Statement of Works: Epidemiological Analysis to Support MND Prevalence Review

Background

The MND Association is undertaking a formal review of national incidence and prevalence estimates for motor neurone disease (MND) in the UK. This work aims to reconcile variation across three primary data sources:

- The MND Register (hosted by King's College London and Oxford University)
- Hospital Episode Statistics (HES)-derived datasets
- The MND Association internal database

The MND Register is recognised as the most clinically robust dataset; however, variation across sources, driven by methodological differences and incomplete reporting, requires structured analytical reconciliation.

The MND Association is working in partnership with the MND Register team to align datasets, quantify completeness, and produce a validated, defensible national prevalence estimate.

Objective

To provide specialist epidemiological and statistical expertise to support the validation and reconciliation of MND prevalence and incidence estimates across multiple datasets, working in collaboration with MND Association and the MND Register team.

Scope

The consultant will deliver the following:

Data audit and harmonisation

- Review structure, completeness, and key variables across:
    - MND Register dataset (via TRE access)
    - HES-derived aggregate datasets
    - MND Association internal dataset
- Identify inconsistencies in case definitions, coding, and inclusion criteria
- Propose a harmonised analytical framework

Case definition and cohort alignment

- Develop and document a standardised case definition for MND across datasets
- Address inclusion of subtypes (e.g. ALS, PLS, PMA, PBP) and uncertain diagnoses
- Align cohorts to enable meaningful comparison

Deduplication and overlap assessment

- Develop methodology to identify and account for duplication within and across datasets
- Provide clear assumptions and limitations
- Quantify overlap where feasible

Survival and mortality adjustment

- Incorporate linked mortality data (ONS) within the MND Register
- Refine estimates of the population currently living with MND
- Assess impact of survival assumptions on prevalence

Capture-recapture and completeness analysis

- Assess feasibility of applying capture-recapture methods
- If appropriate, produce adjusted estimates of total case ascertainment
- Provide confidence intervals and sensitivity to assumptions

Sensitivity analysis

- Develop low, central, and high prevalence scenarios
- Quantify impact of:
  - Under-reporting
  - Site non-submission
  - Case definition variation

Outputs and reporting

- Produce:
  - Aggregated analytical outputs suitable for export from the TRE
  - A technical methodology report
  - Summary outputs suitable for senior stakeholders (ELT)
- Clearly document assumptions, limitations, and recommended interpretation

Reproducible code

- Develop and document all analytical code within the TRE environment
- Ensure code is accessible and interpretable by the MND Register team
- Support reproducibility of analysis

Working environment (essential requirement)

The consultant will work within the King's College London Trusted Research Environment (TRE) where the MND Register data is securely held.

This includes:

- Accessing and analysing data within the TRE only (no local download of raw data)
- Using available analytical tools (e.g. R, Python, MATLAB)
- Exporting only approved, aggregated outputs in line with disclosure control requirements
- Collaborating with the MND Register team on data structure and analytical approach

Experience working within secure data environments (e.g. TREs, NHS Digital, ONS Secure Research Service) is essential.

Deliverables

- Data audit and harmonisation report
- Standardised case definition framework
- Deduplication and overlap methodology
- Survival-adjusted prevalence estimates
- Capture-recapture feasibility assessment and outputs (if applicable)
- Sensitivity analysis scenarios
- Final technical report
- ELT-level summary outputs
- Fully documented analytical code within TRE

Timeline

- **Duration:** Up to 6 months
- **Start date:** June 2026

Governance and collaboration

The consultant will:

- Work closely with:
    - MNDA Prevalence Working Group
    - MND Register data science team (KCL)
- Attend regular technical and progress meetings

- Operate within agreed governance, data sharing, and publication frameworks

Person specification

Essential:

- Advanced expertise in epidemiology, biostatistics, or health data science
- Experience applying statistical methods such as capture–recapture or similar
- Experience working within secure data environments (TRE, NHS Digital, ONS, etc.)
- Strong programming skills (R / Python / MATLAB preferred)
- Flexible working pattern (expected 2–3 days per week equivalent)

Desirable:

- Experience with neurodegenerative disease datasets
- Understanding of NHS data structures (HES, ONS)
- Experience working in multi-partner research collaborations
- Demonstrable experience working with disease registries or population health data

Procurement and next steps

Interested candidates/suppliers should provide:

- A brief proposal outlining approach to the scope
- Relevant experience and examples of similar work
- Availability and proposed timeline
- Day rate and estimated cost within the stated budget

Key considerations

- This work is a collaborative exercise, not an independent audit
- The MND Register is the primary reference dataset; analysis should support alignment and understanding of variation
- Outputs must be suitable for both technical validation and strategic communication