

Measuring the impact of engaged rare disease communities

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Background

- The rare disease ecosystem is characterized by fragmented resources, information gaps, low patient numbers, and limited understanding of disease pathology and the patient journey (Figure 1)
- To better understand the impact of rare disease online communities, we looked at quantitative measurements of participation across several rare disease-specific digital education communities* to determine whether the goals of establishing a robust, informed, and engaged community are being achieved
- The reach and impact of an online rare disease community can be measured in many ways, including the following:
 - Geographic representation
 - Role of members in the rare disease community
 - Volume and frequency of member conversations
 - Content of member conversations
 - Number of users overall
 - Number of registered community members
 - Access to resources provided
 - Session duration
 - Assessment of usage by language
 - Repeat visitors
 - Community response to polls and surveys
- Note that each community has its own methodology for attracting community members, and each addresses a unique disease with its own set of challenges

Figure 1. Fragmented Rare Disease Ecosystem



Objective

To demonstrate the impact of engaged rare disease online communities on diverse stakeholders

Methods

- We reviewed visitor (user and member) participation across online educational rare disease communities in 5 different diseases
- We drew from a plethora of community effectiveness metrics, all of which are captured within each community

Results

- In rare diseases, where the number of people affected is small, it is useful to consider the size of the community (disease prevalence) when assessing reach and impact. Comparing the number of unique users to disease prevalence revealed that participation totals were nearly equal to or exceeded the disease prevalence in most of the online communities we assessed (Table 1).

Table 1. Reach and Impact of Rare Disease Online Communities

Platform name	Disease prevalence (US)	No. of unique users
oneSCDvoice	100,000	78,556
oneAMYLOIDOSISvoice	10,000	23,745
oneGRAVESvoice	30,000	13,036
oneFAPvoice	30,000	34,710
oneXLHvoice (new platform: Brazil and Mexico only)	4500	TBD
TOTALS	174,500	150,047

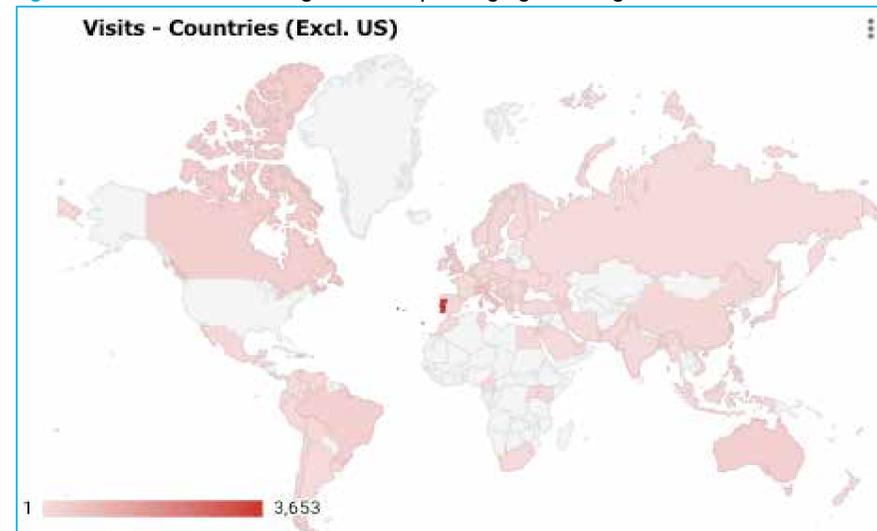
- The average session duration among the rare disease online communities assessed is approximately 2.5 times longer than session duration on other health care sites.* Further, 1.5 times more pages were viewed vs industry average.¹ Both metrics suggest that people are interacting longer with content in disease-specific rare disease communities (Table 2).

Table 2. Engaging Members Longer

	Time (min) spent on platform, 2021 (registered members)	No. of pages per session, 2021 (registered members)
Platform average	5.37	4.56
Industry average	2.00	3.00

- Moreover, when a multilanguage feature was added to one online community, the usage expanded globally, enabling broader access to the educational offerings and discussions in the online community (Figure 2).

Figure 2. Global Reach Resulting From Multiple-Language Offering



- Additional metrics demonstrate that rare disease community members are active poll participants, offering real-world, real-time insight into their personal journeys by completing more than 5000 polls across communities.
- While patients, advocates, and caregivers represent most of the user base in these rare disease online communities, the communities also include physicians, allied health professionals, researchers, pharmaceutical company employees, and other family members who—when combined—create a diverse and committed user base.

Limitations

- The metrics provided present a snapshot in time of when those data were generated. The data will likely have changed between the time the data were collected and the time of this presentation.

Discussion

- At the time of diagnosis of a rare disease, the patient's and family's world can turn upside down
- Trying to find reliable information, sometimes during periods of high stress, in what is often a fragmented rare disease ecosystem, can be a frustrating challenge
- Assessing a variety of metrics from comprehensive, bespoke rare disease communities has proven that there is a need for organized communities that can help the individuals along their personal journey (Figure 3)

Figure 3. An Organized Rare Disease Community



Conclusions

- Structured, informative online rare disease communities can provide a safe haven for those impacted by rare disease to connect, learn, and share experiences
- Measuring the impact of these communities can be achieved in a variety of ways
- Continuous improvement of rare disease online communities based on these metrics will enrich the user experience and broaden impact
- Learning from metrics to develop features and content provides ongoing learning opportunities for users and, ultimately, improved understanding of the rare disease
- Defining key performance indicators (KPIs) and reviewing these KPIs periodically enables an unbiased review of community performance for ongoing improvement

Note

*The communities assessed are powered by onevoice, a custom platform designed to engage and educate people impacted by rare disease.

Reference

1. 2020 performance benchmarks for healthcare digital marketing. 9Clouds, p. 6.