
Plan Overview

A Data Management Plan created using DMPonline

Title: Shkorey - Verbeterde ondersteuning, samenwerking en doelgroep participatie bij de aanpak van onbedoelde zwangerschappen en kwetsbaar (jong) ouderschap bij Eritrese statushouders

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Funder: ZonMw (Nederlands)

Template: Data management ZonMw-template 2019

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Project abstract:

Shkorey beoogt meer kennis, geïnformeerde (gedrags)keuzes, doelgroep participatie en betere samenwerking en cultuursensitief werken bij de zorg/ondersteuning t.a.v. zwanger- en ouderschap onder Eritreeërs in Leeuwarden te realiseren. Dit alles moet leiden tot betere seksuele en reproductieve gezondheid, minder onbedoelde cq. onvoorbereide zwangerschappen en minder kwetsbare jonge gezinnen. Hiervoor ontwikkelen we het Ghanese project My Jorley door tot het cultuursensitieve spel Shkorey (incl. randprogrammering).

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Shkorey - Verbeterde ondersteuning, samenwerking en doelgroep participatie bij de aanpak van onbedoelde zwangerschappen en kwetsbaar (jong) ouderschap bij Eritrese statushouders

1. General features of the project and data collection

1.1 Project leader contact details

Geertje Postma
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06-43709248

1.2 I have composed my DMP with the assistance of a data stewardship (or management) expert. List his or her name, function, organisation/department, phone number and email address.

- The expert is not connected to my department or institution (please explain his/hr expertise related to data stewardship)

RDM (Research Data Management) support University Utrecht

1.3 In collecting data for my project, I will do the following:

- Generate new data
- Use existing data (please specify)

In this research project we will generate new data by means of focusgroup discussions and a questionnaire.

Next, we will use existing data entered in a mobile app (if consent is given to obtain those data).

1.4 In my research, I will use:

- A combination of quantitative and qualitative data

Qualitative data from focus groups

Quantitative data from a questionnaire and obtained from the app

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

- Yes, I have permission to use the data, but I am required to destroy them at the end of the project

We have promised to destroy the data after using it for our study due to privacy reasons.

1.6 In collecting new data, I will be collaborating with other parties.

- Yes, I will collect the new data in conjunction with other researchers or research groups

We have drawn up collaboration agreements with the co-researcher including safe exchange of data, ownership, co-authorship, responsibilities and ethical standards.

1.7 I am a member of a consortium of 2 or more partners. Clear arrangements have been made regarding data management and intellectual property. (also consider the possible effect of changes within the consortium on issues of data management and intellectual property)

- No, I am not working with 2 or more partners

1.8 I can give an estimate of the size of the data collection; specifically, the number of participants or subjects (“n=”) in the collection and its size in GB/TB

- Yes (please specify)

Questionnaires: n=40

App data: n=100

Focus group discussions: n=35

1.9 The following end products I will make available for further research and verification (please elaborate briefly)

- Other products (please specify)

This study deals with personal data of vulnerable people (refugees living in the Netherlands) on a sensitive topic (pregnancies, family planning, social norms). As the communities are small, stories can easily be recognised, so we can not guarantee anonymity when sharing data. Therefore we can not share data, but we can and shall share our research instruments, our results and our evaluation including lessons learned

1.10 During the project, I will have access to sufficient storage capacity and sites, and a backup of my data will be available. (please elaborate briefly)

- Yes, I will make use of my institution's standard facilities for storage and backup of my data

I will follow Rutgers rules on data storage.

2. Legislation (including privacy)

2.1 I will be doing research involving human subjects, and I am aware of and compliant with laws and regulations concerning privacy sensitive data.

- Yes, I will involve human subjects in my research. I will comply with the Algemene Verordening Gegevensbescherming (AVG)
- The Wet Medisch-Wetenschappelijk Onderzoek met Mensen (WMO, or Medical Research (Human Subjects) Act) applies to my project; I will have it reviewed by a Medical Research Ethics Committee. In addition I will comply with the Kwaliteitsborging Mensgebonden Onderzoek (Quality Assurance for Research Involving Human Subjects)

We have obtained ethical approval from the ethics review board of the faculty of social & behavioural sciences from Utrecht University.

2.2 I will be doing research involving human subjects, and I have (a form of) informed consent from the participants for collecting their data.

- Yes (please describe the form this consent takes)

We will inform participants of the goal of the study, the use of their stories and the way data are stored and anonymity is safeguarded. We will emphasize that participants have the right to withdraw anytime. We will take every effort possible to ensure their anonymity. We will ask each participant to sign an informed consent form.

2.3 I will be doing research involving human subjects, and I will protect my data against misuse.

- Yes, the data will be anonymised. I realise that this will limit the options for re-use of my data. (explain)

Although the data will be anonymised, we realize that some stories might be familiar within small communities. So we can not share these stories beyond the researchers, in order to safeguard the privacy of the participants. We will protect the data against misuse by storing them in secured place, and my making sure interviews are securely sent to the translator and that the researcher and translator delete the data on their own device.

2.4 I will stick to the privacy regulations of my organisation

- Yes

I will follow Rutgers' rules on privacy.

3. Making data findable

3.1 The data collection of my project will be findable for subsequent research. E.g., on a catalogue, a web portal, or through the search engine of the repository (note: this is key item 3, which you should report to ZonMw at the end of your project).

- No, I have not yet chosen an archive or catalogue/web portal

Because we have too sensitive data, we can not share them (see 4.1).

3.2 I will use a metadata scheme for the description of my data collection (note: this is key item 7, which you should report to ZonMw at the end of your project).

- No, I have not yet chosen a metadata scheme

My metadata scheme will include information about the research team and their affiliations, funding and ethical permission, the data collection procedure (including recruitment and data cleansing), response rates and sample characteristics, an overview of the concepts and the research instruments, and a codebook in Dutch and English (including routing).

3.3 I will be using a persistent identifier as a permanent link to my data collection (note: this is key item 1, which you should report to ZonMw at the end of your project).

- No, I will not be using a persistent identifier (please explain)

Because we have too sensitive data, we can not share them (see 4.1).

4. Making data accessible

4.1 Once the project has ended, my data will be accessible for further research and verification.

- No (please explain)

This study deals with personal data of vulnerable people (people with a migration background living in the Netherlands) on a sensitive

topic (health, pregnancies, family planning). We will collect personal information on app use, and how certain stories on reproductive choice, and the impact of religion, gender norms and family/cultural norms are received, through focusgroups discussions. As the communities the respondents live in are small, stories can easily be recognised, so we can not guarantee anonymity when sharing data. In other words, sharing data might harm the privacy and safety of our participants. Therefore we can not share data, but we can and shall share our research instruments, our results and our evaluation including lessons learned.

4.2 Once the project has ended, my data collection will be publicly accessible, without any restrictions (open access).

- No, there will be access restrictions to my data collection (please explain)

We will only share the research instruments, a description of the research process, the results and our evaluation of the research.

4.3 I have a set of terms of use available to me, which I will use to define the requirements of access to my data collection once the project has ended (please provide a link or persistent identifier; also note that this is a key item 4, which you should report to ZonMw at the conclusion of your project).

- Yes, my institution employs internationally available terms of use

Because we have too sensitive data, we can not share them (see 4.1).

4.4 In the terms of use restricting access to my data, I have included at least the following:

- Other (please explain)

Because we have too sensitive data, we can not share them (see 4.1).

5. Making data interoperable

5.1 I will select a data format, which will allow other researchers and their computers (machine actionable) to read my data collection (note: this is key item 5, which you should report to ZonMw at the end of your project).

- No (please explain)

Because we have too sensitive data, we can not share them (see 4.1).

5.2 I will select a terminology for recording my data (e.g., code, classification, ontology) that allows my dataset to be linked or integrated with other datasets (note: this is key item 6, which you should report to ZonMw at the conclusion of your project).

- No (please explain)

Because we have too sensitive data, we can not share them (see 4.1).

5.3 I will be doing research involving human subjects, and I have taken into account the reuse of data and the potential combination with other data sets when taking privacy protection measurements.

- No (please explain)

Because we have too sensitive data, we can not share them (see 4.1).

6. Making data reusable

6.1 I will ensure that the data and their documentation will be of sufficient quality to allow other researchers to interpret and reuse them (in a replication package).

- I will document the research process (please explain)

I will document how the research was conducted, the process of peer research, the instruments used and the evaluation.

6.2 I have a number of selection criteria, which will allow me to determine which part of the data should be preserved once the project has ended. (see also question 1.9 and 6.1)

- Yes

Clearly, safeguarding privacy is the key criterium, which makes it impossible to share data.

6.3 Once the project has ended and the data have been selected, I can make an estimate of the size of the data collection (in GB/TB) to be preserved for long-term storage or archival.

- Not yet (please explain)

Because we have too sensitive data, we can not share them (see 4.1).

6.4 I will select an archive or repository for (certified) long-term archiving of my data collection once the project has ended. (note: this is a key item, which you should report to ZonMw at the conclusion of your project)

- Not yet

Because we have too sensitive data, we can not share them (see 4.1).

6.5 Once the project has ended, I will ensure that all data, software codes and research materials, published or unpublished, are managed and securely stored. Please specify the period of storage.

- Yes, in accordance with VNSU guidelines (please specify the number of years)

We will keep our data, the analysis, research materials, etc. for ten years in a safe place.

6.6 Data management costs during the project and preparations for archival can be included in the project budget. These costs are:

- Unknown (please explain)

We do get free advice from University of Utrecht, and as we cannot make data accessible, we will not have any storage costs, beyond our own storage.

6.7 The costs of archiving the data set once the project has ended are covered.

- Yes (please elaborate)

Archiving the data will only take place on our own secure environment, so no extra costs

are involved.