

The engagement continuum: strategies for connecting with community members and encouraging conversation

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Background

- Patients, advocates, and caregivers (PACs) utilize social platforms to communicate thoughts and ideas and interact with one another^{1,2}
- Different social platforms decide for themselves whether they will be public or private and whether they will verify their members²
- onevoice communities are created with the vision of empowering those impacted by rare disease through facilitating access to curated information and community support
- We explore different strategies for engagement and ask what methods are most effective for connectivity engagement
- The purpose of this analysis is to measure engagement rates and assess whether private or public forums make a difference in PACs' desire to interact

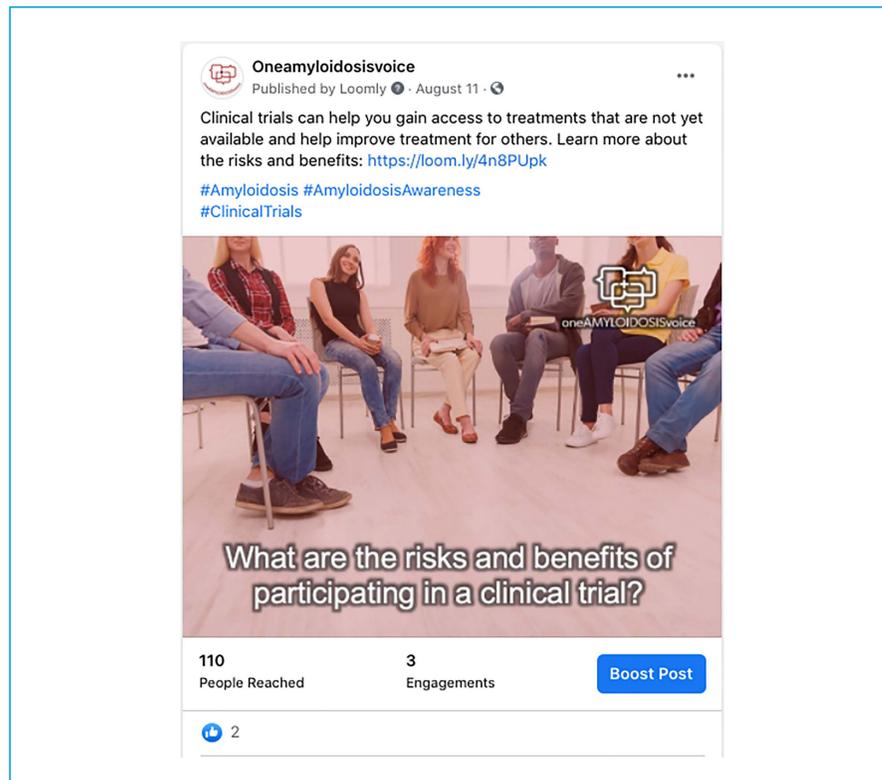
Objective

- To determine the impact of privacy on PAC's willingness to engage with a post by measuring the engagement rate

Methods

- We analyzed member interactions (ie, total number of posts, post reach, and post reactions) from 2 platforms:
 - Total engagement was used to determine which platform had a greater number of interactions
 - Reach was calculated using the total number of unique page views from Google Analytics
 - We analyzed results from the promotion shared on Facebook and the Social Wall during March 2021 (Amyloidosis Awareness Month)

Figure 1. Sample Post on the oneAMYLOIDOSISvoice Facebook Page



The platforms assessed were as follows:

- oneAMYLOIDOSISvoice Facebook page
 - Data from March 2021 were collected using the Facebook Business Suite
- oneAMYLOIDOSISvoice Social Wall
 - Data from March 2021 were collected using Google Analytics

Results

- There were several important differences between the 2 primary member channels (platforms for engagement) considered here:
 1. Social media via Facebook
 - Sharing content, eg, videos, infographics, and health articles, to provide educational value
 - Anecdotal information to encourage engagement
 2. Social Wall on oneAMYLOIDOSISvoice
 - Community members engaging with content in a private (ie, members only), secured group on a onevoice platform are more likely to ask questions and initiate conversations
 - The Social Wall provides members with an opportunity to engage and interact with “peers” or other members of the community
 - The Social Wall is monitored by a Community Manager who is an expert in the field of amyloidosis
- By sharing content and analyzing community interactions on the oneAMYLOIDOSISvoice Facebook page and the Social Wall, we found the following:
 - The Social Wall had an engagement rate of 43%, with an approximate reach of 1816 (Table 1)
 - By contrast, Facebook had a reach (total post exposure) of 5800, but it had an engagement rate of only 4%

Table 1. A Comparison of Reach and Engagement Between Facebook and oneAMYLOIDOSISvoice

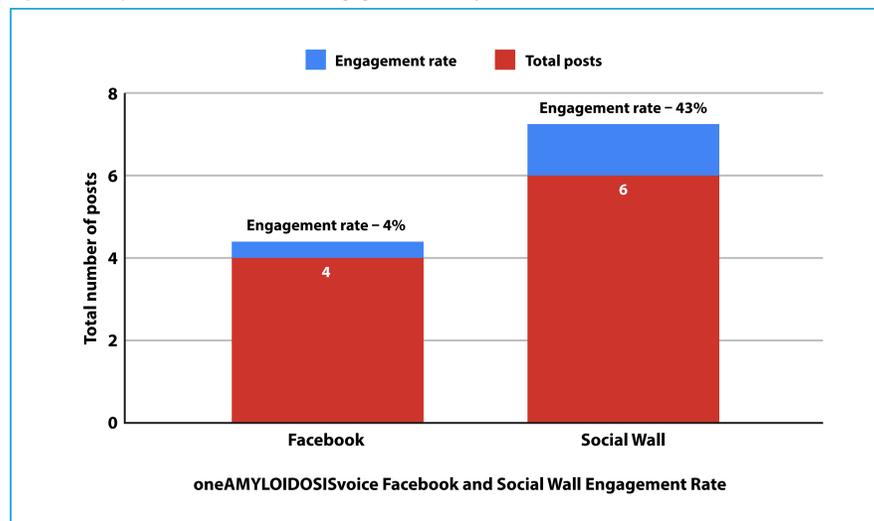
	oneAMYLOIDOSISvoice	Facebook
Exposure	1816	5800
Total interactions	780	232
Engagement rate	43%	4%

Engagement rate is calculated by dividing the total number of engagements (likes, comments, and shares per post) by the total reach of the post (total number of people who viewed the post).

Posts were more common on the oneAMYLOIDODISvoice Social Wall than on Facebook (Figure 2)

- Facebook accumulated a total number of 4 posts during the time period assessed
- oneAMYLOIDOSISvoice accumulated 6 posts (3 moderator posts and 3 member posts)

Figure 2. Comparison of Total Posts and Engagement Rate by Platform

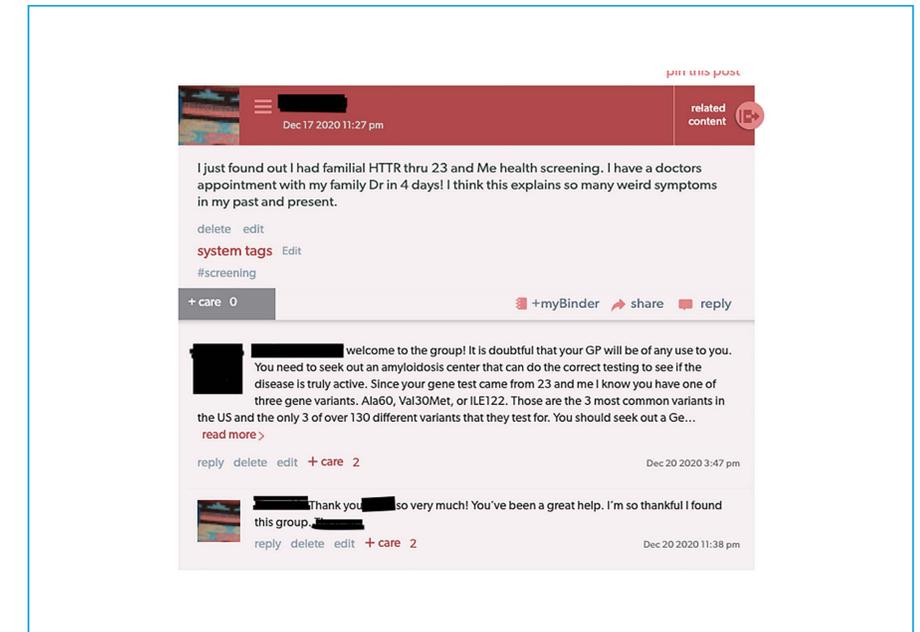


- A key difference was found in the total number of posts on the Social Wall:
 - There was a greater number of posts initiated by private members, while Facebook posts were only initiated by an administrator or moderator

Discussion

- We believe that there is a correlation between privacy and security and a member's willingness to engage with content on a particular theme or topic (such as hereditary transthyretin amyloidosis) (Figure 3)²
 - This analysis poses the question, is a user more likely to engage when their communications are private?

Figure 3. Interaction on the oneAMYLOIDOSISvoice Social Wall



There is value in public platforms for the purpose of recruiting new members and establishing an initial touchpoint, but private platforms foster greater engagement and openness to communication^{1,2}

- We use several strategies to encourage participation and interaction on the Social Wall, including the following:
 - Working closely with the Community Manager, Paula Schmitt, on the welcome strategy for new members
 - Specifically, she sends a direct message to each new member, providing them a personalized introduction to the Social Wall and the platform in general and encouraging them to post
 - We have found that welcoming new members as part of our engagement strategy encourages participation, as does the transparency of seeing other member names and faces and knowing just “who” all the members are through the design of the platform
 - Utilizing social media outlets to drive traffic to the platform
 - Initiating discussions on the Social Wall
 - Using notifications to inform members that new conversations have been initiated

Limitations

- This is an assessment of a single platform; future assessments of other private rare disease groups are warranted to confirm our findings
- We provide results from a 1-month assessment; extending the duration of the assessment period may reveal seasonal trends, and aggregation over time may reveal more robust data

Conclusions

- By analyzing different touchpoints and measuring members' engagement in a public (oneAMYLOIDOSISvoice Facebook page) compared to a private (oneAMYLOIDOSISvoice Social Wall) platform, we conclude the following:
 - The Social Wall provides a private and supportive environment for conversations and dialogue among stakeholders such as patients, caregivers, family, and friends where emotional connections create strong engagement
 - Engagement rates and interactions are higher in a private platform setting
 - A more robust and managed offering may meet more community needs, including the need to connect with others on the same journey

References

1. Wilson S. The era of antisocial social media. *Harvard Business Review*. February 5, 2020. Accessed September 28, 2021. <https://hbr.org/2020/02/the-era-of-antisocial-social-media>
2. Public social networks versus private online communities. *Hivebrite blog*. November 20, 2020. Accessed September 28, 2021. <https://blog.hivebrite.com/public-social-networks-versus-private-online-communities>