

Patient Centered Outcomes Research in Pulmonary, Critical Care and Sleep Medicine

An Official American Thoracic Society Workshop Report

Laura C. Feemster*, Howard L. Saft*, Susan J. Bartlett, Sairam Parthasarathy, Teresa Barnes, Peter Calverley, J. Randall Curtis, David H. Hickam, Richard A. Mularski, David H. Au, Linda L. Chlan, Lynn F. Reinke, Colin R. Cooke, Christopher E. Cox, Jerry A. Krishnan, Eileen Rubin, Smita Shah, Donald R. Sullivan, and Erin K. Kross; on behalf of the American Thoracic Society Behavioral Sciences and Health Services Research Assembly and Nursing Assembly

ONLINE DATA SUPPLEMENT

Supplemental Table 1: Selected examples of international efforts to increase patient and stakeholder participation in research-related activities over time

Year	Country/Region	Event	Description
1978	United Kingdom	National Association for Patient Participation formed (1)	Organization of patients partnering with primary care practices to encourage self-efficacy, disseminate evidence based resources, improve communication with primary care providers, and recruit patients for participation in research across a wide range of geographical, demographic and disease states.
1996	United Kingdom	National Health Service National Institute for Health Research (NIHR) established INVOLVE (2)	National Advisory Group, funded by and part of NIHR, designed to support public involvement in public health and social care research, including its prioritization, design, conduct, and dissemination
2002	United Kingdom	Citizen's Council of the National Institute for Health and Care Excellence (NICE) founded (3)	Members of the public provide formal input related to moral, ethical and practical issues that need to be considered in creation of care guidelines
2002	Australia	National Health and Medical Research Council & Consumers Health Forum of Australia collaborate to produce a statement to support patient participation in research (4)	Statement entitled "Statement on Consumer and Community Participation in Health and Medical Research" (48) was the result of the collaboration between the two groups and developed objectives to guide "consumer" participation across all levels and types of medical and health research. Subsequent collaborations resulted in two additional publications that provided a framework and resource guide to conducting this type of research. This statement was later replaced by "Statement on Consumer and Community Involvement in Health and Medical Research" (5).
2003	United States	National Institutes of Health established Rare Disease Clinical Research Network (6)	Initially consisted of 10 research consortia – expanded to 22 in 2014 – and a data coordinating center. Consortia consist of researchers across multiple international sites collaborating now with more than 130 patient advocacy groups to design and conduct clinical trials across a spectrum of rare diseases (7).
2007	Canada	Canadian Institutes of Health Research (CIHR) launched "Citizen Engagement Initiative" (8)	Created to allow increased participation by Canadians in CIHR funded research using a framework that consists of 4 areas of focus: CIHR board and committee membership; feedback on corporate and institute strategic plans, policies and guidelines; setting research priorities; and dissemination efforts and public outreach.
2010	European Union	Unbiased biomarkers for the prediction of respiratory disease outcomes (U-BIOPRED) asthma consortium established (9)	Consortium of 20 academic institutions, 11 pharmaceutical industry partners, 6 patient advocacy groups, across 11 European countries. Patients are incorporated as part of the "Ethics Board", "Safety Monitoring Board", and "Patient Input Platform" (serves to advise researchers throughout design and conduct of study through dissemination of results).
2010	United States	Patient Centered Outcomes Research Institute (PCORI) established (10)	Independent, nonprofit organization with mission of improving the quality and relevance of evidence available to help patients, family members, clinicians, employers,

			insurers and policy makers make informed healthcare decisions.
2010	Canada	Strategy for Patient Oriented Research (SPOR) (11)	Collaboration of researchers, policy makers, authorities of provinces and territories, academic centers, health care providers, patients and families. This is a ten-year initiative to improve infrastructure to conduct PCOR; provide PCOR specific career development training for researchers; increase efficiency through organizational, regulatory and financial support for PCOR; and promote development and implementation of high-quality clinical guidelines by partnering researchers with guideline developers
2014	United States	National Patient-Centered Clinical Research Network (PCORNet) started (12)	Collaboration between patient powered research networks (PPRN) and clinical data research networks that is supported by a coordinating center to provide technical and logistic support and enable large pragmatic clinical trials.

Supplemental Table 2. Workshop morning presentations

Presentation title	Speaker	Brief description
Definitions and Examples of PCOR	Susan Bartlett, PhD	Focused on key outcomes in PCOR, definitions including those put forth by PCORI, and description of study using PCOR methods with emphasis on stakeholder engagement
Improving Communication about Palliative Care: PCORI Study	J. Randall Curtis, MD MPH	Described PCORI-funded study about communication in serious illness, focused on methods including qualitative methodologies to include patient voice
Example from Sleep Medicine	Sairam Parthasarathy, MD	Discussed “patient-centeredness” as goal in sleep research, provided description of PCORI-funded study of patient and peer driven intervention to improve outcomes for patients who use CPAP for OSA
Patient Centered Outcomes Research: An International Perspective	Peter Calverley, MB ChB	Provided a historical and current perspective of PCOR overseas including a discussion of important areas of impact in PCOR
PCORI’s Approach to Patient Centered Outcomes Research	David Hickam, MD PhD	Focused on PCORI’s approach to PCOR as a key funder of research in the U.S, including definitions and ways PCORI is promoting high-quality PCOR
Practical Considerations in PCOR—experiences of a patient-research partnership	Richard Mularski, MD, MSHS John W. Walsh, patient advocate	Described effective patient-researcher partnership through multiple research projects in COPD, focused on aspects of interaction and differential expertise
Involving patients in research – Patient Advisory Roundtable (PAR) perspective	Teresa Barnes, BA, patient advocate	Described personal journey of involvement in research, focused on experience of patients and advocates
Panel Discussion	Susan Bartlett, PhD (Chair) J. Randall Curtis, MD MPH Sairam Parthasarathy, MD Peter Calverley, MB ChB David Hickam, MD PhD Richard Mularski, MD MSHS John Walsh Teresa Barnes, BA Lynn Reinke, PhD ARNP Linda Chlan, PhD RN	Open discussion in follow-up of morning topics

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12. National Patient-centered Clinical Research Network (PCORnet) [2017; accessed 2017 Sept 19]. Available from: <http://www.pcornet.org/>.