

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	The Needs and Provision Complexity Scale: a multi-centre prospective cohort analysis of met and unmet needs and their cost implications for patients with complex neurological disability.
AUTHORS	Turner-Stokes, Lynne; McCrone, Paul; Jackson, Diana; Siegert, Richard

VERSION 1 - REVIEW

REVIEWER	Dr Joanne Greenhalgh Principal Research Fellow in Health Care Evaluation School of Sociology and Social Policy University of Leeds I have no competing interests
REVIEW RETURNED	04-Dec-2012

THE STUDY	<p>This is a very interesting paper. Its validity hinges on (1) whether the NPCS is a valid and reliable measure of met and unmet needs, especially whether patients and carers can report in a valid way on the level of care they have received in the last 6 months and (2) whether the costing algorithm is valid/accurate.</p> <p>Currently, the paper refers the reader to a number of other papers (an unpublished report, poster and a paper in press) to make these claims but provides very little detail to support the claims made. While word count will not permit a detailed description, some information would be useful to reassure readers of this paper. For example, were patients and carers able to report in a valid way about the care they received over 6 months and how was this tested? Are patients and carers able to distinguish between the different clinicians they see and know whether their care was co-ordinated or not? Further - could these reports have been affected by the mode in which the questionnaire was administered? For example, an interview provides greater opportunity for clarification (but also possibly distortion) by the interviewer compared with the patient or carer completing the questionnaire online or by post.</p> <p>Further, it would also be helpful to comment on the assumption which appears to be inherent in the measure that care needed and provided and thus the costs remain static over the time period studied, which may not be the case. It would be helpful to know how the measure would be able to accommodate variations in care provided over time.</p> <p>I am not a health economist, but further information on the robustness of the cost algorithm would be useful - for example, was any sensitivity analysis undertaken to check whether the conclusions drawn from it were affected by changes in assumptions about the</p>
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	<p>costs of care?</p> <p>The authors use parametric tests for the subsales and non parametric the items - it would be useful to provide further justification for this difference, given that it is the same data being analysed.</p> <p>There are still a number of typos in the manuscript that require correction.</p>
REPORTING & ETHICS	The authors do not indicate whether ethical approval was granted for the study or whether patients gave informed consent to participate.

REVIEWER	<p>Dr Lynette Lee Program Director Geriatric and Ambulatory Medicine St Vincent's Hospital Sydney Conjoint Associate Professor University NSW Australia</p>
REVIEW RETURNED	11-Dec-2012

GENERAL COMMENTS	<p>This report of an extensive health service evaluation study validates the clinical impression of the costs of long term care and support of quality of life for individuals with profound and complex disabilities. It demonstrates the ease with which the outcomes from an individualised case conference checklist can be aggregated for planning and service development purposes. The conclusions and associated costing relativities will surely be useful for policy makers in many jurisdictions in terms of justification and comparative allocations of resources.</p>
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REVIEWER	<p>Dr Margaret Phillips Clinical Associate Professor Division of Rehabilitation Medicine University of Nottingham UK</p> <p>ICMJE conflicts of interests form completed.</p>
REVIEW RETURNED	18-Dec-2012

THE STUDY	<p>1. With regard to study design: one of the research questions was to determine the extent to which needs for health and social care were met in this cohort of patients. The extent to which needs were met was determined by the difference between their treating rehabilitation team's completion of the NPCS-Needs at the time of discharge and the patient's (+/- carer's) completion of the NPCS-Gets at six months. My concern is that time difference in this design - i.e. the fact that the scales that are being compared have a six month time gap - and that different respondents complete the measures, could have a confounding influence on the results. This would also affect the question of the impact of these needs on costs. One methodological aspect that is not described but is crucial in understanding the extent of this possible confounding effect is what instructions were given to the patients with regard to the period of time they should be considering when they complete the NPCS-Gets at six months - if they are asked to consider provision during the</p>
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	<p>whole of the previous six months this would lessen the effect (although still subject to recall bias), but if they are asked to consider provision at around the six month mark this could result in quite a difference as their needs may have well changed (and should have if they are participating in outpatient rehabilitation) by that time. The legend to Table 2 suggests it is actually at six months. There may also be a difference in perception of needs between clinicians and patients, so that patients may even have answered differently if asked at the same time as the clinicians.</p> <p>Some ways to clarify these issues would be to give further information on the time period patients were asked to consider when completing the six month NPCS-Gets; consider a figure or an appendix that shows the actual questions asked of clinicians and patients in order to derive the two NPCS, or put this on the LTNC dataset webpage and give the webpage address as a reference in place of the asterisk on page 4 line 48; state if there are any interobserver data between clinicians and patients on the two NPCS and what these are; consider adding the issues to the discussion section on limitations.</p> <p>2. Description of methods. As stated above I think it would be helpful to describe the NPCS-Needs and Gets in further detail, probably by a figure or appendix with the actual questions and the instructions as to what time period the participants are asked to consider when completing them. The former information would allow the reader to understand how similar the two scales are. It even be more useful to have the questions asked in figure 1 rather than the score sheet if space is limited.</p> <p>The Neurological Impairment Scale is also used in this study, as reported in table 1. I would suggest its use is explicitly stated in page 7, lines 27/28, rather than just coming under the heading of baseline characteristics, and that its origin is referenced.</p> <p>3. Accuracy of limitations - this is in reference to the answer stated in (1) above.</p> <p>Abstract, summary and key messages - if the concerns I have described regarding the timing of measurement are thought to be relevant (much of which depends on what time period the patients were asked to consider) then I would suggest the abstract, summary and key messages are adapted in some way, perhaps by noting this possible limitation.</p>
RESULTS & CONCLUSIONS	<p>The reason I have put 'no' with regards to interpretation and conclusion is because of the concerns I have raised above regarding the time mis-match between assessment of needs and needs provision. Further methodological detail may show this concern is unwarranted, but if it is I would suggest that the interpretation and conclusions are adjusted to at least take into account there may have been a confounding effect.</p>
GENERAL COMMENTS	<p>Overall I thought it was a really valuable paper. There were a few places which were not crucial or covered by the questions above where I thought it could have been made a little neater - one was a partial repetition of the analysis on page 6 lines 54 - 58 following onto page 7 lines 3 and 4, which could have been amalgamated with the information on this topic given in the analysis section. I also would suggest clarifying the statement in the introduction, page 5 , line 3 where it is stated the NPCS is the 'first of its kind'. This depends on what you mean by 'first of its kind' as some might interpret that as a measurement of needs assessment in patients with complex neurological conditions, which has been attempted elsewhere, e.g. in the Southampton Needs Assessment Questionnaire, so perhaps this needs to be clarified.</p>

VERSION 1 – AUTHOR RESPONSE

As there was some overlap between the three reviewers, we have listed the main points raised below, and interspersed our response with an explanation of how we have addressed the issues.

1. Validity of the NPCS: As the NPCS is a relatively new tool the main concerns raised were
- whether the NPCS is a valid and reliable measure of met and unmet needs
 - whether patients and carers can report in a valid way on the level of care they have received in the last 6 months

Whilst recognising that space limitations may not provide a very detailed description, given that the supporting literature was as yet not in the public domain, reviewers reasonably asked for:

- A slightly more detailed description of the tool itself (or access to it) and the evidence gathered so far to support its validity / reliability.
- More information about the associated questionnaires, and interviewing techniques to tease out patients experience of services received,
- More acknowledgement that needs may vary over time, and how the measure or study design could accommodate this
- Recognition that there might be a difference in perception between clinicians and patients, so that they may have answered differently if asked at the same time.
- More discussion in the limitations section about what is not yet known about the NPCS and
- If necessary a downgrading of the conclusions.

RESPONSE:

We agree that these are all very important points, that are key to the article, and therefore worthy of further elaboration.

There is no doubt that the NPCS is in need of further exploration and evaluation, which we had already highlighted in the original submission but perhaps not sufficiently. At the same time, we recognise that, in our efforts to be concise, we had omitted some salient methodological detail, which would have addressed some of the concerns raised.

We have now added some of these details into the text. Although the article is slightly longer at 4039 words, we hope that this additional information will both provide clearer information for readers and also add weight to our conclusions.

In response to the points raised, we have adjusted as follows:

- a slightly more detailed description of the tool itself (or access to it) and the evidence gathered so far to support its validity / reliability.

RESPONSE: We recognise that the paper currently refers to sources due to appear very shortly, but not yet in the public domain. As an update:

- The main study report (a detailed 50,000 word account) is in its final stages of revision in response to peer review and will be re-submitted to the NIHR HS&DR by 14.1.13. It should be available on the website shortly afterwards, and so we anticipate that it will be accessible to readers by the time this article is published.
- The full NPCS resource (including the tool itself, self report versions, details of the costing algorithm, references and copies of the posters) is on our website and is freely available to download. The URL for this site is now given as a reference so that readers may visit the site directly.
- The psychometric analyses of the NIS and NPCS (currently published in poster form) have been submitted as manuscripts and are currently under review by Disability and Rehabilitation. Copies of the submitted manuscripts are available on request. However, the salient information is freely available for download in the form of the posters on our website.

In the meantime, as suggested we have added a short paragraph within the paper (Page 6 para 2) summarising the results of psychometric evaluation of the NPCS.

b) More information about the associated questionnaires, and interviewing techniques to tease out the patients' experience of services received,

RESPONSE: The reviewers raised some concerns that the apparent shortfall in service provision could result from the mis-interpretation of instructions. Patients/carers might have thought they were being asked to report only the level provided at six months, and so potentially have failed to report previous more intensive levels of service provision earlier in the 6 month period.

We accept that this is a potential concern and that it is helpful to provide more detail about the safeguards that were put in place to prevent this problem.

a) Patients were asked to indicate the level of service provided 'within the last 6 months'. If more than one option applied they were asked to choose the option nearest the bottom of the list (ie the maximum level)

b) When questionnaires were received they were checked for any missing data or ambiguous responses by trained research assistants, and respondents were contacted by telephone to clarify their answers and to confirm their experience of met/unmet needs.

c) The data were transcribed onto the scores sheet given in figure 1. If the level of service varied during the 6-month period, the maximum level was recorded.

The questionnaire also asked if the respondent felt that the level of service was the right amount, too much or too little. A text box was provided to elaborate - which many did in some detail. In the study as a whole, the patients completed the NPCS three times over the course of the year. In addition, details of service received were recorded by the CSRI. Whilst we recognise that there is always room for improvement in questionnaire design, we are reasonably confident that, with the support described above, the majority of respondents understood what they were being asked.

Importantly, the differential findings of 'over-' and 'under-provision' in the different domains of the scale also suggest that reported deficits were not simply due to misunderstanding of the questionnaire or lack of recall.

We have added more detail in the methods to describe how the questionnaires were presented and handled on page 8, and have also added a section to the discussion (page 12, para 3) to address this issue.

c) More acknowledgement that needs may vary over time, and how the measure or study design could accommodate this

RESPONSE: Again this is an important point and we recognise the lack of formal re-assessment of need as a weakness in the study design.

On the other hand, this was a group of patients with complex needs, in whom we did not expect rapid change over the first 6-month period. This assumption was supported by the fact that their levels of dependency, caregiver burden and community integration did not change, suggesting that they had ongoing needs for health and social services support.

We recognise that our failure to report this information was an omission, which we have now corrected by adding these parameters to the bottom of table 1 and describing the absence of statistically significant improvement in the text (page 10 para 2).

d) Recognition that there might be a difference in perception between clinicians and patients, so that they may have answered differently if asked at the same time.

RESPONSE: Yes, this is an interesting point. Within the larger study we did attempt to track down treating clinicians for the subgroup of patients reporting high levels of unmet need to see if these would be confirmed by their treating clinicians. In fact the clinicians were extremely hard to trace and it was difficult to get reportable data.

We agree that future evaluations should take into account both user and professional perspectives, and have added a point to the strengths and limitations section (bullet point 5) to discuss future options for data collection that would take into account both perspectives.

e) More discussion in the limitations section about what is not yet known about the NPCS and

RESPONSE: We agree this will be helpful

We have highlighted the above issues in the discussion of strengths and limitations (page 14, bullet point 4 and 5).

We have also added slightly to the earlier part of the discussion, to highlight the possible alternative explanations for our findings and to provide added justification for our conclusions.

f) If necessary a downgrading of the conclusions.

RESPONSE: We have also stressed again in the conclusions the need for further evaluation of the NPCS. However, we hope that the additional information now given in the revised draft will help to reassure the reviewers and other readers of the validity of our findings – especially given their resonance with other reports in the literature.

2. Health economics; whether the costing algorithm is valid/accurate, and whether the conclusions drawn may be affected by changes in the assumptions about costs of care.

RESPONSE: We have provided some more detail about the development of the costing algorithm, in particular clarifying how the parallel CSRI data were used to support the assumptions.

We have also given a direct link to our website which includes the tool itself with the costing algorithm and annualised costs, and as before we have noted in the discussion that the algorithm requires further validation.

3. Statistics: Justification for the use of parametric and non-parametric statistical analysis.

RESPONSE:

Yes - there is ongoing debate in the literature about the use of parametric vs non-parametric statistics for ordinal data, with strongly held views on both sides. In fact both techniques gave similar results, and we opted to report parametric statistics for the long ordinal and summed data in line with the recommendations of Altman and Bland 2009, although medians and interquartile ranges are more interpretable for individual item data.

We have provided justification for this and cited the Bland and Altman reference in the analysis section on page 9 para 2

4. Ethics approval and consent: whether ethical approval was granted for the study or whether patients gave informed consent to participate.

RESPONSE:

Ethics approval and consent procedures were given on page 21 in the original submission. In keeping with the journal style, we have left the section on ethics there, but have moved the description of consent procedures to the methods section on page 7, para 3

5. Typographical and wording adjustments: Reviewer 2 kindly suggested some proof-reading changes, and Reviewer 3 suggested some tidying of the text

RESPONSE:

We have been through again to check for typos and done some general tidying of the text. We have taken up the proof-reading editorial suggestions kindly provided by Reviewer 2.

Other specific points:

Reviewer 3: The Neurological Impairment Scale is also used in this study, as reported in table 1. I would suggest its use is explicitly stated in page 7, lines 27/28, rather than just coming under the heading of baseline characteristics, and that its origin is referenced.

RESPONSE: We have noted the used of the NIS under data collection (Page 7) and provided references

Reviewer 3: I suggest clarifying the statement in the introduction, page 5, line 3 where it is stated the NPCS is the 'first of its kind', as some might interpret that as a measurement of needs assessment in patients with complex neurological conditions, which has been attempted elsewhere, e.g. in the Southampton Needs Assessment Questionnaire.

RESPONSE: Yes, we agree that this is an important distinction to make

We have added a sentence and some additional references to explain the difference between the NPCS and the Southampton Needs Assessment Questionnaire, highlighting that the NPCS is the first tool designed to be used both as a measure of the 'metness' of need in routine practice, and to estimate the cost of meeting unmet needs (Page 4/5)

Once again we are most grateful to the reviewers and editor of BMJ Open for allowing us to respond to the points and amend the paper accordingly. We believe that we have now addressed the various issues raised by the reviewers and hope that the revised submission will now be considered acceptable for publication in BMJ Open

VERSION 2 – REVIEW

REVIEWER	Greenhalgh, Joanne University of Leeds
REVIEW RETURNED	14-Jan-2013

GENERAL COMMENTS	The authors have responded to my comments adequately.
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REVIEWER	Dr Margaret Phillips Clinical Associate Professor University of Nottingham UK
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	I have no competing interests
REVIEW RETURNED	29-Jan-2013

GENERAL COMMENTS	Thanks for addressing the points raised, I feel they clarify the paper and have confirmed a valuable conclusion.
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