



Yorkshire and the Humber
Specialised Commissioning Group

Yorkshire and the Humber Renal Network Strategy for Renal Services

2009 – 2014

DRAFT

Draft Version
Version 8.3
9th November 2009

Yorkshire and the Humber Renal Network Strategy for Renal Services 2009 - 2014

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Yorkshire and the Humber Renal Network Strategy for Renal Services 2009 - 2014

1 Background.

Chronic Kidney Disease (CKD) is a long-term condition and is defined as either kidney damage (proteinuria, haematuria or anatomical abnormality) or GFR <60 ml/min/1.73m² present on at least 2 occasions for more than or equal to 3 months ¹. It is an umbrella term for all types of kidney disease that can slowly damage the kidneys over months or years.

CKD may be progressive and its prevalence increases with age, male sex, and South Asian and African Caribbean ethnicity. People of South Asian origin are particularly at risk of CKD-linked diabetes. Diabetes is more common in this community than in the population overall. People of African and African Caribbean origin have an increased risk of CKD linked to hypertension. It is therefore important to understand the needs of the local population.

Acute kidney injury (AKI), formerly known as acute renal failure, is both a prevalent and serious problem amongst hospitalised patients. Clinically, AKI should be easily recognised by the onset of oliguria, anuria and/or deteriorating biochemistry. However, if unrecognised and allowed to deteriorate, AKI will result in uraemia, acidosis, hyperkalaemia and ultimately death. Strategies to reduce the risk of AKI are well known; they include identifying relevant risk factors, appropriate monitoring of blood biochemistry, rapid remedial action when AKI occurs, and appropriate referral of patients to specialist services. However, it is unknown if these strategies are being implemented and many factors around patients with AKI, both amongst those admitted to and already within UK hospitals remain unclear ².

1.1 National Context

The Renal National Service Framework ³ (NSF), published in 2004 and 2005, set out a 10 year plan for the improvement of renal services and included comprehensive quality markers across the pathway of renal disease. The NSF thus represents the benchmark against which the Yorkshire and the Humber Renal Network will develop services.

In addition, there is a range of associated guidance and quality standards the Network will aim to meet. These include relevant National Institute of Clinical Excellence (NICE) guidance ⁴, Quality and Outcomes Framework ⁵ (QOF) standards, Putting Prevention First ⁶, the Organ Donation Taskforce recommendations ⁷ and the End of Life Care in Advanced Kidney Disease Framework ⁸.

Treating patients with Acute Kidney Injury (AKI) especially those with disease so severe as to require dialysis support is a key service offered by specialist renal units. The recently published results of a National Confidential Enquiry into Patient Outcome and Death (NCEPOD) ² review of the care of patients who DIED in hospital with a primary diagnosis of AKI indicated that only 50% of patients were deemed to have received an overall standard of care that was considered good. This was particularly striking for those who developed AKI post admission where only one third received good care.

1.2 The Strategy

The Yorkshire and the Humber Renal Network Strategy outlines the aims of the Network and sets out a 5-year work plan. This strategy will be reviewed on an annual basis. The Network is supported by three Local Implementation Groups, based around the clinical networks for renal services.

Figure 1: Map of region with location of main units / satellites / stations & inpatient beds and capacity and including the configuration of Local Implementation Groups to be inserted here.

2 Commissioning Framework and Governance.

Most patients with CKD will be managed within the primary care sector. For those patients who require it, it is important that there are clearly identified clinical and commissioning pathways in place to ensure a smooth transition from primary to secondary and tertiary care, with appropriate referral and patient choice mechanisms in place. The commissioning of renal care should reflect the role of Practice Based Commissioning and individual PCTs.

The Renal Network is responsible for providing clinical advice to commissioning, and setting the overall service development and quality framework for all renal services in the region. Clinical networks (Local Implementation Groups) are principally responsible for ensuring implementation of the Renal NSF locally; for developing proposals for service developments and improvements and for ensuring a link into primary care. Individual PCTs may also wish to integrate renal services into the local Vascular and Diabetic Programme.

3 Health Need

3.1 Chronic Dialysis

There are approximately 4.9 million people living in Yorkshire and Humber. It is estimated that there are approximately 359,000 adults (18+) with Chronic Kidney Disease (CKD) (stages 3-5) in Yorkshire and the Humber. 167,000 have been diagnosed (QOF 07 08), this indicates a significant undiagnosed population with CKD.

Approximately 550 new patients start Renal Replacement Therapy (RRT) every year. The majority would be treated initially by dialysis, with a small number receiving a “pre-emptive” renal transplant. Bradford and Kirklees have a higher than expected (taking into account age and gender characteristics) rate of CKD5 (End Stage Renal Failure) who are treated by dialysis / transplantation. Although the data are less reliable it is thought that these two districts have a higher rate of CKD 3-4. In contrast, Doncaster and East Riding have a lower than expected rate of CKD5 (End Stage Renal Failure) who are treated by dialysis / transplantation.

In total there are 4,313 patients receiving RRT across the region in 2009. Of these approximately 48% are transplant patients and there are 2,258 dialysis patients in the region. Further data regarding the current and projected positions are detailed in the table below.

Figure 2: Current and Projected Position

	Current position	
Estimated Number of patients 18+ with CKD	359,000 (2007-08)	
Number of patients 18+ diagnosed with CKD	167,000 (QOF 06-07)	
Number of Renal Centres	6	
Number of Satellite Units	19	
	Current position 2009 / 10	Projected 2014 / 15
Total number of dialysis patients	2,258	2,495
Total number of haemodialysis patients	1806	2062
Total number of peritoneal dialysis patients	389	430
Total number of transplant patients	2,055	2,334
TOTAL (on RRT)	4,309	4,819

3.2 Home-Based Therapies

NICE has recommended that all patients who are suitable for home haemodialysis (HD) should be offered the choice of having haemodialysis in the home or in a renal unit⁹. Patients currently treated in hospital that are potentially suitable for home haemodialysis on clinical grounds, but who have not previously been offered a choice, should be reassessed and informed about their dialysis options. The absolute number of patients receiving home haemodialysis in Yorkshire and the Humber is low but the proportion is slightly higher than the UK average which is 2%.

The UK Renal Registry data for 2008¹⁰ indicates that the percentage of dialysis patients receiving home HD varied from 0% in 20 centres in the UK, to greater than 5% of all dialysis activity in the following 6 centres, Sheffield (5.2%), London Guys (5.1%), Brighton (5.5%), Bangor (5.1%), Bristol (5.5%) and Manchester Royal Infirmary (8.6%).

NICE guidance indicates potential scope for expansion of home HD, and that this is a cost effective option which delivers better outcomes and quality of life for patients. The number of patients who would preferentially opt for home HD rather than peritoneal dialysis (at home) and who are unlikely to receive a transplant in the near future AND are clinically suitable for it is unknown. The proportions vary across the region (see figure 3 for total number), a Health Technology Appraisal by NICE indicated that there is the potential to explore a significant increase in numbers with this option, with them setting a target minimum of 15%.

Figure 3: Current position regarding Home Haemodialysis (HD)

	Current position (2009 / 10)
Total number of patients on haemodialysis	1865
Total Number of patients on home HD	57
% of patients on home HD	3%

3.3 Acute dialysis

Although no definitive studies have been undertaken in the UK the prevalence amongst hospitalised patients in the US is 4.9%¹¹ and associated mortality rates have been wide ranging¹².

In all the specialist renal units in the region facilities to manage haemodialysis patients with AKI are shared with some facilities to treat patients with established renal failure. In the last few months pressure on these facilities has resulted in renal centres declining referrals for the management of AKI from their traditional referral hospitals for a period of several weeks.

The Yorkshire and the Humber Network will undertake further work to pilot the incorporation of the acute renal care bed base across the region into the new Clinical Management System "Live" Bed Management West Yorkshire Critical Care Network Pilot, in order to more effectively manage acute admissions.

3.4 Transplantation

Renal transplantation for suitable patients offers a very significant improvement in quality of life, and patients are a third less likely to die one year post successful transplantation compared to those who stay on dialysis (but are deemed suitable for a transplant). Each transplant saves approximately £250K of health care costs over a patient's lifetime.

The Leeds and Sheffield Centres provide transplant services for Yorkshire and the Humber. The majority of renal donors are from individuals who have died due to "brain stem death", and kidneys from these donors are allocated by a nationally agreed set of rules. Recent changes to these rules mean that predicted transplants from this source will decrease in Leeds for the next two years, and then increase, and in Sheffield will increase somewhat steadily. Kidneys are also retrieved from donors who have died following "cardiac death", and Leeds has a reasonably well established programme for retrieval that in Sheffield is yet to be firmly established. Investment in this donor source would be appropriate. The third source of kidneys and the best results are obtained from living donors. The Specialised Commissioning Group has invested significantly in this activity and the Renal Network will performance manage the expected steady growth in this area.

Leeds has recently made a preliminary application to secure funding from the National Specialised Commissioning Advisory Group in order to develop combined pancreas/renal transplantation. The nearest units currently offering this service are Manchester and Newcastle.

3.5 Predicted Future Demand

Current Department of Health models predict that over the next 9 years (up to 2018) the region will have an additional 430 patients in the prevalent population requiring dialysis. It should be noted that the figures stated in this section are subject to review and may change. Further work is being done on future demand modelling currently. The detail of this should not delay planning for increasing the capacity in dialysis services, particularly haemodialysis.

Although chronic haemodialysis capacity has improved over the last few years the projected increase in demand requires significant capital investment. In addition to this growth in expected need, there are concerns regarding

existing estates and facilities with a number of units operating in outdated premises. Furthermore, there are units operating out of leased premises which will need to be relocated in the near future. It is anticipated that the new national tariff for haemodialysis may not provide enough funds to allow step wise construction of new satellite units nor the replacement of unfit estate.

Options for expansion of dialysis capacity that require smaller capital investment include:

- A higher proportion of patients to opt for home based therapies (peritoneal dialysis or home haemodialysis).
- An increase in the number of shifts that current units are staffed for.
- To secure capacity from independent sector providers therefore paying out of revenue. *There has been significant independent sector provision in the South of the region and more recently in Humberside. The latter was "pump primed" by central government in a way that is unlikely to occur again in the immediate future.*

There is a requirement for continuity of funding, skilled capacity management and planning across Yorkshire and the Humber. Urgent consideration therefore needs to be given to the provision of capital funding over the next five years for the replacement and refurbishment of existing facilities and the development of new satellite haemodialysis facilities.

4 Strategic Aims.

The aims of the Yorkshire and the Humber Renal Network are:

1. To prevent the occurrence of renal disease, through systematic identification of at risk groups, and reduction of risk factors.
2. To slow the progress of renal disease, through ensuring high coverage of disease management interventions across primary and secondary care.
3. To ensure early identification and referral of patients likely to need Renal Replacement Therapy, and adequate preparation and choice of treatment type.
4. To ensure timely availability of Renal Replacement Therapy for those likely to benefit from treatment by haemodialysis in designated renal units (or associated satellite units), by receiving a renal transplant, peritoneal dialysis or home haemodialysis.

5 Implementation and Interfaces.

The Yorkshire and the Humber Renal Network is responsible for the implementation of this strategy. A component of this work is the establishment of a single commissioning framework (including performance management and quality) for Renal Services in the region.

An early task is to provide an assessment of progress towards implementing NSF; to include a review of capacity, clinical policies and pathways for dialysis, transplant and primary care management of CKD across Yorkshire and Humber.

The interface between this renal strategy and prevention of renal disease, primary care management of renal disease, pathways into secondary and tertiary care for all types of renal disease, renal input into end of life care, renal input into critical care networks where appropriate, and the role and

capacity of the independent sector in the region all fall within the scope of this strategy.

A regional approach to planning is not about imposing a single model of care, but about ensuring there is a consistent approach to planning of services and moving towards equity of provision – whatever the actual model of delivery at the front line.

Important outputs of the Network will be agreed and include prioritised service development / improvement plans, provision of consistently high standard and equitable services across the region (through care pathway development and other quality improvement measures), with a clear mechanism for clinicians and patients to influence directly the commissioning arrangements for renal care.

The Yorkshire and the Humber Renal Network has agreed a 5 year work plan (see appendix 1). The work plan sets out a comprehensive set of actions to improve the care for renal patients in the region and is appended. It will be regularly reviewed to ensure it reflects current and future planning priorities.

Together with patients, local communities and all other stakeholders the Renal Network is committed to transforming renal care across the region.

6 References

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7 Appendices

Appendix 1

Work Plan of YH Renal Strategy: 2009/10 – 2013/14

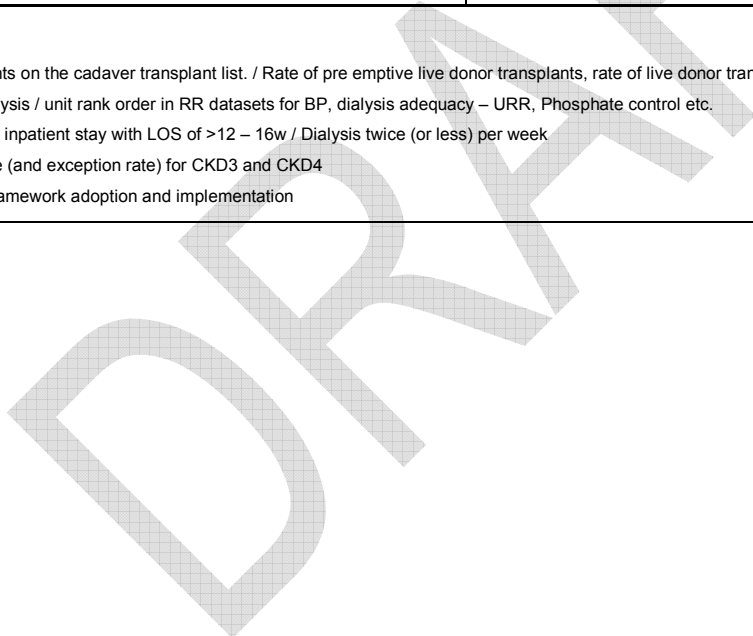
Priorities 2009-10	Objective	Action
1. Pandemic Flu	To ensure that services for patients requiring renal replacement therapy have robust business and service continuity plans in place.	<ul style="list-style-type: none"> Network to seek formal assurance from all providers that robust (and tested) contingency plans are in place in hospital and independent sector units <p>Lead: Chas Newstead/Greg Fell</p>
2. Haemodialysis Capacity and Health Needs Assessment	To undertake a comprehensive assessment of haemodialysis capacity currently available in all units.	<ul style="list-style-type: none"> Analysis of QOF achievement at practice level, outpatient utilisation trends Re run Demand Model (existing and MORRIS model) Match this against actual and expected need Identify service pressures/gaps Reinforce policy that patients that are clinically suitable should be dialysed as close to home as possible Identify and address any specific current issues Identify medium term planning needs Identify scope for growth in home haemodialysis programmes Use routinely available data to provide quality overview of current services Identify investment that may be required to meet future need. <p>Lead : Greg Fell</p>
3. Future capacity planning	To use information on health need, and a wide range of other information, to make prioritised service development proposals to SCG and other commissioning bodies.	<ul style="list-style-type: none"> Network to establish concrete proposals to increase dialysis (and related) capacity to meet future need. Review the role and capacity of the independent sector in the region <p>Lead : Jackie Parr/Greg Fell</p>
4. Acute Kidney Injury and Critical Care	To ensure that provider trusts have robust plans to manage acute admissions in addition to chronic care.	<ul style="list-style-type: none"> The Network is working in partnership with the West Yorkshire Critical Care Network (WYCCN) and planning for more effective management of acute admissions This should be linked to a systematic approach across the region, so that both provider trusts and PCTs are clear how best to manage occasional crises. This should include within its scope critical care capacity, pathways and protocols and link to nursing workforce

		<p>shortages.</p> <ul style="list-style-type: none"> Consistent approach to renal input into critical care networks where appropriate (for example Acute Kidney Injury and acute post transplant care) <p>Lead: Jackie Parr (as member of the WYCCN group)</p>
5. Transplant Capacity	To undertake a local review of the recommendations of the Organ Donation Taskforce Review and identify gaps in local provision and areas for service growth.	<ul style="list-style-type: none"> Local review of the consistency of transplant pathway in Leeds/Sheffield (and feeder trusts) Identify the process for implementing the recommendations of the Organ Donation Taskforce Identify the specific interventions (health care system, clinical, public health, other) that might be undertaken in Yorkshire & the Humber Further investment will/may be required. Priority for next planning round <p>Lead: Chas. Newstead</p>
Ongoing work 2010-14	Objective	Action
6. Patient & Public Engagement & Involvement	To ensure patient input into commissioning, performance management and service improvement arrangements.	<ul style="list-style-type: none"> Develop an ongoing programme of patient involvement and consultation. Ensure that there is patient representation and a patient voice, at all relevant SCG/LIG meetings Develop an information pack and programme of support for patient representatives Ensure that the Network is available to attend patient groups This will include consistent access and availability of appropriate information to facilitate an informed and planned care pathway. <p>Lead: Dennis Crane/Rebecca Campbell</p>
7. Workforce Planning	<p>To understand the scope and nature of the current issues in the workforce, including nursing, medical and ancillary clinical and support services.</p> <p>To identify the workforce models that exist in the region and how this fits in with recommended best practice.</p> <p>To identify the high impact actions that can be taken to address current shortages in the renal nursing</p>	<ul style="list-style-type: none"> To scope out the nature and extent of the issues Workforce issues to be discussed with the Workforce Planning Lead at the Strategic Health Authority Develop workforce plan <p>Lead: Elaine Harrison</p>

	workforce.	
8. Transport	<p>To review current arrangements for transport services for RRT patients in light of the national audit.</p> <p>To ensure the recommendations of the national audit are implemented</p> <p>To continue to develop the pilot arrangements for Personalised Health Budgets for Renal Transport</p>	<ul style="list-style-type: none"> Review findings of national audit. Review current arrangements across the region, Consideration of value for money in current local arrangements Identify and share best practice. Highlight planning gaps locally. Highlight any specific issues that need to be addressed by PCTs locally <p>Lead: Chas Newstead/Elaine Harrison/ Rebecca Campbell</p>
9. NSF milestones	To assess progress against the National Service Framework (NSF) milestones and identify gaps and areas for development	<ul style="list-style-type: none"> Review of progress towards implementing NSF milestones Template for this established by Regional Group, Local Implementation Groups to undertake the review and identify gaps and issues that should be addressed <p>Lead: Rebecca Campbell</p>
10. Equity	To review existing service pathways and commissioning policies across the renal pathway.	<ul style="list-style-type: none"> Review existing pathways for dialysis and transplant and develop consistent care pathways for renal care, thus improving equity of care across the region Develop commissioning policies (and associated service specifications) to support ongoing service development and reduce variation in the level and availability of services. This may focus on home HD, conservative care and renal input into end of life care, AAPD, new primary care services (shared care arrangements; EPO / Anaemia Management and pre dialysis year). Interface between children's and adult services <p>Lead: Jackie Parr</p>
11. Primary Care capacity, quality and expertise	To make assessment of current expertise in primary care	<ul style="list-style-type: none"> Assess current expertise in primary care for the identification & management of renal disease This will be informed by a practice level analysis of performance against the QOF standards. Identify training needs Consider the establishment of a central web based renal resource for the region. Such a resource might serve to harness creative thinking from primary care around service redevelopment Ensure consistent and appropriate links between renal care and prevention of renal disease (a consistent approach across the region, linked to the vascular programme work)

		<ul style="list-style-type: none"> Establish referral pathways into secondary for all types of renal disease <p>Lead: Michael Gordon</p>
12. Pre Dialysis Year	To review current practice in pre dialysis care across the renal units in the region.	<ul style="list-style-type: none"> Small group to review current practice across the renal units in the region in collaboration with GPs Identification of best practice Develop a commissioning framework to implement what is identified/agreed to be best practice Ensure implementation at a local level <p>Lead: Chas Newstead</p>
13. Anaemia Management	To undertake a review of current arrangements for Anaemia Management across primary care in the region.	<ul style="list-style-type: none"> Small group to be established across Yorkshire & the Humber to better understand best practice and share widely Implementation of best practice is a Local Implementation Group or individual PCT issue, requiring close liaison between renal units and local GPs This work should include EPO, Shared care arrangements, Prescribing protocols, Locally Enhanced Services (LES) arrangements <p>Lead: Michael Gordon</p>
14. Conservative Care	To Develop a Palliative/Conservative Care Strategy/ Commissioning Framework for the region. This should be based on the End of Life Care in Advanced Kidney Disease Framework	<ul style="list-style-type: none"> Jackie Parr to link up with regional Darzi work-stream Develop a YH commissioning policy for conservative care and renal input into end of life care <p>Lead: Jackie Parr</p>
15. Commissioning standards	To advise SCG on standards against which to commission renal services in YH.	<p>Renal Network to develop a set of recommended minimum standards against which RRT services should be commissioned</p> <p>These standards may include:</p> <ul style="list-style-type: none"> The configuration of clinical networks for renal services (main renal units, satellite units – independent sector and NHS, and links to primary care) RRT programme size and capacity Links between transplant and renal dialysis unit Consistency of clinical policies, protocols and care pathways Multi-disciplinary team discussion about new and existing patients, and care planning for all patients, coordination of different disciplines On-call arrangements Links between RRT services and inpatient beds

		<ul style="list-style-type: none"> ● Staffing models; technical, IT, and surgical support ● Governance arrangements between main and satellite units ● Contribution to surveillance and monitoring of QOF and Renal Registry ● Minimum set of qualityⁱ and performance standards for RRT services. Within this, agree indicators of high and low quality care ● To consider the development of a single tariff and costing framework for the region, dependent on national developments in this area ● Costing arrangements should reflect different types of RRT (including transplant, and transplant work up – donor and recipients); conservative care, pre dialysis care, electronic and phone advice to non renal physicians, delivery of training and education <p>Lead: Jackie Parr</p>
<p>A number of suggestions have already been put forward:</p> <p>Quality markers for RRT</p> <p>Good Fistula v line access for dialysis / Timely listing of patients on the cadaver transplant list. / Rate of pre emptive live donor transplants, rate of live donor transplants, rate of non heart beating donor transplants. Absolute number of transplants / 3 or greater times per week dialysis / unit rank order in RR datasets for BP, dialysis adequacy – URR, Phosphate control etc.</p> <p>Poor - High rate of acute inpatient stay with LOS of >12 – 16w / Dialysis twice (or less) per week</p> <p>Quality Markers for CKD - QOF performance (and exception rate) for CKD3 and CKD4</p> <p>Quality markers for Conservative Care- Gold Standard Framework adoption and implementation</p>		



Appendix 2**Yorkshire and the Humber Renal Strategy Group Members**

Ivan Ellul	Chair of Yorkshire & the Humber Renal Strategy Group Chief Executive of NHS East Riding of Yorkshire
Rebecca Campbell	Renal Network Manager
Dr Chas Newstead	Clinical Lead
Dr Michael Gordon	GP Lead
Elaine Harrison	Nurse Lead
Greg Fell	Public Health Lead
Dennis Crane	Patient Representative
Jackie Parr	Senior Commissioning Manager Yorkshire & the Humber Specialised Commissioning Group
Matt Neligan	Chair of West Yorkshire & York Local Implementation Group Director of Commissioning, NHS Bradford & Airedale
Gary Lusty	Chair of North & East Yorkshire and North Lincolnshire Local Implementation Group Assistant Director of Planning, NHS East Riding of Yorkshire
To Be Appointed	Chair of South Yorkshire / North Trent Local Implementation Group
Dr Russell Roberts	Consultant Nephrologist Bradford Teaching Hospitals NHS Foundation Trust
Dr Ian Stott	Consultant Nephrologist Doncaster & Bassetlaw Hospitals NHS Foundation Trust
Dr Helen Collinson	Consultant Nephrologist Hull & East Yorkshire Hospitals NHS Trust
Dr Mark Wright	Consultant Nephrologist Leeds Teaching Hospitals NHS Trust
Dr William McKane	Consultant Nephrologist Sheffield Teaching Hospitals NHS Foundation Trust
Dr Paul Laboi	Consultant Nephrologist York Hospitals NHS Foundation Trust

Appendix 3

Summary of National Service Framework standards, quality requirements and markers of good practice

These standards apply to all patients. In some cases, for example children and young people and some older people, they will also apply in varying degrees to families, guardians or carers.

Part One of the NSF:

STANDARD ONE: All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.

Markers of good practice

- Provision of high quality, culturally appropriate and comprehensive information and education programmes.
- Education programmes tailored to the needs of the individual.
- Individual care plans, regularly audited, evaluated and reviewed.
- Access to a multi-skilled renal team whose members have the appropriate training, experience and skills.
- For children and young people, meeting the standards of *Getting the right start: National Service Framework for Children, Young People and Maternity Services*.

STANDARD TWO: All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

Markers of good practice

- Referral to a multi-skilled renal team, where possible at least one year before the anticipated start of dialysis treatment, for appropriate clinical and psychological preparation. This principle should also be followed for people with a failing transplant.
- Accelerated process with intensive input from the renal team for those who present late to renal units or as acute uraemic emergencies.
- People with ERF given information about all forms of treatment so that an informed choice can be made.
- Patients put on the national transplant list within six months of their anticipated dialysis start date if clinically appropriate.
- Anaemia treated to maintain an adequate haemoglobin level.
- Management of cardiovascular risk factors and diabetes according to the National Service Frameworks for Coronary Heart Disease and for Diabetes.

STANDARD THREE: All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity.

Markers of good practice

- Early referral for assessment and investigation for the best means of access, and timely surgery (current best practice being six months before haemodialysis, four weeks before peritoneal dialysis) which enables patients to begin dialysis with their vascular or peritoneal dialysis access established and functioning.
- Monitoring and early intervention to minimise complications of the access.
- Recording and regular auditing of the type of access in use at the start of dialysis, time from referral to surgery, and complication rates for each procedure. Temporary access replaced by permanent access as early as possible.
- Proper training for patients, carers and members of the renal team in the care of the access.
- For children and young people: Dialysis access surgery to follow the principles set out in *Getting the right start: the National Service Framework for Children, Young People and Maternity Services – Standard for Hospital Services*.

STANDARD FOUR: Renal services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.

Markers of good practice

- All dialysis methods available interchangeably for patients, including home haemodialysis and automated peritoneal dialysis.
- Patients receive an adequate and effective dialysis dose.
- Peritonitis rates to be less than one per 18 patient months for adults undergoing peritoneal dialysis, one per 14 patient months for children.
- Patients have their nutritional status monitored and appropriate nutritional support in place.
- Efficient patient transport services available.
- Specialist renal staff, equipment and care available throughout admission, whatever the setting, for patients with established renal failure admitted to hospital.

STANDARD FIVE: All children, young people and adults likely to benefit from a kidney transplant are to receive a high quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.

Markers of good practice

- Early provision of culturally appropriate information; discussion with and counselling of patients, relatives and carers about the risks and benefits of transplantation with a clear explanation of tests, procedures and results.
- Application of a national matching scheme using criteria agreed through UK Transplant to optimise blood group and tissue matching for kidneys from deceased donors.
- Effective preventive therapy to control infections.
- Timely operating theatre availability to ensure optimal cold ischemia times.
- Appropriate immunosuppression and anti-rejection treatment in accordance with forthcoming NICE guidance and effective monitoring and treatment to minimise the risks of adverse effects of immunosuppressive treatment.
- Clear explanation for patients of tests, procedures and results, and especially information and education about anti-rejection therapy.
- Specialist advice from the transplant team available for patients with a renal transplant admitted to hospital, whatever the setting.
- Organ procurement and transplantation to follow the principles set out in *Saving Lives, Valuing Donors: A Transplant Framework for England*.

Part two of the NSF:

QUALITY REQUIREMENT ONE: People at increased risk of developing or having undiagnosed chronic kidney disease, especially people with diabetes or hypertension, are identified, assessed and their condition managed to preserve their kidney function.

Markers of good practice

- All people at increased risk of CKD are identified, and given appropriate advice, treatment and support (which is sensitive to the differing needs of culturally diverse groups) to preserve their kidney function.
- People identified as having an increased risk of CKD have their kidney function assessed and appropriately monitored, using estimated GFR.
- Implementation of the NICE clinical guideline on the management of Type 1 diabetes.
- Implementation of the NICE clinical guidelines on the management of Type 2 diabetes: renal disease; blood glucose; blood pressure and blood lipids.
- Implementation of the NICE clinical guideline on the management of hypertension in adults in primary care.
- For children and young people with potential urinary tract infection, accurate diagnosis and prompt antibiotic treatment, and investigation sufficient to identify structural renal defects and to prevent renal scarring.
- For children and young people with bladder dysfunction, planned investigation and follow-up, with access to urology services with paediatric expertise.

QUALITY REQUIREMENT TWO: People with a diagnosis of chronic kidney disease receive timely, appropriate and effective investigation, treatment and follow-up to reduce the risk of progression and complications.

Markers of good practice

- All people diagnosed with CKD have access to care which is sensitive to the differing needs of culturally diverse groups, to maximise the benefits of treatment and minimise the effects of the disease; and have a care plan.
- Use of the best available evidence to inform the management of blood pressure, cardiovascular disease and cardiovascular risk, and urinary tract obstructions and infections in people with CKD.
- In people with diabetes and CKD, interventions to reduce microvascular complications, in accordance with the *National Service Framework for Diabetes*.
- Implementation of the forthcoming NICE guideline on the treatment of anaemia in CKD.
- Referral from primary care to the specialist renal service at an appropriate stage to optimise outcomes.

QUALITY REQUIREMENT THREE: People at risk of, or suffering from, acute renal failure are identified promptly, with hospital services delivering high quality, clinically appropriate care in partnership with specialised renal teams.

Markers of good practice

- Timely identification and referral to renal and critical care services for specialist, culturally appropriate advice and assessment.
- Appropriate pre-operative testing and interventions, in accordance with the NICE guideline on pre-operative testing.
- Involvement of local critical care networks in planning, commissioning and monitoring the delivery of critical care services to acutely ill renal patients.
- Liaison with specialist renal services to facilitate optimal management of people with ARF in the most clinically appropriate setting.
- For children and young people: Treatment and care in accordance with *Getting the right start: National Service Framework for Children, Young People and Maternity Services*.

QUALITY REQUIREMENT FOUR: People with established renal failure receive timely evaluation of their prognosis, information about the choices available to them, and for those near the end of life a jointly agreed palliative care plan, built around their individual needs and preferences.

Markers of good practice

- The renal multi-skilled team has access to expertise in the discussion of end of life issues including those of culturally diverse groups and varied age groups, the principles of shared decision making, and training in symptom relief relevant to advanced non-dialysed ERF.
- Prognostic assessment based on available data offered to all patients with stage 4 CKD as part of the preparation for RRT described in standard two of part one of this NSF.
- People receive timely information about the choices available to them, such as ending RRT and commencing non-dialytic therapy, and have a jointly agreed care plan built around individual needs and preferences in line with palliative care principles.
- People who are treated without dialysis receive continuing medical care including all appropriate non-dialytic aspects of CKD, and wherever possible are involved in decisions about medication options.
- Individuals are supported to die with dignity, and their wishes met wherever practicable regarding where they die, their religious and cultural beliefs, and the presence of the people closest to them.
- The care plan includes culturally appropriate bereavement support for family, partners, carers and staff.

Appendix 4

Glossary of terms

Primary Care Trust (PCT) is a type of NHS Trust responsible for commissioning primary, community and secondary care services from providers. Many PCTs are now calling themselves NHS and then the name of their geographical area to make it easier for local people to understand how the NHS is managed locally. Collectively PCTs are responsible for spending around 80% of the total NHS budget. PCTs have their own budgets and set their own priorities, within the overriding priorities and budgets set by the relevant Strategic Health Authority (SHA) they belong to, and the Department of Health (DH).

Strategic Health Authorities (SHA) are responsible for enacting the directives and implementing policy as dictated by the Department of Health (DH) at a regional level. In turn each SHA area contains various NHS Trusts which take responsibility for running or commissioning local NHS services. The SHA is responsible for strategic supervision of these services.

Commissioning is the strategic activity of assessing needs, resources and current services, and developing a strategy to make best use of available resources to meet identified needs. Commissioning involves the determination of priorities, the purchasing of appropriate services and their evaluation.

Specialised Commissioning is the commissioning of a specific set of services which are classified as 'specialised'. These services, which include renal services, are defined as those that need to be planned across a bigger area and require specialist (more complex) clinical input. The commissioning of these services is the responsibility of the **Specialised Commissioning Group (SCG)** which is a permanent Joint Committee of, and acts on behalf of all the Primary Care Trusts (PCTs) in the Strategic Health Authority (SHA). In Yorkshire and the Humber the Yorkshire and the Humber Specialised Commissioning Group (Y&H SCG) covers 14 PCTs.

Practice-Based Commissioning (PBC) is a Department of Health (DH) policy designed to give general practitioners (GPs), nurses and other primary care professionals the power to decide how NHS money is spent in their local area. Whilst Primary care trusts (PCTs) have overall accountability for healthcare commissioning.

National Tariff is a standardised price list for operations and procedures applied nationally.

The **Yorkshire and the Humber (Y&H) Renal Network** has been established to lead on the modernisation and development of Renal Services across the region. The strategic planning and commissioning of renal services across Yorkshire and the Humber, in accordance with the National Service Framework (NSF) for Renal Services and National Institute for Health and Clinical Excellence Guidance (NICE) is delivered through the Renal Strategy Group (RSG), which is supported by three Renal Local Implementation Groups (LIG). These reflect and support local commissioning, provider and patient population groups and relationships within the region.

Renal Replacement Therapy (RRT) is the term used for life-supporting treatments for kidney disease. It includes haemodialysis, peritoneal dialysis and transplantation. In practice dialysis only provides about 5% and a renal transplant about 40% of "normal" kidney function.

Haemodialysis (HD) is a form of Renal Replacement Therapy (RRT) in which the blood is purified outside the body by passing it through a filter called a dialyser. The filter is connected to a machine which pumps the blood through the filter and controls

the entire process. For patients with established renal disease each dialysis session normally lasts from 3-5 hours and the sessions are almost always needed three times a week. Haemodialysis can either be carried out at home (HHD), or in a satellite or main renal unit.

Peritoneal Dialysis (PD) is a form of Renal Replacement Therapy (RRT) in which blood purification takes place using the patient's own peritoneum as the membrane. Bags of dialysis fluid containing glucose and various other substances are drained in and out of the abdominal cavity via a PD catheter.. It is a home-based treatment usually performed by patients themselves.

This may be in the form of Continuous Ambulatory Peritoneal Dialysis (CAPD) performed manually, usually 4 times throughout the day, or Automated Peritoneal Dialysis (APD) which uses a machine to perform the exchange of fluid overnight whilst the patient sleeps. Assisted APD (aAPD) provides support to patients who may not be able to perform all components of the dialysis by themselves.

Transplantation is the replacement of an organ in the body by another person's organ. About 40% of patients with established renal failure are suitable for transplantation. As well as offering much the best quality of rehabilitation, there is an improved survival for patients who receive a renal transplant. Pancreatic transplants will treat diabetes which may be the cause of renal failure. By performing a simultaneous kidney and pancreas transplant both the diabetes and the renal disease will be treated.

Pre-emptive Transplant is carried out before dialysis is required and is considered to be the optimum form of treatment.

Living donors are those where the kidneys for transplantation are donated by a member of the recipient's family (**live related**) or by an individual who is not blood related (**live non-related**). The results from transplantation from a live donor source are better than when the donor has deceased.

Cadaveric donors are those where a kidney is donated from an anonymous individual who has recently died. The majority of renal donors are from individuals who have died due to **brain stem death**.

Kidneys are also retrieved from donors who have died following **cardiac death** which refers to natural death from cardiac causes, heralded by abrupt loss of consciousness within one hour of the onset of acute symptoms.

Estimated Glomerular Filtration Rate (eGFR) is a measure of the level at which the kidneys are working based on a calculation of the Glomerular Filtration Rate (GFR) most commonly from the patient's serum Creatinine, age, sex and ethnicity.

Proteinuria is the presence of an excess of serum proteins in the urine and is almost always a sign of renal damage. Since serum proteins are readily reabsorbed from urine, the presence of excess protein indicates either an insufficiency of absorption or impaired filtration. The most common cause of proteinuria is diabetes.

Haematuria is the appearance of blood in the urine. Any part of the urinary tract from the kidneys to the bladder and urethra may be a cause of haematuria. This may be due to diseases that cause renal failure or inflammation but renal tract cancer is another important cause of haematuria.

Oliguria is the decreased production of urine.

Anuria means passage of almost no urine and is practically defined as passage of less than 50 milliliters of urine in a day. Anuria is the inability to urinate due to failure

in the function of kidneys or more commonly because of obstruction from prostatic disease, kidney stones or tumours. Anuria is also sometimes called anuresis.

Uraemia is a term used to describe the illness accompanying renal failure, in particular the syndrome due to accumulation of nitrogenous waste products associated with the failure of the kidneys.

Acidosis is an increased acidity. Metabolic acidosis is an increased production of metabolic acids, usually resulting from disturbances in the ability to excrete acid via the kidneys. Renal acidosis is associated with an accumulation of urea and creatinine as well as metabolic acid residues of protein catabolism.

Hyperkalaemia is an elevated blood level of the electrolyte potassium.

Stages of Chronic Kidney Disease (CKD)

To help improve the quality of care for people with kidney disease, the National Kidney Foundation (NKF) created a guideline to help non specialist doctors identify each level of kidney disease. The NKF divided kidney disease into five stages.

Stage 1 Chronic Kidney Disease (CKD1) A person with Stage 1 CKD has kidney damage with a GFR at a normal or high level greater than 90 ml/min. There are usually no symptoms to indicate the kidneys are damaged.

Stage 2 Chronic Kidney Disease (CKD2) A person with Stage 2 CKD has kidney damage with a mild decrease in their GFR of 60-89 ml/min. There are usually no symptoms to indicate the kidneys are damaged.

Stage 3 Chronic Kidney Disease (CKD3). A person with Stage 3 CKD has kidney damage with a moderate decrease in the GFR of 30-59 ml/min.

Stage 4 Chronic Kidney Disease (CKD4). A person with Stage 4 CKD has advanced kidney damage with a severe decrease in the GFR to 15-30 ml/min. It is likely someone with Stage 4 CKD will need dialysis or a kidney transplant in the near future.

In stages 3 and 4, as kidney function declines waste products can build up in the blood causing uraemia and a person is more likely to develop complications of kidney disease such as high blood pressure, anaemia (a shortage of red blood cells) and/or early bone disease.

Stage 5 Chronic Kidney Disease (CKD5). A person with Stage 5 CKD has end stage renal disease (ESRD) with a GFR of 15 ml/min or less. At this advanced stage of kidney disease the kidneys have lost nearly all their ability to do their job effectively, and eventually dialysis or a kidney transplant is needed to live.