ISRCTN62469166 https://doi.org/10.1186/ISRCTN62469166

Improving peer online forums

Submission date	Recruitment status	[X] Prospectively registered
04/08/2022	No longer recruiting	[X] Protocol
Registration date	**Overall study status**	[X] Statistical analysis plan
28/10/2022	Completed	[_] Results
Last Edited	**Condition category**	[_] Individual participant data
19/03/2025	Mental and Behavioural Disorders	[X] Record updated in last year

Plain English summary of protocol

Background and study aims
When people experience mental health difficulties, they often look for help online. This increased during the Covid-19 pandemic because it was 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. We do not know why these differences occur. This means that we do not know how to make forums better, or which ones should be offered to people seeking help.

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 from online mental health forums.

Who can participate?
Participating forums must:
1. Focus on supporting mental health
2. Be UK based
3. Aim to support young people or adults and/or be able to extract data from people aged 16+
4. Be hosted by a healthcare provider, charity, or commercial organisation
5. Sign up for a data sharing agreement
6. Not have anything in terms and conditions that would prohibit the use of data for research

Posts - All users aged 13 years and over
Survey - All users aged 16 years and over participating in forums
Interviews - All users, moderators and hosts of participating forums, plus other stakeholders who can contribute expertise to the development and testing of programme theories

What does the study involve?
In workstream 1 (1-18 months), we will pull together relevant knowledge from the research literature. We will also interview people who currently use, support, or have studied online

forums. Based on what we find, we will develop some specific theories about how online forums work.
In workstream 2 (6-30 months), we will test and refine our theories in a range of different mental health forums. We will use surveys to measure impacts for different groups of forum members, and interviews to understand the experiences of forum users and moderators. We will also analyse what is happening in the text of the forum conversations.
In workstream 3 (2-34 months), we will use the theories to co-design tools and training designed to improve peer online forums. We will work with our Expert Groups to ensure these are designed and shared in ways that make them easy to find and use.

What are the possible benefits and risks of participating?
There are no direct benefits to taking part in the research. Participants will be offered a £10 voucher for participating in each of 3 timepoints in the survey, and a £30 voucher for participating in an interview. Talking about personal experiences in an interview, or completing an online survey related to mental health may be distressing. Participants will be reminded of their right to take breaks during the study or withdraw entirely if they wish. If they experience any distress following participation they will be encouraged to inform the researcher and use the resources outlined here in a Resources Sheet provided.

Where is the study run from?
Berkshire NHS Foundation Trust. The research partner and sponsor is Lancaster University (UK)

When is the study starting and how long is it expected to run for?
March 2022 to November 2024

Who is funding the study?
This study/project is funded by the National Institute for Health and Care Research (NIHR) (UK), 134035. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care

Who is the main contact?
1. For general project enquiries please contact ipof@lancaster.ac.uk
2. Prof Fiona Lobban (Chief Investigator) (UK)
f.lobban@lancaster.ac.uk

Study website
https://www.lancaster.ac.uk/health-and-medicine/research/spectrum/research/ipof/

Contact information

Type(s)
Scientific

Contact name
Dr Julia Halstead

Contact details
iPOF Project Manager
Division of Health Research
Health Innovation One (D01)
Sir John Fisher Drive

Lancaster University
Lancaster
United Kingdom
LA1 4YW
None available
ipof@lancaster.ac.uk

Type(s)
Public

Contact name
Dr General Enquires

Contact details
Sir John Fisher Drive
Lancaster University
Lancaster
United Kingdom
LA1 4YW
None available
ipof@lancaster.ac.uk

Type(s)
Principal Investigator

Contact name
Prof Fiona Lobban

ORCID ID
http://orcid.org/0000-0001-6594-4350

Contact details
Professor of Clinical Psychology
Division of Health Research
Health Innovation One (D01)
Sir John Fisher Drive
Lancaster University
Lancaster
United Kingdom
LA1 4YW
None available
f.lobban@lancaster.ac.uk

Additional identifiers

EudraCT/CTIS number
Nil known

IRAS number
314029

ClinicalTrials.gov number
Nil known

Secondary identifying numbers
CPMS 53032, IRAS 314029

Study information

Scientific Title
Realist evaluation of online mental health communities to improve policy and practice

Acronym
iPOF

Study objectives
By understanding the impacts of using peer online forums to support mental health, for who, how and in what context, we can create best practices and policy guidance to improve the design and delivery of peer online forums.

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 20/06/2022, Solihull Research Ethics Committee (Equinox House, City Link, East Midlands REC Centre, Nottingham, NG2 4LA; +44 (0)207 104 8191, +44 (0)207 104 8269; solihull.rec@hra.nhs.uk), ref: 22/WM/0132

Study design
Observational cohort study

Primary study design
Observational

Secondary study design
Cohort study

Study setting(s)
Community

Study type(s)
Other

Participant information sheet
Not available in web format, please use the contact details to request a patient information sheet

Health condition(s) or problem(s) studied
Mental health

Interventions

The study is divided into 3 workstreams
Workstream 1 is a realist synthesis. The aim is to develop theories about how online forums for mental health work. This will be done by synthesising stakeholder views gleaned from individual interviews. These stakeholders will be people who have studied, hosted, moderated or commissioned online mental health forums, and will be recruited via our participating forums or direct contact with academic authors of relevant literature. We anticipate interviewing up to 20 people. Interviews will be primarily one-to-one and online using Teams, though we will be flexible and offer group or face-to-face interviews if needed or preferred.

Workstream 2 is a realist evaluation of our initial theories. We will do this by studying up to 6 online mental health forums. These will vary in design, context, and aims. One of these forums is hosted by Berkshire NHS Foundation Trust, which is a research site for the study. This is the only forum (called SHARON) which is linked to an NHS or social care organisation.

We will collect 3 kinds of data:
1. Online forum posts
We will use corpus linguistic methods to explore in-depth, what is happening in the conversations in forums. We have developed a very comprehensive and detailed ethical framework for managing this data. All of the forum posts we analyse will be de-identified prior to analysis by the forum hosts. Some forums are openly available and the posts are publically available. We will analyse these posts only with consent and in collaboration with the forum hosts and moderators. Some forums require a login and users have a higher expectation of privacy. We will only analyse posts from users who have explicitly given consent for their posts to be used for research. Forums, where consent has not been given, will require people to give individual consent for their posts to be used in the study. This includes the SHARON forum. We will make it very clear that taking part (or not) will have no impact on access to this forum or any other support they receive. The timeframe for the forum posts to be accessed will vary depending on what is available in each forum, but where possible will include posts made between March 2016 and March 2024. Posts between March 2023 and March 2024 will correspond to the period of data collection of surveys and interviews, and allow us to triangulate the findings in each dataset so we can answer our questions using a range of methods. This will only be done with participants who consent to their data being linked.

Consistency in findings across different methods is generally considered more valid, and having parallel datasets allows us to explore hypotheses generated in one, in the other. It also ensures that the broad societal context is equal across the datasets. The different methods will allow also us to test different aspects of our programme theories. We know that use of online forums has changed considerably since Covid 19 lockdown in March 2020 as many more people have been seeking help online. Mental distress has been higher, and access to face-to-face services much lower. Therefore, where possible, we want to compare posts made between the beginning of lockdown (March 2020) and the end of our data collection window (March 2024), with those made for the mirror period prior to lockdown ie March 2016 – March 2020. Forum users will also be given the opportunity to take part in a survey and /or to be contacted about an interview. They will give individual consent for each of these.

2. Online surveys
We will recruit users of online mental health forums using posts in the forums and/or emails (depending on the forum design) and invite them to complete a survey online at 3-time points at 0, 6 and 12-week follow-up. Participants will be sent a thank you email and a £10 shopping voucher for each round of survey completed. We have provided a template of the survey items. We will finalise the exact measures, once we have our final programme theories from works stream one, and these will be submitted as an amendment for approval. At this point, we

anticipate measuring positive and negative impacts on community members' emotional wellbeing or functioning using the GAD-7 for anxiety PHQ-9 for mood, and the Global Rating of Change (GRC) which have been shown to represent more accurate descriptions of mental state changes than symptom measures. We will collect information on participant use of healthcare services, personal social services and medicines using the adapted Client Service Receipt Inventory (CSRI). Measuring at multiple time points allows us to describe patterns of change over time for different participants, and compare these across contexts and between cases. For example, we expect less change and more resilience in established users compared to new ones, but without measuring outcomes at multiple time points for all users we have no way of testing this. We use three-time points as the minimum required to estimate longitudinal mediation models, which are much less prone to bias than cross-sectional mediation models. Mediation models allow us to evaluate hypothesised mechanisms by which contextual differences bring about changes in outcomes. Our power calculations suggest we need a minimum of 602 participants in the survey.

3. Interviews
We will interview key stakeholders online using Microsoft Teams and include approximately, 10-12 community members, 4-5 moderators, and 1-2 hosts and commissioners in each of our community cases (total sample up to 114). Each participant will be paid £30 in a shopping voucher per interview. We will sample to include diversity across levels of use (including observers) and report positive and negative impacts. Where possible, and depending on how the forum works, we will also invite people who have been referred to the forum but chosen not to use it, in order to understand what puts people off from engaging. This is possible within the SHaRON forum and invites will be sent from the SHaRON team so no personal details of anyone will be given to the research team prior to consent. Regarding realist methodology, topic guides will be used to test our programme theories. We will make it very clear that taking part (or not) will have no impact on access to this forum or any other support they receive.

The triangulation of these methods to test realist theories is novel. All methods have limitations, and by combining our survey, interviews, and analysis of community posts, we can ensure that: we have a full range of perspectives (including those who choose not to take part in all aspects); we can purposively sample for interview on the basis of self-reported and real-time evidence of specific impacts, or membership to specific subgroups; we can move between broad contextual data, such as the size and structure of the community, to detailed analysis of individual conversations.

The design of the study was developed with input from a group of 12 people with a PPI perspective. All of the recruitment materials, information sheets, and consent forms have been developed with input from service users in our research team. The materials will undergo further adaptation with each of the forum hosts so that they are happy to use them in their forums. Any changes to the content in the templates submitted as part of this application will be submitted for ethical approval. The output from WS2 will be final and tested programme theories about how online forums work, for who, why and in what context. These theories will be used in WS3 to codesign our best practice and policy tools.

Workstream 3
Our policy and practice tools will be Co-Designed with our PPI group. This will include approximate 8 people with experience in using, moderating or hosting forums, recruited from our participating forums. We have costed for 10 workshops at up to £100 per person per workshop to include additional costs of childcare etc where relevant. The Codesign process will be done using a combination of face-to-face, Teams, and offline comments using Miro. The tools will include:

For people with mental health difficulties, referrers, and commissioners
1. Knowledge exchange video/animation tools to widen access and promote greater uptake through a better understanding of the role of online mental health communities and how they work. For community moderators. Community of Practice (CoP) for moderators which aims to build capacity through facilitating mutual engagement, joint enterprise, and shared practice.
2. E-learning curricula to train and support moderators in reflexive practice including understanding the moderator role; ethics of moderation; encouraging activity; understanding mental health; spotting moments of change (introductory linguistic analysis); managing challenging situations; widening access and welcoming diversity; identifying and managing risks; looking after yourself; role of supervision & peer support; signposting; continuing professional development (CPD). For community providers/hosts, commissioners and policymakers.
3. Best practice design principles for online mental health communities to widen access, maximise positive impacts, and minimise harm. This guidance will provide:
3.1. High-level design principles to guide community design and moderation
3.2. Practical guidance for implementing design features to improve the usefulness and safety of online communities
3.3. Examples of best practices and case studies on community design and moderation practices
4. Resource requirements for implementation of best practice design principles based on the disaggregation of the programme theories into resources and reasoning
5. Standardised community characterisation and evaluation framework based on the best practice design principles i.e. consistent and detailed information about each community which focuses on the features identified as crucial to the triggering of underlying causal mechanisms
6. Methodological guidance on how to evaluate online mental health communities based on methodological insights from carrying out this study. For further theory and practice development
7. Programme theory and evidenced-based tools for online mental health communities that have relevance to online health communities of other health conditions, and in other countries, and to offline peer-to-peer support

Intervention Type
Other

Primary outcome measure
Current primary outcome measures as of 04/11/2022:
Consistent with the realist approach, the exact outcomes and measures will be determined by the findings of the realist synthesis in phase 1 of the study. However, at the point of registration, we anticipate these will include:
1. Anxiety using the Generalised Anxiety Disorder Assessment (GAD-7)
2. Mood using the Patient Health Questionnaire-9 (PHQ-9)
3. Change using the Global Rating of Change measure
4. Use of services using an adapted version of the Client Service Receipt Schedule (CSRI)

Outcomes will be measured using:
1. Online forum posts. We will use corpus linguistic methods to explore outcomes identifiable from what forum members say in their posts to the following timepoints:
1.1. First download and analysis of open, consented or fully anonymised posts from April 2022 to January 2023
1.2. Second download and analysis of posts (from March 2016 to March 2023) to analyse (March 2023 to May 2023)
1.3. Third download and analysis of posts (since the last download from March 2024 to September 2024)

2. Online surveys with three waves of data collection at sign-up and 6 and 12 weeks later, starting from February 2023- January 2024
3. Interviews with forum members, moderators and hosts. We will sample across use levels and explore in-depth positive and negative impacts.

Previous primary outcome measures:
Consistent with the realist approach, the exact outcomes and measures will be determined by the findings of the realist synthesis in phase 1 of the study. However, at the point of registration, we anticipate these will include:
1. Anxiety using the Generalised Anxiety Disorder Assessment (GAD-7)
2. Mood using the Patient Health Questionnaire-9 (PHQ-9)
3. Change using the Global Rating of Change measure
4. Use of services using an adapted version of the Client Service Receipt Schedule (CSRI)

Outcomes will be measured using:
1. Online forum posts. We will use corpus linguistic methods to explore outcomes identifiable from what forum members say in their posts to the following timepoints:
1.1. First download and analysis of open, consented or fully anonymised posts from April 2022 to January 2023
1.2. Second download and analysis of posts (from March 2016 to March 2023) to analyse (February 2023 to May 2023)
1.3. Third download and analysis of posts (since the last download from February 2024 to September 2024)
2. Online surveys with three waves of data collection at sign-up and 6 and 12 weeks later, starting from February 2023- January 2024
3. Interviews with forum members, moderators and hosts. We will sample across use levels and explore in-depth positive and negative impacts.

Secondary outcome measures
There are no secondary outcome measures

Overall study start date
01/03/2022

Completion date
07/11/2024

Eligibility

Key inclusion criteria
Participating forums must:
1. Focus on supporting mental health
2. Be UK based
3. Aim to support young people or adults and/or be able to extract data from people aged 16 years old and over
4. Be hosted by a healthcare provider, charity, or commercial organisation
5. Sign up to a data sharing agreement consistent with the procedures outlined in this document
6. Not have anything in terms and conditions that would prohibit the use of data for research

Participating posts must:
Posts from all forum users aged 13 years old and over are eligible for analysis

Participating in the survey:
All users over the age of 16 participating in forums will be eligible for the survey

Participating in interviews:
All users, moderators and hosts of participating forums, plus other stakeholders who can contribute expertise to the development and testing of programme theories will be eligible for the interviews

Participant type(s)
Mixed

Age group
Adult

Lower age limit
16 Years

Sex
Both

Target number of participants
Planned Sample Size: 1134; UK Sample Size: 1134. It is impossible to determine the sample size of the number of people contributing forum posts, as this will depend on the size of the participating forums recruited to the study, and the rate of consent. We have estimated 1000 people. The survey requires a minimum of 602 people based on our power calculation (see detailed research plan). However, with more participants we can draw more accurate conclusions and test more complex models. We have estimated up to 1000 people. The interviews will include up to 20 people in workstream 1, and approx 114 in workstream 2.

Key exclusion criteria
Current participant exclusion criteria as of 04/11/2022:
1. People living outside the UK
2. Forums hosting data outside the UK or EU
3. Aged 15 years old and under for interview and survey data

Previous participant exclusion criteria:
1. People living outside the UK
2. Forums hosting data outside the UK
3. Aged 15 years old and under for interview and survey data

Date of first enrolment
01/01/2023

Date of final enrolment
14/10/2024

Locations

Countries of recruitment
England

United Kingdom

Study participating centre
Berkshire Healthcare NHS Foundation Trust
Fitzwilliam House
Skimped Hill Lane
Bracknell
United Kingdom
RG12 1BQ

Study participating centre
University of Lancaster
University House
Lancaster
United Kingdom
LA1 4YW

Sponsor information

Organisation
Lancaster University

Sponsor details
University House
Lancaster
England
United Kingdom
LA1 4YW
+44 (0)1524 594902
sponsorship@lancaster.ac.uk

Sponsor type
University/education

Website
https://www.lancaster.ac.uk/

ROR
https://ror.org/04f2nsd36

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care Research; Grant Codes: NIHR134035

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Publication and dissemination plan
1. Peer reviewed scientific journals
2. Internal report
3. Conference presentation
4. Publication on website
5. Other publication

Intention to publish date
30/06/2025

Individual participant data (IPD) sharing plan
All papers will be published with open access. We are big supporters of open access and data sharing principles. However, given the nature of these data, we will not share the forum datasets openly as they contain personal and sensitive information.
De-identified survey data will be openly shared on PURE. Please note that the link on PURE will be available only after the data has been deposited there. Interview data will be restricted access and available by request to legitimate research parties assessed on a case-by-case basis if the purpose is consistent with the consent given for this research. To apply for interview data please contact Prof Fiona Lobban (Chief investigator), f.lobban@lancaster.ac.uk.
Best practice tools will be disseminated by the host Trust and in accordance with the implementation plan developed in workstream 3. They will not refer to any identifiable data.

IPD sharing plan summary
Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
HRA research summary			28/06/2023	No	No
Protocol article		30/07/2023	31/07/2023	Yes	No
Statistical Analysis Plan			05/03/2024	No	No