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Participant Information Sheet

Study 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."

Invitation and Summary

My name is Bryony Dale and I am currently undertaking a Mental Health Research Fellowship with the Applied Research Collaborative, East of England.

I would like to invite you to take part in my research study. Joining the study is entirely up to you and would be done voluntarily. Before you decide whether you would like to take part, we would like you to understand why the research is being done and what it would involve for you.

Please read this information carefully and feel free to email any questions you may have to: bryony.dale1@nhs.net.

What's Involved?

The aim of this study is to investigate the impact of the Service User Network (SUN) on the wellbeing of individuals living with Personality Disorder and Complex Needs, as an additional support to therapeutic support. This aim will be achieved through conducting interviews with people who have accessed the SUN for 2 months+.

This study has three objectives:

(a) To explore what factors contribute to the experience of the SUN for service users. Specifically, if and how it has supported their recovery and wellbeing, what particularly has contributed to their health and wellbeing outcomes, and what role the SUN facilitators play in these outcomes.
(b) To develop a model to understand the process through which the SUN supports individuals living with Personality Disorder.
(c) To build a theory around what elements of peer-led intervention are most meaningful for individuals living with Personality Disorder.

What Would Taking Part Involve?

You have been asked to participate in this study because you have accessed the SUN for 2+ months. You will be asked to provide some information including your age, gender, locality, ethnicity, and how long you have been accessing the SUN, however it is your choice as to whether you provide this information.

You will be invited to take part in an interview on MS Teams, which is anticipated to last approximately between 45 - 90 minutes. Ahead of the interview you will be invited to a group discussion to learn more about the study to ensure you are fully informed of what taking part will involve.

You will be given time to decide whether or not you would like to participate following this group discussion, and will be provided with a link to a consent form to complete should you choose to participate.

What Are The Possible Benefits of Taking Part?

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.

As a thank you for your time, you have the option to receive a gift of a £20 Amazon voucher.

What Are The Possible Disadvantages or Risks Of Taking Part?

There should be no more than minimal risk from participating in this study. You should not experience any distress beyond what is experienced in day-to-day life. However, due to the potentially sensitive nature of the study, please refrain from taking part if you feel like questions related to your mental health and experiences may negatively affect you.

If you do choose to take part, and feel like this study raises concerns for your wellbeing, please take immediate action by contacting your friends, family, medical professional or the following helplines:

- Crisis Line: Phone: 111, option 2
- Samaritans: Phone: 116 123 (free 24 hour helpline)

There will be support (from the Lead Researcher and Peers) provided before, during and after the interview; contact details are provided at the end of this information sheet.

What will happen in the interview*?*

The interview will be arranged at a mutually convenient time over MS Teams (or in person if favoured). You do not have to have your camera on during the interview, though this is preferred. If you do use your camera, you may use a virtual background if you would like to protect your surroundings from being seen, but this is up to you. We ask that you find a private space where you cannot be heard and/or interrupted.

You will be asked an open question which you will have been given ahead of the interview. Following the interview, there will be an opportunity to debrief with the interviewers.

The interview will be recorded using the recording function on MS Teams. This will then be transferred to an audio recording which will be shared with the external organisation who will be transcribing it. There will be no information given to this organisation that identifies you.

What will happen if I don't want to carry on with the study*?*

You may withdraw from the research at any time, during or until 2nd February 2023 for any reason, without having to provide an explanation. If you would like to withdraw, please contact myself on bryony.dale1@nhs.net to let me know.

If you wish to withdraw whilst completing the interview, simply let me know and the meeting will be terminated. The recording up until that point will be deleted.

Will my taking part in this study be kept confidential*?*

Essex Partnership University NHS Foundation Trust (EPUT) is the Lead Sponsor for this study based in the United Kingdom. Only the lead researcher will have access to your identifiable information. Your data will be allocated a code number instead. The lead researcher will act as the data controller for this study on behalf of EPUT. This means that they are responsible for looking after your information and using it properly. You can find out more about how we use your information by contacting epunft.dpo@nhs.net or by going on line and accessing the EPUT privacy notice www.eput.nhs.uk/contact/your-health-records-information/

Additionally you can access further information specific to research participation at www.hra.nhs.uk/information-about-patients/

We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm (e.g disclosure of current risk, safeguarding, or criminality). If this arises, you will be informed that confidentiality cannot be maintained for this reason, and the appropriate personnel will be informed. All relevant professional codes of conduct, Trust policy and procedures will be adhered to as necessary for relevant disclosures.

What will happen to my information*?*

The identifying information being collected about you initially is your name and e-mail to attend the group discussion. Should you decide to participate your name will be on the Consent form which will be stored securely and separately from all other research data within a locked file on a secure EPUT computer drive.

Additionally for participation in the interview, if you choose to provide it, demographic information will be requested to include: age, gender, locality, ethnicity, and how long you have been accessing the SUN. This information will not be attached to any anonymous quotes, and will only be used by the Lead researcher to summarise the combined characteristics of all participants. We will only use the information you choose to provide when writing up the findings of this research project. No further information will be used (e.g. from your medical records).

All of the research data being collected from you is anonymous through the allocation of a unique code identifier and will be stored electronic. All electronic data will be held on a secure database on a password-protected, encrypted computer that only the lead researcher has access to. These will be destroyed after 3 years from completion of the Fellowship (September 2023).

The Research Team* cannot access confidential information provided in the demographic information form, however there is a chance they could learn of confidential information during the process of interviews and analysis. Confidentiality will be maintained throughout and every member of the research team has signed a confidentiality agreement. It is requested that you be as honest as possible in your answers.

Who will have access to my recording/interview transcript*?*

Interviews will be transcribed by an external transcription service, who uphold the strictest confidentiality (Antonia Reed Free Lance Transcription Service). To ensure the validity of the research, transcripts will be reviewed by members of the Research Support Team. No identifiable information will be given with the transcripts (e.g. name or consent form).

The interview recordings will be converted to an audio file and will be sent to the independent transcriber via a secure transfer system (Egress), and who must follow our rules about keeping your information safe. The transcriber will not have access to your demographic information or consent forms. The transcriber will remove any potential identifiers from the transcript (e.g. removing your name if mentioned in the audio).

You will be able to obtain a copy of your interview transcript (either electronically or a hard copy), and you will have the opportunity to review the document. You can therefore review what was said, add more information if you would like to, or clarify anything said. This is called 'member checking'.

What will happen to the results of this study?

Analysis of the data will be undertaken by the Research team and will result in a report being written that will be published as an academic journal article and distributed internally within the Trust. You will not be identified in this report. This document could also form the basis of further documents or presentations related only to this research. You will be sent a copy of the overall results from this study/the final write up via email, and can request a hard copy. A lay summary of the findings will be also be available once the study is finished.

Will the use of my data meet GDPR rules*?*

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules. As detailed above the research data collected within this study is anonymised and the identifiable data you are required to provide of your name on the Consent form will be separately recorded and securely stored with only the lead researcher having access to the unique identifier code to link consent forms with demographics and data collection. If you would like more information on research data please contact the local research department via e-mail: epunft.research@nhs.net

Who has reviewed the study?

All NHS research is looked at by an independent group of people, where this involves staff as participants the group is called the Health Research Authority (HRA) in order to protect participants' safety, rights, well-being and dignity.

This study has been reviewed and received approval by the HRA. The study has also received confirmation of capacity and capability from the Trusts Research department.

What next?

Please take a moment to think about whether you would like to participate and thank you for taking the time to read this information sheet.

Please feel free to email any questions you may have to: bryony.dale1@nhs.net

THE RESEARCH SUPPORT TEAM*

Lead Researcher: Bryony Dale

Consultants: Scott Waple (Expert by Experience), Carolyn Pardey (Expert by Experience), Sandie Delmar-Morgan (Expert by Experience), Malina Moris (Expert by Experience), Christine Cantello (Senior Patient Experience Coordinator, Essex Partnership University NHS Foundation Trust)

Research Support: Danny Wright (Assistant Psychologist, Essex Partnership University NHS Foundation Trust), Ina Hoxha (Assistant Psychologist, Essex Partnership University NHS Foundation Trust)

Research Supervisors: Andrew Bateman (Academic Supervisor, University or Essex), Helen Ellis-Caird (Trust Research Supervisor, Essex Partnership University NHS Foundation Trust), Mhairi Donaldson (Professional Supervisor, Essex Partnership University NHS Foundation Trust).

Transcription Service: Antonia Reed Freelance Transcription Service.

Research Sponsor: Pauline Young (Research & Innovations Manager, Essex Partnership University NHS Foundation Trust)

To contact the Research Sponsor:

Mobile: 07939 008588 Email: pauline.young3@nhs.net

What if something goes wrong?

If you have a concern about any aspect of this study, or wish to make a complaint about the conduct of the study you should ask to speak with one of the following:

EPUT Research Manager, Pauline Young: Mobile 07939 008588 or e-mail: Pauline.young3@nhs.net

Andrew Bateman (Academic Supervisor, University or Essex, Mobile: 07926 223203 or e-mail: a.bateman@essex.ac.uk

In the unlikely event something goes wrong or you are harmed by taking part in this study, there are no special compensation arrangements. If you are harmed because of someone's negligence, then you may have grounds for a legal action for compensation against EPUT, but you may have to pay for your legal costs.

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, please contact Patient Advice and Liaison Service (PALS) on 0800 085 7935 or you can email epunft.pals@nhs.net

Thank you for considering taking part in this research study