ODigital Health Coalition



In 2012, Sarah Krug stepped in as president-elect of the Society for Participatory Medicine — a group at the forefront of the empowered patient movement. She is also the Executive Director of Cancer101. We asked her to reflect on the term "e-patient", how pharmaceutical companies can partner with patients in the digital world, and what the future holds in store for digital health and wellness.

SARAH KRUG

We hear a lot about this new world of empowered patients and consumers. When you hear the term "e-patient" ... what comes to mind?

Empowered health consumers who are:

- Engaged in their own care
- Equipped with a skillset to manage their condition
- Enabled to make informed decisions
- Experts on their day to day lives
- Equal partners in the circle of care
- Educated

Is digital at the center – or just a tool that makes it much more efficient to be an e-patient? Can you be an e-patient without being digital – being online?

The digital age has facilitated engagement and empowerment, as epatients use electronic communication tools to gather information and obtain support. Although technology has

served as a catalyst in these efforts, digital is not implicit in the definition of an e-patient. One does not need to be Internet savvy to be an "empowered" patient.

Any advice to patients seeking to use health and medical information from the Internet with their personal physician?

The amount of information online can be overwhelming and perplexing to navigate. It's important to seek out credible sites for information to reinforce understanding of one's condition, options, risks/benefits, and questions to ask. However, information found on the Internet should not substitute medical advice. Ideally, one's doctor provides them with a "prescription to learn" and arms the patient with a toolkit of validated and filtered online resources.

Some experts have argued we need to talk about a code of conduct between patients and commercial sponsors supporting patient education and content online? Agree?

A code of conduct governs healthcare professional education to ensure that healthcare professionals have access to unbiased and fair balanced education, and that any education that is not "independent" from commercial influence is disclosed as such. Similarly, guiding principles should be established for patient education to ensure that patients not only have access to unbiased and fair balanced education, but that they are also able to distinguish between education that is developed in collaboration with a commercial sponsor and education that is completely independent from influence.

Transparency and long term commitment is critical to obtaining trust among patients. To take that trust to a new level, brand teams must master the "art of listening" to understand patient needs, concerns, barriers, and ideas and then connect the dots with sustainable solutions both internal and external to the organization.

How can patients evaluate the credibility of health and medical content they access online?

Finding valuable and reliable information on the Internet can be compared to gold mining, where one has to filter out the garbage from the gold. To determine credibility one should understand the origin of the information and how it's managed, the funding source and its purpose, the medical accuracy review process, how current the information is, and privacy policies if any information is being collected.

Any general advice to a brand team seeking to engage with their patients online?

When is the last time you went off the grid for at least 24 hours?

From the cliff sides of the Greek Isles, the sand dunes along the Great Pyramids to the remoteness of the Caribbean jungles—I have always found a way to "connect". With smartphone in hand, I've felt immersed in the "social surround sound"—never missing a beat, regardless of where I traveled. About 2 years ago, I lost my lifeline when I couldn't get a signal for 4 days. Imagine being forced for 96 hours into a 1:1 with the brilliant blue waters and exotic landscape of Sharm El-Sheikh, a coastal strip along the Red Sea. Withdrawal was torturous, but somehow I managed to overcome.