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) A team led by the American Sleep Apnea Association has been approved for a funding award by the Patient-Centered Outcomes Research Institute (PCORI) to develop and expand a health data network that will be part of PCORnet: the National Patient-Centered National Clinical Research Network. The Sleep Apnea Patient-Centered Outcomes Network (SAPCON) data network is one of 29 that were approved for a total of \$93.5 million from PCORI on December 17 to form this new national resource that aims to boost the efficiency of health research.

PCORI envisions PCORnet to be a secure, national data network that improves the speed, efficiency, and use of patient-centered comparative effectiveness research (CER). By integrating data available in the 29 individual networks, PCORnet aims to provide access to a large amount of diverse, nationally representative health information that can support a range of study designs. It will reduce the time and effort needed to launch new studies and focus research on questions and outcomes especially useful to patients and those who care for them.

Moreover, PCORnet will join together networks operated by both patient communities and health systems and will require patients' and other stakeholders' involvement in all aspects of the collection and use of the data. By enabling researchers and patients, clinicians, and other end-users of study results to interact directly and jointly determine research priorities, such as the selection specific studies to support, PCORnet aims to advance the shift in clinical research from investigator-driven to patient-centered studies.

During the next 18 months, the ASAA-led team will use the PCORI funds to expand and improve its systems, work to standardize its data, and be part of the process to develop policies governing data sharing and security and protection of patient privacy. It also will refine its network's capacity to engage and recruit patients and other stakeholders interested in participating in research.

The team is led by principal investigator Susan Redline, MD, MPH, Peter C. Farrell Professor of Sleep Medicine, Director of Programs in Sleep and Cardiovascular Medicine, Brigham and Women's Hospital and Beth Deaconess Medical Center, Harvard Medical School, and member, American Sleep Apnea Association Medical Advisory Council. The team includes several partner organizations: The CTSA Sleep Research Network and Harvard's i2b2 / Shared Health Research Informatics Network (SHRINE) .

## ASAA awarded contract to establish patient powered research network

Written by Australian Business

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"Creation of this patient powered research network for sleep apnea patients promises to transform research by linking patients, providers and other key stakeholders across the U.S. and support this community with an innovative web portal. New Resources will provide the ability to conduct the comparative effectiveness research needed to advance patient care and improve the health and well being of the millions of patients suffering from sleep apnea" said Dr. Redline on notification of the award.

Adam Amdur, a patient, ASAA Board Chair and Co-Chair of the SAPCON Steering Committee, says of the award, "through the network patients like me will be empowered to provide direction for their care and to get answers to the questions that are important to them."

"We are pleased that the Sleep Apnea Patient-Centered Outcomes Network will be part of this exciting initiative to build the data structures needed to significantly enhance the speed and efficiency of patient-centered comparative effectiveness research," said PCORI Executive Director Joe Selby. "The process to select the awardees was very competitive and SAPCON demonstrated it has the expertise, resources, and commitment to engaging patients and other stakeholders to be an excellent fit in PCORnet."

The Sleep Apnea Patient-Centered Outcomes Network was selected through a review process in which patients, caregivers, and other stakeholders joined scientists to evaluate the proposals. Applications were assessed for the capacity of their network to collect complete, comprehensive clinical data, how well they will engage patients and other stakeholders, and their ability to maintain data security and patient privacy among other criteria.

All awards are approved pending completion of a business and programmatic review by PCORI staff and issuance of a formal award contract.

PCORI has awarded a total of \$464.4 million since it began funding CER in 2012. For more information about PCORI funding, visit <http://pcori.org/funding-opportunities/> .