Improving Peer Online Forums (iPOF)

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Aims

1. To understand the impacts (positive and negative) of using online mental health forums
2. To understand the roles of forum moderators and how they impact forums
3. To codesign best practice guidance and support for forum designers, hosts, and moderators

The study was a realist evaluation using a mixed-methods, case series design in collaboration with 7 peer online mental health forums in the UK. Case summaries are available online. We published a detailed protocol paper here.

We first did a comprehensive review of the existing literature (102 documents) and talked to staff who host and moderate forums (n = 18), to come up with an initial programme theories about how forums work. This is published here. We then tested and refined these theories using data collected from people who use forums including a large online survey (n = 791) and in-depth realist interviews (n=52). We also analysed forum posts to identify in situ evidence for our revised theories. This paper is published here. We only used forum posts from individuals who had freely consented to posts being shared for research because there are a lot of ethical and methodological challenges with using online data to evaluate forums which we discuss in detail here. We are currently using these findings to design a tool to support ethics committees in decision making about use of online data.

We wrote a paper about who uses forums and why (published here), including accessibility issues for ethnic minority groups (described here). We are exploring how forum use impacts use of other wider mental health services (in prep- watch this space!)). We learnt about how forums users share lived experience in forums here, and about how some forum users become “super-users” and why its important to nurture them (in press). The importance of psychological safety came out as key, so we wrote a separate paper focussing on this which is here.

Moderators play a key role in managing online forums. This role can be very rewarding but also challenging. We wanted to understand the impacts of the role on moderator wellbeing, and work out how best to support them. We reviewed the academic literature (n=9), moderator training manuals (n=5) and the staff interviews (n=18). We highlighted the need to meet moderator needs for autonomy, competence and relatedness. Findings are here.

All data collection and analysis involved extensive input from our patient and public involvement group, including forum users, moderators, and senior forum staff (n=22), which met monthly for 22 two-hour-long workshops throughout the study. With this group, we codesigned

1. An animation for people with mental health difficulties, referrers, and commissioners to better understanding of the role of online mental health communities and how they work. Animation is accessed here.

2. Guidance on how forums can best be designed to maximum the positive impacts and minimize the negative impacts. This paper is written up here and summarized in this table.
3. An elearning curriculum to train and support forum moderators. This is freely available here. The codesign process is described in detail here.

We are collaborating with Hyfon to share this learning as part of their community of practice for forum moderators and hosts. You are welcome to join this community here. This is a professional space for people who guide, facilitate, and sustain peer-led communities, a place to share practice, exchange ideas, and strengthen collective impact. By joining Hyfon, you'll connect with others who understand the challenges and rewards of facilitating peer support. You'll gain access to shared learning, resources, and discussions designed to help you create safe, inclusive, and effective spaces for others.