

Editorials

Welcoming *AFP's* Patient Partners

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See related Lown Right Care on page 748.

In this issue, the Lown Right Care: Reducing Overuse and Underuse department on the pros and cons of anticoagulation for stroke prevention includes a new section called the Patient Perspective.¹ We would like to welcome Helen Haskell and John James in their new roles on *American Family Physician's* (*AFP's*) Editorial Advisory Board (<https://www.aafp.org/journals/afp/about/advisory.html>), in which they will serve as *AFP's* first-ever official patient partners. Helen and John are key members of the Right Care Alliance Patient Council, which “brings together patients and their families to radically transform our health care system into one that places the health and well-being of patients first and delivers Right Care to all people.”²

John is a medical scientist with a PhD in pathology who served as the chief toxicologist at NASA for 25 years before retiring in 2014. He became a patient safety activist after the death of his 19-year-old son because of uninformed and unethical medical care, which led him to write a memoir, *A Sea of Broken Hearts*, and create an organization to educate the public about patient safety issues. He has also published a literature review that estimates harms associated with hospital care using the Global Trigger Tool.³ John works to empower patients to take better control of their medical care through shared decision-making and informed consent based on the wishes of a reasonable patient.⁴ He is a member of several patient safety organizations and serves on two National Quality Forum committees.

Helen is a former archaeologist, with degrees in anthropology and classics. Like John, Helen turned to patient advocacy following a personal tragedy: the death of her young son Lewis because of a medical error following elective surgery. In her home state of South Carolina, she successfully advocated for the passage of the

Lewis Blackman Patient Safety Act, focused on transparency and communication, and the Hospital Infections Disclosure Act, a state-level precursor to public reporting from the Centers for Medicare and Medicaid Services. Helen has also worked and written on a wide range of topics relevant to patient safety in primary care, including patient engagement, medical education, medication safety, overtreatment, and diagnostic error. In addition to holding leadership roles with the nonprofit organizations Mothers Against Medical Error (which she founded) and Consumers Advancing Patient Safety, Helen serves on the boards of directors of the Institute for Healthcare Improvement and the Accreditation Council for Graduate Medical Education. She also cochairs Patients for Patient Safety, the World Health Organization's patient program.

This is not the first time that *AFP* has collaborated with patients directly. Between 2007 and 2019, the recently retired Close-ups feature told patients' stories in their own words.⁵ So, why enter into a formal partnership now? A national survey fielded by the Right Care Alliance Patient Council between November 2018 and March 2019 found that many patients are worried about being misdiagnosed, receiving unnecessary or harmful treatment, and not receiving enough information to make good medical decisions.⁶

In addition, coronavirus disease 2019 (COVID-19) has widened the patient-clinician divide because the fear of exposure to severe acute respiratory syndrome coronavirus 2, tight finances, and loss of health insurance have dramatically reduced outpatient visits, despite the expansion of telemedicine.⁷ In addition to other initiatives that *AFP* is launching to respond to the pandemic,⁸ we hope to involve our patient partners in developing new strategies to help family physicians address the evolving concerns of patients in the COVID-19 era.

AFP is one of only a few medical journals to include patient representatives as active members on its editorial advisory board. The *BMJ*, which has included patient editors for more than 20 years, has found that content that is written or cowritten by patients “provides valuable insights, not least into the reality of care at the sharp end and ideas on how to improve it.”⁹

John and Helen have a long history of partnering with health professionals in research, writing,

and medical publishing (Helen is also a member of the *BMJ*'s patient advisory panel). One of the lessons they have learned from these partnerships is that successful change, similar to a successful patient-clinician relationship, requires collaboration. John and Helen represent a larger population of patients whose views will be taken into account in their contributions to *AFP*.

In this issue's contribution, Helen and John observe that "the goal of patients is their global well-being, a goal that does not necessarily align with the optimal end point for each of their medical conditions. It is the fundamental role of the primary care physician to balance these conflicting concerns."¹ Moving forward, we hope that our patient partnership will help *AFP*'s readers better align medical care with patients' goals and values.

Editor's Note: Dr. Lin is deputy editor of *AFP*.
Dr. Sexton is editor-in-chief of *AFP*.

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References

1. Roth AR, Lazris A. Anticoagulation in older persons. *Am Fam Physician*. 2020;101(12):748-750. Accessed May 19, 2020. <https://www.aafp.org/afp/2020/0615/p748.html>
2. Right Care Alliance. Patient council. Accessed May 7, 2020. <https://rightcarealliance.org/groups/patient-council/>
3. James JT. A new, evidence-based estimate of patient harms associated with hospital care. *J Patient Saf*. 2013; 9(3):122-128.
4. James JT, Eakins DJ, Scully RR. Informed consent, shared-decision making and a reasonable patient's wishes based on a cross-sectional, national survey in the USA using a hypothetical scenario. *BMJ Open*. 2019;9(7):e028957.
5. Wellbery C. Farewell to Close-ups. The *AFP* Community Blog, November 25, 2019. Accessed May 7, 2020. <https://afpjournal.blogspot.com/2019/11/farewell-to-close-ups.html>
6. James J, Scully RR, Quinlan C, et al. Patient worries as a central feature of the health care experiences. The Health Care Blog. February 6, 2020. Accessed May 7, 2020. <https://thehealthcareblog.com/blog/2020/02/06/patient-worries-as-a-central-feature-of-their-health-care-experiences/>
7. Mehrotra A, Chernew M, Linetsky D, et al. What impact has COVID-19 had on outpatient visits? The Commonwealth Fund. April 23, 2020. Accessed May 7, 2020. <https://www.commonwealthfund.org/publications/2020/apr/impact-covid-19-outpatient-visits>
8. Sexton S. *AFP*'s approach to COVID-19. *Am Fam Physician*. 2020;101(9):518. Accessed May 4, 2020. <https://www.aafp.org/afp/2020/0501/p518.html>
9. Richards T, Schroter S, Price A, et al. Better together: patient partnership in medical journals. *BMJ*. 2018;362:k3798. ■