DMP title

Project Name My plan (C1-C2-IDN DMP) - DMP title

Project Identifier IDN/21/004

Principal Investigator / Researcher Niels Hendriks

Description To realize person-centred care for persons with high support needs, it is necessary to have a clear image of the personâ€™s identity and to integrate this in daily care practices. This project focuses on persons with profound intellectual and multiple disabilities and persons with dementia, as exemplary for persons who experience limitations across multiple domains and whose verbal communicative means are severely hindered. The first aim is to build a conceptual framework on identity of these persons, based on theories from different disciplines as well as on experiential and practical knowledge of family and professional carers. Secondly, a toolkit with innovative methods, practical tools and strategies will be developed, that will enable carers to access and to record the explicit, observable and tacit knowledge on a personâ€™s identity. The third aim is to implement and evaluate the developed toolkit into daily life and care. This projectâ€™s results will contribute to evidence-based methods, tools and strategies, which are essential to change the long term health care towards more person-centered care for persons with high support needs.

Institution KU Leuven

1. General Information

Name of the project lead (PI)

Niels Hendriks

Internal Funds Project number & title

“How to understand, access, record and integrate identity in care contexts for persons with high support needs who cannot speak for themselves.”

3H210372

2. Data description

2.1. Will you generate/collect new data and/or make use of existing data?

- Generate new data

2.2. What data will you collect, generate or reuse? Describe the origin, type and format of the data (per dataset) and its (estimated) volume. This may be easiest in a numbered list or table and per objective of the project.

1.	Qualitative data from concept mapping (focusgroup context, 80 persons)	statements collected in Microsoft Excel + personal information from questionnaire +homework assignement in Microfsot Word.	10 GB	Created during concept mapping
2.	qualitative data from observations (ECD context, 6 persons)	notes in a handwritten notebook + sketches in a notebook, later digitalised in PDF.	50 pages (to be expected)	Created during observation and after the fact
3.	Qualitative data from cultural probes (given to 12 persons)	A collection of pictures, collages, texts, later digitalised in PDF.	20 pages (to be expected)	Created individually for each participant (carer)
4.	qualitative data from interview (IPA context, 18 persons)	audio recordings stored in uncompressed wav-format; transscribed as text doc (MS word)	2 GB	Face-to-face with participants
5.	Testing notes (18 persons)	Handwritten notes stored in the researcher's notebook, translated to a digital format as an MS Word document	50 paged (to be expected); No more than 100Mb in size	Created in or after interactions with participants and created toolkits
6.	Qualitative data based on literature review	Shared document that summarizes literature insights from the various disciplines involved (shared via a MS Excel Document)	6 tabs (to be expected)	Created in a pre-phase
7.	Qualitative data based on focus groups (4 focus groups, 8-12 persons)	audio recorded and stored in uncompressed wav-format; transscribed as text doc (MS word)	2 GB	Created during focus group
8.	Quantitative evaluative data	Will be determined later on in the project.	Will be determined later on in the project.	Will be determined later on in the project.
9.	qualitative data from shadowing (6 persons)	Handwritten notes stored in the researcher's notebook, translated to a digital format as an MS Word document	50-100 paged (to be expected); No more than 200Mb in size	Created during shadowing observation

3. Ethical and legal issues

3.1. Will you use personal data? If so, shortly describe the kind of personal data you will use. Add the reference to the file in KU Leuven's Record of Processing Activities. Be aware that registering the fact that you process personal data is a legal obligation.

Personal data will be used. This will consist of directly identifiable data that will be pseudomised concering name, age, adres, contact information and health data. Special categories of personal data will also be used, more specifically it is neccesary for this project to collect data concerning religious or philosophical beliefs, health, sexual orientation and ethical background.

3.2. 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, add the reference to the formal approval by the relevant ethical review committee(s).

SMEC Research approved G-2022-4759 on 23-2-2022 (focusgroups)

SMEC Research pending G-2021-4413 (ECD, cultural probes)

CTC approval pending, will be followed up by EC Research.

3.3. Does your research possibly result in research data with potential for tech transfer and valorisation? Will IP restrictions be claimed for the data you created? If so, for what data and which restrictions will be asserted?

Not relevant

3.4. Do existing 3rd party agreements restrict dissemination or exploitation of the data you (re)use? If so, to what data do they relate and what restrictions regarding reuse and sharing are in place?

Not relevant

4. Documentation and metadata

4.1. What documentation will be provided to enable understanding and reuse of the data collected/generated in this project?

1. For the survey data a codebook will be generated containing study design, sampling methodology, variable-level information (lael, question text, codes, frequencies).

2. For the data resulting from interviews and focus groups details on the contexts of the interview, discussion, focus groups the consent giving process, the questions asked (or subjects discussed) and the instructions (or predefined scenario) will be shared in a Word and/or excel document.

3. The data coming from cultural probes will be documented with information on the setup of the probe exercise (what type of format, what type of questions/assignments given, etc.), the detailed instructions and the contexts in which it was used.

4. Data coming from testing notes will be documented with testing setups, type of prototypes tested, instruction to testing leaders and contexts of the testing setup.

For all data: The researchers will pseudomise the data.

4.2. Will a metadata standard be used? If so, describe in detail which standard will be used. If not, state in detail which metadata will be created to make the data easy/easier to find and reuse.

This will be determined later on in the project.

5. Data storage and backup during the project

5.1. Where will the data be stored?

The questionnaire, informed consent and the COVID-19 information papers that return by e-mail will be saved on the secured network drive of KU Leuven (OneDrive).

All Microsoft Excel and / or Microsoft Word sheets used during this project will be saved on the secured network drive of KU Leuven (OneDrive).

The statements collected during the focus groups and the prioritizing and categorizing task will be inserted and analyzed using R-CMap. These files will also be saved on the secured network drive of KU Leuven (OneDrive).

Observations stored in a physical notebook will later be digitalised on the encrypted KU Leuven (OneDrive). Video or audio recordings of the participants interacting with the tools during ECD, or during significant moments when designing by immersion will also be saved on the secured network drive of KU Leuven (OneDrive).

The physical cultural probes will be stored by the involved researcher in a locker that can only be accessed by him/herself at LUCA Genk campus. After the collection of the cultural probes, this physical data will be pseudonymized and digitalised. The digitalised PDF version of the cultural probe will stored online on the secured network drive of KU Leuven (OneDrive). Online stored data will be organized in different files according to content (ex. all sleeping habits in one file). The physical data will also be reorganized according to the content. One cultural probe used by a specific person will not be stored in its entirety in one place. After the project has been finalised, all paper data will be handed over to the supervisor of the project (Niels Hendriks) who will store these data in their office in a locked drawer or cupboard that can only be accessed by himself.

Files stored on the shared KULeuven OneDrive of the project will only be available to access by the neccesary researchers.

5.2. How will the data be backed up?

The data will be stored on the university's central servers (KU Leuven OneDrive) with automatic daily back-up procedures.

5.3. Is there currently sufficient storage & backup capacity during the project? If yes, specify concisely. If no or insufficient storage or backup capacities are available, then explain how this will be taken care of.

Currently there is enough storage space on the KU Leuven OneDrive.

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

As the data generated will not contain large amounts of data, we expect the cost to be non-existed or limited. The costs will be covered by the RU Inter-Actions.

5.5. Data security: how will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?

all the information is password protected on the secured KU Leuven OneDrive. The KU Leuven login of all researchers is is also equipped with multi-factor authentication to adequately protect data and the researchers will work on encrypted laptops.

6. Data preservation after the end of the project

6.1. Which data will be retained for the expected 10 year period after the end of the project? If only a selection of the data can/will be preserved, clearly state why this is the case (legal or contractual restrictions, physical preservation issues, ...).

All e-mail addresses of the participants will be destroyed after the study. The informed consent forms and the other personal data will be kept up to 10 years after the publication. In addition, only the researcher and supervisors will have access to the data stored on the KU Leuven OneDrive.

6.2. Where will these data be archived (= stored for the long term)?

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.

6.3. What are the expected costs for data preservation during these 10 years? How will the costs be covered?

As the data generated will not contain large amounts of data, we expect the cost to be non-existed or limited. The costs will be covered by the RU Inter-Actions.

7. Data sharing and re-use

7.1. Are there any factors restricting or preventing the sharing of (some of) the data (e.g. as defined in an agreement with a 3rd party, legal restrictions or because of IP potential)?

No such restrictions are known

7.2. Which data will be made available after the end of the project?

Anonymised audio and video recordings will not be made available publicly, but can be shared under certain conditions. Data from interviews, focus groups, ECD, cultural probes and test setups will be made available under a CC-BY License. when asked via email.

All data will have to be pseudomised before being made available.

All data results will be shared in the form of publications.

7.3. Where/how will the data be made available for reuse?

- Upon request by mail

Open Science framework + Research catalogue

7.4. When will the data be made available?

- Upon publication of the research results

No privacy sensitive data will be shared. Upon request certain data can be shared, but this will be discussed intern between the different researchers. Designed results and publication based on this data will be shared during the research.

7.5. Who will be able to access the data and under what conditions?

Upon request certain data can be shared, but this will be discussed intern between the different researchers.

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

Costs for sharing data will be minimal and can be covered by the project's budget.

8. Responsibilities

8.1. Who will be responsible for the data documentation & metadata?

Data documentation & metadata lies within each research unit

- data from concept mapping, interviews, shadowing -> GOP
- data from cultural probes, immersion, ECD -> LUCA
- data from surveys, observations, focus groups and interviews -> LUCAS

8.2. Who will be responsible for data storage & back up during the project?

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

8.3. Who will be responsible for ensuring data preservation and sharing?

LUCA will be responsible for data preservation. Sharing will happen from each research unit or from LUCA.

8.4. Who bears the end responsibility for updating & implementing this DMP?

The end responsibility for updating and implementing the DMP is with the supervisor (promotor).