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.

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1. Summary

There are around 10.000 people with renal disease in Wales and many more at risk from this disease. The Welsh Assembly Government has developed a National Service Framework (NSF) for Renal Services which sets out a number of standards supported by key interventions, the progressive implementation of which, will improve the quality of care for those with or at risk from renal disease.

As required by *Designed for Life*, the purpose of this document is to set out the Assembly Government's specific policy aims, which are to tackle renal disease. The document also recognises that we need to focus our efforts and it signals our intent to bring about a much more holistic and integrated approach to tackling this disease, at a national and local level, across Wales. This document sets the strategic direction for renal disease and puts in place a policy framework to underpin and guide all activity. If any activity cannot be linked back to the strategic aims in this document, then it must be reviewed urgently. Any significant developments in the future which impact on the strategic aims will trigger a review of those aims.

In order to guide activity at all levels and inform annual planning and commissioning considerations, this policy statement will be supplemented by a number of 3-year strategic frameworks mirroring the approach in *Designed for Life*. Section 5 of this document brings together a number of specific and challenging implementation targets that must be delivered by March 2008, the end of the first 3-year strategic framework in *Designed for Life*, in order to move towards achieving the long term policy aims.

A further set of implementation targets for the next strategic framework, from April 2008 up to March 2011, will be set in the future to define the progress that needs to be made during that time period. This will be followed again by a further set of targets for the period 2011 to 2015.

2. Introduction

In many respects, Wales has led the way for the other countries in the United Kingdom by its innovative development of renal services. Evidence of this is that the first of the 'satellite' dialysis units in the United Kingdom was established in Wales in 1985 and the launch of the UK-wide kidney donor card scheme was pioneered by the Kidney Research Unit Foundation for Wales, based in Cardiff. By 1994 the number of patients taken onto the dialysis programme in Wales was about 106 per million of the population compared with 77 per million in England and 76 per million in Scotland.

Other developments also came early to Wales. Renal transplantation was made available in Cardiff and Liverpool in the late 1960's and became successful during the 1970's. There was significant development of children's renal services in the 1980's with the appreciation that even the youngest infants and children could be treated by dialysis and by transplantation with very good long-term results.

Despite this past record of innovation and vision, in the development of care for patients with renal disease, time has overtaken the provision of renal services in Wales. Services now face growing demand in the face of finite resources[1]. It is therefore clear that action is needed to improve upon the way renal disease is tackled in Wales. We need:

- To do more to prevent and detect it
- To do more to protect those at risk
- To improve services to treat and care for patients with renal disease.

What is the size of the problem?

The full extent of renal disease in the population is not clearly defined. Although statistical analysis of patient numbers and patient mortality is available for patients with Established Renal Failure and for renal transplantation, there is a paucity of data identifying how many patients in the population have renal disease, where they live and if their care is appropriate.

This information gap needs particular attention since services in Wales also need to be planned to deal with the high levels of social deprivation in areas of North and South Wales and the geographical isolation and rural nature of areas of North and Mid Wales.

How do services need to change?

Historically, the focus of renal service development has been on the provision of renal replacement therapy (RRT), rather than on a balanced approach covering the whole spectrum from prevention through to palliative care. Geographically in Wales the development of specialist nephrology units that manage renal disease has been determined by the location of dialysis units.

The great majority of patients in the community with renal disease will never progress to the stage where they require dialysis. They do however need to be identified at an early stage so that those who require specialist care can be referred appropriately. For those patients whose disease does progress there needs to be a pathway in place so that they receive early advice and treatment. Current information shows that the take-on rate (incident rate or new patients receiving RRT each year) for RRT is 127 (113 - 138) per million per annum[1]. This represents no significant change from 128 per million in 1998[2]. The current prevalence (cumulative rate of new plus existing patients per year) however is 283 (263 - 302) per million (up by 22% in 4 years) reflecting the overall growth in patient numbers. These patients require early detection of their disease and an individualised patient plan aimed at slowing the progress of their disease. When appropriate they should be prepared in advance for a programme of integrated RRT.

It is also essential when planning renal services to understand that although transplantation offers the best end result for patients on RRT, at least 50% of patients are not suitable for transplantation, hence the increase in the population of very long term dialysis patients with increasing needs. The provision of dialysis services must therefore be tailored to meet the rising demand in patient numbers. It is anticipated that the rise in numbers of patients who are overweight will lead to increased numbers of diabetics - a significant risk factor for renal disease.

In parallel with a rise in patient numbers is a change in the average age of patients requiring RRT. In many cases elderly patients may choose not to dialyse or may be so restricted by other medical conditions that dialysis is not a viable option. In such cases, other systems of care must be made available for all patients. Equally, if a patient chooses to stop dialysis or when a patient requires end of life care, then an appropriate supportive care pathway and accompanying infrastructure support should be available. Renal teams frequently receive no special training in end of life care. The availability of palliative care, psychological support and appropriate care facilities and services is patchy and variable. Most patients on RRT die in hospital, on wards more traditionally equipped for curative and rehabilitative purposes. When the end of life stage is reached then the model of care should change to focus on comfort and dignity.

These problems are exacerbated by the parallel failure in identifying the needs of the renal workforce. This has resulted in an imbalance between the number of renal healthcare professionals and the growing demands of the increasing number of patients with renal disease.[3] In taking this forward, improvements in the care of patients with renal failure must be supported by robust data collection[4] through an All Wales IT strategy and effective workforce planning.

Future demand for services

It is predicted that there will be a year on year increase of 3-4% in total patients requiring RRT. In view of the changing demography of the population this means that there will be an annual increase of 7% in the number of patients requiring HD. In addition the number of patients with a functioning transplant has not risen in parallel with the demand. The reasons for this is that the availability of cadaveric grafts (grafts secured from deceased donors) is declining, and the rise in living donation is insufficient to cope with the rising number of potential recipients.

3. The Strategic Context

Implementing change to tackle renal disease must take place in the context of the broader transformation of services in Wales. This will see a stronger focus on promoting and protecting people's health throughout their lives, and on creating effective integrated working between service providers in social care and primary, secondary, and tertiary health care. Increasingly, individuals and communities must also be helped and encouraged to take responsibility for their health and wellbeing, and the hugely important role of informal carers and volunteers recognised and supported.

The way ahead has been set by *Designed for Life*, a ten-year strategy to develop world class health and social care services in Wales[5]. The objectives will be to work with the public and professionals to design a system that uses resources effectively[6] to:

- Deal with needs as early and quickly as possible
- Offer services when and where they are needed, minimising the need to travel
- Ensure services are increasingly safe, effective, timely, efficient, and patient-focused
- Provide services carefully matched to people's specific needs, making the best use of the latest technology
- Put in place the right blends of skill and equipment at different levels of need
- Co-ordinate all the different levels and streams of care within a single well-run network

This requires radical redesign of services[7, 8] to move the focus to the prevention of problems and to earlier intervention, move services out into the community, and break down artificial barriers at all levels. This transformation will be achieved through a sequence of 3-year strategic frameworks.

There is a new, sharper, focus on people with long-term conditions. The intention will be to have far better planned and co-ordinated services, organised around an agreed "care pathway" that all relevant

agencies understand and support. The development of such an integrated care pathway will be supported by the Integrated Care Pathway Guide to Good Practice[9]. Individuals will be helped to become "expert patients", taking a high degree of control over their treatment. In the future, where possible, the aim will be to provide all services in or close to the individual's home.

Designed for Life has an overarching vision for 2015.

By 2015, through the efforts of the Assembly Government, the NHS, local authorities, their partners, the community and individuals, Wales will have minimised avoidable death, pain, delays, helplessness and waste.

Vision 2015 will be delivered through a series of strategic frameworks, each covering three years. This strategy will launch the first framework; thereafter at the start of each stage a "fit for a purpose review" will take place to assess progress and ensure that the most effective approach and structure is in place. Challenging targets will be set in key policy areas, such as chronic disease, for the three-year period. Annual targets will be agreed for years one and two of each framework and will be included in the annual Service and Financial Framework ('the SaFF') planning process for the NHS in Wales. The three-year cycle will therefore define the progress that is to be achieved and will strengthen performance management and accountability.

In June 2005, the Welsh Assembly Government published *A Profile of Long Term and Chronic Conditions* to help inform planners and commissioners of services. This will affect the way in which services monitor and manage people at risk from or with renal disease. In line with *Designed for Life*, a new strategic approach to focus on chronic disease management in Wales is being adopted by the Welsh Assembly Government with an emphasis on prevention, early intervention and appropriate care and support that will provide considerable long term health benefits for patients and better organised health service capacity.[5, 10]

In line with the strategic approach on chronic disease, work is underway on the development of a strategic care pathway for renal disease spanning prevention/maintenance of good health, self management, primary care, through to acute care, discharge/support,

and secondary prevention. Guidance regarding good practice in the development of integrated care pathways can be found in the 'Integrated Care Pathways, A Guide to Good Practice'.[9]

Similarly, the publication of the All Wales Care Pathway for the Last Days of Life provides a framework for the integration of end of life care into the provision and planning of renal services.[11]

4. Our vision of the future

The Welsh Assembly Government's vision is that there needs to be much better awareness across the community of the risks of developing renal disease and that renal services should be able to respond quickly, equitably, efficiently and effectively to individual patient needs. Renal care should be patient-centred and available to all irrespective of age, co-morbidity, gender, race and locality.[7]

This document sets out the Assembly Government's policy aims up to 2015 which must underpin decisions taken at national and local level, by central and local government and by the NHS, on all aspects of care for people at risk from or with renal disease.

Designed for Life states that it is vital that the NHS and its partners demonstrate from the start their determination to achieve its overarching vision through their actions over the coming years. In terms of renal disease, delivering *Designed for Life's* vision 2015 will require:

- Preventing renal disease rather than waiting for it to occur
- Detecting renal disease early where it does occur
- Improving access to all elements of renal disease diagnosis and treatment
- Providing better designed, better delivered renal services

We have developed a National Service Framework (NSF) which provides a holistic approach to achieving more prevention and early detection, improved access and better services in terms of renal disease. This NSF is integral to the Healthcare Standards for Wales published in May 2005, which set out the overall level of quality all organisations providing NHS funded care should achieve or work towards. The NSF for Renal Services sets standards for the whole spectrum of care supported by specific Key Interventions to inform the commissioning process and direct action to achieve the quality of care demanded by the Healthcare Standards for people at risk from or with renal disease.

To support the implementation of the NSF, the policy aims and implementation targets set out below, the Assembly Government has established a Renal Advisory Group. This Group will develop and deliver programmes of work needed at an all Wales level to support the implementation process. This includes the development of a set of key indicators for monitoring compliance with the NSF, care pathways, a common dataset to audit the pathways, patient information and education programmes, and competence frameworks. It will advise and inform the review of commissioning on the role of 2 renal networks, one each, in North Wales and in South Wales. It will undertake the future reviews of the Renal NSF standards in light of new clinical evidence.

The Assembly Government's policy aims for renal disease are set out below.

(a) More Prevention & Early Detection

Policy Aim

To reduce the incidence of renal disease in Wales through primary prevention; and where it does occur, to detect it early and delay its progression. In particular, to have comparable incidence rates with the lowest World quartile by 2015.

Reducing the level of renal disease in Wales will require an emphasis on identifying those people at increased risk of developing the disease and then proactively managing that risk. Services need to be organised in such a way that where renal disease does occur that it is detected early and its progression is delayed, again through a proactive monitoring and appropriate treatment.

We need to manage those at increased risk of renal disease as we do those at risk of coronary heart disease and diabetes. In other words, we should care for those at risk as part of a coherent strategy for managing chronic disease. This approach will ensure that where renal disease does occur, that it identified at an early stage and proactive action can be taken to delay its progression.

(b) Improved Access to Services

Policy Aim

To provide diagnosis, appropriate treatment and palliative care services for people with renal disease that match or surpass the best in the World in terms of **access**. In particular, to achieve a prevalence rate per million population for renal replacement therapy above the 50th centile for the world by 2015.

There is a growing body of literature highlighting the negative impact of under and late referral of patients with renal impairment. Observational studies have uniformly shown higher morbidity, lengthened hospital stay, and increased costs of treatment following late referral of patients starting long-term dialysis. This is partly related to failure to detect kidney disease in at risk populations.

Where renal impairment is detected, services need to be organised in such a way that patients have prompt access to the specialised care of a Multi Disciplinary Renal Team. Where patients are referred for renal replacement therapy, they should be able to access dialysis services sufficiently to ensure optimal care, as close to home as possible, at a time that is as convenient as possible. This means that dialysis capacity must grow to match demand.

We must optimise the opportunities for transplantation by increasing the number of kidneys available. Our efforts to raise awareness of the importance of registering as an organ donor must be sustained and improved upon and other opportunities explored. Our aim in Wales is to have at least 800,000 people registered as organ donors by 2010 in line with UK targets.

(c) Better Services

Policy Aim

To provide diagnosis, treatment and palliative care services for people with renal disease that match or surpass the best in the World in terms of quality. In particular, to achieve and sustain the best **quality** of life and survival rates for all patients receiving renal replacement therapy comparable with the top world quartile by 2015.

We have set clear standards of care for those at risk from or with renal disease through the NSF. Each aspect of the patient journey is defined in terms of the desired level of quality of care and the delivery of care should be audited against those standards. The standards should form the basis of Health Commission Wales' and Local Health Boards' commissioning requirements.

These standards address the issue of patient information and education so patients can take informed decisions about their own care. Another fundamental feature of setting standards is putting in place a mechanism for auditing their implementation and using that information for future developments.

Through its policy aims and the NSF standards, the Assembly Government's expectation is that patients should have prompt access to high quality and efficient renal services that maximise patient outcomes. This must be delivered through the commissioning process. It is, therefore, the responsibility of commissioners to ensure that their commissioning arrangements are designed to deliver this requirement in line with stated deadlines.

The commissioning of renal services in Wales takes place at a national, regional and local level. This process needs to be directed by a structure that has access to detailed and specialist knowledge of existing renal services and their development needs as required by the NSF standards of care. Clinical input to the process of commissioning based on effective monitoring of the quality of services is the key to effective commissioning.

The two Renal Networks, one based in South Wales and one based in North Wales, will provide this clinical input together with a clear understanding of service provision and development needs.

The Renal Networks, through their core teams, will also have a more operational function in terms of supporting the delivery of services. Their role will be to share best practice and to support service improvement initiatives.

5. Strategic framework 1 up to March 2008

This section sets out the key targets for renal disease up to the end of the first of *Designed for Life's* 3-year strategic frameworks (2005-06 to 2007-08) which are supporting the progressive delivery of Vision 2015 in *Designed for Life* and its own high level strategic framework targets.

(a) More prevention & early detection

By March 2008:

- Reduction in the risk and development of renal disease is being supported by evidence based programmes to address lifestyle factors such as diet, physical activity and smoking, targeted at high risk individuals such patients with diabetes and Coronary Heart Disease.
- The quality of monitoring patients at risk is improved by implementing an agreed common method for measuring renal impairment.
- A care pathway has been developed for the care of people at risk of renal disease and how the disease's progression will be delayed through proactive management.

(b) Improved access to services

By March 2008

- It is projected that the number of patients receiving haemodialysis (prevalent patients) will have risen from the July 2004 level of 824 (283 per million population) to 1060 (365 per million population).
- At least 80% of prevalent haemodialysis patients are receiving dialysis using arterio-venous fistula/grafts which in turn will maximise the benefits of their treatment.
- 725, 000 people in Wales are registered as organ donors.

(c) Better services

By March 2008

- A set of key indicators for monitoring progress with the NSF at a national level has been defined.
- Self-assessment audit tools for measuring compliance with the National Service Framework standards of care have been developed for commissioners and providers.
- A common set of information requirements for auditing the quality and effectiveness of renal services against the National Service Framework for Renal Services standards of care has been defined.
- 2 Renal Networks, one for North Wales and one for South Wales to help improve commissioning of renal services and support service improvement have been established.
- An All Wales renal patient education and information programme has been defined.
- The All Wales Care Pathway for the Last Days of Life is routinely being delivered by all providers.

6. Strategic Framework 2 for 2008 to 2011

Progress on the targets for Strategic Framework 1 will be monitored and performance managed. This process will inform the development of targets for the next period, 2008 to 2011.

References

1. Ansell D, Feest T, editors (2005) The eighth annual report, The UK Renal Registry, 2005 Bristol. UK Renal Registry
2. Ansell D, Feest T, editors (2003) The sixth annual report, The UK Renal Registry, 2003 Bristol. UK Renal Registry
3. Recommendations of the Renal Workforce Planning Group. A Renal Team: A Multi Professional Renal Workforce Plan for Adults and Children with Renal Disease, 2002
4. Welsh Assembly Government (2005) Healthcare Standards for Wales, Cardiff: Welsh Assembly Government, May 2005
5. Welsh Assembly Government (2005) Designed for Life: Creating world class Health and Social Care for Wales in the 21st Century. Cardiff: Welsh Assembly Government, May 2005
6. Welsh Assembly Government (2004) Making the Connections: Delivering Better Services for Wales, Welsh Assembly Government, October 2004
7. Welsh Assembly Government (2003) Wales: A Better Country. The strategic agenda of the Welsh Assembly Government, Cardiff: Welsh Assembly Government, September 2003
8. Welsh Assembly Government (2003) The Review of Health and Social Care in Wales, (advised by Derek Wanless). Cardiff: Welsh Assembly Government, 2003
9. National Leadership and Innovation Agency for Healthcare, (2005) Integrated Care Pathways: A Guide to Good Practice Llanharan: NLIAH; 2005
10. Welsh Assembly Government/National Public Health Services for Wales (2005) A profile of long-term and chronic conditions in Wales. Cardiff: Welsh Assembly Government/NPHS
11. Welsh Health Circular 030 (2006) End of Life Care - All Wales Care Pathway for the Last Days of Life. Cardiff: Welsh Assembly Government