# PEER REVIEW HISTORY

## ARTICLE DETAILS

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| **TITLE (PROVISIONAL)** | Description of the BRIGHTLIGHT Cohort: the evaluation of teenagers and young adult cancer services in England |
| **AUTHORS** | Taylor, Rachel; Fern, Lorna; Barber, Julie; Alvarez-Galvez, Javier; Feltbower, Richard; Morris, Stephen; Hooker, Louise; McCabe, Martin; Gibson, Faith; Raine, Rosalind; Stark, Dan; Whelan, Jeremy |

## VERSION 1 – REVIEW

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| **REVIEWER** | Sumit Gupta<br>Hospital for Sick Children Toronto, Canada |
| **REVIEW RETURNED** | 22-Nov-2018 |

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| **GENERAL COMMENTS** | Thank you for the opportunity to review this manuscript. The authors should be congratulated on building a TYA cohort despite significant challenges. I look forward to seeing future results. I have several suggestions for the authors however in terms of this manuscript, which describes the cohort in detail.<br><br>Major Comments<br><br>1. I would suggest a new title as I find the current one somewhat misleading. The Brightlight cohort was built to answer several questions, not just the ones comparing specialist and non specialist services. The current title makes it sound as if the manuscript will go into results of that question, which of course it does not. Something more reflective of the general descriptive nature of the paper should be used.<br><br>2. In the comparison of participants and non-participants, is it possible to compare any measure of SES, even if just IMD quintile?<br><br>3. Survival difference – The authors state that the reasons for the differences in survival between participants and non participants is unclear. It would be helpful to see whether this is simply a function of different cancer types. Are there any differences if restricted to certain common malignancies (say looking at sarcoma, or HL, or acute leukemia only)?<br><br>Minor Comments<br><br>1. Abstract – In the findings section, it is not clear what "non-participants" refers to: those approached who declined, those never approached, etc… This is clear in the manuscript, but should be clear in the abstract as well. |

| | 2. "Young People" is sometimes used, while "TYA" is used at other times. These terms should be harmonized.<br><br>3. In the first of the five bullet points, the authors state that "this is the largest ever cohort…" The word "prospective" should be added as larger retrospective cohorts exist.<br><br>4. In the fourth bullet point, "results provide new information…. And determines if access…" would be changed to future tense (e.g. will provide) as this manuscript does not give those results. |
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| REVIEWER | Fiona McDonald<br>CanTeen, Australia |
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| REVIEW RETURNED | 02-Dec-2018 |

| GENERAL COMMENTS | Thank you for the opportunity to review this important manuscript. Overall the paper is thorough, and the process followed clearly articulated. In particular the Introduction provides a clear and comprehensive summary of the specific needs of young people diagnosed with cancer and the apparent need for age appropriate care. The measures used are comprehensive. The data collected via the Health economics questionnaire will add considerable value to the field. A few possible improvements are listed below.<br><br>In the 'Findings to date' section of the Abstract there is mention of the QoL scores being lower than a published threshold. I presume the relevant section in the manuscript is Table 5 and accompanying text. There is little detail on the published threshold in the body of the manuscript. Additionally, the use of word 'other' prior to 'patient reported outcomes' implies that there is variation in QoL and HADs scores for the variables listed. Is this what was intended? Where statistical analyses conducted for the data presented in Table 5?<br><br>While the overall purpose of the BRIGHTLIGHT study is clear and provides context to this manuscript, in neither the abstract or the manuscript is there a clear statement of the purpose of this manuscript.<br><br>Table 1 – Summary of BRIGHTLIGHT survey. Additional information on the psychometric properties of measures would be beneficial.<br><br>Table 3 – Comparison of characteristics. Was analysis undertaken to determine if the differences between the Cohort and non-participants were significant?<br><br>Table 3 and Figure 3. Figure 3 looks like a Table? It would be clearer if the same terminology was used to label the non-participants across figures and tables.<br><br>Figure 2 footnote. The hyphen is incorrectly placed. |
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**VERSION 1 – AUTHOR RESPONSE**

**Reviewer: 1**

**Reviewer Name: Sumit Gupta**

**Institution and Country: Hospital for Sick Children - Toronto, Canada**

Thank you for the opportunity to review this manuscript. The authors should be congratulated on building a TYA cohort despite significant challenges. I look forward to seeing future results. I have several suggestions for the authors however in terms of this manuscript, which describes the cohort in detail.

- Thank you for your comments and taking the time to review our manuscript

Major Comments

1. I would suggest a new title as I find the current one somewhat misleading. The Brightlight cohort was built to answer several questions, not just the ones comparing specialist and non specialist services. The current title makes it sound as if the manuscript will go into results of that question, which of course it does not. Something more reflective of the general descriptive nature of the paper should be used.

- The title has been changed as requested

2. In the comparison of participants and non-participants, is it possible to compare any measure of SES, even if just IMD quintile?

- We do not have access to these data so we are unable to answer this but have made reference to this as potential limitation on page 19.

3. Survival difference – The authors state that the reasons for the differences in survival between participants and non-participants is unclear. It would be helpful to see whether this is simply a function of different cancer types. Are there any differences if restricted to certain common malignancies (say looking at sarcoma, or HL, or acute leukemia only)?

- We have reported the results of a Cox regression analysis which includes adjustment for type of cancer. This shows that the survival difference between cohort participants and non-participants remains even after accounting for type of cancer (reported in page 14).

Minor Comments

1. Abstract – In the findings section, it is not clear what "non-participants" refers to: those approached who declined, those never approached, etc… This is clear in the manuscript, but should be clear in the abstract as well.

- The text has changed for clarity

2. "Young People" is sometimes used, while "TYA" is used at other times. These terms should be harmonized.

- The words young people have been used when referring to human beings and TYA where it is referring to services. The text has been checked and this is consistent throughout

3. In the first of the five bullet points, the authors state that "this is the largest ever cohort…" The word "prospective" should be added as larger retrospective cohorts exist.

- This has been added as suggested.

4. In the fourth bullet point, "results provide new information…. And determines if access…" would be changed to future tense (e.g. will provide) as this manuscript does not give those results.

- This has been changed as suggested.

**Reviewer: 2**

**Reviewer Name: Fiona McDonald**

**Institution and Country: CanTeen, Australia**

Thank you for the opportunity to review this important manuscript. Overall the paper is thorough, and the process followed clearly articulated. In particular the Introduction provides a clear and comprehensive summary of the specific needs of young people diagnosed with cancer and the apparent need for age appropriate care. The measures used are comprehensive. The data collected via the Health economics questionnaire will add considerable value to the field. A few possible improvements are listed below.

- Thank you for your comments and taking the time to review our manuscript.

In the 'Findings to date' section of the Abstract there is mention of the QoL scores being lower than a published threshold. I presume the relevant section in the manuscript is Table 5 and accompanying text. There is little detail on the published threshold in the body of the manuscript. Additionally, the use of word 'other' prior to 'patient reported outcomes' implies that there is variation in QoL and HADs scores for the variables listed. Is this what was intended? Where statistical analyses conducted for the data presented in Table 5?

- We have added detail in Table 1 of the threshold. The text accompanying Table 5 is based on an observation of data; no statistical comparison has been made between the groups as this is baseline description of the cohort only.

While the overall purpose of the BRIGHTLIGHT study is clear and provides context to this manuscript, in neither the abstract or the manuscript is there a clear statement of the purpose of this manuscript.

- The objectives of the paper have been added on page 5 after the aims of the BRIGHTLIGHT cohort.

Table 1 – Summary of BRIGHTLIGHT survey. Additional information on the psychometric properties of measures would be beneficial.

- In line with CONSORT PRO guidance we have provided the reference supporting the psychometric properties of the measures rather than specifying this in the table as this would make the table difficult to read (due to the wide variation in methods used to test each measure).

Table 3 – Comparison of characteristics. Was analysis undertaken to determine if the differences between the Cohort and non-participants were significant?

- The significance has been added to table 3.

Table 3 and Figure 3. Figure 3 looks like a Table? It would be clearer if the same terminology was used to label the non-participants across figures and tables.

- The table accompanying Figure 3 is a footnote to the Kaplan Meier graph, providing explanatory detail

Figure 2 footnote. The hyphen is incorrectly placed.

- This has been changed as requested.

**VERSION 2 – REVIEW**

| REVIEWER | Fiona McDonald CanTeen, Research, Evaluation and Social Policy |
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| REVIEW RETURNED | 22-Jan-2019 |

| GENERAL COMMENTS | Thank you for your responses to my review. I have a couple of follow-up comments from this. |
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| | In relation to the QoL scores being lower than the published threshold. It should be possible to do a one-sample t-test to compare the baseline data with this threshold. The scores are close to the threshold and the variation is high and I feel without a statistical analysis we can not be confident in the conclusions drawn (page 14, lines 46=47 and Table 5). |
| | You mention not needing to provide psychometric properties of the measures in the paper in keeping with CONSORT PRO guidance which I appreciate. I feel however, that there would be benefit in stating whether they have been validated for the age range in the BRIGHTLIGHT study and providing relevant references. |

## VERSION 2 – AUTHOR RESPONSE

Reviewer: 2

Reviewer Name: Fiona McDonald

Institution and Country: CanTeen, Australia

In relation to the QoL scores being lower than the published threshold. It should be possible to do a one-sample t-test to compare the baseline data with this threshold. The scores are close to the threshold and the variation is high and I feel without a statistical analysis we cannot be confident in the conclusions drawn (page 14, lines 46=47 and Table 5).

- We chose not to report P-values in describing mean QoL scores relative to the published threshold as our intention was simply to make a statement of observation regarding the BRIGHTLIGHT cohort and not to tempt any inferential conclusions. However, as the reviewer rightly points out, some of the mean scores are close to the threshold, and we have added to and altered the text on page 14 to clarify this.

You mention not needing to provide psychometric properties of the measures in the paper in keeping with CONSORT PRO guidance which I appreciate. I feel however, that there would be benefit in stating whether they have been validated for the age range in the BRIGHTLIGHT study and providing relevant references.

- A paragraph has been added to page 19 as a potential limitation, which clarifies the validity of the use of the selected measures in this age range.

## VERSION 3 – REVIEW

| REVIEWER | Fiona McDonald |
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|  | CanTeen, Research, Evaluation and Social Policy |
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| **REVIEW RETURNED** | 01-Feb-2019 |

| **GENERAL COMMENTS** | Thank you for your thorough consideration of my feedback. I have no further concerns with the paper. |
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