Reviewer’s report

Title: The feasibility of collecting information from people with Multiple Sclerosis for the UK MS Register via a web portal: characterising a cohort of people with MS

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Reviewer: Lau Thygesen

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Review of Ford et al: The feasibility of collecting information from people with Multiple Sclerosis for the UK MS Register via a web portal: characterising a cohort of people with MS.

The paper presents a newly collected register on UK people with MS. The register is patient driven in that patients answer questionnaires concerning diagnosis and living with MS. This is both a strength and a limitation of the study. My main concern is the self-selection of persons included in the register. I’m not sure that this sample is representative of the whole UK MS population. I have several questions concerning this issue and other issues of the paper.

The register is basically a prevalence based register, which should be highlighted both in the abstract and in the interpretation. It is very important to note that the population both consists of long-term patients and newly diagnosed patients. This information should also be included in the paper since it is very important to understand the demographics and educational level of the population.

Page 3. The authors state that only one or two sources are used for the construction of the MS registers in other countries. I’m not sure about other countries, but the Danish MS register collects data from a number of sources, but is not dependent on any reporting from the MS patients themselves. Thereby this register minimizes the risk of selective sampling. This should be described more precisely in the text. On page 6 it is repeated that only 1-2 sources are used for the Danish register. What is correct is that 1-2 sources are the most important sources, but other sources are added to the construction of the register.

How was the contact to the MS patients established more precisely? Was it only advertisements and mails to SM society members that were used? Please clarify since it sheds some light on the selection of respondents. It should also be highlighted that the sample is purely self-selected, which may give a immense selection bias in the study.

What does it mean that informed consent at the clinics was obtained? How large a proportion of individuals treated at the clinics have not given informed consent? How was the linkage with the three databases obtained? Which variables were used to obtain identificability of the individual records? And how was it secured that the same MS patient was not included with several records? I’m not convinced how the authors make sure that the same person is not included in the
register more than once.

Page 6. The authors state ‘…this self-reported information has been provided in sufficient quality and volume to provide a profile of the respondents.’ I don’t see how the authors can make this statement. The population is compared to the general population (Table 1), which shows large differences, but I’m not sure what to expect. It should also be highlighted that only 7-8% of the MS population is included in the register (approx. 7,000 included of a population if 85,000 persons). What will the researchers do to increase this low participation rate?

Do the authors have any plans for any updating of the life living with MS? The paper do not make any comments on any plans for updating information in the register. Information on changes would be very valuable both to describe how the decline of MS patients are over time and to study factors at baseline/at diagnosis that influence the decline of functionality and other aspects of MS living. Are there any plans for this updating and is it possible with the data structure?

I think it is a validity problem that the information form MS patients are not validated by neurologists. Have the authors done anything to validate the self-reported diagnostic information from the MS patients?

Do the authors have any information on MS patients not participating in the study? As I mentioned above you could argue that the response rate is very low – any selective differences between participants and non-participants should be described.

General comments on figures and table. It is not customary to comment on the figures and table in the headings. Please move this interpretation to the text.

Figure 1. Is this pattern observed in other countries where nationwide registration of the MS population is available, e.g. the countries mentioned on page 3. I was surprised that there was no gender difference for the progressive subtypes, while females was clearly overrepresented for the relapsing/remitting type.

Figure 3 compared to the national figures? In Denmark, no differences were observed – could this show the selection bias by the sampling method?

Table 1. This pattern is very remarkable. Is this a result of the selection of occupations by the MS patients (no elementary occupations, machine operatives occupational groups) or is it because of a selective self-selected highly educated sample?

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: Yes, and I have assessed the statistics in my report.