Integrated Services for People with Long-term Neurological Conditions: Evaluation of the Impact of the National Service Framework:

Appendices

Project 08/1610/124

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Appendix A Scoping findings: SHAs and the NSF

Between November 2006 and January 2007 a researcher contacted each of the ten Strategic Health Authorities (SHAs) in England. When the scoping exercise was conducted, these SHAs were[1]:

East of England SHA
East Midlands SHA
London SHA
North East SHA
North West SHA
South East Coast SHA
South Central SHA
South West SHA
West Midlands SHA
Yorkshire and the Humber SHA

SHAs were contacted by telephone and asked to identify the person who took the lead role for long-term neurological conditions. These individuals, where identified, were then contacted either by telephone or by email and asked to respond the questions below:

- Does your SHA have a designated lead for long-term conditions and does their specific remit include neurological conditions?
- Are there designated leads within Primary Care Trusts (PCTs)?
- Is there a neurological network operating in your locality?
- To what extent is there integration between health and social care (H & SC) commissioning locally?
- Is a Single Assessment Process (SAP) used locally? If for certain groups/in certain settings only, what are these?
- Which areas within the SHA do they think have made more/less progress towards implementation of the NSF for LTNCs?

Numerous phone calls had to be made to identify key people with responsibility for/knowledge of implementation in each SHA area and it was common to be redirected many times. In some areas, the SHAs were unable to direct us to the key people dealing with the NSF, neurology or even the wider remit of long-term conditions (see Table A.1). With persistence, often by finding alternative routes via PCTs or specialist service providers, some information was gathered in all but one SHA area (SHA8).

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[1] Listed in alphabetical order. Note that this is not the order in which SHAs are listed in the results section of this paper.

Table A.1 Results of attempts to contact SHA leads November 2006 – January 2007

SHA	SHA Lead	Neuro-Network (NN)	Services/Progress towards NSF	Comments
SHA1	No longer a named lead	Previous SHA Lead established NN but current status unknown	Some PCTs have submitted specific plans for implementation of NSF, others are incorporating it into existing work plans	4 SHA contacts reached: all found it difficult to give information following reconfiguration – structures not yet in place
SHA2	No named lead at SHA but are at PCT level	Established NN led by lead PCT	Active NN looking at neurological rehabilitation, inequity in access to neurology services; and ensuring adequate patient voice	PCT lead reported that many LTNC relevant groups operate in the community but who they are and what they do is not well documented
SHA3	No longer a named lead.	Unclear	No clear picture of the services available now or in development. No staff from PCT responded	Severe confusion about roles at PCT and SHA level. Directed to the same person, who no longer worked on these topics, by 3 different people
SHA4	Lead identified	NN developed in some areas and work underway to join these up	Looking to use NSF across all long-term conditions not only neurological. Focusing on community care. Planning to review specialist nurse posts and conduct feasibility study on transfer of care from acute to community	SHA lead seemed well aware of what was going on in some (but not all) of the patch since reconfiguration. Appears to be considerable activity regionally led by NSF lead for one of the PCTs
SHA5	Generic LTCs lead identified	No overarching NN identified	SHA gives strategic guidance but responsibility of individual PCTs to take forward implementation	SHA lead seemed well organised and had people in post. Aware of progress at national and regional level but less so at practical/local implementation level
SHA6	Lead identified	SHA lead unsure about existence of NN	SHA lead not clear about current level of service or service development as just getting to grips with new SHA	Not much information. Despite repeated contact the SHA lead did not give further details. Busy post reconfiguration. Suggested different contact who also did not respond.
SHA7	SHA not able to assist	Well developed NN (clinical) in part of patch but not all	Identified activity in area with clinical NN but unable to ascertain level of progress in rest of patch	Some lack of clarity about posts/responsibilities etc and how this will impact on the different services and networks locally. Lots of staff movement
SHA8	SHA lost NSF	No information	PCTs to lead but none in post at time of	Despite repeated contacts no information given and

SHA	**SHA Lead**	**Neuro-Network (NN)**	**Services/Progress towards NSF**	**Comments**
	lead in reconfig.		contact	no advice on who to contact at the PCT as no leads in this area yet appointed
SHA9	Generic LTCs lead identified. Future in reconfig. uncertain	NN put on hold pending reconfiguration	NSF external reference group with wide representation. NN to be reconfigured – will act as advisory body to share good practice across local groups. History of partnership working. Health &Social Care Commissioner to lead locally. NSF not a priority, most of attention focused on major causes of emergency admissions.	SHA contact knowledgeable about local services, pockets of good practice across SHA area. Structures, services in state of flux, including own post. Neurological conditions not debated at a national level.
SHA10	SHA will have a generic LTCs lead	Well established NNs in some areas	PCT leads and local implementation teams in most areas (but structures subject to change with reconfiguration)	SHA contact (‘old’ lead for NSF for LTNCs) seemed knowledgeable of services and approaches to NSF implementation in most areas of patch

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A.1 SHAs

With the exception of SHA2 (who immediately directed us to a PCT-based lead), SHAs did not find it easy to identify leads for the implementation of the NSF or for long-term conditions, more generally. The most common reason given for this was that SHAs and PCTs had recently undergone major reconfiguration; indeed, most were still undergoing this process. With SHAs merging, PCTs joining together to form larger health service organisations and changes in internal management structures, SHA staff had not had time to learn who was now in the position to take on these leads. In many areas, it was unclear whether the SHA would continue to maintain these roles post reconfiguration. Often, it was suggested that questions about policies and service development for people with long-term neurological conditions be directed to local authorities, who dealt with social care for people with disabilities. However, despite numerous approaches to adult social care in these areas by telephone and email, there was little response. Where contact was made with adult social care teams, it became clear that the NSF was not considered a major priority when placed in a broad and rapidly changing policy arena. Policies that were viewed as having immediate and long-term effects particularly relevant to social care were given priority, such as the Carers Equal Opportunity Act (2004)[2], as were newer policy initiatives such as the White Paper: Our Health, Our Care, Our Say (2006).[3]

Where SHAs were able to provide names and contact details for people taking a lead on the NSF, or for long-term conditions more widely, these were often redundant as the person was no longer employed in the same role, or at all, following reconfiguration. On the whole, therefore, it seemed that SHA staff did not appear to be up to date with changes within their organisations at the time the scoping information was collected.

Reconfiguration also led to inconsistencies within SHA boundaries. The merger of pre-existing SHAs led to some parts of the newly formed SHAs having made significantly more progress on the NSF than other parts. This was the case in SHA1, where three SHAs had merged. It was reported that one of these former SHAs had made progress on NSF implementation and LTNC service development, whilst two of them had not. In addition, in some areas, previously existing strategies for integrated working were affected detrimentally by the SHA and, particularly, the PCT reconfiguration. People reported that many formal and informal relationships that previously existed to provide service integration would have to be rebuilt in the context of the new organisational structures.

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[2] HM Government (2004) *Carers (Equal Opportunities) Act 2004*, The Stationery Office http://www.opsi.gov.uk/ACTS/acts2004/ukpga_20040015_en_1.

[3] Department of Health (2006) *Our Health, Our Care, Our Say: A new direction for community services*, Cm 6737, London: The Stationery Office.

A.2 PCTS

Some SHAs had lead PCTs which led either on implementation of the NSF for LTNCs or, more generally, on neurology service provision and/or commissioning. As would be expected, some PCTs were more advanced in terms of the development of neurological services and the NSF programme than others. Many who responded to requests for information stated that the recent reconfiguration was a hindrance to implementation. Issues raised by PCTs were similar to those described above relating to SHA reconfiguration. In particular, there was a sense that the merging of numerous PCTs had resulted in little coherence in structures across the new PCT locales, at least in the short term.

A.3 Neurological networks

Four SHAs were aware of a neurological network existing in their area, three of which were well developed. These, however, were restricted by similar problems to those outlined above, in that they only covered certain areas of the SHA or indeed, relevant PCTs. For example, in SHA7, a specialist commissioning network existed but only covered part of the SHA area. Other formal neurological networks may have existed elsewhere in the SHA patch, but none were reported to us. In two SHA areas, a neurological network had existed but in one SHA its current status was unknown, and in the other, it had been suspended pending the outcome of reconfiguration. In a further four areas, no neurological network was identified. In one area, no information was available as contacts did not respond.

A.4 Other formal partnerships

At this initial scoping stage, few formal partnerships between social services and PCTs were identified to take the NSF forward. Some PCT and social services contacts suggested that the cultural, structural and policy differences between the health and social care sector made service integration between them difficult.

A.5 Care Services Improvement Partnership (CSIP)

The Care Services Improvement Partnership (CSIP) held a series of workshops around the country in March 2006 to support the implementation of the NSF for LTNCs. The notes of these workshops (publicly available on the CSIP website) supported our initial scoping findings that there had been little movement towards realising the vision of the NSF for LTNCs at that time. CSIP events highlighted lack of leadership on the NSF at both SHA and PCT level as one of the key reasons for slow implementation.

A.6 Conclusions from scoping phase

Achieving integrated care for people with LTNCs and a ‘seamless’ service across organisational boundaries was an objective which underpinned the QRs of the NSF, but seemed particularly difficult to implement. Although levers to promote joint working existed, policy and services were essentially health-led. Policy and practice focus in recent years had favoured a particular model of management of LTCs, which had prioritised certain conditions and specific targets. There was widespread disappointment and disillusionment about the impact of the NSF to date. It was widely felt that if people with neurological conditions were to benefit from the reconfiguration and development of services, there needed to be a shift from policy which concentrated on short-term gains to an understanding of the multi-faceted aspects of care over time.

It was also apparent, at the time of this initial scoping phase of the research, that the strategic health system was in turmoil and the staff members contacted displayed little awareness of relevant roles, responsibilities or structures in the new and larger SHAs or PCTs. Furthermore, there was little information available regarding progress towards implementation of the NSF for LTNCs. However, this lack of information may have been a symptom of the reconfiguration, rather than an accurate reflection or predictor of progress of implementation of the NSF in the longer term.

Scoping interviews also revealed a lack of clarity and consistency about what ‘integration’ actually means, its purpose, or its impact on service users. The literature contains examples of three main types of intervention described as ‘integration of health and social care.[4] At the structural (macro) level, for example, ‘integration’ might be about bringing health and social care provision and/or commissioning into a single organisation. The second type of intervention relates to relationship issues (meso-level), for example, facilitating joint planning, the exchange of information or budget sharing. Thirdly, the intervention may be about co-ordinating care at the level of the service user (micro-level), for example, via care/case management or single assessment processes. Throughout discussions, it became clear that there were many different approaches to integration at a local level, which may affect the experience of a ‘joined-up’ service for people with LTNCs.

The meanings and relative importance of integration at policy, organisational and individual practitioner and service user levels, were explored in more depth in the case study phase of this research.

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[4] Parker, G., Bernard, S. and Aspinal, F. (2009) Assessing outcomes of integrated care for long-term conditions *NIHR SDO call IHS240 – Evaluating innovations in integrating health and social care for adults and older people.*

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Appendix B Case study documents

B.1 Service user letter of invitation

LETTER HEADED PAPER

[Name
Address]

E-mail: [fa112@york.ac.uk]

[Date]

Dear Sir/Madam

Re: Research into Services for People with Long-Term Neurological Conditions

[Name of] Primary Care Trusts is taking part in a research project about services for people with a range of health conditions. We have been given your name because we understand you use some of these services and we would, therefore, like to invite you to participate in an interview.

The interview will help us to identify what services are available in your area, your experiences of those services and what you think is important about them. It will also help us to understand how different professionals work together and how well you feel they communicate with you and with each other.

The interview will last about an hour and will be audio recorded with your permission. If you would prefer to communicate in writing or with the help of somebody else, then please let us know or ask them to contact us directly.

The enclosed information sheet gives more detail about the main aims of this research and what you being interviewed would involve. If you **would like to take part** please indicate this on the enclosed response form and we will contact you to arrange an interview. If you **do not wish to take part**, it would be helpful if you complete and return the response form, so that we do not contact you again.

We would be very interested in talking to you about your experiences and opinions and hope that you decide to participate. Should you require any further information please do not hesitate to contact me.

We look forward to hearing from you.

Yours faithfully

[**Fiona Aspinal**] (on behalf of the project team)
Research Fellow

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Direct line: 01904 321985

This research is part of a wider research initiative funded by the Department of Health. It has been reviewed and approved by ***[name of relevant Research and Development Committee and Research Ethics Committee].***

B.2 Service user information sheet

Participant Information Sheet

Services for People with Long-Term Neurological Conditions

INTERVIEWS

You are being invited to take part in a research study being conducted by the Social Policy Research Unit at the University of York. This study is part of a Department of Health programme to improve services for people with a range of conditions. It has been reviewed and approved by **[name of relevant Research and Development Committee and Research Ethics Committee].** Before you decide whether you wish to take part or not, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and take your time to decide whether you wish to take part.

What is the purpose of the study?

These interviews form part of a research project set within your local area that will look at the services provided. It focuses particularly on the way in which services and professionals, such as nurses, social workers and doctors, work together.

We are interested in learning about your experiences of services and hearing how important different aspects of them are to you. We would also like to hear your views on how local services and professionals work together and how well you feel they communicate with you.

Why have I been contacted?

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You are being contacted because we understand you have a health condition and are receiving health, social and/or voluntary services in **[name of locale].**

What are the benefits of this research?

The information you provide will be invaluable in understanding the range of views and experiences of people using services in your local area. You will be invited to describe your experiences and opinions of the services you use and how well services and professionals work together. This information will help us to identify where things are done well and to develop a standard against which other services can be assessed.

Will my taking part in this study be kept confidential?

Your involvement in the study, and the information that you provide, will be kept confidential. A personal identification number will be used throughout the research for each participant and all data will be anonymised. Data will be held in accordance with the 1998 Data Protection Act and University of York Ordinances.

There are rare circumstances where the researcher is required to disclose someone's participation to a doctor, nurse or other health care professional. However, this will only happen if the researcher is extremely concerned about their well-being. We will not tell the professional anything that was said in the interview unless it is directly related to the reason we were concerned.

Will taking part in this study affect my care?

No, taking part will not affect your care or the services you receive in any way. Similarly, if you decide not to take part your care will not be affected in any way. It is up to you whether or not you decide to take part and your decision will be kept completely confidential.

What will taking part involve?

If you would like to take part, you will need to complete the enclosed response form and return it to me in the enclosed freepost envelope. Please retain this information sheet.

I will then contact you to answer any questions you may have and to arrange a mutually agreeable time and place to conduct the interview.

On the day of the interview there will be further opportunity for you to ask questions and raise concerns. If you are still happy to go ahead, I will ask you to complete a consent form (a copy of which will be given to you for your records). The interview will take approximately 1 hour and give you an opportunity to describe your views fully. It will be audio-recorded (with your permission). Recordings will be destroyed when the research is complete.

If you do decide to take part, you are still free to withdraw at any time and without giving a reason.

What if I choose not to take part?

Participation in this research is entirely voluntary. If you choose not to take part, just complete the top half of the response form indicating your choice and return it to me in the freepost envelope so that I do not contact you again. You do not have to provide a reason or complete the demographic form, but doing so would enable me to understand your reasons for declining to participate which might help when planning future studies. (**Note**: *you do not have to give your name and your reasons would be recorded anonymously)***.**

If you have any questions or would like more information, please contact [Fiona Aspinal on 01904 321985 or email fa112@york.ac.uk]

THANK YOU

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B.3 Service user response form

ID Number:

THE UNIVERSITY of York

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SOCIAL POLICY RESEARCH UNIT

Services for People with Long-Term Neurological Conditions

Response Form - Interview

Please read the enclosed information sheet outlining what agreeing to the interviews would involve. Please complete and return this form as an email attachment. If you would like more information before deciding, please contact me on 01904 321985 or fa112@york.ac.uk.

Yes, I would like to take part
Please indicate here if you would like to take part by typing "Yes" in the box below, then complete your contact details at the end of this form.

No, I would not like to take part
Please indicate below if you would prefer not to take part by typing "No" in the box below. You do not have to give a reason, but if you would like to tell us why, it will help us to understand why some people choose not to take part.

Please complete the attached demographic questionnaire

If you would like to take part in an interview, please complete the following section and we will contact you with further details. (Please do not complete this section if you have decided not to take part).

Name: ______________________________________

Telephone Number: ______________________________

If you have any specific requirements you would like us to take into consideration for the interview, please indicate what these are below:

Please return to: fa112@york.ac.uk

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Thank you.

B.4 Service user demographic form

ID Number:

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Services for People with Long-Term Neurological Conditions

Demographic Form

PLEASE TICK THE APPROPRIATE BOX (UNLESS INDICATED OTHERWISE)

Age Group

18-29 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐

60-65 ☐ 66-75 ☐ 75-85 ☐ 85+ ☐

Gender

Male ☐ Female ☐

Ethnicity

Asian ☐ Black/Black British ☐ Chinese ☐

Mixed ☐ White British ☐

White Other ☐ *(please specify)* ______________________________

Any other ethnic background *(please specify)* ______________________

We understand you have a neurological condition. If you have a diagnosis, please tell us what it is:

____

____

Please return to:

LTNC Team, Social Policy Research Unit, University of York, **FREEPOST YO378,** Heslington, York, YO10 1GY

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B.5 Service user consent form

ID Number: ☐☐☐

THE UNIVERSITY of York

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SOCIAL POLICY RESEARCH UNIT

Consent Form

Project Title:

Services for People with Long-Term Neurological Conditions

Interviews

Please initial box

1. I confirm that I have read and understand the information sheet dated .... (version ....) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary. I also understand that I am free to withdraw at any time, without giving a reason, and without the services I receive being affected. ☐
3. I agree to allow the interviews to be audio-recorded. ☐
4. I agree to take part in the above study. ☐

Participant	Date	Signature
Researcher	Date	Signature

Copies: 1 for participant, 1 for researcher

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B.6 Service user reminder letter

LETTER HEADED PAPER

[Name
Address]

E-mail: [fa112@york.ac.uk]

[Date]

Dear sir/madam

Re: Research into Services for People with Long-Term Neurological Conditions

We wrote to you recently inviting you to participate in the above study. **[Name of]** PCT is participating in a research project about services for people with long-term neurological conditions. We have been given your name because we understand you use some of these services and we would, therefore, like to invite you to participate in an interview.

The interview will enable us to identify what services are available for people with long-term neurological conditions in your area, your experiences of those services and how important different aspects of them are to you. It will also help us to understand how local services and professionals work together and how well you feel they communicate with you and with each other.

The interview will last about an hour and will be audio recorded with your permission. If you would prefer to communicate in writing or with the help of somebody else, then please let us know or ask them to contact us directly.

If you have already returned your response form or contacted us, please accept our apologies for contacting you again, and discard this letter. If you have not yet responded and you **would like to take part** please indicate this on the enclosed response form and we will contact you to arrange an interview. If you **do not wish to take part**, it would be helpful if you complete and return the response form, so that we do not contact you again.

We would be very interested in talking to you about your experiences and opinions and hope that you decide to participate. Should you require any further information please do not hesitate to contact me.

We look forward to hearing from you.

Yours faithfully

[**Fiona Aspinal**] (on behalf of the project team)
Research Fellow
Direct line: 01904 321985

This research is part of a wider research initiative funded by the Department of Health. It has been reviewed and approved by ***[name of relevant Research and Development Committee and Research Ethics Committee].***

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B.7 Service user topic guide

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Topic Guide

Semi-Structured Interview with Service Users

A form asking for basic background information (age, sex, ethnicity, neurological condition, main carer(s), where and with whom the interviewee lives etc) will be completed prior to the interview. Explanation about the study will be given verbally and on paper and will include a list of possible services/support.

Before commencing

Discuss:

- **Purpose and focus of research**
- **Confidentiality and consent**
- **Interviewee's right to stop the interview or skip questions at any time**
- **Any further questions before proceeding**

Topics to be covered

General information:

- Living arrangements
- Employment status
- Type of neurological condition
- Support received
  - probe for full range (formal and informal)

Service use history: ***(long-term continuity)***

- Initial diagnoses and receipt of support
  - who involved
  - timings
  - views on process (positive/negative etc)

- Use of services over time
  - stayed the same/changed?

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  - reasons
  - views on process (positive/negative etc)
- Access to / type of contact with services
  - On the books or actively using services?
  - Open access/ referral?
  - Reviews?
  - views on this/ reasons

- Interruptions or disruption to your care?
  - reasons
  - impact

People involved: ***(longitudinal continuity)***

- number and range of people seen
  - reasons for seeing different professionals
  - part of team (s)?
  - views on number seen (too many? too few?)

- anyone you wanted to see but couldn't?
  - details

Therapeutic relationship: ***(relational, personal and therapeutic continuity)***

- relationships with individual professionals
  - importance of seeing same person?

- factors influencing who is seen

- named contacts/ key workers?
  - details of relationship
  - impact/ importance

- influence of self/ friends and family over care

Cross boundary/team working and Communication/information flow: ***(communication continuity)***

- info about condition/ notes of assessments etc
  - who has copies (do you?)
  - ease of access

- communication within and between teams
  - info sharing (systems, consent, benefits to SU?)
  - how well informed are professionals (about you/ your condition)
  - any repetition in info you have to give?

- communication with service user and carer
  - method of communication
  - does it work?

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  - are you able to access information when you need it?
  - any suggestions?

Flexibility: ***(flexible continuity)***

- do services meet needs now?

- how flexible are services?
  - times of visits/apps, etc
  - self-referrals/reviews
  - views on this

- adaptable to changing needs?
  - examples
  - views on this

- ever been refused services or charged for them?
  - details
  - views on this

Social/economic participation and personal relationships: ***(continuity of social context)***

- effect on social and personal relationships
  - partners
  - family
  - friends
  - local community
  - role of services (statutory or voluntary)

- impact on employment/ ability to work
  - role of services (statutory or voluntary)

- able to participate in things you want to?
  - role of services (statutory or voluntary)

- quality of life, overall?
  - role of services (statutory or voluntary)

Overall experience: ***(experienced continuity)***

- what is the most important thing to you in the support and services you receive?
- what could be done to make things better?
- comparative feelings about past, present and future experiences?
- anything else?

Remember to provide information sheet with support contact details and remind participant they can contact research team after interview if they wish.

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B.8 Staff information sheet

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Participant Information Sheet

Services for People with Long-Term Neurological Conditions

INTERVIEWS

You are being invited to take part in a research study being conducted by the Social Policy Research Unit at the University of York. This study is part of a wider research initiative funded by the Department of Health to support the implementation of the National Service Framework for Long-term Neurological Conditions and has been reviewed and approved by [name of relevant Research and Development Committee and Research Ethics Committee]. Before you decide whether you wish to take part or not, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and take your time to decide whether you wish to take part.

What is the purpose of the study?
These interviews form part of a research project set within your PCT area that will look at the services provided for people with long-term neurological conditions. It focuses particularly on the way in which services and practitioners work together to provide continuity of care.

We are interested in learning about your experiences of working within the PCT and hearing your opinions about services for people with long-term neurological conditions.

Why have I been chosen?
You are being contacted because you work for [name of PCT] and you have a role in service provision or strategy development for people with long-term neurological conditions.

What are the benefits of this research?
The information you provide will be invaluable in identifying the issues, including facilitators and barriers, to the provision of a seamless service for people with long-term neurological conditions. More specifically, it will help us to map services in your locality and to identify benefits and problems associated with implementing the National Service Framework for Long-term Neurological Conditions. This information will help us to identify models of good practice and will assist in the development of national benchmarks.

Will my taking part in this study be kept confidential?
Your involvement in the study, and the information that you provide, will be kept confidential. A personal identification number will be used throughout the research for each participant and all data will be anonymised. Data will be held in accordance with the 1998 Data Protection Act and University of York Ordinances.

There are rare circumstances where the researcher is required to disclose someone's participation to a doctor, nurse or other health care professional. However, this will only happen if the researcher is extremely concerned about their well-being. We will not tell the professional anything that was said in the interview unless it is directly related to the reason we were concerned.

Will taking part in this study affect my employment?
No, taking part in the research will not affect your employment in any way. Similarly, if you decide not to take part your employment will not be affected in any way. It is up to you whether or not you decide to take part and your decision will be kept completely confidential.

What will taking part involve?
If you agree to take part, you will need to complete the enclosed response form and return it to me in the enclosed freepost envelope. Please retain this information sheet.

I will then contact you to answer any questions you may have and to arrange a mutually agreeable time and place to conduct the interview.

On the day of the interview there will be further opportunity for you to ask questions and raise concerns. If you are still happy to go ahead, I will ask you to complete a consent form (a copy of which will be given to you for your records). The interview will take approximately 1 hour and give you an opportunity to describe your views fully. It will be audio-recorded (with your permission). Recordings will be destroyed when analysis is complete.

If you do decide to take part, you are still free to withdraw at any time and without giving a reason.

What if I choose not to take part?
Participation in this research is entirely voluntary. If you choose not to take part, just complete the top half of the response form indicating this choice and return it to me in the freepost envelope so that I do not contact you again. You do not have to provide a reason but doing so would enable me to understand your reasons for declining to participate which might help when planning future studies. (Note: you do not have to give your name and any reasons you give would be recorded anonymously.)

If you have any questions or would like more information, please contact [Fiona Aspinal on 01904 321985 or email fa112@york.ac.uk]

THANK YOU.

B.9 Topic guide for staff interviews

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Services for People with Long-Term Neurological Conditions

TOPIC GUIDE FOR STAFF INTERVIEWS

The interview will explore issues surrounding:

Organisation

- Organisational structure
- Organisational aims
  - National Service Framework
  - Long-term neurological conditions
  - Integration
- Progress
  - National Service Framework
  - Long-term neurological Conditions
  - Integration

Service landscape

- Organisations involved locally
- Services available locally
- Allied organisations and/or services

Integration

- Integration strategy/policy
- Levels of integration
  - Which services
  - Which staff
- Facilitators to integration
- Barriers to integration
- Suggestions for promoting service/organisational integration

Identification of other key contacts

Identification of relevant meetings

Identification of documentation

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B.10 Letter of invitation for observation groups

LETTER HEADED PAPER

[Name

Address]

E-mail: [fa112@york.ac.uk]

[Date]

Dear [name]

Re: Research into Services for People with Long-Term Neurological Conditions

[Name of PCT] PCT have agreed to assist with our research looking at the implementation of the National Service Framework for Long-term Neurological Conditions. The Chair of the **[name of committee/meeting/group]** you attend will have passed this information onto you to invite you participate in the observation component of this research project.

Your participation would consist of you and your colleagues in the **[name of committee/meeting/group]** agreeing to let us observe some of your meetings over a six month period. In-depth field-notes and audio recordings would be taken during these observed meetings (except when closed agenda items are discussed).

The enclosed information sheet gives more detail about the main aims of this research and what your participation would involve. If you **would like to take part** please indicate this on the enclosed response form. If you **do not wish to take part**, it would be helpful if you complete and return the response form, so that we do not contact you again.

This component of our research project will enable us to identify the key people working with, and services available for, people with long-term neurological conditions in your area and to understand the structures within which you all work. It will also help us to identify methods of working. As such, we would be very interested in observing your meetings and hope that you can assist with this matter. Should you require any further information please do not hesitate to contact the project team.

I look forward to hearing from you in due course.

Yours sincerely

[Fiona Aspinal] (on behalf of the project team)
Research Fellow
Direct line: 01904 321985

This research is part of a wider research initiative funded by the Department of Health. It has been reviewed and approved by ***[name of relevant Research and Development Committee and Research Ethics Committee].***

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B.11 Observation information sheet

Participant Information Sheet

Services for People with Long-Term Neurological Conditions

OBSERVATION

You are being invited to take part in a research study being conducted by the Social Policy Research Unit at the University of York. This study is part of a wider research initiative funded by the Department of Health to support the implementation of the National Service Framework for Long-term Neurological Conditions and has been reviewed and approved by **[name of relevant Research and Development Committee and Research Ethics Committee].** Before you decide whether you wish to take part or not, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and take your time to decide whether you wish to take part.

What is the purpose of the study?
The observation of your meeting forms part of a research project set within your PCT area that will look at the services provided for people with long-term neurological conditions. It focuses particularly on the way in which services and practitioners work together to provide continuity of care.

We are interested in learning about your experiences of working within the PCT and hearing your opinions about services for people with long-term neurological conditions.

Why have I been chosen?
You are being contacted because you work for **[name of PCT]** and you attend the **[name of meeting]** meeting that is concerned with strategy development and/or services for people with long-term neurological conditions.

What are the benefits of this research?
The information you provide will be invaluable in identifying the issues, including facilitators and barriers, to the provision of a seamless service for people with long-term neurological conditions. More specifically, it will help us to map services in your locality and to identify benefits and problems associated with implementing the National Service Framework for Long-term Neurological Conditions. This information

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will help us to identify models of good practice and will assist in the development of national benchmarks.

Will my taking part in this study be kept confidential?
Your involvement in the study will be kept confidential. Although we cannot guarantee confidentiality within the meeting because you will be discussing issues with your colleagues, outside the meeting, the information you provide will be kept strictly confidential. A personal identification number will be used throughout the research for each participant and all data will be anonymised. Data will be held in accordance with the 1998 Data Protection Act and University of York Ordinances.

Will taking part in this study affect my employment?
No, taking part in the research will not affect your employment in any way. Similarly, if you decide not to take part your employment will not be affected in any way. It is up to you whether or not you decide to take part and your decision will be kept completely confidential.

What will taking part involve?
If you agree to take part, you will need to complete the enclosed response form and return it to me in the enclosed Freepost envelope. Please retain this information sheet.

The researcher will attend some of the **[name of meeting]** meetings to observe how they work over a six-month period. The researcher will not participate in any discussions or ask any questions during these observations but will take notes of observations which may be important to the research. Meetings will also be audio-recorded to ensure accuracy. Notes and recordings will be destroyed once analysis is complete. All confidential discussion or debates will remain confidential to the meeting.

Before the observation takes place, you will need to complete a consent form, a copy of which will given to you for your records. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

What if I choose not to take part?
Participation in this research is entirely voluntary. If you choose not to take part, just complete the top half of the response form indicating this choice and return it to me in the freepost envelope so that I do not contact you again. You do not have to provide a reason but doing so would enable me to understand your reasons for declining to participate which might help when planning future studies. (Note: you do not have to give your name and any reasons you give would be recorded anonymously.)

If you have any questions or would like more information, please contact [Fiona Aspinal on 01904 321985 or e-mail fa112@york.ac.uk]

THANK YOU

Appendix C Local profiles

C.1 Site A

C.1.1 Socio-demographic context

Site A was a small but growing city with a resident population of about 166,000 people in 2006 and a younger than average age structure. The growth in population was partly attributable to a higher than average fertility rates but also the result of significant inward migration to the area. The 2001 census reported slightly higher than average ethnic diversity in Site A, but since this time it was thought there had been considerable change to the ethnic make-up of the population. The majority of the economic migrants requesting NI numbers, for example, were from Poland. In 2005, 400 gypsies and travellers were also thought to be based in the area[1].

Table C.1 Socio-demographic profile

Population*	Resident population estimate 170,0001
Age structure	Younger than national average[5]
Black or Minority Ethnic Population	Slightly above average2
Index of multiple deprivation	High[6]
Unemployment	Above average[7]
Rural/urban	Urban

* All populations are rounded to nearest 10,000.

Site A had above average levels of multiple deprivation as a whole and higher than average unemployment rates. There was also significant inequality *between* different electoral wards within the city and tackling inequality in life expectancy was therefore one of the key priorities arising from the areas 2007 Joint Strategic Needs Assessment[1].

C.1.2 Local organisational context

Site A PCT covered the whole of site A and since October 2006 had been coterminous with the city council boundaries. There had long been a history of partnership working between the local authority and the PCT, and in 2004 health and adult social care services were formally integrated. At the time of our fieldwork, the

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[5] 2001 Census.
[6] Index of Multiple Deprivation, 2007.
[7] http://neighbourhood.statistics.gov.uk.

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PCT was responsible for commissioning and delivery of all local health and adult social care services, although responsibility for delivery had been devolved to an arm's length trading organisation. A separate mental health trust was responsible for the commissioning and provision of mental health services across the county.

Table C.2 Structure and performance indicators

Structure	PCT established 1st October 2006 (coterminous with site A City Council). PCT is responsible for commissioning both health and adult social care service for site A. PCT's arms length trading organisation is responsible for delivering local community health and adult social care services. 1 NHS hospitals foundation trust, with 2 hospital sites inside Site A geographic boundaries and one in a neighbouring PCT.
HCC annual performance rating 2007/08[8] Quality of services: Use of resources:	PCT Foundation Trust Fair Weak Fair Excellent
CSCI annual performance rating 2007/08 Adult Social Care[9] FACS eligibility threshold	Two star (good) High moderate, substantial and critical
City Council CPA (Audit commission Comprehensive Performance Assessment) 2008[10]	Three star (performing well & improving adequately)

One NHS hospital foundation trust operated in the area, with two hospital sites situated within the PCT boundaries and one in a neighbouring town. At the time of our field research there was no in-patient neurology unit on any of these sites, but there were plans for some dedicated beds on a new hospital site (currently under construction). In the mean time, patients requiring in-patient neurology treatment or investigation could be seen on the stroke ward in site A or transferred to a regional neurosciences centre in a city 40 miles away. Patients with LTNCs who had other presenting conditions would be admitted to generic or other specialist wards. An out-patient neurology service was available in Site A, but patients had to travel to the regional centre for some out-patient investigations. The hospitals trust did not employ a rehabilitation consultant but those in site A with specialist rehabilitation needs might be referred to a specialist independent rehabilitation unit out of area.

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[8] Healthcare Commission, 2008, *Annual health check 2007/08.* www.cqc.org.uk.

[9] Commission for Social Care Inspection, 2008, *Annual performance assessment 2007/08.* www.cqc.org.uk

[10] Audit Commission, 2008, *Scores and analysis of performance in single tier and county councils 2008.* www.audit-commission.gov.uk/reports.

At the time of our fieldwork the PCT was piloting a community clinic for headache led by a GPSI and supported with the acute trust's resident neurologist. This service was currently being evaluated but the results were not yet available. Twenty-seven GP practices operated in the area and were grouped into a number of practice based commissioning localities. District nurses were based in GP practices but were jointly managed as part of an integrated team with social workers. One community interdisciplinary neurological rehabilitation team operated in the area but only had a remit to work with people who had experienced traumatic brain injury.

Social housing in site A was provided by a number of housing associations and housing support was available through Supporting People. Only one facility in the area provided permanent residential care for younger disabled people, the alternative being to go out of area or to go into generic (older people's) residential care.

A range of voluntary sector agencies provided specialist condition specific and more generic support to people with LTNCs in Site A. Notably, however, there was no Headway service in the area, and people with brain injury would travel long distances to attend Headway day services in other areas.

C.2 Site B

C.2.1 Socio-demographic context

Site B was a predominantly rural county of approximately 515,400 people. Since the last census in 2001 there had been an increase in population of approximately 3.5 per cent, although this was not spread evenly throughout the county, with very low population density in some rural areas.

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Table C.3 Socio-demographic profile[11],[12],[13]

Population	515,400 (mid-2005 estimate)
Age structure	Older than national average
Black or Minority Ethnic Population	Low
Index of multiple deprivation	High
Unemployment	Low
Rural/urban	Rural

The population was older than the national average, with a high number of people over the age of 50 and nearly ten per cent over 75. The black and minority ethnic population (i.e. non 'White British') was low compared with the national average. Recent migration had been largely from the expanded European Union, particularly Portuguese and Polish migrant workers, and was associated with particular industries or workplaces. There was also a higher than average inward migration of people over the age of 50 and a higher than average migration out of 16-25 year olds.

Overall unemployment was lower than the national average, while comparison of indices of multiple deprivation (IMD) suggested that deprivation was also low. However, this overall measure masked unequal distribution and varying elements of deprivation throughout the county. There were pockets of deprivation in urban areas, more likely to be associated with material deprivation, and some areas, particularly in the west of the county, where social deprivation was most common.

C.2.2 Local organisational context

National re-organisation of PCTs in 2006 had reduced the number of PCTs from four to one organisation which was co-terminous with the county council. At the time of fieldwork, the PCT was undertaking a major review of provider services bringing services from the former PCTs under a single management structure with plans to develop an arm's length organisation. At the end of 2007, services were very much in a transitional phase with operational teams largely managed in their old PCT structures. There were 13 community hospitals across the county. In-patient services in community hospitals were consistent across the PCT, but models for community

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[11] [Site B] PCT, 2007, Strategic framework for improving health in [Site B] 2008/09-2012/13.
[12] [SiteB] County Council, 2008, 2008 [SiteB] economic digest.
[13] Department of Health, 2007, Factsheet: Primary Care Trust – [Case study site B] PCT. www.info.doh.gov.uk/nhsfactsheets.nsf.

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rehabilitation were different across the four historical PCT areas. The PCT was in the process of introducing a standardised model across the county with a consistent infrastructure, line management and strategic approach.

Table C.4 Structure and performance indicators

Structure	PCT, formed October 2006 Acute Trusts 2 NHS Foundation Trusts (foundation status 2006/07 & 2007/08 Authority with responsibility for adult social care – County Council
HCC annual performance rating 2007/085 Quality of services: Use of resources:	PCT Foundation Trust1 Foundation Trust2 Good Good Excellent Good Excellent Excellent
CSCI annual performance rating 2007/08 Adult Social Care6 FACS eligibility threshold	Three star (excellent) Critical, substantial
County Council CPA (Audit commission Comprehensive Performance Assessment) 2007/087	Four star (performing strongly & improving strongly)

Site B was served by two NHS district hospitals, one hosting a neurosciences centre with a neurology ward which also included neuro-rehabilitation beds (since the closure of a separate acute neuro-rehabilitation unit in 2007). The neurosciences directorate provided a visiting neurology service to the other acute hospital. People requiring neuro-surgery were referred to a tertiary centre to the north of site B and second opinions were sought nationally for complex neurological cases.

Adult social care was provided via the County Council. On the operational side, social care services were divided on a locality basis into multidisciplinary teams of social workers, OTs (focusing on provision of adaptations as opposed to rehabilitation), and vocational staff. Since 1991, social care had been commissioned largely through external provision, being one of the first authorities to externalise its services. Joint commissioning of adult services in Site B was confined to services for mental health (through the mental health trust) and learning disabilities. Commissioning discussions with the PCT around LTNCs had tended to focus, so far, on particular aspects, such as acquired brain injury (ABI), and still lacked a clear strategic direction either for LTNCs specifically, or physical and sensory impairment issues generally.

C.3 Site C

C.3.1 Socio-demographic context

Site C was one of the most densely populated areas of the country and comprised some areas of great wealth and many areas of extreme deprivation meaning that overall, this site had a very high deprivation ranking. Data from 2007 showed that two-thirds of all children living in site C were living in income-deprived families, with over 50 per cent of primary school and nearly 60 per cent of secondary school children in the area qualifying for free school meals, compared with national averages of 16 per cent and 14 per cent respectively.

Site C had a relatively young population compared with the national average, with over 80 per cent of the population being less that 50 years old and the under 20s comprising over a quarter of the population. The 2001 Census showed that almost 50 per cent of the local population defined themselves as coming from a non-white ethnic group, of which the largest is the Bangladeshi population, making up 34 per cent of the borough population in 2001. This may account for the young population because Bangladeshi residents have a younger age profile than those from other ethnic groups. The diverse population meant that over 90 different languages were spoken, with 69 per cent of school children in the area having English as a second language.

Table C.5 Socio-demographic profile[14]

Population	207, 948 (2005)[15]
Age structure	Younger than average
Black or Minority Ethnic Population	Very high
Index of multiple deprivation	Very High
Unemployment	High
Rural/urban	Urban

Unemployment rates in site C were amongst the highest in England. Bangladeshis had the highest unemployment rates, particularly for those aged under 25.

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[14] [Site C] PCT, 2007, [Case study site C] Public Health Report.

[15] Department of Health, 2007, Factsheet: Primary Care Trust – [Site C] PCT. www.info.doh.gov.uk/nhsfactsheets.nsf (accessed 24.4.2007).

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C.3.2 Organisational context

Site C was an inner city PCT, coterminous with the corresponding Borough Council. This was a long standing arrangement and not as a result of recent reorganisations of PCTs and SHAs as the boundaries for this PCT did not alter. It was a small borough council geographically, covering an area of only 7.7^2miles (20^2km). Two large acute hospitals were situated within the boundaries of the PCT, both of which provided services for people across the case study area, regionally and, for some conditions, nationally. One of these hospitals was a major trauma unit and specialised in neurology and neurosurgery. There was one community hospital, funded by the PCT, also based in the locality.

Table C.6 Structure and performance indicators

Structure	Integrated PCT & Borough Council 1* Community Hospital (run by PCT) Adult social care – Borough Council Acute NHS Trust 2 acute hospitals (1 is neuro regional centre)
HCC annual performance rating 2007/085	PCT
Quality of services:	Fair
Use of resources:	Good
CSCI annual performance rating 2007/08 Adult Social Care6	Three star (excellent)
FACS eligibility threshold	Critical, substantial
County Council CPA (Audit commission Comprehensive Performance Assessment) 2007/087	Four star (improving well)

Adult social care was provided via the borough council with some social workers integrated into acute and community health teams. The table above shows the results of performance reviews undertaken by national monitoring organisations in health and social care. Further information about the structure and provision of health and social care for people with LTNC who resided in the area served by this PCT are described later in this report.

C.4 Site D

C.4.1 Socio-demographic context

Site D was a large and growing city with an estimated population in 2005 of 723,000 people. The city had a younger than average age structure with high fertility rates and a significant transient population of students.[16]

Table C.7 Socio-demographic profile

Population	Estimated to be 723,100 (2005)13
Age structure	Younger than average13
Black or Minority Ethnic (BME) Population	Below average2
Index of multiple deprivation (IMD)	High3
Unemployment	Slightly above average4
Rural/urban	Urban

Although the 2001 census showed there to be below average ethnic diversity in this area, this was not evenly distributed, with almost one-third of the city's 78,000 people from BME communities living in just three wards. Moreover, the ethnic makeup of the city was likely to have changed substantially since the census. During 2006–07, 8,480 non-UK nationals from 69 countries registered for NI numbers from addresses in Site D. Over 1,000 gypsies and travellers were also known to reside in the area.

Site D had above average multiple deprivation and unemployment rates as a whole. Within the site there was considerable inequality between different super output areas (SOAs). IMD 2007 showed Site D to have 22 SOAs in the most deprived three per cent on the national scale and 95 SOAs in the ten per cent most deprived.

C.4.2 Local organisational context

In October 2006, five PCTs in the Site D area came together to form a single PCT covering the whole city which was coterminous with the local authority (LA). At the time of our fieldwork the LA had also recently been through a reorganisation: splitting adults' from children's services and provision from commissioning functions. With these changes in both health and social care, a new overarching governance structure was being developed. This would be headed up by a Commissioning

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[16] [Site D] PCT, 2007, [Site D] Joint Strategic Needs Assessment: Information Pack.

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Executive with high level representation from both the PCT and Adult Social Care, but was not yet fully functioning. At the time of our fieldwork a notional split between commissioning and Care Services was in operation. Commissioning for LTNCs came under the Strategic Development Directorate, separate from commissioning for general long-term conditions (such as diabetes and CHD). A joint PCT and LA team in this directorate had responsibility for the strategic planning of both health and social care services for older people and disabled people, including those with LTNCs.

Table C.8 Structure and performance indicators

Structure	5 site PCTs merged into one covering the whole city and coterminous with the city council in October 2006 1 teaching hospitals NHS trust with 8 sites across the city
HCC annual performance rating 2007/085 Quality of services: Use of resources:	PCT Foundation Trust Weak Weak Weak Fair
CSCI annual performance rating 2007/08 Adult Social Care6 FACS eligibility threshold	1 star (adequate) Critical, substantial
City Council CPA (Audit commission Comprehensive Performance Assessment) 20087	Three star (performing well & improving adequately)

All service provision specifically for people with LTNCs had been brought together under a single provider side management structure, although generalist community therapy services (like domiciliary physiotherapy) came under a separate directorate. Services brought together under this umbrella included an in-patient community rehabilitation unit with liaison health visitor, a community brain injury rehabilitation team, a community MS team, a Young Adults’ Team, a community stroke team and a PD nurse specialist. All came under the management of the PCT’s provider side head of neurology services and all but the stroke and PD services served the whole of the city and were co-located.

One hospital trust operated across site D with two main hospitals and a number of smaller sites. The two neurology departments had been amalgamated to form a 28 bedded regional neurosciences centre (although at the time of our fieldwork four of these beds were closed due to staffing issues). The MS multidisciplinary team was not based in the regional centre but at one of the secondary sites, where a ward had

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been converted to hold accessible multidisciplinary clinics staffed by specialist nurses, specialist physiotherapists and a social worker.

C.5 Site E

C.5.1 Socio-demographic context

The demographic characteristics of the population served by Site E PCT are shown in the table below. As the Table shows, this case study site, served a large population, 24 per cent of which was classified as residing within a rural area. In some localities (defined by civil parishes) of the PCT area, however, up to 100% of the community were living in areas defined as rural[17]. There were seven small ‘urban’ centres within the PCT. Most SOAs in the PCT fell within the 20 per cent second least deprived SOAs based on national IMD scores, with only 24 SOAs falling into the most deprived SOAs in the country. Overall, therefore, the PCT had a population that could be viewed as neither deprived nor affluent based on IMD scores.

Table C.9 Socio-demographic profile[14]

Population	573,440 (2005)[18]
Age structure	Approximately national average
Black or Minority Ethnic Population	Low
Index of multiple deprivation	Average[19]
Unemployment	Low
Rural/urban	Semi-rural (24% of population live in areas classified as rural compared with 19% nationally)

C.5.2 Local organisational context

This PCT was formed in October 2006 as a result of the merger of four smaller PCTs[18] and covers an area of 600^2miles (1554^2kms)[15]. There was no clearly defined centre of the PCT around which the population was distributed nor a central point of service provision. Rather, population and services were based around some of the

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[17] From [Case study site E] PCT Public Health Intelligence Team, 2008, Health Profile for [Case study site E] Local Authority, unless otherwise stated.

[18] Department of Health, 2007, Factsheet: Primary Care Trust – [Case study site E] PCT. www.info.doh.gov.uk/nhsfactsheets.nsf (accessed 24.4.2007).

[19] Director of Public Health, [Case study site E] PCT, 2007, Public health for practice-based commissioning. The report of the director of public health for [Case study site E] Primary Care Trust.

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small ‘urban’ centres within the PCT. Three small acute hospitals were located within the PCT area, two in the north-west and one in the east. There were also two community hospitals in the south-east of the PCT. However, some residents were not well served by these hospitals because they did not live within easy proximity to them. Instead, some people within the PCT’s catchment area needed to access support, care and treatment via acute district and regional hospitals in neighbouring PCTs.

Table C.10 Structure and performance indicators

Structure	PCT - formed October 2006 2* Community Hospitals (run by PCT) Practice Based Commissioning 3* Acute NHS Trusts Adult social care – County Council
HCC annual performance rating 2007/085 Quality of services: Use of resources:	 Fair Good
CSCI annual performance rating 2007/08 Adult Social Care6	Two star (good)
County Council CPA (Audit commission Comprehensive Performance Assessment) 2007/087	Three star (improving strongly)

Adult social care was provided via the County Council. Social work teams were based in localities around the county (PCT area). The table above shows the results of performance reviews undertaken by national monitoring organisations in health and social care. Further information about the structure and provision of health and social care for people with LTNC who reside in the area served by Case study site E PCT are described later in this report.

C.6 Site F

C.6.1 Socio-demographic context

Site F covered a mainly urban area centred on three main townships and its local authority was also part of a larger city-regional conurbation. The age structure of its population was younger than that of England and Wales and also of the wider conurbation. It was one of the most deprived areas in England ranked 25th out of 354 local authorities with particularly high concentrations of deprivation associated with the main townships. There were 22 neighbourhood renewal strategy (NRS) areas within the borough, containing approximately one-third of the population and including a larger proportion of people from minority ethnic backgrounds. The majority of people in Site F were of white British background (86%). People of Pakistani background made up the largest minority ethnic group (7.7%), white Irish the second highest (1.5%) followed by Bangladeshi at 1.3 per cent. There was a significant Kashmiri community who would have been included in the Pakistani ethnic group for census purposes in 2001.

Table C.11 Socio-demographic profile[20,21]

Population	206,500 (mid-2005 estimate)
Age structure	Younger than national average
Black or Minority Ethnic Population	Average
Index of multiple deprivation	Very High
Unemployment	Above average
Rural/urban	Urban

Unemployment rates were higher than the national and regional averages and were the joint second highest in the city-region. Employment rates for disabled people and black or minority ethnic (BME) residents were below national and regional averages.

C.6.2 Local organisational context

Site F was part of a neurosciences regional network, launched in response to the NSF, and based on a ‘hub and spoke’ design. The acute foundation trust within the lead commissioning PCT area acted as the ‘hub’, providing a specialist neurosciences/neurosurgery centre. The network was responsible for overarching strategic development around services for LTNCs in the city-region. A separate acute trust provided general acute care and services through four district general hospitals, two of which were located within Site F. An intermediate rehabilitation unit, one of four serving the city-region provided intermediate rehabilitation for two other adjacent PCT areas as well as Site F.

Table C.12 Structure and performance indicators

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[20] Department of Health, 2007, Factsheet: Primary Care Trust – [Case study site F] PCT. www.info.doh.gov.uk/nhsfactsheets.nsf.
[21] [Site F] Borough Council, 2007, [Site F] Borough Profile 2007. *[Site F] in context*.

Structure	PCT, formed October 2006 NHS Acute Trust formed 2002 covers 5 hospital sites including 2 in CSF Authority with responsibility for adult social care – metropolitan borough council
HCC annual performance rating 2007/08[5] Quality of services: Use of resources:	PCT Acute Hospital NHS Trust Excellent Good Good Fair
CSCI annual performance rating 2007/08 Adult Social Care[6] FACS eligibility threshold	Two star (Good) Critical, substantial, moderate
County Council CPA (Audit commission Comprehensive Performance Assessment) 2007/08[7]	Three star (improving well)

National reorganisation of PCTs in 2006 had produced a merger of two PCTs to create one organisation which was co-terminous with the metropolitan borough council. At the time of fieldwork there was no clear commissioner – provider split, although a provider board was considering options.

The PCT provided a network of health centres and clinics around the borough through which it provided a range of services. At the time of fieldwork, the main centre for adult rehabilitation services, including physiotherapy was relocating to a centre in the west of the PCT area. The newly formed community neurological rehabilitation team was the key rehabilitation service for people with a primary neurological diagnosis.

Restructuring of the metropolitan borough council (MBC) in 2005 had created a large directorate responsible for adult care services, housing, regeneration and health partnerships. Within adult social care, community equipment and physical and sensory impairment (P&SI) services had been separated out to provide a separate resource which had a direct role in the care of people with LTNCs.

At a service commissioning and delivery level there were a number of joint initiatives. A joint commissioning role for adults and older people, jointly funded by health and social care had been established two years previously. Services were more formally integrated around older people’s services, although increasingly there were areas of adult care where services were integrated across health and social care and other sectors.

Appendix D Framework themes

We had two frameworks to aid analysis of staff interviews; one focused on descriptions of case study sites, the other on analysis of barriers and facilitators to integrated working and promoting continuity of care for people with LTNCs.

D.1 Staff interviews - description

1. **Background to case study sites**
    1.1. Socio-demographics of area

2. **Organisational structure**
    2.1. Health and social care integration
    2.2. Commissioning for neurology
    2.3. Implementation of the NSF
    2.4. Service delivery including
        2.4.1. Health-acute
        2.4.2. Health – PCT
        2.4.3. Health - palliative care
        2.4.4. Health - mental health (counselling, psychology, etc)
        2.4.5. Social - adult social care
        2.4.6. Joint delivery
        2.4.7. Employment
        2.4.8. Leisure
        2.4.9. Transport
        2.4.10. Training
        2.4.11. Housing
        2.4.12. Independent sector (for profit/not for profit)
        2.4.13. Services for BME groups

3. **Service pathways**
    3.1. Overarching pathways
    3.2. Information pathways

4. **Service integration**
    4.1. Horizontal within health - same tier
    4.2. Vertical within health (acute-primary-community)
    4.3. Between health and social care
    4.4. Between statutory & voluntary sector

5. **With mental health trust**
    5.1. Other e.g. employment, private sector

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D.2 Staff interviews - Barriers and facilitators to integration and continuity of care

1. **Overall structure**
   1.1. National policy (locally implemented)
   1.2. Underpinning philosophy/culture (impact of)
   1.3. Process of commissioning:
   1.4. Specific issues around implementation of the NSF for LTNCs

2. **Service provision**
   2.1. Underpinning philosophy (success/feasibility of)
   2.2. Models
   2.3. Availability/access
   2.4. Awareness
   2.5. Gaps

3. **Service pathways**
   3.1. Overarching pathways
   3.2. Information pathways (impact and feasibility of)

4. **Facilitators/barriers to service integration**
   4.1. Horizontal within health - same tier
   4.2. Vertical within health (acute-primary-community)
   4.3. Between health and social care
   4.4. Between statutory & voluntary sector
   4.5. With mental health trust
   4.6. Other e.g. Employment, private sector

D.3 Service user interviews

1. **Continuity of information**
   1.1. About social/leisure opportunities
   1.2. Sources of info
   1.3. Records/notes
      1.3.1. Discharge letters
      1.3.2. Hospital records
      1.3.3. Patient held records
   1.1. About employment/training

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   1.2. About how to self manage
   1.3. About service system
   1.4. About condition

2. Continuity of personal agency (and lack of)

   2.1. Confidence building (or undermining)
   2.2. Peer support
   2.3. Self-care/management
   2.4. Expertise of patient/carer
   2.5. Service users initiating service development

3. Continuity of social context

   3.1. Lack of continuity of social context
   3.2. Enablers
   3.3. Type of activity

4. Management continuity

   4.1. Communication
      4.1.1. Within team
      4.1.2. Cross-sector
      4.1.3. Agency/SU or carer
      4.1.4. Between teams (within sector)
      4.1.5. Prof/SU
   4.2. Cross boundary co-ordination

5. Longitudinal continuity

   5.1. Benefits of longitudinal continuity
   5.2. Lack of longitudinal continuity
      5.2.1. Consequences

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6. **Relationship continuity**
    - 6.1. Impact on trust
    - 6.2. Importance of seeing the same person
    - 6.3. Impact on info flow
    - 6.4. Impact on communication

7. **Long-term continuity**
    - 7.1. Transition from children's to adult's services
    - 7.2. Impact of change to services
    - 7.3. Follow-up/regular appointments
    - 7.4. Cases being closed/re-opened
    - 7.5. Lack of long-term continuity

8. **Flexible continuity**
    - 8.1. Responsiveness (or lack of)
        - 8.1.1. Responsiveness in emergency
    - 8.2. Flexibility (or lack of)
        - 8.2.1. Review of needs and services

9. **Experienced continuity**
    - 9.1. Within benefits system
    - 9.2. Across whole system
    - 9.3. Within voluntary sector
    - 9.4. Views on quality of service overall
    - 9.5. Within social care
    - 9.6. Within health system

10. **NSF**
    - 10.1. Knowledge or/involvement in

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11. Accessing support/services

  - 11.1. Rural issues
  - 11.2. Eligibility
  - 11.3. Ongoing access/telephone contact
  - 11.4. Re-entry to the system/specific services
  - 11.5. Knowing who to contact (and how)

12. Working the system/taking matters into own hands

13. Generalist vs specialist

  - 13.1. Expertise

14. Control

15. Family (or other informal carer)

  - 15.1. Support for the family
  - 15.2. Other family issues
  - 15.3. Support from family
  - 15.4. Impact on family
  - 15.5. Concerns for family

16. Feeling supported/able to access support (or not)

17. Cognitive/behavioural problems

  - 17.1. Needs not catered for (not got training etc)
  - 17.2. Needs not recognised

18. Ethos/approach

  - 18.1. Target driven
  - 18.2. Proactive/reactive?

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- 18.3. Whole person?

19. Geographical boundaries

20. Financial issues

- 20.1. Control of finances
- 20.2. Income/benefits
    - 20.2.1. Perverse incentives

21. Models of improving continuity

- 21.1. Other models
- 21.2. Young adult's team
- 21.3. Co-location (or lack of)
- 21.4. Care co-ordination/key workers
- 21.5. Community rehab (MDT)
    - 21.5.1. Condition specific teams
    - 21.5.2. In patient
- 21.6. Nurse specialist (NS)
    - 21.6.1. Acute vs community based?
    - 21.6.2. Importance of NS

22. Diagnosis

- 22.1. Delay
- 22.2. Family's reaction
- 22.3. SU's reaction
- 22.4. Support at diagnosis (or lack of)

23. Acute service

- 23.1. In-patient rehab
    - 23.1.1. Separate unit

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        - 23.1.2. Acute trust ward
    - 23.2. Out-patient rehab (i.e. Rehab consultant)
    - 23.3. In-patient mental health
    - 23.4. Out-patient therapies (pt, salt, etc)
    - 23.5. Other out-patient
    - 23.6. General in-patient (non-neurology)
        - 23.6.1. Impact of no specialist care
    - 23.7. Out-patient neurology
    - 23.8. Out of area
    - 23.9. In-patient neurology

24. Independent sector rehab unit

25. Discharge from in-patient service

- 25.1. To community hospital
- 25.2. To home
    - 25.2.1. Support/community services
- 25.3. To other in-patient service

26. Primary care/GP

27. Community therapies (not linked part of MDTs)

28. Psychological support

29. Aids and adaptations

- 29.1. Delays

30. Social care

- 30.1. Home care

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        - 30.1.1. Positive aspects of home care
        - 30.1.2. Restrictive aspects of home care
    - 30.2. Social work
    - 30.3. Other
    - 30.4. Day centres/resource centres
    - 30.5. Respite
    - 30.6. Carers' assessment/support
    - 30.7. Direct payments
    - 30.8. La vs agency provision
    - 30.9. Children's social services

31. Housing

- 31.1. Warden/housing related support
- 31.2. Provision of housing
- 31.3. Suitability
- 31.4. Location
- 31.5. Lives with
- 31.6. Type of accommodation

32. Transport/travel

- 32.1. Transport provided by other service
- 32.2. Private transport
- 32.3. Public transport
- 32.4. Hospital transport

33. Employment/training

- 33.1. Staying in employment/training
    - 33.1.1. Support (or lack of)
- 33.2. Relationship with employer
- 33.3. Leaving employment/training

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        - 33.3.1. Support (or lack of)
    - 33.4. Re-entering work/training
        - 33.4.1. Support (or lack of)

34. Leisure/social life

- 34.1. Support
- 34.2. Barriers

35. Exercise

36. Independent sector

- 36.1. Instability
- 36.2. Feedback re a particular service/agency

37. Private provision

38. Gaps

- 38.1. Lack of capacity/resources
- 38.2. Reduction of services

39. Other support

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Appendix E Development of the Benchmarking tool

E.1 Suggestions from initial contributors

E.1.1 Question wording/layout

This section provides a summary of the comments contributors made about the way questions were worded and how to avoid misinterpretation of questions:

- Add examples to some of the models to prevent confusion about what type of services we are asking about.
- Begin with an overview of the purpose of the tool.
- Include a definition of ‘care plans’.
- Ask about how long services/professionals provide support rather than just if ongoing support is provided.
- Change ‘independent sector’ to ‘voluntary/private sector’ to ensure that people know both of these are covered by this question.
- Put the section about ‘Day opportunities’ before ‘Other forms of care co-ordination’.

E.1.2 Suggestions for additional questions

Some contributors made suggestions for additional/subsidiary questions. Questions were added only where staff and service user interviews supported these suggestions. The questions added were:

- Add the name of the interviewer and date of interview to Section A.
- Ask when the cross-sector strategic group last met.
- Ask whether service users or their carers were involved in the cross-sector group.
- Ask when any action plans for implementing the NSF for LTNCs were last audited.

E.2 Changes to the tool following pre-pilot interviews

E.2.1 Introduction and headings were revised

1. Sections C-F were renamed ‘Service’ Models to make it clearer what these sections were about.
2. The introduction for nurse specialists was updated to make it clear that we were keen to learn about nurse specialists in community and in acute settings.

3. Emphases was added to the care co-ordination pre-amble around co-ordination within and across sectors and to indicate that we were interested in these services even if they were provided by non-health providers.
4. Emphases was added to the resource centre pre-amble to show the types of things the service needed to be providing to fit into our category.
5. A section name was changed from ‘Resource Centre’ to ‘Day Opportunities’.
6. ‘Ongoing’ was emphasised in the section about ‘other services’, (Section G).

E.2.2 Some questions were added

1. Section G was supplemented by specific questions about occupational therapists with an expertise in neurology. These followed the same template as neuro-physiotherapy questions after the amendments to questions and response options reported below.
2. Information re: neuro-psychologists was changed from being an open question into the format as described below (re: Section G).
3. We added an open question to allow services not yet reported to be listed.

E.2.3 Some questions were removed

1. The question asking about the population of specific conditions was removed because respondents suggested that PCTs were unlikely to be able to distinguish between populations for specific conditions and for LTNCs generally.

E.2.4 Some questions were amended

1. We reworded the question about action plans by adding the word ‘written’ to reflect that we were interested in formal arrangements rather than simply an informal service or professional led plan.
2. We reworded the question about implementation of action plan priorities to ask about the percentage of priorities from the action plan that had been implemented rather than just asking if any had. Respondents felt that percentages would be more useful for benchmarking over time.
3. This change (to ask about percentages) also applies to how much time nurse specialists spent providing support in different settings.
4. Questions about access to condition specific and non-condition specific teams were replaced with one 5 pt ‘Likert scale’ question asking how easy it is to access the service (very easy - very difficult).
5. Questions about telephone access were changed to emphasise that this was not just the usual phone number to call to make an appointment but a way of getting

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advice and support - ‘Can people ring the team for advice and support from the service as needed?’

6. ‘Total’ was added to the question about caseloads – some services provided support for people with LTNCs and also other conditions – it was felt by respondents that it was important to know the total number because this would impact on waiting times and what input could be provided in what settings.
7. The first question re: resource centres was changed to make it easier to understand – newly reads ‘Do you have a service that provides some or all of the above opportunities?’
8. In Section G, questions about inclusion criteria were removed and replaced as reported in point 4 above.
9. In Section G, ‘community’ was added to all questions about Speech and Language Therapy to show that we did not want to have in-patient only services reported.
10. The independent sector question was reworded to make it clear that this referred to both voluntary and private sector provision of information.
11. The open question about counselling services was changed to be about all psychological services (but not neuro-psychology because specific questions were asked about this).

E.2.5 Response options were adapted

1. A ‘don’t know’ option was included on the CINR Team question to allow a response from people who did not know what conditions it covered.
2. A comment was added to the response option ‘health trust’ to show that we are asking about PCT or Acute Trusts.
3. Response options for the length of time a person could remain on the service’s active case loads were changed as below:
    a. Ongoing with intermittent reviews or open ended *(depending on section).*
    b. Time limited - based on goals or determined by outcomes of reviews *(depending on section).*
    c. Time limited – pre-specified.
4. A space was included to record whole time equivalent for nurse specialists.

E.3 Changes to the tool following pilot interviews

E.3.1 Introductions were revised

Section E – Day Opportunities

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Despite changing the name of this section (as indicated in Appendix A) some respondents in the pilot were confused about the services that should be included within this section. We added additional emphases to the section pre-amble (by underlining some words) (see also some questions were amended).

Section F – Care Co-ordination
A note that was included in the first question, stating that service could be provided by different sectors was moved so that it was included in the section blurb

Multiple sections
Directions were included on extra questions (B6; G1-4e)

E.3.2 Some of the questions/sections were moved around

Section B – Strategy and organisation

1. Needs assessment for people with LTNCs
    a. This was changed to be a stand-alone question rather than a subsection of the question about the cross-sector strategic group. This was because some people wanted to give an answer to this question even though they had answered ‘no’ to the cross-sector group question.

E.3.3 Some questions were added

Section C - CINR teams

1. The case load question included in the other sections was replicated in this section.

E.3.4 Some questions were amended

Section E – Day Opportunities

1. To make it clear that services need to include both social and learning/employment support, we amended the first question to reflect this. The question wording was changed from ‘Do you have a service that provides some or all of the above opportunities?’ to ‘Do you have a service that provides the above opportunities?’

Section F – Care Co-ordination

2. In the pilot, people had suggested that they were not sure if they should include general services, as opposed to neuro services only. Thus, additional examples of care co-ordination services were provided within the first question.

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Section G – Other Services

3. Waiting time
    a. The question wording was changed to reflect the longest wait people with LTNCs could have once referred to the service: ‘Currently, what is the maximum waiting time for new referrals?’

       Response: Up to ______weeks

E.3.5 Response options were amended

Some people were confused about how to answer questions because they felt some of the response options did not necessarily reflect their experience or the context in which they were working. Changes made for these reasons are reported below.

Section B - Strategy and Organisation

1. JSNA including reference to LTNCs
    a. Response option ‘Yes’ was split into two: ‘Yes, refers to LTNCs in general’ and ‘Yes, refers to one of more specific LTNCs’
2. Involvement of people with LTNCs
    a. Instead of a list where respondents tick the types of involvement – each type of involvement was given ‘yes’, ‘no’ and ‘don’t know’ options.
3. Needs assessment for people with LTNCs
    a. The response option ‘yes, as a separate exercise’ was split into two: ‘yes, as a separate exercise for LTNCs in general’ and ‘yes, as a separate exercise for one or more specific LTNCs’
4. Auditing against action plan
    a. Two additional response options were included: ‘never, because the action plan is new’ and ‘currently auditing’

Section D - Nurse Specialists

5. Percentage of nurse time spent in different settings
    a. Many respondents found it difficult to answer this question but given the recommendations in the pre-pilot testing it was felt important that it was retained. Those that had been able to give answers were not able to distinguish between the percentage of time spent in people’s homes and time spent in other community settings. Thus, ‘service user’s own home’ was removed and the ‘community’ option extended to include service users’ homes.

Section E - Day Opportunities

6. What conditions services covered?

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   a. The format of responses was changed so that respondents could indicate whether the service was condition specific (and to specify what conditions it covered), for people with any LTNC or for people with any conditions.

Multiple sections

7. Can people with LTNCs access …?
   a. Where questions had the response option ‘Yes, already described the service in previous sections’ (i.e. Questions F1, G1a, G2a, G3a, G4a) a response option was added to allow a record of which previously described service this referred to.
8. Who provides the service?
   a. A response option ‘other statutory’ was added

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Appendix F Conducting the national survey

F.1 Letter for national benchmarking audit

Dear

I am sending this as a follow-up to the discussion a couple of months ago when I explained that the Social Policy Research Unit, based at the University of York, are undertaking a national benchmarking survey of services for people with long-term neurological conditions (LTNCs). This survey has been commissioned by the Department of Health.

The benchmarking tool is based on findings from interviews with people with long-term neurological conditions and professionals working with this client group. It highlights the key service models and elements of services that were highly valued by our interviewees.

A member of the LTNC team will be calling you during the next few days to arrange a date and time to complete the benchmarking tool over the phone (see attached). By talking to you directly we hope to limit any ambiguities that may arise when analysing the data.

We are aware that you may not have all the relevant information immediately available, so we have included 'don't know' options for most questions. Alternatively, you may wish to confer with colleagues prior to completing the form, please allow sufficient time for this process when scheduling the telephone appointment.

An information sheet with details of the audit and your participation is attached, but if you have any other concerns or questions, please do not hesitate to contact a member of the research team.

Kind Regards

Rachel

F.2 Participant information sheet for Benchmarking audit

THE UNIVERSITY *of York*

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Participant Information Sheet

Services for People with Long-Term Neurological Conditions

Benchmarking Audit

You are being invited to take part in an audit being conducted by the Social Policy Research Unit at the University of York. This audit is part of a wider project funded by the Department of Health to support the implementation of the National Service Framework for Long-term Neurological Conditions. Before you decide whether or not you wish to take part, it is important for you to understand why the audit is being done and what it will involve. Please read the following information carefully and take your time to decide whether you wish to take part.

Ethical review

As this audit is simply collecting information about what services your PCT commissions, NRES has designated this phase of our project as a service audit and, therefore, as being exempt from requiring ethical review.

What is the purpose of the audit?

This national benchmarking audit will collect information about services that are provided for people with long-term neurological conditions.

Why have I been chosen?

You are being contacted because you have a role in commissioning services for people with long-term neurological conditions in your PCT.

What are the benefits of this audit?

The information that you provide will help to set benchmarks against which PCTs can monitor their progress in implementing the National Service Framework for Long-term Neurological Conditions. This will allow individual PCTs to monitor their progress over time and also to monitor their progress in relation to a national benchmark.

Will my taking part in this audit be kept confidential?

Your involvement in the audit, and the information that you provide, will be kept confidential. A unique identification number will be used throughout the audit for each PCT and all data will be anonymised. Data will be held in accordance with the 1998 Data Protection Act and University of York Ordinances.

Will taking part in this audit affect my employment?

No, taking part in the audit will not affect your employment in any way. Similarly, if you decide not to take part your employment will not be affected in any way. It is up to you whether or not you decide to take part and your decision will be kept completely confidential.

What will taking part involve?

If you choose to take part in the audit, you will need to complete a benchmarking tool about the services that are commissioned by your PCT for people with Long-term Neurological Conditions. It will take approximately 45 minutes to complete.

What if I choose not to take part?

Participation in this audit is entirely voluntary. If you choose not to take part, it would be very helpful if you would let us know, stating the PCT you are representing, so that we do not contact you again. You do not have to provide a reason but doing so would enable us to understand your reasons for declining to participate which might help when planning future projects.

If you have any questions or would like more information, please contact Fiona Aspinal on 01904 321985 or fa112@york.ac.uk

Thank You.

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F.3 Guidance notes for completion of long-term neurological conditions (LTNCs) benchmarking tool

General
Emphasise that if respondent has difficulty answering a question, there is usually a ‘don’t know’ option.

If there is just a box to enter the answer, as in D.2 whole time equivalent, please write ‘don’t know’ or ‘d/k’.

Section C: CINRTs
If you are unsure whether an identified team fits this definition, check:

- Does it deliver services in the community?
- Is it interdisciplinary, as in a number of disciplines working together? (See note on NSF definition).
- Is it specifically or mainly for people with LTNCs?
- Does it provide rehabilitation?

The answer must be yes to all of the above to be included.

C.3 How easy is it to access the service? *(Also applies to D.3, E.3 and G.1-4b)*

This is an overall judgement based on multiple factors, including those listed.

C.5 Who provides the service? *(Also applies also to E.5, F.4.)*

We understand that the ‘Health Trust’ option to include acute trust, PCT, community foundation trust or a combination of these. We are benchmarking whether it is **cross-sector** rather than cross-organisation within a sector.

Section D: Nurse Specialists

- If information is only provided for teams not individuals – record as if for individual but do not record whole time equivalents *(NOTE: later amended as now we record whether respondent is referring to a team or an individual)*
- This includes nurse specialists who are available to people living within the PCT area.
- They can be based in the community or in an acute hospital.

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D.2 What conditions does each nurse cover?

- Record each individual on a separate line, so WTE will always be less than or equal to 1 *(NOTE: later amended – see earlier note)*
- If part-time, record approximate WTE, if not known, record as ‘don’t know’.

D.5 What percentage of the nurse specialist’s time is spent providing the service in the following settings?

- This only needs to be an approximate estimate against which change can be tracked

Section E: Day Opportunities

- Services recorded here do not have to be neuro-specific. However, those only for people who have had a stroke should **not** be included.
- Day centres may be included **if** they provide access to **meaningful creative, learning and/or employment opportunities.**
- If unsure, record details and the LTNCs project team will discuss. (Service may not be included in final reporting.)
- We would read out the pre-amble and emphasise the importance of services offering all the types of opportunities (i.e. social **and** vocational) not just one of the types.

Section F: Other forms of care co-ordination

By way of example, social work teams, ‘Every Adult Matters’ services, District Nurses who provide care co-ordination and Community Matrons could be included here. Please note that this is not an exhaustive list.

F.5 What is the size of their total case load?

- Overall total, not just people with LTNCs.
- This only needs to be an approximate estimate.

Section H: Demographic characteristics

- Record everything mentioned that may be relevant.

F.4 Benchmarking tool

National Benchmark of Services for People with Long-term Neurological Conditions (LTNCs)

This benchmarking tool asks about key services that people with neurological conditions and staff who work with them have told us are highly valued. We are using it to benchmark the extent to which these services are provided in England and how they are delivered. Services that only provide for people with dementia or stroke should not be reported in this tool, as there are separate stroke and dementia strategies.

At the beginning of each section, we have included a description of the service models people with LTNCs told us they value. Please read these sections so that you can be clear whether or not the services commissioned by your PCT are similar to those described.

If you have any questions about completing the benchmarking tool or about the project more generally, please do not hesitate to contact a member of the **LTNCs Project Team** at the Social Policy Research Unit, University of York.

LTNCs Project Team
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Email: fa112@york.ac.uk

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Benchmarking Tool

Section A: Information about the PCT

A.1 Name of PCT

____

A.2 Name, designation and preferred contact details of person completing the benchmarking tool

Name ____

Designation ____

Tel. number ____

Email ____

Completion Date____

Interviewer Name ____

Section B: PCT strategy and organisation

B.1 Has the Trust completed a Joint Strategic Needs Assessment (JSNA) that includes a reference to long-term neurological conditions (LTNCs)?

Yes, refers to LTNCs in general ☐

Yes, refers to one or more specific LTNC ☐

No ☐

Don't know ☐

B.2 Do you currently have joint health and social care commissioning arrangements for LTNCs?

NOTE: **Fully** may be via a single health and social care organisation or joint/integrated commissioning team, accountable to both bodies and using pooled budgets. **Partially,** includes less formal arrangements where individual stakeholders remain accountable to their own organisation but some joint commissioning arrangements exist, which could include aligned budgets.

Yes, fully ☐

Yes, partially ☐

No ☐

Don't know ☐

B.3 Are people with LTNCs and/or their carers formally involved in …

	Yes	**No**	**Don't know**
Commissioning decisions	☐	☐	☐
Service development	☐	☐	☐
Audit and/or evaluation	☐	☐	☐
Other	☐	☐	☐

If other, please specify____

B.4 Is your PCT systematically recording numbers of people with LTNCs?

Yes ☐ **If yes**, for which conditions ______________________________

No ☐ ______________________________

Don’t know ☐ ______________________________

B.5 What is the approximate percentage of people with LTNCs who currently have a care plan? (Please provide details or tick the ‘don’t know’ option, as appropriate)

NOTE: By ‘care plan’ we mean an overarching single care plan that is owned by the person but can be accessed by those providing direct care/services or other relevant people as agreed by the individual (Commissioning Personalised Care Planning, 2009, p11)

Percentage ______________________________ Don’t know ☐

B.6 Do you have a cross-sector strategic group with responsibility for service improvement for LTNCs (e.g. Local Implementation Team for the NSF for LTNCs)?

Yes ☐ Please go to B6a

No ☐ Please go to B7

Don’t know ☐ Please go to B7

a) Are any people with LTNCs and/or their informal carers members of this group?

Yes ☐

No ☐

Don’t know ☐

b) When did this group last meet?

Within the last 3 months ☐

Within the last 6 months ☐

Within the last year ☐

More than one year ago ☐

Don’t know ☐

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B.7 Have you completed a needs assessment for people with LTNCs?

Yes, as part of the JSNA ☐

Yes, as separate exercise for LTNCs in general ☐

Yes, as separate exercise for one or more specific LTNCs ☐

No ☐

Don't know ☐

B.8 Do you have a written action plan for implementing the NSF for LTNCs?

Yes ☐

No ☐ Please go to Section C

Don't know ☐

a) **If yes**, when did you last audit or measure progress against this plan?

Never, because action plan is new ☐ Go to Section C
(i.e. finalised within last 6 months)

Currently auditing ☐

Within the last year ☐

Within the last 3 years ☐

More than 3 years ago ☐

Not audited ☐

Don't know ☐

b) Approximately, what percentage of the priorities from the **action plan** have been implemented to date?

Percentage ____________________________ Don't know ☐

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Sections C to F: Service Models

Our research has identified four key service models that improve continuity of care for people with Long-term Neurological Conditions. These are:

Section C: Community interdisciplinary neurological rehabilitation teams

Section D: Nurse specialists for neurological conditions

Section E: Day opportunities

Section F: Other forms of care co-ordination

These sections ask whether people with long-term neurological conditions in the PCT can access services provided via these service models.

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Section C: Community interdisciplinary neurological rehabilitation teams

Evidence from our research suggests that people with LTNCs value the support of an interdisciplinary neurological rehabilitation team, working mostly in the community (including people's own homes) that provides a person-centred service for as long as is needed.

NOTE:
Interdisciplinary teams *use an integrated approach to service planning and provision; they 'work together to a set of agreed goals, often undertaking joint sessions', whilst multidisciplinary refers to interventions that are delivered in parallel rather than in close collaboration (NSF for LTNCs p.16)*

C.1 Do you have one or more community interdisciplinary neurological rehabilitation teams providing services for people with LTNCs operating in the area covered by the PCT?

Yes ☐ Please list all applicable teams below

No ☐ Please go to Section D

Don't know ☐ Please go to Section D

C.2 Which condition(s) does it cover?

Team Name	**Neurological conditions covered** (if all LTNCs are covered by the service, please write 'all')	**Don't know**
		☐
		☐
		☐
		☐
		☐

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C.3 How easy is it to access this service? (Consider things like waiting times, eligibility criteria and service location. You may want to discuss this question with colleagues and arrive at a consensus.)

Team Name	**Very easy**	**Easy**	**Neither easy nor difficult**	**Difficult**	**Very difficult**	**Don't know**
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐

C.4 What percentage of the PCT's geographical area does it cover?

Team Name	**Approximate percentage**	**Don't know** (please tick)
		☐
		☐
		☐
		☐
		☐

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C.5 Who provides the service? (Tick one option only)

Team Name	**Health Trust** (Acute or PCT)	**Adult social care**	**Health & social care**	**Health, social care and other statutory**	**Non-statutory** (e.g. voluntary sector/ private)	**Statutory and non-statutory together**	**Don't know**
	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐

C.6 What is the size of the team's total caseload? (We are defining caseload here as the number of individuals who have contact with the team at least once per year)

Team Name	**<50**	**50-100**	**101-200**	**201-500**	**>500**	**Don't know**
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐

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C.7 Can people with LTNCs self-refer to the team?

Team Name	**Yes**	**No**	**Don't know**
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐

C.8 How long can people remain on the team's active caseload? (Tick **one** box that most closely describes the service)

Team Name	**On-going with intermittent reviews**	**Time-limited – based on goals**	**Time limited – pre-specified**	**Don't know**
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐

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C.9 Can people ring the team for advice and support from the service as needed?

Team Name	Yes	No	Don’t know
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐

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Section D: Nurse specialists for neurological conditions

Our research shows that people with long-term neurological conditions value support from nurse specialists who bring specialist knowledge about their condition, know the local system and are able to co-ordinate care within and across different sectors. This could be a nurse specialist based in a hospital and/or in the community.

D.1 Do you have neurology nurse specialists (e.g. MS, Parkinson's Disease or general neurology nurse specialist) **operating in the PCT area?**

Yes ☐ Please list all applicable nurse specialists below

No ☐ Please go to Section E

Don't know ☐ Please go to Section E

D.2 What conditions does each nurse cover? Please list each nurse specialist on a separate line (for example, if you have two MS nurse specialists, one might be NS1 and the other NS2)

	Neurological conditions covered (if all LTNCs are covered by the service, please write 'ALL')	**Team or individual (Enter T or I)**	**Whole Time Equivalent (wte)**
Nurse Specialist 1 (NS1)			
Nurse Specialist 2 (NS2)			
Nurse Specialist 3 (NS3)			
Nurse Specialist 4 (NS4)			
Nurse Specialist 5 (NS5)			
Nurse Specialist 6 (NS6)			
Nurse Specialist 7 (NS7)			

Please answer questions D.2 - D.8 in the box corresponding to the nurse specialist(s) listed above.

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D.3 How easy is it to access this service? (Consider things like waiting times, eligibility criteria and service location. You may want to discuss this question with colleagues and arrive at a consensus.)

	Very easy	**Easy**	**Neither easy nor difficult**	**Difficult**	**Very difficult**	**Don't know**
NS1	☐	☐	☐	☐	☐	☐
NS2	☐	☐	☐	☐	☐	☐
NS3	☐	☐	☐	☐	☐	☐
NS4	☐	☐	☐	☐	☐	☐
NS5	☐	☐	☐	☐	☐	☐
NS6	☐	☐	☐	☐	☐	☐
NS7	☐	☐	☐	☐	☐	☐

D.4 What percentage of the PCT's geographical area do they cover?

	Approximate percentage	**Don't know** (please tick)
NS1		☐
NS2		☐
NS3		☐
NS4		☐
NS5		☐
NS6		☐
NS7		☐

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D.5 What percentage of the nurse specialist's time is spent providing service in the following settings? (Complete **all** that apply)

	Community (including service user's home)	**Acute** (i.e. hospital)	**Don't know**
NS1	______ %	______ %	☐
NS2	______ %	______ %	☐
NS3	______ %	______ %	☐
NS4	______ %	______ %	☐
NS5	______ %	______ %	☐
NS6	______ %	______ %	☐
NS7	______ %	______ %	☐

D.6 What is the size of their total caseload? (We are defining caseload here as the number of individuals who have contact with the nurse at least once per year)

	<50	**50-100**	**101-200**	**201-500**	**>500**	**Don't know**
NS1	☐	☐	☐	☐	☐	☐
NS2	☐	☐	☐	☐	☐	☐
NS3	☐	☐	☐	☐	☐	☐
NS4	☐	☐	☐	☐	☐	☐
NS5	☐	☐	☐	☐	☐	☐
NS6	☐	☐	☐	☐	☐	☐
NS7	☐	☐	☐	☐	☐	☐

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D.7 Can people with LTNCs self-refer to the nurse specialist?

	Yes	**No**	**Don't know**
NS1	☐	☐	☐
NS2	☐	☐	☐
NS3	☐	☐	☐
NS4	☐	☐	☐
NS5	☐	☐	☐
NS6	☐	☐	☐
NS7	☐	☐	☐

D.8 How long can people remain on the nurse specialist's active caseload?

(Tick **one** box that most closely describes the service)

	Open-ended	**Time-limited - determined by outcomes of reviews**	**Time limited - pre-specified**	**Don't know**
NS1	☐	☐	☐	☐
NS2	☐	☐	☐	☐
NS3	☐	☐	☐	☐
NS4	☐	☐	☐	☐
NS5	☐	☐	☐	☐
NS6	☐	☐	☐	☐
NS7	☐	☐	☐	☐

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D.9 Can people ring the service for advice and support from the nurse specialist as needed?

	Yes	**No**	**Don't know**
NS1	☐	☐	☐
NS2	☐	☐	☐
NS3	☐	☐	☐
NS4	☐	☐	☐
NS5	☐	☐	☐
NS6	☐	☐	☐
NS7	☐	☐	☐

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Section E: Day Opportunities

In our research people with LTNCs said they valued services that offered **peer support, social/leisure opportunities <u>and</u> access to meaningful, creative, learning and/or employment opportunities in the community**. These types of services may be delivered via a 'one stop shop' style community centre or a virtual system of provision. They could be provided by statutory, voluntary or other independent sector agencies.

E.1 Do you have a service that provides the above opportunities?

Yes ☐ Please list all applicable services below

No ☐ Please go to Section F

Don't know ☐ Please go to Section F

E.2 Which conditions does it cover? (Please list each service and indicate whether or not it is condition specific)

Service Name	**Specific LTNC** (please list conditions)	**LTNC but not condition specific**	**Any condition** (not only for people with LTNCs)	**Don't Know**
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
Total number				

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E.3 How easy is it to access the service? (Consider things like waiting times, eligibility criteria and service location. You may want to discuss this question with colleagues and arrive at a consensus.)

Service Name	**Very easy**	**Easy**	**Neither easy nor difficult**	**Difficult**	**Very difficult**	**Don't know**
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐

E.4 What percentage of the PCT's geographical area does it cover?

Service Name	**Approximate percentage**	**Don't know** (please tick)
		☐
		☐
		☐
		☐
		☐

E.5 Who provides the service? (Tick **one** option only)

Service Name	**Health Trust** (Acute or PCT)	**Adult social care**	**Other statutory**	**Health & social care**	**Health, social care and other statutory**	**Non-statutory** (e.g. voluntary sector/ private)	**Statutory and non-statutory together**	**Don't know**
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐

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E.6 Can people with LTNCs self-refer to the service?

Service Name	**Yes**	**No**	**Don't know**
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐

E.7 How long can people continue to use this service? (Tick **one** box that most closely describes the service)

Service Name	**Open-ended**	**Time-limited - determined by outcomes of reviews**	**Time limited - pre-specified**	**Don't know**
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐

E.8 Can people ring the service for advice and support as needed?

Service Name	**Yes**	**No**	**Don't know**
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐

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Section F: Other forms of care co-ordination

Our research shows that having access to a named person, able to co-ordinate care **within and across** different sectors, improves continuity of care for people with long-term neurological conditions. This may be located in a sector other than health (e.g. adult social care) and may be an individual practitioner or a team. *(It may be provided as part of the models described earlier, i.e. as part of the community neurological rehabilitation team role, the nurse specialist's role or by the centres for people with LTNCs).*

F.1 Are there any services in the PCT area providing care co-ordination within and across different sectors for people with LTNCs? (e.g. Adult social care, community matrons) **Tick all that apply.**

Yes, already described in previous sections ☐

Please specify which service/s? ____________________________ Go to Section G

Yes, but not yet described ☐ Continue with Question F2-9

No ☐ Go to Section G

Don't know ☐ Go to Section G

F.2 Who delivers the service and what conditions does it cover? (Please list each service and indicate whether or not it is condition specific)

Care Co-ordination Service	**Specific LTNC** (please list conditions)	**LTNC but not condition specific**	**Any condition** (not only for people with LTNCs)	**Don't know**
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐

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F.3 What percentage of the PCT's geographical area does it cover?

Care Co-ordination Service	**Approximate percentage**	**Don't know** (please tick)
		☐
		☐
		☐
		☐
		☐
		☐
		☐

F.4 Who provides the service? (Tick one option only)

Care Co-ordination Service	**Health Trust** (Acute or PCT)	**Adult social care**	**Other statutory**	**Health & social care**	**Health, social care and other statutory**	**Non-statutory** (e.g. voluntary sector/ private)	**Statutory and non-statutory together**	**Don't know**
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐	☐	☐

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F.5 What is the size of their total caseload? (We are defining caseload here as the number of individuals who have contact with the care co-ordination service at least once per year)

Care Co-ordination Service	**<50**	**50-100**	**101-200**	**201-500**	**>500**	**Don’t know**
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐

F.6 Can people with LTNCs self-refer to the care co-ordination service?

Care Co-ordination Service	**Yes**	**No**	**Don’t know**
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐

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F.7 How long can people remain on the care co-ordinator’s active caseload?

(Tick **one** box that most closely describes the service)

Care Co-ordination Service	On-going with intermittent reviews	Time-limited – based on goals	Time limited - pre-specified	Don’t know
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐

F.8 Can people ring for advice and support from the care co-ordination service as needed?

Care Co-ordination Service	Yes	No	Don’t know
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐

Section G: Other Services

As well as the service models described above, our research shows that being able to access a number of other services and information on an **ongoing** basis is important to ensuring people with long-term neurological conditions experience continuity of care.

G.1 Neuro-Physiotherapy

a) Can people with long-term neurological conditions access neuro-physiotherapy in the PCT area? (Tick **all** that apply)

Yes, already described in previous sections ☐

Please specify which service/s? ________________________________ Go to G1e

Yes, but not yet described	☐	Continue with Question G1b-e
No	☐	Go to G2
Don't know	☐	Go to G2

b) How easy is it to access these other neuro-physiotherapy services?
(Consider things like waiting times, eligibility criteria and service location.)

Very easy	**Easy**	**Neither easy nor difficult**	**Difficult**	**Very difficult**	**Don't know**
☐	☐	☐	☐	☐	☐

c) Currently, what is the maximum waiting time for new referrals?

Up to ______ weeks Don't know ☐

d) How long can people remain on the neuro-physiotherapist's active caseload? (Tick **one** box that most closely describes the service)

On-going with intermittent reviews	Time-limited – based on goals	Time limited - pre-specified	Don't know
☐ Go to G1e	☐	☐	☐ Go to G1e

i) If time limited, can the person using this neuro-physiotherapy service, re-enter the service without being re-referred?

Yes	☐
No	☐
Don't know	☐

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e) **What percentage of the PCT's geographical area is covered by a neuro-physiotherapy service in total?** (Please include the area covered by this service and by the models described earlier)

Approximate percentage ______________________ Don't know ☐

G.2 Occupational Therapy (OT) with an expertise in neurology

a) **Can people with long-term neurological conditions access an OT with an expertise in neurology in the PCT area?** (Tick **all** that apply)

Yes, already described in previous sections ☐

Please specify which service/s? ____________________________ Go to G2e

Yes, but not yet described ☐ Continue with Question G2b-e

No ☐ Go to G3

Don't know ☐ Go to G3

b) **How easy is it to access these OT services?** (Consider things like waiting times, eligibility criteria and service location. You may want to discuss this question with colleagues and arrive at a consensus.)

Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know
☐	☐	☐	☐	☐	☐

c) **Currently, what is the maximum waiting time for new referrals?**

Up to ______ weeks Don't know ☐

d) **How long can people remain on the OT's active caseload?** (Tick **one** box that most closely describes the service)

On-going with intermittent reviews	Time-limited – based on goals	Time limited - pre-specified	Don't know
☐ Go to G2e	☐	☐	☐ Go to G2e

i) **If time limited**, can the person using this OT service, re-enter the service without being re-referred?

Yes ☐

No ☐

Don't know ☐

e) **What percentage of the PCT's geographical area is covered by an OT with an expertise in neurology in total?** (Please include the area covered by this service and by the models described earlier)

Approximate percentage ______________________ Don't know ☐

G.3 Community Speech and Language Therapy (SaLT)

a) **Can people with long-term neurological conditions access community SaLT in the PCT area?** (Tick **all** that apply)

Yes, already described in previous sections ☐

Please specify which service/s? ____________________________ Go to G3e

Yes, but not yet described	☐	Continue with Question G3b-e
No	☐	Go to G4
Don't know	☐	Go to G4

b) **How easy is it to access these other community SaLT services?** (Consider things like waiting times, eligibility criteria and service location. You may want to discuss this question with colleagues and arrive at a consensus.)

Very easy	**Easy**	**Neither easy nor difficult**	**Difficult**	**Very difficult**	**Don't know**
☐	☐	☐	☐	☐	☐

c) **Currently, what is the maximum waiting time for new referrals?**

Up to ______ weeks Don't know ☐

d) **How long can people remain on the community SaLT's active caseload?** (Tick **one** box that most closely describes the service)

On-going with intermittent reviews	**Time-limited – based on goals**	**Time limited - pre-specified**	**Don't know**
☐ Go to G3e	☐	☐	☐ Go to G3e

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i) **If time limited**, can the person using the community SaLT service, re-enter the service without being re-referred?

Yes	☐
No	☐
Don't know	☐

e) **What percentage of the PCT's geographical area is covered by a community SaLT service in total?** (Please include the area covered by this service and by the models described earlier)

Approximate percentage ____________________ Don't know ☐

G.4 Neuro-psychology

a) **Can people with long-term neurological conditions access neuro-psychology in the PCT area?** (Tick **all** that apply)

Yes, already described in previous sections ☐

Please specify which service/s? ________________________ Go to G4e-f

Yes, but not yet described	☐	Continue with Question G4b-f
No	☐	Go to G4f
Don't know	☐	Go to G4f

b) **How easy is it to access neuro-psychology?** (Consider things like waiting times, eligibility criteria and service location. You may want to discuss this question with colleagues and arrive at a consensus.)

Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Don't know
☐	☐	☐	☐	☐	☐

c) **Currently, what is the maximum waiting time for new referrals?**

Up to ______ weeks Don't know ☐

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d) How long can people remain on the neuro-psychologist's active caseload? (Tick **one** box that most closely describes the service)

On-going with intermittent reviews	**Time-limited – based on goals**	**Time limited - pre-specified**	**Don't know**
☐ Go to G3e	☐	☐	☐ Go to G3e

i) **If time limited**, can the person using the neuro-psychology service, re-enter the service without being re-referred?

Yes	☐
No	☐
Don't know	☐

e) What percentage of the PCT's geographical area is covered by a neuro-psychology service in total? (Please include the area covered by this service and by the models described earlier)

Approximate percentage ______________________ Don't know ☐

f) What other psychological support services are available for people with LTNCs who live in the PCT area? (Please list below)

____

____

____

G.5 Information

How do people with LTNCs who live in the PCT area access advice and information about benefits and/or financial issues?

____

____

____

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G.6 Voluntary and Private Sector

Does the PCT commission the voluntary or private sector to provide information and advice or support for people with LTNCs who are living in the PCT?

Yes ☐

No ☐

Don’t know ☐

G.7 Please tell us about any other services for people with LTNCs in your area? (Please give details below)

____

____

____

____

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Section H: Demographic characteristics

This section asks about the characteristics of the PCT's population.

H.1 What information do you use to find out about the diversity of your population?

____

____

____

____

H.2 Which socio-economic, ethnic or other groups in the PCT area may find it difficult to access services?

____

____

____

____

H.3 Are there any services designed to meet the needs of specific groups (not defined by their LTNC) (e.g. language/cultural/socio-economic/age/gender/communication needs**) that adults with LTNCs might use?**

____

____

____

____

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Additional question:

Identification of a named individual with a leading role for LTNCs can facilitate communication with external stakeholders and aid the commissioning process (CSIP, 2007). In light of this, we would like to make a list of people leading on implementation of NSF for LTNCs publicly available? Can we add the name and contact details to this list?

Yes ☐

No ☐

References

Care Services Improvement Partnership (2007) *Commissioning Services for People with Long-term Neurological Conditions*, London: Department of Health.

Department of Health (2005) *National Service Framework for Long-term Conditions*, London: Department of Health.

Department of Health (2009) *Supporting People with Long-term Conditions. Commissioning Personalised Care Planning: A guide for commissioners*, London: Department of Health (www.dh.gov.uk/publications).

Appendix G National benchmarking data

Section B: Strategy and organisation

Table G.1 Completed JSNA with reference to LTNCs (Q: B.1)[22]

	Frequency	Percentage
Yes, refers to LTNCs in general	52	44.1
Yes, refers to one or more specific LTNCs	12	10.2
Yes to both	2	1.7
No	46	39.0
Don't know	6	5.1
Total	**118**	**100.0**

Table G.2 Commissioning arrangements for LTNCs (Q: B.2)

	Frequency	Percentage
Yes, fully	14	11.9
Yes, partially	73	61.9
No	29	24.6
Don't know	2	1.7
Total	**118**	**100.0**

---

[22] Number in brackets refers to question number in benchmarking tool.

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Table G.3 Service users and/or carers involved in commissioning decisions (Q:B.3a)

	Frequency	Percentage
Yes	74	62.7
No	38	32.2
Don't know	6	5.1
Total	**118**	**100.0**

Table G.4 Service users and/or carers involved in service development (Q: B.3b)

	Frequency	Percentage
Yes	95	80.5
No	17	14.4
Don't know	6	5.1
Total	**118**	**100.0**

Table G.5 Service users and/or carers involved in audit and/or evaluation (Q: B.3c)

	Frequency	Percentage
Yes	67	56.8
No	40	33.9
Don't know	11	9.3
Total	**118**	**100.0**

Table G.6 PCT systematically recording numbers of people with LTNCs (Q: B.4a)

	Frequency	Percentage
Yes	55	46.6
No	57	48.3
Don't know	6	5.1
Total	**118**	**100.0**

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Table G.7 Conditions systematically recorded (Q: B.4b)

	Frequency	Percentage (of PCTS that record numbers of people with LTNCs)	Percentage total PCTs
All	18	33.3	15.3
Brain Injury	1	1.9	0.9
MS	2	3.7	1.7
Epilepsy	15	27.8	12.7
Multiple LTNCs (not all)	16	29.6	13.6
Don't know	2	3.7	1.7
Total	54	100.0	
Missing	1		0.9
NA	63		53.4
Total	**118**		**100.0**

Table G.8 Approximate percentage of people with LTNCs currently having a care plan (Q: B.5)

Percentage (estimate)	**Frequency**	**Percentage**
0	2	2
1	1	1
10	2	2
20	1	1
50	1	1
75	1	1
80	1	1
100	4	3
Don't know	105	89
Total	**118**	**100**

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Table G.9 Approximate percentage of people with LTNCs currently having a care plan (grouped) (Q: B.5)

	Frequency	Percentage
50 % or below	7	5.9
Greater than 50%	6	5.1
Don't know	105	89.0
Total	**118**	**100.0**

Table G.10 Cross-sector strategic group (Q: B.6)

	Frequency	Percentage
Yes	78	66.1
No	37	31.4
Don't know	3	2.5
Total	**118**	**100.0**

Table G.11 Service users and/or carers involved in cross-sector strategic group (Q: B.6a)

	Frequency	Percentage	Percentage total PCTs
Yes	53	68.0	44.9
No	19	24.4	16.1
Don't know	6	7.7	5.1
Total	78	100.0	
Not applicable	40		33.9
Total	**118**		**100.0**

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Table G.12 Cross-sector strategic group last met (Q: B.6b)

	Frequency	Percentage	Percentage total PCTs
Within the last 3 months	63	87.5	53.4
Within the last 6 months	4	5.6	3.4
Within the last year	4	5.56	3.3
Don't know	1	1.4	0.9
Total	72	100.0	
NA	46		39.0
Total	**118**		**100.0**

Table G.13 Needs assessment completed (Q: B.7)

	Frequency	Percentage
Yes, as part of the JSNA	19	16.1
Yes, as separate exercise for LTNCs in general	32	27.1
Yes, as a separate exercise for 1 or more specific LTNCs	17	14.4
Yes, for both JSNA and LTNCs in general	4	3.4
Yes, for both LTNCs in general and specific LTNCs	2	1.7
No	41	34.8
Don't know	3	2.5
Total	**118**	**100.0**

Table G.14 Written action plan for implementing NSF (Q: B.8)

	Frequency	Percentage
Yes	59	50.0
No	56	47.5
Don't know	3	2.5
Total	**118**	**100.0**

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Table G.15 Last audited or measured progress against action plan (Q: B.8a)

	Frequency	Percentage	Percentage total PCTs
Never because action plan is new	16	27.1	13.6
Currently auditing	11	18.6	9.3
Within the last year	21	35.6	17.8
Within the last 3 years	4	6.8	3.4
More than 3 years ago	2	3.4	1.7
Not audited	4	6.8	3.4
Don't know	1	1.7	0.9
Total	59	100.0	
NA	59		50.0
Total	**118**		**100.0**

Table G.16 Approximate percentage of priorities from action plan implemented to date (Q: B.8b)

Percentage (estimate)	Frequency	Percentage	Percentage total PCTs
0	1	4.2	0.9
10	1	4.2	0.9
12	1	4.2	0.9
20	1	4.17	0.9
25	2	8.3	1.7
30	3	12.5	2.5
40	2	8.3	1.7
50	7	29.2	5.9
61	1	4.2	0.9
70	2	8.3	1.7
75	3	12.5	2.5
Total	24	100.0	
Missing	1		0.9
NA	81		68.6
Don't know	12		10.2
Total	**118**		**100.0**

Table G.17 Approximate percentage of priorities from action plan implemented to date (grouped) (Q: B.8b)

	Frequency	Percentage
greater than 50%	6	5.1
50 % or below	18	15.3
Don’t know	12	10.2
NA	81	68.7
missing	1	0.9
Total	**118**	**100.00**

Section C: Community interdisciplinary neurological rehabilitation teams (CINRTs)

Table G.18 CINRT(s) operating in PCT area (Q: C.1)

	Frequency	Percentage
Yes	86	72.9
No	32	27.1
Total	**118**	**100**

Table G.19 Number of CINRTs by PCT (Q: C.1)

	Frequency	Percentage
No Team	32	27.1
Single Team	61	51.7
Two Teams	16	13.6
Three Teams	7	5.9
Four Teams	1	0.8
Five Teams	1	0.8
Total	**118**	**100**

Table G.20 PCTs with CINRTs by LTNC (Q: C.2)

	Frequency	Percentage
All LTNCs	56	47.4
Multiple LTNCs	15	12.7
Brain Injury	25	21.1
MS	4	3.4
MND/ALS	3	2.5
Epilepsy	1	0.8
Other	1	0.8
Don’t know	1	0.8

(based on 118 PCTs)

Table G.21 CINRTs by LTNC (Q: C.2)

	Frequency	Percentage
All LTNCs	72	58.5
Multiple LTNCs	15	12.2
Brain Injury	26	21.1
MS	4	3.3
MND/ALS	3	2.4
Epilepsy	1	0.8
Other	1	0.8
Don’t know	1	0.8
Total	**123**	**100.0**

(aggregated data from 86 PCTs)

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Table G.22 Ease of access to CINRTs (Q: C.3)

Ease of access to CINRTs	Frequency	Percentage
Very easy	27	22.0
Easy	46	37.4
Neither easy nor difficult	30	24.4
Difficult	14	11.4
Very difficult	0	0.0
Don't know	5	4.1
Missing	1	0.8
Total	**123**	**100.0**

(aggregated data from 86 PCTs)

Table G.23 Coverage of PCTs' geographical area (Q: C.4)

	Number of Teams	Percentage
Full coverage	91	74.0
Partial coverage	29	23.8
Don't know	3	2.4
Total	**123**	**100.0**

(aggregated data from 86 PCTs)

Table G.24 Provider of CINRTs (Q: C.5)

	Frequency	Percentage
Health Trust provided	86	69.9
Adult Social Care provided	2	1.6
Health and Social Care provided	21	17.1
Health, Social Care and Other Statutory provided	4	3.3
Non-statutory provided	4	3.3
Statutory and non-statutory together provided	4	3.3
Don't know	2	1.6
Total	**123**	**100.0**

(aggregated data from 86 PCTs)

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Table G.25 Case load of CINRTs (Q: C.6)

	Frequency	Percentage
Caseload less than fifty	6	4.9
Caseload 50-100	20	16.3
Caseload 101-200	9	7.3
Caseload 201-500	19	15.5
Greater than 500	16	13.0
Don't know	49	39.8
Missing	4	3.3
Total	**123**	**100.0**

(aggregated data from 86 PCTs)

Table G.26 Self-referral to CINRTs (Q: C.7)

	Frequency	Percentage
People can self-refer to team	68	55.3
People unable to self-refer to team	48	39.0
Don't know	7	5.7
Total	**123**	**100.0**

(aggregated data from 86 PCTs)

Table G.27 Involvement with CINRTs (Q: C.8)

	Frequency	Percentage
Ongoing with intermittent reviews	50	40.7
Time limited based on goals	54	43.9
Time limited pre-specified	6	4.9
Don't know	12	9.8
Missing	1	0.8
Total	**123**	**100.0**

(aggregated data from 86 PCTs)

Table G.28 Ring CINRTs for advice and support (Q: C.9)

	Frequency	Percentage
Able to ring team for advice and support	115	93
Unable to ring team for advice and support	0	0
Don't know	7	6
Missing	1	1
Total	**123**	**100**

(aggregated data from 86 PCTs)

Section D: Nurse specialists

Table G.29 Nurse specialists available in PCT area (Q: D.1)

	Frequency	Percentage
Yes	110	93.2
No	6	5.1
Don’t know	2	1.4
Total	**118**	**100.0**

Table G.30 PCTs with nurse specialists by LTNC (Q: D.2)

	Frequency	Percentage
All LTNCs	16	13.6
Brain Injury	11	9.3
MS	92	77.9
PD	93	78.8
Epilepsy	59	50.0
MND/ALS	26	21.9
HD	2	1.7
Neuromuscular	0	0.0
Other LTNCs	11	9.2
Multiple but not all LTNCs	8	6.7
Don’t know LTNC	3	2.5

(based on 118 PCTs)

Table G.31 Type of nurse specialist (Q: D.2)

	Frequency	Percentage
All LTNCs	16	3.5
Brain Injury	11	2.5
MS	126	28.1
PD	127	28.3
Epilepsy	68	15.2
MND/ALS	29	6.5
HD	2	0.4
Neuromuscular	0	0.0
Other LTNCs	27	6.0
Multiple but not all LTNCs	9	2.0
Don’t know LTNC	33	7.4
Total	**448**	**100.0**

(aggregated data, teams or individuals based on 110 PCTs)

Table G.32 PCTs reporting individual practitioners and/or teams of nurse specialists (Q: D.2)

	Frequency	Percentage
Individual nurse specialists	91	77.1
Teams of nurse specialists	33	27.9

(based on 118 PCTs)

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Table G.33 Ease of access to nurse specialists (Q: D.3)

	Frequency	Percentage
Very Easy	104	23.2
Easy	174	38.8
Neither Easy nor difficult	60	13.4
Difficult	27	6.0
Very Difficult	4	0.9
Don't know	79	17.6
Total	**448**	**100.0**

(aggregated data, teams or individuals, based on 110 PCTs)

Table G.34 Coverage of PCTs' geographical area (Q: D.4)

	Frequency	Percentage
Full Coverage	327	73.0
Partial coverage	56	12.5
Don't know	65	14.5
Total	**448**	**100.0**

(aggregated data, teams or individuals, based on 110 PCTs)

Table G.35 Community versus acute setting (Q: D.5)

	Frequency	Percentage
Work >= 50% in community	154	34.3
Work < 50% in community	132	29.5
Don't know	162	36.1
Total	**448**	**100.0**

(aggregated data, teams or individuals, based on 110 PCTs)

Table G.36 Self-referral to nurse specialists (Q: D.7)

	Frequency	Percentage
People can self-refer to nurse specialist	234	52.2
People unable to self-refer to nurse specialist	106	23.7
Don't know	108	24.1
Total	**448**	**100.0**

(aggregated data, teams or individuals, based on 110 PCTs)

Table G.37 Involvement with nurse specialists (Q: D.8)

	Frequency	Percentage
Open-ended	267	59.6
Time limited determined by outcomes of reviews	44	9.8
Time limited pre-specified	3	0.7
Don't know	112	25.0
Missing	22	4.9
Total	**448**	**100.0**

(aggregated data, teams or individuals, based on 110 PCTs)

Table G.38 Ring nurse specialists for advice and support (Q: D.9)

	Frequency	Percentage
Able to ring nurse specialists for advice and support	394	87.9
Unable to ring nurse specialists for advice and support	1	0.2
Don't know	53	11.8
Missing	0	0.0
Total	**448**	**100.0**

(aggregated data, teams or individuals, based on 110 PCTs)

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Section E: Day Opportunities

Table G.39 Day opportunities in PCT area (Q: E.1)

Day opportunities	Frequency	Percentage
Yes	77	65.3
No	24	20.3
Don't know	17	14.4
Total	**118**	**100.0**

Table G.40 PCTs by conditions covered by day opportunities (Q: E.2)

	Frequency	Percentage
Specific LTNC	53	44.9
LTNCs but not condition specific	13	11.0
Any condition (not only for people with LTNCs)	46	39.0
Don’t know conditions	2	1.7

(based on 118 PCTs)

Table G.41 PCTs by specific LTNCs covered by day opportunities (Q: E.2)

	Frequency	Percentage
Head injuries	43	36.4
MS	16	13.5
PD	9	7.6
Epilepsy	1	0.8
MND/ALS	4	3.4
HD	1	0.8
Other LTNCs	3	2.5

(based on 118 PCTs)

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Table G.42 Type of specific day opportunity (Q: E.2)

	Frequency	Percentage
Head injuries	49	55.1
MS	17	19.1
PD	9	10.1
Epilepsy	1	1.1
MND/ALS	4	4.5
HD	1	1.1
Other LTNC	8	9.0
Totals based on 77 PCTs	**89**	**100.0**

(aggregated data based on 77 PCTs)

Table G.43 Ease of access to day opportunities (Q: E.3)

Ease of access to day opportunities	Frequency	Percentage
Very easy	28	13.3
Easy	94	44.8
Neither easy nor difficult	42	20.0
Difficult	27	12.9
Very difficult	1	0.5
Don't know	18	8.6
Total	**210**	**100.0**

(aggregated data based on 77 PCTs)

Table G.44 Coverage of PCTs' geographical area (Q: E.4)

	Frequency	Percentage
Full Coverage	164	78.1
Partial coverage	34	16.2
Don't know	12	5.7
Total	**210**	**100.0**

(aggregated data, based on 77 PCTs)

Table G.45 Provider of day opportunities (Q: E.5)

	Frequency	Percentage
Health Trust provided	18	8.6
Adult Social Care provided	43	20.5
Other statutory	4	1.9
Health and Social Care provided	5	2.4
Health, Social Care and Other Statutory provided	1	0.5
Non-statutory provided	100	47.7
Statutory and non-statutory together provided	26	12.4
Don't know	13	6.2
Total	**210**	**100.0**

(aggregated data, based on 77 PCTs)

Table G.46 Self-referral to day opportunities (Q: E.6)

	Frequency	Percentage
People can self-refer to day opportunities	125	59.5
People unable to self-refer day opportunities	71	33.8
Don't know	14	6.7
Total	**210**	**100.0**

(aggregated data based on 77 PCTs)

Table G.47 Involvement with day opportunities (Q: E.7)

	Frequency	Percentage
Open-ended	121	57.6
Time limited determined by outcomes of reviews	48	22.9
Time limited pre-specified	10	4.8
Don't know	29	13.8
Missing	2	1.0
Total	**210**	**100.0**

(aggregated data based on 77 PCTs)

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Table G.48 Ring day opportunities for advice and support (Q: E.8)

	Frequency	Percentage
Able to ring day opportunities for advice and support	162	77.1
Unable to ring day opportunities for advice and support	25	11.9
Don't know	23	11.0
Total	**210**	**100.0**

(aggregated data based on 77 PCTs)

Section F: Care co-ordination services

Table G.49 Care co-ordination services in PCT area (Q: F.1)

Care co-ordination	Frequency	Percentage
Yes, already described in previous sections	14	11.9
Yes, but not yet described	32	27.1
Yes to both already described and not yet described	61	51.7
No	8	6.8
Don't know	3	2.5
Total	**118**	**100.0**

Table G.50 LTNCs care co-ordination services by PCT (not necessarily covered by CINRT, nurse specialists or day opportunities) (Q: F.2)

	Frequency	Percentage
Specific LTNC	11	9.3
LTNCs but not condition specific	19	16.1

(based on 118 PCTs)

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Table G.51 PCTs by specific LTNCs covered by care co-ordination services (Q: F.2)

	Frequency	Percentage
Head injuries	2	1.7
MS	3	2.5
PD	1	0.8
Epilepsy	1	0.8
MND/ALS	3	2.5
HD	1	0.8
Neuromuscular disorders	1	0.8
Other LTNCs	1	0.8

(based on 118 PCTs)

Table G.52 Numbers and type of LTNC care co-ordination services (Q: F.2)

	Frequency	Percentage
Head injuries	2	5.7
MS	3	8.6
PD	1	2.9
Epilepsy	1	2.9
MND/ALS	4	11.4
HD	1	2.9
Neuromuscular	1	2.9
Other LTNC	1	2.9
Multiple (not all LTNCs)	1	2.9
All LTNCs	21	60.0
Totals based on 30 PCTs	**36**	**100.0**

(aggregated data based on 30 PCTs)

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Section G: Other services

G.1 Neuro-physiotherapy

Table G.53 Availability of neuro-physiotherapy (Q: G.1a)

	Frequency	Percentage
Yes, already described in previous sections	35	29.7
Yes, but not yet described	38	32.2
Yes to both already described and not yet described	36	30.5
No	3	2.5
Don't know	6	5.1
Total	**118**	**100.0**

Table G.54 Neuro-physiotherapy service previously described (Q: G.1a)

	Frequency	Percentage
Provided by CINRTs	64	90.1
Provided by more than one service previously described	4	5.6
Provided by care co-ordination service	3	4.2
Total	71	100.0
Missing NA	47	
Total	**118**	

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Table G.55 Ease of access to neuro-physiotherapy service (Q: G.1b)

	Frequency	Percentage
Very easy	1	1.3
Easy	25	33.3
Neither easy nor difficult	25	33.3
Difficult	14	18.7
Very difficult	2	2.7
Don’t know	8	10.7
Total	75	100.0
Missing NA	43	
Total	**118**	

Table G.56 Waiting times for neuro-physiotherapy new referrals (grouped) (Q: G1.c)

	Frequency	Percentage
1 month or less	16	21.3
5-18 weeks	27	36.0
19 weeks – 6 months	1	1.3
Over 6 months	1	1.3
Don’t know	30	40.0
Total	75	100.0
Missing NA	43	
Total	**118**	

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Table G.57 Length of time on neuro-physiotherapist's active case load (Q: G1.d)

	Frequency	Percentage
Ongoing with intermittent reviews	14	18.7
Time-limited based on goals	39	52.0
Time-limited pre-specified	3	4.0
Don't know	19	25.3
Total		100.0
Missing NA	43	
Total	**118**	

Table G.58 Re-entering the service without re-referral (if time limited) (Q: G1.di)

	Frequency	Percentage
Yes	20	47.6
No	18	42.9
Don't know	4	9.5
Total	42	100.0
Missing NA	43	
Total	**118**	

Table G.59 Neuro-physiotherapy geographical coverage of PCT (Q: G1.e)

	Frequency	Percentage
Full coverage	93	87.7
Partial coverage	13	12.3
Total	106	100.0
Missing NA	12	
Total	**118**	

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G.2 Occupational therapy (OT) with expertise in neurology

Table G.60 Availability of OT service with expertise in neurology (Q: G.2a)

	Frequency	Percentage
Yes, already described in previous sections	55	46.6
Yes, but not yet described	24	20.3
Yes to both already described and not yet described	18	15.3
No	13	11.0
Don't know	8	6.8
Total	**118**	**100.0**

Table G.61 Occupational therapy service previously described (Q: G.2a)

	Frequency	Percentage
Provided by CINRTs	68	93.2
Provided by more than one service previously described	1	1.4
Provided by care co-ordination service	4	5.5
Total	73	100.0
Missing NA	45	
Total	**118**	

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Table G.62 Ease of access to OT service with expertise in neurology (Q: G.2b)

	Frequency	Percentage
Very easy	3	6.8
Easy	12	27.3
Neither easy nor difficult	13	29.5
Difficult	8	18.2
Very difficult	1	2.3
Don't know	7	15.9
Total	44	100.0
Missing NA	74	
Total	**118**	

Table G.63 Waiting times for OT service with expertise in neurology new referrals (grouped) (Q: G.2c)

	Frequency	Percentage
1 month or less	11	25.0
5-18 weeks	16	36.4
19 weeks – 6 months	0	0
Over 6 months	0	0
Don't know	17	38.6
Total	44	100.0
Missing NA	74	
Total	**118**	

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Table G.64 Length of time on OT's active case load (Q: G.2d)

	Frequency	Percentage
Ongoing with intermittent reviews	7	15.9
Time-limited based on goals	22	50.0
Time-limited pre-specified	2	4.5
Don't know	13	29.5
Total	44	100.0
Missing NA	74	
Total	**118**	

Table G.65 G1di Re-entering the service without re-referral (if time limited) (Q: G.2di)

	Frequency	Percentage
Yes	12	48.0
No	10	40.0
Don't know	3	12.0
Total	25	100.0
Missing NA	93	
Total	**118**	

Table G.66 OT geographical coverage of PCT (Q: G.2e)

	Frequency	Percentage
Full coverage	80	77.7
Partial coverage	23	22.3
Total	103	100.0
Missing NA	15	
Total	**118**	

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G.3 Community Speech and Language therapy (SaLT)

Table G.67 Availability of SaLT (Q: G.3a)

	Frequency	Percentage
Yes, already described in previous sections	22	18.6
Yes, but not yet described	54	45.8
Yes to both already described and not yet described	35	29.7
No	4	3.4
Don't know	3	2.5
Total	**118**	**100.0**

Table G.68 SaLT previously described (Q: G.3a)

	Frequency	Percentage
Provided by CINRTs	53	93.0
Provided by more than one service previously described	1	1.8
Provided by care co-ordination service	3	5.3
Total	57	100.0
Missing NA	61	
Total	**118**	

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Table G.69 Ease of access to SaLT service (Q: G.3b)

	Frequency	Percentage
Very easy	5	5.6
Easy	21	23.3
Neither easy nor difficult	31	34.4
Difficult	16	17.8
Very difficult	1	1.1
Don't know	16	17.8
Total	90	100.0
Missing NA	28	
Total	**118**	

Table G.70 Waiting times for SaLT new referrals (grouped) (Q: G.3c)

	Frequency	Percentage
1 month or less	10	11.11
5-18 weeks	25	27.8
19 weeks – 6 months	2	1.0
Over 6 months	0	0
Don't know	53	58.9
Total	90	100.0
Missing NA	28	
Total	**118**	

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Table G.71 Length of time on SaLT's active case load (Q: G.3d)

	Frequency	Percentage
Ongoing with intermittent reviews	21	23.3
Time-limited based on goals	34	37.8
Time-limited pre-specified	3	3.3
Don't know	32	35.6
Total	90	100.0
Missing NA	28	
Total	**118**	

Table G.72 Re-entering the service without re-referral (if time limited) (Q: G.3di)

	Frequency	Percentage
Yes	19	48.7
No	12	30.8
Don't know	8	20.5
Total	39	100.0
Missing NA	79	
Total	**118**	

Table G.73 SaLT's geographical coverage of PCT (Q: G.3e)

	Frequency	Percentage
Full coverage	96	90.6
Partial coverage	10	9.4
Total	106	100.0
Missing NA	12	
Total	**118**	

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G4 Neuro-psychology

Table G.74 Availability of neuro-psychology (Q: G.4a)

	Frequency	Percentage
Yes, already described in previous sections	23	19.5
Yes, but not yet described	45	38.1
Yes to both already described and not yet described	14	11.9
No	23	19.5
Don't know	13	11.0
Total	**118**	**100.0**

Table G.75 Neuro-psychology service previously described (Q: G.4a)

	Frequency	Percentage
Provided by CINRTs	35	94.6
Provided by more than one service previously described	1	2.7
Provided by care co-ordination service	1	2.7
Total	37	100.0
Missing NA	81	
Total	**118**	

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Table G.76 Ease of access to neuro-psychology service (Q: G.4b)

	Frequency	Percentage
Very easy	1	1.7
Easy	4	6.7
Neither easy nor difficult	10	16.7
Difficult	21	35.0
Very difficult	17	28.0
Don’t know	7	11.7
Total	60	100.0
Missing NA	58	
Total	**118**	

Table G.77 Waiting times for neuro-psychology new referrals (grouped) (Q: G.4c)

	Frequency	Percentage
1 month or less	2	1.7
5-18 weeks	21	35.0
19 weeks – 6 months	0	0.0
Over 6 months - 1 year	3	5.0
Over 1 year	1	0.8
Don’t know	33	55.0
Total	60	100.0
Missing NA	58	
Total	**118**	

Table G.78 Length of time on neuro-psychologist’s active case load (Q: G.4d)

	Frequency	Percentage
Ongoing with intermittent reviews	11	18.3
Time-limited based on goals	21	35.0
Time-limited pre-specified	5	8.3
Don’t know	23	38.3
Total	60	100.0
Missing NA	58	
Total	**118**	

Table G.79 Re-entering the service without re-referral (if time limited) (Q: G.4di)

	Frequency	Percentage
Yes	6	22.2
No	16	59.3
Don’t know	5	18.5
Total	27	100.0
Missing NA	91	
Total	**118**	

Table G.80 Neuro-psychology geographical coverage of PCT (Q: G.4e)

	Frequency	Percentage
Full coverage	67	69.1
Partial coverage	30	30.9
Total	97	100.0
Missing NA	21	
Total	**118**	

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Table G.81 PCT commission voluntary or private sector to provide information and advice/support (Q: G.6)

	Frequency	Percentage
Yes	61	52.1
No	41	35.0
Don’t know	15	12.8
Total	117	100.0
Missing	1	
Total	**118**	

Tests of relationship between ‘strategy and organisation’ and models of care

Table G.82 ‘Strategy and organisation’ by CINRTs

		CINRT		Total
		Yes	No or don’t know	
Joint commissioning arrangements (fully and partially	Yes	68	19	87
	No or don’t know	17	12	29
Total		85	31	116
Cross-sector strategic group	Yes	62	16	78
	No or don’t know	24	16	40
Total		86	32	118
Service users involved in commissioning decisions	Yes	59	15	74
	No or don’t know	27	17	44
Total		86	32	118
Completed Needs assessment	Yes	54	20	74
	No or don’t know	32	12	44
Total		86	32	118

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Table G82a Tests of association

	Pearson Chi-Square	df	Contingency coefficient	Asymp. Sig. (2-sided)	Significance at 5% level
Joint commissioning by CINRT	4.241	1	0.188	.039	S
Cross-sector strategic group by CINRT	5.080	1	0.203	.024	S
Service users involved in commissioning decisions by CINRT	4.709	1	0.196	.030	S
Completed needs assessment by CINRT	0.001	1	0.003	.977	NS

Table G.83 ‘Strategy and organisation’ by nurse specialists

		Nurse specialists		Total
		Yes	No or don’t know	
Joint commissioning arrangements (fully and partially	Yes	81	6	87
	No or don’t know	27	2	29
Total		108	8	118
Cross-sector strategic group	Yes	74	4	78
	No or don’t know	36	4	40
Total		110	8	118
Service users involved in commissioning decisions	Yes	72	2	74
	No or don’t know	38	6	44
Total		110	8	118
Completed needs assessment	Yes	70	4	74
	No or don’t know	40	4	44
Total		110	8	118

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Table G.83a Tests of association

	Pearson Chi-Square	df	Contingency coefficient	Asymp. Sig. (2-sided)	Significance at 5% level
Joint commissioning by nurse specialists	.000	1	0.000	1.000	NS
Cross-sector strategic group by nurse specialists	.993	1	0.091	.319	NS
Service users involved in commissioning decisions by nurse specialists	5.219	1	0.206	.022	S
Completed needs assessment by nurse specialists	.593	1	0.071	.441	NS

NB 1 cell (25%) has expected count less than 5. Minimum expected count is 2.98.

Table G.84 ‘Strategy and organisation’ by day opportunities

		Day opportunities		Total
		Yes	No or don’t know	
Joint commissioning arrangements (fully and partially	Yes	63	24	87
	No or don’t know	14	15	29
Total		77	39	116
Cross-sector strategic group	Yes	59	19	78
	No or don’t know	18	22	40
Total		77	41	118
Service users involved in commissioning decisions	Yes	54	20	74
	No or don’t know	23	21	44
Total		77	41	118
Completed needs assessment	Yes	55	19	74
	No or don’t know	22	22	44
Total		77	41	118

Table G.84a Tests of association

	Pearson Chi-Square	df	Contingency coefficient	Asymp. Sig. (2-sided)	Significance at 5% level
Joint commissioning by day opportunities	5.678	1	0.216	.017	S
Cross-sector strategic group by day opportunities	10.949	1	0.291	.001	S
Service users involved in commissioning decisions by day opportunities	5.215	1	0.206	.022	S
Completed needs assessment by day opportunities	7.201	1	0.240	.007	S

Table G.85 Tests of association between ‘structural and organisational’ variables

	Pearson Chi-Square	df	Contingency coefficient	Asymp. Sig. (2-sided)	Significance at 5% level
Joint commissioning by cross-sector strategic group	8.819	1	0.266	.003	S
Joint commissioning by service users involved in commissioning decisions	8.410	1	0.260	.004	S
Joint commissioning by completed needs assessment	2.438	1	0.143	.118	NS
Cross-sector strategic group by service users involved in commissioning decisions	8.118	1	0.254	.004	S
Cross-sector strategic group by completed needs assessment	8.118	1	0.254	.004	S
Service users involved in commissioning decisions by completed needs assessment	11.444	1	0.297	.001	S

Table G.86 Backward stepwise (likelihood ratio) model of predictors of CINRTs

		B (the set of coefficients estimated for the model)	S.E.	Wald	df	Sig.	Exp (B)
Step 1	joint commissioning	-.599	.501	1.430	1	.232	.550
	cross-sector strategic group	-.738	.476	2.397	1	.122	.478
	service users involved in commissioning decisions	-.728	.477	2.328	1	.127	.483
	completion of a needs assessment for LTNCs	.517	.489	1.118	1	.290	1.676
	Constant	1.560	.345	20.441	1	.000	4.761
Step 2	joint commissioning	-.578	.494	1.366	1	.242	.561
	cross-sector strategic group	-.650	.463	1.971	1	.160	.522
	service users involved in commissioning decisions	-.608	.458	1.763	1	.184	.545
	Constant	1.663	.336	24.475	1	.000	5.277
Step 3	cross-sector strategic group	-.768	.449	2.927	1	.087	.464
	service users involved in commissioning decisions	-.720	.445	2.623	1	.105	.487
	Constant	1.588	.327	23.607	1	.000	4.896
Step 4	cross-sector strategic group	-.927	.434	4.553	1	.033	.396
	Constant	1.355	.280	23.335	1	.000	3.875

Nagelkerke R^2= .056

Table G.87 Backward stepwise (likelihood ratio) model of predictors of nurse specialists

		B (the set of coefficients estimated for the model)	S.E.	Wald	df	Sig.	Exp (B)
Step 1	joint commissioning	.691	.916	.569	1	.451	1.996
	cross-sector strategic group	-.546	.800	.466	1	.495	.579
	service users involved in commissioning decisions	-1.812	.897	4.076	1	.043	.163
	completion of a needs assessment for LTNCs	-.065	.787	.007	1	.934	.937
	Constant	3.668	.788	21.644	1	.000	39.175
Step 2	joint commissioning	.695	.916	.576	1	.448	2.004
	cross-sector strategic group	-.554	.795	.486	1	.486	.574
	service users involved in commissioning decisions	-1.829	.873	4.384	1	.036	.161
	Constant	3.652	.763	22.940	1	.000	38.556
Step 3	joint commissioning	.538	.884	.371	1	.542	1.713
	service users involved in commissioning decisions	-1.915	.863	4.920	1	.027	.147
	Constant	3.513	.723	23.611	1	.000	33.545
Step 4	service users involved in commissioning decisions	-1.792	.842	4.532	1	.033	.167
	Constant	3.584	.717	24.989	1	.000	36.000

Nagelkerke R^2= .115

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Table G.88 Backward stepwise (likelihood ratio) model of predictors of day opportunities

		B (the set of coefficients estimated for the model)	S.E.	Wald	df	Sig.	Exp (B)
Step 1	joint commissioning	-.646	.483	1.788	1	.181	.524
	cross-sector strategic group	-.901	.447	4.054	1	.044	.406
	service users involved in commissioning decisions	-.301	.455	.438	1	.508	.740
	completion of a needs assessment for LTNCs	-.655	.442	2.201	1	.138	.519
	Constant	1.565	.342	20.998	1	.000	4.783
Step 2	joint commissioning	-.713	.471	2.289	1	.130	.490
	cross-sector strategic group	-.937	.444	4.460	1	.035	.392
	completion of a needs assessment for LTNCs	-.720	.431	2.798	1	.094	.487
	Constant	1.504	.326	21.298	1	.000	4.501
Step 3	cross-sector strategic group	-1.086	.431	6.358	1	.012	.338
	completion of a needs assessment for LTNCs	-.757	.426	3.157	1	.076	.469
	Constant	1.376	.307	20.031	1	.000	3.958

Nagelkerke R^2= .137

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Table G.89 Correlations between independent predictor variables

	Pearson Chi-Square	df	Contingency coefficient	Asymp. Sig. (2-sided)	Significance at 5% level
Joint commissioning by cross-sector strategic group	8.819	1	0.226	0.003	S
Joint commissioning by service users involved in commissioning decisions	8.410	1	0.260	0.004	S
Joint commissioning by completed needs assessment	2.438	1	0.143	0.118	NS
Cross-sector strategic group by service users involved in commissioning decisions	8.118	1	0.254	0.004	S
Cross-sector strategic group by completed needs assessment	8.118	1	0.254	0.004	S
Service users involved in commissioning decisions by completed needs assessment	11.444	1	0.297	0.001	S

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