

# The National Service Framework for Long Term Conditions: the challenges ahead

Lynne Turner-Stokes and Diana Whitworth

*National Service Frameworks (NSFs) set out standards for health and social care provided by the NHS and social services in England. The latest in this series – the NSF for Long Term Conditions – was published recently. This editorial discusses some of the challenges for its development and implementation.*

## Background

In 2001 Alan Milburn, the then Secretary of State for Health, announced plans for a National Service Framework for Long Term Conditions.<sup>1</sup> An External Reference Group (ERG) was duly appointed in autumn 2002 to prepare advice for the Minister on priorities for the NSF. A ‘scoping’ workshop was held in November 2001 with a wide cross-section of stakeholders,<sup>2</sup> marking the beginning of an 18-month period of consultation, debate and exploration of published literature used to formulate that advice, which was delivered to the Minister in May 2004. The NSF was released in March 2005.

This NSF has differed from its predecessors in a number of important respects, which will have an impact on delivery. The earlier NSFs came with ring-fenced funding and have been implemented through the setting of clearly defined national targets, for example the ‘two-week waiting time’ for consultation in cases of suspected cancer,<sup>3</sup> or the 30-minute ‘door-to-needle time’ for thrombolysis in acute myocardial infarction.<sup>4</sup> Although the value of these targets has been questioned in that they divert attention away from other critical elements of the care pathway,<sup>5,6</sup> they have undoubtedly raised awareness and changed healthcare provision in many respects.<sup>7</sup>

## A ‘new style’ NSF

By contrast, this NSF for Long Term Conditions is a ‘new style’ NSF, which does not come with earmarked funding. Implementation costs are expected to be met from increased funding allocations in general health and social services, but will have to compete with other priorities. In place of standards, targets and milestones, new-style NSFs have ‘Quality Requirements’ to be implemented locally over a period of 10 years, and local bodies can set their own pace of change within this period, according to local

priorities.<sup>8</sup> It is expected that implementation will be monitored by means of ‘improvement reviews’ carried out by the Healthcare Commission and Commission for Social Care Inspection (CSCI). The potential advantage of these methods is that they allow a more holistic approach to service planning and evaluation throughout the care pathway, but time alone will tell whether they provide sufficient incentive to bring about the required service developments.

## A neurological focus

The primary focus of this NSF is on ‘people with long term neurological conditions including brain and spinal cord injury’.<sup>1</sup> Considered in relation to incidence, many individual neurological conditions may appear to be relatively rare, but taken together and over an individual’s lifespan, this group of conditions forms a substantial proportion of the load on health and social services. For example, they are estimated to account for 20% of acute hospital admissions and are the third most common reason for attending a GP. An estimated 350,000 people across the UK need help with daily living activities because of a neurological condition, and some 850,000 people care for someone with a neurological condition.<sup>9</sup> However, these longer-term interventions are poorly recorded and go largely unreported through current information systems, so the epidemiology of ‘need’, as opposed to ‘disease’, is as yet poorly understood.

## Approach to development

The ERG faced considerable challenges in developing the recommendations for such a broad-based NSF which encompassed a diverse set of conditions. Rather than develop a series of mini-NSFs for each of the different diagnoses, the ERG considered the needs of people in groups according to the nature of presentation and progression. These were:

- (a) ‘sudden onset’ conditions such as brain or spinal cord injury, where a catastrophic onset is followed by a variable degree of recovery
- (b) ‘intermittent’ conditions, such as epilepsy or relapsing remitting multiple sclerosis, where the condition itself may fluctuate, although the problem of unpredictability is ever present

**Lynne Turner-Stokes** DM FRCP, Deputy Chair and Clinical Lead, NSF External Reference Group; Herbert Dunhill Professor of Rehabilitation, King’s College London; Director, Regional Rehabilitation Unit, Northwick Park Hospital

**Diana Whitworth**, Chair, NSF External Reference Group; former Chief Executive, Carers UK

*Clin Med* 2005;5:203–6

- (c) *'progressive' conditions*, where impairment and disability gradually increase over a period of time, which may vary from a few months (in the case of 'rapidly progressive conditions' such as motor neurone disease) to many years (for example, in secondary progressive multiple sclerosis or Parkinson's disease)
- (d) *'stable' conditions*, for example cerebral palsy or post polio, where the condition itself is static, but additional effects of degenerative change are superimposed by age.

A long-term disabling condition affects not only the individual concerned but also their family and carers. All of these 'service users' provided substantial input into the development of the NSF, giving it a strong user-focused perspective. In addition to the need for better health and social services, people reported that many of the most significant problems they face while living with a life-long condition relate to areas controlled by other government departments, such as housing, employment and transport. Important though these issues are, it was recognised that many of them lay outside the remit of the NSF and would need to be addressed by other policy initiatives.

The final NSF consists of 11 evidence-based Quality Requirements (QRs)<sup>10</sup> (see Box 1) which reflect the various stages in the care pathway schematically illustrated in Fig 1. Clearly not everyone, though, will need to access all stages in the pathway.

### The evidence base – a new typology

Establishing the evidence base to underpin the NSF recommendations required the development of a new 'typology of evidence', to give due weight to the opinions of users, carers and professionals as well as to formal research. Randomised controlled trials and other population-based experimental methodologies continue to form the cornerstone of the evidence base for relatively short-term interventions, but are not necessarily best suited to research questions where quality of experience is the critical outcome – especially where this is judged on a lifelong time-frame. The typology developed for this NSF recognises the full range of research designs which are applicable in this context, emphasising the quality of the research, the integrity of its conclusions, and its relevance to the needs of this population. It represents an important departure from traditional classifications of evidence, many of which focus on research design – often at the expense of quality or applicability. We welcome the Department of Health's endorsement of this approach in accepting a broader church of research methodology, and hope that the model will be taken up more widely in future policy developments.

### The wider agenda and the challenges ahead

One of the principal challenges throughout the development of this NSF has been to define its scope against a changing background in NHS politics. During its gestation period, the management of long-term conditions in all their

#### Box 1. The Quality Requirements (QRs) within the NSF for Long Term Conditions.

##### QR 1: A person-centred service

People with long-term neurological conditions (LTNCs) are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

##### QR 2: Early recognition, prompt diagnosis and treatment

People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

##### QR 3: Emergency and acute management

People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

##### QR 4: Early and specialist rehabilitation

People with LTNCs who would benefit from rehabilitation are to receive timely, ongoing, high-quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

##### QR 5: Community rehabilitation and support

People with LTNCs living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

##### QR 6: Vocational rehabilitation

People with LTNCs are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

##### QR 7: Providing equipment and accommodation

People with LTNCs are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.

##### QR 8: Providing personal care and support

Health and social care services are to work together to provide care and support to enable people with LTNCs to achieve maximum choice about living independently at home.

##### QR 9: Palliative care

People in the later stages of LTNCs are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

##### QR 10: Supporting family and carers

Carers of people with LTNCs are to have access to appropriate support and services that recognise their needs both in their roles as carers and in their own right.

##### QR 11: Caring for people with neurological conditions in hospital or other health and social care settings

People with LTNCs are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

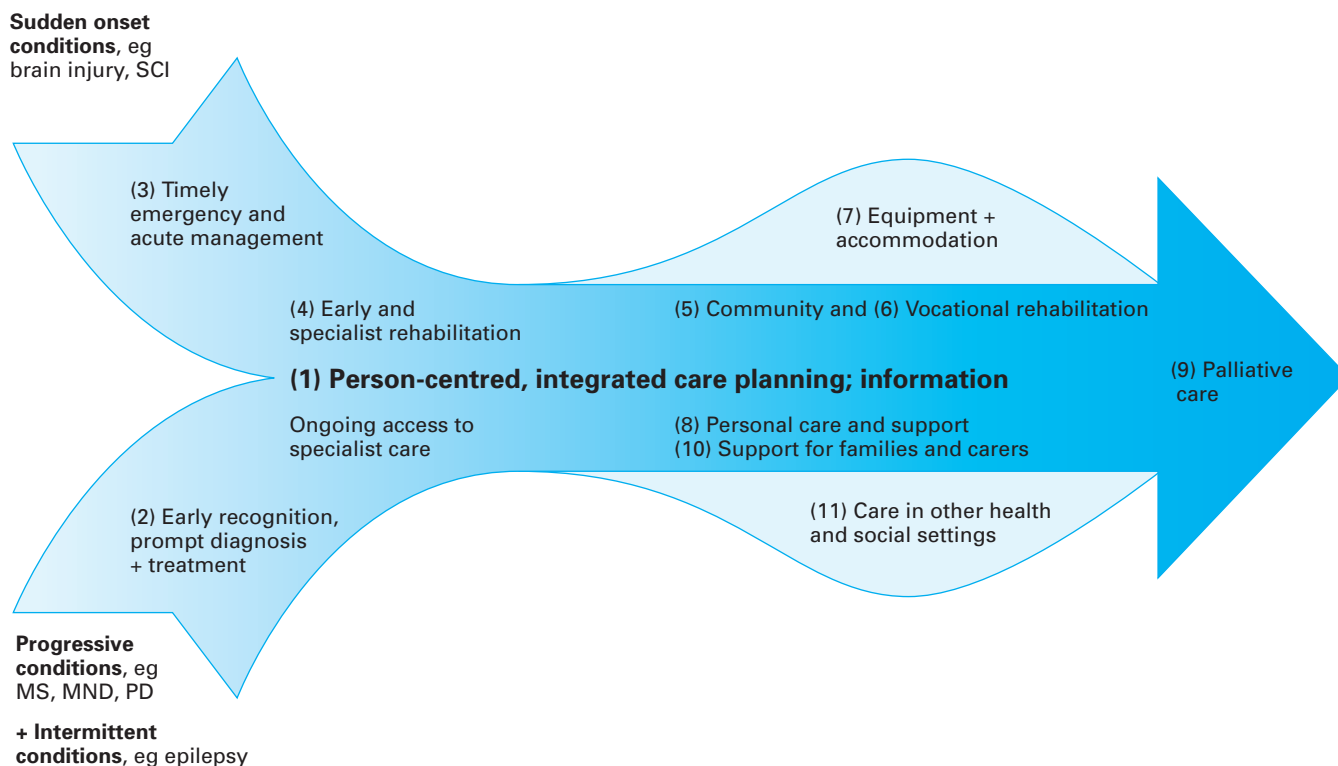


Fig 1. Schematic diagram of the care pathway addressed by the Quality Requirements (QRs) in the NSF for Long Term Conditions. MND = Motor neurone disease; MS = multiple sclerosis; PD = Parkinson's disease; SCI = spinal cord injury.

forms moved higher up the government agenda. There has been considerable debate as to whether this NSF should cover all long-term conditions (as its name suggests) or neurological conditions as originally announced.<sup>1</sup> In January 2005, the Department of Health published a blueprint for NHS and social care, *Supporting people with long term conditions*.<sup>11</sup> This document shares and the NSF share substantial common ground. Nevertheless, it has been agreed that in its implementation this NSF should preserve the neurological focus and ensure that it maintains its own discrete identity, under the umbrella of the broader long-term conditions programme – not least because this was the basis on which its cost calculations were made.

That said, much of the NSF guidance can be extended in principle far more widely. The need for timely intervention, integrated care planning and provision of the right information at the right time applies across many other conditions; likewise, the need to provide support for carers, long-term care and improvements in community equipment. The challenge for the government will be to provide adequate resources within the health and social services to cater for this wider need. After more than a decade in which the primary focus for development has been on the emergency and frontline services, service provision in many areas of chronic disease has been progressively eroded. The current drive to address the needs of people with long-term conditions is therefore most welcome, but requires a sea change in our approach to service planning. Starting from such a low

service base, the recommendations in the NSF cannot be achieved simply by reorganisation but will need significant investment. Cost-effective provision will require collaborative service planning and development, especially for specialist services to meet more complex needs. Networking across all boundaries is therefore critical to its success, and will mean avoiding potential fragmentation where primary care trusts and foundation hospitals respond to different local priorities on different timescales. The involvement of users, both in planning and evaluation of services, is essential, but will require the development and central recognition of appropriate techniques for research and audit to give proper emphasis to this vital user perspective.

### Towards the future

Looking positively towards the future, this NSF is being implemented in tandem with a number of other initiatives which also take a longer-term view of health and social care centred on the needs and choices of the individual.<sup>12,13</sup> It is hoped that this framework will mark the beginning of a new era in which adequately resourced health and social services support users, carers and professionals to work together in partnership for the benefit of all. Much depends, however, on the government's continued commitment to ensure (a) that primary care trusts and other commissioners are held accountable through their star

ratings for the commissioning of appropriate services to meet the Quality Requirements, and (b) that successive ‘uplifts’ in funding throughout the coming decade really do make provision to address the recognised severe shortfalls in current care and services.

### Acknowledgements

The authors would like to acknowledge the work of the ERG members, the Department of Health NSF Team and all those who contributed to the development of the NSF. Financial support for the preparation of this manuscript was kindly provided by the Luff Foundation.

### Conflicts of interest

As Chair and Deputy Chair of the NSF ERG, the authors naturally have a desire to see that the recommendations are successfully implemented. Any opinions expressed in this article are their personal viewpoints and are not necessarily shared by the ERG membership or the Department of Health NSF team.

### References

- 1 Health Secretary announces new plans to improve health in poorest areas. In: [www.publications.doh.gov.uk/nsf/longterm/pressreleases/nsf-press-feb01.PDF](http://www.publications.doh.gov.uk/nsf/longterm/pressreleases/nsf-press-feb01.PDF); 2001.
- 2 NSF for Long Term Conditions Scoping Workshop, 12 Nov 2001: Report of the day. In [www.dh.gov.uk/assetRoot/04/07/47/08/04074708.PDF](http://www.dh.gov.uk/assetRoot/04/07/47/08/04074708.PDF); 2001.
- 3 Department of Health. *The NHS cancer plan*. London: DH, 2000.
- 4 Department of Health. *National Service Framework for Coronary Heart Disease*. London: DH, 2000.
- 5 Public Administration Select Committee. *On target? Government by measurement*. London: The Stationery Office, 2003.
- 6 Yoong KK, Heymann T. Target centred medicine: targets can seriously damage your health. *BMJ* 2003;327(7416):20.
- 7 Robinson D, Bell CM, Moller H, Basnett I. Effect of the UK government’s 2-week target on waiting times in women with breast cancer in southeast England. *Br J Cancer* 2003;89(3):492–6.
- 8 Department of Health. *Standards for better health*. London: DH, 2004.
- 9 Neurological Alliance. *Neuro numbers*. London: Neurological Alliance, 2003.
- 10 Department of Health. *The National Service Framework for LongTerm Conditions*. London: DH, 2005.
- 11 Department of Health. *Supporting people with long term conditions: an NHS and Social Care Model for improving care for people with long term conditions*. London: DH, 2005.
- 12 Department of Health. *Building on the best: choice, responsiveness and equity in the NHS*. London: DH, 2003.
- 13 The new vision for adult social care: results of the SCIE survey and the development of a Green Paper. [www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/fs/en); 2005.