Author’s response to reviews

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

Authors:

Karin Blomberg (karin.blomberg@oru.se)
Agneta Anderzén Carlsson (agneta.anderzen-karlsson@regionorebrolan.se)
Lars Hagberg (lars.hagberg@regionorebrolan.se)
Östen Jonsson (osten.jonsson@regionorebrolan.se)
Lena Leissner (lena.leissner@regionorebrolan.se)
Mats H Eriksson (Mats.h.Eriksson@oru.se)

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Author’s response to reviews:

Dear Editor-in-Chief, BMC Pediatrics

Please find attached a revised version of the manuscript entitled “Quality of life and trust among young people with narcolepsy and their families, after the Pandemrix® vaccination: protocol for a case-control study” (BPED-D-15-00358R1) to be considered for publication. We were very pleased to receive such constructive comments and suggestions, and have made efforts to improve the manuscript accordingly. We respond to the comments below, clarifying in detail the changes made to the article, highlighted changes (in yellow) in the attached manuscript. The final version has been reviewed and approved by all authors.

We thank you for your consideration of the manuscript.

Sincerely,

Karin Blomberg, corresponding author, PhD, Associate Professor
Reviewer 1

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.

Authors’ response: Thank you very much.

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

Authors’ response: We have made changes in the text in order to shorten the Introduction.

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)

Authors’ response: Thank you, we have now revised the text and added references to clarify the increased risk of narcolepsy.
3. Figure 1 as such is more confusing than clarifying. Especially I find it not self-explanatory.

Authors’ response: We have decided to remove the Figure 1 as it seems to confuse readers.

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?

Authors’ response: We have try to clarify that inclusion criteria is being a child (age <18 years) at disease onset.

b. Exclusion criteria? None? Previous diseases (psychic, neuropsychiatric?), current diseases?

Authors’ response: Thank you, we will not have any exclusion criteria as this is not possible to gain knowledge of from the registry. We will include any cases documented as a Narcolepsy diagnose in the Swedish nationally register of diagnosis (diagnose code G47.4). We have now revised and added text to clarify this.

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

Authors’ response: We will not use MSLT as an inclusion criteria as it is ongoing discussion about its validity. The cases will be included based on having a Narcolepsy diagnosis documented in the Swedish nationally register of diagnosis (diagnose code G47.4). We have added text in the manuscript to clarify this.
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?

Authors’ response: Our investigation of trust among this group of young people and their families will not only be assessed by these instruments but also by interviews and social media. We have revised the text and hope this is clearer.

Minor remark: Page 11 third chapter ref missing.

Authors’ response: Thank you, we have missed it, however it might not be necessary with a reference here as this is a ‘well-known’ declaration (Declaration of Helsinki).

Reviewer 2

The authors have done a wonderful job in planning this study. This manuscript is well written and clearly describes the intention to perform a relevant and important project. My only query is that the structure of individual paragraphs could be better constructed to avoid a jumble of words and ideas.

Authors’ response: Thank you very much! We have revised the text in order to better structure paragraphs.

The BACKGROUND section is particularly long and has cumbersome paragraphs. Perhaps the authors could shorten this section, or divide it into subsections. The paragraphs within this section should also be restructured to avoid long and wordy. I look forward to reading results from this study once the project is completed.

Authors’ response: Thank you. The Background is shortened and divided into subsections. As mentioned above, the paragraphs have also been restructured.