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Understanding Disparities in Persons with Multiple Chronic Conditions: Research Approaches and Datasets

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Final White Paper

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Understanding how to provide better care for individuals with multiple chronic conditions (MCC) is a priority for the Department of Health and Human Services. Persons with MCC represent almost one-third of the U.S. population and account for two-thirds of health care spending, yet most research on chronic conditions focuses on single diseases. In response to this growing challenge, the Department of Health and Human Services (HHS) led the development of the Strategic Framework on Multiple Chronic Conditions, a roadmap for federal MCC priorities.

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1. Executive Summary

Understanding how to better care for individuals with multiple chronic conditions (MCC) is a priority for the Department of Health and Human Services. Persons with MCC represent almost one-third of the U.S. population and account for two-thirds of health care spending, yet most research on chronic conditions focuses on single diseases. In response to this growing challenge, the Department of Health and Human Services (HHS) led the development of the *Strategic Framework on Multiple Chronic Conditions*(HHS 2010).

This white paper contributes to meeting the goals outlined by the HHS strategic framework by examining promising data, methods, and topics for future disparities research within the MCC population. It builds on a previous white paper titled "Understanding the High Prevalence of Low-Prevalence Chronic Disease Combinations: Databases and Methods for Research", which describes the "long tail" of the MCC distribution: approximately one-third of all Medicare patients have one of the most common combinations of MCC, but another third of all patients have one of two million unique combinations of MCC and account for 79% of health care costs. This poses a unique challenge for research because of the small number of persons within each unique combination of MCC in the "long tail" of the distribution (Exhibit 1). For disparities research, the challenge is even greater as stratification by race, ethnicity and sociodemographic variables further reduces sample size.

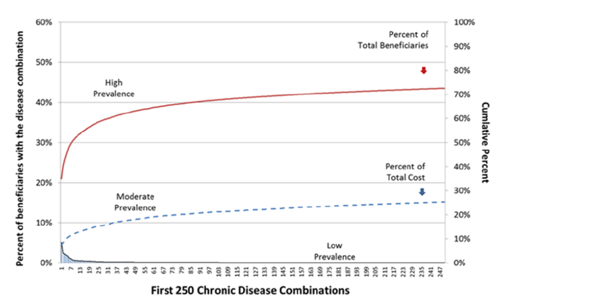
The present paper summarizes the current literature on MCC disparities, describes how the methodological challenges of disparities research are further manifested in MCC research, reviews promising methods, and assesses the usability of various data systems and datasets for MCC disparities research.

Study methods for this paper included a literature review (Appendix B), interviews with nine key informants (Appendix C) who were identified by ASPE project officers and our Technical Advisory Group (Appendix D), a review of datasets and data systems identified in the first White Paper (Appendix E), to assess their potential for MCC disparities research, and integration of input and feedback from key informants and the Technical Advisory Group.

Study results showed that most of the existing disparities research to date has focused on individual chronic conditions. There has been little research on the extent, causes, and strategies for reducing disparities within the MCC population. Further research is needed to test and replicate findings from recent studies before patterns can be confirmed. Results from our literature review suggest that:

- Women are more likely than men to be classified as having MCC (Ashman et al., 2013; CMS, 2012; Ward et al., 2012; Machlin et al., 2013).
- The number of chronic conditions rises with age (Freid et al., 2012).
- Hispanic patients have the lowest MCC prevalence (Ward et al., 2013; Steiner et al., 2013). Mexican-Americans have lower initial levels of MCC and slower accumulation of comorbidity compared to non-Hispanic White and non-Hispanic Black patients (Quinones et al., 2011).
- MCC prevalence among Asian Americans is lower compared to white or black MCC patients (Machlin et al. 2013), though Asians/Pacific Islanders had the highest mortality and cost per case compared to all other groups (Steiner et al., 2013).

Exhibit 1: Percent of Disease Prevalence and Cost in the Beginning of Medicare's Long Tail



Note on the Exhibit: The exhibit displays the first 250 Disease Combinations (ranked by prevalence) from the baseline HCC analysis as calculated by Sorace and colleagues (Sorace et al. 2011). Chronic disease combination classifications (e.g. high, moderate and low) were assigned, but only represent rough approximations; specific criteria for each classification have not been defined. Note that the left Y-axis represents the proportion of the population that is included in each unique disease combination, and is adjusted for the 32% of beneficiaries and 6% of expenditures that are associated with the no-HCC population. The right Y-axis represents the cumulative percent of the total population (red format) and the total expenditure (blue format). Note that approximately 75% of expenditures are associated with the 27% of patients that are not represented by the most prevalent 250 disease combinations. As there are over 2 million disease combinations calculated by this methodology, the figure's X-axis would need to be extended over 8,000 fold to the reader's right before both cumulative lines reached 100%.

Future research on disparities in the MCC population would be facilitated by the development of a conceptual model of MCC disparities that incorporates the roles of biological, behavioral, health care, socio-economic, community and environmental factors; and by further development of the research infrastructure, for example through continued efforts to improve the reporting of patient race, ethnicity, language, and other sociodemographic variables.

Several immediate MCC disparities research opportunities are identified in this paper, including secondary data analyses, intervention research, and research using complementary methods such as qualitative methods, positive deviance research, metasynthesis and rare disease surveillance.

2. Introduction

Adults with multiple chronic conditions (MCC) represent a growing percentage of the population as well as a large percentage of health care services utilization and cost. To date, however, most research on chronic conditions focuses on individual conditions, in isolation from chronic comorbidities. Consequently, research results often are not applicable to the population of persons with MCC. Research on the unique challenges facing individuals with multiple chronic conditions (MCC) is an emerging field of study supported by the Department of Health and Human Services (HHS). In 2008 HHS formed the Interagency Workgroup on Multiple Chronic Conditions which developed a strategic framework for improving health care for people with multiple chronic conditions and created an inventory of HHS activities focused on MCC (HHS 2010 & 2011).

As part of its MCC strategic framework, HHS specified a goal related to research gaps with a sub goal (objective) and strategies related to addressing disparities:

- "Goal 4: Facilitate research to fill knowledge gaps about, and interventions and systems to benefit, individuals with multiple chronic conditions.
  - Objective D: Address disparities in multiple chronic conditions populations.
    - Strategy 4.D.1: Stimulate research to more clearly elucidate differences between and opportunities for prevention and intervention in MCC among various sociodemographic groups.
    - Strategy 4.D.2: Use research findings on group-specific indicators for MCC risk and intervention options to leverage HHS disparities programs and initiatives to address the MCC population."

This white paper advances HHS's Goal 4 by describing health disparities research challenges, accomplishments, and opportunities in the MCC field.

The standard challenges of studying disparities are compounded by similar research challenges relating to MCC. These challenges include:

- Sample size: Only a limited number of administrative and epidemiological datasets provide a sufficiently large sample size to study MCC, let alone detect disparities in persons with MCC. (For a full discussion of issues related to studying MCC see *Understanding the High Prevalence of Low- Prevalence Chronic Disease Combinations: Databases and Methods for Research*. Rezaee M. et al. September 2013, available at: http://aspe.hhs.gov/.
- Data quality: Of the datasets that are large enough to study the numerous unique combinations of MCC, many have data quality issues that result in the misclassification of persons into (or out of) groups burdened by disparities.
- Data capture: Datasets developed through healthcare provider and insurance systems only capture people with MCC who utilize the health care system.
- Lack of standard definitions: The concepts of disparities and MCC are defined differently by different researchers, making it difficult for researchers in the field to build on each other's findings.
- Constantly evolving methods: Methods used to study both MCC and disparities are continually evolving, complicating disparities-sensitive measures of health care quality for patients with MCC.
- Limited information: The factors that drive differences in MCC prevalence and healthcare utilization/cost in race/ethnic groups may include genetics, circumstances (e.g. health immigrant effect), inaccurate data collection procedures, patient access to healthcare (sampling issues), etc. When interpreting the research on racial/ethnic disparities it is important to understand the potential limitations of the data.

Despite these methodological challenges, the body of knowledge on MCC disparities is growing as discussed later in the report.

2.1 Study Purpose

The current report is the second of two related papers commissioned by Health and Human Services. The first paper outlined the research challenges and techniques of studying multiple chronic conditions, with an emphasis on studying the "long tail" of the distribution of multiple chronic conditions (Rezaee, et.al. 2013). There are many unique combinations of chronic conditions with a relatively small number of people experiencing each combination. Any one provider or insurer will have a subset of patients with a particular combination, making it difficult to study or develop optimal care plans for each group of patients.

The purpose of the study is to assess the existing data sources and methods that can be used to investigate disparities and MCC. The paper is intended to serve as a resource for investigators working on disparities MCC with a goal of identifying promising areas for research, data sources and methods. The information can help both researchers and stakeholders better understand and interpret research results, as well as consider what steps might be taken in the future to improve the knowledgebase on health care for MCC. It may also be useful to researchers implementing the National Strategic Disparities Plans produced by other agencies and stakeholders (See Exhibit 2).

The white paper addresses the following questions:

- What combinations of comorbidities are most critical in terms of identifying opportunities for targeting and reducing disparities in care utilization and cost in MCC adult populations?
- What data systems and datasets exist that can be analyzed to better improve our understanding of and approaches to addressing disparities in MCC adult populations?

Exhibit 2: National Strategic Disparities Plans

HHS Agency/ Organization	Title	Year	Summary	Citation
Agency for Healthcare Research and Quality (AHRQ)	**National Healthcare Disparities Report**	2012	Highlights healthcare access for racial and ethnic groups from 2002–2008.	Agency for Healthcare Research and Quality. (2013). *2012 National Healthcare Disparities Report.* Rockville, MD.
Centers for Disease Control and Prevention (CDC)	**CDC Health Disparities and Inequalities Report – United States, 2011**	2011	Consolidates national data on disparities in mortality, morbidity, behavioral risk factors, healthcare access, preventive health services, and social determinants of critical health problems in the US.	Centers for Disease Control and Prevention. (2011). CDC Health Disparities and Inequalities Report – United States, 2011. *Morbidity and Mortality Weekly Report,60* (Suppl),1-114.
Institute of Medicine (IOM)	**How Far Have We Come in Reducing Health Disparities?: Progress Since 2000: Workshop Summary**	2012	Summarizes an IOM workshop on April 8th, 2010 during which progress to address health disparities through a number of federal initiatives was discussed.	IOM Institute of Medicine. (2012). *How far have we come in reducing health disparities: Progress since 2000: Workshop summary.* Washington, D.C.: The National Academies Press.
National Institutes of Health (NIH)	**NIH Health DisparitiesStrategic Plan and Budget Fiscal Years 2009-2013**	2009	Details the major priorities and NIH initiatives currently being undertaken to eliminate health disparities.	National Institutes of Health. *NIH Health Disparities Strategic Plan and Budget Fiscal Years 2009-2013.* U.S. Department of Health and Human Services, Bethesda, MD.
National Partnership for Action to End Health Disparities (NPA)	**HHS Action Plan to Reduce Racial and Ethnic Health Disparities National Stakeholder Strategy for Achieving Health Equity**	2011	Outlines goals and actions HHS will take to reduce health disparities among racial and ethnic minorities.	U.S. Department of Health and Human Services. (2011). *HHS Action Plan to Reduce Racial and Ethnic Disparities: A Nation Free of Disparities in Health and Health Care.* Washington, DC.
National Partnership for Action to End Health Disparities (NPA)	**National Stakeholder Strategy for Achieving Health Equity**	2011	Provides a common set of goals and objectives for public and private sector initiatives and partnerships to help racial and ethnic minorities–and other underserved groups – reach their full health potential.	National Partnership for Action to End Health Disparities. (2011). *National Stakeholder Strategy for Achieving Health Equity*. Rockville, MD: U.S. Department of Health & Human Services, Office of Minority Health.

2.2 Organization of the Paper

The first section of the report presents common definitions of disparities and reviews variables currently used to identify disparities. We then describe the methods we used in developing the paper, and report on the findings from the literature review and data systems review. We conclude with considerations for future research priorities, which were developed in collaboration with HHS and the Technical Advisory Panel.

3. Methods

The methods for addressing the two disparities research questions included a review of the peer-reviewed and grey literature, key informant interviews with academic and disparities policy experts, a review of databases that can be used to study disparities in the MCC population and discussion of the findings and recommendations by a Technical Advisory Group. Each method is described below.

It is important to note that definitions of disparities have changed over time and also vary according to different scholars and practitioners. As background for the methods description, we provide a short summary of definitions of disparities and variables used to discern disparities.

3.1 Definitions of Disparities

The multiple ways of defining and measuring disparities make it difficult to synthesize research on disparities and health equity. In a 2012 report by the IOM, one of the recommendations was to standardize the definition of disparities (IOM 2012). A seminal paper by Braverman (2006) provides a history of definitions and measures beginning with Whitehead's (1992) notion that disparities in health are differences that are avoidable, unjust and unfair. While other authors define any difference in health outcomes as a disparity (Murray, et. al 1999), most incorporate the concept that disparities are due to a disadvantage of one kind or another, e.g. discrimination, place of residence, etc. Because inequity is a result of disadvantage, if one employs Whitehead's interpretation of disparities, they are avoidable and unjust.

Because it is not always possible to identify differences that are unjust, simple differences by race, ethnicity and other variables such as disability status have been used historically to explore disparities. Many disparities researchers focus their research exclusively on differences by race and ethnicity. In addition, a considerable body of evidence exists on gender disparities. More recently, researchers have also stratified results by socioeconomic status, level of education, geographic region, disability, and sexual preference and orientation. There is tremendous overlap among categories like minority groups, the disabled, low educational attainment, dual-eligibles (Medicaid and Medicare eligible beneficiaries), poverty level, and zip code. With growing discussion of race as a social construct rather than a biological characteristic, measurement of race and ethnicity[1] becomes increasingly complicated. Alternative variables that are associated with health outcomes, like zip code and education level, are becoming more attractive to health researchers who wish to move away from using race and ethnicity categories that can lead to stigmatization, discrimination and profiling. The new variables may be more precise in identifying disparities without the negative connotations.

The HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011) included explanatory information on the many factors that affect health outcomes, as follows, "the World Health Organization (WHO) defines these 'social determinants of health' as the conditions in which people are born, grow, live, work and age that can contribute to or detract from the health of individuals and communities. Marked difference in social determinants, such as poverty, low socioeconomic status (SES), and lack of access to care, exist along racial and ethnic lines. These differences can contribute to poor health outcomes" (p. 3). The social determinants of health illustrate how the health care system alone cannot address all health disparities.

A recent National Institute on Aging (NIA) Council report urged the adoption of an integrative conceptual model to approach health disparities research, which conveys that health disparities are multidimensional, and are caused by factors operating at various levels of analysis, including the biological, behavioral, sociocultural, and environmental. The report urges the NIA to identify which factors are important to examine and how various dimensions or factors leading to health disparities interact. It further states that these interactions are important, because the biological factors underlying health disparities are not independent of socioeconomic factors, and health disparities will not be understood simply by focusing on one level of analysis.

While the definitions above convey a nuanced understanding of what causes disparities and how disparities should ideally be studied, to-date most research on disparities in the MCC population has primarily utilized demographic variables to identify differences between groups.

Given the sparse literature specifically focused on MCC disparities, for the purpose of the paper we define disparities as any observed difference in health care quality or health outcomes between population groups characterized by sociodemographic variables such as by race, ethnicity, gender, and socioeconomic status. This broad definition allows us to cast a wide net in identifying relevant research.

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[1] Race is defined as the biological differences among groups, while ethnicity is defined as a common cultural identity in a group (Cunningham, 2012).

3.2 Socio-demographic Variables Used to Identify Disparities

To study trends in disparities over time, consistent race and ethnicity variables are necessary. The federal government has tried to develop more sensitive variables over time, but also preserve the ability to examine longitudinal trends. The Census Bureau, Office of Management and Budget, Institute of Medicine and Department of Health and Human Services have all grappled with this issue. The current HHS standards for collecting disparities data is provided in Appendix A. The Affordable Care Act mandated that these data variables be included in all federal health surveys. More information on these standards is included in Section 5.2.1.

3.3 Literature Review

Abt Associates conducted a review of the peer-reviewed and grey literature related to disparities and multiple chronic conditions over the last 10 years. Of the 751 peer-reviewed articles identified in our targeted PubMed search only 16 (2.1%) pertained to disparities in the MCC population. Our MEDLINE search strategy can be found in Appendix B. The purpose of the literature review was to identify recent MCC research studies and methods papers addressing health disparities. Studies that focused on individual chronic diseases were excluded from the review. The findings are described in Section 4 of the white paper.

3.4 Key Informant interviews

To further inform the study of disparities in MCC populations, Abt and ASPE conducted key informant interviews with six experts from academic, research and policy organizations. A list of key informants can found be found in Appendix C. Each expert was asked to share his or her perspective and knowledge regarding a framework and research priorities for studying disparities within MCC populations. The information gleaned from key informants is integrated throughout the report.

Key Informant Perspectives

- Health Disparities Research
- Large-scale Demonstrations
- Minority Health Policy
- Clinicians

3.5 Review of Databases

The Abt Associates team conducted a detailed review of 17 databases that may potentially be used for research on disparities in MCC populations. The datasets were initially reviewed to assess their potential for studying the "long tail" of people with MCC, then re-reviewed to assess their capacity for disparities research on groups with MCC. An example of the detailed description of the datasets can be found in Exhibit 7 and the full review of datasets is contained in Appendix E.

3.6 Technical Advisory Group

A Technical Advisory Group (TAG) comprised of nine disparities and MCC experts from a several key HHS agencies provided advice and feedback on the project. A list of TAG members and their affiliations is contained in Appendix D. On December 18th, 2012, Abt and ASPE conducted an initial in-person meeting with the TAG, the last portion of which was devoted to discussing the white paper on disparities and MCC. The objectives were to:

1. Outline an initial framework and approach to studying disparities in MCC populations.
2. Discuss the findings from the preliminary literature and database review related to disparities and MCC, as well as the search strategy itself.
3. Technology (ONC) Identify additional peer-reviewed articles and grey literature, and databases that were relevant for the project.

On August 14th, 2013, the TAG was reconvened by teleconference to review and provide edits and suggestions on the first draft of the paper. TAG input was incorporated into the final draft.

HHS Agencies Represented by the TAG

- Agency for Healthcare Research and Quality (AHRQ)
- Assistant Secretary for Planning and Evaluation (ASPE)
- Centers for Medicare & Medicaid Services(CMS)
- Centers for Disease Control and Prevention (CDC)
- National Institute on Aging (NIA)
- Office of the Assistant Secretary for Health (ASH)
- Office of Minority Health (OMH)
- Office of the National Coordinator for Health Information
- Technology (ONC)

4. Findings from MCC Literature on Disparities

Research on disparities among the MCC population is not well-developed. Many studies have looked at disparities among individuals with a specific chronic condition, even with two and three chronic conditions, but the research has not been synthesized or considered as a body of research on MCC. Governmental priorities such as the HHS Interagency Workgroup's objective to address disparities in MCC patients through research on different socio-demographic groups, are intended to spur studies to fill the knowledge gap. As stated earlier in the report, research on multiple chronic conditions is lacking in general, and research on ***disparities*** in the MCC population even more so.

Similar to other forms of disparities research, the studies that have been conducted on the MCC population to-date have been descriptive in nature. The research has focused on identifying the existence of potential disparities in the MCC population, rather than examining the root-causes of these disparities or potential measures for resolution, and is limited in its ability to suggest evidence-based interventions to reduce disparities among persons with MCC.

Based on the findings from our literature review, key informant interviews, and TAG meetings, we summarized the available MCC disparities research into the following topic areas:

1. Non-disease specific disparities
2. Most common disease clusters in men and women
3. Disease-specific disparities

The literature related to each topic is summarized in turn, below. We describe the kinds of research being conducted under each topic and highlight the findings.

4.1 Non-Disease Specific Disparities in the MCC Population

For the purposes of this white paper, non-disease specific disparities are defined as disparities that relate to MCC in general, rather than a specific combination of chronic conditions. As discussed in depth in the first white paper (Rezaee, 2013) many MCC studies use counts of chronic conditions as a way of categorizing groups because of the complexity of parsing the myriad disease combinations that exist. Groups of consumers are categorized as having two, three, four, etc. chronic conditions but the conditions are not necessarily the same ones. One person in a group with three chronic conditions may have diabetes, hypertension and Multiple Sclerosis while another might have diabetes, COPD and arthritis. By contrast, disease specific disparities investigate differences that occur among patients with a specific combination of chronic conditions (e.g. hypertension, diabetes, and MS). Only individuals with those specific MCC combinations are considered in the research.

> Non-disease specific MCC studies use counts of the number of MCC that a person has (2, 3, 4, etc.). Cases are grouped by the number of MCC although the specific conditions may differ.

Non-disease specific disparities research has examined MCC prevalence, healthcare utilization and cost, and the occurrence of common chronic disease combinations across different MCC patient groups. Exhibit 3 describes studies conducted on non-disease specific disparities to-date. Several of the papers represent a coordinated effort by the HHS Interagency Workgroup to review national datasets that could be used for MCC research, and the findings were published in the Journal of Preventing Chronic Disease The articles are available online at: http://www.cdc.gov/pcd/collections/pdf/PCD_MCC_Collection_5-17-13.pdf. The authors chose 20 chronic conditions in order to compare the ability of each dataset to address specific MCC (Goodman, 2013).

The datasets focus on adult and elderly populations (versus children) and use the number of chronic conditions a person has to create groups. The most common differences explored in MCC groups are by gender, age, and race/ethnicity differences. In the sections that follow, we discuss the findings of the research conducted to investigate disparities among people with the same number (non-disease specific) of MCC. The findings are organized by gender, age, race/ethnicity, insurance status, and education.

Exhibit 3: Summary of Non Disease Specific MCC Disparities Studies

Citation	Year	Sample	Data Source	# of CC studied by authors	Disparities Investigated	Disease Clusters Investigated
Ashman JJ, Beresovsky V. Multiple chronic conditions among US adults who visited physician offices: data from the National Ambulatory Medical Care Survey, 2009. Prev Chronic Dis 2013; 10:120308.	2013	Adult Civilian Patients N=28,693	National Ambulatory Medical Care Survey	13*	Gender Age Race/Ethnicity Insurance Type	Yes
Centers for Medicare & Medicaid Services (CMS). Chronic Conditions among Medicare Beneficiaries, Chartbook. 2012 Edition. Baltimore, MD. 2012.	2012	Medicare Patients N=31,313,344	CMS Chronic Condition Warehouse	15	Gender Age Race/Ethnicity Dual Eligibility Status	No
Ford ES, Croft JB, Posner SF, Goodman RA, Giles WH. Co-occurrence of leading lifestyle-related chronic conditions among adults in the United States, 2002-2009. Prev Chronic Dis 2013;10:120316.	2013	Adult Civilians N =196,240	National HealthInterview Survey	9*	Gender Age Race/Ethnicity Education	No
Freid VM, Bernstein AM, and Bush MA. Multiple chronic conditions among adults aged 45 and over: Trends over the past 10 years. NCHS data brief, no.100. Hyattsville, MD: National Center for Health Statistics. 2012.	2012	Adult Civilians N = 30,682	National HealthInterview Survey	9	Age Race/Ethnicity	No
Hidalgo CA, Blumm N, Barabási A-L, Christakis NA(2009) A Dynamic Network Approach for the Study of Human Phenotypes. PLoS Comput Biol 5(4): e1000353.	2009	Medicare Patients	Medicare Provider and Analysis Review File	16,459	Race & Ethnicity	Yes
Lochner KA, Cox CS. Prevalence of multiple chronic conditions among Medicare beneficiaries, United States, 2010. Prev Chronic Dis 2013;10:120137.	2013	Medicare Patients N=31 million	Medicare Claims	15*	Gender Age Race & Ethnicity Dual Eligibility Status	Yes
Machlin SR, Soni A. Health care expenditures for adults with multiple treated chronic conditions: estimates from the Medical Expenditure Panel Survey, 2009. Prev Chronic Dis 2013;10:120172.	2013	Adult Civilians N=24,870	Medical Expenditure Panel Survey	20*	Gender Age Race & Ethnicity Insurance Type Utilization	No
Steiner CA, Friedman B. Hospital utilization, costs, and mortality for adults with multiple chronic conditions, Nationwide Inpatient Sample, 2009. Prev Chronic Dis 2013;10;120292.	2013	Adult Inpatients N=7,810,762	Nationwide Inpatient Sample	15*	Gender Age Race & Ethnicity Insurance Type Mortality Utilization & Cost	Yes
Steinman, M.A., Lee, S.J., John, B.W. et al. Patterns of Multimorbidity in elderly veterans. J Am Geriatr Soc. 2012 Oct;60(10):1872-80.	2012	VA Patients N=2,002,693	VA Databases	23	Gender	Yes
Ward BW, and Schiller JS. Prevalence of multiple chronic conditions among US adults: estimates from the National Health Interview Survey, 2010. Prev Chronic Dis. 2013;10:E65.	2013	Adult Civilians N=27,157	National HealthInterview Survey	10*	Gender Age Race & Ethnicity Insurance Type	Yes

Note: The Office of the Assistant Secretary for Health (OASH) developed a list of 25 (1-25) that they then drafted down to a smaller set of 10 (1-10) based on the Ottawa Studies, the number of (1-5) from the first authors (Harris M et al.) represented by an asterisk (*).

5.1.1 Gender

Evidence suggests that small, yet significant, disparities may exist between men and women who have HIV/AIDS in the quality of care they receive (Bozzette et al. 2003; Kelly et al. 2000; Kitahata et al. 1996; comparison in Hellinger et al., 2005; Cohen, 2002; Wu et al., 2003; Nachman et al., 2003). For example, the 2002 Edition of the CDC Sexually Transmitted Diseases Treatment Guidelines reported that over 25% of women in the study had at least one sexually transmitted disease (compared to approximately 10% of men) (Cohen, 2002; CDC, 2002). The difference in other sexual behaviors underlying potential risks for other diseases (such as cervical cancer) may also be significant (Cohen, 2002). Other studies have found that women are more likely than men to be diagnosed with AIDS and to have higher survival times, even after controlling for HIV-related risks and higher CD4 cell counts (Bozzette et al., 2003; Kitahata et al., 1996).

Exhibit 10.1: Differences in HIV Prevalence Rates between Men and Women in the Studies

5. Percent of Individuals with CD4 in Chronic Conditions, by Gender
Chronic Conditions, by Gender
Chronic Conditions, by Gender

		procedures.
Healthcare Cost & Utilization Project - Kids' Inpatient Database (KID)	Age, Gender, Race/Ethnicity, Place of Residence and Median Household Income.	• Sampling frame is limited to pediatric discharges from community, non-rehabilitation hospitals in participating HCUP partner states. • Some hospitals and HCUP State Partners do not supply certain patient demographic information; for example, race is missing on 15% of discharges for the 2009 KID.
Healthcare Cost & Utilization Project–Nationwide Emergency Department Sample (NEDS)	Age, Gender, Urban-Rural designation, Expected Payment Sources, and Zip Code.	• NEDS is developed using a 20% stratified sample of institutional ED discharge data; a sample of U.S. hospital-based EDs who participate in the program. • Information derived from inpatient claims; data collection methods vary depending on local hospital and state procedures. • Available patient demographic information can vary by state, such as race/ethnicity, geographic location and primary payer data.
Healthcare Cost & Utilization Project-Nationwide Inpatient Sample (NIS)	Age, Gender, Race/Ethnicity, Zip Code, Expected Primary and Secondary Payment Sources, and Place of Residence.	• Information derived from inpatient claims; data collection methods vary depending on local hospital and state procedures. • Some hospitals and HCUP State Partners do not supply certain patient demographic information; race is missing on 10% of discharges for the 2011 NIS. A 20% sample of the NIS is available, containing information from states/hospitals with known high quality demographic reporting. Some states have begun to collect patient language.
Medical Expenditure Panel Survey (MEPS)	Age, Gender, Race/Ethnicity, Insurance Status, Marital Status, Disability Status, Family Income as Percent of Poverty Line, Employment Status, Total Income, Geographic Location, and Size of Family.	• Self-reported information; not ascribed by interviewer. • Insufficient sample size is often a problem to report information by patient subgroups. • MEP identifies all five OMB race/ethnicity categories (White, American Indian or Alaska Native, Asian, Black or African American, and Native Hawaiian or other Pacific Islander), and a multiple race category for those who identify more than one race (SHADAC, 2009). • Does not provide information on immigrant groups, but additional detail on Hispanic origin so Hispanic subgroups can be disaggregated.
Center for Disease Control and Prevention		
Behavioral Risk Factor Surveillance System (BRFSS)	Age, Gender, Race/Ethnicity, Hispanic vs. Latino, Military Status, Insurance Status/Type, Educational Obtainment, Disability Status, Income, Household Size, Employment Status, Household Income, Zip Code, and Own vs. Rent Home Status.	• Self-reported information; not ascribed by interviewer. • The BRFSS provides several race variables, allowing researchers to choose one race category with multiple races or a recode that allocates multiple race individuals to a race category based on self-identified preferred race; does not identify place of birth or immigrant group (SHADAC, 2009). • State age, gender and race data are compared to census data on a monthly basis to ensure data accuracy and catch potential coding mistakes; considered to be more valid and reliable compared to other household surveys (Mokdad, 2009).
National Ambulatory Medical Care Survey	Age, Gender, Race/Ethnicity, and Place of Residence	• Data for a systematic random sample of visits are recorded by the physician or office staff on an encounter form. • Provides ability to study nationally representative populations over the age of 18, by gender, and three racial/ethnic categories: 1) White, 2) Black, and 3) Other • Subject to non-sampling errors, including reporting and processing error, and biases due to nonresponse and incomplete data. In 2010, race data were missing for 24.9% of visits and ethnicity data from 23.3% of visits (CDC, 2012).
National Health Interview Survey (NHIS)	Age, Gender, Sexual Orientation, Employment Status, Type of Employment, Employment-related Activities, Size of Business, Paid by Hour or Salaried, Paid Sick Leave, Multiple Job Held Status, and Time at Current Residence.	• Self-reported information; not ascribed by interviewer. • The NHIS provides several race variables, allowing researchers to choose one race category with a residual multiple race category or a recode that allocates multiple race individuals to a race category base on self-identified preferred race; only public use data set with expanded race variables for Asian subgroups (SHADAC, 2009). • Distinguishes individuals U.S. born from those born in 10 broad global regions including a residual foreign-born category (SHADAC, 2009).
National Health and Nutrition Examination Survey (NHANES)	Age, Gender, Race/Ethnicity (including subgroups), Language, Educational Attainment, Marital Status, Health Insurance Status, Veteran Status, Occupation, Employment Status, and Income.	• Self-reported information; not ascribed by interviewer. • Low-income persons, adolescents 12-19 years of age, persons 60 years of age and over, African Americans, and persons of Mexican origin are purposely oversampled.The sample is not designed to provide nationally representative estimates for the population of U.S Hispanics; the survey is not geographically representative. Able to distinguish Mexican from other Hispanic and non-Hispanic individuals (SHADAC, 2009). • For most estimates by race and ethnicity, 3 years of NHANES data is needed to obtain an adequate sample size. Many of the results of the NHANES that are reported are still limited to reports of only whites, blacks, and Mexican Americans because of constraints of sample size (Anderson et al., 2004).
Centers for Medicare & Medicaid Services		
Medicare Claims	Age, Gender, Race/Ethnicity, Geographic Location (including mailing zip code), Dual Eligibility Status, and Medicare Enrollment Dates.	• Often based on administrative observation or a clinical employee's observation. • Race/ethnicity codes for White and Black Medicare beneficiaries are fairly accurate, but the codes for the other categories are much less so. The Hispanic race/ethnicity codes capture one-third beneficiaries who identify as being from Hispanic/Latino origin (Waldo, 2005). • Race/Ethnicity misclassification is most prevalent for Asian and American Indians/Alaskan Natives; most minority groups are misclassified as whites (McBean, 2004).
Medicaid Claims	Age, Gender, Race/Ethnicity, Marital Status, Insurance Type, Dual Eligibility Status, Geographic Location, and Enrollment Dates.	• CMS does not provide instructions to state programs on how race/ethnicity information should be collected and coded. As a result, some states may rely on the observations of eligible workers, while other use self-reported data from applicants (Kronick et al., 2007). • Significant amount of missing demographic information; in 2003 race and Hispanic ethnicity data were listed as "unknown" for more than 20% of Medicaid individuals in New York, Rhode Island and Vermont (McAlpine et al., 2007).
CMS Chronic Condition Warehouse	Age, Gender, Race/Ethnicity, Insurance Type, Dual Eligibility Status, Age, Preferred Language, Marital Status, Zip Code, Primary Payment Source.	• In addition to Medicare claims race/ethnicity coding, the warehouse contains the Research Triangle Institute (RTI) Race Code. This code provides enhanced race/ethnicity designation based on an algorithm that analyzes a beneficiary's first and last name (CMS, 2013).
CMS Medicare Provider Analysis and Review (MedPAR) File	Age, Gender, Race/Ethnicity, and Geographic Location.	• Information obtained from inpatient hospital and Skilled Nursing Facility final records. • Race information is present for nearly all MedPAR discharges (Barrett et al., 2010). • Race/ethnicity categories prior to July 1994 included: White, Black, Other and Unknown; 1994 to present, race/ethnicity categories include Asian or Pacific Islander, Hispanic, Black (not of Hispanic origin), American Indian or Alaskan Native, White (not of Hispanic Origin), Other or Unknown.
Medicare Health Outcomes Survey	Gender, Age, Race/Ethnicity, Educational Attainment, Marital Status, Annual Household Income, English Language Skills, Household Size, and Place of Residence.	• Self-reported information; not ascribed by interviewer. • Subject to small sample sizes for patient groups, resulting in the need for data aggregation. • Provides ability to study Hispanic/Spanish subgroups (i.e. Cuban, Puerto Rican) and an extended number or race/ethnicity categories (i.e. Korean, Samoan, Japanese).
Other		
HMO Research Network	Age, Gender, Race/Ethnicity, Insurance Type, Hispanic vs. non-Hispanic, Educational Attainment, Employment Status, Geographic Location, and Income.	• Health plans employ a variety of different strategies to collect demographic information on their enrollees; both indirect and direct methods are utilized. A significant percentage of health plans do not collect disparity-related demographic data at this time (AHIP-RWJF, 2006). • Electronic abstraction of race from progress notes in electronic medical records is possible, but subject to limitations (i.e. spelling, abbreviations) (Roblin et al., 2010).
National Institute on Aging	Age, Gender, Race/Ethnicity, Insurance Type, Hispanic vs. non-Hispanic, Educational Attainment, Employment Status,income, assets, housing status. Non-Hispanic Blacks are oversampled	• Self-reported information • Small sample size (N=8,000) • Allows assessment of functioning/ ability to perform valued activities of daily living/environmental/social adaptations made to allow independent/safe living.
State All Payer Claims Databases (general)	Age, Gender, Race/Ethnicity, Insurance Type, Marital Status, and Geographic Location.	• Demographic and SES information collected for patients differs by state; non-standardized collection procedures.
Health and Retirement Study	Age, Gender, Race/Ethnicity, Educational Attainment, Disability Status, Language, Marital Status, Occupation, Employment Status and Income.	• Self-reported information; not ascribed by interviewer. • Uses a national area probability sample of U.S. households with supplemental oversamples of Blacks, Hispanics and residents of the state of Florida. Complete data on longitudinal socioeconomic experiences for specific metrics (Hayward).
Health insurer databases	Race/Ethnicity	• Kaiser and Aetna are moving towards self-reported race/ethnicity, with Aetna achieving about 30% reporting and Kaiser achieving about 60-70% reporting due to greater integration with providers. • Data may only be available to researchers within each plan, and results may only be applicable within the plan

8. Conclusions and Considerations for Future Research on Disparities in Groups with MCC

8.1 Conclusions

Reducing disparities in health outcomes, access to care, and healthcare quality are ongoing priorities in the United States and other countries. As part of the initiatives to achieve health equity, HHS has made a priority in the report, *Multiple Chronic Conditions: A Strategic Framework*, to assess disparities among the adult MCC population. Most of the existing disparities research focuses on individual chronic conditions, and there has been little research on the extent, causes, and strategies for reducing disparities within the MCC population.

The limited research is a reflection of the complexities involved in analyzing disparities within the MCC population. Disparities research in the MCC population is impeded by several methodological challenges including sample size issues; data quality issues, particularly unreliable sociodemographic variables in many databases; data capture issues regarding patients who do not access the health care system; lack of standard definitions of disparities and MCC; constantly evolving methods; and limited information about the underlying causes of disparities or interventions to reduce disparities. Additionally, meta-analysis is difficult in MCC disparities research due to the lack of standard ways to aggregate socio-demographic categories. For example, researchers use different age cutoffs to investigate disparities by age. Another analytical challenge affecting the potential for meta-analysis is the lack of standardized measures sensitive to MCC disparities.

Despite these methodological challenges, the body of knowledge on MCC disparities is growing. As more studies are published, early results can be tested for replication. Results from our literature review, included in this paper, suggest that

- Women are more likely than men to be classified as having MCC (Ashman et al., 2013; CMS, 2012; Ward et al., 2012; Machlin et al., 2013).
- The number of chronic conditions rises with age (Freid et al., 2012).
- Hispanic patients have the lowest MCC prevalence (Ward et al., 2013; Steiner et al., 2013). Mexican-Americans have lower initial levels of MCC and slower accumulation of comorbidity compared to non-Hispanic White and non-Hispanic Black patients (Quinones et al., 2011).
- MCC prevalence among Asian Americans is lower compared to white or black MCC patients (Machlin et al. 2013), though Asians/Pacific Islanders had the highest mortality and cost per case compared to all other groups (Steiner et al., 2013).
- Patients with dual eligibility status (Medicare and Medicaid) have an elevated prevalence of MCC compared to non-dual-eligible beneficiaries (CMS, 2012).

Numerous papers examine one dimension of disparities among patients with combinations of two conditions. For example, utilization of care is lower for African-American patients with COPD and asthma, compared to non-Hispanic White patients with the same conditions (Shaya et al., 2009); African-Americans with hypertension and chronic kidney disease had more poorly controlled hypertension compared to African-American women and non-Hispanic White patients with the same conditions (Duru et al., 2009); and men with type II diabetes and coronary heart disease were more thoroughly treated compared to women (Kramer et al., 2012). However, the narrow focus of such analyses makes it challenging to identify overall patterns of disparities.

Future research on MCC disparities may be facilitated by efforts to improve reporting on race, ethnicity and other socio-demographic variables, by efforts to identify disparities-sensitive measures of the quality of care, and by the future availability of new databases such as electronic health record based registries, large employer databases, managed care patient registries, practice-based network data, and other data sharing and collection initiatives.

It is important to acknowledge the overlap of persons with MCC and the disabled, dual eligible Medicare/Medicaid beneficiaries, and common combinations of chronic conditions that have been studied (e.g. diabetes, hypertension and hyperlipidemia). There may be disparities research on these groups that can be synthesized to contribute to the body of MCC disparities research.

8.2 Considerations for Future Research

One of the strategies identified by the Interagency Workgroup on MCC is to "stimulate research to more clearly elucidate differences between and opportunities for prevention and intervention in MCC among various sociodemographic groups" (DHHS 2010.) To that end, we offer below a list of considerations and opportunities for future research. Disparities research on persons with MCC is at an early stage of development. Therefore it is important to carefully review results, and to look for replication of the study findings.

8.2.1 Definitional/conceptual work

Our key informants and technical advisory group members mentioned the importance of developing a multi-level, multi-sectorial model of MCC and MCC disparities that incorporates the roles of biological, behavioral, health care, socio-economic, community and environmental factors. This model could then serve as a framework for analyses focused on the MCC population.

Developing such a model may facilitate consensus-building on a definition of disparities to be used for MCC disparities research.

8.2.2 Research infrastructure development

To facilitate further research in MCC, elements of the research infrastructure will need to be improved. For example:

- Improving existing datasets to allow MCC disparities analyses. For example, efforts to improve the reporting of race, ethnicity and language data in HCUP and other datasets should continue, and researchers should report on what additional variables (e.g., socioeconomic variables, neighborhood indicators) should be added to existing datasets to enhance researchers' ability to study MCC disparities.
- Developing scientific standards for the enrollment of persons with MCC into research studies. Persons with MCC are typically excluded from studies on chronic conditions, resulting in the production of research findings that are inapplicable to the MCC population. This situation should be addressed by funding bodies, since many patients have more than one chronic condition.
- Defining the appropriate unit(s) of analysis to examine disparities among people with MCC. For example, is it most appropriate to examine health care and health outcome disparities across groups that have the same number or combination of chronic conditions?

8.2.3 Data sources and analysis

Needed analyses:

- Most prior studies on MCC disparities have only examined MCC and disparities at a crude level. There is still a need for basic research using large datasets to examine disparities for the most common combinations of health conditions.
- Disparities related to socioeconomic factors such as income, occupation/employment, wealth/poverty, place of birth/geography, housing and disability have not yet been explored, and little is known about disparities in cost and utilization patterns.
- Research is needed to examine how well the health needs of different MCC populations are being served by the health care system, and how this contributes to or mitigates disparities.
- Data analysis could also help to identify disparities "hot spots" to be targeted for intervention, i.e. population subsets that have worse trajectories and cause lower performance or higher cost for a health plan.

Promising datasets for analysis:

- Some of the more reliable HCUP datasets may be useful to explore MCC disparities by race, ethnicity and socio-economic factors. To identify states that provide high-quality data, researchers can rank states based on the extent of missing/incomplete data on key variables of interest, and use data from states with the least amount of missing data.
- It may also be useful to conduct analyses on disparities in care affecting the Medicare-eligible population under age 65. This population is eligible for Medicare because of disabilities. Disability is both a chronic condition and a stratifying variable for disparities analysis. Research could focus on challenges experienced by persons with disabilities to receive care for any conditions other than their main disability.

Analytic methods:

- Publications are needed to describe what types of statistical models and advanced multivariate techniques can provide insights into the drivers of disparities for the MCC population
- In developing analytic methods, researchers should be aware that certain types of analyses can increase risks for communities of color. For example, employers may discriminate against employees or potential employees based on information that is reported to them about the MCC risks and costs experienced by various populations. One way to minimize this risk is to focus analyses on how well various populations are being served by the health care system. Such analyses are less likely to perpetuate disparities compared to research examining disparities in the prevalence and incidence of MCC in various populations.

8.2.4 Intervention research

Most of the disparities research that has been conducted on the MCC population to-date has been focused on measuring the magnitude of disparities rather than analyzing the causes of the disparities or methods of reducing disparities. The following types of research may be useful to develop interventions aimed at eliminating disparities.

- Local intervention research, which takes into consideration the populations, resources and infrastructure that are specific to each setting. Such research is more likely than national research to allow analyses on and adaptations for within-group variations (e.g. Puerto-Rican or Mexican-American instead of Hispanic)
- Interventions leveraging electronic medical records (EMRs). Due to the adoption of EMRs, health plans and health practices are becoming increasingly able to analyze causes of disparities and address them within their patient population. It may be useful to produce case studies of EMR use to reduce disparities, for example focusing on patients with HIV or diabetes, and pediatric patients with special needs.
- Supplemental analyses on grants from the Centers for Medicare and Medicaid Innovation. Some CMMI grantees who are testing health system interventions are finding that enrolled patients include a high proportion of minority patients and persons with multiple chronic conditions. While the CMMI studies are not focused on MCC per se, they have an opportunity to provide new insights to the MCC field.

8.2.5 Complementary Methods

In addition to the analysis of large databases and intervention research, several other research methods
may shed light on the epidemiology of and remedies for MCC disparities.

- *Qualitative Methods* such as interviews, focus groups, and observation can be enlightening when there are a small number of cases to study (as in the case of the "long tail" of the MCC distribution, described above). Qualitative methods are also useful when the research is at a formative stage, or when insights are needed to interpret quantitative findings. Finally, qualitative research can also address disparities by helping to identify best practices in personalized care and self-management, so that these practices can be extended to populations that bear a disproportionate burden of disease or poor outcomes.
- *Metasynthesis*, a technique to facilitate comparisons across qualitative studies, might uncover potential disparities that could be tested with quantitative methods, or shed light on the different kinds of obstacles faced by people with specific combinations of MCC.
- Analyzing data from *rare disease surveillance systems* may point to disparities that could also be tested in other datasets.
- A *positive deviance* approach is recommended by Rust et al. wherein researchers look for example of health equity, or the absence of disparities, or trends in disparities reductions, and look for explanations and interventions that can be tried in other communities. (Rust et al. 2012). A promising area for a positive deviance study is research to understand why the Hispanic population has a lower burden and slower accumulation of MCC compared to non-Hispanic White and non-Hispanic Black populations.

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Appendices

The appendices listed below are attached.

Appendix A – HHS Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status (2011)

The HHS Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status are the current standards for collecting disparities data in federal surveys. These standards were developed in response to an Affordable Care Act mandate to collect specific socio-demographic and health information.

Appendix B – Literature Search Methodology

The literature search methodology outlines the MEDLINE search terms that were used to conduct the literature review related to multiple chronic conditions, disparities, and analytic techniques for chronic disease and disparities research. The search strategy outlined in this Appendix was used to identify MCC research studies and methods papers on multiple chronic conditions research and disparities.

Appendix C - Key Informants

The Key Informant List provides a list of the individually interviewed experts and their affiliations. Key informants were identified by the ASPE Project Officers and the Technical Advisory Group (TAG). Key informant interviews were conducted to provide the Project Team with in-depth expertise on topics covered in the White Paper. Findings from the Key Informant Interviews have been incorporated throughout the White Paper.

Appendix D – Technical Advisory Group Members

Technical Advisory Group (TAG) List provides of experts consulted about the overall conduct of the studies and their affiliations. TAG members participated in the initial in-person December 2012 TEP meeting and provided feedback on the original literature review to determine additional databases, grouping systems, and methods for studying MCC in disparities populations. They also participated in a second meeting by teleconference in May 2013 to review and provide feedback and revisions for the first draft of the White Paper, "Understanding the High Prevalence of Low-Prevalence Chronic Disease Combinations: Databases and Methods for Research," and a third meeting by teleconference in August 2013 to review and provide feedback and revisions for the first draft of the White Paper, "Understanding Disparities in Persons with Multiple Chronic Conditions: Research Approaches and Datasets."

Appendix E – Review of Datasets and Data Systems: Summary Tables

The Data Systems Datasets Review provides an overview of sixteen potential datasets that can be used for multiple chronic conditions and disparities research, including a description of each datasystem, the diagnosis information measured in each data system, the cost, utilization, and clinical information captured in each datasystem, and the strengths, limitations, and feasibility of each datasystem for MCC research.

Appendix A – HHS Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status (2011)

I and II. Race and Ethnicity

Ethnicity Data Standard	Categories
Are you Hispanic, Latino/a, or Spanish origin (One or more categories may be selected) a. ____No, not of Hispanic, Latino/a, or Spanish origin b. ____Yes, Mexican, Mexican American, Chicano/a c. ____Yes, Puerto Rican d. ____Yes, Cuban e. ____Yes, another Hispanic, Latino, or Spanish origin	These categories roll-up to the Hispanic or Latino category of the OMB standard

Race Data Standard	Categories
What is your race? (One or more categories may be selected) a. ____White b. ____Black or African American c. ____American Indian or Alaska Native	These categories are part of the current OMB standard
d. ____Asian Indian e. ____Chinese f. ____Filipino g. ____Japanese h. ____Korean i. ____Vietnamese j. ____Other Asian	These categories roll-up to the Asian category of the OMB standard
k. ____Native Hawaiian l. ____Guamanian or Chamorro m. ____Samoan n. ____Other Pacific Islander	These categories roll-up to the Native Hawaiian or Other Pacific Islander category of the OMB standard

III. Sex

Sex Data Standard
What is your sex? a. ____Male b. ____Female

IV. Primary language

Data Standard for Primary Language
How well do you speak English? (5 years old or older) a. ____Very well b. ____Well c. ____Not well d. ____Not at all

Data Collection for Language Spoken (Optional)
1. Do you speak a language other than English at home? (5 years old or older) a. ____Yes b. ____No For persons speaking a language other than English (answering yes to the question above): 2.What is this language? (5 years old or older) a. ____Spanish b. ____Other Language (Identify)

V. Disability Status

Data Standard for Disability Status
1. Are you deaf or do you have serious difficulty hearing? a. ____Yes b. ____No 2. Are you blind or do you have serious difficulty seeing, even when wearing glasses? a. ____Spanish b. ____Other Language (Identify) 3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older) a. ____Yes b. ____No 4. Do you have serious difficulty walking or climbing stairs? (5 years old or older) a. ____Yes b. ____No 5. Do you have difficulty dressing or bathing? (5 years old or older) a. ____Yes b. ____No 6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older) a. ____Yes b. ____No

Appendix B – Literature Search Methodology

Search Strategy

MEDLINE

Date - Last 10 Years (as of January 1, 2013)

Language - English

Limits - Human

Limits - Abstract Available

Search Field Tags - All fields

Key terms

Search #	Key Terms/Search Strategy/History	Number of Articles
#1	Chronic Disease/classification/epidemiology/economics	**2,425**
#2	Multiple Chronic Conditions	**127**
#3	Multimorbidity	**207**
#4	Comorbidity	**42,895**
#5	Disease Combinations	11
#6	Aging Chronic Disease	3,236
#7	Disparities	**15,740**
#8	# 4 AND #7	**503**
#9	# 3 AND #7	**3**
#10	# 2 AND #7	**5**
#11	# 1 AND #7	**240**

Article Selection

A title review of 732 articles.

- 695 articles eliminated due to one of following:
  - Single disease focus
  - Unrelated to topic
  - Commentary

An abstract review of 37 articles.

- 15 articles eliminated due to one of the following:
  - Single disease focus
  - Unrelated to topic

22 relevant articles were identified during the abstract review for potential incorporation into the white paper. Additional relevant articles, not identified by the search methodology, were identified by the co-project officers, TAG and Key Informants.

Appendix C – Key Informants

Key Informants	
Susan Fleck, RN, MMHS Government Task Leader Health Disparities Program Centers for Medicare and Medicaid Services (CMS)	**Allen Freemont, MD, PhD** Natural Scientist Rand Corporation
Robert Fullilove, EdD, MS Associate Dean Mailman School of Public Health Columbia University	**Nadine Gracia, MD, MSCE** Deputy Assistant Secretary for Minority Health & Director of the Office of Minority Health Office of Minority Health
Warren Jones, MD xecutive Director Mississippi Institute for the Improvement of eographical Minority Health Disparities niversity of Mississippi Medical Center	**David Meltzer, PhD, MD** Associate Professor Department of Medicine University of Chicago
Ernest Moy, MD, MPH Medical Officer Center for Quality Improvement and Patient Safety Agency for Healthcare Research and Quality (AHRQ)	**Sally Okun, RN, MMHS** Vice President, Advocacy, & Patient Safety PatientsLikeMe
George Rust, MD, MPH Professor of Family Medicine & Director of thNational Center for Primary Care Morehouse School of Medicine	

Appendix D – Technical Advisory Group Members

Technical Advisory Group Members	
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Marcel Salive, MD, MPH Medical Officer, Division of Geriatrics and Clinical Gerontology National Institute on Aging Bethesda, MD Marcel.Salive@nih.hhs.gov (301) 496 -6761	**Susan Fleck, RN, MMHS** Government Task Leader CMS Health Disparities Program Division of Quality Improvement Boston, MA Susan.Fleck@CMS.HHS.GOV 617-565-1305
Jesse James, MD, MBA Senior Medical Officer, Meaningful Use Office of the National Coordinator for HealthIT Jesse.James@hhs.gov (202) 260-2068	**Valerie Welsh, MS, CHES** Division of Policy and Data Office of Minority Health Rockville, MD Valerie.Welsh@hhs.gov (240)453-8222

Appendix E – Review of National Datasets and Data Systems: Summary Tables

Disclaimer:
The information contained in this appendix was compiled by Abt Associates Inc. under contract #HHSP233700IT to the Assistant Secretary for Planning and Evaluation (ASPE) in September 2013. Abt and ASPE are not liable for the accuracy or completeness of the information contained in this document, as the specifications of each data system described below are subject to change. For the most up to date and accurate information on each data system, please visit the website or contact the sponsor for more detail.

Agency for Healthcare Research and Quality Datasets

Consumer Assessment of Healthcare Providers & Systems (CAHPS)	
Database Description	
White Paper(s):	Multiple Chronic Conditions and Disparities
Sponsorship:	Agency for Healthcare Research and Quality
Description:	CAHPS is a series of surveys that are used to ask consumers and patients about their experiences with healthcare. These surveys cover a wide spectrum of topics, such as provider communication skills and healthcare access. The goal of CAHPS is two-fold: 1) to develop standardized patient surveys that can be used to compare results across providers over time and 2) to generate tools and resources users can use to create comparative information for all stakeholders. There are CAHPS surveys for a variety of different care settings, including hospital, home health care, health plans, and in- center hemodialysis and clinician groups.
Database (Scope, Size, Setting, Population, Age Range)	CAHPS surveys are used at various levels in the healthcare delivery system; anywhere from individual practices to national samples.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Survey & Program Database. The CAHPS Database is a compilation of survey results from a large pool of healthcare consumers that are maintained in a national database.
Database Source/Origin:	Survey Data
Date or Frequency of Data Collection:	Annually, since 1995.
Longitudinal vs. Cross-sectional Database:	Serial Cross-Sectional Survey
Data Collection Methodology:	Data collection methodology varies by CAHPS sponsor and vendors administering the CAHPS survey. Surveys can be completed via the mail, telephone or internet.
Sampling Strategy:	Sampling strategies for CAHPS vary by sponsor. CAHPS provides guidelines for sampling, including determining eligibility, calculating the estimated sample size needed for reporting, and creating a sub-sample of a specific patient population.
Unit of Analysis:	Multiple (patients, providers, health plan, etc.) and dependent on survey type.
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	A patient's principal diagnosis at discharge is used to determine whether he or she falls into a specific service line for CAHPS eligibility. Diagnosis is not capture on the survey itself.
Diagnosis Codes: (ICD-9, ICD-10, SNOMED, CPT)	Principal diagnosis ICD-9 codes at discharge.
Number of Diagnoses Captured:	Only the principal diagnosis at discharge is used to determine CAHPS eligibility.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	CAHPS does not include measures of cost.
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of	CAHPS does not include measures of healthcare utilization, but the number of survey respondents can be used as a proxy for the number of discharges.

Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	
Measures of Healthcare Access:	Ease of access to healthcare services.
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, Sex, Educational Attainment, Hispanic or Latino, Race/Ethnicity, Language
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	CAHPS does not include additional clinical information.
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Health Literacy/Understanding
Site of Service Information:	Limited - Department Based
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Self-reported health status, Self-reported mental health status, Quality of Care, Quality Measures and Patient Satisfaction
Strengths, Limitations & Feasibility	
Data Strengths:	Select CAHPS datasets contain a large number of minority respondents. Data are collected on key health policy issues, including health status.
Data Limitations:	The CAHPS survey is not administered in a consistent fashion. The CAHPS database is a collection of surveys administered at various levels. As such, not all providers participate each year, so the mix of users will vary across years. Sampling and data collection methods also vary by user and are cross-sectional.
Data Access Restrictions:	To access CAHPS data, a data release agreement, description of the planned research, and IRB documentation must be submitted to AHRQ. Survey instruments are publically available.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	No unique identifiers. However, CAHPS surveys have been administered to Medicare Fee-for-Service patients, which may have resulted in a linked CAHPS-claim dataset.
Related Grouping Systems:	n/a
References Agency for Healthcare Research & Quality. Consumer Assessment of Healthcare Providers and Systems (CAHPS). 2013. http://cahps.ahrq.gov/about.htm	

Healthcare Cost & Utilization Project–Kids' Inpatient Database	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities
Sponsorship:	Agency for Healthcare Research & Quality
Description:	The Kids' Inpatient Database (KID) is a unique and powerful database of hospital inpatient stays for children. The KID was specifically designed to permit researchers to study a broad range of conditions and procedures related to child health issues. Researchers and policymakers can use the KID to identify, track, and analyze national trends in health care utilization, access, charges, quality, and outcomes. It is the only all-payer inpatient claims database for children in the U.S.
Database (Scope, Size, Setting, Population, Age Range)	National; Adolescents Only (< 20 years old); 2-3 million records a year.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	A Federal-State-Industry database of Medicare, Medicaid, Private Insurance and Uninsured patient discharges.
Database Source/Origin:	Administrative data from 4,121 community, non-rehabilitation hospitals in 44 states.
Date or Frequency of Data Collection:	1997-2009; updated every three years.
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	Discharge data submitted by participating organizations.
Sampling Strategy:	Sampling frame is limited to pediatric discharges from community, non-rehabilitation hospitals in participating HCUP partner states. For sampling, pediatric discharges in participating States are stratified by uncomplicated birth, complicated birth, and all other cases. To ensure an accurate representation of each hospital's case-mix, the discharges are sorted by State, hospital, DRG and a random with each DRG. Systematic random sampling is then used to select 10% of uncomplicated births and 80% of complicated births and other cases form each from hospital
Unit of Analysis:	Multiple (patient, region, etc.)
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Number of Chronic Conditions (based on a list of 25 possible chronic condition indicators) Primary and Secondary Diagnoses Admission and Discharge Status
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9-CM codes
Number of Diagnoses Captured:	KID contains up to 25 diagnoses per patient per record. This number can vary by State.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Expected Primary and Secondary Payer Total Charges
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Admission Type Procedure Type ED Visits Length of Stay Number of Discharges
Measures of Healthcare Access:	Database used to evaluate healthcare access through the use of geographic and hospital type variables (i.e. critical access).
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age at Admission Gender Race Hospital Characteristics Physician Identifiers
Clinical Information: BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Comorbidity Measures Birth Weight
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Place of Residence Median Household Income
Site of Service Information:	Hospital Location (e.g. State, zip code, etc.) Site of Service Transition Information
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	In-Hospital Mortality Disposition of Patient
Strengths, Limitations & Feasibility	
Data Strengths:	Representative of all insurance types. Large sample size that allows researchers to study rare conditions.
Data Limitations:	Missing data values can compromise the quality of estimates. If the outcome for discharges with missing values is different from the outcome for discharges with valid values, then sample estimates for that outcome will be biased and inaccurately represent the discharge population. For example, race is missing on 15% of discharges in the 2009 KID because some hospitals and HCUP State Partners do not supply it.
Data Access Restrictions:	Access to KIDs is open to users who complete a Data Use Agreement and purchase the data. Uses are limited to research and aggregate statistical reporting.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	The database contains AHA hospital identifiers. However, many states do not report this information.
Related Grouping Systems:	HCUP Clinical Classifications System (CCS)
References Overview of the Kids' Inpatient Database (KID). 2013. http://www.hcup-us.ahrq.gov/kidoverview.jsp Introduction to The HCUP KID's Inpatient Database (KID) 2009. Healthcare Cost and Utilization Project (HCUP). 2013. http://www.hcup-us.ahrq.gov/db/nation/kid/KID_2009_Introduction.pdf	

Healthcare Cost & Utilization Project - Nationwide Emergency Department Sample	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities
Sponsorship:	Agency for Healthcare Research & Quality
Description:	The Nationwide Emergency Department Sample (NEDS) is a unique and powerful database that yields national estimates of emergency department (ED) visits. The NEDS was created to enable analyses of emergency department (ED) utilization patterns and support public health professionals, administrators, policymakers, and clinicians in their decision-making regarding this critical source of care. NEDS is the largest all-payer ED database in the U.S.
Database (Scope, Size, Setting, Population, Age Range)	National; 25 - 30 million records
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	A Federal-State-Industry database of Medicare, Medicaid, Private Insurance and Uninsured ED patient discharge records.
Database Source/Origin:	As of 2010, NEDS contains administrative data from over 961 hospitals in 28 States.
Date or Frequency of Data Collection:	2006-2010; updated yearly.
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	NEDS is developed from data from ED visits submitted by participating States.
Sampling Strategy:	Similar to the design of the Nationwide Inpatient Sample (NIS), NEDS is developed using a 20% stratified sample of institutions; NEDS is a sample of U.S. hospital-based EDs who participate in the program (n=28). Sampling rate is 20% NEDS to Universe and 37.6% NEDS to Frame.
Unit of Analysis:	Episode
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Number of Chronic Conditions Primary and Secondary Diagnoses Injury Descriptive Variables
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9-CM, CPT-4
Number of Diagnoses Captured:	NEDS contains up to 15 diagnoses per record. This number may differ by State.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Total ED charges and total hospital charges (for inpatient stays for those ED visits that result in admission. ED Event Type/Number of Visits Length of Stay Number of Discharges
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	ED Event Type/Number of Visits Length of Stay Number of Discharges
Measures of Healthcare Access:	Database used to evaluate healthcare access through the use of geographic and hospital type variables (i.e. critical access).
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Gender, Age, Urban-Rural designation of resident, expected payment source (e.g. Medicare, Medicaid, self-pay)
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	ICD-9-CM and CPT-4 procedures and diagnoses Identification of injury-related ED visits including mechanism and intent of injury and severity of injury Discharge status from the ED
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	National quartile of median household income (from patient's ZIP Code)
Site of Service Information:	Hospital location (e.g. State, zip code, etc.) and characteristics (e.g. teaching status, region, ownership type).
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Discharge Status
Strengths, Limitations & Feasibility	
Data Strengths:	NEDS is the largest all-payer ED database in the U.S., with many research applications. It includes information on patients covered by all types of insurances.
Data Limitations:	The NEDS contains event-level records, not patient-level records. This means that individual patients who visit the ED multiple times in one year may be present in NEDS multiple times. There is no uniform patient identifier available that would allow a patient-level analysis with the NEDS. In contrast, the HCUP state databases may be used for this type of analysis
Data Access Restrictions:	Access to NEDS is open to users who complete a Data Use Agreement and purchase the data. Uses are limited to research and aggregate statistical reporting.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	For most States, the NIS includes hospital identifiers that permit linkages to the American Hospital Association Annual Survey Database and county identifiers that permit linkages to the Area Resource File.
Related Grouping Systems:	HCUP Clinical Classifications System (CCS)
References Overview of the Nationwide Emergency Department Sample (NEDS). 2013. http://www.hcupus.ahrq.gov/nedsoverview.jsp	

Name: Healthcare Cost & Utilization Project - Nationwide Inpatient Sample	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities
Sponsorship:	Agency for Healthcare Research & Quality
Description:	The Nationwide Inpatient Sample (NIS) is a unique and powerful database of hospital inpatient stays. Researchers and policymakers use the NIS to identify, track, and analyze national trends in health care utilization, access, charges, quality, and outcomes. It is the largest publicly available all- payer patient care database in the U.S.
Database (Scope, Size, Setting, Population, Age Range)	National; Information available on approximately 8 million hospital stays per year.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	A Federal-State-Industry database of Medicare, Medicaid, Private Insurance and Uninsured patient discharges.
Database Source/Origin:	Administrative data from 1,051 hospitals from 44 states.
Date or Frequency of Data Collection:	1988 - 2010; updated yearly
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	NIS contains clinical and resource use information included in a patient discharge abstract and is submitted to HCUP by over 1,000 hospitals in the U.S.
Sampling Strategy:	The NIS is a stratified probability sample of hospitals, with sampling probabilities calculated to select 20% of the universe of community, non-rehabilitation hospitals in specific strata for ease of use. The entire sampling frame from 46 states includes >90% of hospitals and >95% of discharges from community hospitals.
Unit of Analysis:	Multiple (patient, hospital, region, etc.)
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Major Diagnosis Category (MDC) Primary and secondary diagnosis Admission and discharge status Number of Chronic Conditions
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9
Number of Diagnoses Captured:	NIS contains up to 25 diagnoses per record (15 prior to the 2009 NIS). The number of diagnoses varies by State; some states provide as many as 66 diagnoses while other states provide as few as 9 diagnoses.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Total Charges
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Length of Stay Type of Admission Number of Discharges
Measures of Healthcare Access:	Database used to evaluate healthcare access through the use of geographic and hospital status variables (e.g. CAH status).
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Gender, age, race, median income for zip code, and Expected Primary and Secondary Payment Sources.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Primary and secondary procedures Disease Severity Measures Comorbidity Measures
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Place of Residence Median household income for patient's ZIP Code
Site of Service Information:	Hospital location (e.g. State, zip code, etc.) and characteristics (e.g. teaching status, region, ownership type).
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Disposition of Patient In-hospital Death
Strengths, Limitations & Feasibility	
Data Strengths:	The NIS is the largest publicly available all-payer inpatient care database in the U.S. with information from 45 states, comprising over 96% of the U.S. population. The NIS' large sample size enables analyses of rare conditions, uncommon treatments, and special patient populations (such as the uninsured).
Data Limitations:	Missing data values can compromise the quality of estimates. If the outcome for discharges with missing values is different from the outcome for discharges with valid values, then sample estimates for that outcome will be biased and inaccurately represent the discharge population. For example, race is missing on over 11% of discharges in the 2010 NIS because some hospitals and HCUP State Partners do not supply it. Not all states report patient identifiers and complete diagnostic information.
Data Access Restrictions:	Access to NIS is open to users who complete a Data Use Agreement and purchase the data.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	The database contains AHA hospital identifiers. However, many states do not report this information.
Related Grouping Systems:	HCUP Clinical Classifications System (CCS)
References Overview of Nationwide Inpatient Sample (NIS). 2013. http://www.hcup-us.ahrq.gov/nisoverview.jsp	

Medical Expenditure Panel Survey	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities
Sponsorship:	Agency for Healthcare Research and Quality
Description:	The Medical Expenditure Panel Survey (MEPS) is a set of large-scale surveys of families and individuals, their medical providers, and employers across the United States. MEPS is the most complete source of data on the cost and use of health care and health insurance coverage.
Database (Scope, Size, Setting, Population, Age Range)	National; approximately 35,000 persons interviewed annually.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Survey/Interviews Two Primary Components • Household component - collects data from a sample of families and individuals is selected communities in the U.S. • Insurance component - collects data from a sample of private and public sector employees on the health insurance plans they offer their employees.
Database Source/Origin:	Survey data from a set of large-scale surveys of families and individuals, their medical providers, and employers in the U.S.
Date or Frequency of Data Collection:	1996-2012; updated annually.
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	For the Household Component, a panel survey design in used to collect data via multiple rounds of interviewing over a two year period of time. For the Insurance component, an annual survey of employers is conducted that collections information on health insurance offerings.
Sampling Strategy:	The Household Component collects data from a sample of families and individuals in selected communities across the U.S., drawn from a nationally representative subsample of households that participated in the prior year's National Health Interview Survey. The Insurance Component collects information from Household Component respondent employers or other non-related employers.
Unit of Analysis:	Household or Employer
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Self-Reported Diagnosis transformed into ICD-9 Codes
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9
Number of Diagnoses Captured:	MEPS identifies specific physical and mental health conditions, accidents, or injuries affecting each respondent. 670 clinical categories are created

Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Total Health Care Expenditures, Total Expenditures Paid by Insurance, Hospital Outpatient Expenditures, Hospital Emergency Room Expenditures, Hospital Inpatient Expenditures, Dental Expenditures, Home Health Care Expenditures, Vision Aid Expenditures, Other Medical Equipment and Service Expenditures, and Prescription Drug Expenditures
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Medical Provider Visits (Physician, etc.), Hospital Outpatient Visits, Hospital Emergency Room Visits, Hospital Inpatient Visits, Dental Visits, Home Health Care Visits, Number of Drugs Prescribed , and Length of Stay
Measures of Healthcare Access:	Presence of provider who provides the usual source of care, reasons why members without usual care do not have it, various aspects of satisfaction with usual care providers, and problems experience in obtaining needed health care
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, Sex, Race/Ethnicity, Insurance Status, Marital Status, and Disability Status
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Prescribed Medicine, Pregnancy Detail,
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Family Income as Percent of Poverty Line, Employment Status, Total Income, geographic location, and Size of Family
Site of Service Information:	Type of Service (e.g. hospital, nursing home, etc.)
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Self-Reported Overall Health Status Self-Reported Physical Health Status Self-Reported Mental Health Status
Strengths, Limitations & Feasibility	
Data Strengths:	MEPS provides a level of breadth and depth of healthcare utilization information that is not captured in other surveys.
Data Limitations:	Even after pooling several years of MEPS data, sample size limitations and confidentiality restrictions make MEPS data unsuitable for certain types of analysis. For example, the MEPS data do not support research on rare conditions. Moreover, information on conditions is household-reported and not verified by clinical records. All MEPS data are reported by one designated household respondent.
Data Access Restrictions:	Some files are accessible to the public; however only researchers and users with approved access can gain access to restricted files.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	Data can only be linked be survey number, which limits the feasibility of linking to non-MEPS-related data sources.
Related Grouping Systems:	ICD-based grouping systems.
References Medicare Expenditure Panel Survey (MEPS). 2013. http://meps.ahrq.gov/mepsweb/	

Centers for Disease Control and Prevention Datasets

Behavioral Risk Factor Surveillance System	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities
Sponsorship:	Center for Disease Control and Prevention
Description:	The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam.
Database (Scope, Size, Setting, Population, Age Range)	National; approximately 350,000 non-institutionalized adults (aged 18 years or older) are interviewed each year. One adult is interviewed per household.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Multi-mode survey (mail, landline, and cell phone)
Database Source/Origin:	Initiated in 1894 with 15 states collecting surveillance data on risk behaviors through monthly telephone interviews. By 2001 the 50 states, District of Columbia, Puerto Rico, and Virgin Islands were participating in the BRFSS.
Date or Frequency of Data Collection:	1984–2012; survey conducted monthly and report compiled by the CDC annually
Longitudinal vs. Cross-sectional Database:	Cross-sectional
Data Collection Methodology:	With technical assistance from the CDC, state health departments use in-house interviewers or contract with telephone call centers of universities to conduct BRFFS survey.
Sampling Strategy:	The survey is conducted using Random Digit Dialing (RDD) techniques on both landlines and cell phones.
Unit of Analysis:	Respondent
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Self-reported conditions
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	The BRFSS does not utilized diagnosis codes.
Number of Diagnoses Captured:	BRFSS asks respondents about the following conditions: MI, CHD, Stroke, Asthma, Skin Cancer, Other Cancer, COPD, Arthritis, Depression, Kidney Disease, Vision Impairment, Diabetes, and HIV/AIDS.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	The BRFSS only asks if cost is a barrier to obtaining healthcare services for specific conditions.
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Utilization of preventive healthcare services information is collected.
Measures of Healthcare Access:	Questions are included related to insurance, regular care provider, and last health checkup.
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment, Income).	Age, Gender, Hispanic vs. Latino, Race, Military Status, Insurance Status/Type, Educational Obtainment, Disability Status and Income.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Hypertension Status, High Cholesterol Status, Risky Health, Behaviors (i.e. tobacco use), Pregnancy Status, Fruit and Vegetable Consumption, Physical Activity Level, and Immunizations.
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Household Size, Employment Status, Household Income, Zip Code, and Own vs. Rent Home.
Site of Service Information:	The BRFSS does not include information on site of service.
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Self-reported Health Status Self-reported Health-Related Quality of Life
Strengths, Limitations & Feasibility	
Data Strengths:	THE BRFSS raking methodology includes categories of age by gender, detailed race and ethnicity groups, education levels, marital status, regions within states, gender by race and ethnicity, telephone source, renter/owner status, and age groups by race and ethnicity. In 2011, 50 states, the District of Columbia, Guam, and Puerto Rico collected samples of both landline and cell phone interviews, while the Virgin Islands collected a sample of landline-only interviews.
Data Limitations:	Limitations on the reliability and validity of self-reported behaviors, with some over-reported, and others underreported. Only administered in English and Spanish. An increasing numbers of households lack landlines.
Data Access Restrictions:	BRFSS data is publicly available.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	No direct identifiers, except telephone number.
Related Grouping Systems:	n/a
References Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance System. 2013. http://www.cdc.gov/brfss/	

National Ambulatory Medical Care Survey	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations
Sponsorship:	Centers for Disease Control and Prevention
Description:	The National Ambulatory Medical Care Survey (NAMCS) is a national survey designed to provide information about the provision and use of ambulatory medical care services in the United States. Data are obtained on patients' symptoms, physicians' diagnoses, and medications ordered or provided. Information on services provided, including information on diagnostic procedures, patient management, and planned future treatment.
Database (Scope, Size, Setting, Population, Age Range)	National; the NAMCS includes data on approximately 11,000 physicians from office-based settings and more than 6,000 CHC providers.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Survey of physicians and providers.
Database Source/Origin:	Findings are based on a sample of visits to non-federal employed office-based physicians who are primarily engaged in direct patient care. Physicians in the specialties of anesthesiology, pathology, and radiology are excluded from the survey.
Date or Frequency of Data Collection:	The survey was conducted annually from 1973 to 1981, in 1985, and annually since 1989.
Longitudinal vs. Cross-sectional Database:	Cross-sectional.
Data Collection Methodology:	Specially trained interviewers visit physicians prior to their participation in the survey in order to provide them with survey materials and instruct them on how to complete the forms. Data collection is from physicians, rather than from patients, which provides an analytic base that expands information on ambulatory care collected through other ambulatory surveys. Each physician is randomly assigned to a 1-week reporting period. During this period, data for a systematic random sample of visits are recorded by the physician or office staff on an encounter form provided for that purpose.
Sampling Strategy:	Data is obtained from sample of visits to non-federal employed office-based physicians who are primarily engaged in direct patient care.
Unit of Analysis:	Physicians
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Common primary diagnosis.
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9-CM. Drug data are coded using a unique classification scheme developed at NCHS.
Number of Diagnoses Captured:	Information is collected on the following chronic conditions: Cerebrovascular disease, Congestive heart failure, Chronic renal failure, HIV, and diabetes.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Source of payment
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Number of past visits in last 12 months, major reason for visit, time spent with the physician, previous care – seen in ED in last 72 hours/ discharged from hospital in last 7 days, counseling/ education/ therapy, surgical procedures, patient's primary care physician provider, was patient referred for visit, and patient seen before.
Measures of Healthcare Access:	NAMCS does not have measures of healthcare access.
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, Sex, and Ethnicity/Race.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Pain level, Tobacco use, Respiratory rate, Episode of care, Glasgow coma scale (GCS), and On oxygen on arrival.
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Place of residence
Site of Service Information:	Hospitals and community health centers identified.
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Discharge status
Strengths, Limitations & Feasibility	
Data Strengths:	Data are collected on key policy issues pertaining to health. There are multiple years of data available.
Data Limitations:	The item nonresponse rate for ethnicity and race is approximately 20%.
Data Access Restrictions:	Data are available to the public at no cost. Restricted files which contain additional variables and non-masked data can be accessed by applying to the NCHS Research Data Center and paying a fee.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	The NAMCS does not include unique identifiers to link patients.
Related Grouping Systems:	ICD-based grouping systems.
References Centers for Disease Control and Prevention. Ambulatory Health Care Data. 2013. http://www.cdc.gov/nchs/ahcd.htm	

National Health Interview Survey	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities
Sponsorship:	Centers for Disease Control and Prevention
Description:	The National Health Interview Survey is the principal source of information on the health of the civilian non-institutionalized population of the United States and is one of the major data collection programs of the National Center for Health Statistics.
Database (Scope, Size, Setting, Population, Age Range)	National; approximately 100,000 individuals.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Household survey
Database Source/Origin:	Surveys of households.
Date or Frequency of Data Collection:	Annually since 1957, but revised every 10-15 years. Sampling and interviewing are continuous throughout the year
Longitudinal vs. Cross-sectional Database:	The National Health Interview Survey is a cross-sectional household interview survey.
Data Collection Methodology:	Sampled by household – one child and one adult are selected to complete the Sample Adult and Sample Child components of the survey. Sampling methods are redesigned after every census.
Sampling Strategy:	Sampling and interviewing are continuous throughout each year. The sampling plan follows a multistage area probability design that permits the representative sampling of households and non-institutional group quarters (e.g., college dormitories). The sampling plan is redesigned after every decennial census. The current sampling plan was implemented in 2006. It has many similarities to the previous sampling plan, which was in place from 1995 to 2005. The first stage of the current sampling plan consists of a sample of 428 primary sampling units (PSU's) drawn from approximately 1,900 geographically defined PSU's that cover the 50 States and the District of Columbia. A PSU consists of a county, a small group of contiguous counties, or a metropolitan statistical area.
Unit of Analysis:	Households, Individuals and Geographic Region.
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Self-reported diagnosis information.
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	Self-report diagnosis.
Number of Diagnoses Captured:	Self-reported diagnosis information collected on: Hypertension/ high blood pressure, High cholesterol, Coronary heart disease, Angina, Heart attack, Heart condition/ heart disease, Stroke, Emphysema, COPD, Asthma, Ulcer, Cancer or malignancy of any kind/ benign tumors/cysts, Diabetes, Seizure disorder or epilepsy, Sinusitis, Chronic bronchitis, Weak or failing kidneys, bladder or renal problem, Liver condition, Fibromyalgia, lupus, Multiple Sclerosis, Muscular Dystrophy, Osteoporosis or tendinitis, Pilio, paralysis, para/quadriplegia, Parkinson's disease, other tremors, Hernia, Varicose veins, hemorrhoids, Thyroid problems, Grave's disease, gout, Hearing problems, Depression, anxiety, or an emotional problem, Pain, ache, stiffness in or around a joint, bone injury, Arthritis, Birth defect, intellectual disability/ developmental problem, Senility, Weight problems, Missing limbs, Circulation problems / blood clots, Severe headache or migraine, Stomach or intestinal illness, Pregnant, Vision/ blindness, Teeth loss, Weak immune system (due to leukemia, lymphoma, HIV), Nerve damage/carpal tunnel syndromes, and Hepatitis.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Affordability of prescription medicines, Affordability of doctors, Affordability of dental care, and Affordability of insurance.
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Emergency room visit/ hospital visit , Asthma action plan/ class on managing asthma, Routine checkup for asthma, Taking insulin, Use hearing aid, Usual place to go when sick, Health care change due to health insurance change, Received home health visits, Received surgery, Received flu/ tetanus/ hepatitis/ HPV shot and Pap smear/ mammogram.
Measures of Healthcare Access:	Lack of transportation to health care, Lack of available doctors, Lack of doctors' offices open at convenient times, Worried about paying medical bills, Health care coverage compared to past year, Skipped medication to save money, and Communicate with a healthcare provider online.
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, sex, sexual orientation.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Smoker status, Exercise, Drinker status, Height and Weight.
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Employment status, Business/ industry, Activities at job, Size of business, Paid by the hour or salaried, Paid sick leave, Multiple jobs held, and time at current residence.
Site of Service Information:	Site of Service is not collected of the NHIS.
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Morbidity and Mortality.
Strengths, Limitations & Feasibility	
Data Strengths:	Includes questions that can be used to analyze demographic and socioeconomic characteristics and health trends.
Data Limitations:	Cross-sectional data; it cannot be used study patients over time. Sample sizes are too small to provide accurate state-level statistics.
Data Access Restrictions:	NHIS data files are available to download at no charge. All files from 1963-2011 are available online
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	AHRQ provides a crosswalk to merge the MEPS and NHIS data. Mortality data, Medicare enrollment and claims data, and social security and benefit history data are all linked to NHIS data. The National Immunization Provider Records Check Survey is also linked to NHIS data.
Related Grouping Systems:	n/a
References Centers for Disease Control and Prevention. National Health Interview Survey. 2013. http://www.cdc.gov/nchs/nhis.htm	

National Health and Nutrition Examination Survey	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities
Sponsorship:	Center for Disease Control and Prevention

Description:	The National Health and Nutrition Examination Survey (NHANES) is a program of studies designed to assess the health and nutritional status of adults and children in the United States. The survey is unique in that it combines interviews and physical examinations. Findings from this survey are used to determine prevalence of major diseases and risk factors for diseases.
Database (Scope, Size, Setting, Population, Age Range)	National; 5,000 Surveys conducted annually.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Survey and Physical Examination
Database Source/Origin:	Health interviews are conducted in respondents' homes. Health measurements are performed in specially-designed and equipped mobile centers, which travel to locations throughout the country. The study team consists of a physician, medical and health technicians, as well as dietary and health interviewers.
Date or Frequency of Data Collection:	As of 1999, NHANES has been conducted on an annual basis.
Longitudinal vs. Cross-sectional Database:	Cross-sectional Survey
Data Collection Methodology:	NHANES includes clinical examinations, selected medical and laboratory tests, and self-reported data. Medical examinations and laboratory tests follow very specific protocols and are as standard as possible to ensure comparability across sites and providers. Beginning in 1999, NHANES became a continuous, annual survey. Data are collected every year from a representative sample of the civilian non-institutionalized U.S. population, newborns and older, by in-home personal interviews and physical examinations in the mobile examination centers.
Sampling Strategy:	The sample design is a complex, multistage, clustered design using unequal probabilities of selection. Low-income persons, adolescents 12-19 years of age, persons 60 years of age and over, African Americans, and persons of Mexican origin are oversampled. The sample is not designed to provide nationally representative estimates for the population of U.S Hispanics.
Unit of Analysis:	Respondent/Interviewee
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Self-Reported Conditions
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	Self-Reported Conditions
Number of Diagnoses Captured:	NHANES primarily studies nine categories of conditions: Obesity, Cardiovascular Health, Oral Health, Arthritis/Body Pain, Bone Density/Osteoporosis, Pulmonary Function, Endocrine Health, Renal Disease, and Allergy Inflammation.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	NHANES does not capture information on cost.
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Hospital Utilization/Stays ED Utilization
Measures of Healthcare Access:	NHANES includes specific questions on healthcare access.
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, Sex, Educational Attainment, Marital Status, Language, Race/Ethnicity, including subgroups and Health Insurance Status.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Health Risk Behaviors, Health Risk Exposure Data, Weight History, Oral Health History, other clinical metrics are obtained during the interview by clinicians (i.e. blood pressure).
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Veteran Status, Occupation, Employment Status and Income.
Site of Service Information:	For each condition, NHANES asks patients if they received care at a certain type of facility (ED, doctor's office, etc.).
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Self-reported Health Status Self-reported Physical Functioning
Strengths, Limitations & Feasibility	
Data Strengths:	Estimates for previously undiagnosed conditions are produced from NHANES.
Data Limitations:	A major limitation of NHANES is that it is not geographically representative of the U.S. The sample selected to be demographically representative, but because two teams can only visit a total of 16 sites a year, it is impossible to achieve a good geographic spread. NHANES may not be optimal for detecting changes over time because one doesn't know if the changes observed are due to geographic irregularities of the survey.
Data Access Restrictions:	Certain public use data files are open to the file. Many survey data elements are not available for public use.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	NHANES data have been linked with multiple years of Social Security Administrative Data, CMS Medicare enrollment and claims files include Part D data, and the National Death Index.
Related Grouping Systems:	n/a
References Centers for Disease Control and Prevention. National Health and Nutrition Examination Survey (NHANES). 2013. http://www.cdc.gov/nchs/nhanes.htm	

Centers for Medicare & Medicaid Services Datasets

CMS Chronic Conditions Warehouse	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations
Sponsorship:	Centers for Medicare & Medicaid Services
Description:	The Chronic Condition Data Warehouse (CCW) is a research database designed to make Medicare, Medicaid, Assessments, and Part D Prescription Drug Event data more readily available to support research designed to improve the quality of care and reduce costs and utilization for chronic disease patients. Data is available across beneficiaries' continuum of care.
Database (Scope, Size, Setting, Population, Age Range)	National-Population-specific; All Medicare patients.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	The CMS Chronic Condition Warehouse is an amalgamation of linked datasets, including Medicare, Medicaid, and Part D Claims and Assessment data.
Database Source/Origin:	CCW contains the following 100% Medicare files for years 1999–2010: • Fee-for-service institutional and non-institutional claims • Enrollment/eligibility • Assessment data 100% Medicaid files for years 1999 - 2008 and 2009/partial states available. 100% Part D Prescription Drug Event data for years 2006–2010 • Plan characteristics • Pharmacy characteristics • Prescriber characteristics
Date or Frequency of Data Collection:	Ongoing; Data from 1999–2010.
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	CCW data are linked by a unique, unidentifiable beneficiary key, which allows researchers to analyze information across the continuum of care.
Sampling Strategy:	All Medicare beneficiaries
Unit of Analysis:	Medicare Beneficiary
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	CCW has a specific condition algorithm to determine chronic condition categories. For each chronic condition category, specific primary, principal or secondary diagnosis codes are used to "flag" the event.
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9, CPT4, HCPCS codes
Number of Diagnoses Captured:	Twenty-seven chronic conditions are maintained in the CCW.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Medicare & Medicare Claims; Part D Prescription Drug Costs
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Number of Claims, Number of Visits, and Type of Procedure.
Measures of Healthcare Access:	CCW includes an Access to Care File.
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Sex, Race, Insurance Type, Dual Eligibility Status, Age, preferred language, marital status, etc.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	n/a
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Zip code
Site of Service Information:	CCW includes information on site of service (hospital, nursing home, etc.)
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Mortality, morbidity, Mobility, functional status, quality of life, quality measures, quality of care.
Strengths, Limitations & Feasibility	
Data Strengths:	Links beneficiaries across multiple care settings and representative of all Medicare patients.
Data Limitations:	Since claims for most services provided to Medicare beneficiaries in managed care do not reach the claim data files, the CCW Medicare claims should be viewed as providing utilization information primarily for the fee-for-service population.
Data Access Restrictions:	CCW data files may be requested for any of the predefined chronic condition cohorts, or users may request a customized cohort(s) specific to research focus areas.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	CCW files can be linked together via a single unique identifier for each beneficiary. ICD-based grouping systems.
References Chronic Conditions Data Warehouse. 2013. http://www.ccwdata.org/web/guest/home	

CMS Medicare Provider Analysis and Review (MedPAR) File	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations
Sponsorship:	Centers for Medicare & Medicaid Services
Description:	The Medicare Provider Analysis and Review (MEDPAR) File contains data from claims for all services provided to beneficiaries admitted to Medicare certified inpatient hospitals and skilled nursing facilities (SNF).
Database (Scope, Size, Setting, Population, Age Range)	National; representative of Medicare patients; 12 million in- patient visits
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Medicare Claims
Database Source/Origin:	Medicare claims for inpatient visits from over 6,000 hospitals.
Date or Frequency of Data Collection:	1991–2012; updated yearly.
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	The Centers for Medicare and Medicaid Services (CMS) collects and releases data for all U.S. hospital inpatient stays for Medicare beneficiaries. Each record in the MedPAR file represents an inpatient stay during the calendar year of the file and has information on diagnosis, procedure, charge, payment, provider and patient for the claim.
Sampling Strategy:	All Medicare related inpatient hospital stays.
Unit of Analysis:	Inpatient Stay
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Principal Diagnosis Admission Diagnosis
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9-CM
Number of Diagnoses Captured:	Up to 9 diagnoses and 6 surgical procedure codes are captured in the MedPAR file.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	TotalTotalCharges Payments
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Number of Inpatients Visits Length of Stay
Measures of Healthcare Access:	n/a
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, Gender and Race.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	n/a
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	State, Country Zip Code
Site of Service Information:	Hospital provider number can be used to identify geographic region.
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Discharge Status
Strengths, Limitations & Feasibility	
Data Strengths:	Representative of all Medicare-related hospital inpatient admissions.
Data Limitations:	MedPAR data is generally available with one year lag time and covers around one-third of all hospital inpatients; and almost all of its patients are 65 plus. Consequently, some specialties such as Pediatrics and Obstetrics are practically absent.
Data Access Restrictions:	Because of data use restrictions, CMS cannot sell access to the raw data, but can provide a wide array of tabulations and descriptive statistics.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	n/a
Related Grouping Systems:	ICD-based grouping systems.
References CMS MedPAR Hospital Data File. 2013. http://www.healthdatastore.com/cms-medpar-hospital-data-file.aspx#	

Medicare Health Outcomes Survey	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations
Sponsorship:	Centers for Medicare & Medicaid Services
Description:	The Medicare HOS is the first outcomes measure used in Medicare managed care programs. The goal of the Medicare HOS program is to gather valid and reliable health status data in Medicare managed care for use in quality improvement activities, plan accountability, public reporting, and improving health. The Medicare HOS 2.0 contains four major components: • the Veterans RAND 12 Item Health Survey (VR-12) • questions to gather information for case-mix and risk- • adjustment • four HEDIS® Effectiveness of Care measures • additional health questions
Database (Scope, Size, Setting, Population, Age Range)	Medicare beneficiaries 18 years or older enrolled in Medicare Advantage Organizations with a minimum of 500 enrollees.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Survey
Database Source/Origin:	Patient Survey Data
Date or Frequency of Data Collection:	Once a year, starting in 1998.
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	Data is collected from participating Medicare Advantage Organizations (MAOs) with a minimum of 500 enrollees
Sampling Strategy:	Each spring a random sample of Medicare beneficiaries is drawn from each participating MAO, that has a minimum of 500 enrollees and is surveyed (i.e., a survey is administered to a different baseline cohort, or group, each year). Two years later, these same respondents are surveyed again. Effective 2007, the MAO sample size is increased to twelve hundred.
Unit of Analysis:	Respondent, MAO's, etc.
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Self-reported diagnosis
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	Self-reported diagnosis
Number of Diagnoses Captured:	Hypertension or high blood pressure, Angina pectoris or coronary artery disease, Congestive heart failure, Myocardial infarction or heart attack, Other heart conditions such as problems with heart valves or the rhythm of heartbeat, Stroke, Emphysema, or asthma, or COPD, Crohn's disease, ulcerative, colitis, or inflammatory bowel disease, Arthritis of the hip or knee, Arthritis of the hand or wrist, Osteoporosis, Sciatica, Diabetes, high blood sugar, or sugar in the urine, Any cancer other than skin cancer, and Poor eyesight.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	n/a
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Enrollment duration Caregiving for others in household
Measures of Healthcare Access:	Difficulty of getting around
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, Gender, Marital Status, Race, and Education.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	BMI, Depression screen indicator, History of pain, Height History of falls, Comorbid Medical Conditions (Beneficiary reported)
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Annual household income English language skills Household size Place of residence
Site of Service Information:	n/a
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Health Status Activity Level
Strengths, Limitations & Feasibility	
Data Strengths:	Data can be used to assess the performance of MAOs and to reward high performers. Data can be used by health researchers to advance the state of the science in functional health outcomes measurement. Data can be used by managed care organizations, providers, and quality improvement organizations to monitor and improve health care quality.
Data Limitations:	Lacks cost information. Lacks information on chronic conditions besides the ones specifically inquired about.
Data Access Restrictions:	Several types of Medicare HOS data files are available for research purposes. Medicare HOS data files are available as public use files, limited data sets, and research identifiable files.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	Beneficiaries are identified through their health insurance claims numbers. However, a beneficiary's HIC number can change through special circumstances.
Related Grouping Systems:	n/a
References: Medicare Health Outcomes Survey. 2013. http://www.hosonline.org/Content/Default.aspx	

HMO Research Network Dataset

HMO Research Network Virtual Data Warehouse	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities.
Sponsorship:	HMO Research Network
Description:	The HMORN Virtual Data Warehouse is a series of datasets developed from data submitted from 19 healthcare delivery organizations with integrated research practices. The purpose of the HMORN VDW is to provide a means by which to conduct broad spectrum population-based research studies to ultimately improve patient health and transform health care practice. HMORN research includes the following topics: biostatistics, mental health, cancer research, comparative effectiveness research, complementary & alternative medicine, communication & health literacy research, dissemination & implementation, epidemiology, genetic research, disparities research, health informatics, health services, infectious & chronic disease surveillance, patient-centered care, pharmaco- epidemiology, primary & secondary prevention, systems change and organizational behavior.

Database: (Scope, Size, Setting, Population, Age Range)	The HMORN VDW is a consortium of 19 healthcare delivery systems that submit claims and EHR data for all patients.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Virtual Database - Data is housed at individual HMOs but can be accessed from anywhere.
Database Source/Origin:	Administrative Data, Claims Data, & Electronic Health Record Data (which includes clinical data).
Date or Frequency of Data Collection:	n/a
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	Programmers at participating sites transform EHR and claims data elements from local data systems to a VDW standardized set of variable definitions, names, and codes. The common structure allows for programming code developed at one site to be used at other sites to extract and analyze data for a research throughout the network.
Sampling Strategy:	All Patients
Unit of Analysis:	Patient
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Primary and secondary diagnoses.
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9-CM (other: CPT-4 & HCPCS, NGC, CPI)
Number of Diagnoses Captured:	n/a
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Insurance Claims
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Inpatient & Outpatient Visits
Measures of Healthcare Access:	n/a
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, gender, race, ethnicity, insurance type, Hispanic vs. non- Hispanic, Educational Obtainment.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Height, Weight, BMI, blood pressure, Laboratory Results, Tumor Status, Tumor Staging, prescription drug use.
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	County, State, Zip, Income
Site of Service Information:	Type of encounter, provider type, facility type.
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Discharge Disposition
Strengths, Limitations & Feasibility	
Data Strengths:	Data submitted to this warehouse is continuously vetted and cleaned. Data maintained in this warehouse can be analyzed using programs written at any HMO.
Data Limitations:	Data is only submitted from health plans in twelve states.
Data Access Restrictions:	n/a
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	Although demographic information is available, a special emphasis of this database is to keep records anonymous.
Related Grouping Systems:	All ICD-related grouping systems.
References National Cancer Institute. HMO Research Network. 2013. http://epi.grants.cancer.gov/pharm/pharmacoepi_db/hmorn.html	

National Institute on Aging Dataset

National Health & Aging Trends Study	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities.
Sponsorship:	National Institute on Aging
Description:	The National Health and Aging Trends Study (NHATS) is a new resource for the scientific study of functioning in later life. The NHATS is being conducted by the Johns Hopkins University Bloomberg School of Public Health, with data collection by Westat, and support from the National Institute on Aging. In design and content, NHATS is intended to foster research that will guide efforts to reduce disability, maximize health and independent functioning, and enhance quality of life at older ages. The NHATS will gather information on a nationally representative sample of Medicare beneficiaries ages 65 and older. In-person interviews will be used to collect detailed information on activities of daily life, living arrangements, economic status and well-being, aspects of early life, and quality of life. Among the specific content areas included are: the general and technological environment of the home, health conditions, work status and participation in valued activities, mobility and use of assistive devices, cognitive functioning, and help provided with daily activities (self-care, household, and medical). Study participants will be re-interviewed every year in order to compile a record of change over time. The content and questions included in NHATS were developed by a multidisciplinary team of researchers from the fields of demography, geriatric medicine, epidemiology, health services research, economics, and gerontology. As the population ages, NHATS will provide the basis for understanding trends in late-life functioning, how these differ for various population subgroups, and the economic and social consequences of aging and disability for individuals, families, and society.
Database: (Scope, Size, Setting, Population, Age Range)	National; persons >=65 years old; Adolescents Only (< 20 years old); 2–3 million records a year.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Survey
Database Source/Origin:	Sample of Medicare beneficiaries
Date or Frequency of Data Collection:	Annual (round 1 completed in 2011)
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	Interview
Sampling Strategy:	Sample of over 8,000 Medicare beneficiaries ages 65 and older living in the contiguous U.S. Age-stratified so that persons are selected from 5 year age groups between the ages of 65 and 90, and from among persons age 90 and older. Oversample of persons at older age groups and persons whose race is listed as Black on the CMS enrollment file. Replenishment of the sample to maintain the ability to represent the older Medicare population is planned at regular intervals.
Unit of Analysis:	Patient
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Number of Chronic Conditions (based on a list of 25 possible chronic condition indicators) Primary and Secondary Diagnoses Admission and Discharge Status
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	None (self-report by patient)
Number of Diagnoses Captured:	10 basic diagnoses (heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, dementia, cancer); more detailed questions are asked about each one if interviewee reports having or having had one or more of these illnesses. Additional questionnaires ask about cognitive status, mobility, sensory and physical impairments, and ACS disability questions
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Out-of-pocket cost of home environment modifications
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Hospital stays/surgery, use of a medical doctor
Measures of Healthcare Access:	Measures of ability to handle medical care activities by oneself, whether patient has a regular doctor
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, insurance, education
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Various indicators of physical, social, sensory and cognitive functioning
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Income, assets, housing, car ownership, labor force participation, helpers
Site of Service Information:	
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Mortality (year to year), mobility, ability to complete activities of daily living, functional status
Strengths, Limitations & Feasibility	
Data Strengths:	Survey, longitudinal
Data Limitations:	Small sample size (8,000), little information about rarer conditions
Data Access Restrictions:	Users must register before downloading the data. Registration is instant and free online.
Data Linking Feasibility: Does not appear to be linkable to Medicare file. (Unique identifiers or sufficient demographics to allow for data linkages)	Does not appear to be linkable to Medicare file.
Related Grouping Systems:	N/A
References Full bibliography available at http://www.nhats.org/scripts/biblioRep.htm	

Utah Department of Health Dataset

Utah All Payer Claims Database	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities.
Sponsorship:	Office of Health Care Statistics; Utah Health Data Committee; Utah Department of Health
Description:	The Utah All Payer Claims Database (APCD) became the fifth operating APCD in the nation on September 13th, 2009 with the receipt of the very first data submissions. Participating plans submit enrollment, medical, and pharmacy files starting from 1/1/2007 until they are current. As of 2010, there are 11 plans in full production; that is, they have submitted all required historic data and are reporting new data on determined schedule
Database (Scope, Size, Setting, Population, Age Range)	State of Utah; all-payer claims data.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Claims and administrative enrollment files. All payer claims database.
Database Source/Origin:	Medicaid Claims, CHIP, PPO's and HMO's in Colorado, Medicare claims are pending inclusion due to cost/infrastructure.
Date or Frequency of Data Collection:	Inpatient Hospital Discharge Data (1992–2010) Ambulatory Surgery Data (1996–2009) Emergency Department Data (1996–2010)
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	Health insurance carriers are required to submit health insurance files.
Sampling Strategy:	All patients receiving and paying for healthcare services in the State of Utah.
Unit of Analysis:	Patient
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Principal Diagnosis Secondary Diagnosis
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9 or ICD-10
Number of Diagnoses Captured:	Up to nine diagnoses are captured for each patient.
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Total Charges, Facility Charges, and Professional Charges
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Length of Stay Discharges Type of Procure Admissions/Hospitalizations
Measures of Healthcare Access:	Yes, but specific measures not reported.
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, Gender, Marital Status, and Race/Ethnicity.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Yes, extensive clinical data from EHRs.
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Place of Residence
Site of Service Information:	Zip Code, Residential County
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Discharge Status Patient Severity Subclass Values Patient Risk of Mortality Values
Strengths, Limitations & Feasibility	
Data Strengths:	Large patient sample size; represents all types of payment sources.
Data Limitations:	Only representative of the State of Utah; still in development and missing claims data for some periods of time.
Data Access Restrictions:	Some files are publically available. However, more advanced files for health care cost, quality and access need to be purchased after IRB and HDC consent is achieved.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	Patient and Physician Identifiers. Data is very easy to link; there are a number of personal identifiers.
Related Grouping Systems:	All ICD-related grouping systems.
References Office of Health Care Statistics Utah Health Data Committee. The Utah All Payer Claims Database (APCD). 2013. http://health.utah.gov/hda/apd/	

State of Colorado Dataset

Colorado All Payer Claims Database	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities.
Sponsorship:	State of Colorado, Colorado Health Foundation, The Colorado Trust, Caring for Colorado Foundation, Rose Community Foundation and Kaiser Permanente Community Benefit Program; Center for Improving Value in Health Care (CIVHC).
Description:	The APCD is a secure database that includes claims data from commercial health plans, Medicare and Medicaid. Created by legislation in 2010 and administered by the Center for Improving Value in Health Care (CIVHC), the APCD is the only comprehensive source of health care claims data from public and private payers in Colorado.
Database (Scope, Size, Setting, Population, Age Range)	State All Payer Database (Commercial carriers, Medicaid, Medicare, Self-funded plans and small group). By 2014, the APCD will have collected claims data for 90% of Colorado's 4.2 million insured.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	All Payer Claims Database
Database Source/Origin:	All claims: commercial carriers, Medicaid, Medicare, self- funded plans and small group plans.
Date or Frequency of Data Collection:	2008-2011; update regularly
Longitudinal vs. Cross-sectional Database:	Longitudinal
Data Collection Methodology:	Health insurance carriers are required to submit health insurance files.
Sampling Strategy:	Information is collected on all Colorado healthcare expenditures.
Unit of Analysis:	Patient
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Admitting Diagnosis Principal Diagnosis 12 "Other Diagnosis" Categories
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	ICD-9
Number of Diagnoses Captured:	n/a
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Total Cost Inpatient Facility Cost Outpatient Facility Cost (including ER cost) Profession Cost Drug Cost
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Hospital Admissions Type of Service (ortho vs. pediatric) Readmissions
Measures of Healthcare Access:	Provider Density Variable
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Sex Gender Age Insurance Status
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Yes, extensive clinical data from EHRs.
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	n/a Zip Code, County, Type of Service (inpatient vs. outpatient).
Site of Service Information:	Zip Code, County, Type of Service (inpatient vs. outpatient).
Measures of Healthcare Outcomes: (Mortality, Morbidity, Mobility, Functional Status, Quality of Life, Quality Measures, Quality of Care, Readmissions)	Discharge Status Readmissions
Strengths, Limitations & Feasibility	
Data Strengths:	Large patient sample size; represents all types of payment sources.
Data Limitations:	Only representative of the State of Colorado; still in development and missing claims data for some periods of time.
Data Access Restrictions:	Data is publically available.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	Social Security Number, Plan Number, Employee Number, Provider Number. Information is grouped by zip code or region to protect personal health information.
Related Grouping Systems:	All ICD-related grouping systems.
References Colorado All-Payer Claims Database. 2013. http://www.colorado.gov/cs/Satellite/HCPF/HCPF/1249996141729	

Health & Retirement Study	
Database Description	
White Paper(s):	Data Systems and the Prevalence of Chronic Disease Combinations & Multiple Chronic Conditions and Disparities.
Sponsorship:	University of Michigan
Description:	The University of Michigan Health and Retirement Study (HRS) is a longitudinal panel study that surveys a representative sample of more than 27,000 Americans over the age of 50 every two years. This study is supported by the National Institute on Aging and the Social Security Administration and is designed to examine changes in labor force participation and the health transitions that individuals experience at the end of their working lives and into the years that follow. It is the leading resource for data on combined health and economic circumstance of Americans over the age of 50.
Database (Scope, Size, Setting, Population, Age Range)	The HRS study surveys more than 27,000 Americans over the age of 50 who represent the Nation's diversity of economic conditions, racial and ethnic backgrounds, health, marital histories and family compositions, occupations and employment histories, living arrangements, and other aspects of life. As individuals drop out of the sample, they are replaced by new participants in their 50's; it is nationally representative of the U.S. population over age 50.
Database Type: (Survey, Registry, Research Study, Program Database, Claims, Administrative Data, and Clinical Databases)	Research study and associated database.
Database Source/Origin:	Participant Interviews
Date or Frequency of Data Collection:	Interviews are conducted every two years.
Longitudinal vs. Cross-sectional Database:	This is a longitudinal panel survey that following individuals over multiple years.
Data Collection Methodology:	The majority of interviews are done by telephone, although exceptions are made when respondents have health limitations that would make an hour-long session on the telephone difficult of impossible. The preferred mode of data collection is face-to- face for the first wave of data collect, followed by subsequent waves of data collection conducted over the phone.
Sampling Strategy:	HRS uses a national area probability sample of U.S. households with supplemental oversamples of Blacks, Hispanics and residents of the state of Florida. Participation in this study/survey is optional, but there are incentives.
Unit of Analysis:	Individual
Diagnosis Information	
Diagnosis Variable Type: (Chronic Condition Status, Principal Diagnosis, Primary Diagnosis, Secondary Diagnosis, Admit/Discharge Diagnosis and Self-Reported Diagnosis)	Self-reported Diagnosis
Diagnosis Codes: (ICD-9, ICD-10, SNOMED)	Self-reported Diagnosis
Number of Diagnoses Captured:	n/a
Cost, Utilization & Clinical Information	
Measures of Cost: (Claims, Out-of-pocket expenses, Self-reported expenditures, and Prescription Drug Costs)	Out-of-pocket expenditures
Measures of Healthcare Utilization: (Number of Visits, Any Procedures/Number of Procedures/Type of Procedure, Number of Admission/Type of Admission, Length of Stay, Hospitalizations, Emergency Department Utilization, etc.)	Health Service Use by Type (i.e. Hospital, Nursing Home, etc.), Number of visits, etc.
Measures of Healthcare Access:	n/a
Demographic Information: (Sex, Age, Race, Ethnicity, Marital Status, Disability Status, Language, Insurance Type, Educational Attainment).	Age, Educational Attainment, Disability Status, Race, Ethnicity, Language, Sex, and Marital Status.
Clinical Information: (BMI, Medical Conditions [high blood pressure], Smoker Status, History of Various Conditions, Preventative Health Measures, Activities of Daily Living, Instrumental Activities of Daily Living)	Disease history, Medicare Use, Physical Activity, Height, Weight, Measurements of Lung Function, Blood Pressure, Grip Strength, and Walking Speed.
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Occupation, Employment Status, Income
Site of Service Information:	Location of Health Service Type
Measures of Socioeconomic Status: (Occupation, Employment Status, Income, Wealth, Place of Residence, Household Size & Composition, geographic location)	Self-reported health status and measure of functional status.
Strengths, Limitations & Feasibility	
Data Strengths:	There are multiple years of data available (longitudinal data). Comprehensive documentation is available for all respondents across a variety of key policy issues. There is a low sample attrition rate.
Data Limitations:	Limited granularity in diagnosis coding, unless linked with Medicare claims data.
Data Access Restrictions:	Data are available to the public at no cost. Detailed race/ethnicity data are available on a restricted basis.
Data Linking Feasibility (Unique identifiers or sufficient demographics to allow for data linkages)	Respondent information can be linked to social security data, Medicare claims data and supplemental employer surveys.
Related Grouping Systems:	n/a
References National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services. Growing Older in America: The Health & Retirement Study. 2007. NIH Publication No. 07-5757	

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