

The Power of Patient Engagement in Biomedical Research



Nancy Brown

CEO

American Heart Association

Listening to patients tell their stories will improve our approach to precision medicine and help refine the care experience.

It's incredible how much we can learn if we stop and listen for a few moments. When we open ourselves up to other people's ideas and allow them to share their stories, we're given the opportunity to see things in an entirely new way.

The undeniable value of listening is the inspiration for a new partnership between my organization, the American Heart Association (AHA), and the Patient-Centered Outcomes Research Institute, which uses crowdsourcing to give patients a powerful voice in their own care.

Every patient has a story to tell, but far too few are offered a forum to do so. There are innumerable barriers that prevent many patients from saying what's on their mind. For example, during a typical office

visit, there's seldom enough time for patients to ask questions or have an in-depth discussion with their provider. Also, many patients may feel too uncomfortable or embarrassed to speak frankly, or may think their concerns seem trivial or inconsequential.

Patients aren't the only ones who encounter these barriers. It's also important to consider family members and caregivers, who are often intimately involved in the patient's care experience yet may feel reluctant to speak up if they have any concerns or doubts.

We believe that crowdsourcing offers a wide range of advantages that are conducive to open communication. Patients are free to tell their stories in their own words and can do so

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in whatever setting they prefer — including from home. They don’t face time limitations and their confidentiality is protected.

Through this partnership, we’re seeking input on critical gaps in the evidence about which prevention, diagnostic and treatment approaches work best for patients, based on their needs and circumstances. The feedback we receive will be a base for designing comparative clinical effectiveness research studies and will also support our efforts to advance precision cardiovascular medicine, which seeks to refine care for patients based on their particular characteristics.

Thanks to research conducted in the laboratory, inspiring progress has been made in our ability to treat illnesses. But how are we doing when it comes to treating patients? The only ones who can answer this question are patients themselves. That’s why we’re urging them to speak up. We want them to tell us what could have been done better and what might have been overlooked. Likewise, we want to know what worked to perfection and what might have been a pleasant surprise. It could have been a pleasant — or unpleasant — experience in the waiting room.

It could have been a follow-up phone call that they received — or didn’t — receive. It could have been specific advice given — or overlooked — about medication tolerance. Everything is on the table. Nothing is considered too “small” or “insignificant.”

They say that if you want something, you should ask for it. We’re glad we did. After sending out a request for submissions for our first crowdsourcing challenge this summer, we were positively overwhelmed by the response. Beyond being thankful, we were genuinely touched by the candor of our respondents. We want to assure every one of them that their stories resonated deeply and will have a lasting impact on the way patients are treated going forward.

Indeed, there is immense value in listening, and we intend to continue doing so. Our second crowdsourcing challenge is currently underway, and we see this strategy as part of the AHA for years to come.

