

The Renal National Service Framework: a step in the right direction

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ABSTRACT – Part one of the National Service Framework (NSF) for Renal Services was published early in 2004. The document covers the treatment of patients with end stage renal failure with dialysis and transplantation. Five standards to be achieved by 2014 are proposed. These cover access to information, timely preparation for dialysis, quality planned access surgery, patient choice for dialysis modality, and improvements in the quantity and success of renal transplants. These standards are underpinned by five early actions to be achieved by 2006. These include improved information flow about current practice and outcomes, increases in haemodialysis capacity and adherence to National Institute for Clinical Excellence guidelines on immunosuppression. The Renal NSF is welcome as a significant boost to the profile of renal services in England. Implementation will be difficult and will require the sustained pressure of the 'Kidney Alliance' representing patients, clinicians and supporting organisations.

KEY WORDS: access surgery, chronic renal failure, dialysis, haemodialysis, National Service Framework, NHS Policy, renal, transplantation

January 2004 saw the publication of part one of the National Service Framework for Renal Services covering the management of end stage renal failure (ESRF).¹ The second part will deal with the treatment of chronic renal failure (pre-end stage) and end of life care. The development of the Renal NSF was stimulated by the publication, in January 2001, of a document by the Kidney Alliance entitled *End stage renal failure – A framework for planning and service delivery*.² The Kidney Alliance is a group composed of interested patient groups and clinicians' associations and its document, supported by a cross-party group of MPs, was released with some fanfare at a meeting in the Houses of Parliament. Although it is likely that the government did not really want to produce a Renal NSF, the publication of the Kidney Alliance document created an unstoppable momentum.

The renal NSF considers the demographics and epidemiology of ESRF and acknowledges that

England has a very low rate of treatment of ESRF compared with other industrialised countries.³ In addition some aspects of quality of care, such as haemodialysis vascular access, are identified as being worse in the UK than other European countries. The document recognises that the treatment of ESRF is resource intensive⁴ and, although the necessary funding is not discussed, it does highlight the need for continued growth in facilities for the management of ESRF. The acknowledgement that renal patients in the UK have had a very poor deal compared with those in countries of similar wealth is very welcome as an honest starting point for improving care.

The document sets five standards that need to be met by 2014, covering patient information, quality of care and patient choice, and five milestones that need to be achieved by 2006, dealing mainly with national and local collection of information. The NSF has a limited number of easily measurable targets and most of the standards relate to less clearly defined areas such as patient education, efficient transport services, individual care plans and access to a multi-skilled renal team. In the renal community the document has had a mixed reception. Critics have argued that it is toothless through lack of measurable targets and proper deadlines and without any specific financial commitments. We take a more positive view, as the document does highlight appropriate areas and its objectives are widely supported. It is a starting point and must now form the basis of both local and national pressure and action. In this article we consider the content of the Renal NSF in the light of current problems and possible solutions. We provide a critique of the key elements of the Renal NSF part one and our views of its strengths and weaknesses. We highlight the areas of greatest concern to the process of implementation.

Unlike the cancer and cardiovascular disease NHS policy documents,^{5,6} the Renal NSF is short on specific targets and carries no funding promises. The Renal NSF is more of an exhortation to implement the changes using local persuasion and negotiation rather than a rigid national blueprint. Nevertheless the document highlights five standards that are broadly agreed to be vital.

NSF proposals

Five standards to be achieved by 2014

- Access to information enabling patients to make informed decisions about their care in order to manage their condition and maximise their quality of life.
- Early preparation for dialysis. Once diagnosed all patients will be prepared for dialysis early enough to maximise their opportunities to receive the broadest range of possible treatment options and minimise the complications and progression of the disease.
- To ensure patients commence dialysis in a planned way. Fast, effective surgery to provide appropriate vascular access for haemodialysis or peritoneal dialysis to ensure patients are well prepared as dialysis becomes necessary.
- Dialysis to best suit the needs and preferences of the individual patient. Patients will be able to interchange between the different types of dialysis depending on their clinical and lifestyle needs.
- Improved access to, and outcome, of renal transplants for all those who will benefit from this treatment.

Five early actions to be achieved by 2006

- A national survey will give a clear snapshot of the national service to help identify local priorities and enable comparison and progression to be evaluated.
- Both home and centre-based haemodialysis should be expanded where appropriate, according to patients' needs and proximity to their homes.
- All renal units will participate in a national comparative audit that will provide managers, professionals and patients with the information they need to spread best practice.
- Every patient should have a choice of the type of dialysis they receive, including home haemodialysis dialysis where appropriate.
- To achieve NICE recommendations on immunosuppressive therapy in renal transplantation.

The accepted background to these proposals is the fact that the UK has fallen behind most wealthy nations in the provision of renal care. In England the take-on rate for new patients with end stage renal failure entering dialysis programmes was 91 per million population in 2002 compared with values in the range of 130–190 in the rest of the European Union and 336 in the USA.³ Similarly, the percentage of patients starting haemodialysis with appropriate vascular access (an AV fistula) is 47 in England compared with estimates of 62 and 83 in France and Germany respectively.⁷ A particular problem in England is the provision of haemodialysis stations and this is recognised in the NSF. Many reasons underlie our current lack of haemodialysis provision, not least of which is the extreme difficulty in finding timely capital within the NHS. This has led a number of units to over-expand their use of peritoneal dialysis as this required little capital. This is now seen to have been a mistake in terms of the

Key Points

The publication of part one of the Renal National Service Framework (NSF) improves the profile of renal services in the competition for NHS resources

The Renal NSF includes five standards to be achieved by 2014 which will improve patient experience and outcome

The NSF will be a valuable tool in local negotiations concerning the planning and funding of renal services

The lack of specific targets in the Renal NSF may on occasions weaken the case for renal funding

quality of patient care and is being reversed. Nephrologists feel that the NSF has chosen the right areas to highlight. Differences exist about the lack of targets and about the lack of a clear strategy for implementation. It is certainly welcome that patient choice and timely preparation for dialysis have been included.

Major issues and problems

The first issue is inevitably funding. No specific funds are earmarked to implement this NSF, with everything left to local negotiation. This means that at the level of the primary care trusts (PCTs) and special health authorities (SHAs) there will continue to be a struggle to convince the holders of funding of the needs of an expanding ESRF population. The arguments are well rehearsed for all nephrologists but require constant repetition as the NHS structures continue to evolve and the managers change roles. There will continue to be problems with the relatively small population remit of PCTs and the high cost per renal patient treated. It is not clear how the new funding structure using 'spells' as a unit of cost will handle chronic care for renal patients. Under the new funding arrangements an episode of care or 'spell' will carry a tariff linked to the complexity of procedures employed for diagnosis or treatment. How renal dialysis will be funded under the new system is unclear and a single national tariff would create considerable problems in some centres.

A second crucial issue in the implementation of the NSF is the need for efforts right across the spectrum from patient groups to primary care through to the tertiary centres. The traditional renal units cannot deliver these improvements alone. For this reason it is vital that the Kidney Alliance should continue to function as a powerful umbrella pressure group.

Opportunities

The publication of the Renal NSF increases the national profile of renal medicine and of renal patients. The specialty has struggled to make itself visible alongside the giant profiles of areas such as cancer and cardiovascular disease. This has been so despite the very high cost per patient of renal failure treatment and despite the close relationship between renal disease and cardiovascular morbidity and mortality. The Kidney Alliance has been instrumental

in bringing about the Renal NSF. It is now up to the local stakeholders in renal care to take advantage of this new profile to make sure renal patients are given the quantity and quality of care to which the NSF aspires. We await the publication of part two of the Renal NSF with interest. Crucial issues will include the efforts required to identify and treat mild and moderate renal failure (glomerular filtration rate range 30–90 ml/min) in an attempt to reduce the burden of disease flowing from progression and the development of ESRF. There is now compelling evidence that the progression of both diabetic and non-diabetic renal failure can be checked in a number of ways including inhibition of the renin-angiotensin axis.⁸ Making this happen is the next challenge and will require the identification of the at-risk patient. Here the integration of renal failure management with the evolving strategies for management of diabetes and cardiovascular risk will be crucial.^{6,9}

The problem of access surgery

The Renal NSF is full of laudable ambitions here but the current problems are depressing and intractable. The structural relationships between renal units and the surgeons who perform access surgery are far from ideal. Renal access surgery has not been a focus of training in the UK and is not seen as a career speciality or sub-specialty. Often the work is done by surgeons whose main interests are elsewhere and who see the work as a nuisance rather than an opportunity to excel. Hospitals have had little incentive to improve these structural problems and indeed the initiatives on waiting lists and a focus on national priorities for other diseases have probably made things worse. The whole provision of access surgery needs to be re-engineered as described in the NSF, but this will be very hard to achieve. To provide the combination of trained surgeon, theatre time and inpatient beds needed to reach the standards we aspire to will be enormously difficult.

Haemodialysis provision

There is agreement that haemodialysis (HD) should be offered to all ESRF patients as an option and that this should be based as locally as possible. One of the most common complaints of the current HD patients is the long travelling time to dialysis coupled with unreliable transport provision. In some units the patient must be able and mobile in order to be offered satellite dialysis, leaving the most unwell patients with the longest and most distressing experiences of transport to and from dialysis. An unresolved issue is the extent to which the private sector should be brought in to aid the provision of local (satellite) haemodialysis units. One view is that the full service can be commissioned from the private sector including both the physical facility and the employment of clinical nursing staff. This approach has sidestepped two of the main hurdles, namely the lack of NHS capital and the shortage of trained staff willing to take NHS posts on dialysis services. However, a different view is that this level of outsourcing is a false economy in terms of capital and merely creates another drain on local trained staff.

Some capital for HD has been allocated in current NHS development plans and this will undoubtedly require further capital to follow. The emphasis in the NSF on home HD and local HD is welcome.¹⁰

Peritoneal dialysis

The NSF is helpful in recognising that some patients are well suited to automated peritoneal dialysis (APD) and that this should be one of the modalities on offer. At present this is recognised by the clinical units but APD availability is often limited by capital costs and by training bottlenecks. One of the few specific targets in the NSF is the maximum peritonitis rate for adults on CAPD of one episode per 18 patient months. This is achievable and will be made more so by the switch of certain patients to the expanded local HD facilities planned.

Renal transplantation

This section of the NSF is the weakest and most vague. It relies heavily on reference to previously published documents on NHS transplant strategy.^{11,12} There is little that is new. This is disappointing as the rate and success of transplantation is the most important issue facing renal services today. Transplantation offers longer life and better rehabilitation than dialysis but our current transplant programs meet less than half of the need. Developments in live related and unrelated transplantation in the USA and elsewhere appear to be well ahead of anything even planned in the UK.¹³ In our view it is the improved provision of live-donor transplants using innovative strategies that will provide the best hope for a renal transplant program which meets need. In this area there is a need for public debate and professional commitment to very large increases in transplantation rates.

Targets – probably not the solution

In our view the relative lack of specific quantified targets in the NSF document is likely to be a blessing. Most clinical staff feel that the target culture is a discredited one. We have been pressed into a focus on certain arbitrary points in the care pathway at the expense of the whole package. Targets have been the excuse for a remarkable outbreak of game playing in the NHS. We support the targets within the NSF, for example the provision of access surgery six months prior to the start of HD. However, these need to be implemented as a part of a rational overhaul of the service and not as ends in themselves.

Renal networks – solutions or another layer of bureaucracy?

Networks are the latest NHS solution to providing care that actually suits patients and works.¹⁴ The Renal NSF proposes that such networks should be encouraged in the provision of renal care. All stakeholders including patients, hospitals, PCTs and SHAs are brought together to work out care pathways and to

design the appropriate physical and staffing structures. It is impossible to know if this will work in practice. In one sense the idea of yet another structure is an admission that the current organisation of the NHS does not do its job. Certainly the layers of management are numerous and growing. At worst the network can become another set of committees and subgroups with little executive power. On the other hand, the network might be a vehicle for making the system work in an integrated fashion and not simply achieve a few isolated targets.

Conclusions

We welcome the publication of part one of the NSF as it provides a way forward and because it raises the profile of the renal patient in the fierce competition for NHS resources. The document is a valuable weapon in local negotiations about service development and is of immediate use in this respect. The long-term goals are very ambitious and will be hard to achieve, not least as they will require a radical revision of both the built environment and of staffing structures and a huge commitment of enthusiasm and hard work.

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