Alzheimer's and Dementia Data:
Current Sources within Oregon State

The following descriptions are of data sources and databases that track data points related to cognitive impairments and dementia in Oregon.

ACS (American Community Survey)

Description: The American Community Survey (ACS) is an ongoing National-level survey that provides data every year—giving communities the current information they need to plan investments and services. Information from the survey generates data that help determine how more than $400 billion in federal and state funds are distributed each year. To help communities, state governments, and federal programs, we ask about age, sex, race, family and relationships, income and benefits, health insurance, education, veteran status, disabilities, where you work and how you get there, where you live and how much you pay for some essentials. All this detail is combined into statistics that are used to help decide everything from school lunch programs to new hospitals. Though the data is collected nationally, access to regional data is available. **Source:** ACS website at https://www.census.gov/acs/www/about_the_survey/american_community_survey/.

Reason for Inclusion: The ACS includes questions regarding disabilities, in addition to other broad demographic information. Currently, question **18a** is the most relevant question to the topic of cognitive impairment. It asks respondents: "**Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?"** Additionally, there are follow-up questions regarding assistance needed for some activities of daily living (ADLs) and instrumental activities of daily living (IADLs), including ambulating, dressing and bathing, and getting to appointments or grocery shopping for individuals living in the surveyed home.

Available Data: For ACS data files that are pretabulated, individuals can download the free information from the File Transfer Protocol (FTP) server at https://www.census.gov/acs/www/data_documentation/data_via_ftp/, or for a fee, can request custom tabulations through the ACS website at https://www.census.gov/acs/www/data_documentation/custom_tabulations/. The website cautions that the minimum cost of a custom tabulation is $3000, and the minimum timeframe is 8 weeks, and frequently higher in both respects. There are two options for working with untabulated ACS records. Both are listed below.

Public Use Microdata Sample (PUMS) files are **"untabulated records about individual people or housing units,"** which **"include population and housing unit records with individual response information such as relationship, sex, educational attainment, and employment status."** This data is redacted and there are certain precautions, such as top-coding, that reduce the likelihood of identification. Geographic area codes are limited, in an effort to protect confidentiality. The PUMS tool can be used to create tables that aren't already pretabulated and available on the American FactFinder website at http://factfinder2.census.gov/faces/nav/jsf/pages/searchresults.xhtml?refresh=t. A guide to using PUMS can be found at https://www.census.gov/acs/www/Downloads/handbooks/ACSPUMS.pdf. Statistical software is required for PUMS files from American FactFinder and the FTP site.

On the ACS website, there are additional options to request greater access to the raw data, but certain conditions must be met, including that the project must **"provide benefit to Census Bureau programs, demonstrate scientific merit, require non-public data, be feasible given the data, and pose no risk of disclosure."** Additionally, the research must be conducted at specific sites, called Research Data Centers (RDC), which are administered by the Center for Economic Studies (CES). The closest site to Oregon is located in Seattle, WA and full list can be found at http://www.census.gov/ces/main/contact.html. According to the CES website, they support microdata research that **"Encourages knowledgeable researchers to become familiar with Census Bureau data products and Census Bureau collection methods in order to improve their utility and quality; creates new products that leverage the value of data that has already been collected; and can address important policy questions without the need for additional data collections."** To apply, interested parties must write a Census RDC Research Proposal. Guidelines for the proposal can be found at http://www.census.gov/ces/pdf/Research_Proposal_Guidelines.pdf.

Contact Information:
See ACS https://www.census.gov/acs/www/guidance_for_data_users/guidance_main/for information on obtaining data, as well as additional information regarding methods and tools.

APAC (All Payers, All Claims)

Description: All Payers, All Claims (APAC) is comprised of medical and pharmacy claims, as well as information from the member eligibility and provider files, as collected from health insurance payers for residents of the State of Oregon. This information encompasses fully-insured and self-insured data. APAC affords a deeper understanding of the Oregon health care delivery system by providing access to timely and accurate data essential to improving quality, reducing costs, and promoting transparency.

According to the APAC website, the APAC database components include **medical claims, pharmacy claims, and information from member eligibility files, provider files, and product files**. It includes **fully-insured, self-insured, Medicare and Medicaid data** and it protects and de-identifies personal and sensitive information. More specific information outlined below.

- All carriers and licensed third-party administrators with at least 5,000 covered lives are required to report to APAC
- In addition, all pharmacy benefit managers, managed care organizations (MCOs), coordinated care organizations (CCOs), and entities with Dual Eligible Special Needs Plans in Oregon are mandatory reporters
- In sum, APAC includes claims information from commercial health insurance carriers, licensed third party administrators, pharmacy benefit managers, Medicaid managed care organizations, Medicaid fee-for-service and Medicare parts C and D
- At present, APAC excludes lines of business not currently required to be reported, such as carriers too small to report; Medicare Fee-For-Service; TRICARE; Federal Employee Health Benefits program; uninsured and self-pay; stand-alone dental, vision, or Rx plans; medical care not included in the statutory definition of health insurance (e.g., Indian Health Service); and other forms of insurance such as workers' compensation or medical liability auto insurance

Source: APAC http://www.oregon.gov/OHA/OHPR/RSCH/Pages/APAC.aspx#APAC_Data_Sets and APAC http://www.oregon.gov/oha/OHPR/RSCH/docs/All_Payer_all_Claims/APAC-Overview-for-Release-Document.pdf.

Reason for Inclusion: APAC includes information regarding ICD (diagnostic codes), which would reflect specific information regarding diagnoses, claims and cost of care for individuals diagnosed with dementia in Oregon.

Available Data: There are two methods of requesting data from APAC, including public use data files and limited data set requests. Both are outlined below.

Public use data files may be requested for $250-$1000, using form APAC-4 and can be found at http://www.oregon.gov/oha/OHPR/RSCH/docs/All_Payer_all_Claims/APAC-4_form.pdf. These files include **hospital inpatient, emergency department, ambulatory surgery, ambulatory outpatient, all medical claims, all pharmacy claims, and episodes of care information.**

For limited data set requests, researchers can use form APAC-5, the Research Application for Limited Data Sets, to request raw data. This form can be found at http://www.oregon.gov/oha/OHPR/RSCH/docs/All_Payer_all_Claims/APAC-5_form.pdf, and is a much more rigorous process, including information regarding IRB approval and methods, for example. Information for this data includes the same information as the public use data files, including **hospital inpatient, emergency department, ambulatory surgery, ambulatory outpatient, all medical claims, all pharmacy claims, and episodes of care information** plus information regarding **OHP FFS, OHP MCO, Medicare Advantage, OEBB/PEBB, private insurance**. The cost for requesting this information varies, but according to the website, ranges from $2,500-$7,500. The website cautions that the price could go higher for **custom data sets, or for applications requiring extensive review or additional staff processing.**

Contact Information: Questions regarding the APAC data and info may be directed to apac.admin@state.or.us. Additional information regarding the information can be found at http://www.oregon.gov/OHA/OHPR/RSCH/Pages/APAC.aspx#APAC_Data_Sets.

Avatar
(Oregon State Hospital (OSH) Internal Records Database)

Description: Internally, OSH tracks diagnoses of all patients, including those with dementia as a diagnosis, as a part of their census records in a database.

Reason for Inclusion: The OSH tracks diagnoses of all patients, including dementia, and is able to provide snapshots of information in the present and over time.

Source: Deborah Howard at OSH 12/2013.

Data Available: According to Deborah Howard, Director of Consumer and Family Services at OSH, they are able to provide the number of patients with dementia, the average length of stay for those patients, the most common diagnoses of dementia, and the percentage of patients with dementia relative to the total OSH population. This data comes de-identified.

Contact Information:
Deborah Howard, Director of Consumer and Family Services
Phone: 503-945-7132
Email: deborah.j.howard@state.or.us

BRFSS (Behavioral Risk Factor Surveillance System)

Description: The Behavioral Risk Factor Surveillance System (BRFSS) is a collaborative project of the Centers for Disease Control and Prevention (CDC), and U.S. states and territories. The BRFSS, administered and supported by the Behavioral Surveillance Branch (BSB) of the CDC, is an on-going data collection program designed to measure behavioral risk factors in the adult population 18 years of age or over living in households. The BRFSS was initiated in 1984, with 15 states collecting surveillance data on risk behaviors through monthly telephone interviews. The number of states participating in the survey increased, so that by 1998, 50 States, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands were participating in the BRFSS. Oregon has been participating since 1988.

The objective of the BRFSS is to collect uniform, state-specific data on preventive health practices and risk behaviors that are linked to chronic diseases, injuries, and preventable infectious diseases in the adult population. Factors assessed by the BRFSS include tobacco use, physical activity, dietary practices, safety-belt use, and use of cancer screening services, among others. Data are collected from a random sample of adults (one per household) through a telephone survey.

Source: Oregon Health Authority Website
http://public.health.oregon.gov/BirthDeathCertificates/Surveys/AdultBehaviorRisk/Pages/brfssum.aspx

Reason for Inclusion: The BRFSS contains questions regarding behavioral risk factors. Three of the questions asked on the basic survey are listed below.

Question 8.23: "Are you limited in any way in any activities because of physical, mental, or emotional problems?"
Question 8.26: "Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?"
Question 8.29: "Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?"
These question, along with the rest of the BRFSS questions regarding health, can be found under Health Problems or Impairments on 2012 BRFSS at http://www.cdc.gov/brfss/questionnaires/pdf-ques/2013%20BRFSS_English.pdf.

Cognition-specific questions are asked in a separate module, called the **Cognitive Impairment Module**. This module is separate from the main survey and is not completed for every state, or for every year. Oregon used this module in 2011 and 2012. The Cognitive Impairment Module can be found at http://www.cdc.gov/aging/pdf/impact_of_cognitive_impairment_module.pdf.

There is also a Caregiving Module available, which is also not completed in every state every year. Information regarding the Caregiving Module can be found at http://www.cdc.gov/aging/caregiving/activities.htm. To date, the actual Caregiver Module questions are not listed on the BRFSS website.

Available Data: Annual Survey Data is available and publicly accessible by visiting the BRFSS website at http://www.cdc.gov/brfss/annual_data/annual_data.htm. This information is already tabulated and there are several options for viewing the data, including geographically on GIS maps at http://www.cdc.gov/brfss/gis/gis_maps.htm. There are also Health Indicator Sortable Stats at http://wwwn.cdc.gov/sortablestats/, where users are able to **view, sort and analyze data** at **state, regional, and national levels**.

Raw BRFSS datasets can be obtained by applying through the Oregon BRFSS Coordinator, Renee Boyd, listed below. Applicants need to submit the data use application (Appendix A), have it signed by all data users and the Principal Investigator (PI), then submit the signed copy to Renee, either electronically, or in hardcopy format. As much detail as possible needs to be included, and if the study has gone through the IRB review, a copy of the signed approval should be included. Submitted data requests are reviewed, and if approved, the workload will need to be reviewed to provide an estimated delivery date. There is a fee of $55 per hour to process the data, and the total depends upon the specific request. According to Renee, the average charge is in the 2-hour range ($110) for one dataset.

Contact Information:
Oregon BRFSS Coordinator, Renee Boyd
Phone: 971-673-1145
Email: Renee.K.Boyd@state.or.us
Please see the CDC's http://www.cdc.gov/brfss/ for more information.

Department of Motor Vehicles (DMV) At-Risk Database

Description: This database is used statewide, and tracks information related to DMV services, including demographics and records.

Reason for Inclusion: One of the topics tracked by this system, is the reason for revocation of a driver's license when the information is reported by primary care physicians, as mandatory reporters.

Source: Bill Merrill at the Department of Motor Vehicles (503) 235-1259.

Data Available: The At-Risk Database does not track diagnostic information for drivers, but when physicians make a mandatory report (not voluntary), they fill out a form that distinguishes between functional impairments and cognitive impairments, which describes specific concerns for the driver continuing to drive in their current state. Some of the specific cognitive impairment symptoms tracked include those related to attention, judgment, problem-solving, and reaction time. Physicians can also state whether the condition is chronic or progressive in nature. Data requests can be made through Lisa Wallig (information below), and they are happy to help out with data requests.

Contact Information:
Lisa Wallig, Medical Program Coordinator with DMV
(503) 945-5295
lisa.j.wallig@odot.state.or.us

MDS (Minimum Data Set)

Description: The Long-Term Care Minimum Data Set (MDS) 3.0 (Appendix B) is a standardized, primary screening and assessment tool of health status that forms the foundation of the comprehensive assessment for all residents in a Medicare and/or Medicaid-certified long-term care facility. The MDS contains items that measure physical, psychological and psychosocial functioning. The items in the MDS give a multidimensional view of the patient's functional capacities and helps staff to identify health problems.

Source: Centers for Medicare & Medicaid Services http://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/IdentifiableDataFiles/LongTermCareMinimumDataSetMDS.html.

Reason for Inclusion: The MDS tracks data for nursing home admissions and stays and includes a variety of health questions, among other demographic information. Sections included in the MDS are below:

A: Select Demographic Items	J: Health Conditions
B: Hearing, Speech and Vision	K: Swallowing/Nutritional Status
C: Cognitive Patterns	L: Oral/Dental Status
D: Mood	M: Skin Conditions
E: Behavior	N: Medications
F: Preferences for Customary Routine, Activities and Community Setting	O: Special Treatments and Procedures
G: Functional Status	P: Restraints
H: Bladder and Bowel	Q: Participation in Assessment and Goal Setting
I: Active Disease Diagnosis	

Some related specifically to dementia include the following:

Brief Interview for Mental Status (BIMS)
In this section of the MDS (Questions C1-C7), the interviewer (generally a nurse or mental health clinician) will ask questions regarding the following skills: **Ability to repeat three words; recall of the three words; temporal orientation; organized thinking.**

Mental Status Exam (MSE)
In this section, mental status is assessed (generally by a nurse or mental health clinician) using questions (C8-C13) regarding short-term, long-term, memory/recall, cognitive skills for daily decision-making, signs and symptoms of delirium, and whether the condition was acute or slow-onset and whether the change occurred in the past 5 days.

Also included in the MDS, are questions regarding mood (D1-D8), particularly depression, and behavior changes, including the frequency and presence of hallucinations and delusions, and verbal and physical agitation. Section E, which tracks these indicators related to behavior, also has questions (E8-E11) regarding **wandering**. In Section I, there is also a neurological section which refers to dementia, including: Alzheimer's Disease, and Non-Alzheimer's Dementia.

Source: http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/downloads/MDS30Draft.pdf

Available Data: All requests for identifiable data must be developed and reviewed with the assistance of the Research Data Assistance Center (ResDAC), who may be contacted at http://www.resdac.umn.edu or at mailto:resdac@umn.edu.
Once your data request has been reviewed by ResDAC, the final request can be sent to the Centers for Medicare & Medicaid Services (CMS) as directed by ResDAC. More Information is provided regarding the process on the following page. See **ResDAC** in Appendix C for more information.

Contact Information: See information regarding ResDAC or ResDAC http://www.resdac.org/cms-data/request/cms-data-request-center.

MMIS (Oregon Medicaid Management Information System)

Description: The MMIS is an integrated group of procedures and computer processing operations (subsystems) developed at the general design level to meet principal objectives. For Title XIX purposes, "systems mechanization" and "mechanized claims processing and information retrieval systems" is identified in section 1903(a)(3) of the Act and defined in regulation at 42 CFR 433.111. The objectives of this system and its enhancements include the Title XIX program control and administrative costs; service to recipients, providers and inquiries; operations of claims control and computer capabilities; and management reporting for planning and control.

Source: http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MMIS/index.html?redirect=/MMIS/ on the Centers for Medicare & Medicaid Services website.

Reason for Inclusion: MMIS tracks ICD-9 (diagnostic) codes, as well as billing codes, which would include diagnoses related to dementia.

Available Data: CMS State Medicaid Research Files (SMRF) were replaced with MAX files beginning in 1999. These data files contain enrollment information and final action claims for all Medicaid beneficiaries. These files do not contain information on individuals who are eligible for Medicaid, but not enrolled http://www.resdac.org/cms-data/file-family/Medicaid-Analytic-Extracts-MAX.

Contact Information: See ResDAC in Appendix C, under subtitle Medicaid Analytic Extract (MAX).

NORS (National Ombudsman Reporting System)

Description: Internally, the Long Term Care Ombudsman Program tracks complaints and cases in the database, called the National Ombudsman Reporting System (NORS). Consultations to individuals or facilities involving incidences or seeking advice but not requiring ombudsman involvement, is not entered into this database. Data is compiled and is available on the state and national level, through the Administration on Aging's AGing Integrated Database (AGID).

Source: Administration on Aging
http://www.aoa.gov/aoa_programs/elder_rights/Ombudsman/docs/Instructions_Final%202015.pdf

Reason for Inclusion: During the course of investigating a complaint, the ombudsman will write a report and will classify the complaint in terms of complainant codes that are directly or indirectly related to dementia. The specific codes are listed below, and could be cross-compared to facilities that serve individuals with dementia (for example, facilities with memory care units), to assist in distinguishing between complaints regarding people who have a diagnosis of dementia or another condition with associated cognition issues. The codes are listed below.

51—Wandering, failure to monitor exit-seeking behavior
56—Mental health, psychosocial services
122—Legal: guardianship, conservatorship, POA, wills
124—Mental health, developmental disabilities, pre-admission screening, resident review

There are no diagnostic ICD-9 codes included in this data at this point, but per the Oregon chapter, there have been discussions regarding increasing the sensitivity of tracking indicators related to many of the complaint codes.

See http://www.aoa.gov/aoa_programs/elder_rights/Ombudsman/docs/Complaint_Code2015.pdf for more information.

Available Data: Pre-tabulated data can be found publicly at http://www.agidnet.org/DataGlance/NORS/ on the Administration on Aging's AGing Integrated Database (AGID) website. This website allows users to manipulated the data and create tables that can be arranged geographically, as well as by specific codes. Available data is often a few years in arrears due to processing time. At this time, 2011 data is available. Raw data is available through the local Oregon Chapter of the ombudsman office. Users will need to contact Bill Bard (contact listed below), and he will assist users in accessing the de-identified data for their specific needs. Data is available by facility, as well as geographically.

Contact Information:
Bill Bard, Volunteer Chair of IT/Data Committee with the Long Term Care Ombudsman for State of Oregon
billbits@comcast.net
or if he is not available:
Mary Jaeger, Director of the Long Term Care Ombudsman for State of Oregon
(800) 522-2602
mary.jaeger@ltco.state.or.us

Oregon Health Authority
Vital Statistics

Description: Vital statistics are the compilation and analysis of information collected from vital event records reported in Oregon. Oregon's Center for Health Statistics is responsible for compiling and analyzing the data from these vital records.

Reason for Inclusion: Vital statistics provides annual reports that have pre-tabulated tables on information ranging from leading causes of death to a mother's access to prenatal care. One of the leading contributors to death in the state of Oregon is Alzheimer's disease, which is reflected in some of the Mortality Tables available.

Available Data: Mortality Tables with specific mention of Alzheimer's Disease: Tables 6-2, 3, 4, 6, 7, 8, 11, 12, 14, 15, 22, 35, 40, 41, 46, 47, 48, 50, 51, 52, 53, 54, 55, 57 This information is open for public use available online. The most recent information is often at least 2 years old due to the time/resources required to analyze and produce the annual report. According to the most current information available, 2011 is the last Annual Report published, and the link to the website can be found here:
http://public.health.oregon.gov/BirthDeathCertificates/VitalStatistics/annualreports/11v2/Pages/chapter6.aspx.

Raw data is available by contacting Joyce Grant-Worley at the office of Vital Records (contact information below). Interested parties should contact her to request a data request form or see Appendix B. After the data request form has been filled out and returned, a review committee looks at the level of inquiry and estimates the amount of time needed to complete the request. Costs are billed in increments of $55/hour. All data comes de-identified, and in some cases, they may restrict access to certain information, or modify or collapse the information in a way that protects individuals, in the event that the information may be specific enough to make a positive identification. They will discuss this with interested parties in the event that this occurs.

Contact Information:
Joyce Grant-Worley, Health Statistics Manager, Oregon Health Authority (OHA) Vital Records- Health Statistics Unit
(971) 673-1156
joyce.a.grant-worley@state.or.us

Research Data Assistance Center (ResDAC)

Description: The ResDAC Assistance Desk, located at the University of Minnesota and staffed by master's-level trained Technical Advisors (TAs), provides technical assistance to researchers interested in using Medicare and/or Medicaid data. ResDAC TAs respond to requests within 7-10 business days. **They are unable to offer direct support in performing statistical analysis.** Visit ResDAC at http://www.resdac.org/cms-data/request/cms-data-request-center. Data requests regarding the MDS are processed through ResDAC's CMS Data Request Center. The CMS maintains three different categories of data files that can be used for research including **Research Identifiable (RIF), Limited Data Sets (LDS), and Public Use Files (PUF).** A description of each can be found below, as well as the process of requesting the data.

Name of Data	Website	Description of Data	Data Request Process
Research Identifiable (RIF)	http://www.resdac.org/cms-data/request/research-identifiable-files	Research identifiable files (RIF) contain beneficiary level protected health information (PHI). Requests for RIF data require a Data Use Agreement (DUA) and are reviewed by CMS's Privacy Board to ensure that the beneficiary's privacy is protected and the need for identifiable data is justified. Source: http://www.resdac.org/resconnect/articles/148	Email all required request materials to resdac@umn.edu. For the initial submission, please send draft documents only (no signatures). Following ResDAC review and appropriate revisions to your request, you may email final materials to ResDAC, and we will forward them to CMS on your behalf. Data request reviews will now be on a rolling basis. Data request materials can be found at http://www.resdac.org/cms-data/request/research-identifiable-files. To request a cost estimate (for grant proposals) or cost invoice (for data requests) for CMS data, please fill out the request document provided (at http://www.resdac.org/cms-data/request/materials/rif-cost-estimateinvoice) and submit to ResDAC either by email (resdac@umn.edu) or using the online submission form.
Limited Data Sets (LDS)	http://www.resdac.org/cms-data/request/limited-data-sets	Limited Data Set (LDS) files contain beneficiary level protected health information; however, selected variables within the files are encrypted, blanked, or ranged. LDS requests require a DUA, but do not go through a Privacy Board review. Per CMS, the LDS Files are only available as a 100% file, or a 5% random sample file. Source: http://www.resdac.org/resconnect/articles/148	All disclosures of the LDS require a signed LDS Data Use Agreement (DUA) between the Centers for Medicare & Medicaid Services (CMS) and the Requester to ensure that the data remains protected against unauthorized disclosure. This DUA ensures compliance with both the Privacy Act and HIPAA. To qualify for LDS, data Requesters must show that their proposed use of the data meets the disclosure provisions for research purposes as defined in both the HIPAA and the Privacy Act. The research purpose must relate to projects that could ultimately improve the care provided to Medicare patients and policies that govern the care. This includes projects related to improving the quality of life for Medicare beneficiaries or improving the administration of the Medicare program, including payment related projects and the creation of analytical reports. LDS Requests do not require approval from the Privacy Board. Exact process for requesting information can be found at http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Privacy/DUA_-_LDS.html. Currently, there are 20 files available for request and can be found at http://resdac.advantagelabs.com/cms-data/search?f%5B0%5D=im_field_privacy_level%3A43. Payments are processed through Pay.gov and the forms can be found at https://www.pay.gov/paygov/forms/formInstance.html?agencyFormId=25851882.
Public Use Files (PUF)	http://www.resdac.org/cms-data/request/public-use-files	Public Use Files (PUFs), also called Non-Identifiable Data Files, have been edited and stripped of all information that could be used to identify individuals. In general the PUFs contain aggregate level information on Medicare beneficiary or provider utilization. Source: http://www.resdac.org/resconnect/articles/148	PUF, or Non-Identifiable Data files, contain the aggregated summary level health information on Medicare and Medicaid beneficiaries. PUF requests do not require a DUA and not go through a Privacy Board review. Currently, there are 19 files available for request and can be found at http://resdac.advantagelabs.com/cms-data/search?f[0]=im_field_privacy_level%3A44. Payments are processed through Pay.gov and the forms can be found at https://www.pay.gov/paygov/forms/formInstance.html?agencyFormId=25851882.

Appendix C

Name of Data	Website	Description of Data	Data Request Process
Medicaid Analytic Extracts (MAX)	http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/MAXGeneralInformation.html	CMS State Medicaid Research Files (SMRF) were replaced with MAX files beginning in 1999. These data files contain enrollment information and final action claims for all Medicaid beneficiaries. These files do not contain information on individuals who are eligible for Medicaid but not enrolled.	Pre-tabulated data files can be downloaded off of the website address listed. MAX files are created by state, calendar year and file type. These files include three major types of records: fee-for-service records, including utlization and payment information, premium payments for persons enrolled in prepaid plans and "encounter" records for persons enrolled in prepaid managed care plans, including utlization but not payment information. It does not appear that raw data is available at this time through MAX.