

Public Document Pack

Supplementary Information for 16th March 2010 Scrutiny Board (Health)

Item 9 – Provision of Dermatogolgy Services – Update: Submission from Leeds Dermatology Patients Panel (LDPP); Leeds Teaching Hospitals NHS Trust and British Association of Dermatologists (BAD)

Item 10 – Renal Services in Leeds: Response to the Scrutiny Board’s Statement and Recommendations – Yorkshire and Humber Regional Network Strategy for Renal Services (2009-2014)

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Leeds Dermatology Patient Panel

Submission for Scrutiny Board Meeting (Health) 16 March 2010

Dear Steven,

As you now know Bill Cunliffe and myself with the help of a few patients have set up a patient panel for dermatology at the LGI with a growing membership, with myself as chairman and Bill Cunliffe as secretary and have compiled a constitution that has been agreed by all members of the panel.

In summary the Dermatology Panel will be

- An Independent Advocate for Dermatology Patients.
- A partnership involving patients and professionals working together to bring about improvements.
- A relationship of collaboration and mutual respect.
- A Forum for ensuring good clinical practice.
- A committee for understanding the different ways a Patient Panel can help to bring about improvements in dermatology services (ie Internal improvements by sharing experiences; acting as a sounding board and by offering new ideas).
- A Forum to assist the Trust meet its Patient & Public Involvement requirements.
- An opportunity to better understand the NHS and how it works.
- Inclusive: it will try to represent the diversity of Dermatology Patients;
- Such that all our activities are transparent with no hidden agendas
- To notify the membership of dermatology fund raising events.

As the panel is newly formed and still evolving has the main aim to contribute to the re-provision of Ward 43 and dermatology services and to maintain the high quality of patient care and to this end the panel has set up links with the following departments, section or a groups representative within the LTHT.

- Directorate Manager of Speciality Medicine - Judith Lund
- Divisional Nurse Manager - Alan Sheward
- Consultant Dermatologist - a representative attends
- Matron Seconded for option appraisal - Beverley Craggs
- Matron (dermatology) - Emma Day
- Senior Sister (dermatology) - Beverley Moussa
- Sister (dermatology) - a representative attends
- Communication Officer - Ross Langford

The national dermatology groups and organisation that we are in contact for support and advice are,

- SCC (The Skin Care Campaign)
- BAD (The British Association of Dermatologist)
- BDNG (The British Dermatology Nursing Group)
- Patient Support Groups (such as the Eczema Society, Psoriasis Society, Etc)

We have on the panel a committee member of the Leeds Local Involvement Network (LINKs) who is also a patient Ken Ward

It took some time to set up and arrange the first meeting as it was difficult to know who to contact and how to be recognised within the Trust Higher Management structure and we were past around departments. So we arranged the first meeting ourselves and invited the above listed representatives who after the first meeting said that the panel was recognised by all and could provide valuable input to dermatology services. Since our first meeting the LDPP has

been meeting every four weeks and my self as chairman meeting with management in between for updates and input from the panel members and all meetings have been open and transparent.

In January a Matron was seconded in for three months to work only on an "options appraisal" for ward 43 possible relocation to be presented I believe at the March LTHT board meeting and then for formal consultation to take place with all interested stakeholders and service providers including the Scrutiny Board.

We have been very active with input into the completion of the option appraisal, by compiling a comparison list between Ward 43 at LGI and a proposed Ward 2 at CAH this has been achieved with visits by Consultants, nursing staff, patients and myself to Ward 2 at CAH, from this comparison we are compiling a survey questionnaire to go out to patients who have been a dermatology inpatient within the last two years. The trust has stated that they will help and fund this survey.

The comparison subjects that are being addressed at the moment with input from consultants, nursing staff, patients and myself are,

- The site of the ward within the city and within the hospital complex
- General ambience and facilities on the ward for patients and visitors
- General ambience for nurses and facilities for nurses
- Facilities for patients and nurses which influence the delivery of care
- Medical care at the two sites
- Requirement for inpatients to have treatment with treatment facilities which are presently in the outpatient department
- Medical student teaching
- Postgraduate training of registrars

During the last three months the Trust has been very helpful open and transparent at all our meetings and with many actions on the trust from questions asked which we believe are honest and open. We are just waiting now to see how the next stage (consultation) will take place.

Lastly it has come to the notice of the LDPP that changes are taking place in community dermatology services commissioned by Leeds NHS PCT that will impact on the Dermatology Department of LGI and if not implemented to the correct level of dermatology knowledge will have an impact on the quality of patient care and lead to patient safety issues. Our understanding is that there has been little or no consultation with involved stakeholders and patients. As we see this as a significant change in the delivery of dermatology services we will be writing to the Leeds NHS PCT asking who has been included in the consultation and when, for this change in service. Although we do not yet have access to all the facts there is a strong possibility that the patient dermatology panel may suggest that these plans be put on hold until there is appropriate consultation between community and the hospital medical, nursing and managerial staff.

Should you require any more information then do not hesitate to contact myself or Bill Cunliffe

Yours sincerely



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**Medicine Division
Specialty Medicine Directorate
Dermatology Services**

Briefing paper for Scrutiny Board Tuesday 16th March 2010

LTHT intends to continue to provide dedicated Dermatology inpatient beds, the continued need for these beds and the need for skilled nursing staff is recognised. LTHT is seeking to reprovide the inpatient beds to another ward location within the Trust.

There is no proposal to change the level of service or support provided to this patient population.

A set of clinical criteria has been produced, led by the Dermatology consultants which has been used as the basis for determining and assessing future options for Dermatology inpatient beds.

A lead Matron has been dedicated to this project on a full time basis initially for 3 months January to March 2010. In close liaison with patients, consultants and the nursing team a draft options paper has been produced for further comments by key stakeholders before completion.

There have been on-going discussions with patients, consultants and the nursing team about the proposed re-provision of up to ten dermatology beds from Ward 43 LGI to another ward location within LTHT.

As part of this project an accommodation appraisal, for the in-patient bed base to move to a location within the LTHT that is suitable for staff and patients, has been carried out. Options for the out patient department to move near/adjacent to the in-patient bed base, has also commenced.

There has been communication on a weekly basis with the ward nursing and medical teams. There has also been communication with the Leeds Dermatology Patient Panel (LDPP) via the chairman, on a two weekly basis, with attendance by the project lead and senior LTHT managers at LDPP monthly meetings.

The Dermatology consultant medical team, eight members of the LDPP and a number of the ward 43 nurses have visited the potential ward area at Chapel Allerton Hospital. In addition the Senior Nurse, in charge of Dermatology Out-patients, has visited potential sites at Chapel Allerton Hospital available to house an outpatient department.

The Leeds Dermatology Patient Panel members are working closely with the project lead to ensure strong and effective communication is developed and maintained.

**Judith Lund
Directorate Manager
March 2010**

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From: Tania von Hospenthal [mailto:tania@bad.org.uk]
Sent: 15 March 2010 16:23
To: Courtney, Steven
Cc: Jones Stephen (Wirral University Teaching Hospital NHS Foundation Trust)
Subject: FW: Health Scrutiny Board draft update from BAD

Dear Steven

Apologies for the delay in responding, I have managed to speak to Mark to provide you with an update of the proceedings so far from our perspective.

In terms of our update please see the following account:

To date the dermatology consultants at Leeds Hospital have been in discussions with trust management over the options for the relocation of the dermatology inpatient beds (Ward 43). It is more than likely this relocation will be to Chappel Allerton. There are a number of factors which need to be considered before such a move can take place such as alterations to the new proposed site so that the new accommodation is able to provide the same facilities and staffing structure which are currently provided on Ward 43.

This of course does create major capital issues for moving an entire department and the details and risk needs to be assessed appropriately and managed accordingly.

We understand that the dermatology patient panel is now up and running, having being accepted by the trust as an important part of meeting its PPI responsibilities. The BAD will continue to offer its support and provide advice to the Leeds patient panel as and when needed.

The recent draft by NHS Leeds for commissioning community dermatology service does raise a number of concerns with the model being proposed model, in particular:

- It does not appear to be based on management of skin disease types and need for specialist input within these proposed levels of care.
- Direct access to care for patients with long term, chronic and complex conditions could be hindered using the proposed care pathways.
- Skin conditions suitable for treatment in community clinics are limited to basic diagnosis and management by GP and GPwSi, complex cases require assessment and investigation by a consultant.
- There has been no local public and patient consultation using the recommended methods for engagement as part of the commissioning framework.
- There seems to be a lack of clinician input into what is being proposed.

Some of these concerns and others have been raised by our consultant members in Leeds Hospital and trust management with the PCT. They are all due to meet on the 19 March 2010 to discuss the problems identified and we hope that a conclusion for a revised service model can be agreed or accommodated through these discussions.

Kind Regards

Tania

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Yorkshire and the Humber
Specialised Commissioning Group

Enclosure S2

Yorkshire and the Humber Renal Network Strategy for Renal Services

2009 – 2014

DRAFT

Draft Version
Version 9.3

19.02.10

Contents

Forward by the Chair and Clinical Lead of the Yorkshire & the Humber Renal Strategy Group	3
1. Introduction	4
1.1 The Strategy	
1.2 Background	
1.3 National Context	
1.4 Local Context	
2 Commissioning Framework and Governance	6
3 Health Need	9
3.1 Prevalence of Chronic Kidney Disease	
3.2 Quality & Outcomes Framework	
3.3 Referral to Secondary Care	
3.4 Incidence & Prevalence of End Stage Renal Disease	
3.5 Transplant	
3.6 Predicted Future Demand	
4 Prevention	13
5 Primary Care	13
5.1 Early Detection & Management	
5.2 Quality & Outcomes Framework	
5.3 Training & Development	
5.4 Anaemia Management	
6 Supporting Young Adults	15
7 Pre-Dialysis Year	15
8 Renal Replacement Therapy	16
8.1 Haemodialysis	
8.2 Peritoneal Dialysis	
8.3 Home-Based Therapies & Self-Care	
8.4 Dialysis Away From Base	
8.5 Conservative Care	
8.6 Transplantation	
8.7 Patient Transport	
8.8 Emergency Planning	
9 Acute Kidney Injury	20
10 End of Life Care	20
11 Patient & Public Involvement	20
12 Workforce Planning & Development	21
13 Productivity	21
14 Resources	22
14.1 Funding Arrangements - Capital	
14.2 Information Management Technology	
15 Interfaces, Implementation & Performance Management	23
15.1 Interfaces	
15.2 Implementation and Performance Management	
16 References	25
17 Appendices	27
Appendix 1: Summary of the National Service Framework	
Appendix 2: Glossary of Terms	
Appendix 3: Yorkshire & the Humber Renal Strategy Group Members	
Appendix 4: Work Plan (2009/10 – 2013/14)	

Foreword:

As the Chair and Clinical Lead for the Yorkshire and the Humber Renal Strategy Group we warmly welcome this document: *Yorkshire and the Humber Renal Network Strategy for Renal Services 2009-2014*.

The National Service Framework for Renal Services provides the vision for kidney services centred on the needs of each patient and forms the benchmark against which the Yorkshire and the Humber Renal Network will develop services. This strategy is an important step in ensuring that Yorkshire and the Humber delivers Renal Services that exceed these standards.

The Yorkshire and the Humber Renal Network has responsibility for the entire patient pathway and makes a commitment to **reduce the development of kidney disease**, through ensuring high coverage of prevention and disease management interventions across primary and secondary care, to **ensure early identification and referral** of patients likely to need Renal Replacement Therapy, and adequate preparation and choice of treatment type and to **ensure timely availability and access** to Renal Replacement Therapy.

These aims will be achieved through the delivery of a comprehensive five year work plan which will be supported by the development of clear standards, performance monitoring mechanisms and commissioning frameworks. This will be underpinned by robust information, and incentives for quality improvement, and strengthened by clinical leadership and patient and carer engagement.

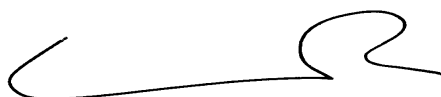
Renal Services, along with services in the NHS as a whole, face challenging times and difficult decisions may be required. The existence of the Yorkshire and the Humber Renal Network means that a collaborative, coordinated and consistent approach to planning and delivering services can be developed within anticipated constraints.

With the publication of the *Yorkshire and the Humber Renal Network Strategy for Renal Services 2009-2014* there is clarification of roles and responsibilities and a comprehensive backdrop against which to address all the challenges and opportunities facing Renal Services over the coming years.

We would like to thank the Renal Community and stakeholders for their commitment to the ongoing development and improvement of services. We look forward to working together to implement this strategy.



Ivan Ellul
Chair of the Yorkshire & the Humber Renal Strategy Group
Chief Executive, NHS East Riding of Yorkshire



Dr Chas Newstead
Lead Clinician for the Yorkshire & the Humber Renal Strategy Group
Consultant Nephrologist, Leeds Teaching Hospitals Trust

1 Introduction

1.1 The Strategy

The revised arrangements for the Yorkshire and the Humber Renal Network were formally agreed in 2008. Prior to this the strategic development of renal services took place on a local level split between North and South Yorkshire. These groups had local strategies and plans, however with the formation of a Yorkshire and the Humber Renal Network it is necessary to update these plans and agree a regional Strategy.

This Yorkshire and the Humber Renal Network Strategy outlines the aims of the Network and sets out a 5-year work plan.

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

1. To reduce the development of kidney disease, through ensuring high coverage of disease management interventions across primary and secondary care.
2. To ensure early identification and referral of patients likely to need Renal Replacement Therapy, and adequate preparation and choice of treatment type.
3. To ensure timely availability and access to Renal Replacement Therapy.

The strategy will be implemented by the Yorkshire and the Humber Renal Strategy Group and reviewed on an annual basis.

1.2 Background

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

A classification developed for the Kidney Disease Outcomes Quality Initiative (K/DOQI ¹) describes five stages of CKD using an estimated glomerular filtration rate (eGFR) to measure kidney function. People with CKD stages 3 to 5 have, by definition, less than 60% of their kidney function. Stage 3 CKD is a moderate decrease in GFR with or without other evidence of kidney damage, stage 4 CKD is severe decrease in GFR with or without other evidence of kidney damage and stage 5 CKD is established renal failure.

CKD is often 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 diabetes-linked CKD. 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.

The increased incidence and prevalence of renal disease in ethnic minority population undoubtedly presents particular cultural and language difficulties to those who care for such patients and this needs to be acknowledged and strategies devised for both preventing and managing it. Renal Registry data highlights a higher than expected incidence and prevalence of stage 5 CKD in Bradford and Kirklees. This almost certainly reflects the ethnic profile of these districts.

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.

1.3 National Context

The National Service Framework (NSF) for Renal Services ³, published in 2004 and 2005, sets 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. See Appendix 1 for a summary of the NSF standards, quality requirements and markers of good practice.

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, 18 week Commissioning Pathway ⁶, Putting Prevention First ⁷, the Organ Donation Taskforce recommendations ⁸ and the End of Life Care in Advanced Kidney Disease Framework ⁹.

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.

1.4 Local Context

There are six main renal units in Yorkshire and the Humber, all of which manage a number of satellite units. There are currently nineteen satellite units in the region. The Leeds Teaching Hospitals Trust and Sheffield Teaching Hospitals Foundation Trust are the transplant centres for the region.

Leeds Teaching Hospitals Trust is the only provider of Children's Renal Services in Yorkshire and the Humber whilst Nottingham University Hospitals Trust serves the South of the region. Although children fall outside the remit of

the Renal Network the interface with children's services and the transition of patients to adult's services are part of the Network work programme.

The Yorkshire and the Humber Renal Network covers all of Yorkshire and the Humber (14 PCT areas) and also includes Derbyshire County and Bassetlaw PCTs from which there are significant patient flows into the renal units in the South of the region.

The Yorkshire and the Humber Renal Network is supported by three Local Implementation Groups, based around the clinical networks for renal services. These reflect and support local commissioning, provider and patient population groups and relationships within the region.

< Figure 1: Map of region with location of main units/satellites/stations & the configuration of Local Implementation Groups to be inserted here >

2 Commissioning Framework and Governance

The majority of patients with renal disease are principally cared for in primary care. Primary Care Trusts (PCTs) are responsible for planning and commissioning these renal services. However, there are significant advantages to some aspects of the renal pathway being planned across more than one PCT boundary. Therefore, certain elements of renal care, namely renal replacement therapy (dialysis and transplantation), are planned collaboratively by PCTs working at a regional level. The Yorkshire and the Humber Specialised Commissioning Group (SCG) has responsibility for commissioning these areas. The Yorkshire & the Humber SCG is a permanent Joint Committee of, and acts on behalf of, all the PCTs in the Yorkshire & the Humber Strategic Health Authority area.

The table below (figure 2) sets out the broad disposition of commissioning responsibility for renal services.

The remit of the Yorkshire and the Humber Renal Network covers all aspects of the renal patient pathway. The Yorkshire and the Humber Renal Strategy Group, and the Local Implementation Groups aligned sub regionally, and local arrangements in PCTs, need to provide expert advice to PCTs on commissioning renal services.

Figure 3 illustrates the responsibilities of the Yorkshire and the Humber Renal Strategy Group and Local Implementation Groups in supporting PCTs. In practice, the dividing line between PCT, sub-regional and regionally-led work will not always be clear cut. In particular, Local Implementation Groups have an important role in both ensuring that PCT views inform SCG priorities and in supporting PCTs with their implementation.

The Renal Network is responsible for providing clinical advice to commissioners, and setting the overall service development and quality framework for all renal services in the region. The most appropriate mechanism to be doing this may be to offer to take over the setting of commissioning standards as well as to advise on the appropriate use of Commissioning for Quality and Innovation (CQUIN) indicators.

Figure 2: Table Illustrating Commissioning /Investment Responsibility

		Integration of renal disease into implementation of vascular risk management	Identification and management of CKD in primary care	General nephrology – outpatient and general nephrology day case / inpatient episodes	Low clearance clinics; preparation for Renal Replacement Therapy	Acute Kidney Injury – links and interface with acute and critical care planning and provision	Renal Replacement Therapy		Conservative Care & End of Life care
							Dialysis	Transplant	
Strategic Planning	Assessing need								
	Reviewing service provision								
	Deciding priorities								
Procuring services	Shaping the structure of supply								
	Planning capacity & managing demand								
Contracting	Service Contracts & Investment								
Evaluation and Monitoring	Supporting patient choice								
	Managing performance								
	Seeking public and patient views								

Key:

Primary Care Trust (PCT)		Y&H Specialised Commissioning Group (SCG)	
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Note: The Yorkshire and the Humber SCG has commissioning responsibility for Renal Replacement Therapy, all other aspects of Commissioning for Renal Services are the responsibility of the individual PCTs.

Figure 3: Table Illustrating Yorkshire and the Humber Renal Network Responsibility

		Integration of renal disease into implementation of vascular risk management	Identification and management of CKD in primary care	General nephrology – outpatient and general nephrology day case / inpatient episodes	Low clearance clinics; preparation for Renal Replacement Therapy	Acute Kidney Injury – links and interface with acute and critical care planning and provision	Renal Replacement Therapy		Conservative Care & End of Life care
							Dialysis	Transplant	
Strategic Planning	Assessing need								
	Reviewing service provision								
	Deciding priorities								
Procuring services	Shaping the structure of supply								
	Planning capacity & managing demand								
Contracting	Service Contracts & Investment								
Evaluation and Monitoring	Supporting patient choice								
	Managing performance								
	Seeking public and patient views								

Key:

Local Implementation Group (LIG)		Y&H Renal Strategy Group (RSG)	
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Note: The Yorkshire and the Humber Renal Network is responsible for all elements of the renal patient pathway and all aspects covered in this table. The Y&H RSG is accountable to the Y&H SCG for development and delivery of the overall strategy for the region. However, the three LIGs hold devolved responsibility for the delivery of certain aspects of the implementation of the strategy.

The Local Implementation Groups (clinical networks) are principally responsible for ensuring implementation of the Renal National Service Framework 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 Diabetes Programme.

3 Health Need

Information on the health needs of patients with renal disease is continually being updated. The most recent comprehensive health needs assessment¹⁰ in this region was undertaken in 2008 prior to the formation of the Yorkshire and the Humber Renal Strategy Group. This was undertaken to inform the development of commissioning arrangements for renal services through the Specialised Commissioning Group. It gives a snapshot of key issues in renal disease. Further work undertaken since this time will be published in due course.

3.1 Prevalence of Chronic Kidney Disease

There are approximately 5.4 million people living in Yorkshire and Humber. It is estimated that there are approximately 358,000 adults (18+) with Chronic Kidney Disease (CKD) (stages 3 to 5) in Yorkshire and the Humber. 168,000 have been diagnosed. This indicates a significant undiagnosed population with CKD. This data is summarised in the table below (figure 4) and the graph (figure 5) illustrates the diagnosed and estimated undiagnosed populations per Primary Care Trust (PCT).

Figure 4: Table of the estimated, diagnosed and undiagnosed Chronic Kidney Disease population in Yorkshire and the Humber

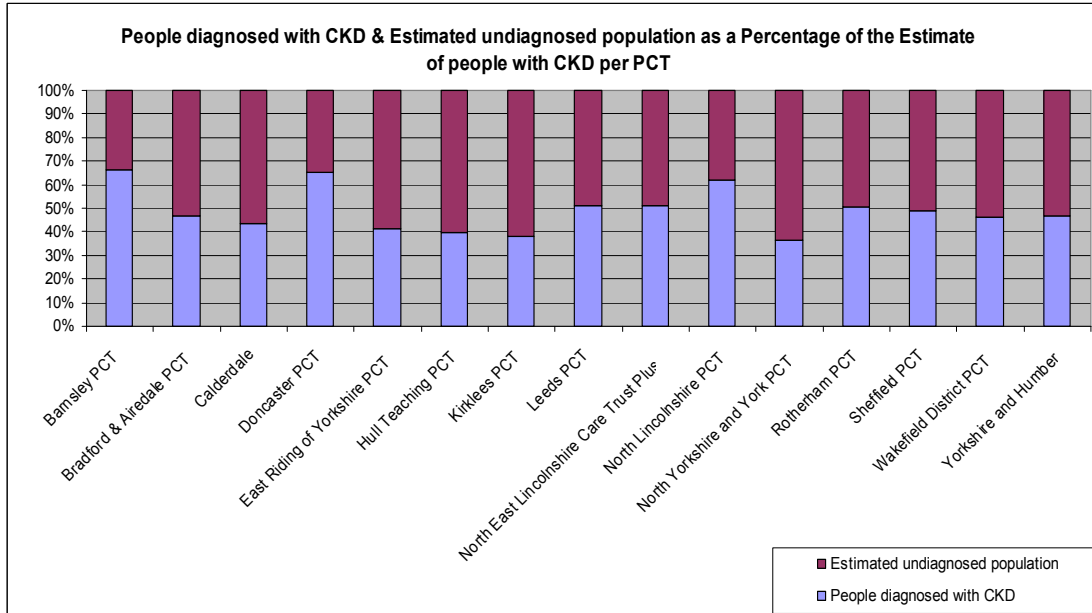
Yorkshire & the Humber	Current position 2009/10
Number of People registered with a GP	5,382,498
Estimated number of people with Chronic Kidney Disease	358,488 ^a (7%)
Number of People diagnosed with Chronic Kidney Disease	168,506 ^b (47%)
Estimated undiagnosed population	189,982 (53%)

Source:

^a Estimate taken from NEOERICA model (2009)

^b NHS Information Centre QOF Extract for Yorkshire & the Humber (2007-08)

Figure 5: Graph of the Percentage of People Diagnosed with Chronic Kidney Disease (CKD) and the Estimated Percentage of Undiagnosed Population as a Proportion of the Estimate of People with CKD per PCT in Yorkshire & the Humber (2009)



Source:

NEOERICA model (2007-08) ¹¹

NHS Information Centre QOF Extract for Yorkshire & the Humber (2007-08)

Note:

This data is also included on the map (figure 1). The percentage of people estimated to have CKD varies across PCTs, from 6% to 9%.

The estimates of true prevalence are taken using the NEOERICA model. This modelling tool has been developed to utilise the data available through the NEOERICA cohort study to generate estimates of true CKD prevalence ¹¹. It is considered an overestimate, although the precise quantification of by how much NEOERICA overestimates prevalence is unknown – it is thought to be an overestimate by 1%.

Although epidemiological evidence paints a mixed picture, it is thought that there is no socio economic or ethnic gradient in the incidence of stage 3 CKD, but that disease progression may be faster in some groups. This highlights the need to ensure high quality CKD management to reduce vascular risk and slow the onset of progression of renal disease, particularly in high risk populations. Ensuring services are able to meet the diverse needs of different communities is a key concern.

3.2 Quality and Outcomes Framework

Analysis of the 2007 / 08 Quality and Outcomes Framework (QOF) data for Chronic Kidney Disease (CKD) (see the 'Glossary of Terms' in Appendix 2 for more information on QOF) has been undertaken for all practices in the region. This will be published in early 2010.

For Yorkshire and the Humber as a whole 74.2% of eligible patients met the CKD 3 QOF Indicator (the percentage of patients on the CKD register whose notes have a record of blood pressure in the previous 15 months) (range 70.8% - 78.0%). There was marked variation at Primary Care Trust (PCT) and practice level.

For Yorkshire and the Humber as a whole 82.6% of eligible patients met the CKD 4 QOF Indicator (the percentage of patients on the CKD register with hypertension who are treated with an angiotensin converting enzyme inhibitor or angiotensin receptor blocker, unless a contraindication or side effects are recorded) (range 79.4% - 85.8%). There was marked variation at PCT and practice level.

The Yorkshire and the Humber Renal Strategy Group will circulate the analysis of QOF data widely, and it will be used as a basis for quality improvement in CKD management, both at practice and at PCT level.

3.3 Referral to Secondary Care

Approximately a quarter of patients are referred to a Nephrologist less than 90 days before dialysis initiation. 40% of this group start dialysis on the same day¹².

Further work may be warranted to assess the consistency of referral protocols in the region. Ongoing development of integrated renal care between primary and secondary care is important for reducing the proportion of late referrals. GPs and a number of specialities in secondary care may need training / guidelines on recognition of and referral of renal disease.

3.4 Incidence & Prevalence of End Stage Renal Disease

Data on incidence and prevalence of end stage renal disease is taken from current demand planning models. Currently there is a model developed by Sheffield School of Health and Related Research being used in the south of the region and a model developed by clinicians and commissioners in the north of the region to estimate demand. Both have historically proved to be fairly accurate predictors of future demand. The Renal Strategy Group has agreed that a single model should be used and that the modelling should be updated, this is being undertaken currently.

Approximately 550 new patients start Renal Replacement Therapy (RRT) every year¹². 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 stage 5 CKD (End Stage Renal Failure) who are treated by dialysis / transplantation. This is almost certainly a reflection of the ethnicity profile of these districts. Although the data are less reliable it is thought that these two districts have a higher rate of stage 3 to 4 CKD. In contrast, Doncaster and East Riding have a lower than expected rate of stage 5 CKD (End Stage Renal Failure) who are treated by dialysis / transplantation.

Based on current planning estimates there are, in 2009/10, 4,309 patients receiving RRT across the region in 2009. Of these approximately 48% are transplant patients and there are 2,254 dialysis patients in the region. Further data regarding the current and projected positions are detailed in the table below (figure 6).

Figure 6: Table of the Current and Projected Position regarding Renal Replacement Therapy in Yorkshire and the Humber (2009/10)

	Current position 2009/10	Projected 2014/15	
		Assumes 0% increase in HHD	Assumes 15% of dialysis on HHD
Total number of centre/satellite based haemodialysis (HD) patients	1,808	2,062	1,834
Total number of peritoneal dialysis (PD) patients	389	430	333
Total number of home haemodialysis (HHD) patients	57	57	382
Total number of dialysis patients	2,254	2,549	2,549
Total number of transplant patients	2,055	2,334	2,334
TOTAL number of patients on Renal Replacement Therapy	4,309	4,883	4,883

Source:

Current demand models in place in Yorkshire & the Humber (2009-10)

3.5 Transplant

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. A critical component of pre dialysis care is an assessment of transplant eligibility. A greater proportion of patients in Yorkshire and the Humber are on an active transplant waiting list compared to England as a whole; this varies from unit to unit. In 2008 / 09 there were approximately 2055 patients with a functioning transplant (Source: current RRT demand model).

3.6 Predicted Future Demand

Current Yorkshire and the Humber models predict that over the next 9 years (up to 2018) the region will have an additional 370 patients in the prevalent population requiring dialysis (Source: current RRT demand model). 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 haemodialysis capacity that require a smaller capital investment include:

- Supporting a higher proportion of patients to opt for home based therapies: peritoneal or home haemodialysis.
- An increase in the number of shifts for which current haemodialysis units are staffed.
- As NHS based capital for expansion of haemodialysis capacity as well as for replacement of current dialysis facilities that is either in a poor state of repair or needs to be vacated for other reasons seems unlikely to be forthcoming, there may be no other option but to secure capital from independent sector providers.
- There has been in the longer term, significant independent sector haemodialysis provision in the south of the Yorkshire and the Humber region, and more recently in Humberside.

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 Prevention

A high proportion of cases of renal failure are preventable through improved lifestyles, vascular risk management, improved management of diabetes, hypertension (and their complications) and improved management of Chronic Kidney Disease (CKD) once diagnosed. Reduction of vascular risk is a key objective of the management of CKD in primary care. There is a much higher risk of cardiovascular events in this population, and thus management of lifestyle and clinical risk factors is critical. A small but significant proportion of patients with stage 3 CKD go on to develop renal failure; and the identification and careful management of those at risk of CKD progression is an important consideration. It is well beyond the scope of this strategy to be highlighting the large scale public health policies and programmes that need to be implemented to reduce some of these risks; however the renal community should play a part in highlighting the relevant issues to reduce the risk in existing and potential future renal patients.

5 Primary Care

Recent national policy statements ³ have rightly recognised the importance of fully engaging the primary care community in the care of patients with renal disease. The Yorkshire and the Humber Renal Network will promote initiatives which aim to deliver improvements in the early detection and appropriate management of patients with Chronic Kidney Disease from diagnosis to end of life.

5.1 Early Detection & Management

Early detection and management of Chronic Kidney Disease (CKD) within Primary Care is critical. There are strong links between kidney disease and other diseases and consequently the National Institute of Clinical Excellence (NICE) guidelines on CKD, Diabetes, Hypertension and Anaemia are proving to be essential in the prevention and management of CKD.

5.2 Quality & Outcomes Framework

The introduction of Chronic Kidney Disease (CKD) to the Quality and Outcomes Framework (QOF) ⁴ in 2006 resulting in GPs being rewarded partly based on how well they manage patients with CKD, has led to an increase in the numbers of patients being diagnosed with CKD.

However, it is important that the issue of low acknowledged prevalence in some GP practices is addressed. The QOF data reveals a wide range in practice level prevalence figures. The Yorkshire and the Humber Renal Network plans to develop an on-line QOF tool which will allow practice staff to compare their data with Primary Care Trust (PCT) averages and local practices. The anticipation is that such awareness will stimulate activity to ensure better coding, fuller CKD registers and improved care for patients.

Data from this source will be scrutinised, processed and distributed to PCTs and practices in a comprehensible form with the intention of allowing meaningful comparisons and promoting creative local initiatives.

5.3 Training and Development

Early and appropriate referral of patients with Chronic Kidney Disease will be promoted by educational initiatives and the development of e-consulting. In recent years pilot work has been undertaken in Bradford. The Yorkshire and the Humber Renal Network will explore the potential to roll this out across the region and with other major GP practice computer systems.

Renal medicine is often overshadowed by other clinical areas therefore it is important to offer support to GPs with a particular interest in renal disease. An on-line GP Renal Reference Group will be established and made available to any GP in the region. This will allow the development of a supportive and creative support group for primary care opinion leaders.

Web based resources such as the Map of Medicine ¹³ will be promoted and local web resources developed when appropriate. GP and practice nursing staff will be able to take advantage of these. Initially some key high quality patient leaflets will be made available for practitioners to print.

5.4 Anaemia Management

Data from different sources suggest that nationally there are around 100,000 people with the combination of Chronic Kidney Disease (CKD) and a low haemoglobin level. Anaemia contributes significantly to the heavy symptom burden of CKD, and is potentially reversible with appropriate treatment, including erythropoietin. The implementation of NICE Guidance on anaemia management in CKD ⁴ is therefore relevant to the Yorkshire and the Humber Renal Network.

As part of a strategy to bring care as close to the patient as is feasible the Yorkshire and the Humber Renal Network will encourage discussion on a reconfiguration of how renal anaemia is managed. Specifically there is a plan to pilot a community based service to administer intravenous iron. Whilst acknowledging work done in other areas, for example the work undertaken by the Anaemia Nurse Specialist Association ¹⁴, local health communities will need to develop their own particular solutions. A successful local pilot would provide a useful exemplar for other Primary Care Trusts in the region.

6 Supporting Young Adults

There is increasing awareness that young adults with complex health needs such as kidney disease need support. It is recognised that during the transition period there is an increased chance of transplant failure ¹⁵. Adherence to medication, diet and other interventions are often difficult during adolescence and moving to an unfamiliar environment can exacerbate the situation ¹⁶. Evidence of the benefits of planned transition is emerging ¹⁷ and a good transition can improve health-related quality of life for young people.

The National Service Framework for Children, Young People and Maternity Services ¹⁸ highlighted the importance of ensuring safe and effective transition through children's services. Other key documents include: You're Welcome Quality Criteria: Making Health Services Young People Friendly ¹⁹, Transition: Moving On Well ²⁰, Think Transition ¹⁶ and Helping Adolescents and Young Adults With End Stage Renal Failure ²¹.

The Yorkshire and the Humber Renal Network will review the existing provision in place to support young adults with kidney disease and develop approaches to support both the transition from paediatric services and presentation in young adulthood.

7 Pre-Dialysis Year

In the year prior to the date of end stage renal disease it is ideal for patients to be followed by a Nephrologist, during which time education about treatment modalities, main unit, satellite and home haemodialysis, peritoneal dialysis including automated peritoneal dialysis, continuous ambulatory peritoneal dialysis and assisted peritoneal dialysis as well as transplantation, either from a cadaveric or live donor source, is carried out. Ideally the patient makes an informed choice in good time and dialysis access is provided, either by the insertion of a peritoneal dialysis catheter or by the formation of a peripheral vascular access for patients proceeding to haemodialysis. Suitability for transplantation and transplantation work up including, where appropriate, that of live donors should also take place. There is substantial evidence that the psychological preparation for dialysis as well as patient survival post the onset of end stage renal disease is favourably influenced by the above management.

There is the difficulty of definition in that the year pre-dialysis clearly can only be defined retrospectively after dialysis has started, so auditing performance in this period is difficult. A proportion of patients have end stage renal disease either as a result of a sudden illness for which prior follow up is not possible or present with advanced kidney disease without having received prior follow up even though the disease progression has been slow. In these latter two groups ideal management can not be delivered. A practical difficulty is that even in specialist kidney units with well established processes, predicting the rate of decline of kidney function and the date at which patients are likely to need to start dialysis is difficult, and this can make timely planning all but impossible.

The Yorkshire and the Humber Renal Network aims to ensure consistent and equitable renal care across the region, including timely and appropriate access to services. Lessons will be learnt from work nationally, including the

Department of Health Action Learning Project in York ²². An annual report will be produced for Yorkshire and the Humber following the publication of the annual Renal Registry Report.

8 Renal Replacement Therapy

8.1 Haemodialysis

Yorkshire and the Humber provide haemodialysis at six renal centres and nineteen satellite units. A number of these units are provided by the independent sector, either through the Department of Health E16 scheme or via local commissioning arrangements.

The majority of patients in Yorkshire and the Humber receive haemodialysis in hospital three times a week and the Yorkshire and the Humber Renal Network is clear that the reduction of dialysis frequency to twice per week because of insufficient dialysis facilities is unacceptable. Where possible the intention is that the satellite units serve those patients with no other major clinical conditions, whilst the main units focus on those patients with more complex needs.

The following issues are of particular relevance to the Renal Network in delivering haemodialysis services, in line with current Renal Association Haemodialysis Guidelines ²³.

- Sufficient capacity
- Standard of facilities
- Equity of services
- Encouragement of enhanced and independent dialysis where possible

The National Institute of Clinical Excellence (NICE) has recommended that all patients who are suitable for home haemodialysis should be offered the choice of having haemodialysis in the home or in a renal unit ²⁴. 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 2008 ²⁵ indicates that the percentage of dialysis patients receiving home haemodialysis 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 haemodialysis, 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 haemodialysis 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 7, section 8.3, for the 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%.

Further action is required to ensure that all dialysis methods are available interchangeably for patients in the region.

8.2 Peritoneal Dialysis

The strong presence of peritoneal dialysis in the UK has fallen over the last decade. The recently published Specification for the Commissioning of Peritoneal Dialysis Pathway ²⁶ is a guide to best practice peritoneal dialysis and aspires to achieve equity in patient access to all peritoneal dialysis treatment modalities. It aims to encourage benchmarking, encourage commissioners to look at and challenge variability in service provision and ensure an appropriate number of patients are on home dialysis treatments.

Whilst it has been shown that 50% of patients given free choice will choose peritoneal dialysis, the percentage on peritoneal dialysis at ninety days still ranges from 0 to 60% ²⁶. In Yorkshire & the Humber, 17% of patients on dialysis are on peritoneal dialysis. The number of patients on peritoneal dialysis across the region has not significantly decreased over the last three years. However, there is a decrease in most units.

8.3 Home-Based Therapies & Self- Care

Your Health, Your Way: A Guide to Long Term Conditions and Self Care ²⁷, focuses on encouraging self-care and for patients to take a more active role in their own health and wellbeing. It set out the national offer, a generic product (applicable to all conditions), which covers the four pillars of existing Department of Health policy on support for self care (information, tools, skills and support networks) together with healthy lifestyle choices. 'Your Health, Your Way' will provide people with long term conditions the information they need about the choices, which should be available to them locally, to enable them to self care in partnership with health and social care professionals.

Accordingly, home-based therapies, namely home haemodialysis and peritoneal dialysis, should be available to patients, where clinically appropriate. There should be information, tools, skills and social networks to support the choice and location of renal replacement therapy. Home-based therapies can be a form of self-care, and patients can also be supported to receive therapies at home (for example, assisted APD) or in other settings (for example, schools, universities, care homes). Similarly, patients receiving dialysis in renal centres or satellite units can play a more active role in their treatment (for example, putting themselves onto the dialysis machine, undertaking blood pressure checks, monitoring results using Renal Patient View).

The number of patients currently receiving home-based therapies remains low, with the majority of home-based patients on peritoneal dialysis (see figure 7). The Yorkshire and the Humber Renal Network is committed to increasing the number of home-based and self-care patients, in line with NICE Guidance.

The Yorkshire & the Humber Renal Network have identified that one of the barriers to increasing the number of patients on home haemodialysis is a lack of clinical leadership to initiate a change in attitude and practice. In addition, a dedicated resource is required to determine and promote a consistent approach across the region.

Figure 7: Table of Total Number of Patients on Dialysis in Yorkshire & the Humber (2009/10)

	Total Number of patients	% of total number of patients on dialysis
Hospital Haemodialysis	1808	80%
Home Haemodialysis	57	2%
Peritoneal Dialysis	389	17%
Total on Dialysis	2254	100%

Source: Current Demand Models in place in Yorkshire & the Humber

Funding has been identified from NHS Kidney Care to appoint a clinical lead, to champion the benefits and to develop a strategy. The aim is to increase the number of patients undertaking home-based therapies and self-care and ensure that all patients are offered these options, where clinically appropriate.

8.4 Dialysis Away From Base

It is made clear in Part One of the National Service Framework for Renal Services that 'for a variety of reasons - work, education, holidays, family visits - it is important that patients can dialyse away from home' ³. Primary Care Trusts and NHS Trusts are encouraged to develop agreed local policies for temporary haemodialysis away from home, which will ensure equity while minimising the impact of renal failure on patients' mobility.

Such policies will need to operate within the framework of the arrangements that were published by the Department of Health in March 2004 ²⁸.

It would be logical for the renal units in the region to adopt a uniform policy agreed by the Yorkshire and the Humber Renal Network.

8.5 Conservative Care

Conservative Care or Management is the delivery of full supportive treatment for those patients with advanced kidney failure who choose not to, or are no longer able to, have dialysis.

Part Two of the National Service Framework (NSF) for Renal Services ³ includes markers for good practice relating to this area:

- People should receive timely information about the choices available to them, including ending Renal Replacement Therapy and commencing non-dialytic therapy and should have a jointly agreed care plan.
- People who are treated without dialysis should receive continuing medical care, including all appropriate non-dialytic aspects of Chronic Kidney Disease, and wherever possible be involved in decisions about medication options.

Services for this group of patients vary across the region and may not be available in satellite units. More work is required to understand the scope and consequent actions required to ensure delivery of services in line with the NSF.

8.6 Transplantation

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 however commissioning of this area is the responsibility of NHS Blood and Transplant. 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 Yorkshire and the Humber 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.

The Renal Network is committed to ensuring equity of service across the region and to increase transplantation where possible within local control.

8.7 Patient Transport

The National Service Framework (NSF) for Renal Services³ states that ‘adequate transport is so important to people on haemodialysis that it plays a vital role in the formation of patient views and attitudes towards dialysis. Good transport systems can improve patient attendance and shorter travel times can improve patient cooperation if the dialysis treatment frequency needs to be increased. Efficient transport facilities reduce interruption to patients’ social lives and may therefore improve their quality of life’.

A significant proportion of haemodialysis patients are unable to transport themselves to and from dialysis. Transport therefore remains a major concern for most patients requiring haemodialysis, with those on hospital-based dialysis making on average 312 journeys to and from the unit per year²⁹.

The National Kidney Care Audit, Patient Transport Survey Report³⁰, reporting on the 2008 survey made eight clear recommendations. A second survey will be undertaken in October 2011.

Commissioning responsibility for patient transport services moves from providers to Primary Care Trusts from April 2010. More work is required to understand the current arrangements across the region and to support the implementation of the recommendations of the Patient Transport Survey and NSF.

The South Yorkshire / North Trent Local Implementation Group is involved in a pilot to assess the potential for the use of Personal Health Budgets for renal transport and will make recommendations for developments across the region.

8.8 Emergency Planning

The Yorkshire and the Humber Renal Network recognises the importance of ensuring that services have robust contingency plans in place to enable continuity of renal replacement therapy services in the event of planned or unplanned events. These business continuity plans will include agreements between providers and include the independent sector.

9 Acute Kidney Injury

Although no definitive studies have been undertaken in the UK the prevalence amongst hospitalised patients in the US is 4.9% ³¹ and associated mortality rates have been wide ranging ³².

In all the specialist renal units in the region facilities to manage haemodialysis patients with Acute Kidney Injury (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 Renal 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.

10 End of Life Care

There is widespread agreement on the importance of End of Life Care in Advanced Kidney Disease and an acknowledgement that there are deficiencies in the knowledge, skills, attitudes and behaviours of staff groups who come into frequent contact with people at the end of their lives. The challenge remains in ensuring that patients and their families are involved in all decisions about options for medication and treatment, and that these are recorded in personal care plans ²⁹.

End of life care was one of the eight clinical pathways developed by each of the Strategic Health Authorities as part of the Next Stage Review ³³ following which the National End of Life Care Strategy ³⁴ was published. The End of Life Care in Advanced Kidney Disease ⁹ provides guidance to support the service to achieve high quality end of life care.

The aim is to develop a Yorkshire and the Humber wide approach integrating published best practice into local performance and incorporating effective multi-professional working across boundaries linking kidney care, primary care, community care and palliative care services.

11 Patient & Public Involvement

Renal services benefit from having a well established culture of patient involvement. Patients and carers stay in contact with their services for many years and develop strong relationships with the clinical teams and they therefore have valuable insights to share.

Renal patients and carers bring a unique perspective which no professional can express and their views are invaluable in ensuring that services remain focused on patient needs.

The Yorkshire and the Humber Renal Network aims to achieve active patient and carer representation and will support involvement in a number of ways:

- Developing an ongoing programme of patient & carer involvement
- Patient representation at all relevant Renal Strategy Group and Local Implementation Group meetings
- Developing an information pack and programme of support for patient and carer representatives
- Establishing links between the Renal Network and the local patient groups/ Kidney Patient Associations
- Maintaining consistent access and availability of appropriate information to facilitate an informed and planned care pathway
- Actively working with the National Kidney Federation regarding initiatives to support patient involvement.

Consideration will be given to ensuring that patients from different backgrounds and communities are involved and that all patients and carers are represented.

The Yorkshire and the Humber Renal Network is committed to involving patients and the public, including Overview and Scrutiny Committees so that their views are taken into consideration during the planning, improvement, monitoring and evaluation of all renal services across the region.

12 Workforce Planning & Development

The Yorkshire and the Humber Renal Network aims to ensure that there is sufficient capacity within the work force to deliver the required standards of renal services within the region and that there is an understanding of the current issues within the work force. The aim is to share models that exist within the region and to ensure that these fit with recommended best practice. There may be a need for flexibility and new ways of working to make the best use of skills and knowledge. In addition, an effective and efficient renal service requires an integrated multi professional and multi agency work force.

This work will build on national development and guidance relating to workforce planning. For example, the joint project between the Department of Health and Skills for Health to look at the workforce planning issues within renal services and the Renal Society recommendations for workforce planning³⁵.

13 Productivity

It is anticipated that there will be significant funding constraints across the NHS from 2011/12 onwards. Nationally, these constraints are expected to be in the region of £15bn - £20bn over the next five years. Productivity improvements will be required.

The NHS and its constituent organisations in Yorkshire & the Humber is working to plan and deliver Quality, Innovation, Productivity and Prevention (QIPP) improvements, in order to deliver on key performance targets and service quality improvements, within these anticipated funding constraints.

The four elements of QIPP are inter-related but distinct, and will come together in different ways to deliver the changes required. Ideally, the different elements of QIPP will overlap. For example, new and innovative care (innovation) will result in a lower cost to output ratio (productivity) and provide better quality of service for the patient (quality) which will prevent the development of disease or clinical deterioration in established disease (prevention). There will also be a number of initiatives which will focus on one, two or three of the elements.

A number of QIPP opportunities are being explored for Renal Services across the region, and across all aspects of the renal care pathway. These are:

- The implementation of consistent prices paid by commissioners (the Specialised Commissioning Group and Primary Care Trusts) to service providers, for the services they deliver.
- An increased emphasis on prevention and early identification and management of renal disease.
- A reduction in the number of patients admitted acutely, through more effective management of “at risk” patients.
- A reduction in the number of patients whose transfer to a Renal Centre is delayed, and more effective management of patients suffering acute kidney injury.
- Increased patient choice of treatment modality, including home-based therapy, where possible and/or appropriate.
- An increase in transplant activity, in line with the National Organ Donation Taskforce recommendations, including live donor transplants.
- More effective utilisation of physical assets, through the introduction of third (twilight) and weekend shifts, thereby reducing the need for further capital investment.
- Region-wide shared resources for training and service development.

14 Resources

14.1 Funding Arrangements - Capital

Capital funding for investment in Renal Services has historically been held by the Department of Health. This is now no longer the case and capital investment in Renal Services will need to be prioritised alongside all other provider Trust capital investments plans.

Although there are no changes planned in 2010/11 to the capital regimes currently operating in either the Primary Care Trusts or the NHS Trust sectors, the Department of Health expects a reduction in capital expenditure over the next Spending Review period, in line with official published projections of public capital investment. This will have a bearing on the level of capital available for NHS organisations, and consequently, all organisations should be preparing for a period of capital constraint. The NHS, both nationally and locally, will need to ensure that limited capital resources are made available to those projects that are demonstrably the most necessary.

It is expected that there will be a need for growth in haemodialysis capacity over the next ten years. Limits on the availability of NHS capital will mean an increase in the number of Independent Sector partnership providers across the region.

14.2 Information Management Technology

Renal services have been at the forefront of using information technology in the management of patients. This started with simple aggregation and presentation of the numerous blood tests that were routinely performed, but has evolved to include advanced decision support IT systems and in many units a near electronic patient record. The systems facilitate an annual national audit of the performance of renal units as well as a system whereby individual patients can, with appropriate data protection, view their own results and letters written about them by the renal service over the internet.

As well as a clinical management tool these systems typically support contracting, machine maintenance and a myriad of other functions including research and audit. Specialised Commissioning Group capital funds prior to the amalgamation of the South Yorkshire services with those of West / North Yorkshire and Hull have been used to procure a new system to serve the renal units of Leeds, York, Bradford and Hull. It would now be sensible to determine whether Sheffield could be added either to this system or to the (separate) system recently purchased by Doncaster.

In addition to the critical role that hospital information technology systems have for renal services, colleagues in Bradford have been piloting a system of virtual consultation whereby primary care practitioners seek an opinion of a Renal Consultant and with the patient's permission that Consultant can access the GP record. This in many cases can avoid unnecessary hospital visits. Such a service is considered an exemplar but has not progressed beyond the pilot stage in part because of a lack of resolution to issues such as an appropriate tariff mechanism. It would be sensible for the Yorkshire and the Humber Renal Network to set appropriate tariffs for such consultations across the region.

15 Interfaces, Implementation & Performance Management

15.1 Interfaces

The interface between the 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 other clinical networks, particularly critical care, cardiac and stroke and NHS Diabetes, where appropriate, and the role and capacity of the independent sector in the region all fall within the scope of this Strategy.

15.2 Implementation and Performance Management

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.

In addition, the delivery of the Strategy will be supported by:

- **Clearer Standards and Performance Monitoring:** The Yorkshire and the Humber Renal Network will develop performance management standards which will be used to show improvements in patient care. These standards will be built into contracts with providers and the Yorkshire and the Humber Renal Strategy Group will publish annual reports to PCTs and providers.
- **Incentives:** Improvement in quality will be incentivised through 'Commissioning for Quality and Innovation' (CQUIN) payments (i.e. tariff top up payments linked to quality improvements).
- **Information:** There is a growing body of comparative data available which can help Primary Care Trusts (PCTs) in their commissioning of renal services. The Yorkshire and the Humber Renal Network has undertaken a health needs assessment for the region ¹⁰ and this will be repeated. The Yorkshire and the Humber Renal Network will also share with PCTs practice level analysis of Quality and Outcomes Framework performance data, identifying any issues of concern.
- **Clinical Leadership and Support:** The Yorkshire and the Humber Renal Network has an important role in ensuring effective communication between renal clinicians across the region and acting as a point of reference and clinical expertise. The structure of the Yorkshire and the Humber Renal Network aims to facilitate this clinical leadership and support. The majority of the members of the Yorkshire and the Humber Renal Strategy Group (see appendix 3) are clinical. In addition, the Local Implementation Groups provide a forum for lead clinicians and nursing staff to engage in local developments.

A GP Renal Reference Group is being established to ensure that there is more effective primary care input into planning and delivery of renal services. A web based renal resource for the region linked to existing resources such as the Map of Medicine will also be developed.

- **Five-Year Work Plan:** The Yorkshire and the Humber Renal Network has agreed a 5 year work plan (see Appendix 4). The work plan sets out a comprehensive set of actions to improve care for renal patients in the region and is appended. It will be regularly reviewed to ensure it reflects current and future planning priorities.

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.

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17 Appendices

Appendix 1:

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

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 2: Glossary of terms

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.

Angiotensin-converting enzyme (ACE) inhibitors and angiotensin II receptor blockers (sometimes called ARBs or A2RBs) are medicines that lower blood pressure. They are used to treat high blood pressure and heart failure and to protect the kidneys from damage in patients with diabetes.

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.

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.

The **Commissioning for Quality and Innovation (CQUIN)** payment framework makes a proportion of providers' income conditional on quality and innovation. For 2010/11, commissioners are required to make 1.5% of contract value available for providers to earn if they achieve locally agreed quality improvement and innovation goals and, for acute providers, two national goals.

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.

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.

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.

Hyperkalaemia is an elevated blood level of the electrolyte potassium.

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

Oliguria is the decreased production of urine.

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.

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.

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).

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.

QIPP - Quality, Innovation, Productivity and Prevention is used to describe the approach to successfully deliver national and local service and quality objectives within the anticipated constraints in future funding. This has been developed following Lord Darzi's Health Care for All: NHS Next Stage Review (2008)

It is made up of four interlinked elements: Quality, Innovation, Productivity and Prevention. Together they will enable the NHS to deliver on its vision for change and improvement whilst maintaining the quality and range of services people want and need.

Quality and Outcomes Framework (QOF)

The Quality and Outcomes Framework (QOF) is a voluntary annual reward and incentive programme for all GP surgeries in England, detailing practice achievement results. It is not about performance management but resourcing and then rewarding good practice.

The QOF gives an indication of the overall achievement of a surgery through a points system. Practices aim to deliver high quality care across a range of areas for which they score points. The higher the score, the higher the financial reward for the practice. The final payment is adjusted to take account of surgery workload and the prevalence of chronic conditions in the practice's local area.

The QOF has undergone several revisions since its introduction in 2004. Chronic Kidney Disease was included as a clinical domain in 2006. The indicators, points and payment stages for 2009/10 are detailed below:

Indicator	Points 2009/10	Payment Stages 2009/10
Records		
CKD 1. The practice can produce a register of patients aged 18 years and over with CKD (US National Kidney Foundation: Stage 3 to 5 CKD)	6	
Initial management		
CKD 2. The percentage of patients on the CKD register whose notes have a record of blood pressure in the previous 15 months	6	40 – 90%
Ongoing management		
CKD 3. The percentage of patients on the CKD register in whom the last blood pressure reading, measured in the previous 15 months, is 140/85 or less	11	40 – 70%
CKD 4. The percentage of patients on the CKD register with hypertension who are treated with an angiotensin converting enzyme inhibitor (ACE-I) or angiotensin receptor blocker (ARB) (unless a contraindication or side effects are recorded) Removed in 2008/09		
CKD 5. The percentage of patients on the CKD register with hypertension and proteinuria who are treated with angiotensin converting enzyme inhibitor (ACE-I) or angiotensin receptor blocker (ARB) (unless a contraindication is recorded) Added in 2008/09 (This is CKD4 updated to include 'and proteinuria')	9	40 - 80%
CKD 6. The percentage of patients on the CKD register whose notes have a record of a urine albumin: creatinine ratio (or protein: creatinine ratio) test in the previous 15 months Added in 2009/10	6	40 – 80%

http://www.nhsemployers.org/Aboutus/Publications/Documents/QOF_Guidance_2009_final.pdf

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 provides approximately 5-10% of the water and waste product removal of normal kidneys but none of the endocrine function, on average a renal transplant delivers 40% of normal kidney function.

SHA - Strategic Health Authorities 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.

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.

Stages of Chronic Kidney Disease (CKD)

To help improve the quality of care for people with kidney disease, the National Kidney Foundation created a guideline to help non specialist doctors identify each level of kidney disease, in which kidney disease was divided into five stages:

Stage	GFR (ml/min/1.73m ²)	Description
1	≥ 90	Normal or increased GFR, with other evidence of kidney damage
2	60 - 89	Slight decrease in GFR, with other evidence of kidney damage
3a	45 – 59	Moderate decrease in GFR, with or without other evidence of kidney damage
3b	30 – 44	
4	15 – 29	Severe decrease in GFR, with or without other evidence of kidney damage. It is likely that a person with Stage 4 CKD will need dialysis or a kidney transplant in the near future
5	< 15	Established renal failure 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.

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.

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.

The **Yorkshire and the Humber (Y&H) Renal Network** has been established to lead on the modernisation and development of Renal Services. 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.

Appendix 3: 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
Dr Chas Newstead	Clinical Lead Consultant Nephrologist, Leeds Teaching Hospitals Trust
Dr Michael Gordon	GP Lead Gleadless Medical Centre, Sheffield
Elaine Harrison	Nurse Lead Hull & East Yorkshire Hospitals NHS Trust
Greg Fell	Public Health Lead NHS Bradford & Airedale
Dennis Crane	Patient Representative North Region Advocacy Officer, National Kidney Federation
Jackie Parr	Senior Commissioning Manager Yorkshire & the Humber Specialised Commissioning Group
Rebecca Campbell	Renal Network Manager
Caroline Briggs	Chair of North & East Yorkshire and North Lincolnshire Local Implementation Group Director of Strategic Commissioning & Development, NHS North Lincolnshire
Matt Neligan	Chair of West Yorkshire & York Local Implementation Group Director of Strategy, NHS Bradford & Airedale
Chris Stainforth	Chair of South Yorkshire / North Trent Local Implementation Group Executive Director of Commissioning & Strategic Development, NHS Doncaster
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
Dr John Stoves	Renal Information Exchange Group Lead for Yorkshire & the Humber Consultant Nephrologist Bradford Teaching Hospitals NHS Foundation Trust

Appendix 4 Work Plan of Yorkshire & the Humber Renal Strategy: 2009/10 – 2013/14

Priority Area	Objective	Action	Outcome	Timescale
1. Transplant Capacity	To ensure equity of service across the region and to increase transplantation where possible within local control	<ul style="list-style-type: none"> To undertake a local review of the consistency of the whole transplant pathway (including post-transplant) in Leeds/Sheffield (and feeder trusts) Lead: Chas Newstead	<ul style="list-style-type: none"> Review undertaken 	<ul style="list-style-type: none"> Sep 2009
2. Patient & Public Engagement & Involvement	To ensure patient & carer involvement is integral to the Renal Network and that is patient & carer input into commissioning, performance management and service improvement arrangements.	<ul style="list-style-type: none"> To ensure that the Network is available to attend patient groups Lead: Dennis Crane/Rebecca Campbell	<ul style="list-style-type: none"> RSG Network Leads identified and allocated to each patient group 	<ul style="list-style-type: none"> Nov 2009
3. Emergency Planning	To ensure that services for patients requiring renal replacement therapy have robust business and service continuity plans in place (to include plans for pandemic flu, and SUIs)	<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 Lead: Chas Newstead/Greg Fell	<ul style="list-style-type: none"> Contingency Plans in place 	<ul style="list-style-type: none"> Dec 2009
4. Patient & Public Engagement & Involvement	To ensure patient & carer involvement is integral to the Renal Network and that is patient & carer input into commissioning, performance management and service improvement arrangements.	<ul style="list-style-type: none"> To develop patient & carer representation and a patient & carer voice at all relevant RSG/LIG meetings Lead: Dennis Crane/Rebecca Campbell	<ul style="list-style-type: none"> Two patient & carer representatives identified for each LIG meeting and patient & carer representation at RSG 	<ul style="list-style-type: none"> Jan 2010
5. Capacity Planning for Dialysis	To ensure an appropriate mix of home haemodialysis, satellite and main unit haemodialysis and peritoneal dialysis capacity appropriate to clinical and geographical need to meet current and future requirements and ensure	<ul style="list-style-type: none"> To undertake a comprehensive assessment of dialysis capacity currently available across the region and develop a capacity plan, to include: <ul style="list-style-type: none"> - Service pressures/gaps - Proposals for addressing current specific issues 	<ul style="list-style-type: none"> Capacity plan developed and signed off 	<ul style="list-style-type: none"> Feb 2010 To be reviewed annually

	care closer to home.	<ul style="list-style-type: none"> - Medium term planning needs - Scope for growth in home based therapies programmes - Investment that may be required to meet future need. - Review of the role and capacity of the independent sector in the region - Quality overview of current services - Concrete proposals to increase dialysis (and related) capacity to meet future need and ensure maintenance of existing capacity <p>Lead : Jackie Parr/Greg Fell</p>		
6. Primary Care capacity, quality and expertise	To identify and support GPs with an interest in Renal Care in the Region.	<ul style="list-style-type: none"> • To develop a virtual GP Renal Reference Group <p>Lead: Michael Gordon</p>	<ul style="list-style-type: none"> • A virtual GP Renal Reference Group developed 	<ul style="list-style-type: none"> • Feb 2010
7. Workforce Planning	To ensure that there is sufficient capacity within the workforce to deliver the required standards of renal services	<ul style="list-style-type: none"> • To undertake a scoping exercise and develop a workforce plan, to include: <ul style="list-style-type: none"> - The scope and nature of the current issues in the workforce, including nursing, medical and ancillary clinical and support services, including dietetics - Models that exist in the region and how these fit with recommended best practice. - The high impact actions that can be taken to address current shortages in the renal nursing workforce. - The implications and transition to the national tariff <p>Lead: Elaine Harrison</p>	<ul style="list-style-type: none"> • Workforce plan in place, including increased capacity from existing/similar nurse work force 	<ul style="list-style-type: none"> • Feb 2010
8. Primary Care capacity, quality and	To analyse data from the general practice Quality and Outcome Framework (QOF) and make this	<ul style="list-style-type: none"> • Develop and promote the use of a QOF CKD tool in General Practice. Using this tool to facilitate more complete practice 	<ul style="list-style-type: none"> • QOF data available on the internet and publicised to practices 	<ul style="list-style-type: none"> • Mar 2010 • To be

expertise	available to PCTs and GP practices in a useful form.	renal registers. I.e. Increase acknowledged prevalence at practice level. • Lead: Michael Gordon/ Greg Fell		reviewed annually
9. Acute Kidney Injury and Critical Care	To ensure a systematic approach to the planning for more effective management of acute admissions across the region so that both provider trusts and PCTs are clear how best to manage acute admissions in addition to chronic care	• To develop a pathway for acute kidney injury Lead: Chas Newstead	• Pathway developed for AKI	• Apr 2010
10. Patient & Public Engagement & Involvement	To ensure patient & carer involvement is integral to the Renal Network and that is patient & carer input into commissioning, performance management and service improvement arrangements.	• To develop an information pack and programme of support for patient & carer representatives Lead: Dennis Crane/Rebecca Campbell	• Printed information pack circulated and meeting held with patient & carer representatives	• Apr 2010
11. NSF milestones	To ensure progress against the National Service Framework (NSF) milestones and identify gaps and areas for development	• To review progress towards implementing NSF milestones, including identification of gaps and issues that should be addressed Lead: Rebecca Campbell	• Baseline position established • Gaps identified & action plan agreed • Process repeated annually	• Apr 2010 • Annually thereafter
12. Home-Based Therapies & Self- Care	To increase the number of patients undertaking home-based therapies (HD & PD) and self-care, ensuring that all patients are offered these options, where clinically appropriate	• To increase clinical support, through the appointment of a clinical lead to champion the benefits (utilising NHS Kidney Care Problem-Solving Funding) Lead: Jackie Parr	• Clinical lead in post	• Apr 2010
13. Pre Dialysis Year	To ensure consistent and equitable renal care across the region, including timely and appropriate access to services	• To produce an annual report from the renal registry report Lead: Chas Newstead	• Annual report of renal registry report	• Jun 2010 • Annually thereafter
14. Patient & Public Engagement & Involvement	To ensure patient & carer involvement is integral to the Renal Network and that is patient & carer input into commissioning,	• To develop an ongoing programme of patient & carer involvement and consultation. Lead: Dennis Crane/Rebecca Campbell	• Contact with all patient groups and attendance at patient groups (as invited)	• Sep 2010 • Annually thereafter

	performance management and service improvement arrangements.			
15. Transport	To ensure that there is equitable, reliable and effective patient transport for renal haemodialysis patients	<ul style="list-style-type: none"> To review transport services for renal patients, to include: <ul style="list-style-type: none"> - Review of findings of national audit. - Review current arrangements across the region, - Consideration of value for money in current local arrangement - Implementation of model contracts as contracts come up for review - Equity of service - Criteria for access - 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>	<ul style="list-style-type: none"> Review of arrangements undertaken & recommendations made 	<ul style="list-style-type: none"> Oct 2010
16. Anaemia Management	To develop alternative models for the provision of IV Iron in primary care and support the implementation of best practice in relation to anaemia management across primary care in the region	<ul style="list-style-type: none"> Conduct a pilot of a community based model. Produce a report on the pilot with recommendations for Local Implementation Groups. <p>Lead: Michael Gordon</p>	<ul style="list-style-type: none"> Pilot underway 	<ul style="list-style-type: none"> Dec 2010
17. Acute Kidney Injury and Critical Care	To ensure a systematic approach to the planning for more effective management of acute admissions across the region so that both provider trusts and PCTs are clear how best to manage acute admissions in addition to chronic care	<ul style="list-style-type: none"> To produce a service specification and commissioning policy to include within its scope critical care capacity, pathways and protocols and link to nursing workforce shortages. <p>Lead: Jackie Parr</p>	<ul style="list-style-type: none"> Service Specification & commissioning policy developed 	<ul style="list-style-type: none"> Dec 2010 To be reviewed annually
18. Home-Based Therapies & Self-Care	To increase the number of patients undertaking home-based therapies (HD & PD) and self-care, ensuring	<ul style="list-style-type: none"> To develop a home-based therapies & self-care strategy, including 	<ul style="list-style-type: none"> Sign-off and launch of strategy & implementation 	<ul style="list-style-type: none"> Dec 2010

	that all patients are offered these options, where clinically appropriate	<p>implementation plan, to include:</p> <ul style="list-style-type: none"> - Decision aids to facilitate patient choice - Development of a patient reference group - Links to national work <p>Lead: Jackie Parr</p>	plan	
19. Acute Kidney Injury and Critical Care	To ensure a systematic approach to the planning for more effective management of acute admissions across the region so that both provider trusts and PCTs are clear how best to manage acute admissions in addition to chronic care	<ul style="list-style-type: none"> • To develop a consistent approach to renal input into critical care networks where appropriate (for example Acute Kidney Injury and acute post transplant care) • Lead: Jackie Parr 	<ul style="list-style-type: none"> • Communication plan developed to ensure links between Renal Network and Critical Care Networks 	<ul style="list-style-type: none"> • Jan 2011
20. Transplant Capacity	To ensure equity of service across the region and to increase transplantation where possible within local control	<ul style="list-style-type: none"> • To develop a service specification and commissioning policy to include designation standards for transplantation for the region. To include: <ul style="list-style-type: none"> - Specific interventions (health care system, clinical, public health, other) that might be undertaken in Yorkshire & the Humber - Performance management of existing investment - Recommendations for further investment <p>Lead: Chas. Newstead</p>	<ul style="list-style-type: none"> • Service Specification & commissioning policy developed 	<ul style="list-style-type: none"> • Jan 2011 • To be reviewed annually
21. Primary Care capacity, quality and expertise	To provide better renal care resources for primary care staff and patients	<ul style="list-style-type: none"> • Increase the use of the Map of Medicine and encourage PCTs to populate it with local information <p>Lead: Michael Gordon</p>	<ul style="list-style-type: none"> • Recommendations made regarding the development of Map of Medicine for Renal use for the region 	<ul style="list-style-type: none"> • Feb 2011
22. Acute Kidney Injury and Critical Care	To ensure a systematic approach to the planning for more effective management of acute admissions across the region so that both provider trusts and PCTs are clear how best to manage acute	<ul style="list-style-type: none"> • To pilot the inclusion of the acute renal bed base across the region into the new Clinical Management System 'Live' Bed Management West Yorkshire Critical Care Network (WYCCN) Pilot and make recommendations for roll-out across all 	<ul style="list-style-type: none"> • Recommendations made re continuation of WYCCN pilot and roll-out across region 	<ul style="list-style-type: none"> • Mar 2011

	admissions in addition to chronic care	critical care networks Lead: Jackie Parr		
23. Transplant Capacity	To ensure equity of service across the region and to increase transplantation where possible within local control	<ul style="list-style-type: none"> To review output from individual Trusts Organ Donation Committee as reported to NHSBT and the Organ Donation Task Force Lead: Chas Newstead	<ul style="list-style-type: none"> Reports Received 	<ul style="list-style-type: none"> Mar 2011 Annually thereafter
24. Patient & Public Engagement & Involvement	To ensure patient & carer involvement is integral to the Renal Network and that is patient & carer input into commissioning, performance management and service improvement arrangements.	<ul style="list-style-type: none"> To maintain consistent access and availability of appropriate information to facilitate an informed and planned care pathway. Lead: Dennis Crane/Rebecca Campbell	<ul style="list-style-type: none"> Consistent patient information across the care pathway and reviewed regularly 	<ul style="list-style-type: none"> Mar 2011 To be reviewed annually
25. Transport	To ensure that there is equitable, reliable and effective patient transport for renal haemodialysis patients	<ul style="list-style-type: none"> To pilot arrangements for Personalised Health Budgets for Renal Transport and make recommendations for development across the region Lead: Jackie Parr	<ul style="list-style-type: none"> Recommendations made 	<ul style="list-style-type: none"> May 2011
26. Anaemia Management	To develop alternative models for the provision of IV Iron in primary care and support the implementation of best practice in relation to anaemia management across primary care in the region	<ul style="list-style-type: none"> Conduct a pilot of a community based model. Produce a report on the pilot with recommendations for Local Implementation Groups. Lead: Michael Gordon	<ul style="list-style-type: none"> Report produced and presented to Local Implementation Groups 	<ul style="list-style-type: none"> Jun 2011
27. Transport	To ensure that there is equitable, reliable and effective patient transport for renal haemodialysis patients	<ul style="list-style-type: none"> To seek assurance of the development of robust transport action plans and the implementation of the recommendations of the national transport audit within provider trusts Lead: Chas Newstead/Elaine Harrison/Rebecca Campbell	<ul style="list-style-type: none"> Provider Trusts to have transport action plans and action planning groups in place 	<ul style="list-style-type: none"> Jun 2011
28. Primary Care capacity, quality and expertise	To provide better renal care resources for primary care staff and patients	<ul style="list-style-type: none"> Make patients lifestyle advice leaflets available on-line for patients with CKD3 Lead: Michael Gordon	<ul style="list-style-type: none"> Leaflets agreed and available on line 	<ul style="list-style-type: none"> Dec 2011

29. Pre Dialysis Year	To ensure consistent and equitable renal care across the region, including timely and appropriate access to services	<ul style="list-style-type: none"> • To develop a commissioning framework and service specification, to include: <ul style="list-style-type: none"> - Care pathways & protocols - Recommendations for the implementation of what is identified/agreed to be best practice - Key performance indicators Lead: Chas Newstead	<ul style="list-style-type: none"> • Commissioning framework and service specification developed, including performance indicators 	<ul style="list-style-type: none"> • Mar 2012
30. Conservative Care	To ensure full supportive treatment for those with advanced kidney failure who, in conjunction with carers & the clinical team, decide against dialysis – Linked to the End of Life Care in Advanced Kidney Disease Framework	<ul style="list-style-type: none"> • To develop a YH commissioning policy for conservative care, to include performance indicators Lead: Jackie Parr	<ul style="list-style-type: none"> • Commissioning policy established 	<ul style="list-style-type: none"> • Mar 2012
31. End of Life Care	To develop a Yorkshire & Humber wide approach to End of Life Care for Advanced Kidney Disease, based on the End of Life Care in Advanced Kidney Disease Framework	<ul style="list-style-type: none"> • To implement the recommendations of the End of Life Care in Advanced Kidney Disease Framework, including: <ul style="list-style-type: none"> - A Review current arrangements - Learning from NHS Kidney Care Pilots - Links with the regional Darzi work-stream - Development of a commissioning policy Lead: Michael Gordon	<ul style="list-style-type: none"> • Implementation of the EOLC recommendations through development of a commissioning policy for end of life care. 	<ul style="list-style-type: none"> • Mar 2012
32. Health Needs Assessment	To ensure that service development and commissioning arrangements are informed by regular health needs assessment	<ul style="list-style-type: none"> • To review the Health Needs Assessment for the region ensuring a focus on the whole renal pathway, with particular focus on: <ul style="list-style-type: none"> - Prevalence of CKD, Gap between diagnosed and estimated at practice level. Identification of areas of concern. - QOF performance. Identification of good and poor performance on CKD indicators. Practice level analysis of performance and exception coding. - Outpatient consultation rates. 	<ul style="list-style-type: none"> • Health Needs Assessment reviewed & updated 	<ul style="list-style-type: none"> • Dec 2012

		<p>Identification of trends and total volume of OP use.</p> <ul style="list-style-type: none"> - ESRD. Forward projection of likely numbers of patients needing RRT in future years. <p>Lead : Greg Fell</p>		
33. Primary Care capacity, quality and expertise	To improve communication links between primary care and renal units	<ul style="list-style-type: none"> • Increase the use of e-consultation <p>Lead: Michael Gordon</p>	<ul style="list-style-type: none"> • A plan developed for the region for increased use of e-consultation 	<ul style="list-style-type: none"> • Jan 2013
34. Supporting Young Adults with Kidney Disease	To review existing provision in place to support young adults with kidney disease and develop approaches to support both the transition from paediatric services and presentation in young adulthood	<ul style="list-style-type: none"> • To develop a Yorkshire & Humber strategy for supporting young adults with kidney disease. To include: <ul style="list-style-type: none"> - Learning from NHS Kidney Care pilot sites and national guidance - A Review of the interface between children's and adult services <p>Lead: Elaine Harrison</p>	<ul style="list-style-type: none"> • Yorkshire & Humber strategy in place 	<ul style="list-style-type: none"> • Apr 2013

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- 1 - York - York District Hospital**
Number of Haemodialysis stations - 13
- 2 - Easingwold**
Number of Haemodialysis stations - 9
- 3 - Harrogate - Harrogate District Hospital**
Number of Haemodialysis stations - 9
- 4 - Hull - Hull Royal Infirmary**
Number of Haemodialysis stations - 26
- 5 - Scarborough - Scarborough General Hospital**
Number of Haemodialysis stations - 10
- 6 - Bridlington - Bridlington & District Hospital**
Number of Haemodialysis stations - 12
- 7 - Scunthorpe - Scunthorpe General Hospital**
Number of Haemodialysis stations - 12
- 8 - Grimsby - Diana Princess of Wales Hospital**
Number of Haemodialysis stations - 12
- 9 - Doncaster - Doncaster Royal Infirmary**
Number of Haemodialysis stations - 17
- 10 - Bassetlaw - Bassetlaw District General Hospital**
Number of Haemodialysis stations - 20
- 11 - Mexborough (due to open Aug 2010)**
Number of Haemodialysis stations - 12

- West Yorkshire and York Local Implementation Group
- North & East Yorkshire and North Lincolnshire Local Implementation Group
- South Yorkshire and North Trent Local Implementation Group
- Renal Main Unit
- Renal Dialysis Satellite Unit
- NHS Yorkshire & Humber
- Adjacent areas with patient flows to renal units

- 12 - Sheffield - Sheffield Kidney Institute**
Number of Haemodialysis stations - 57
- 13 - Chesterfield - Chesterfield & North Derbyshire Royal Hospital**
Number of Haemodialysis stations - 12
- 14 - Rotherham - Rotherham General Hospital**
Number of Haemodialysis stations - 14
- 15 - Barnsley - Barnsley District General Hospital**
Number of Haemodialysis stations - 13
- 16 - Sheffield - Heeley**
Number of Haemodialysis stations - 20

- 17 - Leeds - St James University Hospital**
Number of Haemodialysis stations - 23
- 18 - Leeds - Beeston Medical Centre**
Number of Haemodialysis stations - 10
- 19 - Leeds - Seacroft - R&S Ward**
Number of Haemodialysis stations - 34
- 20 - Leeds - Seacroft - B Ward**
Number of Haemodialysis stations - 10
- 21 - Wakefield - Clayton Hospital**
Number of Haemodialysis stations - 12
- 22 - Dewsbury District Hospital**
Number of Haemodialysis stations - 12
- 23 - Huddersfield - St. Luke's Hospital**
Number of Haemodialysis stations - 10
- 24 - Halifax - Calderdale Royal Infirmary**
Number of Haemodialysis stations - 10
- 25 - Bradford - St. Luke's Hospital**
Number of Haemodialysis stations - 32
- 26 - Skipton - Skipton General Hospital**
Number of Haemodialysis stations - 9

Source of data: NOERICA Model (2009)
 NHS Information Centre QOF Extract for Yorkshire & the Humber (2007-08)

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