

When patients reach out, scientists should reach back carefully

Paul S Knoepfler

In the digital age, biomedical scientists are frequently contacted by lay individuals seeking medical help, but they still receive little, if any, training in how to respond. Researchers need to reach back to these patients, but in a way that steers clear of giving medical advice.

When a PhD colleague of mine in the stem cell field answered the phone a few years ago, she had her first experience of talking to a stranger who was looking to her for medical advice. The man had multiple sclerosis, and he was considering going outside mainstream medical care. The scientist was largely at a loss as to how to answer the patient's questions about stem cell clinical research. For instance, the man asked whether he should go to a stem cell clinic offering a treatment that had not been approved by the US Food and Drug Administration. And could she recommend a specific clinic? The scientist had more general questions herself. What considerations should go into patient decisions about whether to get experimental medical interventions? These and other weighty questions regularly arise during such interactions. She turned to me for help, because she knew that I had interacted with patients more often than the average PhD life scientist, as a result of blogging and my presence on social media.

Over the past few years, my colleagues and I have frequently found ourselves in much the same situation. Patients are increasingly contacting scientists directly, probably thanks to the rapid penetration of Internet culture into our daily lives. Today, anyone can search the web, including PubMed, to identify scientists studying a condition of interest and find their contact information. Physicians and basic scientists have different ways of communicating (*Dis. Model. Mech.* 4, 423–426, 2011). Yet whereas medical schools teach their students how to communicate with patients, PhD scientists generally receive no training in communication with the public, and only recently have granting agencies begun to require lay abstracts, straightforward summaries without jargon. When patients reach out to scientists, it is both a challenge and a growing opportunity for the latter group to directly engage with the former and to positively foster education.

As a biomedical scientist who regularly blogs about stem cells, I am on the front line of scientist and patient interaction. After more than five years of blogging, it is no longer unusual for me to hear from several patients each week. Sometimes they ask for medical advice or for opinions about specific clinics. At other times, they ask me to conduct a medical procedure either on them or a loved one. It is important to realize that something spurred them to reach out. That should not be brushed off or taken lightly. Unfortunately, scientists are largely on their own when it comes to navigating patient communication. For example, the US National Institutes of Health (NIH) has not yet developed a widespread program or issued any guidelines to this effect.

In the absence of clear direction on patient communication from a formal institution, there are some core guiding principles based on common sense and experience. The first rule is to respect patients and their confidentiality. Although basic researchers do not take the Hippocratic oath, ethically they should still endeavor foremost

to do no harm in patient interactions. Secondly, they should avoid giving medical advice. This applies even to physician-scientists, who, although trained as both scientists and physicians, should not give medical advice to people who are not their own patients. This puts patients at risk of receiving advice not personally tailored to them and thus of serious harm from inappropriate treatment. In addition, you set yourself up for potential legal trouble.

I always try to ask the patient what his or her own personal doctor has said about the question at hand. What is their physician's perspective on and advice about the situation and the experimental treatment under consideration? The rationale for this is that their own physician knows them best. If they have not asked their doctor, then I encourage them to do so. If they have made a query, I do not judge the doctor's response. At the same time, I encourage patients to get multiple opinions, because, most often, their queries relate to experimental treatments that entail higher risks and about which physician opinions may vary more.

If someone requests direct access to an experimental medical procedure or unapproved drug, you cannot responsibly facilitate the request for many reasons, including both ethical and regulatory constraints. Even if you yourself are involved in running a specific clinical trial, and a patient should contact you about possibly enrolling in that trial, tread carefully. Refer the patient instead to the clinical trial manager. You can also direct people to the US government-run website ClinicalTrials.gov. Before doing so, however, be sure to give them some context: remind them that clinical trials can be risky. My own policy is not to recommend any specific trial, and I often also point out the widely accepted standard that patients should not have to pay to participate in a clinical trial.

Finally, many institutions have bioethicists who can help with complex situations involving patients who have reached out. If your institution doesn't have a bioethicist on staff, then reach out to experts by e-mail, or contact me directly. Although I am not a bioethicist myself, I know many who would be willing to help.

I offer these possible best practices for scientist-patient interactions merely as a starting point. Ultimately, it will be crucial for the NIH and other governmental bodies to craft formal guidelines and to support the training of biomedical researchers in this increasingly important arena. In an ever more interconnected world, it is essential for biomedical researchers to know how to deal with questions from individuals seeking medical advice—the wrong response could lead to patient harm or litigation against the researcher.

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