Benchmarking integrated care for people with long-term neurological conditions

Sylvia Bernard, Fiona Aspinal, Kate Gridley, Gillian Parker

Social Policy Research Unit, University of York

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Structured Abstract

Purpose

This paper reports results from a national survey of primary care trusts (PCTs) that explored the strategic, organisational and practice context of services for people with long-term neurological conditions (LTNCs). It provides benchmarks for integrated service provision and discusses possible reasons for the variability in progress .

Design/methodology/approach

Earlier phases of the research identified three models of care that promoted continuity of care for people with LTNCs: community interdisciplinary neurological rehabilitation teams, nurse specialists and pro-active day opportunities. Based on this evidence, a benchmarking questionnaire was developed and a telephone survey of PCTs in England undertaken in 2009.

Findings

The survey found that the prevalence of models of good practice varied widely across and within PCT areas. Strategic support and commissioning arrangements were also variable. A little over half of responding PCTs had completed a joint strategic needs assessment (JSNA) that included a reference to LTNCs and a quarter of PCTs had no joint commissioning arrangements in place for LTNCs. The complex interplay between , strategy, organisational structures and models of delivery, in a context of competing priorities, may account for this variation and patchy progress.

Research limitations and implications

Robust design and implementation methods secured a high response rate, but information on non-responders was lacking. In the context of current NHS reforms, survey results provide a baseline immediately before restructuring took place, important for monitoring future progress towards integration. However, for local comparisons over time, equivalence of geographical areas (PCTs) will be lost in new configurations.

Originality/value

Service provision for people with LTNCs is an under-researched area, despite having major implications for long-term care and support. The paper will be valuable to policy-makers and commissioners in benchmarking organisational activity and models of good practice for integrated services.

Keywords: Long-term conditions; Neurology; Integration; Continuity of care; Benchmarking healthcare; Community services.

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Introduction

In the prolonged debate that has characterised the passage of the Health and Social Care Act 2012 (HM Government 2012), the challenges posed by an ageing population and the management of long-term conditions have been enduring preoccupations. Ways to tackle these demographic realities are high on the agenda of most European countries. Healthcare systems of differing configurations share persistent problems of fragmentation of services and a damaging lack of continuity of care (Mur-Veeman *et al*., 2008). In England, the discourse around better co-ordination and integration of services at times has seemed to be in danger of being overwhelmed by a priority in health policy to embrace competition as the key driver of efficiency and to further marketise provision (Hawkins, 2011; Lewis and Thorlby, 2011). However, in the summer of 2011, a re-focusing on ‘integration’ emerged. The economic regulator, Monitor, was given a new duty in the Health Bill to consider integration within the National Health Service (NHS) and with social care, alongside that of promoting competition (Lewis, 2011). Integration was named as a prominent workstream in the second phase of the NHS Future Forum, the body set up to oversee the government’s listening exercise to inform the NHS reforms. Integration was highlighted by the Future Forum as an important responsibility of the proposed NHS Commissioning Board, designated to provide leadership for the new commissioning system and with overall responsibility for the NHS budget (NHS Future Forum, 2011a; NHS Future Forum, 2011b). The importance of closer integration of care, especially for people with long- term conditions, was last formally addressed in policy in the ‘Next Stage Review’, (Department of Health, 2008), the final report of Lord Darzi’s reforms to improve the quality of care in the NHS, and was more specifically defined in guidance in

2009 on supporting people with long-term conditions (Department of Health, 2009).

A lack of clarity about the meaning of integration and its implementation within current reforms persists and the relationship between the twin imperatives of integration and competition remains problematic. Whichever way the new arrangements evolve in practice, it will be useful to benchmark where organisational activity and services were positioned at the end of the last government and before a major overhaul took place. In 2009 we conducted a national audit of primary care trusts (PCTs) in England (152 at the time of the audit) that focussed on services for people with long-term neurological conditions (LTNCs). We report here on findings relating to strategy and organisation and the practice models promoting continuity of care that our earlier case studies identified were highly valued by service users (Bernard *et al*., 2010).

Background

Neurological conditions are a major cause of disability with long term consequences and substantial implications for support across service boundaries. They affect approximately ten million people across the UK, account for up to 20 per cent of hospital admissions and are the third most common reason for people needing to see their general practitioner (Neurological Alliance *et al*., 2003). The fragmentation of, and lack of access to a range of support for people with LTNCs have been evident in the UK for many years (Elian and Dean,1983; Pope, 1992; Lloyd, 2000; Joule, 2001). The National Service Framework (NSF) for Long-term Neurological Conditions was introduced by the Department of Health in England in 2005 and aimed to ‘bring about a structured and systematic approach to delivering treatment and care for people with long-term conditions’ (Department of Health, 2005, p.3). The need for an integrated approach to service provision was made clear, explicitly and implicitly, in all 11 Quality Requirements (QRs) of the NSF.

The NSF was part of a broader strategic framework promoting integration. Provision of integrated care and arrangements for joint working between health and local authority services has been at the heart of government policy in recent years. Our research was part of a Department of Health research initiative to support the implementation of the NSF, with a specific focus on integration. The study aimed to:

a) Identify what helps or hinders integrated services and identify models of good practice that deliver 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.

In this paper, we present some of the findings from the benchmarking phase of this research.

The first phase of our research was a systematic literature review of the impact and costs of integrated models of care for people with LTNCs, and of evidence about what is needed to make these models operate well. The review identified three main models of integrated care from the international literature: multi-disciplinary teams or clinics, clinical nurse specialists and assessment and disease management models (Parker *et al*., 2010).

However, it found little conclusive or consistent evidence of positive or negative impact on service user or family outcomes of these models, or the service delivery and organisational elements that needed to be in place in order for them to work well. The second, case study, phase of the research used qualitative in-depth interviews with service users and staff to identify service models and types of services that promoted continuity of care and that were valued by people with LTNCs. Three service models stood out in our analysis:

Model 1: Community interdisciplinary neurological rehabilitation teams (CINRTs)

Community rehabilitation teams, incorporating professionals from a range of disciplines working together in an interdisciplinary way, were successful in promoting continuity of care. These teams were most highly valued by service users where professionals in the teams had expert knowledge about neurological conditions, where support was ongoing and where provision was flexible to meet the needs of the person with the LTNC.

Model 2: Nurse specialists

People with LTNCs valued the nurse specialists’ expert knowledge of neurological conditions, 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 that offered peer support, social and leisure opportunities, as well as access to meaningful activities and/or learning opportunities were highly valued. They provided a focal point for care co-ordination as well as supporting people to build confidence and enjoy social activities. Those specialising in meeting the needs of people with a specific LTNC were felt to be particularly valuable and for many, were key to maintaining quality of life.

Access to other services

Those who were able to access therapy services (including neuro-physiotherapy, occupational therapy with expertise in LTNCs, community-based speech and language therapy and neuro-psychology) on an ongoing basis, felt well supported. Such services may be available via the models described above. However, our case studies suggested that access 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 vital to help people navigate complex systems.

Methods

We triangulated evidence from earlier scoping work, the systematic literature review, and case studies to develop benchmarks of good practice that could assess the type, quality and impact of integrated services in local areas. A benchmarking questionnaire 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. While the thematic content of the questionnaire was determined by the findings of the literature review and analysis of case study data, pre-pilot (cognitive interviews) and pilot interviews were undertaken to help to further develop the benchmarking tool. Pre-pilot interviews were conducted in each of our six case study areas and pilot interviews in 15 randomly selected PCTs (10% of PCTs current at the time).

The final questionnaire comprised eight sections that asked about the PCT and the identified models of care provision and services.

Table 1 Benchmarking questionnaire - 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 other 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 intelligence PCT commissioners use to inform service development

The designated lead commissioner for LTNCs (or nominee) at each PCT in England was contacted and the survey conducted by telephone between July and September 2009. Further details of the development of the questionnaire, survey methods and analysis are in the final report (Bernard *et al*., 2010)

and the benchmarking tool itself can be found at http://www.york.ac.uk/inst/spru/research/pdf/LTNCsBenchmarkingTool.pdf. In this paper, we focus on the audit findings relating to strategy and organisation and the practice models promoting continuity of care that our case studies identified were highly valued by service users.

Results

Response and completion rates

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. Response, completion rates and method of completion are summarised in Table 2.

Table 2 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

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 people with LTNCs. Questions were framed in the context of current policy and guidance around integrating services. For the full questions, see (Bernard *et al*., 2010).

A summary of key findings relating to the PCT strategy and organisation section of the benchmarking tool are reported in Table 3.

Table 3 PCT strategy and organisation

	Percentage of PCTs (based on 118 PCTs)
Joint Strategic Needs Assessment (JSNA) mentions LTNCs	56
Joint commissioning for LTNCs	
full	12
partial	62
none	25
Cross-sector strategic group	66
Out of responding PCTs with cross-sector strategic group:	68
service users and/or carers involved	88
met in last 3 months	
completed needs assessment	63
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

Community interdisciplinary neurological rehabilitation teams

Data were collected only about community interdisciplinary neurological rehabilitation teams (CINRTs) with a specific neurological focus that worked mostly in the community (including people's own homes) to provide a person centred service. These were interdisciplinary teams as defined by the NSF for LTNCs, i.e. they 'work together to an agreed set of goals, often undertaking joint sessions' (Department of Health, 2005, p.16).

Table 4 shows the presence of CINRTs in PCTs, while information about access, type of provider, caseload, referral, and whether support was ongoing and included telephone advice is presented in Table 5 as aggregated (national) data. This reflects the fact there may be more than one such team within a PCT and that characteristics of teams varied *within* PCTs as well as *across* PCTs.
In considering access, commissioners were asked how easy they felt it was to access (each of) their CINRTs, taking into account influences like waiting times, eligibility criteria and service location. This was a subjective assessment and it was suggested that they might wish to discuss this question with colleagues to arrive at a consensus. The same question wording and response categories were used in considering nurse specialists and day opportunities.

Table 4 Presence of community interdisciplinary neurological rehabilitation teams (CINRTs) in PCTs

	Percentage of PCTs
CINRTs operating in PCT area	73
CINRTs covering all LTNCs	47
Most common condition specific CINRT- brain injury	21
N (100%)	*118*

Table 5 Characteristics of CINRTs (aggregated data)

	Percentage of teams nationally (aggregated data)
CINRTs 'very easy' or 'easy' to access	59
CINRTs covering the whole PCT area	74
Provider of CINRTs	
health trust	70
adult social care	2
joint health and social care	17
joint health and social care and other statutory	3
non-statutory	3
statutory and non-statutory together	3
don't know	2
Self-referral to CINRTs possible	55
Duration of support available from CINRTs	
ongoing with intermittent reviews	41
time limited based on goals	44
Able to ring CINRTs for advice and support	93

Nurse specialists

Our case studies showed that people with LTNCs valued support from nurse specialists who had specialist knowledge about their condition, knew the local system and were able to co-ordinate care within and across different sectors. Although nurse specialists operated in the majority of PCT areas, most were condition specific and the conditions covered varied widely between PCTs.

Table 6 shows the presence of LTNC nurse specialists in PCTs and Table 7, aggregated data about their characteristics.

Table 6 Presence of LTNC nurse specialists in PCTs

	Percentage of PCTs
Nurse specialists operating in PCT area	93
Nurse specialists covering all or multiple LTNCs	20
Most common condition specific nurse specialists	
Parkinson’s Disease	79
Multiple Sclerosis	78
Epilepsy	50
N (100%)	*118*

Table 7 Characteristics of nurse specialists (aggregated data)

	Percentage of nurse specialists nationally (individuals and/or teams aggregated data)
Nurse specialists ‘very easy’ or ‘easy’ to access	62
Nurse specialists covering the whole 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 possible	52
Time on active case load open-ended	60
Able to ring nurse specialists for advice and support	88

Day opportunities

In our qualitative interviews, 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. Only day opportunities which fitted this definition were recorded.

Table 8 shows the presence of such day opportunities for people with LTNCs in PCTs and Table 9, aggregated data about their characteristics.

Table 8 Day opportunities

	Percentage of PCTs
Day opportunities available in PCT area	65
Day opportunities covering specific LTNCs	45
Most common condition specific day opportunity - head injury	37
N (100%)	*118*

Table 9 Characteristics of day opportunities (aggregated data)

	Percentage of day opportunities nationally (aggregated data)
Day opportunities 'very easy' or 'easy' to access	58
Day opportunities covering the whole PCT area	78
Provider of day opportunities	
non-statutory organisations	48
joint statutory and non-statutory organisations	12
Self-referral to day opportunities possible	60
Involvement with day opportunities open ended	58
Able to ring day opportunities for advice and support	77

Access to 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 only 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 expertise in neurology, speech and language therapy (SaLT) and neuro-psychology. In some areas access may be via CINRTs, but benchmarking data reinforced findings from the case studies that overall, such therapies were often difficult to access and unlikely to be ongoing. This especially applied to neuro-psychology where, of the 70 per cent of PCTs who reported that neuro-psychology was available in their area, almost two-thirds (63%) claimed that their service was ‘difficult’ or ‘very difficult’ to access.

Relationships between PCT ‘strategy and organisation’ and models of care

To examine the influence of strategic 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). Within the PCTs' strategies 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 local implementation team (LIT)
- whether service users were involved in commissioning decisions
- completion of a needs assessment for LTNCs.

However, the results of the statistical modelling analyses suggested that the selected independent variables associated with models of care may themselves be correlated with each other. Overall, there was a significant, but weak association between the four selected ‘strategic and organisational’ variables and the models of care, and the independent variables had limited predictive ability. Detailed statistical results for the modelling analyses are presented in the main report (Bernard *et al*., 2010).

Discussion

From its publication in 2005, the NSF for LTNCs was to have a ten-year implementation period. This survey generated a range of indicators that allowed localities to benchmark their performance against national progress at almost ‘halfway’, and offered potential for future use in providing a baseline for monitoring continuous improvement.

Strengths and limitations

The survey questionnaire was grounded in the evidence from earlier stages of the project. Clear benchmarks were derived for 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 better integration and the implementation of the NSF. We consulted widely and pre-tested the tool, and telephone survey methods achieved robust data and a high response rate. However, 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 is possible that non-responders were PCTs where commissioning activity for LTNCs was at a lower level than in participating PCTs.

Implications for policy and practice

There were some clear messages from the benchmarking survey that are relevant to current and future efforts to promote integration. Despite several years where better integration of health and social care had been a policy priority and performance management used as a tool for improvement, there was considerable variation in the degree to which strategic level organisations had taken steps to integrate commissioning or service delivery for people with LTNCs.

The Local Government and Public Involvement in Health Act 2007 (HM Government, 2007), required PCTs and local authorities to produce a Joint Strategic Needs Assessment (JSNA), as the means of describing the future health, care and well-being needs of local populations and the strategic direction of service delivery to meet those needs. A little over half of responding PCTs had completed a JSNA that included a reference to LTNCs (in general or in relation to specific conditions), despite their numerical importance and long-term impact on services. However, several areas made use of other approaches to engage the wider community in discussions about local needs and service provision. Two-thirds of PCTs had an active cross-sector strategic group tasked with implementing the NSF for LTNCs, often with service user and carer involvement and action plans, formulated against the NSF's QRs.

A minority 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. There were some consistent gaps in knowledge across PCTs. Less than half systematically recorded numbers of people with LTNCs and commissioners generally 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.

In relation to the models of good practice identified in earlier phases of the research, many people with LTNCs would struggle to receive a service. Although nearly three-quarters of PCTs reported having one or more CINRTs, less than half of these covered all LTNCs, meaning that in over half of all areas, some diagnosis groups had no such service. Brain injury was the condition most commonly covered. Nurse specialists were widespread, but again the coverage of conditions was extremely variable, the most common being Parkinson's disease and multiple sclerosis. Pro-active, care co-ordinating 'day opportunities' were less commonly available than either CINRTs or nurse specialists. Over half of all such services reported were specifically for people with head injuries and the majority were provided by the voluntary sector. These services were often key to maintaining quality of life and feeling valued, but were unavailable to many.

This benchmarking audit suggested that in 2009 there was wide variation in the treatment and care that people with LTNCs could expect to receive depending on their geographical location, the type of condition they had and their access to care co-ordination, despite policy efforts. Although models of good practice exist that can fulfil the NSF's quality requirements, nearly halfway through its implementation period, many PCTs were struggling to make progress.

Some association was evident 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 delivering best practice. However, the strategic and organisational context and the existence of particular models of delivery were often associated in complex ways. Evidence from our case studies was able to illuminate the complex interplay; in particular, how financial and/or policy preoccupations influenced commissioning behaviour and how the effectiveness of LITs was highly variable. The overwhelming view from PCT 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 that were backed by financial incentives (such as the long-term conditions programme). In comparison, the NSF for LTNCs came with no new money, no firm targets, but 'softer' quality requirements and was largely overtaken by competing policy, organisational and financial priorities that PCTs and other organisations had to deal with. 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.

Radical reorganisation plans in the NHS will see central planning and performance management reduced and the direction and responsibility for service improvement devolved to local health and well-being boards and clinical commissioning consortia (Department of Health, 2010). The role of the NHS Commissioning Board in providing central support for integration is likely to be concerned with vertical integration (Wistow, 2011), but has so far lacked focus (Ham *et al*., 2011). Responsibility for driving horizontal integration through the JSNA will transfer to health and well-being boards (Dow, 2011). The model may be an appropriate vehicle for the JSNA, although from evidence presented here and elsewhere (Ellins and Glasby, 2011), a more robust approach to the JSNA and mechanisms for wider engagement are needed. Evidence from our most recent work suggests that many of the local forums for promoting better joint-working and integration, that previously engaged commissioners, providers (including voluntary organisations) and service users, have been lost, or their activities suspended, in the climate of uncertainty around future directions and the disruption to established relationships. Moreover, the ability of general practitioner-led commissioning groups to champion the sorts of services that work across boundaries in a more holistic way is unproven (Gridley *et al*., 2012).

A review of evidence in 2010 describes the wide range of approaches to integrated service provision across North America and Europe. It concludes that policy-makers should continue to encourage closer integration of care in the English NHS and recommends multiple strategies at different levels (Curry and Ham, 2010). Our research also highlights the need to strengthen system and service level initiatives, as well as micro-level co-ordination and communication arrangements, to improve support for service users and carers.

Conclusions

In the urgency to create a new health service landscape with innovative models and ideas, policy-makers need to pay heed to past experiences, and commissioners to the accumulated evidence of good practice.

At a time when priorities are shifting, there is a need to safeguard the models of service delivery that can promote more integrated working and improve the quality of care for people with LTNCs. A bank of knowledge and evidence, based on service user experience, can demonstrate successful practices in care co-ordination and integrating services in the context of long-term conditions. Robust comparable information will continue to be needed to provide the local, accessible intelligence required to benchmark progress, thus improve services, and guard against greater inequalities in access.

Furthermore, an understanding of how macro and meso level inter-relationships create complex dynamics, which themselves change with shifting priorities can explain why progress is achieved in some areas and not in others. A light touch approach can allow statutory organisations flexibility in determining how they achieve policy aims and develop services in line with the needs of their local population, but can also lead to national inconsistency in provision. In such a climate, it is frequently ‘front-line champions’, coupled with systems that can accommodate innovative practice and enable influence on decision-making, that can drive improvement. Their specialist knowledge and relationships are key, but also may be at greatest risk in times of major structural change.

(3702 words, excluding abstract)

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