

## CPFT Research Database Oversight Committee

### Role profile for Expert by Experience (EbE) Representative

The [CPFT Research Database](#) is an information source that allows Trust staff and researchers to carry out research and audits using anonymised information from the Trust's clinical records. Under certain circumstances it is also possible for CPFT researchers to request direct contact with potential research participants who have provided their consent. The CPFT Research Database Oversight Committee is the committee that oversees the overall governance and management of the database.

The CPFT Research Database has received ethical approval from an independent NHS Research Ethics Committee as a safe, secure and confidential information source for research. The database uses validated software for anonymisation.

The remit of the CPFT Research Database Oversight Committee is as follows:

- Accountable for overall governance and oversight of the database and its methods
- Managing the database (including any technical issues)
- Approving researchers and projects to use the database

The committee is responsible for ensuring the processes involved in using the database are transparent; for overseeing approvals for studies; for ensuring that queries do not carry a significant potential for de-anonymisation (e.g. through extremely specific queries and/or relating to very rare diseases); and for monitoring patient recruitment. The committee has nine members, three of which are experts by experience.

The committee aims to meet monthly. It is chaired by Rudolf Cardinal and the research database is managed by Jonathan Lewis, who also supports the committee administratively.

#### **What will the Expert by Experience representative do?**

- A key role for the EbE representative is to ensure that service user/carer views and experiences inform the work of the group and project team.

As part of your role you will need to:

- Develop familiarity with the concepts and language used in research involving anonymised data.
- Attend and actively participate in the monthly meeting of the Committee. Contact the chair or admin support of the committee if unable to attend.

- Prepare for meetings by reading the agenda papers in advance and raising any issues for clarification with the chair during or before the meeting as appropriate.
- Contribute to discussions that take place during meetings, based on your experience and your reflections on the papers provided.
- Assist the group to understand the wider perspectives of service users/carers that are relevant to its work.
- Maintain the confidentiality of agenda papers, discussion and decisions made.
- Keep records of meetings attended and preparation time and liaise promptly with the User and Carer R&D Manager regarding expenses

## **Term and time commitment**

Under current restrictions meetings are held virtually, usually on the third Thursday of every month from 11:15am-12:15pm. In normal circumstances meetings will be held in Cambridge. Each meeting will usually involve some preparation. Approval of projects can also be done via email. Payment for work undertaken above and beyond this will be negotiated separately.

## **Payment**

Expenses for attendance at meetings will be reimbursed at £15.70 per 1hr meeting (including preparation time and review of proposals via email), plus 56 pence per mile, or bus/taxi/standard rail fares with receipts. This is in line with the Cambridgeshire and Peterborough NHS Foundation Trust policy.

Please note that accepting payments may affect any state benefits you may be receiving and may also be liable to income tax. If you are concerned about the possible impact of accepting payment on your benefits and allowances please contact your local Jobcentre Plus office and/or your local benefits advice agency.

## **Support**

Support for the role will be provided and tailored to individual needs and requirements. You have a right to expect that:

- Your opinions will be actively invited. Your contributions will be valued, your views heard and acted upon where practicable
- You will be appropriately briefed and supported by the chair of the committee (Rudolf Cardinal) and the CPFT User and Carer R&D Manager (Iliana Rokkou) prior to your involvement. Clear information will be given about what is required in relation to particular roles; research and involvement objectives; procedures of sharing work and decision-making.
- Preparation and debrief meetings (if needed) will be provided to enable you to participate meaningfully
- Where required, information will be provided in an accessible form (e.g. easy read; face to face meetings)

- Where appropriate, training will be provided
- Reasonable notice is given with regard to meeting dates and any other activity, taking into account suitable dates, times and venues for meetings

## Person specification

Although no formal qualifications are required it is important that you have the following experience, knowledge and skills.

| Criteria          | Essential attributes  | Desirable attributes  |
|-------------------|---|---|
| <b>Experience</b> | <p>Experience of mental health as a service user or carer</p> <p>Experience of participating in formal meetings, e.g. committees</p> <p>Experience of reading and reviewing written documents</p>   | <p>Linked to NHS/patient, carer, and community networks/groups</p> <p>Experience of health service research, e.g. as a member of a study or as a member of a research project team</p> <p>Experience of involvement in health services, e.g. as a member of an advisory group</p> |
| <b>Knowledge</b>  | <p>An understanding of issues that are important to service users and/or carers (e.g. as a service user and/or member of a relevant service user organisation)</p> <p>An understanding of capacity and consent issues from a service user/carer perspective</p> <p>An understanding of the importance of and need for mental health research within the NHS</p> <p>Willingness to become familiar with relevant research and medical language</p> | <p>An understanding of expert by experience involvement in research and the benefits it brings</p>  |

|                                 |   |  |
|---------------------------------|---|--|
|                                 | An understanding of, and commitment to, confidentiality   |  |
| <b>Skills</b>                   | <p>Confidence to contribute to group discussion</p> <p>Have good communication and team working skills</p> <p>Ability to refer to personal experience and knowledge of services and research appropriately to inform the work of the committee</p> <p>Ability to understand and refer to the broader range of patient / public perspectives beyond own personal experience and to use that appropriately within the role</p> <p>Good time management skills</p> | <p>Confident user of e-mail, internet and word processing packages</p> <p>Ability to use and communicate well on Zoom.</p> |
| <b>Personal Characteristics</b> | <p>Ability to travel to venue of meetings</p> <p>Have time to commit to the work of the group - attending meetings but also to do background reading, comment on draft products of the group etc.</p> <p>Have a friendly and approachable manner</p> <p>Enthusiastic and willing to learn</p> <p>Reliable and trustworthy</p>   |  |

## HOW TO EXPRESS YOUR INTEREST

Please submit a letter of expression of interest via email ([iliana.rokkou@cpft.nhs.uk](mailto:iliana.rokkou@cpft.nhs.uk)) no later than **22<sup>nd</sup> February 2021.**

The letter should cover the following:

- Why you are interested in this role

- What previous experience you have had which you believe is relevant to this post
- How you feel you meet the person specification – please consider your specific experience, knowledge, skills and personal characteristics.
- What support and training you feel you may need in the role

Interested applicants are encouraged to contact Iliana Rokkou, User and Carer R&D Manager, to discuss this opportunity further: Email: [iliana.rokkou@cpft.nhs.uk](mailto:iliana.rokkou@cpft.nhs.uk)

Applications will be shortlisted against the role profile to identify the candidates that will fit the requirements of the role. Brief interviews will take place if needed.