Plan Overview

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Title: Co-designing mental health services: An evaluation of the experiences of Black and South Asian Communities in Bradford and its impact on their care

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Project abstract:

This collaborative PhD project, undertaken jointly with the University of Bradford and the local NHS Mental Health Team, aims to redesign mental health services to enhance cultural appropriateness for Black and South Asian communities in Bradford. Embedded within the mental health team, the researcher will co-produce the study alongside community experts-by-experience. The project will identify key barriers to access, including inequality, racism, and lack of trust and apply co-design principles to develop services that are responsive to the cultural, religious, and individual needs of these communities. The objective is to improve service uptake and mental health outcomes through culturally tailored, community-informed interventions.

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Co-designing mental health services: An evaluation of the experiences of Black and South Asian Communities in Bradford and its impact on their care

Assessment of existing data

Provide an explanation of the existing data sources that will be used by the research project, with references

I will be accessing two existing data sources:

1. Bradford District Care NHS Foundation Trust conducted prior co-production workshops with service users from Black and South Asian background on the mental health services in Bradford. While at this stage the details still held on these participants are unknown, we understand that the NHS may have contact details for them. If this is the case and, there is prior demonstrable consent for participation in further research projects (to be assessed from the prior project), I will request Bradford District Care NHS Foundation Trust (BDCT) to get in touch with them and ask on my behalf whether they would like to take part in my research BDCT will invite all participants (should their details be available) including those who did not attend the co-production workshops and/ or 'dropped out' following attendance at one or two workshops.
2. I will also be carrying out a scoping review (form of desk-based literature review). I will be accessing a range of peer reviewed and grey literature, all of which is in the public domain.

Provide an analysis of the gaps identified between the currently available and required data for the research

The research I am trying to conduct with the service users who took part (or decided not to take part) in the co-production of mental health services in Bradford is currently unavailable. The contact details will allow me to reach out to this cohort of participants and ask them whether they would like to evaluate the services they co-produced previously.

Information on new data

Provide information on the data that will be produced or accessed by the research project

Participants will be invited to co-design workshops or interviews, where they will discuss their experiences of being involved in the co-production journey of mental health services in Bradford. This includes service users and staff that were involved in the co-production process. I will also invite individuals that were invited to take part but decided not to participate in the co-production process. Following the receipts of consent form, I will contact the participants to agree the logistics of the co-creation workshop and focus group/interviews. Their involvement will require two stages and the following data will be produced:

Stage 1 – Co-creation: workshops/one-to-one interviews (3 to 5 participants).

Historically there has been a low take up of workshops in Bradford, so there will be a range of ways people can be involved in the co-production process, this is to increase access to participants. Participants will also be offered to participate in group workshops. Additionally, I will offer one-to-one phone and in person interviews in homes and community centres or gathering feedback via lead professionals or trusted voluntary sector workers. I will co-facilitate the groups with trusted members of various organisations; warm handovers are much more likely to yield better results.

They will be consulted on what questions to ask and themes to explore when they will be brought together again in stage 2. As individuals who were involved in the co-production of mental health services, their lived experience will be consulted to organise the next session, so that the right questions and topics of discussions will be in place. Key themes will be brought to them, so that they are able to put together the right questions.

During the participatory action research process, the participants will have answered the following broad research themes. The list below is not exhaustive; the idea is to allow the workshop to creatively allow for discussion points and questions to arise:

- What was their experience of the co-production journey
- Do they feel this was a genuine co-production
- Was it culturally and religiously sensitive

- Did they find the process meaningful or was it superficial
- Did they feel Eurocentric models were used
- Did it represent the multitude of voices and experiences from the Black and South Asian communities

Stage 2 – Focus group or interviews (3 to 5 participants).

The same participants and more individuals will be invited to stage 2 to answer the questions or discuss the points finalised in stage 1. For those not wanting to attend the focus groups, they will be offered to answer and discuss through a one-to-one interview.

Upon completion of data collection, I will thematically analyse the data. I will interpret the data with the guidance of my supervisors to produce findings from the focus groups and interviews.

Quality assurance of data

Describe the procedures for quality assurance that will be carried out on the data collected at the time of data collection, data entry, digitisation and data checking.

The entire PhD research is being supervised by a total of four supervisors. Additionally, one supervisor is a Consultant Clinical Psychologist who will supervise the data collections through the workshops and interviews I intend to conduct. I have monthly supervisions with my supervisors who are guiding me in every aspect of my research. In particular the supervisors will quality assure the data included in the scoping review, the transcriptions collected and coded and, the final output (PhD Thesis and, accompanying peer reviewed papers).

Backup and security of data

Describe the data security and backup procedures you will adopt to ensure the data and metadata are securely stored during the lifetime of the project.

Data Management, documentation and curation.

In managing and curating data, all raw data will be stored on my dedicated NHS laptop and backed up according to the robust information management policies the NHS has. Anonymised data will be transferred to the University of Bradford computers and backed up according to the university data protection policy (e.g., see https://www.bradford.ac.uk/data-protection/, https://www.qmul.ac.uk/media/arcs/policyzone/Data-Protection-Policy-v03.1.pdf

Both the NHS and the university will ensure the quality and integrity of the data. It will be accurate, complete, and contemporaneous, and attributable to the anonymised person by whom it is generated. Qualitative transcriptions will be checked for accuracy to preserve the quality and characteristics of the original data. All data will be kept in adherence to Good Clinical practice Guidance which includes storing data in a cabinet in locked premises and destroying recordings after transcription.

Information governance teams at the University of Bradford oversee data management and are available to advise teams as required. Data will be collected in accordance with the study protocol and procedures through regular supervision meetings.

2. Data Security and confidentiality

Data will be stored in a secure environment to industry standards and accreditation and securely and regularly backed-up. Qualitative interview data will be collected and stored using encrypted digital audio recording (e.g., MP3). Physical data (e.g., digital audio-recordings) will be kept until transcribed, checked to allow traceability and stored securely. All data will be anonymised. All identifiable data will be held and only analysed by the PhD researcher. Secure Data transfers will take place from the NHS servers to the University of Bradford using NHS encryption software. All documents will be assigned version numbers, which will be presented in headers and electronic filenames. For long-term storage, data will be archived in line with ESRC guidance. All anonymised data will be made available to supervisors of the PhD researcher.

3. Responsibility for data management.

The Principal Investigator, Cooper, will have overall responsibility for data management, metadata creation, and data security. No data will be gathered before permissions are received from the relevant Research Ethics Committee. During the active life of the project, the day-to-day responsibility for managing, anonymising, and holding all data will be delegated to the PhD researcher.

Management and curation of data

Outline your plans for preparing, organising and documenting data.

1. Pre-Data Collection: Recruitment, Ethical Preparation, and Technical Set-Up
Before I collect any data, I will establish clear systems for recruitment, participant information, and data infrastructure to ensure consistency, transparency, and compliance.

- Recruitment and Advertising: To reach potential participants, I will design and distribute standardised posters across relevant locations (e.g., community centres, NHS venues, GPs, university departments, online forums). Each poster will clearly state the purpose of the research, the time commitment required, and my contact details. To track recruitment effectiveness, I will log where each poster is placed and note which channels yield the highest response rates.
- Participant Information and Informed Consent: Every potential participant will receive a Participant Information Sheet (PIS). This sheet will outline the research aims, what participation involves, data storage procedures, anonymity measures, and their right to withdraw. I will ask participants to sign two copies of a Consent Form—one for my records and one for them to keep. I will maintain a Master Consent Tracking Log (a password-protected spreadsheet) that records which Participant ID has signed consent, ensuring I never accidentally analyse data from a participant who has not formally agreed.
- Ethical Documentation & Data Management Plan (DMP): I will create a formal DMP outlining who has access, where data is stored, and the retention period.
- Template Creation: I will design standardised templates for:
- Field Notes: To record observations during workshops (e.g., group dynamics, non-verbal cues).
- Interview Guides: To ensure all interviews follow the same thematic structure.
- Reflexivity Log: A separate journal to document my own biases and assumptions before and after each session, to ensure I am bracketing my preconceptions.

2. Data Collection: Real-Time Organisation
During the workshops and interviews, I will implement a "tidy-as-you-go" approach to prevent backlogs.

- Naming Conventions: I will use a strict file-naming protocol. This ensures I never confuse files.
- Hardware Redundancy: I will use two recording devices (primary and backup) for all interviews. For workshops, I will take high-resolution photographs of all physical artefacts (flip charts, post-its) immediately after each activity, before they are moved.
- Participant Tracking: I will maintain a Master Participant Log (an Excel Sheet) that links Participant IDs to their consent status, interview date, and workshop attendance, ensuring I can track who has provided what data.

3. Post-Collection: Data Preparation and Cleaning
This is the critical step where raw data becomes analysable text.

- Transcription: I will transcribe audio interviews verbatim (or use a secure AI-assisted transcription service, manually checking for accuracy). I will adopt a standardised transcription protocol.
- Anonymisation: Immediately upon transcription, I will use the "Find and Replace" function to redact all identifying information (names, places, company details) and replace them with placeholders like [PERSON] or [LOCATION]. The original audio will be stored in a password-protected folder separate from the transcripts.
- Workshop Data Synthesis: For workshop artefacts, I will create a digital summary sheet for each activity, documenting the theme of each sticky note or flip-chart entry in a structured Word/Excel table, linking them back to the specific workshop group.

4. Data Organisation: Storage, Categorisation, and Software Use
I will organise data by type and stage of analysis to make retrieval efficient, utilising qualitative software to manage complexity.

- Folder Structure: I will use a hierarchical folder system on the secure university server.
- Use of NVivo: I will import all cleaned transcripts, workshop summaries, field notes, and even photographs of workshop artefacts into NVivo. Within the software, I will:
- Create an initial codebook (a hierarchical system of nodes) based on my interview questions and research objectives, but leave room for emergent codes (inductive coding).
- Use NVivo's case classification feature to assign demographic attributes (e.g., age, role, workshop group) to each participant. This will allow me to run comparative queries later (e.g., comparing how different workshop groups responded to the same theme).
- Use NVivo's memo-linking function to attach my reflexive thoughts directly to specific data segments, ensuring my interpretations are transparently documented.
- Version Control: I will date-stamp all analysis files, so I can track how my interpretations evolve over time.

5. Documentation and Audit Trail
This ensures the research is trustworthy, replicable, and that I can justify every decision.

- The Audit Trail: I will keep a detailed research diary that chronologically logs every decision I make—why I changed an interview question, why I discarded a particular data point, why I merged two NVivo codes, or why I chose to follow up on a specific workshop theme. This proves my methodology is systematic.
- Data Tracking Log: I will use a simple spreadsheet to track the "lifecycle" of each file, noting when it was collected, transcribed, anonymised, coded in NVivo, and finally, when it was used in a draft chapter.
- Backup Schedule: I will set an automated daily backup to the university cloud storage and a physical external hard drive. I will also regularly export and save my NVivo project file (.nvp) to these backup locations, as NVivo projects can become corrupted if not backed up properly. I will test the restore function weekly to ensure backups are not corrupted.

6. Post-Project Archiving and Secure Disposal

- At the end of the project, I will separate the anonymised transcript data from the signed consent forms (which I will store securely in a locked drawer for the required retention period). The Master Consent Tracking Log will be kept separately from the anonymised NVivo database. Finally, I will permanently delete all raw audio files and workshop videos as per my ethics approval and data protection regulations.

By implementing these systems—from poster-based recruitment and informed consent through to NVivo organisation and secure archiving—before data collection begins, I will minimise human error, protect participant confidentiality, reduce analysis time later, and maintain a clear chain of evidence from raw participant voice to final research conclusions.

Difficulties in data sharing and measures to overcome these

Identify any potential obstacles to sharing your data, explain which and the possible measures you can apply to overcome these.

Data sharing will adhere to the policies of both organisations, the University of Bradford (https://www.bradford.ac.uk/about/legal-and-governance/policies-statements/research-data-management-policy/) and BDCT. The University of Bradford's Information Commissioner's Office (ICO) registration code is, Z8986266, while BDCTs is Z6261301. At no point will personal data be transferred without prior permission of the research participant. Should permission be In place, we will apply secure data transfer over a FIPS 140-2 compliant SSL connection (which has equivalence to the security of bank transfers). No further identifiable information from the research project will be shared between the organisations, with all information anonymised e.g., any identifiers stripped from transcripts or thesis chapters (see Stage 2., below).

Consent, anonymisation and strategies to enable further re-use of data

Make explicit mention of the planned procedures to handle consent for data sharing for data obtained from human participants, and/or how to anonymise data, to make sure that data can be made available and accessible for future scientific research.

To ensure that data obtained from human participants can be made available and accessible for future scientific research, I have embedded consent for future sharing directly into my Consent Form, and I have designed a rigorous anonymisation pipeline that transforms raw participant data into a shareable, ethically compliant dataset.

Stage 1: Obtaining Informed Consent for Future Data Sharing (As per the Consent Form)

My Consent Form explicitly addresses future data sharing through two key statements, which participants must tick to confirm:

1. Publication and Dissemination: "I understand that anonymised information may be used in reports, journal articles, community events and conference presentations." This ensures participants are aware from the outset that their anonymised contributions will enter the public domain in aggregated or quoted forms.
2. Future Research Storage: "I agree that anonymised data may be stored for future research use by the University of Bradford." This is the critical clause that permits me to deposit the anonymised dataset in a repository for access by future researchers. Importantly, this is presented as a separate tick-box, meaning participants actively opt in to this specific use of their data—they are not coerced into agreeing as a condition of participation.

Additional Participant Safeguards on the Consent Form:

- The form clearly states that "information collected will be looked at by authorised and responsible personnel at the University of Bradford," which sets expectations about controlled access.
- Participants are informed that "my interview will be audio recorded (with my consent) and fully anonymised in the research," establishing that anonymisation is a deliberate and guaranteed process.
- The form includes my full contact details (telephone and email), ensuring participants can ask further questions or withdraw consent if they change their mind about future data sharing.
- The optional tick-box for "I would like to receive a summary of the findings from this study" allows participants to remain engaged with the research outcomes, potentially increasing trust in how their data is used long-term.

Stage 2: Anonymisation Procedures to Enable Future Sharing

Anonymisation is not a single step—it is a multi-layered process designed to ensure that no participant can be re-identified, even by future researchers who may access the stored dataset. This directly fulfils the promise made on the Consent Form that data will be "fully anonymised in the research."

2.1 Immediate Pseudonymisation:
Upon collection, all participants will be assigned a unique Participant ID . The master list linking these IDs to real names and contact details (provided at the bottom of the Consent Form) will be stored in a separate, encrypted file on the secure BDCFT system, accessible only to me. This master list will never be shared or deposited.

2.2 Systematic Redaction of Direct Identifiers:
Before any data is transferred to my university account or prepared for future sharing, I will systematically remove all direct identifiers from transcripts and workshop summaries. This includes:

- Replacing all names (including names of family members, colleagues, or clinicians mentioned) with placeholders like [PERSON].
- Replacing all place names (hospitals, clinics, towns) with placeholders like [LOCATION].
- Removing or generalising any specific dates (e.g., "I was admitted in March 2024" becomes "I was admitted in early 2024").
- Removing any job titles that could be identifying in a small organisation (e.g., "I am the only occupational therapist in this ward" becomes "I work in a clinical role").

2.4 Workshop Data Anonymisation:
For visual workshop data (photographs of flip charts, sticky notes, or drawings), I will:

- Blur or crop any handwritten names or identifying markings.
- Transcribe the content of sticky notes into a digital summary sheet, so that the original photographs can be stored securely and not shared, while the text-based data can be shared anonymously.

2.5 Audio Data:
Raw audio recordings of interviews will never be shared. They will be stored securely and destroyed after the project retention period, as per my ethics approval. Only the anonymised written transcripts will be prepared for future access.

Stage 3: Preparing the Final Dataset for Future Access

Once anonymisation is complete, I will prepare a safeguarded dataset specifically for future researchers, in line with the consent given by participants.

3.1 Creating a "Sharing-Ready" Dataset:
I will create a clean, well-documented dataset containing:

- Anonymised interview transcripts.
- Anonymised workshop summaries.
- A data dictionary (a separate document explaining the structure of the dataset, the Participant ID system, and any abbreviations used).

3.3 Excluding Identifiable Audio and Visual Data:
I will not share raw audio recordings, video footage, or identifiable photographs, as these cannot be sufficiently anonymised. These will be stored securely and destroyed after the project retention period.

Stage 4: Participant Withdrawal and Future Data

The Consent Form states: "I understand that my participation is voluntary and that I can withdraw from the study at any time without giving a reason. If I choose to withdraw from the study, I understand the researcher will use the information already collected. But no further information will be collected and no further research activities will take place with me."

I will make it explicit during the consent process—and reinforce in the Participant Information Sheet—that if a participant withdraws after anonymisation and deposit, their data cannot be retrieved from the repository. This is a standard limitation of anonymised data sharing and will be clearly communicated before participants tick the future storage box.

Copyright and intellectual property ownership

State who will own the copyright and IPR of any new data that you will generate.

The copyright and intellectual property rights in the new data generated by this research will be owned by the principle investigator/PhD Researcher. This is in accordance with the University's Intellectual Property Policy.

Responsibilities

Outline responsibilities for data management within research teams at all partner institutions

The University of Bradford, and BDCT operate to high standards in respect of the security of data and the research environment. As highlighted above, both are registered (now termed 'notification') under the Data Protection Act 2018 and compliant with all obligations. Furthermore, staff are required to complete mandatory training in GDPR which is updated annually.

The data management within this PhD programme (collection, storage or processing of personal data) will be guided by the data security plan. This will detail data security procedures to be applied, list (by name) those who have access rights to respondent confidential data, third party involvement, and requirements for data destruction (where applicable). Plans will be updated throughout the project, ensuring on-going and appropriate security.

To negate the risk of data loss, both the University of Bradford and BDCT deliver backups across seven days. Monthly backup copies are created from the last "full" backup in a calendar month period. All backup medias are encrypted and are stored securely on a site other than the one where the server it relates to is located.

Both organisations are experienced in mitigating the risk of data security breach to protect against disclosure of personal or sensitive data. In the unlikely event of a breach to our data security procedures, this will be immediately raised by the two leads (Cooper, University of Bradford; Van der Gught, BDCT) as an Information Security Incident. Incidents will be written up, reviewed by the PhD student (Uddin) and, the wider supervision team (Sah and Windle) and proposed corrective actions will be agreed with the governance departments in each organisation. This will include amendments to the data security plan (as necessary).

Preparation of data for sharing and archiving

Are the plans for preparing and documenting data for sharing and archiving with the UK Data Service appropriate?

This is a PhD project and given the costs and time necessary to appropriately archive the qualitative data, this will not be carried out at this time.

Is there evidence that data will be well documented during research to provide highquality contextual information and/or structured metadata for secondary users?

As we have highlighted throughout, this is a funded PhD project (White Rose ESRC). We have detailed (see section Management and curation of data) the processes for coding and analysing the qualitative data as well as the quality assurance process undertaken by the wider supervision team. As we have decided it is not possible to archive the small qualitative data sample owing to cost and time, structured metadata will not be available.