

## **CPFT Research Database Oversight Committee**

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

The CPFT Research Database Oversight Committee is a committee that oversees and directs a project involving the use of a database system for research and audit within CPFT. The CPFT Research Database **allows researchers to carry out research and Trust staff to conduct audits using anonymised information from the Trust's clinical records. Under certain circumstances, it can also enable researchers to request direct contact with potential research participants via an ethically approved system for identifying patients subject to their consent.** The CPFT Research Database uses validated software for anonymisation.

The CPFT Research Database provides a cost-effective way for us to dramatically improve the accessibility of clinical data to support research. It can also make it easier to conduct clinical audits and can increase visibility of overall patterns of service use.

The CPFT Research Database has received ethical approval from an independent (non-Trust) NHS Research Ethics Committee, as a safe, secure and confidential information source for research.

The remit of this 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 will ensure that the process is conducted transparently; will oversee approvals for researchers and studies (and may delegate aspects of approval to an appropriate subcommittee); will ensure 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 will monitor patient recruitment (including recruitment requests involving children and/or patients who may lack capacity) to ensure that requests are proportionate and are conducted with due regard for the principles and methods governing access to sensitive patient-identifiable data and contact with patients for research purposes.

This committee meets on a monthly basis. 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:

- To attend and actively participate in the specified meetings. These will be held in Cambridge.
- To 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.
- To contribute to discussions that take place during meetings, based on your experience and your reflections on the papers provided.
- To assist the group understand the wider perspectives of service users/carers that are relevant to the work of the group.
- **To maintain the confidentiality of agenda papers, discussion and decisions made.**
- To listen to other members in the group and participate in group discussion
- To be respectful of other ideas in the group
- To keep records of meetings attended and preparation time and liaise promptly with the User and Carer R&D Manager regarding expenses
- To contact the chair of the committee or the committee's admin support if unable to attend a meeting.

**Term and time commitment:** Two years in the first instance. Meetings usually occur on the third Thursday of every month from 11:15am-12:15pm 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 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.

<b>Criteria</b>	<b>Essential attributes</b>	<b>Desirable attributes</b>
<b>Experience</b>	Experience of mental health as a service user or carer  Experience of participating in formal meetings, e.g. committees  Experience of reading and reviewing written documents	Linked to NHS/patient, carer, and community networks/groups  Experience of health service research, e.g. as a member of a study or as a member of a research project team  Experience of involvement in health services, e.g. as a member of an advisory group
<b>Knowledge</b>	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)  An understanding of capacity and consent issues from a service	An understanding of expert by experience involvement in research

	<p>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, and commitment to, confidentiality</p>	
<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>
<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>	

	Reliable and trustworthy	
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### **Any concerns or worries**

If you have any concerns or worries during the duration of the project, please do not hesitate to speak to Rudolf Cardinal ([rnc1001@cam.ac.uk](mailto:rnc1001@cam.ac.uk); 01223 768501) or Iliana Rokkou ([iliana.rokkou@cpft.nhs.uk](mailto:iliana.rokkou@cpft.nhs.uk); 01223 465182)

### **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)) or post (Iliana Rokkou, CPFT R&D Office, Douglas House, 18 Trumpington Road, Cambridge, CB2 8AH) no later than **7<sup>th</sup> November 2019.**

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: Tel: 01223 465182 or 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.