IPOF: Improving Peer Online Forums
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Introduction
When people experience mental health difficulties, they often look for help online. This has increased during Covid-19 because it has been harder to get in-person help. Online searches will lead them to a range of mental health peer forums (also called online communities). These are websites where people with a shared interest or concern can post messages to others and get their advice and support. Online forums can be very helpful. Some people report feeling less distressed, less alone, and more able to cope. However, others have reported feeling more distressed and less able to cope after using forums. There is very little research so far on why these differences occur. This means we do not know how to make forums better, or which ones should be offered to people seeking help.

Project Overview
We aim to find out: how online mental health forums work; why some work better than others; and why some people find them helpful and others do not. Based on what we find, we will work with people who use forums; people employed to support forums; and people who set up and fund forums; to develop tools to improve the design and support of online mental health forums. Throughout the project, we will work closely with those who are involved with forums on a day-to-day basis. This includes those with lived experience of mental health issues and use forums, those who help to support forums (moderators), those who help to design and run forums, and those in senior positions of healthcare services who determine whether to fund online forums.

Our team includes people with experience in seeking support for mental health problems; people who fund, run and support online mental health forums; and people with the skills to collect and analyse the data. Our outputs will be shared with people taking part in the research, and then widely across mental health and academic groups. The iPOF project is hosted by Bartshealth Healthcare Foundation Trust and includes a wider team, including colleagues from the University of Manchester. This study is funded by the NIHR Health and Social Care Delivery Research (HSR) (NIHR134035). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. https://fundingawards.nihr.ac.uk/award/NIHR134035

Corpus Construction
We are working with seven forum partners. Each of these forums has been assigned a bird code name - this is to further protect the anonymity of the forums and their users (beyond anonymisation of usernames) and to allow each forum to promote their involvement with the iPOF project in their own way. Some of our forums have sub-forums denoted by a number. We have so far collected data from five forums:

- Forum A: 4 sub-forums
- Forum B: 1 sub-forum
- Forum C: 2 sub-forums
- Forum D: 1 sub-forum
- Forum E: 1 sub-forum

Sentiment and Emotion Analysis
Part of our current analysis involves examining the change in a user’s sentiment over time. Initially we have used a pre-trained sentiment model[1] and analysed how the sentiment of the original poster in a thread changes as they reply in the same thread and converse with peers. Plots show the mean and standard deviation.

The same approach can be applied to see how the predicted emotions of a user change during a conversation using a pre-trained Plutchik emotion model[2].

Topic Modelling
To better understand what people are talking about on peer support mental health forums, we applied topic modelling across all the data we have gathered so far. We used Bertopic[2] with default parameters to generate this topic model using whole conversation threads as texts rather than individual posts. By applying it in this way, we can avoid issues of very short texts in individual posts.

Ethical Concerns
Each forum partner can be categorised into three groups with specific ethical concerns around collection of their users’ data.

- Open: For forums that are publicly viewable, data has been collected by web scraping the forum site. Prior to this, the nature of the iPOF study was advertised directly on each of the forums, with forum users offered the opportunity to withdraw their data from the study by contacting the project team.
- Consent-to-share: Several forum partners are charity organisations or commercial businesses that have adopted a policy of offering users the opportunity to consent to share their data for research purposes at sign-up. For these forums, only data from users who have given such consent was provided by the forum host organisation.
- Individual informed consent: two of our forum partners are closed forums without any such consent policy available at sign-up (as described above). For these forums, we advertised the study and provided a PIS (Participant Information Sheet) and informed consent forms for users of the forums to allow collection of their data. This ongoing process was done collaboratively with the forum partners; only the data from users who have filled in the informed consent will be gathered.

As well as anonymisation of usernames, texts have also been blanked of any named entities that were identified as persons or geographic place names.

We have developed a comprehensive ethical framework for this study, which has been developed with input from legal, clinical, academic and lived expertise, and approved by the Health Research Authority (IRAS 314029).

Programme Theories
The study takes a realist approach, which focuses on developing theories to explain how health and social care programmes lead to positive and negative impacts, for whom, and under what circumstances. Our initial theory development work has involved extensive public and patient engagement, literature reviewing, and interviews. This has informed six broad theory areas: ‘mental health self-efficacy’ identifies ways in which users use forums to promote their wellbeing and manage their illness; ‘safety’ explores factors impacting on perceptions of online safety and potential harms; ‘forum moderators’ explains the role and influence of forum staff; ‘social support’ articulates the process underpinning the value of connecting with others online; and ‘forum design’ highlights elements of forum functionality and implementation that influence the user experience.

Theory Testing
The next stage in the iPOF project will focus primarily on testing realist programme theories developed in the first year of the study. We will use a novel approach to data triangulation, drawing on methods expertise in clinical psychology, natural language processing, and corpus linguistics. To date, the team have developed a theory-informed online survey and interview topic guide, which will be used to explore the experiences of those who regularly use our forum partner’s platforms. Initial corpus linguistic analysis has identified expressions of gratitude and empathy as important targets for further theory development. Natural language processing methods including sentiment and emotion analysis, and topic modelling have been applied so far in data-driven investigations.

References