In the **Internet** we trust?

discerning quality rare disease information

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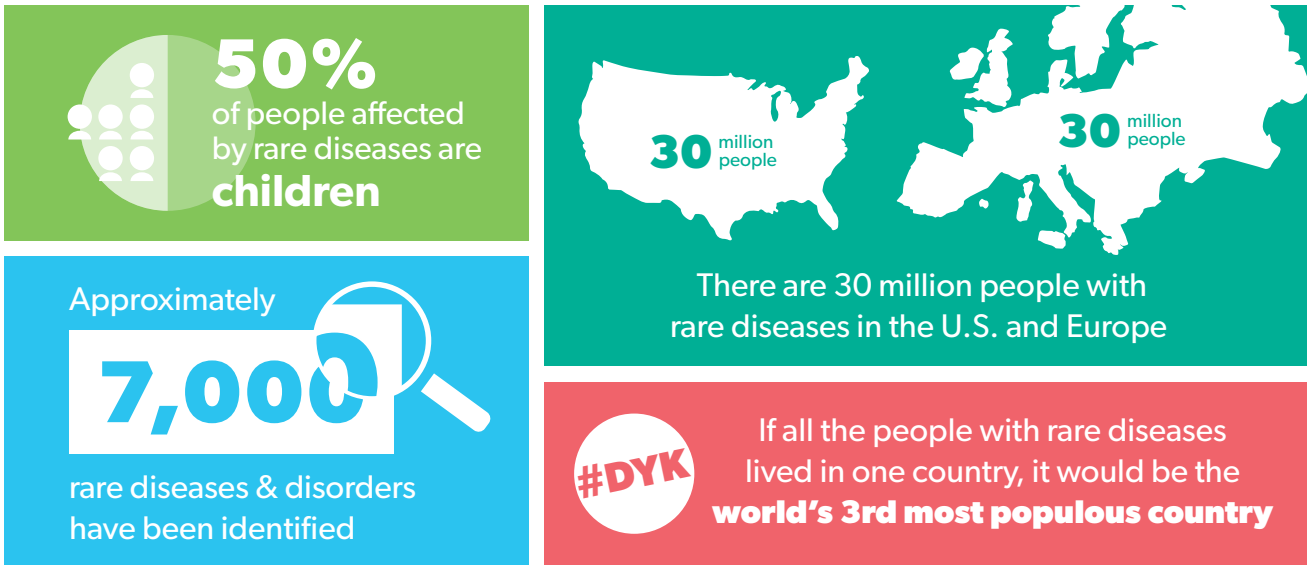
When Brett's son was diagnosed with a rare condition at 3 months of age, Brett and his wife were, understandably, nearly catatonic with grief. Then he did what most parents of children diagnosed with a rare disease do: **he turned to the Internet.**

"It was a lonely battle," he said. "It's really hard to find information, to synthesize it, and to understand what you're up against."

The Internet has become the key source of information for those living with a rare disease and their families, more so than for people living with the more common medical conditions.[1,2] Patients with rare conditions or their families go online looking for the names of specialists, medications to try, tests and procedures, symptoms and so much more.[2] Indeed, online research by the patient or their family can even help doctors with diagnosis and treatment. Unfortunately, too often the reason families go online is because they have been bouncing from doctor to doctor, often for years, before they receive an accurate diagnosis.

The frustration of the more than 250 million people worldwide living with one or more of the identified 7,000 rare conditions today is growing exponentially. A contributing factor to this growing frustration is the difficulty in finding trustworthy, understandable information about their condition, treatments, and clinical trials online.[3]

Illustration 1: Rare Diseases by the Numbers



Source: Global Genes, https://globalgenes.org/rare-diseases-facts-statistics

Yet, as a 2015 McKinsey report noted: Individuals are starting to control their own health treatments, with patients becoming more than just passive recipients of therapies.[4]

Indeed, numerous surveys of patients, caregivers, families, and advocates affected by a rare disease come to similar conclusions: quality information is critical in managing the condition and yet is difficult to find. Indeed, just 15 percent of the more than 7,000 identified rare diseases have dedicated patient organizations[5] that can provide that information.

Illustration 2: The Electronic Haystack

Searching for valuable information on the Internet for rare disease families is like finding the needle in the electronic haystack.

A survey of nearly 600 families with rare conditions across the UK found that:[3]

	About half of the respondents felt they had not received enough information about the condition after diagnosis. As one family member wrote: "We simply received the name of the condition, then Googled [it]."
	Even when patients did receive information, including web sites, they often did not understand it.
	Just 35 percent said they were informed about clinical trials in their condition. One family only found out about a clinical trial at the hospital where their son had been treated after he died. Greater knowledge about clinical trials would lead to greater participation in the trials, the survey's authors noted.
	About half of patients received information about their disease from advocacy organizations or random Internet searches.
	The patient or family member often diagnosed their condition themselves after doing their own research.
	More than a third of patients said they did not have anyone they could approach with questions about their condition.
	Only 33 percent of respondents felt they received sufficient support for their social needs, while just 29 percent felt they received sufficient psychological support.

Table 1: UK Survey Finds Frustrated Patients and Families

As the authors wrote: "These patients are left to their own initiative to find information on their condition (despite the fact that good-quality information is not always easy to find without guidance), or they may come across information only by chance."[3]

Not only do patients and families with rare diseases frequently face a battle to get a diagnosis, they then have to battle to find out the medical impact and how to manage their condition as well as having to cope with day-to-day life without adequate support.

– UK Experiences of Rare Diseases, 2010

It's not for lack of trying. One survey of 128 parents of 117 children with rare conditions found that 22 percent searched the Internet for healthcare information about their child's condition several times a week; 20 percent searched the internet every day (Figure 1).

Yet only about a third found the information they needed most of the time, while 15 percent reported that they hardly ever or never found that which they were looking for.

Most participants said they made some kind of decision about their child's condition based on Internet-sourced information, with 20 percent reporting that the information they found was a major influence. The information improved their understanding of their child's condition, they reported; enabled them to explain the condition to others; and enhanced their ability to manage and care for their child. However, about a third of parents also reported that the information they found increased their anxiety.

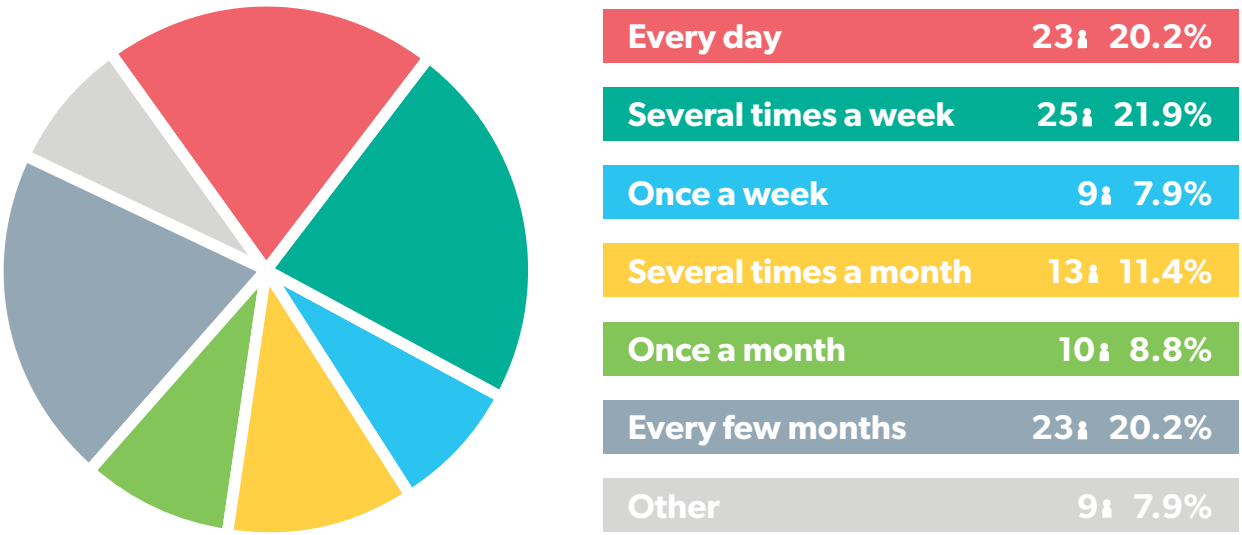


Figure 1: How often do you use the Internet to find information about your child's condition?

Source: J Med Internet Research. 2017 Feb; 19(2): e51

Poor Quality Information

Despite the desperate need for credible information, numerous studies over the past two decades confirm that the majority of medical information available on the Internet, including that related to rare conditions, is of poor quality.[6,7]

Seventy percent of the 79 studies assessed for a review article concluded that quality medical information is a problem on the Internet. Just 9 percent determined that quality information is available.[7]

The authors of the review article found that many sites were incomplete or included inaccurate information, and/or failed to provide the date of the last update (medical information is incredibly dynamic, thus sites should be updated on a regular basis). There was no way for consumers to assess the quality of the information, identify bias, or determine if the information applied to them.

A recently published study in the Journal of Medical Internet Research focused on the quality of rare disease web sites. While conducted in Germany, its findings should be applicable to other countries, including the US.[8]

The German researchers identified 13 quality criteria for a rare disease web site (Table 2) then assessed the quality of 693 German-language web sites. As they concluded: "In many cases, the quality of these websites, based on the defined quality criteria for websites containing information about rare conditions, can be assessed as insufficient."

Table 2: Elements of Quality Web Sites for Rare Diseases [8]

1	Performed a systematic literature search prior to providing information for the home page
2	Experts in the field are involved in providing the information
3	There is documentation of the process of providing information
4	Users are informed about this process
5	Information about the authors of the site is included
6	Information about others who contributed to the site is included
7	User-generated content is distinguishable and labeled with a username
8	The information contains primary sources of information
9	If there is no primary sources of information, external sources are quoted
10	Creation date is mentioned
11	Content update date is mentioned
12	Privacy policy is used
13	Users are informed of privacy policy

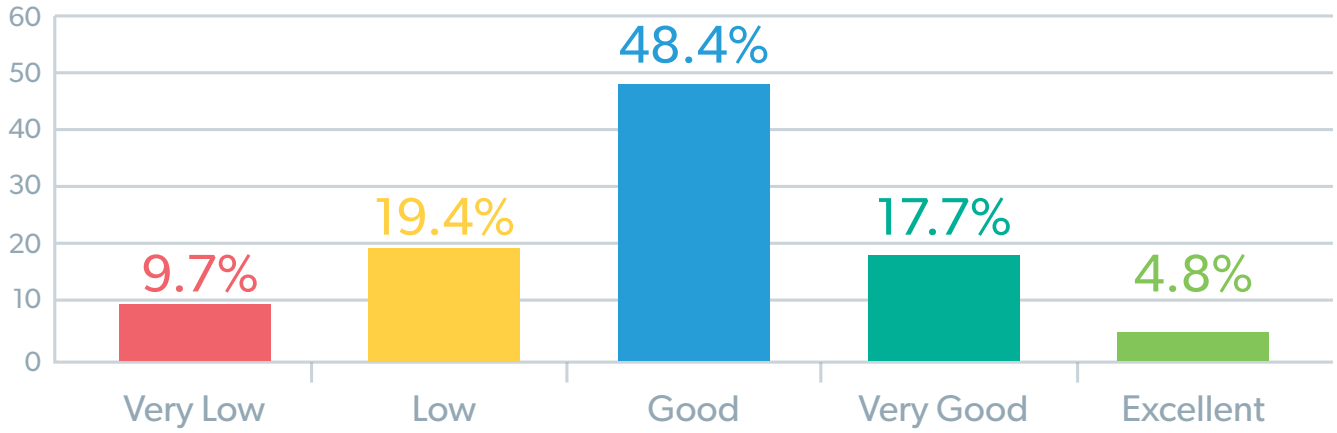
Specifically, just 4 percent of sites were certified by the International Health on the Net Foundation Code of Conduct (HONcode). Only about 67 percent provided information on when the site was last updated, while just 68 percent provided privacy statements. The researchers also found problems with accessibility; the use of simple language (indeed, none of the sites searched provided information based on the simple language rules); and a lack of information about sources and conflicts of interest.

Few sites included information about family planning, social-legal advice, or psychosocial counseling, all of which are important topics to members of the rare disease community.

The German researchers found the highest quality information came from support groups, patient organizations, and medical organizations, although even those sites demonstrated substantial weaknesses.

In another study assessing the availability of rare disease information on the Internet in a Croatian population (Figure 2), nearly a third of respondents said the availability of rare disease information was low or very low. Just one in five rated it as very good or excellent. Those reporting lower quality information also reported that they felt they had less control over their condition and less understanding.[5]

Figure 2: Availability of Understandable Information on Rare Disease Online



Katavic S, Tanackovic F, Badurina B. Illness perception and information behaviour of patients with rare chronic diseases. Information Research, 21(1). Information Research. 2016;21(1):Paper 707.

"...when there is no monitoring of the quality or reliability of Internet-based information, the resultant information can be questionable."

– Nicholl H, Tracey C, Begley T, King C, Lynch AM. Internet Use by Parents of Children With Rare Conditions: Findings From a Study on Parents' Web Information Needs. J Med Internet Res. 2017;19:e51.

A Potential Oasis: Online Customized Rare Disease Communities

The growth of social media and online communities for people with chronic disease has revolutionized the way these individuals receive information and support. The benefits of participating in an online community are numerous, including an improved sense of well-being, control over the disease, personal empowerment, and medical knowledge. Patients may even be able to improve their medical decision making and make positive lifestyle changes.[9,10]

One analysis found that computer-based programs for patients that combine health information with online peer support, decision support, or behavior change can even improve clinical outcomes.[11]

However, it is critical that such communities be moderated and the information provided curated if it is to successfully engage participants and have an educational impact.

This includes the availability of moderators around the clock who are intimately familiar with the rare condition.

Without such oversight, online communities can become infiltrated by "trolls" and "snake oil salesmen" insulting group members and hawking unproven magic elixirs that truly desperate people will buy.

Without a moderator, it is difficult to establish a safe, trustworthy space for those who are already dealing with incredible stress.

Indeed, a Pew Research Center survey of 2,156 members of the National Organization for Rare Disorders (NORD) found that this peer-to-peer health care is particularly profound for those coping with a rare condition.[1] As one participant wrote: "The first time I met another patient, face to face, I sobbed. I was overjoyed and began to communicate with them on a regular basis and my network grew."

A 2010 study from the online network PatientsLikeMe found that people who shared their personal health data and tips about the disease made more informed treatment decisions, particularly around managing side effects.[10]

One survey of 128 parents of a child with a rare disease found that 80 percent belonged to some kind of web-based forum or social network devoted to their child's condition. Most shared information about their child's condition with these communities.[6]

"I am so thankful for all of you, for even though I have not participated on the chat line, silently you have all been helping me cope. I find not many of my wonderful family or friends can understand the roller coaster of emotions you face when dealing with a chronic illness."

– Post on a daily digest listserve for people with primary biliary cirrhosis.

Using Online Social Networks for Medical Research

Healthcare organizations, clinical researchers, and pharmaceutical companies are all beginning to realize that rare disease social networks can provide a rich source of information for studies and a greater understanding of the needs of those living with a rare disease.

They find a receptive audience online; people with rare conditions and their families are happy to help.

For instance, researchers from the Mayo Clinic created a survey to determine if social media could aid in research on protein losing enteropathy and plastic bronchitis. They posted the survey on web and Facebook portals for one year. They had 671 respondents, with 84 percent coming from social media sites. Basically, the survey went viral within that rare disease community.[12]

The researchers received a rich data set regarding patient disease history, risk factors, and therapy which, they noted, was not available anywhere else in the medical literature for these conditions.

Here are just a few other ways in which medical and commercial entities are interacting online with people affected by rare conditions and others:

1. Researchers at the University of Utah are mining social networking sites to identify the vocabulary and new health terms used by people who talk about their conditions online.[13]

2. Boston Children's Hospital partnered with the online community TuDiabetes to design software that protects user privacy while allowing individuals to chart their blood sugar levels for research purposes.[13]

3. The Mayo Clinic in Rochester, MN used an online discussion board to recruit patients with a rare cardiac condition for a clinical trial. Within a week of receiving IRB approval for the study, 18 patients wanted to enroll, but the IRB approval limited enrollment to 12.[14]

4. In the first launch of a the guided community platform in familial adenomatous polyposis (oneFAPvoice.com), the community quickly grew to nearly 450 members, and actively engaged in numerous, quick 1 question polls, more in-depth surveys, and contributed 84 responses in just 2 weeks when the sponsor of a clinical trial sought community input on a pediatric trial protocol in FAP.

"Our highly engaged and committed study participants, linked only via the internet, demonstrated levels of sophistication and specificity in their patient-initiated researcher questions that were on par with those developed by formally organized groups."

– Tweet MS, Gulati R, Aase LA, Hayes SN. Spontaneous coronary artery dissection: a disease-specific, social networking community-initiated study. Mayo Clin Proc. 2011;86:845-50.

Developing the Ideal Online Rare Disease Community

Researchers who study consumer use of online medical information have reached several conclusions about what users want and need, as well as the elements of a successful site.[6] These include sites that:

- **Provide relevant, accurate, trustworthy, and up-to-date information**
- **Address the most commonly searched topics: condition and symptoms; diagnosis; management; treatments; and support groups**
- **Contain a Web-based forum or social network component**
- **Is integrated with social media and is mobile friendly**

The social component of any site is particularly important when it comes to rare disease research, in which patient populations may be miniscule. To date, there are FDA-approved treatments for just 5 percent of identified rare conditions.[15]

The Role of Pharmaceutical Companies in the Rare Disease Online Community

As the 2015 McKinsey report noted, the greater control that patients are taking over their own health requires that pharmaceutical companies find new ways to engage them. One of those ways, a pharmaceutical executive told the interviewer, is through online communities.[4]

That's an approach pharmaceutical giant Pfizer has taken, with a top executive telling the online publication PharmaVoice that "because of the complexity and smaller affected populations, it often falls to patients to be involved in everything from clinical trial recruitment to access and reimbursement." Thus, the company has made close involvement with rare disease groups a key part of its mission in developing drugs to treat rare diseases.[16]

> "The power and influence of patient groups has grown considerably throughout healthcare, but I believe it is heightened in the rare disease space because of the intensity and impact these conditions and diseases have on people's lives."
>
> – *Joe Kuchta, CEO, Sandbox, as quoted in Robinson R. Patients and Patient Organizations Power Rare Disease Therapies. PharmaVoice. February 2016.*

A top executive of a Danish pharmaceutical company described how his company views patient-centricity: "To me, patient-centricity means being deeply entrenched in patient's needs, not just thinking about how to develop new products and new features. It means reaching out to patients and considering treatments that will help them in whatever situation they find themselves in."[17]

Another pharma CEO said his company's close involvement with patients and caregivers affected by a rare neuromuscular condition helped them hone in on the medical needs of the community.[16]

Much of this is driven by patients themselves, who are demanding a seat at the table with pharma and other healthcare entities. For instance, it was the parents of children with muscular dystrophy who submitted a patient-centered benefit-risk assessment study to the FDA – an important step in designing clinical trials for the disease. Patients with other rare diseases have formed foundations specifically to fund research into the condition.

A major benefit of this outreach is finding the population needed for clinical trials. Not only to ensure a large enough cohort of patients, but to

ensure that the patient voice is part of the trial itself, from the design to the reporting of results. This is not just a "nice-to-have" approach, but one now mandated by the Food and Drug Administration.[18]

Indeed, a survey of nearly 50 patient advocacy organizations by public relations company Inventive Health found that their greatest wish is to be more involved in the drug development process.[19] Other key findings that pharmaceutical companies should take note of are detailed in table 3:

Stay engaged. Too often, pharma companies pull back their support of and engagement with patient groups when their medication loses its patent.
Recognize the expertise patient groups have in their disease areas and treat them as respected experts.
Call on them first to develop patient registries and convince patients to join clinical trials – they may have more credibility.
Encourage and support greater collaboration between advocacy organizations and patient groups that may have overlapping interests. After all, many rare diseases have similar underpinnings.

Table 3: Be More involved in the drug development process

In today's technology rich environment, engagement often means using digital tools available to the community. And yet a McKinsey analysis based on 18 common practices spanning four dimensions of digital engagement (Figure 3) find that pharma performs far worse than other industries, including the banking and insurance sectors in digitally connecting with patients and physicians.[20] As the authors of the report noted: "Most pharma companies recognize that digital will have a disruptive impact on healthcare. Only 10 percent, however, base their strategic decisions on a quantified, granular understanding of how digital affects their competitive environment and business model, compared with 22 percent across all industries and 37 percent for digital leaders."

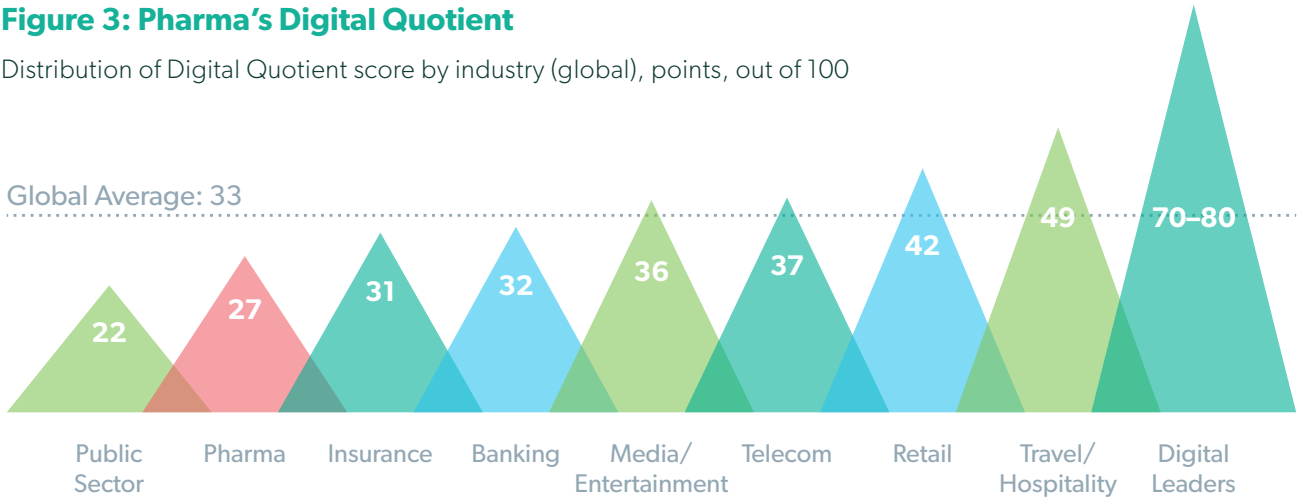
Barriers include ensuring a customer mind-set, including paying too little attention to the customer decision journeys that patients and healthcare providers undertake to access, interact with, and benefit from their products; and failing to build strategy around digital engagement with patients versus the other way around.

"To compete in today's digital age, every pharma company—regardless of its aspirations or positioning—needs to reassess how patients and physicians prefer to learn and interact."

– Fox B, Paley A, Prevost M, Subramanian N. Closing the digital gap in pharma. McKinsey; November 2016.

Figure 3: Pharma's Digital Quotient

Distribution of Digital Quotient score by industry (global), points, out of 100



Source: McKinsey & Company

The good news is there is a lots of room for improvement for pharma to engage digitally. Better still, because rare community members are so eager to connect and participate, pharma has a receptive audience with whom to partner.

Conclusion

Those living with a rare condition and their families face numerous frustrations and have a multitude of unmet needs. The state of the internet in helping them on their journey leaves a lot to be desired. It may take them years to get an accurate diagnosis; physicians who understand their symptoms are few and far between; and understandable, accurate information is hard to find.

As described in this paper, the need for such information is tremendous. Patients and their families need clear, accurate, up-to-date, curated information on their condition if they are to become empowered. At the same time, they need a safe, secure space in which to network with others who have the same or similar conditions.

Meeting these needs will benefit not only the patient, but the healthcare community as a whole.

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