Plan Overview

A Data Management Plan created using DMPonline

Title: How and Why is Western Herbal Medicine used for chronic fatigue?

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Template: DU Standard DMP Template V2a

Project abstract:

The emergence of post-COVID Syndrome (PCS) in the wake of the 2020 pandemic brought the issue of (bio)medically-unexplained, chronic fatigue back into the forefront of healthcare research and public consciousness. PCS joins a roster of poorly-understood syndromes involving chronic (i.e. lasting more than 3 months) and debilitating fatigue that includes Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) (Snair et al. 2024). The small amount of recent epidemiological data available for these conditions varies considerably, but sources agree on the considerable personal and social impacts they have (NICE 2021b, Haffke et al. 2022, The ME Association 2024). Individuals with these conditions suffer from stigma associated with conditions that resist biomedical understanding and cause physical limitations (Cortes Rivera et al. 2019). Treatments are limited, leading some people in the UK to seek alternatives in the form of Western Herbal Medicine (WHM), a practice that entails the administration of medicinal plants (Pilkington et al. 2020).

Current research into WHM use is ethnographically 'thin' and lacks the level of detail found in studies of alternatives to biomedicine in other settings around the world. No ethnobotanical surveys nor systematic records of its use have been published. As its practitioners grapple with the role that biomedicine plays in their practice, questions concerning the efficacy of WHM and how to evaluate it remain unanswered.

The main aim of this project is to understand how and why WHM is used for chronic fatigue (CF). To this end, I will combine methods from ethnobotany to survey the use of medicinal plant species with participant observation and interviews with both herbalists and their patients to provide a rich context for analysis. Following this introduction, I will outline biomedical and anthropological research into chronic fatigue, before reviewing the main themes that anthropologists have developed regarding complementary and alternative medicine (CAM), WHM, and the efficacy of non-biomedical healing systems. Principally, this project seeks to deepen our understanding of CF, address the pressing need to explore alternative approaches to its management, and contribute to the question of why WHM use remains widespread. Lying at the interface of medical anthropology and ethnobotany, this project answers the call from Waldstein and Adams (2006) to pursue research that leads to a more sophisticated understanding of the efficacy of ethnomedical approaches that employ medicinal plants.

ID: 178846

Start date: 01-07-2025

End date: 01-10-2029

Last modified: 27-05-2025

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How and Why is Western Herbal Medicine used for chronic fatigue?

Data collection

What data will you collect or create? Please include computer code if you write code.

Survey data

- names of participants
- postcode of practice
- self-identified answers to the following:
 - to what extent are you confident in dealing with chronic fatigue (1-5 Likert scale)
 - how many cases of chronic fatigue have you treated (number)
 - to what extent do you use the biomedical model in your practice (1-5 Likert scale)

semi-structured Interview data

- thoughts and opinions on practice (qualitative)
- biographical data
- names and quantities of medicinal plants used
- case histories (including anonymised information about the symptoms suffered by the patient and their age at the time of treatment)

unstructured interview data

- experiences with chronic fatigue including how it affects them
- experiences of using herbal medicine

How will the data be collected or created?

A survey in the form of an online form

In-person or online ethnographic interviews, recorded using voice recording software then transcribed

How much data do you expect to produce?

difficult to predict - total sample size will probably not exceed 25 people, so I am not expecting to generate more than 20GB.

Documentation and metadata

What documentation and metadata will accompany the data?

The data will be accompanied by the data management plan and data access statements noting any restrictions e.g. ethical / commercial. Metadata will include; Title, Description, Keywords, Publisher, Publication Year, Date (publically) available, Creators, creation date, storage location and DOI.

Ethics and legal compliance

How will you manage any ethical issues?

Prior to any work beginning the project will go through the University's Ethical review and approval process as described in the <u>Ethics Policy</u>. Any high-risk areas (including data-related) will be highlighted and appropriate management and mitigation approaches put into place. It is not foreseen that any further ethical issues will arise within the project, however if they do, appropriate advice will be sought from the departmental ethics convenor and the University's Research Data Management service.

This project involves collecting personal (health) data, i.e. experiences of symptoms relating to chronic fatigue (duration, severity, impact), use of herbal remedies, age when using these remedies, gender, biographical details relating to their symptoms. Before any participants are enrolled in this study, they will receive a full explanation of the project (participant information sheet and privacy notice) and provide written consent, recorded in the consent form. Each participant will be given an alias, and all data will be stored under this alias from the beginning. The condition for processing this special category data is Archiving, research and statistics. Any data pertaining to participants will be deleted entirely if they request this.

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

Broad IPR positions will be addressed within the project set-up documentation; Contracts, collaboration agreements etc. In the eventuality that the project produces commercially valuable IP then this will be handled in accordance with the agreed position and the University's <u>Intellectual Property Policy</u>

Short-term storage and management of active research data

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

All data will be stored on a password-protected computer in password-protected files, and in the cloud storage provided by Durham University.

How will you manage access and security?

Only I will have access to the data. I will not transport this data outside the UK. These arrangements comply with requirements.

Data deposit and long-term preservation

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

Not applicable.

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

Anonymised or non-sensitive supporting research data will be retained for validation / re-use purposes in line with the University's <u>Research Data Management Policy</u> for 10 years from the date of publication or end of the project if there are no publications.

Supporting research data will be preserved by deposit in the University's Research Data Repository.

Data sharing

How will you share the supporting research data and / or code at the end of the funding period?

Supporting research data or code will be published in the University's Research Data Repository.

Are any restrictions on data sharing required?

None are expected for non-personal data. Data will be shared under a CC-BY-NC licence which will require attribution to both funder and Durham University.

Responsibilities and resources

Who will be responsible for data management?

I, Nicholas Edwards, will be responsible for data management.

As stated in the Research Data Management (RDM) policy, the principal investigator has overall responsibility for research data management. Support is available through the <u>RDM Service</u>. It is not expected at this point that any of the PI's responsibilities will be devolved to any other members of the project team however if they are, then the data management plan will be updated to detail this.

What resources will you require to deliver your plan?

No additional resources are required beyond those already made available by the University.

Planned Research Outputs

Dissertation - "How and Why is Western Herbal Medicine used for Chronic Fatigue"

Planned research output details										
Title	DOI	Туре	Release date	Access level	Repository(ies)	File size	License	Metadata standard(s)	May contain sensitive data?	May contain PII?
How and Why is Western Herbal Medicine used for Ch		Dissertation	Unspecified	Open	None specified			None specified	No	No