

## SPECIAL ARTICLES

# Patient Partnerships Transforming Sleep Medicine Research and Clinical Care: Perspectives from the Sleep Apnea Patient-Centered Outcomes Network

Susan Redline, MD, MPH<sup>1,2</sup>; Si Baker-Goodwin, EdD<sup>2</sup>; Jessie P. Bakker, PhD<sup>2</sup>; Matthew Epstein, JD<sup>2</sup>; Sherry Hanes<sup>2</sup>; Mark Hanson<sup>2</sup>; Zinta Harrington, MD<sup>3</sup>; James C. Johnston II, PhD<sup>2</sup>; Vishesh K. Kapur, MD, MPH<sup>2,4</sup>; David Keepnews, PhD, JD, RN<sup>2,5</sup>; Emily Kontos, ScD<sup>1,2</sup>; Andy Lowe<sup>2</sup>; Judith Owens, MD<sup>2,6</sup>; Kathy Page<sup>2</sup>; Nancy Rothstein<sup>2</sup>; for the Sleep Apnea Patient-Centered Outcomes Network

<sup>1</sup>Brigham and Women's Hospital, Harvard Medical School, Boston, MA; <sup>2</sup>Sleep Apnea Patient-Centered Outcomes Network; <sup>3</sup>Department of Respiratory and Sleep Medicine, Liverpool Hospital, Sydney, Australia; <sup>4</sup>University of Washington Medicine Sleep Center, Seattle, WA; <sup>5</sup>Hunter-Bellevue School of Nursing, Hunter College/CUNY, New York, NY; <sup>6</sup>Boston Children's Hospital, Harvard Medical School, Boston, MA

Due to an ongoing recent evolution in practice, sleep medicine as a discipline has been compelled to respond to the converging pressures to reduce costs, improve outcomes, and demonstrate value. Patient "researchers" are uniquely placed to participate in initiatives that address the specific needs and priorities of patients and facilitate the identification of interventions with high likelihood of acceptance by the "customer." To date, however, the "patient voice" largely has been lacking in processes affecting relevant policies and practice guidelines. In this Special Report, patient and research leaders of the Sleep Apnea Patient-Centered Outcomes Network (SAPCON), a national collaborative group of patients, researchers and clinicians working together to promote patient-centered comparative effectiveness research, discuss these interrelated challenges in the context of sleep apnea, and the role patients and patient-centered networks may play in informing evidence-based research designed to meet patient's needs. We first briefly discuss the challenges facing sleep medicine associated with costs, outcomes, and value. We then discuss the key role patients and patient-centered networks can play in efforts to design research to guide better sleep health care, and national support for such initiatives. Finally, we summarize some of the challenges in moving to a new paradigm of patient-researcher-clinician partnerships. By forging strong partnerships among patients, clinicians and researchers, networks such as SAPCON can serve as a living demonstration of how to achieve value in health care.

**Keywords:** comparative effectiveness research, patient networks, sleep apnea, outcomes

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## INTRODUCTION

Sleep medicine has been forced to respond, perhaps even more urgently than other disciplines, to the converging pressures to reduce costs, improve outcomes, and demonstrate value. In this commentary, the Sleep Apnea Patient-Centered Outcomes Network (SAPCON), a collaborative group of patients, researchers, and clinicians, discuss these interrelated challenges in the context of sleep apnea, and the role patients and patient-centered networks may play in transforming both research and clinical care. We first discuss the challenges facing sleep medicine associated with costs, outcomes, and value. We then discuss the novel role patients and patient-centered networks can play in efforts to design research to support better sleep health care. We include direct insights from patient leaders of SAPCON who responded to several key questions regarding patient values and patients' roles in network research. Network activities of SAPCON are approved by the Partners HealthCare System Institutional Review Board.

## COSTS

Concerns over the impact of spending approximately 18% of the U.S. Gross Domestic Product on healthcare, particularly in light of the ongoing significant inequalities in the health of our citizens, have captivated the attention of policy makers and the general public. For sleep medicine, these concerns, and specifically the rising costs for sleep tests (costs increasing 4-fold from 2001–2009), have led some payers to implement procedures that restrict access of patients to sleep specialists, reduce reimbursement for many services including cognitive behavioral therapies, and mandate home sleep apnea testing rather than laboratory-based polysomnography. Although there are urgent imperatives to improve efficiencies, these health care delivery service decisions appear to have been made with little input by key stakeholders including patients and sleep clinicians. For example, in a one-sided effort to cut costs, some insurers have misused the research literature on home testing that supports the use of home-based interventions, but only in the context of specialty-based educational support and comprehensive patient

management.<sup>1,2</sup> Yet some insurers have used this literature to justify exclusive contracts with home sleep apnea testing programs that lack precisely those key components, resulting in reduced patient satisfaction and quality of care.

## OUTCOMES

Parallel with rising costs is the vexing concern over the effectiveness of health care in regards to relevant health outcomes. While our health care system has achieved improvements in mortality, the burden of disease (defined as life lost due to premature death, poor health, or disability) has actually increased inequitably in recent years, despite the availability in many cases of effective treatments.<sup>3</sup> For instance, looking at available metrics in sleep medicine, we can identify a strong evidence base showing that positive airway pressure (PAP) treatment improves the apnea hypopnea index and blood pressure in patients with sleep apnea.<sup>4,5</sup> There is also evidence, albeit less strong, from observational research showing that sleep apnea confers an approximately 50% increased risk of mortality, and that PAP therapy is associated with a significant reduction in fatal cardiovascular disease.<sup>6,7</sup> Numerous studies have shown that treatment of sleep apnea reduces sleepiness, improves quality of life, and mitigates depressive symptoms.<sup>4</sup> However, the benefits of PAP on these outcomes in comparison to alternative treatments, such as mandibular advancement devices, are less clear.<sup>4</sup> Furthermore, rigorous analyses of whether or not subpopulations of patients with sleep apnea differentially improve on specific therapies are wanting. Therefore, similar to medicine as a whole, sleep medicine needs to generate higher levels of evidence, especially to guide choice of sleep interventions across the patient population. A major limitation has been the relative paucity of well-designed and sufficiently large clinical trials and comparative effectiveness studies.<sup>8</sup> In this era of moving towards a “personalized medicine” approach, high quality, patient-centered studies are desperately needed to inform clinical practice aimed at reducing sleep disorders-related symptoms, morbidity, and mortality, and ensuring that the most appropriate screening, diagnostic and treatment procedures are offered to each individual patient.

## VALUE

It has been proposed that efforts to improve health care delivery would benefit by increasing focus on “value,” which integrates information on both outcomes and cost, and has been defined as “health outcomes achieved per dollar spent.”<sup>9</sup> The American Academy of Sleep Medicine has taken many important steps towards focusing attention on sleep-related outcomes (the numerator of the equation) as integral to all aspects of sleep medicine, and indeed, to the mission of the Academy. A notable advancement was the recent publication of a guide for measuring quality outcomes in sleep medicine that included a discussion of the importance of the availability of high quality sleep health services on a broad array of medical conditions and quality of life.<sup>10</sup> An active Academy

Task Force furthermore is addressing processes for integrating sleep data and associated quality metrics into the electronic health record, which would leverage the power of electronic health record systems to utilize multiple sources of information to better screen, diagnose, and manage patients. Better integration of sleep data within the electronic health record also would provide improved economic data needed to fully evaluate “value.” The latter requires consideration of both direct and indirect costs, such as the impact of sleep apnea on chronic disease health burden.

## ROLE OF PATIENTS

In considering value, we are reminded by Dr. Porter in his commentary in the *New England Journal of Medicine*, that “value should always be defined around the customer,”<sup>9</sup> or specifically, *by the patient*. Over the past several years some medical and research communities accordingly are stepping back from traditional biomedical models to explore more patient-centered models of care and scientific investigation. This paradigm shift has occurred within health care organizations, and among industry leaders and federal funding and regulatory agencies such as the National Institutes of Health and the Food and Drug Administration. Patients are increasingly engaged at various levels, including as members of patient advisory groups as well as partners and co-leaders in health policy development, improving access to care and clinical research endeavors. Notably, in 2010, the Patient-Centered Outcomes Research Institute (PCORI) was established by Congress as an independent, nonprofit, nongovernmental agency with the mandate to “improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions.” Essential to their philosophy is the centrality that patients play in the entire research life cycle—from identifying important research questions, to designing and implementing the study, and finally, to dissemination of results. This spirit is captured by Dr. Selby and his colleagues’ vision, “If each patient were an active and informed participant in clinical research as part of their regular health care, a visit to a doctor’s office would have the potential to transform the health of millions of individuals.”<sup>11</sup>

As this new paradigm takes form, we see emerging initiatives that help amplify issues and concerns of patients and their caregivers allowing their voices to be heard in assessing the value of their healthcare options.<sup>12</sup> Across many fields, there is an emergence of research co-designed by patients.<sup>13,14</sup> For sleep medicine, in particular, there are exciting opportunities for patient researchers to partner with clinicians, “traditional” researchers, and other stakeholders to enhance communications and disseminate information that is relevant and understandable. Patient-researchers are uniquely placed to participate in initiatives that address the specific needs and priorities of patients and facilitate the identification of interventions with high likelihood of acceptance by the “customer.” Rather than the traditional “one size fits all” approach to medicine and research, larger scale research that uses information on health risk factors, biomarkers, background and characteristics of each person’s

sleep disorder—and *patient preference*—could markedly enhance the availability of more individualized approaches.

## SLEEP APNEA PATIENT-CENTERED OUTCOMES NETWORK

The creation of the Sleep Apnea Patient-Centered Outcomes Network (SAPCON; MyApnea.Org) responds to these needs and opportunities. SAPCON is a patient-powered research network initiated in 2013, stimulated by PCORI's vision of creating a "network of networks"<sup>11</sup> of diverse stakeholders working together to accelerate patient-centered comparative effectiveness research (CER). Conducting responsive, patient-centered CER via patient-stakeholder engagement is its primary goal. This requires building a trusting and respectful community that stimulates the generation of ideas from *all* members, and that openly shares information that can have both direct educational impact as well as leads to novel hypotheses and research initiatives.

SAPCON leadership consists of a Steering Committee that includes patients, clinicians, and researchers, and an 8-member Patient Engagement Panel (PEP), who represent a diverse group of patients from across the U.S. People with (or at-risk of) sleep apnea as well as family members of those with sleep apnea are invited to share information, provide support, and help design, direct, and participate in sleep research. Members of SAPCON are brought together via the freely available MyApnea.Org, an online portal with currently over 6,900 members representing all 50 U.S. states and 41 countries. The interest of patients in an effort of this type is evidenced by a growing membership and frequent portal visits, with approximately 500 unique visitors to the site per day.

The idea that patients and their needs should be placed at the center of care and outcomes research is endorsed by SAPCON PEP Chair and Steering Committee Co-Chair, Kathy Page. When Ms. Page was introduced to patient-centered research, she noted:

"Patient-centered? Someone actually wants to know what is important to patients? This shouldn't be that exciting or unusual. All treatments, physician visits and research should be patient-centered. But in the real world, this doesn't seem to be the way of it. When I learned that MyApnea.Org was looking for patients to be part of a new initiative, I asked to be considered. I am now chair of the Patient Engagement Panel. I am proud of what we have accomplished in the short time that patients have been involved. We are a work in progress which is good; we are evolving which means we are not stagnant. The PEP is not only charged with developing new ideas, we are listened to and our input is valued. Our biggest problem is that we have too many ideas! We are still taking baby steps but we are prepared to run. I have been on other boards that do great things but never one where the patient is so involved."

Network members have the opportunity to complete a series of health related surveys, nominate and vote on research questions and can participate in forums to discuss a wide variety of

topics, ranging from self-care to research priorities. The MyApnea.Org portal was designed with patient-centeredness in mind. Content has been vetted, and often developed by patients, and includes educational content on a LEARN tab (<https://myapnea.org/learn>), as well as information on research findings and new research studies on a RESEARCH tab (<https://myapnea.org/research-topics>). After completing the online patient reported outcomes surveys, patients are able to immediately view their own responses in relation to those of other network members. Contextual information—on why specific questions are asked and guides to interpreting responses—are provided for many surveys. Several *de novo* surveys have been designed by teams of patients and researchers to address specific concerns generated by network members. For example, one new survey assesses CPAP adherence patterns. Stimulated by SAPCON survey data showing that over 65% of respondents reported diagnostic delays of more than 2 years, another new survey was developed to better understand the reasons for such marked diagnostic delays. An additional survey instrument was designed to quantify the level of patient satisfaction with sleep apnea education materials and better understand health information seeking patterns of patients in order to ultimately address noted gaps.

Patient network members have also expressed keen interest in learning from each other's narratives, as well as from clinicians and researchers working in sleep apnea. To meet this need, a NARRATIVE section of MyApnea.Org is currently in development, which will feature personal "stories" about the experience of those individuals living with sleep apnea, whether as patients, partners or caregivers, and those who in their professional lives are deeply touched by sleep apnea.

## PATIENT PRIORITIES

SAPCON PEP members have identified a number of priorities. One key need is to improve the access to better information, communication and support for sleep apnea patients. This has been articulated in many ways by SAPCON members. A few examples are given below:

"My sleep doctor is good and has sleep apnea himself. He answers all my questions but doesn't really ever give me information unless I ask for it. Speaking as a patient, this seems to be the wrong approach. I am a firm believer in patient education. Learning all you can about whatever disease or illness a person has helps in making informed decisions about health care and outcomes, especially when used to build a working relationship with the physician. My personal experience with most doctors is that occasionally they will give you a generic brochure to look at right before they walk out the door. Often, patients don't get that unless they ask and sometimes not even then."

"Anyone participating in the diagnosis and treatment of SA needs access to patient tailored briefing materials and support services to ensure that as soon as they are identified as at-risk they get the best information and services available. While much of the material needed

may exist, I do not know where to find it for myself or to share with others. My own experience informs me that my family and care givers are as in need of these materials as well.”

“Using sleep apnea as an example, patients are hit with words such as central, obstructive, and complex apneas, AHI, RDI, blood oxygen saturation to try to understand. What type of CPAP or BIPAP machine is needed? What type of mask or nasal pillow works best? For a long time, I thought a nasal pillow was an actual pillow with some strange breathing apparatus attached. Patient education is imperative. Most doctors assume patients understand what is being told to them because they don’t ask questions. Patients don’t ask questions because they don’t know what questions to ask. Many patients will turn to the internet for answers instead. Hopefully they find a reputable site.”

A related need that has been frequently endorsed is to empower patients to seek greater self-care and self-management. Several PEP members note:

“Ideally in parallel to the collection, customization, and publication of such materials, there should be a focus on best practices in the self-care for sleep apnea patients as well as about behaviors, practices, and habits that will benefit anyone whether or not they have the condition: sleep hygiene, communicating, and where to look for the most reliable information for examples.”

“Wearing a CPAP machine is an inconvenience and difficult to comply. Being diagnosed in my 20s (30 years ago), I have tried many modalities to treat my sleep apnea as well as tried to just pretend it didn’t exist at times. I have used and still mostly use CPAP. I have tried a range of facial masks and nose pillows. I have a dental device. I have Pro-Vent Nasal patches. I have an acupuncture ring. There is nothing out there right now that is not somewhat invasive in my opinion. Patients need to understand the risks involved of not getting tested or treating apnea or not complying with their treatment. This education is very important so that patients are willing to be inconvenienced to follow through with their treatment.”

“There are areas that doctors can’t help with. Patients need support for getting used to CPAP therapy—the mask hurts our nose bridge, it leaks, we are claustrophobic—the list goes on and on. We need support from others. All this looking for information and support takes time, it can be very stressful and often patients will just give up and stop the therapy.”

Another key concern is that research be designed with the *patient* in mind, and without bias. Examples of this call for inclusion and transparencies are given below:

“All too often there are industry funded studies designed to promote their own products and drugs and public

dollars controlled by small cliques of recognized leaders who speak mainly to themselves. Their research design is often elegant with carefully crafted protocols and sophisticated statistical analyses. Too bad they often answered the wrong questions. If those scarce resources could be directed toward the solutions sought by patients, that great work would result in drastically improved outcomes with high efficiency and enthusiastic dissemination. That is the promise of active patient involvement in research.”

“Including patients in strong research and reporting practices—in the development, evaluation, and dissemination process—will increase the likelihood that both publications and processes will be used.”

The promise of patient-centered research is described by one member in the following way:

“Research will be better-designed when patients are made part of the team at the design stage. We are the experts in our condition; we will think of things researchers without the disorder would not; we will learn things from the researchers that will make us more effective as we hope our experience will make them more effective. And possibly research designed with patients will carve shorter paths to effective care for all of us in the system.”

Finally, patients enthusiastically endorse the need for research to identify alternative treatments. One member shares her aspirations:

“I would like to see less invasive treatments discovered and approved. I think that unless you are really committed, it is difficult to comply with current available treatments. I believe there are well-meaning patients who attempt to comply on a nightly basis who fall short by morning.”

In addition to these reflections from PEP members, an analysis of activity within the MyApnea.Org portal provides insights on issues of importance to patients. The forum currently includes over 2,200 posts on over 250 different topics. In the last year, there were almost 400,000 “page views.” The most popular topics have been: use of distilled water in CPAP machines (n = 26,191), CPAP pressure too high (n = 24,078); research comparing oxygen to CPAP (n = 7,532), sleep apnea and sinus problems (n = 6,988), and still sleepy on CPAP (n = 6,241). These patterns underscore: (a) the needs for sleep apnea patients to receive fundamental accessible information on sleep apnea/CPAP self-management; (b) interest in CPAP alternatives; and (c) common concerns over persistent sleepiness.

## SLEEP CLINICIANS AND RESEARCHERS

An underlying tenet of SAPCON is that the community is strengthened by a respectful partnership among all stakeholders. In addition to patients, sleep researchers and clinicians are



encouraged to join SAPCON. Researcher-subscribers have posted research summaries on a variety of topics. These include associations of sleep apnea with atrial fibrillation, diabetes, hearing loss, dental disease, and an in-depth explication of complex sleep apnea. Additionally, sleep researchers using the portal as a research vehicle have access to its aggregate data. Using the forums and a portal tool we call *Rank the Research*, researchers float ideas to solicit patient-subscriber input—a process designed to assist with the development of research protocols that are patient-centric. In addition to opportunities to contribute to the various forums, provider-subscribers can create their own specific landing pages with unique web addresses and welcome messages for their patients. These customized web links enable providers to promote MyApnea.Org among the patients they serve. Once a provider has 20 patients registered for the site, aggregate patient reported outcomes for their patient panel can be viewed and results can be compared against the entire patient-subscriber community, potentially supporting quality improvement initiatives at the individual provider or provider network level.

## CHALLENGES

Patient-centered research is not without its challenges. As we forge a new way of conducting research we must find common ground, a shared language and mutual understanding across multiple stakeholders. Often this requires multi-directional learning which can be complex and time intensive. There also needs to be an explicit exploration of existing myths in an effort to minimize preconceived biases and any “*us vs. them*” dialogue in order to move forward as a cohesive team with a common mission.

Many patients have been frustrated by their personal experiences with health care, with delays in diagnosis a chief concern. It is critical to channel the ensuing energy to achieve positive change while not disenfranchising valuable partners. Likewise, clinicians and researchers often have little experience working with patients as partners. Medical schools and other professional training do not typically include guidance on how best to empower patient partners (and patient researchers) to meet their full potential, and “blueprints” for achieving these goals are still to be developed. Researchers working to meet tight and ambitious timelines can find it difficult to “slow down” sufficiently to try new forms of communication and build the trust needed for successful partnerships.

The academic environment and the research process also can appear at best “byzantine” to the newly involved. For example, although the vagaries of institutional review boards are part of the “academic medical culture,” the language and changing rules associated with ethics and privacy can be confusing and off-putting to patients. Similarly, the grants funding process, needed to support the work of patient networks, can be perplexing and appear to be frustratingly slow. Research designs often appear obtuse. For example, while co-designing research studies, our researchers quickly saw how troublesome concepts such as “sham-CPAP” and other “control arms” were to our patient partners. While PCORI has highlighted the need

to use well-validated and patient-centric instruments, some of these are viewed by patients as being inappropriate or lacking responsiveness. For example, several of our patient leaders challenge using the Epworth Sleepiness Scale (which some have noted is repeatedly administered as part of their clinical interactions without evident benefit) and existing sleep apnea screening questionnaires (which some feel are inadequate for early detection of sleep apnea, especially in women and the non-obese). Having a patient network initiate the development of “patient-centric” questionnaires would appear very valuable; however, survey development and validation can be complex and expensive and may exceed the network’s resources.

Patients and researchers attracted to participate in networks such as SAPCON often do so because of their own personal experiences and the desire to have an impact across many areas. However, from a practical standpoint, it can sometimes be difficult within a patient-centered framework to create agile teams that optimally utilize individual talents and different levels of commitment and availability for a wide variety of tasks. Patient-centered networks, due to their democratic, inclusive, and optimistic outlook are at risk of trying to be everything to everyone: a research organization, a patient support and advocacy network, and educational resource. Achieving consensus and focus is perhaps the greatest challenge of all. Finding ways to bridge the gaps between patient and researchers is both the starting point for this endeavor and an ultimately worthwhile final outcome.

## CONCLUSIONS

While progress has been made, we all must continue to strengthen collaborative efforts among patients, clinicians, and researchers, and others with a stake in the diagnosis, treatment, and ongoing care for those with sleep apnea. Also essential are the continued improvement and dissemination of patient education and other resources that support the patient and improve outcomes, and are guided by best practices and evidence-based research. The paradigm shift to patient-centered care in sleep apnea can serve as a model for other medical conditions. By forging a strong and long overdue partnership that puts patients at the center, we are confident that networks such as SAPCON can transform sleep medicine and serve as a living demonstration of how to achieve value in health care. We conclude with a quote from a PEP leader who reflects on how our network may make a difference in patients’ lives:

“MyApnea.Org has and will make a difference on both the macro and micro level. Everyone who logs on or even just reviews the postings learns something. Those not yet diagnosed increase the likelihood of meaningful evaluation. Those already diagnosed learn from the experience of others how to better improve their own outcomes. Clinicians learn to do a better job identifying sleep apnea among their patients. Researchers learn what patients care about and how they can seek and produce meaningful answers. It also is a paradigm shift, helping to create a world where patients, clinicians, and researchers collaborate for the benefit of all with

the promise that someday it will be the norm for all conditions.”

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## SUBMISSION & CORRESPONDENCE INFORMATION

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Address correspondence to: Susan Redline, MD, MPH, Professor of Sleep Medicine, Harvard Medical School, Brigham and Women's Hospital, 221 Longwood Ave, room 225, Boston, MA 02115; Tel: (617) 732-5859; Email: sredline@partners.org

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