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 Longitudinal, Multi-Centre, Cohort Study of Community Rehabilitation Service Delivery in Long-Term Neurological Conditions
AUTHORS	Siegert, Richard; Jackson, Diana; Playford, E.; Fleminger, Simon; Turner-Stokes, Lynne

VERSION 1 - REVIEW

REVIEWER	Mark Weatherall University of Otago Wellington New Zealand
REVIEW RETURNED	23-Oct-2013

GENERAL COMMENTS	The two major issues with the material are the very high level of non-response. Although the authors comment on this it is rather down-played. Non-response bias is highly likely to be present and so it is very uncertain how the findings of this study might apply to the target population. Although the P-value for significance has been 'reset' at 0.01 the authors have carried out many many statistical tests so of course there will still be type 1 error rate inflation. For the tests that are not statistically significant it is unclear for each hypothesis being tested what a scientifically meaningful difference is.

REVIEWER	Barbara Singer Centre for Musculoskeletal Studies School of Surgery The University of Western Australia Professor Lynne Turner-Stokes is an adjunct professor at the Centre for Musculoskeletal Studies. I do not consider this to represent a conflict of interest as we have not published together nor do we share any research funding.
REVIEW RETURNED	04-Nov-2013

GENERAL COMMENTS	This is a substantial paper which addresses the important question of the long term needs of people living in an area in the UK with a chronic, complex neurological condition, and the extent to which these needs are met by current services. While this information has a specific jurisdictional application, it is likely to be broadly relevant to the provision of a range of other health and social services in other jurisdictions.

	The introduction, while short, sets out the relevant background to the investigation and the purpose and study aims. It would be helpful to have a brief discussion of the authors’ view that the first six months after discharge from inpatient rehabilitation is ‘critical’. The methods of data collection, analyses and results are appropriate and well set out. However, the paper ends rather abruptly. It would be helpful for the authors to reflect briefly on the clinical implications of these data, and any recommendations for the way that Quality Requirement 1 of the NSF for LTNC might be achieved for this group of patients with complex needs Some specific comments are provided below for the authors’ consideration: There is inconsistency with regard to the placement of the ‘period’ (full stop) in the in text citations. P4 – LTNC has already been defined in line 7, and does not need to be repeated in line 19. P4 line 51 – this sentence needs to be re-worded to avoid the possible interpretation that families contribute to the ‘hidden disabilities’. P5 line 13 should read ‘a LTNC register’ P5 line 22 – it is a little confusing to head this section (which is really the study objectives): “This article reports the key findings of that study”. It would be better to simply state that the current investigation had two parts and then to detail those components and the objectives of each – without reference to ‘findings’ at this stage. P6 line 6 – it would be helpful to cite the 2009 publication details that are referred to here as well as reproducing the figures that give an overview of the LTNC framework. P8 lines 15-16 – reference 19 would be suitable to support this statement about the NIS being a valid and reliable measure of neurological impairment suitable for use across a wide range of neurological conditions. P10 lines 41-44 – although the NPDS has been shown to be valid and reliable previously this has been completed by a health professional (or team) – is there any evidence that this is equally reliable as when completed by the patient (or proxy)? P12 line 44 should read ‘..patients whose needs for rehabilitation..” Figure 2 – it would be helpful to briefly detail why subjects were withdrawn (apart from those who had deceased). P15 the location of Table 3 – currently in the middle of a sentence – will need to be addressed. P16 line 1 should read …‘best responder’ group. P16 line 19 should read …”despite the continuing levels of dependency and carer burden in the respondents” or …”despite continuing high levels of dependency and carer burden”. P18 line 54-5 should read …” showed significantly lower gains in CIQ than those for whom

	provision did not meet their predicted need …" Competing interests: Professor Lynne Turner-Stokes is an adjunct professor at the Centre for Musculoskeletal Studies. I do not consider this to represent a conflict of interest as we have not published together nor do we share any research funding.

REVIEWER	Elizabeth Kendall Griffith University, Australia
REVIEW RETURNED	18-Nov-2013

GENERAL COMMENTS	This paper is a good study based on the exploration of a register to monitor patients with neurological conditions. The paper has two aims – to pilot the register and to understand the needs of people in the 12 months following discharge. The paper is divided into two parts accordingly. The introduction to the paper is very descriptive, rightly establishing the case for the register. However, this means that some justification for the choice of scales and research questions is missing. This is not a serious problem, but there is literature available that reflects on registers in TBI and unmet needs. Some of this literature, if reviewed, may have contributed to the interpretation of the findings. Overall, the paper describes a very thoughtful method. A great deal of attention has been given to different methods of data collection, piloting of the surveys, follow-up, missing data, recruitment of hospitals. The effort put into this register is significant and commendable. Given that the paper describes a register, it would be helpful to have more information about the utility of some selected tools and the rationale for using these tools rather than those used by other registers around the world. The scale selected have been developed and reported on elsewhere, but it is not clear if they have been used extensively in TBI beyond this registry study. The process of producing "metness" of needs may require some discussion in relation to its limitations. For instance, is it appropriate for clinicians to evaluate needs and patients to evaluate subsequent services. The ratings of clinicians would differ depending on the discipline background of the clinician. It is difficult to understand the suitability of "metness" scores without more detail of the scale and algorithm.

In terms of patient recruitment, the authors sought a consecutive sample. Consent was taken by the discharging clinician after a suitable period for reflection. It is not clear what this actually means in practice – who actually approached patients? Did they have a script to follow? What was the context of recruitment? How long were patients given to make a decision about participation? What would have been the potential impact of this recruitment process?

The baseline data collection was conducted by the discharge team – they assessed severity of impairment, needs, willingness to be included in the register, support referrals and contact details. Who in the team rated needs? What was the potential for bias in this baseline data collection? As above, would this have influenced the extent to which people agreed to be on the register? Would needs assessment have been biased by the constitution of the treating discharge team?

Data collection by the research team then proceeded in one of three ways – postal, web-based or telephone. The authors present some analysis of the different data collection processes, but it would be interesting to know if there were any differences in outcomes for those who completed the data through different methods. It would also be interesting to know how many of those who agreed to participate in each method did not eventually respond – ie., was the response rate different for different methods.

As the authors note, it is surprising that despite their thorough follow up, less than 50% of those recruited participated in the register. The paper is about the utility of a register, so this finding requires greater discussion in the conclusion of the paper. Perhaps it would be helpful to compare this finding to other registers or even to large longitudinal studies in the same population. It would also be helpful to know if the method-specific response rates (i.e., of those who chose each method, how many responded) differed and the cost implications of these effects.

As mentioned in relation to the introduction, it would be useful to have some theoretical rationale (or an empirical rationale) for the selection of variables to enter into the regression equations. The variables selected could just as easily have been other variables, so it is important to discuss why this group was most important. Similarly, the choice of only two outcome variables requires justification. Further, the selection of variables for inclusion in the stepwise regression requires some rationale. It would be usual to show a correlation matrix and have a consistent empirical method for deciding which variables should be included in subsequent analyses. Alternatively, a theoretical rationale would be equally useful and important to justify the hypotheses that have been developed.

In terms of analysis, the paper is based on a large number of statistical analyses. It would be helpful to have a discussion of whether or not simply raising alpha is sufficient to combat inflated error rates.

A minor point is that the first research question on page 14 should read “Do patients want to be entered on an LTNC register and which patients might be most likely to agree?”

Of 576 patients, 499 were eligible – who assessed eligibility prior to consent and based on what criteria? Did those who declined to participate (either 7 or 8% which should be clarified on page 12) give reasons for refusal? These reasons would be interesting and useful.

Of those who dropped out, is there any information about why? Of those who were recruited to the study, 22% did not respond to the question about whether they would participate in a register. What is the likely reason for this non-response to the item?

Attrition was highest for non-white participants, which has significant implications for a register – perhaps include some discussion about the implications of this trend and compare to other statistics (i.e., incidence/prevalence rates in non-white samples, other attempts to recruit non-white samples etc.).

The finding that participation was not consistent over time is also important – ie., different people responded at different times – only 31% were the “best responders”. It is important to fully understand this group if conclusions are to be based on them. Although the authors state that they are not significantly different from the other participants, there are some important differences in that they were more likely to be discharged to home (slightly less likely to go to nursing home or ongoing rehab) and slightly less likely to have needs for social support. It is also likely that this group contained fewer non-white participants given the higher attrition for this population. However, on page 19, the manuscript states that the best responders included a higher proportion of non-white participants (It is not clear where this finding is discussed). These are important differences that are likely to influence the findings and should be discussed.

Table 3 is very difficult to interpret because the headings are not really helpful. It seems to indicate that the best responders report higher levels (maybe not statistically significant) than the total sample at all three phases. Is this significant? What are the implications? Is this because they were more likely to go home and therefore have carers?

The best responders demonstrated unmet needs in rehabilitation, social support and equipment in the first 6 months and a decline in services received in the next period. It is equally important to note that health, personal care and accommodation needs are being met for this group, probably as a result of their discharge destination and probably accounting for high rates of caregiver burden.

Table 4 is also difficult to interpret – are change scores the best way to deal with outcomes? The changes in “metness” at 12 months are really not that reliable as there is no way of knowing whether or not needs have changed dramatically. It is highly likely that needs assessed by clinicians prior to discharge are inaccurate. The paper should contain some discussion of this problem (i.e., the reliability of needs assessments by clinicians prior to discharge, the impact of discharge on needs, the problems associated with assuming that receipt of a service equates with needs being met etc.).

Why were CIQ and SNN not included in the regression predicting services received in the first 6 months (in Table 5)? Similarly, decisions about the inclusion of predictors on page 19 require justification. Either a consistent approach or a well-justified decision-making process seems important for credibility. There is nothing wrong with the analyses, but the way they are reported needs to be clearer.

The counter-intuitive finding that those whose rehabilitation needs were met or exceeded had poorer community integration outcomes is so important and warrants much more discussion. Who were this group of 31 participants? Notwithstanding the problems associated with calculating metness using clinical judgements of need and subsequent service usage, the findings are not overly surprising in that those who were more dependent were more likely to have their needs met and then were less likely to have good community integration outcomes. The authors conclude that services are

	probably provided to those with the highest needs, which is the most likely interpretation of this finding. This finding may also highlight the fact that clinician judgements about rehabilitation needs do not always match reality and may not take into account the impact of different community environments on dependency. Alternatively, the process of focusing on continuing rehabilitation may have simply prevented community integration, possibly due to a strong emphasis on physical rehabilitation in response to the high level of physical impairments. A conclusion reached on page 19 is that the study has suggested that integrated care planning should involve face-to-face meetings, and that this will be effective for the register. However, this is the way in which recruitment and baseline data collection was conducted (by clinicians and treatment teams in person). A minor point is that on page 20, the authors state “in face, if anything, we showed the opposite”. This sentence should be reworded so it reflects what was actually found.

VERSION 1 – AUTHOR RESPONSE

Reviewer Name: Mark Weatherall

1. Comment:
The two major issues with the material are the very high level of non-response. Although the authors comment on this it is rather down-played. Non-response bias is highly likely to be present and so it is very uncertain how the findings of this study might apply to the target population.

Response:
We agree that this is a limitation of the study, which may give rise to response bias. In response to this comment, we have emphasised the point under study limitations to indicate that “non-response bias is likely to be present. Consequently it is uncertain how well the findings of this study might apply to the broader population of people with LTNC”. (see p.24, para 1).

That said, follow-up in this population is acknowledged to be difficult and the attrition rates in this population are similar to those reported in other series, so we have also extended the discussion on this point in the second paragraph of the Discussion, with some added references to put this in perspective. (p.22).

2. Comment:
Although the P-value for significance has been 'reset' at 0.01 the authors have carried out many many statistical tests so of course there will still be type 1 error rate inflation. For the tests that are not statistically significant it is unclear for each hypothesis being tested what a scientifically meaningful difference is.

Response:

We could have set a more stringent P-value at 0.001 for an overall alpha level of 0.05 using the Bonferroni method. However, this can increase the likelihood of type II errors, so that truly important differences are deemed non-significant, and create more problems than it solves (Perniger, 1999). The Bonferroni method is concerned with the general null hypothesis – that all null hypotheses are true simultaneously – which is rarely of interest or use to researchers. Reviewing the actual levels of sigificance, we are confident that the adjusted level does not alter the principal conclusions of the study.

Nevertheless, we accept that this is a potential criticism and have added to the limitations sections to justify our choice of P-value. (p.24, para 2).

Reviewer Name: Barbara Singer

This is a substantial paper which addresses the important question of the long term needs of people living in an area in the UK with a chronic, complex neurological condition, and the extent to which these needs are met by current services. While this information has a specific jurisdictional application, it is likely to be broadly relevant to the provision of a range of other health and social services in other jurisdictions.

1. Comment: The introduction, while short, sets out the relevant background to the investigation and the purpose and study aims. It would be helpful to have a brief discussion of the authors¹ view that the first six months after discharge from inpatient rehabilitation is critical.

Response: This period was considered to be particularly critical for the provision of services to support adjustment and (where possible) re-ablement following newly-acquired disability. We have added a sentence to this effect (see p.14, lines 1-3).

2. Comment: The methods of data collection, analyses and results are appropriate and well set out. However, the paper ends rather abruptly. It would be helpful for the authors to reflect briefly on the clinical implications of these data, and any recommendations for the way that Quality Requirement 1 of the NSF for LTNC might be achieved for this group of patients with complex needs.

Response: We have extended the discussion section slightly and added a summary paragraph (p.24).

3. Comment: Some specific comments are provided below for the authors' consideration: There is inconsistency with regard to the placement of the 'period' (full stop) in the in text citations.

Response: In text citations have been corrected (throughout manuscript).

4. Comment: P4 LTNC has already been defined in line 7, and does not need to be repeated in line 19.

Response: The LTNC definition in line 19 has been deleted

5. Comment: P4 line 51 this sentence needs to be re-worded to avoid the possible interpretation that families contribute to the hidden disabilities.

Response: The sentence now reads, 'Particular concerns were raised about lack of support for patients with complex needs arising from 'hidden disabilities' due to cognitive/behavioural problems, and the impact of these problems on their families.' (see p.4).

6. Comment: P5 line 13 should read a LTNC register

Response: The wording has been corrected (see p.6, line 1).

7. Comment: P5 line 22 it is a little confusing to head this section (which is really the study objectives): ‘This article reports the key findings of that study’. It would be better to simply state that the current investigation had two parts and then to detail those components and the objectives of each without reference to findings at this stage. (see bottom of p.5/top of p.6).

Response: The wording has been adjusted accordingly

8. Comment: P6 line 6 it would be helpful to cite the 2009 publication details that are referred to here as well as reproducing the figures that give an overview of the LTNC framework.

Response: Unfortunately, the NHS Information Centre documentation was archived in the course of transition to the new Health and Social Services Information Centre. We have lodged a request for this to be re-instated on the HCSIC website. In the meantime we have given a website reference to where more information about the LTNC dataset can be found. (see p.4, para 3).

9. Comment: P8 lines 15-16 reference 19 would be suitable to support this statement about the NIS being a valid and reliable measure of neurological impairment suitable for use across a wide range of neurological conditions.

Response: We agree and have added this reference to the statement. (p.9, para1).

10. Comment: P10 lines 41-44 although the NPDS has been shown to be valid and reliable previously this has been completed by a health professional (or team) is there any evidence that this is equally reliable as when completed by the patient (or proxy)?

Response: In the early stages of development of the NPDS postal version, a small validation study was conducted against the clinician-administered tool, which demonstrated acceptable levels of agreement. This information was presented in abstract form, but never formally published. A brief report of this study is being made available on our website.

11. Comment: P12 line 44 should read ...patients whose needs for rehabilitation.

Response: Thank you - The wording has been corrected (p.14, line 11-12).

12. Comment: Figure 2 it would be helpful to briefly detail why subjects were withdrawn (apart from those who had deceased).

Response: A footnote has been added to Figure 2 stating that reasons for withdrawal were: Not wanting any further involvement 24/43 (56%), unwilling or unable to fill in questionnaires 6/43 (14%), re-admission to hospital 2/43 (5%) and being uncontactable 11/43 (25%).

13. Comment: P15 the location of Table 3 currently in the middle of a sentence will need to be addressed.

Response: Thank you - The text has been re-located to below Table 3

14. Comment: P16 line 1 should read best responder group.

Response: Thank you - The text has been revised (p.18, para 1)

15. Comment: P16 line 19 should read despite the continuing levels of dependency and carer burden in the respondents or ‘despite continuing high levels of dependency and carer burden’.

Response: Thank you - The text has been revised to read, ‘despite continuing high and unchanging levels of dependency and carer burden’. (p.18, para 2).

16. Comment: P18 line 54-5 should read showed significantly lower gains in CIQ than those for whom provision did not meet their predicted needs.

Response: Thank you - The text has been revised (p.21)

Reviewer Name Elizabeth Kendall

This paper is a good study based on the exploration of a register to monitor patients with neurological conditions. The paper has two aims to pilot the register and to understand the needs of people in the 12 months following discharge. The paper is divided into two parts accordingly.

1. Comment: The introduction to the paper is very descriptive, rightly establishing the case for the register. However, this means that some justification for the choice of scales and research questions is missing. This is not a serious problem, but there is literature available that reflects on registers in TBI and unmet needs. Some of this literature, if reviewed, may have contributed to the interpretation of the findings.

Response: We have adjusted the introduction to make it clearer that the LTNC dataset was already developed and published prior to the onset of the study so to some extent we had to work with the tools that had already been selected. The LTNC Dataset Development Group had also highlighted the need for other measures to support the evaluation of long term outcomes at the level of societal participation, including measures of community re-integration and carer burden, although specific tools were not stipulated. (See Introduction, p. 4 para 5 – p.5, paras 1-2)

As already noted (p.10), we selected the additional tools (the Community Integration Questionnaire and the Zarit Carer Burden Interview) on the basis that (a) they are widely used, psychometrically robust and applicable in LTNC, (b) they are freely available and not restricted by license and (c) they are easily understood and timely to apply.

2. Comment: Overall, the paper describes a very thoughtful method. A great deal of attention has been given to different methods of data collection, piloting of the surveys, follow-up, missing data, recruitment of hospitals. The effort put into this register is significant and commendable.

Response: Thank you.

3. Comment: Given that the paper describes a register, it would be helpful to have more information about the utility of some selected tools and the rationale for using these tools rather than those used by other registers around the world. The scales selected have been developed and reported on elsewhere, but it is not clear if they have been used extensively in TBI beyond this registry study.

Response: The LTNC Registry is designed for a wide range of neurological conditions, of which TBI form only a relatively small proportion (15% in this study). We do not believe that a detailed discussion of the tools that have been used in TBI or indeed the various other condition specific registers around the world is especially useful here – many of which use tools that are restricted by licence or clinician-completed. However we have added some information under the description of the tools to highlight their wider use. (pp. 9 – 10)

4. Comment: The process of producing 'metness' of needs may require some discussion in relation to its limitations. For instance, is it appropriate for clinicians to evaluate needs and patients to evaluate subsequent services. The ratings of clinicians would differ depending on the discipline background of the clinician. It is difficult to understand the suitability of 'metness' scores without more detail of the scale and algorithm.

Response: We have given the reference to our website from which the NPCS, the algorithm and other information about the tool can be downloaded. (p.9, para 2). We have also referenced a previous paper published in BMJ Open which described use of the NPCS to quantify met and unmet needs in relation to cost (ref # 20). The NPDS-Needs was assessed by the MD Team at discharge from the service, not by individual disciplines so we do not believe that this would have an impact – the composition of the MD teams in the 9 services was largely similar. Moreover teams were asked to record the NPCS-Needs in relation to services that they reasonably expected the patient to receive, based on the referrals they were making for ongoing support and rehabilitation, rather than those they might wish for 'in an ideal world'. We have added some text to explain this more fully –see paragraph starting 'Baseline data were recorded….' bottom of p.11.

5. Comment: In terms of patient recruitment, the authors sought a consecutive sample. Consent was taken by the discharging clinician after a suitable period for reflection. It is not clear what this actually means in practice who actually approached patients? Did they have a script to follow? What was the context of recruitment? How long were patients given to make a decision about participation? What would have been the potential impact of this recruitment process?

Response: Under ' the sections entitled 'Participants' and 'Data collection procedure', we have added more detail on the method of recruitment, which varied somewhat from centre to centre to fit in with local practice, (so to reflect differences that are likely also occur in real life) (p.11). With respect to who actually approached the patient, we have also added a brief section in first paragraph of results to describe the impact of different approaches to recruitment (p.14).

6. Comment: The baseline data collection was conducted by the discharge team they assessed severity of impairment, needs, willingness to be included in the register, support referrals and contact details. Who in the team rated needs? What was the potential for bias in this baseline data collection?

Response: This is partly dealt with above, under 'Data collection procedure', but we have also added a note to explain that the MD Team approach to shared decision-making in the assessment of needs reduced the potential for clinician bias across different disciplines, as the representation of disciplines within the teams was broadly similar across the nine specialist rehabilitation units (P.11, last para).

7. Comment: Data collection by the research team then proceeded in one of three ways postal, web-based or telephone. The authors present some analysis of the different data collection processes, but it would be interesting to know if there were any differences in outcomes for those who completed the data through different methods. It would also be interesting to know how many of those who agreed to participate in each method did not eventually respond ie., was the response rate different for different methods.

Response: We did not analyse outcomes according to the method of questionnaire completion because the vast majority (>80% at each time point) responded by combination of written questionnaire and telephone interview to maximize the completeness of response.

8. Comment: As the authors note, it is surprising that despite their thorough follow up, less than 50% of those recruited participated in the register. The paper is about the utility of a register, so this finding requires greater discussion in the conclusion of the paper. Perhaps it would be helpful to compare this finding to other registers or even to large longitudinal studies in the same population. It would also be helpful to know if the method-specific response rates (i.e., of those who chose each method, how many responded) differed and the cost implications of these effects.

Response: This has already been highlighted above - we have expanded the discussion with additional references to note that our non-response rate was not dissimilar to that in other studies, which also had <50% response rates (p.22, para 2). As noted above, nearly all respondents used the same method for response so this did not significantly impact on recruitment. We did not perform a cost analysis of the different methods.

9. Comment: As mentioned in relation to the introduction, it would be useful to have some theoretical rationale (or an empirical rationale) for the selection of variables to enter into the regression equations. The variables selected could just as easily have been other variables, so it is important to discuss why this group was most important. Similarly, the choice of only two outcome variables requires justification. Further, the selection of variables for inclusion in the stepwise regression requires some rationale. It would be usual to show a correlation matrix and have a consistent empirical method for deciding which variables should be included in subsequent analyses. Alternatively, a theoretical rationale would be equally useful and important to justify the hypotheses that have been developed.

Response: The potential predictor variables for the level of services received (NPCS gets) in the critical first 6-months after discharge are listed in the section ‘Data management and analysis’, points a) to e). These include the demographic variables and all of the measures listed in the measurement tools section, (except for the NPCS itself). All of these were included in the initial univariate regression analyses, and then those that showed a significant relationship with NPCS-Gets at 6 months (ie the impairment, dependency nursing needs and community integration) were all entered into the stepwise regression analysis. Some of the single variables were different subscales of the same instrument (ie the NPDS-Phys and NPDS CB are both subscales of the NPDS-BCN. In this case we chose the NPDS-BCN for inclusion in the stepwise analysis as it was the most highly correlated in the univariate analyses). We have added to the text to make this sequence of analysis much more clear (p.13, lines 15 -20). We have also added a table (Table 5) to show the correlation matrix as suggested by the reviewer.

In the regression comparing outcomes at the level of participation (community integration and carer burden) with metness of rehabilitation need the variables entered into the model were selected on a priori theoretical grounds, given the strong inter-relationship between these outcomes and dependency. We have clarified this in the text.

10. Comment: In terms of analysis, the paper is based on a large number of statistical analyses. It would be helpful to have a discussion of whether or not simply raising alpha is sufficient to combat inflated error rates.

Response: A paragraph has been added to the limitations sections to justify our choice of P-value (p.24, para 2). We agree that we could have set a more stringent P-value at 0.001 as suggested by the Bonferroni method. However, this can increase the likelihood of type II errors, so that truly important differences are deemed non-significant, and create more problems than it solves (Perniger, 1999). The Bonferroni method is concerned with the general null hypothesis – that all null hypotheses are true simultaneously – which is rarely of interest or use to researchers. Moreover, given the P values reported, we are confident that the adjusted level does not alter the principal conclusions of the study. (see also ref # 43, Perneger, 1998, BMJ)

11. Comment: A minor point is that the first research question on page 14 should read ‘Do patients want to be entered on an LTNC register and which patients might be most likely to agree?’

Response: We have changed the wording ‘use it’ to ‘participate’. As discussed in that paragraph, agreeing to be included did not necessarily mean that patients would respond to the questionnaires when these were sent out. So this section addresses more than just which patients agree to inclusion. (Results section, p.16)

12. Comment: Of 576 patients, 499 were eligible who assessed eligibility prior to consent and based on what criteria? Did those who declined to participate (either 7 or 8% which should be clarified on page 12) give reasons for refusal? These reasons would be interesting and useful.

Response: The criteria for inclusion in the study was having a LTNC (ie neurological condition that was likely to have an enduring effect). 8% declined. Patients were not required to give reasons for refusal so this information was not usually available

13. Comment: Of those who dropped out, is there any information about why? Of those who were recruited to the study, 22% did not respond to the question about whether they would participate in a register. What is the likely reason for this non-response to the item?

Response: The reasons for withdrawal are addressed in no. 12 above by a footnote to Figure 2. The most common reason for not responding to the question of whether they would be willing to participate in a register is most commonly because the team did not ask it. This is now noted in the text. (see Fig. 2, p.28)

14. Comment: Attrition was highest for non-white participants, which has significant implications for a register perhaps include some discussion about the implications of this trend and compare to other statistics (i.e.incidence/prevalence rates in non-white samples, other attempts to recruit non-white samples etc.).

Response: We have added to the Discussion section to discuss potential reasons for attrition in the non-white group, with reference to the literature. (Discussion, p.22, para 2)

15. Comment: The finding that participation was not consistent over time is also important ie., different people responded at different times only 31% were the ‘best responders’. It is important to fully understand this group if conclusions are to be based on them. Although the authors state that they are not significantly different from the other participants, there are some important differences in that they were more likely to be discharged to home (slightly less likely to go to nursing home or ongoing rehab) and slightly less likely to have needs for social support. It is also likely that this group contained fewer non-white participants given the higher attrition for this population. However, on page 19, the manuscript states that the best responders included a higher proportion of non-white participants (It is not clear where this finding is discussed).. These are important differences that are likely to influence the findings and should be discussed.

Response: The statement on page 19 indicating that the best responders included more non-white participants was a typographical error which should have read … ‘more white participants’… and has been changed accordingly.
The poorer response from non-white males is not unexpected and is observed in other contexts – we have highlighted this in the discussion as noted above. The lower response from patients in hospitals

and nursing homes reflects the fact that this group is generally sicker or more disabled and less likely to be able to respond for themselves – it was often difficult to find a member of staff who was willing or who knew the patient well enough to be able to respond on their behalf. This is also now included in the discussion. (p.22, para 2)

16. Comment: Table 3 is very difficult to interpret because the headings are not really helpful. It seems to indicate that the best responders report higher levels (maybe not statistically significant) than the total sample at all three phases. Is this significant? What are the implications? Is this because they were more likely to go home and therefore have carers?

Response: We apologise for the headings not being clear and have adjusted Table 3 (p.17) to improve interpretability. We believe that the reviewer is referring to the figures for carer burden, which are marginally higher for the best responder group. This was not a significant difference, but moreover we did not consider it appropriate to report signficance between the best responders and the groups responding at each phase as the former were also included in the responders at each time point. The data are provided for descriptive purposes only.

17. Comment: The best responders demonstrated unmet needs in rehabilitation, social support and equipment in the first 6 months and a decline in services received in the next period. It is equally important to note that health, personal care and accommodation needs are being met for this group, probably as a result of their discharge destination, and probably accounting for high rates of caregiver burden.

Response: We take the reviewer’s point that needs for personal care being met might have contributed to carer burden at months 12, but we have not demonstrated a clear relationship in this study and so would rather not speculate on this point.

18. Comment: Table 4 is also difficult to interpret are change scores the best way to deal with outcomes? The changes in ‘metness’ at 12 months are really not that reliable as there is no way of knowing whether or not needs have changed dramatically. It is highly likely that needs assessed by clinicians prior to discharge are inaccurate. The paper should contain some discussion of this problem (i.e., the reliability of needs assessments by clinicians prior to discharge, the impact of discharge on needs, the problems associated with assuming that receipt of a service equates with needs being met etc.).

Response: We have already acknowledged the limitation that care needs were not reassessed for the second 6 months time period (p.23, para 3). We still believe that it is valid and useful to describe the change in levels of service provided between the first and second 6-month periods.

As noted above we have explained in more detail in the text about the basis on which ‘needs’ were assessed. We do not think that the clinicians’ assessment of needs was inaccurate as they would have spent a lot of time in MD discharge planning considering the needs of the patients and how they would be met in the community. We do agree that needs made be expected to have changed somewhat in the second 6 months, although perhaps not quite so much as the reviewer implies as this was a population of patients with complex needs arising from LTNCs. We therefore expected them to have a substantial level of ongoing needs and this is support by the overall lack of change in dependency, community integration and carer burden.

As noted above we have added to the text to explain the basis on which NPCS needs were assessed at discharge. We accept that the discrepancy scores between NPCS-Needs and Gets provide only a limited assessment of ‘metness’ of needs in the wider sphere, but that is true of any structured measurement instrument.

19. Comment: Why were CIQ and SNN not included in the regression predicting services received in the first 6 months (in Table 5)? Similarly, decisions about the inclusion of predictors on page 19 require justification. Either a consistent approach or a well-justified decision-making process seems important for credibility. There is nothing wrong with the analyses, but the way they are reported needs to be clearer.

Response: This query is dealt with in point 24 above

20. Comment: The counter-intuitive finding that those whose rehabilitation needs were met or exceeded had poorer community integration outcomes is so important and warrants much more discussion. Who were this group of 31 participants? Notwithstanding the problems associated with calculating metness using clinical judgements of need and subsequent service usage, the findings are not overly surprising in that those who were more dependent were more likely to have their needs met and then were less likely to have good community integration outcomes. The authors conclude that services are probably provided to those with the highest needs, which is the most likely interpretation of this finding. This finding may also highlight the fact that clinician judgements about rehabilitation needs do not always match reality and may not take into account the impact of different community environments on dependency. Alternatively, the process of focusing on continuing rehabilitation may have simply prevented community integration, possibly due to a strong emphasis on physical rehabilitation in response to the high level of physical impairments.

Response: We agree that this is an important findings and have added text to the discussion, which also cites the ‘Inverse therapy rule’ previously described by John Young and colleagues (p.23, para 3). Given a) the detailed discharge planning accompanied by graded discharge programmes that were standard in this cohort, b) the fact that clinicians based their realistic assessment of needs based on the knowledge of services to which patients had been referred and c) the lack of change also in physical dependency (all of which are now highlighted in the paper) we believe that the alternative explanations proffered are much less likely in this context.

21. Comment: A conclusion reached on page 19 is that the study has suggested that integrated care planning should involve face-to-face meetings, and that this will be effective for the register. However, this is the way in which recruitment and baseline data collection was conducted (by clinicians and treatment teams in person).

Response: Yes, we accept that, and overall recruitment to the study was indeed quite successful (>90% of subjects approached). The problem was attrition once in the community. There may be several explanations for this including questionnaire fatigue, as relatively few actively withdrew – the majority just failed to respond.

In clinical practice, integrated care planning reviews most commonly involve face-to-face meetings with the patient and carer, and we believe that this is likely to offer a more effective route for data collection than the postal questionnaire/telephone follow-up used in this study. We have added to the discussion to clarify this point (Discussion, p.24, first third and final paras)

22. Comment: A minor point is that on page 20, the authors state ‘in fact, if anything, we showed the opposite’. This sentence should be reworded so it reflects what was actually found.

Response: This sentence has been re-worded (p.23, para 2) ..’their outcomes were worse.’

In summary we have revised the manuscript substantially to address all of the major and practically all the minor points raised by the three reviewers. We look forward to hearing from you in due course and to publishing this article in the BMJopen.

VERSION 2 – REVIEW

REVIEWER	Barbara Singer The University of Western Australia Australia
REVIEW RETURNED	24-Jan-2014

GENERAL COMMENTS	The authors have carefully considered the extensive commentary by the three reviewers regarding the initial manuscript, and have amended and added to the paper as suggested; resulting in a considerably improved paper.