NeDiPal
Negotiating Digital Technology in Palliative Home Care

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EUROPEAN COMMISSION (HORIZON): HORIZON EUROPE DMP + - FULL DMP

VERSION INFORMATION

101202730

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Version 1.0 – 22.06.2026

1. DATA SUMMARY

1.1 Will you re-use any existing data and what will you re-use it for?

Existing data will not be reused.

1.2 What types and formats of data and other research outputs will the project generate or re-use?

#	DATA TYPE	FORMAT	NEW/REUSED
1	Metadata	XML, pdf	New
2	Interviews	WAV, FLAC	New
3	Transcripts	Text	New
4	Observation records	Text (handwritten, files)	New
5	Project website	HTML, CSS	New
6	Social Media	Text, Image	New
7	Reports	Text	New

1.3 What is the purpose of the data generation or re-use and its relation to the objectives of the project?

1 is needed for the project to be partly compliant with the FAIR Principles.
2 is the audio file generated during the recording of the interviews.
3 are the transcribed audio files and are needed for data analysis.
4 observation records are needed for data analysis.
5 and 6 are needed for the communication and dissemination.
7 is required by the funding program.

1.4 What is the expected size of the data that you intend to generate or re-use?

1 and 3-7 are very lightweight and certainly below 1 GB.
The WAV files for 2 will be 44.1 kHz, 16-bit, stereo which results in a file size of around 600 MB per interview. Since 50 interviews are expected, the total size would be around 30 GB. With FLAC files, the size would be around 15 GB.

1.5 What is the origin/provenance of the data, either generated or re-used?

All the data will be produced by the researcher and, in the case of 2 and 4, with the help of participants and expert collaborators involved in the research.

1.6 To whom might your data be useful ('data utility'), outside your project?

1 will be interesting for researchers in the field wanting to reproduce the research results. It will be also interesting to readers of scientific publications of the project, as they can get more insights into the data and the project.
2 is only useful for research in that it is the basis for the transcripts. It will not be used outside the project.
3 and 4 is mainly useful for the data analysis within the project. As small parts of them will be cited in publications, it is also useful for project publications and thereby interesting for potential readers of these publications.
5-7 is useful for other researchers interested in palliative care, but also for the general public.

2.1 FAIR DATA: MAKING DATA FINDABLE, INCLUDING PROVISIONS FOR METADATA

2.1.1 Will data and other research outputs be identified by a persistent identifier?

- Yes: describe below

1 will be made available via ZENODO and will receive a DOI.
5 has a URL as a persistent identifier.
6 uses the websites URL as a permanent handle.

2.1.2 Will rich metadata be provided to allow discovery?

What metadata will be created?
What disciplinary or general standards will be followed?
In case metadata standards do not exist in your discipline, please outline what type of metadata will be created and how.

Metadata for interviews and observation records will be created (data type 1). Study material such as recruiting information or promotional materials will also be part of the metadata repository. Additionally, material for reproducing the study such as interview guides will be part of the metadata repository.

2.1.3 Will search keywords be provided in the metadata to optimize the possibility for discovery and then potential re-use?

- Yes: Search keywords will be provided with the publication of the metadata repository.

2.1.4 Will metadata be offered in such a way that it can be harvested and indexed?

- Yes: describe below

Yes, by using a standardized vocabulary as far as possible, the metadata should be easily machine readable and could therefore be harvested and indexed. Some parts of the metadata such as study material might not be machine readable.

2.2 FAIR DATA: MAKING DATA ACCESSIBLE

2.2.1 Will the data and other research outputs be deposited in a trusted repository?

- Yes: describe below

All data from data type 1 will be publicly available and uploaded to ZENODO.

Data type 2, 3 and 4 have to remain strictly confidential. During the project duration, the confidential data will be stored in a separate VUB Pixiu bucket. The buckets name is “brispo-tor-nedipal”. Only the principal investigator has access to this bucket.

For long term storage of the pseudonymized data, the VUB Institutional Data Repository will be used.

2.2.2 Have you explored appropriate arrangements with the identified repository where your data and other research outputs will be deposited?

- No: There are no special arrangements required.

2.2.3 Does the repository ensure that the data and other research outputs are assigned an identifier? Will the repository resolve the identifier to a digital object?

ZENODO provides DOIs to appropriately identify digital objects.

2.2.4 Will all data and other research outputs be made openly available?

- No, certain datasets cannot be shared openly for the following reasons:

As described under 2.2.1, data types 2, 3 and 4 cannot be made publicly available. Palliative care patients and informal caregivers are vulnerable groups. They need special protection, also of their personal data. To protect their anonymity, their data cannot be shared publicly. Regarding the interviews with palliative care professionals, to have an open and honest interview atmosphere, the researcher has to be able to guarantee full confidentiality. Therefore, it is not possible to share complete transcripts or complete observation records. Sharing of data is only possible within publications as limited quotes from the material.

2.2.5 Is an embargo applied to give time to publish or seek protection of the intellectual property (e.g. patents)?

- No

2.2.6 If an embargo is applied (see question 2.2.5), specify why and how long this will apply, bearing in mind that research data should be made available as soon as possible.

N.A.

2.2.7 Will the data and other research outputs be accessible through a free and standardized access protocol?

- Yes: The data will be deposited in ZENODO, which uses https://, which is a standardized access protocol.

2.2.8 If there are restrictions on use, how will access be provided to the data, both during and after the end of the project?

Non anonymized data will not be accessible to anyone. Pseudonymized data could be made accessible to other researchers upon reasonable request after the project. For the reasons stated above, also pseudonymized data cannot be made publicly available in full.

2.2.9 How will the identity of the person accessing the data be ascertained?

All electronic device which are used for processing the data are password protected and have encrypted hard drives, using current standard encryption technologies (XTS-AES with 256-bit keys).

Access to VUB Pixiu is secured through a completely separate Access Key ID and Secret.

2.2.10 Is there a need for a data access committee (e.g. to evaluate/approve access requests to personal/sensitive data)?

- No

Access to personal data and other sensitive information will not be granted in any case, so there is no need for a data access committee.

2.2.11 Will metadata be made openly available and licenced under a public domain dedication CC0, as per the Grant Agreement? If not, please clarify why.

- Yes. ZENODO allows the publication under a CC0 license, CC-BY 4.0 or MIT License.

2.2.12 Will metadata contain information to enable the user to access the data?

- No. There will be no access to raw data.

2.2.13 How long will the data remain available and findable? Will metadata be guaranteed to remain available after data is no longer available?

The public metadata set will be available as long as possible through ZENODO. If necessary, a different repository will be chosen.

2.2.14 Will documentation or reference about any software needed to access or read the data be included? Will it be possible to include the relevant software (e.g. in open source code)?

The metadata will be created in such a way that special software would not be needed for accessing it.

2.3 FAIR DATA: MAKING DATA INTEROPERABLE

2.3.1

What data and metadata vocabularies, standards, formats or methodologies will you follow to make your data interoperable to allow data exchange and re-use within and across disciplines?
Will you follow community-endorsed interoperability best practices? Which ones?

Name	Value	Ontology Mapping
Case ID	single digit numeric value	
Data ID	alphanumeric string	
File Name	alphanumeric string	
Data Format	GeneralDataFormat (DDI)	DDI
Content	alphanumeric string	
DC Method	ModeOfCollection / TypeOfInstrument (DDI)	DDI
Language	three character string	ISO 639-3
Event	alphanumeric string	
DC Date	DateType (DDI)	
Event duration	Time Interval	ISO 8601
Gender	alphanumeric string	
Birth year (min)	birthDate	Schema.org
Birth year (max)	birthDate	Schema.org
Occup. Status	alphanumeric string	
School grad.	alphanumeric string	
Place of Birth	birthPlace	Schema.org

2.3.2 In case it is unavoidable that you use uncommon or generate project specific ontologies or vocabularies:
Will you provide mappings to more commonly used ontologies?
Will you openly publish the generated ontologies or vocabularies to allow reusing, refining or extending them?

Yes, it is unavoidable that an uncommon vocabulary will have to be used, as there is no single cohesive vocabulary for qualitative research. Where possible, mappings to commonly used ontologies will be provided, see table above.

2.3.3 Will your data and other research outputs include qualified references to other data (e.g. other data from your project, or datasets from previous research)?

- No

2.4 FAIR DATA: INCREASE DATA RE-USE

2.4.1 How will you provide documentation needed to validate data analysis and facilitate data re-use?

The already existing study protocol will be added. Additionally, the interview guides will be provided, which allow for the reproduction of the interviews.

2.4.2

Will your data and other research outputs be made freely available in the public domain to permit the widest re-use possible?
Will your data and other research outputs be licensed using standard reuse licenses, in line with the obligations set out in the Grant Agreement?

Only metadata can be made publicly available under CC BY or CC 0 licenses. As explained above, data types 2, 3 and 5 cannot be made publicly available, as this would create an obstacle for the research. Qualitative research about sensitive topics like death and dying but also about burnout, stress and high workloads cannot work without granting the participants full confidentially.

2.4.3 Will the data and other research output produced in the project be useable by third parties, in particular after the end of the project?

- Yes, the metadata, but also all the other materials (interview guide, recruiting material, etc.) can be used by third parties. Only data 2-5 cannot be used by third parties and remain inaccessible.

2.4.4 Will the provenance of the data and other research outputs be thoroughly documented using the appropriate standards?

- Yes

2.4.5 Describe all relevant data quality assurance processes.

I will use validator software (e.g. from w3c) to validate the XML of the metadata.

The quality assurance regarding the research data and its analysis will be carried out by regular meetings with the supervisor as well as regular presentations and data sessions within the research group. The scientific publications of the project will undergo double blind peer review procedures to ensure the quality of the published results.

3. OTHER RESEARCH OUTPUTS

3.1 Do you have any additional information, that was not addressed in the previous sections, which you wish to provide regarding other research outputs that are generated or re-used throughout the project?

No, there is no additional information.

4. ALLOCATION OF RESOURCES

4.1 What will the costs be for making data and other research outputs FAIR in your project?

The costs associated with implementing FAIR principles include maintaining both online and offline data storage infrastructure, as well as the staff time required to prepare, document, and curate data to meet FAIR standards. Expenses related to open-access publishing can also be considered part of the effort to ensure that research outputs are openly accessible and aligned with FAIR practices.

4.2 How will these be covered?

The infrastructure and resources available at VUB, together with the use of freely accessible platforms such as ZENODO, ensure that the costs associated with online data storage are already covered. The time required to make data FAIR is likewise accounted for through the principal researcher's allocated effort for project and data management. Additional expenses are expected only for offline data storage and open-access publication fees. These costs can be supported through grant funding.

4.3 Who will be responsible for data management in your project?

During the research project, the principal investigator Anna Bauer will be responsible for data management. After the end of the project, the supervisor Werner Schirmer will be responsible, as he holds a permanent position at VUB.

4.4 How will long term preservation be ensured?

The publicly available metadata will be long term available via ZENODO. The availability of the website will be insured by using a low maintenance Content Management System and the own infrastructure of the researcher.

5. DATA SECURITY

5.1 What provisions are or will be in place for data security?

There are several security measures: Working with data will only happen on password encrypted modern computers, using standard XTS-AES with 256-bit keys as encryption method. Project data that may contain sensitive data or personal data will be stored separately in VUB Pixiu.

Transcription of audio data will be carried out using NoScribe. This app uses a local, pre trained LLM based on Open AI Whisper to transcribe audio files. The app is fully GDPR compliant.
The interview data will not be printed in order to avoid it getting in the hands of unauthorized persons.

5.2 Will the data be safely stored in trusted repositories for long term preservation and curation?

- Yes, for long term storage of pseudonymized transcripts and observation records, the VUB Institutional Data Repository will be used.

6. ETHICS

6.1 Are there, or could there be, any ethics or legal issues that can have an impact on data sharing?

- Yes: According to the ethics approval of the project, granted by the Commissie Medische Ethiek (UZ Brussel) in April 2026 (Registration number: EC-2026-28), the interview recordings, transcripts as well as the observation records cannot be shared publicly, mostly for ethical reasons.

6.2 Will informed consent for data sharing and long term preservation be included in questionnaires dealing with personal data?

- Yes, participants are informed about data sharing and long term preservation procedures via the mandatory ICF procedures. They have to give written consent to this in order to be able to participate.

7. OTHER ISSUES

7.1 Do you, or will you, make use of other national/funder/sectorial/departmental procedures for data management? If yes, which ones (please list and briefly describe them)?

- No

EUROPEAN COMMISSION (HORIZON): HORIZON EUROPE DMP + - GDPR RECORD

GDPR RECORD

Have you registered personal data processing activities for this project?

- Not applicable

EUROPEAN COMMISSION (HORIZON): HORIZON EUROPE DMP + - DPIA

DPIA

Have you performed a DPIA for the personal data processing activities for this project?

- Not applicable

Signature Fellow Signature Supervisor