

# CHANGING THE PATIENT–SCIENTIST DIALOGUE

► *Paul Kidwell, Senior Public Relations/Patient Advocacy Consultant & Podcaster, for the life-sciences industry provides an insider's view into the need for increased communication between patients and scientists.*

**PV: What has been your experience in terms of the typical interaction between patients and biopharma scientists?**

**KIDWELL:** When scientists communicate regularly, clearly, and in a manner in which a “small child or Golden Retriever” can understand, science comes alive; it breathes and anyone within earshot of the information benefits intellectually, if not therapeutically. There is no more collaborative discipline across a multitude of channels than biomedical research, and yet traditionally that process has been to the exclusion rather than the inclusion of patients; particularly at those critical times of discovery and early clinical development when having patient input would be of great value. When a scientist speaks to a patient about a specific research program — its relevance and potential impact on patients’ lives — the result makes for a more informed patient. The feedback provided to the researcher can also help guide the ongoing R&D program and provide scientists with a real-world perspective they might not otherwise receive in the cloistered environment of the lab. Additionally, opening up lines of communication between these two involved groups allow patients to gain an understanding of how science fits within the context of their illness and treatment, and can lead to a more educated patient who now is armed with information they might not otherwise have to impact decisions they may make in living with their illness. It also sets a precedent for researchers who may not impart this process to younger scientists who come into the laboratory environment without this understanding, thus setting the stage for a continuation of open communication.

**PV: What do you believe needs to change?**

**KIDWELL:** Historically, there was a gap — actually more of a wall — between scientists and patients. In recent years, due to a number of proactive industry advocacy professionals and patient foundations, those walls began to crumble and patient engagement became a more prominent business discipline between the two entities. Another phenomenon was the earlier engagement between the two that fostered an increased number of emerging and early-stage biotech companies establishing a more proactive, patient-centric business strategy that was being led by a new group of committed advocacy executives, many of whom were now sitting in or very close to the C-suite.



Paul Kidwell

The energy established by this groundswell of activity needs to continue and become even more forthright, and with patients assuming a stronger leadership position as a catalyst for change. The opportunities for more consistent and transparent interaction are governed by a set of regulatory policies that, as they exist presently, may be too stringent for future engagement and these need to be re-examined and modernized to fit this existing scenario. Scientists and patients communicating with one another is an idea whose time has certainly come and there is little place for those historical barriers that do little to advance this discussion.

**PV: Why do you believe this would make a significant difference for patients?**

**KIDWELL:** With enhanced interaction between scientists and patients, patients should expect an active role in, and often shared responsibility for, making care decisions that are best for them. Scientists should anticipate a better-informed patient and, in turn, welcome the chance to show respect and support for patients within the context of this role, ultimately deploying this information in making informed drug development decisions and shaping ongoing and future R&D programs. All patients will tell you that during the entire disease life cycle — from diagnosis, to treatment, to remission, to cure — information is king. The reliance on data from a select group of trusted sources is a constant in their lives, and anything that helps them gather, distill, and use information about their illness, treatments, and ongoing research has value. The goal of all biomedical research and the work of scientists is to develop therapeutics that have the potential to improve patients’ health, prognosis, and quality of

life. The modern approach in accomplishing these goals is based largely on a strong and evolving patient-scientist collaboration, in which an open exchange of insights from both parties is at the core of this partnership. Data has always driven this program and is used in developing and delivering enhanced standards of care tailored to the specifics of each patient’s circumstances. Patients can now expect from scientists a consistent exchange of ideas underscored by a posture of active listening that reflects patient values, preferences, and needs, all of which will lead to better outcomes.

**PV: What would the benefits be to a pharmaceutical/biopharma company?**

**KIDWELL:** Receiving unfiltered information based on personal experience with a specific disease from patients has the potential to result in the creation of more effective and safer medicines. Medicines developed within the context of this improved communication milieu will often result in a greater therapeutic impact on patients — i.e. better medicines — a smarter use of R&D dollars and resources, a shorter development trajectory, and a potentially smoother regulatory/approval process. A comprehensive understanding of patient information, including clinical endpoints as well as quality of life data can be reflected in a drug developer’s approved medicine; information that is likely provided by the patient. A better-informed patient is one who is more fully engaged with their biopharmaceutical collaborator; particularly as they share a deep understanding of their condition.

The collaboration also has the potential to help nurture the patient-scientist interaction, which can lead to a greater level of commitment to one another, the therapy, and its manufacturer. Plus, don’t underestimate the level of influence patients now bring to the social media environment where a well-placed comment about a positive experience can help cascade that experience to a legion of committed followers also in search of information about their disease and treatment options.

Since the first time I overheard a patient exclaim, “Oh, this is great, patients never get a chance to speak with the scientists,” during a patient-industry event, I knew we had uncovered a rare opportunity to not only change the dynamic of how patients and researchers communicate with each other, but how this evolution would impact how medicines are created. **PV**

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