

**Office of the Secretary Patient Centered Outcome Research Trust Fund
Project HP 17 – 002**

**Centers for Medicare & Medicaid Services - Enhancing Data Resources for
Studying Patterns and Correlates of Mortality in Patient-Centered Outcomes
Research**

**FINAL REPORT
December 28, 2018**

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Patterns and Correlates of Mortality in Patient-Centered Outcomes Research**

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Objective

This project aimed to purchase National Death Index (NDI) data from NCHS for known Medicare and Medicaid deaths and then link the NDI data to Medicare and Medicaid data in the Chronic Condition Warehouse (CCW). The Medicare and Medicaid data in the CCW includes claim and enrollment information that can be used for Patient Centered Outcomes Research (PCOR).

Schedule of Deliverables

Phase	Objective	Deliverables
Phase 1	<ul style="list-style-type: none">• Signed IA with ASPE• Approved NDI data request with NCHS	<ul style="list-style-type: none">• Signed IA and transfer of PCOR funds• Approved NDI data request
Phase 2	<ul style="list-style-type: none">• Modification to CCW contract to purchase NDI data, prepare finder file, receive the NDI data and perform linkage	<ul style="list-style-type: none">• Modified CCW contract
Phase 3	<ul style="list-style-type: none">• HealthApt received, loaded, validated and linked NDI data	<ul style="list-style-type: none">• Confirmed receipt of the NDI data and linkage to Centers for Medicare & Medicaid Services (CMS) files
Phase 4	<ul style="list-style-type: none">• Outreach and Dissemination	<ul style="list-style-type: none">• Announcement of availability of linked data (i.e., website, conferences)• Quarterly Reports to ASPE• Final Report to ASPE

Background - CCW

CMS created the Chronic Condition Warehouse (CCW) in response to Section 723 of the Medicare Prescription Drug, Improvement and Modernization Act (MMA) of 2003, which directed CMS to develop a data warehouse to support studies associated with improving quality of care and reducing cost of care for chronically ill Medicare beneficiaries. The CCW houses

CMS data that are easily linked, at the individual patient level, for all Medicare claims data, eligibility and enrollment data, nursing home and home health assessments, beneficiary survey data and Part D drug event data. The CCW also contains enrollment and claims data for Medicaid individuals. This data warehouse transforms and summarizes CMS administrative data into research data files which can be easily linked across file types and years for analysis. The CCW also contains 27 pre-defined Medicare chronic condition flags and 24 pre-defined Medicaid chronic condition flags that researchers can use when studying the chronic condition burden in CMS programs.

The CCW supports CMS staff and contactors from across the agency. It also supports academic and federal researchers, interested in accessing CMS data to conduct health services research and PCOR. External researchers have the option of physically receiving a data extract or virtually accessing the data in the CCW's Virtual Research Data Center (VRDC). The VRDC was developed to provide a more secure and efficient access method for accessing and analyzing data within the CCW environment.

Background - Need for NDI Data

Medicare and Medicaid disproportionately cover individuals at risk for premature mortality including low-income individuals, individuals with disabilities, and those over age 65. CMS's CCW Medicare and Medicaid research data only contains information on fact of death, but only certain years of Medicare data (1999-2008) and Medicaid data (1999-2007) contained information on the cause and manner of death. Linked data between health care claims, including diagnoses, and cause and manner of death enables many types of PCOR research, including descriptive epidemiology, predictive modeling to identify high value intervention targets, and comparative effectiveness. The benefit of this linkage is particularly high for recent years of data given changes to the programs, e.g. Medicare prescription drug benefits starting in 2006, and Medicaid expansion in many states starting in 2012.

Project Scope and Methods

April 2017 – CMS prepared and submitted a modification to the CCW/VRDC contract to have HealthApt pay for, receive, validate and link the NDI data. The modification was awarded on April 29, 2017.

August 2017 - CMS worked closely with the NDI staff at NCHS and submitted the NDI data application to the NDI Advisory Board. The request was approved August 23, 2017.

October 2017 - HealthApt prepared and submitted the finder file to NDI. The finder file included known deceased beneficiaries for Medicare from 2008-2017 and Medicaid from 2007-2013.

December 2017 to March 2018 – HealthApt received the matched files back from NDI and then validated and loaded the data into the CCW database. The validated data was then linked and the

Master Beneficiary Summary File (MBSF) and Medicaid Enrollee Summary File (MESF) were updated with the additional years of NDI data.

April 2018 - The updated files were announced at the Academy Health Conference on April 26, 2018, during the presentation “The Centers for Medicare & Medicaid Services Data and Information Products” by Ronnie Tan. Additionally, the updated files were announced to the public on April 26, 2018 via the ResDAC website and CCW website.

Websites Updated with the NDI Information

<https://www.resdac.org/cms-news/updated-cause-death-information>

<https://www.resdac.org/cms-data/files/mbsf-ndi>

<https://www.resdac.org/cms-data/files/mesf-ndi>

<https://www.ccwdata.org/web/guest/data-dictionaries>

Accomplishments

CMS requested and received the updated years (2008-2017) of the NDI data. The updated data was used to update the MBSF and MESF files. The updated files were announced to the public on April 26, 2018. CMS is accepting requests for the updated data files and has approved 13 requests for the updated NDI data through the approved process. The approved requestors have included internal CMS components, CMS contractors, other federal agencies, states and academic research organizations.

Additionally, CMS has reported to ASPE quarterly on the progress of the project and has prepared this final report.

Projects Approved for the Updated NDI Data

A Surveillance of Cancer and Blood Disorders in the General Medicare Population

Medicare Co-Insurance and Risk of Death from Colorectal Cancer

State Innovations Model All-Payer Operations

Surveillance of Diabetes, Prediabetes, and Prevention Efforts

Development and Validation of a Risk Stratification Index (RSI) Based Suite of Predictive Algorithms to Analyze Health Care Outcomes and Costs

Enhancing the Measurement of Health Care Quality to Improve the Value of Care in Medicare and Medicaid

How to Request NDI data from CMS?

NDI Cause of Death Information is now available from 1999-2016 for Medicare beneficiaries and 1999-2013 for Medicaid recipients. This data is available through the NDI segment of the [Master Beneficiary Summary File](#) and [Medicaid Enrollee Supplemental File](#).

In order to request the NDI data, please contact the Research Data Assistance Center (ResDAC). ResDAC is a CMS contractor that will assist requestors through the data request process and will submit your data request to CMS for approval. The NDI data does require an additional approval from the NDI Advisory Board at NCHS. CMS will coordinate that approval as part of the data request process. For more information, please use this link.

<https://www.resdac.org/research-identifiable-files-rif-requests>

ResDAC

<https://www.resdac.org/about-resdac#contact>

resdac@umn.edu

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