Plan Overview

A Data Management Plan created using DMPonline

Title: Extending the crosswalk dataset for EQ-5D-Y-3L and EQ-5D-Y-5L: delivering new inputs

Creator:ea stolk

Principal Investigator: Elly Stolk

Contributor: Bram Roudijk

Affiliation: Erasmus University Rotterdam

Template: DCC Template

ORCID iD: 0000-0001-5968-0416

Project abstract:

A new tool for measuring children’s health, the EQ-5D-Y-5L, is expected to be officially approved soon. To ensure it can be used effectively, we need to understand how its results compare to those of an older, widely used version (EQ-5D-Y-3L). Establishing this link—known as a "crosswalk"—allows researchers and healthcare professionals to interpret and compare data across studies, even when different versions of the tool have been used. This is important for tracking health trends over time, combining results from different studies, and making well-informed decisions in healthcare and policy. To create this link, we need high-quality data from children in different healthcare settings. We received funding to contribute to collecting that data.

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Copyright information:

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Extending the crosswalk dataset for EQ-5D-Y-3L and EQ-5D-Y-5L: delivering new inputs

Data Collection

What data will you collect or create?

We will generate cross-sectional data from a survey that we will distribute among participants. The participants will be recruited from an online panel (N=90, panel: RarePatientVoice).

The data collected in the online survey will be exclusively quantitative data, including demographics and responses from validated questionnaires.

How will the data be collected or created?

The new data will be collected with help from an online panel (RarePatientVoice, RPV). RPV will only be involved in the data collection process, by allowing us to send a link to an online survey to members of their panel.

Through the RPV we will invite parents of children with Cystic Fibrosis to administer a survey about the general health of their child and questions linked to the disease. We will also ask sex and age of the child.

We will also ask panel members to provide their RPV panel member ID number, in order to inform RPV which members have completed the study and need to be paid.

The survey data can be accessed by us, not by RPV. No other organizations will be involved in the data collection process.

All data is de-identified; we will not be able to relate the survey responses to a specific individual.

Documentation and Metadata

What documentation and metadata will accompany the data?

- codebook
- documentation of the research process including an identifier of the funded research proposal and a brief description of the group of participants.

The survey will produce fully anonymized data. The panel from which respondents are recruited is from the US.

Ethics and Legal Compliance

How will you manage any ethical issues?

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.

I will comply with the Algemene Verordening gegevensbescherming (AVG) We expect that the WMO does not apply to the online data collection and this will be confirmed during the review from the ESHPM ethics committee.

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

This informed consent allows for the reuse of data (note that in the Code of Conduct for Medical Research, ‘reuse’ is
also referred to as ‘further use’)

We will seek informed consent from all online participant. We base our informed consent form on the EUR template. The informed
consent form will be reviewed by expert support staff before it is presented to respondents.

Respondents will be informed about the possibility of reusing the research data in new research project and that only fully
anonymised data will be accessible to other researchers. Respondents will also be informed that the data will be made publicly available in an online repository for future use.

2.3 I will protect my data against misuse

The link to the online survey will be send to people meeting the inclusion criteria by RarePatientVoice. The identity of the respondent will not be known to the research team. The research team will have access only to the anonymised data.

To also limit the possibility for re-identification based on the data that will be collected, these measures will be taken.

- no direct identifiers will be collected, such as names, email/IP adresses, phone numbers, social security numbers, living area (state/, zipcode)
- We'll ask for age as an integer, rather than age of birth
- panel-member ID will be saved only for audit purposes, separately from the rest of the data with role-based access limited to the PIs

RarePatientVoice has access to other personal data (such as contact information for contacting potential participants and renumeration). However, that data is stored separately from the research data and the research team has no access to it.

Rare Patient Voice (RPV) aims to empower patients and family caregivers to have their voices heard through participating in all kinds of research. Patients and family carers have voluntarily registered for panel membership, which gives them opportunity to participate in research ad in order to participate in research. The ultimate goal is to improve the lives of patients.

During the registration process, RPV gathers personal information (name, address, age, etc.). After registration, RPV may ask members to provide additional information regarding their condition. They do this so they can send members invitations to participate in research that best corresponds with their current status and interests. Participants have previously agreed to the privacy policy of RarePatientVoice, and shared their details based on Informed consent and Legitimate interests.

Rare Patient Voice, LLC complies with the EU-U.S. Data Privacy Framework (EU-U.S. DPF) and the UK Extension to the EU-U.S. DPF as set forth by the U.S. Department of Commerce. Rare Patient Voice, LLC has certified to the U.S. Department of Commerce that it adheres to the EU-U.S. Data Privacy Framework Principles (EU-U.S. DPF Principles) with regard to the processing of personal data received from the European Union in reliance on the EU-U.S. DPF and from the United Kingdom (and Gibraltar) in reliance on the UK Extension to the EU-U.S. DPF.

GDPR rights apply, e.g. participants have the right to access the data that RPV has collected, and they can for instance change, delete, or restrict access to. They als have right to file a complaint with supervisory authorities.

How will you manage copyright and Intellectual Property Rights (IPR) issues?

The data will be owned by the EuroQol's Research Foundation and they will manage data access for data reuse requests.
EuroQol datasets available for re-use are presented here: https://euroqol.org/research-at-euroqol/fair-principles-saved-data-repository/
Researchers interested in using any of these datasets can apply for it. A Data Access Committee will review the request and present the Data Applicant with a Data Transfer Agreement to agree on the terms and conditions for sharing the data. Once signed, a copy of the DTA will be saved with the dataset among other completed data transfer agreements.
There are no restrictions on reuse of the data, since it's fully anonymised.

Storage and Backup

How will the data be stored and backed up during the research?

The size of the data is < 1 GB. It will be stored on a server managed by EuroQol based in Europe. All data in the server is automatically backed up. In the case of an event, recovery of the data will be the responsibility of the third-party provider of server IT services. All sensitive personal data will be protected in accordance with applicable privacy regulations.

How will you manage access and security?

For the data archive M-Files will be used.
When a dataset is requested for re-use, a subfolder will be created in M-files named 'Data for Transfer'
The requested data wil be downloaded from M-files in stored in the Data for Transfer folder. Access to this folder will be provided with the researcher who requested the data, who can download it for re-use. The Data recipient warrants in the DTA to also be fully GDPR compliant.

Selection and Preservation

Which data are of long-term value and should be retained, shared, and/or preserved?

The RarePatientVoice ID number can be removed from the data once it is no longer necessary to keep it for audit purposes .

All other data will be kept long term.

The foreseeable research use of the data is by researchers for methodological research. The reason for collecting the data is to create "mappings" between multiple instruments that can be used to assess quality of life in children. Researchers accessing the data may be interested to reproduce our mapping or to test the performance of newer or more advanced mapping algorithms.

There is also some potential for the data to be reused in the context of psychometric research.

What is the long-term preservation plan for the dataset?

The data will be held in the established data repository of the EuroQol Research Foundation. The EuroQol data archive includes a wide range of datasets, including the datasets collected in valuation studies that are re-used frequently.

No costs are involved for archiving data or for sharing data.

EuroQol members and their collaborators are most likely to be interested in this data.

Data Sharing

How will you share the data?

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Researchers interested in using any of these datasets can apply for it. A Data Access Committee will review the request and present the Data Applicant with a Data Transfer Agreement to agree on the terms and conditions for sharing the data. Once signed, a copy of the DTA will be saved with the dataset among other completed data transfer agreements.

Recipients of the data will receive a secure link to a folder where the data can be downloaded.

All datasets have a unique identifier in M-files. If the datasets have a DOI it wil be saved with the data, but the Foundation at the moment doesn't apply for getting DOIs for the data.

Are any restrictions on data sharing required?

- the team is not requesting exclusive use of the data. Access to the data can be requested and will be provided as soon as the dataset is ready and properly archived.
- data recipients will need to sign a data sharing agreement to receive access to the data.

Responsibilities and Resources

Who will be responsible for data management?

During the project, the PI is responsible for data management.
After completion of the study, the EuroQol Research Foundation's data management team will be responsible.

What resources will you require to deliver your plan?

No resources are needed to deliver the plan for data management.

Planned Research Outputs

Dataset - "Crosswalk dataset for EQ-5d-Y-3L and EQ-5D-Y-5L extension: cystic fibrosis"

Responses from parents of children with cystic fibrosis about their child's health condition and general health

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Planned research output details

Title	DOI	Type	Release date	Access level	Repository(ies)	File size	License	Metadata standard(s)	May contain sensitive data?	May contain PII?
Crosswalk dataset for EQ-5d-Y-3L and EQ-5D-Y-5L ex ...		Dataset	2025-12-14	Restricted	None specified	5 MB	None specified	None specified	Yes	No