Plan Overview

A Data Management Plan created using DMPonline

Title: Roadmap to an inclusive patient-centered care Involvement of patients with non-Western background in their healthcare

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Template: 1. UvH template PhD/WP

Project abstract:

The number of elderly people with comorbidity is increasing in our society due to the aging of the population, earlier detection, better treatment options and higher survivability[1]. This results in a shift in health care according to which health gains and full recovery are seen as less relevant and realistic than social participation and increasing self-reliance. The Dutch government approaches prevention and self-management in healthcare as a paradigm shift from a paternalistic model to a participatory model emphasizing on 'participation', 'autonomy', 'self-direction' and 'self-care'.

However, this policy approach does not seem to sufficiently include the growing group of non-Western migrants with comorbidity. Many preventive care interventions and activities reach immigrants less well.

The aim of this research project is to develop an inclusive patient-centred approach. The challenge is to improve accessibility to health care, strengthening the quality and effectiveness of care for people with chronic diseases who have a non-western migrant background.

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Roadmap to an inclusive patient-centered care Involvement of patients with non-Western background in their healthcare

1. General features of the project

Please fill in the table the table below.

DMP template last edit	18-08-2022
Project number (if available)	
Name of Research folder on the UvH R: drive	N/A
Name Chairgroup	Ethics of care
Name Chairgroup leader	Carlo leget
Name Promotor	Carlo Leget
Name data consultant/data steward	Yvonne Drost
Check date data consultant/data steward	20-2-2023

2. Data collection and re-use

2.1 In collecting data for my project, I will:

- Generate new data

2.2 I will be reusing existing data, and I have the owner's permission for that.

- No, I will not be reusing existing data

2.3 In collecting new data, will you be collaborating with other parties such as project partners and/ or suppliers of data.

- No

2.4 What method(s) do you use for the data collection?

- Individual interviews non-structured
- Group interviews/Focus groups
- Literature study
- Survey(s)
- Individual interviews (semi-)structured

2.5 Check boxes and describe the tools/software you will use for the data collection.

- audio recording tool
- software for survey research (e.g. Qualtrics)
- video recording tool
- Video MP4 N=10-20, a minimum of 10 ,maximum of 10 interviews

- Audio MP3 N=10-15 a minimum of 10 maximum of 15 interviews
- Audio MP3 N=4, a minimum of 4 focus groups, a maximum of 10
- spreadsheat XLS 1 as part of the analysis of the Scoping Review
- Spreadsheat XLS 2 as part of the analysis of the survey

2.6 Describe what metadata and documentation will accompany the data?

In question 8.1, I check the boxes for the documentation that will be in my data package. The documentation will involve data documentation in the form of:

- files describing inclusion and exclusion criteria articles scoping review
- Logbook documentation of research proces and workshops
- data collection , methodology, interview (topic list) and data analysis
- SPPS syntax survey en data analysis
- data atlas

3. Data storage

3.1 Will you store your data at the universities network drive?

- No

3.1.a Please indicate:

The reason why data will be stored elsewhere	The data will be stored at my employer, also collaborative organisation in the study. Carlo Leget of the University of Humanistic studies will be granted access to Research Drive
Where the data will be stored	Erasmus MC Rotterdam
How data security will be guaranteed	Data will be stored on research drive department Reumatology Erasmus MC
How long the data will be preserved	Data will be achived in accordance with erasmus MC rules (METC)

3.2 Please fill in the table below about which file types you will have and what the format and volume will be. Think about all information that you will have at the end of the project.

File type	Format	Volume
video	JPEG	2000 GB
Audio	MP3	2,0 GB
spreadsheet	XLS	1 MB
tekst	Word	1 MB

3.3 Do you need to store non-digital data, e.g. on paper? If so, please describe which data, whether the data are personal data and who will have access to the data.

N/A

4. Data analysis

4.1 What will be the method by which you will analyse the data?

- (semi) structural interviews: narratieve analysis
- Focus groups: content analyses
- survey: qualitative & quantitative analyses
- descriptive & interpretive phenomenology (RLA) formulating the essence of the phenomenon.

4.2 Which tools will you need to process, analyse or visualise the data?

- ATLAS.ti
- SPSS

5. Participants and Personal data

5.1 Does your research involve human subjects?

- Yes

5.2 Please read the Research Datamanagement Policy outline on this page of the intranet (ENG) or 'Hooflijnen beleid' on this page (NL) of the UvH. Subsequently, check the boxes below.

- I will submit my resesarch proposal and this DMP for review to the ethical review committee of the UvH
- I have read the Research Datamanagement Policy outline and will comply to that

5.3 Give a description of the sample participants and whether they are considered as a vulnerable group.

The research project focuses on elderly (> 50 years, first and second generation, man, and woman) with a non-western migrant background with chronic care or disabilities who are characterized by lower health skills on average (feelings of insecurity and loss of grip, untapped talents, debts, vulnerability in education or the labour market). This is a population that, due to cultural diversity, deals with discrimination and mistrust regarding care. Usually, these are interrelated problems linked to a lifestyle that, from a Western medical perspective, is considered unhealthy. The focus of research is on patients of immigrant (gender diverse) origin living in Rotterdam. In Rotterdam two-third of this group is of non-western descent. Research concentrates on two culturally different groups that form large communities in Rotterdam: Moroccans and Cape Verdeans.

The inclusion of patients will be conducted in collaboration with general practitioners, health educators and medical specialists specialised in chronic diseases such as Rheumatoid arthritis e.g.

5.4 Which personal data are you going to collect? Check the boxes and explain why you need them.

- Gender
- Age
- Nationality, country or place of birth
- Contact data limited (e.g. name, email)
- Racial or ethnic origin
- Religious or philosophical beliefs
- Experiences (work, education)
- Health data

Contact data will be collected in order to contact participants for interview or workshop

Gender, age, nationality experiences , ethic origin re,iqiouw of philosophical beliefs and health data are part of the inclusion criteria study and to gain insight in relationships

5.5 What legal right do you have to collect the personal data you selected in the question before?

- Informed consent

5.6 Is there, at any time during the research process, a third party handling personal data from your data collection? If so, please give the name of the company, the link to their website and the legal base for processing.

- No

5.7 Describe how you will register participants and how you separate personal data from research data.

- Each participants wll asked for permission through informed consent
- all personal data will be anonymised
- key (personal data,analysis) will be stored in digital codebook on separate folder .I have access to the folder

6. Information and consent

6.1 Describe how you inform participants and receive their consent to use their personal data.

- All the participants will be informed about the content of the research by een information flyer adapted to the native language.
- data survey are processed anonymously. each participant is coded to be able to analyze and report the data.
- Only the principal investigator keeps a list of names and corresponding numbers separate from the data. Document with names will be destroyed after the investigation. The data can only be viewed by members of the research team during the research period
- the participants will be asked permission to make video and audio recordings
- audio and video recording are transcribed immediately after recording. Transcription will be anonymized. Recordings are destroyed within one month.

6.2 Will participants, parents or guardians receive any reward for participating?

- No

6.3 Will the participants, parents or guardians be debriefed at the end of the data collection session or at the end of the project? Please explain.

- Yes

The community-based participatory research (CBPR) approach is especially fit for health-focused scientists to eliminate health disparities among people of ethnic minority groups. CBPR is a research approach that involves the patients in different stages of the research process from problem identification to research design and in data collection, analysis, interpretation, and dissemination. It reduces the impact of power imbalances often inherent in research (i.e., between researcher and those being ‘researched’) and create safe, respectful, responsible, high quality and relevant research of benefit to the community.The strength of this approach is to addresses underlying cultural sensitivities (suppression of inferiority) by establishing trust and collaborative relationships.

In this research project, the target group participates not only as subject of the research but also at project level by evaluation and validation.Some of the participants will be involved in the project as participants and others will be invited to the workshop meetings as community partner and co-researcher.

7. Privacy and Data Security

7.1 When you deal with large scale, systematic data collections of personal data, you need to do a full Data Protection Impact Assessment (DPIA) to fully describe the mitigations and consult the privacy officer of the UvH. Does this apply for your project?

- No

7.2 How do you take care of the rights of participants? Please copy the table form the example answer and fill in the third column.

Right of participant	**Consideration**	**Describe how you do it**
Right of access	When a participant wants to know which personal data you collect, in what way will you manage that?	every participant will get information letter that accompanies the informent consent. We mention the list of data we are going to collect. So the participant already know to the particicpants. For the interviews
Right to rectification	When a participant lets you know that the personal data are not right, how will you manage and how will you let him/her know that it's done	elaborations of the interviews are submitted to the participants for verification In case (of changes) of contact data, we will contact the person We will document (log) what has been changed
Right to objection	When a participant objects to use his/her personal data, what will you answer and how is this documented?	In the informatie letter we indicate that all information tha has been collected before moment of objection , will be kept pseudonymised. The informed consent will be also kept. All personal dta in the key file will be destroyed and the person will not be approached futher.
Right to be forgotten	How do you manage deletion of one's personal data upon request?	The same applies as in case of the right to objection
What measures do take to protect the privacy of a person?	How do you make sure that the personal data will not be accessed by unauthorised persons?	The data will be stored on a dedicated storage (data disk) at the Erasmus Medical centre Rotterdam. Only limited number authorised persons have access to the data. Personal data (e.a. videoO that need to be stored on other devices are transferred to the secure storage of de the EMC as soon as possible and will be deleted at the recoding devices. Possible we wil use the very secure video application of codific fo recording video. application has been tested and allowed within the hospital.

8. Data Preservation and Archiving

8.1 What data will be in your data package? Please explain if necessary.

- Raw data
- Data documentation
- Syntaxes, scripts, algorithms
- Documentation of the research process

transcripts are kept of video and audio recordings

8.2 In which repository will the data package be archived and made available for re-use, and under which license?

- I will deposit my data package with DANS and will use the Dublin Core metadata standard

8.3 Give the details of the other repository where you will deposit your data.

Name of the repository	N/A
Which persistent identifier	
Which metadata standards	
Which information will be publicly shared	
Which licenses and permissions are in place	

8.4 Upon finishing your project you need to hand over the data package to the UvH, so you need to inform yourself in how to do this. Please read the guidance and check the proper box below.

- I have read the minimal requirements before graduation on the intranet and will comply to that
- I have read the paragraph on Archiving in the Research Data Management Policy and will comply to that

9. Data Sharing

9.1 Describe what re-use of your research data you intend or foresee, and what audience will be interested in your data.

1. My peers will be re-using all research data in the final dataset to generate new research questions.
2. The raw data can be of interest for other researchers or for spin off projects.

9.2 Are there sharing requirements by third parties? (e.g. funder data sharing policy)? Please explain how you will comply with those requirements.

- No

9.3 Are there any possible restrictions to data sharing or embargo periods?

data will be available after completion of research

9.4 Please state per data type in what way the scientific community will have access to your data.

Data type	Full access	Restricted access	Embargo period	Data immediately linked in the publicatoin	Explanation
metadata	yes	no	no	yes	all metadata documents will be freely accessible
audio	no	yes	no	no	audio provide personal information, so anonymity cannot be guaranteed when videos are released
video	no	yes	no	no	videos provide a lot of personal information, so anonymity cannot be guaranteed when videos are released
transcipts	yes	no	no	yes	all data will be freely accessible

10. Costs

10.1 Will you have to hire personnel for the data collection process or any other stage in datamanagement? Please explain and make an estimation.

- Yes

We may have to use external personnel(students is a option) to elaborate interviews (task barrier). Currently applying for grants

10.2 Will there be costs for data archiving, e.g. when you work with very large datasets, such as audio and video? Please explain and give an estimation.

- No

The costs for storage in Research Drive, archiving and publishing in DataverseNL are covered by Erasmus MC Rotterdam