Plan Overview

A Data Management Plan created using DMPonline

Title: Sea-View: Seeking Empowerment in Alzheimer's disease and other dementia's- the value of coastal assets.

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Project abstract:

This project investigates the barriers and facilitators to timely diagnosis and care in coastal communities, examining how geographical context interacts with health service organisations, professional practice and lived experience. The study adopts a sequential mixed-methods design comprising three stages: a systematic review (stage 1), secondary data analysis of existing datasets (stage 2), and a qualitative Comparative Case Study (stage 3), involving interviews with key stakeholders and people affected by dementia.

The research will generate and integrate qualitative and quantitative data, including sensitive health and demographic information. Secondary datasets will be accessed and analysed in accordance with data provider agreements. Primary qualitative data will be audio-recorded, transcribed, pseudonymised and securely stored. All data will be managed in line with UK GDPR, the Data Protection Act 2018 and university governance policies.

The study responds to a critical gap in the literature, where coastal communities are frequently poorly defined, or aggregated with rural and urban populations, obscuring the distinct challenges associated with the coastal geography, infrastructure and service provision. Through careful data management and governance, the project aims to generate nuanced, context-sensitive evidence understanding to inform clinicians, service planners and policy makers in developing more accessible and responsive healthcare pathways

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Sea-View: Seeking Empowerment in Alzheimer's disease and other dementia's- the value of coastal assets.

Data Collection

What data will you collect or create?

This is a mixed-methods PhD programme comprising 3 stages: a systematic review (Stage 1), secondary data analysis (Stage 2), and a qualitative Comparative Multiple Case Study (Stage 3).

Study 1: citation data will be extracted from electronic databases and will be stored on the University of Plymouth OneDrive, managed using citation software Zotero/Mendeley (.ris,4000kb). Included studies will be downloaded (.pdf 50mb), with extracted charting data in Word and Excel (.docx/.xlsx<500kb).

Study 2: Secondary anonymised quantitative data related to accessing dementia diagnosis and support will be accessed from a relevant existing database (TBC). data accessed may include demographics (age, gender, ethnicity, education, etc.)., contextual information (e.g. geographic setting), and healthcare access outcomes (e.g. time to diagnosis, frequency accessing support). Data accessed will be in line with the restrictions and governance of those that own the datasets. Any data accessed will be password protected and encrypted on the University of Plymouth OneDrive and will be analysed using SPSS.

Study 3: up to 120 audio records (.mp3s, typically 20-100mb, max 500mb will be captured during interviews. Audio recordings transcribed and anonymised (.doc/<1mb). Demographic information (e.g. geographic location, age, gender) will be collected separately and digitised (.pdf, approx.100mb) before being entered into an SPSS file (.sav, <5mb). Personal identifiable data (e.g. name and address) will be collected purely for contact purposes and only stored separately within and encrypted password excel file (.xlsx, <1mb).

How will the data be collected or created?

Stage 1: Data extracted from included studies entered onto pre-piloted charted templates (Word/Excel,. doc or .xls <500kb). Data managed locally on University of Plymouth systems.

Stage 2: Data received through secure and approved channels, in line with the ethics and governance of the dataset holder.

Stage 3: Interviews will be audio-recorded on an encrypted digital audio recorder (mp3, <20GB) and transcribed verbatim (anonymising when needed) using University approved software (e.g. Nvivo). Data analysis will involve inductive and deductive coding and divergent themes across the case (Word/Excel, .doc or .xls <1mb). Audio files and transcriptions will be stored on password protected files on OneDrive

Documentation and Metadata

What documentation and metadata will accompany the data?

Stage 1: The systematic review protocol (.pdf)

Stage 2: Variables dictionaries (e.g., .csv, .pdf), SPSS syntax (.sps) and analysis outputs (.spv).

Stage 3:

Interview guides

Consent forms and analytical memos (undecided and will be informed as the research progresses).

Nvivo project files will be used for coding and theme development (.nvp), and

An audit trail describing methodological analytical decisions (.docx).

Ethics and Legal Compliance

How will you manage any ethical issues?

Ethical Approval:

Stage 1: Uses only published literature. No ethical approval required. All primary ethical approvals rest with the original study authors. Extracted data are study-level and non-identifiable.

Stage 2: Any dataset accessed will have already received ethical approval and informed consent for research use. Any dataset will be anonymised. The University of Plymouth Research Ethics Committee will be consulted about whether additional ethics approvals are needed to use the data set.

Study 3: Approvals will be obtained through the University of Plymouth Research Ethics Committee and the Health Research Authority (HRA). Information sheets and questionnaires will be developed alongside the recommended PPIE. Participants and/or their consultees can withdraw at any stage without consequence; this will be included in the information sheets on how to achieve this. Identifiable data will be anonymised with an identification number and stored separately from the research data. This data will later be destroyed once digitised and stored securely, adhering to the University of Plymouth Research Data Policy.

Capacity, Consent and Safeguarding:

Stage 3: Some of the participants may have a diagnosis of dementia and could experience a fluctuating capacity. Capacity will be assessed in accordance with the Mental Capacity Act 2005 (sections 30-34). Where capacity will be assumed unless informed or evidenced otherwise. Should the participant lose capacity or the consultee feel they are unable to continue, they can withdraw at any time without consequence.

Any safeguarding disclosed during the interviews will be managed in line with the University of Plymouth safeguarding policies. Safeguarding procedures will follow the Safeguarding Vulnerable Groups Act (2006) and the Protection of Freedoms Act (2012).

GDPR and Data Protection:

This project involves special category personal data (e.g. health and location). In compliance General Data Protection Regulations (GDPR and the Data Protection Act (2018), only data pertinent to the study will be collected with the following rationale for conducting the information gathering:

i) Lawful basis for processing (GDPR Article 6(1)(e)): Processing is necessary for the performance of a task carried out in the public interest, namely academic research.

ii) Special category condition (GDPR Article 9(2)(j)): Processing is necessary for scientific research purposes with appropriate safeguards in place.

Data processing will comply with the UK GDPR, Data Protection Act 2018 and the University of Plymouth data protection policies. The University of Plymouth will act as data controller, and the Data custodian will be the Principal Investigator (PI).

How will you manage copyright and Intellectual Property Rights (IPR) issues?

Consideration will be given to the management of intellectual property and personal identifiers will be removed and each participant will be allocated a unique personal identifier, ensuring anonymisation and confidentiality, in accordance with the University of Plymouth code for good research practice. Data sources for Stage 1 and Stage 2 and any other intellectual content will be properly cited in accordance with standard academic conventions. The originality of all research outputs will be maintained using plagiarism detection tools (e.g. Turnitin). Contributions, collaborations or co-authorship will be clearly defined and acknowledged and will not contravene the IPR of others.

In accordance with University of Plymouth policy, the University will retain ownership of the IPR. Anonymised data may be available via the University repository (PURE), subject to appropriate licensing agreements and ethical approval. Access to restricted data will be managed by the Director of Studies for the PhD student in line with the University of Plymouth information governance and research policies. Data will be retained for a minimum of 10 years following the project completion, along with doi and recommended citation.

Storage and Backup

How will the data be stored and backed up during the research?

All data collected will be systematically stored with uniform version control and standardised file naming conventions on the University's secure Microsoft OneDrive system. Data may be temporarily stored on University of Plymouth password-protected IT systems for pragmatic reasons (e.g. audio device, university laptop) and then transferred to OneDrive in an encrypted format. Access will be password-protected and restricted to the PI and supervisory team. Data will automatically be regularly updated on OneDrive and supported by the University of Plymouth IT systems.

Stage 3: Interview transcripts will be uploaded to Nivvo for systematic coding and analysis, and all digital files will be stored on the University of Plymouth, secure OneDrive, protected by institutional encryption. Any hard copies of data (e.g. demographic data, consent forms) will be scanned and stored on the OneDrive system. These will be treated as the original copies and the original paperwork will be securely destroyed. Consideration will be given to Audio files these will only be accessed by the research team and to be stored in Free Lossless Audio Codec (FLAC) format or MP3. After the transcripts have been anonymised and checked for accuracy, the original audio files will be deleted.

In the event of data loss or breach, the data security procedure of the University of Plymouth will be followed.

How will you manage access and security?

All data will be managed with confidentiality at all times during the study, with data only being accessible to the research team, with further reduced access to identifiable data or location (e.g. PI and DOS). Personal identifiable data will be anonymised with personal identifiers and stored separately from the research data and stored in an encrypted format. The PhD student (PI) will manage access and be responsible for security with oversight of the supervisory team. In accordance with the UK Data Service Guidance, the use of secure networks and the University of Plymouth VPN authenticator will be used for processing and storage. Maintaining security will be a priority throughout the project and after completion. Should a data breach be encountered, it will be reported to the Data Protection Offices and the University of Plymouth data breach process will be followed.

Selection and Preservation

Which data are of long-term value and should be retained, shared, and/or preserved?

Data collected from all stages has long-term potential value. Stage 2 gathered data and Stage 3 anonymised data of comparison studies, will inform related policies and interventions. Identifiable data (e.g. consent forms, contact details, audio recordings) will be stored securely during the PhD and then destroyed on completion of the PhD.

The anonymised research data (e.g. transcripts, coded datasets) will be retained by the University. The research team will appraise selected research data for long-term preservation and data stewardship. Identifiable data (e.g. consent forms, contact details, audio recording) will be stored securely during the PhD and then destroyed on completion of the PhD.

What is the long-term preservation plan for the dataset?

In accordance with the University of Plymouth Research Data Policy, data will be retained for a minimum of 10 years from the collection of data and uploaded to the University of Plymouth repository, ensuring management and long-term storage. All shared datasets to include metadata documentation and protocols. Conditions of access will be proportional to any anonymised data required, and access will be provided by the PI and the research team in accordance with the University of Plymouth Research Data Policy.

Data Sharing

How will you share the data?

The research team will look to publish findings and attend conferences to share knowledge. The findings will be shared with other professional groups and relevant research networking groups to facilitate further research and collaborative work. Further areas for dissemination can be identified through the funders, stakeholders and PPIE networks.

The University of Plymouth repository can be used for publishing anonymous data with accompanying metadata and documentation, with proportional access to information controls in accordance with the University of Plymouth Policy.

Are any restrictions on data sharing required?

Because of the sensitive nature of the data and the small geographical populations, raw, qualitative data will not be made publicly available. Proportional access controls will be applied to any future data sharing and will require formal approval from the University of Plymouth. Access to anonymised data will be restricted to the PI and supervisory team, and to ensure transparency, the metadata and methodological documentation can be shared.

This approach is consistent with ethical and legal obligations for dementia research.

Responsibilities and Resources

Who will be responsible for data management?

The PhD student will be responsible for the day-to-day management and implementation of the data management plan and data security. Responsibility for quality assurance, oversight and review of the data management plan at regular intervals will be with the supervisory team. The University of Plymouth will act as the data controller and provide long-term secure data storage and governance. They will maintain storage of the archived data for future sharing, and the University of Plymouth IT support team will support with any technical infrastructure.

What resources will you require to deliver your plan?

The required resources for this project will include a secure, adequate storage infrastructure. Access to appropriate data management and analysis software (e.g. SPSS and Nvivo) and IT support. Additional storage is not anticipated; the research team will budget for additional allocations. Data collection resources include a digital audio recorder for interviews and limited printing and postage of questionnaires, and sufficient OneDrive storage (resources are covered by the University of Plymouth).