Plan Overview

A Data Management Plan created using DMPonline

Title: House of Memories-Brazil: An International Model for Museum-led Dementia Care

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Funder: Arts and Humanities Research Council (AHRC)

Template: AHRC Data Management Plan

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Project abstract:
House of Memories is a dementia awareness programme pioneered by National Museums Liverpool (NML) in the UK, with repeated investment from the Department of Health, and other commissions from national agencies including Health Education England. Launched in 2012, the initiative is unprecedented in its scale, reach and impact as a cultural intervention in health and social care. The proposed research centres on an in-depth exploration and evaluation of the transferability of this programme to a non-Anglophone context by co-creating a version for use in Brazil. Multi-disciplinary research by an international team will assess the translatability of culture-led dementia care, establishing evidence-based conclusions that will inform policy on a global scale. A central focus of the research will be to evaluate the mental health benefits for people living with dementia (PLWD) of using audio-visual stimuli in reminiscence activities relating to museum collections. The World Health Organization (WHO) recognises dementia as an increasing threat to global health, with an estimated 35.6 million people currently living with the disease worldwide, a figure set to double by 2030 and triple by 2050. Consequently, care for PLWD is a major global health and development challenge that significantly threatens the welfare of those directly affected in low- and middle-income countries, as well as their caregivers and family members. The WHO Global Plan of Action on the Public Health Response to Dementia 2017-25 advocates the importance of community-based, culture-led interventions. The field of museum studies has paid particular attention, in this context, to the value of museums as community assets in dementia care. Research shows, for example, that museum-based activities have therapeutic value, leading to positive social and cognitive outcomes for PLWD and carers (Goulding, 2013; Windle et al., 2014; Young et al., 2015). The Museu Paulista (MP) of the University of São Paulo (USP) is the oldest public museum in the city of São Paulo and will be the central hub for House of Memories-Brazil. Established in 1895, the MP-USP has a permanent collection of over 450 thousand items from the 16th to the 20th centuries. Since 2001, the MP-USP's education department has developed socially inclusive projects, aimed at ensuring universal access, and offers guided tours for adults and children with multiple disabilities and

disorders. Following MP-USP's re-opening after a substantive phase of capital development, this research will evaluate the mental health benefits for dementia carers of its adoption and embedding of House of Memories-Brazil as a signature social programme, including digital resources, with enhanced audio-visual content, for use in reminiscence work. This project builds on previous research by the PI in modern languages that has explored cultural memory and reminiscence using audio-visual material, translating findings into practical development outcomes for dementia care, mental health and wellbeing in the UK and Brazil. The PI, with members of the research team, will assess the importance of socio-cultural specificities, such as race, ethnicity, religion and class, for the success of culture-led dementia care frameworks translated from other national and linguistic contexts. This research will explore the impact of these specificities on understandings of wellbeing, ageing, dementia, cultural heritage and memory, thus informing and shaping the evolution of the Brazilian version of HoM. The full action research programme will support the development of a multi-disciplinary, cross-sector, international community of practice. Together, we will co-create the full HoM-Brazil programme; consider its impact on participating carers and PLWD, with an emphasis on mental health and wellbeing; and review the efficacy of the development process to inform future professional development in global cultural health and wellbeing practice.

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House of Memories-Brazil: An International Model for Museum-led Dementia Care

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University of Liverpool Required Information

What stage are you at in this project?

- Pre-award

Which faculty do you belong to?

- Humanities and Social Sciences

Do you have, or will you be applying for Ethics approval for your project?

- Yes

Does your project deal with personal or sensitive data as defined under the terms of GDPR?

- Yes

Will you require space on the Active DataStore?

- Yes

How much ADS Space will you require?

- 0.5TB

Will you be depositing your data in an open repository at the conclusion of your project?

- Yes

Which repository will you be using?

- Liverpool Data Catalogue

Data Summary

1. Briefly introduce the types of data the research will create. Why did you decide to use these data types?

The research will create audio files (MP3) and video files (MP4). MP3 audio files are the most convenient way of recording and the most accessible way of accessing data obtained via interviews; MP4 video files are the most convenient way of recording and the most accessible way of accessing data obtained via reminiscence interventions;

Data Collection

2. Give details on the proposed methodologies that will be used to create the data. Advise how the project team selected will be suitable for the data/digital aspects of the work, including details of how the institution's data support teams may need to support the project

The data will be collected during the reminiscence interventions in the UK and Brazil using the My HoM app downloaded to a table computer from the HoM website. PDRA Waldock is experienced in using audio and video recordings in interventions of this kind, including setting up and checking the equipment and saving, naming/version controlling and storing the resulting data. She will consult the University of Liverpool's data support teams where necessary.

On the day of the recording, these digital files will be immediately transferred from the memory cards used in the MP3 audio recorder and MP4 video recorder to the University of Liverpool's password-protected M: drive and the originals will be immediately destroyed. Handwritten notes will be transcribed into Word files on the day the notes are taken on a laptop, and these Word files will then be saved on the UoL password-protected server (M: drive). The original hand written notes and electronic copy on the laptop will then be destroyed immediately.

Data on hard copies resulting from the questionnaire study, and consent forms from the focus groups, will be stored in a locked filing cabinet in a locked room, only accessible through a swipe-card access corridor at the University of Liverpool.

The first generated version of the file, containing the output data, will always be kept. Major subsequent versions will be saved with a higher version number so that the version history can be easily traced.

Our data will be regularly reviewed by the principle and co-investigators of the project. Data (eg

storage; protection; safety) will be a standing agenda item at all project management Executive Board meetings, held every month for the duration of the project.

Short-term Data Storage

3. How will the data be stored in the short term?

Our institution is able to store the data appropriately during the lifecycle of the grant. We will consult with all relevant people and a storage plan will be considered and agreed.

Our institution has considered all the risks, and storage will be in line with the institution's data management policy. Our instution has a Information Security Policy and RDM policy. Please see: https://www.liverpool.ac.uk/media/livacuk/computingservices/regulations/informationsecuritypolicy.pdf

3a What backup will you have in the in-project period to ensure no data is lost?

The University's Active Data Store has a robust backup system. All files saved on the University network drive (M: drive) are automatically backed up. In addition to this, all files considered data files will also be saved into the University's Active Data Store which has a robust backup system. Both the Active Data Store and the University network drive are backed up 3 times in two separate locations.

Long-term Data Storage

4. How the data will be stored in the long term?

The data will be stored for 10 years on the University of Liverpool's data repository, in line with University policy, and will only be re-usable by approved researchers who will be required to ensure that confidentiality is maintained.

We will consider which data will require long-term storage and which not. The selected research data, or a record of restricted research data, which will require long-term storage, will be deposited in an appropriate research data catalogue, this comprising the Liverpool Research Data Catalogue. We will get a DOI for the data or the record that details the data, clarifying what data is restricted and which is not. We intend to make as much data open as possible.

4a. Where have you decided to store it, why is this appropriate?

The University has an appropriate storage system called Liverpool Research Data Catalogue. Please see:
http://datacat.liverpool.ac.uk/

4b. How long will it be stored for and why?

Following RCUK standard practices, our research data wil be retained in an appropriate format and storage facility for a period of at least 10 years.

4c. Costs of storage – why are these appropriate? Costs related to long term storage will be permitted providing these are fully justified and relate to the project Full justification must be provided in Justification of Resources (JoR)

We will outline any relevant costs in the Justification of Resources (JoR).

Data Sharing

5. How the data will be shared and the value it will have to others

Wherever possible we will make available to other researchers and impose as few restrictions as possible so that our findings can be reused and re-applied to other research projects.

5a. How the data will enhance the area and how it could be used in the future?

The data could be used by others conducting research into the use of non-medical interventions in the care of people living with dementia (PLWD), and the effectiveness of reminiscence activities and/or app-based, personalised cultural interventions in improving the mental wellbeing of PLWD.

5b. Releasing the data – advise when you will be releasing and justify if not releasing in line with AHRC guidelines of a minimum of three years. If the data will have value to different audiences, how these groups will be informed?

At the end of our research, we will have a plan in place to share the research data as soon as possible and in line with the AHRC's guidelines (minimum of 3 years).
Whatever data we can share openly, we will deposit in an open data repository, such as the Liverpool Research Data Catalogue. We will obtain DOIs for data sets and collect sufficient metadata so as to help make the dataset discoverable.

5c. Will the data need to be updated? Include future plans for updating if this is the case.

We do not plan to update our data, since it is project-specific.

5d. Will the data be open or will you charge for it? Justify if charging to access the data

As much data as possible will be open. We have no plans to charge for it.

5e. Financial requirements of sharing – include full justification in the JoR

We will outline any relevant costs in the Justification of Resources (JoR).

Ethical and Legal Considerations

6a. Any legal and ethical considerations of collecting the data

The University of Liverpool has a robust research ethics approval process and a dedicated Research Ethics team. We will consult with all relevant parties. Since the research involves human participants we will seek ethical approval before we commence the project. As we are working with an NHS Trust and conducting research on NHS patients on NHS sites, we will also seek Health Research Authority approval via the relevant research ethics committee before we commence the project.

6b. Legal and ethical considerations around releasing and storing the data – anonymity of any participants, following promises made to participants

All our data collection, creation, storage and dissemination will conform to the University of Liverpool's ethical policy. Accordingly, participant information sheets and consent forms will be provided in Portuguese translation for Brazilian participants. These documents (in English for UK participants/ in Portuguese for Brazilian participants) will be read aloud where necessary to address problems of literacy/ physical impairments to sight, and in the case of PLWD/individuals unable to give informed consent, the nominated consent-giver will be required to read and sign this material.

Data Anonymization and Security

To ensure anonymisation at data collection point, study participants will be assigned a unique random ID. The files linking personal data to this random ID will be stored according to university policy on the University M-Drive.