

Foreword

Following a period of formal consultation, we are pleased to be able to introduce this Policy Statement and National Service Framework *Designed to Tackle Renal Disease in Wales*.

Wales has long demonstrated an innovative and visionary approach to the development of renal services, often leading the way in terms of dialysis programmes, satellite dialysis units, organ donation and transplantation. There have also been significant developments to improve children's services for dialysis and transplantation. NHS Wales now faces the challenge of responding to a growing demand for renal services in the face of an ageing population and finite resources, but also the need to ensure equity and continuity of services. This Policy Statement and National service Framework seeks to build on existing good practice, and to facilitate the sharing of innovative and effective practice across all of Wales.

The development of the Policy Statement and National Service Framework would not have been possible without the contribution of many stakeholders, including, of course, renal patients and carers, members of the Renal NSF Project Board and in particular Professor John Williams, Consultant Nephrologist and Lead Renal Clinician; we thank them all for their hard work and enthusiasm.

The Policy Statement is structured around the themes set out in *Designed for Life* of more prevention, early detection, improved access and better services; it aims to ensure that the right services are provided in the right place at the right time.

The standards in the National Service Framework describe the services and facilities that patients should expect and covers all aspects of the disease pathway, emphasising patient centred care and multidisciplinary team working. The standards of care for children are to be implemented as part of the Children and Young Person's Specialised Services Project.

The implementation targets largely reflect work that is currently underway and cover the period up to March 2008. Mirroring the approach in *Designed for Life*, there will be further strategic framework covering the period 2008 to 2011.

The scale and complexity of the task of transforming health and social care over the next decade means that change must be managed as a whole. *Designed to Tackle Renal Disease in Wales* shows how commissioners and providers of renal services, working through the networks that will be established, must target their actions to a national and a local level, working in partnership. Together we can strive to achieve world class services that will improve the health, wellbeing and quality of life of children, young people and adults with or at risk of developing renal disease in Wales.



A handwritten signature in black ink, appearing to read 'Ann Lloyd', with a long horizontal line underneath.

Mrs Ann Lloyd
Head, Health &
Social Services Department;
Chief Executive, NHS Wales



A handwritten signature in black ink, appearing to read 'Tony Jewell', with a long horizontal line underneath.

Dr Tony Jewell
Chief Medical Officer, NHS Wales

What is the National Service Framework?

The National Service Framework (NSF) “Designed to Tackle Renal Disease” is a plan to develop services in Wales for people with Renal disease (renal means anything to do with the kidney).

It covers all aspects of patient care, by establishing the standards of care that the patient should expect. Within each Standard there are key interventions. These key interventions describe the services and the systems, which must be in place in order to meet the Standards.

What is it for?

The key aims of the NSF are to ensure the quality of renal care, through:

- improved prevention and early detection of renal disease;
- improved quality of the care and treatment of those people who are at risk from, or who have renal disease;
- effective and integrated Renal Replacement Therapy (dialysis and transplantation) services;
- increased number of available kidneys for transplant by raising awareness amongst the public, through organ donor registration and by improving communication between hospitals with regards to the availability of kidneys;
- developing a network of support for alternative models of care including those patients who choose not to dialyse;

How will it deliver the standards?

It will deliver the standards through:

- establishing national implementation targets that have been set for the Local Health Boards, Health Commission Wales, National Health Service Trusts and other providers;
- defining the quality of care that best reflects the needs of those children, young people and adults at risk from, or who have renal disease;

- ensuring that all patients and their families or carers, have all the necessary information at all stages of care, and by helping them to make choices between appropriate treatment options;
- ensuring that renal care for all patients is delivered in appropriate facilities and convenient locations by the most appropriate specialist staff;
- ensuring that renal care is based around a set of standards that can be regularly measured so that the quality of care can be reviewed, maintained and if necessary, improved;
- setting up Renal Networks which will support commissioning as well as the local delivery of these standards. Commissioning involves specifying, securing and monitoring services to meet individual's needs;

Layout of the NSF

The NSF consists of a number of different Standards which, with the exception of Standard 1 are grouped together in a series of Modules. The Standards are based on the best available evidence, against which the quality and effectiveness of care will be measured.

Standard 1 ‘Care for All’ is an overarching standard that sets out a new structure for the delivery of renal services across Wales.

Module 1: Care of Children and Young People
(Children’s Standards 1 - 10)

Module 2: Prevention, early detection and management of chronic kidney disease and prevention and management of acute renal failure
(Standards 2 - 6)

Module 3: Effective Delivery of Dialysis (Standards 7 - 11)

Module 4: Organ Donation and Transplantation
(Standards 12 - 13)

Module 5: Alternative Models of Care (Standards 14 - 17)

Linked to each Standard there are key interventions which outline how that Standard will be delivered.

Standard 1 - Care for all

Standard 1 sets out a basic structure, involving renal networks that will bring together representation from all those with an interest in renal services, including patients themselves. These networks will lead and monitor the implementation of the NSF standards, for delivering an integrated and high quality renal service across Wales.

The aim of this standard is to ensure that patients become fully involved in taking informed decisions about their own care, working with health professionals and their families and carers. Renal services will be planned, organised and delivered around the needs of the patients and their families.

Module 1:

Care for Children and Young People

This Module has been developed to ensure that children with acute renal failure, chronic kidney disease and established renal failure are not disadvantaged because of their age, size, dependency, where they live, their family or social circumstances or because certain services are designed around the needs of adults. Contained within this module are 10 standards that are focused on the needs of children and are additional to the standards set for adults in this National Service Framework.

Children's Standard 1 is the overarching standard that defines how children's renal services will be set up in Wales and how patient care will be provided with a child and family centred approach.

Children's Standard 2 identifies the ways that renal disease can be recognised early and prevented. It also defines how complications and progression can be minimised through monitoring and early management of problems.

Children's Standard 3 deals with the recognition and management of acute renal failure. The aim is to maximise patient survival and recovery of renal function in infants and children with, or at risk of acute renal failure.

Children's Standard 4 sets out a framework for the preparation of children and young people with established renal failure (and their families) for renal replacement therapy. This will allow them to fully understand all the options available and enable them to participate fully in decisions with the help of an expert team. They will then be able to choose the treatment that is most suitable for them medically and most compatible with their needs and family circumstances.

Children's Standard 5 sets out a strategy for maximising the access to and effectiveness of transplantation.

Children's Standard 6 considers dialysis and the way it is provided most effectively for children by maximising the benefits and minimising the negative effects of dialysis on the child and family.

Children's Standard 7 details immunisations and medication required by children with kidney disease. The interventions will ensure that children are prescribed and given the medications they need in a safe and effective way.

Children's Standard 8 defines the requirements of transport and travelling to services to enable children with their families, wherever they live, to have equal access to expert renal care.

Children's Standard 9 considers the issues of supporting children and young people who choose not to dialyse, to stop dialysis or who are terminally ill by:

- Providing a framework that will enable the provision of appropriate information and support to children and young people as well as their parents and carers so that a decision can be made not to dialyse if this is in the best interests of the child.
- Ensuring that children with established renal failure who do not receive dialysis continue to receive appropriate child and family focussed care from specialist services as well as in the community.
- Ensuring that if dialysis becomes an intolerable physical or psychological burden or if such treatment becomes futile then it is withdrawn ethically and openly and that under these circumstances children and their families or

carers are provided with appropriate psychological, social and spiritual support, understand what the future will bring and what practical support they can have either in the hospital or in the community.

- Ensuring that children with established renal failure who are in the terminal stage of their illness have access to a range of services to ensure that they and their families' physical, psychological, social and spiritual needs are met effectively.

Children's Standard 10 defines a smooth and efficient transition of care from paediatric to adult renal services at an appropriate age for the child, between 16 and 19 years.

Module 2:

Prevention, early detection and management of chronic kidney disease and, prevention and/or management of acute renal failure

Module 2 covers prevention, early detection and management of chronic kidney disease (standards 2 - 4) and, the prevention and or management of acute renal failure (standards 5-6). The primary aim is to slow down progression and to prevent or minimise complications.

Standards 2 - 4 are aligned with other National Service Frameworks whose standards have an impact on patients with renal disease. In turn, those caring for patients with other conditions or diseases, such as heart disease or diabetes, will be able to draw on these renal standards.

Standards 5 and 6 focus on the prevention or early recognition of acute renal failure. They are intended to ensure the most appropriate care of patients with acute renal failure in, the right environment.

Standard 2 provides a framework to identify those people in the community who are at risk of developing renal disease. It puts in place the means to identify those risks and to minimise them.

Standard 3 is concerned with identifying patients with renal disease at an early stage so that they can be properly investigated and a plan set up for their long term care.

Standard 4 is focussed on those patients who have established renal disease with the aim of slowing down the disease progression. It also sets out a plan for identifying the complications of renal disease at an early stage and a means to treat or minimise them.

Standard 5 sets out interventions that will minimise the development of Acute Renal Failure.

Standard 6 defines the care of patients with acute renal failure. Its aim is to maximise patient and kidney recovery and survival.

Module 3:

Effective delivery of dialysis

This module covers the provision of effective delivery of dialysis and defines the care of those patients approaching dialysis and who are receiving dialysis.

For those patients approaching dialysis it emphasises the need to educate and inform patients and their families about the decisions they need to take regarding their treatment.

Careful planning of dialysis is essential so that care is of the highest quality and maximises the outcome for patients.

Standard 7 makes sure that all individuals who are approaching dialysis receive the best care to minimise the progression, and complications of their disease, are able to make an informed choice about the most appropriate therapy.

Standard 8 ensures that patients with chronic renal failure have a smooth entry on to their chosen dialysis programme, by achieving timely creation of permanent vascular or peritoneal access.

Standard 9/10 makes sure that all forms of peritoneal dialysis or haemodialysis are available to patients so that quality of life and survival are maximized.

Standard 11 ensures that all patients on haemodialysis have access to a facility and a transport system that keeps their travel times to a minimum aiming for an average of thirty minutes or less for each journey.

Module 4:

Organ Donation and Transplantation

The availability of kidneys for transplantation has fallen over the last ten years this is partly due to a reduction in deaths related to road-traffic accidents, and reflects the success of seat belt and crash helmet legislation. As a result, in order to increase the number of organs available for transplantation different strategies must be put in place. These include, increasing living donation and maximising the number of donor kidneys available from deceased patients.

New developments in medical practice have also seen major improvements in the techniques of organ transplantation, post-operative care and in the range of immunosuppressive drugs that are available.

Standard 12 is focussed on maximising the quantity and quality of kidneys available for transplantation.

Standard 13 makes sure that patients receiving a kidney transplant receive the best possible standard of care to ensure the best outcome for the transplant.

Module 5:

Alternative models of care

Module 5 sets out standards of care for those patients who, either chose not to undergo dialysis or because of their medical condition are not able to undergo dialysis. Patients need a great deal of support when they are asked to decide about whether they wish to undergo dialysis and need to be given a clear picture of what their care will consist of whether or not they chose to dialyse.

Standard 14: ensures that a patient who does not wish to dialyse makes this decision with the appropriate support and adequate information.

Standard 15 ensures that patients who do not receive dialysis continue to receive appropriate care from specialist hospital services as well as from services in the community.

Standard 16 ensures that if dialysis becomes so difficult, physically or psychologically for a patient that they can, if they so wish, choose to stop treatment. If dialysis is no longer a benefit to the patient, then that treatment will be withdrawn ethically and openly. It is essential that under these circumstances, patients and their families and/or carers are provided with all required support in order that they understand what the future will bring and what backing they will have, either in hospital or in the community.

Standard 17 ensures that patients with established renal failure who are in the terminal stage of their illness have access to services that will allow them to die with dignity in a place of their choice.