



EQ-5D

EQ-DAPHNIE Project Data Charter

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A. Principles:

- Data sets arising from the EQ-DAPHNIE Project will be governed under generally accepted principles and frameworks such as the General Data Protection Regulations (GDPR) for the European Union, and other similar frameworks internationally.
- As per the GDPR (and similar) frameworks, persons who provide their personal data remain the principle owners of their data.
- Where relevant, policies and principles reflecting Indigenous ownership and stewardship of data will be respected.
- Data sets arising from the EQ-DAPHNIE Project will be stewarded by the EQ Research Foundation. The EQ Research Foundation would be considered a Data Controller and Data Processor under GDPR regulations.
- Data sets arising from the EQ-DAPHNIE Project will be managed by the EQ Office, in alignment with the guidance of the SAVED Project.
- Data sets arising from the EQ-DAPHNIE Project will address specific primary research objectives identified by the EQ-DAPHNIE Project Team, as outlined in the Project Team Terms of Reference.
- Data sets arising from the EQ-DAPHNIE Project should also be made available to support a sustained production of secondary research outputs/manuscripts, not necessarily originally envisioned as the primary research objectives of the EQ-DAPHNIE Project.
- Data sets arising from the EQ-DAPHNIE Project are intended for broad scientific enquiries by EQ members and their collaborators (who may or may not be EQ members).
- As such, data sets arising from the EQ-DAPHNIE Project should be available to all EQ Group members to address topical and relevant research questions.
- Data sets arising from the EQ-DAPHNIE Project will not be made available to individuals or organizations external to the EQ Group for commercial purposes.
- The EQ-DAPHNIE Project will create an infrastructure for data collection reflecting the health of populations; future use of the infrastructure (e.g., survey platform) for independent research projects proposed by EQ members will not be governed by this data charter.

B. Ethical Considerations:

- Data collection for EQ-DAPHNIE will be undertaken following appropriate review and approval from relevant ethics review committees in line with their processes.
- As the EQ-DAPHNIE Project is coordinated by the APERSU team at University of Alberta, an initial and overall ethical approval will be obtained by the University of Alberta Health Research Ethics Board (HREB).

- Additional ethical reviews and approvals will be sought for countries where data will be collected, as required for participation by local EQ-DAPHNIE Project Team members (i.e., active co-investigators).
- Additional ethical reviews and approvals will be sought as needed for countries where data will be collected where no local EQ-DAPHNIE Project Team members exist.
- Secondary use of data collected as part of EQ-DAPHNIE requested by EuroQoL members who are part of the original EQ-DAPHNIE Project team will not require additional ethical review and approval (unless such use involves data linkages, see below).
- Secondary use of data collected as part of EQ-DAPHNIE requested by EQ members who are not part of the original EQ-DAPHNIE Project team will require separate review and approval from relevant ethics review boards. Such review will be the responsibility of researchers proposing such analyses.
- Secondary use of data collected as part of EQ-DAPHNIE that involves linkage with any other data source (e.g., local administrative health care utilization data) will require separate review and approval from relevant ethics review boards. Such review will be the responsibility of researcher proposing such linkage and analyses.

C. Guidelines for Secondary Data Use:

1. Requests for access to data arising from the EQ-DAPHNIE will be submitted to a Data Access Review Team (DART), comprised of up to 4 members of the EQ-DAPHNIE Project Team and one representative of the SAVED Data Access Committee.
2. Such requests must be made by an EQ member identified as a project Principal or Co-Principal Investigator.
3. Such requests for secondary data use would be required by all EQ members, whether a member of the EQ-DAPHNIE Project Team or not.
4. DART reviews are not intended to limit access, but rather encourage and support the use of data sets arising from the EQ-DAPHNIE Project. The intended purposes of DART reviews are:
 - a. to ensure data requests conform to the above principles and ethical considerations;
 - b. to facilitate the most efficient use of available data (e.g., can the proposed research question be addressed with the available data?); and
 - c. to coordinate similar requests or interests amongst EQ membership.
5. EQ members proposing projects involving secondary use of data sets arising from the EQ-DAPHNIE Project may apply for independent project funding through the EQ Executive Committee review. Such funding applications should be submitted only after approval via DART review.
6. Authorship of reports/manuscripts arising from data arising from the EQ-DAPHNIE Project should follow the EQ-DAPHNIE Project Authorship Guidelines (see Appendix).