Plan Overview

A Data Management Plan created using DMPonline

Title: Data collection to support developing a crosswalk between EQ-TIPS and EQ-5D-Y

Creator:ea stolk

Principal Investigator: Leona Hakkaart van Roijen, Elly Stolk

Data Manager: Elly Stolk

Contributor: Yan Li

Affiliation: Erasmus University Rotterdam

Template: Data Management Plan v4.6

ORCID iD: 0000-0003-0635-7388

ORCID iD: 0000-0001-5968-0416

Project abstract:

EQ-TIPS is a new health measurement tool designed for young children, with its descriptive system now nearly finalized. To develop value sets for EQ-TIPS and enable meaningful comparisons of its results with the widely used EQ-5D-Y (a well-established pediatric health assessment tool), we aim to support developing a crosswalk between these two instruments. This crosswalk will allow researchers, clinicians and policymakers to interpret and integrate health data collected with either tool, supporting robust research findings, consistent tracking of children's health outcomes, and well-informed decision-making in pediatric healthcare and health policy. To create this reliable crosswalk, we need high-quality paired data on both EQ-TIPS and EQ-5D-Y from parents of young children with chronic conditions across multiple countries. Additionally, family burden will be measured to enrich contextual evidence regarding caregiver perspectives and the broader familial impact of chronic childhood conditions, and we have received funding from EuroQol to support this international data collection effort.

ID: 204877

Start date: 01-10-2025

End date: 30-09-2026

Last modified: 05-08-2026

Grant number / URL: EuroQol Research Foundation, 2138-TR

Copyright information:

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Data collection to support developing a crosswalk between EQ-TIPS and EQ-5D-Y

General

Please tick the following boxes if you agree to act according to the following terms:

- I will answer all questions truthfully and to the best of my knowledge
- I will discuss the data management plan with my research team
- I will check and, if necessary, update my data management plan a minimum of once a year

Support in writing a data management plan is available through the faculty Data Stewards. Which research support professional is available for you?

- Data Steward of my own faculty - ESHPM

Scientific research must be conducted in line with existing guidelines on good research practices and integrity. Please tick the boxes if you have read and understand these guidelines and will act accordingly.

- The European Code of Conduct for Research Integrity (ALLEA, 2023)
- The Netherlands Code of Conduct for Research Integrity (VSNU, 2018)

Administration and Project Description

1. Provide the details of your project
Project title

Data collection to support developing a crosswalk between EQ-TIPS and EQ-5D-Y

Project start date as intended

2025-10-01

Project duration in months as intended

8

Funding body (if applicable)

EuroQol Research Foundation

Grant number (if applicable)

2138-TR

Date of DMP Version 1

2026-05-21

Current DMP - Version [if other than version 1]

Question not answered.

Current DMP - Date [if other than version 1]

Question not answered.

2. List the name and affiliation of all members of the research team.
List the researcher responsible for research data management first.
For PhD projects, please indicate the Promotor(s) and/or Daily Supervisor(s) with a (!)

	Name	Email	ORCID	Research Institution
1	Elly Stolk	stolk@eshpm.eur.nl	0000-0001-5968-0416	EuroQol Research Foundation; ESHPM
2	Leona Hakkaart-van Roijen	hakkaart@eshpm.eur.nl	0000-0003-0635-7388	ESHPM
3	Yan Li	yan.li.9@student.unimelb.edu.au		University of Melbourne
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3. Briefly summarize the project background and research question(s) to help others understand the purpose for which the data are being collected or created

We will generate cross-sectional quantitative data via an online survey distributed to eligible participants. Participants will be recruited by the professional panel provider Dynata, with a target sample of 10,000 respondents (1,000 participants per country across 10 countries: Argentina, Canada, China, Germany, India, Mexico, Spain, Taiwan, UK, US).

The data collected in the online survey will be exclusively quantitative data, including child & parent demographics and responses from validated questionnaires (EQ-TIPS-5L, EQ-5D-Y-5L, EQ-HWB, CarerQol, IPCQ), as well as related health characteristics and caregiving burden.

4. Specify the research type and briefly describe the methodology, how the data will be collected, and the tools used for data collection, processing and analysis:

Cross-sectional cohort, all participants will fill out one online questionnaire, programmed in Limesurvey by survey host Maths in Health. Maths in Health is a consulting service collecting data on behalf of the study team. Dynata will recruit participants for the survey, while the survey itself will be programmed in LimeSurvey and administered by Maths in Health.

Through Dynata, we will invite parents of children aged 24–59 months with a healthcare professional–confirmed chronic condition to complete a survey on the child's health-related quality of life, the condition's impact on the family, and related health and demographic information. Participants will be redirected to the survey website to complete the questionnaire and then returned to Dynata for reimbursement. A unique Dynata panel ID will be captured to identify completed surveys for payment and prevent duplicate responses.

The survey data can be accessed by us, not by Dynata. All data will be de-identified; we will not be able to relate the survey responses to a specific individual.

The data will be processed by Maths in Health and saved on one of their servers, located in the EU. As survey host, MiH will have access to the survey data and will maintain secure backup copies in its archives in accordance with its data management and retention policies.

MIH will have access to IP addresses and Dynata panel IDs only for study administration purposes, including preventing duplicate responses and facilitating participant reimbursement. Once these purposes have been fulfilled, these identifiers will be removed from the active research dataset. Identifiers may remain in archived backup copies for a limited period in accordance with data retention and backup procedures; however, these backup copies will be phased out over time through routine backup rotation and

deletion processes.

5. Are additional (financial or time) resources required for data management in this project?

- No, I will use the services and resources provided by the EUR

Preparation: Legal Arrangements and Policy

6. With whom will you need to make legal arrangements?

- With research participants
- With third parties

7. List the agreements that you will initiate and with whom will you make them.

Who	Type of agreement
Participants	Informed consent
Dynata	Participant recruitment
Maths in Health	Survey hosting
Multiple copyright holders	License agreements for the use of their respective PROMS (incl EQ-5D, CarerQol, IPCQ)
Yan Li	Independent researcher

8. List the agreements or other data management policies that you need to uphold but did not initiate. If you are reusing existing data, list the terms of use under which you may re-use them.

Who	Type	Version and Date
Funder	master Service Agreement with Maths in Health for hosting surveys of this kind	
	License agreements governing use of included instruments	

9. Do you need to obtain ethical approval for your research project?

- Yes, I am preparing to submit my application

10. If you have obtained ethical approval, list the reference number

preliminary ID assigned to the draft ethical application: ETH2526-0795

During research: Collecting and analyzing

11. Specify what data you will be collecting and indicate format, estimated size, and whether this is data that you will be generating or existing data that you will be re-using.

Type	Data Classification	Format	Estimated size	Generate or Re-use
Digital survey data	Internal	.csv	1-5 GB	Generate

12. Will you be collecting or re-using (sensitive) personal data?

- Yes – Personal data that is sensitive --> Consult your faculty's Privacy Officer

13. If you collect or re-use (sensitive) personal data, how will you protect the privacy of participants?

- I will pseudonymize the data

14. Please elaborate on your anonymization/ pseudonymization plans. If you are working with multiple datasets, please specify which datasets will be anonymized and which will be pseudonymized.

Anonymization plans

- A panel-assigned pseudonymous respondent ID and the participant's IP address are collected during the survey solely for operational and data-quality purposes, namely: 1) to enable participant reimbursement, and 2) to verify data integrity by detecting duplicate or fraudulent responses
- IP addresses will be collected **temporarily** for data-quality and duplicate-response checks and will be deleted once these validation procedures have been completed.
- Panel-assigned participant ID numbers will be retained separately in a secure and access-restricted administrative file for payment administration, audit, or research integrity purposes. Neither IP addresses nor participant ID numbers will be included in the analytical research dataset.
- These identifiers will not be used for participant identification

The survey hosting provider **Maths in Health** may temporarily retain encrypted server logs and backup copies in accordance with standard security and disaster recovery procedures. Such retention is governed by the provider's data protection and retention policies and is not used for research purposes. The research team will ensure that identifying information is removed from the analytical dataset as soon as operationally feasible and that all active research data are deleted or anonymized in accordance with institutional and legal retention requirements

Pseudonymization

- To minimize the risk of participant re-identification on the basis of survey data, the survey has been designed according to principles of data minimalization.
  - Only birth month/year will be collected, no exact dates
  - No address, postcode, or city-level location data will be collected; location information will be limited to whether participants reside in urban or rural area

15. Will you be collecting or re-using non-personal sensitive data?

- Yes

response to 12, 13 and 15 updated based on feedback from the Privacy officer

16. Where will you store your data during the project? You can select multiple options.

- EUR OneDrive

The research team wil use One-Drive to save the data during the project. All data exchanges will be handled through secure upload and download environments, such as one-drive.

18. What hardware and software do you use? Select all applicable options.

- Private hardware [e.g. personal laptop, private external hard-drive]
- EUR supported software as found in the software catalog

19. If you use private hardware, software, or freeware, please specify what and for what reason:

The data is stored in secure cloud environments.
I do not have a EUR laptop so i am using my own device when i need to view the data during fieldwork. No copies of the data will be retained on my personal device.

20. Are regular backups made of your data?

- Yes, I use only EUR supported tools (as listed in Q18), thus to a limited extent backups are made automatically
- Yes, manually (please specify WHO makes the backups and HOW OFTEN backups are made in the additional information box).

The survey hosting provider **Maths in Health** may temporarily retain encrypted server logs and backup copies in accordance with standard security and disaster recovery procedures. Such retention is governed by the provider’s data protection and retention policies and is not used for research purposes. The research team will ensure that identifying information is removed from the analytical dataset as soon as operationally feasible and that all active research data are deleted or anonymized in accordance with institutional and legal retention requirements

21. Who manages access to the data?

- Researcher responsible for research data management

I (Elly Stolk) will manage the data during the project. Upon completion of the project, only a fully anonymized copy of the data will be retained and made available for secondary use via EuroQol's data repository SAVED

22. Who will have access to the data (during the project)?

- A third party involved in my research (please specify in the additional information box)
- Only researchers as indicated under ‘Administration & Project description’
- Maths in Health (survey host)

23. How are you going to make sure your data will be accessible in case of staff changes, illness, etc?

- I have not yet discussed this with the research team or checked with my department or faculty

24. Have you and your research team agreed on a way to name and order project folders and files?

- No - I have not yet discussed this with the research team

25. Have you and your research team agreed on how to handle versioning of files?

- No - I have not yet discussed this with the research team

Research Publication: Data sharing and re-use

26. What data (and code) will be shared in a research data repository?

- All data (and code) produced in the project

27. Please specify why you are unable to share (all) data (and code)

Upon completion of data collection, after quality checks

28. List the data (and code) that you plan to share in a research data repository. Also list the information / documentation / metadata that you will include to make the data package self-explanatory and re-usable in the future (for other researchers and yourself)

Data	Format	Size
anonymized survey data	.csv	< 1 GB
codebook	.pdf	< 1 GB

29. In which repository will you place the metadata, data, and/or code that are associated with your paper?

- Other (please specify in the additional information box).

EuroQol's data repository

30. What metadata standard will you use to document your research?

- DCMI [Dublin Core Metadata Initiative] (Note: Default within the EUR Data Repository)
- Other (please specify in the additional information box).

extension: retention period (not relevant for this data set)

31. Will you place any restrictions on re-using the data you plan to share?

- No

34. Under what license will you make your data available for re-use?

- Creative commons (e.g. CC0 or CC-BY, please specify in Q.35)

35. Please specify which license

CC-BY

After research: Archiving

36. You may be obliged to destroy some data before archiving. Do any of such obligations apply to you?

- Yes - Privacy law [e.g. personal data of participants]

We'll protect the privacy of participants by deleting panel ID and IP addresses.

37. List the data and all documentation you will be archiving. These data constitute your archival package.

Data	Format	Size
raw data	.csv	< 1 gb
processed data	.csv	<1 gb
meta data	M-files fields	< 1 gb
code book	pdf	< 1 gb
informed consent forms	pdf	< 1gb
terms of use	pdf	< 1 gb
Ethics approval document	pdf	< 1 gb
DMP	pdf	< 1 gb
legal arrangements	pdf	< 1 gb

38. Where will you be archiving your data?

- Other --> Specify which in Q.39

39. Please list the name of the archive and link to the archive

Name of Archive	retention period	Link
SAVED	> 10 years	https://euroqol.org/research-at-euroqol/fair-principles-saved-data-repository/

SAVED is an acronym: Storage and Access to Valuable Euroqol Datasets

Note: the repository is currently still under development. Datasets are still being added and meta data entry is ongoing to improve searchability of the datasets included in the repository.

In the back end, M-files Cloud is used to store and manage data sets. There are daily back ups. Data access requests will be handled by a dedicated Data Manager. Mf-iles is a general Document Management System also used for other purposes. FAIR principles are applied were possible

- structured metadata and presentation in a searchable catalogue allows the data to be discovered
- data can be retrieved in a controlled way

Datasets currently do not have a DOI

A copy of the data will be retained in MiH archive. The MiH archive stores data primarily for backup, preservation, recovery, or record-keeping purposes. Data in archives are typically not actively used and may be retained according to backup or retention schedules.