

Policy

Integrated policy making in England for adults with long-term neurological conditions (LTNCs): some preliminary findings from a scoping study

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Abstract

Introduction: Long-term neurological conditions are a major cause of disability in the UK and internationally. Their successful management, in order to enhance health and well-being, requires both sophisticated organisation across a number of health, social care and other service boundaries, and the real involvement of people with neurological conditions and members of their support networks.

Policy development: This paper reports on part of the preliminary scoping phase of a study designed to evaluate the impact of the National Service Framework for long-term neurological conditions on integrated care. It describes current policies in England and reports on discussions with a range of people involved in the planning, provision or use of services, which took place during the scoping exercise. These interviews inform how policy affecting people with long-term neurological conditions has been received and implemented so far.

Conclusion and discussion: Findings suggest that progress towards integrated service provision is patchy and slow. In the competing priorities within government policy, neurological conditions have tended to be marginalised, within healthcare policy generally and in initiatives to support people with long-term conditions in particular. The reasons for this are explored and will inform the next stages of the research.

Keywords

long-term neurological conditions, integrated care, health and well-being

Introduction

The National Service Framework¹ (NSF) for long-term neurological conditions (LTNCs) was published by the Department of Health (DH) in England in March 2005 and has the potential to improve services and outcomes for a wide range of disabling conditions. Neurological conditions are a major cause of disability, affecting approximately 10 million people across the UK. They 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 [1]. LTNCs, by definition, are an ongoing part of

individuals' lives and create diverse needs. They may be present from birth or develop later in life, may be slow or rapidly progressing, episodic or continual. They have substantial implications for health and social services support and, in particular, need integrated services because of relatively unpredictable and diverse service need. Providing such integrated care needs provision across agency, organisational and professional boundaries: co-ordination and collaboration are thus key to achieving this.

The English Department of Health has established a programme of research to support the implementation of the NSF. We are carrying out a project focused directly on integration, including the different meanings people may attach to the concept. The aims are to

¹A rolling programme of National service frameworks (NSFs) was launched in 1998. They are long-term strategies for improving specific areas of care within set time frames.

identify different models of integrated services, practices judged to work well, and to establish an evidence-based benchmarking system to assess the impact of the NSF on integration.

The initial stage of the project involved a scoping exercise on how best to achieve continuity of care for people with LTNCs. This included a rapid systematic review of evidence coupled with a 'consultation exercise' to gather information on what constitutes good practice and identify the impact that recent government policy in England has had on promoting integration and/or continuity of care for people with LTNCs. Arksey and O'Malley [2] in their methodological framework for scoping studies, identify the consultation exercise as an optional, but valuable stage. It not only provides additional references about potential studies to include in the review, but also insights into the important issues which can provide 'added value'. It is this consultation element of the scoping phase which we report on here, in particular the findings related to the impact of recent policy changes in England on the care of people with LTNCs. A number of people representing the voluntary organisations supporting people with LTNCs, those delivering services, and service users or informal carers were interviewed either face-to-face or by telephone. These preliminary, unstructured discussions covered the implementation of the NSF and its relationship to wider policy initiatives, and provided insights into the policy making process and what helps or hinders effective policy integration. This paper presents the findings of the consultation element of the scoping exercise.

The international context

The challenge of achieving integrated, 'holistic' care for people with long-term conditions and complex care needs has been taken up within different care systems and cultural contexts. Much of the early discourse focused on healthcare, emanating from models of care management in the United States, usually from a medical perspective [3]. Increasing emphasis on social inclusion and patient-centred care has widened the approach to include a range of social support services. A variety of meanings, approaches and practices exist across different countries, but contemporary systems share structural divisions which lead to fragmentation and a lack of coherence for service users. Demographic pressures of ageing populations in western societies have meant that the main thrust of response has been around the care of older people. Projects included in the European Commission's 'Quality of Life and management of Human Resources' programme present a cross-national analysis

of ways of working and provide a resource for the challenge of delivering integrated services, extending beyond the care of older people [4, 5]. Large scale models of care linked specifically to neurological conditions are rare. In the Netherlands, a network of specialised epilepsy centres delivers comprehensive care, with a multidisciplinary approach [6].

Policy development in England

There have been general policy initiatives to encourage integrated or joint working within and between health and social care services in the UK, and between the care system and people with disabling conditions [7–9]. 1999 Health Act flexibilities, in particular, have offered a mechanism by which integration might be more easily delivered [9]. Despite these innovations and policy changes, however, achievement of real integrated services remains patchy. While recent policy initiatives have seen organisational change in older people's and mental health services [10–12], services for people with LTNCs seem to have lagged behind [13, 14]. This is despite the clear messages from people with LTNCs and their organisations that experiencing integrated provision is an important contributor to quality of life [13].

The NHS Improvement Plan, launched in June 2004 [15] outlined the importance of supporting people with long-term conditions and the subsequent Department of Health publication in 2005 [16] provided more detail recommending the appointment of 'community matrons'² and disease-specific case management to help smooth the pathways between different service providers. The National Service Framework (NSF) for long-term neurological conditions (LTNCs), published two months later [17], sets out 11 quality requirements (QRs) to improve the planning and delivery of services for people with LTNCs, to be achieved by 2015 (see Table 1).

The need for integrated care is explicit or implicit throughout the 11 QRs, but all require degrees of integration that seem largely lacking in current service provision [13].

The 2005 Green Paper on adult social care [18] talked about the need for well-planned and integrated services and the inclusion of all sections of the community, including the NHS, in delivering the new vision for social care. Its overall ambition was achieving 'person-centred, proactive and seamless' services. This

²Community matrons are senior nurse practitioners who use case management techniques with people who meet criteria denoting very high intensity use of health care. The aim is that with special intensive help, these people are able to remain at home longer and to have more choice about their health care.

Table 1 Quality requirements (QRs)

NSF for LTNCs Quality requirements (QRs)	Area of care
QR1	A person centred service
QR2	Early recognition, prompt diagnosis and treatment
QR3	Timely emergency and acute management from teams with appropriate skills and facilities
QR4	Early and specialist rehabilitation
QR5	Community rehabilitation and support
QR6	Vocational rehabilitation
QR7	Providing equipment and accommodation
QR8	Providing personal care and support
QR9	Palliative care
QR10	Supporting family and carers
QR11	Caring for people with neurological conditions in hospital or other health and social care settings

government paper made suggestions about ‘streamlining assessment’ (identifying the need and type of care) between agencies, ‘strengthening joint working between health and social care services’ (working effectively and efficiently across different agencies), and developing ‘strategic commissioning’ (the planning and purchasing of appropriate services) across *all* partners. When the subsequent White Paper, ‘Our Health, Our Care, Our Say: a new direction for community services’ was published [19], working together, ‘joined up’ care, information sharing, joint health and social care managed networks or teams, and integrated personal health and social care plans were all mentioned and the latter particularly in relation to people with long-term or complex needs.

The NSF is thus part of a broader strategic framework and wider package of initiatives designed to enable people with long-term conditions in England to lead as independent lives as possible, but retains a specific neurological focus. However, the means to achieving integration are less clear.

To mark the first anniversary of the NSF, the Neurological Alliance³ carried out a brief survey of Strategic Health Authorities (SHAs) to assess progress with some of the initial strands of NSF work [20]. The survey asked whether local implementation teams were in place in all PCTs, whether stakeholder events had been held and whether a managed neuroscience network had been set up in their area. It also asked whether audits of services and service users had taken place and what proportion of service users had

³The Neurological Alliance includes a wide range of neurological charities which have come together to support people with a neurological condition in the UK.

received an integrated assessment/personal care plan since the NSF was launched.

The survey response from SHAs covered 47 per cent of all then current PCTs. However, the Alliance noted that NSF implementation seemed to be patchy and inconsistent. There appeared to be little consistency in either the supporting structures being put in place or the aspects of the NSF being focused upon.

... The impression is that, rather than approaching the NSF as a policy initiative in its own right and tackling it holistically, it is all too often being viewed as an additional piece of work that can simply be slotted into other work programmes already underway. The result seems to be a rather piecemeal and selective approach, with many areas keen to align aspects of the NSF with existing structures and activities.
(Neurological Alliance newsletter, May 2006).

Findings from consultation exercise

Interviews within our scoping study, revealed a widespread feeling that neurology has been overlooked within wider policy initiatives historically, and was in danger of being further neglected by more recent policy and changes in health and social care practice. Targets introduced by earlier health strategies, such as ‘Health of the Nation’ from 1992 to 1997 [21] and ‘The NHS Plan’ in 2000 [22] failed to include neurological conditions. The inclusion of a NSF for LTNCs was therefore, widely welcomed as an important element in initiatives to improve services for people with long-term conditions generally and in the

modernisation of neurology services in particular. In 2003, the Association of British Neurologists (ABN) had highlighted the limitations and geographical variations in current provision in the UK. The ratio of neurologists cited, 1:170,000 of the UK population, compares unfavourably with most other European countries [23].

Consultation prior to publication of the NSF had identified a consensus on the range of problems facing neurology—including a long standing shortage of neurologists, lack of understanding of many conditions, lack of information and prompt access to early diagnosis and changing care needs.

Some of the challenges to implementing the NSF were identified by the earlier *Action on Neurology* (AON) programme set up in 2003 and designed to find and test different ways of working to improve both access to and the quality of neurological services [24]. However, although highlighting the complexity of the care pathway for people with LTNCs and introducing new initiatives, mainly in primary and secondary care, the programme was felt to have had a limited impact on the overall integration of neurological services and the implementation of the NSF.

The opinion was that neurology was disadvantaged compared with other specialties in the wider *Action on* programme. The projects were late additions to the programme and suffered from the closure of the Modernisation Agency in March 2005⁴, and they were constrained in their implementation by beginning from a less developed baseline than other specialties. Lack of disease specific data within neurology to understand the profile of caseloads and measure outcomes, frequently hindered establishing pilot projects. Adequacy of baseline data, funding and training for new roles, and sustainability of new ways of working were common problems raised by some of the pilot projects.

On publication in March 2005 the NSF, although welcomed, was felt to have been overshadowed by, rather than integrated with, more recent health care policy. There was a common view that the timing of its introduction and the lack of any extra money or clear targets to implement the NSF meant it would be afforded a low priority compared with a wider chronic disease programme.

The Public Health White Paper 'Choosing Health' [25] underpins the long-term conditions (LTCs) approach. The NHS Improvement Plan [15] published in the same year, set out the government's priority to improve care for people with long-term conditions. It

⁴Between 2001 and 2005 the NHS Modernisation Agency provided leadership for improvement in healthcare services at a national level to drive forward modernisation of the NHS.

was followed in January 2005 by 'Supporting People with Long-term Conditions' [16] which set out the NHS and social care model and included the appointment of 3000 community matrons based on United States 'Evercare' and similar models of case management. This population management approach is based on a model of demand management and a preoccupation with thresholds for acute care. The policy to improve the management of people with chronic illness and LTCs is driven by the Public Service Agreement (PSA) target to reduce emergency bed days by five per cent (based on a baseline 2004–2005) by 2008.

Current initiatives around avoidance of unnecessary hospital admissions and tackling the 'revolving door' problem are aimed primarily at those with multiple pathologies or very high intensity users (VHIUs). People with conditions such as diabetes, chronic obstructive pulmonary disease and coronary heart disease are those primarily identified as disproportionate users of health services, located in the high risk/high complexity segment of the Kaiser Permanente triangle described in the NHS and social care long-term conditions model [16]. The DH and long-term conditions policy team have provided an on-line toolkit which focuses on conditions accounting for the highest number of emergency bed-days. It provides data at national and primary care trust level with evidence-based intervention models [26].

The scoping interviews suggested that, neurological conditions have not been deliberately overlooked, but,

Localities currently are tackling the areas where there is most potential for gain.

PCT Long-term Conditions Lead (SE12).

Many neurological problems are not a burden to the health service and are not visible. Admission to hospital, when it occurs, is generally not avoidable. There was a widespread view from the statutory and voluntary sectors that attention was focused on the major causes of emergency admissions which, in terms of volume, did not tend to include neurological conditions.

Respiratory conditions and diabetes are high cost if not well-controlled, whereas people with neurological conditions can have a very poor quality of life and end up sitting at home and not costing anyone very much.

Neurological charity representative and service user (SE9).

For many with neurological conditions, it is co-morbidities which cause hospital admissions and which will be recorded in hospital episode statistics. As the AON pilots found [24], collecting data for a specific

condition within the overall neurology specialty is difficult within existing IT systems in both primary and secondary care.

The high profile preoccupation with emergency admissions and using this measure as an indicator of the success of the LTC programme ignores the many different aspects of improving care and underestimates its complexity. In so doing, it has created a tension in a unified approach to the management of LTCs, such that neurological conditions which do not fit comfortably into selected measures, are less visible.

The fact that the LTCs programme was launched so close to the NSF, and a late switch of name from 'chronic' to 'long-term' conditions, was viewed by some to further detract from the neurological focus of the NSF. Initiatives such as 'community matrons', tended to be seen as clouding the issue for neurology. It was felt that their more generic role was unable to provide the necessary specialist neurological expertise. Whereas some thought there may be the potential to help with complex neurological conditions, others saw funding for community matrons as a shift of resources and a threat to the role of specialist neurology nurses in particular. The argument that targeting VHIUs (and thereby, particular conditions) would ultimately free resources for other LTCs, does not seem to be borne out by evaluations of 'Evercare' case management pilots [27], where in some places, at least, there was no overall effect on hospital admissions and instead pilots were identifying previously unmet need.

In a climate of successive policy initiatives, all competing for resources, the implementation of the NSF was said to have been further usurped by the White Paper 'Our Health, Our Care, Our Say' published in January 2006 [19]. Providing integrated, person-centred care with a diversity of services closer to people's homes is a policy imperative which, in many areas, links with the NSF QRs. The best hope of raising the profile of the NSF, since it lacks its own money and targets, was felt to lie with linking with the priorities of the White Paper and identifying where they overlap with the NSF. However, the point was made that many neurological conditions do not follow a classical pathway. The rhetoric of 'choice' is not always appropriate for those whose mobility or cognitive ability may be impaired and require:

... responsive services on the doorstep, when they need them.

Regional Service Development Manager, neurological charity (SE3).

Where there is ongoing degeneration with no current cure, a lack of immediacy and visibility means that the

long-term support and investment needed for some neurological conditions is overlooked in the current policy climate. Moreover, housing the NSF in the social care directorate of the DH, and having separate policy teams for the NSF and LTCs programme policy team, may have further distanced it from mainstream 'health' policy. The feeling was that the policy area, as it related to neurological services, was confused, and exacerbated by:

the speed and regularity of new initiatives, with no chance to bed in the last initiative.

Regional Service Development Manager, neurological charity (SE3).

It feels as if it's all got mixed up with problems of resourcing the NHS.

Neurological charity representative and service user (SE9).

The NSF is part of the government rhetoric about patient involvement, self-management... but reports on the ground are that they just hit impenetrable barriers.
Chair of neurological charity (SE7).

Effect of the introduction of the NSF

Despite the NSF for LTNCs being well-received when launched, there was a common perception that there was no clear thinking about how to deal with it, and generally no one taking responsibility for action strategically. Apart from confusion in the policy context, the lack of targets, money or sanctions if the QRs were not met were repeatedly cited as reasons for the NSF having little impact so far.

It's been difficult to sustain interest because there were no targets and no cash.

PCT Physical Disabilities and Sensory Impairment Services manager (SE15).

The NSF has not hit the ground in any practical way.

PCT Long-term Conditions Lead (SE12).

The NSF says all the right things, but as a strategic document is difficult to deliver.

General Practitioner (SE13).

As a piece of health and social care policy the NSF is excellent, the problem is implementation.

Chair of neurological charity (SE7).

NICE⁵ guidelines for selected LTNCs (currently multiple sclerosis, head injury, epilepsy and Parkinson's

⁵The National Institute for Health and Clinical Excellence (NICE) is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.

disease), were felt to be more influential in delivering good care. Moreover, it was felt that opportunities had been missed to integrate the NSF with NICE guidelines, so that they did not necessarily support each other and connections were difficult to make.

In a more positive light, for at least one community physician, having an NSF provided support to counter a shift of resources to secondary care and argue for more community development; while another practitioner welcomed the fact that it put carers and families on the map and had facilitated new work.

The view was expressed that the timing of the launch—immediately before not only a general election, but also a major reorganisation of Primary Care Trusts (PCTs)—could not have been worse for bedding in new policy. PCTs were charged with providing lead professionals, but interpretations of the role varied and the neurology focus was sometimes lost. Furthermore, in the turbulence of organisational change, development plans frequently stalled as people changed or lost their jobs. The immediate priority for many PCTs in their new configurations was felt to be straightening finances and ‘balancing the books’.

Commissioning and financial considerations

Limited budgets for health and social care and financial deficits of some NHS organisations were seen as key issues threatening attempts to integrate care across organisational boundaries. Achieving financial balance has been a priority for newly configured PCTs. Moreover, they work within a number of financial incentives and mechanisms designed to support the delivery of care, such as payment by results, practice based commissioning and the quality and outcomes framework attached to GP contracts⁶. In some instances, these may produce perverse incentives in the context of care of people with neurological conditions. The focus on reducing emergency admissions offers financial rewards for tackling some conditions, while LTNCs generally do not represent the same opportunities for savings. They may not have been deliberately overlooked, but

The LTC programme has looked to where the payback is.

SHA Service Improvement Manager (SE12).

⁶The Quality and Outcomes Framework (QOF) is the annual reward and incentive programme detailing GP practice achievement results. QOF rewards surgeries achievement points against a range of clinical, organisational and care indicators. Epilepsy is the only LTNC to be included in the clinical domain indicators.

The over-riding factor (in COPD) is frequent trips to Accident and Emergency, relatively short spells in hospital but all generating lots of bills for the PCT under the payment by results criteria. ... You look at patients with neurological conditions and the same thing doesn't really happen there. They might go into hospital once or twice at the beginning while they get diagnosed, and then towards the end of life, but not often in between.
SHA Service Improvement Manager (SE11).

Practice based commissioning was also felt to work to the disadvantage of neurological conditions. In the absence of a central lead with targets, and small numbers of many conditions at a PCT or locality level, priorities will lie where there are sufficient numbers of people warranting a post or a service. Reliable prevalence data are lacking for many neurological conditions, such that the definition of need of the population, to which a commissioning process is applied, is problematic. Although, collectively, neurological conditions make up 17 per cent of GP consultations, individually conditions may be rare and in the disease based approach which dominates medical practice, generic issues and a focus on common symptoms become neglected.

GPs see a lot of neuro symptomatology as 'heart-sink' stuff. The perception is that they're not going to be able to do anything that will make a difference, and it will cost a lot.

Chair of Neurological charity (SE7).

The QOF includes a reward system to GPs for the management of ten chronic diseases. Epilepsy has the highest prevalence within the range of neurological conditions (430–1000 cases per 1000,000 of population) and the most likely impact on general practice. It is the only neurological condition to have a QOF indicator, attracting payment points for keeping a register of patients affected and meeting targets for review and management of their condition.

In the context of financial management, it is often difficult to work out how much each section of care costs and thus provide differently. One SHA representative observed:

The difficulty with neurology is that money is wrapped up in acute care or specialist rehab for complex problems, which may be out of area and are costly. There is no extra money around ... (for community based care management and support).

SHA Service Improvement Manager (SE11).

Moreover, costs may be difficult for the PCT to identify and lie more in terms of Social Services care packages and quality of life issues.

Across organisational boundaries, fragmented funding and different bases to entitlement to health and social care have particular implications for neurology services. Scoping interviews revealed a number of different approaches to bridging the health and social care divide. These would be explored in detail in the next stage of case studies, but ranged from formal arrangements under Section 31 of the Health Act 1999 which incorporated pooled budgets, and joint commissioning and management arrangements, to models which sought solutions at a practice rather than strategic level.

Recent policy initiatives

Recent policy changes are designed to have a further impact on integrated planning and working across administrative boundaries. The Local Government and Public Involvement in Health Act 2007 [28] requires PCTs and local authorities to produce 'joint strategic needs assessments' (JSNAs) of the health and social care needs of their populations and places a legal duty on partners such as 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 commissioning. The new DH commissioning framework for health and well being [29] reiterates that JSNAs will form the basis of a new duty to co-operate for PCTs and local authorities and also proposes that GPs will be able to prescribe social care support.

For life-long neurological conditions, the need for services will vary over time and timely access is key to maintaining independence and well-being. On-going access to specialist medical services that copes with fluctuating and often unpredictable need must be integrated with appropriate community support. Many quality of life issues which primary health care, social care and other services must address will not be condition specific, but centre round mobility, support, employment, housing and social interaction. For many, access to equipment and early intervention can make the difference between remaining independent and being forced into residential care. At times, the complexity of the needs of those with neurological conditions lies in the management of their diversity and unpredictability, rather than the needs themselves.

Conclusion

Achieving integrated care for people with LTNCs and a 'seamless' service across organizational boundaries is an objective which underpins the QRs of the NSF,

but seems particularly difficult to implement. Although levers to promote joint working exist, policy and services are essentially health-led, and policy and practice focus in recent years has favoured a particular model of management of LTCs, which has prioritised certain conditions and specific targets. If neurological conditions are to benefit from the reconfiguration and development of services, there needs to be a shift from policy which concentrates on short-term gains to an understanding of the multi-faceted aspects of care over time. This demands integrated working at a number of levels, not least at a policy level, with parity of influence across health and social care.

Our consultation exercise identified the problems in integrating policy across *all* long-term conditions and highlighted how the different levels of complexity involved in neurological conditions present particular challenges. In the next stage of this project, case study investigations will look at how different approaches to integration at a local level have affected 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 will be explored. This work will enable us to identify benchmarks of good practice which are tied to the NSF QRs and improve overall continuity of care for those with LTNCs.

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