

Rob Strong



EMPOWERING PATIENTS

A S A YOUNG PHD CANDIDATE IN HEALTH SERVICES RESEARCH AT QUEEN'S UNIVERSITY IN BELFAST, IRELAND, PAUL BARR, MSc, PhD, read through a staggering 2,500 medical records in an attempt to understand the drivers of decision making in red cell transfusions. Along the way, he made an unanticipated discovery: he could count on one hand the number of times a patient was involved in a conversation about whether a transfusion would occur. The omission got the young investigator thinking about a new topic: doctor-patient communications and the shared decision-making process. He hasn't stopped.

Today, Barr is an assistant professor at The Dartmouth Institute for Health Policy and Clinical Practice and a rising star in his field. In 2015, he received one of only four Patient and Family Engagement Early-Career Investigator Awards from the Gordon and Betty Moore Foundation to support his work on the Open Recording Automated Logging System (ORALS), a platform that allows routine audio recordings of conversations between clinicians and patients with relevant information in the recordings (i.e., medication discussion) automatically indexed.

At present, there are several factors that hamper the shared decision-making process, says Barr. "For example, a patient may not know what treatment options are available, and thus be unsure what questions to ask or feel that 'the doctor knows best' and not wish to raise any issues." Doctors are also under pressure to see as many patients as possible and often create shortcuts to communicate with their patients. "This can hamper the decision-making process for patients, because a condition or illness that's commonplace to the doctor—and thus seemingly unnecessary to discuss in detail—may be life-altering to the patient."

It's this potential imbalance that makes shared decision making so important, Barr explains. "Our goal is to reduce the asymmetry of the relationship through improved communications. We want to help doctors work with their patients to find the best methods possible to treat the problem, things that fit into the patient's lifestyle and ease their concerns."

To that end, Barr has been heavily involved with the creation of several

shared decision-making tools. As a post-doctoral fellow, Barr and his colleagues, under the leadership of Glyn Elwyn, MD, PhD, director of The Dartmouth Institute's Patient Engagement Research Program, developed CollaboRATE—that enables patients to report on their shared decision-making experience through completion of a short survey. "The survey is now a required measure in Patient Centered Outcome Research Initiative (PCORI) implementation projects and is under consideration as a National Quality Forum-endorsed performance measure in the U.S. for shared decision making," says Barr.

His current undertaking is the ORALS project, an initiative through which Barr and his team are creating audio and video recordings of patient visits. This work has been leveraged by Barr and his colleague Saeed Hassanpour, PhD, an associate professor of biomedical data science and epidemiology, to develop ORALS into an Audio Personal Health Library for patients, that creates hyperlinks from the indexed information, such as a medical condition, to trustworthy patient information, and peer support communities. "We then share these recordings with patients, who in turn can share them with loved ones, thereby allowing family members to participate in the decision-making process with the patient, no matter where they are located."

Barr's Open Recordings research group has several initiatives currently underway in cardiology, primary care and neurology, to further understand the implications and applications of audio/video-recording clinic visits. With the growing use of recordings and advances in data science,

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Barr is excited by the future innovations to come in this area, especially for patients and their families.

"Studies show that patients forget between 40 to 80 percent of the medical information they've been given within 15 minutes of leaving the doctor's office, so having a recording of the visit can be incredibly helpful," Barr explains. Patients indicate that they review the recordings to clarify answers to questions they might have as well as to generate questions for their next visit. "Patients report that they listen to the recordings to hear what they've told their doctor and ensure that they haven't forgotten anything," says Barr. "They say they want to be the best patients possible, and these recordings help them to achieve that goal."

"At a recent conference, someone said to me, 'shared decision making is too niche,'" Barr observes. "My response was, 'Too niche? Think of the number of clinic visits that happen each day in the U.S. where on average 6 - 13 decisions are made per visit—that's a lot of decisions! I would argue that making decisions that align with patient preferences and communicating information in a way that empowers patients is fundamental in a high-quality healthcare system.'"

There's strong evidence to indicate that when shared decision making is used, patients are happier, says Barr, and from an ethical standpoint, he argues, it's imperative. "People need to be involved in decisions about their own healthcare," he says. "It's only right."

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