Plan Overview

A Data Management Plan created using DMPonline

Title: Monitoring long-term impact of COVID-19 on people with MID or low literacy skills

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Funder: ZonMw (Nederlands)

Template: Radboudumc Data Management Plan

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Project abstract:

The COVID-19 pandemic and the preventative measures taken to control it, had a great impact on our society. It was difficult to provide vulnerable people, such as people with a mild intellectual disability (MID) and people with low literacy skills, with adequate information on the preventative measures and these groups were highly impacted by social restrictions in place. To gain insight into their mental health and wellbeing, we developed a survey that was tailored to the needs and capacities of the target groups, that was conducted three times during the pandemic.

In this survey 300-400 people with MID and/or low literacy skills participated, as well as 3000 regular survey participants, per round. Results show that the pandemic had influenced their daily structure and activities and reduced their already small number of social contacts even more. Mental health was lower in these groups than in the general population during the pandemic, although more positive feeslings were reported towards the end of the pandemic.

Because these subpopulations have poorer health and are more vulnerable in social interactions, long term effect of the COVID-19 pandemic may nowadays still be present. The aim of this study is conduct a fourth survey round among the same response populations, approximately 2 years after the pandemic and preventative measures were gone, in order to monitor long-term impact at several domains.

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Monitoring long-term impact of COVID-19 on people with MID or low literacy skills

1. Project info

1.1 DMP version and date

Version 0.1 / 30-Jan-2024: first DMP draft, unrevised
Version 1.0 / 04-Apr-2025: plan revised by researcher
Version 1.1 / 16-Apr-2025: version delivered to funder

1.2 Name of data management support staffconsulted during the preparation of this plan anddate of consultation.

Mirjam Brullemans
Datasteward
Technology Center Data Stewardship
Mirjam was consulted several times during our previous study. This datamangementplan is set up according to our previous version

1.3 Does the project consist of multiple (sub)projects?

- No

1.4 Project number(s)

PaNaMa nr 110820

1.5 Project leader (PI); provide contact information (Name, email address, phone number)

Fieke Raaijmakers, fieke.raaijmakers@vggm.nl, 06-31997169

1.6 Science department
(and if applicable, also add the research programme and research group(s) involved in the project)

Radboud university medical center Research Institute for Medical Innovation
Department: Primary and Community Care, Radboudumc
Research groups: Healthcare for people with an intellectual disability/Academic collaborative Sterker op eigen benen and Academic collaborative AMPHI IGB.

1.7 Will non-human research (i.e. research NOT performed on human subject data) be performed in this project?

- No

1.8 Will the research conducted in this project involve human participants (WMO compliant / non-WMO)?

- Yes, non-WMO research (please specify which (sub)projects)

1.9 Is review of this DMP needed in order to obtain approval by the Executive Board (Local Feasibility procedure ('Lokale Uitvoerbaarheid'))?

- No, this is not needed.

2. Planning and design

2.1 Will this research project involve collaboration with other parties? (E.g. in collecting, processing, analyzing and/or publishing the data).

- Yes

See 2.2

2.2 If yes, which parties will be involved, and what will be their contribution with regard to collection, processing, analysis and/or publishing of project(s) data?

This research is a joint project of Academische werkplaats Amphi IGB and Academische werkplaats Sterker op eigen benen. Data is collected by all parties and shared with Radboudumc for the purpose of this research. Crowdience is host for the survey platform 'I co-research' that is used for data collection.
Consortiumpartners GGD Gelderland-Midden, GGD Gelderland-Zuid, MEE Gelderse Poort and Pharos are involved in study design, interpretation of results and dissemination.

2.3 If yes, describe which agreements (have been made / will have to be made) with these parties regarding data management and intellectual property?

Agreements with participating centers are laid down in a Consortium Agreement.

A Data Transfer Agreement (DTA) is used to make sure that transferred data from Ico-research (Crowdience) to Radboudumc is only used for the purpose agreed upon.

2.4 Who are the persons involved in data management? Mention all persons that have access to the data, and in which role they will participate.

Institute	Name	Role
Radboudumc - Intellectual disabilities and health	Meike Theunissen	• Data Manager • Data collection • Data processing, analysis (researcher)
Radboudumc - Intellectual disabilities and health	Monique Koks-Leensen	• Data Manager, • DMP writer • Data processing, analysis (researcher)
Radboudumc - Intellectual disabilities and health	Kris Bevelander	• Data processing, analysis (researcher)
Radboudumc - Intellectual disabilities and health	Jane van Geenen	• Data processing, analysis (researcher)
Radboudumc - AMPHI IGB	Fieke Raaijmakers	• Data processing, analysis (researcher)
Radboudumc - AMPHI IGB	Anouk Menko	• Data processing, analysis (researcher)
Crowdience (SST)	Leonie Taxx	• Data collection
Pharos/Stichting ABC	Paméla Melkert	• Data processing, analysis (researcher)
Pharos	Eline Heemskerk	• Data processing, analysis (expert)
MEE Gelderse Poort	Michelle Coenen	• Data processing, analysis (expert)
GGD Gelderland Zuid	José Ketelaar	• Data processing, analysis (expert)

2.5 For human-related research, describe the informed consent procedure. Will consent be obtained from the participants to collect and process their data? Multiple options can be selected, specify the informed consent procedure for the applicable project(s).

- Yes (please specify)

We are using an online informed consent form.
The data is collected anonymously.

We do ask people if they want to leave their emailadress and phonenumber if they want to receive the results of the research, if they want to participate in other research projects, or if they want to have an chance at winning a voucher.
The contactdetails will be exported in an different file than the surveydata, which is deleted after the survey was finished. There is no linkage possible of the personal data to survey data.

2.6 If yes, will consent be obtained from the participants to share and re-use their data for future research, according to the FAIR principles?

- Yes

The obtained informed consent allows for the reuse of data
People have to agree with us using their data for this research and for further research. If they do not agree they can not fill in the survey.

3. Collect and Create

3.1 Will existing data be used for this project?

- Yes (specify which data sources)

For reasons of comparison, we use data from our previous survey rounds.
These data are available to us, and are saved at our own department server.

3.2 Do restrictions apply to the use of these existing data? Describe how the use of these data will be arranged with the owners of the data.

no restrictions apply, we own the data ourselves

3.3 Will human patient data be used from Radboudumc's clinical archives, like Epic, GLIMS, PACS , Dentium, etc.?

- No

3.6 How will privacy of the human participants be safeguarded?

- The data will be anonymized

3.7 How will pseudonymization/ anonymization/other be arranged?

- The data will be pseudonymized / anonymized by using a tool or system different from PIMS (explain in next question)

Data is collected without any personal identifiers, through direct entry in the survey.
The data is collected anonymously.
We do ask people if they want to leave their emailadress and phonenumber if they want to receive the results of the research, or if they want to have an chance at winning a voucher. These contactdetails will be exported in an different file than the surveydata and can never be linked to survey answers.The contactdetails are deleted after finishing the project

3.8 Please specify how pseudonymization or anonymization will take place. How is the subject ID composed, will identifying elements be omitted, where (and/or in which system) will the Subject Identification Log be saved?

NA

3.9 Provide the details from the Identification Log data in PIMS.

NA

3.10 Describe the data that will be collected / created:
(optional: the data can be described per (sub)project, for instance workpackages or chapters)

(Sub)Project *(optional)*	**Volume, N=**	**Existing / new data**	**Data source**	**Data collection tool / system**	**Data Type**	**File Format**	**Storage space**
Survey data from target group	n=220	new	direct entry onto research platform	online platform ico-research	quantitative survey data	.xls	<1 GB
Survey data from MHS panel	n=2500	new	direct entry onto research platform	online platform ico-research	quantitative survey data	.xls	<1 GB
e-mail from those participants willing to receive results or incentive	n=170	new	direct entry onto research platform	online platform ico-research	quantitative survey data	.xls	<1 GB

3.11 Are study participants randomly allocated to groups? Select which option applies to the randomization (if any) of the participants.

- No randomization will take place.

4. Store and analyze

4.1 Where will the data be stored during the data collection (e.g. for combining, processing, and/or analyzing data)? Check the boxes for both digital and paper data storage.

- Data will be stored in one (or more) dedicated and secure workspaces(s) in the Digital Research Environment (DRE)

4.2 Give a short description of all the options that will be used for data storage during the data collection. Provide the locations for digital and paper data.

Research data is stored in the DRE, workspace name *dws-687-COVIDMTR*

4.3 How will data security be ensured during the data collection?

Not applicable, since standard Radboudumc facilities are used.

4.4 How often, where and by whom will backups be made of the data?

Not applicable, since standard Radboudumc facilities are used.

4.5 How will access to the data be arranged for all parties, internal and external (if applicable); which restrictions will be applied to data access during the data collection?

Access to the DRE workspace is only granted by the delegated owners of the workspace to individual members of the research team. These are both Radboudumc members and members of external parties.

4.6 Which software or tools will be needed to process or analyze the data?

- Microsoft Excel
- SPSS

4.7 Will standard facilities, (like Zero Clients "werkplek 2.0", Fat clients provided by Radboudumc ICT or DRE), be sufficient to process and analyze the data or will extra computing power and memory be required ?

- The Radboudumc standard facilities will suffice for processing and analyzing the data (virtual 'werkplek 2.0', standard fat clients, standard DRE work space)

4.8 What will be the estimated costs for managing the dataduring the study, and how will these be covered?

All costs for data management during the study (the use of RDR, servers, standard DRE workspace) are covered by the department (overhead) or by the Radboudumc.

4.9 How will you structure your data? Briefly elaborate on the naming conventions and the structure of the files and directories.

Files will be structured in folders using the following naming scheme: date_namefile_version number.

4.10 How will version control be applied, with clear version numbers, to maintain all changes that will be made to the data?

A 'revision' numbering system is used (v01, v02 etc), if necessary, initials are added to version numbers to show who has made the amendments.

4.11 Which documentation will be added to the data to (further) describe the data collection?

- I will make use of a codebook, that describes all data items in the data collection
- I will link the data to one or more scientific publications
- I will include software (versions) that will be used to process and/or analyze the data
- I will include syntaxes that will be used to process and/or analyze the data

5. Archive and share

5.1 Describe the data that will be archived for the predetermined legal retention period.

All source data - in raw and processed data files, and other study essential documents (research files) that are required for verification purposes will be archived within the Radboudumc for 10 years

5.2 Where will the data (described in question 5.1) be archived for the predetermined legal retention period after the research? Provide the locations for digital and paper data.

Research files are archived at a departmental shared network folder
Research data is archived in the Radboud Data Repository, collection identifiers:

ru.rumc.cov19lvblg_t0000020a_dac_543,
ru.rumc.cov19lvblg_t0000020a_rdc_406

5.3 Will there be any issues that affect the sharing of (parts of) the data collection after the research? If so, briefly describe these issues.

- No, all data from my research project will be shared after the publication of the results.

5.4 Which (part of the) data will be made findable and shared for reuse and/or verification?
(See also the table from question 3.10 that describes the data collection)

• Final versions of raw data collections and analyzed data
• Documentation/codebooks necessary for understanding the data
• Questionnaires that were developed for this project, such as the patient (food) diaries
• Read me.txt for understanding the structure and contents of the documents

5.5 How will the data be made findable and shared for reuse and/or verification? Select the options that apply, and provide further details the comments field.

- Data will be published in a data repository or other online data archive (e.g. Radboud Data Repository, DANS Data Station, disciplinary repository, data archive) (please specifiy)

The RDR will be used to guarantee long-term accessibility of the research data from this project.

5.6 Will restrictions be applied to access to (parts of) the data?

- No, all data will be made available without restrictions

The anonymized data will be accessible in the Radboud Data Repository under open access.

5.7 Will a license be applied to the published data? If yes, what license?

The license applied is CC BY-NC: This license allows reuse for non-commercial purposes only, and only for the period that is given. Anyone reusing the data must provide credit to the original author.

5.8 In case of restricted access, what are the conditions for access to the data? If yes, how are these defined, e.g. in a consortium agreement, data use agreement and/or other terms of use?

NA

5.9 How will metadata be published to describe the data collection, and to enable findability of the data collection? And which metadata will be shared, e.g. will standards be used?

- Dublin Core and DataCite Metadata about the data collection will be registered in RIS
- Metadata about the data collection will be published via the data repository/repositories (see above, please specify which metadata standard(s))

5.10 Will the dataset be made findable by means of linkage to a persistent identifier (PID) like a DOI, a Handle or other PID? Please provide the PID here as soon as it is available!

Yes a DOI will be assigned to the published data collections in Radboud Data Repository: ru.rumc.cov19lvblg_t0000020a_dsc_242

5.11 Which documentation will be added to the published data collection to enable reuse? (see also 4.6 and 4.11 for examples of data documentation)

• Documentation/codebooks necessary for understanding the data
• Read me.txt for understanding the structure and content of the documents
• SPSS syntaxes that were used to transform, restruct and analyze the data.

5.12 What will be the estimated costs for data archiving and/or publication after the study, and how will these be covered?

Costs for data management have not been budgeted for this project. These costs are covered by the department (overhead) or by the Radboudumc.
Collections in the RDR are free, as this is the case for up to 200GB storage per year, per research project.

5.13 Which (bio)medical or other discipline specific terminology (vocabularies, classifications, ontologies or other standards) will be used within the data collection?

None

5.14 Which data formats will the data collection contain? See also 3.10, is there a need to migrate the data to (a) preferred data format(s)?

For this project, the following preferred data format are used:
- Word and other text documents are saved as .PDF files.
- Excel files are saved as .CSV files.
- SPSS files are saved as .DAT/.SPS (syntax) files.

5.15 If applicable, describe your strategy for publishing the analysis software that will be generated in this project.

SPSS is used to process and analyze data