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Research Initiative for **Long Term Neurological Conditions** LTNC

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

Project 08/1610/124

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Glossary of terms/abbreviations

ADMM	Assessment and Disease Management Model
CAF	Common Assessment Framework
CINRT	Community Interdisciplinary Neurological Rehabilitation Team
CHD	Coronary Heart Disease
CNS	Clinical Nurse Specialist
CRD	Centre for Reviews and Dissemination
DH	Department of Health
GP	General Practitioner
HD	Huntington's Disease
IV	Intravenous
JSNA	Joint Strategic Needs Assessment
LA	Local Authority
LAA	Local Area Agreement
LIT	Local Implementation Team
LTC	Long-Term Condition
LTNC	Long-Term Neurological Condition
MDT	Multidisciplinary Team
MND	Motor Neurone Disease
MNDA	Motor Neurone Disease Association
MREC	Multi-site Research Ethics Committee
MS	Multiple Sclerosis
NHS	National Health Service
NS	Nurse Specialist
NSF	National Service Framework
OT	Occupational Therapist
PbR	Payment by Results
PCT	Primary Care Trust
PD	Parkinson's Disease
QOF	Quality and Outcomes Framework
QR	Quality Requirement
RCT	Randomised Controlled Trial
SaLT	Speech and Language Therapist
SAP	Single Assessment Process

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Contribution of authors

Sylvia Bernard (Research Fellow) managed the project, was a member of the rapid systematic review team, undertook data collection at all stages of the project, analysed qualitative and quantitative data and co-wrote the final report.

Fiona Aspinal (Research Fellow) was a member of the rapid systematic review team, undertook data collection at all stages of the project, analysed qualitative data and co-wrote the final report.

Kate Gridley (Research Fellow) was a member of the rapid systematic review team, undertook data collection at all stages of the project, analysed qualitative data and co-wrote the final report.

Gillian Parker (SPRU Director) developed the original proposal, advised on methods and analysis, was a member of the rapid systematic review team, analysed its results and wrote the technical report, and co-wrote the final report.

Executive summary

Background

Many people with long-term neurological conditions (LTNCs) require substantial service support, yet the fragmentation of, and lack of access to, social, psychological, specialist and non-specialist support has been evident for over 20 years. The successful management of LTNCs, in order to enhance health and well-being, needs both sophisticated management across a number of health, social care and other service boundaries, and involvement of people with LTNCs and members of their support networks.

The National Service Framework (NSF) for Long-term Neurological Conditions aimed to 'bring about a structured and systematic approach to delivering treatment and care for people with long-term conditions'. The need for an integrated approach to service provision was made clear, explicitly and implicitly, in all of the NSF's 11 Quality Requirements (QRs).

Aims

The current study aimed to:

a) Identify what helps or hinders integrated services and to identify best models and practice of delivering continuity of care from the perspectives of people with LTNCs, their families or informal carers and the professionals who deliver those services.

b) Develop a benchmarking system, based on these models/practice, to assess the initial impact of the NSF for LTNCs on integrated service provision.

Methods

The research had three main components:

1) A rapid systematic literature review of evidence on best models of integrated service provision for LTNCs and how to achieve these models.

2) In-depth case studies in six neurology 'service systems' to identify the key indicators of good quality, integrated service provision and understand its impact on service users and their families or informal carers. Six areas with different approaches to integration were selected. To enable comparisons of similar and different populations and services, the six cases study areas also reflected geographic and demographic diversity.

Tracking and tracing the processes involved in integration is complex. The main *outcome* we might expect from integration is continuity of care. This concept was used as a framework for our case studies. It can be experienced in different ways and we began by using the definitions developed and elaborated by Freeman and colleagues. Qualitative methods, including telephone and face-to-face interviews, non-participant observation and collection and analysis of local literature were used to explore the experience of continuity of care for people with LTNCs.

3) A benchmarking tool to assess the development of integrated services nationally during implementation of the NSF. We triangulated evidence from the literature review and case studies to develop benchmarks which could assess the type, quality and impact of integrated services in local areas. We then designed a questionnaire using the benchmarks and carried out a national survey.

During the case study phase of our research we interviewed a total of 151 staff from a wide range of statutory and non-statutory organisations across the case study sites. We also interviewed 71 people with LTNCs covering the full range of condition subcategories identified in the NSF for LTNCs. The telephone survey methods used in our national benchmarking survey allowed us to contextualise information and achieve a high completion rate (78%). Evidence from the research overall was strengthened by triangulation of different types of data.

Results

The **literature review** found that the evidence base about a) the impact and costs of integrated models of care for people with LTNCs; and b) the service delivery and organisation elements that need to be in place to make these models operate well, was weak. The choice of outcome measures for many of the studies was limited to the conventional, and measures which addressed issues of personal choice, empowerment, or the experience of continuity of care were largely absent. There was some limited evidence that home-based models of integrated care may reduce health service costs and, possibly, those of service users and their families.

Bringing together the views and experiences of staff and people with LTNCs in our **case study sites**, we identified three models of 'best practice' for integrated service delivery, each of which contributed to the experience of continuity of care. These were:

1. **Nurse specialists**
   o   This model can promote all forms of continuity of care and is highly valued by people with LTNCs, their families and carers, and other professionals and volunteers working with them. Where the model worked most effectively, nurse specialists acted as key-workers, engaging in active care

co-ordination and advocacy to ensure that people with LTNCs could access a broad system of support. With their specialist knowledge and accessibility, they were often people's first port of call, able to answer questions, allay fears and access further support as the need for this arose.

2. **Community interdisciplinary neurological rehabilitation teams (CINRTs)**
   o People in receipt of services from a CINRT (as opposed to lone therapists or hospital services) tended to have improved experiences of continuity of care. Ongoing access to community rehabilitation was important for the people we interviewed to generate improvements, but also to *maintain* physical functioning and psycho-social well-being. The interdisciplinary way that team members worked, undertaking joint assessments and interventions and sharing case information, meant people with LTNCs received a seamless service from a wide range of professionals. Responsive, flexible services were valued most, particularly where interventions could be provided at a time and location convenient for the person with the LTNC and their families or carers. When social workers and health care professionals worked in an integrated way in CINRTs a more holistic approach could be taken and cross-sector boundaries became less problematic.

3. **Day opportunities**
   o Services that offered peer support, social and leisure opportunities, as well as access to meaningful activity and/or learning and employment opportunities were highly valued. These provided a focal point for care co-ordination as well as supporting people to build confidence and enjoy social activities. Those which specialised in meeting the needs of people with a specific LTNC were felt to be particularly valuable. For many people, these services were key to maintaining quality of life and feeling like a valued, valuable member of society.

We also concluded that **care co-ordination** is an element of service provision central to the experience of continuity of care, although this does not constitute a discrete model in itself.

Specialist expertise in LTNCs, or a particular neurological condition, was common to those services valued most by people with LTNCs.

Voluntary sector organisations, particularly those with a focus on specific neurological conditions, were central to the delivery of continuity of care, working hand-in-hand with the above models of service provision.

Timely **access** to valued services, intervention and support was central to the experience of continuity of care. However, it was frequently compromised in a number of ways, including a lack of local availability or capacity of services, restrictive eligibility criteria, referral anomalies and pathways that were ill-defined and unclear to people with LTNCs and professionals.

Results from the **national benchmarking survey** reinforced findings from earlier phases of the research. Nearly half way through the ten-year implementation period of the NSF for LTNCs, only half of Primary Care Trusts (PCTs) had a written action plan for implementation and very few had carried out their plans. The models we had identified as important were found across PCT areas, but there were noteworthy gaps. Data about access to and coverage of models of care and other services endorsed the findings from our case studies that many people with LTNCs struggle to get a service. Among neuro-therapies, neuro-psychology was particularly scarce with referral systems and waiting lists problematic and nearly two-thirds of PCTs describing the service as 'difficult' or 'very difficult' to access. The importance of ongoing access to services for people with LTNCs was a recurring theme in our qualitative interviews. In the benchmarking survey, only 19 percent of PCTs described their neuro-physiotherapy services as 'ongoing'.

Conclusions

Our research suggests that the NSF for LTNCs, coming with no new money and no firm targets, has been largely overtaken by competing policy, organisational and financial priorities that PCTs and other organisations have had to deal with. Nurse specialists, CINRTs and certain types of day opportunities are particularly successful in promoting continuity of care for people with LTNCs, and yet it is clear that many do not have access to these services. Given the long-term and often progressive or fluctuating nature of neurological conditions, the ongoing nature of these and other services is particularly important.
Future research could usefully focus on:

- Appropriate outcome measures and the cost-effectiveness of the 'gold-standard' models of care we identified.

- The impact of the different ways that nurse specialists work.

- The specific experiences of people with LTNCs from different socio-economic and ethnic groups.

- The impact that the failure to access our 'stronger' models of care has on both the person with the LTNC and their families and carers.

- An international comparison of how other countries strive to meet the needs of people with LTNCs.

1.   Introduction

The National Service Framework (NSF) for Long-term Neurological Conditions (LTNCs) was introduced in 2005 and aimed to 'bring about a structured and systematic approach to delivering treatment and care for people with long-term conditions'[1] (LTCs). The need for an integrated approach to service provision was made clear, explicitly and implicitly, in all 11 Quality Requirements (QRs) in this NSF.

Although funded by NIHR SDO, this project was also part of a wider Department of Health (DH) programme of research to support the implementation of the NSF for LTNCs. It aimed to identify what helps or hinders integrated services and to identify best models and practice which seem to work well in delivering continuity of care from the perspectives of people with LTNCs, their families or informal carers and the professionals who deliver those services.

The project included a rapid systematic literature review, in-depth case studies and the development of a benchmarking tool that could be used to assess the development of integrated services nationally during the implementation of the NSF.

This document reports the methods, findings and conclusions from each phase of the research project.

1.1   Background

Most LTNCs have substantial implications for service support, yet the fragmentation of, and lack of access to social, psychological, specialist and non-specialist clinical, and other forms of support has been evident for over 20 years ([2;3;4]). By definition, LTNCs are an ongoing part of people's lives, thus both clinical and non-clinical interventions have to be carefully interwoven with other aspects of those lives. The successful management of LTNCs, in order to enhance health and well-being, needs both sophisticated management across a number of health, social care and other service boundaries as well as *real* involvement of people with LTNCs and members of their support networks.

Successful management also has to recognise diversity of need. Sex, age, and ethnicity might influence what best suits an individual's needs and his or her experience of integration. Similarly, the different types and stages of the LTNC – whether present since birth or early childhood or of later onset, whether slowly or rapidly progressing, whether episodic or continual, and so on – would also be expected to influence needs and experience.

Responses to criticisms of available support have led to the establishment of standards of care for some LTNCs[5] and there have been service initiatives, for example, the development of a specialist role for nursing[6;7]. There have also been general policy initiatives to encourage integrated or joint working within and between health and social care services, and between the care system and people with long-term conditions[8;9;10].

1.1.1 National policy context

Provision of integrated care and arrangements for joint working between health and local authority (LA) services has been at the heart of government policy in recent years. Section 31 of the1999 Health Act[10] formalised arrangements and removed some of the obstacles that had historically hindered joint working. These were consolidated in section 75 of the National Health Service (NHS) Act 2006[11], providing the mechanism by which integration might be more easily delivered.

The 'NHS Plan' in 2000[9] affirmed the government's belief in joint working and was supported by the Health and Social Care Act 2001[12], based on principles of:

- Pooled budgets (partner organisations contribute to a common budget).
- Lead commissioning (one partner organisation commissions integrated services provided by both partners).
- Integrated provision (a single organisation provides health and social care services).

The importance of supporting people with long-term conditions was outlined in the NHS Improvement Plan[13], launched in June 2004. The subsequent Department of Health publication in 2005, 'Supporting People with Long Term Conditions'[14] set out the NHS and social care model for long-term conditions and provided more detail, recommending the appointment of 'community matrons' and disease-specific case management to help smooth the pathways between different service providers. The National Service Framework (NSF) for Long-term Neurological Conditions, also published in 2005[1], aimed to

> bring about a structured and systematic approach to delivering treatment and care for people with long-term conditions[1].

The need for an integrated approach to service provision was made clear, explicitly or implicitly, in all 11 Quality Requirements (QRs) of the NSF:

- Integrated assessment and care planning (QR1).
- Prompt access to specialist expertise (QR2).
- Timely access to emergency and acute health management by teams with appropriate skills (QR3).

- Links between hospital-based and community-based rehabilitation (QR4).

- Ongoing access to a range of services to meet continuing and changing needs (QR5).

- Links to educational and occupational services (QR6).

- Provision of appropriate accommodation and equipment (QR7).

- Joint working between health and social care services to achieve maximum choice for the person with a LTNC (QR8).

- Access to palliative care services (QR9).

- Supporting family and carers (QR10).

- Provision of neurological care during treatment or care for other reasons (QR11).

All these require degrees of integration that seem largely lacking in current service provision (Neurological Alliance, 2001).

Concurrently, the 2005 Green Paper on adult social care 'Independence, well-being and choice'[15] emphasised the need for well-planned and integrated services, the inclusion of all sections of the community, including the NHS, in delivering the new vision for social care, and the ambition of achieving 'person-centred, proactive and seamless' services. Suggestions were made about streamlining assessment between agencies, strengthening joint working between health and social care services, and developing strategic commissioning across *all* partners.

When the subsequent White Paper, 'Our Health, Our Care, Our Say: a new direction for community services'[16] was published in 2006, Government requirements around integration and particularly in relation to support for people with long-term or complex needs were quite specific:

> By 2008 we expect all PCTs and local authorities to have established joint health and social care managed networks and/or teams to support those people with long term conditions who have the most complex needs[16].

The Local Government and Public Involvement in Health Act 2007[17] placed a legal duty on county and unitary authorities, Primary Care Trusts (PCTs) and NHS Trusts to co-operate in the design and delivery of Local Area Agreements (LAAs) with an expectation of joint appointments, pooled budgets and joint commissioning. The 2007 Commissioning Framework for Health and Well-being[18] added a further dimension, placing a duty on PCTs and local authorities to produce a joint strategic needs assessment (JSNA) of the health and social care needs of their populations to inform LAAs and the sustainable communities strategy.

The historical preoccupation with organisational structures has more recently shifted to an emphasis on services promoting integrated care provision,

to enable partners to join together to design and deliver services around the needs of users rather than worrying about the boundaries of their organisations.
'High Quality Care for All: NHS Next Stage Review' 2008[19]

The Integrated Care Pilot programme was one of a number of initiatives seeking to deliver these objectives. It began with 16 sites in April 2009 and was designed to explore the different ways health and social care could respond in an integrated way to address a particular local need[20]. Pilots were selected to reflect different groups and settings and an evaluation of the programme will assess the impact integration of services across health and social care has on improving the health and well-being of local populations.

The NSF for LTNCs has thus been part of a broader strategic framework and wider package of initiatives designed to enable people with long-term conditions to lead as independent lives as possible, but retains a specific neurological focus.

1.2   The need for research

At the time this research was commissioned, although the NSF included an extensive list of quality requirements, there was little information on barriers and facilitators to implementation, or about how to evaluate whether these requirements had been achieved. Policy initiatives and the developing evidence base for integrated care had seen organisational change in older people's and mental health services[21;22;23], but services for people with LTNCs seemed to lag behind[24;25]. This was in spite of the clear messages from people with LTNCs and their organisations that the experience of integrated provision is a very important contributor to quality of life[24].

1.3   The research questions

This study aimed to answer the following research questions:

- How are services for people with LTNCs integrated within the health service and to what effect?
- How are services for people with LTNCs integrated between health, social care and other relevant services (including the independent sector), and to what effect?
- How do people with LTNCs, their families and informal carers experience integration and to what effect?
- How do services deal with diverse needs (both the diversity created by different conditions and different disease progression and that created by the needs of different parts of the population)?

- Which models of service provision seem to work well in delivering continuity of care, from the perspectives of service users, their families or informal carers, and the professionals who deliver them?

- What impact do different types and levels of integration have on continuity of care?

1.4 The conceptual framework

Integration of services can take place across a number of boundaries. This can be between primary, secondary and tertiary health care; between health and social services and other services; between the statutory and non-statutory sectors; between specialist and non-specialist care; between the person with a LTNC (and his/her family or friends) and any element of the service system; between different levels of professionals and care workers, and so on. Tracking and tracing so many different types of integration is complex. However, the main *outcome* we might expect from integration is continuity of care and we used this concept as a framework for this study.

Continuity of care is experienced in different ways. We began by using the definitions developed and elaborated by Freeman and colleagues[26;27]. Based on an initial review of the literature and subsequent fieldwork, their work concluded that a 'minimum definition' of continuity of care should be about the experience of a co-ordinated and smooth progression of care from the service user's (and informal carer's) point of view (**experienced continuity)** and should involve the following components:

- **Relational, personal and therapeutic continuity** - the provision of one or more named, individual professionals with whom the service user (and informal carer) can establish and maintain a consistent therapeutic relationship.

- **Longitudinal continuity** - the provision of one or more named, individual professionals - care provided from as few professionals as possible, consistent with need.

- **Long-term continuity** - the provision of uninterrupted care for as long as the service user requires it.

- **Flexible continuity** - flexibility and adjustment to the needs of the individual over time and in their own personal and social context.

- **Continuity of social context** - sustains a person's preferred social and personal relationships in the community and enhances quality of life.

- **Information continuity** - excellent information transfer following the service user (and informal carer).

- **Cross boundary** - smooth transition between different providers and/or levels of services and how well services communicate between sectors, within sectors, within teams and between services and service user/carer.

These definitions provided us with a way of examining the *effects* of integrated services without necessarily having to trace out every pathway along which integration can or should take place.

1.5 The research process

Service users and other representatives from voluntary organisations were involved in the research not only as participants in interviews, but throughout the research process via the Department of Health long-term neurological conditions research initiative programme advisory group, the specific project advisory group and the SPRU adult consultation group, a standing group of service users and carers. Presentations and progress updates were made to these three groups throughout the project and feedback received. Specific advice on drawing up topic guides, recruitment of participants, analysis and interpretation of findings was sought from the project advisory group and the adult consultation group. The latter also helped identify interviewees for piloting service user topic guides. Questions included in the topic guide were influenced by the adult consultation group and reflected their concerns. Members of this group also helped identify interviewees for piloting service user topic guides.

We aimed to answer our research questions in five phases:
1. A scoping exercise and rapid review of evidence on best models of integrated service provision for LTNCs, how to achieve these models, and their impact on the different types of continuity of care.
2. In-depth case studies in six neurology 'service systems' to identify the key indicators of good quality, integrated service provision and understand its impact on service users and their families or informal carers.
3. Use material from (1) and (2) to develop benchmarks to assess the type, quality and impact of integrated services in local areas.
4. Test and, if necessary, adjust the benchmarks. Develop benchmarks into a questionnaire to be used in phase 5 of the project.
5. Develop a questionnaire using the benchmarks to assess the development of integrated services nationally during initial implementation of the NSF.

Our original intention had been to repeat the benchmarking exercise. This phase of the proposed work was removed from the project after initial discussion with the advisory group to the DH programme (see above).

1.6 Ethical review

The research underwent formal review at a number of stages. For the case study work (phase 2), the research was initially reviewed and approved by the University of

York's Humanities and Social Science Ethics Committee and was then reviewed and approved by Multi-site Research Ethics Committee (MREC) for Wales.[1] Ethical review was undertaken by MREC for Wales for the national benchmarking of services (phases 4-5) and was deemed to be audit rather than research[28]. Research Governance was sought from and agreed by PCTs, acute trusts and LAs at all case study sites prior to phase 2.

1.7   Scoping exercise

The initial scoping phase of the project took place in parallel with the rapid systematic literature review between November 2006 and summer 2007. It aimed to gather information about what was currently known about the best ways to achieve and deliver integrated services for people with LTNCs, drawing on the experiences of people with LTNCs, their organisations and the professionals who work with them.

We reviewed the information provided about evaluated examples of good practice included in the NSF Good Practice Guide[29] and, where necessary, contacted those providing the service. We also spoke to leads for long-term conditions at Strategic Health Authorities (SHAs) in England.

We obtained an overview of the structures in which the NSF for LTNCs was being implemented and explored people's views on the working of the NSF in their region. We also gained some understanding of the position of the NSF for LTNCs in the context of other policy from the perspective of professionals. Views on policy that were identified during this scoping phase were discussed in a published paper[30]. Findings about levels of integration across SHAs are presented in Appendix A and helped inform our sampling frame for case study sites for phase 2 (as described in Chapter 3).

Throughout the scoping phase, it became clear that there were many different approaches to integration at a local level, which might 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 next stage of case study investigations.

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[1] MREC for Wales was the MREC with the first available meeting when the application was submitting via the Co-REC system and does not necessarily reflect the location of case sites.

1.8 Structure of report

The structure of this report reflects the iterative research process adopted. It is organised into nine chapters as follows:

Chapter 1 provides the introduction to the research. It presents an overview of the study area and explains why the research is important. The introduction outlines the research context, research questions and the methods used for data collection.

Chapter 2 gives a summary of the findings of the rapid systematic literature review. It reports existing evidence on models of 'best practice' of integrated service provision and their impact on continuity of care for people with LTNCs. A full description of the methods used is in a supplementary technical report[31].

Chapters 3-6 present the case studies methods and findings. **Chapter 3** explains how case study sites and participants (staff and people with LTNCs) were selected and recruited, and describes the methods used to collect data about models and integration of services in each of the case study sites. **Chapter 4** reports findings from staff data about the implementation of the NSF for LTNCs and progress towards joint working. Cross-case comparison of data allowed factors that facilitate or hinder joint working to be identified and these are also reported here. **Chapter 5** draws service user data from across the six case study sites together using Freeman's continuity of care conceptual framework. **Chapter 6** reports three key service models that our analysis shows promote continuity of care for people with LTNCs, and also highlights elements of service provision central to the experience of continuity of care.

Chapter 7 describes how a benchmarking tool for PCTs was developed based on the findings presented in Chapters 4-6. The methods used for conducting a national survey of PCTs and analysing the subsequent data are reported. The findings from the national survey are also presented.

Chapter 8 concludes the report with a summary of the conceptual and empirical contribution made and presents a schematic model of continuity of care. An assessment of the limitations of the research and recommendations for future research in this area are presented. The implications of this research for policy are also discussed.

2. Rapid review of the evidence on integrated care models for people with long-term neurological conditions

A 'rapid' review of evidence about the outcomes of models of integrated care for people with long-term neurological conditions (LTNCs) was proposed as the first phase of the project described here. A full report of the review, its methods and findings is available as a technical appendix to this report[31]. Here, we include only summary details of the review.

2.1 Objectives

The first objective was to identify models of integrated service provision for people with LTNCs from the research literature and to evaluate their impact on different types of continuity of care and other outcomes. The second objective was to understand what the evaluative and descriptive research literature suggested about how best to achieve models of integrated care that delivered continuity.

2.2 Methods

A 'rapid' review searches systematically but not necessarily exhaustively for available evidence, critically appraises studies and sifts out those that are 'of poor quality'. The material is then used to collate descriptive outlines of the evidence, provide an overview of it and what it says[32]. We divided the work on our review into two parts. In the first, we dealt with the evaluative literature, and messages about the outcomes that models of integrated care could deliver. In the second part, we analysed descriptions of models of integrated care included in both the evaluative literature reviewed in the first part and in the wider descriptive literature. This second part reviewed evidence on how integrated models of care operated, who worked in them, what elements of service provision they included, and what types of continuity they appeared to deliver. Here and in the technical report, we call these two different approaches the 'evaluative review' and the 'descriptive review'.

Full details of our main search strategy, including the electronic databases searched, the keyword strategy, search restrictions, additional searching strategies, inclusion and exclusion criteria and how these were developed, the selection of material for review, data extraction and quality assessment are all included in the technical report. Overall, we followed the Centre for Reviews and Dissemination (CRD) guidance for systematic reviews[33] in all elements of both reviews, working together

as a team to develop common understandings and checking our decision making throughout.

2.3 Analysis and outcomes

The evaluative review presented a narrative synthesis of quantitative findings from the primary studies reviewed. The outcomes reported were: access to and use of services; service users' views of the model of care; disability and impairment; quality of life; clinical outcomes; mental health outcomes; hospital admission and length of stay; impact on family or carers; expressed need; knowledge of the condition; communication; costs to the health service; costs to service users and families; socio-economic outcomes; staff views about the model of care; coping or stress; and mortality.

The descriptive review converted text statements from publications that described models of integrated care into two categories – 'clearly present in the description' and 'not clearly present in the description'. These data were then subject to simple frequency analysis and cross-tabulation by model of care. The main issues covered were: What is the model of care? Where is it delivered? What conditions does it cover? Who delivers it? What service elements are included? What type of continuity of care does it deliver? For this last question, we used the Freeman et al[26;27] model as our starting point.

2.4 Included studies

Two thousand four hundred and seven publications were identified in the searching, 573 of which were initially selected as of potential relevance.

Of these, 49 separate studies, covering 47 models of care and reported in 68 publications were eventually included in the **evaluative review**. Fourteen randomised controlled trials (RCTs) and one pseudo-randomised study were included, alongside 14 other studies using a comparative design of some type. There were also four studies based on surveys, nine based on audit or retrospective record review and five based on 'other' designs. The majority of studies (33), 12 of which were RCTs, had been carried out in the UK. Most studies were about epilepsy (15), Multiple Sclerosis (MS) (14) or Parkinson's Disease (PD) (11).

One hundred and twenty-seven descriptions of models of care, including the 47 models included in the evaluative review, were included in the **descriptive review**. The majority of descriptions were about models of care for MS (41), epilepsy (36) or Parkinson's Disease (36).

2.5 Findings of the evaluative review

Table 1 summarises the findings from the evaluative review, reported in full detail in the technical appendix. As the table shows, there is little conclusive or consistent evidence of positive or negative impact on the service user or family outcomes reported in the evaluative research we reviewed. However, there is some limited evidence that home-based models of integrated care may reduce health service costs and, possibly, those of service users and their families as well. However, there is a substantial research agenda here, with few existing studies reporting these economic outcomes.

Table 2.1   Summary findings from studies included in evaluative review

Outcome	Number of studies reporting	Overall findings
Use of or contact with services	21	No consistent evidence about improved access to or use of services
Service users' view of model of care	18	Service users value new models of care but with little comparative information it is difficult to know whether this reflects gratitude for any service
Disability/impairment	17	Half of RCTs showed significant improvement, others did not. Evidence from other types of studies inconsistent.
Quality of life	15	Little secure evidence of positive impact on QoL for any model evaluated
Clinical outcomes	15	Inconsistent evidence
Mental health	11	Small but not statistically significant improvements in depression
Impact on family and/or carers	8	Specialist palliative care services for people with MS may improve care outcomes (1 RCT only), no evidence of positive impact from any other study or model
Costs to health services	8	Some limited evidence of reduced costs for home-based services. No adequate research re: nurse specialists or multidisciplinary teams
Hospital admission	6	Small but promising reductions in admission/length of stay,

Outcome	Number of studies reporting	Overall findings
		particularly for multidisciplinary care. Needs further research.
Communication in team or with patient	5	No conclusive evidence and lack of comparative data.
Patient or carer expressed need	4	Evidence of benefit is unclear
Knowledge of condition	4	Some evidence from single study of epilepsy that those with low levels of initial knowledge benefit from nurse specialist input.
Socio-economic outcome e.g. education, employment	3	No controlled studies.
Staff views of model of care	3	Positive views in all three studies. Integrated care systems and user-led care pathway said by staff to improve joint working, information exchange, and personalisation of care
Mortality	3	One study of multidisciplinary specialist clinic for motor neurone disease suggests improvement in mortality over general neurological care. No evidence of impact in other studies.
Costs to service users or families	2	One study only provided comparative data. Home-based IV may be less costly for service users and families.
Coping or stress	1	No evidence of impact.

The lack of evidence of impact from these studies does not mean that there is no impact to be found. Many studies were of relatively poor methodological quality and, where of better quality, too small to demonstrate impact. Further, the choice of outcome measures for many of the studies was limited to the conventional. Given the nature of many of the conditions studied here, looking for differences in clinical or impairment outcomes is probably always going to be relatively fruitless although, when the research is of high quality and large enough, lack of difference can mean that the new model produces similar outcomes to usual care. By contrast, outcomes that might have real meaning to service users were largely notable by their absence. For example, while two studies showed that professionals felt that integrated care models increased the active participation of service users in their care, or increased their empowerment, no study seems to have asked service users themselves about these important types of outcome!

2.6 Findings of the descriptive review

Three main models of integrated care were identified in the descriptive review – multidisciplinary teams or clinics (MDTs), clinical nurse specialists (CNSs) and assessment and disease management models (ADMMs). Some were delivered as a single approach, others in combination with another model or aspect of integrated care. In total, 41 descriptions involved MDTs, 20 CNSs, and 29 assessment and disease management initiatives. There were 32 separate 'other' models of care, ranging from a rapid response team for administering intravenous (IV) therapy at home, to a specialist transition clinic for young people moving onto adult services. The three main models were used to analyse the descriptive material, thus allowing us to compare and contrast different ways of delivering integrated care.
The descriptive literature was dominated by UK publications, given that this was the main focus of the descriptive review (see technical report).

2.6.1 Multidisciplinary teams or clinics

The 41 descriptions and evaluations of MDTs showed that they were most often based in hospital (in-patient and out-patient) settings. However, 12 of the described teams also delivered care in service users' own homes. MDTs were significantly more likely to be associated with care for people with motor neurone disease (MND) or MS than were other models of care, and less likely to be associated with epilepsy. Although reporting of which staff were involved in MDTs and how many was variable across the descriptions, as one might expect, MDTs were more likely to include certain types of professionals than were other models of care. All types of therapists, psychologists, social workers, and care co-ordinators or care managers were significantly more likely to be mentioned in publications about MDTs than in those about other models. However, while rehabilitation medicine specialists were also significantly more likely to be mentioned, MDTs were no more or less likely to include neurologists. Over two-thirds of the described MDTs involved at least six different types of professional staff and, again, this was significantly different (higher) than in other models of care.

Despite these differences, the service elements described as part of MDTs[2] were not very different from those described in other models of care. MDTs were more likely to

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[2] These covered diagnosis; assessment of condition, disability and impairment, service need, nursing need and other; patient-held care file; professional-held care file; patient-held care plan; professional-held care plan; care or service co-ordination; care management; drug or medication review; equipment or aids supply; goal setting; information, education or training for carer; information, education or training for patient; information, education or training for professionals; monitoring and review; multidisciplinary meeting or consultation; other clinical care; palliative care; advice/contact/help line; rehabilitation care; specialist clinics; carers' support group; patients' support group; telemedicine; and counselling care.

be reported as providing diagnosis, rehabilitation input, assessment of disability or impairment, and palliative care, and to involve multidisciplinary meetings or consultation. By contrast, the descriptions were less likely than those for other models of care to refer to providing information, education or training for professionals. Beyond these differences, the service elements involved were similar to those provided in the other models of care.

The descriptions of MDTs were significantly more likely to suggest that they provided cross-boundary or team continuity (as would be expected) and longitudinal continuity (care provided from as few professionals as possible, over time, consistent with need). However, the descriptions were less likely to suggest that MDTs provided any of the other types of continuity in the Freeman model although with the exception of information continuity, the differences were not at a level that reached statistical significance.

2.6.2 Clinical nurse specialists (CNSs)

We included 30 descriptions or evaluations of CNSs, either as a stand-alone model or in combination with some other aspect of care. Clinical nurse specialists were no more or less likely than other models of care to be based in hospital (in-patient or out-patient) or community health settings. However, they were significantly less likely than other models to be working in patients' own homes. CNSs were significantly more likely to be described in relation to Parkinson's Disease, and less likely in relation to MND or MS, than were other models of care.

CNSs are, by definition, uni-disciplinary so it is not surprising to find that the descriptive literature reflects this, referring less often to working in teams involving neurologists, therapy professionals, psychologists and social workers. This does not mean that CNSs do not work with other professionals or as members of wider teams, rather that the descriptive literature tends to concentrate on their clinical role, rather than their place in a multi-professional context. However, some CNSs, and particularly those in primary care, were effectively lone workers, albeit that they might be providing out-reach from or in-reach to a hospital-based neurology service.

Despite their uni-professional and often solitary role, the descriptions of CNSs suggest that they were no less likely than other models of care to provide a wide range of elements of care (see footnote 2). No CNS services involved diagnostic services, as one might expect, but they were significantly more likely than other models of care to be involved in providing advice, contact or a help-line service.

There were clear differences in the types of continuity of care that the descriptions of CNSs included, compared to other models of care, with aspects of relational,

personal and therapeutic continuity, and flexible continuity referred to significantly more often.

2.6.3 Assessment and disease management models of care

There were 29 descriptions or evaluations of ADMMs in the descriptive review. These were no more or less likely than other models to be delivered in hospital (in-patient and out-patient), community health settings or service users' own homes. They were slightly different from other models in that the condition focus of the largest group was epilepsy (12), though followed by MS (10) and Parkinson's Disease (6). ADMMs were also significantly more likely than other models to report a focus on general or 'all and any' neurological conditions and less likely to focus on Motor Neurone Disease.

Neurologists were more likely to be part of the staffing of ADMMs, compared to other models but there were few other differences in the types of staff involved. They were as likely as other models of care to be uni- or multi-professional; most teams involved between two and five different types of professional.

ADMMs were more likely to provide diagnosis and to assess service users' condition, but there were few other differences in the elements of care provided (see footnote 2).

With the relatively small numbers of ADMMs included in the review, identifying any significant differences in the types of continuity described was difficult. However, of the four descriptions that clearly outlined experienced continuity of care, three were of ADMMs and this difference did reach statistical significance. Other indicative, though not significant differences, included more descriptions of flexible continuity and of cross-boundary or team continuity. By contrast, relational, personal or therapeutic continuity was less often described.

2.6.4 Aspects of service delivery and organisation

Reporting of aspects of service delivery and organisation – such as referral and access routes, exclusion criteria, and funding – was rare in both the descriptive and evaluative accounts that we included in the descriptive review. We therefore did not carry out any further analysis of this material.

2.7   Conclusions

Our overall conclusion from this element of the project is that the evidence base, about both the impact and costs of integrated models of care for people with LTNCs and about the service delivery and organisation elements that need to be in place to

make these models operate well, is weak. The evaluative literature is characterised by relatively poor quality research, regardless of its design, while the descriptive literature is variable in what it describes about how these models of care work in practice. Further, there is little sense in the evaluative research that outcomes that would be valued by service users and their families have informed the choice of outcome measures in the evaluations. Issues of personal choice, empowerment and, indeed, the experience of continuity of care (in any of its guises) are largely absent.

3. Case study methods

As outlined in Chapter 1, the second phase of our study was six case studies of neurology 'service systems'. In this chapter we outline the methods we used for these case studies and the sites we included.

3.1 Rationale for case study design

For this phase of the research, in-depth case studies were undertaken in six PCT areas and included associated local authorities, NHS Trusts and other relevant agencies (i.e. a service system[3]). Bowling[34] states that the case study approach 'focuses on the circumstances, dynamics and complexity of a single case or a small number of cases' (p.403). As Yin[35] notes, it is particularly useful when the study aims to investigate 'a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident' (p.13) for example, in circumstances where the relationship between organisational structure or approaches to practice, and outcomes for people using those services, are unclear. It is distinguished from other methods, such as experiments, in that it does not attempt to control or exclude variables. Instead, it is a holistic approach that enables the complex nature of an issue to be explored[34]. The case study approach, therefore, enables understanding of the actions within and interactions between complex social situations[35]. Multiple case studies enable increased generalisability of research data to other situations and contexts[35].

Although using a case study design does not necessarily exclude quantitative methods, qualitative methods were used here because of the broad nature of this research. Gaining an understanding of the service systems for people with long-term and complex conditions, where people may have formal support from multiple statutory and non-statutory agencies as well as more informal support from family and friends, and where service use may change over time, can lead to complex interactions and relationships. These types of phenomena, linked with the complexity, are best understood using qualitative techniques.

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[3] Service system is used to refer to all the services in the area covered by the PCT that make up services for people with LTNCs, including for example, statutory and voluntary services.

3.2 Research methods

The methods used during the case study phase of the research were qualitative and included telephone and face-to-face interviews; non-participant observation and collection and analysis of local literature.

3.2.1 Collection of documentary evidence

We wanted to learn about local official strategy and policy, service maps (current and historical) and statistical information that described the way in which the services were structured within the locale. We collected and analysed local documentary information to help with this. Documentary analysis is widely used in social research[36] and also in health research[34]. We were interested in the content of these reports, rather than with what Prior[36] suggests is the common focus of documentary analysis; how the document is written or used. This is because documentary evidence was used to provide an understanding of the service context in which services for people with LTNCs were being developed and provided and the local context in which people with LTNCs lived.

3.2.2 Non-participant observation

Non-participant observation is a classic method that has been used extensively and is particularly useful for organisational analysis and evaluation[34]. It comprises observation of behaviour, actions, activities and interactions to inform understanding of complex situations and interactions[34]. As indicated above, the complexity of the systems being researched for this study, made this approach particularly useful. Furthermore, non-participant observation is, by its nature, context specific[37]. Given that we were interested in understanding the local context (see above) and how this related to the national policy context, non-participant observation of meetings that focused on LTNCs were expected to provide interesting insight into these issues.

While some limitations may be associated with this approach, namely observer bias and the Hawthorne effect (whereby the observed changes in some way simply as a result of being observed) we were able to reduce the impact of these limitations by using multiple methods of data collection and triangulating data from each of the methods.

The purpose of these observations in this study was to establish who was involved in decisions made about service development for people with LTNCs and what was achieved in terms of integrated working and outcomes.

3.2.3 In-depth qualitative interviews

Qualitative interviews look below superficial and readily observable phenomena, allowing deep exploration of the study area. Interviews can elicit data able to inform understanding of deep issues, such as motivations for behaviour and relationships between people and services and between events[34][37] and can enable clarification of complex issues. They were, therefore, a particularly useful research method for this study.

Interviews can be structured, semi-structured or open. For the purposes of this study open interviews were used. Open interviews are particularly useful for investigating areas where little is known and, as such were, particularly suited for this study where much complexity exists and there is minimal understanding about the interactions between policies, services, professionals and those using the service.

Open interviews use a topic guide rather than pre-set questions. The topic guide acts as an aide memoire for the researcher to ensure that certain relevant topics of interest are addressed, however, participants are encouraged to provide a personal narrative about the issue being studied. This results in data reporting personal experience of the issue being explored. Open interviews thus enabled each member of staff to describe commissioning, developing and/or providing services and support to help us understand, from their perspective, the issues that facilitated or hindered integrated working and that affected implementation of the NSF for LTNCs. People with LTNCs were enabled to 'tell their story' about how they experienced their condition, service use, and social and cultural issues affecting them.

One of the limitations linked with this method is subject bias. This can be introduced when the person being interviewed cannot remember situations correctly, where they may have limited knowledge about a situation, or where they frame situations within their own interpretation. This was not a particular problem for this research because we were interested in hearing about people's experiences and their interpretation of the context in which they worked and/or lived. However, to counter any limitations of the subjective experience, data from other data collection methods were triangulated with interview data. In addition a wide range of people was interviewed (see below) within and across case study sites. Different levels of staff working within relevant organisations were interviewed as were service users with different conditions and different needs, thus building a more complete picture of service systems in the case study sites.

3.3 Selection and recruitment of case study sites

3.3.1 Selection of case study sites

In the proposal for this study we stated that our case study areas would consist of three areas identified during the first phase of our work as operating good integrated services alongside three others that seemed to operate more basic models.

Through the initial scoping in phase 1, however, we discovered that this criterion of more and less well developed integration did not reflect the realities of health and social care integration in England at the time. In several areas we found formal integration of *some elements* of front line or back office services, but quite separate working arrangements in others. An area might have a strong model of integrated service commissioning for older people, for example, but this may not have been applied to commissioning for people with LTNCs. Alternatively, there might be an integrated team of front-line health and social care professionals, but no joint working at a higher strategic level. Some areas had implemented only minimal levels of formal integration, but operated very strong partnerships and joint working arrangements. In other areas, PCTs and local authorities were formally integrated, but still operated very separate health and social care services on the ground. As a result, it was not possible simply to select three case study sites demonstrating good integration and three more basic models. Instead, we selected six areas with different approaches to integration and joint working which could help to demonstrate the breadth of different approaches in operation.

To enable comparisons of similar and different populations and services, selection of the six cases study areas was also made based on the following criteria:

- Geographic diversity – urban/rural mix, size of the PCT and population density.
- Demographic diversity - deprivation ranking and ethnic diversity within the population.

3.3.2 Approaching and recruiting case study sites

Based on these factors, we shortlisted 14 PCTs. We contacted the relevant commissioners in each of the PCTs, sending them the research proposal and the protocol so that they knew what the research was about and what being a case study site would entail. We spoke with commissioners in each of the area to discuss the research, clarify any point and answer any questions. After discussing the research with colleagues within the PCT and service system, six PCTs agreed to be case study sites. These sites are described in Table 3.1. The demographic information contained in the appendix reports local organisational documents and national statistics (Appendix C).

To ensure that these data did not identify case study sites we rounded population sizes to the nearest 10,000 and we did not report the site's specific Index of Multiple Deprivation (IMD) ranking. Instead, we broke the rankings into quintiles. There were 354 Boroughs that were ranked between 1 and 354, where 1 was the most deprived and 354 the least deprived. Figure 3.1 below shows how we ascribed the labels reported in the summary table. We reported ethnic diversity as described in local documentation and as summarised in the case study sites' public health reports (see Appendix C).

Figure 3.1   Labels for IMD rankings

IMD ranking	1-70	71-141	142-212	213-283	284-354
Label	Very high	High	Average	Low	Very low

Table 3.1   Summary of case study sites

Case study site A Small urban PCT Population: 170,000 Ethnic diversity: above average Deprivation rank: high	**Case study site B** Large rural PCT Population: 600,000 Ethnic diversity: low Deprivation rank: high
Case study site C Small London PCT Population: 210, 000 Ethnic diversity: very high Deprivation rank: very high	**Case study site D** Large metropolitan PCT Population: 720,000 Ethnic diversity: below average Deprivation rank: high
Case study site E Large rural PCT Population: 570,000 Ethnic diversity: low Deprivation rank: average	**Case study site F** Small metropolitan PCT Population: 210,000 Ethnic diversity: average Deprivation rank: very high

For further information about the organisational and socio-demographic profile of the case study sites see Appendix C.

Before participants were contacted and data collection began in any of the case study sites, ethical approval (via MREC for Wales) and research governance in each of the case study sites was granted.

3.4 Sample recruitment

We sought to interview people working in the service system for people with LTNCs and people with LTNCs themselves. This was to gain an insight into the numerous and different perspectives of people who were part of, or who used, the service system. Thus, we recruited people with a LTNC and members of staff working at different levels across the service system.

3.4.1 Link person

Once PCTs had agreed to participate in the research and the relevant research approvals were granted, a key person in each of the case study areas, who had a central role in the commissioning, development and/or management of services for people with LTNCs, was contacted.

They were asked to advise and direct us to other key people in the organisation, relevant meetings, other relevant organisations working with them to commission or provide support to people with LTNCs, relevant local organisational and policy literature, and information on service structure. This work was conducted via electronic and/or telephone contact prior to making any visits to the case study areas. Throughout the fieldwork in each case study area, this link contact represented the first port of call if additional information was needed. These link contacts were also invited to take part in a formal interview.

3.4.2 Organisational staff

Based on information provided by the link person we began to contact chairs of relevant meetings in the PCT and individual members of staff from different parts of the service system. All staff invited to participate were over 18, able to give informed consent, and had a standard of English that enabled them to participate in an interview.

3.4.2.1 Observations of meetings

The link contacts identified meetings where issues of relevance to services for people with LTNCs were to be discussed. The chair of the meeting was approached by letter informing them what participation in the research would involve, including the methods of data recording (field-notes and audio-recording) and inviting them to participate in the study. They were asked to inform the other members of the group (and to forward the information sheet and response form) about our study and seek their agreement for us to observe the meeting. Once participation was agreed, the researcher attended the meeting and, prior to observation, asked *all* attendees to sign a consent form (a copy of the consent form was given to all participants for their records). Attendees were also informed about the interviews taking place and asked

to approach/contact the researcher to discuss these further or to arrange an interview if they wished.

These meetings, relevant to services for people with LTNCs, did not necessarily convene regularly. We attended at least one meeting around service development and planning in each of the case study sites, but in most sites (A, B, C, D, E) we attended multiple meetings and remained on the mailing list for that group throughout the period of data collection.

3.4.2.2   Interviews with organisational staff

Key people in the service system were contacted by letter (electronic or post, depending on contact details provided) other than those staff identified through the observed meetings. All were sent an information sheet and response form and asked to return the response form indicating whether or not they wished to take part in an interview. If they did not wish to take part they were given the opportunity to provide a reason, but assured that this was entirely voluntary. Any reasons for not taking part were recorded. By using the response form we were able to avoid re-contacting people who did not wish to take part. Reminder emails/letters were sent three weeks after the first invitation letter and two weeks after the first reminder if responses had not been received. If no response was received after the two reminders had been sent, the person was not contacted again.

If a response form was received indicating that a member of staff wished to participate in an interview, they were contacted by telephone or electronic mail to clarify any issues, answer any questions and arrange a time for interview. The interviews were conducted over the telephone or in person, depending on the preference of the interviewee. If conducted over the telephone, they were sent a consent form to complete and return to the researcher by post. The researcher signed the consent form, took a copy and returned it to the participant. When conducting face-to-face interviews, the consent form was completed in duplicate prior to the interview commencing and a copy given to the participant. At the end of interviews, staff participants were asked to identify other organisations and staff within the system, until a full range of staff was identified. Staff members were also asked to pass on invitation packs to people with LTNCs who fulfilled our eligibility criteria. Some, due to the nature of their work, were not able to pass on invitation packs and others offered to pass on invitations to several people with LTNCs.

As the number and designation of people involved in each service system differed depending on service structures, a snowball sampling method was used. Interviews continued until data saturation was achieved; that is, until a comprehensive overview of services was given and interviewers were no longer identifying new issues.

We recruited and interviewed a range of staff from across the service system representing different levels in statutory and non-statutory organisations. Table 3.2 shows the number and role of people we interviewed.

Table 3.2   Organisational staff interviewed across six case study sites

Designation	Organisational staff interviewed
PCT Commissioner	13
Health care senior manager	12
Health service manager	8
Nurse Specialist	21
Consultant	13
Other clinical professional	19
Social care senior manager	4
Social care manager	12
Social care practitioner	7
Independent sector service manager	6
Voluntary sector representative	33
General Practitioner	3
Total	151

3.4.2.3   Challenges recruiting organisational staff

We gave staff members the opportunity to participate in either a telephone or a face-to-face interview so that they could fit the interview into their schedules and we were, therefore, able to recruit many staff working in service development or provision for people with LTNCs. However, some people did not have time to take part in this research. Across all case study sites, we invited 188 organisational staff members to participate in an interview and as the table above shows 151 agreed to take part in an interview.

3.4.3 Service users - people with LTNCs

We aimed to recruit service users from each of the four trajectories identified in the NSF for LTNCs (sudden-onset conditions; intermittent and unpredictable conditions; progressive conditions; and stable neurological conditions but with changing need due to development or aging,[1]. We also used a range of organisational sources for recruitment, so that we were able to identify the key issues for people with different types of need and different service use.

Service users were excluded from the study only if they were under 18 years of age, or they had cognitive impairments (as assessed by a health care professional using their usual assessment procedures) because we were concerned that we would be unable to assess whether consent was informed. Service users were identified, in line with these criteria, and given an invitation pack by the professional or service that identified them. The invitation pack comprised an introductory letter and information sheet explaining the research and what taking part would entail. Services kept a record of who packs were sent to (so that they could send reminder packs if the research team informed them that no response had yet been received) but they were never told whether the responses received were refusals or requests to be contacted. Thus, the services and professionals involved in recruitment did not know which service users chose to take part in the research.

Service users were asked to complete and return (to the research team) the enclosed response form indicating whether or not they wanted to be contacted about taking part in an interview and, if they did, a brief demographic form (see Appendix B.4 and below). The process for returning the response form and sending reminder letters followed that described above for staff interviews. Those indicating that they wanted to be contacted by the research team were either telephoned or emailed (depending on their preference) to clarify any issues, answer any questions, and arrange a time for interview. Face-to-face or telephone interviews were conducted (again, depending on participant's preferences). Consent followed the same procedures as those outlined above for staff interviews.

At interview, people with LTNCs were asked to identify all agencies or support services they used that were relevant to the study. Where such services had not yet been identified by the research, they were contacted and invited to be involved in the study following the processes described above.

We did not pre-specify an optimum sample number as we were interested in breadth of experience, as is appropriate in qualitative research, rather than statistical representativeness. To help the research team to attain this breadth of experience we asked people with LTNCs to complete a short demographic form prior to interview (see section 3.5) and we used these data to help inform recruitment. We asked staff to direct invitation packs to people with, for example, particular conditions and from BME backgrounds. We continued to recruit until we achieved data saturation.

Table 3.3 below reports the number of people interviewed and their neurological condition.

Table 3.3   Service users interviewed across six case study sites

Condition	Service users interviewed
Parkinson's Disease	12
Multiple Sclerosis	19
Motor Neurone Disease	8
Brain injury	12
Spinal injury	4
Epilepsy	4
Neuro-muscular conditions	3
Multiple neurological conditions	4
Other	5
Total	71

3.4.3.1   Challenges recruiting service users

In all, 188 invitation packs were given to organisational staff to be passed onto people with LTNCS. However, staff were not always able to forward packs within the timescales of the project. While accessing service users through services is clearly useful to prevent breaches of data protection legislation, given the workload and limited time available to staff, this method of recruitment could be problematic.

In most case study areas we were able to recruit people with LTNCs with little trouble. However, in one area we recruited only six service users to the study although many of the staff seemed keen to be involved. This was despite giving more than 40 service user invitation packs to staff in various statutory and non-statutory organisations and frequent liaison with them to ensure initial and reminder packs were sent out.

While we could advise staff, based on the demographic data we collected, to whom to direct invitation packs, we had no real influence over this and so had no control over our service user sample. Though we encouraged staff to send invitation packs to people of a particular age or ethnicity, we had little control over whether or not this occurred and this may have affected the diversity of our samples.

3.4.4 Consent

All potential participants were given information detailing the aims of the study and how the information they provided would be used. They were given time (at least 24 hours) to consider their involvement and ask questions before deciding whether to participate. The participant information sheet (see Appendix B.2) stressed that participation was voluntary and that the participant could withdraw at any time. This

was reinforced on the consent form participants signed and was repeated verbally before interviews began. Participants were informed in the information sheet and reminded at interview that the information they provided would be kept confidential and anonymous. Copies of the information sheet and consent form were given to participants for their records.

For service users who had impairments that made it difficult for them to read paperwork or sign the consent form by hand, documents were made available electronically or discussed with them verbally. Electronic consent was accepted from people with an LTNC where researchers could confirm that participants had understood the purpose of the study and what participating in the research would entail, and this was confirmed in person on the day of the interview. In cases where communication difficulties made written or electronic informed consent difficult to obtain, informed verbal consent was accepted.

3.5   Data collection

Data collection took place between November 2007 and May 2008 across the six case study sites.

3.5.1   Documentary evidence

Desk research was conducted prior to visits to case study areas and during interviews staff members identified additional relevant local literature. Key documents, including local official strategic and policy documents, previous service maps and statistical information that described the way in which the services were structured within the locale, were collected via telephone and email correspondence with the link person. Information that was available publicly about the local policy context, organisational structures, services available and expenditure was also collected at this initial stage. Throughout the fieldwork period new and additional documentary evidence was collected as we learnt about it.

3.5.2   Non-participant observation

Non-participant observation was conducted at Local Implementation Team (LIT) meetings and other strategic planning or commissioning meetings that focused on services for people with LTNCs. With all participants' consent, these meetings were audio-recorded and field-notes taken as appropriate. Throughout the data collection period, meeting documents, such as agendas, minutes and documents for discussion were sent to the researchers. This ensured that researchers were up to date with service development decisions even if they were unable to attend and observe the meeting.

3.5.3 Interviews

3.5.3.1 Demographic information

All participants were asked to provide some information about themselves to give context to their narratives. Staff were asked about their roles and background during the interview, but service users were asked to provide some demographic information and details of any communication needs prior to interview. This allowed us to focus service user interviews, often with people who became fatigued quickly, on collecting qualitative views and opinions, rather than gathering basic descriptive information. These data gave a general description of our interviewees and also helped to inform recruitment (see section 3.4.3).

3.5.3.2 Interviews with organisational staff

Telephone or face-to-face interviews (depending on the preference of the participant) were held with staff from all parts of the service system (statutory and non-statutory – see Table 3) to inform understanding of issues that facilitated or hindered integrated working and that had affected implementation of the NSF for LTNCs.

These interviews elicited views on:

- Organisational structure and aims (generally, and in relation to the NSF for LTNCs).
- Progress towards implementation of the NSF for LTNCs (and reasons for this).
- Current and planned service landscapes.
- Integration strategy and outcomes.
- Facilitators and barriers to integration.
- Suggestions for promoting service and/or organisational integration.

The topic guide for these interviews is in Appendix B.9.

The interviews took approximately an hour and were audio-recorded where the participant consented to this. Where participants did not consent to audio-recording of the interview but wished to take part, detailed field-notes were taken.

3.5.3.3 Interviews with service users

Face-to-face or telephone interviews (depending on their preference) were held with people with LTNCs to gain an understanding of their views and experiences of the service system. The timing and location of interviews was arranged around the preference of the interviewee. In general, people with LTNCs preferred face-to-face interviews to be conducted in their home but some people requested that the interview be held in a different location, such as a day opportunity centre. These interviews elicited views on how the local system suited their needs and explored experiences of service use based around the different aspects of continuity of care.

Interviewees were encouraged to make suggestions about things that might improve their experience of continuity of care. The topic guide for these interviews is in Appendix B.7).

To ensure we gained some understanding of how people with diverse and complex needs were affected by provision, no-one was excluded on the basis of language or other communication limitations. Where someone had communication difficulties and was able to communicate using information and communication technologies, interviews were administered and/or answered via computer or other specialist equipment. Where this was not practicable, the service user chose an assistant, usually an informal carer, to translate for them. Where language translation was needed, we arranged appropriate translation services.

We decided not to undertake interviews with carers because a sister project in the Department of Health LTNCs research programme was already focusing specifically on the experiences of carers. However, some service users requested that their carer be present when they were being interviewed. Carers would sometimes clarify points or answer some questions as the service user desired; thus, some joint accounts of service provision were collected as part of the service user interviews.

As with staff interviews, service user interviews were audio-recorded with the consent of the participant and were transcribed in preparation for analysis.

3.6   Analysis

Data were analysed by case study area in the first instance to produce service system mapping in each site. Thematic analysis of primary (interview) data was conducted using the Framework approach, a data management approach widely used in the social sciences[38]. Non-participant observation and secondary (documentary) evidence provided context and supplemented information obtained through individual interviews with staff members. It enabled an explanation to be developed of the barriers and facilitators to integrated working by identifying initial themes and concepts, data-labelling, data-sorting and summarising the data to build to an explanation. Framework uses a matrix based approach that provides a paper trail, thus ensuring clarity and transparency. The Framework themes used for analysis of staff interviews are presented in Appendix D.1-D.2.

Service user data, which were generally more complex than data generated from staff, were managed using MAXqda, a computer-based qualitative data management program and analysed as described above (using the Framework approach). The Framework themes used for analysis of service user interviews are presented in Appendix D.3. The themes identified in each of the case study sites were then

compared and contrasted across all the case study areas and triangulated with staff data and earlier findings from the literature review.

To develop the Framework themes for both the staff and the service user interviews we undertook the following procedure. After each member of the team read the same transcripts, common issues and concepts were identified. These became the basis of the Framework themes. The content and parameters of themes were decided and sub-themes identified where necessary. Data were then extracted into these themes, discussing any difficulties about the parameters of the themes as they arose and redefining them as necessary. Where issues or concepts did not fit into one of the existing themes, an additional theme was developed (as described above). Data were extracted by one person and checked for accuracy and compliance with the theme parameters, by another. Where anomalies existed, the research team discussed the most appropriate theme to extract the data into and, if necessary, the parameters of themes were redefined accordingly.

Together, analyses of these data provided an overview of the services that promote continuity of care for people with LTNCs upon which we based benchmarks for phases 3 to 5 of this project.

3.7   Reporting

3.7.1 Anonymity and identifiers

In order to maintain the anonymity of the staff and service users who took part in this research, we have removed any identifying information from all public reports. Each case study site has been given a unique identification code (i.e. sites A-F) and no names of local organisations or locations have been included. Where we have drawn on local documents, we have removed the case study area name from the reference and inserted the unique code.

Staff who participated in research have also been given a unique identification number. When quoted, we report the type of organisation they work for (for example, acute trust, adult social care) rather than the position they hold in that organisation, to prevent any identification of staff via designation, and the site code is included only where this does not risk compromising individuals' anonymity. To clarify where we have deliberately anonymised quotations, reference to the interviewee is italicised.

Service users have been assigned pseudonyms. In general, where we have quoted a service user we have referred to them by their pseudonym, their condition and the code for the case study area from which they were recruited. However, where the combination of these could compromise a person's anonymity, one or more of these labels have been removed. Some of the people we interviewed had rare neurological

conditions and where this could make them identifiable either the condition is not reported or a more general description of the condition is given. To clarify where we have deliberately anonymised quotations, reference to the interviewee is italicised.

3.7.2 Use of quotations

Quotations used within this report are not exhaustive of the issue being discussed but rather are illustrative examples of key issues that were common across the six case study sites and across the people with LTNCs who were interviewed. Where any views expressed and associated quotations are particular to a person or to a case study site, this is made clear within the text.

4. Integration and implementation of the National Service Framework for Long-Term Neurological Conditions: findings from interviews with staff

As described in Chapter 3, staff from all parts of the service system (statutory and non-statutory) were asked about the issues they felt were aiding or impairing integrated working and the implementation of the NSF for LTNCs. In this section we give an overview of these views, presenting a picture of progress towards implementation three years into the NSF's ten year life span and looking at some of the reasons behind this.

4.1 Approaches to integration of services and joint working

As noted in earlier (see Chapter 3) it was not possible simply to select three case study sites demonstrating 'good' integration and three 'more basic' models because such clear delineations did not exist in practice. Instead we selected six areas with six different approaches to integration and joint working which could help to demonstrate the breadth of different approaches in operation. This first section gives an overview of the sites' differing approaches and sets out what staff members told us about how well these approaches worked in practice.

4.1.1 Site A

Site A had formally integrated health and social care structures, with the PCT responsible for all adult social care service commissioning as well as all local health services. Nevertheless, on the ground, health teams and social care teams worked quite separately. Thus, a community health worker commented

> … to be honest, in our department, it doesn't translate very significantly, because we don't have very close links with social workers I suppose. I don't feel as though it's made that much difference to my working practice day to day.
> (AS18, PCT)

District nurses were jointly managed with social workers, but they were not co-located:

> … the reality is we see very little of them, which is why we have these locality meetings I guess, to pull everyone together.
> (AS07, adult social care)

Moreover, when this site first launched its LIT for the NSF for LTNCs, it neglected to invite anyone from the adult social care section of its commissioning or provider

teams. Being formally integrated does not, then, necessarily ensure a joined up approach to service improvement. The flexibilities afforded by formal integration did, however, mean that there was scope for innovative, cross-boundary developments. A team of social care support workers, for example, who had previously worked exclusively with social workers, had begun supporting the clients of health teams including those with brain injury. Similarly, social workers were now allowed to refer directly to community therapists without having to request a referral from a General Practitioner (GP) first.

4.1.2 Site B

Site B was not formally integrated and had few formal health and social care partnerships in place at the time of our fieldwork. Instead it relied on leadership, personal relationships, and specific co-ordinating roles at certain vulnerable points in order to ensure a joined up approach. Despite the lack of formally integrated structures, however, staff interviewees in this site reported feeling part of a well established culture of collaboration that facilitated effective joint working:

> Rather than specific integrated services, what we do have is a lot of collaboration … there are a lot of times when different services will work together very closely and in terms of our assessment and management processes, we have had since 1993, a very clear process of all our assessments particularly for nursing care, for example, have to be on a joint basis.
> (BS23, adult social care)

It was suggested to us that this culture was sustained by the relatively low turnover of staff in site B. Nevertheless, social care and health staff teams were subject to different pressures and constraints which risked pulling them in different directions. In particular, social care staff members felt that they were able to be more flexible and person-centred in their approach, whereas health teams were constrained by national targets and directives.

4.1.3 Site C

Site C had no formal health and social care integration at the time of our fieldwork other than the minimum requirement covering equipment stores. Partnership boards were in place for older people's services, learning difficulties and mental health, but not for physical disability or long-term conditions. Instead, both the local authority and the PCT ran separate boards. The PCT long-term conditions board had no local authority representation (and its primary focus was not LTNCs). The local authority physical and sensory impairment board did have PCT input and fed into the cross-sector local strategic partnership, but again there was no focus on LTNCs. In recognition of this, a LIT had recently been established to focus specifically on the

NSF for LTNCs. However, this group did not have a commissioning role and at the time of our fieldwork it was felt to have made little progress (see below, section 4.3). Given the absence of integrated working at a strategic level to develop services for people with LTNCs, it was surprising perhaps that it was here that we found our most complete model of integrated health and social care service delivery for people with LTNCs. The community interdisciplinary neurological rehabilitation team (CINRT) in site C provided the full range of health and social care services in an integrated, person-centred way and was very highly rated by all staff and service users who spoke about it. The social workers and occupational therapists (OTs) on this team were employed by the local authority, but worked as part of the (otherwise PCT provided) rehabilitation team. Not only did this facilitate joint working between health and social care professionals on the team, it also provided a visible social care contact point for health professionals outside the team.

4.1.4 Site D

In site D there was some strategic level integration, but no pooled budgets or joint appointments. The local authority and PCT had a team of cross-sector managers with a broad remit for joint strategic development which included the implementation of the NSF for LTNCs. However, each manager was employed either by health *or* social care and staff in this team reported finding it difficult to commission services jointly because each organisation still held its own separate budgets:

> We've never really got over those issues around employment. About actually having a pooled budget where the partners aren't going to say, well this is really mine, and that bit's mine, you know, we haven't ever got to that stage.
> (DS01, PCT)

On the ground there were mixed reports about how well health and social care services worked together. Specialist community neurological services were all commissioned and provided by the PCT, but a specialist neurological social worker did link with these teams. In itself, this role was highly valued, but one social worker alone did not have the capacity to ensure continuity across the entire system. As a result, several of the service users we interviewed reported experiencing poor management continuity at the interface between health and social care.

4.1.5 Site E

In site E there were pockets of integrated working at an operational level between individual professionals, but no consistent strategic approach. Since the area had, until recently, been covered by four different PCTs, there was still a number of different service models and strategic approaches in operation. Social services had gone through internal restructuring at the same time as the four PCTs had reconfigured and some staff members at a strategic level felt there had been a

missed opportunity here, as health and social care structures were not brought closer together at the same time. Adult social care and the new PCT were felt to be '*out of synchronicity*' (ES2, PCT), with no joint commissioning arrangements in place or in the pipeline. This was reflected in the community neuro-rehabilitation team which, despite being interdisciplinary *within* health, was not formally linked with adult social care. The establishment of a LIT for the NSF for LTNCs in one sub-area of the PCT did help to achieve greater partnership working between health and social services in that area, providing an opportunity, for instance, to discuss and improve the single assessment process (SAP). However, as this team covered only one fifth of the case study site area, the scope of their joint working was limited.

4.1.6 Site F

In site F there was a view amongst staff that, historically, integrated care for people with LTNCs had not been good, and there was still some considerable way to go in joining up services. The 'hub and spoke' model in the city-region of which site F was part, was only partially successful in bringing together services. Although there was a regional integrated model of neuro-rehabilitation and pathways were established, there were still some problems in their working. The neurosciences network had had more impact, so far, on developing and integrating services within the acute neurosciences centre and was only just beginning to extend its focus to tackle ways of linking with community services. Trying to integrate management from the acute centre with the rest of the system, and streamline people through the layers more appropriately was a challenge, but ultimately:

> If you've not got decent community rehab, you end up with hold-ups and blockages.
> (FS09, voluntary sector)

Locally, a renewed impetus at a strategic level and the evolving strategy around physical and sensory impairment over a number of years were key in shaping services. This created a readiness to explore innovative solutions and support was evident from both the PCT and adult social care with an emphasis on greater joint commissioning. In the area of neurological rehabilitation in particular, a CINRT had recently been formed by combining a former impairment therapy based team with a social inclusion one, promoting an explicitly social model of rehabilitation. The impetus for this joining-up had been provider led, rather than commissioned, and it challenged conventional delivery systems. At the time of our fieldwork, this joint team was still very new, but there was a commitment on both sides and all levels to make it work.

> A significant issue for us is that rehabilitation for us is about context-based rehabilitation, about social inclusion … so it still remains a complexity. We are a very innovative team. We find that the PCT and local authority will listen to what

we say, but their systems are not yet flexible enough to deliver care that might be unusual or off the norm.
(FS04, PCT)

4.2   Strategic partnerships and strategic approaches

All six case study sites were emerging from a period of slow progress in strategic development at the time of our fieldwork. Reorganisations following 'Commissioning a Patient Led NHS'[39] had seen existing structures disbanded, and financial pressures meant that in some areas all but the highest priority work plans had come to a standstill. Some strategic level groups had stopped meeting, and representation on those that continued was patchy and inconsistent. Reorganisation was also underway in several of the local authorities in our case study areas. The result on both sides was a focus on internal issues and structures, rather than the greater integration with external agencies advocated in the NSF.

All but one of our case study sites had a designated commissioning lead or leads charged with implementation of the NSF. However, LTNCs tended to be just one of a number of work-streams under these individuals' remits, meaning the NSF was continually competing with a range of other priorities for commissioners' limited time and attention.

Since the NSF is a cross-sector piece of guidance, implementation cannot be achieved without cross-sector collaboration at a strategic level. We did come across some examples of joint strategic leadership, but this appeared to function more effectively in some areas than in others. In site D, for example, despite there being a team straddling both health and social care that had responsibility for implementing the NSF, the approach of the PCT and the local authority more generally was to keep health and social care budgets separate. As such, NSF leads could plan developments jointly, but they were more difficult to commission jointly. It was suggested by this team that commissioning for service improvement would be much simpler if health and social care budgets were pooled from the beginning. As one interviewee explained:

> … it needs to start from the Department of Health and if they had joint budgets and that money came down to local government and local NHS organisations as a joint budget then there wouldn't be any of this 'oh this is our money, we're not going to use it for that we've got other priorities that we're going to use it for.' If it came as a single budget it would make it a lot, make life a lot easier.
> (DS09, PCT)

In another area, formal partnership arrangements between the PCT and the metropolitan borough council had been good over a number of years and were built on long standing personal relationships, particularly around disability issues.

Interviewees in this area were confident that a joint management team across health and social care could be successful in building capacity and securing resources to promote joint strategic development for LTNCs. Here, joint working extended to active engagement of the voluntary sector through a local disability support group:

> We have moved beyond consultation to real involvement in developing services.
> (FS25, voluntary sector)

This suggests that integrated working is possible without formally integrated budgets, as is full engagement of the voluntary sector. Nevertheless, the reliance on personal relationships brings with it the risk that these successful joint-working arrangements could be lost if key individuals move on. As we discuss further in section 4.4, this is exactly what happened in a number of areas in the aftermath of the 'Commissioning a Patient Led NHS'[39] reconfigurations.

There was variation across sites as to the structure of local authority social work services. Some sites had locality based teams working with all adults in a particular area who had social care needs (sites A and B), others had separate physical and/or sensory impairment team(s) separate from teams that worked with older people. Staff in site F saw their evolving strategy around physical and sensory impairment as key to shaping services for people with LTNCs and meeting the requirements of the NSF locally. It provided a specific focus on the needs of younger disabled people, which otherwise was in danger of being overwhelmed by the greater numbers coming through older people's services. The separation of physical and sensory impairments for adults of working age during the reconfiguration of adult social care was endorsed as potentially a better model for delivering services for many people with LTNCs. In site A, social care services had moved in the opposite direction, from a team specialising in physical disability to generic locality teams. It was suggested that this diluted the expertise of the team and reduced opportunities for joint working with other disability specialists:

> we all worked in the same team at that point, when we had the physical disability team, we were all made up of sensory support workers, social workers who specialised in under 65s with phys' dis' and occupational therapists, so we all worked as a team specialising in that and that was a bit of a shame really when that went.
> (AS07, adult social care)

One of the central recommendations of the NSF was the establishment of neuroscience networks to coordinate the planning, commissioning and provision of services for people with LTNCs. Only two of the six case study areas in our research were covered by a neuroscience network. One of these had not met since the associated SHA had reconfigured, but the other was fully functioning. It was intended to be both a clinical and a commissioning network with wide-ranging buy-in, but some

respondents felt social care representation had been poor, with a focus instead on acute, clinical care that limited the scope for wider improvements:

> In theory [the neuro-network is] very important in planning and developing services, in practice it still seems to spend a lot of time talking about developments in the neurosciences centre rather than monitoring what is happening around the region, though that is one of its remits.
> (FS9, voluntary sector)

> There is a need to work bottom-up and the danger is the network has been medically driven. … It's fantastic for certain bits of the pathway, but it cannot deliver community services.
> (FS01, adult social care)

It was, however, hoped that new initiatives within the network, including the appointment of a project manager and the establishment of a service level agreement with the local neurological alliance, would help pull together commissioning information and shift the focus to local communities.
While respondents in this area felt that they were making some progress towards implementation of the NSF, those in other areas were despondent about the lack of momentum and, in some cases, actual halting of developments:

> Having started from quite a high point in terms of, you know, having a champion in the PCT, having a big [site D] meeting about the NSF, and setting up the groups, then I think we have been adversely affected by the reorganisation of the PCT.
> (DS04, acute trust)

> I think because, you know there was no financial commitment following it, and because there was sort of 10 years for implementation, it kind of feels now on reflection that it kind of died a bit of a death. There was no urgency.
> (AS33, voluntary sector)

At a time when the NHS was under considerable pressure to regain financial balance and reorganise internal structures, any initiative that PCTs were not performance managed against risked falling by the wayside. The NSF for LTNCs had no clear targets or timescales and was variously described by our interviewees as 'woolly', 'vague' and 'just not practical'. There was also a lack of clarity over whether it was guidance primarily targeting people with neurological conditions, or long-term conditions more generally. If the latter was argued, PCTs could tag the NSF onto other existing work streams such as the stroke strategy, or work to reduce hospital admissions for people with diabetes or Coronary Heart Disease (CHD), both of which were felt to be higher priority, but this approach singularly failed to recognise what was particular about the needs of people with LTNCs. These and a number of other issues affecting the implementation of the NSF are discussed in more detail in the sections below.

## 4.3	Local Implementation Teams (LITs)

All but one case study area had a dedicated LIT in place for the NSF for LTNCs when we began our fieldwork. These teams were felt to be having varying levels of success. Members of the voluntary sector commented that LITs had the potential to provide a valuable vehicle for meaningful dialogue with statutory bodies. As one voluntary sector interviewee explained:

> It's very difficult when you're on the outside, to get inside information, and know who the best people are for you to speak to.
> (AS33, voluntary sector)

However, whether LITs successfully fulfilled this potential depended both upon their range of voluntary sector involvement and on whether those in a position to effect change actually listened to and took seriously the voluntary organisations involved. This was not always the case and voluntary sector representatives, in particular could feel excluded by the dominance of health professionals and the use of technical language at LIT meetings. Indeed, in site C there was a functioning LIT but a voluntary sector representative still commented that the PCT was inward looking and weak on user involvement, with only select 'in' groups being fully involved.

LITs could, nevertheless, have an important role in involving users and voluntary sector organisations in planning developments and changes to services. One of the first tasks of the site B LIT, for example, had been to complete a user and carer survey. The questionnaire, based on the quality requirements of the NSF, was designed by a voluntary sector representative and supported by stakeholders across the health community, local authority and voluntary sector. However, progress towards implementing the resultant action plan later stalled when PCTs were reorganised (see section 4.4).

Site A did not have a LIT when we began the fieldwork, but established one whilst we were there, with some instant, observable effects. This group brought professionals from across the service system face to face, in some cases for the first time, facilitating communication and helping to raise awareness of previously unacknowledged gaps in service. However, representation on the group, at least in those initial stages, did not cover all relevant elements of the service system and its scope may, therefore, have been limited. In site E, the LIT covered only one of the five sub-areas of the PCT and so, whilst this did have cross-sector membership, the developments planned only applied to a sub-section of the area's population. Staff members covering other areas of the site reported confusion over whether a group did or did not exist and how they were expected to engage with it. Moreover, a hospital-based LIT was in operation at this time but was completely separate from the PCT LIT. With no system of information exchange between the two groups, it was noted that neither knew what the other was doing. As one member of staff explained:

> it was a complete surprise to the hospital LIT that there is a LIT in the PCT.
> (ES16, acute trust)

In contrast, there was widespread agreement in site F that the formation of a LIT had given impetus to some important developments. A key strength of this LIT was the attendance of people at a senior level who were directly engaged in PCT and adult social care strategic commissioning processes. Thus, during our period of fieldwork this LIT was developing an action plan based around the NSF's Quality Requirements (QRs) to feed into the Local Development Plan. Nevertheless, incomplete representation was still felt to pose a problem for this site. There was wide-ranging attendance from the PCT, local authority and the voluntary sector, but the lack of involvement of anyone from the acute trust or general practice was viewed as a potential barrier to achieving and taking forward a comprehensive plan.

Uneven representation also posed a problem for the LIT in site B. Although involvement was wide-ranging, numerically it was health dominated, which led to some participants feeling that medically based process issues took precedence in meetings. There was no local authority or service user representation at the meeting observed by our researcher and no-one attended from private sector providers of social care. There was also concern in site B that the absence of ongoing involvement from the PCT at a high strategic level could impair the influence of the LIT. This lack of support at a strategic level could be very restrictive. The LIT in site D, for instance, was viewed positively for having brought people with an interest and expertise in LTNCs together from across the service system. However, the group was essentially felt to be lacking in 'teeth', particularly after the PCT reconfiguration, when it lost input from commissioners with the authority to take plans forward:

> I think it's been difficult to engage commissioners in the NSF. ... We've managed to do some work to get some fairly junior level people to come along ... to the NSF groups but I think the problem has been there's been a whole scale reorganisation at the PCT and it seems to have taken quite a long time to get new people in post, and I would say the NSF isn't high priority. I don't mean for me, but for the commissioners.
> (DS04, acute trust)

> You need the clinical and practitioners type of input, but you also need some managers to make some decisions, and it's that decision making thing that we found was just sort of floating off a bit really [once reconfiguration began], it floated off altogether.
> (DS01, PCT)

This group was supposed to report into a higher level modernisation team, but at the time of our fieldwork the modernisation team had not met for over ten months. Some progress in areas that did not need high level approval had been achieved, such as better joint working between front line staff members, but more strategic

improvements could not be made until the new structure was in place and an executive director joined the group:

> at the moment if you asked any executive in the PCT I don't think they would have ever heard of it [the NSF].
> (DS09, PCT)

In site C, a LIT had been formed after commissioners became aware that the local physical and sensory impairment group had little knowledge of neurological conditions and poor links with the PCT's long-term conditions board. The group did not have a commissioning role *per se*; rather its aim was to collate information so that collaborative commissioning could begin in the future. After initial excitement and wide ranging representation the group had, however, begun to lose momentum. Meetings had become less frequent and a mapping exercise had been misplaced. LIT members we interviewed expressed frustration that the group was 'not really working to clear goals*'* (CS30, adult social care) and some were considering withdrawing their support altogether:

> I'll give it one more meeting and if there is no improvement I will have to, reluctantly, drop out.
> (CS04, voluntary sector)

This example suggests that simply having a LIT – even one with good representation – is not in itself enough to ensure progress will be made in implementation. Members need to be convinced of the value of the group and see that their involvement is leading to tangible improvements. Having a 'front line' clinical champion for LTNCs, or a particular neurology service, had in some cases been instrumental in affecting positive change. In site E, for example, a member of 'front line' staff had been the driving force behind the creation of a CINRT and another had been successful in securing dedicated community rehabilitation beds for people with LTNCs. A local champion in site F had, similarly, recognised the need to bring existing health and social care services together into a CINRT and successfully lobbied for its creation. What appeared to be important here was that structures were in place to enable these champions to influence decision making. Furthermore, it is essential that a lack of effective systems for involving front line staff, service users and voluntary sector agencies, does not act as a barrier to innovative practice and service improvement.

4.4   Impact of reorganisation

Interviews with staff members confirmed the findings of our original scoping exercise[30]: that the timing of the publication of the NSF, immediately before a major reorganisation of PCTs, 'could not have been worse for bedding in new policy' (p.6). All but one of our sites had seen significant PCT reconfiguration after 'Commissioning a Patient Led NHS'[39] and local authorities in some of our case study

areas had also restructured. In each of these areas, staff members talked about initial progress towards implementing the NSF being slowed or even coming to a full stop as boundaries changed and key players moved jobs:

> It [the NSF] came at a really bad time … the reconfiguration, the SHAs had to change, the PCTs had to change, adult social care is changing, there isn't anybody in continuity, everybody is changing.
> (DS09, PCT)

In some areas, specific pieces of work such as joint health and social training were cancelled, in others the LIT simply stopped meeting, meaning there was no longer any vehicle for progressing NSF implementation. Front line staff continued to provide services as best they could, adopting where possible a 'business as usual' attitude. However, they reported that broader service improvement was very difficult to achieve at this time:

> you were okay doing the things you do every day but you couldn't service improve, you couldn't develop, because you didn't know who the management were or would be …
> (ES01, PCT)

Where reorganisation was seen to be part of a necessary transition to a better structure, it was felt that this temporary hiatus was a price worth paying. In site B, for example, it was thought that the move from four PCTs to one would enable a county-wide approach to service development which could make strategic partnerships much easier to make and sustain. Such partnerships had functioned well in earlier years, with the old health authority and county council boundaries, and it was hoped that this success could be recreated with the new coterminous structures:

> … we are at the stage now of reforming different levels of partnership and re-strengthening those. … It's easier to develop partnerships when there is one PCT. It was very difficult when there was four.
> (BS25, adult social care)

In contrast in site E, whilst it was recognised that there could be benefits to having one large PCT, it was noted that the new PCT did not *feel* like a single coherent organisation and, indeed, a key strategic manager commented that in her view it never would feel that way as it was spread over too wide and diverse an area.

Staff members in all areas talked about the unsettling effects of instability and change itself. A manager in site B, for example, commented:

> Constant reorganisation is very destabilising, especially to the small staff groups like therapists. … We need a period to make changes and consolidate them.
> (BS31, PCT)

Most interviewees did see the co-terminosity of local authorities and PCTs as a potentially important benefit of reconfiguration that could support the joined-up implementation of the NSF. However, at the time of our fieldwork such benefits were not yet being seen. In site D, for example, commissioning processes were still in flux and organisational memory was being eroded by staff changes in both the local authority and in health. As already noted a city-wide cross-sector group, which had previously taken decisions at a chief executive level, had stopped meeting and new decision making structures were not yet in place. This left strategic development planning in limbo and several of the staff members we interviewed felt it was a serious barrier to implementation of the NSF:

> … we stopped doing anything about a year ago because we just weren't getting anywh ... there was nowhere to take any decisions at all really.
> (DS01, PCT)

Valuable time and momentum has been lost, therefore, and it remains to be seen whether the potential future benefits of reorganisation will make up for these losses. It was certainly the opinion of some of the staff members we interviewed that the moment for implementing the NSF had come and gone, overshadowed by the wider upheavals of the time. Another such issue was the financial difficulties that struck some PCTs shortly after the NSF was published. The impact of this is covered in more detail below.

4.5   Financial pressures

The launch of the NSF for LTNCs coincided with a period of financial difficulty in the NHS. A number of trusts were struggling to balance the books, and the total NHS deficit at the end of 2005/6 was £547 million[40]. As one interviewee observed:

> if you go back to when this was brewing, probably 2005, everybody's' attentions turned to finances … a lot of emphasis was put on balancing the books and the attention was taken off the patients.
> (AS04, PCT)

In three of our case study areas financial pressures were cited as having a substantial impact on implementation of the NSF. In site A, for instance, the local acute trust reported a £7.7m deficit at the end of 2004/5 and in 2006 the PCT was working to a £4.5m financial recovery plan[41]. Staff members in this site talked about the difficulties in prioritising implementation of the NSF in a context where financial recovery had primacy. One PCT commissioner commented:

> Obviously with the financial deficit there's no new money … so within that no new projects can effectively start up.
> (AS01, PCT)

The situation was similar in site D, with progress stalling after the needs assessment and action planning stage because there was no new money to invest in identified priorities (and no structures in place to authorise investment – see above):

> … people have to be creative in order to implement anything because there's no money: so you could do all the benchmarking you want to do but at the end of the day if there's no resources to do it you're just stuck with your benchmarking, you can't move forward.
> (DS09, PCT)

The fact that this NSF came with no new money and no firm targets effectively positioned it as a lower priority than other work-streams:

> … it's quite hard in the current financial climate to be looking at anything that needs different funding. … It's looking at where can we redesign services to move funding across. … What new money there is, is getting eaten up in 18 weeks [target] which is the priority, and Continuing Care.
> (DS01, PCT)

Site B had largely escaped the task, being tackled by many newly formed PCTs, of addressing financial deficits. The SHA prided itself on its financial management such that the new site B-wide PCT was in balance. However, from a social care perspective, it was felt that the preoccupation with financial balance in the PCT had driven a lot of the thinking around partnership working, such that some of the perceived risks with joint commissioning had not been taken.

By the time our fieldwork began, the acute trust in site A had reduced its deficit by about half and was expected to achieve financial balance by year end. However, acute trust staff members still felt their potential to implement the NSF was limited by financial constraints. It was noted, for example, that, for the size of the population, the acute trust should have had more full time neurologists. However, it was hard to make a business case for more neurologists when much of their work was with patients under other specialisms (e.g. respiratory medicine, elderly care) and so would not be directly reimbursed through payment by results (PbR). As one interviewee explained:

> The fact of the matter is that it's very, very hard now under payment by results to make a business case and get it to stack up to say you want to invest more in a service which actually you're already providing a service for, it's just not a very good quality service.
> (AS02, acute trust)

Similarly, in site B, it was felt by some that the recent closure of the acute-based rehabilitation unit and relocation of neuro-rehabilitation services to within the hospital wards (effectively closing beds) was a result of financial pressures. The financial imperative to save costs had, they argued, pushed through a fundamental change in

the service which over-rode consideration of a wider commissioning strategy. The outcome was an erosion of trust between the different organisations and a perceived regressive step in rehabilitation services.

4.6   NSF for LTNCs in the context of national policies

A number of comparisons were made by staff between the NSF for LTNCs and other policies and targets that were felt to have more force. In acute trusts, the 'woolly' nature of the quality requirements, when set against the very clear targets to be met in other clinical areas, made prioritisation of LTNCs almost impossible:

> I have to say, in the scheme of things, this is not a priority. There are no national targets against this. We've got, we are absolutely flat out trying to get the cancer targets sorted out, the rapid access chest pain clinics, the sexual health attendance targets, the 18 week target, and frankly, if it hasn't got a target, we haven't got the time to do it.
> (AS02, acute trust)

> There are so many other things that we are required to count I'm not sure it [the NSF]'s going to bubble up to the top of the priorities for a while.
> (BS07, acute trust)

It was suggested that the NSF's lack of targets made key staff members reluctant to give up their time to attend meetings and prioritise action. Interviewees pointed out that, while targets are unpopular, they are also the incentives that drive their organisations. Without strong performance management there was nothing to compel PCTs, local authorities or acute trusts to achieve the NSF's quality requirements. When faced with other guidance and targets against which they would be assessed, the NSF inevitably took a back seat:

> … the reason we're still here talking about it four years later is because there were no targets. And although people say that we don't like targets and we don't like lists but to be honest if there's no targets it's not on the execs'… it's not on the exec directors' radar.
> (DS01, PCT)

> We are well aware it [the NSF] doesn't come with any penalties for non-compliance or rewards for the Trust in achieving it. … Management know about the NSF, but it's way down their list because there are no incentives or penalties to do anything about it.
> (FS20, acute trust)

National agendas that were cited as taking precedence included the 18 week waiting time target, Choose and Book, the Older People's NSF[42], the Stroke Strategy and the Long-term Conditions (LTCs) Programme. The LTCs Programme, launched immediately prior to the NSF, 'caused major confusion' (FS10, voluntary sector

representative). In theory the programme covered all long-term conditions; in practice there was a concentration on those conditions which had the greatest impact on hospital admissions, such as diabetes, CHD and chronic respiratory conditions. Targets *were* set for numbers of community matrons[13] and a reduction in hospital bed days[43], and PbR meant PCTs would get financial rewards for avoiding hospital admissions. Thus, case management of 'very high intensity users'[14] and the development of intermediate care services to avoid or reduce the length of hospital stays became the focus of the long-term conditions programme. Since, in theory, the LTCs programme covered all long-term conditions, commissioners and general managers with limited capacity could argue that they were working towards implementing the NSF through their implementation of the LTCs programme. However, in practice, the main beneficiaries of this programme were not people with LTNCs, as this group do not tend to be 'very high intensity users' of hospital services, particularly once initial onset has been stabilised. Moreover, the prioritisation of the LTCs programme of work meant little capacity remained for implementing those elements of the NSF that required a specific focus on LTNCs, or had more to do with integrated support and quality of life than with hospital admissions.

The development of new commissioning arrangements and self-care initiatives also reflected these broader national agendas. In site B, for example, it was felt that the national approach to self-management and intermediate care had influenced the type of community rehabilitation services that had developed. These tended to be goal-oriented and time-limited, models which were less well suited to supporting the ongoing and changing needs of people with LTNCs. Similarly, interviewees in site E talked about the priorities for practice-based commissioning being primarily determined by national targets, despite rhetoric about the importance of local priorities. With the focus of 'world class commissioning' on life expectancy and inequalities, statistics were leading commissioners straight back to conditions such as CHD and chronic obstructive pulmonary disease, and still further away from LTNCs.

Some interviewees talked about the unintended consequences of other national agendas for people with LTNCs. In site F, for example, national targets for seeing new patients and for the length of time from diagnosis to treatment were felt to have created huge problems for follow-up, which was not similarly prioritised. Many people with LTNCs require continuing follow-up or an ability to dip in and out of rehabilitation, and for those with rapidly progressing conditions, timely follow-up is critical. Although efforts were made to accommodate people's needs as much as possible, follow-up appointments after 18 months were not unknown. Moreover, some acute trust interviewees reported feeling pressure to discharge patients they knew would require follow-up, so that they could be seen in the future as new referrals and thus attract a higher PbR payment. Interviewees said they were reluctant to do this because of the implications for continuity of care, and the peace

of mind of their patients. It was noted, however, that to preserve this continuity, one of the central tenets of the NSF, they had to swim against the flow of national targets and incentives.

Where interviewees were working specifically on service improvement for people with LTNCs, NICE guidance was treated as higher priority, because it specified tangible outputs that trusts had to report on. Moreover, front line practitioners were in a position to implement some of the NICE guidelines themselves, as they related to specific areas of practice, whereas the NSF QRs tended to be more strategic and cross cutting. Both health and social care staff, and voluntary sector representatives, used the NSF as a tool to influence commissioners, but it was noted that NICE guidance was again more useful in this respect. The top five recommendations in the NICE guidance for Parkinson's Disease, for example, were felt to be much clearer and more tangible than the NSF QRs, thus providing a stronger lever in negotiations with PCTs. The ten-year time scale for implementation of the NSF was also felt to undermine the case for swift action.

For adult social care, where people were supported on the basis of need, it was difficult to identify and target neurological conditions, especially since a clear strategic direction, or how the NSF fitted in with other developments, such as outcomes based commissioning, was felt to be under-developed. For many of those delivering services in social work and social care, the NSF itself was argued to have had little impact as a policy document directly influencing practice. It was 'not something that crosses the horizon' (BS05) in the same way that, for example, the older people's NSF[42] had done. The exception came in areas where services were specifically designed to meet the needs of people with LTNCs. In site D, for example, staff at the local authority run resource centres specialising in brain injury felt that the QRs dovetailed well with their existing ethos. They valued the NSF highly, using it as both a training document and as a framework for service development. The compatibility of the NSF with this particular model of service delivery is notable because national policy currently directs commissioners away from this style of 'centre' based day service.

Another policy direction felt by some to be at odds with the needs of people with LTNCs was the national 'pathways to work' programme. This focused on employment outcomes, which were seen as unrealistic for many people with LTNCs. At the same time, Learning and Skills Council funding changes were limiting opportunities for non-vocational learning.

Some of those working in adult social care and the voluntary sector commented that physical disability seemed to have become low priority generally in recent years. The example was given in site A of a day centre that previously provided services to physically impaired people, but now worked almost exclusively with people with

learning difficulties. While some of those displaced now accessed alternative services using direct payments, others were 'still at home, and that's not ideal, is it?' (AS29, adult social care). The local area agreement (LAA) in this site made little mention of disability or long-term conditions, neurological or otherwise. This had as much to do with priorities at a national level as it did with those in site A, since there were few relevant priorities on the national list to chose from. As one interviewee (who had been involved in the LAA prioritisation process) commented: 'we can't choose them if they're not there' (AS31, voluntary sector).

4.7 Facilitators and barriers to joint working

Integration and joint working are key themes within the NSF for LTNCs, cutting across all 11 QRs. In addition to the barriers and facilitators to implementing the NSF directly, we therefore asked staff members about the things that helped or hindered integration and joint working in their day-to-day operations. Five main facilitators and four main barriers emerged from our analysis.

4.7.1 Facilitators

4.7.1.1 Co-location, leadership and a shared approach

Locating services on the same site is often thought to be a means of facilitating joint working and ensuring continuity of care. A King's Fund study into the international experience of co-locating primary care services, however, reached the conclusion that co-location alone is not sufficient to guarantee integrated working practices. Co-location can provide opportunities for joint working, but in practice these opportunities are often lost if overall governance structures and management are not also joined up[44].

In our sites there were several examples of service co-location which supported joint working to varying degrees. In site F the co-location of the new CINRT was seen to be an important element of its interdisciplinary approach, facilitating ongoing communication beyond the weekly multidisciplinary team meetings. This was felt to work well, as one member of the team commented:

> Health and social care have really come together here in a joint partnership.
> (FS08, PCT)

There were some very practical advantages to services being based physically close to one another other. The MS nurse specialist (NS) in site A, for example, valued being near the neurologist because she could see him informally to agree changes to patients' treatment rather than them 'having to wait months for a consultant's appointment' (AS11, acute trust). Similarly, in site E, the co-location of services in the community hospital was said to help with referrals, which were usually made verbally

by just 'walk[ing] down the corridor and talking to the professionals' in question (ES8, PCT), before being followed up by a formal referral. The co-location of services was also seen to be a strength of the day hospital in site B. On the other hand, those who were not co-located in this site found it harder to link their services in:

> … Trying to forge the links that we don't have because we are on separate sites.
> (BS05, Mental Health Trust)

Nevertheless, co-location did not necessarily translate into close working relationships. In site A, the domiciliary physiotherapy team were co-located with a number of other therapists but found there was little cross referral between disciplines. In keeping with the findings of the King's Fund report[44] and with the recent review of the NIHR SDO programme of research on continuity of care[45] co-location did not appear to lead to integrated working practices if service management was not conducive to this. Thus, a co-located and jointly managed hospice and day centre struggled to work together until the overall management of both had changed:

> I feel it's better now … my previous manager sort of let you get on with things, if I had a problem I went to them, but there was that divide, really. But now, with sort of new management that's a lot better, and we work more together now, and more, included. It's a lot better, a lot better than it was.
> *(voluntary sector)*

In addition to management, another contributing factor was the overall culture and approach of different teams. In site D, the majority of community neurological services were based on the same site and under common overall management. However, interviewees in these teams had different perceptions of best practice and, despite their physical proximity, it was proving difficult to bring working practices together. Similarly, in site C, acute and PCT services were felt to adhere to different models and this was impairing joint working. The successful integration of the CINRT in site F was felt by some of those we interviewed to have as much to do with developing commitment to joint working in this area as it did with co-location.

> [Co-located] teams don't always work - they have to get on, seize opportunities and get along together and communicate well … it is more about relationships than teams.
> (ES15, acute)

Arguably, this comes back to management and leadership of the teams in question. In site B, for example, there were two acute based multidisciplinary teams, one of which functioned much more cohesively than the other. It was felt that the more successfully integrated team had stronger leadership from a clinician who fully involved all members of the team.

4.7.1.2   Informal links and relationships

In the absence of formal links between teams, many professionals had developed integrated ways of working through informal networking and liaison. One particularly successful example of this was the PD nurse specialist (PDNS) in site A, who had developed a 'virtual team' of service providers with an interest in PD over the 12 years she had been in post. Similarly, in site B, the PD nurse had developed links with local pharmacists and was currently working with them on a patient-held medicines information card. In this site, informal channels of communication were valued as highly as more formal measures. However, such ad hoc 'linkages', while valued, lack the infrastructure to embed them into practice across sites. Thus, there were risks associated with a reliance on informal integration, as one interviewee noted:

> Informal relationships can work but under crises or change, they can fall apart.
> (CS6, voluntary sector)

4.7.1.3   Meetings and networks

As discussed above (section 4.3) LITs can bring together professionals and stakeholders from across the service system to work together on service improvement. At an operational level, formal cross-sector meetings can also help facilitate joint working. In site E, the health based CINRT held monthly meetings with social workers and local authority occupational therapists, as well as a representative from the local carers association. In the absence of any formal cross-sector integration, these regular meetings provided a stable infrastructure upon which joint working could be based. Such meetings are, however, subject to the same risks of incomplete representation and coverage as the more strategic meetings. While the cross-sector rehabilitation review meetings in site B, for example, could provide 'a nice safety net' (BS09, acute trust) with which to pick up on discontinuities, their value was dependent on attendance, which could be sporadic.

Cross-sector events were felt to be good ways (and in some places the only way) of getting people together from across the system. These worked best when they were held on an ongoing basis, such as the NSF audit sessions in site D, rather than when they were one-off educational or consultation events. Condition specific networks, often facilitated by the voluntary sector, formed the basis of regular sessions of this sort in some areas. In site A, for example, the Parkinson's Disease nurse specialist ran a link group with more than 40 members from health, social care, mental health and the voluntary and independent sectors, which met quarterly. As well as joint training, these meetings facilitated regular information exchange and referral across the system. The MND Association ran similar professional forums in some areas, providing opportunities for peer support amongst professionals, as well as a forum to discuss cases and making referrals. Nevertheless, in site A it was felt to be 'a shame' that a wider group of professionals either did not know about the forum or chose not to attend meetings.

4.7.1.4   Key workers and Community Interdisciplinary Neurological Rehabilitation Teams (CINRTs)

Informal linkages, as well as these more formal meetings and networks, were most often created and maintained by key professionals or interdisciplinary teams with a specific focus on LTNCs, or one LTNC in particular. Thus in site C the PCT based CINRT held shared education days with acute staff at a regional level and provided a link between health practitioners in the area and adult social care. A nurse specialist in site C commented that the existence of this team made things much easier, and in boroughs where there were no specialist community rehabilitation teams 'life is more difficult for everybody' (CS14, acute trust). Similarly, in site E where there was considerable variation across the geographical areas, it was felt that things worked better where there was a co-ordinating service. Where the MND Association had worked with acute trusts to bring care together in MND Care Centres, joint working was particularly effective.

In many areas, the co-ordinating services were not full teams but individual key workers, usually in the form of nurse specialists, although occasionally they were from the voluntary sector or adult social care. Parkinson's Disease Society information and support workers, for example, have a key co-ordination role and close working relationships with practitioners from across the system. The relative success of such roles, however, depends to some extent on how open statutory sector professionals are to working in true partnership with them. In one of the areas, for example, the Parkinson's Disease Society information and support worker liaised closely with two care of the elderly specialists but had struggled to strike up a dialogue with the neurologists in the area. This, she felt, was detrimental to the well-being of newly diagnosed patients in particular, and she explained:

> I just wish there was more dialogue with the neurologists because on several occasions I've had feedback from patients that had been newly diagnosed by consultants or a member of the team who had been given absolutely no information whatsoever.
> *(voluntary sector)*

In site D, a specialist social worker acted as a valuable link between some community health teams and social services, but she had limited capacity and so several gaps remained. In site F, there had been an 18 month trial of a dedicated social worker on the intermediate rehabilitation unit which was viewed as successful, but had not been extended.

Nurse specialists were by far the most prevalent key workers we came across in our case studies, and these tended to be highly valued for their ability to span boundaries and link services. The remit of the physical disability nurse specialist in site B, for example, was to 'follow the patient' for complex cases, and as one voluntary sector representative in this area commented:

> Specialist nurses are very good at establishing links and networking.
> (BS22, voluntary sector)

Nurse specialists can bring together health services (for example, the rehabilitation nurse specialist in site E saw herself as a 'go-between' linking the patient, the GP and the consultant) and they can also bridge the gap between the voluntary and statutory sectors. Thus, the epilepsy nurse specialist in site E was the main link between health services and Epilepsy Action. Nurse specialists also provided training to voluntary sector organisations ensuring a common approach across sectors.

The extent to which acute based nurse specialists were able to link with and across community services depended to some extent on the internal pressures they faced within their own trust. The acute based MND nurse in site D, for example, worked very much as a community practitioner and regularly conducted joint home visits with community therapists. The acute based nurse specialists in site B, on the other hand, were limited in the number of such visits they could offer as their service was intended to be primarily hospital based.

4.7.1.5 Systems for sharing information

None of our case study sites operated a single integrated system of assessment and information sharing that worked across boundaries. Whilst some areas did use electronic records, these tended to function effectively only until they reached edges of a particular organisation. Thus, in site F, an electronic patient record was used across specialities *within* the neurosciences centre and it was easy for documentation to be shared via this system. However, electronic systems across different hospitals often used different software and interfaces, so that sharing of information between one site and another was problematic.

> It's been completely piecemeal the way the IT stuff has happened.
> (FS20, acute trust)

In site B, recently installed electronic systems had enhanced sharing of records within social care across both community and hospital teams, and a secure email link had been established with the mental health trust. In contrast, health records were still paper based. An exception was the neuro-email link between GPs and neurologists which was described as 'brilliant' (BS06, primary care). In some areas even the sharing of information within a single site posed a problem. At the community hospital in site E, for example, there was no system for ensuring that patients' (paper based) notes followed them as they moved around the service so individual practitioners had to resort to making photocopies.

Most areas had some kind of Single Assessment Process (SAP) in place across parts of the services system, but we did not see any examples of this functioning effectively across a whole system. In site F, the SAP was quite well developed

among specialist teams, for example in intermediate care and the physical and sensory impairment team, but more generally it was questionable as to how far people had engaged with it. In site A, the SAP had been around for a long time but tended not to be used outside of adult social care. Social care practitioners did use a computerised system that, in theory, health professionals could also access, but as one interviewee commented:

> I think very few assessments have been done by nurses to be honest.
> (AS07, adult social care)

Similarly, in site B, SAP was well established but was not used uniformly and views of staff using SAP were mixed. Its being paper based was seen as a limitation and it was felt to become out of date very quickly. More specifically, SAP did not lend itself well to LTNCs which often fluctuated. Some of those we interviewed were hopeful that the Common Assessment Framework (CAF) would solve these problems, but it was still in the early stages of implementation at the time of our fieldwork so it was too soon to tell.

4.7.2 Barriers

Staff members talked about a number of barriers which they felt impaired their ability to ensure continuity of care.

4.7.2.1   Organisational boundaries

Discontinuities arose at the interface between primary and secondary healthcare, social care and health services (acute and community), and services designed to meet mental health needs as opposed to physical or social needs. This latter boundary posed particular difficulties for people with neurological conditions, where there was often disagreement about whether people were experiencing neurological difficulties, mental health problems, or some combination of the two. There was lack of clarity in many areas about where the responsibilities of PCT and acute services should stop in such circumstances, and where those of the mental health trust and adult social care should start:

> I think we do tend to get into more battles these days with mental health and
> social work about, you know, you should be doing this, we shouldn't be trying to,
> not that it gets us very far, but we do try I think.
> (AS06, PCT)

Where complicated arrangements existed for the provision and funding of neuropsychological services, such tensions could be exacerbated. In site F, for instance, the neuropsychologist was based in the mental health trust but funded by two different PCTs and one acute trust. The implications of these different funding

streams were that he had to seek clarification each time he saw a new patient about whether he was actually funded to work with them.

Disagreements over the remit of adult social care, particularly with respect to people with brain injury, could be equally problematic. Thus, the above interviewee continued:

> when we phone up and say can a social worker see them we're asked can they get themselves washed and dressed? Well yes. Well sorry they don't meet the criteria.
> (AS06, PCT)

The risk here was that people who were physically well did not receive adequate support for social and behavioural problems, and when navigating complex systems. A particular concern for those with traumatic brain injury (TBI) raised in site A was that social workers were not advocating for those involved in court proceedings, partly because the police service were not aware of the needs of people with TBI, but also because they did not meet adult social care eligibility criteria.

The boundaries between acute healthcare and community-based adult social care could also be problematic. In site F, social workers found it hard to establish standard hospital discharge arrangements as people with LTNCs could be cared for in a number of different hospitals. One neurologist in a different area confessed that he had no idea how adult social care was organised and so rarely referred to them:

> I mean I basically make very few referrals personally to social services because I wouldn't even know how to go about it.
> *(acute trust)*

By contrast, the consultant in site C had no problems referring to social services as the CINRT there had an integral social worker, so he simply referred patients directly. In site B, interim 'step down beds' funded by social care with rehabilitation input from the PCT were being piloted in two sub-areas, but, as with site F, there was no consistency across the site.

Despite being part of the same sector, acute and community health services also appeared to be divided by organisational boundaries. Poor communication and lack of adherence to protocols meant that community services were not always informed and ready to receive patients when they left hospital. As one member of a CINRT team explained:

> unfortunately what tends to happen is, even when we've had input on the ward, we tend to be the last to know in terms of they'll say, they'll phone up and say oh we sent them home yesterday, can you see them?
> *(PCT)*

This team said they would like to be more involved in hospital discharge and had told the hospital this, but to no avail. A model in site F that did appear to be working was that adopted by the new physical and sensory impairment team. Here, they had moved away from the model of a hospital discharge team handing over to a community team, to a preferred in-reach model where they could work with patients as part of a multidisciplinary team *before* discharge.

In some areas, for some conditions, there were good links between voluntary sector organisations and statutory services which spanned the sectors. In site D, for example, the MND Association had played a key role in bringing together statutory services and continued to work hand in hand with them to coordinate care. The capacity of voluntary sector agencies to achieve this, however, depended to some extent on the size and stability of the group locally. A voluntary sector representative in another area thus explained to us:

> I haven't really had anything to do with the neurology department personally yet, because ... we hadn't got the branch going, and as I was the only branch member I couldn't really take it on single handed.
> *(voluntary sector)*

A final organisational barrier staff talked about was the gap between children's and adult services. In some areas there was considerable divergence between models of children's and adults' service provision. These also differed between health and social care, so for example, in site F, the transition for some health services was at 16, but for adult social care was 18 or even 25 years old for some services.

4.7.2.2 Separate health and social care commissioning
Where services were commissioned and funded either by PCTs or by adult social care, problems could arise over the definitions of types of care and who should fund it. This has long been an issue for continuing care, but interviewees from the voluntary sector also told us about the difficulties it could cause:

> Things get complicated – rehab is seen as a health care issue and social care is social services and because we have quite a programme that we try and do for our clients, they consider that a lot of the time a health issue and think health should pay for it and unfortunately health don't give us any funding.
> (BS18, voluntary sector)

Such difficulties had been overcome to some extent in site A, where the PCT commissioned both health and social care services. Thus, a PCT day opportunities service (similar to the voluntary sector one referred to above) was able to provide a mixture of health and social care services without issue. The manager of this service explained to us that the distinction between health and social care 'doesn't matter anymore because it's in the same pot' (AS29, PCT).

4.7.2.3 Ineffective pathways and silo working

Given the numerous organisational and service boundaries impacting on the care of people with LTNCs, the existence of effective pathways to guide people through the system is essential. However, in many areas there were no such pathways in place, or there were but they did not function as intended. As one interviewee from the voluntary sector explained:

> we pick people up after they've been missing out on things for years … you don't see it happening in isolation, you see it happening time and time again, because nobody's taken responsibility for it. They'll do their own bit, and then it just doesn't get referred on anywhere.
> (AS31, voluntary sector)

This silo working, where individual therapists took responsibility for their own section of the care pathway but did not look to link this with the rest of the system, was attributed by some to the strength of professional cultural boundaries. As one service manager told us:

> It's very easy for OTs to fall into defining a particular role they are going to have and cherry pick certain aspects of somebody's care and assume somebody else will pick up the rest. ... Sometimes it's the professionals themselves who seem to define an area that they are prepared to take on.
> (FS23, adult social care)

Across our case study sites, bringing together individual therapists and professionals into interdisciplinary teams which raise awareness of the interconnectedness of all that they do was particularly beneficial.

4.7.2.4 Staffing issues

As noted in the section on facilitators, informal links and relationships can help facilitate joint working. However, such arrangements are reliant on the stability of staff structures and the capacity of staff members to maintain relationships. One interviewee noted, for example, that she had tried to develop working relationships with social care colleagues over a long period of time but had been unable to do so because social care staff were so regularly moved on. The reconfiguration of health services just prior to the commencement of our fieldwork meant that in many areas health staff had also recently moved. Such restructuring is common in healthcare and so informal relationships are likely to be undermined again in the future.

Lack of capacity was the other key staffing issue affecting joint working. The success of posts intended to facilitate care co-ordination was often impaired by the limited hours people were employed to work on this, or the lack of additional staffing available to cover sick leave or holiday entitlement. When funding was in jeopardy, posts such as link nurses were often the first to be threatened, appearing more expendable than the more tangibly clinical posts.

4.8   Summary and discussion of staff views

The evidence from our interviews with members of staff suggests that formal integration between health and social care can create the flexibility to implement innovative ways of working. However, formal integration alone does not guarantee effective joint working. There also needs to be the forethought and will (at all levels) to engage all stakeholders fully and join services together. This takes strong leadership and a shared vision of desired outcomes. Similarly, personal relationships and an organisational culture of collaboration can support integrated working, but these may be inconsistent across sites and are at risk of being lost when individual staff members move on.

With respect to implementation of the NSF for LTNCs, only one of our six case study sites was covered by a neuroscience network. In this site, progress had been made but was hampered by uneven representation on the network which favoured development of specialist clinical services at the expense of community-based care. By the end of our fieldwork, all sites had at least some coverage from a dedicated LIT for the NSF for LTNCs. These were useful in bringing people together with an interest in LTNCs from across the system, helping to raise awareness of gaps in provision and looking into ways of improving services. However, a number of barriers impairing the ability of LITs to implement service improvement were identified by the staff members we interviewed:

1. **Incomplete representation:** where key professionals (or in some cases entire sectors) were not represented at LIT meetings, plans for implementation were incomplete or skewed and lacked the mandate of all stakeholders. This could occur because key individuals or groups were not invited to attend, or were unable to because of limited capacity. It could also occur if existing members became disillusioned and lost faith in the group, or were compelled to move on when organisations restructured.

2. **Incomplete (geographical) coverage:** if LITs only covered a sub-area of the case study site then they could only influence service improvement in this geographical area. This, in turn, could lead to or exacerbate inconsistencies and inequity within sites.

3. **Poor involvement of those represented:** if those in attendance were not listened to or felt excluded, resultant needs assessments and plans would again be incomplete and without legitimacy.

4. **Absence of support from senior staff members:** where LITs had little or no involvement from senior strategic staff with the authority to agree and support developments, plans for implementation could not be taken forward.

5. **Systems not in place to authorise proposed developments**: where a LIT was not linked up with wider structures, implementation plans could not be signed off and taken forward

6. **Instability and staff changes:** when LIT members changed roles or left jobs, momentum and organisational memory was lost, and those left behind did not necessarily know who to liaise with in future.

A number of these barriers were brought on or exacerbated by the NHS reconfiguration after Commissioning a Patient Led NHS[39]. Staff members changed roles, PCTs became inward looking, some LITs stopped meeting and the NSF for LTNCs was not a high enough priority to stay on the agenda. In some areas, boundary changes meant LITs no longer covered the entire PCT area and wider structures were disbanded without immediately being replaced. The instability itself was unsettling for staff members, but it also led to uncertainty about where proposals for service development should be taken. This latter point is important since several of the models of good practice we identified had been initiated by key provider side champions who had found support for their ideas amongst those with the authority to sanction (and find funds for) developments. With commissioners distracted by organisational change, there was less opportunity for new ideas to feed up and secure support in this way.

Perhaps some other guidance - with more clearly defined responsibilities and intended outputs, with firmer targets that PCTs and local authorities were compelled to report on, or were incentivised to meet - could have withstood the turbulence of this time and remained on the agenda. The NSF for LTNCs, however, came with no such targets and had a ten year time span for implementation. It also came with no extra funding at a time when many NHS organisations were experiencing severe financial deficits. The overwhelming view from the staff members we interviewed was that the NSF for LTNCs could not compete with more highly performance managed work streams (such as those linked to waiting time targets), those that came with money (such as the stroke strategy), and those which were backed by financial incentives (such as the long-term conditions programme). Where progress had been made, this was often driven by front line staff or voluntary sector organisations rather than strategic level integrated service planning. Thus, incremental but positive changes had been achieved in areas where systems could accommodate innovative practice and there was opportunity for front line staff to influence decision making.

5. Delivering continuity of care: perspectives of people with long-term neurological conditions

5.1 Introduction

Integration of services can take place across a number of boundaries. These can be between primary, secondary and tertiary health care; between health and social services and other services; between the statutory and non-statutory sectors; between specialist and non-specialist care; between the person with a LTNC (and his/her family or friends) and any element of the service system; between different levels of professionals and care workers, and so on. Tracking and tracing so many different types of integration would be complex. However, the main *outcome* we might expect from integration is an experience of continuity of care and we, therefore, used this idea as a conceptual framework for this study.

The SDO programme has funded a number of scoping, review and empirical studies on continuity of care. The 'Freeman model' of continuity of care was initially developed in a scoping study[26] and later refined as further empirical and review work was carried out as part of the programme. Our proposal suggested using the revised 'minimum definition' proposed in 2002[27]. However, further empirical studies have allowed the model to be refined again, and in 2007, a matrix of three continuity types was proposed[46]. This latest model grouped together previously defined aspects of continuity thus:

- Relationship continuity – constituting elements previously defined as 'longitudinal', 'relational, personal and therapeutic' and 'long-term' continuity.

- Management continuity – constituting elements previously defined as 'cross-boundary', 'flexible' and 'team' continuity.

- Informational continuity – as previously defined, although now clearly involving the service user and family in the 'information loop'.

Continuity of social context, which had been a part of the 2002 model, was not explicitly included in the 2007 model, perhaps because both this and 'experienced continuity' were by this stage seen as *outcomes* to which the other forms of continuity should contribute.

This shifting of the conceptual framework for continuity of care has posed some challenges for our analysis, not least, because the 2002 model we proposed using has been superseded, albeit retaining most of the elements of the 2002 version. Further, when we carried out our systematic review, we identified what we believed to be another, and distinct, type of continuity – that of personal agency – that had not been included in any of the other models. We defined this as continuity that enabled

people to retain control over their own lives and to manage their own health and well-being.

We have therefore grouped the material in this chapter, which explores the perspectives of people with LTNCs about continuity of care, into the three types of continuity of the 2007 Freeman model, but subdivided by the constituent parts that formed the 2002 model. This has enabled us to keep to the analytical framework with which we started our work (and used extensively in the systematic review) but also to acknowledge the model's further development. We present the material on our new element of continuity – personal agency – alongside that on continuity of social context in a final section of the chapter.

5.2 Relationship continuity

5.2.1 Long-term continuity

Long-term continuity refers to the provision of uninterrupted care for as long as the service user requires it. By their nature, long-term neurological conditions (LTNCs) are ongoing and might fluctuate or deteriorate over time. It is not surprising, therefore, that long-term continuity was highly valued by the people with LTNCs that we interviewed and that there was a strong feeling that services should be ongoing too.

A key issue for many of those interviewed was regular review and follow-up appointments over the course of their illness from professionals such as consultants, nurse specialists, therapists and social workers, and via services such as 'day opportunities', community interdisciplinary neurological rehabilitation teams (CINRTs) and regional specialist centres. These were appreciated and valued and people with LTNCs reported that having regular follow-up resulted in their 'feeling supported' and more able to cope.

However, the balance of comment was about the negative effects of *not* receiving this type of regular contact. Most of the people with LTNCs that we interviewed were unhappy with services or professionals providing short-term input that addressed a particular issue or episode, only to withdraw support as soon as this episode was over. This could leave them having to navigate through the whole referral and assessment process again when their next issue or episode arose. This seemed to be particularly the case with social work and physiotherapy.

Where there were interruptions in long-term continuity, people with LTNCs reported feeling 'nervous' (Freda, MS & epilepsy, site A), 'housebound' (Zoe, cerebral ataxia, site A) 'abandoned' (Sophie, encephalitis, site F) 'distressed' (Flora, MS, site B) and 'forgotten about' (Lee, MND, site D). Those we interviewed described how capacity

and finances seemed to play a major role in determining whether a long-term approach was even considered for service provision, and whether interruptions in long-term provision arose.

Some professionals or services could help when interruptions did occur. Interviewees reported that key people for 'stitching services back together' were nurse specialists and general practitioners (GPs). Where CINRTs existed, they could also help co-ordinate services to limit the length and effect of interruptions.

However, there were some caveats about the benefits of regular reviews and follow-up. Regular follow-up on a long-term basis was not helpful where people had to repeat information about themselves, their condition and their treatment to service providers and where it resulted in numerous professionals visiting them on a regular basis with little or no co-ordination. Further, they suggested that it was not enough simply to have regular reviews and appointments but that it was essential to complement regular reviews by 'ad hoc' access to services and professionals.

For example, Emma described how the CINRT provided support for her after she contacted them about problems she was having with arm mobility:

> The Physio [from the CINRT] is coming out to see me quite regularly at the moment because I've had problems with my arms, so she's given me exercises to do, she came out to see how they were going. She's been out a couple of times and now she's coming back on six weekly check-ups to make sure that things are still going.
> (Emma, MS, site E)

Indeed, despite the desire for long-term input from services, people did not want services and/or professionals to be actively involved in their lives at all times. Instead, those interviewed for this study preferred ongoing access to services and professionals rather than continuous input. That is, whilst people with LTNCs wanted to know that professionals in the system knew about them, took an interest in them and could provide assistance as and when required, they also appreciated professionals who, at the appropriate stage, would step back, enabling the service user to take control over when input was needed or wanted. People we interviewed described how CINRTs and nurse specialists, in particular, promoted this empowering approach:

> I only contact her if I need to now ... I've got her [MS nurse specialist] number on my mobile.
> (Simon, MS, site B)

> I suppose it's knowing that's – if you – 'cause sometimes you just get so, you know, that you're desperate, that there is someone [MS nurse specialist] I can ring up now. I could pick the phone up now and just, sort of, say, 'Help,' you

know. Whether there's any help there or not, but somebody's going to listen to me. And that makes a difference.
(Olivia, MS, site F)

Thus, models and processes that enabled re-admission, or which re-activated support when needed, could influence people's well-being. Interviewees were open-minded about the method of re-accessing this support. They were happy to be able to telephone professionals or services for advice and support in the knowledge that they would be advised to attend a face-to-face meeting, if needed.

Having said all this, however, whilst statutory services did provide some long-term input, in the main, continuity of support for people with LTNCs was managed by family members and voluntary groups via local peer support groups:

> *Raymond:*   *So my wife is persistently chasing up, chasing up, chasing up.*
> ***Interviewer:***   ***Hmmm, that's like a long-term job in itself****.
> *Raymond:*   *She does at least 40% of their work and it involves me, but she doesn't get paid for it.*
> (Raymond, MS, site D)

The central issues reported by people with LTNCs in relation to long-term continuity were thus the need for regular reviews by key specialist professionals involved in planning and providing their care and support; the ability to access them between reviews if necessary; and long-term access and re-access to services as and when need arose. The latter could be as simple as being able to call the service or professional for advice and support, as long as the service would re-admit them if necessary. When asked what was important about his care, Malcolm said:

> … knowing someone is there, absolutely correct. And they're ready and prepared to, sort of, come over and to see what stage and development of needs that you require and they'll be supportive in that respect.
> (Malcolm, MS, site C)

The models that seemed to meet these needs and, therefore, provide long-term continuity, were nurse specialists, CINRTs, day opportunities and GPs, alongside support from the person's family and the voluntary sector.

It is also clear from the above that other types of continuity could compensate to some degree if long-term continuity was not in place or was weak. For example, management or information continuity might militate against people feeling that they were having to retell their story, when re-engaging with services, thus contributing to the sense that their care had been uninterrupted.

Other types of continuity could also strengthen the experience of long-term continuity. For example, the trust that might develop between people with LTNCs and

professionals over time (relational continuity) could enhance the experience of long-term continuity.

5.2.2 Longitudinal continuity

Longitudinal continuity refers to care provided by as few professionals as possible, consistent with need. This is a challenging form of continuity to provide for people with LTNCs. Because of the multi-faceted nature of need for most of those with serious conditions, different *types* (and therefore numbers) of professionals are inevitably involved. Further, the episodic nature of some LTNCs means that people have to engage with professionals and services over very long periods – at diagnosis, during episodes of acute illness, when palliative care becomes necessary – but possibly with substantial time gaps between. There are thus at least two different ways of providing longitudinal continuity for people with LTNCs as defined in the Freeman model. First, at any given time of need, as few professionals as possible, consistent with need, should care for the person with a LTNC, perhaps with a key-worker who acts as a link between the different people involved. Secondly, at different periods of need, people with LTNCs should experience as few changes as possible in the professionals caring for them.

Service users frequently saw large numbers of people and, as with long-tem continuity, their experience of longitudinal continuity was closely linked to relational and information continuity. However, the need for numbers of different people to be involved in their care was often acknowledged as an inevitable trade-off to ensure different perspectives and specialist input. Wendy (PD, site E) had seen a number of different nurse specialists and consultants at different hospitals, but viewed this as acceptable since it represented a progression to more specialist input. Nonetheless, getting the balance right and not becoming weighed down by too many appointments and seeing too many different people was important.

Thus, the classic example of *not* experiencing longitudinal continuity was having to repeat one's story to different people. This was frustrating and undermined people's confidence in their care:

> It started off, it was [neurologist] that I was seeing. But I only saw her about a couple, two or three times when I was going. Then seen various other assistants of hers. But I never see the same person. So then when I was going, I took me diary with me, which had all the various types of attacks and when I'd had me attacks, and how often I'd had them. But then the only problem with that is that you'd go and see somebody and they didn't know your problem and they hadn't seen you before, so they'd be reading through your file. And then they'd ask you all the questions right from the beginning again. It was a bit of a waste of time really …. So now I'm seeing this chap who I saw in, when was it, January I saw him. And I'm seeing him again in July. But he said to me that I'd be seeing him all the time now, 'cause he's put in there regular now. So hopefully I'll be seeing him regular.
> (Liam, epilepsy, site F)

Trade-offs between different types of continuity, and other aspects of care, were possible. For example, people were less concerned about longitudinal continuity if they felt that the service was responsive and professionals shared information about them. For example, although many valued the relationship built up by seeing a particular GP, others were not so concerned if they felt that they could be seen quickly, they were understood and received appropriate treatment.

In some instances, longitudinal continuity could be more associated with a cohesive team than with individual professionals. Margaret with MS (site D) commented that although she preferred to have her own specialist nurse, it was good not to be reliant on individuals in case they were away when she needed them; knowing there were other MS nurses was reassuring.

Multidisciplinary team working and/or key workers enhanced people's experience of longitudinal continuity. Magda (neuromuscular condition, site B) had researched a specialist multidisciplinary service outside her PCT area that she was unable to access and instead, was referred to the local acute based rehabilitation service. She attended an out-patient clinic with misgivings, but was reassured by the way she had been able to see different members of the team individually and then in a joint meeting to assess her needs, all within the one hospital visit. For Thomas, who had been an in-patient in the same hospital, although his individual therapists had changed, the fact that they were part of an integrated rehabilitation team and that he had a key-worker for his physiotherapy worked well in providing a consistent service.

Where people were in contact with a cross-sector interdisciplinary team, they particularly valued its capacity to support their different needs via a single team. After a spinal injury, Sam had received physiotherapy, aids and adaptations to his house via the CINRT team in site F. They had also helped him to apply for benefits, put him in touch with a debt counsellor and arranged for education and employment training at the local day centre.

> They talked through – asked us obviously, what had happened, why I was the way I was. Asked us what help they could provide. As I was saying, from having no support, nothing, to getting – having the referral done by the [CINRT], everything, sort of, went [whistles]…
> (Sam, spinal injury, site F)

Similarly, in site D, Jeremy (brain injury) required a number of services to be involved in his support. The head injuries team co-ordinated his care, provided for longitudinal continuity and picked up discontinuities as they arose. Those in contact with an MND care centre particularly valued the way professionals were available on one site, at one time. Visits could take a full half day but people spoke positively of the experience and of the feeling of support that care by an interdisciplinary team provided.

High staff turnover, particularly among social workers and paid carers, was common in all case study sites and a significant barrier to longitudinal continuity. Toby, (brain injury, site A) described how he had seven different social workers since his brain injury. It was important that people came to know him to appreciate the effects of his injury and how it had affected his life. In terms of information continuity, handovers had been efficient; the negative impact was more to do with loss of specialist expertise and with having got to know someone over time, who then moved on. Similarly, interviewees with intensive care packages often acquiesced to a situation of changing agency carers, but nonetheless appreciated having the same person, especially for their personal care.

> If I have a different carer, you have to tell them everything, but if you have the same carer, you know, you know that she knows your body, she knows you and everything.
> (Zoe, cerebral ataxia, site A)

Relatives of people with Huntington's Disease (HD) (in site F) described how familiarity and routine were particularly important. Max was now in nursing home care in a specialist HD unit, but his wife described how having the same carers at regular times had been critical in his support at home. Jessica's (HD, site F) sister described the negative consequences for her sister of seeing too many people. The distress it had caused forced her to minimise the services involved and only contact people if the family were unable to cope. In the HD unit at the nursing home, the small specialist team, with minimal staff turnover, provided stability and improved continuity of care in a number of overlapping ways.

A lack of longitudinal continuity could lead to a withdrawal from services, not only in the context of HD where it was essential for people's well-being, but also with other conditions if people felt their care became disjointed. For Sarah with MS and encephalitis (site D), hospital services were spread across different sites, and she saw a number of different people. However, having a pro-active neurologist and good information systems made her feel care was well co-ordinated and services felt joined up. In contrast, in a different site, Samantha, also with MS, described how she had been to a number of different places for physiotherapy and had seen several different people.

> They come and go, yeah. It's like when I go to the rehab physio, you see a different person nearly every time we go. There's not one set physiotherapist. So all of, all these factors came to come together … . So we left it. And we've not actually been back since, [to the physiotherapy service] have we?
> (Samantha, MS, site F)

The consequences of discontinuities in longitudinal care had been particularly critical for some. GP 'out of hours' services or emergency acute admissions where a number of different professionals had become involved but were unfamiliar with a person's

condition or history, had exacerbated already vulnerable situations. In site D, Sarah with MS and encephalitis struggled with short-term memory problems, and seeing the same GP was particularly important to her. During an episode where she had deteriorated rapidly, her GP had responded to changes and admitted her to hospital. However, on the admissions ward with minimal information and constantly changing staff her deterioration had continued until her GP intervened. Thomas, who had been admitted as an emergency after a spinal stroke, echoed the impact of changing staff:

> They [NHS nurses] knew that I couldn't do that and I couldn't this. They knew how ill I was. And that lack of continuity, you know, of the bank nurses, who seemed to go anywhere in the hospital you know, you didn't see the same bank nurse even, or even the same contract nurse, you would see different bank and contract nurses.
> (Thomas, spinal injury, site B)

As with long-term continuity, there were obvious links between longitudinal continuity and other types. A lack of longitudinal continuity was often closely linked to weak or absent relational and information continuity. However, discontinuities not only affected therapeutic relationships and in-depth knowledge about service users, but also could introduce confusion and chaos into people's care, with negative consequences. Having an individual or a team able to provide ongoing care minimised the risk of such discontinuities occurring, and such services were also well placed to recognise the vulnerable points in people's care and smooth their overall pathways. Cross-sector interdisciplinary teams, such as CINRTs or the MND care centres that we encountered in our case study sites, were particularly successful in promoting longitudinal continuity of care.

5.2.3 Relational, personal and therapeutic continuity

Relational, personal and therapeutic continuity (later re-designated as relationship) as defined in Freeman et al.[26;27] is provided through one or more named individual professionals with whom the service user can establish and maintain a consistent therapeutic relationship. This type of continuity was central to the experience of good quality care for people with LTNCs, and those we interviewed valued the feelings of trust, personal interest, and better communication and information about their condition that this form of continuity engendered.

The relationship with GPs was one that people frequently saw as key in helping them manage their ongoing condition. Seeing the same person over time provided the opportunity to build up a good relationship, and having someone who knew and understood them as a person was an important element of this. Karen (MND, site A) valued the way her GP talked to her as a 'friend' not a 'doctor'. The awareness a GP gained of people's wider family circumstances could also be beneficial.

Good communication and a feeling of being listened to and understood was central to the therapeutic relationship. Such support from their GP helped many to manage their condition or cope with sudden crises. Greg's (PD site B) wife expressed concern about plans to create larger GP centres that might threaten the viability of their local health centre. She saw the trend as 'disastrous' for people like her husband who depended on an ongoing relationship with a GP to appreciate the changes in his condition. Jason, who had moved house, thereby breaking the long-standing relationship he had built with his small GP practice, provided another example of the importance of this source of support. However, although the relationship with his GP had been important, he acknowledged that it might be less so now he had access to the MS nurse specialist as well.

> Unfortunately, the guy we're with [now] is a very quiet, non-communicative bloke and he's not – we're not, sort of, engaging with him in the same way, … I'm fortunate, at the moment, it's not too much of an issue, and I guess …
>
> … it was nice to have the other relationship, but with the MS Nurse in post, it's not quite as important as it might have been.
> (Jason, MS, site A)

Service users who had access to nurse specialists particularly valued the way they combined specialist expertise with a personal relationship, and often saw them as the key person to contact when in need of advice or support:

> [MS nurse specialist] would be my first port of call because she's nice and she's always there to, you know, to listen to you, they're specialist in MS, and know what I'm going through more so than the doctor, 'cause doctors, sort of, like generalise on everything, don't they, really? It's not just specialising in MS, so it's always first port of call is always the MS Nurse.'
> (Olivia, MS, site F)

> The MS Nurse is – it's good it's there. It's just there when you feel, can't cope anymore, I've had enough. I don't want to, you know. So you can ring her up and just say, shout at her, but people I know with MS, don't use the MS Nurse at all, you see. And I say, well I think, 'Well, why?' That's what they're for.
> (Isabel, MS, site F)

For Paula with PD (site D), part of the nurse specialist's value was the time she was able to spend with her, in comparison to the consultant , who always seemed more rushed.

Positive therapeutic relationships were described in a variety of situations, but a common theme was the value people placed on the personal rapport and interest in them as a 'whole' person.

> She was not so much just her being my occupational therapist, but she became, sort of, a 'friend' to me if I needed somebody to talk to about, you know, normal stuff, like. I'm not talking about decision making things, but, you know, if I needed – if I wanted to ask her something, I could ask her.
> (Gordon, spinal injury, site C)

Jack, (site A), whose PD caused communication difficulties, was prepared to travel further to see a particular consultant because of their personal relationship and because he felt his consultant focused on him. Face-to-face communication was emphasised as important in developing a good relationship and in getting the best out of people.

For Robert (site E), recovering from viral encephalitis, relational continuity had been less important to him in the acute phase of his care when the only thing that had concerned him was that professionals were competent and confident. However, for his wife, relationships were always important because she needed reassurance of his progress, which was gained from people seeing him over time.

Relational continuity improved the confidence service users had in their care, but also their own self-confidence. Harry described how his visits to the MND Care Centre were important to his morale and sense of well-being.

> But certainly you go to – when you go to the Motor Neurone Clinic at the hospital [the approach is] 'There are no clocks in here. We all sit and talk as long as we want to,' and you just see each set of people, as we've said, and we've gone through and we have a great laugh, you know, sometimes.
> (Harry, MND, site F)

Interviewees with MND and HD, who currently saw no hope of a 'cure' or effective treatment, stressed the importance of being given time and sympathetic understanding. In contrast to the experiences of Harry above, the wife of Max, who also had HD, described their earlier visits to a specialist clinic where no-one seemed to be prepared to spend time with them. Their relationship with the specialist HD unit at the nursing home had been entirely different. The manager of the unit had been able to establish a relationship with Max while he had lived at home and was coming in to the nursing home for periods of respite, before becoming a permanent resident. The unit offered a calm environment with staff who had time to spend with residents.

> Max (wife):   Here, I've got faith, trust.
> **Interviewer: What makes this different for you and for Max?**
> Max (wife):   Because they care. The care and the love and the attention. That's all you can ask for. And the trust. That's all you can ask for.
> (Wife of Max, HD, site F)

Positive relationships and seeing someone on a regular basis meant that staff were more likely to be tuned into and responsive to changes in someone's condition, which was especially important for those with fluctuating conditions. The relationships Raymond had established with his therapists meant that they had a good understanding of the way his capabilities could change.

> Well, it's very important because one, you don't have to start from the beginning. ... So – but they know your moods. They can tell if you're up to whatever they're wanting you to do. They know how to structure the plan of action to suit you. They basically know what makes you tick … I know that if I'm not up to it, or I just don't feel like doing it, I can honestly say, 'Look, [OT], sorry, I just can't do this' and not feel totally guilty about saying that.
> (Raymond, MS, site D)

Continuity of therapeutic relationships promoted a better appreciation of progress and support to attain goals. Martin (spinal injury, site E), described how he had been doing well – able to take a few steps – with the goal of walking his sister down the aisle. A week prior to the wedding, he had a fall. The physiotherapist referred him immediately for an x-ray and then gave him extra sessions so that he would still be able to accompany his sister, which he achieved. He felt that without this relationship the physiotherapist would not have worked so hard for him, because she would not have understood the importance of the event, and he would not have achieved his goal.

In other contexts, sensitive adjustments to people's needs were seen as a benefit of continuity of personal relationships. Sam regularly attended classes at a local day centre.

> With yeah, with coming here, the people, you get to know the people so you can, sort of, see if someone's struggling or if I was struggling, so yeah. 'Do you want to have a break and we'll have a talk?' Or something like that. 'Do you need this today?'
> (Sam, spinal injury, site F)

The system of having a key-worker, commonly found in resource centres in several case study areas, enhanced experienced continuity overall, but the opportunity it gave to establish a relationship, or 'friendship', was at the heart of the perceived improved outcomes for service users.

Discontinuities in relational continuity were often keenly felt. Julia (MS, site A) regretted the loss of carers who had been with her for 17 years, until her care was transferred from the local authority provider to a private agency. Social workers frequently moved on. Emma felt that social services support had deteriorated in recent years. She no longer had a designated social worker and had to re-refer each

time she needed support. The discontinuity made it difficult to plan for her future needs and wants.

> The support from Social Services now is nowhere near as good as it was, I don't think. You haven't got any continuity. So before I knew I'd got the same social worker. I'd got the same OT, so you built up a, sort of, relationship and they knew me and I knew them. Now it's a case of having to re-refer every time almost. You know, self-refer, and start off with a new person.
> (Emma, MS, site E)

Several people talked of being a 'number' and the consequent feelings of not being valued. Matthew coping with a brain injury (site A) lived in warden controlled housing and was trying to move to a ground-floor flat. There was no named person at the housing association to liaise with and he found negotiations with a faceless organization difficult.

The impact of the loss of relational continuity could be distressing and have consequences for psychological and physical well-being. Joseph in site B, who had suffered a traumatic brain injury, described how losing his counsellor had adversely affected him. He felt the replacement counsellor did not understand the subtleties of his moods and the flash points for his anger, exacerbating some of his problems.

Potential instability in relationships could cause anxiety. Alan used an agency to provide his care at home. He currently had the same carer, but he was concerned that, by the very nature of agency style working with its high staff turnover, he would have to get to know new people regularly. This caused him a lot of anxiety, which in turn affected his condition.

> And that, with my condition, and I'm sorry if I sound as I'm whinging. But it creates a lot of anxiety and a lot of difficulties until you do get that comfortable feeling with someone. And the anxieties make your symptoms much worse and have a bigger impact.
> (Alan, MS, site E)

As this suggests, a sustained relationship was particularly valued in the context of paid carers. Interviewees were often resigned to seeing a large number of different carers, but they appreciated continuity when possible, providing them with greater trust and confidence:

> I'm now set up with one carer who comes in Monday, Tuesday, Thursday and Friday, who I've got to know well. She's a super Polish girl. We get on well and she knows me and she knows what I can do and can't do, and she is just great, and the half hour she whips through it, and we're just great.
> (Thomas, spinal injury, site B)

Relational continuity was critical where carers lived-in. Julia, a woman with advanced MS, described the difficulties of finding the right person.

> Well if you've got someone living in your house, then they need to be as comfortable with you as a couple, as a member of your family is with you.
> (Julia, MS, site A)

As this analysis has shown, relational continuity involved not just being able to see the same person, but the personal rapport and trust that was established. Having someone who listened, knowing there was someone on their side, who understood their condition, was a common theme throughout peoples' narratives, which made a difference to their feeling of being supported in the present, and to being able to plan for the future. A key-worker role, frequently adopted by nurse specialists but also by other practitioners, fulfilled the need for the positive personal relationship people described as crucial to their care. Further, as we have seen, while relational continuity was found in a variety of settings, it underpinned and facilitated many other types of continuity.

5.3   Management continuity

5.3.1 Flexible continuity

Flexible continuity is a feature of service provision or professional involvement that allows adjustment to the needs of the individual over time. As we argued above, LTNCs pose particular challenges because of sometimes episodic and often fluctuating needs. The needs of people with LTNCs can vary and change over time, often in unpredictable ways, and it is important that services can respond quickly and be adaptable to changing circumstances. Our interviews showed that relationships with individuals might influence how responsive they were, but elements of service systems, for example around appointments, reviews and location could also facilitate or create barriers to flexible continuity.

There were several examples of GPs and district nurses, in particular, being on call if needed. There was an awareness among people we interviewed that demands on district nursing services were great, but also confidence that they would respond if truly needed. One person also found that, where their general practice systems had seemed not very responsive, district nurses had managed to make things move more quickly. Nurse specialists were also highly valued for their flexibility and for the way they facilitated responsiveness in the system.

> Yeah, because she's [MS nurse specialist] – honestly, she's sound. She always says, you know, 'It doesn't matter, you don't have to get in touch with me when I'm here on a Tuesday. … You can phone me up anytime, Harvey, anytime.'
> When I had the accident in town I phoned her up the same day. And that was on

> a – I think it wasn't on a Tuesday, it was in the week, Thursday or Friday, I can't
> remember … Oh, no, she's there at the end of the phone.
> (Harvey, MS, site F)

This responsiveness and flexibility were important factors in making nurse specialists a reliable point of contact. However, although they were generally flexible in the times they were available, they varied in the extent of their community-based work. Agatha (MS, site C) appreciated telephone and email access to nurse specialists, making it possible to make appointments when needed, but all her appointments were hospital-based. In contrast, being able to see her nurse specialist at her choosing, either at hospital or home, was important for Charlotte with MS in site E, particularly when incontinence problems became an issue. Even where nurse specialists focused their time in the community, interviewees in some areas reported that lack of capacity, nurse specialists covering large geographical areas, and being too busy, could be major barriers to the flexibility and responsiveness of the service and its ability to work effectively.

In contrast, appointments with neurologists or consultants were often seen as not as flexible. The opportunity to discuss problems and concerns was important, but clinic review processes were often fixed.

> It's quite often difficult to do these things at short notice, you know. Very often
> you can pick up the phone, and you'll get an appointment, but it's not for three
> months or something like that. Whereas what I feel that I would want in those
> circumstances is to phone up and have a chat, you know in about a fortnight's
> time at the most if something was worrying me specifically.
> (Thomas, spinal injury, site B)

Rebecca described how she had difficulty in getting in to her neurologist's clinic during a suspected relapse of her MS, even though he had told her to ring his secretary if needed.

> … Because for the whole seven months, I'd been feeling I was relapsing, getting
> through it, and relapsing and relapsing and relapsing, and there was – the doctor
> was doing a very good job for me. ... The – my GP was doing a good job for me,
> sorting me out. … But it was – the neurologist could have sorted it out maybe a
> lot quicker.
> (Rebecca, MS, site A)

In another area (site D), new systems were in place to provide access to a special relapse clinic. Margaret (MS, site D) emphasised how such a speedy and flexible response was critical to her during a relapse. However, she would have appreciated greater flexibility in where her intravenous (IV) steroids were administered. Currently, there was a trade off between taking oral drugs at home, which might not be so effective, and waiting to go into hospital as a day case for IV administration. For

Paula with PD in the same area, an emergency clinic for PD also provided flexibility in access to her neurologist between the scheduled six-monthly appointments.

The means to by-pass or over-ride customary systems provided people with greater flexibility. GP surgeries also varied in their responsiveness. Some people described difficulties in securing appointments, others succeeded in an ad hoc way, while yet others made use of more formal systems. Harry with MND in site F described how he was on his surgery's 'alert' list for vulnerable patients, which guaranteed him speedy access to an appointment.

Flexibility towards the needs of their clients was seen as a particular strength of the CINRTs found in our case study sites. People in site C stressed how they appreciated the way the team fitted in with their requirements. The team was based at a local community hospital, but the location of sessions could vary, not just because of the therapies being undertaken, but also for the convenience of service users. Similarly, support from the Motor Neurone Disease Association (MNDA) Care Adviser and MND Care Centre available to those in site F, was both flexible and responsive which was particularly important in the context of a terminal illness. Not only were people easily able to change the timings of their reviews at the care centre if there were any concerns, but also:

> You can ring anybody at any time and the motor neurone's number is 24 hours anyway, to ring them, and it's up to ten p.m. every night. You can always get contact with somebody. And we've got [MNDA care adviser's] mobile and home number, and the works number, so you can literally ring her at any time, doesn't matter when, if you need to speak, feel a bit down. Because let's face it, with motor neurone, you're dying, you know you're dying.
> (Harry, MND, site F)

Knowing that there was responsive support when needed enabled people to cope with the present, but also helped allay their fears for the future.

Experiences in the flexibility of response among social workers varied widely, but people appreciated social workers who let them make decisions in their own time and also change their mind. Criticisms of inflexible services were frequently aimed at home care and support. Examples mainly related to the lack of flexibility in the timing of home calls, but also in the sorts of tasks that carers would help with. One interviewee described how she had accepted her care package as a condition of being allowed home from hospital, but now found her life overly regulated and constrained by the set times her carers called. She had, therefore, cancelled weekend calls to maintain some 'normality' in her life.

> I'm like a cabbage when I have to have the carers coming into me. But then, at the weekends, we just, sort of, manage without them. And it's like coming back to life.
> *(site A)*

She and her husband worried that cancelling her care would make re-instating support, if she later deteriorated, problematic. Direct payments might have provided more flexibility, but they felt they had 'enough to deal with'.

Rules about aids and adaptations provided by statutory services at times seemed arbitrary and inflexible. Sometimes this centred on the type of equipment or adaptation offered:

> It's stupid because they say that it's difficult getting funds for a mattress, but if you ordered a complete bed, you could have it straightaway. ... It would have meant for me to be sleeping in what really looks like a hospital bed.
> (Lee, MND site D)

But for two people in site D, who had refused to have hoists installed, interpretation of health and safety legislation had led to a refusal to provide home care. People found themselves caught between the rigidity of different services. For example, trying to co-ordinate timings of carers, transport and hospital appointments had been a regular challenge for Thomas in site B.

The need for flexibility extended beyond immediate health or social care services and was equally important in other areas of people's lives. For Lisa with cerebral palsy in site D, the flexibility and responsiveness of the support staff in her sheltered accommodation helped her maintain her independence as much as possible. After spinal surgery following an injury, Sam had been unable to continue with his previous employment and was taking courses to develop new skills at the local day centre. He appreciated the flexible learning environment:

> If you take longer to do something, you need to take longer to do something. There's no pressure on having to finish an assignment by such and such. You explain, 'I'm having trouble with this, I will do it, I just need a little bit longer.' And, sort of, 'Okay, well we can't put you in for the exam this term, but we'll extend it next term.'
> (Sam, spinal injury, site F)

Service provided or community transport, for example, transport for hospital appointments or the booking system for 'Ring and Ride' services, were sometimes unable to provide adequate flexibility. Joshua's wife described the local service:

> They can't do block bookings. They can only book it on the same day, you ring and ring and ring all morning, to find out that it's full by the time you've got through.
> (Wife of Joshua, PD, site F)

Inflexible attitudes and a lack of understanding among employers was a common theme for those of working age, especially for interviewees with epilepsy. Some had chosen to give up work after becoming disillusioned with attitudes within the

workplace or lack of support from Job Centres. For others, their confidence to continue had been severely shaken. Olivia was in dispute with her employer's refusal to accommodate her need for part-time working since the onset of her MS. This was still unresolved and had affected her confidence to return to work:

> I had these two guys from Head Office in London coming up, making a judgment on my work performance, who never even knew me, never even seen how I've worked and just turning round and at the end of it all, sort of, like the report came back, sort of, like two weeks later, and they were dragged in the office to read it, and it just said, the bottom line was, 'Recommended termination.' … And it was just – it was like being hit in the face with a bag of bricks.'

Despite legal advice, there was an ongoing dispute:

> We said, 'Well, look, all right, the neurologist said I can't do full time, 'cause I can't be stood up for long periods, but there's nothing ruling out part-time.' 'Oh, no, no, no, we can't do part-time.'
> (Olivia, MS, site F)

To sum up, flexibility and responsiveness within service systems, but also underpinning the attitudes of individual professionals, were highly valued by service users. Nurse specialists and CINRTs were models of care that service users highlighted as particularly good at providing flexibility. Examples were found also among other individual professionals where there was a personal willingness to adopt flexible working practices, which helped to promote continuity of care. Relationships between service users and professionals thus were often central to improving flexibility and responsiveness. Difficulties were often attributed to organisational problems such as inflexible appointment systems, time-regulated and task- oriented carers and an ignorance about the needs of people with LTNCs. A lack of understanding was especially common outside immediate health or social care concerns, such as in employment issues. Where flexibility, and the responsiveness that often accompanied it, were found they helped support people's independence, maintain 'normality' in their current lives and reassured them that future needs could be met.

5.3.2 Cross-boundary and team continuity

Cross-boundary and team continuity involve effective communication and co-ordination across and within service and sector boundaries, and between professionals, service users and their families or carers[46]. It thus involves both cross-boundary continuity and issues of communication between professionals and with the service users and their informal care networks. Through our case studies, we found that this type of continuity was most effectively achieved where a named professional, team or service acted as a focal point for a person's care, guiding them through the system and helping to resolve discontinuities where these arose.

The importance of cross-boundary and team continuity, and the factors that promote it, are most evident where those factors are absent. In the in-patient environment, poor communication between ever-changing staff groups and between professionals and service users and/or carers caused confusion and distress. The people we interviewed gave examples of information not being passed between professionals in relation to infections, medication, and the specific support needs of patients. In the main, such experiences arose when people with LTNCs spent time on generic, rather than dedicated neurological wards.

People with LTNCs talked more positively about their experiences of cross-boundary and team continuity as hospital out-patients. They gave accounts of timely and smooth transfer though the system and effective communication both within neurology departments and between these and other hospital services. In part, people attributed this to the systems and services in place (for example, a relapse clinic for MS patients), but it was also linked to key care co-ordination roles such as nurse specialists and condition specific teams:

> … I know that I need steroids [when I have a relapse], so they'll arrange it [the MS nurses], you know, quite quickly, arrange to get me in to see the doctor 'cause they've got a Relapse Clinic now…
> (Margaret, MS, site D)

Conversely, a lack of co-ordination in the community was most evident when a number of different professionals were involved, but no single person or team had responsibility for overall organisation of the individual's care. In the example below, none of the professionals working with Rose appeared to have an overview of her case, leaving her husband to 'worry' about her alone:

> After Rose's chest infection we were actually in this room, and the GP was here, and the OT was here and I think one of the district nurses or somebody else was here and we were talking about the transition onto the hoist, because Rose was just getting to the stage where she couldn't really use the turner anymore and I said, 'Who is in charge of this case? Who's overlooking this, who's got the folder to see how Rose is getting on?' … And there's no real answer to that question. There doesn't seem to be anybody who sits around worrying about Rose [laughs], apart from me.
> (Husband of Rose, MND, site B)

It was not until the local hospice became involved and a key-worker was allocated, that both Rose and her husband felt reassured. The hospice key-worker visited once a month and would come more often if required. Rose's husband commented that there was 'nothing like that through the NHS', adding that, although their GP was 'wonderful' in emergencies, she did not provide active care co-ordination.

Discontinuities arose frequently at the point of discharge from hospital to home. Interviewees told us how poor communication between acute and community

services caused delays and anxiety. For example, Freda had been admitted to hospital over 30 times for complications associated with her MS and epilepsy, and almost every time she and her husband felt let down by the system. Her husband said of the times she had returned from hospital:

> So she should have had a physio follow-up. She should have had the social worker. She should have actually had a visit from the district nurse. She should have had updated medication, and her original medication sent home. And there's a couple of other things that should have been done. And on only one occasion in that period of time that she'd been going backwards and forwards, did that ever take place, and that was 'cause I had an argument with one of the ward staff about it, and I got explained what the procedures were on her discharge. But that never, ever happened. It was always, she came back into my care, and that was it. And I was left with it.
> (Husband of Freda, MS and Epilepsy, site A)

Sam, from site F, spoke of feeling 'abandoned' after returning home with spinal injury. After three months, a CINRT intervened and his experience changed. This team assessed not only his physical and mobility needs but also his wider needs for financial advice and retraining, putting him in touch with relevant agencies in other sectors. This was highly valued, with Sam seeing the input as 'the biggest part of me recovery really'.

Such teams are critical to ensuring management continuity both within the health service and across sectors. However, as Sam's example illustrates, it is essential that there is smooth and timely transition to these teams from the outset and that service users are informed about the support available. This was the case in site C, where people we interviewed reported high satisfaction with their transfer from hospital to the CINRT. Malcolm, for example, commented:

> I felt initially, greatly comforted by the consultant, the team, bringing me then to the next stage, quite quickly. … There was a direct link from there to there, and quickly. … So I think after a couple of weeks, I got a letter from the [CINRT].
> (Malcolm, MS, site C)

Where CINRTs did not exist, experiences of cross-boundary continuity were dependent on there being other teams or individuals responsible for care co-ordination. In site A, for example, there was no CINRT for people with MND. However, the intermediate care team had a strong re-ablement focus and staff actively liaised with social care and voluntary sector colleagues to ensure that, when the period of intermediate care ended, there was a robust package of long-term care in place to go forward. For people with LTNCs it is essential that such support has this long-term focus, and is not solely about the point of transition from hospital to home. Thomas provides a good example of what happens when this long-term focus is not in place. He spoke highly of the support he received initially from his hospital

social worker and physical disability nurse specialist, who together co-ordinated his return home after a spinal injury:

> … their job was to prepare you in – closely, you know, for coming out, and trying to work out – and they'd all been here to the house. I mean, [physical disability nurse specialist] led a great party of people here to the house to have a look at, you know, what I'd got and what I would need, and things like this. So that was brilliant.
> (Thomas, spinal injury, site B)

However, once he was home, the co-ordination of his care ended:

> Thomas: Once the hospital seemed to have sorted that out and it seems to, that's it, it's handed on, you know, and he's [social worker] then busy with all the new people coming out of the hospital as opposed to the continuity of the people he's seen out.
>
> **Interviewer: And there hasn't been a social worker or anyone in the community that you've had the ongoing contact with?**
>
> Thomas: No, no, no.
> (Thomas, spinal injury, site B)

The people we interviewed stressed repeatedly the importance of having a named individual or team co-ordinating support across boundaries. Nurse specialists were the professionals most often identified as successfully undertaking this role, although in some areas social workers, voluntary sector workers or CINRTs also co-ordinated care. Accolades for nurse specialist support came up frequently in our interviews:

> Oh, the service we've had is exceptional … [consultant] almost starts the appointment with the latest letter he's had from [nurse specialist], so it is working well. It's a, you know, it's a triangulation and the GP knows what's going on and [consultant] knows what's going on and [nurse specialist] is effectively facilitating all of that.'
> (Husband of Paula, PD, site D)

The proactive approach of nurse specialists meant that discontinuities could be picked up and resolved before becoming insurmountable. Lee and his wife, for example, recounted several instances where their MND nurse had brought together otherwise disparate professionals and intervened when communication broke down. In the extract here, a physiotherapist had failed to get back to Lee after doing an initial home visit:

> Wife: … [nurse specialist] got in touch with her, she [the physiotherapist] admitted that she forgot to get back in touch with us, so he [Lee] didn't get any more for, like, six weeks, but now she's coming again on Friday.
>
> Lee: Because we thought oh, well, we've heard all this before.
>
> Wife: We were sort of thinking, well, we're going back to square one.

> **Interviewer:** Hmmm. Here we go again.
>
> Wife: Here we go again, they're not bothered, [but] anyway, [nurse specialist] got in touch, didn't she?
>
> Lee: But she is coming out again.
>
> Wife: And she says 'She's sorry, she forgot you.' She's coming this Friday.
>
> (Lee and his wife, MND, site D)

Similarly, CINRTs often stepped in to pick up the threads across service boundaries, liaising with local authorities, care agencies, and even banks and solicitors where necessary. Value was placed not only on signposting to appropriate services, but also on teams actively advocating on behalf of people with LTNCs:

> They really helped me, the [CINRT] which form part of the PCT were behind me all the way and helped me contact the right people at the local authority, actually got them round here and they came and sort of, backed my case up, sort of thing.
> (Agatha, MS, site C)

Day opportunities and resource centres could also act as focal points for co-ordinated care. These centres often spanned service boundaries, pulling together health, social care, local authority and voluntary sector services. As well as providing opportunities for people with LTNCs to take part in activities and access services across the system, they could provide a bridge from in-patient to community living and often hosted cross-sector meetings to co-ordinate ongoing support.

Examples where cross-boundary and team continuity worked effectively across the system and on an ongoing basis, tended to involve a combination of the above elements. Jeremy, for example, was very happy with the organisation of his discharge from an independent sector brain injury unit to a package of co-ordinated support in the community. The social worker assigned to him when he was in an in-patient remained with him when he returned home and is still his social worker today. She organised for him to attend a resource centre specialising in brain injury whilst he was still an in-patient and he continued to attend this until he found paid employment. She also referred him to a CINRT who directly provided occupational therapy and neuropsychology, and liaised with his local college and employer. The resource centre hosted regular cross-sector review meetings with representatives from the CINRT, his social worker and training providers. When asked if the services he had received felt joined up he replied:

> Yeah, well, I mean, it all happened, like, [wife] used to come to me reviews here and I think it's a good service that were provided for me … especially when I needed it …
> (Jeremy, brain injury, site D)

To sum up, our case studies suggest that cross-boundary and team continuity is improved when a named professional, team or service acts as a focal point for a person's care, guiding them through the system and helping to resolve discontinuities as these arise. Other approaches to improving this form of continuity, such as the use of a Single Assessment Process or patient/user held records, did not feature centrally in the accounts of the people we interviewed. In the few instances where respondents did have user-held records, these were often not completed for long stretches of time, or were only used by professionals from one part of the service system (most frequently home care). Where large numbers of professionals were involved in a person's care and no designated worker or team had responsibility for care co-ordination, it often fell to the person's family or carer to keep track of their care and intervene when problems arose. This puts considerable pressure on informal carers and led to a number of couples we interviewed feeling unsupported and let down.

5.4   Information continuity

Information continuity as originally defined in the Freeman et al.[26] model referred to excellent information transfer that *followed* the service user. Subsequently, research underlined the need for excellent information transfer *between* services or professionals and the service user[46]. As might be expected, this latter form of information dominated the accounts of people with LTNCs and we concentrate on that aspect in this section of the chapter. Issues about information following service users were more often talked about in relation to care co-ordination and have consequently been included in the section on cross-boundary and team continuity (see above).

People we interviewed talked about the importance of receiving high quality, timely information about their condition and the support that was available to them. Clear and open communication at the point of diagnosis was valued, as was knowledge about how to obtain extra support and information should it be needed in the future. It was also important to know how conditions might progress over time so that people with LTNCs and those close to them knew what to expect. In addition, participants valued having an ongoing point of contact for information so that, as their condition changed, they could ask further questions and allay new fears:

> … it becomes less frightening once you know. … That's what they don't – the professionals don't always realise and you like a line of contact. You need to see somebody on a regular basis so that you have – you feel there's somebody out there who knows. ... Because most illnesses are frightening …
> (Pippa, PD, site A)

Pippa had experienced blurred vision and at first did not know that this was a common symptom of PD. When she did find out she felt reassured, even though there was nothing that could be done to treat her.

The majority of people we interviewed had very little knowledge of neurological conditions before they became ill, and in many cases the unknown made their diagnosis more frightening. Raymond, for example, had never heard of multiple sclerosis. When an unfamiliar GP gave him this diagnosis and mentioned wheelchairs, he said he felt like his world had been 'turned upside down':

> 'Yes, you've got MS.' Well she might as well have said Marks & Spencer's because I just had no idea what MS was. And she says, 'But it doesn't mean a wheelchair straightaway, so don't worry.' … Well soon as she mentioned wheelchair, I'm thinking all sorts, am I going to die?
> (Raymond, MS, site D)

The information given with and immediately after diagnosis is particularly important. In Raymond's case, he left the surgery uninformed, but his usual GP visited his house the same night and answered his questions. In many cases, however, people were given no further information. When asked whether she felt the information she had been given at diagnosis was adequate, Constance replied:

> No, no. My diagnosis was given to me, 'Well I suppose you know what's the matter with you? Yes, it's Parkinson's. Well, you know, go off and live.' I said, 'Well, you know, what do I do? Do I exercise? Do I need any special diet?' 'Oh, no, just go off and live your life, I'll see you in six months.' There was no, 'Do you need any information? Can I – would you like to be put in touch with the Parkinson's Disease Society?' Nothing, absolutely nothing … I was disgusted at the way it was broken to me…
> (Constance, PD, site A)

In contrast, those who had received more information, or who had been asked how much information they would like and then communicated with accordingly, were much more satisfied:

> … he said, 'Are you the sort of person that likes to know the possibilities?' and I said, 'Yeah'. And he spent about three quarters of an hour telling me about MS … and it, sort of, explained everything really, everything, sort of, slotted into place and so I was really grateful to him for that.
> (Caroline, MS, site D)

Often, being told that a national voluntary sector agency exists is enough to enable people to tap into a network of information and support. For example, Mary, was given a booklet at the hospital that mentioned 'something called the Parkinson's Disease Society'. She contacted the organisation and learned about support groups in her area for people with PD, as well as nurse specialists whom she could contact

for extra support. She also heard about the Expert Patient Programme though the society. Her discovery of this information, however, relied upon her taking the initial steps to contact the society:

> I feel if I had not taken the trouble to get myself involved with the Parkinson's Society, I think I would have just sat here and not known about all these things, 'cause I don't think anybody else would have bothered
> (Mary, PD, site E)

Similarly, when Tina, from the same site, was first diagnosed she was not informed about the local PD Society group, either by her consultant or by her GP:

> … the Consultant didn't tell me and nor did my GP which I think they ought to have done.
> (Tina, PD, site E)

Several interviewees expressed disappointment that professionals did not take more responsibility for ensuring that they were fully informed. In some cases, it was felt that the level of information received depended on asking the right questions, which put those not already in the know at a disadvantage. The husband of an interviewee with encephalitis and MS, for example, commented that you are unlikely to have prior knowledge of the sorts of supports available for people with LTNCs in advance:

> You've nothing that prepares you. You don't do anything like this at school. And it seems really poor that the people dealing with you, whether it's your doctor, or your hospital … cannot tell you how to go on from there. And can't even say, 'These are the lines of avenue you might pursue. And some will close off and some won't, but it's up to you.' There's absolutely nothing.
> (Husband of Sarah, encephalitis and MS, site D)

The only medical professional who had offered any information that Sarah and her husband deemed useful was the MS nurse, but they did not gain access to her services until a formal diagnosis of MS was received, some years after Sarah first became ill. In the absence of information from the NHS or social services, this couple had found the Encephalitis Society particularly valuable.

Voluntary sector organisations specialising in particular LTNCs were repeatedly cited as the most important sources of information and support for people with LTNCs. It varied as to whether interviewees made most use of information from national newsletters and websites, or local groups and information days, but almost all spoke highly of the voluntary sector as a source of information.

Interviewees told us that having information about one's condition and its treatment gave a sense of empowerment:

> I had a computer at the time, and eventually I got onto the Parkinson's Helpline,
> and when I got – came off there, I felt like a king, but there was nothing in [site F]
> at all.
> (Joshua, PD, site F)

Some of the people we interviewed had attended self-management or education groups that were expressly designed to enable people to take control of their own care by improving access to information. Again, it was common for these groups to be set up and facilitated by voluntary sector agencies specialising in particular LTNCs, often with the combined objective of providing a social outlet and access to information. People with LTNCs and their carers obtained valuable information through the social elements of these groups as well as through their more formal sessions. For example, agencies might arrange for the local nurse specialist or speech and language therapist (SaLT) to talk to a group, but the informal networking opportunities afforded by bringing people with the same LTNC together were also very valuable:

> It is useful to get together with people of the same kind, as it were, that is useful
> … I think the medical profession, whatever illness you have, ought to be aware of
> that, that that's as good as seeing the doctor, yes, to see other people and talk
> about your problems.
> (Pippa, PD, site A)

The importance of discovering that other people are going through similar experiences should not be underestimated; valuable learning and information can be pooled and passed on:

> I find that, if you're speaking to somebody who's in a wheelchair, … and you ask
> them how, you know, 'Well how did you get your injury?' basically, and then they
> say to you, 'Well, I got me injury 20 years ago.' You suddenly think, 'Well, hang
> on, that's 20 more years' knowledge than I've got already, so what do you know
> that I could use for me?' … And then you pass that on to whoever you can pass it
> on
> (Martin, spinal injury, site E)

Peer support groups do not necessarily need to meet face-to-face in order to be useful. Simon, for example, was a member of an internet based MS forum that he found helpful:

> Somebody will post up on the forum that they're having problems with this and
> problems with that. So someone else who's had that kind of problem, will reply
> with, 'This is what I did to get round it, maybe you could try doing that?'… Yeah, it
> can be very helpful.
> (Simon, MS, site B)

People we interviewed also told us about self-care and education groups run by statutory organisations and health professionals. Programmes that were most

consistently valued were those that focused on specific LTNCs, and where participants were at a similar stage in the progression of their condition. Olivia had attended sessions for people newly diagnosed with MS, which she found particularly helpful:

> … you used to go once a week for five weeks, and they had all sorts of information there. They had, sort of, like the neurologist there explaining everything to you one week, and then they had a guy from the Social Security explaining about, you know, all the benefits you can get. And then they had a woman there from, you know, for yoga, who, sort of, like her husband's got MS and she's developed a yoga routine, you know, to help, and all this lot.
> (Olivia, MS, site F)

In site A, the PD nurse specialist and team ran several education groups for people at different stages of PD that were repeatedly cited as valuable sources of information, both about the condition itself and about the support available to people with PD. Different health and social care professionals spoke at these sessions, and this was often where people with PD first heard about local services. In this way, the education group linked participants with the wider service system, promoting management as well as information continuity.

Other models that supported such linkages through the provision of information and signposting were nurse specialists, voluntary sector information workers, and CINRTs.

Often teams or professionals with a special interest in neurological conditions were felt to provide better information about benefits and employment than agencies designed for this purpose:

> The Job Centre weren't very forthcoming with any advice at all. And again, no-one even mentioned – I didn't even know what Disability Living Allowance was until [manager CINRT] had explained, you know, and put a claim in for this, you know.
> (Sam, spinal injury, site F)

Here again, the voluntary sector was seen as a valuable source of information about financial issues and benefits, and this was especially so where there was face-to-face contact with a designated information or support worker. Newsletters were welcomed, but there was preference for information to be transferred personally. Thus, in site F, the MS nurse specialist, the MS Society's welfare adviser, and the PD Society's community support worker were all trusted sources of information because of the relationships they established.

Across all sites, however, there were instances where people with LTNCs did not feel that they had been given sufficient information. Where the system worked best, nurse

specialists and CIRNTs acted as integral points of contact for specialist knowledge within a network of support including voluntary sector groups, information workers, hospital and primary care services. Even where such services existed, however, not everyone with an LTNC had access to them. Paula and her husband (site D), for instance were unaware of the support available to them until a questionnaire from the PD Society asked if Paula's husband was registered as a carer. He visited his GP to look into this, and the GP put him in touch with the PDNS and PD Society Information Worker, who in turn told him and his wife about a range of services and support to which they were entitled. Before this neither he nor his wife had benefitted from these services.

In summary, our case studies suggest that people with LTNCs and their families and carers value receiving high quality, timely information both about their condition and about the full range of support available to them. Voluntary sector organisations specialising in particular LTNCs are a vital source of this kind of information, which they provide in a variety of media including newsletters, websites, local groups, workshops and information days. Statutory sector services and professionals also provide valuable information, particularly when they have neurological expertise and the time to answer questions in full. Condition specific education and peer support groups run by the statutory or voluntary sector are valued formats for information sharing. In addition to their formal teaching elements, both facilitate the spread of information through word of mouth, ensuring that the expertise of people with LTNCs and their carers accumulated through firsthand experience is not lost.

A key pre-requisite to people with LTNCs benefitting from any of these sources of information, however, is that they are aware of and have access to them in the first place. Information provision and signposting need to begin at the point of diagnosis and continue, as people's openness to, and need for information change over time. Ongoing access to a key professional or specialist service able to answer questions and allay concerns as and when they arise is one way of ensuring this.

5.5   Continuity of social context and of personal agency

5.5.1   Continuity of social context

Continuity of social context refers to people being able to maintain preferred social and personal relationships and activities in order to enhance their quality of life and well-being. As we suggested in the introduction, this type of continuity might be seen as an outcome to which other types of continuity could contribute.

For the people with LTNCs that we interviewed, sustaining social and personal relationships could be problematic. They also reported difficulties with maintaining everyday activities, such as employment and daily household activities, as well as

being able to continue with hobbies and other leisure activities. When people were unable to maintain social relationships and activities, they reported loss of confidence, which in many cases was reported to have had a detrimental impact not only on their quality of life, but also on their condition. Where able to maintain these activities and relationships or develop new ones, people felt that they were able to look into the future with a more positive attitude.

Through narratives of their experiences of services and environment, people with LTNCs identified factors that helped and factors that hindered continuity of social context. The main factors were physical accessibility, attitudes of other people, financial concerns, the way some services were provided and the approach of the person themselves. Family and friends were seen to be key factors in promoting continuity of social context.

Many people reported giving up or changing hobbies, interests, work and leisure activities as their condition deteriorated. For some, this was related to physical accessibility, but for others fatigue, tremors and cognitive functioning were the main reasons. Interviewees described how they had felt it necessary to reduce their work hours, or the type of work or social and leisure pursuits they undertook, to limit the negative impact of these activities on their condition.

> I think when I was first diagnosed I, sort of, like wouldn't, kind of, accept it. So I always used to fight against it and, you know, push myself further and further, whereas now I'm thinking well, no, I'll bugger myself up worse that way. Now you've got to learn to work with it, and I've learnt to work with it now, instead of against it.
> (Isabel, MS, site F)

Whilst some people reported that these changes were demanded by the nature of their neurological condition, others were less clear that changes were solely related to this. Being able to get to, enter and use facilities within buildings was important to maintaining social continuity. People with LTNCs described the difficulties they experienced because they now had to consider these access issues. For example, before they went to any social or leisure events, people had to consider a number of accessibility issues, such as how easy it was to get there, how busy it would be and whether toilets could be easily accessed.   In a number of cases, poor physical accessibility had made attending family gatherings, such as weddings and funerals very difficult and, in some cases, impossible:

> My nephew's wedding, there wasn't a toilet where he had his reception, but he said 'Oh, there's one in [name of shop] opposite.' And there wasn't, so we didn't go to the reception [laughs].
> (Emma, MS, site E)

Difficulties with travel could also limit social continuity for people with LTNCs, especially when travelling longer distances or on a regular basis. For many, the cost of transport could be prohibitive, particularly for the majority who were no longer in paid employment or were in lower paid positions. 'Dial and ride' schemes across the case study sites were seen as being useful but in some places were very busy meaning that using them demanded forward planning, something that the unpredictability of LTNCs sometimes made it difficult to do.

Supported by the 'blue badge' (disabled badge) system, where people can park closer to amenities, many saw car ownership as a necessity to help overcome these issues and relied on the mobility element of the Disability Living Allowance to meet their transport costs:

> 'cause I was on the two amounts, but they do stop me £180 a month now, which I do miss, don't I? We do miss it, but we can't manage without the car. ... But it's still – we couldn't afford to buy a new car, not with no money coming in. And it means that I'd never be able to get out or, you know, do things. … You couldn't rely on public transport.
> (Samantha, MS, site F)

The bureaucratic complexity that people had to navigate in order to apply for, be assessed for and purchase adapted private vehicles could be confusing and sometimes led to delays in exploring car ownership as an option, thus constraining their social continuity.

Some of the people we interviewed felt that the level of understanding others had could significantly affect their options for maintaining continuity of social context. Most reported that they had lost some friends since their diagnosis and as their condition deteriorated. However, lack of understanding and stigma were most strongly felt in relation to employment. Where people had been able to stay in employment, this was largely reported as due to the attitudes and associated flexibility of employers and colleagues:

> … I work full time, but in the last 18 months, work were very good that they allowed me to adjust my role at work. So that I don't have line management responsibilities, and I'm able then to work in the office two days a week and I condense my meetings, and then work at home for the remainder.
> (Agatha, MS, site C)

> … because the [name of organisation] is so good, they'd arranged it so that I could – I'd got somebody to go with me on the train, but also they arranged it so I could do some interviewing in the morning, and they'd got a room that I could have a sleep in and then come back and do the rest of the interview in the afternoon, which is how it should be … the [name of organisation] was set up by – it was begun by a disabled woman, called [name], and it's like a – it's a national body now.
> (Caroline, MS, site D)

These experiences contrast strongly with those reported by Olivia in section 5.3.1. In getting information about how to enter and re-enter work and about social security benefits, people had found their local job centre of little help. Lily summed up some of the problems people with LTNCs had experienced with this service:

> But I didn't get very far with it. I [pause] – and [Job Centre Disability Advisers] were suggesting all sorts of things for me to go for and it just went worse and worse. They were saying, 'Oh, you could do this or you could do that.' So I just gave up in the end.
> (Lily, epilepsy, site F)

People with LTNCs did describe a number of service models that promoted social continuity. Across all sites, day opportunity services, CINRTs and voluntary organisations played key roles. People felt that these services understood them and their needs and helped to promote social continuity by providing appropriate equipment, practical and emotional support, and information and advice.

In the case of day opportunities and voluntary services, the people we interviewed also viewed them as a place where people could come together and make friends, and for some people they provided opportunities to take part in activities in which they had always been interested. Lisa provides an example of this:

> ... The main things that I take part in are the drama group on a Wednesday afternoon, and I've been part of that group for about eight years now. Yeah, and a lot of stuff that I've done around drama, I wouldn't have done without that drama group really.
> (Lisa, Cerebral Palsy, site D)

As well as these services, people reported the role of key individuals in providing the information that enabled them to pursue work, training or leisure activities. These included nurse specialists, occupational therapists, and disability advisers at colleges and universities.

Being able to plan and adapt to services, the environment and other people's attitudes were key to maintaining existing and developing new work and social or leisure activities, and were viewed as being part and parcel of self-management. However, some people found it difficult to do this without support. The services and professionals identified here (community rehabilitation teams, day opportunity services, voluntary organisations, and specialist professionals) because of their specialist knowledge of the person, their condition and local services, were able to advise people on mechanisms and processes that might help them plan for the future and thus to tackle possible barriers to work, social and leisure continuity.

However, most people agreed that the main factor promoting continuity of social context was their family and friends. It was here that people were able to be

themselves and continue to be treated as individuals with individual preferences. Families and friends, often by adapting their own social and work life, provided support that helped the person with an LTNC make changes as and when needed.

5.5.2 Continuity of personal agency

Continuity of personal agency refers to people retaining control over their lives, managing their own health and well-being and making their own choices. As such, it is a key element of independent living. It can be seen as an outcome of other forms of continuity explored in this chapter and is closely related to but distinct from the concept of continuity of social context.

Other people's attitudes and the ability of people with LTNCs and their family and friends to adapt had considerable implications for personal agency.

Staff attitudes could act as a barrier to continuity of personal agency, for example, when professionals dismissed the expertise of people with LTNCs or their family members. Family attitudes could also help or hinder the person with an LTNC to live with as much control over their lives as possible. For example, families could support the development of mechanisms to give the person with a LTNC more control over their day-to-day life. Sarah (MS and encephalitis, Site D) described how her and her husband writing lists of what needed to be done meant that she could manage the memory difficulties she had experienced since she had encephalitis. However, family members could also act as a barrier to independence by being so protective as to not allow the person with an LTNC to make decisions for themselves.

Whilst other people's attitudes could affect continuity of personal agency, people with LTNCs described how their *own* attitudes were also linked to choice, control and independent living. Many of those we interviewed reported that it had been important to get to a point where they accepted at least some of the situation and tried to 'get on with it' and 'not give up'.

> … and I'm now Chair of the local town disability group. … So you've just got to get out there. Which doesn't mean to say you can't still feel sorry for yourself sometimes but, you know, you've got to get on with it.
> (Flora, MS, site B)

Services could help or hinder this. Having the support of CINRTs, voluntary organisations, day opportunities, therapists and nurse specialists meant that people were more likely to learn coping mechanisms that made retaining these attitudes most of the time, more possible.

Positive attitudes were further promoted by attending group sessions, particularly those in the voluntary sector and those provided through day opportunity services,

where people with LTNCs were reassured that they were not alone. However, Caroline noted a contradiction between maintaining a positive attitude to help maintain her personal agency and needing to emphasise the negative in order to access services.

> … you spend a lot of your time trying to be really positive and trying to say 'I can do this. I can do this. I'll do this. I can manage this,' and really, you feel like social services were pushing you in this corner where you have to go, 'Oh, you know, I can't do that and I can't put my socks on and I ...,' you know, and you spend your whole life trying to be positive but to get support, you have to be completely negative and so psychologically, it's a really – it's a bad thing
> (Caroline, MS, site D)

An important factor in maintaining a positive approach to life and dealing with their condition was people's life partners. As with the day opportunity and voluntary sector services, where people were supported by family they felt that they were not alone. This support was characterised by the person with a LTNC and their partner's or family's joint narratives: '… we paddle our own canoe and live very independent lives' (Neil, Cerebral Palsy, site D).

For some, sharing narratives was linked to more direct experiences and understanding of the condition. Because of the inherited nature of some conditions, such as Huntington's Disease, the condition had dominated their, and their family's, lives and capacity for independence often for years before they became ill themselves:

> Cause, I mean, she [Jessica] was still at home with me mum, but when me dad had it, she looked after me dad with me mum. We all looked after our [sister2], so she'd seen a lot of it, like we had. You know, and she weren't surprised in the least when they said that's what it was.
> (Sister of Jessica, HD, site F)

People with LTNCs reported that it was important to feel 'normal', to have a purpose and to be valued as an individual in their own right. Ways of achieving this included undertaking voluntary work, continuing with hobbies and by involvement in voluntary organisations where people understood them and were understood by them. Joseph described how the day opportunities service he attended made him feel valuable:

> … always like to feel useful but that's the one thing now, you feel so like you ain't no use to life, and you're not worth anything and you've got no purpose, you've got no reason here … But it's nice to be able to come to [Resource Centre] and yeah, once a month, once every couple of weeks or something like that, somebody might have a bit of a problem and I'll go and have a chat to them.
> (Joseph, brain injury, site B)

Being involved in decision making about their own care and in setting goals was also associated with feeling valued. Confidence, as discussed above, could impact on personal agency and could be undermined when the person with the condition was not included in decisions made about their own care or in goal setting. For Isabel (MS, site F), the CINRT's intervention had been a 'morale booster'. The team had assessed her needs in a holistic way and provided physiotherapy at home and also support with improving her confidence to shop at her local supermarket. The important confidence building and motivational side of the team's work was endorsed by Sam (spinal injury, site F). After his discharge from hospital he had experienced bouts of depression. Since the CINRT's intervention

> That's been the biggest part of me recovery really. From sitting in the house …
> and twiddling your thumbs 'cause you're bored, and you can't do nothing. So
> yeah, from the motivation side of it, you don't have to sit and fester, you know,
> there is things out there, but it's being introduced to them.
> (Sam, spinal injury, site F)

Through the team he had been introduced to employment and training services, based at the local day centre, which were now an important focus for his support, and also contributing to his sense of personal agency. He was currently mentoring other people with disabilities who were trying to access further education and felt more confident about the future.

By leading or taking part in goal setting, people with LTNCs could ensure that their priorities were dealt with and that only achievable goals were set. Where this did not happen, it could leave people with LTNCs feeling unsafe. Toby's out-patient physiotherapist, for example, did not involve him in the goal she set for him; that he would walk with a Zimmer frame. Neither he nor his wife felt that this was achievable and that it

> … wouldn't be functional, because, you know, it's easier to [laughs] just get in the
> wheelchair and be safe …
> (Toby, brain injury, site A)

Furthermore, they felt that he had more pressing needs, such as learning how to roll over. Not being involved in making decisions about his own care, therefore, meant that Toby's most pressing needs were not being met and left him and his wife feeling that having this physiotherapy had been 'a bit of a waste of time.'
Almost all interviewees explicitly discussed self-management and adapting their lives around the parameters imposed by the condition and the environment. For example, Tina said,

> I was a busy person, definitely and I have deliberately withdrawn from too much
> to do and feel better for it especially with the balance and the walking.
> (Tina, PD, site E)

However, getting information about self-management and available services could be problematic. As Martin (spinal injury, site E) explained it was difficult to know what questions to ask and what services to ask about without already having some knowledge of the system. Not knowing what support was available could leave people with LTNCs without appropriate services. Magda (neuromuscular condition, site B), though encouraged by her physiotherapist to get extra help, had received no social care assessment and therefore assumed she would be ineligible for support and Rose (MND, site B) had received no financial assistance when purchasing an adapted vehicle and had been unaware that help may have been available.

Nonetheless, most interviewees were able to describe some services that promoted self-management and, consequently, personal agency. Daniel, for example, described the input from the intermediate care team who had visited in the weeks following his discharge from hospital as being useful and promoting an element of his independence.

> … they don't just wash you and dress you, they train you to wash and dress yourself as much as you can, you know, so it's not just an ordinary carer, they are specialised people.
> (Daniel, MND, site A)

However, the short-lived nature of intervention made this type of approach to service provision problematic, particularly for people with fluctuating or progressive conditions. The longer-term nature of some services was, therefore, particularly important for some people with LTNCs. Those we interviewed described the ongoing nature of input from nurse specialists, CINRTs, day opportunities and voluntary organisations as being helpful. This promoted personal continuity in a number of ways. Building a relationship with a particular professional or team over time could help to generate trust, which in turn meant that people with LTNCs were trusted to self-manage. Robert describes how the PD nurse, after she had known him a while was willing to negotiate with him about his medication regimen:

> [PD CNS] said I could take it, take the tablet, but I explained to her what was happening and said, 'I think I'm going to stop taking it' which I didn't think it was really benefiting, it was benefiting me and I was getting a better night's sleep or part way through the night, and it lasts about four hours, but I don't think the side effects is worth it, and I'm trying to keep the drug down to a minimum level really.
> (Christopher, PD, site E)

Most people with LTNCs we interviewed saw knowing that they could access support as and when needed, as the key to promoting personal agency. It allowed them choice and control over when they wanted intervention and when they wanted to manage without service intervention. Similarly, where people were allowed some choice over the location and time of appointments, this inevitably improved personal agency.

Being able to access services at a point of the person's own choosing was important in relation to voluntary organisations also. Some people reported that there had been points since diagnosis when they had not wanted to go to support groups because they did not want to see people 'further down the line' than they were.

Professionals' and team's specialist knowledge was also essential for promoting personal agency. People with LTNCs could learn ways of managing their condition, finances and services at one point in the development of their condition, but these mechanisms might not survive later changes. Specialist teams and practitioners were able to assist people to bridge these gaps until they were able to develop their next set of coping mechanisms. Speaking of his local CINRT, Alan said:

> I think the first thing to say about the nature and the progression of the illness is that it's quite cruel in one way because you develop coping strategies at each stage, and then something seems to happen that takes those away and you've got to start again. So maintaining motivation is one of the key issues. That is helped with the support that you get, from the Rehab Team.
> (Alan, MS, site E)

In this situation, specialists acted as an information resource and, in some cases, provider of specialist equipment and technology. Equipment, such as electric wheelchairs, communication devices and computers, was particularly valued. For example, computers enabled people to continue household management tasks, such as shopping and paying bills.

The key models that seemed to promote continuity of personal agency were day opportunity services, CINRTs and nurse specialists. Voluntary services also played a key role, as did some individual therapy professionals.

5.6   Summary and discussion

There are many facets to continuity of care, and the interplay between the different types of continuity is complex. However, clear themes run through the experiences of people with LTNCs and a number of key factors play a role in promoting continuity of care. In particular, the experience of continuity is tied up with having choice and control over the timings and settings of care, and the ability to access support as and when it is required. Flexible support to achieve aspirations and maintain not only physical functioning, but social lives and personal agency, is provided by a number of services, but three particular models stand out. These are nurse specialists, CINRTs and proactive, holistic day opportunity services. People with LTNCs repeatedly cited these services as helping them to continue to live their lives in the ways that they wanted. Their services were provided on a long-term basis, with a single individual or team taking responsibility for care co-ordination, ensuring longitudinal continuity and the optimum conditions for developing and maintaining relationship continuity.

Constant input is not always required (or necessarily desired), rather people want the ability to access support from a known and trusted service *as and when they need it*.

The services most valued by people with LTNCs have specialist knowledge about neurological conditions and associated support, with continuity of information so service users and their families can readily access expertise. These services are often supported, if not directly provided and/or funded, by neurological charities and other voluntary sector organisations. Where models work best they cross boundaries, able to co-ordinate care provided by a number of different services either by bringing them together in one team (as in the case of CINRTs) or by providing a focal point (both physically, as in the case of day centres and community hospitals, and by there being a visible key worker for other services to liaise with). These models also play a vital role by monitoring and following up interventions, enabling them to step in and resolve discontinuities if they arise. Without such services, the onus often falls to people with LTNCs themselves, their families or other informal carers to navigate through the complex system of health and social care. This can be exhausting and, without the links and specialist knowledge of professional service providers, continuity of care cannot always be achieved.

In the next section we take a closer look at these three models of service delivery, pulling together data from staff and people with LTNCs. We also consider the importance of care co-ordination in the delivery of continuity of care, as well as specialist knowledge and the role of the voluntary sector.

6.   Models of best practice

As Chapter 5 suggests, the research material from people with LTNCs identified three models of 'best practice' for integrated services, each of which contributed to the experience of continuity of care. These were nurse specialists, community interdisciplinary neurological rehabilitation teams (CINRTs), and day opportunities that offer peer support, social or leisure opportunities and access to meaningful, creative, learning and/or employment opportunities in the community. We also found that care co-ordination is an element of service provision central to the experience of continuity of care, although this does not constitute a discrete model in itself, and that specialist expertise was common to services valued most by people with LTNCs. Voluntary sector organisations, particularly those with a focus on specific neurological conditions, are central to the delivery of continuity of care, working closely with those who provide these models of care.

In this chapter, we concentrate on the three models and the perspectives of both people with LTNCs and professionals from the case study sites. Despite all working in slightly different ways, nurse specialists are dealt with as a single group since there are some clear commonalities bringing them together. This is the same with day opportunity services. CINRTs, on the other hand are, are divided into those which provide community in-patient rehabilitation, those which provide care in people's homes for people with a certain condition, for example, community MS or head injury teams, and those which provide care in people's homes for those with any type of LTNC. The latter tend to be larger than the condition specific teams, with more opportunities for integrated working, and have a broader reach, meaning more people with LTNCs are able to benefit from their combined expertise. To close this chapter we bring in the three cross-cutting issues of care co-ordination, specialist expertise and the voluntary sector, illustrating how these run through the above models and are integral to the delivery of continuity of care.

6.1   Nurse specialists

6.1.1 Promoting continuity

Where the nurse specialist model works most effectively, it can promote all aspects of continuity of care and is very highly valued.

Acting as key workers, nurse specialists promoted both management and longitudinal continuity, ensuring that people with long-term neurological conditions had a single point of access to a broad system of support:

> … when the MS Nurse was there, you got one person. If you had any problem, wanted anything sorting, you just talked to her and she'd organise it, you know.
> (Jason, MS, site A)

> … anything that I have problems with, I always refer straight back to [name], which is my MS Nurse. So she'd been very, very good, you know, sorting out the Pain Clinic for me and sorting out – 'cause I had problems with me bladder and bowels, so I had to go to see the incontinence nurse, so she sorted all that out for me, even sorted out a psychologist, you know, neuropsychologist.
> (Olivia, MS, site F)

> For us, it makes it very easy ... She will act as a focal point and contact whoever is needed.
> (Nigel, MND, site A)

Nurse specialists promoted management continuity by guiding people with LTNCs through often very complex health and social care systems. They also helped to link different elements of the system by facilitating good communication between key players:

> Oh, the service we've had is exceptional, I think. … Because they do appear to work together. I mean, when [PD nurse specialist] comes here, she writes it up for [consultant] and the GP … it is working well. It's a, you know, it's a triangulation and the GP knows what's going on and [consultant] knows what's going on and [PD nurse specialist] is effectively facilitating all of that.
> (Husband of Paula, PD, site D)

Interviews with members of staff supported the view that nurse specialists can, and regularly do, facilitate management continuity, both for service users and for professionals. The epilepsy nurse specialist in site C, for example, saw his role as 'the lynchpin to develop a seamless service', liaising with a wide range of service providers and across the acute/community divide in order to achieve this. This positive view was expressed not just by nurse specialists themselves, but by other professionals too. For example, a social worker in site B said:

> The physical disability nurse role works very well both in terms of assessments for people leaving hospital and the support she provides to district nurses and social workers and follow-up of patients once they have left hospital. People, not just patients, but professionals, rely very heavily on her input. That really does work well.
> (BS29, social worker)

In some areas this 'joining up' was organised formally through education or self-help groups led by the nurse specialist. Such groups were highly valued and, in addition to improving management continuity by bringing professionals together in a single co-ordinated programme, they improved information continuity and continuity of personal agency through taught sessions and opportunities for peer support.

With their specialist knowledge and accessibility, even those nurse specialists who did not run education sessions were a valuable source of information continuity. In addition to providing information at diagnosis, most were just a telephone call away: able to answer people's questions and allay their fears as and when these arose:

> Cause if I've got any concerns, they niggle away at my mind … It's nice to have somebody that you can – somebody who is an expert, for want of a better word. That can give you some, sort of, guidance and reassurance. But, I mean, any questions about anything to do with it really … [PD CNS] is wonderful because she's available on her phone. I can always phone her …
> (Mary, PD, site E)

This availability by telephone was a particularly important aspect of the service model. Almost all those covered by a nurse specialist commented on the reassurance afforded by being able to pick up the 'phone and speak to an 'expert' with easy access to the wider service system, as and when they needed to. The nurse specialist thus tended to be people's first port of call for information and further support.

6.1.2 Capacity

The only times interviewees felt less well supported by nurse specialists was when a nurse had limited capacity or covered a wider area than they could comfortably serve. In one striking example, all the interviewees with PD in a particular case study site spoke of an excellent PD nurse specialist whose services they valued, but who was severely over stretched:

> Well, she's a very busy lady … There's a lot of people with Parkinson's wanting her time. She does a lot of, you know, does some training, and although she's got [another nurse], who helps her now, you still often have to wait a while to get a response back from them, which, when people are desperate, you know …
> *(Woman A with PD)*

> I mean, she is, of course, very busy because she covers a large area …

> … but she's got an assistant, [name], who is another nice lady. I mean, [nurse specialist] will come to the house if you're not well and you're really desperate, she'll come, so we do have quite a good backup service.
> *(Woman B with PD)*

> Well I see her when I need to see her, and she comes, but she's got such a big area and workload.
> *(Man with PD)*

Capacity relates not only here to the ratio of nurse specialists to patients, but to what other responsibilities the nurses have in their remit and what support they get to

provide these. In the above example, the PD nurse specialist was supported by another nurse, and patients still had regular contact with the service through her. In site E, staff noted that the quality of the epilepsy nurse specialist service had declined since the acute trust withdrew funding for its administrative support.

Lack of capacity was the biggest barrier to the achievement of continuity of care by nurse specialists. Nurses were most highly valued where they had time to spend with patients and their families or carers, which affected whether people reported good relationship continuity. One interviewee told us that her PD nurse specialist had spent the whole afternoon with her and her husband, observing her 'on' and 'off' periods, commenting that no doctor would have the time to get to know her needs in this way. Another, in site F, explained that, whilst her relationships with both her doctor and her nurse specialist were important, the nurse would be her first port of call because she had specialist knowledge about MS and the time to spend with her so that she could fully benefit from it:

> … the thing I like about [MS nurse specialist], and my doctor is they remember you, so just by saying 'Oh, hi, it's Olivia here.' 'Oh, hi, Olivia, how you doing?' And then explain it all and [MS nurse specialist] would be my first port of call because she's nice and she's always there to, you know, to listen to you, and if it's not [MS nurse specialist], then it will be another MS Nurse because that's my first port of call really, to get – 'cause they're specialist in MS, and know what I'm going through more so than the doctor, 'cause doctors, sort of, like generalise on everything, don't they, really? It's not just specialising in MS, so it's always first port of call is always the MS Nurse.
> (Olivia, MS, site F)

Similarly, this combination of specialist knowledge and time to spend with patients was valued in the MS nurse in site A. When asked how important the MS nurse there was, one interviewee replied:

> Very. Very important, yeah. She really is, 'cause she's got the knowledge to be able to talk, and she has the time, so you have an hour appointment with her. And that's really important 'cause you can – 'cause often, I find, if you go to the GP or something and there's three or four things you thought you wanted to talk about, and you get to the first two, and you've forgotten the others. And he's run out of time …
> (Jason, MS, site A)

Nurses that had the capacity to work flexibly and arrange appointments around the needs and lifestyles of the people using their services were also able to promote both flexible continuity and continuity of social context. Lee, for example, used a ventilator 24 hours a day and found it very difficult to travel:

> That's why I think [the nurse specialist] tends to come out to see us when we need her, and if necessary, she will then relay anything that we say direct back to [the consultant] when she sees him in clinic
> (Lee, MND, site D)

This meant that Lee did not feel pressured to go in to the hospital, even now that there was a new MND Care Centre, as he was linked to it through the MND nurse specialist. No less important were the smaller things nurses used, like email, to make flexibility possible:

> I also have the email addresses for one or two of [the MS nurse specialists], so sometimes I'll just drop them the email and say, 'Look, I've, you know, can you bring forward an appointment for me, because of x, y and z?'
> (Agatha, MS, site C)

6.1.3 Wider structures

The extent to which nurses were able to operate in these flexible ways depended upon the wider structures within which they worked. Most of the specialist nurses in our case study sites were hospital based and their ability to provide services in the community varied. An epilepsy nurse specialist based in an acute hospital, for example, explained that she would prefer to do more home visits but her 'management' was less keen:

> The theory is that people should come here rather than taking us, time wise, out of the hospital, but obviously you know, I'm sorry, not everyone can fit that criteria.
> *(acute trust)*

The impact of this inflexibility on the accessibility of support for people with LTNCs could be substantial. Lily, for example, had turned down the opportunity to see an epilepsy nurse because the clinic was too far away and she did not drive. As she pointed out:

> … not a lot of us drive. It would be more useful if she would come to [centre of site F] to us. She would see more people actually.
> (Lily, epilepsy, site F)

There were advantages for information flow and management continuity when nurse specialists were based in, or at least had close links with, acute medical teams. However, hospital based services can be subject to perverse incentives that create challenges for nurses trying to provide flexible, supportive care. One MS nurse specialist, for example, explained that being based in an acute setting meant that her services were measured and funded through Payment by Results. Under this system, follow-up appointments attracted a lower payment than new referrals. Thus, from a financial perspective the incentive was to sign patients off as soon as an individual episode of care was complete and then take them on as a new referral if they needed further support in the future. She continued:

> But that's about money, that's not about the patient.
> *(acute trust)*

The PD nurse specialist in the same case study area was, on the other hand, PCT-based and not subject to such disincentives. She could tailor her services and the settings of care to the needs of the patients without worrying about the tensions this might create, and the ongoing aspect of her service was particularly highly valued.

Wider structures thus affected whether nurse specialists were able to ensure relationship and long-term continuity. One hospital based PD nurse specialist explained that in order to ensure long-term continuity she directly contravened her manager's wishes, keeping patients on her books over the longer term, even though she had been instructed to discharge them. Insecure funding and staff turnover, as well as the limited capacity already touched upon, also threatened long-term and relationship continuity. Samantha's husband in site F explained that, because the MS nurse specialists in their area 'come and go' regularly, he and Samantha had to go through 'the same rigmarole' of explaining Samantha's case almost every time they saw one. Many nurse specialist roles were 'pump primed' by voluntary sector agencies, with monies for two to four years made available on the condition that PCTs picked up and mainstreamed the funding in future years. In one of our case study areas, such an agreement was causing concern, as the PCT had subsequently reconfigured and was no longer bound to honour its commitment to fund the PD nurse specialist. This nurse was highly valued, but covered only one fifth of the new PCT area. Whilst there was general agreement that the entire PCT should be covered by a PD nurse specialist, in reality there was a chance that even the small area currently covered would soon lose its nurse.

In areas where there was no specialist nurse for a particular condition, other workers were left to try to plug the gap, often without the time or expertise to do so adequately. The lack of a PD nurse specialist in one site, for example, left the PD Society's Information Worker struggling to provide a level of support that was beyond her remit, as she explained:

> There's no time to explain all the difficulties they come across and then I get all the 'phone calls. ... When people 'phone I haven't a PD nurse to go back to and it isn't my remit to deal with medication. The only thing I can do is keep writing to the consultant and hope they get them back into the clinic fairly quickly.
> *(voluntary sector)*

6.1.4 Access

Not all people with a LTNC have access to a nurse specialist. All of our case study sites had some coverage from MS nurse specialists, but not all had nurse specialists for people with PD, MND or epilepsy, and there were no local nurses in any of the

sites for people with Huntington's disease, brain injury, cerebral ataxia or other conditions. As part of the regional 'hub and spoke' model, people with LTNCs in Site F had access to a range of nurse specialists at the neurosciences centre, but only the MS nurse specialists had a local remit. Site B had a generic 'physical disability' nurse specialist and site E a rehabilitation nurse specialist; despite not having a condition specific focus, they were nevertheless highly valued.

Access to a nurse specialist is important, not only because of the services they directly provide, but because they can act as an access point to a wide range of other services. Their role is not merely one of signposting; often they engage in active care co-ordination and advocacy. As the wife of one interviewee with MND explained:

> But she's got access – since we've had her she's got access to a lot more things. …Than what we ever had access to, if you know what I mean? ... If you didn't have her to fight your corner…you've got no chance … You just don't get listened to.
> *(wife of man with MND)*

However, even in areas that did have nurse specialists, there was no guarantee that everyone who should be able to access the service actually did. Nurses based in acute hospitals, especially regional centres, were sometimes too far away for people to travel to. The MND nurse above, for example, worked flexibly in the community and visited the interviewee's home, often jointly with other professionals. In site A, on the other hand, the only MND nurse specialist was based in the regional hospital over 40 miles away and did not visit people's own homes. Distance could deter people from accessing all the help available to them, especially as LTNCs can make travel difficult. Samantha's husband, in site F, for example, explained that they had opted to see the nurse specialist only once a year because a six monthly appointment would mean 'traipsing Samantha out in the middle of winter to [hospital] at nine o'clock in the morning, which it isn't great' (Samantha's husband, MS, site F).

Several interviewees also reported that they were not automatically put in contact with the nurse specialist, and in some cases, they found out about the nurse only by accident. Others were officially on a nurse's caseload but, due to the limited capacity of the few nurses there were, did not see them as much as they would like. One interviewee said of MS nurse specialists, 'They're like gold dust'.

6.2   Community interdisciplinary neurological rehabilitation teams (CINRTs)

It was clear from our analysis that people in receipt of rehabilitation services from a CINRT (as opposed to lone therapists) tended to have improved experiences in many, if not all, types of continuity.

We found several examples of CINRTs during our case work. As Table 6.1 shows, one of the sites did not have any CINRTs and one site had three. These teams worked in different ways, comprised different types of staff and provided support for different client groups. They also provided input in different settings; one team worked in a community in-patient unit and other teams visited people in their own homes. Another team was based in a community hospital and provided much of its support at the hospital, although home visits were also provided, depending on the clinical needs of clients and the interventions being undertaken.

Table 6.1   CINRTs across the six case study sites

Case sites	Number of CINRTs	Conditions covered
A	1	Condition specific
B	0	
C	1	Any neurological condition
D	3	Condition specific Condition specific Any neurological condition
E	1	Progressive neurological conditions
F	1	Any neurological condition

The way these services were structured and managed, and the settings in which they provided interventions, had important implications for how they affected continuity for people with LTNCs.

6.2.1 In-patient CINRT

The main positive aspects of the in-patient neurological rehabilitation service identified by clients using this service were that it had multiple disciplines working in the same team, it had expertise in intensive neurological rehabilitation and it provided access to specialist equipment.

The interdisciplinary approach used between the multiple disciplines in this team was seen to complement and build on the expertise of individual professionals. OTs, physiotherapists, dieticians, nurses and a medic worked collaboratively, ensuring relevant information reached the appropriate team members, thus promoting management continuity. However, it is possible that this team was particularly valued because it was difficult to access other ongoing therapy services in this area, particularly specialist neurological therapies, in community settings.

Expertise in neurological conditions was valued, not simply because staff members were aware of the most effective and appropriate interventions for clients, but also because staff at the unit accepted how important it was to *maintain* clients'

functioning levels rather than simply focusing on improving them. This meant that staff members commenced therapy, but also taught clients appropriate techniques and exercises to continue at home to maintain their existing functioning levels. This approach helped promote personal agency, by supporting self-management, and social context, by limiting the impact of the condition on people's social lives. However, follow-up at home to ensure exercises were being done correctly and, indeed, that they were still appropriate exercises, was not possible given the intermittent and in-patient focused nature of this service.

For some people who had repeated stays in the rehabilitation unit, the service could also promote relationship and long-term continuity. People got to know the therapists and were able to call them for advice and support between in-patients stays. An additional benefit of attending an in-patient unit for neurological rehabilitation was that it offered respite for the person, and for their family and/or carers, when they were admitted. Access to specialist equipment could also be important. Lee (MND, site D) highlighted how specialist equipment helped to maintain a degree of normality for him, because he was able to have a 'proper' bath when he was an in-patient.

In short, this service could provide social, personal agency, relationship and informational continuity, for some people and in some circumstances. However, there were a number of limitations. Interventions could be provided only on-site, and while the team did provide telephone support to previous clients who sought it, they did not routinely or proactively support people at home. This was problematic because the nature of LTNCs means that people's condition can change rapidly and significantly. Furthermore, in general, people with LTNCs across our case study sites preferred rehabilitation interventions in their own homes.

6.2.2 Condition specific CINRTs

Condition specific CINRTs were identified in sites A[4] and D. As with the in-patient unit, the specialist expertise of these teams - about the condition, its treatments and the local services available to them - meant that they were highly valued. Staff specialising in the particular condition were able to anticipate clients' needs well in advance and plan care and support with them, promoting information continuity and continuity of personal agency. As Patrick said of the head injury team in Site D:

> … if it weren't for [site D] Head Injury Team [sighs], I would not be anywhere near what I am 'cause to me [site D] Head Injury Team, no disrespect, but they're the best thing ever.
> (Patrick, brain injury, site D)

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[4] All comments about this service are from staff interviews as no service users who used it were interviewed.

This team comprised several therapy disciplines, but it lacked designated physiotherapy input, meaning that the full range of therapy services was not available for clients. In site A, the community brain injury team had input from more disciplines, but again did not have a designated physiotherapist. This latter team also had eligibility criteria that severely limited who could use the service.

People using a community MS team, which also did not have a physiotherapist, echoed concerns about a limited physical rehabilitation focus. The lack of physiotherapy provision within this team, compounded by the very limited community provision of physiotherapy in the area generally, meant that people with MS found accessing any physiotherapy very difficult and this may have affected the progression of their condition.

CINRTs were particularly valued where rehabilitation went beyond improving physical functioning and it was based on a social model that addressed people's needs in an holistic way. As indicated above, CINRTs' knowledge of local and national services and support available for people with particular conditions, and their understanding of the sorts of problems people might face, helped them to ensure that social needs were met. These specialist teams also dealt with concerns outside immediate and obvious 'caring' issues. For example, Jeremy described how the team in site D helped him to get his bank accounts unfrozen, and Patrick explained how the team helped him to get back his driving licence. Despite taking a holistic approach to rehabilitation, however, neither of the head injury teams had a social worker on the team and both felt that their services would have been improved through more integrated working with social services.

The condition specific teams we came across provided a valued service but worked with only a very select sub-group of people with a LTNC. They were available only to those with a particular diagnosis, and this was compounded by eligibility criteria that could further restrict access to the team. In addition, the examples of condition specific teams in our case study sites did not have the full range of disciplines that people with LTNCs told us they required to deal with all their needs.

6.2.3 General neurological CINRTs

Generic teams in sites C, E and F were also valued for the reasons described above: specialism in neurology, even if not in particular conditions; multiple disciplines working together and using a holistic approach; awareness of local services and support; providing services in the person's own home; being flexible; and providing a holistic approach to care co-ordination.

The general CINRTs, however, tended to have a greater range of disciplines working together, which enabled them to enhance these factors, making the experience for

those with LTNCs using them more positive. All the generic CINRTs in our case areas had both OTs and physiotherapists, and in some teams they also had SaLTs (C, F), psychologists (C), nurse specialists (E), social workers (C, F) dieticians (F) and rehabilitation support workers (F). The interdisciplinary way that these professionals worked together, undertaking joint assessments and interventions and sharing case information across the team, meant that clients could get timely, responsive access to a wide range of professionals. This greater range of disciplines could also improve information continuity because there was a wider pool of expertise to draw from. Furthermore, where the teams adopted a more explicitly social model of rehabilitation, they were particularly effective at promoting continuity of social context and personal agency.

In site E, where social and health care staff teams were not integrated, but social workers attended monthly multidisciplinary meetings, people with LTNCs and staff working with these clients praised the team. However, as described in the section on long-term continuity (section 5.2.1), often people in this site did not retain the same social worker over time and were discharged from social services after each intervention. In contrast, in the areas where social workers were integrated members of the team, they worked with clients on a longer-term basis. When social workers and health care professionals worked in an integrated way in CINRTs, as in sites C and F, they were able to be more responsive to the needs of clients and their families and to provide social care input in a timely manner.

CINRTs worked in a flexible way, arranging or rearranging appointments to fit with clients' preferences and needs. They also regularly undertook interventions in people's homes - thus offering flexibility of location of therapy sessions and interventions that worked towards independence in a person-centred way:

> The philosophy runs through the whole service, it's the end in mind, it's the whole purpose. ...There's a skill in pulling out what that person actually wants.
> *(adult social care, site F)*

Both people with LTNCs, and the staff members we interviewed valued the long-term nature of the support provided by the CINRTs in sites C and E. Alongside helping people with LTNCs to attain continuity of care, staff argued that the comprehensive approach of these CINRTs also helped to prevent hospital admissions and speed up discharge.

6.3 Day opportunities

6.3.1 Valued services

People with LTNCs told us they valued services that offered peer support and social and leisure opportunities, as well as access to meaningful activity and/or learning and employment opportunities. Indeed, several of the people who used and valued day services identified them as one of the most important things in their lives. Oscar in site B, for example, described the manager of the local Headway affiliated group as '*absolutely the best thing in this country*' and continued:

> Oh and not just me, everyone here, yeah, loves it here.
> (Oscar, brain injury, site B)

Lisa similarly identified her local resource centre as the most important service she used, saying it helped her to build a full social life and gave her the confidence she has today:

> … I'm pretty happy with the way things are … there's, like, lots of different things that I'm involved in, mainly through the different organisations I've worked with, like I said. A lot of the stuff that I do, do, I wouldn't have been able to do it without the help of [name of resource centre] …
> (Lisa, Cerebral Palsy, site D)

Some went so far as to say that without such services there would be little meaning to their lives:

> … you know, I've only got to take my girlfriend out of the picture and [name of day opportunities service] out of the picture, what is my f***ing purpose of being here?
> (Joseph, brain injury, site B)

The day services that were most highly valued provided access to meaningful activity and opportunities to develop new skills or build on existing interests, and these services were offered on an ongoing basis.

6.3.2 Promoting continuity of social context and personal agency

Part of the appeal of day services for people with LTNCs was social, with benefits for them and their families and/or carers. Sophie, for example, enjoyed the activities organised by the local authority day centre in site F and described the people at the centre as '*a really nice bunch*' [Sophie, encephalitis, site F]. Similarly, Nigel, who had MND and communicated through a laptop, commented:

> [name of day service] provides me with an opportunity to interact outside the home. While I'm here, [wife] goes into work [pause] [typing]. It is great for the both of us.
> (Nigel, MND, site A)

Matthew regularly travelled to a Headway centre outside his PCT area because he enjoyed the debates in the 'contentious issues' sessions so much. The importance of this social element should not be underestimated. Several interviewees noted that it not only improved the quality of their social lives, it also helped them to build confidence and independence skills: that is, it promoted continuity of personal agency. One person we interviewed, whose confidence had been severely reduced after a brain injury, regained his love of public speaking by giving after dinner talks at a voluntary sector day service. In another example, Zoe was supported by her day centre key worker to get an electric wheelchair so that she could go shopping on her own, which she said made 'loads' of difference to her independence.

Since a number of the people interviewed had conditions that could be maintained or even improved through exercise, the opportunity to access supported exercise and therapies through day services was also highly valued. Freda in site A, for example, had MS and found it difficult to exercise independently. Through the local day centre she was able to use a toning table and go swimming, both of which she found very useful. Some Headway centres had gyms or facilitated supported access to sporting facilities. Other services, like MS Therapy Centres, provided a range of complementary and alternative therapies that interviewees felt were helpful.

Another important element of these services was their specialism in neurological conditions, or a specific LTNC. Whilst some staff members expressed concerns about 'ghettoisation', the people with LTNCs we spoke to all valued being around other people who had similar conditions. Joseph in site B, for example, valued the day centre as a 'safe haven':

> Nobody that hasn't had brain damage, and it doesn't matter whether it's a psychologist, a brain specialist or whatever, if you haven't had brain damage you don't understand it, you just do not. Whereas with this crew, all the other clients at [name of day service], doesn't matter what their condition is with the injury and how physical it is whatever, there's all these underlying factors, motivation, emotional, confusion, feeling useless, pointless, worthless, that are nearly, sort of, uniform right across everybody.
> (Joseph, brain injury, site B)

The importance of this shared understanding applied not only to brain injury; people with MS, PD and cerebral ataxia all talked about it. However, in many cases, such condition specific services were available only through the voluntary sector. This was the case in site C, where people with MS accessed a supportive day service through the MS Society:

You know, everyone has got MS, in that group or – and the carers or whatever. And you can talk and they – yeah, people talk about their medication or maybe their incontinence or, but all manner of things. But you don't feel uncomfortable 'cause you know that everyone is there, you know, in the same thing. And it's very, very supportive.
(Malcolm, MS, site C)

6.3.3 Meaningful activity and employability

The focus of many day opportunities providers has been redirected in recent years towards training and employment, something that in itself was valued by some of the people with LTNCs that we interviewed. Sam in site F, for example, was involved in an initiative based at his local day centre where:

… they, sort of, retrain and, you know, you might not be ready to go to work yet, or for a couple of years, but there's things you can be doing rather than sitting in the house twiddling your thumbs.
(Sam, spinal injury, site F)

However, a number of interviewees stressed that involvement in creative, meaningful activity was a valuable end in itself. As Philip, a man in his 40s with brain injury, explained:

Once your brain switches off, that's it, you're knackered, aren't you?
(Philip, brain injury, site D)

He went on to give credit to the resource centre in site D for ensuring that this hadn't happened to him:

this place [name of day service] has really brought me on as a person, you know…
(Philip, brain injury, site D)

Moreover, whilst some people did see day services as a stepping stone into paid employment (Jeremy, for example, had been attending a resource centre in site D since his brain injury, but intended to leave the service now that he had found a job) others felt the unique strength of these services was that they did *not* pressurise people into finding work. Thus, when Joseph was asked what it was about the day service in site B that was particularly good, he said:

Well the fact there's no pressure. There's no – there's nobody making me do this, or saying, 'This has got to be done by such and such a time,' or, 'you've got to do this today,' you know, it's down to you to work out what you want to do.
(Joseph, brain injury, site B)

The nature of many neurological conditions means that finding paid employment is not always achievable, or indeed desirable. Those with deteriorating conditions such as PD, or conditions that impact on social functioning such as brain injury, may not be interested in or able to take up paid employment, yet their need for a fulfilled and happy life is as great as anyone else's.

6.3.4 Ongoing support and care co-ordination

In addition to these specific opportunities, some day services also provided care co-ordination and a first point of contact for people to access further support. Thus, in site D, Lisa, Philip and Jeremy all said that their resource centres would be their first port of call should they have a problem:

> Well, it's like I say, if I need help or anything with owt … I'd just contact someone at the Centre, 'cause it's a fantastic place, this … and the officers that work here … they'd get on to them for me and they'd arrange it and they'd either meet up with them and organise whatever needed doing, you know.
> (Philip, brain injury, site D)

The ongoing nature of this support was particularly highly valued:

> They're a 'phone call away … I've got their number down in me mobile …– and I'll give them a ring if I need them. ...They're there for advice, you know, at least they'll listen to you.
> I've always got these [resource centre staff] if I wanted to fall back on …
> (Jeremy, brain injury, site D)

This was something staff members also highlighted as an important aspect of day services. There was no time limit on the service provided by the PCT-run day service in site A, for instance, although people were regularly reviewed against eligibility criteria. The centre manager illustrated the importance of this open-endedness for a client who used the service for three years after brain surgery. The service worked closely with the local brain injury rehabilitation team, supporting him to continue with physiotherapy and develop independence skills. This client went from using the service five days a week to just 'popping in' now and then, and is now living independently in a flat with a voluntary job: 'but it has taken years, rather than weeks or months' (PCT, site A).

6.3.5 Access and current trends

Many of the people we spoke to with LTNCs valued the day services available to them, particularly where these offered access to meaningful activity, the chance to socialise with people in similar situations, and support to access learning or employment opportunities. However, these services were not universally available, and in some areas they were being actively decommissioned. Thus, in some case

study sites people regularly travelled considerable distances to access Headway day centres because there was nothing comparable available in their locality. This could be particularly traumatic for those with continence problems.

> … the places I go to are fine. I just wish that – I wish Headway had a branch in [his area]. I really do, 'cause it does – most – the worst thing about going to [city] is the travelling.
> *(brain injury, site A)*

Some day services were in the process of being reduced and this was a source of concern for several of the people with LTNCs we interviewed. Freda, for example, used to attend her local day centre twice a week, but this had recently been reduced to just one day, and activities she valued had been discontinued:

> Now they've changed that again to just one day a week, and there's so many alterations going on that it's a bit confusing, what they'll be doing …
>
> Well, I used to be able to go on the standing frame there. But then it, sort of, changed, I should think, two or three years ago, where there used to be a nurse there … but then, once it changed, everything seemed to – we didn't seem to do so much there. Where I used to be on the standing frame nearly every time I went there now it's just a case of when they say that I can go on it … I seemed to get on better on the standing frame. It was helping me.
> (Freda, MS and epilepsy, site A)

In other areas, services were being closed completely:

> … I also used to use a resource centre called [name] as well, but unfortunately, that doesn't exist anymore. I mean, I stopped using it quite a few years ago now, but at the time, I did use it, I found it quite helpful.
> (Lisa, Cerebral Palsy, site D)

Some of the people we interviewed were concerned about the move towards making day opportunities time-limited. One man with brain injury in site A, for example, was appalled by the idea that a day service he had attended for several years would now be offering only a six-month service to new clients. This, to him, made little sense, since long-term conditions are by their nature ongoing:

> Well, it wouldn't be enough for people with brain injury.
> *(brain injury, site A)*

Some staff interviewees also expressed concern that reductions in day opportunities would have a detrimental knock-on effect for people with LTNCs. A nurse specialist, for example, said there had been an increase in falls in people's homes since day centres in her area had closed and people with PD were no longer being regularly monitored. A specialist neurological OT similarly felt that her patients would become

more reliant on their carers as day services closed, and pointed out that these carers would in turn have fewer options for respite. An adult social care manager in the same area expressed concern that social relationships that had developed over some time would be lost as day centres closed and were not replaced.

Some staff suggested that alternative services purchased via direct payments or personal budgets could replace traditional services. However, such alternatives were not always available. Thus, a Headway staff member in one area complained that some social services departments were reluctant to fund places in their day centres despite there being no alternative on offer. Moreover, very few of the people with LTNCs we interviewed used direct payments:

Interviewer:	**And you don't have – you've not had any discussions with anyone about Direct Payments?**
Lee's wife:	No.
Interviewer:	**No. Which are, you know, do you know what Direct Payments are?**
Lee:	Not really, no.
(Lee, MND, site D)	

Interviewer:	**And were you ever offered Direct Payments? Do you know the, kind of – do you know that scheme?**
Freda's husband:	Yeah, we have been, yeah.
Interviewer:	**And you decided not to have it?**
Freda's husband:	Yeah, basically, because it meant an awful lot more paperwork and stuff from our point of view, to actually do that. And we just felt, between the two of us, there was enough to deal with, basically…
(Freda, MS and epilepsy, site A)	

Those who did use direct payments in our sample tended to do so only to pay for home care, respite and holidays, rather than to access meaningful daytime activities. Moreover, staff felt that more middle-class disabled people who are actively working (so seeking flexibility), articulate, and well informed about disability rights generally take up direct payments. Those who start at a disadvantage are therefore likely to fare worse if not supported.

Several of the day centres in our case study sites were innovative, providing access to a wide range of stimulating activities and supporting the personal and social development of individuals in a 'safe' environment. However, the external perception of day centres remains negative, as one centre manager explained:

> I still think there's a lot of stigma with the day centres, and people still think it's sitting around playing bingo, basket weaving … [but] for a lot of people I think there's still a great need for these day centres
> *(PCT)*

Moreover, centres that tried to develop and better meet the needs of their clients were sometimes hampered by the inflexibility of their local authority and PCT funders. In one site, an emphasis on purposeful learning appropriate to the needs of people with LTNCs had been actively promoted through day centres; however, projects were felt to be continuously at the mercy of shifting funding streams and government priorities, which at times contradicted the NSF, making it problematic to provide sustainable solutions locally for people with LTNCs.

6.4   Care co-ordination

Care co-ordination was an important and valued element of the service models described earlier in this chapter and was essential in promoting many types of continuity of care. People with LTNCs wanted someone who could provide relevant and accurate information, had awareness of the most appropriate services to contact or refer to, could foresee and pre-emptively plan for future needs, and who provided a 'focal point' of contact for the person with a LTNC and those involved in their care and support.

This type of care co-ordination was considered helpful because, as Nigel responded when asked about a person who co-ordinated care for him:

> For us, [care co-ordination] makes it very easy
> (Nigel, MND, site A)

Staff reported that care co-ordination, over time, over services and over sectors was also important to them and helped provide the best service possible.

However, outside the service models already described, namely CINRTs, neurology nurse specialists and day opportunity services, we did not find any models of care co-ordination for people with LTNCs that were common across case study sites. Thus, where these service models were absent, care was often not co-ordinated and no one took responsibility for individual cases. People with LTNCs could identify professionals they would contact should they need advice or assistance, such as district nurses, GPs, voluntary organisations, occupational therapists and social workers, but these professionals did not necessarily co-ordinate care.

Many of the individual professionals that service users suggested provided some care co-ordination did little more than refer clients on to other services and, moreover, these referrals often resulted from a direct request from the client after identifying their current needs themselves:

> Any problems I have, I tell the neurologist. And he'll refer me in the right direction
> (Simon, MS, site B)

While people with LTNCs clearly appreciated being able to access wider services via these professionals, holistic and pre-emptive care co-ordination was rarely experienced outside the three models of 'best practice' identified above. Since not everyone with a LTNC had access to one or more of these models , there was not necessarily anyone with an overview of people's needs who took responsibility for co-ordinating current, and helping to plan future, care. As Wendy's husband said:

> We've had problems with co-ordination. … Well, we've had the social services occupational therapist involved, the health service occupational therapist involved, physiotherapist, the – our own GP, specialists, the Parkinson's nurse specialist, and there have been times when they've all been doing their own thing, and not talking to each other.
> (Husband of Wendy, PD, site E)

6.4.1 Social workers

Some staff felt that care co-ordination was part of the social workers' role because of their responsibility in discharge planning and in assessing for, and arranging, longer-term social care. Despite some people with a LTNC saying that their social worker would be their first port of call if they needed something specific, both staff and service users reported that social workers rarely had the time to co-ordinate care actively in the ways needed. Social work provision was criticised as having become frequently a one-off intervention rather than long-term support. Many people with LTNCs described how, in the past, their social worker had co-ordinated their services or benefits, but increasingly their support was problem or issue-based. Only three of the people with LTNCs interviewed reported that social workers continued to co-ordinate their care by organising benefits, social care provision and equipment provision.

Where social workers had provided, or continued to provide, care co-ordination, it seemed to be associated with individual practitioners' working practices rather than a system-based approach to supporting people with LTNCs. As Caroline said:

> I think it's all down to individuals really … but she was fantastic and I think that, partly I think – and that's just down to individuals. She was just a brilliant social worker; she just thought of everything.
> (Caroline, MS, site D)

Providing pre-emptive and holistic care co-ordination was appreciated. However, to be able to provide this type of care co-ordination, social workers needed a good understanding of the neurological condition, probable condition progression and associated needs.

Providing support to people with a neurological condition over time could go some way to honing this knowledge. One area employed a specialist social worker who

was able to provide a holistic approach to care co-ordination, liaise with relevant services, and provide training to, and be a specialist point of contact for, generic social workers. However, due to lack of capacity her role had lately become more advisory and she was acting as a link between neurological health and social care services, rather than as a direct provider of care co-ordination.

6.4.2 Community matrons

Some staff reported that community matrons provided care co-ordination, and one area had a community matron specifically for neurology. At the time of fieldwork, this was a new appointment and it was too early fully to evaluate the role. However, as the post was developing, it was felt not to suit the community matron label entirely, where the emphasis was on case management and admission avoidance. Co-ordinating care and linking with other agencies was becoming central, although some staff felt being a lone worker based in the PCT compromised the community matron's capacity to work effectively with other specialists. Staff elsewhere felt that community matrons needed to have some knowledge of neurology generally, or of specific conditions, in order to be able to co-ordinate care appropriately. However, the only person with a LTNC who spoke about community matrons in relation to care co-ordination reported that the community matron had relinquished this role to the PD nurse specialist:

> The physiotherapist said, 'Well look, there's a community matron who should look after these aspects.' So she spoke to the community matron, who said, 'No, it's not me, there's a Parkinson's nurse involved, she's the specialist. She's the co-ordinator.' So it got landed on [nurse specialist]'s [laughs] desk, if you like.
> (Husband of Wendy, PD, site E)

Wendy and her husband felt that the nurse specialist did not have the time to undertake care co-ordination wholeheartedly because of her very high client numbers (the nurse specialist reported having 600+ clients on her list). As a result, Wendy's husband did much of the care co-ordination himself, on top of his already extensive practical caring role.

6.4.3 Voluntary sector care co-ordination

Staff suggested that voluntary sector workers could promote care co-ordination by liaising between different services and between clients and services, providing specialist information and promoting the benefits of care co-ordination. People with LTNCs. who described how welfare representatives and volunteer visitors based in voluntary organisations, such as those working for the PD Society and MNDA, had helped to co-ordinate the different aspects of their life and the services they used, reinforced this. For example, Pippa described how the welfare officer linked to the PD society helped her to access benefits:

> … she came out to see me, and she said to me, 'Do you claim any money?' And I said to her, 'Well no, I didn't think I was entitled.' She said to me, 'I'm sure you are.' And she came to see me and we filled in these forms and she got me, me DLA
> (Pippa, PD, site A)

Edith (MND, site B), reported that the MNDA representative in her area was trying to pull together different professionals with an interest in MND. Though it was proving difficult, Edith saw this process and the tenacity of the MND representative as an important step forward. Harry and Joshua, both in site F, appreciated the way that representatives of condition specific voluntary organisations provided holistic care co-ordination. For Harry, the MNDA care adviser helped to pull together his services and for Joshua, the support worker from the PD Society was the key to his service provision in an area where there were no other Parkinson's specialists.

MND care centres also improved care co-ordination between professionals working at centres, between professionals and patients, and between services and sectors. For people with MND this co-ordination was particularly useful as MND is often a rapidly deteriorating condition, with multiple and diverse symptoms, and timely intervention from multiple services is needed. The potential complexity of care, coupled with relatively short life expectancy, means there is little time for people with MND or their families to learn how to navigate the service system. Co-ordinating these services so that people with MND and their families are supported and able to see relevant services or professionals in a timely manner is, therefore, particularly important and it is imperative that care co-ordination is provided by people with expertise in MND. This expertise was one of the great strengths of the condition specific, voluntary sector provision of care co-ordination.

6.4.4 The person with the LTNC and their family and/or friends

Most commonly, responsibility for care co-ordination fell to the person with the LTNC themselves, and/or their family or close friends. Despite the complexity of the systems, indeed maybe because of this complexity, people with LTNCs felt that they were generally the only people with an overview of their own treatment and care:

> Yeah, it's just that some – just the feeling I get with the physio, you know, that obviously she doesn't know exactly what the neurologist has said to me at the last, you know, review, kind of thing, and 'cause it didn't – at one time it didn't appear as though the injections were being effective, you know, and so she's asking me what, you know, 'Has he said this, is he going to change your medication?,' you know ...
> (Margaret, MS, site D)

Some people used formal systems to help promote care co-ordination, such as direct payments, which were seen as a useful way of enabling people to manage their own care and provide an element of control over their life and service use:

> They give you the money to pay for your own care. Which suits me much better, 'cause I can tailor it to what, you know, to the care, when I want it and how I want it. And I've been using Direct Payments now for eight years, I think … Because social services couldn't work out – the way their carers worked didn't, sort of, fit in with the needs that I wanted, and the social worker that I'd got at the time, who was very, very good, said that she thought that, you know, direct payments would be better for me. And I think it's brilliant.
> (Emma, MS, site E)

However, most people co-ordinated their own services and other life issues in more informal ways. For example, throughout his interview Gordon (spinal injury, site C) emphasised the importance of maintaining control and independence, but he tended to do this via informal routes, such as friends, the internet and professional contacts. Nigel and his family laid the foundations for the co-ordination of his care early on, before the symptoms of his MND became too severe for him to co-ordinate things for himself:

> Very early on, we decided to get all the services we would need around the same table. This has proved very good at ensuring they know who is responsible for what.
> (Nigel, MND, site A)

People with LTNCs often co-ordinated their care with their spouse or another member of their family, as Raymond explained:

> So my wife is persistently chasing up, chasing up, chasing up … She does at least 40% of their work and it involves me, but she doesn't get paid for it.
> (Raymond, MS, site D)

For others, friends were the key people providing care co-ordination.

> Now that my sons know, they would – well, [son] would be quite good in planning, you know, monetarily, but my friend in [location] I would count as one of my, sort of, kingpin planners, because she knows how to deal with the NHS. She knows what you have to do and shout at them. She – and the one up the road, I mean, if it came to it, I would nominate her as a person to, sort of, guide my sons…
> (Tina, PD, site E)

6.4.5 Other ways of co-ordinating care

People with LTNCs identified several services providing care co-ordination in their particular site that were not evident in others. For example, Nigel, with MND,

described how a community outreach nurse worked specifically with people with neurological conditions and successfully co-ordinated his care. He also had a key-worker from a Veterans agency who had supported him when he left paid employment. Toby described a brain injury rehabilitation unit in the independent sector that provided care co-ordination while he was an in-patient and in preparation for his discharge. In sites B and D there were neurological in-reach services based in acute hospitals that did not have neurological wards. These provided 'neurology care co-ordination' while people with neurological conditions were in-patients and, in site B, linked to community teams. Day hospitals in sites B and E also fulfilled a care co-ordination role. The day hospital in site E co-ordinated therapy needs within the unit as well as support for people at home with the provision of equipment, vocational and social support.

6.5   Specialist expertise

Another key feature common to almost all the highly valued services identified through our case study work was their specialism, either in a particular neurological condition or in LTNCs in general. In each of the three models identified above, this was an important, if not the most important, feature of the service.

Nurse specialists are by definition specialist practitioners, but it is notable that it was their specialist knowledge and expertise that made them particularly valuable to many of the people we interviewed:

> I feel that she [the specialist PD nurse] provides a great service for people with Parkinson's because she's got that specialist knowledge that a lot of the GPs don't have.
> (Constance, PD, site A)

> Eleanor: But I have nothing but the highest praise for those specialist nurses. They really do seem to have a compassion and an intelligence that's rare to find in …
> **Interviewer: What about them is so important, do you think?**
> Eleanor: You just – you get the feeling that they know their stuff.
> (Eleanor, PD, site C)

Nurse specialists were often the first port of call when someone's condition changed or a new problem arose. Their sensitivity and accessibility was praised, but when asked whether their value was rooted in there just being *someone* available to talk to, this was strongly refuted:

Interviewer:	… would it be useful for you to have someone you could just talk to, not necessarily a specialist, but someone you could just talk to?
Mary:	No, because I need somebody who's knowledgeable … and can tell me that this is what I should be doing or not doing. ... It's not just a sounding board.

(Mary, PD, site C)

They were also valued for facilitating access to a range of other specialist services. Thus, Constance in site A said she would always go to her nurse specialist first if she needed to be referred for further support or therapy because she knew then she could be referred on to someone who 'knows what they're doing', whereas this was not guaranteed through her GP. Indeed, some interviewees made the comparison between the specialist expertise of nurse specialists and the more generalist knowledge of GPs explicitly:

if anything new came up then, I suppose you would ring the MS nurse, you know, they'd be the first point of call, 'cause it would be a bit pointless probably going to your GP … 'cause they'd say, you know, check with them [the MS nurses].
(Husband of Sarah, MS and encephalitis, site D)

Interviewer:	Do you ever see the [GP]?
Margaret:	Not about the MS, no. Because, you know, 'cause it's such a specialist thing, like with any other condition I suppose, they don't, you know, they'll say, 'Oh, you'd better speak to your Neurologist,' or, you know, 'You'd better speak to your MS Nurse.'

(Margaret, MS, site D)

The importance of being able to see a neurologist or other consultant with specialist expertise (such as an elderly care or rehabilitation consultant) was also emphasised, but the benefit of the nurse specialists came from their accessibility. While the specialist expertise of a consultant might be available once every six months, that of a nurse specialist could be accessed simply by picking up the telephone. GPs, though relatively accessible, tended not to have the knowledge or experience of specific conditions that nurse specialists had. Thus, although interviewees *could,* in theory, contact their GP if they had a problem, they often chose not to:

Interviewer:	So you don't have an awful lot of contact with your GP then?
Edith's husband:	No … you see, they [GPs] don't know anything about Motor Neurone Disease.

(Edith, MND, site B)

Well even the doctors don't understand it [brain injury].
(Toby, brain injury, site A)

> They're good, but I think that the whole of the team in [name of GP practice] need to know a lot more about Parkinson's.
> (Tina, PD, site E)

Exceptions to this were found where GPs had taken a particular interest in a neurological condition, or had significant experience of a condition from a previous role. An interviewee with epilepsy also said that, for her, the generalist approach of her GP was preferable to the service provided by her neurologist, which she found patronising and which lacked the continuity of the GP relationship. For this individual, the nurse specialist was not accessible (the nurse clinic was a long way away, she did not drive and the nurse did not do home visits) so the ideal combination of accessibility and specialist expertise was not available to her.

CINRTs combined the specialist expertise of a number of neurology-focused professionals within a single team. In addition to improving continuity of care (see section 6.2), this improved access to different types of specialist expertise and had benefit when this expertise was combined in joint assessments and care planning. As Alan said, his CINRT 'seem to have a better knowledge of requirements [of people] in my position,' and continued:

> They recognise that it's not down to one individual. They have specialist areas … obviously they realise that there's going to be a multidisciplinary approach required and that comes across loud and clear, and I … I do benefit from that.
> (Alan, MS, site E)

The day opportunity services that interviewees told us they most valued were also specialist, in that they tended to support people with particular LTNCs. This was appreciated because the staff running services were well informed about the needs of people with those conditions and how to support them. Emma, for example, said she would ring the MS resource centre in her area if she needed any support because:

> … it is only people – basically, mainly people with MS that go there. … And because they are just MS, they've got a lot [sighs] – they've obviously got far more concentrated experience really
> (Emma, MS, site E)

As noted above (see section 6.3) the condition specific focus of day opportunities also tended to be valued because users had shared experience and could understand and support one another. The exchange below serves to illustrate just how important this was for some people:

Interviewer:	… what's the key thing?
Tina:	That there's somebody there who you can talk to, who knows approximately what you're on about. The support they give in that sense is the main thing.
Interviewer:	**Hmmm hmm. So somebody who understands the condition?**
Tina:	Yeah.
Interviewer:	**Yeah.**
Tina:	Hmmm, which the Parkinson's Group certainly do. … Because I think I mentioned the fact that people think, oh, it's going to be tremor, but it's not, there's a mass of symptoms which can be connected with it and so, people who know that somebody else has that, or somebody else finds this is very reassuring.

(Tina, PD, site E)

It is notable that voluntary sector organisations provided, or in some cases funded, many of these specialist models of service. In the final section of this chapter we briefly summarise our findings on the role of the voluntary sector in providing services that promote continuity of care.

6.6 Role of the voluntary sector

Voluntary sector organisations played a major role in the delivery, and sometimes also planning and commissioning, of services for people with LTNCs in each of our six case study areas.

Several of the nurse specialists were initially funded by voluntary sector organisations on the understanding that PCTs would later take on their funding. The PD Society, MS Society and Epilepsy Action all have programmes of work designed specifically to support the establishment of nurse specialist services. Similarly, some of the CINRTs in our areas were part-funded by voluntary sector organisations (notably the MS Society), and the MND Association led the development of MND Care Centres in collaboration with acute trusts. The voluntary sector had led or facilitated a number of other developments, including the Marie Curie 'Delivering Choice' project looking at improving end-of-life care. In one area, the MS Society had funded a specialist social worker for MS and in another a MS physiotherapist.

Without this push (backed by funding) from the voluntary sector, it is doubtful whether many of the services we identified as promoting continuity of care would have existed. Commissioners and acute trust staff talked of opportunistically collaborating with voluntary sector agencies, and where such opportunities were not available, statutory bodies did not always take the initiative themselves to meet identified needs. Thus, in one of our case study areas where the Epilepsy Action branch had little presence and no capacity to work with the health service, there was no epilepsy nurse specialist, even though the need for one had been identified over a decade earlier:

> … what we need is a neurology nurse specialist specialising in epilepsy - we
> don't have an epilepsy nurse specialist, it's a big, big hole'... It's been talked
> about on and off for 14 years.
> *(acute trust)*

The implications of this persistent gap were made plain by another member of staff in this area, who explained that a person newly diagnosed with epilepsy would typically be given a 20-minute out-patient appointment with the consultant neurologist:

> … and then they get sent away with some pills and that's it. And some
> information to take away with them. So they get a pretty rubbish service.
> *(acute trust)*

Reliance on voluntary sector funding for such essential services, however, can become problematic when the agreed pump-priming period ends and PCTs are expected to take services on. At the time of our research, the PD nurse post in one of our areas was under threat for this very reason, and uncertainty about the future meant that any planning for improvement of the existing service was low priority. In one of our areas there was also a CINRT that had come to the end of its voluntary sector funding, leading to, as one interviewee described it, 'a bit of a crisis' (voluntary sector). It was noted that, in addition to the risk of valued services being decommissioned when voluntary sector funding ended, those where funding was taken on by PCTs were often altered. In one area, for example, the PD nurse specialist was given responsibility for managing a CINRT when responsibility for her funding transferred to the PCT, and this severely reduced her capacity to provide PD services directly. In another area, when MS Society funding for the MS specialist social worker ended, her remit was broadened to cover all LTNCs, although in practice it was not possible for her to do this effectively.

Voluntary sector organisations provided some of the most highly valued day opportunity services in our case study areas, either with funding from statutory agencies, or entirely independently. Headway services were particularly appreciated in this respect, although MS therapy centres and Sue Ryder services also received praise. Where services were provided by the statutory sector, voluntary sector agencies still worked closely with them and supported people to access them. Some voluntary sector groups had dedicated paid workers providing care co-ordination - for example, the PD Society Information and Support Workers - while others such as the Encephalitis Society and Scope provided vital information that people with LTNCs were unable to access from statutory sources.

6.7   Summary

Bringing together the views and experiences of staff and people with LTNCs in our case study sites, we identified three models of good practice, each of which

contributed to the experience of continuity of care and in combination provided 'best practice' and a 'gold standard' for integrated service delivery. These were nurse specialists, CINRTs, and day opportunities that offer peer support, social or leisure opportunities and access to meaningful, creative, learning and/or employment opportunities in the community.

The nurse specialist role can promote all forms of continuity of care and is highly valued by people with LTNCs, their families and carers, and other professionals and volunteers working with them. Where the model worked most effectively, nurse specialists acted as key workers, engaging in active care co-ordination and advocacy to ensure that people with LTNCs could access a broad system of support. With their specialist knowledge and accessibility, they were often people's first port of call, able to answer questions, allay fears and access further support as and when the need for this arose. However, not all people with a LTNC had access to a nurse specialist. Even in areas that did have nurse specialists, there was no guarantee that everyone with a LTNC would receive their services. Moreover, limited capacity meant that nurses were not always able to work in the flexible, responsive way that best supports ongoing continuity, or spend the time with patients necessary to develop and maintain relationship continuity. Full coverage and access to nurse specialists with sufficient capacity to provide ongoing, user centred support is an important element in ensuring continuity of care to all people with LTNCs.

People in receipt of rehabilitation services from a CINRT tended to have improved experiences of continuity. The interdisciplinary way that team members worked, undertaking joint assessments and interventions and sharing case information, meant people with LTNCs received a seamless service from a wide range of professionals. Responsive, flexible services were valued most, particularly where interventions could be provided at a time and location convenient for the person with the LTNC and their families and/or carers. Nevertheless, CINRT services were often available only to a select sub-group of people with a LTNC. Eligibility was most often based on diagnosis, but other criteria included the service user's age and the number of different rehabilitation needs they had. Teams that consisted solely of (physical) health professionals also struggled at the boundaries between health and social care, and between physical and mental health. In our case study areas, the services that worked most effectively for the greatest numbers of people were the larger teams that integrated health and social care professionals *and* provided a service for people with any neurological condition. Where such a service works closely with condition specific services, including nurse specialists and holistic day opportunities, it is likely that people with LTNCs will experience continuity of care.

The NSF for LTNCs set out quality requirements not only for treatment and rehabilitation, but also for life-long care. For many people with LTNCs, the aspiration may not be to improve physical functioning but to maintain quality of life and feel like

a valued, and valuable, member of society. This is an important contributor to continuity of care. Interviewees with LTNCs told us that day opportunities offering peer support, social and leisure opportunities, as well as access to meaningful activity and/or learning and employment opportunities provide high quality, life-long care. Indeed, several of the people who used and valued day services identified them as one of the most important things in their lives. As with nurse specialists, however, these services were not universally available. Some people travelled considerable distances to access condition specific day centres because there was nothing comparable available in their locality. Moreover, the day services that did exist were in some areas being reduced, and in others being redirected to have a greater emphasis on training and employment. Concern was expressed by people with LTNCs, their carers and a number of the staff members we interviewed about the implications of this. The specific nature of many neurological conditions means that finding paid employment is not always achievable, or indeed desirable. Those with deteriorating conditions such as PD, or conditions that affect social functioning such as brain injury, may not be interested in, or able to take up, paid employment. The shift in some areas towards prioritising work and education over social support was felt to risk compromising the effectiveness of the few existing services that recognised this.

Active care co-ordination was an important element of nurse specialist, CINRT and holistic day opportunity services. No additional models of care co-ordination stood out in our case study sites as making a comparable contribution to continuity of care. Individual specialist practitioners did sometimes take on a degree of care co-ordination, but usually only within specific sectors and rarely on an ongoing, proactive basis. Generic workers, including some social workers, GPs and community matrons, did provide elements of care co-ordination. However, in order to co-ordinate effectively and pre-emptively across the service system, practitioners required a good understanding of the neurological condition and associated needs of people with the condition and their families and carers, as well as knowledge of the services available to meet these needs. Most generic practitioners did not have this level of expertise.

Another key feature common to the models identified through our case study work was their specialism, either in a particular neurological condition, or in LTNCs in general. In each of the three models, this was an important, if not the most important, feature of the service. Nurse specialists are by definition specialist practitioners, and it was their specialist knowledge and expertise that made them particularly valuable to many of those we interviewed. CINRTs combined the specialist expertise of a number of neurology-focused professionals within a single team, improving access to different types of specialist expertise, which was particularly effective when combined through joint assessments and care planning. The most valued day opportunity services tended to specialise in supporting people with a particular LTNC. This was

appreciated because service staff were well informed about the needs of people with that condition, and because users had shared experience and could understand and support one another.

Finally, it is important to recognise the role of the voluntary sector in the delivery, planning and commissioning of these models of best practice. Not only do voluntary sector agencies plug gaps in statutory provision, they drive development through pump priming and contribute to needs assessment and improvement planning through LITs. On the ground, they also provide care co-ordination and access to condition specific information. Nevertheless, there is considerable variation in their influence both geographically, and by condition, and the degree to which statutory services actively collaborate with voluntary sector agencies also varies considerably between locations.

7. National benchmarking

The third phase of our research was to triangulate evidence from the earlier scoping work and 'rapid' literature review, and case study phases in order to develop benchmarks of good practice. We were then to develop these benchmarks into a questionnaire (phase 4) to be used in the final phase of the project. Benchmarking information would be used to assess the type, quality and impact of integrated services and provide a means of assessing the implementation of the NSF and improving services. By undertaking this benchmarking process nationally, data would be available for analyses at PCT, SHA and national levels.
This section is split into four parts:

1. The first section describes how the benchmarking tool was developed in line with findings from the scoping work, review and case study components of the project. The processes used to refine the tool and arrive at the final version of the questionnaire are described.

2. The methods of data collection and analysis are reported.

3. An overview of the national data is presented and discussed.

4. Strengths and limitations of the benchmarking tool are discussed and recommendations for its further development and processes for conducting a similar audit in the future are made.

7.1 Developing the national benchmarking audit tool

7.1.1 Item identification

Items to include in the benchmarking tool were informed by the scoping work, literature review and developed by analyses of service user and staff interviews carried out during the in-depth case study phase (Phase 2) of this project. Comparisons of data within and across case study sites showed that people with LTNCs valued a number of service models and types of services. Analysis of staff interviews not only reinforced the importance of these models and services for people with LTNCs, but also illustrated how valuable they were for staff working with people with LTNCs.

Model 1: Community interdisciplinary neurological rehabilitation teams (CINRTs)
Analyses showed that service users valued community rehabilitation teams, incorporating professionals from a range of disciplines working together in an interdisciplinary way. These teams were most highly valued where professionals in the teams had expert knowledge about neurological conditions, where care was

ongoing and where provision was flexible to meet the needs of the person with the LTNC.

Model 2: Nurse specialists

Another model of service provision identified as valuable was nurse specialists. Again, people with LTNCs valued the nurse specialists' expert knowledge of their neurological condition, their knowledge of the local health and social care system, and the long-term nature of their input. Frequently, they were reported to be people's first port of call and the person who would co-ordinate care and services within and across the health and social care system.

Model 3: Day opportunities

Services providing opportunities to take part in meaningful activities in the community were also identified as being important by people with LTNCs. These services were preferred when staff had an understanding of neurological conditions and other users had been through similar experiences and could provide peer support. Such services offered not only social outlets but creative vocational and learning opportunities. They also provided a setting in which information about the service system spread through word of mouth and service providers met to co-ordinate and review care.

Care Co-ordination

As well as the three specific service models outlined, service users also valued individuals and services that co-ordinated the myriad of services, be they specialist or generic, that they might need to access. Specialist expertise about the needs of both the person with the neurological condition and the wider service system was important, as was care co-ordination that was available on an ongoing and accessible basis.

Other services

Access to some therapy services including neuro-physiotherapy, occupational therapy with an expertise in LTNCs, community-based speech and language therapy and neuro-psychology was also found to be valued. Those who were able to access these services on an ongoing basis felt well supported, but availability was often patchy and time limited, with long waiting lists.

Access to timely and relevant information about services, benefits and financial issues was also considered to be vital to help people navigate complex systems.

7.1.2 The benchmarking tool

The benchmarking tool was developed to reflect these findings and provide the potential to explore the models of good practice in relation to overarching aspects of PCT strategy and organisation.

The tool comprises eight sections which asked about the PCT and the identified models of care provision and services:

Benchmarking tool: Section summaries

Section A	Information about the PCT/respondent
Section B	Information about the PCT's strategy and organisation
Section C	Information about community interdisciplinary neurological rehabilitation teams operating within the PCT area
Section D	Information about neurology nurse specialists operating within the PCT area
Section E	Information about day opportunity services operating within the PCT area
Section F	Information about care co-ordination services operating within the PCT area
Section G	Information about other services including therapy services, neuro-psychology and information services as listed above
Section H	Information about the demographic information PCT commissioners use to inform service development

As far as possible, questions had tick box answers, such as 'Yes', 'No', 'Don't know'. Questions requiring a qualitative response were kept to a minimum. The benefits of asking questions in this way were two-fold:

- The time needed to complete the benchmarking audit tool was minimal.
- The use of quantitative questions ensured that results:
  - could be compared across PCTs to provide a national picture
  - would be readily comparable over time within each of the PCTs.

The research team's preferred option for this initial benchmarking survey was to complete the tool by 'phone. This allowed responses to be contextualised and any ambiguities clarified immediately.

While the thematic content of the tool was determined by the analysis of case study data, the wording of questions was informed by contributions from the project's Advisory Group, representatives from the Department of Health's Long-Term Conditions Team, and staff from the Adults, Older People and Carers Team in SPRU. Comments and recommendations from these contributors about question wording are reported in Appendix E.1.

In addition, pre-pilot (cognitive interviews) and pilot interviews were undertaken to help develop the benchmarking tool.

7.1.3 Sampling frame

The target population for the benchmarking survey was PCTs in England. The total number of PCTs in England at the time of the audit was 152.

7.1.4 Pre-pilot interviewing

Telephone interviews were undertaken with representatives of seven PCTs: one with the key contact in each of the case study sites and one with an additional PCT commissioner who also had policy expertise. The purpose of these interviews was to determine the face validity of the benchmarking tool; that is whether or not the questions in the benchmarking tool were asking what we intended them to ask.

For each draft question, a member of the research team asked what the interviewee understood the question to mean and what response they would give for their PCT. As the research team had undertaken in-depth fieldwork in each of these six case study site areas already, they were in a position to ascertain whether or not the draft questions picked up all relevant services. Where any services were not reported, the researcher was able to discuss the reasons for this omission with the interviewee. Notes were taken throughout interviews, both about the interviewee's understanding of questions and how they were answered, to inform any reworking of questions.

These interviews led to a number of changes to the benchmarking tool, which are reported in Appendix E.2.

7.1.5 Pilot interviewing

A pilot study was undertaken to test the tool with a wider sample of PCTs and to test the process that would be used to undertake the national audit. The tool and process were tested with a ten per cent sample of the target population (i.e. commissioning leads for LTNCs in 15 of the 152 PCTs in England[5]).

The sample was generated by ordering the database of contacts by the initial of the lead commissioner's name in each PCT[6] to ensure that the population was randomly ordered. We then included every tenth PCT in the pilot sample. Where the tenth PCT

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[5] Concurrent with the development of the benchmarking audit tool, a member of the research team had contacted each PCT in England to identify and confirm the name and contact details of their lead commissioner for LTNCs.

[6] Not all PCTs were able to identify a commissioner with responsibility for LTNCs. Instead, these PCTs referred the research team to provider arm representatives or senior practitioners who were also involved in strategic planning.

was one that had been involved in the pre-pilot testing they were excluded and the PCT falling after it in the list was included in its place.

Fifteen PCTs were identified for the pilot study. Lead commissioners[2] were contacted by email and invited to take part in the pilot study by completing the benchmarking audit tool over the 'phone with a researcher (for more details of the process see Appendix F).

Of the 15 PCTs contacted, eight were able to take part within the timescale allowed for the pilot testing. These eight 'interviews' highlighted various issues and identified a number of points needing clarification. Participants also made some useful recommendations for improving both the tool and the survey process to increase participation rates. The tool was adapted as shown in Appendix E.3 and guidance notes were developed based on participant recommendations and researcher experience of conducting the pilot testing (see Appendix F.3)

These changes resulted in the development of the final benchmarking tool that was used for the national audit of services for people with LTNCs (see Appendix F.4).

7.2   Conducting the national benchmarking audit

The national survey took place over a three month period, beginning at the end of July 2009 and ending in September 2009.

7.2.1 Participants

Each person who had been identified as the lead commissioner dealing with the National Service Framework for Long-term Neurological Conditions[1] was contacted to confirm that they were the correct person to complete the questionnaire or to nominate someone else.

7.2.2 Consent

Verbal consent to participate was accepted when the NSF lead commissioner (or nominee) agreed to complete the form over the 'phone having been given the opportunity to ask any questions. For those who requested postal or email returns, consent was assumed when a completed version of the benchmarking tool was returned by post or email.

7.2.3 Recruitment and data collection procedure

The final version of the benchmarking tool was emailed to the NSF lead commissioner (or nominee) explaining the research and attaching an information

sheet and the benchmarking tool. They were advised that they would be contacted by a member of the research team within the next week to discuss participation in the audit and to arrange a date and time to complete the form over the 'phone with the researcher, if they agreed to take part. While the research team's preferred option was to complete the tool by 'phone, so that responses could be contextualised and any ambiguities clarified immediately, a minority of PCTs asked to reply by post or email. In these cases, where any clarification of responses was needed, the research team contacted the respondent as soon as possible after receipt of the completed tool.

To ensure consistency between researchers when completing the benchmarking tool, interviewers worked to the guidelines that were developed after conducting the pilot survey (see Appendix F.3). These guidance notes were sent to participants who had asked to respond by post or email.

There were some instances where responses were referred for discussion by the whole research team, usually in relation to meeting the criteria of the definitions for specific models. In these cases, the respondent was informed that we would discuss it with the team and it would either be included in the section as reported, or would be recorded in 'other services'. We did not move information without explaining to the respondent that this might be a possibility.

Each PCT was given a unique identification number to ensure that anonymity was maintained, after a representative completed the benchmark tool.

Data were entered into SPSS (version 17) for analysis. Responses to open questions were recorded in Excel.

7.3   Findings from the national benchmarking audit

7.3.1 Response, completion rates and analysis

Out of 152 PCTs nationally, 137 (90%) responded to a request to participate in the benchmarking audit. One hundred and eighteen PCTs (78%) completed the questionnaire within the allotted time frame. By the end of the data collection period in September 2009, there were two PCTs where interviews had been arranged but not completed and 13 PCTs where no member of staff with responsibility for LTNCs could be identified to complete the tool. No firm conclusions could be drawn about the 34 (22%) of PCTs who did not participate in the benchmarking survey. However, one interpretation might be that non-participants included PCTs where implementation of the NSF and services for people with LTNCs were of particularly low priority. Response and completion rates and method of completion are summarised in Table 7.1 below.

Table 7.1   PCT Response and completion rates

	Number	*Percentage*
PCTs responding	137	90
PCTs completing questionnaire	118	78
Method of completion		
By telephone	102	86.4
By email	12	10.2
By post	4	3.4

Responses to the questionnaire were analysed, generating descriptive frequency tables for each section and further manipulating data to provide insight into questions around accessibility and coverage at a national aggregated level.

Relationships between PCT strategy and organisation and the different service models were explored to assess the impact of macro and meso levels of integration. Data tables are presented in Appendix G.

7.3.2 PCT strategy and organisation

Participants were asked a range of questions relating to their PCT's needs assessment procedures, commissioning arrangements, strategic planning and service user involvement at different levels for services for people with LTNCs. Tables G.1-G.17, covering questions B.1-B.8 in the benchmarking tool, record frequencies and percentages based on the 118 participating PCTs.

The Local Government and Public Involvement in Health Act 2007[17] required PCTs and local authorities to produce a Joint Strategic Needs Assessment (JSNA), as the means by which to describe the future health, care and well-being needs of local populations and the strategic direction of service delivery to meet those needs. Forty-four percent of responding PCTs had completed a JSNA that included a reference to LTNCs in general, with 10% referring to one or more LTNCs specifically (2% of PCTs answered 'yes' to both) (Table G.1).

The extent of joint commissioning arrangements for LTNCs was explored. Twelve percent of PCTs reported that commissioning arrangements for LTNCs were via a single health and social care organisation or joint/integrated commissioning team accountable to both bodies and using pooled budgets. The majority (62%) had less formal arrangements where individual stakeholders remained accountable to their own organisation, but some joint commissioning arrangements existed, including aligned budgets. A quarter of PCTs had no joint commissioning arrangements in place for LTNCs (Table G.2).

Service user and/or carers were likely to be involved in service development (81% of PCTs), although over half of PCTs involved service users and/or carers in commissioning decisions (62%) and audit and/or evaluation (57%) (Tables G.3-G.5).

PCTs were almost equally divided as to whether they systematically recorded numbers of people with LTNCs (Table G.6). Of the 47 per cent who did, a third reported that all LTNCs were recorded (Table G.7). Epilepsy was the single condition most likely to be recorded (28% PCTs), which probably reflected awareness of the requirements of the quality and outcomes framework (QOF).

Knowledge of care plans was limited with 89 per cent of commissioners not knowing the approximate percentage of people with LTNCs in their area who were likely to have one (Tables G.8 and G.9). By 'care plan' we were referring specifically to an overarching single care plan as set out in the 2009 DH guidance[47]; that is, one that is owned by the person but can be accessed by those providing direct care or services, or other relevant people as agreed by the individual. Responses may reflect the relative newness of this requirement with people as yet unlikely to have such a comprehensive care plan, or it may reflect an absence of systems in place at PCT level to record such information.

A cross-sector strategic group with responsibility for service improvement for LTNCs (e.g., a local implementation team for the NSF for LTNCs) was found in 66 per cent of PCTs (Table G.10) with just over two-thirds of these groups (68%) involving service users and/or carers (Table G.11). Most groups appeared to be active, 88 percent having met in the last three months (Table G.12).

Over a third (35%) of PCTs had not completed a needs assessment for LTNCs, either as part of the JSNA or as a separate exercise (Table G.13). Half of PCTs had a written action plan for LTNCs (Table G.14), and 36 per cent of these had audited or measured their progress against the plan within the last year or were currently doing so (19%) (Table G.15). A quarter of PCTs with action plans reported that they had implemented more than 50 per cent of priorities from the action plan to date, representing five per cent of PCTs overall (Tables G.16 and G.17).

A summary of key findings relating to the PCT strategy and organisation section of the benchmarking tool are reported in Table 7.2 below.

Table 7.2   PCT strategy and organisation

	Percentage of PCTs (based on 118 PCTs)
JSNA mentions LTNCs	56
Joint commissioning for LTNCs	
full	12
partial	62
Service users and/or carers involved in commissioning decisions	63
Service users and/or carers involved in service development	81
Service users and/or carers involved in audit and/or evaluation	57
Systematically record numbers of people with LTNCs	47
More than 50% of people with LTNCs currently have a care plan	5
Cross-sector strategic group	66
Service users and/or carers involved	68
Met in last 3 months	88
Completed needs assessment	63
Written action plan for implementing NSF	50
Audited or measured progress against the plan within the last year or currently	54 (27% overall)
Implemented more than 50% of priorities from the action plan to date	25 (5% overall)

7.3.3 Community interdisciplinary neurological rehabilitation teams (CINRTs)

Information about CINRTs was confined to rehabilitation teams which were specifically neurological in focus, working mostly in the community (including people's own homes) to provide a person centred service. They were interdisciplinary teams as defined by the NSF for LTNCs[1], that is, they 'work together to an agreed set of goals, often undertaking joint sessions' (p.16). Information for CINRTs is reported in Tables G.18-G.28 based on responses to questions C.1–C.9.

Seventy-three per cent of PCTs reported having one or more CINRTs operating in their area (Table G.18), the majority having a single team (Table G.19). Just under half of PCTs (47%) reported CINRTs covering all LTNCs (Table G.20). Where a team covered only a single condition, brain injury was the most common condition reported. Data were aggregated over all PCTs. Out of 123 CINRTs reported nationally 59 per cent of teams covered all LTNCs with a similar breakdown by condition as occurred at PCT level (Table G.21).

Information concerning access, type of provider, case load, referral, and whether support was ongoing and included telephone advice is presented nationally for aggregated data. This reflects the way such characteristics of teams varied *within* PCTs as well as *across* PCTs.

Access was an important issue identified by our case study research. We therefore, asked how easy commissioners felt it was to access (each of) their CINRTs, considering influences like waiting times, eligibility criteria and service location. This

was a subjective assessment and we suggested that they might wish to discuss this question with colleagues to arrive at a consensus. Fifty-nine per cent of CINRTs were felt to be 'easy' or very easy' to access (Table G.22). Approximately three-quarters of teams covered the entire PCT area (Table G.23).

Seventy per cent of CINRTs were provided by a health trust, the remainder encompassing a variety of permutations between statutory and non-statutory provision. After health trust providers, joint health and social care provision was the most common scenario (17%) (Table G.24).

Case loads varied widely from less than fifty to over 500 although the size of case load was unknown for 40 percent of CINRTs. The modal case load was 50-100 (Table G.25).

Means of referral was an important element of access to services. In just over half (55%) of CINRTs, PCTs reported that people with LTNCs were able to access directly and refer themselves (Table G.26).

The length of time people could remain on the team's active caseload was split mainly between 'ongoing with intermittent reviews' and 'time limited based on goals'. For five per cent of teams, interventions were for a pre-specified length of time (Table G.27).

Ninety-three per cent of participants, who knew this information, reported that service users were able to ring teams for advice and support (Table G.28).

A summary of key findings relating to section C of the questionnaire, community interdisciplinary neurological rehabilitation teams (CINRTs) is in Tables 7.3 and 7.4 below.

Table 7.3   Community interdisciplinary neurological rehabilitation teams (CINRTs)

	Percentage of PCTs *(based on 118 PCTs)*
CINRTs operating in PCT area	73
CINRTs covering all LTNCs	47
Most common condition specific CINRT brain injury	21

Table 7.4   Community interdisciplinary neurological rehabilitation teams (CINRTs) (aggregated data)

	Percentage of teams (aggregated data)
CINRTs 'very easy' or 'easy' to access	59
CINRTs full coverage of PCT area	74
Provider of CINRTs	
health trust	70
joint health and social care	17
Self-referral to CINRTs	55
Involvement with CINRTs	
ongoing with intermittent reviews	41
time limited based on goals	44
Able to ring CINRTs for advice and support	93

7.3.4 Nurse specialists

Our research showed that people with LTNCs valued the support from nurse specialists who brought specialist knowledge about their condition, knew the local system and were able to co-ordinate care within and across different sectors. Tables G.29-G.38 refer to responses to questions about nurse specialists in section D of the benchmarking tool.

Ninety-three per cent of PCTs reported that neurology nurse specialists were operating in their area (Table G.29). Conditions covered varied across PCTs. Twenty per cent of PCTs had access to nurse specialists who covered all or multiple LTNCs, but the majority were condition specific (Table G.30). PCTs were most likely to have MS and PD nurses available in their area (78% of PCTs with MS nurse specialists and 79% with PD nurse specialists). When data were aggregated, over half of all nurse specialists (individuals or teams) were accounted for by MS and PD nurse specialists (56% together) (Table G.31).

Nurse specialists worked in different ways, as individual practitioners or through teams, covering single or multiple PCTs, based in hospitals and/or the community. We wanted to capture the diversity of working found not only across PCTs nationally, but also within PCTs. Although sometimes recording both individual nurse specialists and teams, PCTs were most likely to have individual practitioners within a PCT area (77% of PCTs). Teams of nurse specialists operating in their area were reported by 28 per cent of PCTs (Table G.32).

Aggregated data are presented for questions D.3-D.9, combining information for individuals and teams. Questions were asked in the same way as for Section C. However, there may be some double counting as, in some areas, nurse specialists worked across PCT boundaries, especially if they were based in acute hospitals in specialist centres. Sixty-two per cent of nurse specialist individuals and teams were reported as 'very easy' or 'easy' to access (Table G.33); 73 per cent were likely to cover the whole PCT area (Table G.34). Just over a third (34%) spent 50 per cent or more of their time working in the community with 30 per cent spending less than half their time in community settings, including people's own home (Table G.35). However, this information was unknown for 36 per cent of nurse specialists. Self-referral to the nurse specialist or team was recorded for 52 per cent of practitioners (Table G.36) and access, once someone was part of the active caseload, tended to be open-ended (60%) (Table G.37). Information provided by PCTs about caseloads was generally of poor quality and not consistently reported by team or individual. It was, therefore, not included in the current analyses. Eighty-eight per cent of recorded nurse specialists were available to ring for advice and support as needed (Table G.38).

The key findings relating to section D of the questionnaire on 'nurse specialists' are summarised in Tables 7.5 and 7.6 below.

Table 7.5   Nurse specialists

	Percentage of PCTs *(based on 118 PCTs)*
Nurse specialists operating in PCT area	93
Nurse specialists covering all or multiple LTNCs	20
Most common condition specific nurse specialists	
PD	79
MS	78
Epilepsy	50

Table 7.6   Nurse specialists (aggregated data)

	Percentage of nurse specialists *(individuals and/or teams aggregated data)*
Nurse specialists 'very easy' or 'easy' to access	62
Nurse specialists full coverage of PCT area	73
Nurse specialists working	
over half or more of time in community settings	34
less than half of time in community settings	30
Self-referral to nurse specialists	52
Time on active case load open-ended	60
Able to ring nurse specialists for advice and support	88

7.3.5 Day opportunities

In our interviews with service users, people with LTNCs said they valued services that offered peer support, social and/or leisure opportunities **and** access to meaningful creative learning and/or employment opportunities in the community. As outlined in the guidance notes researchers only included services in this section which strictly fell within the criteria of our definition. Other sorts of day opportunities which may contain elements of our definition were recorded in question G.7 of the benchmarking tool. Data relating to day opportunities are reported in Tables G.39-G.48.

Sixty-five per cent of PCTs reported day opportunities which fitted the definition outlined in section E of the questionnaire (Table G.39). In 45 per cent of PCTs these services were specific to particular LTNCs (Table G.40) and in just over a third of PCTs these were for head injury specifically (Table G.41). When data were aggregated, day opportunities for those with head injuries comprised over half (55%) of all such services reported (Table G.42). Similarly, where PCTs reported more than one day opportunity in their area these were most likely to be for people with head injury.

Fifty-eight per cent of day opportunities recorded were judged as 'very easy' or 'easy' to access (Table G.43) and 78 per cent provided full coverage of the PCT area (Table G.44). The biggest provider of such services was non-statutory organisations (48%), with a further 12 per cent provided jointly by statutory and non-statutory organisations (Table G.45). People were able to self-refer to the service in 60 percent of cases (Table G.46). Fifty-eight per cent of day opportunity services offered open-ended support (Table G.47) and in 78 per cent of cases, people were able to ring the service for advice and support (Table G.48).

The key findings relating to section E of the questionnaire, 'day opportunities', are summarised in Tables 7.7 and 7.8 below.

Table 7.7   Day opportunities

	Percentage of PCTs (based on 118 PCTs)
Day opportunities available in PCT area	65
Day opportunities covering specific LTNCs	45
Most common condition specific day opportunity head injury	37

Table 7.8   Day opportunities (aggregated data)

	Percentage of day opportunities (aggregated data)
Day opportunities 'very easy' or 'easy' to access	58
Day opportunities full coverage of PCT area	78
Provider of day opportunities	
non-statutory organisations	48
joint statutory and non-statutory organisations	12
Self-referral to day opportunities	60
Involvement with day opportunities open ended	58
Able to ring day opportunities for advice and support	77

7.3.6 Other forms of care co-ordination

Having access to a named person able to co-ordinate care within and across different sectors improved continuity of care for people with LTNCs. Care co-ordination may be provided as part of the models already described. However, our research showed that this could also be provided in other ways and we attempted to explore the range of care co-ordination services which commissioners were able to describe. Information about these services is reported in Tables G.49-G.52.

Seventy-nine per cent of PCTs had services fulfilling a care co-ordination role that had not yet been reported (Table G.49). A quarter of all PCTs reported such care co-ordination services that were directly for people with LTNCs; nine per cent overall were confined to specific LTNCs (Table G.50). Table G.51 provides a breakdown of the conditions covered by these condition specific care co-ordination services. MND and MS were the LTNCs most frequently reported as covered by a dedicated care co-ordination service. Table 7.9, below, provides summary data for other forms of care co-ordination reported by PCTs.

As well as care co-ordination for LTNCs, other services which could provide care co-ordination were described. These most commonly included social workers, community matrons, district nurses and continuing healthcare teams. Such services are found across all PCT areas, but were not consistently reported in the current survey. This may reflect commissioners' level of awareness about the role of universal services within their area, or that the capacity of such services to provide care co-ordination within and across different sectors varies widely between PCTs. Aggregated data for this section, therefore, were not felt to be reliable. It was not possible to disaggregate care co-ordination for LTNCs from data about care co-ordination overall. Therefore, although questions about access and availability corresponding to those asked in preceding sections were asked, responses were not analysed or presented here.

Table 7.9   Other forms of care co-ordination

	Percentage of PCTs (based on 118 PCTs)
Other forms of care co-ordination available in PCT area	79
Other forms of care co-ordination specific to LTNCs	25
Most common condition specific care co-ordination	
MS	3
MND/ALS	3

7.3.7 Other services

In addition to the service models reported above, our research showed that being able to access a number of other services and information in the community (not just as an in-patient), on an ongoing basis, was important to ensuring people with LTNCs experienced continuity of care. These services were specifically neuro-physiotherapy, occupational therapy (OT) with an expertise in neurology, speech and language therapy (SaLT) and neuro-psychology. Data covering these questions are presented in Tables G.53-G.81 and summarised in Table 7.10 below.

7.3.7.1 Neuro-physiotherapy
A total of 93 per cent of PCTs reported that out-patient or community neuro-physiotherapy was available in their area to people with LTNCs. This may be through the models already described in previous sections of the questionnaire, although nearly two-thirds of PCTs identified a separate service (Table G.53). PCTs with neuro-physiotherapy provided through a service already described, the majority (90%) referred to CINRTs (Table G.54). Just over a third (35%) of PCTs described their 'other' neuro-physiotherapy service as 'very easy' or 'easy' to access (Table G.55). The modal maximum waiting time was 5-18 weeks (36% of PCTs) although 40 percent of PCTs did not have this information (Table G.56). Nineteen percent of

PCTs described the length of time on the neuro-physiotherapist's active case load as 'ongoing with intermittent reviews'. Just over half (52%) of PCTs reported services as 'time-limited based on goals' (Table G.57), with PCTs almost evenly divided as to whether people were able to re-enter the service without re-referral (48%) or not (43%), where the service was time-limited (Table G.58). Eighty-eight percent of PCTs with a neuro-physiotherapy service estimated that the whole of their geographical area was covered by the service (Table G.59).

7.3.7.2   Occupational therapy (OT) with expertise in neurology

Occupational therapy (OT) with expertise in neurology was available in 82 per cent of PCTs through the models already described in previous sections of the questionnaire, and/or as a separate service (35%) (Table G.60). Again, out of PCTs with neuro-OT provided through a service already described, the most likely model of providing occupational therapy with expertise in neurology was through a CINRT (93% of PCTs), where services had already been described (Table G.61). A similar percentage of PCTs (34%) as in neuro-physiotherapy described their OT service as 'very easy' or 'easy' to access (Table G.62). Five to 18 weeks was the most likely reported maximum waiting time for new referrals (36% of PCTs) and none reported maximum waiting times longer than this (Table G.63). The shortest maximum waiting time of one month or less was reported by 25 per cent of PCTs, a greater percentage than for other therapy services. In addition, this was the only therapy service not to report a maximum waiting time of greater than 18 weeks. Half of PCTs reported the length of time on the OT's active case load as 'time-limited based on goals' (Table G.64). Where OT services was time-limited, service users could re-enter the service without re-referral in 48 per cent of PCTs. Again, a minority (16%) described the service as 'ongoing with intermittent reviews' (Table G.64). Seventy-eight percent of PCTs with occupational therapists with expertise in neurology estimated that the whole of their geographical area was covered by the service (Table G.66).

7.3.7.3   Community speech and language therapy (SaLT)

A total of 94 per cent of PCTs reported that people with LTNCs could access community SaLT services in their area. This was unlikely to be through the models already described (19% of PCTs). In most cases SaLT was provided in addition to or as a separate service (75% of PCTs) (Table G.67), but where provided as part of a previously reported model, CINRTs again were the likely vehicle (93%) (Table G.68). Twenty-nine per cent of PCTs rated their SaLT service as 'very easy' or 'easy' to access (Table G.69). Five to 18 weeks was the most likely reported maximum waiting time for new referrals (28% of PCTs). Only one PCT reported maximum waiting times longer than this (Table G.70), but 59 per cent of PCTs did not have this information. The length of time on the active case load was described as 'time-limited based on goals' by 38 per cent of PCTs but a greater percentage (23%) than for neuro-physiotherapy or OT reported the SaLT service as 'ongoing with intermittent reviews' (Table G.71). Where access was time-limited, service users could re-enter the

service without re-referral in a similar percentage (49%) of PCTs to other therapy services (Table G.72). Full geographical coverage was reported by 91 percent of PCTs (Table G.73).

7.3.7.4 Neuro-psychology

Our case studies had suggested that not only was access to neuro-psychology highly valued, but was also a more scarce resource relative to other therapy services. This seemed to be borne out by the national benchmarking data.

Neuro-psychology was provided in 70 per cent of PCTs (Table G.74). Twenty per cent of PCTs reported that neuro-psychology was provided through the models reported earlier in the questionnaire and this again was most likely to be via CINRTs (95% of PCTs) (Table G.75). In contrast to the other neuro-therapy services, only eight per cent of PCTs described the neuropsychology service as 'very easy' or 'easy' to access, 63 per cent of commissioners choosing 'difficult' or 'very difficult' to describe access to neuropsychology (Table G.76). Maximum waiting times were also longest for this service; six per cent of PCTs reported over six months, although the modal maximum waiting time was comparable with other therapy services (35%, 5-18 weeks). The shortest maximum waiting time of one month or less was reported by only two per cent of PCTs (Table G.77). Just over a third of PCTs (35%) described the length of time on the neuropsychologist's active case load as 'time-limited based on goals'. 'Ongoing with intermittent reviews' was reported by 18 per cent of PCTs (Table G.78). The option to re-enter the service without re-referral, (where it was time-limited), was available in only 22 per cent of PCTs, less than half the percentage of PCTs compared with other therapy services (Table G.79). A similarly reduced percentage of PCTs (69%) reported full coverage of their area by a neuropsychology service, when compared with other therapies (Table G.80).

7.3.7.5   Information

Just over half (52%) of PCTs commissioned the voluntary or private sector to provide information and advice or support to people with LTNCs living in their area (Table G.81). An open question about sources of information yielded a wide range of statutory and non-statutory providers of information, advice and support. Many were generic services, but commissioners emphasised the importance of nurse specialists and condition specific voluntary organisations in fulfilling this role. Innovative models were described, such as care advisers based in GP surgeries to provide information and signposting, and 'information prescriptions' (one of the commitments of the NHS Constitution 2009[48] were being rolled out in a number of areas for people with LTNCs.

Other services for people with LTNCs which had not been described in earlier sections were explored in an open question. There was a range of services provided by neurological charities, or jointly with statutory services, which had not fallen within

the criteria of 'day opportunities' as defined by the benchmarking questionnaire, but nonetheless provided an integral part of the local service map offering a specialist focus. Also included in this section were community integrated rehabilitation teams which were generic teams, but included people with LTNCs as part of their total case load.

Table 7.10   Therapy services

	Neuro-physiotherapy	OT with expertise in neurology	SaLT	Neuro-psychology
	% of PCTs	% of PCTs	% of PCTs	% of PCTs
Service available in PCT area	93	82	94	70
through models already described	30	47	19	20
in addition to or as a separate service to the models already described	63	35	75	50
Separate service 'very easy' or 'easy' to access	35	34	29	8
'difficult' or 'very difficult' to access	21	21	19	63
Shortest maximum waiting time reported	1 month or less (21%)	1 month or less (25%)	1 month or less (11%)	1 month or less (2%)
Greatest maximum waiting time reported	over 6 months (1%)	5-18 weeks (36%)	19 weeks-6 months (1%)	over 6 months (6%)
Length of time on active case load:				
ongoing with intermittent reviews	19	16	23	18
time-limited based on goals'	52	50	38	35
Re-entering the service without re-referral (if time limited)	48	48	49	22
Service provides full coverage of PCT area	88	78	91	69

7.3.8 Demographic characteristics

In response to the open questions about the type of information used to find out about the diversity of the population, most PCTs cited local Public Health Informatics and JSNAs coupled with local authority community profiling, regional Public Health Observatories, and ONS census data as a national resource. Some commented that it was not easy to find local information specific to LTNCs.

Asking about people from particular socio-economic, ethnic or other groups in the PCT area who might find it difficult to access services gave an indication of the level of awareness of issues around inequalities. Some commissioners were very specific about the sorts of groups who might be at risk, the characteristics of their area which could create barriers and the inherent difficulties in the 'visibility' of such problems. However, others did not identify any concerns or relied on Equality Impact Assessments to highlight potential problems as new services were commissioned.

The final question in this section asked about services designed to meet the needs of specific groups (not defined by their LTNC), but which people with LTNCs might use. This included the sorts of services which addressed language, cultural, socio-economic, age, gender and communication needs. Responses ranged from none that were known about to, commonly, interpreting and translation services, advocacy services, and in some cases, more pro-active initiatives, such as 'health trainers' or 'health activists' to work with specific groups which could include BME populations, but also those in prisons and asylum centres.

7.4   Relationships between PCT 'strategy and organisation' and models of care

7.4.1 Tests of association

In an attempt to examine the influence of structural and organisational characteristics on the provision of models of care, measures of association were examined appropriate to nominal, categorical data (X^2, contingency coefficient (C)). These associations were further explored using logistic regression analysis to identify macro and meso level factors (the independent variables) which might be useful in predicting the occurrence of particular models of care (the dependent variables). Items were re-coded into dichotomous variables - 'yes'/'no' or 'don't know'.

Within the PCTs' structures and organisation, four factors appeared to be associated with the three models of care that were examined in detail (CINRTs, nurse specialists, and day opportunities). These were:
- joint commissioning arrangements
- the existence of a cross-sector strategic group, for example, a LIT
- whether service users were involved in commissioning decisions
- completion of a needs assessment for LTNCs.

Preliminary analyses (looking at the size of the contingency coefficient, C, and level of significance) suggested that the strongest association with CINRTs was having a cross-sector strategic group, although joint commissioning and service users being involved in commissioning decisions were also significant. The association with nurse

specialists was significant only for service user involvement in commissioning, while for day opportunities, cross-sector strategic group yielded the highest value of C and greatest significance, although all four 'structural and organisational' factors were significantly associated. Results are reported in Tables G.82-G.85 and summary statistics are reported in Table 7.11 below.

Table 7.11   Tests of association

	Pearson Chi-Square	df	Contingency coefficient,C	Asymp. Sig. (2-sided)	Significance at 5% level
CINRTs					
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
Nurse specialists					
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
Day opportunities					
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

7.4.2 Logistic regression analysis

A backward stepwise (likelihood ratio) method of logistic regression analysis was selected, with the four 'structural and organisational' variables as categorical predictor variables and each 'model of care' in turn included as the dependent variable.[7] Results for analysis are reported in Appendix G, Tables G.86-G.88.

The models generated did not significantly improve predictive ability for CINRTs, nurse specialists or day opportunities. In relation to CINRTs, the initial logistic regression model (step 0) correctly classified 73.3 per cent of participants, while the final model, including only the predictor variable, 'cross-sector strategic group', also correctly classified 73.3 per cent of participants (Nagelkerke R^2=0.056). Similarly, for nurse specialists, the initial logistic regression model (step 0) correctly classified 93.1 per cent of participants, while the final model, including only the predictor variable, 'service users involved in commissioning decisions', also correctly classified 93.1 per cent of participants (Nagelkerke R^2=0.115). In relation to day opportunities, predictive ability was slightly improved. The initial logistic regression model (step 0) correctly classified 66.4 per cent of participants, while the final model, including a combination of the two of the four predictor variables, 'cross-sector strategic group' and 'completed a needs assessment', correctly classified 69.8 per cent of participants. However, the Nagelkerke R^2 value was still low (0.137).

The closeness of the values of the measures of association, the results of the modelling analyses and the inferences which can be made from findings from case studies, suggested that the selected independent variables associated with models of care may themselves be correlated with each other. This proved to be the case; a complex multi-colinearity between the four 'structural and organisational' variables was found when independently correlated (Table G.89).

The conclusions that could be made from analysing these inter-relationships, therefore, were that, overall, there was a significant, but weak association between the four selected 'structural and organisational' variables and the models of care. Factors closest to the specific concerns of LTNCs were foremost, but they had limited predictive ability. This was borne out by our case study work. Although the existence of a cross-sector strategic group for LTNCs in some circumstances can be an important driver for assessing and improving services, it does not guarantee an effect. As confirmed by our case studies, considerations such as type and level of representation, power relationships and changing higher level priorities can over-ride its potential for change. Moreover, the direction of causality cannot be assumed. For

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[7] For further explanation of methods used see A. Field, 2000, Discovering Statistics using SPSS for Windows, London: Sage. Chapter 5 pp.163-204.

example, again as our case studies showed, individual champions can bring about improvements through actions at a micro level, and thus exert influence on strategic decision making and structural innovation. 'Bottom-up' initiatives in achieving integrated services were a feature of our case studies as much as those that were 'top-down'.

7.5 Strengths and limitations of the benchmarking tool and its future use

7.5.1 Content

The benchmarking tool was grounded in the evidence from earlier stages of the project. The scoping work, literature review and, in particular, the case studies provided in-depth qualitative data about the types of services and practices that service users and staff highlighted as important in providing continuity of care. As such, the questionnaire was informed by a 'rich' source of data, but its development also presented a challenge in translating the less tangible, but important, characteristics contributing to an overall experience of continuity of care into 'hard' benchmarks. For example, the existence of a service, such as nurse specialists, could take a PCT some way towards achieving the quality requirements of the NSF, but invariably it was issues around ways of working, availability and accessibility, which underpinned achieving integration of services and continuity of care. Moreover, related to this, there was often wide variation within a PCT in the way the different examples of a particular model of care were delivered. It was, therefore, easier to provide summary information around the therapy services in section G of the benchmarking tool, than for the diversity of CINRTs, nurse specialists, day opportunities and care co-ordination that were described in sections C-F.

Questions around structure and organisation (section B of the benchmarking tool) identified structures and organisational approaches conducive to implementation of the NSF. However, as discussion of the modelling analyses suggested, the existence of such structures and the existence of particular models of delivery were often associated in complex ways. This was also evident in our case studies where macro and meso level inter-relationships created complex dynamics, which themselves changed with shifting priorities. For example, case study analyses showed how financial and/or policy preoccupations influenced commissioning behaviour, while the effectiveness of LITs was highly variable (see section 4.3).

7.5.2 Process

Bearing in mind such limitations in capturing and defining the benchmarks, the processes used in developing the tool and its application proved robust. Pre-pilot and

pilot interviews with case study sites and randomly selected PCTs, as well as consultation with other stakeholders and advisers, tested the validity of questions and improved both the tool and the survey process. The completion of the tool by 'phone achieved not only a high response and completion rate, but also allowed information to be contextualised and any ambiguities clarified immediately. 'Phone contact with PCTs also provided feedback as to the perceived value of conducting such a benchmarking survey.

7.5.3 Impact

Views on the exercise were not actively sought, but a number of commissioners expressed their opinions. Comments, where made, were generally positive, in that the survey would provide information to the PCT, and LITs in particular, which would not otherwise be easily available. One person felt that the information was too detailed for commissioners to provide, but the same person concluded that it had been a useful exercise pulling it together. Others remarked that it was the sort of information that commissioners *should* know and it had been useful to ask the questions. In areas where there had been little or no leadership around LTNCs, people welcomed the tool as a starting point to provide a baseline and begin to benchmark their progress. For some, the questionnaire highlighted gaps around LTNCs and how they had suffered by being 'hidden' within the LTCs agenda. In one case at least, the survey prompted immediate actions specifically around a number of issues flagged up by the questionnaire and more generally to ensure re-engagement with the NSF. Conducting a national benchmarking survey helped to raise the profile of LTNCs and, at the very least, stimulated people to ask questions and in some cases prompted actions.

7.5.4 Analysis

Clear benchmarks were derived around elements of PCTs' structure and organisation that might facilitate the implementation of the NSF and which could be linked to benchmarks around the existence of particular models of care and other services identified as embodying good practice. Further, in-depth analyses of the questionnaire exposed a tension between producing distinct national benchmarks and capturing the wide variation, not only in the types of services available, but also in the ways they were delivered and how different (or the same) services approached the key issues of availability, eligibility and access. Such variation existed *within* as well as *across* PCTs so that aggregating quantitative data at a national level for some of the services recorded, proved problematic.

In particular, the section on care co-ordination revealed wide differences which proved difficult to capture via the questions as currently framed in the benchmarking tool. Care co-ordination was evident more as an approach than a 'model' of care and

could be adopted by a range of different services that might be universal. However, across different localities, there was variation as to whether such services provided care co-ordination at the interface between services. For example, social workers and district nurses were identified by some PCTs as providing care co-ordination. Although such generic services exist within all localities, they are not necessarily indicative of providing care co-ordination within and across different sectors for people with LTNCs. This may be a feature of some teams in some areas, or a feature of individual professional practice. Therefore, the reporting of such services by some PCTs and the responses to subsequent questions in section F did not provide a reliable benchmark around care co-ordination. Such characteristics of care co-ordination were discussed also in relation to case study analyses (section 6.4).

7.5.5 Future use

On publication in 2005, the NSF for LTNCs[1] was to have a ten year implementation period. This survey stands alone as a snap-shot of the implementation of the NSF for LTNCs and current services four years after publication of the NSF. As such it allows localities to benchmark their own performance against national progress so far, but should be repeated if it is to be of value as a benchmarking tool that effectively charts progress and aims to improve services over time, at least up until 2015.

Considerable time was spent in identifying PCT leads for LTNCs. By securing permission to include contact details on a publicly available list, it is hoped that a future repeat survey could enlist informed support with reduced preparation time. However, staff turn-over within organisations could militate against this, depending on the interval between benchmarking surveys. As mentioned earlier, a strength of the telephone survey method was the opportunity it gave to discuss and contextualise the information provided, but it meant that conducting the survey was time and labour intensive. The questionnaire could be adapted to an electronic or web-based version, bearing in mind the trade-off between speedier administration and quality and consistency of information.

Analyses in this version were completed using SPSS version 17, but data could be imported easily into a Microsoft Office Excel database for wider use. Basic descriptive benchmarking information would be accessible in this format, but inter-relationships and modelling analyses restricted.

8. Discussion

The overall aims of the research reported here were to identify best models/practice for integrated services and to develop a benchmarking system, based on these models/practice, to assess the initial impact of the National Service Framework for LTNCs[1] on integrated service provision. Key research questions included how services for people with LTNCs are integrated within and across health, social care and other sectors (including the independent sector); how diversity of need is addressed; which models of service provision seem to work well in delivering continuity of care and what impact different types and levels of integration have on continuity of care. In this final chapter we discuss the findings in relation to these main aims, the strengths and limitations of the work, and the implications of the findings for policy, practice and future research.

8.1 Best models/practice for integrated services

Our rapid systematic review of evidence on integrated services for people with LTNCs found that the evidence base, about both the impact and costs of integrated models of care for people with LTNCs and about the service delivery and organisation elements that need to be in place to make these models operate well, is weak. Further, there are few studies of models of care for people with some of the most complex conditions (for example Huntington's Disease, brain injury).

The evaluative literature is characterised by relatively poor quality research, regardless of its design, while the descriptive literature varies in what it describes about how the models of care work in practice. Further, there is little sense in the evaluative research that outcomes that would be valued by service users and their families have informed the choice of outcome measures in the evaluations. Issues of personal choice, empowerment and the experience of continuity of care (in any of its guises) are largely absent. Despite this, the descriptive literature does suggest that multidisciplinary teams or clinics, alongside clinical nurse specialists, would provide a wider range of types of continuity of care for people with LTNCs than would either alone.

In-depth case studies in six neurology 'service systems' identified the key indicators of good quality, integrated service provision and the impact of different models of service provision on service users and their families or informal carers.

Interviews with members of staff working in neurological service systems in our case study areas informed us about the issues they felt were affecting integrated working for people with LTNCs:

- **Formal integration between health and social care** can create the flexibility needed to implement innovative ways of working, but this alone does not guarantee joined up service planning and delivery. Forethought and will (at all levels) are necessary to engage all stakeholders fully and join services together. This takes strong leadership and a shared vision of desired outcomes.

- **Personal relationships and an organisational culture of collaboration** can support integrated working, but these may by unsustainable and vary across systems.

- **Co-location** can help to bring professionals closer together, but again it does not guarantee close working relationships, as these are also affected by culture and management.

- **Initiatives designed to improve the flow of information across boundaries** (such as the SAP) had varying degrees of success depending on organisational cultures, available technology and ways of working.

- **Cross-sector strategic groups** such as Local Implementation Teams were useful in bringing together stakeholders from across the service system to identify areas and strategies for improvement.

- **Key professionals** who specialise in LTNCs create and maintain informal links and pathways, helping people with LTNCs to navigate complex systems.

- **CINRTs** bring staff together from across the system to work side-by-side, overcoming organisational and geographical boundaries and also providing a focal point for others.

People with LTNCs informed us that the experience of continuity of care was associated with having choice and control over the timings and settings of care, and the ability to access support as and when it is required. Flexible support to achieve aspirations and maintain not only physical functioning but also social lives and personal agency, is provided by a number of services, but three particular models stood out. These were nurse specialists, CINRTs and proactive, holistic, day opportunity services. People with LTNCs repeatedly cited these services as helping them to continue to live their lives in the ways that they wanted. Services that were provided on a long-term basis, with a single individual or team taking responsibility for care co-ordination, ensured longitudinal continuity and the optimum conditions for developing and maintaining relationship continuity. Constant input is not always required (or necessarily desired); rather people wanted the ability to access support from a known and trusted service *as and when they needed it*.

The services most valued by people with LTNCs have specialist knowledge about neurological conditions and associated supports, and there is continuity of information so service users and their families can readily access it. Neurological charities and other voluntary sector organisations often supported, if not directly provided and/or funded, this specialist care. Where models work best, they cross

boundaries, being able to co-ordinate care provided by different services either by bringing them together in one team (as in the case of CINRTs) or by providing a focal point (both physically, as with day centres and community hospitals, and by there being a visible key worker for other services to liaise with). These models also play a vital role by monitoring and following up interventions, enabling them to step in and resolve discontinuities if they arise. Without such services, the onus often falls to people with LTNCs themselves, their families or other carers to navigate through the complex system of health and social care. This can be exhausting and, without the links and specialist knowledge of professional service providers, continuity of care cannot always be achieved.

Figure 8.1   Models of Best Practice for Integrated Service Delivery

Bringing together the views and experiences of staff and people with LTNCs in our case study sites, we identified three models of good practice for integrated service delivery, each of which contributed to the experience of continuity of care and in combination constituted current 'best practice'. These were:

1.   **Nurse specialists**

2.   **Community interdisciplinary neurological rehabilitation teams (CINRTs)**

3.   **Day opportunities** (that offer peer support, social/leisure opportunities *and* access to meaningful, creative, learning and/or employment opportunities in the community)

We also concluded that **care co-ordination** is an element of service provision central to the experience of continuity of care, although this does not constitute a discrete model in itself.
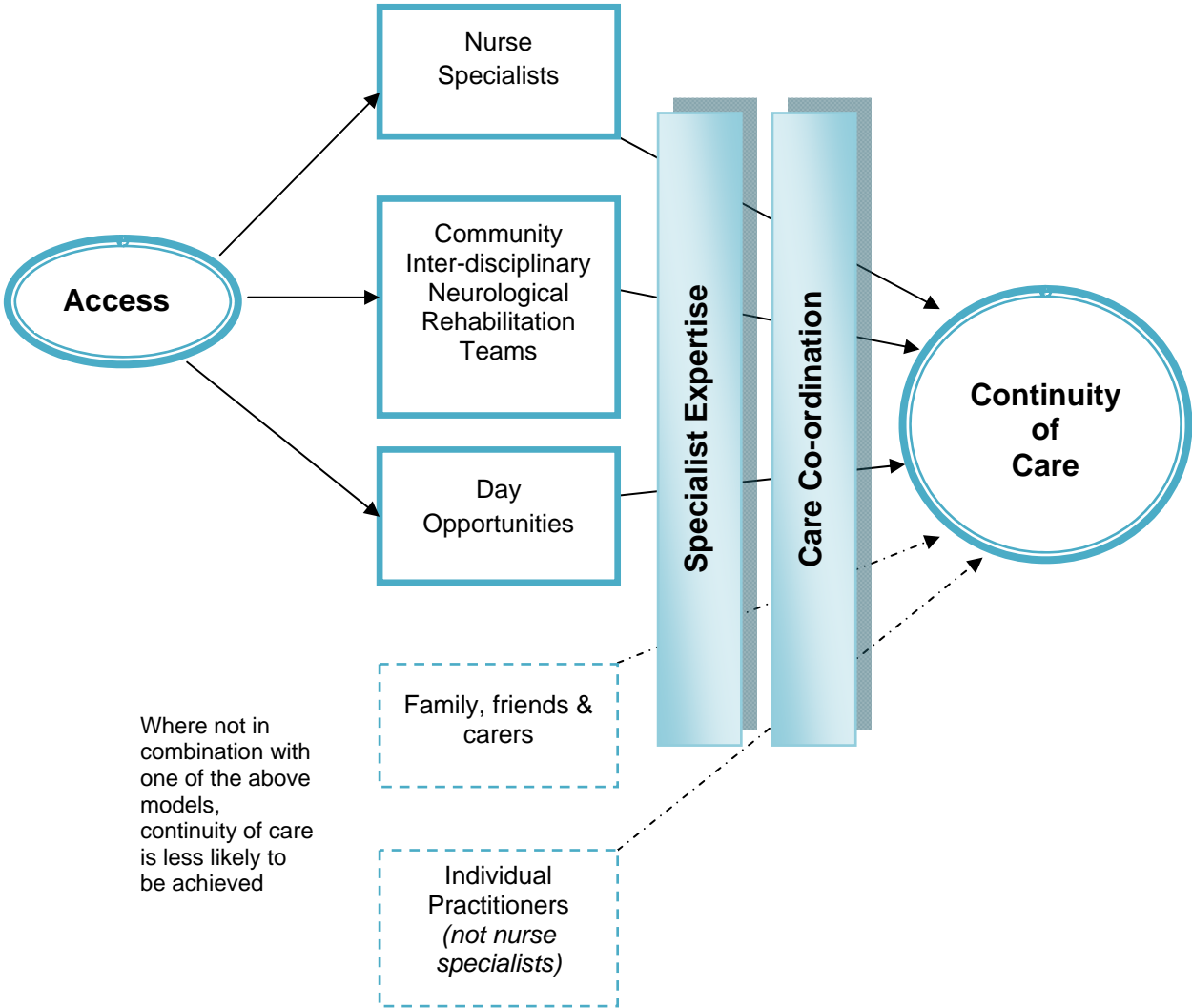
Specialist expertise was common to services valued most by people with LTNCs.

Voluntary sector organisations, particularly those with a focus on specific neurological conditions, were central to the delivery of continuity of care, working hand in hand with the above models of service provision.

Access to these models of best practice was, however, limited and varied across geographical area and as well as within areas for different groups of

The importance of these models, and of the elements that accompany them, is depicted below in Figure 8.2. Nurse specialists, CINRTs, and the types of day opportunities described in this report, all offer care co-ordination with a neurological focus that ensures people with LTNCs experience continuity of care. However, the evidence from our case studies, and from the benchmarking survey (see below), suggests that not all people with LTNCs currently have access to one or more of these three models. Where people do not have access, they may instead rely on an individual professional without a cross-sector care coordinating role (such as their neurologist) or without a neurological specialism (such as their GP) to help them navigate the system. It is here that discontinuities can arise. Evidence from our case studies suggests that in such circumstance the onus for care co-ordination again often falls to the person with the LTNC, their families or carers. This can put them under considerable pressure and may result in their feeling let down by, or lost in, the system.

Figure 8.2   Representation of models and processes influencing Continuity of Care

8.2 Benchmarking progress toward implementation of the NSF for LTNCs

The second overall aim of the project was to develop a benchmarking tool that could be used to audit services for people with LTNCs and assess the development of integrated services nationally during the implementation of the NSF.

Benchmarking is recommended as one activity that can inform the process of better governance and service improvement[49;50]. It can be seen as 'a direction-setting procedure that helps to manage the relationship between systematic policy developments, inefficient processes, identified clinical pathways and evidence based outcomes'[51]. The current survey generated a range of indicators that could benchmark PCTs' progress towards implementing the NSF for LTNCs and provided a baseline for continuous improvement.

There were some clear messages from the benchmarking survey:

- Nearly half way through the ten-year implementation period of the NSF for LTNCs, only half of PCTs had a written action plan for implementation and very few had carried out their plans.

- Quantitative data supported and reinforced many of our qualitative findings.

- Although nearly three-quarters of PCTs reported having one or more CINRTs, less than half of these covered all LTNCs, (brain injury being the condition most commonly covered), leaving many people without such a service.

- Although nurse specialists were widespread, the coverage of conditions was extremely variable. For example, while epilepsy has a prevalence of 500 per 100,000 population (compared with MS 144 per 100,000, PD 200 per 100,000)[52], only 50 per cent of PCTs reported having epilepsy nurse specialists (compared with 78% MS, 79% PD). The survey confirmed that nurse specialists are often key to the provision of care-co-ordination, information and advice. Unequal access to nurse specialists therefore has serious implications for continuity of care.

- 'Day opportunities', as defined in the benchmarking tool, were less commonly available than either CINRTs or nurse specialists. Over half of all such services reported were specifically for people with head injuries.

- There were some consistent gaps in knowledge across PCTs. For example, 89 per cent of PCT commissioners did not know how many people with LTNCs in their area had a comprehensive care plan. Similarly, information about caseloads, waiting times for services and the way interventions were rationed (or not) was often unknown.

- Data about access to and coverage of models of care and other services endorsed the findings from our case studies that many people with LTNCs would struggle to get a service.

- Among neuro-therapies, neuro-psychology was particularly scarce, with problematic referral systems and waiting lists and nearly two-thirds of PCTs describing the service as 'very difficult' or 'difficult' to access.

- The importance of ongoing access to services for people with LTNCs was a recurring theme in our qualitative interviews. In relation to access to therapies, it was an aspiration rarely met, a finding confirmed by our survey. For example, only 19 per cent of PCTs described their neuro-physiotherapy service as 'ongoing'.

- Voluntary organisations were key players in providing day opportunities. Condition specific voluntary organisations played an important specialist role in this area, as well as in providing valued specialist advice, information and support.

- Commissioners (and other staff) were not always aware of the way socio-demographic issues affected access to services for people with LTNCs.

- Interactions between organisational drivers for implementing the NSF and the provision of more integrated services often involved a complex interplay of factors. Nevertheless, strategic or organisational initiatives close to 'front-line' services, for example having a cross-sector strategic group, service user involvement in commissioning services and completing a needs assessment around LTNCs, were associated with positive progress.

8.3   Implementing the NSF for LTNCs

The NSF for LTNCs[1] aimed to 'bring about a structured and systematic approach to delivering treatment and care for people with long-term conditions' *(p.3).*

Evidence from our case studies and benchmarking survey suggests that this has not, as yet, been achieved. There is wide variation in the treatment and care that people with LTNCs can expect to receive depending on their geographical location, the type of condition they have and their access to care co-ordination. The relationship between organisational structures, processes and the provision of more or less integrated services is multifaceted. Evidence from our case studies suggests that neuro-networks (where they exist) and local implementation teams for the NSF for LTNCs are useful in bringing people with an interest in LTNCs from across the system together, helping to raise awareness of gaps in provision and providing opportunity for joint planning of service improvement. However, staff identified a number of barriers impairing the ability of networks and LITs to implement the NSF for LTNCs including: incomplete representation, incomplete (geographical) coverage, poor involvement of those represented, absence of support from senior staff members, absence of systems to authorise proposed developments, structural instability and staff changes. Results of the benchmarking survey showed some association between strategic or organisational initiatives close to 'front-line' services

(such as having a cross-sector strategic group, service user involvement in commissioning and completing a needs assessment around LTNCs) and positive progress towards implementation. Evidence from our case studies was able to illuminate the complex interplay that occurs and show that progress is often driven by front line staff or voluntary sector organisations. It is perhaps the combination of front line champions driving improvement, coupled with the existence of systems to accommodate innovative practice and to enable champions to influence decision making that is most conducive to implementation.

As well as quality requirements (QRs) encompassing treatment and rehabilitation, the NSF for LTNCs emphasised the importance of lifelong care. Evidence from our case studies highlighted how timely access to valued services, intervention and support was central to the experience of continuity of care. However, it was frequently compromised in a number of ways, including a lack of local availability or capacity of services, restrictive eligibility criteria, referral anomalies and pathways that were ill defined and unclear to people with LTNCs and professionals alike. The benchmarking survey confirmed that these sorts of barriers to accessing support were widespread, leading to inequities in provision and failures to meet the NSF QRs.

8.4   Strengths and limitations of the study

8.4.1   The rapid systematic review

Although characterised as a 'rapid' systematic review, our evaluative review had many of the features of a full systematic review. We carried out extensive electronic searches, systematically selected material for relevance and then for review, extracted data systematically, and carried out a full narrative synthesis of findings. We confined the evaluative review to studies that allowed some form of comparison to be made between people receiving the model of care being evaluated and those not, thus enhancing the opportunities for robust messages to emerge. We did not search exhaustively for material from the grey literature and relevant websites, and we did not include all the additional material identified in the reference lists of included studies. However, we did include any RCTs of models of integrated care identified through this route. Overall, we feel that the review was comprehensive but not necessarily exhaustive.

A conceptual limitation applies to the reviews. We were interested in models of care that could be described as integrated in some way and which might thereby deliver one of more types of continuity of care. Decisions about whether the material we found through the search strategies was relevant, given this focus, were thus potentially more subjective than would be the case with, say, a review of a clearly defined clinical intervention. However, we reduced this subjectivity to a minimum by

using algorithms to guide selection and by extensive discussion between the review team members.

A related issue was how to decide whether the papers we identified through the searches could facilitate continuity of care and, if so, of which type. Again, we dealt with this by discussion in the team, but we were inevitably restricted in our decisions by the type and extent of detail provided in the selected material.

The main limitation of the review, however, is the quality of the research we found. For example, while many of the RCTs in the evaluative review had been carried out since the CONSORT guidelines were published[53], few were of high quality. Further, the choice of 'routine' clinical outcomes in the evaluative literature leaves a large part of service users' experiences of models of integrated care un-researched.

8.4.2 Case studies

Using a case study approach enabled us to investigate the 'circumstances, dynamics and complexity'[34] inside and outside complex service systems that affect continuity of care for people with long-term neurological conditions. We were able to interview staff from all parts of the service system that people with LTNCs used, including from non-statutory organisations (e.g. neurological charities, carers' organisations, advocacy services and independent sector residential settings) as well as statutory services (in particular, health services and social services). As shown in Chapter 3 we interviewed 151 members of staff covering all levels of the system in our case study areas, including commissioners, service managers, front line professionals and volunteers. Collecting data from all these staff in each of our case study areas meant that we were able to gain an understanding of the system from a variety of professional perspectives.

We interviewed 71 people with LTNCs, covering the full range of subcategories identified in the NSF for LTNCs[1] (sudden-onset conditions, intermittent and unpredictable conditions, progressive conditions, stable neurological conditions, but with changing needs due to development or ageing). Thus, we were able to draw attention to similarities and differences in needs for those with different conditions and identify if there were any elements of services that needed development to meet the needs of people with specific conditions (e.g. cognitive support for people after a brain injury).

Our primary method of data collection, in-depth interviews, enabled people with LTNCs to discuss the aspects of their condition, their service use and their lives that illustrated their most pressing concerns, as well as their positive experiences. We can, therefore, be assured that the models and approaches we reported as being important to people with LTNCs, were identified directly by those most affected.

Furthermore, the importance of these models was evident across the different case study sites, across different conditions, and across socio-demographic differences.

The multiple case study site approach allowed us to triangulate findings across different case study sites. The PCT areas included demonstrated different organisational structures and different demographic characteristics, but given the case study nature of this research, it is possible that these findings may not be directly applicable to other PCTs in England. Moreover, while we were able to undertake many interviews with people with LTNCs (see Chapter 3), our sample was not large enough to allow meaningful analysis by socio-demographic characteristics or condition.

As described earlier in this report (see Chapter 3) people with LTNCs were recruited via services and professionals. This could have led to several limitations. First, it is possible that people with LTNCs who were sent invitation packs were those who staff knew would give a positive view of their service. We countered this problem by asking all those interviewed, no matter which service or professional invited them to participate, about *all* the services with which they were in contact. In this way, people who were not necessarily recruited via a particular service were able to give us their views about that service.

Secondly, we recruited through gatekeepers and thus had little control over the diversity of the people we interviewed. Despite issuing all recruiters with criteria for selection, few people from BME backgrounds agreed to participate in the research. Given the population diversity in some of the areas (see Table 3.1), we might have expected more people from BME groups in our samples. Since we asked staff to keep confidential those whom they invited to take part (in order to protect their anonymity and right to refuse), we have no way of knowing whether fewer people from BME groups received invitations, or whether they were invited but did not respond. Staff in some of the case study areas reported that few people from certain BME backgrounds used, or were involved in, relevant services. To counter this problem, we sought assistance from link-workers with BME communities to aid recruitment from different ethnic groups, but they were unable to increase participation. Low service uptake might reflect the lack of services meeting the needs of people from different ethnic backgrounds. As such, hearing from these groups could have been an important contribution to our understanding of service systems and continuity of care.

Thirdly, we had little opportunity to interview people with a LTNC who were not using or not able to access any services, because by definition these people were not in touch with the services doing the recruiting. Although we asked advocacy services in the case study areas to pass on information packs to any of their clients whom they

knew were not accessing other services, we did not recruit anyone to our study via this route.

8.4.3 Benchmarking

The benchmarking tool was grounded in the evidence from earlier stages of the project. In particular, the views of people with LTNCs and staff from a wide range of statutory and non-statutory organisations informed our understanding of services and practices important in providing continuity of care and determined the content of the questionnaire. We consulted widely and pre-tested the tool, and the telephone survey methods achieved robust data and a high response rate. Conducting a national benchmarking survey helped to raise the profile of LTNCs, potentially provided PCTs with useful information and, in some cases, prompted actions. Clear benchmarks were derived around particular models of care and other services identified as embodying good practice and which could be linked to elements of PCTs' structures and organisation that might facilitate the implementation of the NSF.

The survey was time and labour intensive and would need to be adapted if a rapid annual benchmarking exercise were required. Moreover, although contact details of most key informants were retained, experience from the case studies and the survey confirmed that staff turnover could impede the completion of such a questionnaire. Although our survey achieved a high response rate, we had no information about non-responders (10% of PCTs). Given the efforts made to contact and engage with those responsible for LTNCs in each area, it would suggest that non-responders might be PCTs where support for LTNCs was at a lower level than those participating in the survey. In terms of content, benchmarks of service models were underpinned by questions around access, availability and ways of working. These supplementary questions identified a widely varying pattern both within and across PCTs and hence generated less clear-cut benchmarks. Furthermore, the way in which these data were collected limited further statistical manipulation. The complex dynamics of inter-relationships within the service system, which our case studies had identified, were evident in the way analyses of the national survey failed to generate a robust predictive model of integration.

8.5 Implications for policy and practice

A concern with integration has been an increasingly common feature of policy in recent years and was prominent in Lord Darzi's review[19] and the most recently published Operating Framework for England[54]. The need for creative thinking that these documents emphasised relates to the interfaces between primary and secondary care, between health, social care and other statutory and non-statutory agencies and between empowered service users and these diverse service providers.

At the time of writing, there is a concern that the steer towards vertical integration of PCT provider arms with acute trusts is at odds with the aspiration to be doing more and transforming services at a community level. Driven by the reality of more limited resources in forthcoming years, community provider services may be in danger of being absorbed into an acute hospital based, medical model of care. There is thus a need to support and protect the partnerships and models of service delivery that our research has shown can promote more integrated working and improve the quality of care for people with LTNCs. In particular, nurse specialists, CINRTs, and day opportunities are key service models underpinning continuity of care, coupled with for voluntary sector organizations taking a central role as full partners in the planning, commissioning and delivery of services.

Our case studies show that the successful evolution of services and improvements in quality are often achieved through permitting innovation in practice rather than the standardisation of care. Harnessing such innovation may deliver the best economic returns as well as improving quality of care. Furthermore, in implementing greater personalisation and individual choice and control, it is also important that policy and practice do not prioritise individualised consumerist options at the expense of collective actions that, as we have shown, are highly valued by many people with LTNCs.

Considering specifically the NSF for LTNCs, our research suggests that its quality requirements were overwhelmed by the hard targets PCTs and other organisations had to deal with. The NSF for LTNCs came with no new money and no firm targets. As such, there was little to compel organisations, already trying to deal with financial pressures, service restructuring and targets with clear sanctions, to devote much time to achieving the 'softer' quality requirements of this NSF. Achieving the quality requirements outlined in this NSF was, therefore, considered a low priority. Furthermore, many of the quality requirements demanded cross-sector working. This meant that staff not only had to negotiate structures and policy-linked targets in their own field but also in other sectors, making meeting these quality requirements even more difficult.

A light touch approach to targets can allow statutory organisations flexibility in determining how they achieve policy aims. In the case of the NSF for LTNCs, the softer quality requirements could mean that PCTs were able to develop services in line with the needs of their local population. However, this can lead to national inconsistency in provision. Our data confirm that there is inconsistent availability and access to the models we identified as being critical to promoting continuity of care for people with LTNCs. If statutory service commissioners and providers want to meet the continuity of care requirements encapsulated in the NSF, and needed by people with LTNCs, it is important that *all* people with an LTNC are able to access one or

more of these models close to home, irrespective of where they live or what LTNC they have.

Having a CINRT large enough to integrate a range of health and social care expertise and provide a service for people with any neurological condition, which works closely with condition specific services, including nurse specialists, and which also provides a route into holistic day opportunities when appropriate, could be the gold standard of best practice and integrated care for LTNCs.

8.6   Implications for future research

1.   Qualitative evidence from our case study research suggests that nurse specialists, CINRTs and certain types of day opportunities promote continuity of care for people with LTNCs, and yet it is clear from our systematic review that there is little evidence available on the cost effectiveness of such services. The few studies that do exist have tended to focus on clinical or functional outcomes, rather than the more holistic benefits of continuity of care that people with LTNCs told us were important to them. It is therefore recommended that future research be carried out into both:

    a)   The outcomes of these models for long-term maintenance, not only of physical health but also social and psychological well-being. New ways of quantifying and measuring outcomes may be needed to achieve this. For instance, the value of the reassurance people with LTNCs get from knowing that there is a trusted service they can contact *if and when they need it* has not, as yet, been quantified, although the people we interviewed told us this was of utmost importance.

    b)   The cost effectiveness of each of these models (using a broad definition of costs including costs and savings across sectors and to people with LTNCs, their families and other informal carers)

2.   Specific research into the experiences of people from different socio-economic and ethnic backgrounds is necessary, as the gatekeeper recruitment strategy used in this study did not allow us to do this. A more targeted approach to recruitment would be necessary here to ensure that those less often heard in research were ensured a voice.

3.   There is at present considerable variation in provision of the three models of care we identified as promoting continuity of care for people with LTNCs. Where people are unable to access such services, the onus for care co-ordination often falls to the person with the LTNC, their families or other informal carers. We recommend that research be conducted into the impact this can have on both the person with the LTNC and their families and carers.

4. Further research around the nurse specialist role would be useful, linked to a greater understanding of the impact of structural and organisational issues on their work. During our research we came across nurse specialists working in different settings and in a range of different ways. How and where they were employed, funding sources and linkages to other professionals all had an impact on their role, which in turn may have an impact on the outcomes for people with neurological conditions.

5. The majority of studies identified by our review were in the UK. An international comparison of how other countries strive to meet the needs of people with LTNCs, and the organisational and financial structures in which their services are embedded, would broaden the evidence base of what improves the quality of life and well-being of people with LTNCs.

Finally, we would make a more general point about the increasing difficulty of carrying out the type of research carried out here. Not being able to make direct contact with potential interviewees, as discussed in the limitations of the case study, had implications for control over recruitment and the composition of the study sample. Exploration of the ways in which national ethical and local research governance procedures make it difficult to conduct this type of non-clinical research is overdue.

8.7 Plans for dissemination

We have submitted two abstracts for presentations at proposed conferences (one international) and have been invited to a regional research dissemination workshop for professionals from statutory and non-statutory organisations. Findings from this study will be further disseminated through SPRU *Research Works,* a series of publications providing summaries of research undertaken by the unit and targeting a wide audience. This audience will include all participants in the study and voluntary organisations representing people with LTNCs. Academic papers in peer-reviewed journals are planned around the role of nurse specialists, tensions in policymaking and its impact on people with LTNCs, and the benchmarking survey. Further publicising results from the benchmarking survey is to be explored with the NHS Benchmarking Network, as well as feeding back results to PCTs. As part of the DH Long-term Conditions Research Initiative we will participate in any events and dissemination processes organised by this group.

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