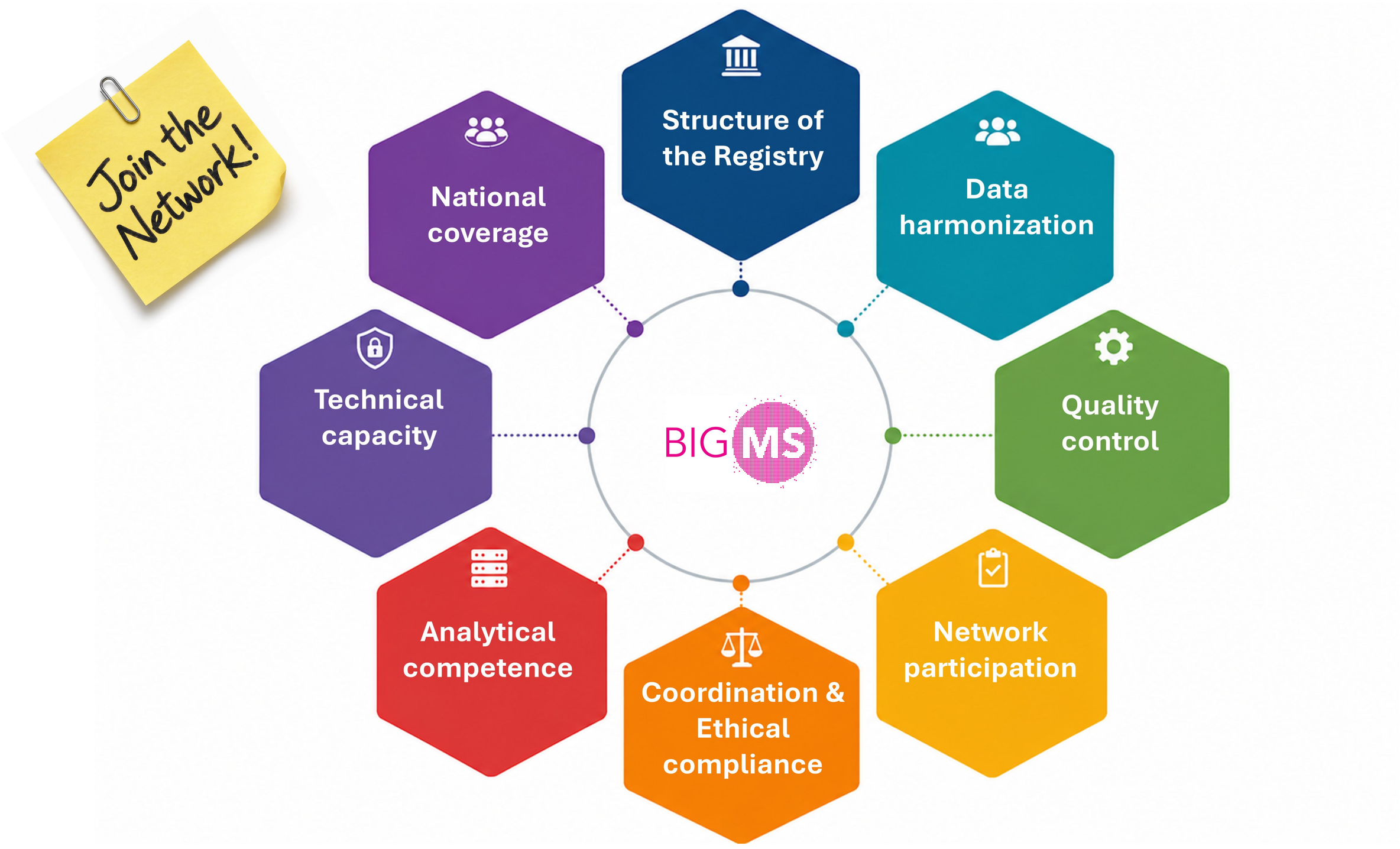
BigMSData Network

Quality Criteria for the Inclusion of New MS Registries

The big Multiple Sclerosis data network

The Big MS Data Network enables collaborative analysis of very large federated or merged amounts of structured data by bringing together leading MS registries and databases. The quality of data offered by the participating Registers is the basis for its excellence in MS research field. In 2025, the Network has finalized a set of criteria for the inclusion of new Registries, based on factors such as registry structure, national coverage, data quality, technical capabilities, and ethical compliance. New applicants need to fulfil the criteria and provide relevant documentation, which will be assessed for the inclusion.



Structure of the registry

- Registry maintained as active and regularly updated
- Availability of basic descriptive analyses
- Collection of data on onset and diagnosis, demographics, DMT treatments, SAEs, clinical outcomes…

Quality control

- Quality control procedures formally defined
- Periodic internal audits on consistency, completeness, and accuracy
- Identification and correction of critical data errors through documented procedures

Network participation

- Formal commitment to active participation in the BMSD network
- Participation in regular meetings
- Adherence to co-authorship policies
- Contribution to CDM updates
- Involvement in scientific initiatives

National coverage

Coverage ≥50% of 85% of the target MS population in the respective country

Analytical competence

- Ability to adapt and implement CDM scripts
- Capacity to participate in federated analyses and federated learning initiatives

Coordination & Ethical compliance

- Definition of a scientific coordination structure
- Collection of informed consent in compliance with GDPR or national regulations
- Availability of ethics committee approval
- Clear identification of the data controller
- Documentation of policies of data access

Data harmonization

- BMSD Common Data Model (CDM)
- Execution of the BMSD script (built on the CDM) and provision of aggregated results

Technical capacity

- Secure infrastructure for data entry, storage, and sharing
- Data anonymization and security measures with national standards