

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

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Background: Patients are increasingly interested in data on the economic burdens and impacts of health care choices; caregivers, employers, and payers are also interested in these costs. Although there have been various federal investments into patient-centered outcomes research (PCOR), an assessment of the coverage and gaps in federally funded data for PCOR economic evaluations has not been produced to date.

Objectives: To classify relevant categories of PCOR economic costs, to assess current federally funded data for coverage of these categories, and to identify gaps for future research and collection.

Research Design: A targeted internet search was conducted to identify a list of relevant outcomes and data sources. The study team assessed data sources for coverage of economic outcomes. A technical panel and key informant interviews were used for evaluation and feedback.

Results: Four types of formal health care sector costs, 3 types of informal health care sector costs, and 10 types of non–health care sector costs were identified as relevant for PCOR economic evaluations. Twenty-nine federally funded data sources were identified. Most contained elements on formal costs. Data on informal costs

(eg, transportation) were less common, and non–health care sector costs (eg, productivity) were the least common. Most data sources were annual, cross-sectional, nationally representative individual-level surveys.

Conclusions: The existing federal data infrastructure captures many areas of the economic burden of health and health care, but gaps remain. Research from multiple data sources and potential future integrations may offset gaps in individual data sources. Linkages are promising strategies for future research on patient-centered economic outcomes.

Key Words: patient-centered care, patient-centered outcomes research, economic analysis, health care costs

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Advances in the science and practice of medicine have brought enormous gains to the United States, curing previously fatal diseases,¹ extending lifespans,² and reducing morbidity.³ These beneficial achievements have improved lives but also bring new challenges, such as patient safety, data security, and privacy. Emerging health threats and escalating health care costs⁴ are also concerns and a growing body of research on the role of social determinants of health (SDOH)⁵ has highlighted wide disparities in medicine and health.⁶

Medical innovations present patients, providers, employers, and health care systems with complex tradeoffs in health care decision-making.^{7,8} These include—but are not limited to—differences in effectiveness, quality of care, outcomes, frequency, duration, invasiveness, side effects, and cost.⁹ Comparative effectiveness research¹⁰ 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 comparative effectiveness research and other activities to promote research into the quality of care and relevance of scientific evidence¹¹ to patients and key stakeholders.

The PCOR Institute, an independent body created by the ACA, described the purpose of PCOR as: “PCOR helps people and their caregivers communicate and make informed healthcare decisions....”¹² Assessing benefits and harms of

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treatment, respecting patient preferences, incorporating diverse participants, and investigating “outcomes while addressing burden to individuals... and other stakeholder perspectives” were also named as components of PCOR.¹³ Notably lacking, however, were economic costs, until the 2019 reauthorization of the PCOR Trust Fund by Congress. This legislation stated: “...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, ..., nonmedical costs to the patient and family, including caregiving, effects on future costs of care, workplace productivity and absenteeism, and healthcare utilization.”¹³ Many researchers also include quality of life and mortality as economic impacts relevant to PCOR, although the valuation of these is difficult and remains unresolved in the literature.¹⁴

To generate evidence about the economic impacts, benefits, and burdens of health care, researchers require data to study the full range of economic 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 3 categories: (1) formal health care sector (health care services for a patient); (2) informal health care sector (transportation, unpaid caregiving, and patient time); and (3) non-health care sector (resources lost as a result of incurring illness or health care treatments, such as loss of labor).¹⁵ Together, these costs represent the total burden of health care and are borne by both patients and their family members and other stakeholder groups, such as caregivers, employers, and insurers.

Key scientific challenges must be addressed for PCOR to fully encompass this broader scope and provide relevance to stakeholders. Most patient-centered research reports only selected elements of the total economic burden that may be experienced by patients, reflecting the limitations of currently available data. Many primary data sources used to measure economic burden contain incomplete measures of patient-centered outcomes.^{16–19} Gaps in data sources or research mean that some types of PCOR economic outcomes that may be relevant for health care decisions are unmeasured.^{20,21} When economic costs and impacts are substantial (eg, 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.

To help researchers and policymakers address these gaps, this paper builds on the PCOR Trust Fund’s expanded reauthorization language by describing existing data resources that could be useful for adding economic outcomes to PCOR studies. Although 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 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. State and private data sources are also important for PCOR, but to maintain focus in

a concise manuscript, they are outside the scope of this study. Accordingly, this paper has 2 key objectives:

- (1) To guide researchers who currently conduct PCOR on concepts and measures of economic impacts and costs under the expanded reauthorization definition of PCOR.
- (2) To 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

To develop the inventory, we followed 3 steps: (1) identifying a list of outcomes relevant to PCOR economic evaluations; (2) cataloging federal data sources that contain information on these economic outcomes; and (3) obtaining feedback on these from subject matter experts via a technical panel and key informant interviews. We focus on federal data sources directly distributed by the US government and federally funded data, such as those produced for wide dissemination under a federal grant. Data sources with partial federal support, such as Medicaid files obtained directly from a state, were excluded. The study was considered nonhuman subject research, and institutional review board review did not apply.

First, we conducted a targeted internet search to compile a set of economic outcomes relevant to PCOR analysis of health and health care. We searched PubMed and Google Scholar to identify sources published in English, using terms listed in Table 1 combined with Boolean operators. This activity led to the outcomes, categories, and perspectives defined in Appendix A (Table A-1, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>). Quality-adjusted life years were not part of the expanded definition of PCOR economic outcomes in the 2019 reauthorization, so they and other nonfinancial impacts are excluded from this paper.

Second, we used a stepwise approach to identify and catalog federal data sources with content on the identified economic outcomes. We began by reviewing 2 data compilations, the National Healthcare Quality and Disparities Report,²² which spans 35 sources of survey and administrative data from primarily federal agencies, and a review by Lund et al,²³ which documents 88 data sources that can be used to estimate health care costs in the United States. After this, we searched federal websites for additional relevant data sources, including data.gov, Agency for Healthcare Research and Quality (AHRQ), Department of Health and Human

TABLE 1. Search Terms for Identification of Economic Outcomes

Stakeholder related	Economic outcome related	Topic related
Patient	Cost of illness	Health care
Caregiver	Burden of illness	
Employer	Indirect cost	
Payer	Productivity	
	Absenteeism	
	Presenteeism	
	Economic impact	
	Economic assessment	
	Economic burden	

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TABLE 2. Fields in the Federally Funded 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	Years of data available	Whether the data are publicly available or not	Available Economic Outcome Categories (eg, formal health care sector costs)	Existing data linkages
Data source acronym	Latest available sample size	Whether additional restricted-use data are available for the publicly available data (NA for data sources not publicly available)	Available Economic Outcome Measures, by category (eg, out-of-pocket health care costs, patient time)	Strengths of data source
Data source steward	Latest available survey response rate (not applicable for administrative data)	Whether there are costs to acquire data	Economic perspectives represented (eg, patients)	Limitations of data source
Data source URL	Population scope of data (eg, US civilian noninstitutionalized population)		Identifiable social determinants of health (SDOH) categories: [*]	Link to data documentation page
Periodicity of data collection (eg, annual)	Whether the data are nationally representative/have national coverage or not		Whether demographics data are available for disparities/equity analysis	Example peer-reviewed publication that has used the data source
Source of data (administrative or survey)	Lowest level of geography available			
Administrative data type (eg, hospital encounter records; not applicable for survey data)				
Lowest level of aggregation (eg, individual)				
Length of observation (eg, longitudinal)				

^{*}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>).

Services, Centers for Disease Control and Prevention, Health Resources and Services Administration, Centers for Medicare & Medicaid Services (CMS), National Center for Health Statistics (NCHS), US Census Bureau, Medicaid and CHIP Payment and Access Commission, US Government Accountability Office, National Institutes of Health, TRICARE (Department of Defense), Department of Veterans Affairs, Office of the Assistant Secretary for Planning and Evaluation, Administration for Children and Families, and Substance Abuse and Mental Health Services Administration. We also reviewed the Research Data Assistance Center website, a clearinghouse for CMS research data, and searched for other relevant reports, reviews, and publications on federal data sources using Boolean operators to combine the Table 1 search terms with “federal” and “data.” Two authors cataloged information on each source in a spreadsheet, which was reviewed and refined by the full study team. Table 2 lists the fields in the inventory, which are organized into 5 categories: characteristics, size and scope, data access, economic outcomes, and other topics.

Lastly, we solicited subject matter expert feedback using 2 channels. We convened 3 meetings of an 8-member technical panel, which included federal and nonfederal experts in PCOR, health economics, evaluation, measurement, and health equity. This panel met before, during, and after the activities described above to review the approach and findings. After the inventory was complete, we conducted 9 individual semistructured interviews with key informants (researchers, data stewards, and patient representatives) to review it and to discuss other potential data sources, linkages, and future research priorities.

RESULTS

We identified 29 federally funded data sources that contained one or more economic outcomes relevant to PCOR. The list of outcomes is shown in Appendix A (Table A-1, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>), and the full inventory is provided in Appendix A (Table A-2, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>).

Following standard taxonomy,¹⁴ the economic outcomes Appendix A (Table A-1, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>) are grouped into 3 categories: formal health care sector, informal health care sector, and non-health care sector. Although the list is long, a PCOR analysis of many health conditions or treatments may need to include only selected outcomes. PCOR data may be relevant to several perspectives, and we indicated how each outcome applies to patients, caregivers, employers, and payers. Formal health care sector costs are those associated with health care services for a patient, including physician services, drugs, and inpatient care. These include the paid amount (an insurer’s payment for health care services); patient out-of-pocket costs after insurance payments; patient expenses for noncovered costs; and insurance premium costs Appendix A (Table A-1, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>). We identified 3 informal *health care sector costs* related to the receipt of

care: transportation, unpaid caregiving, and patient time. Lastly, we identified 10 types of *non-health care sector costs*, reflecting the value of resources that may be lost from illness or health care. These include absenteeism or work loss associated with health care or health problems; presenteeism (reduced workplace productivity); other labor impacts, including wages, benefits, early retirement, and disability; paid childcare; housekeeping; special food; home modifications; relocation/moving; clothing/laundry; and home production/leisure.

Table 3 displays key characteristics of the data sources. Most are funded by Health and Human Services agencies (AHRQ, Centers for Disease Control and Prevention, CMS, National Institutes of Health, and Substance Abuse and Mental Health Services Administration), with AHRQ supporting the most. We found nearly equal numbers of survey and administrative sources and individual versus encounter-level data. Three quarters of the data are collected on an annual basis, with the majority also cross-sectional. All identified data sources captured information on at least 1 dimension of SDOH. Figure 1

TABLE 3. Select Characteristics of Federally Funded Data Sources With Information on PCOR Economic Outcomes

Characteristic	Number of data sources	Percent of data sources (%)
Data source steward		
Agency for Healthcare Research and Quality (AHRQ)*	9	31
Bureau of Labor Statistics (BLS)	3	10
Centers for Disease Control and Prevention (CDC)*	4	14
Centers for Medicare and Medicaid Services (CMS)*	5	17
National Institutes of Health (NIH)*	3	10
Substance Abuse and Mental Health Services Administration (SAMHSA)*	1	3
US Census Bureau	2	7
US 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†		
Panel/longitudinal	11	38
Cross-sectional	18	62
Time series	1	3
Periodicity of data collection‡		
Annual	22	76
Biennial	2	7
Monthly	1	3
Quarterly	1	3
Other§	4	14
Observable Social Determinants of Health (SDoH) Domains¶		
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

The findings in this table are based on the 29 federally funded data sources identified using the search process described earlier.

*Indicates agencies of the US Department of Health and Human Services (HHS).

†These categories are not mutually exclusive. The National Study of Caregiving has historically been cross-sectional data. However, longitudinal data collection began in 2017, and will continue to be implemented going forward, so this data source was counted as both cross-sectional and longitudinal data.

‡These categories are not mutually exclusive. The Panel Study of Income Dynamics provided annual data from 1968 to 1997 but changed to biennial after 1997. These data sources were counted as both annual and biennial data.

§Values in "Other" include: (1) every 60 days until discharge (Home Health Outcome and Assessment Information Set); (2) every 3 years (Kids' Inpatient Database); (3) continuously as each admission and discharge record is mined for data (Treatment Episode Dataset); and (4) every 4 months for 2.5–4 years (Survey of Income and Program Participation).

¶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 2021 Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government.

PCOR indicates Patient-Centered Outcomes Research.

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presents information on the scope and access of federal data sources. The vast majority (90%) of sources provide nationally representative information. About half are publicly available at no cost. On the other hand, 26 of the 29 sources have additional data available for restricted use, with variable costs.

Table 4 summarizes the specific measures within each of the 3 outcome categories. Across all the 29 data sources, paid/reimbursed amounts are the most commonly available measure both within the formal health care sector cost category and across all measures (48% of sources). Unpaid caregiver time is the most commonly available informal health care sector cost (28%), followed by patient time (14%). Among non-health care sector costs, the most prevalent outcome in federal or federally funded data sources is time in home production and leisure (24%), followed by absenteeism or lost wages (both 21%). No sources provided information on relocation costs or specialized clothing. The Medical Expenditure Panel Survey was the only data source among the 29 to provide information in all 3 domains, although coverage within them is incomplete (Appendix A, Table A-2,

Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>).

Data linkages represent a significant potential advance for improving PCOR-relevant economic studies since only 1 data source individually captures all 3 domains, albeit incompletely. Linkage information is described further in Appendix A (Table A-2, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>). Of the identified data sources, 17 are linkable to at least 1 other source. Several other data sources are not currently available in a publicly linked form, although in discussions with the technical panel and key informants, we learned that some researchers have performed special linkages, or new projects to create public linkages are underway.

Other strengths and limitations of the sources are also described further in Appendix A (Table A-2, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>). Surveys have several strengths for capturing PCOR economic studies, such as questions that may capture a fuller range of informal health care sector costs and non-health care sector costs not



FIGURE 1. Scope and access of federally funded data sources with information on patient-centered economic outcomes.

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TABLE 4. Economic Outcomes in Federally Funded Data Sources With Information on PCOR Economic Outcomes

Outcome category	No. data sources	Percent of data sources (%)
Formal health care sector costs		
Paid/reimbursed amount	14	48
Out-of-pocket health care costs and/or medical expenses	8	28
Insurance premiums	3	10
Informal health care sector costs		
Transportation costs	3	10
Unpaid caregiver time	8	28
Patient time	4	14
Non-health care sector costs		
Paid professional care (childcare expenses, housekeeping)	1	3
Special food	2	7
Home modifications	1	3
Relocation/moving costs	0	0
Specialized clothing/laundry costs	0	0
Value of time spent in home production and leisure	7	24
Value of absenteeism	6	21
Value of presenteeism	3	10
Lost wages from inability to work	6	21

The findings in this table are based on the 29 federally funded data sources identified using the search process described earlier. Also, some of the cost components from Appendix Table A-1 (Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>) are grouped into the same row in this table, for brevity of reporting. PCOR indicates Patient-Centered Outcomes Research.

available in administrative sources. Surveys also capture SDOH and health equity-relevant characteristics, which are limited in many administrative sources. However, most surveys also have limited detail on health outcomes and conditions, such as disease onset or severity, and do not necessarily sample or oversample based on health conditions. Therefore, although they are reasonable for making inferences about the general population, finding a sufficient sample size for PCOR analysis of surveys can be challenging for many research questions, even the study of prevalent conditions like cancer, and this is magnified when investigating health equity across subgroups or studying rarer health concerns. In contrast, administrative samples often include large populations, which facilitate such analyses. Another strength of administrative sources is the potential measurement of precise, detailed medical expenditures along with specific diagnosis or procedure codes, which measure health outcomes. However, with high rates of managed care enrollment in Medicaid and, increasingly, Medicare, service-level payments are not available or applicable for these sources. Administrative data often span large populations, but in some cases, this is limited to a specific program such as Medicaid or Medicare. Other weaknesses of administrative data include limited demographic information and a lack of most SDOH or contextual information.

DISCUSSION

Comparing the data inventory of federal sources (Table A-2, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>) to the relevant economic outcomes (Table A-1) (Appendix A, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>), several gaps are apparent. Under formal health care sector costs, paid/reimbursed amounts are available in several administrative sources but few surveys. This finding was expected because health care payments or charges are often captured directly in billing or discharge records, and it is unrealistic for survey respondents to accurately report detailed health expenditures. Medical Expenditure Panel Survey is a unique and invaluable data source for PCOR economic studies, as it combines features of both survey and administrative sources. There are fewer sources for other formal health care sector costs, indicating an important gap for PCOR-related economic studies. In contrast, several sources for measuring non-health care sector costs exist; outcomes such as absenteeism, disability, and labor force participation are captured in several surveys. No federal administrative sources of non-health care sector care costs were identified.

The gaps that are apparent in the data inventory to date may also be considered around equity²⁴ and distribution of PCOR economic outcomes. Although we primarily evaluated the completeness of data sources, costs vary by health conditions. To the extent that the incidence of health concerns varies by race, ethnicity, sex, age, and other factors, addressing data gaps may improve efforts to monitor and improve equity in PCOR economic outcomes. However, sample size is also an important issue for equity. Many surveys may not have sufficient sample sizes for precise intersectional analyses, which may be fundamental to the research question or related to the incidence of health outcomes.

On the basis of our findings, we offer several considerations toward improving the usage of federally funded data for PCOR economic evaluations. First, efforts to link survey and administrative data sources should be continued and expanded. All data sources identified have strengths and weaknesses for PCOR economic studies, but where feasible, linkages have the potential to capture additional relevant economic outcomes. Linkages may add concerns around privacy, but secure options exist, such as Census or NCHS Research Data Centers²⁵ and the Medicare Chronic Conditions Data Warehouse. Expanded clinical registries, such as for Alzheimer or other chronic conditions,²⁶ could build on the frameworks of the successful SEER-Medicare and SEER-Medicaid linkages for cancer research.^{27,28}

Second, lower costs and administrative barriers would facilitate more PCOR research with restricted data sources. Many of the most fruitful data sources in the inventory are not public use. Administrative and financial costs reduce the number of studies based on these sources and the number of researchers who can access them. Although confidentiality and data use agreements are vital, more central clearinghouses for “prelinked” data sources could facilitate this, such as the agreement between CMS and the National Institute on Aging to develop MedRIC.²⁹ Clearinghouses could also ensure consistency of linkages and variable definitions across studies. Several key informants voiced support for the 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.³⁰ If these barriers are reduced, we would expect to see more researchers conducting important PCOR economic research that reaches more stakeholders.

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Third, consistent measurement of some economic outcomes could increase measure comparability, albeit with tradeoffs. For example, few surveys capture presenteeism, an outcome that is recognized by employers but without a consistent definition. Standardization might encourage its adoption in more datasets. However, there is a cost to this too, since adding it to other studies could crowd out items of interest to other researchers, increase respondent burden, or decrease precision relative to a specialized scale. Regarding employment, changes in career trajectories or role functioning are important to patients but not captured consistently, if at all, on surveys. Within formal health care sector costs, data sources often report either charges or payments, but few report both. Charges are a compromise when payments are proprietary information, although payments reflect the most relevant PCOR economic outcome for insurers, patients, and their families.

Fourth, existing surveys can undertake greater measurement of informal health care and non-health care sector costs and SDOH. Key gaps include limited data on time costs, transportation costs, childcare, relocation, and labor force measures (participation, disability, absenteeism, wages), and their collection in combination with measures of health problems or medical care. Some non-health care sector costs also have important caregiver and sex differences within families. Several forms of SDOH items can be captured only through survey items rather than administrative records, and capturing these is vital to assess equity and distribution in PCOR economic costs.

There are several limitations of our work. First, to focus on the reauthorization of the PCOR Trust Fund, we limited the scope to federal and federally funded data sources. We excluded private sources (eg, MarketScan) and state-specific data sources, such as all-payer claims databases, which may be used in PCOR economic research.²³ Future researchers may wish to consider a similar inventory approach using nonfederal sources. Second, our search may have missed data sources or specific economic measures within sources. We excluded data with partial federal support, but some data may be viewed differently by other researchers. Third, although our list of economic outcomes was derived from recent literature,¹⁴ the concepts in Table A-1 (Appendix A, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>) are inconsistently used by researchers.³¹ Some readers may draw different conclusions. Fourth, although discussions with the technical panel and subject matter experts were invaluable, those perspectives are not necessarily representative of their fields or wider perspectives. Lastly, in constructing the inventory in Table A-2 (Appendix A, Supplemental Digital Content 1, <http://links.lww.com/MLR/C641>), we excluded merges that join datasets with other sources for contextual information, such as county-level or community-level characteristics. For example, data from the American Community Survey or the Area Health Resources File can be merged at county or state levels to augment other data sources. These merges are an integral part of many health services research studies, and future researchers could link data sources in the inventory at the geographic level to the extent that merging identifiers are present. For this manuscript, we elected to focus on the coverage, strengths, and weaknesses of the core, underlying data sources for PCOR economic outcomes rather than provide a list of potential public use linkages for narrower research topics.

CONCLUSIONS

Informed health care decision-making by any stakeholder requires data on both clinical impacts and on the economic burdens of different treatment choices on patients' lives and on their families. PCOR-relevant economic assessments can be generated by the scientific community only when access to high-quality, comprehensive data sources are widely available. This paper has shown that current federally funded data sources only capture a limited range of relevant economic outcomes, particularly within individual sources. Data linkages represent a significant and efficient potential advance for increasing and improving PCOR-relevant economic burden studies. We also identified tradeoffs around the standardization of PCOR economic measures, a need for greater attention to SDOH measures, and improved access to data.

The full potential of enhanced data sources and expanded PCOR research will be unlocked when it is supported by greater translation, dissemination, and implementation to wider audiences. Emerging and existing decision support tools³² should strive to include greater detail on out-of-pocket costs, patient outcomes, caregiver implications, and non-health care sector costs. For example, a family might consider multiple surgical options to deal with a child's acute bone injury, weighing any clinical recommendations with fuller information on the types of economic outcomes covered in this manuscript. Among older ages, Medicare.gov helps patients to search for 8 types of facilities (eg, dialysis, nursing home), providing a 5-star rating system for each. These ratings are based on health outcomes but could be further enhanced by adding PCOR economic outcomes. Regardless of how they access or use it, we believe that most stakeholders will benefit from greater PCOR economic data.

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