The Diabetes National Service Framework – a real opportunity?

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ABSTRACT -The Diabetes National Service Framework (NSF) represents a new style of this relatively new policy instrument. It sets clear 10year targets but leaves a large part of implementation decision-making to local teams. It is clear that the central priorities of people with diabetes are therapeutic partnership, expert guidance and integrated service provision. These underpinning themes transcend all of the more specific objectives of the NSF. Realising both the themes and the specific objectives will, in many localities, mean tackling guite challenging transformational programmes. They will probably need to include changed ways of working and information systems development, as well as constructive partnership between primary and secondary care and between many different healthcare disciplines. This may appear a formidable task but having diabetes firmly on the 'must do' healthcare agenda for the first time creates a tremendous opportunity. The way physician specialists in diabetes, the natural local leaders, rise to the challenge will be a key determinant of whether this NSF leads to real improvements in the experience and outcome of care for people with diabetes.

KEY WORDS: chronic disease management, diabetes, experience of care, integrated care, national service framework

The multiple delays and baffling secrecy associated with the development and release of the Diabetes National Service Framework (NSF) inevitably heightened hopes and expectations. Sadly, many feel they have been dashed already. Yet these characteristics of the process reflect the inescapable reality that national service frameworks are politically designed and centrally controlled instruments of healthcare policy. The attendant baggage is inevitable. So, what are the realistic expectations? Will life for people with diabetes, and the healthcare professionals who try to serve them, now change discernibly and for the better? Is it likely that the NHS, and more importantly people with diabetes, will consider that this initiative has been a success or a failure, during or after its 10-year lifespan?

The evolution of NSFs

National service frameworks are a policy instrument still in a rapid state of evolution. Even a cursory glance at the Diabetes NSF will reveal that it is a very different animal from its predecessors. This is because it is the first national service framework to be released since Shifting the balance of power was published.1 This conscious move to delegate responsibility for achieving NHS delivery targets to primary care trusts (PCTs) that are performance managed by strategic health authorities means that the long lists of centrally determined, time-limited targets and 'ring-fenced' central funding that accompanied the Coronary Heart Disease NSF have largely been abandoned. This change has occurred in response to more generic pressure for lessening central control within the NHS and before there has been an opportunity properly to evaluate the preceding NSF approach. It remains mandatory to achieve new NSF standards but the mechanism(s) for achieving them and the resources available will largely be controlled by local commissioners, ie PCTs. Nonetheless, the fact that there is a Diabetes NSF means that for the very first time diabetes is a 'must do' on the agendas of all health service managers and auditors, most importantly the Commission for Health Improvement (CHI) (from April 2004 the Commission for Healthcare Audit and Inspection (CHIA)).

The Diabetes NSF

So, accepting the constraints of our ever-changing NHS, what should we look for in this voluminous policy document? Are there any pearls that can help us towards a world in which the experience and outcome of diabetes is genuinely improved for all the people living with one of our most common and severe chronic conditions?

The views of people with diabetes

People with diabetes were given a real opportunity to articulate their priorities in the early stages of the NSF development process. They identified three main priorities for change. Perhaps health professionals would do well to keep these firmly to the Bob Young MSc MD FRCP, Department of Diabetes and Endocrinology, Hope Hospital,

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2004;4:69-71

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forefront of NSF-facilitated local negotiations to improve diabetes services. They may not have the formal authority of the official standards but they infuse every aspect of this NSF and progress in achieving them would, I believe, provide every locality with sound foundations.

- Firstly, people with diabetes want a change in attitude by healthcare professionals. They do not want to be the subjects of patronising direction, however well intentioned. Rather, they wish to have the opportunity to participate in decisions about their management and to have self-enabling information appropriate to their particular condition. They want a change from paternalism to partnership. When asked to identify where these characteristics existed at present, they were particularly critical of doctors and particularly complimentary about diabetes specialist nurses.
- Secondly, people with diabetes want better access to routine services and to specialist advice. Importantly, specialist capability was not equated with a particular type or grade of healthcare professional. Rather it was a term reserved for those who really did understand what patients were taking about and could convey that understanding and associated reassurance to people with diabetes.
- Thirdly, they want service integration. They want the multitude of different services that necessarily contribute components of their care during a lifetime of diabetes to communicate properly with one another, to produce joint management plans and policies and not to erect a seemingly interminable series of hurdles, compounded by conflicting information, which can make living with diabetes unnecessarily miserable.

In summary, people with diabetes want therapeutic partnership, expert guidance and integrated service provision.

It is not surprising that these priorities reflect, predominantly, the experience of care. The nature of care received is usually the priority of patients even though, mostly, they also share the predominant concern of professionals, namely minimisation of complications. Of course, as the NSF points out, there is a convergence of interest here. The most effective chronic disease management is undertaken by patients who are informed and

Key Points

National service frameworks have changed since *Shifting the balance of power* (Department of Health)

- People with diabetes want therapeutic partnership, expert guidance and integrated service provision
- Success in implementing the Diabete NSF will require change and renewal of working practices, information systems, and professional and organisational relationships
- Specialist diabetes physicians have an opportunity to lead social service transformation that could produce enormous health benefits

confident enough to manage their condition themselves (empowered). So an effective therapeutic partnership meets both agendas. Reflecting this theme, patient-centred language is a characteristic that clearly distinguishes the Diabetes NSF from its predecessors. But achieving it presents quite a challenge to many traditional modes of healthcare delivery.

The challenges of the Diabetes NSF

To achieve the changed attitudes and behaviours that would necessarily underpin a new shared, competently guided and integrated experience for people with diabetes will be a formidable task for the professional leads of many locally managed diabetes networks (local implementation teams). Yet there are good examples of such organisations already in existence and the Diabetes NSF website is quite a useful source of guidance.² Furthermore, properly implemented, the tangible NSF 'deliverables' such as personal healthcare records, personal healthcare plans, improved education and named contacts for diabetes services coordination, could shift the balance of power significantly towards people with diabetes. This could activate widespread, meaningful and effective patient participation in healthcare which would undoubtedly spread rapidly beyond the boundaries of diabetes into chronic disease management in general.

The aforementioned patient priorities are largely encompassed by the radical Standard 3 in the NSF. When reviewing the healthcare aspirations of the other 11 Standards, many beleaguered healthcare professionals, particularly those working in localities that have traditionally neglected diabetes care, may justifiably be forgiven for experiencing a dispiriting sense of *déjà vu*. After all, from an evidence-based healthcare standpoint the biomedical aspirations are incontestable. But they could have been, and indeed largely were, specified ten years ago by the St Vincent declaration¹ and the subsequent UK St Vincent task force.³ And what happened then? Very little, because there was no central drive to support the recommendations.

Now, despite the apparent commitment to making progress toward these long-standing goals, many may feel anxious about control of their lives and their workload given the presumptions in the Delivery Strategy, ie that success is likely to be achieved only through:

- changed ways of working
- information systems development and implementation
- effective joint primary and secondary care partnership
- multidisciplinary working.

Yet all of these formidable and anxiety-provoking aspirations really just reflect secular trends in healthcare delivery that are highlighted by, but far from unique to, the Diabetes NSF or indeed the UK. As so often, therefore, diabetes care is at the leading edge of healthcare reform – an exciting but not necessarily entirely comfortable situation! Nonetheless it seems inevitable that these and other possibly even more radical approaches will have to be explored as mechanisms that might be appropriate to tackle the large and complex healthcare problem of diabetes. In the face of the burgeoning volume and complexity of diabetes care, 'more of the same' cannot be a viable option.

So, with diabetes now an NHS priority, a concurrent information strategy that has the potential to gather the evidence to support and monitor service improvement and effectiveness, plus the recognition of an important role for professional leads in managed diabetes networks, there is a real opportunity for diabetes specialists to guide sensible reform of diabetes care in an environment that should be conducive to constructive change. Such reforms must deliver the patient-centred, expert, integrated services that are the articulated priorities of people with diabetes, as well as achieving the potential health benefit which the evidence shows should be possible. Of course, it may not always be easy. Although the general environment for diabetes care services should be improved immeasurably by the fact of the Diabetes NSF, predictable challenges are already emerging:

- Healthcare professionals are often sceptical about 'patientcentred care' when face-to-face contact time is so constrained.
- Expertise is at a premium; diffusing it throughout a range of new professionals and organisational structures requires confidence building and investment in training.
- The NHS is so riven by institutional 'organisationalitis' and inter-professional 'factionalitis' that it often seems designed to prevent rather than facilitate 'whole systems', integrated care. The battles to overcome such systemic disorders can exhaust and dispirit the reformers.
- Individual healthcare professionals can be so anxious about change that their instinct to 'hold onto nurse for fear of finding something worse' may lead to an inertia that reinforces the worst conservative aspects of the organisations in which they often feel undervalued and overworked.

The diabetes NSF will not be delivered as envisaged unless such issues can be acknowledged, addressed and surmounted constructively. These are both exciting and challenging times for physician specialists in diabetes. How can s/he make a difference?

The way forward

For the NHS this is very much a step into the unknown. The agenda as reflected in the standards document of the NSF is ambitious and, if achieved, would undoubtedly have enormous health benefit. But, apart from some limited early targets, each locality must work out its own strategy for delivering the programme over the next 10 years. Resources are being expanded generally but as ever there will be many competing demands, not least from other NSFs. It would seem common sense to try, wherever practicable and appropriate, to pool those resources where they overlap, as they obviously do between diabetes, coronary heart disease, stroke, and the future renal and children's NSFs. Hopefully, most healthcare communities will grasp these opportunities enthusiastically and use the NSF as a chance to lever real improvements in the organisation and efficiency of services for people with diabetes. Real progress will probably be predicated on strong, dedicated clinical leadership. It remains to be seen whether monitoring via mandatory national diabetes audit, and diabetes-focused CH(A)I inspections backed up by managerial control mechanisms that include 'accountability agreements' between PCTs and strategic health authorities, will be sufficient to ensure that the less committed do not fail their local populations. Nonetheless, in the hands of determined, clinically led local implementation teams, as advocated by the NSF, such benchmarked data should provide powerful evidence to argue for necessary reforms and resources.

Diabetes is the paradigm for chronic disease. Chronic diseases make up about 60% of the work of Western healthcare systems.⁵ In many respects, the future of chronic disease management rests on the success or failure of the diabetes NSF. We must hope that its implementation can begin to address the legacy of neglect identified by the Audit Commission in their review of diabetes services, *Testing times*:⁶

Many of the problems of poorly coordinated services are not unique to diabetes. The Long Term Medical Conditions Alliance published a report in 1997 of a study involving users from 15 user organisations... These covered conditions such as arthritis, asthma and multiple sclerosis as well as diabetes. Some of the top concerns mirror issues raised by users of diabetes services in this study. These include problems of transferring information across organisational boundaries, the need for support from other people with the same condition, the lack of shared protocols and guidelines, problems in obtaining advice out of hours, and the lack of continuity of care. Access to services was an issue for all patients but particularly ethnic minority groups, young adults and older people with chronic conditions.

The agenda is broad and those implementing the Diabetes NSF have a wide responsibility. Improving 'door-to-needle times' and increasing the number of coronary artery bypass grafts is one thing; challenging the traditional organisational arrangements and healthcare professionals' attitudes within services for people with chronic disorders in order to create a professional–patient partnership that can transform their lives and health is quite another. But that is what the Diabetes NSF beckons us to do and its existence creates the best opportunity for success in the history of the NHS thus far. If it is a success it will be in large part because highly motivated diabetes specialists have grasped this very real opportunity and helped lead an effective programme of change appropriate to their locality.

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