Reviewer’s report

Title: Quality of life and trust among young people with narcolepsy and their families, after the Pandemrix® vaccination: protocol for a case-control study

Version: 1 Date: 06 Oct 2016

Reviewer: Tomi Sarkanen

Reviewer's report:

The authors present here a protocol for an extensive and interesting study focusing on quality of life and trust in healthcare in children with post-Pandemrix narcolepsy and their families. In addition, they collect registry data on e.g. income of parents, healthcare consumption and various variables of social media use and effects. Overall, the protocol paper is well written and the study is of great importance. I am looking forward to the first results from the study. I have only few comments to add at this point.

1. Introduction is rather long and there is some repetition (e.g. end of page 3 and in parts describing discussion in social media),

2. In the beginning of discussion, it stated that Pandemrix caused threefold increase in the risk of narcolepsy. This probably accurate for young adults and maybe older adolescents but in younger age groups risk increase was higher. Increased risk has also been reported in a case control study in France. I would also prefer referring individual studies to VAESCO study (ref 1) because of methodological issues (e.g. follow-up period, case collection)

3. Figure 1 as such is more confusing than clarifying. Especially I find it not self-explanatory.

4. The authors state that invite all Swedish children with narcolepsy following Pandemrix vaccination to study. Some questions:
   a. Does this mean age at vaccination, age at onset of the disease or current age?
   b. Exclusion criteria? None? Previous diseases (psychic, neuropsychiatric?), current diseases?
c. How are the cases verified? ICSD-2 or 3? Type 1 narcolepsy vs type 2? All with cataplexy? I would suggest including only clear type 1 narcolepsy cases with orexin deficiency or clear-cut cataplexy and positive MSLT

5. One of the main aims of the study is assessing the trust. However, in current manuscript, only two questionnaires are addressing the issue. Are these two questionnaires sufficient and accurate enough to answer the study question?

Minor remark: Page 11 third chapter ref missing.

**Are the methods appropriate and well described?**
If not, please specify what is required in your comments to the authors.

Yes

**Does the work include the necessary controls?**
If not, please specify which controls are required in your comments to the authors.

Yes

**Are the conclusions drawn adequately supported by the data shown?**
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