

What is a rare disease “community” anyway?

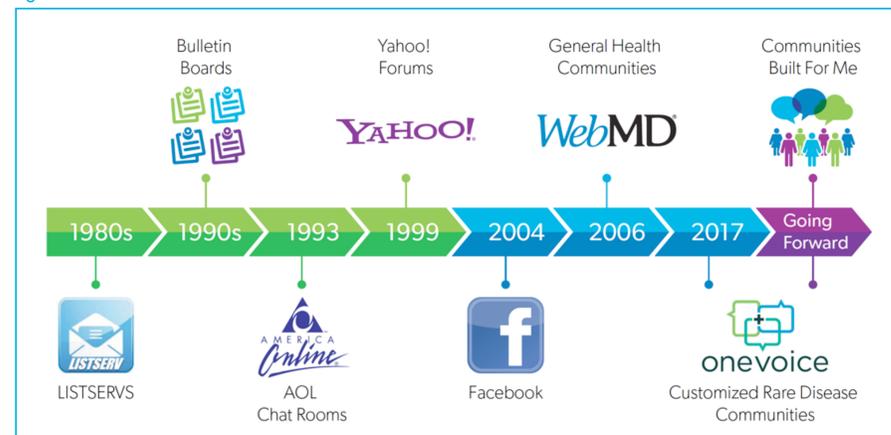
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Background

In the rare disease arena, the word “community” is used with impunity and inconsistent connotations.^{1,2} To better define a rare disease online community, we explored the evolution of digital communities as they developed over the years (Figure 1). We also set out to understand what those impacted by rare diseases seek from a community and its potential role in improving drug development and commercialization.³

- Ever since LISTSERVs and AOL chat rooms emerged in the 1980s and 1990s, people have been gathering online to discuss and share ideas on topics of interest
- As technology advanced and health care started to emerge as a leading search topic of interest, the general fora became too broad
- Demand for greater specialization and personalization led to customized disease-specific communities

Figure 1. The Evolution of Online Communities



Objective

To define effective rare disease online communities and their ability to shape the real-world ecosystem

Methods

- Through quantitative research via structured surveys of community members; interviews with users, potential users, and oversight councils; and real-world observations of platform activity, we assessed the defining characteristics of an effective rare disease online community
- We then analyzed case studies to determine whether the defining characteristics were present and whether the real-world ecosystem benefitted from engaging in an effective rare disease community

Results

Discussions with patients, advocates, caregivers, researchers, physicians, and industry executives allowed us to identify the 8 characteristics of a true rare disease online community (Table 1).

Table 1. Characteristics of a True Online Community

Characteristic	Definition
Current	Delivering up-to-date information
Compliant	Following a transparent code of ethics
Informative	Providing information in a variety of learning styles
Secure	Protecting personal health information and personally identifiable information
Intuitive	Welcoming members with a simple interface and positive user experience that encourages repeat visits
Safe	Offering community managers who are also community members and encouraging positive, supportive discussions
Trustworthy	Sharing only valid disease-specific information, not like the “Wild West” of unreliable information on the internet at large
Friendly	Provides a feeling akin to a warm, informed hug from a friend

When it includes all of these traits, an effective rare disease online community is a supportive, highly productive, and informative place for members

- It provides immediate and long-term benefits to its members
- It can provide real-world outcomes that ultimately improve patient care, product development, and treatment commercialization

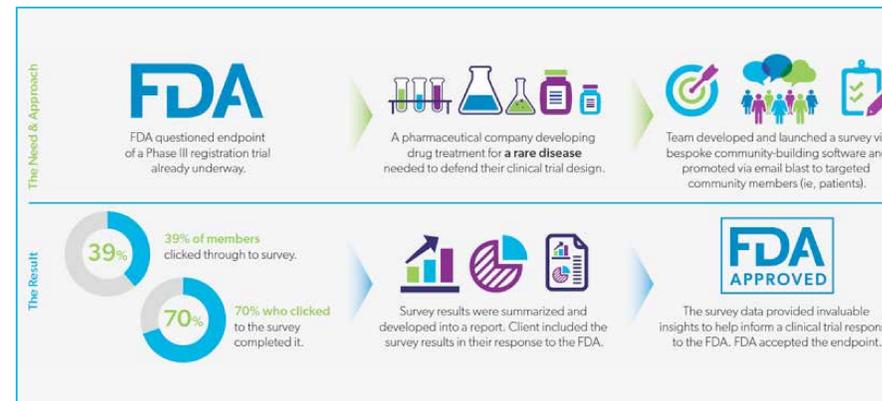
Real-world positive outcomes from true communities included the following:

- Protocol improvements based on feedback from parents of children with a rare disease
- Community input into trial design (Figure 2)
- Enhanced recruitment for a rare clinical trial (Figure 3)
- Market research and insights to shape the regulatory strategy of a rare disease
- The transformation of a grandmother’s rare journey from frightening to comforting within 48 hours of finding support in a true online community (Figure 4)

Case Studies

The impact of true, engaged rare disease communities should not be underestimated. The following case studies demonstrate how true rare disease communities can influence the outcomes of their own diseases.

Figure 2. Engaged Community-influenced FDA Response Package



FDA indicates US Food and Drug Administration.

Community input was critical and allowed the trial to be completed, the results of which could potentially benefit a significant segment of the patient population should the drug be approved.

Figure 3. Community-based Trial Recruitment



MLR indicates medical legal review.

The digital community was engaged and accelerated the recruitment of patients to the trial, thereby shortening the time for the trial being conducted and the results becoming available.

Figure 4. Why Engaged Communities Matter: One Grandmother’s Journey Into the World of Familial Adenomatous Polyposis (FAP)



HCP indicates health care professional.

The digital community provided much-needed support for a new caregiver who was out of her depth dealing with a recent rare disease diagnosis and guided her to the resources she needed—an immediate benefit to a new community member.

Limitations

- By their nature, online communities comprise those with reliable internet access and comfort with the online experience
- The current climate of distrust around social networks more broadly may contribute to potential limited interest in participating in any online community
- The impact of broader social media perceptions on rare disease communities also needs to be better understood

Discussion

Ideally functioning rare disease communities allow those with rare diseases and/or their caregivers to find the resources and connections they need to navigate their journey. For example, these might include clinical trials of interest, relevant blogs, scientific articles, or local specialists. Effective, helpful rare disease-specific communities support members and fill their needs throughout their journey. Communities can do the following:

- Provide emotional support along the entire rare disease journey while reducing the burden of the unknown
 - Reduce patient and caregiver sense of isolation and disease burden
 - Share information about promising treatments and research
 - Provide trustworthy information
 - Advocate and generate funding for research and diverse treatment modalities
 - Influence protocol design
 - Define meaningful clinical end points so that trial results are relevant to patients’ real-world experiences
 - Design, manage, and participate in registries to generate real-world evidence that advances knowledge of disease and impact of current treatment modalities
 - Participate in natural history studies to elucidate understanding of disease and patient journeys and inform development of disease treatments
 - Quickly connect patients with relevant clinical trials
 - Collect and disseminate Patient Experience Data—an essential component for the US Food and Drug Administration
- Additionally, there is opportunity for further research into the level of perceived benefit of online community participation across different community member types: those who simply consume trustworthy aggregated content, those who read community forums but do not actively participate in conversation (commonly known as “lurkers”), and those who actively engage in community conversation.

Conclusions

- Digital communities are complex—but building and maintaining true online communities for those impacted by rare disease can fundamentally improve the patient and family journey and experience in the immediate term.
- Communities can advance the understanding of the disease and improve treatment development and commercialization.
- Rare disease online communities must give members the 8 characteristics (current, compliant, informative, secure, intuitive, safe, trustworthy, friendly) of a true community before they “take” information, data, or insights. By authentically providing all 8 characteristics, a true rare disease online community will be built on mutual trust and collaboration that benefits the entire ecosystem online and in the real world.
- There is evidence that real-world positive outcomes from true rare disease online communities include improved protocol design, better clinical trial recruitment, enhanced market insights, and improved family journey.
- The authors believe that other beneficial outcomes can be expected, such as improved disease awareness, earlier diagnosis, improved lobbying for critical legislation such as newborn screening, generation of patient-reported outcomes data, and better understanding of the patient and caregiver journey.

References

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