Plan Overview

A Data Management Plan created using DMPonline

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

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Template: Data Management Plan v4.6

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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: 16-06-2026

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

the creator(s) as the source of the language used, but using any of the plan's text does not imply that the creator(s) endorse, or have any relationship to, your project or proposal

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

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

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
2	Leona Hakkaart-van Roijen	hakkaart@eshpm.eur.nl	0000-0003-0635-7388	ESHPM
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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:

Crosssectional cohort, all partcipants will fill out one online questionnaire, programmed in Limesurvey by survey host Maths in Health.

Dynata will recruit participants for the survey, while the survey itself will be programmed in LimeSurvey and administered by Maths in Health. Participants recruited through Dynata will be redirected to the survey website to complete the questionnaire. Upon completion, respondents will be redirected back to the Dynata environment in order to process participant reimbursement.

Through Dynata we will invite parents of children aged 24–59 months with a chronic health condition confirmed by a healthcare professional to complete a survey about the child's health-related quality of life, family impact of the child's condition, and related health and demographic information. We will also ask for the child's age and sex, and parent demographic information (age, sex, education level, employment, income etc.).

We will also ask panel members to have their unique Dynata panel member ID captured by the survey platform, in order to inform Dynata which members have completed the study and need to be paid, and to prevent duplicate survey completions.

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.

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 third parties
- With research participants

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 (inclEQ-5D, CarerQol, IPCQ)

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?

- No – My research involves human participants, but I will collect or re-use fully anonymous data

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

- I will fully anonymize 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?

- No

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.

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

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

I do not have a EUR laptop so i am using my own device, while using EUR cloud-services

20. Are regular backups made of your data?

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

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.

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)
- 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?

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

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]

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
meta data	M-files fields	< 1 gb
code book	pdf	< 1 gb
informed consent forms	pdf	< 1gb
terms of use	pdf	< 1 gb

38. Where will you be archiving your data?

- I do not know