

Patient Research – the Changing Landscape: Harnessing the Voice of the Citizen Expert

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Citizen experts are emerging as the new voice of healthcare. In this white paper we present the views of 30 such people who directly influence around 820,000 others on a monthly basis via online destinations and social networks. They were asked what pharma can do to better engage with patients in diabetes and oncology.

Patient influence takes shape

The patient voice may be recognized by regulators, payers and medical professionals as the missing link in maximizing value from the global healthcare bill, but harnessing that voice has never been easy.

Patients do not speak with one voice, even when they have the same disease. They do not pretend to be impartial when it comes to securing resources for their condition, and many struggle to appraise the risks and benefits of treatments.

Despite these real obstacles, the patient voice continues to gain traction among all stakeholders in the scientific world of healthcare at a rapid speed. Everyone wants to hear what patients have to say. The FDA's Patient-Focused Drug Development Initiative, for example, is a commitment under the fifth version of the Prescription Drug User Fee Act (PDUFA) that aims to more systematically gather patients' perspectives on their condition and the available therapies to treat it.

Benefits of patient engagement

Similar initiatives at the highest levels of command are being implemented across the globe as notions of patient centricity finally start translating into healthcare practices and cultures that are more open, more engaging and, critically, more accountable.

In addition to empowered patients taking control of their own disease education via Dr. Google, regulators and payers also are driving this patient-led revolution in healthcare because they want real-world evidence that enables them to continue appraising the safety, efficacy and value of medicines over their full lifecycle. But the movement to make healthcare more accountable and more responsive to the end users of medicines is not limited to these players. How patients take their medicines, how they respond, what they think of them, and what else they do to help

their condition have become critical to the changing healthcare landscape in the US and across the world.

New ways of harnessing the patient voice

We wanted to explore new ways of harnessing the patient voice, as we have believed for some time in the importance of patient education, a direction that has gradually evolved into the idea of the informed patient and now to this latest stage of empowerment where patients are authenticated to speak on behalf of their communities. As such, we felt it was important to build a perspective of the new ideas and technologies in patient research and, specifically, those focused on what the leading patient influencers are saying.

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Social media channels have long been essential agents of change in the patient empowerment movement. Sites like patientslikeme.com, for example, have challenged conventional scientific methods by applying algorithms to their databases to find patients who qualify for control groups, thereby eliminating some of the bias factors inherent in social media. The results of such studies have been compared with those of controlled clinical trials set up to answer identical questions. The online methods are not only quicker and cheaper than conventional research but also arrive at the same conclusions.

Introducing the citizen expert

Similarly, market research is being transformed as new ways are pioneered to harness the patient voice. California-based Vocalize has created an innovative research platform called Truvio that allows companies to conduct quantitative and qualitative market research where respondents record their voice in real time via their mobile phones. WEGO Health, a company dedicated to identifying and empowering health activists, has developed a platform for identifying the leading patient influencers in any disease area and has partnered with Vocalize to license their technology so that any company can get insights from patient influencers in 24 to 48 hours.

Ross Fetterolf, senior vice president of innovation at WEGO Health, explains that everyone who joins the WEGO Health network is asked to fill in a questionnaire. *“We want to get an idea of their level of social engagement – the channels in which they participate and the number of people they reach on an ongoing basis,”* he says. *“We look for their Twitter followers and how many people read their blogs. We also ask them how active they are online, what sites they visit, and how often. We want to understand their online activity level and influence with respect to health. Our aim is to develop a relationship with these patient influencers, supporting them in their efforts and nurturing an ongoing engagement.”*

Influence is not easy to measure uniformly as patient communities have different population numbers as well as different issues that concern them. *“The challenge is that every condition has its own unique online community and experience. In rare diseases each follower is weighted more highly than in a broader condition like diabetes. We have partnered with the online health community for seven years now and can appreciate more than most that it is a complicated story. But when we turn the microphone over their involvement in their respective communities comes across in terms of the roles they play,*

the information they uncover and the grasp they have on the condition and what it means for patients on a day-to-day basis.”

Patient Empowerment study: the patient panel

Within the study, we sought insights from community leaders in the patient empowerment movement by using two of WEGO Health’s largest communities, people living with cancer or diabetes.

These disease areas were selected because they affect large numbers of patients and are both highly competitive on the treatment front. But a third, and focal reason, is that it provided the opportunity to see whether there are any differences in the responses from people in a primary care therapy area and one that is more specialized.

The sample sizes were small, just 30, compared with the thousands that are typically recruited via more traditional market research methods, but because they are actively engaged in an average of six sites devoted to their condition and are highly influential in terms of levels of social engagement, their collective reach can be shown to have touched a total of 817,499 other people with related concerns. As Fetterolf points out, “While there is clearly a degree of overlap in terms of their sphere of influence, the intent is to find a measure of a new breed of online patient influencer.”

“The typical panelist is someone who has made it their business to engage with the best doctors, to know the treatments – both on the market and in development – to appreciate what they cost and how they are administered.”

“The typical panelist,” he says, “is someone who has made it their business to engage with the best doctors, to know the treatments – both on the market and in development – to appreciate what they cost and how they are administered. They use this knowledge along with their own experience of living with the condition to connect with as many other people as possible.” While there is no one ‘formula’ for becoming an online health activist, the common thread is that these patients have earned the authority to talk about their condition. “This is why the platform is known as Truvio,” Fetterolf continues. “It stands for the true voice of health.”

Patient Empowerment study: the method

We wanted to hear the authentic voices of these citizen experts about the changing healthcare landscape and the role for empowered patients in shaping that. To that end the Patient Empowerment study asked three questions to explore how empowered patients are thinking: where they feel the online health movement is headed, what is spurring it on and, conversely, what is holding it back.

Two more sets of questions asked the panelists about recommendations they make to their own communities and also, given the

chance, those they would offer to the CEO of a pharma or medical device company. These questions were answered in the experts’ own voices via mobile phone.

Patient Empowerment study: the results

Unsurprisingly, virtually all participants were enthusiastic about the growth of the empowered patient movement and strongly agreed with the statement that everyone needs to join up.

1. Drivers of the patient empowerment movement

The factors driving the movement can be seen in Figure 1, which reveals technology to be leading the way in panelists’ first and second choices. When the results are weighted to give a first choice two points and a second choice one, technology sweeps in with more than half (53.3 percent) of the available points. The ability to talk and share information online vastly outstrips busy physicians, costs and mistrust in the healthcare system as the principal driver of the empowered patient movement.

Diabetes and cancer influencers agree that technology is the principal driver, but the

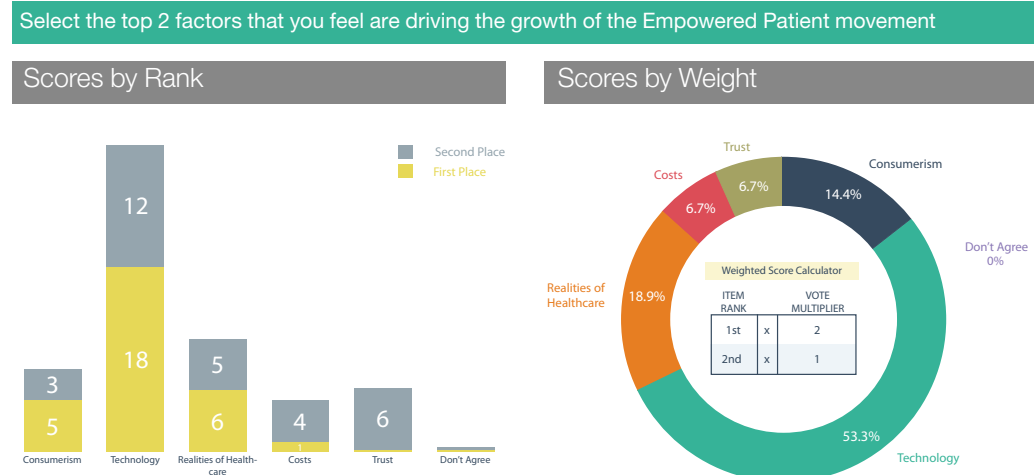


Figure 1: Technology is the leading factor driving the empowered patient movement.

Question 1: The role of the empowered patient in changing healthcare

On a scale of one to five, to what extent do you agree with the following statement: *“Healthcare has changed and so has the role of the patient. Today, more than ever, every consumer needs to be an empowered patient – meaning they need to be active participants in every step of their healthcare journey, from healthy living to diagnosis, treatment and collaboration with healthcare professionals.”*

Question 2: What is driving patient empowerment?

Select and rank the top two factors that you feel are driving the growth of the empowered patient movement.

Question 3: What is impeding patient empowerment?

Select the top two factors that you feel create barriers to the empowered patient movement.

Question 4: How do you advise your community?

- What advice would you give people regarding how to best deal with some of the challenges of playing a participatory role in their healthcare?
- What can people do to create a healthier partnership with their healthcare providers while also taking a more active role in their health?

Question 5: What advice and recommendations do you have for industry?

- What can and should manufacturers be doing to support the empowered patient movement?
- What advice would you give them about how to engage with the patient community, about educating consumers, about supporting patient-physician collaboration, or other ideas?

diabetics were twice as likely to cite *“realities of healthcare,”* which translates in part as lack of doctor time, as cancer patients. Trust (embracing such factors as perceived lack of transparency and product safety concerns), meanwhile, was significantly more important to cancer patients than to the diabetic community.

with diabetes to be able to live happily for years while remaining in control of their illness because it is a managed condition. In contrast, there are much more severe repercussions for patients with cancer in terms of likely outcomes and quality of life. However, the argument can be presented that diabetes affects every aspect of day-to-day

life, which may explain why these patients are just as interested in new information as people with a more critical condition.

The individuals also spoke fairly unanimously when it came to the voice-response questions, more details of which are given in the following sections.

2. Brakes on the patient empowerment movement

The picture is more varied when considering the factors impeding the empowered patient movement. Figure 2 shows how the top two responses relate to the doctor-patient relationship. One is from the perspective of the doctor resisting patient involvement, and the other comes from the patient who is uncomfortable questioning the doctor.

What is surprising is the extent to which patients from both primary care and specialized care were speaking with a consistent voice. While there were some differences, one might have expected patients

Select the top 2 factors that you feel are impeding the growth of the Empowered Patient movement

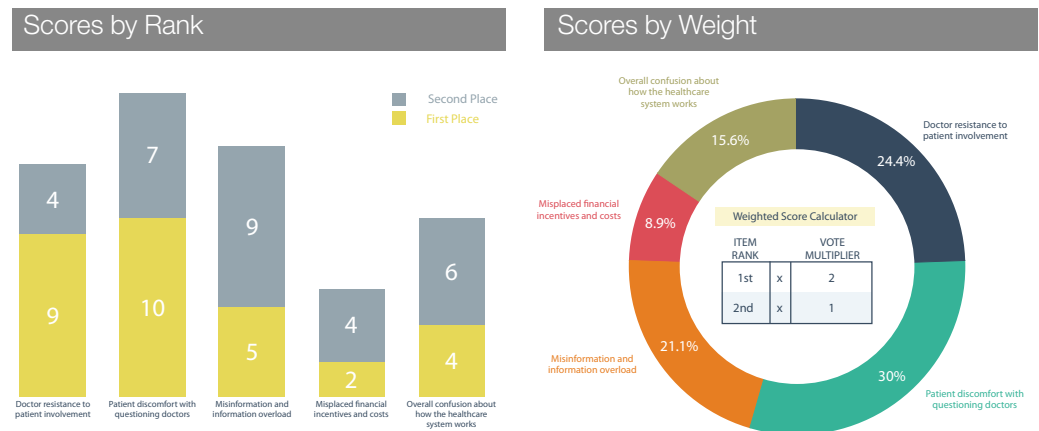
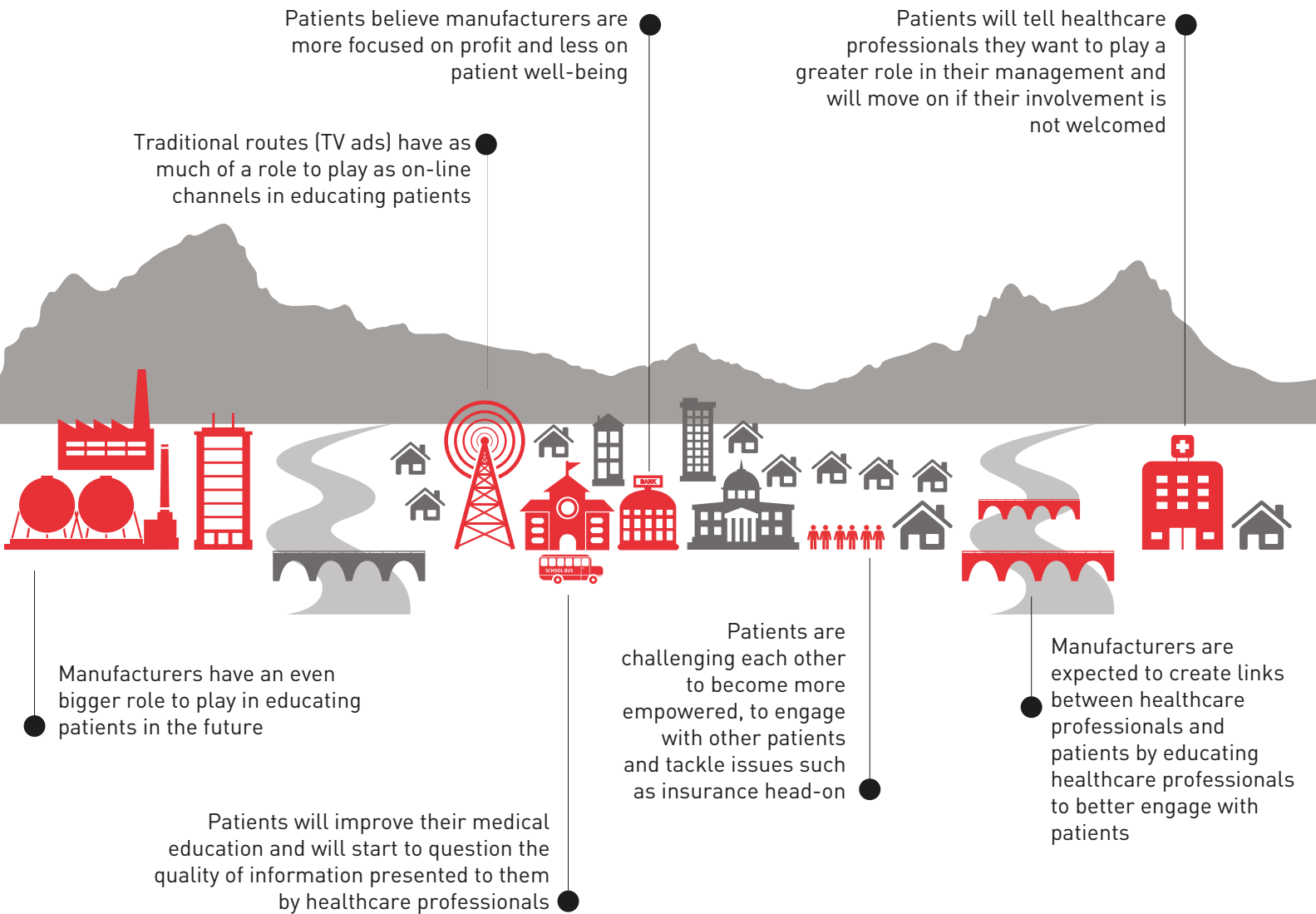


Figure 2: Doctor-patient relations are responsible for the two leading factors impeding the empowered patient movement.

Patient Research - The Changing Landscape

The Patient Empowerment Movement.

The proliferation of online health resources and wearable medical technology has enabled patients to be more actively involved in their own healthcare management.



Patient advice to pharma companies

What empowered patients expect of pharma companies came over loud and clear in the individual stories they told. Certainly, all of our pharma clients are talking about corporate reputation, using buzzwords like patient-centricity and really trying to put the patient at the heart of their strategy, but the reality is that these patient influencers perceive it slightly more cynically. They do not seem to buy into the idea that the efforts of pharma companies are directed toward improving patient outcomes, so it shows that there is still some way to go for pharma companies in driving trust and integrity with patients.

Despite this, patients also were clear that they want more contact with industry. *“Have a conversation with patients,”* one said. *“It is very important because yes, the doctors prescribe the medication, but the patients are the ones dealing with the medical devices. The patients are the ones that when it comes down to the bottom line you are really selling to because if a doctor prescribes a patient medication, they don’t have to take it.”*

So patients want to be directly involved with pharma companies, act as advocates for treatments and be involved in consultative panels. But despite this clear appetite to work more closely the pharma industry still has to ensure it clearly communicates that the best interests of patients are as important a driver as commercial profitability.

The research also revealed that pharma companies could carve a role for themselves in terms of encouraging a more collaborative approach between patients and doctors. Some doctors can feel threatened and challenged by the empowered patient rather than seeing them as presenting an opportunity to work together to manage the condition and pharma companies are well positioned to help explain the benefits of the partnership approach.

Summary of findings

- **Encourage a patient-doctor relationship approach to disease management**
 1. Promote the importance of patient-doctor interactions
 2. Encourage collaborative relationships
 3. Educate doctors to engage with informed patients via workshops and the production and distribution of educational materials in the disease area
- **Engage patients**
 1. Listen to patients and involve them in the design and development of treatments/devices via patient panels and reaching out to patient groups and individuals directly rather than via doctors
 2. Use patients as spokespeople via online panels to act in an advisory capacity to the company, to doctors and to other patients
 3. Reward patients for their involvement
 4. Introduce patient representatives to hospitals to explain how a device works
- **Educate patients via both traditional and online channels**
 1. Make information on products readily available to patients on the brand website, including contraindications; side effects; safety and testing results; how to use products; prices/long-term cost of treatment; and patient assistance programs
 2. Make information easy to access and understand, which means it should be in large print and suitable for children as well as their parents
 3. Pitch patient information at various levels to satisfy a range of needs, from the most simple to the relatively sophisticated
 4. Educate doctors to educate patients
 5. Use a range of channels to educate patients, including the usual suspects such as TV ads; online patient communities and forums; websites; pamphlets in doctors’ offices; and patient education events. A more unusual thought was to weave salient points of an illness into the story line of television drama and comedy shows so people can more easily absorb the information
- **Build corporate reputation**
 1. Get to know patients
 2. Try to shift patient perceptions of the company from a profitable organization to a partner in patient care
 3. Concentrate on scientific results
 4. Build trust and integrity

Patient advice to fellow patients

Perhaps the biggest surprise from this study is the extent to which patient influencers recommend to other patients that they should be willing to walk away from a relationship with a healthcare professional. They are clearly saying that if a patient is not getting what he or she needs from a doctor, that patient should find a new doctor rather than just seek a second opinion.

Another highlight was the extent to which these patient influencers are challenging other patients to really take responsibility for their care. The clear message they are giving is that *“no one cares more about your condition than you do.”* They recommend recording symptoms to share with the doctor, taking responsibility to ask questions, more than once if necessary, and being proactive about prevention, not just treatment. Ultimately, it shows that many patients still tend to think they've got a condition with a rigid, defined way for it to be treated by others, rather than personally managing it from a more holistic perspective.

In conclusion, it is clear that the empowered patient movement is healthy and strong. This study was based on a US site with experts responding to the effects of the empowered patient movement and other changes that are specific to their country, so one could argue whether it is globally representative. *“In the US there is a great deal of concern about the healthcare system,”* says Fabio Gratton, co-founder and CEO of Vocalize, the technology company that built the Truvio platform. *“People are looking for and finding alternative sources of care by using technologies such as social media to find what works, to locate better doctors and to generally find ways to improve their health. It is a people-powered revolution where the system can't change fast enough for some people.”*

But the same is true across the world because patient engagement drivers, like diseases, know no boundaries. Everyone wants better health and value for money, which is why citizen experts are likely to appear across the globe and be increasingly listened to by pharma companies.

Summary of findings

- **Be informed: Research and educate yourself in the condition and its treatment**
 1. Understand your health condition and treatment
 2. Seek information by finding out what data sources are available to you and having an idea about the quality of these sources
 3. Look to doctors to provide education but be prepared to educate yourself
- **Manage the relationship with your doctor**
 1. Develop a relationship with your healthcare professional
 2. Tell them you want to be involved in managing your condition and the treatment decisions
 3. Don't be afraid to ask questions
 4. Change doctors if your participation is not welcome
 5. Seek a second opinion
- **Accept responsibility for your condition and do what's necessary to take care of yourself**
 1. No one cares more about your condition than you do
 2. Enquire about preventive measures as well as the diagnosis
 3. Create a diary to capture the history of your condition
 4. Access test results and charts online
 5. Contact insurance companies directly and don't wait for the doctor to do so
- **Join an online health community focused on your condition**
 1. Seek peer support
 2. Get involved in an online patient forum
 3. Share information about the condition and experiences

About Kantar Health

Kantar Health is a leading global healthcare consulting firm and trusted advisor to many of the world's leading pharmaceutical, biotech, and medical device and diagnostic companies. It combines evidence-based research capabilities with deep scientific, therapeutic and clinical knowledge, commercial development know-how, and brand and marketing expertise to help clients evaluate opportunities, launch products and maintain brand and market leadership.

Kantar Health deeply understands the influence of patients, payers and physicians, especially as they relate to the performance and payment of medicines and the delivery of healthcare services. Its 700+ healthcare industry specialists work across the product lifecycle, from pre-clinical development to launch, acting as catalysts to successful decision-making in life sciences and helping clients prioritize their product development and portfolio activities, differentiate their brands and drive product success post-launch.

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