PROJECT REPORT

Federal Data for Conducting Patient-Centered Outcomes Research on Economic Outcomes

Prepared for
**the Office of the Assistant Secretary for Planning and Evaluation (ASPE)
at the U.S. Department of Health and Human Services**

by
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Office of the Assistant Secretary for Planning and Evaluation

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Abstract

Background. Patients are increasingly interested in information about the economic burdens and impacts of different treatment choices on their lives and on their families. These may include direct medical costs that are directly tied to the receipt of specific health care services (e.g., out-of-pocket medical expenses), direct non-medical costs that are associated with health care or illness but are not part of the purchase of medical services (e.g., transportation costs associated with seeking medical care), and indirect costs which represent the value of resources lost as a result of incurring illness or health care treatments (e.g., lost wages and benefits from voluntary or involuntary unemployment). Such types of impacts are also relevant for non-patient stakeholder groups such as caregivers, employers, providers, and insurers and payers. While there have been and continue to be federal investments into patient-centered outcomes research (PCOR) and health care data collection, a greater understanding is needed on the gaps in federal and federally funded data that can be used for PCOR economic evaluations.

Objective. To assess the current landscape of federal and federally funded health care data relevant to PCOR and economic analysis to identify gaps for data stewards, researchers, and future collection efforts.

Methods. A targeted internet search was conducted to identify a list of outcomes relevant to PCOR economic evaluations, and federal and federally funded data sources that contain information on identified economic outcomes. Information from the search was supplemented by semi-structured individual interviews with nine key informants representing researchers, data stewards, and patient representatives. The interviews sought to gather additional feedback on economic outcomes and data sources, as well as identify unanswered research questions for the PCOR field to consider.

Results. Four types of direct medical costs, 12 distinct direct non-medical costs, and four types of indirect costs, were identified as being relevant for PCOR economic evaluations. With regard to the current data infrastructure, 29 federal or federally funded data sources were identified as containing information on one or more of these outcomes. Most of the identified data sources (65 percent) contain elements related to direct medical costs. Data on direct non-medical costs and indirect costs were less commonly captured; 34 percent of data sources contain information on one or more direct non-medical costs, while 48 percent of data sources contain information on at least one type of indirect cost. With regard to the characteristics of the included data sources, 76 percent are funded by agencies within the U.S. Department of Health and Human Services. Most data sources were surveys (52 percent), provide information at the individual level (52 percent), and collect data on an annual basis (76 percent). The vast majority of data sources (90 percent) provide nationally representative information, and about 62 percent of data sources are cross-sectional in nature.

Conclusion. The existing federal data infrastructure captures a limited range of the full economic burden of health and health care, when considering the perspectives of patients, caregivers, employers, and insurers. No single source exists that spans the full range and all perspectives, but research from multiple data sources, and potential future data integrations, can fill in important gaps. Data linkages appear to be an efficient and important strategy for improving PCOR-relevant economic burden studies. Further standardization of PCOR economic measures across data sources may also improve comparability and utility of research findings for patients, caregivers, employers, and insurers.

Introduction

Advances in the science and practice of medicine have brought enormous gains to the United States, curing many previously fatal diseases[i], extending lifespans[ii], and reducing morbidity.[iii] These beneficial achievements have improved lives, but the technology of medicine also brings a new set of challenges, for example, around data security and privacy, and patient safety. Emerging health threats and escalating health care costs[iv] are also concerns, and a growing body of research on the role of social determinants of health[v] has highlighted wide disparities in medicine and health.[vi]

Even when access is addressed, patients are increasingly faced with the need to understand how treatments affect health outcomes such as survival, quality of life, symptoms, and functionality. Medical innovations also present providers, employers, and health care systems with complex tradeoffs in health care decision-making.[vii,viii] These include—but are not limited to—differences in effectiveness, quality of care, outcomes, frequency, duration, invasiveness, side effects, and cost.[ix] Comparative effectiveness research (CER)[x] is one potential tool for assessing the range of scientific evidence on specific types of health care and for helping stakeholders to make health care decisions for patient and population health needs. The Patient Protection and Affordable Care Act (ACA) of 2010 established the Patient-Centered Outcomes Research (PCOR) Trust Fund to support CER and other activities to promote research into quality of care and relevance of scientific evidence[xi] to patients and key stakeholders.

PCOR and Economic Outcomes

The Patient-Centered Outcomes Research Institute (PCORI), an independent body created by the ACA, defined the purpose of PCOR as: "PCOR helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options."[xii] Furthermore, PCORI established that PCOR should include assessing benefits and harms of treatment, respecting patient preferences, incorporating diverse participants, and investigating "outcomes while addressing burden to individuals … and other stakeholder perspectives."[xiii] Economic costs were excluded from the initial definition. However, in 2019, the PCOR Trust Fund was reauthorized by Congress, and the scope of PCOR studies was expanded to include economic and cost burdens of health care: "…clinical and patient-centered outcomes shall include the potential burdens and economic impacts of the utilization of medical treatments, items, and services on different stakeholders and decision-makers respectively. These potential burdens and economic impacts include medical out-of-pocket costs, including health plan benefit and formulary design, nonmedical costs to the patient and family, including caregiving, effects on future costs of care, workplace productivity and absenteeism, and healthcare utilization."[xiv] Many researchers also include intangible costs, such as quality of life and mortality, as economic impacts relevant to PCOR, although valuation of intangible costs is difficult since "market" prices do not exist.[xv] Given this difficulty, and the fact that the expanded definition of PCOR in the 2019 reauthorization does not explicitly list intangible costs, they are excluded from this paper.

To generate evidence about the economic impacts, benefits, and burdens of health care, researchers require data to study the full range of health outcomes to thereby meet the needs of patients, clinicians, purchasers, and policymakers in making informed health decisions. Economic outcomes and impacts relevant to PCOR can be broadly grouped into three categories: (1) direct medical costs (those tied to the receipt of specific health care services for a patient); (2) direct non-medical costs (those associated with health care or illness, but not part of the purchase of medical services); and (3) indirect costs (the value of resources which are lost as a result of incurring illness or health care treatments).[xvi] Together, these costs represent the total burden of health care and are borne by both patients and their family

members, and non-patient stakeholder groups, such as caregivers, employers, providers, and insurers and payers.

Key scientific challenges must be addressed for PCOR to fully encompass this broader scope and provide relevance to stakeholders. Most patient-centered research reports limited elements of the total economic burden that can potentially be experienced by patients, reflecting currently available data. Many primary data sources used to measure economic burden contain limited measures of patient-centered outcomes.[xvii,xviii,xix,xx] Gaps in data sources or research mean that some types of PCOR economic outcomes that may be relevant for health care decisions are unmeasured.[xxi] When economic costs and impacts are substantial (e.g., a complex surgery or costly new therapy), this gap in PCOR may be highly consequential and have a substantial impact on patients and their families. Therefore, the current PCOR data infrastructure can be strengthened to better measure patients' economic outcomes.

Purpose of the White Paper

While there have been and continue to be federal investments into PCOR and health care data collection, a greater understanding is needed on the gaps in federal data, in order to identify additional areas (such as data linkages) where new work may be needed toward enhancing the utility of the federal data infrastructure for PCOR researchers. The overall aim of this paper is to respond to the Trust Fund's reauthorization language by describing existing economic data resources that could be useful for a variety of PCOR studies.

This paper has three key objectives:

1. Guide researchers who currently conduct PCOR on the concepts and measures of economic impacts and costs under the expanded reauthorization definition of PCOR;
2. Facilitate engagement across federal agencies on potential economic analyses that could be undertaken as part of PCOR studies; and
3. Report findings of a review of existing federal data sources relevant to PCOR and identify gaps for future efforts to expand data capacity for PCOR.

Methods

Our approach to compiling an inventory of federal and federally funded data sources that can be used for PCOR economic analyses comprised three steps: (1) first, we identified a list of outcomes relevant to PCOR economic evaluations; (2) second, we identified federal data sources that contain information on these economic outcomes; and (3) third, we sought feedback on economic outcomes and federal data sources from subject matter experts via a Technical Expert Panel (TEP) and key informant interviews. Below we describe each of these steps in more detail.

Identification of Economic Outcomes

We conducted a brief, targeted internet search to compile a set of economic outcomes relevant to this white paper. We relied on PubMed and Google Scholar to identify sources published in English, using the search terms listed in Exhibit 1. We used Boolean operators to combine these search terms.

Exhibit 1. Search Terms for Identification of Economic Outcomes

Stakeholder-Related	Economic Outcome-Related	Topic-Related
■ Patient ■ Caregiver ■ Employer ■ Payer	■ Cost of illness ■ Burden of illness ■ Indirect cost ■ Productivity ■ Absenteeism ■ Presenteeism ■ Economic impact ■ Economic assessment ■ Economic burden	■ Health care

Identification of Federal/Federally Funded Data Sources

We followed a stepwise approach to efficiently identify federal data sources with information on identified economic outcomes, which built on our existing knowledge of data sources. First, we reviewed two compilations of data sources: the National Healthcare Quality and Disparities Report (NHQDR),[xxii] and a 2009 peer-reviewed publication in *Medical Care.*[xxiii] The NHQDR, published annually by the Agency for Healthcare Research and Quality (AHRQ), is based on survey and administrative data from a host of contributing agencies and organizations (federal and non-federal), many of which contain variables related to health care costs. The *Medical Care* article documents 88 data sources that can be used to estimate health care costs in the United States.

Second, we did an internet search of websites to identify federal and federally funded data sources that capture the identified economic outcomes, including: data.gov, AHRQ, Department of Health and Human Services (HHS), Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Centers for Medicare & Medicaid Services (CMS), National Center for Health Statistics (NCHS), U.S. Census Bureau, Medicaid and CHIP Payment and Access Commission (MACPAC), U.S. Government Accountability Office (GAO), National Institutes of Health (NIH), TRICARE/Department of Defense (DoD), Department of Veterans Affairs (VA), Office of the Assistant Secretary for Planning and Evaluation (ASPE), Administration for Children and Families (ACF), and Substance Abuse and Mental Health Services Administration (SAMHSA). We also reviewed the website of the Research Data Assistance Center (ResDAC), a CMS contractor that provides information to the research community for CMS research data. Finally, we performed a targeted internet search for additional relevant reports, reviews, and publications on federal data sources using Boolean operators to combine the search terms listed in Exhibit 1 with the terms "federal" and "data."

Once the list of data sources was identified, relevant information was abstracted from each of them into a spreadsheet inventory. Exhibit 2 lists the fields included in the inventory, organized by category. Fields have been grouped into five categories related to characteristics (e.g., the periodicity of data collection, and source of data), size and scope (e.g., whether the data are nationally representative/have national coverage), data access (whether the data are publicly available, and the purchase cost), economic outcomes (both the three domains of outcomes and available measures in each domain), and other topics (e.g., strengths and limitations of the data).

Exhibit 2. Fields in the Federal Data Inventory

Fields related to Characteristics	Fields related to Size and Scope	Fields related to Data Access	Fields related to Economic Outcomes	Other Fields
■ Data source name ■ Data source acronym ■ Data source steward ■ Data source URL ■ Periodicity of data collection (e.g., annual) ■ Source of data (administrative or survey) ■ Administrative data type (e.g., hospital encounter records; NA for survey data) ■ Lowest level of aggregation (e.g., individual) ■ Length of observation (e.g., longitudinal)	■ Years of data available ■ Latest available sample size ■ Latest available survey response rate (NA for administrative data) ■ Population scope of data (e.g., U.S. civilian non-institutionalized population) ■ Whether the data are nationally representative/have national coverage or not ■ Lowest level of geography available	■ Whether the data are publicly available or not ■ Whether additional restricted-use data are available for the publicly available data (NA for data sources not publicly available) ■ Whether there are costs to acquire data	■ Available Economic Outcome Categories (e.g., direct medical, costs) ■ Available Economic Outcome Measures, by category (e.g., out-of-pocket health care costs for direct medical costs) ■ Economic perspectives represented (e.g., patients) ■ Identifiable SDOH categories* ■ Whether demographics data are available for disparities/equity analysis**	■ Existing data linkages ■ Strengths of data source ■ Limitations of data source ■ Link to data documentation page ■ Example peer-reviewed publication that has used the data source

*This field was populated on the basis of five social determinants of health (SDOH) categories that were defined based on AHRQ's framework (https://www.ahrq.gov/sdoh/about.html).

**In addition to age and sex, other demographic characteristics that were used to populate this field were derived from the *Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*.

Engagement with Subject Matter Experts

We solicited subject matter expert feedback on the list of economic outcomes and federal data sources, using two channels. First, we convened an eight-member TEP comprised of ASPE and non-ASPE staff. We included a diverse array of experts in PCOR, health economics and evaluation, health economic measurement, and health equity. We met with the TEP three times between May and August 2021 to gather feedback on economic outcomes and data sources, as well as on drafts of this white paper. We also conducted nine individual semi-structured interviews with key informants representing researchers, data stewards, and patient representatives. Questions in the interviews centered around identifying outcomes and data sources, discussing existing and potential linkages that can be implemented with these data sources, and prioritizing research questions that the PCOR field could explore in the future. Appendix B contains the stakeholder-specific discussion guides used for these interviews.

Findings

We present our findings in two parts. In the first part, we describe the key economic outcomes that were identified as being relevant for this paper. In the second part, we describe the salient features of the federal and federally funded data sources with information on one or more of these identified outcomes. All findings reflect the internet scans for outcomes and data sources, as well as our engagement with the TEP and key informants.

Findings on Economic Outcomes

The various economic outcomes that were identified to be relevant are shown in Appendix A, Exhibit A-1. As seen, there are three categories of economic outcomes: direct medical costs, direct non-medical costs, and indirect costs, which are mapped to four stakeholder perspectives—patients, caregivers, employers, and payers—who represent the entities most likely to use economic information in decision-making. To measure the economic burden associated with health care treatment or illness, we are interested in the incremental change of each category associated with that treatment or illness—in other words, not total costs which include amounts incurred in normal healthy living, but the amounts attributable to a particular treatment or illness (in economic terms, the "marginal cost" associated with an illness).

We identified **four major types of *direct medical costs*—**costs tied to the receipt of specific health care services for a patient**.** The paid amount represents the insurer's payment to providers for health care services. This is usually less than the billed charge and—except for the uninsured—is not a financial cost to the patient. Patient out-of-pocket (OOP) costs include both the health care costs of covered medical expenses (the patient's balance due after all insurance payments), and all types of non-covered medical expenses. The insurance premium cost is also a major health care cost to patients and employers.

We identified **12 distinct *direct non-medical costs*** relevant to various stakeholders—costs associated with health care or illness, but not part of the purchase of medical services. The value of informal caregiving is a substantial time cost borne by caregivers, who provide valuable unpaid health and home care. We identified three potential types of paid, professional care when a patient cannot perform certain tasks due to medical needs: child care, housekeeping, and elder care. Other types of direct non-medical costs associated with a health condition include patient time for seeking care, travel and transportation costs, relocation or moving costs, vehicle modifications (e.g., wheelchair lift), specialized food, specialized clothing, or laundry costs.

Finally, we identified **four types of *indirect costs*—**the value of resources which are lost as a result of incurring illness or health care treatments. Absenteeism or work loss associated with medical treatment or a health condition is relevant to employed patients, caregivers, and employers. (Time is counted only once: above it is direct time associated with receiving care, and here time is an indirect outcome.) The same groups may also incur costs of reduced productivity in the workplace (presenteeism). Lost home production and reduced leisure time is another cost to patients and potentially, caregivers. (Similarly, time is an indirect outcome here when it is ancillary to receiving health care.) Finally, many patients and/or their caregivers may face reduced education or career prospects, or eventually separate from the labor force due to permanent disability, early retirement, or other health-related factors. This sequence of events has a series of costs which are collected together under indirect earnings and benefits costs.

Findings on Federal/Federally Funded Data Sources

Below we describe the key characteristics of identified data sources, the economic outcomes available in each, the data linkages possible, and relative strengths and limitations. Summarized frequencies are presented for select characteristics in exhibits, and an abbreviated version of the data inventory underlying these summaries is available in Appendix A, Exhibit A-2. The full version of the data inventory is available on https://aspe.hhs.gov/.

Select Characteristics. We identified 29 federal or federally funded data sources for inclusion in the inventory. Exhibit 3 displays some of the key characteristics of the included data sources. Overall, the majority of data sources (76 percent) are funded by HHS (the associated agencies are AHRQ, CDC, CMS, NIH, and SAMHSA), with 31 percent of data sources funded by AHRQ. Survey data sources (52 percent) slightly outnumber administrative data. Similarly, slightly more data sources (52 percent) provide information at the individual level, and most collect data on an annual basis (76 percent). About 62 percent of data sources are cross-sectional in nature, followed by longitudinal or panel (38 percent).

All identified data sources capture information on at least one dimension of social determinants of health (SDOH), and as seen in Exhibit 3, the most commonly observed dimension is social context (captured by 100 percent of data sources). With respect to characteristics relevant for health equity, age and sex are most commonly captured, with all data sources containing these two factors. Urban-rural status is the next most common (in 79 percent of data sources), followed by income or income status (in 76 percent of data sources).

Exhibit 3. Select Characteristics of Federal/Federally Funded Data Sources with Information on PCOR Economic Outcomes

Characteristic	Number of Data Sources	% of Data Sources
Data Source Steward		
AHRQ*	9	31%
Bureau of Labor Statistics (BLS)	3	10%
CDC*	4	14%
CMS*	5	17%
NIH*	3	10%
SAMHSA*	1	3%
U.S. Census Bureau	2	7%
U.S. Department of Veterans Affairs	1	3%
University of Michigan	1	3%
Source of Data		
Survey	15	52%
Administrative	14	48%
Lowest Level of Aggregation		
Individual	15	52%
Encounter/claim	14	48%
Length of Observation[1]		
Panel/Longitudinal	11	38%
Cross-sectional	18	62%
Time series	1	3%
Periodicity of Data Collection[2]		
Annual	22	76%
Biennial	2	7%
Monthly	1	3%

Characteristic	Number of Data Sources	% of Data Sources
Quarterly	1	3%
Other[3]	4	14%
Observable Social Determinants of Health (SDOH) Domains[4]		
Social context	29	100%
Economic context	25	86%
Education	13	45%
Physical infrastructure	13	45%
Health care context	26	90%
Observable Health Equity-Related Factors		
Age	29	100%
Sex	29	100%
Race/ethnicity	21	72%
Income or income status**	22	76%
Urban-rural status**	23	79%
Disability status**	14	48%
Religious affiliation**	2	7%
LGBTQ+ status**	1	3%

Notes: The findings in this table are based on the 29 federal and federally funded data sources identified using the search process described earlier. Although a comprehensive scan was conducted, the table may not represent all datasets with PCOR economic outcomes.

* Represents agencies at HHS.

[1] These 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.

[2] These categories are not mutually exclusive. The Panel Study of Income Dynamics provided annual data from 1968-1997, and then changed to biennial after 1997. Therefore, this data source was counted as both annual and biennial data.

[3] Values in "Other" include: (1) every 60 days until discharge (Home Health Outcome and Assessment Information Set); (2) every three years (Kids' Inpatient Database); (3) continuously as each admission and discharge record is mined for data (Treatment Episode Data Set); and (4) every four months for two and a half to four years (Survey of Income and Program Participation).

[4] These are based on AHRQ's framework (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*.

Scope and Access. Exhibit 4 presents information on the scope and access of federal data sources. The vast majority of data sources (90 percent) provide nationally representative information. Most data sources (52 percent) are publicly available, and of these, 80 percent have additional data available for restricted-use. With regards to cost, all public-use files are free, while the cost for most restricted-use files (73 percent) varies by the scope of the project or amount of data requested.

Exhibit 4. Scope and Access of Federal/Federally Funded Data Sources with Information on PCOR Economic Outcomes
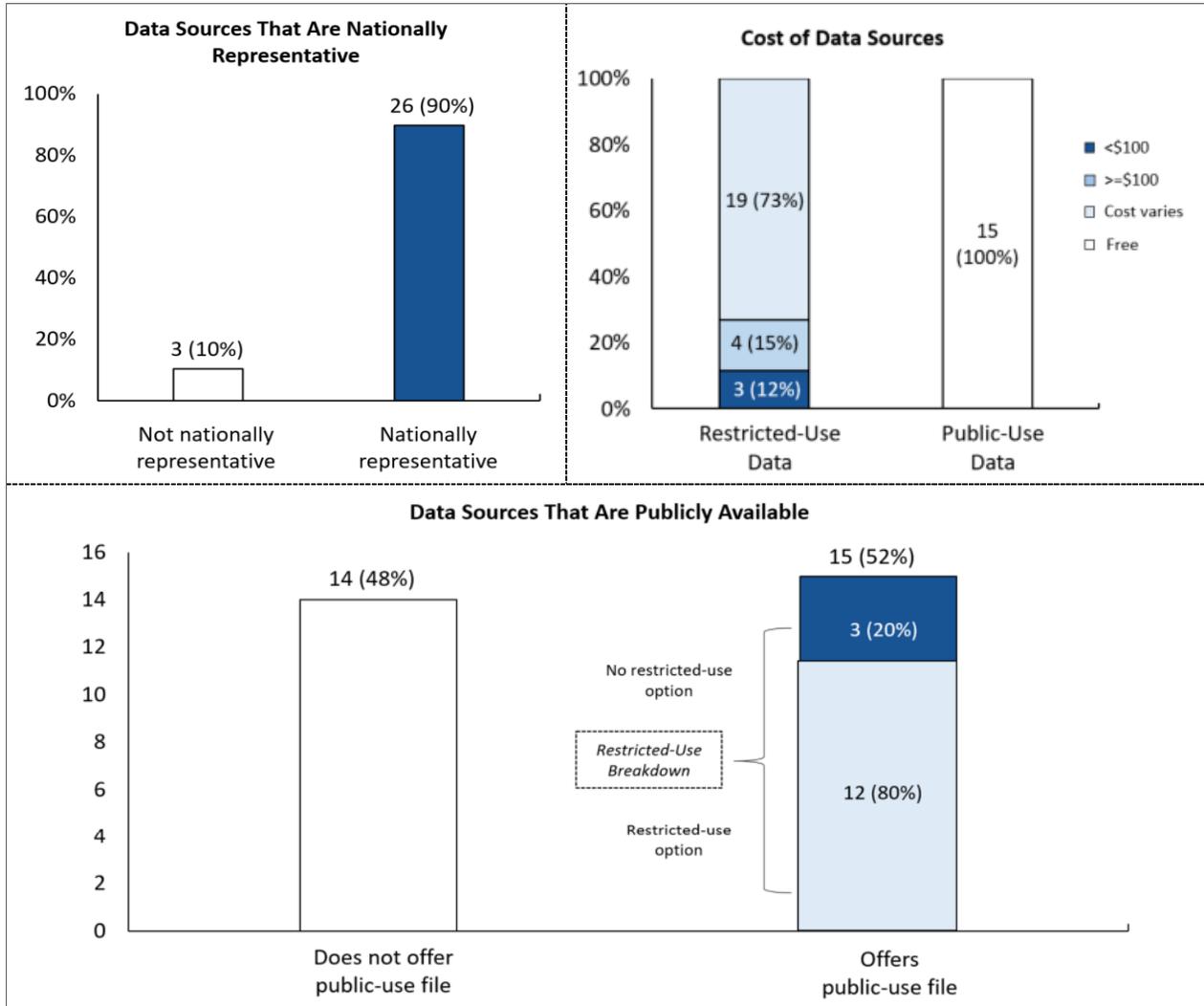
Data Sources That Are Nationally Representative

- Not nationally representative: 3 (10%)
- Nationally representative: 26 (90%)

Cost of Data Sources

Legend:
- ■ <$100
- ▣ >=$100
- □ Cost varies
- □ Free

Restricted-Use Data:
- 19 (73%)
- 4 (15%)
- 3 (12%)

Public-Use Data:
- 15 (100%)

Data Sources That Are Publicly Available

- Does not offer public-use file: 14 (48%)
- Offers public-use file: 15 (52%)
  - No restricted-use option: 3 (20%)
  - Restricted-use option: 12 (80%)

Restricted-Use Breakdown

Note: The findings in this table are based on the 29 federal and federally funded data sources identified using the search process described earlier. Although a comprehensive scan was conducted, the figure may not represent all datasets with PCOR economic outcomes.

Economic Outcomes. Most of the identified data sources (65 percent) contain elements related to direct medical costs. Data on direct non-medical costs and indirect costs were less commonly captured in federal and federally funded sources; 34 percent of data sources contain information on one or more direct non-medical costs, while 48 percent of data sources contain information on at least one type of indirect cost. It should be noted that economic outcome categories are not mutually exclusive across data sources; that is, several data sources capture more than one outcome category. Furthermore, of the 22 data sources maintained by agencies at HHS (AHRQ, CDC, CMS, NIH, and SAMHSA), the majority (73 percent) capture information on direct medical costs, and 41 percent capture information on indirect costs. Direct non-medical costs were much less prevalent in HHS data sources; only 27 percent of such data sources contain information on direct non-medical costs.

Exhibit 5 summarizes the specific measures within each of the three outcome categories that are observable in our identified federal data sources. As seen, paid/reimbursed amounts is the most commonly available measure both within the direct medical cost category and across all measures, in 48 percent of data sources. In the direct non-medical costs category, the value of informal caregiving is most commonly available (in 28 percent of data sources), followed by the value of time spent seeking health care (14 percent). None of the identified data sources have information on relocation/moving costs, or specialized clothing/laundry costs. Finally, for the indirect costs category, the most prevalent outcome in federal or federally funded data sources is the value of time spent in home production and leisure (in 24 percent of data sources), followed by value of absenteeism and lost wages from inability to work; these elements are each available in 21 percent of data sources.

With the exception of the Medical Expenditure Panel Survey (MEPS), no other data source in our identified list of 29 sources contained outcomes in all three domains. However, even in the case of MEPS, very few outcomes are captured within each domain. Specifically, MEPS provides information on (1) insurance premiums, paid/reimbursed amounts, and OOP health care costs under the direct medical cost domain; (2) informal caregiving under the direct non-medical cost domain; and (3) absenteeism under the non-medical cost domain. These outcomes facilitate a cost-of-illness study for a condition such as diabetes, which is self-reported in MEPS. However, other outcomes would still be excluded, and MEPS has significantly limited detail in the public use files on precise health care conditions or treatments. Other datasets are useful for other specific outcomes but often do not contain as wide a range for a given health condition or treatment.

Exhibit 5. Economic Outcomes in Federal/Federally Funded Data Sources with Information on PCOR Economic Outcomes

Outcome Category	Number of Data Sources	% of Data Sources
Direct Medical Costs		
Paid/reimbursed amount	14	48%
Out-of-pocket health care costs and/or medical expenses	8	28%
Insurance premiums	3	10%
Direct Non-Medical Costs		
Transportation and/or travel costs associated with seeking medical care	3	10%
Vehicle modification expenses	0	0%
Paid professional care (child care expenses, senior care expenses, and/or housekeeping expenses)	1	3%
Relocation/moving costs	0	0%
Specialized clothing/laundry costs	0	0%
Value of time spent in seeking health care	4	14%
Value of informal caregiving	8	28%
Special food	2	7%
Home modifications	1	3%
Indirect Costs		
Value of absenteeism	6	21%
Value of presenteeism	3	10%

Outcome Category	Number of Data Sources	% of Data Sources
Value of time spent in home production and leisure	7	24%
Lost wages from inability to work	6	21%

Note: The findings in this table are based on the 29 federal and federally funded data sources identified using the search process described earlier. Although a comprehensive scan was conducted, the table may not represent all datasets with PCOR economic outcomes.

Data Linkages. Data linkages represent a significant potential advance for improving PCOR-relevant economic burden studies since none of the data sources individually capture all economic outcome domains. Surveys may best capture patient-centered outcomes and contextual information (e.g., non-medical and indirect costs), while administrative sources capture granular health care or expenditure data, health outcomes from diagnosis codes, and program enrollment (e.g., monthly Medicaid eligibility). Linkages typically begin with a survey-based sample for contextual data (e.g., National Health Interview Survey [NHIS]) and are combined with an administrative source using confidential individual identifiers in each data source. (Outside the scope of this paper and the parameters of this review, we acknowledge that a variety of clinical registries or specialized cohorts have been linked by investigators to administrative sources such as Medicare (for example, the Nurses Health Study).)

Of the identified data sources, 17 (or 59 percent) are linkable to at least one other data source. A few of the existing data sources have been linked and are available for public distribution, although usually with additional data use restrictions, which often include review of a research proposal, human subjects (Institutional Review Board [IRB]) clearance, signed data use agreements (DUA), time-limited access, data security protocols or access restrictions (e.g., Federal Statistical Research Data Center access), and significant financial costs.[xxiv] For example, some key informants mentioned Surveillance, Epidemiology, and End Results (SEER)-Medicare, a linkage of cancer registry data and Medicare claims maintained by the National Cancer Institute to support evaluations of cancer treatment costs for Medicare beneficiaries, including select OOP costs incurred by patients. On the administrative side, Medicare and Medicaid claims from CMS have frequently been linked, and access permissions are well established under the Health Insurance Portability and Accountability Act (HIPAA) and CMS procedures; researchers seeking data from CMS work with ResDAC for assistance and approvals. On the survey side, many federal surveys from CDC/NCHS, CMS, U.S. Census Bureau, BLS, and publicly funded research studies have been linked on an individual research project basis. Several other data sources are not currently available in a "public" linked form, although in discussions with the TEP and key informants, we learned that researchers have, in some cases, performed special linkages, or new projects to create public linkages are underway. Outside the scope of this paper, but still potentially relevant for PCOR economic studies, are linkages of proprietary or commercial data sources (e.g., a major health insurer) with other private surveys or administrative records. State "all payer" claims databases (APCDs) may also include identifiers to allow longitudinal research of patients in a given geographic area across providers and insurance plans (payers). APCDs are a significant, promising advancement in health services research, but since these are mostly state, not federal efforts, they fall outside the scope of this white paper.

While we describe above the types of linkages that can strengthen data on economic outcomes, it should be noted that many of the listed data sources can be linked to other data sources that may provide useful contextual information on county- and community-level characteristics, even if not health information. One such example is the American Community Survey (ACS). County- or zip-code-level indicators from the ACS can proxy for the socioeconomic environment that a patient is subject to, which

can contribute to determining not just selection into treatments or interventions, but also PCOR economic outcomes. Some examples of community-level indicators from the ACS that might be relevant for PCOR economic analyses include unemployment rates, poverty rates, degree of income inequality (measured by the Gini coefficient), percentage of residents with internet access (can proxy for access to economic information), percentage of residents with a high rent burden, percentage of households with children, percentage of the population with less than a high school diploma, percentage of the population with limited English-speaking skills, and percentage of the population participating in the Supplemental Nutrition Assistance Program. Additionally, the Census Bureau also provides restricted-use, individual-level data linked to the Census Numerical Identification file (Numident), for researchers interested in research on all-cause mortality.

Strengths and Limitations. Surveys have several strengths for capturing PCOR economic studies. Questionnaires potentially allow for capturing the full range of indirect costs and non-medical economic costs. These items typically fall outside of the health care billing system behind administrative sources. Surveys also capture SDOH and equity measures which are limited or not available in most administrative sources. As stated earlier, while non-medical costs and indirect costs were relatively less prevalent in HHS data sources than direct medical costs (27 percent and 41 percent respectively, versus 73 percent), HHS-maintained survey data were more likely to contain economic outcomes pertaining to non-medical costs and indirect costs than HHS-maintained administrative data. Many federal surveys also have robust sampling designs which allow for national inference and have been collected for several years, facilitating time and trend studies. A few employ longitudinal designs which permit robust statistical and causal inference methods (e.g., Survey of Income and Program Participation [SIPP], National Health and Aging Trends Study [NHATS], and Consumer Expenditure Survey [CES]).

Several weaknesses affect the utility of surveys for PCOR economic studies. First, most surveys have limited detail on health outcomes and conditions, since individuals cannot reasonably be asked to report health problems or treatments beyond major categories and common conditions (e.g., diabetes). This presents a key problem for PCOR-related economic research: even if the burden is assessed, it must still be tied to a health condition or treatment. Similarly, surveys use relatively small, finite samples which may limit subgroup analysis or inhibit the study for rarer health events. Geographic detail is also often limited or not available in public-use sources. Although many surveys have been collected for several years, sampling designs, questionnaires, and other features may change over time, limiting the ability to perform trend analysis.

A primary strength of administrative sources is the measurement of precise, detailed medical expenditures along with specific diagnosis or procedure codes, which measure health outcomes. However, among CMS claims, it should be noted that beneficiary-level OOP costs are captured only in Medicare FFS data; they are not captured in current national Medicaid data (Transformed Medicaid Statistical Information System [T-MSIS] Analytic Files [TAF]). Administrative sources are frequently extremely large by nature of capturing a "system" (e.g., Medicare, Medicaid) or a geographic population (e.g., National Death Index [NDI], Healthcare Cost and Utilization Project [HCUP]). Administrative sources may also include detailed geographic information since they are often recorded as part of enrollment data; these elements may be reformatted and released at detailed but privacy-protected levels in analytic files for researchers. Administrative sources also eliminate concerns of recall bias or precision by the respondent. Longitudinal and long-term assessment is also possible with many administrative sources as long as a person remains eligible for coverage or assessment in the same system.

Weaknesses of administrative sources include that same "system" feature, which is especially relevant for children and persons under 65, who may regularly churn between private or other health insurance plans, as well as a lack of data on the uninsured population. Other key weaknesses include limited demographics and lack of most SDOH or contextual information. For example, disability status and lesbian, gay, bisexual, and transgender (LGBTQ) status, which have both been identified as priority populations in the *Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, are generally not identifiable in administrative data sources.[xxv] Like surveys, administrative sources are also limited based on their coding procedures. For example, race and ethnicity may be measured more coarsely than desired, or not available at all. Finally, a key limitation of administrative data sources relative to survey data sources is that the vast majority of the former group are not publicly available; in fact, of the 14 administrative data sources identified in this paper, only one (the Treatment Episode Data Set) is publicly available.

Discussion

Comparing the data inventory of federal sources (Exhibit 6) to the economic outcomes relevant to patients, caregivers, employers, and payers (Appendix A, Exhibit A-1), several gaps are apparent. Under direct medical costs, paid/reimbursed amounts are available in several administrative sources but very few surveys. This is not unexpected because detailed health care costs are captured directly in claims or indirectly (as charges) in discharge records, but most survey respondents can typically provide only an approximation of expenditures. MEPS is a unique data source, combining features of both survey and administrative sources through an intensive, multi-method design. There are fewer sources for the other direct medical costs. The direct non-medical cost category is captured in only a limited number of survey sources, indicating a gap for PCOR-related economic studies. Since many of these costs are relevant only to select populations, it is unclear how feasible it may be to add these items to general surveys. In contrast, several sources for measuring indirect costs exist, because concepts such as absenteeism and inability to work (disability and labor force participation) affect large populations and can easily be captured in generalized surveys. No federal administrative sources of indirect health care costs were identified. However, nonfederal sources, such as employers, could potentially capture indirect costs through employment records.

The gaps that are apparent in the data inventory to date may also be considered around the topic of equity and distribution of health care costs. While we primarily evaluated completeness of various data sources relative to the framework, certain types of costs clearly vary by the type of health condition. (For example, informal caregiving is important for Alzheimer's and dementia, and disability is more salient for COVID-19 than for a seasonal cold virus.) To the extent that health conditions impact various population groups differently than others, addressing data gaps could improve the ability of researchers and policymakers to measure and improve equity.

Considerations for the PCOR Economics Field

The authors of this paper highlight several considerations toward (1) improving the usage of the federal data for PCOR economic evaluations, and (2) raising unanswered research questions for the PCOR field to consider.

First, there need to be continued and additional efforts to link survey and administrative data sources. All data sources identified have strengths and weaknesses for PCOR economic studies, but when combined through a linkage, weaknesses may be reduced or eliminated. Moreover, this is efficient, since considerable federal resources are also independently employed to disparate data sources,

surveys, and administrative systems. It can also be responsive to minimizing the burden on the public if, for example, a linkage eliminates the need for additional survey-based data collection. While confidentiality of sampled members is often a concern around linked data, precedents for secure, accessible research environments exist (e.g., U.S. Census or NCHS Research Data Center (RDC), Medicare Chronic Conditions Data Warehouse [CCW]). A related opportunity in this area could be the linkage of potential clinical registries, such as those for Alzheimer's or other chronic conditions.[xxvi] The SEER-Medicare linkage is an excellent example of how cancer registries can be used for PCOR and policy research, and efforts to produce a SEER-Medicaid linkage are continuing.[xxvii, xxviii] The Enhancing Health Data (EHealth) program at the U.S. Census Bureau is an example of emerging improvements, where survey and administrative records link data to enhance health records with social determinants of health, provider, and their employer characteristics.[xxix]

Second, more efforts are needed to streamline and lower the costs associated with access to restricted data sources. A significant number of the most fruitful sources are not public-use data. Researchers who wish to use—or link—different sources face a number of particular hurdles in obtaining data. This includes administrative costs of preparing paperwork, time costs during review panels or data preparation, and financial costs of purchasing data. While individual stewards must maintain confidentiality, current procedures may be redundant and could be improved under more of a central clearinghouse with common interests. Several key informants voiced support for development of a secure central, federal service for linking datasets. Emerging efforts under the Evidence Act may potentially pave the way for reduced administrative burdens that still maintain security, confidentiality, and integrity of data sources.[xxx] If these barriers are reduced, we would expect to see more researchers conducting innovative and important PCOR economic research in the coming years, adding value for patients, caregivers, providers, payers, employers, policymakers, and other stakeholders. The existence of "pre-linked" data sources such as SEER-Medicare or Health and Retirement Study (HRS)-Medicare should be encouraged and maintained, since these lower costs, reduce administrative burden, and make it more likely that PCOR economic research will be conducted.

Third, all three domains of economic outcomes - non-medical and indirect costs, and direct medical costs - require greater standardization of measures. Relatively few surveys capture non-medical costs, and measures are not always collected in a standardized way, an issue several key informants mentioned should be a priority for PCOR research in the next five to 10 years. This is also an issue, but less significant, for indirect costs. Standardization may occur organically within the research community, but the federal government plays a critical role through the design of large surveys (e.g., MEPS, ACS). For direct medical costs, the main concern about standardization lies with the gap between charges and actual payments. The former are captured in the HCUP suite and other sources, such as certain state APCDs. However, actual economic costs are relevant to patients and others. These costs are generally captured in Medicare and Medicaid claims, and non-federal private payer databases; they are also available in MEPS.

Fourth, existing surveys can undertake greater measurement of non-medical costs, indirect costs, and SDOH. As above, we see this as a cost-effective way to improve the quality of existing data collections rather than develop entirely new surveys or collection platforms. Although various data sources exist which capture most of the non-medical costs and indirect costs, these are still somewhat disparate and not fully attributable to medical conditions as a result of measurement limitations on the surveys alone. Key gaps include limited data on time costs, transportation, other travel costs, childcare, relocation, and labor force measures (participation, disability, absenteeism, wages) which can be tied to health problems or health care. Some of these indirect costs also have important caregiver and gender

differences within families and households. Other measures, such as presenteeism, are recognized as essential by employers but only loosely defined in the research community and therefore not consistently or widely measured. Several forms of SDOH items can be captured only through survey items rather than administrative records, and capturing these is vital in order to assess equity and distribution in PCOR economic costs. Unfortunately, adding more measures incurs costs, so there is a tradeoff against breadth and completion. More items increase respondent burden and may reduce survey response rates, increasing financial and statistical costs of collection. This is especially important since declining survey response rates are a broader problem than PCOR, and reduced face validity or potentially larger nonresponse bias may compromise the quality of survey data. Alternative forms of measurement (e.g., mobile device apps, cell phone data) could be explored as a way to measure certain kinds of patient-centered economic costs.

Limitations of this Study

There are several limitations of this work. First, we limited the scope to federal and federally funded data sources and excluded strictly private sources (e.g., MarketScan, Kantar National Health & Wellness Survey), as well as state-specific data sources (e.g., APCDs). Second, while our list of economic outcomes were derived from the literature, it involves concepts about which the academic community does not necessarily have a full consensus (e.g., lack of standardization on the operationalization of some measures). Thus, some readers may draw different conclusions or findings from the authors of this report. Third, even among federal data, our search may have missed certain data sources, or specific economic or PCOR measures within the data sources. Fourth, while discussions with subject matter experts were an invaluable resource, like the research team, they represent a set of perspectives from professional and personal experiences, which may not necessarily be representative.

Conclusion

Informed health care decision-making by any stakeholder requires data and evidence on both clinical impacts and on the economic burdens of different treatment choices on patients' lives and on their families. PCOR-relevant economic data can be generated by the scientific community only when access to high quality, comprehensive data sources are widely available to researchers. Thus, patients, clinicians, purchasers, and policymakers have a shared interest in access to PCOR-relevant research and data sources.

This paper has shown that data on the economic impacts and potential burden of health care relevant to patients, caregivers, employers, and insurers is currently available only on a limited basis. No single data source exists that captures all PCOR-relevant economic outcomes. Research from combined sources can be highly useful in overcoming this, but increased burden and expertise are required to undertake such work. Furthermore, a "least common denominator" problem also affects combining of data sources. If a given measure such as SDOH is not available for one domain, but it is for another, researchers generally choose not to report such breakdowns. To overcome this, data linkages represent a significant and efficient potential advance for increasing and improving PCOR-relevant economic burden studies. We also identified a need for greater standardization of PCOR economic measures and attention to gathering SDOH measures. At the same time, access to enhanced data sources and expanded research alone is not enough to improve patient outcomes. Dissemination and implementation of PCOR relevant economic research are vital to help patients, caregivers, and stakeholders to navigate a complex health care environment. This topic is beyond the scope of this paper but warrants further consideration during efforts to improve the PCOR data infrastructure.

This paper is limited to federal sources, and future researchers may wish to consider a similar inventory approach using nonfederal sources. Combined with this work, such an effort would illustrate the full potential range available for researchers to capture PCOR-relevant economic outcomes.

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Appendix A: Economic Outcomes and Federal/Federally Funded Data Sources

Exhibit A-1. Economic Outcomes Relevant to PCOR Analysis of Health Care Interventions

Economic Outcome Category	Economic Outcome Measure(s)	Economic Outcome Description	Economic Outcome Example(s)	Patient/ Family Perspective	Caregiver Perspective	Employer Perspective	Payer/ Insurer Perspective
Direct Medical Costs	Paid/reimbursed amounts	Amount that insurer pays a provider for any type of covered medical care	Paid for physician, inpatient, outpatient, pharmacy/drug, lab			X	X
	Out-of-pocket (OOP) health care costs	Amount that individuals are responsible for after insurance	Copayments, coinsurance, deductibles, etc. associated with any covered service, including (1) costs associated with adverse events due to medical treatment, and (2) alternative medical treatments (e.g., acupuncture, massage, psychotherapy, personal trainers, and health coaches)	X			
	Other OOP medical expenses	Health-related expense not covered by an insurance plan	Over-the-counter drugs, other services not covered by insurance including (1) costs associated with adverse events due to medical treatment, (2) alternative medical treatments (e.g., acupuncture, massage, psychotherapy, personal trainers, and health coaches), or (3) genetic testing	X			
	Insurance premiums	Premium cost to purchase any type of health insurance	Health, dental, vision, drug, long-term care insurance, etc.	X		X	

Economic Outcome Category	Economic Outcome Measure(s)	Economic Outcome Description	Economic Outcome Example(s)	Patient/ Family Perspective	Caregiver Perspective	Employer Perspective	Payer/ Insurer Perspective
Direct Non-Medical Costs	Transportation costs	Transportation costs associated with seeking medical care	Bus, taxi, car, mileage, gas, parking, etc.	X	X		
	Travel costs (non-transportation)	Other non-transportation travel costs associated with seeking medical care	Hotel, food, etc.	X	X		
	Vehicle modification costs	Costs associated with accessibility changes to personal vehicle	Wheelchair lift for a car	X	X		
	Child care and other child-related expenses	Paid care when patient cannot do this due to medical needs	Babysitter, nanny - in or out of home, paid tutoring, or homeschooling	X	X		
	Housekeeping costs	Paid care when patient cannot do this due to medical needs	Housecleaner	X	X		
	Elder care costs	Paid care when patient cannot do this due to medical needs	Elder care - in or out of home	X	X		
	Special food costs	Costs associated with dietary modifications for medical treatment or condition	Prep for colonoscopy	X	X		
	Home modification costs	Costs associated with accessibility changes at home	Bath, shower, stairs, ramps	X	X		
	Relocation/ moving costs	Costs incurred from a long-term, permanent move associated with treatment or condition	Cost of rent or mortgage associated with moving into a more accessible home, educational costs incurred by patient's family members (e.g., children) because of relocation	X	X		

Economic Outcome Category	Economic Outcome Measure(s)	Economic Outcome Description	Economic Outcome Example(s)	Patient/ Family Perspective	Caregiver Perspective	Employer Perspective	Payer/ Insurer Perspective
	Clothing/ laundry costs	Costs associated with specific modifications needed for medical treatment or condition	Hospital gown for home use	X	X		
	Time costs: Health care seeking	Any time-related costs associated with health service, medical treatment, or condition	Time in doctor's office, waiting, receiving care, etc.	X	X		
	Time costs: informal caregiving	Time spent caring for patient needs as a result of their medical treatment or condition	Value of assistance (time) from an unpaid relative or friend		X		
Indirect Costs	Lost wages from absenteeism	Work loss (days/hours) associated with medical treatment or condition	Missed work	X	X	X	
	Lost wages from reduced productivity (presenteeism)	Reduced productivity on the job, associated with medical treatment or condition	Less productive on the job	X	X	X	
	Time Costs: Home Production and Leisure	Reduced home productivity and leisure associated with medical treatment or condition	Activity limitation days	X	X		
	Lost wages and benefits from losing work	Voluntary unemployment, involuntary unemployment, early retirement, or exit from labor force due to disability associated with medical treatment or condition	Labor force participation; retirement; permanent disability affecting work or career and associated earnings and benefits	X	X		

Exhibit A-2. Federal Data Sources for PCOR Economic Evaluations

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
Medical Expenditure Panel Survey (MEPS) *AHRQ*	Survey	Individual	Yes	Yes	Direct Medical Costs, Direct Non-Medical Costs, Indirect Costs	<u>Direct Medical Costs:</u> Insurance premium, OOP health care costs <u>Direct Non-Medical Costs:</u> Informal Caregiving <u>Indirect Costs:</u> Absenteeism	Social context, Economic context, Education, Physical Infrastructure, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO:</u> Race/ethnicity, Urban-rural status, Income or income status	NHIS
State Inpatient Databases (HCUP-SID) *AHRQ*	Administrative	Encounter/ claim	No	No	Direct Medical Costs	<u>Direct Medical Costs:</u> (Approximation of) paid/reimbursed amount**	Social context, Economic context, Physical Infrastructure, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO:</u> Race/ethnicity, Urban-rural status	American Hospital Association (AHA), SEDD, SASD, (selected vars***)

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
Home Health Outcome and Assessment Information Set (OASIS) *CMS*	Administrative	Encounter/ claim	Yes	No	Direct Medical Costs, Indirect Costs	<u>Direct Medical Costs</u>: Paid/reimbursed amount <u>Indirect Costs</u>: Time costs: home production and leisure	Social context, Economic context, Education, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Urban-rural status, Income or income status	Other Centers for Medicare & Medicaid Services (CMS) data
National (Nationwide) Inpatient Sample (HCUP-NIS) *AHRQ*	Administrative	Encounter/ claim	Yes	No	Direct Medical Costs, Direct Non-Medical Costs	<u>Direct Medical Costs</u>: (Approximation of) paid/ reimbursed amount** <u>Direct Non-Medical Costs</u>: Time costs: health care seeking	Social context, Economic context, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Income or income status, Urban-rural status	None since 2012

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
National Health Interview Survey (NHIS) *CDC*	Survey	Individual	Yes	Yes	Direct Medical Costs, Indirect Costs	Direct Medical Costs: OOP health care costs Indirect Costs: Absenteeism, Time costs: home production and leisure, Inability to work, Productivity	Social context, Economic context, Education, Physical Infrastructure, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Race/ethnicity, LGBTQ+, Disability status, Urban-rural status, Income or income status	National Immunization Provider Record Check Study (NIPRCS), National Death Index (NDI), Social Security Administration (SSA), U.S. Department of Housing and Urban Development (HUD), Medicare, Medicaid, MEPS, NHANES
United States Renal Data System (USRDS) *NIH*	Administrative	Individual	Yes	No	Direct Medical Costs	Direct Medical Costs: Paid/ reimbursed amount, OOP health care costs	Social context, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Race/ethnicity, Urban-rural status,	The United Network for Organ Sharing (UNOS), CMS

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
Kids' Inpatient Database (HCUP-KID) *AHRQ*	Administrative	Encounter/ claim	Yes	No	Direct Medical Costs	Direct Medical Costs: (Approximation of) paid/ reimbursed amount**	Social context, Economic context, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Race/ethnicity, Income or income status, Urban-rural status	None since 2012
Nationwide Readmissions Database (HCUP-NRD) *AHRQ*	Administrative	Encounter/ claim	Yes	No	Direct Medical Costs	Direct Medical Costs: (Approximation of) paid/ reimbursed amount**	Social context, Economic context, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Income or income status, Urban-rural status	None (observations are linked within the dataset)
Nationwide Ambulatory Surgery Sample (HCUP-NASS) *AHRQ*	Administrative	Encounter/ claim	Yes	No	Direct Medical Costs	Direct Medical Costs: (Approximation of) paid/ reimbursed amount†	Social context, Economic context, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Income or income status, Urban-rural status	None

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
State Ambulatory Surgery and Services Databases (HCUP-SASD) *AHRQ*	Administrative	Encounter/ claim	No	No	Direct Medical Costs	Direct Medical Costs: (Approximation of) paid/ reimbursed amount†	Social context, Economic context, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Race/ethnicity (some states), Income or income status, Urban-rural status	SEDD, SID, AHA (selected vars***)
Nationwide Emergency Department Sample (HCUP-NEDS) *AHRQ*	Administrative	Encounter/ claim	Yes	No	Direct Medical Costs	Direct Medical Costs: (Approximation of) paid/ reimbursed amount†	Social context, Economic context, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Income or income status, Urban-rural status	None
State Emergency Department Databases (HCUP-SEDD) *AHRQ*	Administrative	Encounter/ claim	No	No	Direct Medical Costs	Direct Medical Costs: (Approximation of) paid/ reimbursed amount†	Social context, Economic context, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Urban-rural status	SASD, SID, AHA (selected vars***)

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
Medicare Health Outcomes Survey (MHOS) *CMS*	Survey	Individual	Yes	Yes	Direct Non-Medical Costs, Indirect Costs	<u>Direct Non-Medical Costs</u>: Informal caregiving <u>Indirect Costs</u>: Time costs: home production and leisure, Productivity	Social context, Economic context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Disability status, Income or income status	Surveillance, Epidemiology, and End Results (SEER)
Behavioral Risk Factor Surveillance System (BRFSS) *CDC*	Survey	Individual	Yes	Yes	Direct Non-Medical Costs, Indirect Costs	<u>Direct Non-Medical Costs</u>: Informal Caregiving <u>Indirect Costs</u>: Time costs: home production & leisure	Social context, Economic context, Physical Infrastructure, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Income or income status, Urban-rural status	None
Current Population Survey (CPS) *U.S. Census Bureau*	Survey	Individual	Yes	Yes	Direct Non-Medical Costs, Indirect Costs	<u>Direct Non-Medical Costs</u>: Informal Caregiving <u>Indirect Costs</u>: Absenteeism, Inability to work	Social context, Economic context, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Disability status, Income or income status	None

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
Panel Study of Income Dynamics (PSID) *University of Michigan*	Survey	Individual	Yes	Yes	Direct Non-Medical Costs, Indirect Costs	Direct Non-Medical Costs: Informal Caregiving Indirect Costs: Absenteeism, Time costs: home production & leisure	Social context, Economic context, Education, Physical Infrastructure, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Race/ethnicity, Religious affiliation, Disability Status, Urban-rural status, Income or income status	Medicare, National Center for Education Statistics (NCES), HUD, NDI
National Longitudinal Survey of Youth (NLSY) *BLS*	Survey	Individual	Yes	Yes	Indirect Costs	Indirect Costs: Productivity	Social context, Economic context, Education, Physical Infrastructure	Age and sex available? Yes Other available characteristics based on the EO: Religious affiliation, Disability status, Urban-rural status, Income or income status	None

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
American Time Use Survey (ATUS) *BLS*	Survey	Individual	Yes	Yes	Direct Non-Medical Costs, Indirect Costs	Direct Non-Medical Costs: Informal Caregiving Indirect Costs: Inability to work	Social context, Economic context, Education, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Disability status, Urban-rural status, Income or income status	CPS
National Health and Nutrition Examination Survey (NHANES) *CDC*	Survey	Individual	Yes	Yes	Direct Non-Medical Costs, Indirect Costs	Direct Non-Medical Costs: Special food Indirect Costs: Time costs: home production and leisure	Social context, Economic context, Education, Physical Infrastructure, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Race/ethnicity, Disability status, Urban-rural status, Income or income status	Medicare, Medicaid, HUD, NDI, SSA

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
National (Hospital) Ambulatory Medical Care Surveys (NHAMCS, NAMCS) *CDC*	Survey	Encounter/ claim	Yes	Yes	Direct Medical Costs	<u>Direct Medical Costs</u>: Paid/ reimbursed amount	Social context, Economic context, Education, Physical Infrastructure, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Urban-rural status	Medicare enrollment and claims data, Social Security Benefit History Data, Dual Energy X-Ray Absorptiometry (DXA) Multiple Imputation Data Files from 1999–2004, NDI Mortality Data, MEPS
Medicare Current Beneficiary Survey (MCBS) *CMS*	Survey	Individual	Yes	Yes	Direct Medical Costs, Direct Non-Medical Costs	<u>Direct Medical Costs</u>: OOP health care costs <u>Direct Non-Medical Costs</u>: Transportation, Time costs: health care seeking	Social context, Economic context, Education, Physical Infrastructure, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Disability Status, Urban-rural status, Income or income status	Medicare claims, Cost & Use, Access to Care, & Cost modules

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
Treatment Episode Data Set (TEDS) *SAMHSA*	Administrative	Encounter/ claim	Yes	Yes	Indirect Costs	<u>Indirect Costs</u>: Inability to work	Social context, Economic context, Education, Physical Infrastructure, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Disability status, Urban-rural status	Unknown
National Health and Aging Trends Study (NHATS) *NIH*	Survey	Individual	Yes	Yesss	Indirect Costs	<u>Indirect Costs</u>: Inability to work	Social context, Economic context, Education, Physical Infrastructure, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Disability status, Urban-rural status, Income or income status	Medicare, National Study of Caregiving (NSOC)

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
Survey of Income and Program Participation (SIPP) *U.S. Census Bureau*	Survey	Individual	Yes	Yes	Direct Medical Costs, Direct Non-Medical Costs, Indirect Costs	<u>Direct Medical Costs</u>: OOP health care costs, Insurance premium <u>Direct Non-Medical Costs</u>: Transportation, Time costs: health care seeking, Informal Caregiving <u>Indirect Costs</u>: Absenteeism, Time costs: home productivity	Social context, Economic context, Education, Physical Infrastructure, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Disability status, Urban-rural status, Income or income status	SSA
Consumer Expenditure Survey (CES) *BLS*	Survey	Individual	Yes	Yes	Direct Medical Costs	<u>Direct Medical</u>: Other OOP Medical Expenses, Insurance Premium	Social context, Economic context, Physical Infrastructure, Healthcare Context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Disability status, Urban-rural status, Income or income status	None

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
National Study of Caregiving (NSOC) *NIH*	Survey	Individual	Yes	No	Direct Non-Medical Costs, Indirect Costs	<u>Direct Non-Medical Costs</u>: Time costs: Informal caregiving, Transportation, Special food, Time costs: health care seeking, home modifications, housekeeping <u>Indirect costs</u>: Absenteeism, Inability to work	Social context, Economic context, Education, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Income or income status	Master Beneficiary Summary Files (MSBF), Medicare, Base A/B/D, Chronic Conditions, Cost & Utilization, Other Chronic or Potentially Disabling Conditions, Part A & B claims, Minimum Data Set, NHATS, OASIS, IRF-PAI, Part D Event, MEDPAR, Encounter files, Medicaid Analytic Extract, Transformed Medicaid Statistical Information System Analytic Files

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
Health Economics Resource Center Average Cost Datasets (HERC) *U.S. Department of Veterans Affairs*	Administrative	Encounter/ claim	Yes	No	Direct Medical Costs	Direct Medical Costs: (Approximation of) Paid/reimbursed amount, OOP health care costs****	Social context	Age and sex available? Unknown Other available characteristics based on the EO: Unknown	VA's Patient Treatment Files (PTF)
Medicare Claims (Research Identifiable Files (RIF), Chronic Conditions Data Warehouse (CCW), MBSF, MedPAR)) *CMS*	Administrative	Individual (enrollment), encounter/ claim (utilization)	Yes	No	Direct Medical Costs	Direct Medical Costs: Paid/reimbursed amount, OOP health care costs	Social context, Economic context, Healthcare context	Age and sex available? Yes Other available characteristics based on the EO: Race/ethnicity, Disability status	Other CMS data, registries (SEER, USRDS), other National Center for Health Statistics (NCHS) surveys (NHIS, NHANES, Longitudinal Study of Aging (LSOA), NNHS), other surveys (Health and Retirement Survey (HRS), NHATS)

Data Source Name (Abbreviation) *Steward*	Source of Data	Lowest Level of Aggregation	Data Nationally Representative/ National Coverage?	Publicly Available Data?	Available Economic Outcome Categories	Available Economic Outcome Measures, by Category	Identifiable SDOH Categories*	Demographics Available for Conducting Disparities/ Equity Analyses**	Existing Data Linkages (with Federal and Non-Federal Data)
Medicaid Claims (Research Identifiable Files) (RIF, Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), Medicaid Analytic Extract (MAX), CCW)) *CMS*	Administrative	Individual (enrollment), encounter/ claim (utilization)	Yes	No	Direct Medical Costs	<u>Direct Medical Costs:</u> Paid/reimbursed amount, OOP health care costs	Social context, Economic context, Healthcare context	<u>Age and sex available?</u> Yes <u>Other available characteristics based on the EO</u>: Race/ethnicity, Disability status, Income or income status	Other CMS data

*These are based on AHRQ's framework (https://www.ahrq.gov/sdoh/about.html).

**Other than age and race, the remaining characteristics are identified as priority populations in the *Executive Order (EO) On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*.

Appendix B: Key Informant Discussion Questions

Researchers

1. We would like to start by having you do a brief introduction of yourself. Please introduce yourself and tell us about your role within {the organization}.

   a. Probe: What is your familiarity and experience with PCOR and/or comparative effectiveness research?
   b. Probe: What about your familiarity and experience specifically with patient-centered economic analyses? For example, your experience with health economic evaluations and analyses?

Economic Conceptual Framework Underlying Healthcare Intervention/Treatment Evaluations

2. Do you think the framework is easy to understand in its current format? Do you agree with the way outcomes and perspectives are represented?

   a. Probe: Do you have any recommendations for how the various perspectives can be linked in this framework?

3. Do you agree with the three outcome categories? Do you have any recommended changes to the terminology (e.g., direct medical costs, etc)?

   a. Probe: Do you agree with the various outcome measures in each category, or would you reclassify any measures into one of the other categories?
   b. Probe: Are there any measures for any of the outcome categories (or any of the perspectives) that you would recommending including that we are not accounting for?

4. Given your research experience, what is your general sense of how these measures have been operationalized? For example, are they used in a fairly standardized way by researchers, or not?

Federal Data Sources for PCOR Economic Analyses, and Available Economic Outcomes

5. Based on your general knowledge about data, does our inventory look comprehensive to you, or are there any data sources that we are missing that provide information about patient-level economic outcomes?

6. Are there any data sources from this list that you use most often in your research to assess patient economic outcomes, or that you think are most useful for patient-centered economic evaluations?

   a. Probe: Do you think we have captured the economic outcomes accurately in these data sources, or are there more outcomes in any than what we've currently included?
   b. Probe: What are the strengths and limitations of these data sources for measuring economic outcomes, relative to others?

Limitations of the Current Federal Data Infrastructure to Conduct PCOR Economic Analysis

7. To what degree do you feel that the measures related to economic outcomes are standardized in federal data sources? What improvements can be made to foster standardization?

8. Do you have any concerns related to the timeliness (i.e., recency) and/or the quality of federal data on economic outcomes?

9. Are there emerging sources of federal or federally-funded data that hold potential but are not yet widely used?

Data Linkage Capacity of Federal Data Sources, and Barriers to Linkages

10. Based on the data sources that you recognize or are familiar with in our inventory, are there any ones that strike you as linkable to a good array of other data sources (i.e., that have good linkage capacity)?

    a. Probe: Are there any data sources you can point to that are not readily linkable to other data sources?
    b. Probe: Are you aware of any emerging data linkages on any of these data sources that may be become available in the future?
    c. Probe: Are there any data or data linkages that are not yet available but that you desire?
    d. Probe: What sort of research questions could this linkage answer, and what is limiting the ability to link the data sources?

11. Generally speaking, what are the common issues that are encountered by researchers such as yourself when trying to link data from various sources? To clarify, we are interested in your insights on any technical issues that researchers may encounter (e.g., lack of streamlined identifiers).

Research Questions for PCOR Economic Analyses

12. What aspects of healthcare costs would you like to see PCOR researchers focus on in the next 5 to 10 years?

    a. Probe: What types of research questions related to PCOR economic evaluations need to be answered going forward?
    b. Probe: What types of data sources and/or data linkages are needed to explore these questions?

Data Stewards

1. We would like to start by having you do a brief introduction of yourself. Please introduce yourself and tell us about your role within {the organization}.

Federal Data Sources for PCOR Economic Analyses, and Available Economic Outcomes

2. We'd like to talk about data sources that contain information about healthcare-related economic outcomes. Based on your general knowledge about data sources, does our inventory look comprehensive to you, or are there any data sources that we are missing? These may either be data sources(s) that you directly oversee or have had experience with.
3. Could you tell me about which data source(s) you oversee or have had experience with and therefore can speak to?
4. *{If data source(s) is already included in the inventory}*: Oh great, we have this data source(s) in our inventory and we have tried to capture the economic outcomes available in it. Are there any economic outcomes in this data source(s) that we've missed?

{If data source(s) is not included in our inventory}: What are the available economic outcomes or measures in this data source(s)?

5. In terms of measuring economic outcomes, are there any limitations of this data source(s) that researchers should be mindful about, or have identified?
6. What are the strengths of this data source(s) for measuring economic outcomes, in your assessment?

Data Sharing and Data Collection Issues Related to Economic Outcomes

7. What are the common issues as they relate to collecting data on economic outcomes in this data source(s)? For example, are there any concerns related to the timeliness (i.e., recency) and/or the quality of data?

   a. Probe: To what degree do you feel the measures related to economic outcomes are collected in a standardized way in this data source(s), relative to how they are captured in other data sources? How can the data collection be improved to foster standardization?

8. What are the Data Use Agreement (DUA) or Data Transfer Agreement (DTA) structures in place with this data source(s) to facilitate data sharing with researchers?
9. What challenges do researchers typically encounter in accessing or using this data source(s)?

   a. Probe: Are there any challenges that come to mind specifically when it comes to researchers accessing or using data on economic outcomes?
   b. Probe: Can you speak to any unique challenges faced by external researchers (i.e., researchers external to the federal government)?

10. Can you think of any improvements to improve the access and usability of this data source(s), especially as it relates to economic outcomes, for researchers in the future, particularly, for external researchers?

Data Linkage Capacity of Federal Data Sources, and Barriers to Linkages

11. Based on the data sources that you recognize or are familiar with in our inventory, are there any ones that strike you as linkable to a good array of other data sources (i.e., that have good linkage capacity)?

    a. Probe: Are there any data sources you can point to that are not readily linkable to other data sources?

12. What are the common issues that are encountered by researchers when trying to link data from various sources? To clarify, we are interested in your insights on any technical issues that researchers may encounter (e.g., lack of streamlined identifiers).
13. Now with specific regard to the data source(s) that you oversee or have had experience with, what other data sources can it be linked with to improve its utility for economic analyses?

    a. Probe: What linkages are most commonly requested or done?
    b. Probe: Are there emerging data linkages that may be become available in the future?

14. What linkages are not yet possible with this data source(s) but are highly desired by researchers, specifically related to economic outcomes if you can speak to that.

    a. Probe: What would it take to make these linkages possible?

Patient Representatives

1. We would like to start by having you do a brief introduction of yourself. Please introduce yourself and tell us about your experience as a patient or caregiver representative.

    a. Probe: What is your familiarity and/or experience with PCOR and/or comparative effectiveness research?

Economic Impacts and Burdens of Healthcare Interventions/Treatments

2. In your experience, what economic impacts do you think patients (and their caregivers) usually or typically take into consideration when seeking healthcare, or deciding whether to utilize a treatment?

    a. Probe: What economic impacts are considered by patients when deciding to utilize a treatment to its fullest (or toward fully completing a treatment regimen)?
    b. Probe: What are the potential benefits that patients (and their caregivers) take into consideration when seeking healthcare, or deciding whether to utilize a treatment?

3. What economic impacts do you think patients (and their caregivers) should take into consideration, but don't necessarily do so all the time, when seeking healthcare, or deciding whether to utilize a treatment (particularly toward treatment completion)?

4. Without worrying too much about the technical terminology used in this framework (e.g., direct vs. indirect), given what you've said, do you think we have captured the most important types of economic impacts relevant for patients and their caregivers?

    a. Probe: In particular, do the types of non-medical costs that we have listed make sense?
    b. Probe: Are there any impacts on patients or caregivers that we are not considering, but that must be accounted for, when one thinks about utilization of a healthcare intervention or treatment? Please think of both costs and benefits.

Availability and Dissemination of Economic Impact Information for Patients and Caregivers

5. What kinds of information about economic impacts are generally available to patients and caregivers?

    a. Probe: What kinds are not available? What kinds of data or information on economic impacts do you wish were more readily available to patients and families?
    b. Probe: Where would you recommend placing information about economic impacts for patients and caregivers to readily access? For example, are there specific organizations or websites who could disseminate this type of information?

6. Given your experience, can you think of an instance when a patient and/or their caregiver was adequately informed about economic impacts so that they were able to make a proper decision about whether to utilize a treatment? Can you describe that instance to me?

    a. Probe: Where did they get this kind of information?
    b. Probe: What did it take to get that information, and what was the quality of that information?

7. Now let me ask the converse question. Given your experience, can you think of an instance when a patient and/or their caregiver was not adequately informed about economic impacts to be able to make a proper decision about whether to utilize a treatment? Can you describe that instance to me?

a. Probe: Why did they not have that information?

8. How do you, as a patient representative, support your clients to help them make an informed decision about utilizing a treatment? For example, do you help them become aware of the various types of economic consequences of utilizing a type of treatment?

   a. Probe: Where do you usually get this kind of information that you can then share with your clients?
   b. Probe: What does it take for you to get that information, and what is the quality of that information when you find it?
   c. Probe: How is this information generally presented (e.g., as a report, research brief)? Are statistics provided? Is the information presented in a way that is accessible to a lay audience?

9. There has been a lot of research done on medical and non-medical costs of treatments and services. How do you think this research should be disseminated to patients and caregivers, and even other stakeholders like their providers or employers?

Research Questions Relevant to Patients' Economic Burden

10. What aspects of healthcare costs would you like to see researchers focus on in the next 5 to 10 years?