

Meet the superusers who hold together health social media

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New research by a multidisciplinary collaboration between Queen Mary University of London, Asthma UK Centre for Applied Research (AUKCAR) University of Edinburgh, University of Nottingham, University of Cambridge and charity Asthma UK, published in the *Journal of Medical Internet Research*, looks at the characteristics of superusers who are actively engaged in the Asthma UK online community and Facebook group to help healthcare professionals better understand the role they play in supporting the management of long-term conditions.

The role of the superuser

Online health communities help people to self-manage certain aspects of their long-term conditions better through harnessing support and knowledge held by other users in the network. They are mostly run on a voluntary basis by their users. Superusers (the 1 percent highly active users) play a central role in these communities as a result of the characteristics of their online activity and their constant engagement.

Online health communities offer high potential for cost-effectiveness in helping to manage long-term conditions. Therefore, understanding the mechanisms of online health communities' effectiveness, how they are organised and how they evolve over time is key. Previous work by the researchers looking at the Asthma UK online community has shown the presence of 20-30 superusers active on a weekly basis among 3,345

users. Removal of these superusers would make the network collapse into isolated non-connected groups. Thus, superusers are responsible for holding the communities together.

Without superusers there would be no effective spread of information and support within the community. However, up until now there has been little research into the characteristics of superusers. This study explores who they are, their motivations behind their engagement, the difficulties they face and what role they wish for [healthcare professionals](#) to play in health [social media](#).

Highly motivated, altruistic, mostly female individuals

The researchers found that superusers in the Asthma UK online community and Facebook group are patients and mothers of children with [asthma](#) of a wide age range. They have a strong intrinsic motivation behind their engagement and their behaviour is self-endorsed, reflecting autonomy. Curiosity about asthma and its medical treatment was a main reason why they engage with the community, and engagement is often determined by availability of spare time when they were off-work due to asthma exacerbations or retired. Their engagement increased over time as participants furthered their familiarity with the online health community, their interest in community members, and their knowledge of asthma and its self-management.

Extrinsic motivation such as financial rewards was not relevant, as their reward came from helping and interacting with others. However, superusers do experience moral pressure to monitor health social media, answer any requests of help, rectify any inappropriate advice (misunderstandings about asthma and its treatment, "miracle cures" or dangerous ideas), or address users who are not seeking medical help

when appropriate. These are things that superusers found difficult and stressful to deal with at times. Despite this, most healthcare professionals are not aware of their patients' engagement with health social media.

Reassuringly, superusers also show judgement about the complexity of coping with the illness and the limits of their advice, knowing when to defer to healthcare providers for appropriate medical advice and intervention.

Olivia Fulton, co-author of the paper and superuser of a large patient advocate network via WEGO Health, said: "I think no matter the condition, superuser traits are the same; I don't think it's unique for certain conditions like asthma. Superusers tend to have long-lived experience of the condition and seek out the most up-to-date information so they know where to direct people should the need arise. Many have been healthcare or allied healthcare professionals but have had to stop work due to ill health and therefore feel that by supporting an online forum, they are still doing something purposeful.

"Superusers are an underutilised ally because often we will see questions from someone newly diagnosed who has felt too embarrassed to ask their GP or nurse, but feel a forum is a faceless platform where they can ask these questions. Although, I am not sure how healthcare professionals would be able to identify superusers among their patients, as I never considered myself as one before it was pointed out to me."

Future research

This study shines a light on a particular group of superusers active in the Asthma UK online community and Facebook group. Further research should also examine whether superuser traits are shared among highly connected individuals in other health social media (eg Twitter). Given the effectiveness in helping people to self-manage their conditions, the

study poses the question as to whether superusers should be formally recognised as allies of the healthcare workforce.

Lead author Dr. Anna De Simoni from Queen Mary University of London said: "As a GP, I have become more inquisitive with my patients about any potential engagement with health social media and support they may need. I believe clinicians can have an important role in conveying norms and values for engaging safely and positively in health social media. During the COVID-19 lockdown, patients with asthma have likely been relying even more on peer support from superusers. Superusers' activity, at the same time, generates the 'hardware of online connections' enabling the crowdsourcing of information and support."

More information: Anna De Simoni et al. Superusers' Engagement in Asthma Online Communities: Asynchronous Web-Based Interview Study, *Journal of Medical Internet Research* (2020). [DOI: 10.2196/18185](https://doi.org/10.2196/18185)

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