

EUREMS CHARTER

EUREMS:

The European Multiple Sclerosis Registry is, until 2014.06.30, a project run by a consortium of academic institutions and non-profit organizations under the auspices of and with major funding from the European Commission.

General clause:

Partners and data providers in C collaboration strive to make optimal use of compiled data on persons with multiple sclerosis (MS) throughout Europe by pooling of data and joint analysis for the good of those affected. Partners and data providers pledge to adhere to the EUREMS Charter.

Participants:

Partners within EUREMS may be MS societies, patient as well as professional, academic institutions, non-profit organizations within the MS field of other kinds, and MS registry organizations.

Data providers:

EUREMS will compile data from national MS registries, Regional MS registries or international network registries. Data from linking with public or health care related databases may be linked to clinical information from registries.

Nature of data within EUREMS:

EUREMS data may be anonymized, pseudonymized or identifiable, following established rules and legislations on informed consent and ethical approval.

Ownership of data:

All data providers retain full ownership of contributed data, including the right to withdraw data at will. EUREMS holds ownership of compiled high level data. Should data be withdrawn after compilation and analysis, EUREMS retains right of results as well as a copy of data used to obtain the results to be used for support of the results only, not for new analysis.

Use of data for analysis:

Any analysis on compiled EUREMS data not initiated by the EUREMS Board (i.e. EUREMS projects, see below on EUREMS publications) should be preceded by a written application to the EUREMS Board, including certification of ethical approval, when appropriate. Data may be exported for analysis after Board approval to either non-profit organizations or academic institutions.

Board:

The work within EUREMS is headed by a Board made up by one representative of each of the EUREMS partners

Governance:

In case of need of conflict resolution between EUREMS partners and/or data providers, a Governance Board of three persons, appointed by but independent from the Partners, will decide based on a majority decision.

Publication policy:

EUREMS strives to make all results available by published scientific reports. Other kinds of reports may complement but not replace scientific publication. There are three types:

1. **Full EUREMS publications:** Publications of projects initiated and performed by EUREMS, published in the name of EUREMS (with partners and data contributors listed).
2. **Partial EUREMS publications:** Projects initiated by individual partners or bodies outside of EUREMS, building on compiled EUREMS data. On such publications, EUREMS is a co-author.
3. **Independent non-EUREMS publications:** Projects initiated by partners or teams of partners within EUREMS and building on EUREMS data originating from the same partners. On such publications, EUREMS should be acknowledged if the EUREMS infrastructure has been used. It is suggested that partners should be generous to include EUREMS as co-author if the EUREMS infrastructure contribution is more than minimal.

Revision of the Charter:

The EUREMS Charter may be revised by a majority decision in the Board together with a majority decision from the Governance group.