Supplemental Appendix I

Systematic Review Data Collection Form

Reference Information:

Authors: _____

Title: _____

Journal: _____

Year: _____   Volume: _____   Issue: _____   Page Numbers: _____

Language of Publication: **_____**

Reason for exclusion:

☐ Non-English
☐ Not relevant (not assessing comorbidity)
☐ Review article
☐ Not original data (data presented in another paper already)
☐ Methods not reported (thus cannot be evaluated)

General Information:

Continent Where Data Collection Occurred (check all that apply)

☐	Africa	☐	Asia
☐	Australia	☐	Europe
☐	North America	☐	South America

Country or Countries Where Data Collection Occurred _____

State/ Province/ County/ City Where Data Collection Occurred (if not national) **_____**

Time Period for Data Collection: _____

Study Population:

Population-Based Sample: ☐ Yes   ☐ No

Sample Size: _____

Response Rate: _____

☐ Unknown

☐ Not Applicable*

Choose not applicable in studies that did not directly contact patients (i.e. chart reviews, administrative data studies, etc)

MS Definition and Description:

Diagnoses included (mark all that apply):

☐ RIS (Radiologically Isolated Syndrome)

☐ CIS (Clinically Isolated Syndrome)

☐ MS (Multiple Sclerosis)

☐ NMO (Neuromyelitis Optica) spectrum disorder

☐ ADEM

☐ Other CNS demyelinating disorder

Diagnostic Criteria used for MS

☐ Schumacher

☐ McAlpine

☐ Rose

☐ Bauer

☐ Poser

☐ McDonald 2001

☐ McDonald 2005

☐ McDonald 2010

☐ Other _____

☐ Not reported

Clinical courses of MS included (mark all that apply):

☐ Relapsing remitting

☐ Secondary progressive

☐ Primary progressive

☐ Progressive relapsing

☐ Uncertain

☐ Not reported

Duration of MS from onset: mean _____   SD _____

Age of MS onset: mean _____   SD _____

EDSS: median _____   range _____

                   mean _____   SD _____

Comorbidity Information:

Definition of condition: _____

_____

_____

_____

Were Diagnostic Criteria Used to Make the Diagnosis of Comorbidity?
    ☐ Yes
    ☐ No
    ☐ Not reported

     If yes, please list the criteria below

       _____

       _____

       _____

Methodological Information:

Data Sources (mark all that apply):
☐	Door-to-door survey	☐	Telephone survey
☐	Mailed survey	☐	Administrative databases
☐	Hospital/clinic chart review	☐	Prescription drug database
☐	Registry/clinical database		
☐	Other (specify): _____		

       _____

How was Diagnosis Established (mark all that apply)?

    ☐ Clinical Assessment by a Health Professional
    ☐ Interview
    ☐ Medical chart review
    ☐ Administrative data codes (specify codes: _____)
    ☐ Self-report of a condition (diagnosed by a health professional)
    ☐ Self-report of a condition (undiagnosed by a health professional)
    ☐ Use of specific prescription drug
    ☐ Genetic test
    ☐ Imaging Test (x-ray, ultrasound, CT, MRI, etc)_____
    ☐ Laboratory test (specify): _____
    ☐ Other (specify): _____

_____

☐   Not reported

If by interview and physical assessment, interviewer blinded to case control status (diseased vs. not diseased)?

☐ Yes   ☐ No   ☐ Not applicable

Overall Incidence in MS population: _____

             LCL _____   UCL _____

Age-standardized incidence: _____

             LCL _____   UCL _____

             Standard population used: _____

Overall Prevalence: _____

Age-standardized prevalence: _____

             LCL _____   UCL _____

             Standard population used: _____

Breakdown of Incidence/Prevalence by Socio-Demographic Factors

		Incidence	Prevalence	Not Specified
Gender	Male			
	Female			
Area of Residence	Urban			
	Rural			
Age				
Ethnicity				

Comparative Data (note this section will also serve to assess quality for studies with controls)

Comparisons to other populations (controls): ☐ Yes ☐ No

If yes, selection of controls:
☐ From literature
☐ Clinic-based
☐ Hospital-based
☐ Community-based
☐ Population-based
☐ Not reported

Comparability of cases and controls on basis of design or analysis:

Matched ☐ Yes ☐ No
     If yes, on ☐ sex ☐ age ☐ ethnicity ☐ region

             ☐ other specify_____

If not matched, study controls for ☐ sex ☐ age ☐ ethnicity ☐ region

             ☐ other specify_____

Definition of controls:
☐ No history of MS
☐ No description
Response rate in controls _____ Same as in MS cases ☐ Yes ☐ No

Assessment of comorbidity comparable in cases & controls ☐ Yes ☐ No ☐ Not reported

Comorbidity data for comparison population

Overall Incidence in comparison population: _____

        LCL _____ UCL _____

Age-standardized incidence: _____

LCL _____   UCL _____

Standard population used: _____

Overall Prevalence: _____

Age-standardized prevalence: _____

LCL _____   UCL _____

Standard population used: _____

Breakdown of Incidence/Prevalence by Socio-Demographic Factors

		Incidence	Prevalence	Not Specified
Gender	Male			
	Female			
Area of Residence	Urban			
	Rural			
Age				
Ethnicity				

Quality Assessment[1,2,3]

<u>REPRESENTATIVENESS OF SAMPLE</u>

1. Is the target population clearly defined?   ☐ Yes ☐ No ☐ Unclear   ☐ Not reported

> e.g. The target population must be defined by shared characteristics assessed and measure accurately. Some of these characteristics include age, sex, ethnicity, income, etc. Clear inclusion and exclusion criteria.

2. Was either of the following ascertainment method used (must be one or the other)

1) probability sampling OR
2) entire population surveyed ☐ Yes ☐ No ☐ Unclear ☐ Not reported

e.g. Members of the target population were identified through a sampling frame or listing of potential respondents. This listing must provide access to all members or the defined target population except for exclusions acknowledged by the study authors.

3. Is the response rate ≥70% ☐ Yes ☐ No ☐ Unclear ☐ Not reported
* note that if entire population captured using health claims data or registry mark 'yes'

4. Are non-responders clearly described? ☐ Yes ☐ No ☐ Unclear ☐ Not reported
☐ Not applicable

5. Is the sample representative of the target population? ☐ Yes ☐ No ☐ Unclear ☐ Not reported

e.g. need to ensure that non responders have similar characteristics as responders (otherwise may have selection bias)
note that if entire population captured using health claims data mark 'yes'

ASSESSMENT OF COMORBID CONDITION

6. Were data collection methods standardized? ☐ Yes ☐ No ☐ Unclear ☐ Not reported

e.g. Identical methods of assessment and data collection were used with all respondents so that the information for analysis is completely comparable. Standardization of methods not only refer to eliciting information from respondents but also to interviewing training, supervision, enlistment of respondents and processing of data.

7a. Were validated criteria used to assess for the ☐ Yes ☐ No ☐ Unclear ☐ Not reported
presence/ absence of multiple sclerosis?

e.g. or a validated scale, diagnostic tool, survey, etc.

7b. Were validated criteria used to assess for the ☐ Yes ☐ No ☐ Unclear ☐ Not reported
presence/ absence of disease?

e.g. or a validated scale, diagnostic tool, survey, etc.

STATISTICAL ANALYSIS

8. Are the estimates of prevalence and incidence given with confidence intervals and in detail by subgroup (if applicable)? ☐ Yes ☐ No ☐ Unclear ☐ NR

9. Are standardized estimates reported? ☐ Yes ☐ No ☐ Not reported

References:

1. Boyle M.H. Guidelines for evaluating prevalence studies. *Evid Based Mental Health*. 1998;1:37-39.
2. Loney P.L. et al. Critical appraisal of the health research literature: Prevalence or incidence of a health problem. *Chronic Dis in Canada*. 2000;19(4) accessed on Nov 27, 2010 on the Public Health Agency of Canada website at: http://www.phac-aspc.gc.ca/publicat/cdic-mcc/19-4/e_e.html.
3. Evans C, Beland S, Kulaga S, et al. Incidence and prevalence of multiple sclerosis in the Americas: a systematic review. Neuroepidemiology 2013;40(3):195-210