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Studying how joining a support group for people with personality disorder affects their well-being

Submission date
18/01/2023

Recruitment status
No longer recruiting

Registration date
24/02/2023

Overall study status
Completed

Last Edited
18/01/2024

Condition category
Mental and Behavioural Disorders

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] Record updated in last year

Plain English summary of protocol

Background and study aims
Personality disorder is a mental health condition characterized by long-term patterns of thoughts, feelings, and behaviors that deviate significantly from cultural and societal expectations. These patterns can cause significant distress and difficulty functioning in relationships, work, and other areas of life.
Individuals with complex needs refer to those who have multiple and interrelated physical, mental, and social health problems, which require coordinated care and support. They may have more than one diagnosis, and their condition may be considered as more difficult to diagnose, treat and support than others. They are often people who have been in and out of different services, and have not had their needs met by any single service.
Examples of individuals with complex needs include those with personality disorder and co-occurring substance abuse, severe mental illness, physical health conditions, history of trauma, homelessness, or involvement in the criminal justice system.

This research proposes to investigate the impact of a Service User Network (SUN) on the lives of individuals living with personality disorder and complex needs as a new addition to therapeutic interventions.
The aim of this study is to understand the perspective of individuals living with Personality disorder who have accessed the SUN, through conducting interviews. This study has three objectives:
a) To explore if and how the SUN has supported service users recovery and wellbeing, and what role the SUN facilitators play in this.
b) To present a model to explain and understand the support received from the SUN.
c) To build a theory around if and how peer-led intervention are meaningful for individuals living with Personality Disorder.

Who can participate?
Adults aged 18 years or older, who have been accessing the Service User Network for a period of at least 2 months. Participants must be living in the community (i.e not currently an inpatient) and must have the capacity to consent to their involvement.

What does the study involve?
Participants will be recruited via individuals who access the SUN groups. Participants will be required to complete a consent form, provide some personal information (e.g. age, locality) and take part in an interview.
This research will use Constructivist Grounded Theory methods. This means that the data received from the interviews and the analysis of this data will be carried out alongside each other. Data analysis will occur until there is a clear set of themes within the data which can be understood as a model.
In addition, the research will involve a group of lived experience consults to guide and support the research.

What are the possible benefits and risks of participating?
There are a number of expected outcomes of this study which will be of benefit to participants. The focus on the experiences of those living with a Personality Disorder will allow the voices of an often excluded group to be meaningfully heard. There should be no more than minimal risk from participating in this study. Participants should not experience any distress beyond what is experienced in day-to-day life.

Where is the study run from?
South Essex Partnership University Foundation NHS Trust (UK)

When is the study starting and how long is it expected to run for?
April 2022 to February 2023

Who is funding the study?
Applied Research Collaborative East of England (UK)

Who is the main contact?
Bryony Dalee, bryony.dale1@nhs.net

Contact information

Type(s)
Principal investigator

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Additional identifiers

Integrated Research Application System (IRAS)
316791

Study information

Scientific Title
Investigating the impact of a service user network on the well-being outcomes of individuals living with personality disorder and complex needs: an addition to therapeutic interventions.

Study objectives
Healthcare systems can expose individuals to risks of avoidable harm, and unwarranted variations in care quality. Though there are notable preconditions for high quality care: funding, infrastructure and staffing to mention a few, the processes and investment into making change needs innovation and investment.

In addition, services that support individuals with Personality Disorder have long been insufficient, however, there has been a significant investment by NHSE in service provision for Personality Disorder and Complex Needs across England, and a system-wide transformation currently being undertaken in Essex which encompasses chief investigators role of Service User Network Manager and Facilitator for Personality Disorders and Complex Needs.

This research will both invest in collating experience and information around service provision, and match these efforts in making the change happen: advancing, refining and expanding a lacking body of knowledge which includes the design and delivery of new peer-led services. More resources are undoubtedly necessary to tackle the inequalities experienced by this client group, and it is important that the research questions address how best we can move forward within services to tackle this, e.g. by investigating what works, what doesn't and why.

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 22/11/2022, HRA and Health and Care Research Wales (Health Research Authority, Skipton House, 80 London Road, London, SE1 6LH, UK; +44 (0)20 7972 2545; hra.approval@nhs.net), ref: 22/SS/0087

Primary study design
Observational

Study design
Constructivist grounded theory with participatory research methods

Study type(s)
Quality of life

Health condition(s) or problem(s) studied
Personality disorder and complex needs

Interventions
In order to understand and conceptualise the collective patterns which contribute to the experience of the Service User Network, and given the lack of current research and literature, this research will use Constructivist Grounded Theory methods (Charmaz, 2000). In addition, participatory research approaches will also be drawn upon throughout, to ensure meaningful engagement and a respectful partnership with the community that the Service User Network serves. Participants will be recruited from attendees of the Service User Network.

After consent is established, interviews will be conducted with each participant, exploring their experience of the Service User Network and the factors that have impacted that experience. Consistent with the Grounded Theory approach, further interviews and/or field work will be tailored to investigate the hypothesis emerging as data collection progresses.
Interviews will be guided by a few prompting questions (semi-structured), conducted by the Chief Investigator and a member of the consultation team (Expert by Experience).

Intervention Type
Other

Primary outcome(s)
Service Users experiences of being a part of the sun will be measured using qualitative interviews. The interviews are semi-structured with 1 pre-determined opening question (Please can you tell us a little bit about your experience of being part of the Service User Network?). Interviews will be analysed using Constructivist Grounded Theory.

Key secondary outcome(s)
There are no secondary outcome measures

Completion date
01/02/2023

Eligibility

Key inclusion criteria
1. The service user must have been accessing the Service User Network for a period of at least 2 months.
2. Participants must be living in the community (i.e not currently inpatient) and must have the capacity to consent to their involvement.
There are no other inclusion criteria and the SUN is a service which is already accessed via inclusion criteria (an individual is presenting in line with Personality Disorder, resides in Essex, and is 18 years or older).

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 Years

Sex
All

Total final enrolment
13

Key exclusion criteria
Does not meet inclusion criteria

Date of first enrolment
22/11/2022

Date of final enrolment
04/01/2023

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
Essex Partnership University NHS Foundation Trust
The Lodge
Lodge Approach
Runwell
Wickford
United Kingdom
SS11 7XX

Sponsor information

Organisation
South Essex Partnership University Foundation NHS Trust

ROR
https://ror.org/05v823t63

Funder(s)

Funder type
Research organisation

Funder Name
Applied Research Collaborative East of England

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study are not expected to be made available due to confidentiality of participants.

IPD sharing plan summary
Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	version 3.2	01/11/2022	26/01/2023	No	Yes