Plan Overview

A Data Management Plan created using DMPonline

Title: Latin America Network for Primary Palliative Care

Creator: David Fearon

Principal Investigator: David Fearon

Project Administrator: Micol Salvetto

Contributor: Liz Grant, Marie Fallon

Affiliation: University of Edinburgh

Template: UoE Default DMP template for Research Staff

ORCID iD: 0000-0002-0295-3118

Project abstract:

Palliative care is the holistic care for people experiencing health related suffering related to life limiting conditions. There has been much improvement in the provision of palliative care across Latin America, however, there remains room for improvement in its availability. Promoting palliative care in primary care contexts is an important step towards improving access to palliative care. It has been proposed that this approach is defined as 'Primary Palliative Care' in contrast to palliative care provided by specialists.

This research is being undertaken by a team from the University of Edinburgh, Scotland, and Pallium Latin America, a non-profit palliative care association based in Argentina with a focus on promoting palliative care across Latin America.

To better support the provision of palliative care in primary care in Latin America there is a need to

- understand how this looks like in Latin American contexts
- explore and describe the models of how palliative care is delivered within primary care
- understand the barriers and facilitators to primary palliative care
- investigate how primary palliative care be more integrated in Latin American health care services

It is also hoped that this research project will build capacity of Latin American primary healthcare workers to advocate for and provide palliative care to their patients, and to construct educational and developmental resources for other healthcare workers to also provide the same.

A Participatory Action Research (PAR) framework will be employed over 24 months, combining both qualitative and quantitative components:

a. Case-based discussion meetings (around 12) and post-meeting questionnaire

b. Individual semi-structured interviews (20-30)

c. Co-researcher focus group discussions (3)

d. Survey

e. Documentary analysis

ID: 195139

Start date: 09-03-2026

End date: 09-03-2028

Last modified: 22-01-2026

Copyright information:

Latin America Network for Primary Palliative Care

Administrative Information

1) School or Institute

- Other (please state)

Edinburgh Medical School and Usher Institute

2) Project start date

2026-03-09

3) Project end date

2028-03-09

4) Project funder or sponsor.

No funder.
ACCORD sponsor

Data Collection

5) Data Collection

Data Information

For each participating co-researcher, a minimum level of personal data (detailed above) will be collected. The research team will only store these details for the duration of the study (24 months). All contact details will be deleted at the end of the study. All participants will be assigned a unique ID. An excel document linking IDs to participants will be kept in an encrypted folder within DataStore. All anonymised documents will be saved under these unique IDs.

Digital consent forms will include co-researchers names. These will be completed using AdobeSign or by emailing a scanned a signed copy to the research project email address. They will be securely stored under in a compiled folder of consent forms so as to not provide a link between ID and name.

This research will incorporate mixed methods of data collection. These are discussed in more detail below

a. Case-based discussion meetings (around 12) and post-meeting questionnaire

b. Individual semi-structured interviews (20-30)

c. Co-researcher focus group discussions (3)

d. Survey

e. Documentary analysis

a. Case-based discussion meetings (and post-meeting questionnaire)

The project will revolve around a series of online case-based discussion meetings with a group of primary care health workers, primarily primary care doctors with an interest in palliative care. These will occur every 6 to 8 weeks, and last around 90 minutes. Each meeting will consist of:

1. 5 minutes introduction to meeting
2. 15-20 minutes presentation of a case which has been prepared by a group member(s) according to a template (appendix 1). This will cover a real experience of caring for a patient and/or family affected by health-related suffering and a life limiting condition. No identifiable data will be shared in the template or in the discussion. Data will cover the demographic information, clinical scenario and context and the questions or challenges that the co-researcher(s) would like the group to discuss. A series of slides of the case will be shared to the group.
3. 40 minutes, the group will ask the presenter(s) questions and discuss the case and the challenges and facilitators.
4. 10-15 minutes where the presenter(s) will have the opportunity to ask questions to the group members
5. 10-minute closing with completion of the case template questions.

At the closing of the meeting, a brief online survey will be made available to all participants (Appendix). The survey will be constructed using University of Edinburgh REDCAP software, which provides data security meeting the university’s requirements. This will cover short reflections, perceived barriers and facilitators to implementing any changes in their own practice and offer the opportunity for additional input into the research. This will promote equity and diversity within the research, as not all co-researchers will be equally confident in expressing themselves in the group discussion.

These meetings will be hosted by Pallium LA and chaired by a Latin American, family medicine doctor co-researcher with experience of chairing such meetings. Meetings will be held primarily in Spanish, with translation into/from English when required for member(s). In line with all such Pallium LA’s online events, meetings will be hosted on their organisation’s Zoom account to optimise attendance across Latin America. Co-researchers’ experiences of online meetings and educational events have shown that zoom is the most reliable and accessible platform in the region. Meetings will be recorded via a data secure method in accordance with the University of Edinburgh’s information security protocol (see DPIA), transcribed verbatim, and translated into English and exported into NVivo for qualitative data analysis.

b. Individual semi-structured interviews

Interviews will be undertaken with co-researchers over the duration of the project. Interviews will mainly be online, with face-to-face interviews where the opportunity arises, such as interviewer and interviewees’ joint attendance at international conferences. Interviews will be hosted on MS Teams at mutually convenient times. They will last 45 to 60 minutes and cover experiences of providing palliative care in their primary care context. This will be an opportunity to explore at more depth and more personal issues, challenges, facilitators and barriers which have arisen throughout the research, and understand how these apply directly to the co-researchers’ specific context. Interviews will be held in either Spanish or English as per the interviewee’s preference. They will be audio-recorded, transcribed verbatim and translated if required into English for data analysis. The interview schedule is presented in Appendix 2

c. Co-researcher focus group discussions

In addition to the case-based discussion meetings, three to five focus group discussions will also be undertaken over the duration of the project. These will differ from the case-based meetings, in that their purpose will be to allow specified time to discuss the research progress and ongoing reflections on the aims and objectives of the research. Topics for discussion will include

- provisional emerging themes from the data collection and analysis (member checking)
- revisiting the emerging Latin American contextualised definition of primary palliative care
- the empowerment of LA primary care healthcare workers to undertaken palliative care, including implementation facilitators and barriers
- direction of the research

The discussions will be chaired by the principal investigator (DF), with translation provided as required. Meeting minutes and outcome points will be produced and distributed to the co-researchers.

d. Survey

Co-researchers will be asked to complete an online survey at three points over the research duration. The survey will be constructed using University of Edinburgh REDCAP software, which will also provide data security. It will cover the demographic details of the co-researchers' clinical context in addition to their views on PPC in their region and country. It will also cover workload, types of diagnoses seen, support available within community, primary, secondary and tertiary care, access to key palliative care medications, and links to any policy documents.

e. **Documentary analysis**

Any relevant documents highlighted by co-researchers as being relevant to primary palliative care in their clinical context, region, country and continent will be analysed. This will create an understanding of the macro-environmental context for the development of the primary palliative care.

In summary, this project will produce the following data:

- Audio and video recordings of online case-based discussion meetings
- Transcriptions and translations of the online meetings
- Case reports for presentation
- Powerpoint slides used for the case-based discussion meetings
- Audio recordings of individual interviews
- Audio and video recordings of online focus group discussions
- Survey data, both raw data and analysed, on RedCap software
- NVivo data files for qualitative data analysis
- Publication and dissemination materials

Documentation & Metadata

6) Documentation & Metadata

ReadMe files will be created for each set of data collected as described in section 5. These will contain the following information

1. Title for the dataset
2. Name/institution/address/email information for
    - Principal investigator (or person responsible for collecting the data)

    - Associate or co-investigators
    - Contact person for questions
3. Date of data collection
4. Information about geographic location of data collection
5. Keywords used to describe the data topic
6. Language information
7. A short description of what data it contains
8. Date that the file was created
9. Links to publications that cite or use the data
10. Description of methods for data collection
11. Description of methods used for data analysis

Ethics & Legal Compliance

7) Ethics & Legal Compliance

The project will be submitted to ACCORD research governance office and the Edinburgh Medical School Ethics Committee (EMREC) for their review and approval.

All data will be pseudonymised at the point of transcription. Individuals will be allocated a pseudonym. A key to this code will be stored in a separate MS Excel document on an encrypted container stored within DataStore.

Participants/co-researchers will be invited to upload relevant clinical case reports using a provided template on a UoE project Sharepoint site. Uploaded cases will be used in the case-based discussion meetings. The case report will be downloaded from UoE SharePoint and uploaded and stored on DataStore, after confirmation that no patient identifiable data is present, and pseudonymization of the submitting co-researcher(s).

Case-based discussion meetings will be hosted on our partner's (Pallium Latin America) zoom account. The meetings will be recorded on the PI’s computer via screen sharing the zoom meeting onto a UoE account MS Teams meeting created for this purpose. Each zoom case-based discussion meeting will be transcribed and recorded using a University of Edinburgh MS Teams account. Recordings will be uploaded from MS teams to DataStore. The audio-video recording will be deleted once the transcription and translation has been verified. Recordings will be transcribed and translated through university of Edinburgh approved services. Pseudonymised transcripts will be exported into Nvivo for qualitative data analysis.

All surveys will be recorded using the REDCAP software. Survey data will be stored securely and analysed within the REDCAP servers in accordance with the UoE information security guidelines. All co-researchers will be invited to complete a short survey at the end of each meeting. This is hosted on REDCAP and will be accessible via an internet link via email or from the meeting chat function. It can be completed from the co-researchers’ personal computer or their mobile device. REDCAP allows secured storage and analysis of data.

Online interviews and focus group discussions will be undertaken with MS Teams. Face to face interviews will be recorded using MS Teams on the PI’s laptop, and uploaded to DataStore. Interviews will be audio-recorded and transcribed verbatim, and translated into English if required. Transcriptions will be stored on UoE DataStore.

Translation and transcription will be carried out through the University of Edinburgh's secure Electronic Transcription and Translation of Audio (ETTA) service.

Storage and Back-Up

8) Where will your data be stored and backed-up during the project?

All data will be stored within the UoE DataStore facility. The pseudonymisation key will be stored within an encrypted container with the DataStore.
Once completed, data will be moved to UoE DataVault facility until it is deleted

Selection and Preservation

9) Where will the data be stored long-term?

Data will be stored in DataVault and then deleted five years after completion of the research

10) Which data will be retained long-term?

None

Data Sharing

11) Will the data produced from your project be made open?

- No: go to 13

13) Please explain why your data cannot be made open.

The output from the research will be made public but the raw data will not be made open. This is due to the sensitivities of participatory action research and the qualitative nature of the research. It was felt that opening of the data to others may risk the openness of health care professionals to share their experiences.

Responsibilities & Resources

14) Who will be responsible for the research data management of this project?

The PI David Fearon, d.fearon@ed.ac.uk

15) Will you require any training or resources to properly manage your research data throughout this project?

There is limited funding required for the REDCAP survey option.
The team will have all completed the UoE data protection and information security training