

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form ([see an example](#)) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

ARTICLE DETAILS

TITLE (PROVISIONAL)	A cross-sectional survey of healthcare professionals to determine what they believe constitutes 'specialist' care for teenage and young adult cancer patients
AUTHORS	Birch, Rebecca; Morris, Eva; West, Robert; Stark, Dan; Lewis, Ian; Morgan, Sue; Feltbower, Richard

VERSION 1 - REVIEW

REVIEWER	Davies, Elizabeth King's College London
REVIEW RETURNED	16-Dec-2012

GENERAL COMMENTS	<p>This study begins to explore variation in specialist opinions about TYA cancer care. Questions about possible differences in opinions about place, kind and aspects of care have been raised by work using cancer registry and other data showing variation in where these patients are treated. The current survey study demonstrates wide variations in the attitudes of those who are involved in the care of these patients. This is despite established in national guidance setting out best practice.</p> <p>The strength of the study is that it is well-conducted and the first to explore the issue of practitioner opinion. It is a pity that the response rate is relatively low (52%). It could possibly be that this reflects some ambivalence or unease among the study subjects about these issues. I wonder if it might have been useful to sample those involved in referring patients for cancer care rather than those involved in providing care to tease out where attitudes varied most. In the discussion the authors mention the influence of clinicians at different points in the pathway and it might be useful to state whether or not it was possible to make some judgement of this from the data on the sample. It would also be useful to comment on whether views are likely to have changed since 2009 when the data was collected and to set out some research designs that might unpick different influences. For example sampling clinicians in regions where national data suggested the most versus least variation in referral patterns.</p>
-------------------------	--

REVIEWER	Susie Pearce Researcher UCLH / UCL UK
REVIEW RETURNED	08-Feb-2013

THE STUDY	It would be good to have some more detail about the site and sample selection.
------------------	--

	<p>Why 98 NHS Trusts? was that the total number in the UK (it was Wales, Scotland, Northern Ireland too?) How were health professionals identified from websites, what criteria were looked for; how many of the sample came from being forwarded onto from others? I wonder why such a high proportion came from CCLGs? is this a limitation?</p> <p>What is the age range of TYA assumed for this study? 15-24, 13-24?</p> <p>Would incidence data of cancers by age/ disease for this group be helpful in the introduction did it influence your sites/ sampling?</p> <p>Refernces to policies occasionally could be clearer. grammer in P 3 sentence from line 27 and should be checked in the introduction.</p> <p>Is there limitations from having such a high proportion being medical staff?</p> <p>Need to use medical and nursing/ other health professionals at times rather than just medical as it is a little confusing not always accurate.</p> <p>Perhaps reference to the NWIS Annual report of TYA notifications in 2009 would be helpful, in relating to data on place of care for at least a proportion of TYA with cancer.</p> <p>A clearer undertanding of the IOG and what it means for different age groups in terms of where they should be cared for at what age ranges and the choice they have (19 plus) would also be an important contextual element.</p> <p>How does this then relate to non England UK studies if they are in fact included? and internationally.</p> <p>In the discussion more needs to written about how the policy context changed from 2009 in terms of the implementation of the IOG, TYA measures, the findings may well be different if done today?</p>
RESULTS & CONCLUSIONS	<p>The results: I am not sure what you mean when the repondents suggest patient range could be decided by socio economic group? Could you expand? There is a large number who did not respond on numbers seen annually, this perhaps should be written in the text of the results. Also implications of the large number only seeing 0-5 patients annually for the results and conclusions of this study.</p> <p>The findings could be disussed more fully in light of policy and the implementation of policy. what does this mean for the development and implementation of specialist TYA cancer care. How will professional preference and attitude be limited by commissioning and the measures (and perhaps is more now). How can professional attitude influence patient choice (19 plus)?</p> <p>How do you think the high percentage of unanswered statements ranked 15th- 25th may be influenced by the characteristics of the sample?</p> <p>The last sentence p 12 line 43 needs to be expanded.</p>
REPORTING & ETHICS	<p>Did this go to a University Ethics Committee? Processes for anonymnity/ confidentiality could be clearer.</p>

GENERAL COMMENTS	<p>Thank you for the paper which I enjoyed reading and the main components of which read well. Relating the sample and findings to the policy and context of TYA cancer care in more detail will draw out more fully the contributions and of course limitations of this study. All of which are important contribution to the field and the development of TYA cancer care.</p> <p>This is not qualitative research as suggested by the secondary subject heading</p>
-------------------------	--

VERSION 1 – AUTHOR RESPONSE

Reviewer: Elizabeth Davies

1. I wonder if it might have been useful to sample those involved in referring patients for cancer care rather than those involved in providing care to tease out where attitudes varied most.

We agree with the reviewer that this additional analysis would provide further insight into the variation in attitudes; this has now been described in the final paragraph of the paper.

2. In the discussion the authors mention the influence of clinicians at different points in the pathway and it might be useful to state whether or not it was possible to make some judgement of this from the data on the sample.

We agree that it would be informative to describe the extent of influence of clinicians at various points through the pathway. Due to the nature of the questions posed in this study it wasn't possible to assess the differing influences of clinicians across the diagnostic and treatment pathway and this is now referred to in the wider implications section. It was however possible to examine the attitudes towards three distinct points, diagnosis, treatment and long term follow up. Further work would be needed to examine this in more depth.

3. It would also be useful to comment on whether views are likely to have changed since 2009 when the data was collected and to set out some research designs that might unpick different influences. As suggested by the reviewer, opinions are likely to have changed since the study was undertaken; however it is believed that the greatest degree of change would have occurred relatively quickly after the publication of the Improving Outcomes Guidance. This has been acknowledged in the limitations section of the discussion.

We felt that multiple influences may have influenced the views of the respondents. In particular, workloads, presence of a principle treatment centre in the local area and the period of time during which the closest centre had been open. Due to the number of responses and the nature of the questions posed it was not possible to address this during this work, however we have included a section at the end of the discussion which makes it clear that this is something we would aim to do in the future.

Reviewer: Susie Pearce

1. It would be good to have some more detail about the site and sample selection. Why 98 NHS Trusts? Was that the total number in the UK (it was Wales, Scotland, Northern Ireland too?) How were health professionals identified from websites, what criteria were looked for; how many of the sample came from being forwarded onto from others?

As recommended by the reviewer, more details regarding the sample selection have been included in the participants and methods section of the article, including the reasoning behind the selection of 98 trusts in the UK.

2. I wonder why such a high proportion came from CCLGs. is this a limitation?

At the time of the study there were 19 CCLG centres in the UK and multiple shared care centres, whilst there were far fewer TCT centres. Thus, a greater proportion of NHS trusts contained a CCLG centre leading to a higher response rate from these staff. In order to explain this in greater detail a

paragraph has been added into the limitations section.

3. What is the age range of TYA assumed for this study? 15-24, 13-24?

There was no age range assumed for this study as the upper and lower age limits were assessed in the survey. Respondents were asked to specify the upper and lower ages they thought were most appropriate, this was posed as an open ended question.

4. Would incidence data of cancers by age/ disease for this group be helpful in the introduction did it influence your sites/ sampling?

We agree that incidence figures may help to set the work in context and have included the number of diagnoses in this age group annually in the second line of the introduction. Due to the relatively small numbers of cases and large number of diagnostic groups, our sampling strategy was broadened to include as many of those who may be involved in TYA cancer care as possible.

5. References to policies occasionally could be clearer.

An attempt has been made to make the references to policies clearer and where a specific policy has been mentioned it has also been referenced in the text. The Improving Outcomes Guidelines are now clearly referenced throughout the introduction. References to additional guidelines are also now made in the third paragraph of the introduction.

6. Grammar in P 3 sentence from line 27 and should be checked in the introduction.

We believed this point to be addressing the following sentence;

Principal treatment centres (PTC) have been advocated where patients have access to specialist environments of care, and also appropriately trained professionals from both site specific and age-specific teams working closely together, with a larger degree of specialisation than other cancer units. This has now been reworded as follows;

Principal treatment centres (PTC) have been advocated where patients have access to specialist environments of care, as were appropriately trained professionals from both site-specific and age-specific teams working closely together. A larger degree of specialisation than other cancer units has been supported.

7. Are there limitations from having such a high proportion being medical staff?

The high proportion of respondents who belonged to a medical speciality may have caused some bias in the results, we felt that this inequality was unavoidable due to the design of the study and have now explained this in the limitations section of the discussion.

8. Need to use medical and nursing/ other health professionals at times rather than just medical as it is a little confusing not always accurate.

A section has now been added to the sample selection section of the article which explains what is meant by the term 'healthcare professional' in terms of this article. The terminology has been altered, where relevant, throughout the article to reflect this.

9. Perhaps reference to the NWIS Annual report of TYA notifications in 2009 would be helpful, in relating to data on place of care for at least a proportion of TYA with cancer.

We agree with the reviewer that being able to identify the place of treatment for TYA patients in the UK would be informative, however the NWCIS report only includes those patients who were treated at principle treatment centres (teenage or children's centres) and not those treated in other NHS settings. Therefore, we decided not to include this report as we felt it was not representative of the entire TYA cancer population.

10. How does this then relate to non-England UK studies if they are in fact included? And internationally.

The first paragraph of the results chapter now includes a breakdown of the respondents according to their geographical location within the UK. Table 2 displays the distribution of respondents from each country by their cluster.

11. In the discussion more needs to be written about how the policy context changed from 2009 in terms of the implementation of the IOG, TYA measures, the findings may well be different if done today? The limitations section now acknowledges that opinion is likely to have changed further since 2009 and includes a section describing the possibility of repeating the work in order to assess the extent of any further change.

12. I am not sure what you mean when the respondents suggest patient range could be decided by socio economic group? Could you expand?
The reference to socio economic group was incorrect and has now been amended and instead refers to diagnostic group.

13. There is a large number who did not respond on numbers seen annually; this perhaps should be written in the text of the results. Also implications of the large number only seeing 0-5 patients annually for the results and conclusions of this study.
We agree that a large number failed to report the number of TYA patients seen annually (38.2%), and this has now been added to the main body of text (1st paragraph of the results). However only 0.6% failed to record the proportion of their total caseload which consisted of TYA patients, therefore it was possible to identify those with both high and low TYA workloads.
Overall, very few healthcare professionals treat large numbers of TYA patients annually, which is reflective of the low annual incidence and is represented in the sample. Unfortunately, due to small numbers, it was not possible to draw any inferences from the differences in opinions between the workload groups. However if this work was repeated, additional questions would be posed in order to investigate this component.

14. The findings could be discussed more fully in light of policy and the implementation of policy. What does this mean for the development and implementation of specialist TYA cancer care?
We agree that the findings could be discussed in more depth in relation to the implementation of the specialist care policy and we have addressed this with the inclusion of an additional paragraph (paragraph 2) in the discussion.

15. How will professional preference and attitude be limited by commissioning and the measures (and perhaps is more now). How can professional attitude influence patient choice (19 plus)?
We felt the reviewer has raised an interesting point. Unfortunately, we were not able to address the effect of commissioning on attitudes, or the effect of attitude on patient choice. However we have added additional text into the discussion sections in order to demonstrate that this would be an ideal area for further research.

16. How do you think the high percentage of unanswered statements ranked 15th- 25th may be influenced by the characteristics of the sample?
As requested by the reviewer we have included further detail in the final paragraph of the results discussing the possible reasons for the specific group of questions going largely unanswered. We referred to previous studies demonstrating irregular referral to these services.

17. The last sentence p 12 line 43 needs to be expanded.
More information has been added to the final paragraph, detailing potential projects which would further the understanding of the area.

18. Did this go to a University Ethics Committee? Processes for anonymity/ confidentiality could be

clearer.

This study was part of a larger piece of work examining variation in uptake, and impact of specialist care for TYA patients, which was approved by the Bradford REC prior to any data collection.