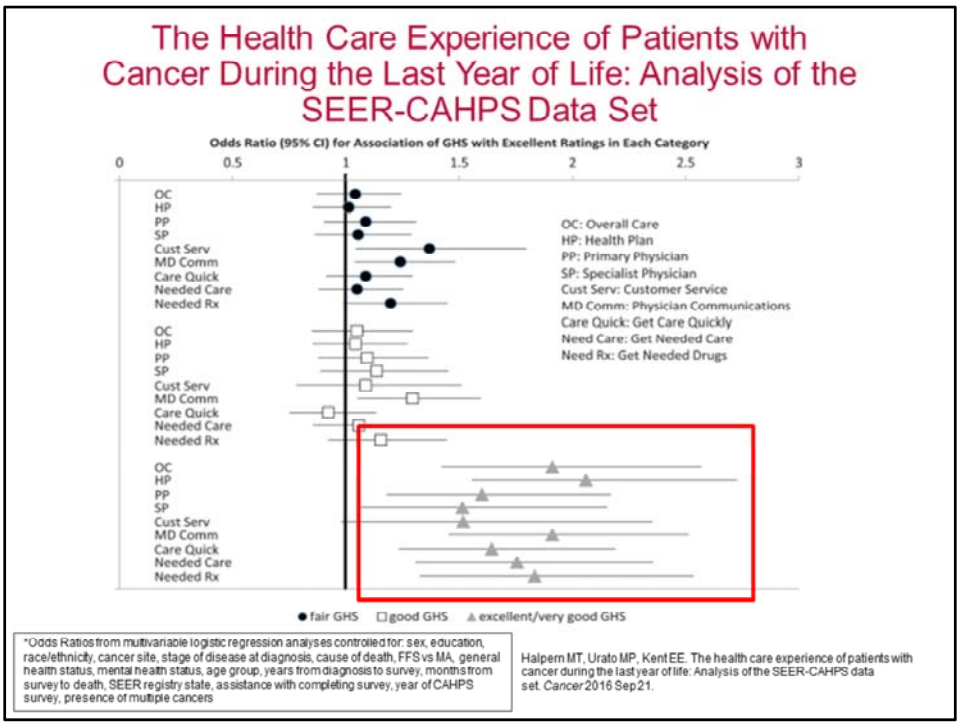
Next we will go through some potential applications of SEER-CAHPS data



There are many different types of research questions that can be answered using the SEER-CAHPS linked data resource, including the questions we've listed here as examples.



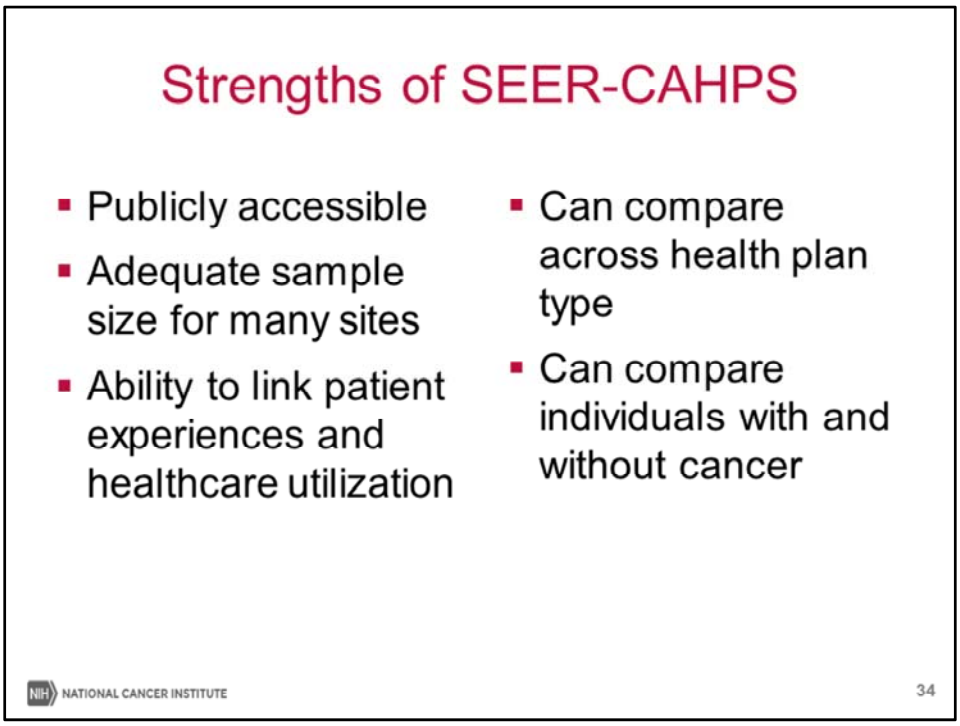
SEER-CAHPS can also be used to answer questions about access to care and patient perceptions of care quality. It's important to note that analyses of some of these topics may require additional linkages by investigators. In addition, availability of data to answer given research questions varies across cancer sites and years of diagnosis.



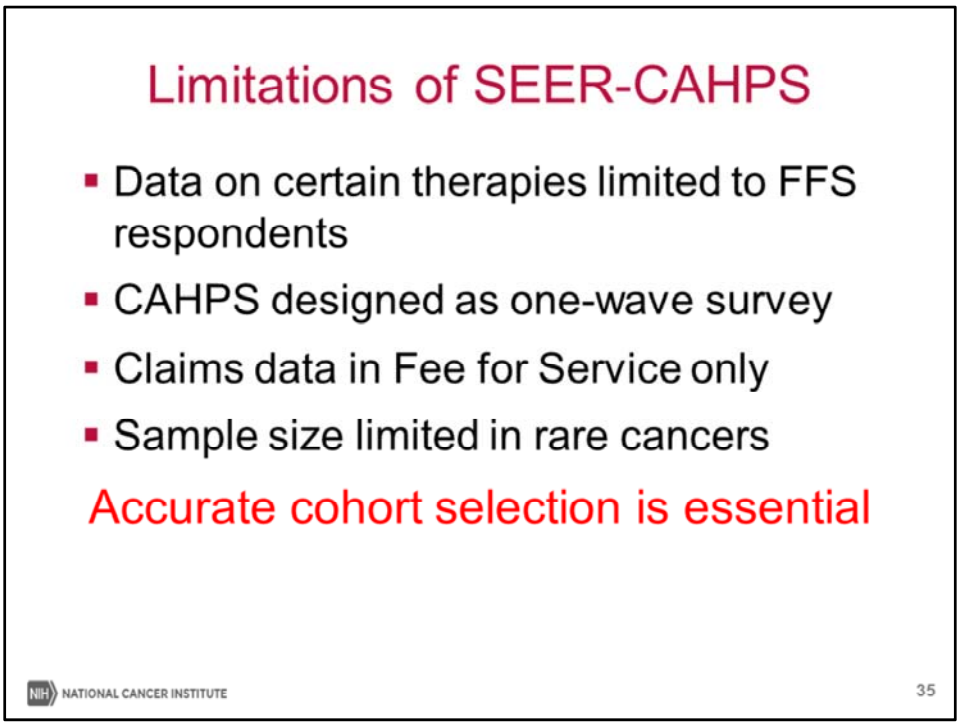
We wanted to show an example of a study that was recently conducted by Michael Halpern and colleagues, including Dr. Erin Kent, which assessed factors influencing health care ratings among individuals with cancer within 1 year before death. Results indicated that patients with higher general or mental health status were significantly more likely to indicate excellent experience with nearly all measures examined.

These are adjusted odd ratios (ORs), adjusting for the following sociodemographic and clinical characteristics: general health status, sex, education level, race/ethnicity, cancer site, cancer stage, cause of death, FFS vs MA, mental health status, age group, years from diagnosis to survey, months from survey to death, assistance with completing survey, state in which SEER registry was located, year of CAHPS survey, presence of multiple cancers.

This is an example of a study that utilized both global ratings of overall care, health plan, primary physician, and specialist physician, and composites such as physician communication, getting care quickly, and getting needed care.



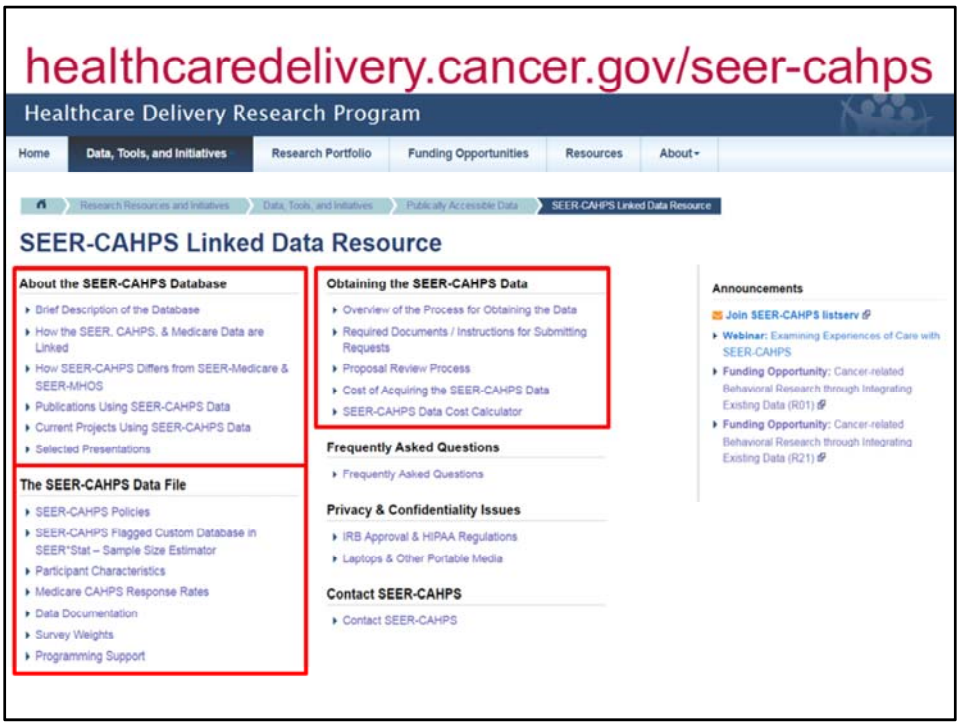
There are several important strengths of SEER-CAHPS. It is publicly accessible, and we will go into the application process later in the presentation. There is an adequate sample size for many sites.
SEER-CAHPS gives us the ability to link patient experiences with healthcare utilization, as well as compare across health plan type. We can also compare individuals with and without cancer.



While we are very enthusiastic about SEER-CAHPS as a resource, there are some limitations to keep in mind as you consider your research questions.
- Data on certain therapies is limited to FFS respondents because of the need for claims data
- The CAHPS was originally designed as a one-wave survey, meaning that although we may have more than one survey for a limited number of CAHPS respondents, it was not designed for longitudinal analysis. That being said, we do have claims over time for FFS beneficiaries
- The sample size is limited for rare cancers.
- Because of these considerations, accurate cohort selection is essential.

At this time, I will turn the presentation over the Maria Rincon, who will provide an overview of the SEER-CAHPS website and process to apply for SEER-CAHPS data.

Good afternoon, my name is Maria Rincon, and I will provide a brief introduction to the recently-launched SEER-CAHPS website, which has a number of useful resources for investigators.



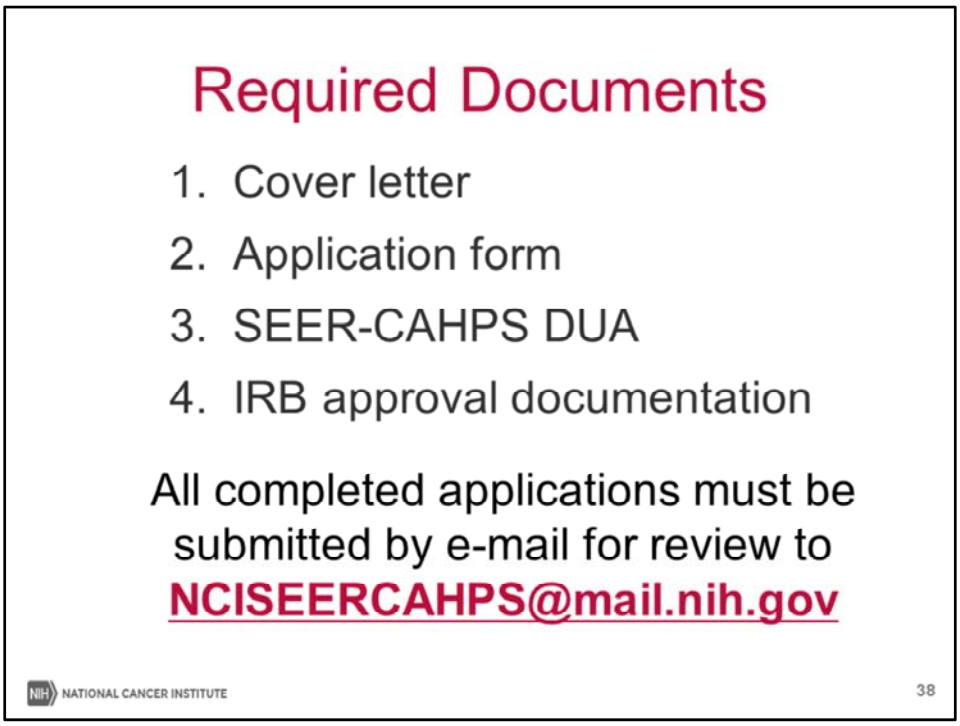
The SEER-CAHPS website can be accessed at the link shown here. We have included on this slide a snapshot of the home page layout. The SEER-CAHPS website is divided into 6 sections. However, in the interest of time, I will be focusing on content included in the first 3 sections, as they contain important information related to the proposal application process.

The first section on the top left, “About the SEER-CAHPS Database”, provides background for the data resource, including the features unique to SEER-CAHPS and similarities with other NCI SEER data linkages, such as SEER-MHOS and SEER-Medicare. In addition, this section provides links to journal publications, project aims currently under development, and abstract information from findings recently presented at scientific meetings.

Below, the “SEER-CAHPS Data File” section presents several features that can aid investigators determine the feasibility of a study using SEER-CAHPS data, including survey variable components and programming support for researchers. Extended versions of the tables described earlier through this presentation are also available under the “participant characteristics” sub-section.

The top section on the right column, Obtaining the SEER-CAHPS Data, houses the information necessary for an investigator’s submission of a research proposal to SEER-

CAHPS staff for review. It is important to point out that all data requests for SEER-CAHPS are processed and fulfilled through Information Management Systems, Inc. (IMS), the information technology contractor for NCI

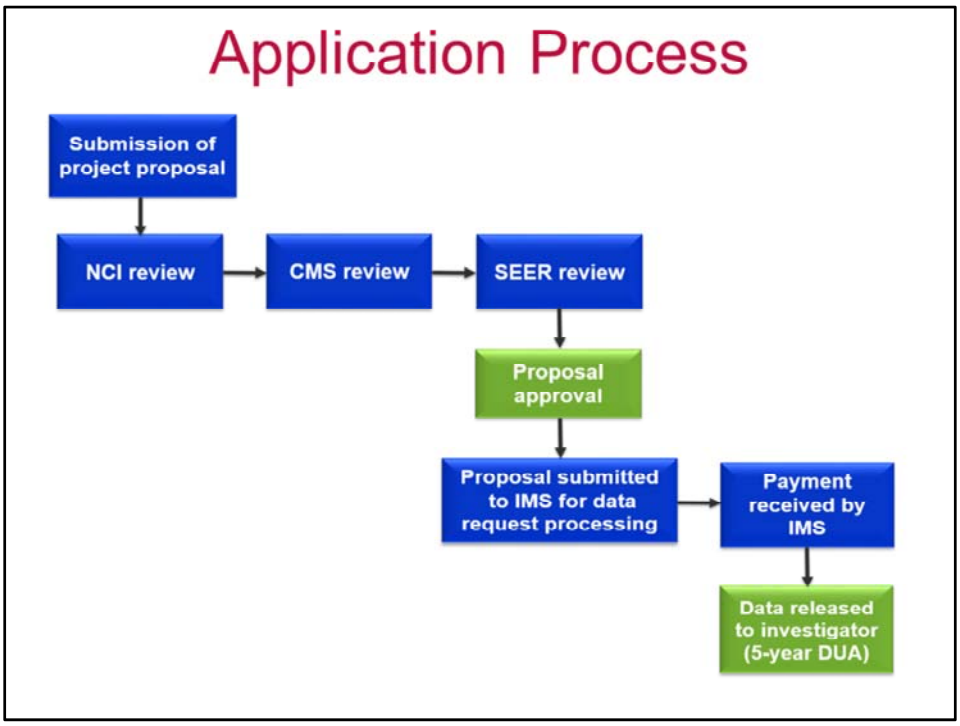


There are several required documents that must be submitted when applying to obtain SEER-CAHPS data. The 4 components listed must all be included in the completed project proposal

Of these documents, the application form and Data Use Agreement can be downloaded directly from the website, through the Required Documents/Instructions for Submitting Requests section.

IRB approval documentation is required for application to obtain the SEER-CAHPS data, however a full IRB review is often not necessary, as many institutional IRBs, including NIH's Office of Human Subject Research, have determined SEER-CAHPS data are exempt. A letter of exemption form from the investigator's institution can be provided to document this exemption.

All the aforementioned documents must be submitted electronically as an e-mail attachment in Word or PDF format to the SEER-CAHPS staff at NCISEERCAHPS@mail.nih.gov

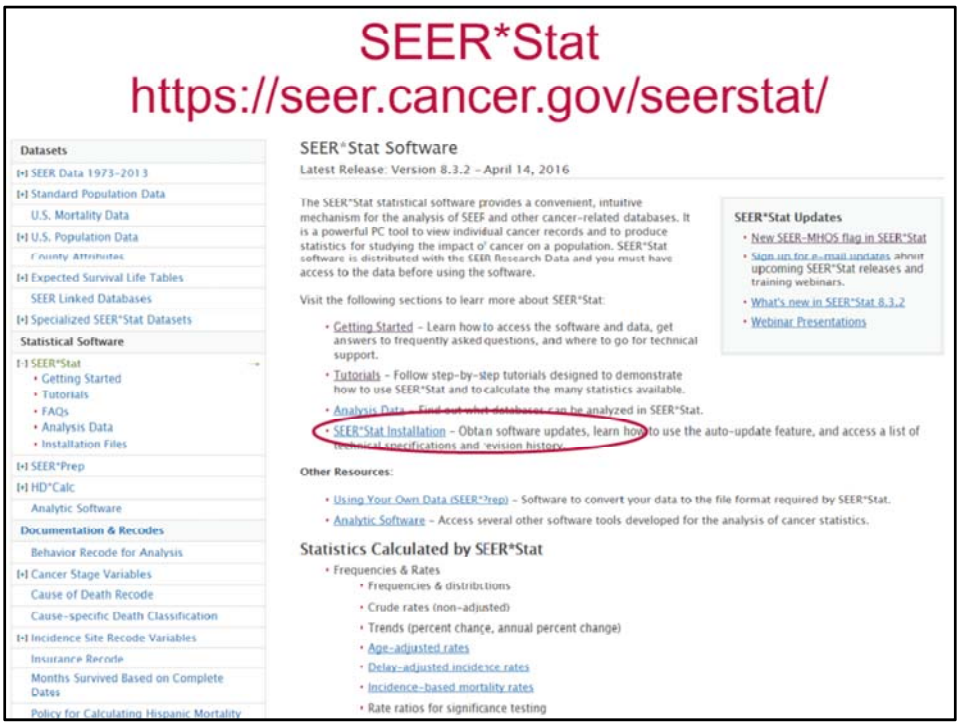


In this slide, we have included a diagram depicting the steps involved in the approval of a SEER-CAHPS proposal. Each application submitted will undergo 3 review steps: an initial review by NCI staff, a review by CMS and a review by a SEER investigator. The primary purpose of the review process is to ensure that research plan preserves the confidentiality of patients and providers in the SEER-CAHPS dataset and a project's relevance towards improving of the quality of care of older cancer patients. It is important to mention that this is an iterative process, and the timeline from submission to approval might vary pending questions and comments from reviewers.

Upon project approval, the primary investigator will be contacted by IMS staff, who will provide a checklist to initiate the processing of the data. Once the data is released to the investigator, the DUA will remain active for 5-years, pending potential renewal, up to 10 years.

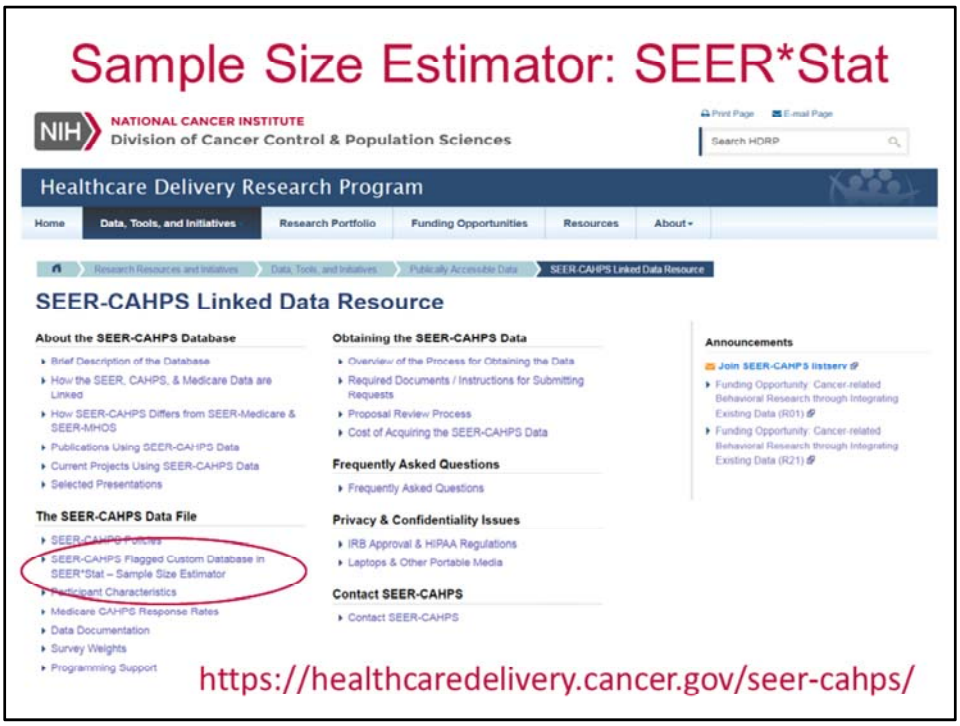
Now, I'd like to introduce Dr. Erin Kent, senior advisor for SEER-CAHPS, who will describe some of the tools available for the development of a proposal.

Now I am going to walk you some tools that we've created to assist investigators prepare applications for SEER-CAHPS. The first is a sample size estimator that we've built through another NCI program, SEER*Stat.



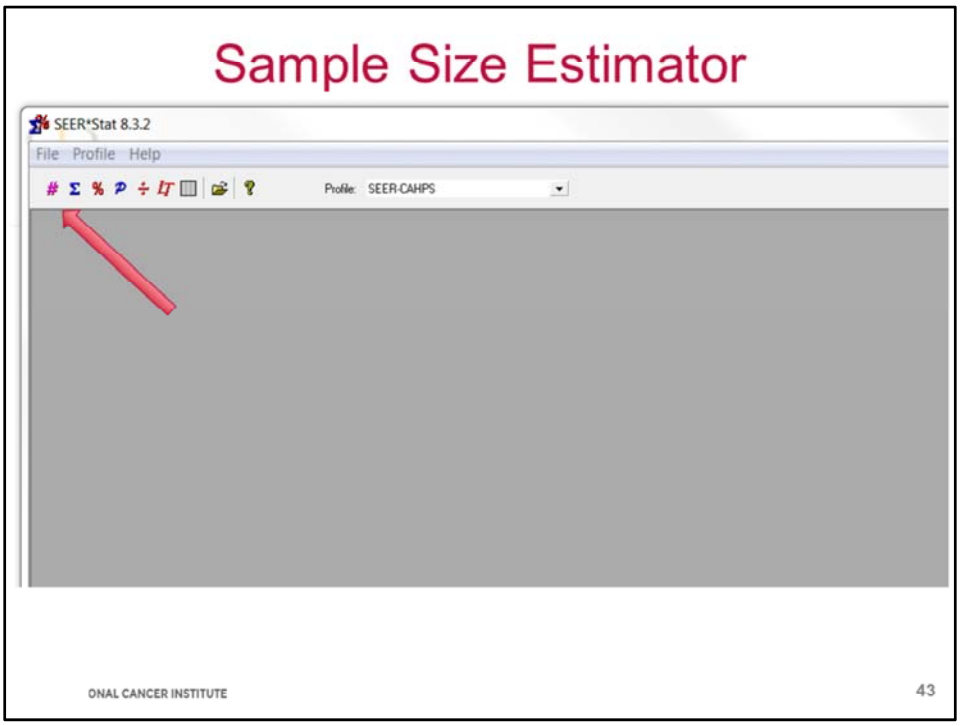
SEER*Stat is free software that provides access to and analysis of SEER data.

The first step needed is to download the SEER*Stat software and sign the data use agreement, which can be returned to the email or fax number indicated on the SEER*Stat website. Then, it is important to spend some time familiarizing yourself with the SEER data and the SEER*Stat interface. There are tutorials on the SEER*Stat website that can help with this.



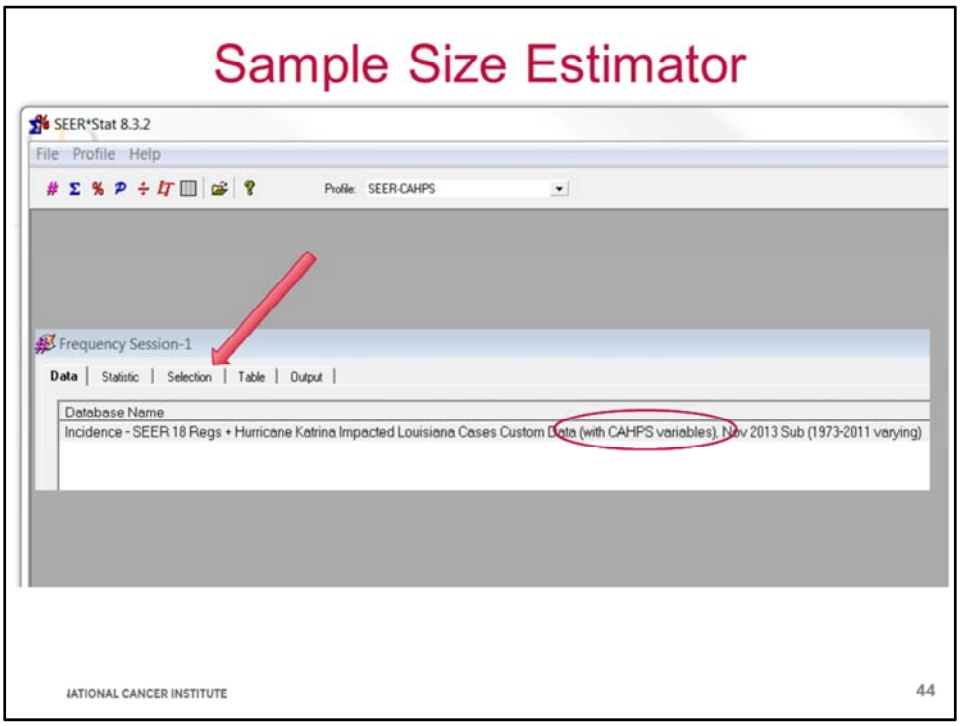
We have created a customized database in SEER*Stat that you can request access to that has flags that indicate the availability of Medicare CAHPS surveys for individuals diagnosed with cancer in SEER.

There are instructions for how to request access to the sample size estimator on the SEER-CAHPS website, shown here.

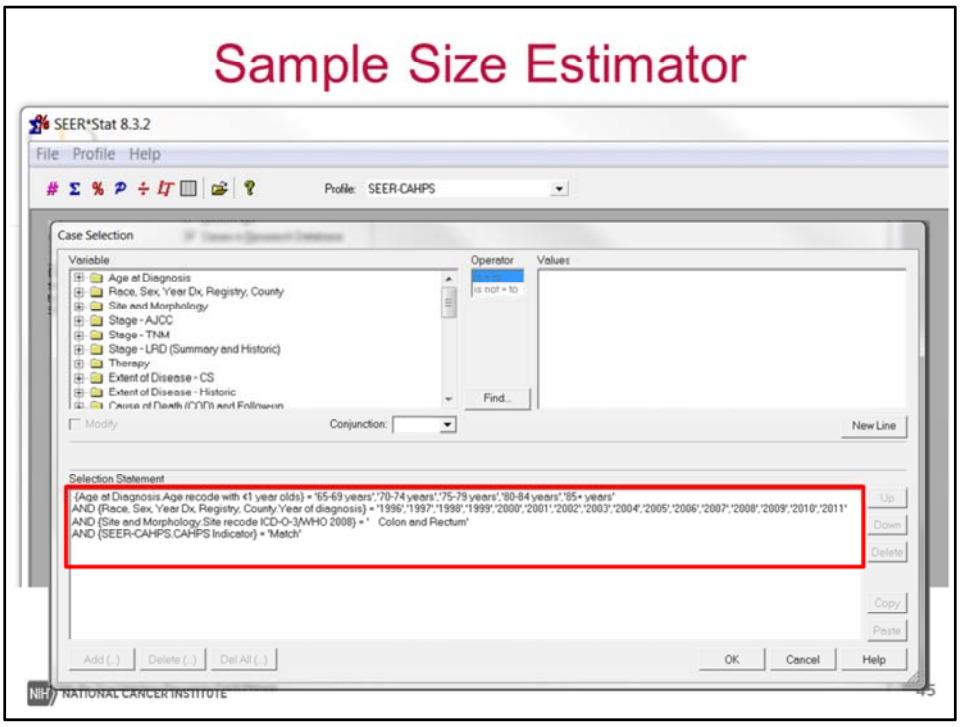


Once you have SEER*Stat installed and access to the SEER*CAHPS customized database, you are ready go. You will open SEER*Stat – it looks like this.

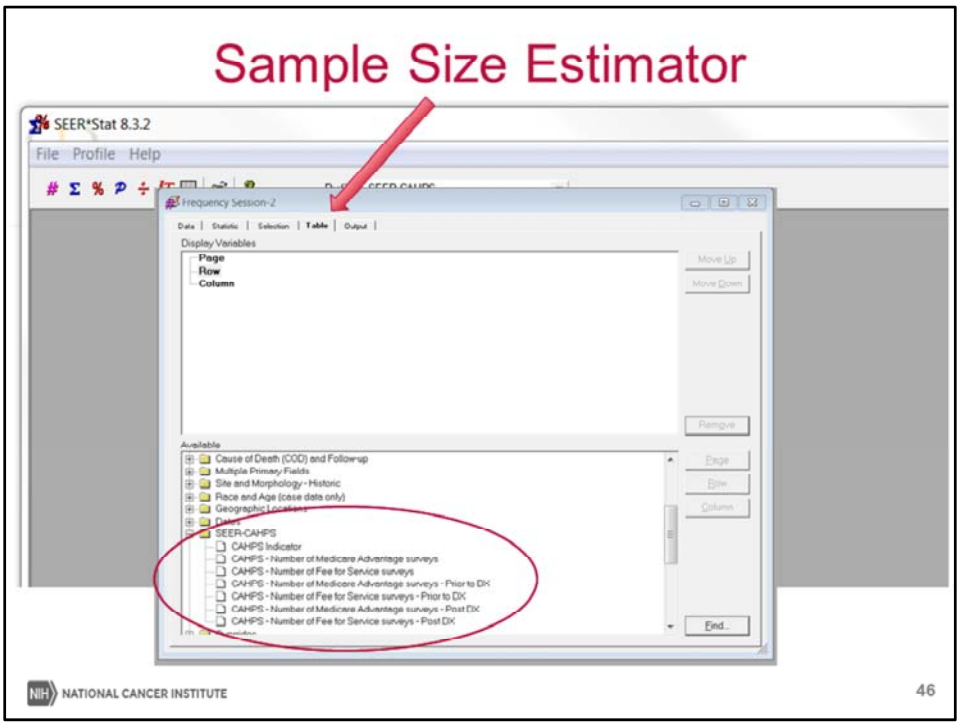
To run a frequency session to estimate the number of individuals with Medicare CAHPS surveys available in the SEER-CAHPS linkage, you'll click this hashtag icon.



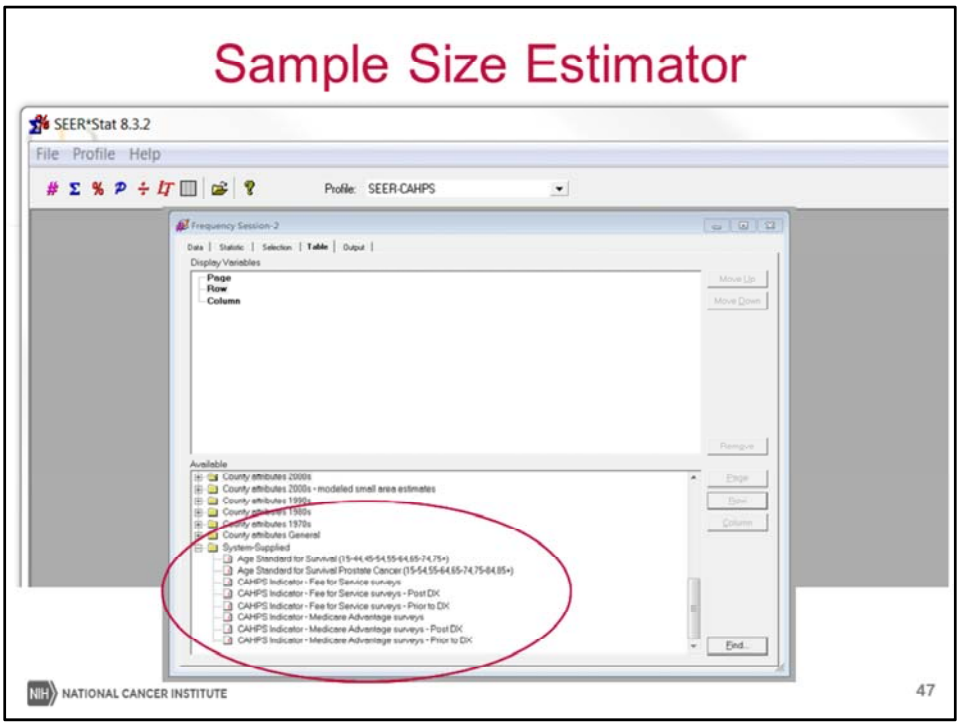
Then, you'll see a window pop up with a number of tabs. On each of these tabs you'll make selections based on your individual research question. On the first tab, under "Data," you'll want to select the database name that includes "with CAHPS variables." The database has limited access, which is why you'll need to request permission to access it on the SEER-CAHPS site. Now I'll take you to the Selection tab, seen here.



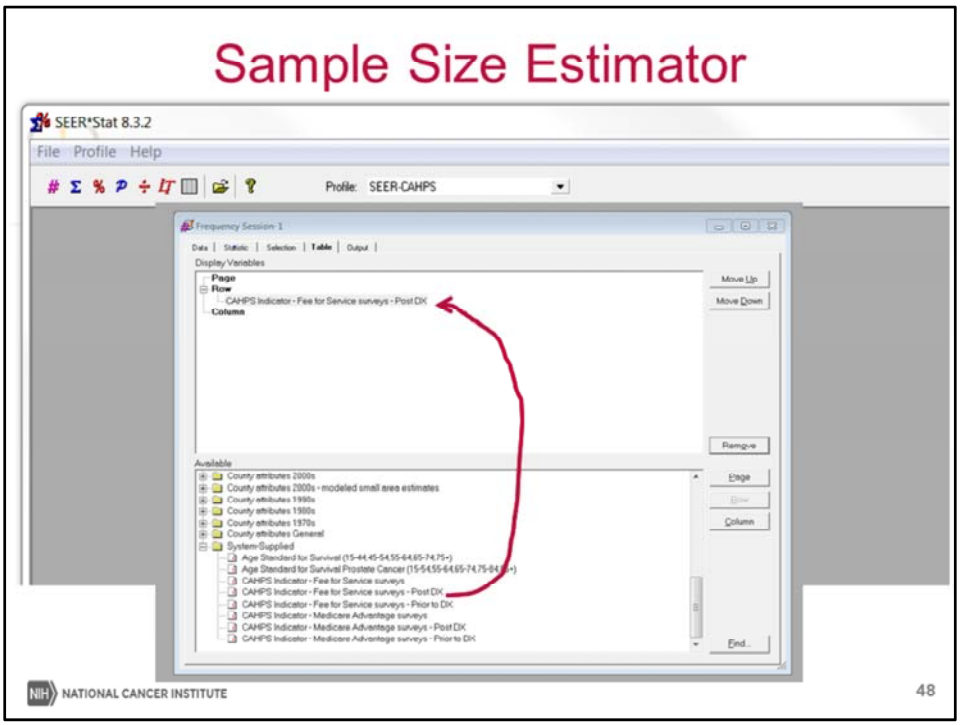
On the selection tab, you'll see a number of variables, the same SEER variables that are available in SEER-CAHPS. Note, you'll only be able to make selections based on variables in SEER-CAHPS that come from SEER. For this example, I limited my selection to those who were ages 65 and over at diagnosis, diagnosed between 1996 and 2011, with sites included within the ICD-O-3/WHO 2008 designation of "colon and rectum," and limited to those with a CAHPS survey.



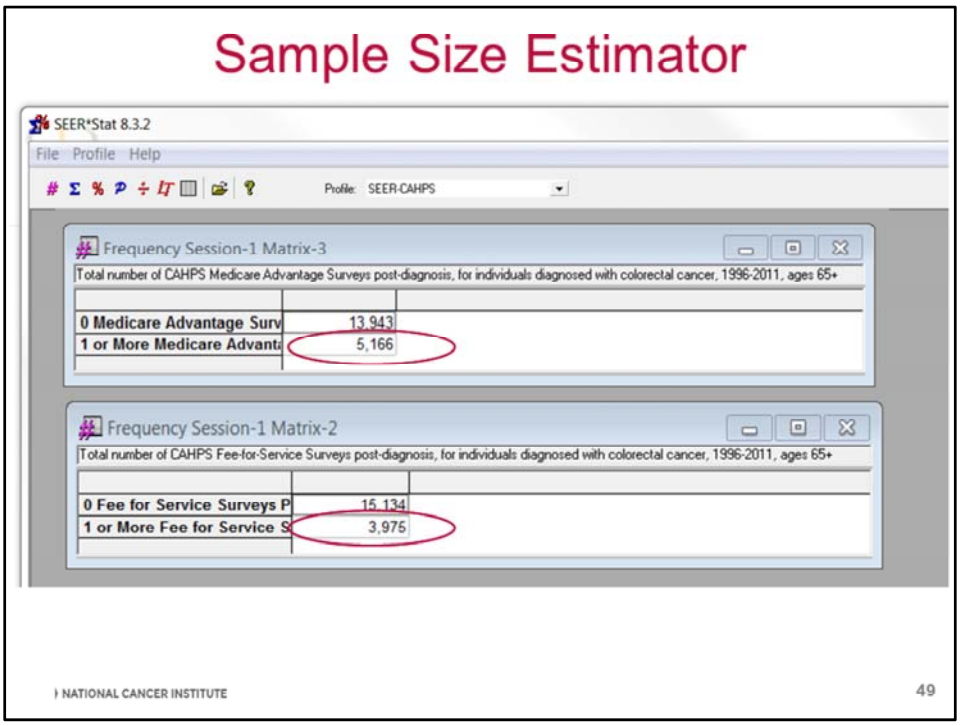
Then, on the “Table” page, I can select from variables under the “SEER-CAHPS” folder, or,



I can go to the “System-Supplied” folder and choose additional CAHPS indicator variables.

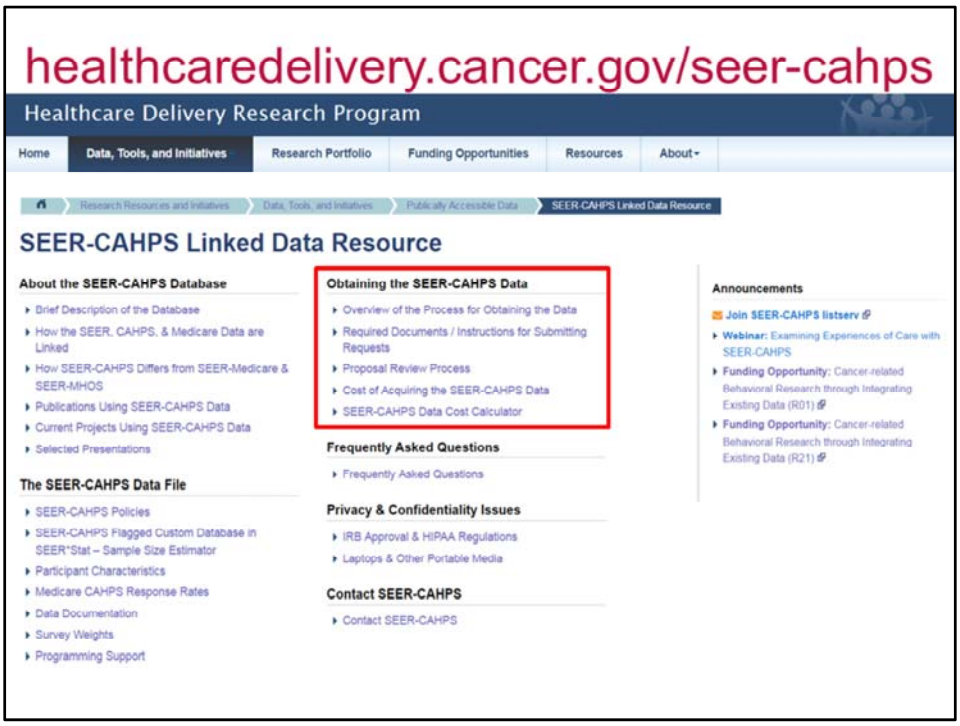


For this example, I chose “CAHPS Indicator – Fee for Service surveys Post Dx” for one run by moving that variable under “Row,” then did another run with “CAHPS Indicator – Medicare Advantage surveys Post Dx.”



After running each session, here is the output I receive. You can see that the number of individuals with CRC and an MA survey post-dx, is 5166, and the number of individuals enrolled in FFS with a CAHPS survey after dx is 3975.

The last two subsections of the Obtaining the SEER-CAHPS Data, a cost calculator and cost sheet**,** were developed to assist investigators in determining the cost of data.


healthcaredelivery.cancer.gov/seer-cahps
Healthcare Delivery Research Program
Home
Data, Tools, and Initiatives
Research Portfolio
Funding Opportunities
Resources
About
Research Resources and Initiatives
Data, Tools, and Initiatives
Publically Accessible Data
SEER-CAHPS Linked Data Resource
SEER-CAHPS Linked Data Resource
About the SEER-CAHPS Database
Brief Description of the Database
How the SEER, CAHPS, & Medicare Data are Linked
How SEER-CAHPS Differs from SEER-Medicare & SEER-MHOS
Publications Using SEER-CAHPS Data
Current Projects Using SEER-CAHPS Data
Selected Presentations
The SEER-CAHPS Data File
SEER-CAHPS Policies
SEER-CAHPS Flagged Custom Database in SEER*Stat – Sample Size Estimator
Participant Characteristics
Medicare CAHPS Response Rates
Data Documentation
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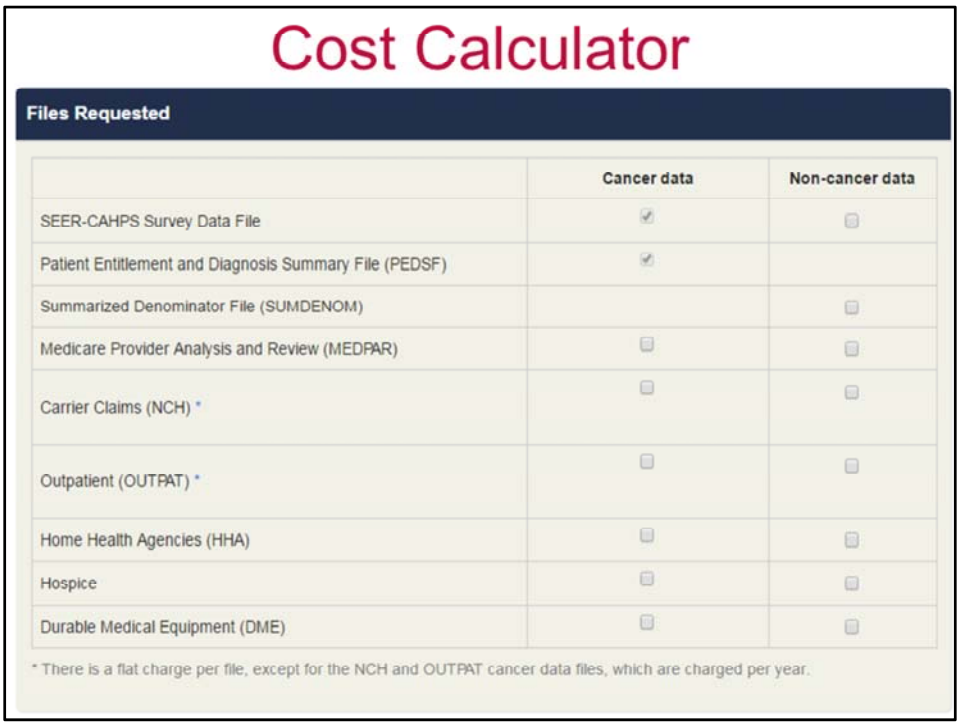
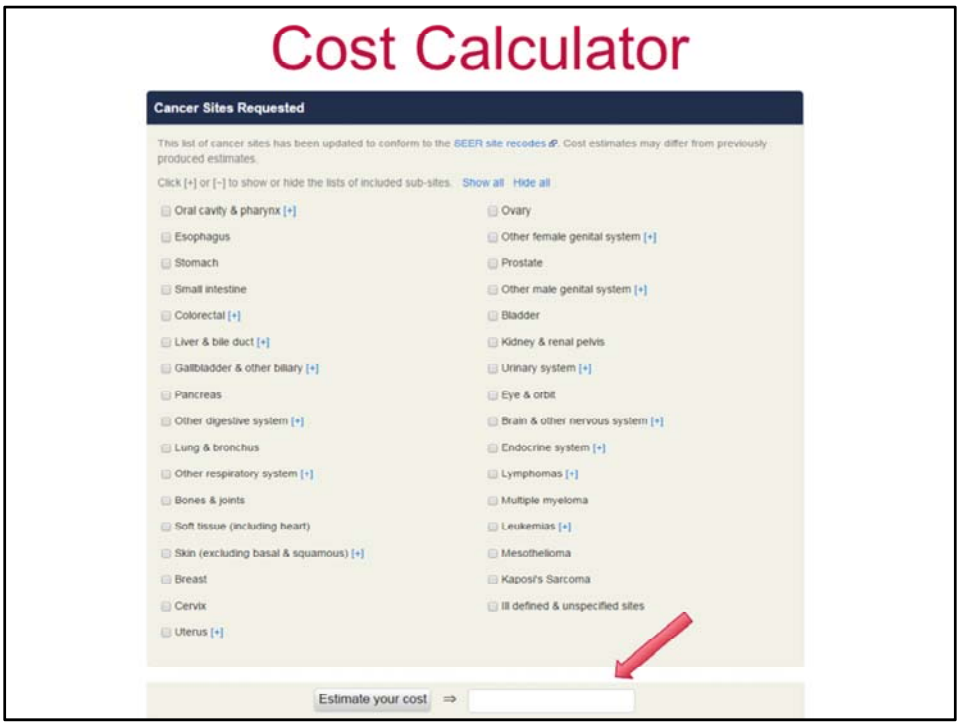
Obtaining the SEER-CAHPS Data
Overview of the Process for Obtaining the Data
Required Documents / Instructions for Submitting Requests
Proposal Review Process
Cost of Acquiring the SEER-CAHPS Data
SEER-CAHPS Data Cost Calculator
Frequently Asked Questions
Frequently Asked Questions
Privacy & Confidentiality Issues
IRB Approval & HIPAA Regulations
Laptops & Other Portable Media
Contact SEER-CAHPS
Contact SEER-CAHPS
Announcements
Join SEER-CAHPS listserv
Webinar: Examining Experiences of Care with SEER-CAHPS
Funding Opportunity: Cancer-related Behavioral Research through Integrating Existing Data (R01)
Funding Opportunity: Cancer-related Behavioral Research through Integrating Existing Data (R21)



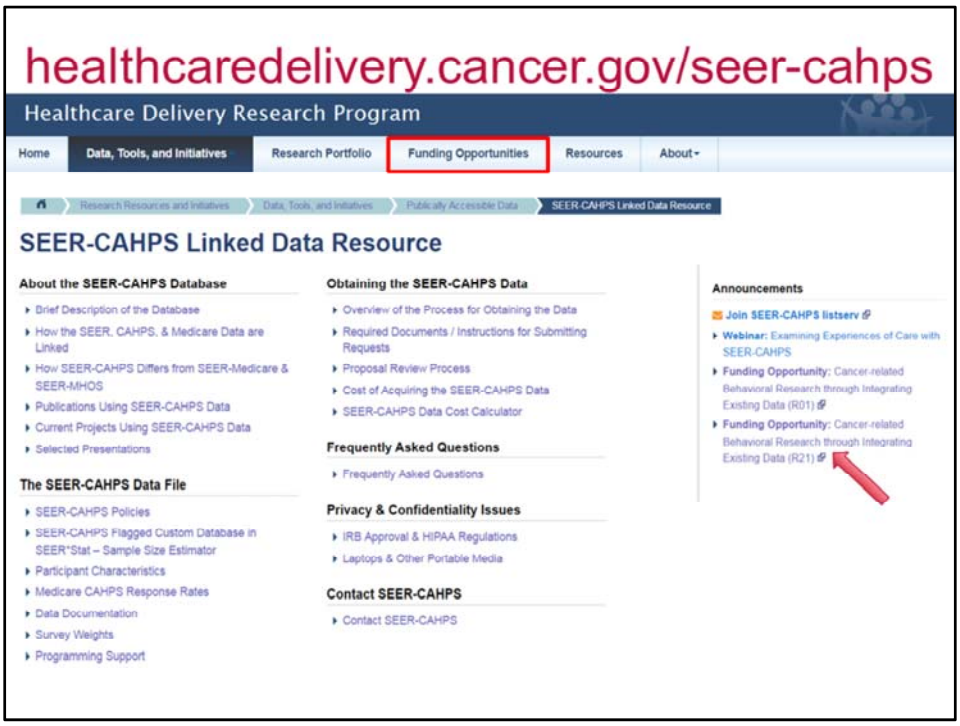
Using the cost calculator, an investigator can customize their request by the types of file requested, as shown here, choice of cancer data, non-cancer data, or both.



Here, you will see a continuation of the cost calculator, which lists the cancer sites you will choose from. Pressing the “estimate your cost” button will calculate an approximate cost for the desired dataset.

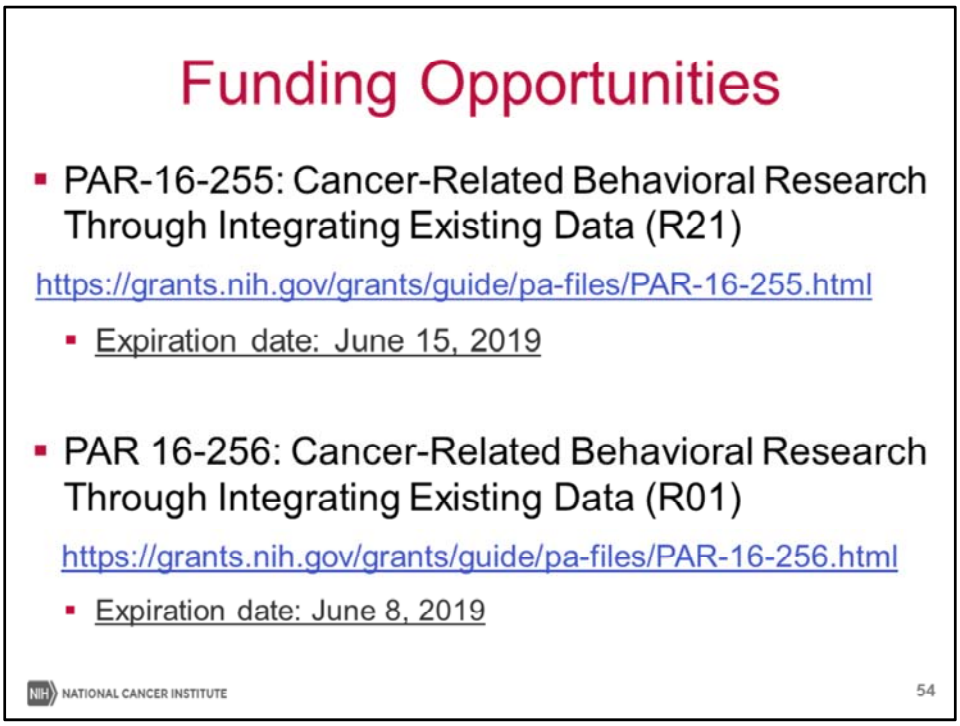
The quoted costs are for files containing cancer cases, newly diagnosed in each year. Costs vary depending on the number of cancer sites selected.

Additional analyses, such as identifying all persons who died of a selected cancer in a year, may require special programming at additional cost. Requesting updated data for an existing project after a new data linkage will incur the cost of recreating the entire data set



Many of you may be interested in seeking funding for your work with SEER-CAHPS. The SEER-CAHPS website includes a link to funding opportunities in the top tab, and an announcement section with current opportunities

Clicking on the funding opportunities button at the top links to the cancer control funding opportunity website.

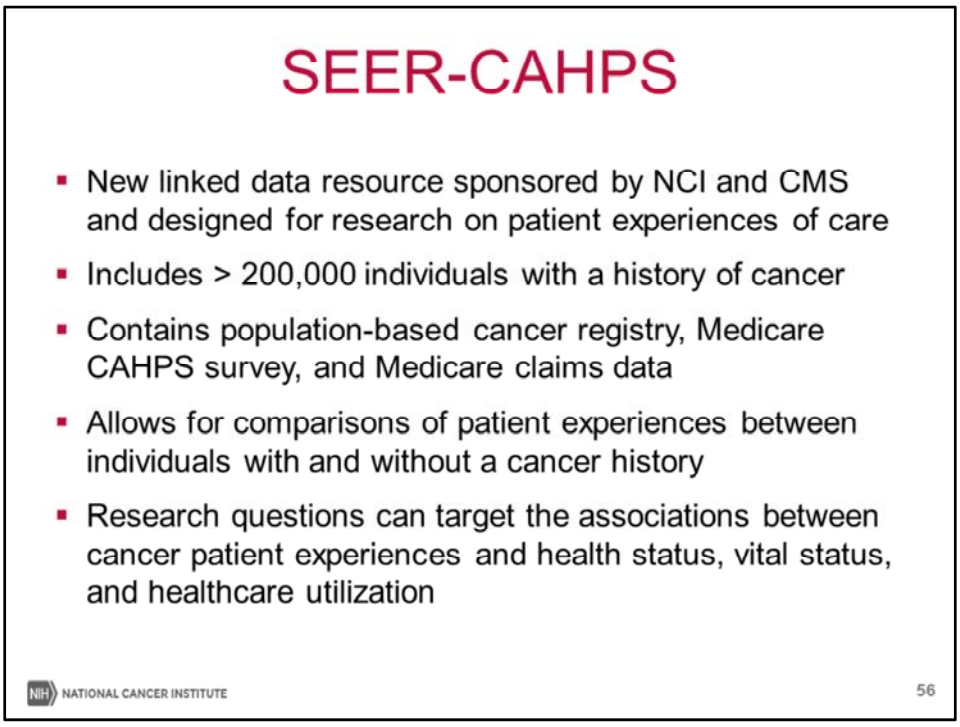


Of the various opportunities you can find on the funding website, we wanted to highlight an FOA at both the R01 and R21 that could be pertinent to those of you seeking funding for your work with SEER-CAHPS:

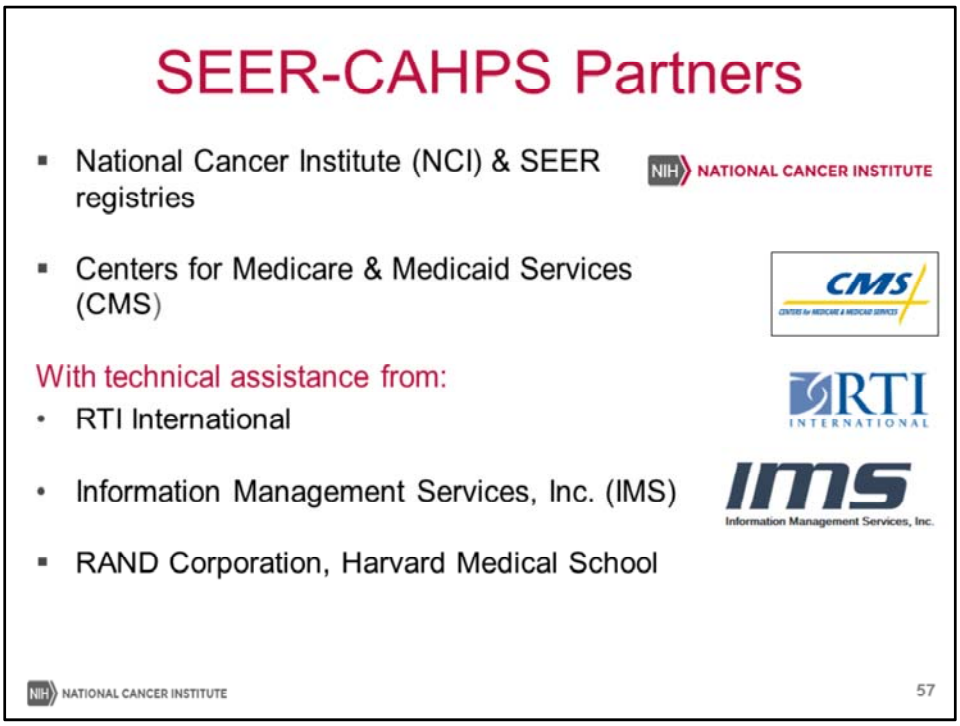
- Cancer-related behavioral research through integrating existing data-please see the websites listed here for more information, including an upcoming webinar on this FOA.

We do want to clarify that the application processes for SEER-CAHPS data and funding are separate. However, we encourage investigators interested in the SEER-CAHPS data resource to reach out to SEER-CAHPS staff prior to submitting a grant proposal for a project requiring SEER-CAHPS data.

In this webinar, we've provided a lot of information about SEER-CAHPS…



In summary, SEER-CAHPS is a New linked data resource sponsored by NCI and CMS and designed for research on patient experiences of care, including over 200K individuals diagnosed with cancer. It contains population-based cancer registry, Medicare CAHPS survey, and Medicare claims. This unique resource allows for comparisons of patient experiences between individuals with and without a cancer history, permitting the study of research questions can target the associations between cancer patient experiences and health status, vital status, and healthcare utilization



We want to acknowledge and thank our partners, first and foremost CMS. We also want to acknowledge the technical assistance we've received both to create and support the SEER-CAHPS linkage: RTI, IMS, Rand, and Harvard Medical School.

Thank you – for more information, please visit our website, email us, and join our listserv.

With that, we'll take some questions from chat…

FAQs received will serve us to expand our current FAQ page, where answers to common questions will be archived

Thank you – for more information, please visit our website, email us, and join our listserv.