Background

Generating evidence on the outcomes, effectiveness, and value of healthcare is important for informing the decisions facing patients, providers, and policymakers. The Patient-Centered Outcomes Research (PCOR) Trust Fund was established by Congress in 2010 and directs the Secretary of Health and Human Services (HHS) to “provide for the coordination of relevant Federal health programs to build data capacity” for research on patient health outcomes. Over the past decade, HHS agencies have collaborated to build a portfolio of projects that support PCOR. In 2019, the PCOR Trust Fund was reauthorized for ten years, and the scope of patient outcomes was expanded to include “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, non-medical costs to the patient and family, including caregiving, effects on future costs of care, workplace productivity and absenteeism, and healthcare utilization.” The law is permissive of studies of other economic impacts on patients, families, and caregivers.

With this expanded scope, there is a renewed opportunity and funding to build and strengthen data capacity for PCOR studies – improving the availability, quality, and accessibility of data on economic variables as well as the analytic resources needed to support the study of economic impacts. To advance this important aspect of PCOR data capacity, the Assistant Secretary for Planning and Evaluation (ASPE), with support from the RAND Corporation, is planning a scientific symposium and accompanying special issue in the journal Medical Care, focused on understanding and advancing the ways in which patient-centered economic data can be collected, linked, and analyzed for PCOR studies. Authors of selected abstracts will develop full manuscripts for consideration in the special issue and will be invited to present their papers at an invitation-only symposium in December 2022 in Washington, DC. Travel support for the corresponding author will be provided.

Call for abstracts

We are accepting abstracts related to patient-centered economic outcomes, with a focus on building data capacity for research. The following are priority areas, although abstracts on other related topics are welcomed.

Building Data Infrastructure

- Data access and data collection (e.g., availability of economic outcomes data for PCOR, innovative data sources and methods for collecting economic outcomes, priorities for addressing data gaps).
- Data quality and standardization (e.g., quality of economic outcomes data, priorities for standardizing economic outcomes, efforts to harmonize collection of economic outcomes data).
- Data linkages (e.g., priorities for expanding data linkages, efforts to link data sources containing economic outcomes, ethical or privacy considerations when linking data).
- Strengthening existing federal data for PCOR economic research.

Improving Measurement and Analysis

- Measurement of economic outcomes (e.g., defining economic outcomes, developing and validating new economic outcomes measures, incorporating economic outcomes in value-based payment models).
- Valuing economic outcomes (e.g., comparisons of valuation methods).
- Data analysis (e.g., accounting for population heterogeneity in PCOR studies with economic outcomes, statistical inference for PCOR studies with economic outcomes).
Generating Empirical Evidence

- PCOR study protocols or research portfolio summaries with discussion of economic outcomes, target audience, and potential impact of the research.
- Completed PCOR studies containing economic outcomes with discussion of the potential impact of the research.
- Summaries of completed PCOR research with economic outcomes on a specific topic and identification of gaps in measurement of economic outcomes.

Health Equity

- Methods for designing PCOR studies and selecting economic outcome measures to strengthen health equity.
- Studies that improve economic outcome measures to better capture diverse patient experiences or validate new or existing economic outcome measures in diverse populations.
- Studies of PCOR economic outcomes and health equity (e.g., analyses of disparate burden).

Authors addressing the first three areas are encouraged to include a focus on health equity, including discussion of how data and methodological improvements or research findings can be used to improve health equity. In addition, priority populations across all topics identified above include individuals served in federal health programs, including Medicare, Medicaid, Health Insurance Marketplaces, Veteran’s Health Administration, Indian Health Service, Ryan White HIV/AIDS program, and federally-qualified health centers (FQHCs).

Abstracts focusing on caregivers, pregnant women and mothers, disabled, dually-eligible Medicare beneficiaries, and individuals with mental health and substance use disorders will also receive high priority, and abstracts targeting low-value care or addressing social determinants of health are particularly welcome.

Abstracts measuring economic outcomes from the perspective of patients, families, and caregivers will be preferred over those reflecting only payer or societal perspectives. Authors are also encouraged to address findings from the recent report entitled, “Building Data Capacity for Patient-Centered Outcomes Research: Priorities for the Next Decade” that was commissioned by ASPE and published by the National Academies of Sciences, Engineering and Medicine.3

Review Process and Criteria

Abstracts will be evaluated by members of a Technical Expert Panel convened to support the special issue and the symposium. Abstracts will be rated on several criteria, including significance, feasibility, scientific merit, and fit with the priorities of the special issue.

Submission Guidelines

Abstracts outlining proposed manuscripts for the special issue should be submitted through the submission portal (https://answer.rand.org/PCORsuppl). Abstracts are limited to 500 words and should use a structured format, as follows. Empirical papers should include the following sections: Background, Objective, Research Design, Participants, Measures, Results, Conclusions. Proposed Literature Reviews should contain the following sections: Objective, Materials and Methods, Results, Conclusions. Commentaries and other non-empirical papers should include the following sections: Background, Objective, Main Arguments. Each abstract should include a one to two-sentence rationale for relevance to the special issue and symposium, using a section header entitled Relevance to the Special Issue. Submissions must include the primary author and planned collaborators, along with their institutional affiliations (this information is excluded from the 500-word limit).

Timeline

Abstracts must be submitted by August 12, 2022 at 5:00 pm ET. Authors will be notified at the end of August if they are invited to submit a full manuscript for the symposium and special issue of the journal. A complete draft manuscript will be required by November 11, 2022 to share with symposium participants for feedback and discussion at the in-person meeting in December, 2022.

For any questions about the call for abstracts contact PCORsupplement@rand.org

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1 See https://aspe.hhs.gov/collaborations-committees-advisory-groups/os-pcortf
3 See https://www.nationalacademies.org/our-work/building-data-capacity-for-patient-centered-outcomes-research-an-agenda-for-2021-to-2030

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