
an explorative research project about intimacy and sexual expression in residential care facilities

A Data Management Plan created using DMPonline.be

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Affiliation: KU Leuven (KUL)

Funder: KU Leuven (KUL)

Template: KU Leuven BOF-IOF

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Grant number / URL: ZKE2247

ID: 196914

Start date: 01-10-2022

End date: 30-09-2023

Project abstract:

The objective of this joint PhD between KU Leuven, LUCA School of Arts (Belgium) and the University of Edinburgh (UK) is to explore how people experience, address and challenge intimacy and sexual expression in care facilities. This research project draws on Participatory Design approached by involving residents and employees of the care facility as experts of their experiences. The research aims to translate sensitive knowledge about intimacy and sexuality into innovative practices that can contribute to the delivery of more inclusive Person-Centered-Care.

In short, for this research project 4 to 8 residents will be invited to participate in the study. Through the use of specially designed 'cultural probes' residents are able to express their experiences, thoughts and ideas of intimacy and sexuality. In addition, 4 to 8 employees are invited to be interviewed which provide the study a broader understanding of how intimacy and sexuality is experienced within the organizational structure in a care facility. The researcher will also conduct 7 to 10 informal interviews with experts in the field of aged sexuality, to share experiences, challenges and to ensure the research is contributing to new knowledge.

Note: The DMP for this particular research project is part of my first year of the PhD. This means that more data will be collected next year. Updates will follow accordingly related to this DMP.

Last modified: 16-02-2023

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Research Data Summary

List and describe all datasets or research materials that you plan to generate/collect or reuse during your research project. For each dataset or data type (observational, experimental etc.), provide a short name & description (sufficient for yourself to know what data it is about), indicate whether the data are newly generated/collected or reused, digital or physical, also indicate the type of the data (the kind of content), its technical format (file extension), and an estimate of the upper limit of the volume of the data.

Dataset name / ID	Description	New or reuse	Digital or Physical data	Data Type	File format	Data volume	Physical volume
Observational notes	Interview notes during expert interviews, Participant Observations in care facility, and methodological reflections after the research activities	New	Digital When notes are written down in a physical book these will be digitized	Textual	doc Software Miro board	<1 GB	NA
Audiovisual and transcribes	Audio recordings of the interviews which will be transcribed and analysed	New	Digital	Audio Textual	Mp4 Doc Excell	< 10 GB 42 audio recordings Approx. 500 pages	NA
Cultural probes 1	Physical probes and printed maps used during the interviews as engagement tools	New	Physical	Printed materials (e.g. dairy booklet, 3d Doll, Cards with images)	Print	32 cultural probes: 8 residents will each have created 4 probe studies 8 interview maps employees	30 x 40 x 30 cm
Cultural probe 2	Polaroid images	New	Physical	Image	Image	64 Polaroid images	10 x 12 x 16 cm
Visual photographs	Photographs are taken on the site, for example when people are interacting with the cultural probes	New	Digital	Image	Jpeg	<200 GB 400 photographs	NA

If you reuse existing data, please specify the source, preferably by using a persistent identifier (e.g. DOI, Handle, URL etc.) per dataset or data type:

NA

Are there any ethical issues concerning the creation and/or use of the data (e.g. experiments on humans or animals, dual use)? If so, refer to specific datasets or data types when appropriate and provide the relevant ethical approval number.

- Yes, human subject data (Provide SMEC or EC approval number below)

A PRET/SMEC review has also been requested (G-2022-5866).

The researcher will pseudonymize all data to protect the privacy of the participants. Names of participants will be replaced with a reference code (E1 or R1). A document that links people's identity with the reference code will be stored separately within the encrypted and password protected data storage of KU Leuven which is only accessible by the main researcher and the promoter. Online stored data, transcribes and cultural probes, will be organized in different files according to content and topics (ex. all intimacy maps together, all self-image expressions together). These files will still be linked to a specific profile using a separately stored coding system, password protected and only accessible by the researcher and the promoter. Audio and photographic recordings will also be collected in a way that protects the participants' identities. When making photographs faces will be avoided at all costs and original audio recordings where participants can be recognized will be deleted after 10 years. The researcher is working with vulnerable people in a care facility and is aware that there is a possibility that participants may deasease after the data collection has been done. Participants would already have given informed consent, and therefore the researcher will still include their data.

Will you process personal data? If so, please refer to specific datasets or data types when appropriate and provide the KU Leuven or UZ Leuven privacy register number (G or S number).

- Yes (Provide PRET G-number or EC S-number below)

Yes I will use process personal data (G-2022-5866).

Data that would include demographic characteristics: Age, gender, marital status, role in the care facility (resident or employee), sexual orientation, ethnic background will be recorded in an excel sheet. No name will be recorded in this recruitment overview, only demographic characteristics. The researcher will have a separate sheet to link back people's reference codes with their names but will be deleted after 10 years.

Data that would have personal characteristics: Audio recordings, transcribes, cultural probes and images that could refer to people's physical appearance, lifestyle habits, ethnic backgrounds or religious beliefs. Names in all data that is generated will be pseudonymized, meaning the names of people will be replaced with a reference code. The name of the audio recording files will be pseudonymized and original files will be deleted after 10 years. People will not be captured recognizable in images. Photographs of the cultural probes would ensure to cover names but handwriting could still be visible.

Data that would include contact details of people: Email address or phone number in Excell sheet of people who would want to stay in contact during the research project, a temporarily planning sheet with participants first name, time, date of the interviews. Temporary documents that contain personal information would have '_GDPR Delete' in their file name so the researcher know to delete it once the project is completed (after 4 years)

Does your work have potential for commercial valorization (e.g. tech transfer, for example spin-offs, commercial exploitation, ...)? If so, please comment per dataset or data type where appropriate.

- No

Do existing 3rd party agreements restrict exploitation or dissemination of the data you (re)use (e.g. Material or Data transfer agreements, Research collaboration agreements)? If so, please explain in the comment section to what data they relate and what restrictions are in place.

- No

The PhD is in collaboration with the University of Edinburgh, meaning the researcher will spend 2x 6 months during her 4 year research in Edinburgh. In the signed agreement, KU Leuven is the main and leading university in this collaboration. Reflections and processed analyzed data is going to be shared during monthly supervisory meetings but no direct data will be accessed by the University of Edinburgh.

Are there any other legal issues, such as intellectual property rights and ownership, to be managed related to the data you (re)use? If so, please explain in the comment section to what data they relate and which restrictions will be asserted.

- Yes

The data that is going to be collected is unique and therefore the researcher will have all copyrights. All participants are asked to sign a consent form. In this consent form people are made aware that they can withdraw from the study any time for the duration of it. However, when they choose to withdraw from the study after all data collection has been documented, the researcher still has the right to use this data for publication according to the AVG/GDPR rules.

Documentation and Metadata

Clearly describe what approach will be followed to capture the accompanying information necessary to keep data understandable and usable, for yourself and others, now and in the future (e.g. in terms of documentation levels and types required, procedures used, Electronic Lab Notebooks, README.txt files, codebook.tsv etc. where this information is recorded).

There is a readme.txt document within the Fieldwork folder for an overview of the data documentation including information about: the research project, project files, storage, methodological information, data access and sharing and specific information about the data itself. This document will be continuously updated once the data collection starts in order to keep it synchronized with the 'live' folders.

With the use of Atlas.ti a codebook is going to be generated with the codes from the observational data, conversational data like transcribes and visual data, the images.

Below is an example of how the organization and documentation of the metadata could look like.

Data set	Method used	Analytical procedure	File name and amount	Definitions of variables	Units of measurements organized by theme, topic or activity
Observational notes	Interview notes, Participant Observations in care facility, and methodological reflections after the research activities	Dairy in docx, Writing memo's in Atlas.ti, organize memo's in Excell and Miro	10x Expert_Interview notes_[name] 1x Observations_Carefacility_dd.mm.jj: 16x Observations_method_[reference code]	Observations will be organized related to the experiences of the different people (employees, residents) or research engagements (reflections on the usage of the designed tool)	Codes still need to be defined – but could include the type of observations (e.g. confrontations, privacy, Intimacy, togetherness etc.)
Audio recordings	Interviews with employees, interviews with residents and group conversations	All audio recordings will be transcribed by the researcher, names of people will be replaced by a reference code and uploaded to Atlas.ti to code the transcribes	42x audio recordings organized by either Employee, Resident or Group interview Audio_E1 Audio_R1 Audio_GR1	Audio recordings and transcribes will be organized by target group (employees, residents, group) to understand each perspective on intimacy and sexuality. Transcribes will be analysed and coded in Atlas.ti.	Codes still need to be defined – but this could be based on the type of stories, the type of theme, or the type of activity
Physical objects	Photographs of the interview materials and the Cultural probes will be made for analysis or they will be digitalized through illustrations	Images will be coded in Atlas.ti and mapping/ clustering images will be done in Miro	18x Physical cultural probes (8 residents will each provide 4 cultural probes) R1-CP1= Resident1-CulturalProbe1 E1-Image= Employee 1-image	The cultural probes will be organized by topic and activity For residents this will be: Map of intimacy, Doll of ageing body, Polaroids on intimate places, Card sorting on sexual topics, Postcards about reflections For employees this will be: Statement cards, example scenario, future ideas, questions	Codes still need to be defined – but this could be based on the type of stories, the type of theme, or the type of activity
Images taken by the researcher	Photographs of the research setting that would support the analysis process by providing context	No specific analysis will be done with the images, as they are mainly supporting the research documentation	Approx. 50 – 100 images Images would be renamed to: Image_dd.mm.jj	Images are organized by the type of fieldwork activity. A selection might be made to highlight research activities	NA

Will a metadata standard be used to make it easier to find and reuse the data ?

If so, please specify which metadata standard will be used.

If not, please specify which metadata will be created to make the data easier to find and reuse.

- Yes

The researcher will use Atlas.ti, a software tool to store, organize and analyze qualitative data sets. This tool allows the researcher to store and code both text based data (e.g. transcribes) as visual data (e.g. images, maps) in one place.

Data Storage & Back-up during the Research Project

Where will the data be stored?

- OneDrive (KU Leuven)

The researcher will be using the recommended KU Leuven OneDrive for Business to store data during the research. This storage will give the researcher 2TB of storage for free, including automatic back-ups and where sensitive data is safe (by multifactor authentication and enables conditional access).

The research results will only be accessible by the researcher herself, and her promotor. Not only will this information be protected by a password, but the KU Leuven login of all researchers is also equipped with multi-factor authentication to adequately protect data.

How will the data be backed up?

- Standard back-up provided by KU Leuven ICTS for my storage solution

Making use of the OneDrive from KU Leuven, as mentioned above, automatic back-ups are included in the OneDrive for Business package. This option also supports to access a version history, which enables the researcher to revert a file to a previous version.

Is there currently sufficient storage & backup capacity during the project?

If no or insufficient storage or backup capacities are available, explain how this will be taken care of.

- Yes

Yes, as mentioned above, KU Leuven provides 2 TB of storage which is enough for the relatively small scale of research data that is normal for qualitative studies.

How will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?

Analogue security: physical documents, like signed consent forms and the physical probes, will be stored in a locker on school which can only be accessed by the main researcher with a key.
Digital security: No use is made of cloud services located outside the EU for the storage or exchange of collecting data.

What are the expected costs for data storage and backup during the research project? How will these costs be covered?

KU Leuven provides free data storage and will be covered by the school

Data Preservation after the end of the Research Project

Which data will be retained for 10 years (or longer, in agreement with other retention policies that are applicable) after the end of the project?

In case some data cannot be preserved, clearly state the reasons for this (e.g. legal or contractual restrictions, storage/budget issues, institutional policies...).

- All data will be preserved for 10 years according to KU Leuven RDM policy

The data will be stored on the university's central servers (with automatic back-up procedures) for at least 10 years, conform the KU Leuven RDM policy.
Physical signed consent forms are also part of these data and will be kept secure in a locker at KU Leuven/LUCA Genk.

Where will these data be archived (stored and curated for the long-term)?

- KU Leuven RDR

Only necessarily research data and documentation that cannot be replicated will have long time value and will be preserved.

What are the expected costs for data preservation during the expected retention period? How will these costs be covered?

KU Leuven will be responsible for data preservation.

Data Sharing and Reuse

Will the data (or part of the data) be made available for reuse after/during the project?

Please explain per dataset or data type which data will be made available.

- Yes, as open data

The interview tools, such as the probe studies developed as part of this research project will be made available (online and/or in print) for others to use. No data with personal and sensitive information of participants (e.g. names and contact details) will be made available.

If access is restricted, please specify who will be able to access the data and under what conditions.

NA

Are there any factors that restrict or prevent the sharing of (some of) the data (e.g. as defined in an agreement with a 3rd party, legal restrictions)?

Please explain per dataset or data type where appropriate.

- Yes, privacy aspects
- Yes, ethical aspects
- Yes, intellectual property rights

Privacy aspects: In section 1 there is more explanation on how to protect participants' privacy (pseudonymise names in data collection like transcripts, and file names), only necessary data will be collected and raw data like audio files will be deleted after 10 years.

Intellectual property Rights: The main researcher, Yoni Lefevre, working at the home university, KU Leuven, will have the IPR

Ethical aspects: Participants will be part of an informed consent, meaning they will be properly briefed and informed about their involvement and expectations before their participation. The researcher will be respected towards research subjects, meaning she will act as a receptive, non-judgemental listening partner. People can also withdraw from the research any time without giving a reason.

Within the signed joint agreement between KU Leuven and University of Edinburgh there is a section:

Article 16. – CONFIDENTIALITY AND DATA PROTECTION

- not to use Confidential Information otherwise than for the purpose for which it was disclosed;
- not to disclose Confidential Information to any third party without the prior written consent by the Disclosing Party;
- to ensure that internal distribution of Confidential Information by a Recipient shall take place on a strict need-to-know basis.

Article 17. – INTELLECTUAL PROPERTY

17.3 Any Foreground Intellectual Property shall be, subject to written agreement to the contrary by the Parties, the sole and exclusive property of the Party creating or developing it (or whose employee created or developed it). Each of the Parties grants to the other Party a non-exclusive, non-transferable licence to use that Party's Foreground Intellectual Property to the extent necessary to fulfill the other Party's obligations under this agreement.

Where will the data be made available?

If already known, please provide a repository per dataset or data type.

- KU Leuven RDR (Research Data Repository)

When will the data be made available?

- Upon publication of research results

Which data usage licenses are you going to provide?

If none, please explain why.

- CC-BY 4.0 (data)

I will share my data under a Creative Commons license

Do you intend to add a persistent identifier (PID) to your dataset(s), e.g. a DOI or accession number? If already available, please provide it here.

- Yes, a PID will be added upon deposit in a data repository

What are the expected costs for data sharing? How will these costs be covered?

Data will be shared according to the KU Leuven 'Research Data Repository' and is in line with the FAIR principles of data sharing (Findable, Accessible, Interoperable and Reusable). What's needed to make use of RDR is a U number (U158468), an ORCID number (0000-0002-1881-9896) and the data sets that is ready to be published, and will therefore be properly pseudonymised. Costs will be covered by KU Leuven.

I intend to publish in Open Access and would opt for Gold Open Access as it's going to be my first published journal. This means that:

- The final published version of my article is permanently and freely available online for anyone, anywhere to read.
- An article publishing charge (APC) is usually applicable. The cost of publication is usually covered by a one-off fee, an article processing charge / APC, paid by the author which is the main researcher. The average cost of an APC is approx. 2000 Euro (ex. VAT at 23%).
- I retain copyright. The agreement includes the Creative Commons license of my choice.
- Publish under a license with few or no restrictions on how people can reuse my work.

Responsibilities

Who will manage data documentation and metadata during the research project?

The day-to-day responsibilities for the Data Management during the research project will be Yoni Lefevre (yoni.lefevre@luca-arts.be), the main researcher for this PhD study.

Who will manage data storage and backup during the research project?

The main researcher, Yoni Lefevre (yoni.lefevre@luca-arts.be) will be responsible for managing data storage and back up during the research project

Who will manage data preservation and sharing?

Each research unit will be responsible for the data to be stored and backed-up at KU Leuven OneDrive. KU Leuven will be responsible for data preservation.

Who will update and implement this DMP?

The end responsibility for updating and implementing the DMP is with the main supervisor and coordinator of Inter-Actions, Niels Hendriks (niels.hendriks@luca-arts.be).