

EDITORIAL

The national service framework for long term conditions: a novel approach for a "new style" NSF

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The setting of uniform standards presents a challenge for health and social care systems anywhere in the world. In the past 5 years, standards for the National Health Service (NHS) in England have been set out in a series of national service frameworks (NSFs). The latest in this series, the NSF for long term conditions, was released in March 2005 and presented some new challenges and novel solutions that have relevance for policy development in both the UK and other countries.

Previously published NSFs in the UK have provided standards for cancer, coronary heart disease, mental health diabetes, older people, children's services, and renal disease. Each set a series of 12 or more standards, and most included clearly defined national targets that service providers were obliged to meet. Many were easily measurable process targets, for example: "No patient should wait longer than 2 weeks for initial consultation in cases of suspected cancer",¹ and "Thrombolysis should be given within 60 minutes of calling for professional help, in all eligible cases of acute myocardial infarction".² Ring fenced funding was made available to help providers to achieve these targets, and a series of "milestones" was drawn up, defining the services that should be in place by specific dates.

While there can be no doubt that these targets have raised awareness and changed healthcare provision in many respects, their value has been challenged in many quarters.^{3,4} Importantly, by focusing on specific steps in the care pathway, they may divert attention from other critical steps. For example, a large study of over 5000 cases of breast cancer in the south of England showed that while the time to initial consultation had decreased, the time from first appointment to actual treatment had actually increased, and consequently total waiting times had changed little.⁵ In some more long term conditions, the focus on acute presentation may be even less productive. Reporting to the Public Administration

Select Committee in 2003,⁴ Richard Harrad, Clinical Director of the Bristol Eye Hospital, recorded that, to meet waiting time targets for new patients in diabetes clinics, 1000 follow up appointments were cancelled per month. Critical incident reporting over a 2 year period had identified 25 patients with diabetes or glaucoma who had lost vision as a result of consequent failure in follow up care.

These experiences have led the UK government to adopt a more "hands off" attitude, moving away from centrally allocated funding dependent on prescriptive targets, and allowing the NHS and social services more freedom in deciding how to meet national and local priorities across the whole care pathway. Future standards in the UK will have fewer national targets and greater emphasis on health outcomes as opposed to inputs.^{6,7} There will also be much greater user involvement in the setting of priorities and in service evaluation.

This latest NSF for long term conditions is therefore a "new style" NSF, set in that context. It goes forward together with a number of other initiatives that take a longer term view of health and social care centred on the needs and choices of the individual.^{8,9} In place of standards, targets and milestones, it has "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. No ring fenced funding is allocated; instead, implementation costs are expected to be met from uplifts in general health and social services funding, but will have to compete with other local priorities. The External Reference Group, appointed to provide advice to the Government on the NSF priorities, had very strong representation from service users and carers, and for the first time had a lay Chair – Diana Whitworth, then Chief Executive of Carers UK. Instead of focusing on specific areas of intervention, this NSF takes a more holistic approach, addressing all stages of the "care pathway"

from initial presentation and diagnosis, through acute management and rehabilitation, into long term care and support, including palliative and end of life care. The ERG was tasked specifically with setting priorities for people with long term neurological conditions, and its membership was selected on this basis, but it was also asked to indicate where standards could be more generally applied to other long term conditions. Nevertheless, in implementation of this NSF, there is agreement on the importance of preserving the neurological focus and ensuring that it maintains its own discrete identity under the umbrella of the broader long term conditions programme¹⁰ in the UK.

Wherever they are applied, all health and social care standards should be based on the best available evidence,¹¹ and a further challenge for this NSF has been the assimilation of research and evidence to underpin the recommendations. For a strongly user focused NSF, it was appropriate that the evidence presented should reflect the value placed on the opinions of users, carers, and professionals as well as formal research. Traditional research hierarchies such as those used by the National Institute for Clinical Excellence in the UK¹² tend to emphasise research design, without due regard for the quality of the research or its applicability to the clinical question.¹³ Randomised, controlled trials have become the recognised gold standard for evidence relating to treatment efficacy, and are well suited to short term interventions in relatively homogeneous populations; however, they have well recognised limitations in more diverse populations with complex needs and cannot realistically be applied to all the questions that need to be answered.¹⁴ In chronic conditions, where the important outcomes are quality of experience over a life long time scale, designs such as longitudinal observational studies or qualitative research techniques are more likely to be appropriate for many of the questions. However, they must be conducted rigorously, with all possible steps taken to reduce bias.

A new typology for research and evidence was therefore developed by the Research and Evidence Group for this NSF, which recognises the breadth of research design required in this area of health and social care. Importantly, it takes account of the opinions and experience of service users, and their families and carers, as well as the views of professionals. It is based on the principle that qualitative, quantitative and mixed studies can have equal validity when used in the appropriate context, rather than suggesting that there is an implicit hierarchy among

Table 1 Summary of evidence typology for the NSF for long term conditions

Expert evidence	
Opinion/experience	Of users, carers (E1) or professionals (E2)
Research based evidence	
Design	
Primary research	Quantitative (P1), qualitative (P2) or mixed methods (P3)
Secondary research	Meta-analysis (S1) or other secondary analysis (S2)
Reviews	Systematic (R1), or other descriptive reviews (R2)
Quality assessment	Rated on five parameters (scored out of 10)
Applicability	Direct (evidence from within long term neurological conditions) or indirect (extrapolated evidence from other conditions)

research designs,¹⁵ and it puts the emphasis on the quality of the study design, and the integrity of its conclusions and their relevance to the population served by this NSF.

To assign the typology: (a) each piece of evidence referenced in the NSF has been given an "E" (expert) or an "R" (research) rating; (b) each piece of research based evidence in the NSF was awarded a rating based on three domains (design, quality, and applicability) (see table 1); and (c) each quality requirement was then presented with a grade of recommendation reflecting the extent, quality, and applicability of expert and research evidence.

The scheme for quality assessment is a simplified rating, based broadly on the methods developed by Van Tulder and colleagues for systematic reviews within the Cochrane Library¹⁶ and adapted by Steultjens *et al* for other designs.¹⁷ Any such quality rating inevitably has an element of subjectivity, and to reduce variation it is therefore recommended that typology should be assigned by at least two raters. The Research and Evidence Subgroup of the ERG evaluated over 600 articles and pieces of evidence to assimilate the evidence base for the 11 quality requirements. The process by which the typology was developed, validated, and applied is currently in preparation for publication.

It is intended that this approach will mark a significant departure from traditional evidence evaluation and that it will take the research community a further step towards recognising the broader church of research methodologies needed to reflect the real life experience of individuals and their families who need to use our health and social services on a life long basis.

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