

Building Data Capacity for Patient-Centered Outcomes Research: Looking Ahead at Data Needs

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What Should PCOR Facilitate?

Patient-Centered Outcomes Research (PCOR) helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the potential benefits, risks, and value of healthcare options. This research answers patient-centered questions, such as:

- “Given my personal characteristics, conditions, and preferences, what should I expect will happen to me?”
- “What are my options, and what are the potential benefits and harms of those options?”
- “What can I do to improve the outcomes that are most important to me?”
- “How can clinicians and the care delivery systems they work in help me make the best decisions about my health and health care?”



What are the main data needs?



Patient-centered outcomes and impacts collected consistently



Burden, including costs incurred by patients and their families



Social determinants of health



Representative populations



Quality and satisfaction with care as defined by patients



Accessibility to patients



Interoperability

Patient-Centered Core Impact Sets

Examples of Patient Experience Information from the *CFS and ME Voice-of-the-Patient Report*

Disease-Related Impact on Feelings and Function	Treatment-Related Impacts	Financial-Related Impacts	Caregiver-Related Impacts
• Post-exertional malaise • Weakness • Muscle and joint pain • Unrefreshing sleep • Decreased quality of family life • Social isolation • Feelings of hopelessness	• Willing to accept significant risk from new treatment to alleviate or cure condition	• Loss of career • Harsh financial difficulties as a result of decreased or lost employment income • High cost of treatment, often because unapproved treatments are not covered by insurance	• Stress on family/family members



CFS: Chronic Fatigue Syndrome; ME: Myalgic Encephalomyelitis

PCORI's Broadened statutory scope presents opportunities to more effectively assess treatment alternatives and value from the patients' perspective

Consideration of the Full Range of Outcomes Data can lead to...

- More holistic evidence relevant to patient decision-making
- More informed decisions as patients navigate their options and understand what treatment impacts might be beyond clinical outcomes



Data on costs that matter to patients should be systematically collected and incorporated into research and decision-making



DIRECT MEDICAL COSTS

Examples

Inpatient or outpatient care
Physician visits
Rx medications and their administration
Durable medical equipment

Private and public insurance programs typically pay providers directly, and patients are responsible for full costs before a deductible, followed by co-pays and/or coinsurance



INDIRECT COSTS: PRODUCTIVITY LOSS

Examples

Forced retirement
Absenteeism
Presenteeism (when employees cannot fully function in the workplace)
Reduction in community participation and volunteer service

Reduces income for patients and caregivers, while reducing productivity for employers, communities, society



NON-MEDICAL & UNCOVERED HEALTHCARE COSTS

Examples

Necessary home or auto modifications
Transportation and education costs
Paid daily care
Healthcare services not covered by insurance: experimental treatments, medical foods, and more

Out-of-pocket costs absorbed directly by families living with RD

What data capacity challenges is HHS best positioned to address in the context of their public mission, authorities, programs, and data resources?



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Thank you!

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