



# Research Addressing the HHS Strategic Framework on Multiple Chronic Conditions

## *Multiple Chronic Condition Project Executive Summary*

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## Table of Contents

<b>1. Overview of the Final Report .....</b>	<b>1</b>
<b>2. Project Summary .....</b>	<b>2</b>
Purpose .....	2
White paper #1: Understanding the High Prevalence of Low-Prevalence Chronic Disease Combinations: Databases and Methods for Research .....	2
White paper #2: Understanding Disparities in Persons with Multiple Chronic Conditions: Research Approaches and Datasets.....	3
Methods .....	4
Key Findings .....	4
Considerations for Future Research .....	5
<b>3. Appendices .....</b>	<b>6</b>
Appendix 1: Literature Search Strategy .....	6
Appendix 2: Technical Advisory Group Members .....	6
Appendix 3: Key informants .....	6
Appendix 4: Datasets and Data Systems Review: Summary Tables.....	6
Appendix 5: Clinical Classification Systems (Grouper) Review .....	6
Appendix 6: Comparison of ICD9 Codes Used in Four Clinical Classification Systems .....	7

## 1. Overview of the Final Report

The final report summarizes the work conducted under Contract HHSP2333700IT: Research Addressing the HHS Strategic Framework on Multiple Chronic Conditions. The work led to two white papers, a review of federal datasets, and other related Appendices. Below is a brief description of the project, including Study Purpose, White paper 1 and White paper 2 research aims, Methods, Key Findings, and Considerations for Future Research. In addition, attached to this Report is a description of the Appendices that were included in the original white papers.

The information contained in this white paper was compiled by Abt Associates, Inc. under contract #HHSP2333700IT to the Assistant Secretary for Planning and Evaluation (ASPE) in September 2013. The findings and conclusions of this report are those of the authors and do not necessarily represent the views of ASPE or HHS.

## 2. Project Summary

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*<sup>1</sup>, a roadmap for federal MCC priorities.

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) has produced two white papers that contribute to one of the goals outlined by the HHS strategic framework: supporting targeted research around individuals with MCC and effective interventions. More specifically, each of the white papers addresses an HHS objective related to that goal: a) supporting research to identify common patterns of MCC, to help in targeting specific interventions for specific subgroups, and b) supporting research that addresses disparities in MCC populations.

### Purpose

This project builds on previous work by ASPE describing the “long tail” of the MCC distribution: approximately one-third of all Medicare patients belong to a complex set of about two million unique disease combinations, which account for 79% of health care costs. The long-tail distribution poses a unique challenge for research because of the small number of cases within each unique combination of MCC (Exhibit 1). ASPE funded the development of the two white papers discussed below to address the research challenges of studying both low-prevalence MCC populations, and disparities populations with MCC.

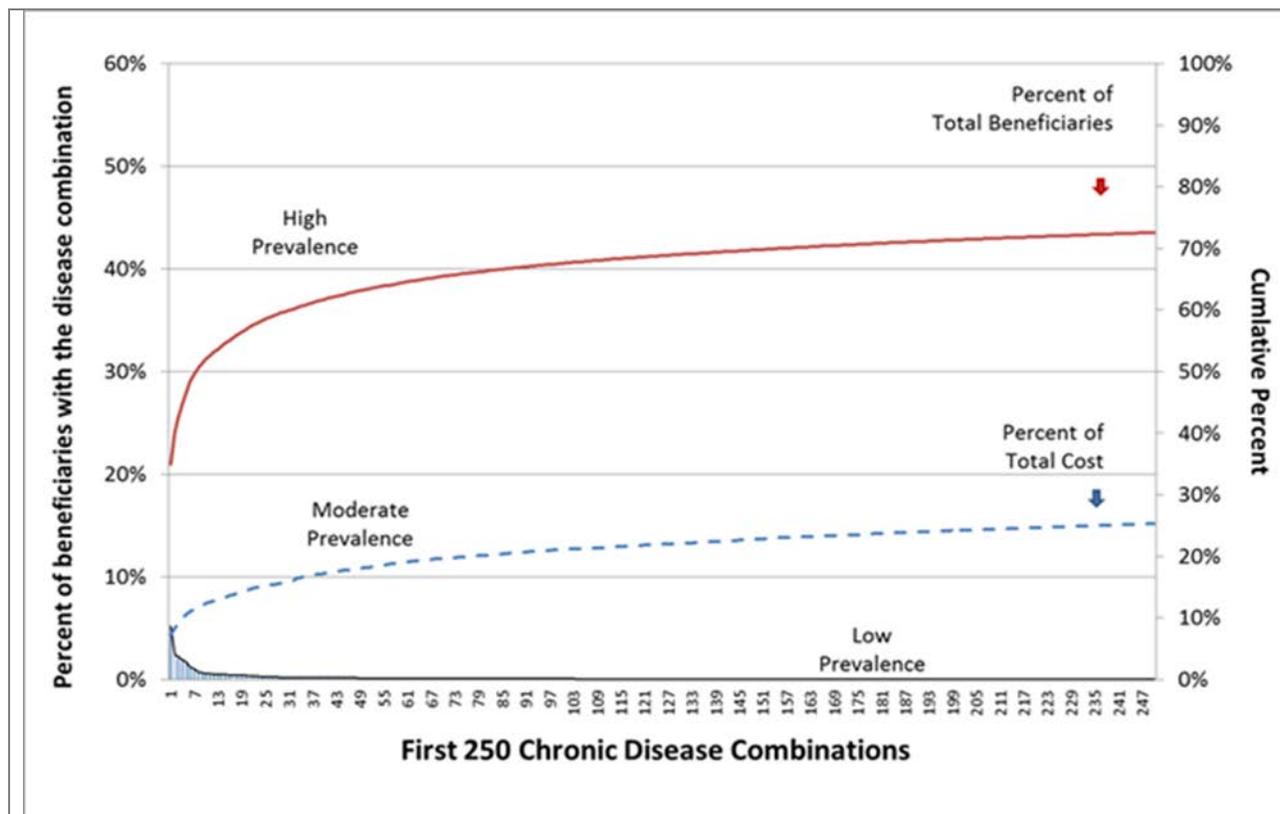
### White paper #1: Understanding the High Prevalence of Low-Prevalence Chronic Disease Combinations: Databases and Methods for Research

The purpose of the first white paper was to explore how the “long tail” of the MCC population can be appropriately studied. As a first step, ASPE wanted to identify the existing data sources that could be used to understand the population, and to consider what steps might be taken in the future to improve the knowledgebase. ASPE’s guiding study questions were:

1. What are the findings from MCC research related to prevalence and patterns of chronic disease combinations, health care utilization and cost, with particular attention to addressing less prevalent combinations of chronic conditions (i.e., the long tail)?
2. What methodologies and analytic techniques have been used to study MCC? What are the potential limitations of these approaches in considering less prevalent combinations of MCC?
3. What data systems and data sets exist that can be analyzed to better improve HHS’s understanding of and approaches to addressing numerous less prevalent combinations of chronic conditions?
4. What combinations of less prevalent combinations of chronic comorbidities are most critical to address in terms of care utilization and cost? What are the future research considerations for MCC research?

The white paper identifies the challenges in studying people with MCC, weaknesses in national datasets, methodological constraints of studying many groups with unique disease combinations, and opportunities for future research.

**Exhibit 1: Percent of MCC Prevalence and Cost in the Beginning of Medicare’s Long Tail**



**Note on the Exhibit:** The exhibit displays the first 250 Diseases 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%.

## White paper #2: Understanding Disparities in Persons with Multiple Chronic Conditions: Research Approaches and Datasets

Building on the first white paper, the purpose of the second white paper was to examine disparities in the population of people with MCC, with the goal of identifying promising areas for MCC disparities research, data sources and methods. Specifically, this white paper addressed the following questions:

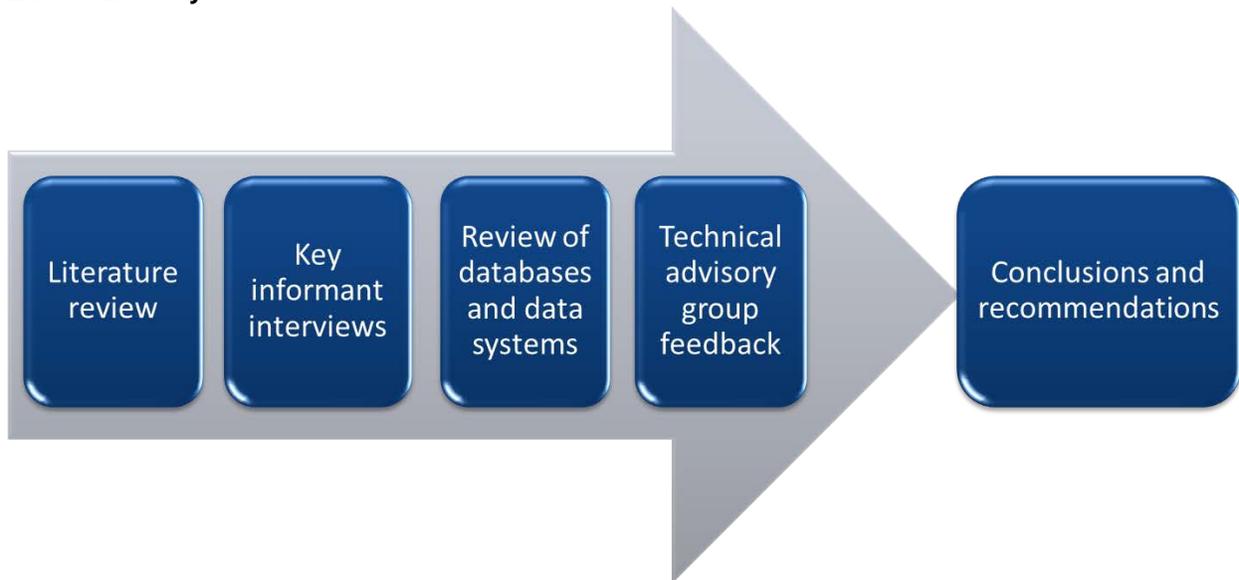
1. What combinations of comorbidities are most critical in terms of identifying opportunities for targeting and reducing disparities in care utilization and cost in MCC adult populations?
2. What data systems and datasets exist that can be analyzed to better improve our understanding of and approaches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

This paper examines techniques for studying disparities within population with MCC, identifying promising data, methods, and topics for future MCC disparities research. The 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 potential utility for MCC disparities research of the data systems and datasets described in white paper #1. Additional data systems and datasets for MCC disparities research are also identified.

## Methods

Study methods were similar for both papers (Exhibit 2). A literature review was conducted using PubMed (Appendix 1). Key informants (eight for White Paper #1, and nine for White Paper #2) were identified through the literature, the project officers and the technical advisory group and were interviewed by telephone (Appendixes 2 and 3). Input from key informants was integrated throughout each white paper. A review of datasets that could be used to study the population of people with MCC led to descriptions of the datasets and the potential each offered for studying MCC among specific groups. Technical Advisory Group feedback was integrated into each paper.

### Exhibit 2. Study Methods



## Key Findings

Most MCC research in the United States has primarily been conducted on chronic conditions that are highly prevalent and well-known. Low-prevalence conditions and less prevalent combinations of conditions have not been well studied, even though patients with these findings represent one-third of all Medicare beneficiaries and 79% of expenditures. Within the “long tail” of the distribution, the sheer number of combinations, and the small cell size within each of those combinations of chronic disease (10–11 beneficiaries nationally, on average), present a great methodological challenge for the study of patients with similar combinations of diagnoses.

White paper #1 reviews the findings in the literature with regards to disease combination complexity, and discusses how variables in study methodologies can greatly influence results. Critical design decisions include sources of data, number of disease codes to be included in the analysis, and the degree to which these primary codes are grouped into a limited set of high-level disease entities. Significant variation in these methodologies hampers interpretation across studies.

As discussed in white paper #2, the literature reports that MCC prevalence is strongly correlated with older age, greater cost, poorer quality of life, greater health care utilization, and higher mortality. Women, African-Americans, and non-Hispanic Whites have the highest MCC prevalence. Hispanics and Asian-Americans have lower prevalence, but Asians/Pacific Islanders had the highest mortality and cost per case compared to all other groups.

Several available datasets and grouping systems were reviewed that can be used to further research MCC and MCC practice.

## Considerations for Future Research

Future research on MCC and MCC disparities may be facilitated by efforts to:

- Include MCC/Disparities considerations in HHS reports and data resources when feasible/appropriate.
- Develop a research agenda for the “long tail” of the MCC distribution.
- Develop scientific standards for the enrollment of persons with MCC into research studies.
- Continue to improve the quality and consistency of race, ethnicity and other socio-demographic variables in national datasets.
- Identify disparities-sensitive measures of the quality of care for persons with MCC.
- Exploit newly available 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.

## 3. Appendices

The appendices included in the two white papers are described below and are attached to the respective reports.

### **Appendix 1: Literature Search Strategy**

The literature search strategy outlines the MEDLINE search terms that were used to conduct the literature review of peer-reviewed and grey literature for both White Paper 1, “Understanding the High Prevalence of Low-Prevalence Chronic Disease Combinations: Databases and Methods for Research,” and White Paper 2, “Understanding Disparities in Persons with Multiple Chronic Conditions: Research Approaches and Datasets.” The literature review of the first white paper identified peer-reviewed and grey literature related to prevalence of MCC, disease combinations, diagnosis coding, and databases and analytic techniques that were used to conduct chronic disease research. The literature review of the second white paper identified peer-reviewed and grey literature related to multiple chronic conditions, disparities, and analytic techniques that have been used to conduct chronic disease and disparities research.

### **Appendix 2: Technical Advisory Group Members**

The Technical Advisory Group (TAG) included experts from federal agencies who were consulted about the content of the studies. The Appendix lists the members and their affiliations. TAG members participated in an initial in-person meeting in December 2012 and provided feedback on the original literature review to determine additional databases, grouping systems, and methods for studying MCC in disparities populations. TAG members then participated in a second meeting by teleconference in May 2013 to review and provide feedback on 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 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 3: Key informants**

The Key Informants Appendix 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 both White Papers. Findings from the Key Informant Interviews have been incorporated throughout each of the White Papers.

### **Appendix 4: Datasets and Data Systems Review: Summary Tables**

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

### **Appendix 5: Clinical Classification Systems (Grouper) Review**

The Clinical Classification Systems (Grouper) Review provides a summary of fourteen systems for organizing and aggregating diagnosis codes into different disease categories, and an assessment of each grouper system’s feasibility for multiple chronic conditions and disease complexity research.

## Appendix 6: Comparison of ICD9 Codes Used in Four Clinical Classification Systems

The Appendix contains a side by side comparison of ICD-9 groupings across four separate grouper systems: 1) AHRQ's Healthcare Cost and Utilization Project Clinical Classifications Software (HCUP CCS), 2) Medicare's Hierarchical Condition Categories (HCC), 3) CMS' Chronic Conditions Warehouse (CCW) condition categories, and 4) Medicaid's Chronic Illness and Disability Payment System (CDPS) classification system.

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<sup>i</sup> Available at <http://www.hhs.gov/ash/initiatives/mcc>