Author's response to reviews

Title: Surveying persons with disabilities: Participation rates, response bias and response behaviours in the community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI)

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Version: 2 Date: 8 May 2015

Author's response to reviews: see over
Dear Editor,

We would like to thank you and the reviewers for the qualified and fruitful comments that have undoubtedly contributed to the improvement of our manuscript.

We hereby submit a thoroughly revised version of the manuscript that in our view effectively addresses all the issues raised. Please find a point-to-point reply of your comments below.

We would be very pleased if you considered our manuscript for publication in BMC Medical Research Methodology.

Yours sincerely,

The Authors

Associate Editor’s Comment:

One of the most striking findings from your analysis is that variables related to impairment were not associated with response behavior as measured by response speed and response mode. While these measures of response behavior tell us something about participation, readers of the journal will be more interested in knowing what effect the impairment measures had on the overall rates of participation and whether overall rates varied by characteristics of the sample members. As noted by Reviewer 3, you reference other manuscripts related to response rates and nonresponse error that are currently under preparation. A single paper featuring these analyses would be of great interest to readers of this journal, and we encourage you to resubmit an article containing these analyses. We note, however, that this invitation is not a guarantee of publication as your resubmission would be resent to the current reviewers.

Thank you for this input. Following your advise we have now included a descriptive analysis of the response and nonresponse to the main module of the survey (2nd module) to the manuscript. Following, in the Methods section we have added text to explain the statistical analysis (lines 272-284). Findings are described in the Results section (lines 351-362) and visualized in a new Figure 3.

If you elect to prepare a revision along the lines indicated, we also request that you carefully respond to each of the comments raised by the reviewers in their thoughtful reviews. In the points below, we highlight some of the comments of the reviewers. We also add a few comments of our own, which we hope you will find useful:

Thank you very much for your thoughtful comments that help improve the manuscript.

1. Both Reviewer 1 and Reviewer 3 ask for more framing regarding the ways in which the various methods chosen for this study were tailored to be adaptive for the population under study. As Reviewer 3 notes, ‘the strategies described in the manuscript, while certainly good practices, are neither novel nor particularly targeted or adapted to meet the needs of people with disabilities.’ Please provide more background for the reader regarding the correspondence between the various methodologies employed and measurement issues among persons with disabilities.

We are aware and acknowledge that the survey methodology used in our study is not novel as such. Yet, little is known regarding the importance of exploiting available methods in surveying populations that are
characterized by substantial variation in levels of physical impairment. In this respect our study in persons living with spinal cord injury makes a valuable contribution by evaluating the preference for certain survey modes as well as the need and effectiveness of reminding in relation to degree of impairment (lesion level; completeness of lesion). To make this focus more clear we have made several changes to the Introduction and Discussion.

2. A figure summarizing your overall methodological design, including the various methods you employed to contact sample members, would be useful for readers, and would likely strengthen the impact of your study design.

   We agree and have included a figure illustrating the recruitment and reminder management process used in the SwiSCI community survey (Figure 1).

3. You write that a notable strength of your manuscript is that you used currently recommended guidelines to transparently report participation rates (line 392), and you cite Slattery et al. (1995, ‘Response rates among control subjects in case-control studies’). While we agree that the source you reference is an excellent article, we advise that you consult and reference the American Association for Public Opinion Research (AAPOR)’s ‘Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys’ (http://aapor.org/Content/NavigationMenu/AboutAAPOR/StandardsampEthics/StandardDefinitions/StandardDefinitions2011.pdf). AAPOR has codified methods for calculating and reporting response rates both for mail surveys and internet surveys, the latter of which were not in existence at the time of publication of Slattery et al.

   We fully agree that the AAPORs guidelines are the more actual and more comprehensive source than the paper by Slattery et al. We decided to adapt our formula’s to the AAPORs guidelines (see Table 1, e.g. Contact rates have slightly changed due to other formula suggested by AAPOR).

4. A large number of your sample members elected to complete the survey online, but you do not mention whether break-offs, especially for the lengthy modules, were a problem? Did all of the sample members who started the survey online complete it?

   Indeed, from the 650 persons who completed the second module online, there were 24 persons who did not finish data entry (3.7% of all online completers). We have now added this information in the results section of the manuscript (lines 382-384): “Among this proportion of online completers, 3.7% of persons who started online completion have interrupted the questionnaire somewhere before the last 20 items.”

5. We did not feel that the analyses of ‘redundant reminding’ made a substantial contribution to the manuscript, and we recommend that you drop this topic from the paper.

   We agree with your opinion and have dropped this analysis from the paper.

6. Among the limitations you list in your concluding comments, we recommend that you note that your conclusions about the effectiveness of the methods you used, for example, the importance of offering both paper-and-pencil and online methods for response, are based on the relationships you observe. Because you do not employ an experimental design to test the effectiveness of the methods, we urge you to be more cautious in you conclusions and recommendations.

   We fully agree and have reformulated our conclusions. We also added a sentence to the Discussion to clarify this point (lines 437-441): “However, as we did not use an experimental design to test effectiveness of the methods used, we cannot conclude that response rates would have been lower in case only one option
would have been offered. Still, there is growing literature in survey methodology stating that mixed mode surveys are more effective than single-mode surveys (Dillman et al. 2014).“

7. In your conclusion you ‘strongly recommend mixed-mode options for response.’ This recommendation is supported not only by your study, but also by a growing literature in survey research methodology on the effectiveness of mixing modes for contacting and survey respondents. We suggest you reference the following source in your conclusions:


Thank you, we have added this reference to the Discussion (see point 6 above) and to the conclusion (line 494): “In line with current survey methodology (Dillman et al. 2014), we would recommend mixed-mode options for response (i.e. paper-pencil and online questionnaires) as we observed associations between participants’ characteristics and the preferences in response modes.”

Thank you for giving us the opportunity to review your research. We hope the comments enclosed will be useful to you as you revise the current manuscript.

Reviewer’s report

Title: Surveying persons with disabilities: Participation rates and response behaviours in the community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI)

Version: 2 Date: 29 September 2014

Reviewer: Alex Wong

Reviewer’s report:

Thank you for giving me the opportunity to review a manuscript entitled “Surveying persons with disabilities: Participation rates and response behaviors in the community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI)”. Based on my evaluation, this manuscript has merit but may not suitable for publication in its present form in the BMC Medical Research Methodology. My comments are listed, in which most of them are addressable, and I hope that the authors will be willing to address them.

We thank the Reviewer again for the thoughtful comments. We are pleased to address them as we believe that they contribute to the improvement of our manuscript.

Line 1:
It is advised to specific title on surveying persons with spinal cord injury as participation varied by types and levels of disabilities. The problems and needs of survey participation on physical disabilities are totally different from that on other types of disabilities.

We agree with the Reviewer that problems and needs of survey participation may differ according to type of disability. However, we would like to attract with a this title a broader readership as we believe that the manuscript covers topics that might be relevant for other researchers planning a survey in populations with disabilities (e.g. how to proceed if no central registries about persons with a specific disability exist?).
Furthermore, it is already mentioned in the title that our survey is on persons with spinal cord injury, we therefore would prefer to maintain the current title.

Line 58:
No keywords were listed?

Thank your for pointing this out. We added keywords below the abstract.

Lines 93-94:
Is this assumption over-generalized? Everyday life performance is challenging but that could be minimized by utilizing assistive technology or being support from others. The participation of community life activities including research study participation would depend on other key factors, like motivation, opportunities to engage. Although persons with SCI are facing difficulties in engaging these community tasks, they are willing to participate if support is covered. This is a dilemma between “do do” and “can do”. Authors are advised to tone down and avoid over generalization.

We completely agree with this concern and have 'toned down' our statements in the Introduction. As you suggested, we added the arguments that other factors such as personal motivation, personal interest in a specific research topic or general attitude towards research may also influence on study participation (lines 101-103).

Line 109-112:
Authors may provide some reviews to support the recruitment efforts in which they believed those could enhance the survey participation of persons with disabilities, especially those with SCI.

We have added a reference that supports the argument of multi-mode surveys enhancing participation rates (Dillman et al.). However, this reference is not specially targeted to surveys on persons with disabilities as specific literature is widely lacking for persons with physical disabilities. In fact, our research methodologies did not substantially differ from survey methods used in persons without physical disabilities and it might be justified to cite literature from ‘general’ survey methodology. Literature on survey methods for persons with disabilities is most often targeted to persons with cognitive impairments, hearing or visual problems. We feel that citing this literature is not suitable in our case as persons with cognitive impairments were excluded from our survey.

Lines 163-164:
Did authors take any preventive action (e.g. checking medical records) to ensure accuracy of self-reported clinical information reported by participants?

Unfortunately, we have not cross-checked the self-reported clinical information with medical records as medical records were only available for a sub-sample of survey participants. We have decided not to mention this weakness in the limitations discussion as it does only marginally affect the topic of this paper. However, the issue of self-report bias/data validity will be an important discussion item in papers where lesion characteristics or health complications are at the core of the interest.

Lines 179-181:
Duplicate "consent form"

We added ‘… a duplicate of the consent form’.
Line 198:
Remove "the"

We removed 'the'

Lines 199-205:
The study did not provide any option for on-line completion for survey respondents at the beginning (i.e., first module, and first mailing of second module). They tended to provide paper-pencil questionnaire followed by the online survey. Why did authors have this intention? Did authors consider that the results of respondents’ behaviors and the response rates would be biased by these recruitment procedures? It is advised to explain this intention.

This is a misunderstanding, participants had the option for online completion at each stage of the survey (i.e. in the first, second, and third modules). We have dropped the paragraph on ‘study material sent with the different modules’ (line 199ff.) and put the relevant information in Figure 1. We hope that this clarifies this issue.

Line 281:
Providing statistical results on Chi-square and t-test comparisons between two modules could manifest whether the characteristics between two modules are comparable.

Thank you for this input. However, we do not agree with the suggestion for the following reasons: The magnitude in difference (effect size) in characteristics between modules indicates if the modules can be compared; it is not the statistical test that indicates comparibility. A small, not meaningful effect size may be statistically significant for large samples, and similarly a tremendous difference in characteristics may not appear significant for small samples, even though it is meaningful. A statistical test in this context does rather say something about the sample size (what we already know) than about how comparable the groups are.

In Table 2, we have added a column to show the effect size and its confidence interval (calculated for two dependent samples, what tremendously decreases the confidence interval for the difference). The confidence interval can be used for statistical inference on the effect size, although we do not advocate such an interpretation due to the reasons given above.

Lines 325-328:
These findings might be biased by the recruitment procedures (refer comments in lines 199-205).

Please see comments above concerning lines 199-205.

Lines 338-336
Redundant reminders to the second module were not independent from the responses to the third module (p=0.0001 from table 6).

This is a good input but not relevant anymore as we dropped this analysis from our manuscript (see comment of the Associated Editor above).

Lines 357-359:
Although authors listed out those were possible reasons for low recruitment rates encountered by persons with disabilities, it is advised to add a few literatures to support these.

We have dropped these arguments form the discussion as there is only limited empirical evidence for them. In the introduction, we list arguments why it is generally difficult to get satisfactory response rates (e.g. over-
surveying, feelings of limited worth of contribution...), but these arguments apply for all kind of surveys, not only for surveys on persons with disabilities.

Lines 369-370:
Another reason for lower responses in subsequent modules could be the lengthy questionnaire.
Thank you for this input, we have added this argument to the Discussion (line 433).

Lines 371-372, and lines 399-400
Not sure if offering telephone interviews in the lengthy survey would work. From lines 311-313, authors stated that only 16 persons completed the survey via telephone. We did not know whether SCI persons would choose the telephone interviews to complete the longer survey as claimed.
This is a justified remark. However, as we do not use an experimental design, we cannot conclude that the used methodologies have advantages over other procedures. We have added this argument to the Discussion (lines 437-441).

Level of interest: An article of outstanding merit and interest in its field
Thank you!

Quality of written English: Acceptable

Statistical review: Yes, but I do not feel adequately qualified to assess the statistics.

Declaration of competing interests: I declare that I have no competing interests.

Reviewer’s report

Title: Surveying persons with disabilities: Participation rates and response behaviours in the community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI)

Version:2 Date: 14 October 2014

Reviewer: Jacob Kean

Reviewer’s report:

Thank you for the opportunity to comment on this well written manuscript, which sought to understand participation rates and response behaviors in persons with spinal cord injury. The paper is largely descriptive and thorough in that description to the degree that it raises awareness of readers to the complexity of doing good survey research. Examples include the discussion of sampling and of the different participation rates featured in the paper.

Major Compulsory Revisions

1. The logistic regression model used to test response speed appears to have been done carefully. However, it is unclear to me why response speed was modeled as a 4-category variable rather than simply utilizing the number of days to response. This seems to risk loss of information and may perhaps compromise understanding. If there is a strong rationale for the ordinal variable, it should be offered.

Indeed, it is a good suggestion to use a continuous variable to address the issue of response speed. However, there is an important argument for the use of a four-categorical variable: Due to feasibility reasons,
it was not possible to send invitations and reminders exactly within the same interval (ideally on day 30). In reality, invitations for subsequent modules or reminders were sometimes sent at day 29, day 32, day 35 etc. If we would use a linear variable to describe ‘days until response’, the results would be biased as some participants may received the reminder on day 29 and answered following this ‘trigger’. This situation would then not be comparable with a person that answered on day 30 without having received a reminder. For this reason, we decided to use the indicator ‘has received a reminder’ to tell something about response speed of participants. However, we have added the argumentation why we used an ordinal variable to the Methods section (lines 288-292).

In addition, the report of the regression could be strengthened by reporting information on the link function, fit of the statistical model, results of residual diagnostics, and any other model assessment strategies. Was multicollinearity a problem?

We have added a description of the model diagnostics to both multivariable analyses (see Results, lines 372f. and 389f.). We checked the proportional odds assumption (Brant test), collinearity (VIF) and goodness-of-fit ($R^2$).

Minor Essential Revisions

1. One important technology that can be employed in survey research is interactive voice response (IVR). IVR might be particularly useful in spinal cord injury for the reasons offered in the manuscript that make pencil and paper response and survey participation, in general, difficult for this population. It could be discussed as a limitation and a future direction for research.

Thank you for this input, we have added this suggestion in the discussion section (lines 443ff.).

**Level of interest:** An article whose findings are important to those with closely related research interests

Thank you!

**Quality of written English:** Acceptable

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

**Declaration of competing interests:** I declare that I have no competing interests

**Reviewer’s report**

**Title:** Surveying persons with disabilities: Participation rates and response behaviours in the community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI)

**Version:** 2  **Date:** 22 October 2014

**Reviewer:** Susan R Magasi

**Reviewer’s report:**

Thank you for the opportunity to review the manuscript “Surveying persons with disabilities: Participation rates and response behaviors in the community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI).” The SwiSCI study is an important cohort study examining health and function among people with spinal cord injury in Switzerland. The parent study was carefully developed and rigorously implemented.
The manuscript under review “Surveying persons with disabilities: Participation rates and response behavioral in the community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI)” raises the potentially important issue of fairness in testing and epidemiological studies among people with disabilities. Specifically, the issues of physical accessibility of surveys and questionnaires as well as more intangible issues like “over surveying” where described as potentially impacting response rates. Unfortunately, the methods described provide limited information about the impact of these issues on participation rates.

We understand the concerns of Reviewer 3. Unfortunately, we do not have relevant information to assess these issues and therefore can only give those arguments with references to other studies who observed these phenomena.

The strategies described in the manuscript, while certainly good practices, are neither novel nor particularly targeted or adapted to meet the needs of people with disabilities, e.g. the reasonable accommodation of interview administered surveys were offered at the first interview but not the second except under “exceptional cases” (page 12, line 312-13). While the authors do recommend this administrators assisted/interview formats as a means of increasing response rates in future studies, they don’t consistently report or elevate the conversation on disability accommodations.

We fully agree with this remark, thank you. It is indeed the fact that our survey methodology is strictly speaking not different to surveys on populations without disability as we do not offer specific equipment or technical devices (we only offered persons with limited hand function to do a telephone interview in the second and third module). We may have overstated that our survey methodology is targeted to persons with disabilities. We therefore tried to attenuate this throughout the manuscript. However, we have included the issue of disability accommodations to the discussion.

The outcomes of time taken to return the survey offers limited insights in to the actual time on task, level of assistance required or if indeed assistance with questionnaire completion was required/requested by the participant. For example, some indication about whether the respondents’ received assistance from someone in the home to complete the surveys and what impact that might have on scores on measures of a sensitive nature, e.g. are depression questionnaires answered openly by someone whose spouse is helping them complete the questionnaire? Some more nuanced discussion about impact of such accommodations or of mode effects impact on scoring would strengthen the paper.

This is a valuable input, thank you. Unfortunately, we do not have information on personal assistance for questionnaire completion. We added this issue to the limitations discussion, lines 437ff.:

“Second, information on the assistance from third persons or the use of assistive devices for study participation (e.g. assistive technologies to facilitate online completion in tetraplegics) is missing. Therefore, we cannot assess whether lack of personal support or lack of assistive devices enhanced non-response or not.”

We agree that the presence of a supportive person might influence scoring in certain sensitive topics, however, these issues of data validity need certainly more discussion in papers where potentially biased data are used (e.g. data on depression, quality of life). As this manuscript is a methodological paper describing study design issues and response behavior, we have decided not to discuss data validity issues here.

Perhaps most interestingly impairment effects were shown not to influence response rates. A more nuanced discussion about why the theorized reasons for low response rates – impairment effects, lack of relevance, “over surveying” did not impact scores would be worth more discuss.

We have now included the non-response analysis in the manuscript. This analysis revealed that severity of disability (indicated by lesion level) was not associated with survey participation (see Results, objective 3 in
The revised manuscript and Discussion, 2nd paragraph. We hope that this additional information adds an interesting aspect to the manuscript.

The characteristics of individuals who select computer based versus pencil and paper administration are potentially of interest but could have again used more nuanced discussion. There appears to be socio-economic issues impacting the choices. This issue warrants some discussion.

We have added a discussion regarding these findings (Discussion, lines 450ff.).

While the parent study is rigorously designed and implemented and will yield important information about life with a spinal cord injury in this Swiss cohort, it is the opinion of this reviewer that current manuscript is not strong enough of a study to stand alone. The authors report that several other manuscripts related to response rates and patterns currently under preparation. Perhaps combining the response data into a single article would yield a stronger paper of more general interest.

Thank you for this input. We have decided to include the analysis on nonresponse error (comparison between respondents and non-respondants) in this manuscript and hope that this adds an interesting argument to our paper (Results, objective 3).

There is also the potential in the study findings for greater discussion of the rules of thumb for longitudinal survey response rates. For example, the first was of data collection had the lowest response rate at 61.1% with subsequent waves at 80.6% and 87.3% “which resulted in cumulative response rates of 49.3% and 42.6% for the second and third modules.” The authors indicate that only the first wave/module met the threshold for adequacy of response rate, e.g. >60%. While the authors indicate that the guidelines are not absolutes, it is potentially to consider if graded recommendations are needed for different waves of data collection. I.e. to realistically hope to achieve a cumulative response rate of >60%, should the threshold be set higher to allow for a reasonable attrition rate?

Thank you for this thoughtful remark. We have added your input to the Discussion (lines 418ff.).

**Level of interest:** An article of insufficient interest to warrant publication in a scientific/medical journal

We have thoroughly revised our manuscript and hope that it is now suitable for publication in a scientific journal.

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:** I declare that I have no competing interests.