I
t’s easy to convince yourself of things that turn out to be completely false. My daughter, a senior in college, is interested in pursuing a career in medicine. This summer, she was preparing for the MCATs. I announced to my spouse with great confidence that the medical school application process was entirely my daughter’s undertaking, and that I was not going to get worked up about things one way or the other. I was quite proud of my ability to remain supportive, but neutral, while lesser mortals would certainly be helping their child develop a study schedule and quizzing them. I drove her to the testing center, still persuaded that I had accomplished the admirable feat of not personalizing my child’s aspirations. The night before the test results were due to be released was a different matter. Neither my wife nor I slept a wink. Every time my phone buzzed I wondered if it was a text from my daughter. When the word finally came that she was pleased with the results, I felt incredible relief. Clearly, I was much more invested in how the test went than I had believed.

As a profession, we have convinced ourselves to a similar degree of certainty that we are extremely patient centered. And, in reality, this assertion involves the same self-deception as did my attitudes about my daughter’s MCAT results. Patient centeredness should be a bedrock principle on which the profession rests. Indeed, the entire concept of a fiduciary relationship between physicians and patients has at its core the importance of physicians orienting themselves completely to advancing the best interests of patients. Yet, one does not need to look far for examples of how our care systems are designed with the interests of others over those of the patients’. Don Berwick aptly noted that every system is perfectly designed to get exactly the results it achieves. If health care were truly patient centered, it would be just as easy to get a lower-extremity Doppler on Sunday as it is on Monday.

It shouldn’t be all that surprising that the profession is far less patient centered than it aspires to be. For centuries, medicine was highly paternalistic. We professed a desire to act in the patient’s best interest, but those interests were defined by what the physician thought would be best for the patient. The patient’s job was to agree with what the doctor recommended. The profession has only recently embraced the notion that patients are the most appropriate judge of what is in their best interests. Debunking the myth of patient centeredness, and rethinking how we can involve patients in the design of our clinical care, education, and research missions, as well as in our Society, is an important new frontier for us individually and for our organization.

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response from a navigator, engaging patients in identifying problems and solutions. But, as we looked for organizations to adopt this model, we found more often than not that organizations actually did not want to know about patients’ experiences of breakdowns, fearing that such reports could overwhelm their system. It’s hard to imagine a less patient-centered perspective.

Looking at our medical education and research programs, one sees a similar gap between patient-centered rhetoric and practice. To what extent are our medical student and resident teaching programs geared towards meeting the needs of learners, rather than the needs of patients who receive care in these settings? Do we involve patients and the public in identifying key research questions and designing studies to address them to the extent that we should?

Fortunately, there are examples of ways that patients can be truly central to our clinical, teaching, and research missions. For many years, most hospitals have had a patient representative on their boards. But, too often, these patient representatives were tokens, not drivers of these leadership groups’ activities. However, many organizations are now developing much more formal and robust Patient and Family Advisory Committees (PFAC), and are ensuring they play a central role in shaping the organizations’ strategic plans. In addition, while Community Based Participatory Research has been occurring in some quarters for decades, the work of the Patient Centered Outcomes Research Institute (PCORI) has greatly accelerated our understanding of how patients can function as partners in the research enterprise.

Patients can also be critical partners in the design of educational programs. A few years ago, I was leading a large grant project on how the response to adverse events could be more patient centered. We asked the project’s PFAC to lead the design and implementation of a day-long multi-stakeholder program to help healthcare leaders understand how patients currently experience the response to adverse events and opportunities for improvement. It seems self-evident that patient input would be critical to such a program. But it was a significant paradigm shift to have the PFAC planning and executing the program. Giving up control over the program’s design and execution was not easy for the faculty. Some of the assumptions we made as “experts” in education on this topic about what would, and would not work made little sense to PFAC (which came as a surprise to the faculty). But once the faculty abandoned its assumptions about roles and responsibilities, and allowed the patients to lead the way, the end result was far superior in that the patient’s voice felt authentic in a way that no amount of faculty expertise could have achieved.

These examples of successful integration of patients and their perspectives into the clinical, education, and research space have several common themes. Just as physicians have struggled to discard their paternalistic attitudes, becoming patient centered requires completely letting go of our prior assumptions regarding authority and expertise, and embracing patients as equal partners. Equally as important is relinquishing our long-held beliefs about how patient care, teaching, and research should be organized, and embracing new and innovative strategies. The profession should adopt a new status quo where patient involvement in these activities is pervasive and robust.

Increasing patient engagement in these activities is not without potential pitfalls. Without sufficient training and support, patients may struggle to have their voices heard. In addition, the type of patient engagement described above works considerably less effectively if the patients involved are single-mindedly advocating for a specific disease or point of view. Well-developed best practices for patient engagement are beginning to emerge.

Is SGIM sufficiently patient centered as a Society? We are currently exploring two options for involving patients more fully in the work of the Society. First, we hope to have a cadre of patient advisers attend the 2018 annual meeting in Denver.
These patient advisers would be participants in plenary and other large group sessions, available to respond to workshop, abstract, and poster presentations, and meet one-on-one with interested SGIM members. We are also considering forming an SGIM PFAC in order to provide more explicit guidance to Council, our Committees, Task Forces, and Interest Groups about how the work of the Society can be better aligned with the needs and experiences of patients. These ideas are early in their development. I welcome your feedback on them and on other suggestions for making SGIM a truly patient-centered organization.

References