Big Multiple Sclerosis Data network: data sharing among five large MS registries

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Introduction

There is a large unmet need in areas of MS research requiring big data which single-country or even international registries lack the sample size and power to address.

The Danish, Italian and Swedish national MS registries, the MSBase and the OFSEP of France merged data for specific projects in the Big Multiple Sclerosis Data (BMSD) Network.

BMSD network mission

BMSD network, by pooling of large scale MS data, aspires to become a leading MS research engine in the world with the ultimate goal of answering and solving key questions in MS research and MS research management.

Purpose

To describe the BMSD network governance, data structure, procedures for data sharing and feasibility of an initial demonstrator project in the BMSD network.

Methods

A feasibility phase of the study has been performed to evaluate differences and commonalities among the five registries.

Data counts of the minimum dataset variables needed to describe the BMSD network, by pooling of large scale MS data, aspires to become a leading MS research engine in the world with the ultimate goal of answering and solving key questions in MS research and MS research management.

Results

The BMSD conceptual organization is reported in figure 1.

A flow chart explaining an example of the selection criteria requested to extract the target population in each registry for a demonstrator project is reported in figure 2.

The BMSD merged datasets for the first demonstrator project aimed at evaluating the longitudinal treatment efficacy in RRMS patients followed for at least 10 years and with at least 3 EDSS score evaluations available consisted of 21,410 MS patients (Table 1).

The treated cohort consisted of 18,275 patients who had received at least 1 DMD prescription, whereas 3,135 patients did not receive any DMD prescription during the follow-up (Table 1).

The follow-up distribution by each registry is reported in figure 3.

Table 1. Main characteristics of the cohort extracted stratified by registry.

<table>
<thead>
<tr>
<th>Registry</th>
<th>Total cohort</th>
<th>Patients with ≥10 years</th>
<th>Follow-up at least 3 EDSS evaluations</th>
<th>Treated patients</th>
<th>Un-treated patients</th>
<th>Total number of EDSS score evaluations</th>
<th>Mean (SD)</th>
<th>Median (min – max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swedish</td>
<td>38,433</td>
<td>9,131</td>
<td>3,810</td>
<td>8,217</td>
<td>9,167</td>
<td>230,401</td>
<td>23.2 (17.0)</td>
<td>11 (3-109)</td>
</tr>
<tr>
<td>Danish</td>
<td>16,502</td>
<td>3,623</td>
<td>3,000</td>
<td>3,623</td>
<td>2,400</td>
<td>20,795</td>
<td>12.8 (4.6)</td>
<td>11 (3-46)</td>
</tr>
<tr>
<td>Italian</td>
<td>1,894</td>
<td>1,716</td>
<td>1,716</td>
<td>1,716</td>
<td>1,168</td>
<td>40,925</td>
<td>21.6 (6.9)</td>
<td>15 (3-122)</td>
</tr>
<tr>
<td>Swedish Brain</td>
<td>1,487</td>
<td>1,168</td>
<td>1,168</td>
<td>1,168</td>
<td>309</td>
<td>8,991</td>
<td>17.6 (5.5)</td>
<td>21 (5-62)</td>
</tr>
<tr>
<td>Other French</td>
<td>916</td>
<td>703</td>
<td>703</td>
<td>703</td>
<td>213</td>
<td>367</td>
<td>2.2 (1.2)</td>
<td>11 (3-102)</td>
</tr>
<tr>
<td>Total</td>
<td>149,636</td>
<td>31,444</td>
<td>31,444</td>
<td>31,444</td>
<td>31,444</td>
<td>437,623</td>
<td>24.4 (17.6)</td>
<td>18 (3-162)</td>
</tr>
</tbody>
</table>

* Excluding Italian Participating Centers

Figure 3. Follow-up distribution by each registry.

The BMSD network will allow pooling of MS data at a scale that raises MS research to a new level, with the ultimate aim of lessening the future burden of the disease for MS patients. BMSD will overcome major unmet scientific needs in MS requiring large long-term longitudinal data.

Conclusions

The BMSD network will allow pooling of MS data at a scale that raises MS research to a new level, with the ultimate aim of lessening the future burden of the disease for MS patients. BMSD will overcome major unmet scientific needs in MS requiring large long-term longitudinal data.

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