

# Medicare Data Linkages for Conducting Patient-Centered Outcomes Research on Economic Outcomes

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**Background:** Medicare patients and other stakeholders often make health care decisions that have economic consequences. Research on economic variables that patients have identified as important is referred to as patient-centered outcomes research (PCOR) and can generate evidence that informs decision-making. Medicare fee-for-service (FFS) claims are widely used for research and are a potentially valuable resource for studying some economic variables, particularly when linked to other datasets.

**Objective:** The aim of this study was to identify and assess the characteristics of federally funded administrative and survey data sources that can be linked to Medicare claims for conducting PCOR on some economic outcomes.

**Research Design:** A targeted internet search was conducted to identify a list of relevant data sources. A technical panel and key informant interviews were used for guidance and feedback.

**Results:** We identified 12 survey and 6 administrative sources of linked data for Medicare FFS beneficiaries. A majority provide longitudinal data and are updated annually. All linked sources provide some data on social determinants of health and health equity-

related factors. Fifteen sources capture direct medical costs (beyond Medicare FFS payments); 5 capture indirect costs (eg, lost wages from absenteeism), and 7 capture direct nonmedical costs (eg, transportation).

**Conclusions:** Linking Medicare FFS claims data to other federally funded data sources can facilitate research on some economic outcomes for PCOR. However, few sources capture direct nonmedical or indirect costs. Expanding linkages to include additional data sources, and reducing barriers to existing data sources, remain important objectives for increasing high-quality, patient-centered economic research.

**Key Words:** patient-centered care, patient-centered outcomes research, Medicare, linked data, economic analysis, health care costs (*Med Care* 2023;61: S122–S130)

Medicare is a large federal health insurance program covering 65 million beneficiaries.<sup>1</sup> In the United States, people ages 65 years and older or with certain disabilities or end-stage renal disease are eligible for Medicare coverage. Since these factors are also associated with health status and health outcomes, Medicare beneficiaries and their families frequently face decisions about the use of health care treatments and services.

The economic impacts of health care decisions on patients and their families were recently identified as a patient-centered outcome in the 2019 reauthorization of the Patient-Centered Outcomes Research Trust Fund. Patient-centered outcomes research (PCOR) is designed to generate evidence about the health and economic outcomes that matter to patients and the people who care for them, with a goal of making better-informed decisions. Linking and analyzing Medicare billing data is one approach for studying the outcomes and effectiveness of treatments and services. Given the large number of Medicare beneficiaries and their high use of health care services, studies that use Medicare data can quickly identify associations between health services use and measures of effectiveness, as well as some of the potential economic impacts of treatment on patients, families, and communities.

For over a decade, clinicians, policymakers, and researchers have begun to emphasize “patient-centered” care as a cornerstone in improving health outcomes and quality of care.<sup>2,3</sup> Additional data on outcomes and measures important to patients could help them to make better health care

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decisions with their families and providers. However, realizing this potential requires evidence, research, and data to facilitate this focus. Although PCOR is growing, it remains limited in part due to available data sources. For the Medicare population of older adults, Medicare program data present a rich potential option for conducting studies, although health care claims are limited in scope when used as the sole source in research.

To explore how Medicare data may be used in certain types of PCOR research, this paper inventories and evaluates linkages of federally funded survey and administrative data to Medicare fee-for-service (FFS) claims, for conducting PCOR on economic outcomes. Linked Medicare data holds tremendous potential for researchers to conduct economic analyses that can be combined with evidence from other studies to support decision-making. While Medicare data can only be used to investigate a subset of economic outcomes questions relevant to patients, Medicare data serve as an available resource to quickly launch multiple economic studies that explore a wide range of conditions, populations, and interventions. When linked to external sources, studies using Medicare data can expand the evidence base where information is lacking and over time be followed up with additional studies using other methodologies and data sources.

Medicare FFS claims (hereafter, “claims”) hold several advantages for researchers seeking to study the health and health-related economic outcomes of Medicare beneficiaries.<sup>4–6</sup> These data capture detailed information about the types of health care received; payments for that care; associated health conditions; and basic patient demographics.<sup>7</sup> Although several types of patient-level Medicare claims files exist, we focus on Medicare FFS claims for several reasons. First, our PCOR interest emphasizes economic outcomes, including Medicare’s costs of treatment and selected costs incurred by patients. FFS data contain charged, allowed, and paid amounts and data on coinsurance and copayments. Medicare Advantage (Part C) “encounter” data do not capture service-level payments, although both FFS and Medicare Advantage data track utilization of specific health services and basic patient demographics.<sup>8</sup> Second, Medicare FFS are widely available, with best practices and limitations established over >2 decades of research, compared with Medicare Advantage encounter data, which have only recently been released to the research community.<sup>9</sup> Third, FFS was historically the largest share of Medicare, although 2022 enrollment in Medicare Advantage<sup>10</sup> nearly equals FFS.

There are also limitations on the information available within all types of Medicare claims. These data contain limited clinical information and exclude noncovered services, lab values, informal caregiving, supplemental insurance payments, over-the-counter medications, social circumstances, and patient experiences. A complete patient-centered perspective on economic costs includes a wide range of economic outcome measures, many of which are not available in Medicare claims. To help address this, data linkages may enable researchers to add economic outcomes from multiple data sources, improving the responsiveness, relevancy, and breadth of patient-centered economic research that may be conducted.

## ECONOMIC OUTCOMES RELEVANT FOR PCOR

Economic outcomes may be directly or indirectly associated with health and health care and include a wide range of costs and financial impacts.<sup>11</sup> In a previous report, 3 domains of economic outcomes relevant to PCOR were defined and related to different stakeholders<sup>12,13</sup>: direct medical costs [tied to the receipt of health care services for a patient (eg, cost-sharing for a doctor visit)]; direct nonmedical costs [associated with health care or illness, but not part of the treatment (eg, transportation to a clinic)]; and indirect costs [resources lost from illness or treatment (eg, missed work time for a doctor visit)].<sup>14</sup> Patient-centered care decisions may be informed by economic outcomes, but noneconomic factors may also be important considerations for patients and families. Researchers also include quality of life or expected length of life as aspects of PCOR. While these outcomes are tremendously important, the valuation of such outcomes is controversial.<sup>14</sup> Further, because these have been studied in other work and the expanded definition of PCOR in the 2019 reauthorization<sup>15</sup> does not explicitly list such costs, the present study focuses on economic outcomes.

## SCOPE AND OBJECTIVES

This paper reviews Medicare claims-based data linkages for conducting PCOR on economic outcomes, taking traditional FFS claims in the CMS Research Identifiable File (RIF) format as a starting point. The richness of linked data sources in general is well known to health services researchers,<sup>16–19</sup> and a previous review<sup>12,13</sup> identified linkages as a key strategy for future research. Medicare claims linkages are salient for several reasons. First, CMS has an established research data infrastructure: the Research Data Assistance Center (ResDAC), the Chronic Conditions Data Warehouse (CCW), and the CCW Virtual Research Data Center (VRDC). Second, Medicare is the largest single payer of health care in the United States, and its expenditures are projected to continue growing.<sup>20</sup> Third, Medicare covers an older population with more health care needs, chronic conditions, and higher costs than in younger populations.<sup>20</sup> Given these factors, research using linked Medicare claims can facilitate meaningful PCOR and economic evaluations for the Medicare FFS population.

This paper has 3 primary objectives:

- (1) To guide researchers on data linkages between Medicare FFS claims and other federally funded administrative and survey data sources that capture information on 1 or more economic outcome domains.
- (2) To identify the specific economic outcome measures with each data linkage.
- (3) To illustrate gaps that remain for economic outcomes for the Medicare population to inform priorities into additional Medicare data linkage efforts.

## METHODS

We followed 3 main steps during April–August 2022 to develop and extract the catalog of eligible data sources capturing economic outcomes relevant to PCOR. Data inclusion criteria were: (1) federally funded; (2) captures at least 1 economic outcome domain relevant for PCOR; (3) linked or

linkable to Medicare claims at the individual level; and (4) available to external researchers. See Appendix Table A-1 (Supplemental Digital Content 1, <http://links.lww.com/MLR/C686>) for the relevant perspectives and examples of economic outcome measures which may be captured under each domain. (Given the large number of datasets surveyed, we do not list all specific variables from each dataset.) The study was nonhuman subjects research, and institutional review board review did not apply.

First, we assessed all data sources in a previous federal report on economic outcomes,<sup>12,13</sup> retaining those which are linked or linkable to Medicare claims. Next, we reviewed the websites of all divisions of the US Department of Health and Human Services (HHS) and of the Medicare and Medicaid Resource Information Center (MedRIC).<sup>21</sup> We then performed a targeted search (PubMed, Google Scholar) for additional data sources or relevant peer-reviewed literature. Search terms are provided in Appendix Table A-2 (Supplemental Digital Content 2, <http://links.lww.com/MLR/C687>).

Second, we abstracted relevant information from each data source: major characteristics (name, steward, URL, source), sample size, economic outcome domains and measures, time frame, and access to Medicare linkage. We also rated the potential of each source for economic evaluations as: high (multiple economic outcome domains and multiple perspectives); medium (at least 1 of: multiple economic outcome domains, multiple perspectives, or multiple economic outcome measures within a domain); or low (all others).

Third, results were reviewed with a 9-member expert panel 3 times during May–September 2022. We included a diverse array of federal, academic, and nonfederal experts in PCOR, health economics, health services research, and health equity. We also conducted 9 individual interviews with additional experts (researchers, data stewards, and Medicare policymakers) to review the findings.

## RESULTS

We identified 18 federally funded data sources (Table 1) which are linked or linkable to Medicare claims and which capture economic outcomes relevant to PCOR. Table 2 shows select characteristics of these data sources. Survey data sources (12 sources) are more prevalent than administrative data (6 sources).

### Capture of PCOR-Relevant Economic Outcomes in Identified Data Sources

Within Medicare FFS claims, only direct medical costs are available, as paid amounts. Among the sources linked or linkable to Medicare claims, most (15 sources) also contain direct medical costs. Two data sources contain information on all 3 economic outcome domains—Panel Study of Income Dynamics (PSID)<sup>22</sup> and Medical Expenditure Panel Survey (MEPS).<sup>23</sup> Both have relatively few economic outcome measures in total within a broader domain, although dozens of individual variables are included to capture detail within an economic outcome measure (eg, out-of-pocket amount for physician services, out-of-pocket amount for inpatient care).

Survey data sources also capture a wider range of economic outcomes than administrative data sources.

We also examined the specific economic outcome measures in each of the 3 domains (Table 3). Out-of-pocket costs and paid/reimbursed amounts are the most commonly available economic outcome measures both within the direct medical cost category and across all economic outcome measures, available in 11 and 10 data sources, respectively. The value of informal caregiving was the most common direct nonmedical cost (3 sources), and the value of absenteeism was the most common indirect medical cost (5 sources).

The rating column in Table 1 displays the potential value for PCOR economic evaluations based on the extent of economic information available. Eight data sources—all surveys—received a “high” rating. Among potential Medicare FFS linkages, the most useful for PCOR economic evaluations are the National Study of Caregiving (NSOC),<sup>24</sup> PSID, and MEPS. These add greater value than other FFS linkages because they contain greater content on economic outcomes and multiple stakeholder perspectives, thereby facilitating more holistic assessments of the economic impacts of medical care among the Medicare FFS population. Linked NSOC-Medicare data provide the richest source of information on both caregiver and patient perspectives on late-life care, covering all 3 economic outcome domains and 10 economic outcome measures. NSOC is a caregiver-focused supplemental survey under the National Health and Aging Trends Study (NHATS)<sup>25</sup>; both sources are linkable to Medicare claims. Linked PSID-Medicare and MEPS-Medicare data also cover all economic outcome domains. PSID includes 5 economic outcome measures, related to both patient and caregiver perspectives, and MEPS includes 4 economic outcome measures, related to all stakeholder perspectives. As above, dozens of individual variables are included to capture detail within these economic outcome measures.

### Other Features of the Resulting Linked Data

Time periods covered by the linkages vary significantly, from 1 to 10+ years of linked data. The longest include Medicare Current Beneficiary Survey (MCBS) (29 y),<sup>26</sup> Health and Retirement Study (HRS) (30 y),<sup>27</sup> PSID, National Health Interview Survey (NHIS), MEPS, and National Health and Nutrition Examination Survey (NHANES) (each 19 y).

Since linked data increase disclosure risks, access permissions are required by both CMS and the owner of the auxiliary data source. For example, linked PSID-Medicare data require CMS and PSID data use agreements and access provisions, and Medicare data linked to selected federal health data (eg, NHANES<sup>28</sup> and NHIS<sup>29</sup>) are available only through the National Center for Health Statistics (NCHS) Research Data Center (RDC) or a Federal Statistical Research Data Center (FSRDC).<sup>30</sup> The effort required to obtain such data presents a barrier to access, and linkages often require additional fees. Linked data obtained through CMS (via ReSDAC) and Surveillance, Epidemiology, and End Results (SEER)<sup>31</sup> have variable costs, depending on years, population

**TABLE 1. Federally Funded Data Sources Currently Linked or Linkable to Medicare FFS Claims**

| Data source name (Abbreviation), <i>steward</i>                              | URL for linked data   | Source of data | Sample size   | Available economic outcome categories         | Available economic outcome measures, by category  | Available time frame for linked data  | Outside researchers' access to linked data                                       | Rating of linked data for PCOR economic evaluations | Rationale for rating  |
|--|---|----------------|---|---|---|---|--|---|---|
| Medicare Part D claims (PDE), <i>CMS</i>                                     | <a href="https://resdac.org/cms-data/files/pde">https://resdac.org/cms-data/files/pde</a>   | Administrative | 48 million  | Direct medical costs                          | <i>Direct medical costs:</i> Insurance premium*; OOP health care costs, Paid/reimbursed amount<br><i>*Premium information is available in the Plan Characteristics file</i>           | 2006–2020   | Via research application to ResDAC; variable fees apply                          | Medium  | Multiple perspectives represented with the linkage  |
| Medicare Current Beneficiary Survey (MCBS), <i>CMS</i>                       | <a href="https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS">https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS</a>   | Survey         | 11,548  | Direct medical costs, direct nonmedical costs | <i>Direct medical costs:</i> Insurance Premium, OOP health care costs, paid/reimbursed amount<br><i>Direct nonmedical costs:</i> Transportation, time costs: health care seeking      | 1991–2020   | Via research application to ResDAC; variable fees apply                          | High  | Multiple economic outcome domains and perspectives represented with the linkage   |
| Medicaid claims (Research Identifiable Files) (RIF), <i>CMS</i>              | MAX: <a href="https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/MAXGeneralInformation">https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/MAXGeneralInformation</a> TAF: <a href="https://www.medicaid.gov/medicaid/data-systems/macbis/medicaid-chip-research-files/transformed-medicaid-statistical-information-system-t-msis-analytic-files-taf/index.html">https://www.medicaid.gov/medicaid/data-systems/macbis/medicaid-chip-research-files/transformed-medicaid-statistical-information-system-t-msis-analytic-files-taf/index.html</a> | Administrative | Varies by file type; 73+ million Medicaid; 6.7 million CHIP | Direct medical costs                          | <i>Direct medical costs:</i> Paid/reimbursed amount, OOP health care costs  | 1999–2019   | Via research application to ResDAC; variable fees apply                          | Medium  | Multiple economic measures and perspectives represented with the linkage  |
| Medicare-Medicaid Linked Enrollee Analytic Data Source (MMLEADS), <i>CMS</i> | <a href="https://resdac.org/cms-data/files/mmleads-1">https://resdac.org/cms-data/files/mmleads-1</a>   | Administrative | 58+ million   | Direct medical costs                          | <i>Direct medical costs:</i> Paid/reimbursed amount   | 2006–2012   | Via research application to ResDAC; variable fees apply                          | Low   | Only one economic domain and one perspective represented with the linkage   |
| National Health Interview Survey (NHIS), <i>CDC/NCHS</i>                     | <a href="https://www.cdc.gov/nchs/data-linkage/medicare.htm">https://www.cdc.gov/nchs/data-linkage/medicare.htm</a>   | Survey         | 30,000  | Direct medical costs, indirect costs          | <i>Direct medical costs:</i> Insurance Premium, OOP health care costs<br><i>Indirect costs:</i> Absenteeism, time costs: home production and leisure, inability to work, productivity | 1994–2018 NHIS data has been linked to 1994–2018 Medicare enrollment data and 1994–2013 and 2016–2018 FFS claims  | Via research application to NCHS Research Data Center (RDC); variable fees apply | High  | Multiple economic outcome domains and perspectives represented with the linkage.<br>(Note: only one sampled adult and child per household is linked.) |
| National Health and Nutrition Examination Survey (NHANES), <i>CDC/NCHS</i>   | <a href="https://www.cdc.gov/nchs/data-linkage/medicare.htm">https://www.cdc.gov/nchs/data-linkage/medicare.htm</a>   | Survey         | 9254  | Direct nonmedical costs, indirect costs       | <i>Direct nonmedical costs:</i> Special food<br><i>Indirect costs:</i> Time costs: home production and leisure  | 1999–2018 Continuous NHANES and Third NHANES (NHANES III) data has been linked to 1999–2018 Medicare enrollment data and 1999–2013 and 2016–2018 FFS claims | Via research application to NCHS RDC; variable fees apply                        | High  | Multiple economic outcome domains and perspectives represented with the linkage   |

(Continued)

**TABLE 1.** Federally Funded Data Sources Currently Linked or Linkable to Medicare FFS Claims (*continued*)

| Data source name (Abbreviation), <i>steward</i>                   | URL for linked data   | Source of data | Sample size   | Available economic outcome categories   | Available economic outcome measures, by category  | Available time frame for linked data   | Outside researchers' access to linked data  | Rating of linked data for PCOR economic evaluations | Rationale for rating  |
|---|---|----------------|---------------|---|---|--|---|---|---|
| The Second Longitudinal Study of Aging (LSOA II), <i>CDC/NCHS</i> | <a href="https://www.cdc.gov/nchs/data-linkage/medicare.htm">https://www.cdc.gov/nchs/data-linkage/medicare.htm</a>                 | Survey         | 7527          | Indirect costs                          | <i>Indirect costs:</i> Absenteeism, Time costs: home production and leisure, inability to work, productivity  | The 1994 LSOA II survey data are linked to 1991 – 2013 Medicare FFS claims   | Via research application to NCHS RDC; variable fees apply   | High  | Multiple economic outcome domains and perspectives represented with the linkage |
| National Hospital Care Survey (NHCS), <i>CDC/NCHS</i>             | <a href="https://www.cdc.gov/nchs/data-linkage/nhcs-linkage.htm">https://www.cdc.gov/nchs/data-linkage/nhcs-linkage.htm</a>         | Survey         | 500 hospitals | Direct medical costs                    | <i>Direct medical costs:</i> Paid/reimbursed amount   | 2014, 2016   | Via research application to NCHS RDC; variable fees apply   | Low   | Only one economic domain and one perspective represented with the linkage       |
| The National Nursing Home Survey (NNHS), <i>CDC/NCHS</i>          | <a href="https://www.cdc.gov/nchs/data-linkage/medicare.htm">https://www.cdc.gov/nchs/data-linkage/medicare.htm</a>                 | Survey         | 1 million+    | Direct medical costs                    | <i>Direct medical costs:</i> OOP health care costs  | 2004 NNHS has been linked to 1999–2018 Medicare enrollment data and 1999–2013 and 2016–2018 FFS claims                       | Via research application to NCHS RDC; variable fees apply   | Medium  | Multiple economic measures and perspectives represented with the linkage        |
| United States Renal Data System (USRDS), <i>NIH</i>               | <a href="https://usrds.org/">https://usrds.org/</a>   | Administrative | 1 million+    | Direct medical costs                    | <i>Direct medical costs:</i> Paid/reimbursed amount, OOP health care costs  | 2011–2019  | Via a research proposal and a USRDS Merged Dataset Agreement for Release of Data; no fees   | Medium  | Multiple economic measures and perspectives represented with the linkage        |
| National Health and Aging Trends Study (NHATS), <i>NIH</i>        | <a href="https://www.medic.info/partners-pages/nhats">https://www.medic.info/partners-pages/nhats</a>                               | Survey         | 16,283        | Direct medical costs, indirect costs    | <i>Direct medical costs:</i> Insurance premium<br><i>Indirect costs:</i> Inability to work  | Longitudinal linked data available for participants in the 2011 cohort and new participants in the 2015 cohort               | NHATS-CMS linked data files are available through MedRIC. Access to linked data requires a DUA with NHATS and data protection plan; no fees | High  | Multiple economic outcome domains and perspectives represented with the linkage |
| National Study of Caregiving (NSOC), <i>NIH</i>                   | <a href="https://nhats.org/researcher/nsoc">https://nhats.org/researcher/nsoc</a>   | Survey         | 2361          | Direct nonmedical costs, indirect costs | <i>Direct nonmedical costs:</i> Time costs: Informal caregiving, transportation, special food, time costs: health care seeking, home modifications, housekeeping<br><i>Indirect costs:</i> Absenteeism, inability to work | Longitudinally linked data available for participants in the 2011 NHATS cohort and new participants in the 2015 NHATS cohort | NHATS-CMS linked data files are available through MedRIC. Access to linked data requires a DUA with NHATS and data protection plan; no fees | High  | Multiple economic outcome domains and perspectives represented with the linkage |
| National Long Term Care Survey (NLTC), <i>NIH</i>                 | <a href="https://www.icpsr.umich.edu/web/NACDA/studies/9681/summary">https://www.icpsr.umich.edu/web/NACDA/studies/9681/summary</a> | Survey         | 35,789        | Direct medical costs                    | <i>Direct medical costs:</i> Paid/reimbursed amount, OOP health care costs, insurance premium   | 1984–2004  | NLTCs linked data are available through MedRIC. Access to linked data requires a DUA and data protection plan; no fees                      | Medium  | Multiple economic measures and perspectives represented with the linkage        |
| SEER-Medicare <i>NIH*</i>   | <a href="https://healthcaredelivery.cancer.gov/seermedicare/">https://healthcaredelivery.cancer.gov/seermedicare/</a>               | Administrative | 6 million+    | Direct medical costs                    | <i>Direct medical costs:</i> Paid/reimbursed amount   | 1999–2019  | Via research proposal to IMS (NCI's information technology contractor); variable fees apply   | Low   | Only one economic domain and one perspective represented with the linkage       |
| Health and Retirement Study (HRS), <i>NIH</i>                     | <a href="https://resdac.org/cms-data/files/hrs-medicare">https://resdac.org/cms-data/files/hrs-medicare</a>                         | Survey         | 27,895        | Direct medical costs                    | <i>Direct medical costs:</i> Insurance premium, paid/reimbursed amount, OOP health care costs   | 1991–2021  | Research application to HRS. Access to linked data through MedRIC. Access requires a DUA and data protection plan; no fees.                 | Medium  | Multiple perspectives represented with the linkage                              |

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| Panel Study of Income Dynamics (PSID), University of Michigan                                    | https://psidonline.isr.umich.edu/                         | Survey         | 26,000                              | Direct medical costs, direct nonmedical costs, indirect costs | 1991–2010   | Research application to PSID. Access to linked data through MedRIC. Access requires a DUA and data protection plan; \$750 fee applies | High   | Multiple economic outcome domains and perspectives represented with the linkage |
|--|---|----------------|-------------------------------------|---|---|---|--------|---|
| Health Economics Resource Center Average Cost Datasets (HERC), US Department of Veterans Affairs | https://www.herc.research.va.gov/include/page.asp?id=home | Administrative | Unknown                             | Direct medical costs  | NA  | Outside researchers must collaborate with a Veterans Affairs researcher; fees may apply   | Medium | Multiple perspectives represented with the linkage                              |
| Medical Expenditure Panel Survey (MEPS) <sup>†</sup> Agency for Healthcare Research and Quality  | https://meps.ahrq.gov/mepsweb/                            | Survey         | 30,716 individuals, 12,756 families | Direct medical costs, direct nonmedical costs, indirect costs | 1996–2019 MEPS linked with 2014–2018 Medicare claims; 1996–2014 MEPS linked with 1999–2013 Medicare claims. (Note: MEPS links to NHIS based on its sampling design, so the NHIS link dates also apply to MEPS.) | Via research application to the National Center for Health Statistics RDC; variable fees apply  | High   | Multiple economic outcome domains and perspectives represented with the linkage |

\*With the exception of the SEER-Medicare data which are already in linked form, the economic outcome measures field for all other data sources represents the specific outcomes that are available independently in the data source versus via the linkage.  
<sup>†</sup>Although publicly available information about the MEPS-Medicare data linkage is not available, a technical expert panel (TEP) member at AHRQ confirmed with the research team that external researchers can request for MEPS-Medicare linked data through the NCHS RDC.  
 DUA indicates data use agreement; FFS, fee-for-service; NA, not available; OOP, out-of-pocket; PCOR, patient-centered outcomes research; SEER, Surveillance, Epidemiology, and End Results.

size, and file types. Data obtained through the NCHS RDC costs roughly \$500 per data year, \$300 per RDC access day, and other fees.<sup>32</sup> There is currently no cost for linked data through MedRIC.<sup>21</sup>

### Strengths and Limitations of Linked Data

Most surveys have limited, self-reported data on health and economic outcomes, so a key advantage of linkages to claims is the ability to more precisely and accurately measure health, health care, and direct medical costs. Longitudinal surveys linked to claims also support analysis using stronger statistical and causal inference methods. Surveys add a wider range of economic outcomes, as well as social determinants of health (SDOH) and equity measures that are not widely available in claims or administrative sources.

Linked survey data have several limitations. Smaller sample sizes may limit analyses of subgroups and rare health events. Most surveys also lag 2+ years before release, and linked files may further lag, decreasing their value for studying emerging research questions. Finally, sampling designs, questionnaires, and other features may change over time, limiting longitudinal or trend analysis.

Linking administrative data sources to Medicare claims may add several strengths for PCOR. Disease registry linkages (SEER,<sup>31</sup> United States Renal Data System<sup>33</sup>) add epidemiologic specificity which is unavailable on claims. Linkages to Medicaid facilitate analyses of the higher cost and need of dual-eligible population.<sup>34</sup> Many administrative linkages potentially span large population groups, include detailed geographic information, and may facilitate robust longitudinal analyses.

Administrative linkages—in contrast to surveys—lack data on direct nonmedical or indirect costs for economic outcomes. They also add limited information on SDOH and equity measures, although this may improve if usage of International Classification of Diseases, 10th Revision (ICD-10) Z codes becomes commonplace.<sup>35–37</sup> In addition, while linked administrative sources often include large sample sizes and cover a national area, time frames may be limited. SEER-Medicare and linked Medicaid RIF data are an exception, spanning 1999–2019.

### DISCUSSION

We identified 18 data sources for PCOR economic evaluations that are currently linked or linkable to Medicare claims data. As shown in Table 1, many of the survey sources—especially MEPS, MCBS, NSOC, and PSID—are valuable as PCOR data sources on their own, regardless of Medicare linkage. If analyzed independently, these sources would provide information about several economic outcomes for populations beyond Medicare FFS, including Medicare Advantage (MCBS) or the full US population (MEPS). Linking these surveys to Medicare FFS is a tradeoff which narrows the population which can be studied. At the same time, it facilitates a granular study of health care encounters, direct medical costs, paid and out-of-pocket amounts, specific prescription drugs, diagnosed health care conditions, health care procedures, and specific facilities which is required for certain types of PCOR questions.

Reviewing the data sources in Table 1, several gaps are apparent and could be targeted in the future. None of the

**TABLE 2.** Select Characteristics of Federally Funded Data Sources Linked or Linkable to Medicare Claims

| Characteristics  | No. data sources | % of data sources* |
|--|------------------|--------------------|
| Data source steward  |                  |                    |
| Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS) <sup>†</sup> | 5                | 28                 |
| Centers for Medicare & Medicaid Service (CMS) <sup>†</sup>   | 4                | 22                 |
| National Institutes of Health (NIH) <sup>†</sup>   | 6                | 33                 |
| University of Michigan, Ann Arbor  | 1                | 6                  |
| US Department of Veterans Affairs  | 1                | 6                  |
| Agency for Healthcare Research and Quality (AHRQ)  | 1                | 6                  |
| Source of data   |                  |                    |
| Survey   | 12               | 67                 |
| Administrative   | 6                | 33                 |
| Lowest level of aggregation <sup>‡</sup>   |                  |                    |
| Individual   | 17               | 94                 |
| Encounter/claim  | 3                | 17                 |
| Length of observation <sup>§</sup>   |                  |                    |
| Panel/longitudinal   | 12               | 67                 |
| Cross-sectional  | 7                | 39                 |
| Periodicity of data collection <sup>  </sup>   |                  |                    |
| Annual   | 14               | 78                 |
| Biennial   | 3                | 17                 |
| Other <sup>¶</sup>   | 2                | 11                 |
| Observable social determinants of health domains <sup>#</sup>  |                  |                    |
| Social context   | 18               | 100                |
| Economic context   | 14               | 78                 |
| Education  | 10               | 56                 |
| Physical infrastructure  | 7                | 39                 |
| Health care context  | 17               | 94                 |
| Social context   | 18               | 100                |
| Observable health equity-related factors   |                  |                    |
| Age  | 18               | 100                |
| Sex  | 18               | 100                |
| Race/ethnicity**   | 14               | 78%                |
| Income or income status**  | 12               | 67                 |
| Urban-rural status**   | 16               | 89                 |
| Disability status**  | 13               | 72                 |
| Religious affiliation**  | 2                | 11                 |
| LGBTQ+ status**  | 3                | 17                 |

Note: Findings are based on the 18 federal and federally funded data sources identified using the search process described in the Methods section. (Although a comprehensive scan was conducted, the exhibit may not represent all datasets that are linked or linkable to Medicare claims.)

\*Totals may not add up to 100% due to rounding or nonmutual exclusivity of categories.

<sup>†</sup>Represents agencies at the United States Department of Health and Human Services (HHS).

<sup>‡</sup>Categories are not mutually exclusive. Medicaid and Part D claims files include both individual-level enrollment data and encounter/claim-level data.

<sup>§</sup>Categories are not mutually exclusive. The National Study of Caregiving has historically been a source of cross-sectional data. However, longitudinal data collection began in 2017, and will continue to be implemented going forward. Therefore, this data source was counted as both cross-sectional and longitudinal data.

<sup>||</sup>Categories are not mutually exclusive. The Panel Study of Income Dynamics provided annual data from 1968 to 1997, and then changed to biennial after 1997. Therefore, this data source was counted as both annual and biennial data.

<sup>¶</sup>Values in "Other" include: (1) every 5 years (National Long Term Care Survey) and (2) 1973–74, 1977, 1985, 1995, 1997, 1999, and 2004 (National Nursing Home Survey).

<sup>#</sup>This field was populated based on 5 social determinants of health (SDOH) categories in a framework from the Agency for Healthcare Research and Quality (AHRQ) (<https://www.ahrq.gov/sdoh/about.html>).

\*\*These characteristics have been identified as priority populations in the *Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*.

LGBTQ+ indicates lesbian, gay, bisexual, transgender, queer or questioning.

**TABLE 3.** Economic Outcome Measures in Federally Funded Data Sources Linked or Linkable to Medicare Claims

| Economic outcome measure   | No. data sources | % of data sources* |
|--|------------------|--------------------|
| Domain: Direct medical costs   |                  |                    |
| Paid/reimbursed amount   | 10               | 56                 |
| Out-of-pocket health care costs and/or medical expenses  | 11               | 61                 |
| Insurance premiums   | 8                | 44                 |
| Domain: Direct nonmedical costs  |                  |                    |
| Transportation and/or travel costs associated with seeking medical care                          | 2                | 11                 |
| Vehicle modification expenses  | 0                | 0                  |
| Paid professional care (child care expenses, senior care expenses, and/or housekeeping expenses) | 1                | 6                  |
| Relocation/moving costs  | 0                | 0                  |
| Specialized clothing/laundry costs   | 0                | 0                  |
| Value of time spent in seeking health care   | 2                | 11                 |
| Value of informal caregiving   | 3                | 17                 |
| Special food   | 2                | 11                 |
| Home modifications   | 2                | 11                 |
| Domain: Indirect medical costs   |                  |                    |
| Value of absenteeism   | 5                | 28                 |
| Value of presenteeism  | 2                | 11                 |
| Value of time spent in home production and leisure   | 4                | 22                 |
| Lost wages from inability to work  | 4                | 22                 |
| Value of absenteeism   | 5                | 28                 |

Note: Findings are based on the 18 federal and federally funded data sources identified using the search process described in the Methods section. (Although a comprehensive scan was conducted, the exhibit may not represent all datasets that are linked or linkable to Medicare claims.) Dozens of variables in a data source may be used to capture specific details about an economic outcome measure.

\*Totals may not add up to 100% due to rounding or nonmutual exclusivity of categories.

linked administrative data sources contain information on direct nonmedical or indirect costs. Such costs can only be measured presently for Medicare FFS beneficiaries using surveys. However, there are examples of measuring some of these outcomes in other, largely nonfederal administrative data sources which are not linked to FFS claims, such as employment records.<sup>38,39</sup> On average, administrative data tend to capture more payer-focused outcomes, such as charges, payments, and charge-to-cost ratios. We also found that some direct nonmedical costs (relocation, vehicle modifications, specialized clothing) were not captured in any source.

Sample sizes are a concern across many survey linkages. While the nationally representative NSOC, MEPS, and PSID have great utility for PCOR economic evaluations, their sample sizes make it difficult to study rarer health outcomes or treatments. MEPS and NSOC have Medicare samples of about 5000 and 10,000 per wave, respectively. PSID has a longer longitudinal sample of Medicare, but fewer health-related survey questions. HRS has the largest Medicare sample in a single wave, nearly 20,000. PSID and HRS also contain unique detail on employment, income, and assets relative to other sources.

Data access and availability is another important consideration for improving research on economic outcomes

relevant to PCOR. RIF Medicare claims have significant costs and access restrictions. These are greater when linked: all sources require research applications and restrictive data use agreements. At the same time, if data are linked for new studies, sustainability and maintenance of linkages present a challenge for dissemination and may inhibit wider PCOR research. Privacy and data protections are critical but also a barrier to research. Emerging solutions, such as synthetic data or protected data enclaves such as MedRIC, may improve access to linked data and encourage greater research. Although some economic outcomes were not captured in any linked sources, efforts that expand existing areas (Tables 2, 3) could broaden study samples to wider populations. Currently, NHIS and NHANES may be especially valuable for marginalized populations and those with health-related social needs through their inclusion of indirect costs and improved measures of SDOH.

The scope of this review excluded geographic linkages in which information from external sources, such as the American Community Survey or Area Health Resources File, is joined at an aggregate level. Such merges are common in health services research and could provide some measures of SDOH or health equity, although they typically do not add individual-level economic outcomes. Our key informants also emphasized the importance of linking claims to supplemental sources that relate to other cost drivers, including clinical data, social and economic context, and health plan features (cost-sharing, networks).

Finally, while we focused on the Medicare FFS population, the growing Medicare Advantage program creates an urgent need for improved data and methods to measure economic outcomes for this population. Recent data show that demographics, income, and health needs are now remarkably similar between the Medicare FFS and Medicare Advantage populations,<sup>40</sup> although Medicare Advantage enrollment is higher in urban areas and lowest in rural states.<sup>10</sup> The Part C data presently available to researchers are encounters, capturing utilization but lacking costs. As Part C enrollment approaches nearly half of Medicare, it will become important to prioritize this population and to identify data sources that can be linked with encounters to study the economic outcomes for Medicare Advantage beneficiaries. Currently, linked HRS and NHATS data include Medicare Advantage via the Master Beneficiary Summary File (MBSF). Medicare Advantage encounter data have also been linked to NHIS, NHANES, National Nursing Home Survey (NNHS),<sup>41</sup> and National Hospital Care Survey (NCHS).<sup>42</sup> All-payer claims databases also hold the potential for measuring the full Medicare population.

## Limitations

This review has limitations. The selected economic outcomes were based upon a previous federal report.<sup>12,13</sup> We believe that list is comprehensive, but varying definitions or omissions are possible. Second, we focused on the Medicare FFS population. Third, we included only federally funded linked sources, which are generally the only standing Medicare data linkages which are publicly available. CMS is the only source of complete Medicare FFS data, but Medicare is partially captured in private and state sources, such as all-payer claims databases

and Healthcare Cost & Utilization Project (HCUP) data, and commercial options exist for Medicare Advantage and supplemental coverage. These other sources may have linkages. We excluded “one-off” projects, where proprietary linkages to Medicare were created but which are not accessible to outside researchers. Fourth, our inventory may have missed certain sources or economic outcome measures. Finally, while discussions with subject matter experts were invaluable, their perspectives may not represent all PCOR stakeholders.

## CONCLUSIONS

Data on economic outcomes are important for patients, families, payers, and other stakeholders, as health care decisions often have significant economic consequences. Improved research on economic outcomes relevant to patients can provide invaluable information to help all stakeholders make better decisions. To date, information and research are often limited by available data sources and a fragmented health care system. This paper shows several different linked data sources which expand the range of economic outcome measures for PCOR research for the Medicare FFS population. Many of the linked sources add new information at the patient level, and research on household economic burdens may continue to be challenging, even with linked data.

Medicare data represent an invaluable resource for conducting PCOR studies of economic outcomes for 65 million beneficiaries. While Medicare FFS claims have several advantages, their scope is limited by a small number of economic outcomes. Consequently, linkages to surveys and other administrative data hold great potential for improving the federal data landscape on economic outcomes relevant to patients. Barriers to access, cost, scope, and generalizability inhibit wider research on existing linkages. However, efforts to continue to improve access and foster new data linkages may encourage innovations and help to produce important applied research.

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