THE UNIVERSITY *of York*

SPRU | Social Policy Research Unit

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.

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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 <u>neurological</u> 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 ☐

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 ❑

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.

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
		❏
		❏
		❏
		❏
		❏

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)
		❑
		❑
		❑
		❑
		❑

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
	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏

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
	❑	❑	❑	❑
	❑	❑	❑	❑
	❑	❑	❑	❑
	❑	❑	❑	❑
	❑	❑	❑	❑

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

Team Name	Yes	No	Don't know
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑

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.

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		❑

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	❑	❑	❑	❑	❑	❑

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	❑	❑	❑	❑

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	❑	❑	❑

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				

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
	❑	❑	❑	❑	❑	❑	❑	❑
	❑	❑	❑	❑	❑	❑	❑	❑
	❑	❑	❑	❑	❑	❑	❑	❑
	❑	❑	❑	❑	❑	❑	❑	❑
	❑	❑	❑	❑	❑	❑	❑	❑

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
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑

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
	❑	❑	❑	❑
	❑	❑	❑	❑
	❑	❑	❑	❑
	❑	❑	❑	❑
	❑	❑	❑	❑
	❑	❑	❑	❑
	❑	❑	❑	❑

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
	❏	❏	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏	❏	❏
	❏	❏	❏	❏	❏	❏	❏	❏

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
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑
	❑	❑	❑

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 ❏

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

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 ☐

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?

_____

_____

_____

_____

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)

_____

_____

_____

_____

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?**

_____

_____

_____

_____

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).

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.

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.