****

**Connected Communities**

**Participant Information Sheet**

**Service User and Service Provider Interview**

**V1.2 [09.01.2023]**

**Please tell us if you need this information in a different language to English, and we will try to provide it.**

**To watch or listen to a recording of this participant information sheet, please scan the QR code above or click the following link: https://arc-nwc.nihr.ac.uk/connected-communities-participant-information-video-wp2/**

**1. Title of Study**

* CONNECTED COMMUNITIES | Implementation of person-centred community-based support services, and lessons for social care providers.

**2. Invitation to participate**

* We are inviting you to contribute to a research study coordinated by a team of researchers at the University of Central Lancashire (UCLan).
* Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask questions or discuss with others if you wish.
* You do not have to accept this invitation, and you should only agree to take part if you want to. Thank you for reading this.

**3. What is the purpose of the study?**

* Person-centred community-based support services (PCCBSS) are services that direct people to a range of activities that might help them improve their health and wellbeing. There is a lack of understanding about how these support services are put into practice, how services work with each other, and how PCCBSS responded to the COVID-19 pandemic.
* The purpose of this study is to explore how new PCCBSS work within usual working practices.
* PCCBSS can be any local service that uses people (‘signposters’) for helping individuals in their community to access appropriate types of personalised support. These services work in the following way:
	+ An individual is (self-)referred to a PCCBSS;
	+ Signposter consults with service user to identify their need(s);
	+ Signposter directs service user to appropriate community-based support.

**4. Why have I been invited to take part?**

* You have been invited to participate because you have previously been referred to a PCCBSS, (e.g. The Life Rooms, Community Connectors, or Social Prescribing Link Workers), or have been involved in working with a PCCBSS.
* We would like to speak to you about your views on the service. We hope to find ways to improve how these services are set up in the future.

**5. Do I have to take part?**

* Participation is voluntary. You can withdraw from the study at any time.
* If you decide to withdraw (see section 11. **What will happen if I want to stop taking part?**), you do not need to give us a reason and there will be no disadvantage for you.

**6. What will happen if I take part?**

* If you would like to take part, please contact our researcher Jo Weldon on jcweldon@uclan.ac.uk. She will be able to answer any further questions you might have.
* If you agree to take part, you will be invited to an interview that will last for no more than one hour and be held at your local service, over the phone, or online using Teams. We will be flexible to your needs and can undertake the interview at a time and date convenient to you (outside working hours if necessary). You can choose how you wish to be interviewed, whether it’s face-to-face (on service premises), over the phone, or through a video-conferencing facility link (Microsoft Teams – no installation will be required).
* The interview will be about your experiences of PCCBSS, we will also ask you about how useful you found the information we provided beforehand (e.g. this leaflet.)
* We will take your consent to take part before we can interview you. To do this we will ask you to either:
	+ initial each of the statement boxes on the consent form (Participant Consent Form – Interview, V1.2, 09.01.2023) and sign it (if participating in a face-to-face interview); or,
	+ to verbally agree to each statement read aloud by the interviewer from that consent form version in a separate consent recording (if participating via a phone or video-conferencing facility).
* Face-to-face and phone interviews will be audio-recorded, and interviews using Teams will be video-recorded.
* If you feel uncomfortable being on camera, you do not need to turn your camera on if you choose to be interviewed through Teams, as we will immediately extract audio from the video-recording after the interview and then delete the original video-recording.
* If you choose a face-to-face interview, to reduce the risks of COVID-19, we ask participants who test positive or have any symptoms of COVID-19 at the time of interview to either reschedule their face-to-face interview for a later date (if possible), or alternatively participate by phone or video-conferencing facilities (if you feel well enough to do so).
* We will ensure that interviews are undertaken in adequately ventilated spaces to reduce the risk of COVID-19 transmission. We will also encourage attending participants to socially-distance and/or wear a face covering (“mask”) if they feel comfortable to do so; however, we understand that it may be harder to hear responses of people wearing masks and we will request that they sit closer to the audio-recording device in these circumstances.

**7. Are there any risks in taking part?**

* Many people enjoy being interviewed but there is always a risk people may feel upset if they describe difficult personal experiences. In this study, interviewers will use an interview distress policy to ensure that participants are supported both during and after participation, and the interview can be stopped at any time. The interviewers are sensitive to these issues and are experienced at supporting people experiencing distress.
* With any research there may be sensitive information shared that the study team have a professional duty to report. This is considered to have a low risk of happening during these interviews, but if such an incident occurs that indicates that you or others may be at significant risk of harm, the researcher may need to report this to an appropriate authority. This would usually be discussed with you first. Examples of those exceptional circumstances could include if the researcher believes you or someone else is at serious risk of harm, either from yourself or others. It could also include disclosures of malpractice by a healthcare professional.
* Any concerns will be referred to the study’s Chief Investigator (Professor Mark Gabbay) who will communicate with the relevant organisations. Any disclosures that require further investigation will be discussed with participants at the time if possible.

**8. Are there any benefits from taking part?**

* There are no benefits from taking part in this research. Sharing your feedback through an interview will help to inform the set-up of future PCCBSS (particularly for social care services) and may improve how well this process works.

**9. Expenses and / or payments**

* Service users who are interviewed will receive a £25 gift voucher as an acknowledgement of their time. Reasonable travel expenses will also be reimbursed.
* If you are interviewed as a service provider (i.e. you have been involved in working with a PCCBSS), you will be supported to be interviewed during your usual working hours (to avoid incurring additional expenses).

**10. What will happen to the results of the study?**

* A summary of the findings will be shared with people who took part in the study, if you would like to receive this. The study results will also be published in academic journals and presented at conferences. The results might also help future services change or develop.
* You (and your data) will not be identifiable in the results shared.

**11. What will happen if I want to stop taking part?**

* Taking part in this project is completely voluntary. You can stop at any time without giving a reason by informing the interviewer at the time, or by emailing our researcher Jo Weldon on jcweldon@uclan.ac.uk.
* You don’t have to answer all our questions, and you can choose not to answer questions you feel uncomfortable with.
* You can withdraw your recorded interview data up to a week after your interview. After this time, the original recordings will have already been deleted and all information will be anonymised and collated; as such, it will no longer be possible to individually identify and remove your data.
* If you lose the ability to give consent/make decisions (after having already provided your consent) during the study discussion, we will withdraw your participation from the study. Identifiable data already collected with your consent will be kept and used in the study; however no further data would be collected or any other research procedures would be undertaken with you.

**12. Who is organising and funding the research?**

The research is funded by a National Institute for Health Research, Applied Research Collaboration National Priorities Programme for Adult Social Care and Social Work award (ARC271). The research is being conducted by research staff from the University of Central Lancashire.

**13. Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the Camberwell St Giles Research Ethics Committee (IRAS ID: 314796).

**14. How will my data be used?**

* The University (UCLan) will process your personal data as part of its research and teaching activities in accordance with the lawful basis of ‘public task’, and in line with the University’s purpose of “advancing education, learning and research for the public benefit”.
* Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University’s research. The University privacy notice for research participants can be found on the attached link <https://www.uclan.ac.uk/data_protection/privacy-notice-research-participants.php>
* No personal data will be transferred outside the European Union.

**Further information on how your data will be used can be found in the table below.**

|  |  |
| --- | --- |
| **How will my data be collected?** | * We will only collect data that is required for the study. This will include your name and contact details to arrange the interview process and will be kept in a password-protected file, separate from the research data (your interview audio and transcript).
* All face-to-face and phone interviews will be recorded with an encrypted audio recorder and all online interviews will be recorded through Microsoft Teams.
* We will anonymise identifiable details in your research data (with a unique code for each participant, and not directly identifiable beyond the research team).
 |
| **How will my data be stored?** | * Your personal details (names and contact details) and consent will be stored in a password-protected file in the research team’s Microsoft Teams secure storage space, along with all anonymised research data (interview transcripts).
* Participants’ written consent forms will be scanned and saved to the same secure digital space, after which original paper documents will be immediately disposed of using confidential waste processes at UCLan.
 |
| **How long will my data be stored for, and how will it be destroyed?** | * Your personal data (contact details and consent) will be kept until the end of the study (December 2023; *unless you choose to receive a copy of the study findings by email, where instead your email address will be kept for up to 12 months after the end of the study*) and then securely destroyed by deletion.
* Your research data (transcript from the interview) will be stored in a password-protected folder (with expiry date for deletion) on the Microsoft Teams secure storage space and will be kept for 7 years, or until the last related study publication (whichever is earlier).
 |
| **What measures are in place to protect the security and confidentiality of my data?** | * Data that personally identifies you (e.g. contact information) will be processed as encrypted email, and immediately stored in a password-protected Excel file held in the research team’s Microsoft Teams secure storage space (removing the need to transfer information between researchers) before being destroyed as described above.
* Personally identifiable data will be kept separate from research data at all times to maintain confidentiality.
 |
| **Will my data be anonymised?** | * All research data will be anonymised using a unique code for each participant and stored in the research team’s Microsoft Teams secure storage space.
* Video recordings (from Teams) will immediately be deleted from the interviewer’s account after the contained audio content has been extracted, and video will not be saved to any location to ensure participants’ privacy is protected.
* Digital audio recordings (which may identify participants by voice) will each be deleted after the resulting transcript is confirmed to be accurate.
 |
| **How will my data be used?** | * Data from your interview will be compiled with other peoples’ and summarised to represent the views of participants.
* We will use this data to present the study findings to focus groups of social care providers and users (to help them think about possible connections to their own services).
* We will also use the compiled data to develop an online ‘toolkit’ which will suggest useful ways PCCBSS can be set up and work in future.
 |
| **Who will have access to my data?** | * Audio recordings will initially be transcribed by University admin support (UCLan’s Research Facilitation and Delivery Unit) as a data processor (which will be compliant with General Data Protection Regulation (EU GDPR), data protection, and confidentiality regulations), before the interviewer completes a final transcription check for accuracy against the audio recording.
* You can request a copy of your interview transcript (at any time after its final accuracy check) by emailing our researcher Jo Weldon (jcweldon@uclan.ac.uk)
* Only the research team will have access to your personal data and interview data.
 |
| **Will my data be archived for use in other research projects in the future?** | * Your data will not be archived for use in other future research projects.
 |

**15. What if I am unhappy or if there is a problem?**

* If you are unhappy or if there is a problem, in the first instance please contact our researcher, Jo Weldon on01772 894959orjcweldon@uclan.ac.uk. The chief investigator [Professor Mark Gabbay] can be contacted if necessary on 01517 945610 or m.b.gabbay@liverpool.ac.uk.
* If you remain unhappy or have a complaint that you feel you cannot share with the research team, then please contact the Ethics, Integrity and Governance Unit at OfficerForEthics@uclan.ac.uk.
* The University strives to maintain the highest standards of rigour in the processing of your data. If you have any concerns about the way in which the University processes your personal data, you have the right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

**16. Who can I contact if I have further questions?**

* If you have any further questions and/or would like to take part in this study, please contact our researcher Jo Weldon on01772 894959orjcweldon@uclan.ac.uk or by writing to BB425, Brook Building, University of Central Lancashire, Preston, PR1 2HE

**Thank you for reading this information sheet and for considering taking part in this research.**