

National Overview

Adult Renal Services



© NHS Quality Improvement Scotland 2003

ISBN 1-84404-115-8

First published March 2003

Copies of the *Clinical Standards for Adult Renal Services* are available from NHS Quality Improvement Scotland.

NHS Quality Improvement Scotland consents to the photocopying, electronic reproduction by 'uploading' or 'downloading' from the website, retransmission, or other copying of the findings of this report for the purpose of implementation in NHSScotland.

NHS Quality Improvement Scotland has offices at:

Edinburgh Office
Elliott House
8-10 Hillside Crescent
Edinburgh
EH7 5EA

Glasgow Office
Delta House
50 West Nile Street
Glasgow
G1 2NP

Copies of this report, the reports on each renal unit, and other documents produced by NHS Quality Improvement Scotland, are available in print format and on the NHS Quality Improvement Scotland website.

Information contained in this report has been supplied by Trusts, or taken from current Trust sources, unless otherwise stated. It is believed to be reliable on publication.

www.nhshealthquality.org

NHS Quality Improvement Scotland
National Overview

Adult Renal Services

Introduction and Acknowledgements

NHS Quality Improvement Scotland was established as a Special Health Board on 1 January 2003 as a result of bringing together the Clinical Resource and Audit Group (CRAG), Clinical Standards Board for Scotland (CSBS), Health Technology Board for Scotland (HTBS), Nursing and Midwifery Practice Development Unit (NMPDU) and the Scottish Health Advisory Service (SHAS).

The purpose of NHS Quality Improvement Scotland is to improve the quality of healthcare in Scotland by setting standards and monitoring performance, and by providing NHSScotland with advice, guidance and support on effective clinical practice and service improvement.

A part of this remit is to develop and run a national system of quality assurance of clinical services. For each project, NHS Quality Improvement Scotland establishes a project group to:

- develop and consult on the standards and self-assessment framework;
- oversee the process of external peer review; and
- report findings to the NHS Quality Improvement Scotland Board.

The Adult Renal Services Project Group was established in May 2001 under the chairmanship of Dr Brian Junor, Consultant Nephrologist, Western Infirmary, North Glasgow University Hospitals NHS Trust. Membership of the Group is given in Appendix 1.

The *Standards for Adult Renal Services* were developed by this group and published in February 2002 following extensive consultation. Copies of the standards are available on request from NHS Quality Improvement Scotland or on the website (www.nhshealthquality.org).

Peer review visits to all renal units in Scotland were conducted between May and October 2002 to assess performance against the standards. Local reports on each visit, including a detailed assessment of performance against each standard, have now been published and are also available on the website.

This report presents a national overview of adult renal services in Scotland, reporting on performance across Scotland against the standards and including examples of local initiatives relevant to them.

NHS Quality Improvement Scotland gratefully acknowledges the work of the Adult Renal Services Project Group for overseeing the project from its inception to the publication of this report. In addition, the contribution made by every member of the peer review teams was crucial to the success of the visit programme.

NHS Quality Improvement Scotland wishes to record its thanks to all the NHSScotland staff, who contributed to the peer review visits and, in particular, the liaison co-ordinators, local review facilitators and lead clinicians in Trusts who were responsible for preparing staff locally for peer review visits and for the compilation of comprehensive self-assessment material prior to visits.

Contents

Introduction and Acknowledgements	3
Executive Summary	7
1 Setting the Scene	15
1.1 NHSScotland List of Main and Satellite Renal Units	
1.2 The NHS Quality Improvement Scotland Approach to Assessment	
1.3 Background to the Clinical Standards for Adult Renal Services	
1.4 Introduction to Renal Disease (including Renal Failure)	
1.5 The NHS Quality Improvement Standards and Your Care	
1.6 Frequently Asked Questions	
1.7 Useful Contacts	
2 National Performance Against the Standards	33
2.1 Standard 1: Haemodialysis	
2.2 Standard 2: Peritoneal Dialysis	
2.3 Standard 3: Haemoglobin in Patients on Dialysis	
2.4 Standard 4: Dialysis Access	
2.5 Standard 5: Nutritional Status	
2.6 Standard 6: Drug Therapy	
2.7 Standard 7: Access to Multidisciplinary Team	
2.8 Standard 8: Assessment for Transplantation	
2.9 Standard 9: Kidney Retrieval	
2.10 Standard 10: Survival Rates	
2.11 Standard 11: Out-patients	
2.12 Standard 12: Provision of Patient Information	
2.13 Standard 13: Transportation for Haemodialysis	
2.14 Standard 14: Audit: Information/Data Collection	

Contents

3	Conclusions	81
----------	--------------------	-----------

4	List of Appendices	85
----------	---------------------------	-----------

Appendix 1 Adult Renal Services Project Group Members

Appendix 2 The Quality Assurance Process: Approach Used in this Review

Appendix 3 Co-ordinating Adult Renal Services

Appendix 4 Adult Renal Services Review Team Members

Appendix 5 Glossary of Terms

Introduction

At present, 3,499 people are on renal replacement therapy in Scotland. Most people who have problems with their kidneys make a complete recovery. However, a small number of them develop chronic kidney (renal) disease and the kidneys gradually stop working. Once the kidneys fail permanently, a patient will die within weeks unless they receive dialysis or a transplant, known as renal replacement therapy.

Everyone with chronic renal disease needs treatment. In the early stages, this may involve a change in diet which requires specialist advice and a commitment to a change in lifestyle. Medication may also be needed, which again requires careful assessment and monitoring, and must be tailored to each individual. In the last stage, either dialysis or a transplant is essential. Dialysis is often a long-term treatment, as there are far more patients with kidney disease than there are donor kidneys. However, dialysis alone is not enough and must be combined with a special diet and medication.

Over the last 10 years, there have been major developments in the treatment of kidney disease, and many people who would not have survived in the past now live active lives and keep on working. As a result of these developments, however, the number of patients receiving treatment for renal disease is rising steadily. In addition, the number of people with diabetes, who are at increased risk of developing kidney disease, is growing. The units providing care are now almost at full capacity and the need for donor kidneys has never been greater.

There are 10 adult renal units in Scotland, three of which are transplant centres. They were all visited during this review, and their performance was assessed against a set of standards that were developed by those responsible for treating people with renal disease, and by kidney patients and members of the public. This report is an important milestone in the treatment of kidney disease, and highlights the strengths of the existing service, together with the challenges that face both NHSScotland and those using the service in the coming years.

Traditionally, renal services have been well organised in the UK, with the UK Renal Association first publishing standards in 1995. The Scottish Renal Registry began collecting and auditing data for patients on renal replacement therapy in 1991. The British Transplantation Society has also published standards of care. Both organisations have worked in partnership with voluntary organisations, notably the Kidney Patients' Association and the National Kidney Federation.

It would not have been possible to report so comprehensively on these services without the work already undertaken by these organisations, and without working in close partnership with them.

The National Overview of Adult Renal Services in Scotland

This summary is presented in four sections which link directly to the standards for adult renal services:

- Clinical Care
- Transplantation
- Patient Focus
- Audit

Clinical Care (Standards 1-7)

The kidneys keep the body in balance. By filtering waste from food and drink, they maintain the correct balance of chemicals, salt and acid in the body; by producing certain hormones, they stimulate the body to make red blood cells, control blood pressure and maintain calcium levels. If the kidneys stop working, suddenly or gradually, waste and fluid build up in the blood and the body loses its vital balance. In the early stages of kidney disease, diet and medication can be used very effectively. Once the kidneys stop working, either dialysis or a transplant is needed or the patient will die. Clearly, effective and prompt treatment is required for anyone with renal disease and the first seven standards focus on this care. Standards 1-4 are concerned with dialysis; Standard 5 relates to nutritional care; Standard 6 covers drug therapy and Standard 7 refers to multidisciplinary working.

There are two types of dialysis:

- **Haemodialysis**, which is usually given in hospital, pumps the blood out of the body to a dialysis machine for purification and then returns the cleansed blood to the body.
- **Peritoneal dialysis** is carried out at home and involves cleaning the blood inside the body, using the lining of the abdominal cavity to do the work of a dialysis machine.

Whichever method of dialysis is used, it is critical that dialysis sessions continue long enough to make sure the blood is fully purified as this helps patients to keep as healthy as possible. This is known as dialysis adequacy. For haemodialysis,

most units do achieve good dialysis adequacy, although in some units dialysis sessions are not continued beyond their scheduled time, even if adequacy is not achieved. Trusts not meeting this criterion should review their services to ensure there is sufficient flexibility to enable patients to receive adequate haemodialysis treatment. This may require a review of the ward space available, as well as considering scheduling of dialysis sessions.

Standard 1 covers haemodialysis, and most Trusts met the criteria set. In particular, every unit offers patients the required frequency of haemodialysis and there was good evidence that patients receiving this treatment are managed appropriately. However, not all Trusts met the criterion for the quality of the water used in dialysis and Trusts should ensure that the necessary water treatment equipment is available. It is also essential that services are provided in a flexible manner to make sure patients get adequate treatment that also meets their needs.

Standard 2 covers peritoneal dialysis and, again, most Trusts meet the set criteria. There is frequent monitoring of vital levels, which was commended by the review teams, and targets for dialysis adequacy are met in most units. Peritonitis is one of the risks associated with peritoneal dialysis. Some Trusts did not meet the criterion relating to peritonitis rates as patients living in remote areas choose to remain on peritoneal dialysis, despite frequent peritonitis, due to the difficulties of travelling for haemodialysis. The challenge for Trusts providing services in these areas is to develop ways of offering all treatment options.

Haemoglobin (red blood cell) levels must be monitored regularly, as dialysis cannot replace the hormones produced by the kidneys and serious anaemia can develop. Standard 3 focuses on measuring haemoglobin in dialysis patients and overall there is frequent monitoring of this across Scotland, with robust anaemia protocols in place. One of these hormones, erythropoietin (EPO), can be given by injection, although this is not available in every unit for all patients who would benefit from it. While haemoglobin levels are well monitored, only three units met the haemoglobin concentration target. The reasons given for not meeting this target included the availability of EPO, recurrent infection from temporary access lines, and poor access to the bloodstream which results in unsatisfactory dialysis.

The route that will be used either to carry the blood in and out of the body (haemodialysis), or to filter fluid in and out of the abdomen (peritoneal dialysis),

referred to as dialysis access, is very important (Standard 4). Most Trusts were unable to meet the set criteria and the main reason given was a lack of dedicated theatre time and the limited number of beds. Some Trusts also reported a shortage of surgical staff. As a result, newly diagnosed patients are attending their dialysis without permanent access to the bloodstream, which can compromise their treatment and result in higher infection rates.

Another key element in the care of renal patients is attention to their diet, which is covered in Standard 5. By working out the correct amount of food and drink a person needs, it is possible to manage the amount of waste that can build up. It is particularly important to monitor those who are not yet on dialysis, as early intervention can prevent malnutrition and help maintain good health. While there are good nutritional protocols in place across Scotland, and staff are clearly aware of the importance of nutrition for renal patients, dietetic staffing is stretched. It may therefore be necessary to look at ways of supporting these services. Anthropometry, or body measurements, for example, could be carried out by an assistant, reserving the analysis of this information for specialist dietetic advice. There was also some evidence that due to staffing pressure, dieticians do not always review those at risk of malnutrition, as they have to prioritise those who already have problems.

Patients on renal therapy also require medication and advice on how best to use this (Standard 6). While there were strong protocols in place, and evidence of high quality information and regular review of in-patient prescriptions, not all units have a designated pharmacist with experience of renal disease, and this should be addressed.

Access to a multidisciplinary team is also critical as there are many disciplines involved in treating renal disease. Review of Standard 7 found that patients in Scotland have good access to clinical staff but there is limited access to counselling and support staff. As renal disease is a lifelong condition, it is important that this is available.

Transplantation (Standards 8-10)

A transplanted kidney may not be a permanent cure for kidney failure. Although some kidney transplants continue to function for more than 30 years, 50% will have ceased to function by 10 years. However, a kidney transplant does significantly improve health and can improve quality of life, as it does away with the need for time-consuming dialysis. Not all patients are suitable, however, and

careful assessment is required. Those that are suitable, and that go on to have a successful transplant, will still need to stay on medication to avoid rejection of the kidney. Review of Standards 8, 9 and 10 confirmed that patients in Scotland are well-informed about kidney transplant and most of them are assessed for their suitability within three months of starting dialysis. Donor kidneys are not always retrieved by a transplant surgeon experienced in this procedure, and this has led to proposals for a National Organ Retrieval Team to be set up in Scotland. Although there are only three transplant units in Scotland, there is still some variation in the criteria for acceptance of donor kidneys; while the use of kidneys from marginal donors increases the number of kidneys transplanted, it does carry a potentially higher risk of non-functioning transplant kidneys. Scotland achieves high patient and kidney survival rates following kidney transplantation – over 95% at one year in all units, and this is to be commended.

Patient Focus (Standards 11-13)

Although kidney disease is a lifelong condition, people on treatment are generally well and can carry on with their normal lives. Work, relationships, children and sport can all continue, although these have to be fitted around treatment. Standards 10–13 all focus on the patient, and cover out-patient services, patient information and transportation. The standard set is that all new patients must have an appointment within one month of referral. In practice, only one unit meets this standard; the shortage of medical staffing was the reason given by other units for not meeting this standard. Kidney patients usually become well-known to units. Communication was reported to be very effective and high quality information is available, supported by the voluntary organisations. Once patients arrive for dialysis, no unit could demonstrate that all their patients began dialysis within 1 hour of their appointment time, making a long day even longer. The problems in achieving this appear to relate largely to the organisation of out-patient clinics as all patients tend to be given the same appointment time within each dialysis shift. Issues were also identified around transport home after dialysis, and only one unit could demonstrate that all patients were collected within one hour after their dialysis. Further, most patients are not waiting for their transport in a comfortable area – either because this is not available, or because they are anxious about missing their transport, and prefer to wait by the pick-up point. A particularly important issue emerged for those living in remote and rural areas who face very long and difficult journeys, and Trusts must work on innovative solutions to these issues.

Audit (Standard 14)

Standard 14 relates to audit. In Scotland, renal services are rightly proud of their attention to the audit of all areas of their activity, and they are in the forefront of audit compared to many other services. All units provide data to the Scottish Renal Registry, although not all electronically, and this has provided a wealth of information about the way in which kidney disease is treated in Scotland. These reports are available on the internet at www.show.scot.nhs.uk/srr.

Conclusion

The care of renal patients in Scotland is well-organised and effective. Due to the success of treatment, the number of patients is increasing and this is placing increasing pressure on the renal units. Four key messages have emerged from this review:

- Early detection and pro-active treatment of kidney disease, together with monitoring of each individual, can reduce complications at later stages. Investment is needed to support this approach, before complete renal failure sets in.
- Patient support is essential if therapy is to work. Key staff such as psychologists, designated pharmacists and dieticians (and support workers) should be in place across Scotland. As renal patients often have specific needs, social work should also be involved.
- Transplants offer hope to many and donors should be encouraged. Once a kidney has been donated and is available, it should be retrieved by a surgeon with experience of kidney retrieval.
- Kidney disease is a lifelong condition. Care for people with this disease needs to be flexible, of high quality and personally tailored. This is a major challenge to Acute Trusts in particular, and links with Primary Care Trusts should be strengthened as they can, and do, support care of renal patients in the community.

Key Recommendations

Clinical Care

- Trusts should ensure there is sufficient flexibility to enable patients to receive adequate haemodialysis treatment. This may require a review of the ward space available, as well as considering scheduling of dialysis sessions.

- Trusts should make good use of monitoring information relating to patients' haemoglobin concentrations, and address reasons why patients do not achieve the target.
- Permanent dialysis access should be in place for all non-emergency patients at least three months before their first dialysis.
- Specialist advice from dieticians and pharmacists should be readily available (although this does not have to be on-site).
- All Trusts should have appropriate water treatment plants, and arrangements in place to regularly check the quality of the water used for dialysis.
- Innovative and flexible options should be available to all patients on dialysis in remote and rural areas to encourage them to take up the most effective treatment.
- Patient access to support staff is crucial and must be in place.

Transplantation

- Donor kidneys should be retrieved by surgeons with experience of this procedure.
- National guidelines for the assessment of donor kidney suitability should be established.
- National guidelines for the assessment of patients' suitability for transplantation should be established.

Patient Focus

- All new patients should have an appointment at a renal unit to discuss their care within 1 month of referral.
- Patient care plans should be flexible, taking into account those living in rural and remote areas.

Audit

- The audit work established by the Scottish Renal Registry should be maintained and data should be submitted electronically.

Chapter 1

Setting the Scene

- NHSScotland List of Main and Satellite Renal Units
- The NHS Quality Improvement Scotland Approach to Assessment
- Background to the Clinical Standards for Adult Renal Services
- Introduction to Renal Disease (including Renal Failure)
- The NHS Quality Improvement Scotland Standards and Your Care
- Frequently Asked Questions
- Useful Contacts

1 Setting the Scene



1.1 NHSScotland List of Main and Satellite Renal Units







- | | | | |
|---|--|----|---|
| 1 | Aberdeen Royal Infirmary
Chalmers Hospital, Banff
Dr Gray's Hospital, Elgin
Peterhead Community Hospital | 7 | Queen Margaret Hospital, Dunfermline
Victoria Hospital, Kirkcaldy |
| 2 | Crosshouse Hospital, Kilmarnock | 8 | Raigmore Hospital, Inverness |
| 3 | Dumfries & Galloway Royal Infirmary, Dumfries | 9 | Royal Infirmary of Edinburgh
Western General Hospital, Edinburgh
Borders General Hospital, Melrose |
| 4 | Glasgow Royal Infirmary
Falkirk & District Royal Infirmary, Falkirk
Stobhill Hospital, Glasgow | 10 | Western Infirmary, Glasgow
Gartnavel General Hospital (Renal Annex), Glasgow
Inverclyde Royal Hospital, Greenock |
| 5 | Monklands Hospital, Airdrie | 11 | Gilbert Bain Hospital, Shetland |
| 6 | Ninewells Hospital, Dundee | | |

The information for **Scotland**, given in the table below, was provided by the Scottish Renal Registry. It represents the total number of people on dialysis or who have had a transplant (referred to as renal replacement therapy), as at December 2002 (A). The number of patients going on to renal replacement therapy during 2002 is also given (B). These numbers represent a ‘snapshot’ of the number of patients on renal replacement therapy.













(A) – Total number of people on renal replacement therapy in Scotland (as at December 2002)	3,499 people (684 per million of the population)
(B) – Total number of new patients going on to renal replacement therapy in Scotland (2002)	572 (112 per million of the population)
















Source: Scottish Renal Registry

The following renal units were reviewed between May – October 2002. Reports for each unit, containing findings of their peer review visit and assessment against the standards, are available on the website (www.nhshealthquality.org) or in print format from NHS Quality Improvement Scotland.

 Number of Patients Number of patients on renal replacement therapy (at time of visit)  Number of new patients in 2001  Number of patients on different forms of renal replacement therapy	Renal/Satellite Unit
 342 ¹  54  Hospital haemodialysis (main unit) 97 Hospital haemodialysis (satellite units) 34 Home haemodialysis 8 CAPD ² 17 APD ³ 13 Renal transplant 173	Aberdeen Royal Infirmary Satellite Units: Chalmers Hospital, Banff Dr Gray’s Hospital, Elgin Peterhead Community Hospital

1 figure provided by the Trust for 2001
 2 continuous ambulatory peritoneal dialysis
 3 automated peritoneal dialysis

Number of Patients	Renal/Satellite Unit
 101  24  Hospital haemodialysis 47 Home haemodialysis 2 CAPD 19 APD 2 Renal transplant 31	Dumfries & Galloway Royal Infirmary, Dumfries
 161  29  Hospital haemodialysis 81 Home haemodialysis 2 CAPD 16 APD 25 Renal transplant 37	Crosshouse Hospital, Kilmarnock
 323  93  Hospital haemodialysis (main unit) 92 Hospital haemodialysis (satellite units) 164 Home haemodialysis 28 CAPD 39 APD n/a Renal transplant Included in figure for Western Infirmary, Glasgow	Glasgow Royal Infirmary Satellite Units: Falkirk & District Royal Infirmary Stobhill Hospital, Glasgow
 155  68  Hospital haemodialysis 120 Home haemodialysis n/a CAPD 22 APD 13 Renal transplant Included in figure for Western Infirmary, Glasgow	Monklands Hospital, Airdire

Number of Patients	Renal/Satellite Unit
 279  60  Hospital haemodialysis 106 Home haemodialysis 3 CAPD 4 APD 25 Renal transplant 141	Ninewells Hospital, Dundee
 160  37  Hospital haemodialysis 73 Home haemodialysis 2 CAPD 1 APD 22 Renal transplant 62	Queen Margaret Hospital, Dunfermline Satellite Unit: Victoria Hospital, Kirkcaldy
 138  32  Hospital haemodialysis 44 Home haemodialysis 1 CAPD 21 APD 11 Renal transplant 61	Raigmore Hospital, Inverness
 553  62  Hospital haemodialysis 122 Home haemodialysis 5 CAPD 29 APD 24 Renal transplant 323	Royal Infirmary of Edinburgh Satellite Units: Western General Hospital, Edinburgh Borders General Hospital, Melrose
 1,160  92  Hospital haemodialysis (main unit + annex) 80 Hospital haemodialysis (satellite unit) 35 Home haemodialysis n/a CAPD 61 APD 12 Renal transplant 804	Western Infirmary, Glasgow Annex: Gartnavel General Hospital, Glasgow Satellite Unit: Inverclyde Royal Hospital, Greenock

There is also a small renal unit at Gilbert Bain Hospital, Lerwick, Shetland, which does not operate as a satellite of any other unit. This unit treats three haemodialysis patients, and was not visited as a part of this review process. Patients from Shetland are referred to Aberdeen Royal Infirmary for renal transplant, and for complicated cases of acute renal failure.

A main renal unit is the centre of renal expertise for a particular geographical area and manages the provision of renal services within that area. Both out-patient and in-patient renal services are offered, as well as specialist services. In some areas the main renal unit is supported by one or more renal satellite unit. A renal satellite unit is a haemodialysis facility which is linked to a main unit, and is not autonomous for medical decisions. They are largely nurse-led and typically provide a more accessible haemodialysis service to chronic renal patients in general good health, and not requiring the services and care of a main renal unit.

1.2 The NHS Quality Improvement Scotland Approach to Assessment

NHS Quality Improvement Scotland uses a methodology which draws upon other quality assurance models to enable it, in partnership with healthcare professionals and members of the public, to develop standards for clinical services and to assess performance across NHSScotland against these standards.

Further information and definitions of the terms used in the standards and in the assessment of performance are contained in Appendix 2.

Assessment Categories

Each review team assesses performance using the categories 'met', 'not met' and 'not met (insufficient evidence)', as detailed below:

- 'Met' applies where the evidence demonstrates the standard and/or criterion is being attained.
- 'Not met' applies where the evidence demonstrates the standard and/or criterion is not being attained.
- 'Not met (insufficient evidence)' applies where no evidence is available for the review team, or where the evidence available is insufficient to allow an assessment to be made.

A final category 'not applicable' is used where a standard and/or criterion does not apply to the Trust under review.

1.3 Background to the Clinical Standards for Adult Renal Services

The *Clinical Standards for Adult Renal Services* were developed as the result of an important collaboration between the Clinical Standards Board for Scotland (CSBS) and the Scottish Renal Registry (SRR). The Renal Association was also closely involved.

The Scottish Renal Registry was founded in 1991 by the Scottish Renal Association with a grant from the Clinical Resource and Audit Group (CRAG). The aim of the SRR is to promote the improvement of renal services for patients who are on renal replacement therapy across Scotland. Its role is to collect and audit data on this group of people. Its first task was to record details of all patients on renal replacement therapy throughout Scotland. Once a system of computerised data collection was operational, the SRR moved on to comparative audit between renal units. This focused on aspects of the quality of care of patients on renal replacement therapy. The SRR is now able to audit most of the standards developed by the UK Renal Association.

The Renal Association is the professional body for UK nephrologists (doctors who specialise in kidney disease). It has developed standards for the treatment of adult patients with renal failure. First published in April 1995, a third edition of the standards has been published in 2002. Standards of care have also been published by the British Transplantation Society. CSBS built on this work, and used these standards as a basis on which to compile clinical standards for adult renal services.

It was recognised that not all aspects of the quality of patient care could be addressed by audit of biochemical and haematological data. In 1998, further funding from CRAG allowed the Scottish Renal Registry to carry out multidisciplinary peer review visits, including patient representation, to all renal units in Scotland. In order to identify patient priorities for quality of care, meetings were held with representatives of the Kidney Patients' Associations in Scotland. The visiting team reviewed how well a renal unit met the Renal Association standards in addition to the requirements of the Patient Associations. Feedback meetings were held after every 2-3 visits to discuss ways of improving the process. A report with comments and recommendations was sent to each renal unit and to the relevant Trust and NHS Board. By May 2001, the SRR had completed the first phase of review visits to all adult units in Scotland.

There was potential for overlap between the work of the Scottish Renal Registry and the role of CSBS in developing standards and carrying out peer review visits. Following discussions between the two organisations it was agreed to work together to develop national Clinical Standards for Adult Renal Services. To take this forward, a project group comprising both healthcare professionals and members of the public was set up to draft the standards. In the development of the standards the project group drew on the work undertaken by organisations such as the Scottish Renal Registry, the Renal Association and the Kidney Alliance. Using the Clinical Standards for Adult Renal Services, 'Phase 2' of the peer review programme was run between May and October 2002, involving healthcare professionals and lay people.

Within this phase of standard setting for Adult Renal Services, the project group agreed to concentrate on chronic renal failure, with reference, where applicable, to acute renal failure. Care of patients with chronic renal failure who receive renal replacement therapy represents the largest element of the workload of renal units. In addition, the treatment given to this group of patients can act as a surrogate marker for the quality of care given to all patients with renal disease.

As there were no accepted standards for paediatric renal services at the time of the standards being set, and there are significant differences between the care provided to adults and children, the project group agreed to focus on setting standards for the treatment of adults with chronic renal failure. Standards for paediatric renal patients have since been developed for the 3rd Edition of the Renal Association standards: *Treatment of adults and children with renal failure: standards and audit measures*.

1.4 Introduction to Renal Disease (including Renal Failure)

Basic Facts About Renal Disease

Renal disease (or kidney disease) is a condition that occurs when the kidneys stop working properly.

Most people are born with two kidneys. Healthy kidneys have several very important roles:

- Firstly they clean the blood of waste and excess water. The food and drink we consume provide the body with the nutrients it needs for energy, growth and repair. After the body has taken in what it needs, it must get rid of what is left over (the waste and excess water). As the blood passes through the kidneys, small filters, called nephrons, remove the waste and excess water, which then become urine.

- This filtering process also allows the kidneys to maintain the correct balance of chemicals, salts and acid in the body.
- Finally, the kidneys produce three hormones, which stimulate the making of red blood cells, control blood pressure and maintain calcium levels in the body.

When the kidneys stop working properly, the waste substances and fluid build up in the blood and damage the body. The kidneys also stop producing hormones, which leads to anaemia, high blood pressure and weakening of the bones.

Types of Renal Disease

Chronic Renal Failure is when a person's kidneys gradually stop working properly. It is often caused by diabetes or glomerulonephritis, an inflammation of the filtering units of the kidneys. Chronic renal failure cannot be cured. It is a lifelong condition that requires more treatment as it progresses, and has a severe impact on a person's life. In the early stages (low clearance or pre-dialysis patients), progress of the disease may be slowed through diet and medication, but eventually it progresses to end stage renal failure.

End Stage Renal Failure is the final stage of renal disease when there is total and permanent kidney failure. A person with end stage renal failure will die within weeks or months unless they receive renal replacement therapy (dialysis or kidney transplantation).

Acute Renal Failure occurs when the kidneys suddenly stop working properly. There are a number of causes including infection, a sudden loss of blood, injury to the kidney or some medicines or poisons. A person with acute renal failure will often recover totally after a short time of treatment. Acute renal failure may be treated by diet, medication or dialysis. Occasionally the kidneys do not recover and the patient may progress to chronic or end stage renal failure.

The Symptoms of Renal Failure

Most kidney diseases develop slowly and at first there may be no obvious symptoms. The first signs of kidney disease are very general: frequent headaches, tiredness and general itching. As the disease progresses some people may need to go to the toilet more frequently, lose their appetite or experience sickness and vomiting. Some people also suffer from swollen ankles, develop high blood pressure and have trouble concentrating. A person with renal disease may experience all or only some of these symptoms, although there are many other non-renal causes for such symptoms.

Causes of Renal Disease

Although renal disease can occur at any age, as a person gets older the risk increases. Many chronic renal diseases damage the nephrons (filters) in the kidneys. The nephrons therefore lose the ability to filter wastes and excess fluid. There are many conditions that can lead to renal disease, the most common being diabetes, glomerulonephritis, genetic disorders (such as polycystic kidney disease) and high blood pressure.

Testing for Renal Disease

Renal disease is usually tested using blood and urine samples, which show whether there are abnormal levels of certain substances in the blood or urine. Further tests are then done using various imaging methods, such as ultrasound or computed tomography scan (CT scan). These methods take pictures of the kidneys and can show the disease in more detail. A renal biopsy may also be carried out, where a sample of kidney tissue is taken using a needle inserted through the skin into the kidney. The sample is then studied under a microscope and can give a more detailed indication of the problem.

Treatment of Renal Disease

Diet: Waste and excess water come from the food and drink we consume. Therefore, modifying the types and quantities of food eaten and limiting the amount a person drinks can help to reduce the build-up of waste and extra water in the body. This can also delay the need for further treatment. Nutrients that may need altered through changes in diet include salt, proteins, potassium, phosphate and water. Energy intake may need adjusting in order to maintain a healthy body weight.

The type of diet suggested will vary for each person depending on appetite, the stage of kidney disease and the results of blood tests.

Medication: Different types of medicine can also help to reduce the build up of certain wastes and extra water in the body. Some medicines help to maintain the balance of chemicals in the body. Diuretics (medicines that increase the flow of urine) may be taken to help control the amount of water in the body.

When renal failure occurs the kidneys are not able to produce their hormones effectively and it can cause problems such as high blood pressure, anaemia and the weakening of bones. Medicines may be taken to prevent or treat these problems.

Dialysis: Once a person's kidneys stop working completely they will need either dialysis or a kidney transplant to stay alive. Dialysis replaces the function of the kidneys and removes waste and extra water from the blood. There are two types of dialysis: haemodialysis and peritoneal dialysis (see below). The choice of dialysis depends on many factors and different treatments suit different people. For most people with end stage renal failure, dialysis is a long-term treatment and must be combined with a special diet and medication to be effective. Dialysis cannot replace the hormones normally produced by the kidneys. The lack of one of these hormones, erythropoietin (EPO), results in anaemia and it can now be given by injection to prevent the symptoms of severe anaemia such as fatigue, breathlessness and long-term damage to the circulation.

Haemodialysis: Blood is pumped through tubes to a dialysis machine that filters away the waste and extra fluid. The cleansed blood is then returned to the body through another set of tubes. Regular and easy access to the bloodstream is needed for haemodialysis. This is achieved through a surgical operation to create an enlarged blood vessel called a fistula, usually in the forearm, into which the needles are inserted for dialysis. Haemodialysis usually takes place at a hospital renal unit, or a 'satellite' dialysis unit, three times a week usually for at least four hours. While having dialysis, the patient can do activities that do not require getting up and moving around, such as reading, sleeping or watching TV.

Peritoneal Dialysis: This type of dialysis cleans the blood inside the body using the lining of the peritoneal cavity (the space in the abdomen that contains the intestines and other internal organs). A solution (dialysate) is put into the abdominal cavity through a tube called a catheter. The solution then absorbs the waste and excess water from the blood through the peritoneal membrane. After a few hours the used solution is drained away and replaced with fresh solution. Patients carry out this procedure themselves at home. The catheter gives permanent access to the abdominal cavity. Surgery is needed to insert it into the abdomen. Part of the catheter stays permanently on the outside of the body to allow the solution to be drained in and out of the body. Continuous ambulatory peritoneal dialysis (CAPD) is the most common form of peritoneal dialysis. The solution is usually changed four times a day and takes 30-40 minutes each time. Automated peritoneal dialysis (APD) uses a machine to change the solution at night while the patient is asleep.

Sometimes a person on peritoneal dialysis can get peritonitis, an infection in the abdominal cavity. Peritonitis occurs if bacteria enter the fluid in the abdominal cavity either by contamination or from an existing infection. It can be treated

using antibiotics. If peritonitis is very severe or occurs several times in succession the doctor may need to replace the catheter. In this case, haemodialysis is needed until peritoneal dialysis can be resumed.

Transplantation: Kidney transplantation is another form of treatment for end stage renal failure and is where the surgeon places a healthy, donated kidney into the patient's abdomen. If successful, the new kidney will take over the functions of the failed kidneys. Dialysis is no longer required and a normal and active life can be resumed. However, there is a risk that the body may try to reject the 'foreign' kidney. The patient must therefore take medication known as 'immunosuppressives' each day to reduce this risk.



Not everyone is medically suitable for a transplant. Therefore, each patient must be carefully assessed before being placed on the waiting list. The waiting list is not like a queue. There are not enough donor kidneys for everyone so when a kidney does become available it is important that it is allocated so that it is most likely to be successful. Research shows that the most successful transplants occur when the kidney is allocated to a patient who has the same blood group as the donor kidney and is a close tissue match. The better the match, the more likely it is that the recipient's body will accept it. The donor kidney is therefore allocated to the patient who has the best match. A national system of kidney allocation is in place and kidneys are sent all over the country so that they can be allocated to the most suitable recipients.

If a transplanted kidney is rejected, dialysis treatment is once again needed. An unsuccessful transplant may not stop the patient from having another transplant, but it may become more difficult to match the patient to another kidney.

Donated kidneys can come from either living or cadaver donors. A donated cadaver kidney comes from the body of a person who has been confirmed as dead by brain stem testing, with appropriate permission having been given for organ donation. The most successful transplants come from living donors, particularly close relatives. In some cases the donor is a spouse or partner.

Regular Medical Check-Ups

People with renal disease require regular check-ups to ensure that waste and extra water are not building up in the blood, and to review their treatment. If there is a build up of waste and extra water, treatment can be adjusted. Access to a multidisciplinary team is essential to ensure that all aspects of the patient's care are addressed.

Renal Disease in Scotland

In 2000, 565 people started long-term renal replacement therapy by dialysis or transplantation in Scotland. Renal failure and its treatment impacts greatly on a patient's life and work. Although no cure exists for renal failure, there is much that can be done to improve outcomes and quality of life for patients. The risk of complications can be reduced by treatment that is both well managed and regularly assessed by a multidisciplinary team, while provision of appropriate information and discussion of treatment options can do much to prepare patients for future treatment.

In Scotland, transport for haemodialysis remains an issue. For those living in rural areas, dialysis days can be very long due to the need to travel long distances to the nearest renal or satellite dialysis unit. The only way to reduce the need for dialysis is to increase the number of transplants. However, the shortage of kidneys available for transplantation is also an issue. The UK has one of the lowest cadaver donor rates in Europe. Scottish Executive figures estimate that if the number of transplants carried out remains constant for the next few years, the need for hospital haemodialysis could increase by a further 60%, due to an overall rise in incidence of renal disease across Scotland. While the standard of care for renal patients has improved in Scotland over recent years, there is still much to do. The clinical standards that have been developed are designed to support this continued improvement of care to patients with renal disease.

1.5 The NHS Quality Improvement Scotland Standards and Your Care

Questions You Might Want to Ask

The adult renal services standards have been summarised and are shown in blue. Each standard is followed by relevant questions you might want to ask about your care.

Standard 1: All people on haemodialysis receive satisfactory dialysis treatment.

- Is my dialysis treatment working satisfactorily?
- If not, why not?
- What can be done to improve my treatment?

Standard 2: All people on peritoneal dialysis receive satisfactory dialysis treatment.

- Is my dialysis treatment working satisfactorily?
- How would I know this?
- If not, why not?
- What can be done to improve my treatment?
- What can I do to improve my treatment?
- Am I using the peritoneal dialysis system which is best to prevent me developing peritonitis?



Standard 3: People on dialysis should not be severely anaemic.

- Am I anaemic? How would I know?
- If so, what can be done to help?

Standard 4: Access for dialysis should be ready for use when treatment is required.

- What type of access is required for my dialysis?
- When will I need this access to be made?
- Who will create the access?

Standard 5: All people with established renal failure are as well nourished as possible.

- Will I need to be on a special diet?
- Which foods do I need to take/avoid?

Standard 6: All people with established renal failure receive drugs appropriately.

- Who should I ask about drug treatment?
- Which medicine do I need?
- Is there any medicine I should avoid?
- Should I avoid alcohol and/or smoking?

Standard 7: Access to other services is easily available when needed.

- Who should I ask when I need help with . . . ?
- Will my treatment be regularly reviewed?
- Who will lead on my care?

Standard 8: All dialysis patients are assessed for possible kidney transplantation.

- Am I suitable for transplantation?
- Who should I ask for information about transplantation?
- How do you decide who receives a kidney transplant?
- Can anyone in my family donate a kidney for me?

Standard 10: The success rate of kidney transplantation is satisfactory.

- What are the chances of my kidney transplant being successful?
- What is the risk to my life of having this operation?

Standard 11: The waiting time for new patients to be seen at the out-patient clinic is short.

- How soon will I be seen at the clinic?
- How soon will my GP hear about your recommendations?

Standard 12: People with established renal failure receive appropriate information.

- Where can I obtain information about my treatment?
- Do I have any choice about the type of treatment I receive?
- What other organisations could I contact?

Standard 13: Transport arrangements for dialysis avoid unreasonable delays.

- What will be the best way for me to attend for dialysis?
- What can be done to avoid delay in coming for and going home from treatment?

Standard 14: There is a regular audit of the quality of treatment of renal failure in Scotland.

- Is my unit as good as the others in Scotland?
- If not, what is being done about this?



1.6 Frequently Asked Questions

Q. How can I tell if I have kidney disease?

A. In mild kidney failure there are often no symptoms, but tests of renal function show some abnormality. The first symptom may be the need to get up more frequently at night to pass urine, even if there has not been an excessive fluid intake before going to bed. This is due to the inability of the kidneys to concentrate the urine.

In more advanced kidney failure, the symptoms can be varied, but include fatigue, loss of appetite, breathlessness, ankle swelling and itch. However, there are many more common reasons for each of these symptoms and your GP will be able to help.

Pain on passing urine usually indicates infection which, if treated early, should not involve the kidneys in most cases.

Q. Is kidney disease preventable?

A. There are many different causes of kidney disease and kidney failure. Only some may be preventable, but the rate of deterioration of kidney failure may be slowed, or even stopped, by such measures as good blood pressure control. For those with diabetes or high blood pressure, satisfactory treatment of the underlying condition may prevent the complication of kidney failure occurring.

Q. If I have kidney disease will my children get it too?

A. Most kidney problems are not passed on to children. In some conditions, there is an increased risk of children developing the same problems as an adult, and investigation may be appropriate. Your GP or consultant will be able to help and advise.

Q. Is kidney failure painful?

A. Not usually. In most cases the symptoms are not obviously related to the kidneys, although patients with kidney stones may experience severe pain. The more common symptoms are those of fatigue and breathlessness, often with a loss of appetite, going on to a feeling of nausea which is usually worse in the morning.



Q. If I develop kidney failure can I receive treatment?

A. Yes. Unlike 20 years ago, all patients who would benefit from dialysis are able to receive treatment.

Q. Is dialysis treatment painful?

A. No. For dialysis to be possible, it is usually necessary to insert two needles into blood vessels in order for the blood to flow from the body to the dialysis machine, and back into the body. There is normally no discomfort during treatment.

Q. If I have a kidney transplant, will it work for the rest of my life?

A. Some people have had transplants which have worked for more than 30 years, but the majority of people will eventually require a further period of dialysis.

Q. What happens if the kidney transplant fails?

A. The situation is the same as for people whose own kidneys are failing. Dialysis is started when required, either because of symptoms or because blood results indicate that this is necessary.



Photo courtesy of the National Kidney Research Fund.

1.7 Useful Contacts

The following organisations can provide information about aspects of renal disease. GPs and healthcare teams treating renal disease can also provide you with information about local support groups.

1. The British Kidney Patient Association

Bordon
Hampshire
England
GU35 9JZ

Tel: 01420 472021
Fax: 01420 475831
www.bkpa.org.uk/

2. National Kidney Federation (NKF)

6 Stanley Street
Worksop
England
S81 7HX

Tel: 01909 487795
Helpline: 0845 601 02 09
www.kidney.org.uk

3. Scottish Federation of Kidney Patients Association

Mr George Scott
Chair
29 Broomlands Road
Cumbernauld
Strathclyde
G67 2PU
Tel: 01236 723113

4. National Kidney Research Fund

Helpline: 0845 300 1499
Email: helpline@nkrf.org.uk
(Provides information and support to kidney patients, their family and friends and associated healthcare professionals)

Charity Affairs (Scotland)

Tel: 01560 486868
Fax: 01560 483128

Charity Affairs (National Office)

Tel: 01733 704678
Fax: 01733 704660

Donation Line - Freephone 0800 783 2973

www.nkrf.org.uk

5. Scottish Renal Registry

www.show.scot.nhs.uk/srr



Chapter 2

National Performance Against the Standards

Quality
Improvement
Scotland

2 National Performance Against the Standards

This section presents the findings across Scotland in terms of performance against individual standards. A number of examples of innovative local solutions and areas of good practice are highlighted throughout the text. These examples are not exhaustive – every review team noted areas of good practice during visits and these were often in place in more than one unit. Challenges are also listed and there is certainly scope for change and improvements in the process of care for adult renal patients. This is recognised by healthcare professionals and by patients and their friends and families, and while in the past there was limited patient involvement in renal care, there are now many examples of successful partnership working.

In common with many conditions, renal care is complex and most treatment is personally tailored to suit each patient's needs. This presents challenges when developing general patient information as it is not easy to achieve a balance between personal expectations and outcomes, and general information.

Feedback from those reviewed and those in review teams is sought after every visit and nearly 105 people responded. Overwhelmingly, those involved in the review process reported that the opportunity to network and the time to consider different ways of addressing shared issues is valuable. Giving the public and the service the chance to review many aspects of the way in which care is provided has been fundamental to the approach taken and is a starting point for many activities including:

- measuring good practice;
- disseminating good practice;
- stimulating multidisciplinary working;
- involving those who use the service; and, perhaps most importantly:
- reviving the appetite to ensure that the provision of patient care is balanced by the monitoring of that care against key performance standards and that the quality of care is continually improved.

During the review of adult renal services, the 10 main renal units in Scotland, along with their related satellite units, were reviewed to assess performance against the standards. Unit-wide information was submitted by the units reviewed, and this national overview summarises 10 local reports. Accordingly, in most cases, the findings presented reflect the number of times where the standard criteria were met, based on the denominator of the 10 local reports. However, it should be noted that some criteria relate solely to the three transplant units in Scotland. Therefore, in the case of **Criterion 6:1b**, **Standard 9** and **Criteria 10.1** and **10.2**, the findings are based on a denominator of these three transplant units.

Information, Data Collection and Audit

There is clearly a commitment to, and an awareness of, the importance and value of data collection and audit for renal services in Scotland. The Scottish Renal Registry has played a significant role in the development of audit in renal services. It was established in 1991 by the Scottish Renal Association, as a computer-based registry for patients receiving renal replacement therapy for end stage renal disease in Scotland. Once a system of computerised data collection was operational, the Scottish Renal Registry moved into comparative audit between renal units.

The Registry is now able to audit many of the standards developed by the UK Renal Association. As a result, renal units across Scotland send data to the Scottish Renal Registry for the purposes of national audit. Between 1998-2001, the Scottish Renal Registry carried out peer review, including patient representation, to all renal units in Scotland. The visiting teams reviewed the audit results, in addition to other aspects of care not covered by the UK Renal Association Standards. In addition to the results of national audits being published in the Registry's Annual Report, all renal units are provided with their individual unit's results alongside the national results.

The Scottish Renal Registry continues to use the audit data it collates to promote the improvement of renal services for patients on renal replacement therapy across Scotland. Future projects planned include:

- an inter-unit comparison of the survival of patients receiving renal replacement therapy, after allowing for co-morbidity;
- the comparison of results by NHS Board area as well as by unit; and
- the extension of audit and research projects.

2.1 Standard 1: Haemodialysis

Standard Statement

All people on haemodialysis achieve the Renal Association targets set for adequacy. There is regular audit of haemodialysis adequacy (see Standard 14).

Essential Criteria

- 1. The target for haemodialysis adequacy is a Urea Reduction Ratio not less than 65% or stable Kt/V not less than 1.2 (dialysis and residual renal function) for thrice-weekly dialysis. This is achieved in a minimum of 85% of patients. Where Kt/V is measured, the method used to calculate is documented.**

This criterion was met in 7/10 renal units.

In most instances, renal units only use the urea reduction ratio (URR) as a measurement of haemodialysis adequacy. Three units did not meet the criterion. The major contributing factors for this were identified as insufficient time and staffing. There was evidence that the set dialysis shift times in place in some units do not allow sufficient flexibility to lengthen dialysis sessions for patients who require this. This lack of flexibility was a particular issue for two units which did not meet the criterion. One unit which did not meet the criterion reported that it was unable to achieve good dialysis adequacy due to poor dialysis access.

- 2. Reasons for patients not achieving the target haemodialysis adequacy are documented and appropriate action taken.**

This criterion was met in 9/10 renal units.

All units record the reasons for patients not achieving the target haemodialysis adequacy, and in almost all units, appropriate action is taken to correct haemodialysis adequacy. The one renal unit which did not meet the criterion had an identified issue with its ability to take appropriate action to correct patients' haemodialysis adequacy. It was noted that fixed dialysis shifts, the organisation of nurse staffing, and patient transportation impacted on the unit's flexibility to extend a patient's time on dialysis.

3. Haemodialysis is offered thrice-weekly unless there are specific circumstances.

This criterion was met in all renal units.

All units offer patients thrice-weekly dialysis. It was noted that, occasionally, patients choose to dialyse less frequently, or are unable to dialyse more frequently due to geographical factors. In such cases, patients typically choose to dialyse twice a week.

4. Quality of water for dialysis and/or dialysis fluid is monitored monthly and meets Renal Association targets for microbial count.

This criterion was met in 6/10 renal units.

The major contributing factor for units not meeting this standard is the lack of central water treatment facilities. However, in most of the affected units, plans are in place to install appropriate water treatment equipment by April 2003.

5. The percentage of patients achieving the Renal Association standards for pre-dialysis potassium, phosphate, and calcium is calculated at a minimum of 3-monthly intervals.

This criterion was met in 8/10 renal units.

All units monitored the biochemical results of individual patients, although not all units calculated the percentage of patients achieving the Renal Association targets. In these units, however, provision is made to assess these biochemical indices for all patients on an individual basis, and there was evidence that units managed patients accordingly.

Strengths

- Almost all units met all of the criteria. Where criteria were not met, units could identify the reasons for this, and in many cases are working towards improvements in these areas.
- Many units demonstrated effective systems and good protocols for haemodialysis.
- There was evidence of good management of patients' haemodialysis treatment, with close monitoring and frequent review of individual patients' results.

Challenges

- Some units experience difficulties in increasing the length of dialysis sessions where appropriate, due to limited facilities, staffing and organisational issues (eg shift patterns).
- In some instances, vascular access for dialysis is not adequate in terms of blood flow, which affects the adequacy of dialysis.
- In some units there is a lack of appropriate water treatment equipment to facilitate regular monitoring of the quality of water for dialysis.

Recommendations

- Trusts should ensure that there are sufficient facilities for dialysis, with the flexibility to ensure patients receive adequate haemodialysis treatment appropriate to their individual needs.
- Facilities for adequate dialysis access creation should be in place.
- Trusts should ensure that appropriate water treatment equipment is available, in order to meet the water quality criterion.

Example of a local initiative

Dumfries & Galloway Royal Infirmary Renal Unit

The review team commended the organisation of pre-dialysis clinics for patients who have not yet started dialysis treatment. Each patient is seen during a half-hour appointment, allowing potassium, phosphate and calcium levels to be monitored and controlled before the patient starts on dialysis treatment. Particular emphasis is given to the control of phosphate levels. Monthly meetings are held to discuss this area of patient care, and are attended by the dedicated phosphate nurse, dietician and staff grade.

2.2 Standard 2: Peritoneal Dialysis

Standard Statement

All people on peritoneal dialysis achieve the Renal Association targets set for adequacy. There is regular audit of peritoneal dialysis adequacy (see Standard 14). There is safe and effective management in place for prevention of peritonitis.

Essential Criteria

- 1. The target for peritoneal dialysis adequacy is a total weekly creatinine clearance (dialysis and residual renal function) not less than 50 l/week/1.73m² and/or weekly urea Kt/V exceeds 1.7 by 8 weeks after beginning peritoneal dialysis. This is maintained in a minimum of 85% of patients.**

This criterion was met in 9/10 renal units.

Almost all units were able to demonstrate that they met this criterion. Issues around insufficient staffing to carry out the creatinine clearance tests were identified as being the reason for the one unit not meeting this criterion.

- 2. Reasons for patients not achieving the target peritoneal dialysis adequacy are documented, and appropriate action taken.**

This criterion was met in all renal units.

Follow-up of patients not achieving the target peritoneal dialysis adequacy is well-addressed, with good documentation of reasons for patients not achieving the target. In some units there was evidence of effective communication between medical and nursing staff. This facilitates continuity of care of patients, and enables prompt action to be taken in response to patients not dialysing well.

3. The percentage of patients achieving the Renal Association Standards for potassium, phosphate and calcium is calculated at a minimum of 3-monthly intervals.

This criterion was met in 8/10 renal units.

There was evidence that all units monitored the biochemical results of individual patients, although not all units calculated the percentage of patients achieving the Renal Association targets. In these units, however, provision is made to assess these biochemical indices for all patients on an individual basis, and there was evidence that units managed patients accordingly.

4. The use of disconnect systems is standard unless contra-indicated.

This criterion was met in all renal units.

Disconnect systems reduce the risk of peritonitis in peritoneal dialysis patients. Data provided by all renal units indicated that all peritoneal dialysis patients in Scotland use disconnect systems.

5. Peritonitis rates are not more than one episode/18 patient-months.

This criterion was met in 7/10 renal units.

The main contributing factor for this criterion not being met in three units was patients in remote and rural areas choosing to remain on peritoneal dialysis, despite frequent peritonitis, due to difficulties travelling to distant haemodialysis facilities.

Strengths

- Almost all units met all of the criteria.
- Effective systems and good protocols are in place for peritoneal dialysis treatment across Scotland to ensure adequacy targets are met by most units.
- Across Scotland, basic information on peritoneal dialysis treatment is well documented.
- There was evidence of good, individualised management of patients' peritoneal dialysis treatment, with close monitoring and frequent review of patients' results.

Challenge

- Difficulties in providing haemodialysis facilities to patients in remote and rural areas result in patients continuing with peritoneal dialysis despite frequent episodes of peritonitis.

Recommendation

- Trusts serving remote and rural areas should develop ways of offering all treatment options, particularly haemodialysis, to remote and rural patients.

Example of a local initiative**Crosshouse Hospital Renal Unit**

Audit data provided by the unit confirmed that peritonitis rates are low. The review team noted a meticulous approach to dialysis management, even to the extent of nursing staff being present during the process of siting and inserting catheters. This attention to detail was suggested as being one of many possible contributory factors for the achievement of the low peritonitis rates.

2.3 Standard 3: Haemoglobin in Patients on Dialysis

Standard Statement

All people on haemodialysis or peritoneal dialysis achieve targets set for haemoglobin levels after 3 months of dialysis. Transfusion is avoided wherever possible.

Essential Criteria

- 1. The target is a haemoglobin concentration not less than 10g/dl (haematocrit is not less than 30%) after 3 months of dialysis. This is achieved in a minimum of 85% of patients.**

This criterion was met in 3/10 renal units.

While seven renal units achieved the criterion in peritoneal dialysis patients, only three met the criterion in haemodialysis patients as well. Of the seven units not achieving the criterion in haemodialysis patients, three narrowly missed the target. A variety of reasons were cited for the criterion not being met, including availability of erythropoietin (EPO), which is the most effective drug in the treatment of anaemia. Poor dialysis due to unsatisfactory vascular access, and recurrent infection from temporary lines, were also identified as reasons for units not meeting the criterion. It was noted that most units have attempted to put measures in place to correct the situation.

- 2. Reasons for patients not achieving the target haemoglobin are documented, and appropriate action taken.**

This criterion was met in all renal units.

All units document the reasons for patients not achieving the target haemoglobin, with appropriate action being taken to increase the target haemoglobin concentration in individual patients. Overall, there was evidence of clear protocols being in place. In many units, the management of anaemia is nurse-led.

3. Iron status is monitored at a minimum of 6-month intervals.

This criterion was met in all renal units.

Iron status is monitored at a minimum of 6-month intervals in all renal units across Scotland. In most cases, monitoring takes place between 1- and 3-monthly for both haemodialysis and peritoneal dialysis patients, and more frequently if required.

4. The number of patients receiving blood transfusions is monitored.

This criterion was met in 8/10 renal units.

The number of patients receiving blood transfusions is monitored in all but two renal units. It was noted that the two units which did not meet the criterion, document, but do not monitor, blood transfusions in renal patients. However, plans are in place to begin monitoring the number of patients receiving transfusions at these two units in the near future.

Strengths

- Overall, there is frequent monitoring of iron status and blood transfusion, which was commended by review teams.
- There was evidence of clear anaemia protocols being in place in all units.
- Most units achieved the target haemoglobin concentration in peritoneal dialysis patients.

Challenges

- Achieving the haemoglobin target in haemodialysis patients.
- For some units, the availability of EPO.
- Ensuring that unsatisfactory dialysis does not contribute to anaemia in dialysis patients.

Recommendation

- Trusts should make good use of monitoring information relating to patients' haemoglobin concentrations, and address reasons why patients do not achieve the target.

2.4 Standard 4: Dialysis Access

Standard Statement

All people requiring dialysis have timely surgery for access.

Essential Criteria

- 1. Permanent access is available at the first dialysis in a minimum of 60% of patients who present at the renal service more than 3 months before requiring dialysis.**

This criterion was met in 4/10 renal units.

Only four units were able to demonstrate they achieve the criterion for haemodialysis patients. A further renal unit provided audit data which suggested the criterion had been achieved in haemodialysis patients, but, due to uncertainty as to whether these data were robust, the review team assessed the criterion as 'not met (insufficient evidence)'. In the case of another unit, it became apparent that calculations based on audit data presented at the time of the visit had been carried out incorrectly. Although corrected calculations indicated that the criterion was achieved, it was not possible for the review team to verify this information; therefore, the criterion was also assessed as 'not met (insufficient evidence)' for this unit.

Overall, the major contributing factors for renal units not meeting this criterion were an insufficient number of in-patient beds, resulting in access procedures being cancelled, and a lack of dedicated theatre time for vascular access surgery for dialysis. It was noted that these were also major issues for units which achieved the criterion. A further issue identified for one unit was insufficient surgical staff.

It was noted that permanent dialysis access is important in achieving effective dialysis and reducing the risk of infection, which can occur through the use of temporary dialysis access lines.

- 2. Reasons for patients not having permanent access available at their first dialysis are documented.**

This criterion was met in 6/10 renal units.

In renal units achieving this criterion, reasons for patients not having permanent access available at their first dialysis are well-documented. Of the four units which did not meet this criterion, two were reviewing the situation at the time of the review visits. In one case, it was highlighted that the information required by the criterion was not documented in all cases due to time constraints.

- 3. There are adequate dedicated theatre sessions (Reference Guideline: one weekly theatre session per 120 patients (approximately) on dialysis – National Service Standard 3).**

This criterion was met in 4/10 renal units.

Overall, the major contributing factor for renal units not meeting this criterion was insufficient dedicated theatre sessions for dialysis access surgery for the patient population. This is a significant issue for renal units, and can result in renal access surgery being cancelled at short notice. This in turn contributes to difficulties in providing permanent access in time for patients' first dialysis, and the resultant use of temporary dialysis access lines.

Desirable Criteria

- 4. A minimum of 70% of patients have arteriovenous fistulae or vein graft as their permanent haemodialysis access.**

This criterion was met in 3/10 renal units.

While three units met this criterion, a further three missed the target percentage by a small margin. The major contributing factors identified for units not meeting this criterion were a lack of theatre time and an insufficient number of in-patient beds. Overall, there were concerns as to the over-reliance on permanent catheters as permanent haemodialysis access. In some areas, it was also expressed that there was a limited availability of experienced vascular surgeons.

- 5. Permanent catheters are used as haemodialysis access in a maximum of 20% of patients.**

This criterion was met in 3/10 renal units.

This criterion is linked to Criterion 4, and it was noted that the three units which achieved Criterion 4 also met this criterion. One unit missed the target percentage of patients by a small margin. Once again, the major contributing factors identified for units not meeting this criterion were a lack of theatre time and an insufficient number of in-patient beds. A limited number of surgical staff was identified as an issue, which, it was noted, had been addressed with the appointment of an additional member of staff in one unit.

Strength

- Trusts providing adequate theatre time and surgical staffing were able to meet the standard.

Challenges

- To provide timely and satisfactory permanent dialysis access, in order to reduce the need for temporary dialysis access lines.
- To reduce the number of permanent catheters used as continuing access by providing arteriovenous fistulae or vein grafts.

Recommendations

- In order to facilitate patients receiving timely access surgery, documentation of the pre-dialysis assessment should include information relating to dialysis access.
- Trusts should ensure provision of dedicated theatre time appropriate to the requirements of the service.
- Dialysis access, which is vital for the quality of life of dialysis patients, should be given greater priority by Trusts.

Examples of local initiatives

Crosshouse Hospital Renal Unit

The review team commended the use of an 'access diary', which is used to document for each patient the type of vascular access used for dialysis, and any complications experienced. It was noted that this diary provides comprehensive data, which could be used for audit purposes.

Ninewells Hospital Renal Unit

The provision of a recently appointed dialysis access nurse was commended by the review team. It is intended that the role of this individual will be to facilitate earlier intervention and improve monitoring of dialysis access.

2.5 Standard 5: Nutritional Status

Standard Statement

All patients receiving dialysis or with low creatinine clearance have nutritional status regularly assessed, evaluated and documented.

Essential Criteria

- 1. All patients are assessed at least 6-monthly to identify those at risk of malnutrition.**

This criterion was met in 5/10 renal units.

Assessment of all patients at a minimum of 6-monthly intervals, to identify those at risk of malnutrition, takes place in half of the renal units. Overall, good protocols are in place for the nutritional assessment of patients. The major contributing factor for units not meeting this criterion was insufficient dietetic staffing: time constraints on existing dietetic staff impact on the number of patients able to be assessed. Some units operate a system of prioritisation to enable those most at risk of malnutrition to be seen. However, this led to concern that some patients at risk of malnutrition could be missed until their condition deteriorates. There is also concern that the anticipated increase in the renal patient population will further exacerbate this issue.

It was noted that regular assessment of renal patients' nutritional status is important in the prevention of malnutrition, with the aim of slowing the progress of renal disease and to improve or maintain the overall quality of life for the patient.

2. Patients identified as at risk have nutritional goals set, documented and monitored in accordance with Renal Nutritional Group Standards.

This criterion was met in 9/10 renal units.

Although some renal units did not assess all groups of patients 6-monthly, nutritional goals are well-addressed for those patients who are identified as at risk. There is an issue around documentation of nutritional goals, which are typically recorded on dietetic record cards. Although it was recognised that information about nutritional goals is shared with members of the multidisciplinary team at some units, there was some uncertainty as to whether this is the case at all units. It was noted that some units have started recording patients' nutritional goals on computerised databases, which can be accessed by members of the multidisciplinary team. However, a paper record is also maintained, resulting in time-consuming duplication of records.

The only unit which did not meet the criterion had an identified issue with dietetic staffing levels, and operated a system of prioritisation whereby patients identified as at risk were seen.

3. Reasons why patients identified as at risk do not achieve nutritional goals are documented, and appropriate action taken.

This criterion was met in all renal units.

All units were able to demonstrate a high standard of documentation of reasons why patients do not achieve nutritional goals. In many cases, decisions regarding patients' treatment are taken following discussion at multidisciplinary meetings. Overall, good protocols are in place, and are routinely followed.

4. There is a designated dietician with a recognised postgraduate qualification and/or renal experience.

This criterion was met in all renal units.

All units have in post designated dietetic staff with the required level of skills. However, this support is not always a whole time equivalent, or sufficient for the number of patients. As a result it was noted that many units were struggling with the issue of insufficient dietetic staffing. This issue also impacts on the level of cover available during periods of staff leave.

Desirable Criterion

5. Baseline anthropometry is documented for all patients at the beginning of dietetic treatment by an individual trained in the technique.

This criterion was met in 5/10 renal units.

A major contributing factor for this criterion not being met in half of the renal units is reported as being insufficient dietetic staffing. In units not achieving the standard, there was evidence of baseline anthropometry being undertaken on an ad hoc basis, with low clearance patients often being missed altogether due to time constraints. It was noted that anthropometry (the measuring of the human body, or part of the body) is important in assessing a patient's nutritional status.

Strengths

- There is a good overall level of attainment of the criteria in this standard.
- A high standard of documentation of nutritional status is in place throughout Scotland.
- There was evidence of comprehensive dietetic protocols.
- Every unit has appropriately trained dietetic staff dedicated to the renal service.
- Staff demonstrated good awareness of the importance of nutrition in renal patients.

Challenges

- The projected increase in the renal patient population will further highlight issues around insufficient dietetic staffing.
- Increasing the focus of nutritional monitoring towards patients with a low creatinine clearance, and broadening the use of anthropometry to include these patients.
- Ensuring dietetic information is shared with all appropriate members of the multidisciplinary team. This would best be achieved by computerisation of nutritional care planning.
- Patient access to renal dietetic services, if required, during periods of staff leave.

Recommendations

- Trusts should ensure forward planning in respect of matching the dietetic resource to the growing renal population.
- Workforce planning and resource issues should be addressed, to ensure a comprehensive dietetic service for all patients on dialysis or with a low creatinine clearance. This should include cover during periods of staff leave, particularly in units where there is only one dietician.
- A wider range of staff should be trained in taking baseline anthropometry to ensure all patient groups are covered.

Examples of local initiatives

Queen Margaret Hospital Renal Unit

Each dialysis patient is provided with an individualised dietetic logbook, which details the patient's dialysis and blood results, which are taken monthly. The logbook informs the patient of the importance of attaining target results in the areas of protein intake, dialysis efficiency, phosphate and potassium, and how they can affect the patient's health. The renal dieticians complete the logbook, and provide written individualised dietary advice or comments against the results for the benefit of the patient.

Raigmore Hospital Renal Unit

The review team commended the redesign of the dietetic record card, which is comprehensive and facilitates improved monitoring of patients.

2.6 Standard 6: Drug Therapy

Standard Statement

All people with chronic renal failure or on renal replacement therapy receive appropriate drug therapy and advice on their medicines.

Essential Criteria

1a. There are protocols for:

- Management of anaemia.
- Treatment of peritonitis.
- Immunisation for Hepatitis B.

This criterion was met in 8/10 renal units.

All renal units have protocols in place for the areas required by the criterion, with the exception of two units which did not have a protocol for immunisation for Hepatitis B. It was noted that, in both of these units, steps were being taken at the time of the visit to produce a protocol in this area. Overall, there is good awareness amongst staff of drug therapy protocols that are in place.

Although it was noted that protocols are updated periodically, with two exceptions, there was no evidence of a formal review system being in place.

1b. In addition, for transplant units there are protocols for:

- Immunosuppressive regimens.
- Cytomegalovirus and pneumocystis infection prophylaxis.
- Renal vein thrombosis prophylaxis.
- Management of delayed graft function.

This criterion was met in all 3 transplant units.

This criterion only applies to transplant units, of which all three have the relevant drug therapy protocols in place for transplant patients. An issue identified for one transplant unit was to increase staff awareness of these protocols. Once again, although the protocols are updated periodically, there was little evidence of formal review systems being in place.

It was recognised that it is beneficial for non-transplant renal units, whose patients return to their care post-transplant, to have copies of these protocols. In cases where renal units had copies of these protocols, staff generally showed good awareness of the protocols.

2. All patients' prescriptions are reviewed to ensure their drug therapy is appropriate for their circumstances.

This criterion was met in 9/10 renal units.

There is regular review of in-patients' prescriptions which, in most units, is undertaken by the pharmacist. All other patients' prescriptions are typically reviewed by medical staff. The one unit which did not meet the criterion had an issue with a subgroup of patients whose prescriptions were not reviewed on a routine basis. It was noted that, in many cases, there is no clear documentation to show that patients' prescriptions are reviewed regularly.

3. Information and advice about the use of drugs in chronic renal failure or in dialysis patients is available to healthcare professionals and renal patients.

This criterion was met in 9/10 renal units.

Overall, the information and advice provided to patients about the use of drugs in chronic renal failure or in dialysis patients, is of a high standard. Verbal information and advice is typically followed up with written information. In particular, locally developed leaflets and drug charts were commended by review teams.

Information and advice for healthcare professionals is typically available in the form of a Renal Drug Handbook and other written guidelines, which can be accessed via the Internet. Healthcare professionals can also access advice from a pharmacist if required. In addition, tutorials are run by the pharmacist for staff at some units.

The one unit which did not meet the criterion had an issue with patients at one site, to whom information and advice was provided on an ad hoc basis.

4. There is a designated pharmacist with a recognised postgraduate qualification and/or renal experience.**This criterion was met in 6/10 renal units.**

Although over half of the renal units have a designated pharmacist in post with the required level of skills, it was noted that pharmacy input is most often weighted towards in-patients, with out-patient clinics lacking input from a pharmacist. There was evidence of insufficient dedicated renal pharmacy staffing, with cover being provided for many units on a part-time basis. There were also frequent issues around cover for periods of staff leave.

Strengths

- The required protocols are in place in most units and staff showed good awareness of the protocols.
- There is comprehensive review of in-patient prescriptions in units across Scotland.
- There was evidence of the availability of high quality drug information and advice.
- Over half of all renal units have a designated renal pharmacist.

Challenges

- The regular, systematic review and audit of protocols.
- Evidence of systematic documentation to demonstrate that patient prescriptions are reviewed regularly.
- Ensuring drug information and advice is available on an equitable basis across all sites and patient groups.

Recommendations

- Workforce planning and resource issues should be addressed, including cover during periods of staff leave, to ensure a comprehensive pharmacy service is available for all renal patients.
- Trusts should ensure that pharmacy advice is available at all out-patient renal clinics.
- All drug therapy protocols should be dated and have a date for systematic review.
- All patients should have access to advice from a designated renal pharmacist.

Examples of local initiatives

Glasgow Royal Infirmary Renal Unit

Drug protocols are continuously available on the Proton database to all members of staff. These protocols are updated regularly.

Queen Margaret Hospital Renal Unit

Each patient is provided with an individualised drug chart which details the name and a description of each drug they have been prescribed. The chart also explains dosage, when the drug must be taken and the purpose of each drug.

Raigmore Hospital Renal Unit

The review team commended the use of a form which in-patients on the ward sign when they receive a copy of the electronic Immediate Discharge Letter. This letter confirms that medical and nursing staff have provided an explanation of their drugs, and that they have understood what they have been told.

2.7 Standard 7: Access to Multidisciplinary Team

Standard Statement

All people with end stage renal failure have access to a multidisciplinary team.

Essential Criteria

- 1. In addition to the regular medical and nursing staff, patients are referred to the following services when required: physiotherapy; pharmacy; dietetics; occupational therapy; designated social worker with a recognised postgraduate qualification and/or renal experience; primary healthcare team; community hospitals (where applicable); transplant co-ordinator/liaison nurse; counselling service; clinical psychology; liaison psychiatry.**

This criterion was met in 2/10 renal units.

The major contributing factor for units not meeting all parts of this criterion was identified as a lack of provision of certain services. In half of all renal units, there is limited or no access to counselling services. In addition, review teams noted issues around access to clinical psychology, physiotherapy, occupational therapy and social work services. In some units, long waiting times influence referral to these services; in other instances there is limited access to these services for renal out-patients. A further concern is the reliance on non-Trust funding for a variety of services, most typically social work and occupational therapy. Alternative funding is often provided by the British Kidney Patients' Association for periods of 2-4 years.

- 2. Dialysis patients are regularly and confidentially reviewed by a multidisciplinary team including medical and nursing staff, dieticians and pharmacists.**

This criterion was met in 4/10 renal units.

Although in most units, dialysis patients are regularly reviewed on a confidential basis by a multidisciplinary team, it was noted that the pharmacist is not always involved in this review.

In two of the four units achieving the criterion, good examples of multidisciplinary team working were seen, with the social worker and occupational therapist attending multidisciplinary team meetings in one instance, and attendance from the renal administrator in another instance.

Strengths

- Each unit is aware of the need for patients to have access to all members of the multidisciplinary team, and most are working towards this.
- Most units seem to have a team, but the composition of the team is not always complete, as detailed in the criterion.

Challenges

- Only two units provide access to the full range of services required by the standard.
- There are particular challenges for access to counselling, psychology and social work services.
- The reliance on 'soft monies' to fund posts. There is a need to plan how to make future provision for posts funded in this way.
- Units need to recognise the value of professional counselling staff as opposed to counselling by nursing staff.
- In relation to patient review, where the multidisciplinary team is not complete, this is mainly due to the lack of a pharmacist.

Recommendations

- Trusts should consider the review of appropriate resources to ensure patients have access to all relevant services.
- Trusts should ensure that all patient groups are reviewed by the full multidisciplinary team.

Examples of local initiatives

Dumfries & Galloway Royal Infirmary Renal Unit

The review team commended the organisation of renal nursing staff whereby each individual has a special area of expertise and acts as a link nurse for that specialty.

Monklands Hospital Renal Unit

The provision of palliative care support for renal patients was commended by the review team. A dialysis nurse, who has been trained in palliative care, provides four sessions per week. Funding for this service is provided by the British Kidney Patients' Association.

2.8 Standard 8: Assessment for Transplantation

Standard Statement

All dialysis patients are assessed for suitability of transplantation within 3 months of starting dialysis.

Essential Criteria

- 1. All patients are assessed for transplantation within 3 months of starting dialysis and those suitable are referred to a Transplant Centre.**

This criterion was met in 9/10 renal units.

Overall, there are systems in place to ensure that all patients are assessed for transplantation within 3 months of starting dialysis. The role of a transplant co-ordinator/link nurse, in ensuring prompt assessment of patients at two units, was commended by review teams.

The only unit which did not meet the criterion had recently introduced a database system, to facilitate prompt assessment of patients for transplantation. It was not clear to the review team whether the system had been fully implemented at the time of the visit.

- 2. Patients referred are seen by a nephrologist and surgeon from the Transplant Centre.**

This criterion was met in 6/10 renal units.

All patients referred are seen by a surgeon from the Transplant Centre in all cases. All patients should also be seen by a nephrologist with experience in acute complications of transplant surgery, and this occurs in the majority of units throughout Scotland.

The four units which did not meet this criterion are situated in the east of Scotland, and three out of the four refer patients for kidney transplantation to the Royal Infirmary of Edinburgh Transplant Unit. It was noted that some units questioned the need for patients to be seen by a nephrologist at the Transplant Centre, if they are also being followed up by a nephrologist from the referring unit.

3. Decisions regarding the patient's assessment at the Transplant Centre are communicated in writing, to the patient, the GP and, where appropriate, the carer.

This criterion was met in 4/10 renal units.

In most cases, decisions regarding the patient's assessment at the Transplant Centre are communicated in writing to the patient's GP. In four of the six units not achieving the criterion, it was noted that patients are notified in writing only if they are added to the transplant waiting list. In all other cases, decisions regarding the patient's assessment are communicated verbally to patients, and carers where appropriate. It was acknowledged that the requirement to communicate all decisions in writing to patients, regarding their assessment, is a recent introduction following recommendations from patient representatives. Although some units visited questioned the need for this requirement, it was noted that some patients who were interviewed during the review visits, remained unclear as to whether or not they were on the transplant waiting list.

4. All patients on dialysis are reviewed annually for their suitability for transplantation.

This criterion was met in 8/10 renal units.

Overall, there are systems in place to ensure that all patients on dialysis are reviewed at least annually for their suitability for transplantation. In many cases, review is more frequent, forming part of regular patient reviews.

In one unit which did not meet the criterion, a major contributing factor for this was insufficient staff and clinical time, and it was noted that a business case had been prepared, outlining the need for additional resources. The second unit was unable to demonstrate evidence of a system being in place for the routine annual review of all patients on dialysis for their suitability for transplantation. However, it was noted that this unit had systems in place to review all patients on the transplant waiting list at the second anniversary and annually thereafter.

5. All patients on the waiting list are informed of the outcome of their annual review either orally or in writing.

This criterion was met in 5/10 renal units.

Half of all units ensure that all patients on the waiting list are informed of the outcome of their annual review either orally or in writing. Typically, this information is communicated orally, with only one unit sending patients written confirmation of the outcome of their annual review. It was noted that some patient interviews, carried out during the review visits, highlighted the uncertainty amongst patients as to their status on the transplant waiting list.

6. The percentage of dialysis patients on the waiting list for transplantation is monitored and reviewed annually.

This criterion was met in 9/10 renal units.

Overall, the percentage of dialysis patients on the waiting list for transplantation is monitored on a regular basis, and reviewed at least annually. The one unit which did not meet the criterion reviews individual patients on the waiting list on a monthly basis. However, there was no evidence that the overall percentage of patients on the waiting list is reviewed annually.

7. The unit takes part in the Renal Donor Sharing Scheme operated by UK Transplant.

This criterion was met in all renal units.

Every unit in Scotland takes part in the Renal Donor Sharing Scheme, which is operated by UK Transplant.

8. Type 1 diabetic patients with renal failure are considered for combined pancreas and kidney transplant.

This criterion was met in all renal units.

Type 1 diabetic patients with renal failure are considered for combined pancreas and kidney transplant in all units across Scotland. It was noted that staff at the Royal Infirmary of Edinburgh Transplant Unit are keen to heighten awareness of the potential benefits of this type of transplant more widely across Scotland.

Strengths

- All units in Scotland participate in the Renal Donor Sharing Scheme operated by UK Transplant.
- All units consider Type 1 diabetic patients with renal failure for combined pancreas and kidney transplantation.

Challenge

- Providing written correspondence with patients regarding the outcome of transplant assessment and reviews.

Recommendations

- Units in the east of Scotland should establish a system to ensure all patients are seen by a nephrologist from the Transplant Centre.
- All units should introduce a system for communicating in writing to the patient to clarify all decisions made at the transplant assessment clinic, with regard to transplantation.
- A system to ensure that patients are kept informed of their status on the transplant waiting list should be established.

Examples of local initiatives

Dumfries & Galloway Royal Infirmary Renal Unit, Dumfries

It was noted that a recent development at Dumfries & Galloway Royal Infirmary Renal Unit is to communicate the outcome of the annual review with all patients on the waiting list. In addition, the review team commended the role of the local link nurse for transplant, who accompanies patients on their first visit to the transplant clinic at the Western Infirmary, Glasgow. This was felt to be beneficial not only to the patient, but also to the renal unit in receiving feedback about the assessment.

Western Infirmary Renal Unit, Glasgow

The review team commended the recent introduction of letters, which are sent to patients detailing information regarding the outcome of their assessment at the Western Infirmary Transplant Unit.

2.9 Standard 9: Kidney Retrieval

Standard Statement

The removal and use of cadaver kidneys for transplantation is carried out to optimise the quality of future renal function.

Essential Criteria

1. Kidneys are retrieved by a transplant surgeon experienced in the procedure.

This criterion was met in 1/3 transplant unit.

With the exception of one transplant unit, there was evidence to suggest that kidneys are not always retrieved by an experienced transplant surgeon in Scottish renal units. This issue is UK-wide and results from a shortage of trained transplant surgeons and trainee medical staff. It particularly impacts on smaller transplant units. It was noted that this issue is being addressed by the Scottish Transplant Group, which has proposed that a National Organ Retrieval Team be established for Scotland.

2. Cold storage time is below 24 hours, where possible.

This criterion was met in all 3 transplant units.

All transplant units in Scotland ensure that cold storage time is below 24 hours, where possible.

3. Reasons for cold storage exceeding 24 hours are documented.

This criterion was met in 2/3 transplant units.

Only one transplant unit in Scotland did not achieve this criterion, although staff had a good awareness as to the reasons for cold storage exceeding 24 hours.

4. Documentation of damage to retrieved kidneys is sent with the donor kidney to the transplant unit.

This criterion was met in all 3 transplant units.

This criterion was achieved by all transplant units in Scotland. It was noted that this is also a requirement of UK Transplant, a UK-wide Special Health Authority whose key role is to ensure that donated organs are matched and allocated in a fair and unbiased way throughout the UK.

5. A minimum of 70% of donor kidneys from people on artificial ventilation, who are confirmed to be dead by brain stem testing, function immediately.

This criterion was met in 1/3 transplant unit.

This criterion relates to cadaver donor kidneys, ie kidneys from a person who has been confirmed to be dead, and where appropriate permissions have been given for donation.

In one transplant unit, the data provided were too small to be representative due to the small size of the unit. A major contributing factor for the criterion not being met at the second transplant unit was the lack of availability of operating theatres.

6. The percentage of kidneys that never function is no more than 5% for people on artificial ventilation, who are confirmed to be dead by brain stem testing.

This criterion was met in 1/3 transplant unit.

In one transplant unit, the data provided were too small to be representative due to the small size of the unit. A major contributing factor for the criterion not being met at the second transplant unit was the lack of availability of operating theatres. An additional factor identified was the higher rate of acceptance of kidneys from marginal donors at one transplant unit which narrowly missed meeting the target percentage.

Strengths

- Cold storage time is below 24 hours, where possible.
- All units send documentation of damage to retrieved kidneys with the donor kidney to the transplant unit.

Challenges

- Retrieval of kidneys by transplant surgeons experienced in the procedure.
- Shortage of transplant surgeons. It was noted that this is a UK-wide issue, which requires to be addressed at a national level.

Recommendations

- All appropriate transplant units should document the reasons for cold storage exceeding 24 hours.
- Trusts should ensure that transplant operations are not delayed by lack of theatre availability.
- There should be on-going review of the proposal for a Scottish National Organ Retrieval Team.

2.10 Standard 10: Survival Rates

Standard Statement

Patient and transplant survival rates following kidney transplantation are within acceptable limits.

Essential Criteria

1. **Following live related donor kidney transplantation: Patient survival rate is a minimum of 95% at 1 year; Transplant survival rate is a minimum of 93% at 1 year.**

This criterion was met in all 3 transplant units.

Review teams commended the high patient and transplant survival rates following live related donor kidney transplantation at all transplant units.

2. **Following first cadaver kidney graft transplantation: Patient survival rate is a minimum of 95% at 1 year and a minimum of 80% at 5 years; Transplant survival rate is a minimum of 85% at 1 year and a minimum of 66% at 5 years.**

This criterion was met in all 3 transplant units.

Review teams commended the high patient and transplant survival rates following first cadaver kidney graft transplantation.

3. **Transplant patients are reviewed regularly by a nephrologist or transplant surgeon.**

This criterion was met in 8/10 renal units.

Transplant patients from all units are reviewed regularly by a nephrologist or transplant surgeon. In most cases this is initially undertaken at the transplant unit, before care of the patient is transferred back to the referring unit. In the case of two renal units, review teams assessed the criterion as 'not applicable' as all transplant follow-up takes place at the transplant unit to which patients are referred.

Strengths

- High rate of patient and transplant survival following both live related donor kidney transplantation and first cadaver kidney graft transplantation.
- The short and medium term results for patient and transplant survival rates uniformly exceed the standards set by the British Transplantation Society.

Challenge

- Maintaining these good results.

Recommendations

- No recommendations were identified.

2.11 Standard 11: Out-patients

Standard Statement

Waiting times for new patient appointments are within acceptable limits and clinic letters are sent out with minimum delay.

Essential Criteria

- 1. New patients are offered an appointment to be seen within 1 month of referral.**

This criterion was met in 1/10 renal unit.

Although almost all of the units did not meet the target of offering new patients an appointment to be seen within 1 month of referral, it was noted that many areas have put in place effective prioritisation systems to ensure urgent cases are seen quickly. Contributing factors for units not meeting this criterion are mainly limited medical staffing, which results in limited clinic time being available to see patients. There is also evidence of systems in place to enable patients living at a distance to be admitted directly to the renal ward, in order to minimise waiting times. In addition, some units are looking at ways of restructuring clinics or introducing systems to ensure investigations are carried out prior to the clinic appointment, to ensure full information is available at the clinic appointment.

- 2. Clinic letters are sent to the GP within 2 weeks of being seen by a nephrologist.**

This criterion was met in 3/10 renal units.

Although three renal units met this criterion, it was noted that one of these was achieving the target through secretarial staff working excess hours. Overall, the major contributing factor for renal units not meeting this criterion was limited secretarial support. Additional issues identified included delays in receiving patients' test results which impacted on ability to issue clinic letters timeously.

3. Changes in medication are communicated to the GP via the patient using a written note or by updating a drug booklet.

This criterion was met in 9/10 renal units.

Although most renal units had systems in place to ensure changes in medication are communicated to the GP, issues were highlighted with regard to communication systems and the potential for error within these. The one renal unit which did not meet the criterion had an identified issue with a small subgroup of patients whereby changes in medication were only communicated via clinic letters. These were sent directly to the GP, although often with some delay.

Strengths

- Even where the target for offering new patients an appointment is not being achieved, there are systems for prioritisation of urgent cases for appointments, which are commendable. However, it was noted that this system does not address patients' anxiety.
- At most sites, changes in medication are communicated to the GP via the patient using a written note or by updating a drug booklet.

Challenges

- Offering all new patients an appointment to be seen within 1 month of referral, in order to alleviate patients' anxiety in respect of how serious, or not, their condition may be.
- Sending out all clinic letters to the GP within 2 weeks of a patient being seen by a nephrologist.

Recommendations

- All Trusts should provide sufficient clinical staffing to ensure all new patients can be offered an appointment within the time limits set by the standard.
- All Trusts should provide sufficient secretarial support to ensure all clinic letters are sent out within the time limits set by the standard.

Examples of local initiatives

Aberdeen Royal Infirmary Renal Unit

The review team commended the development of an electronic referral system for GPs as part of a national initiative. This system will enable GPs to book their patients' appointments directly with the unit, and receive an appointment date at the time of booking.

Western Infirmary Renal Unit, Glasgow

The review team commended the patient drug record booklet in which changes in medication are recorded, and also the detailed letters outlining patients' results and current medication that are sent to GPs from Inverclyde Royal Hospital every 3 months.

2.12 Standard 12: Provision of Patient Information

Standard Statement

All people with chronic renal failure or on renal replacement therapy, and carers where appropriate, are given information to help them make informed choices.

Essential Criteria

- 1. All people diagnosed with chronic renal failure, and carers where appropriate, are provided with appropriate information materials which are evidence-based, identify treatment options, possible outcomes, risks, possible side-effects, and sources of further information.**

This criterion was met in 9/10 renal units.

The high standard of written information provided to patients at most units was commended by review teams. As well as provision of information, review teams were looking for evidence of individualisation and effective communication of this information to patients to ensure it is understood.

Some good examples of ways in which this was facilitated included home visit programmes, evening meetings to which new patients, and carers where appropriate are invited, dedicated telephone advice lines, and tailored individualised information, including in braille and languages other than English.

The one unit which did not meet this criterion had some difficulty in providing information to all groups of patients.

2 Medical and nursing staff discuss possible treatment options which may include home and hospital dialysis, CAPD and APD, cadaver and live donor transplantation, with patients, and carers where appropriate, at a dedicated appointment or home visit.

This criterion was met in 8/10 renal units.

Overall, discussion of treatment options with patients was well addressed with examples of pre-dialysis nurses and pre-dialysis clinics as means of facilitating information provision and discussion. In addition, there were examples of home visits and carer involvement in discussions.

In one unit, it was highlighted that when treatment options were being discussed with patients, availability of automated peritoneal dialysis (APD) could be an issue due to the cost of this treatment.

3. Patients, and carers where appropriate, are involved in decisions about treatment and changes in treatment.

This criterion was met in 9/10 renal units.

There was evidence of patients, and carers where appropriate, being fully involved in decisions about treatment and changes in treatment. A multidisciplinary approach was evident at many units, with demonstrations of systems for documenting decisions made and clinics being open to carers to ensure their involvement.

The one unit which did not meet this criterion had some difficulty in providing information to all groups of patients.

Desirable Criterion

4. There is a designated pre-dialysis nurse specialist.

This criterion was met in 5/10 renal units.

Half of the renal units had in post a designated pre-dialysis nurse specialist. It was noted that some of these posts were funded on a short-term basis only, and not always by the Trust/NHS Board.

Strengths

- Most units provide comprehensive information to all patients, and carers where appropriate. In many cases the quality of information provided was commended by review teams.
- There were a range of innovative examples of ways in which information is provided, including home visit programmes, evening meetings and a range of formats of information.

Challenges

- Tailoring of information to individual patient needs.
- Provision of pre-dialysis nurse specialists at all units.

Recommendation

- All Trusts should consider the development of pre-dialysis nurse specialist roles.

Example of local initiatives**Dumfries & Galloway Royal Infirmary Renal Unit**

At meetings held twice a year in Dumfries and Stranraer, pre-dialysis patients and their carers are able to meet staff, and learn more about renal failure. Good links exist between the renal unit and the Kidney Patients' Association. In addition, informal study days for both patients and carers are held at venues outwith the hospital.

Ninewells Hospital Renal Unit

The review team commended the pre-dialysis education meetings for patients and carers. These meetings are held during the evening. Members of the multidisciplinary team cover a variety of topics relevant to the pre-dialysis patient.

2.13 Standard 13: Transportation for Haemodialysis

Standard Statement

Delays for patients attending for dialysis are minimised through reasonable measures taken by the Trust.

Essential Criteria

1. 50% of all patients using hospital transportation are collected from home within half an hour of their allotted pick-up time, and all are collected within 1 hour.

This criterion was met in 7/10 renal units.

Apart from one unit, where the data were unclear, the remaining nine renal units presented data which indicated that 50% of patients are collected from home within half an hour of their allotted pick-up time. However, only seven units were able to confirm that all patients were collected within 1 hour.

It was, however, significant that at many of the units which met the criterion, staff and patients confirmed that their perception was that the audit findings were not representative. Without repeating the audit, it is not possible to determine whether the discrepancy was a result of mistaken perception or an unrepresentative audit.

It was noted that, in some cases, patients were being picked up in advance of their allotted pick-up time. Although this would ensure that the criterion was met, it was agreed that this is not desirable as these patients are then likely to have a prolonged wait at the renal unit before starting dialysis.

Examples of systems for patient transport which have resulted in improved transport performance included a dedicated renal transport system run by the Red Cross, a system for using lease cars with dedicated drivers and a car system for twilight dialysis shifts. There were good examples of collaborative working between renal units and the Scottish Ambulance Service, including a scheme where ambulance service staff had spent some time working in the renal unit.

2. 50% of all patients begin dialysis within half an hour of appointment time, and all begin within 1 hour.

This criterion was met in none of the renal units.

Apart from one unit where the data were unclear, the remaining nine renal units all presented data which indicated that 50% of patients begin dialysis with half an hour of appointment time. However, no unit was able to confirm that all patients started dialysis within 1 hour.

Contributing factors included limited staffing to start patients on dialysis and fixed appointment times, such that a group of patients were due to start dialysis at the same time. However, it was acknowledged that the target of 100% of patients starting dialysis within 1 hour does not allow for contingency if, for example, a patient is late arriving or a previous patient's dialysis shift runs over time. The target is therefore challenging, although a number of units came very close.

3. 50% of all patients using hospital transportation are collected within half an hour of the end of dialysis, and all are collected within 1 hour, provided they are clinically fit.

This criterion was met in 1/10 renal unit.

Apart from one unit where the data were unclear, the remaining nine renal units all presented data which indicated that 50% of patients are collected within half an hour of the end of dialysis. However, just one unit was able to confirm that all patients were collected within 1 hour.

Issues were identified with regard to the use of emergency ambulances, which were not always available, as well as grouping patients together for transportation particularly on the homeward journey, such that patients had to wait together for one vehicle.

Again, it was acknowledged that the target of all patients being collected within one hour did not make any provision for contingency if, for example, a patient was late finishing dialysis. The target is therefore challenging.

4. Reasons for delays of more than an hour are documented.

This criterion was met in 4/10 renal units.

It was agreed that documentation of the reasons for delays of more than 1 hour is important, but the action taken is more crucial.

Examples of effective systems included a transport audit tool in place at one unit and the provision of a local co-ordinator to work with the Scottish Ambulance Service, which had resulted in an improved service, at another unit.

5. Patients who wait for hospital transport do so in comfortable surroundings.

This criterion was met in 4/10 renal units.

The major contributing factors for this criterion not being met were insufficient capacity for the number of patients and the lack of availability of a comfortable waiting area. It was noted that in a few units, despite provision of a waiting area, patients choose not to wait in this area due to the risk that they may be missed for transport collection. In some cases the waiting area was in an inappropriate location; in other cases it was not comfortable.

It was noted that some units had plans in place to refurbish waiting areas.

Desirable Criterion

6. Within the constraints of population density and geography, a unit is available within half an hour's travelling time for patients.

This criterion was met in 1/10 renal unit.

It was acknowledged that measurement of performance against this criterion is necessarily subjective; however, the criterion was included to ensure renal units were considering the possibility of satellite units where appropriate, to minimise travelling times for patients.

Although nine renal units were assessed as not met, the impact was greatest in remote and rural areas, with some patients making extremely lengthy journeys on a regular basis for haemodialysis. Even in areas where there was provision of satellite units it was noted that some of these were working to capacity which resulted in patients living in the catchment area for the satellite unit having to travel to the main unit as the satellite unit was full.

Most units recognised that establishment of more satellite units would alleviate the problem and many had put plans for more satellite units in place. However, these plans were not always formalised, approved or funded.

Strengths

- Collection of patients using hospital transportation within 1 hour of their allocated pick-up time.
- Innovative developments at some units to improve transportation for haemodialysis.

Challenges

- Ensuring all patients begin dialysis within 1 hour of appointment time, and all patients using hospital transportation are collected within 1 hour of the end of dialysis, providing they are clinically fit.
- Documentation of reasons for delays of more than 1 hour.
- Provision of comfortable surroundings which patients are encouraged to use.

Recommendations

- Trusts should ensure that an already long dialysis day for patients is not extended unnecessarily. This would be best addressed by making efforts to improve hospital transportation so that no patient waits for more than half an hour from their allocated time to be collected from home, or to be collected at the end of dialysis. In addition, efforts should be made to ensure that all patients begin dialysis without undue delay.
- All Trusts should provide, at all units and satellite units, comfortable and appropriately sited waiting areas, with sufficient capacity for the number of patients.

Examples of local initiatives

Aberdeen Royal Infirmary Renal Unit

The review team commended the dedicated renal transportation service, which is currently run by the Red Cross with new funding from NHS Grampian. This service was developed following a review carried out in 1999. While it was recognised that some developments could still be made to the service, both patients and staff reported that it had resulted in good improvements in waiting times for collection from, both home before dialysis, and from hospital at the end of dialysis.

Glasgow Royal Infirmary Renal Unit

The review team commended the use of cars for patients on the twilight dialysis shift. These cars are driven by ambulance drivers.

Monklands Hospital Renal Unit

The review team commended the dedicated renal transportation system which is in place. Jointly funded by NHS Lanarkshire, Lanarkshire Acute Hospitals NHS Trust and the Scottish Ambulance Service, the service is operated by the latter in liaison with the renal unit. Dedicated drivers have been trained specifically in the needs of renal patients, and transport the same patients to their dialysis sessions, facilitating good relationships between drivers and patients. A dedicated staff member from the renal unit works with the Scottish Ambulance Service to schedule the pick-up and collection of patients. Implementation of the system has resulted in a reduction in the waiting time for transportation to and from dialysis.

Raigmore Hospital Renal Unit

The review team welcomed the acceptance of a business case for a four-space satellite unit in Wick, which will help to improve the travelling times for dialysis patients in this area. It is hoped that this unit will be commissioned in January 2003.

Royal Infirmary of Edinburgh Renal Unit

Negotiations are on-going between the renal unit, Scottish Ambulance Service and NHS Lothian, with a view to introducing a dedicated renal patient transport service in spring 2003. It is hoped that this system will facilitate an improvement in the length of time patients wait for transport to and from the unit for dialysis.

2.14 Standard 14: Audit: Information/Data Collection

Standard Statement

There is continuous data collection to facilitate regular national audit through the Scottish Renal Registry.

Essential Criteria

1. There are information systems in place for continuous collection of the Scottish Renal Registry core data set to facilitate audit.

This criterion was met in 9/10 renal units.

Overall, there are computerised information systems in place for continuous collection of the Scottish Renal Registry core data set to facilitate audit. The one unit which did not meet the criterion had no computerised information system in place for the continuous collection of these data; data are therefore being collected manually.

2. The unit takes part in comparative audits of dialysis and transplantation through the Scottish Renal Registry and, where appropriate, UK Transplant.

This criterion was met in all renal units.

All units participate in comparative audits of dialysis and transplantation through the Scottish Renal Registry and, where appropriate, UK Transplant.

3. There is data collection of the following, where appropriate, to facilitate regular audit: Haemodialysis adequacy (monthly for hospital dialysis and every 3 months for home dialysis); Peritoneal dialysis adequacy (6-monthly); Haemoglobin levels (monthly for hospital dialysis and every 3 months for peritoneal and home dialysis); Peritonitis (occurrence, investigation, treatment and cause); Type and time of access surgery; Immediate function of cadaver kidneys; Patient and transplant survival rates.

This criterion was met in 4/10 renal units.

Overall, there is good data collection of most of the elements required by the criterion. The major contributing factor for units not achieving this criterion was the lack of collection of type and/or time of access surgery.

Desirable Criterion

4. There is collection of incidence, management and outcome data on acute renal failure.

This criterion was met in 9/10 renal units.

Although most units are involved in the collection of these data, this is as a result of participation in a national research project. However, it was noted that this study was due to conclude at the end of December 2002. While some units had plans in place to continue collection of these data after the end of the research project, it was noted that other units would be unable to continue without additional funding.

Strengths

- The collation of data and audit through the Scottish Renal Registry.
- Audit for renal services is further advanced than many other clinical services.

Challenges

- To further improve the network of data collection.
- To ensure all data items are routinely collected (eg type and time of access surgery; acute renal failure).
- For some units, electronic transfer to the Scottish Renal Registry database.
- Provision of local IT resources to reduce the time spent undertaking manual data entry.

Recommendations

- Trusts should ensure that all units have a computerised database for all renal patients.
- Provision should be made for all units to automatically download data to the Scottish Renal Registry.
- Trusts should ensure that data collection, especially type and time of access surgery, is carried out.
- Continue to collect as much of the acute renal failure data as possible following the end of the national study in December 2002.

Chapter 3

Conclusions



This national overview and the accompanying local reports set out the performance of NHSScotland as a whole, and of each Trust hosting a renal unit, against the adult renal services standards published in February 2002. A number of general themes have emerged which apply across the country.

Firstly, the review team was struck by the commitment, dedication and hard work of the staff involved in providing renal services, frequently under considerable pressure. It is clear that these services seek, wherever possible, to be responsive to patient needs and a number of innovative service developments were seen. However, the renal units and their satellites are currently at capacity and Trusts need to take this into account when service planning for renal treatment.

There is much informal networking taking place across Scotland among those providing renal services, and the review teams felt that renal services across Scotland may wish to formalise this and set up a Managed Clinical Network. This would allow them to share expertise, specialist resources and data, and will also prompt the development of innovative solutions to the problems faced by those living in remote and rural areas. It is also important to build on the work of the Scottish Renal Registry to take this forward into the future.

Secondly, members of the public have been involved at every stage of the renal services project. This has provided a very valuable perspective to the work of the project group in setting the standards and on review visits. It has also given members of the public a chance to contribute to all aspects of the review process, rather than just receive a report prepared without their input.

Thirdly, review teams found that there are policies and protocols in place for the treatment and care of renal patients. These are underpinned by training and regular refresher courses, and review teams concluded that staff providing renal services across Scotland are well trained, are following clear protocols and have a high level of awareness of the needs of patients with renal conditions.

Finally, review teams found that renal services in Scotland are well organised, and that the outcomes achieved for patients are very successful. There is an urgent need for more organ donors, as this offers people with renal disease a real opportunity to get away from dialysis and the need to attend such frequent clinics. There are also a number of research projects underway that may bear fruit for renal patients in the future. Over the next ten years it is important that there is sufficient theatre time to provide good access for dialysis; that there are

adequate medical staff to ensure these patients receive the care they require; and that support staff are designated to work with renal patients so that even better outcomes can be achieved.

NHS Quality Improvement Scotland looks to each Trust hosting a renal unit, guided by its Clinical Governance Committee, to ensure that, in close collaboration with the staff responsible for providing the service, practice is reviewed in the light of this report's findings and recommendations and appropriate action is taken. Each NHS Board is responsible for the performance of its local NHS services and is accountable to the Scottish Executive Health Department, who will use the reports and local responses to them to monitor local and national performance.

Considerable momentum has been built up and it is important to use this enthusiasm to take forward the work on strengthening and improving renal services. The public, both locally and nationally, also has an important role to play in ensuring the changes are made. NHS Quality Improvement Scotland reserves the right to revisit a unit where it considers there are serious issues that need further external monitoring and report. NHS Quality Improvement Scotland intends periodically to review and raise these standards in light of the latest evidence about 'best practice' and the performance of the service, and to conduct further national and local reviews, so as to encourage continuing quality improvement.

Appendices



Adult Renal Services Project Group Members

Chair

Dr Brian Junor

Consultant Nephrologist, North Glasgow University Hospitals NHS Trust

Project Group Members

Mr Murat Akyol

Consultant Transplant Surgeon, Lothian University Hospitals NHS Trust

Mrs Caroline Arnott

Ward Manager, Fife Acute Hospitals NHS Trust

Dr Gordon Baird

General Practitioner, Dumfries & Galloway Primary Care NHS Trust

Mrs Megan Casserly

Lay Representative, Greater Glasgow

Mrs Rhona Duncan

Renal Dietician, Ayrshire & Arran Acute Hospitals NHS Trust

Mr James Dunleavy

Renal Pharmacist, Lanarkshire Acute Hospitals NHS Trust

Mr Sandy Glass

Lay Representative, Highland

Dr Chris Isles

Consultant Physician/Nephrologist

Dumfries & Galloway Acute & Maternity Hospitals NHS Trust

Ms Lesley Logan

Operations Manager, Renal Medicine, Transplant and Vascular Services,
Lothian University Hospitals NHS Trust (until November 2002)

Project Manager, National Services Division (current)

Professor Alison MacLeod

Honorary Consultant Physician/Nephrologist and Chair of Renal

Association Standards Group, Grampian University Hospitals NHS Trust

Mrs Maureen Perry

Specialist Nephrology Nurse, Tayside University Hospitals NHS Trust

Dr Keith Simpson

Consultant Physician and Chair of Scottish Renal Registry

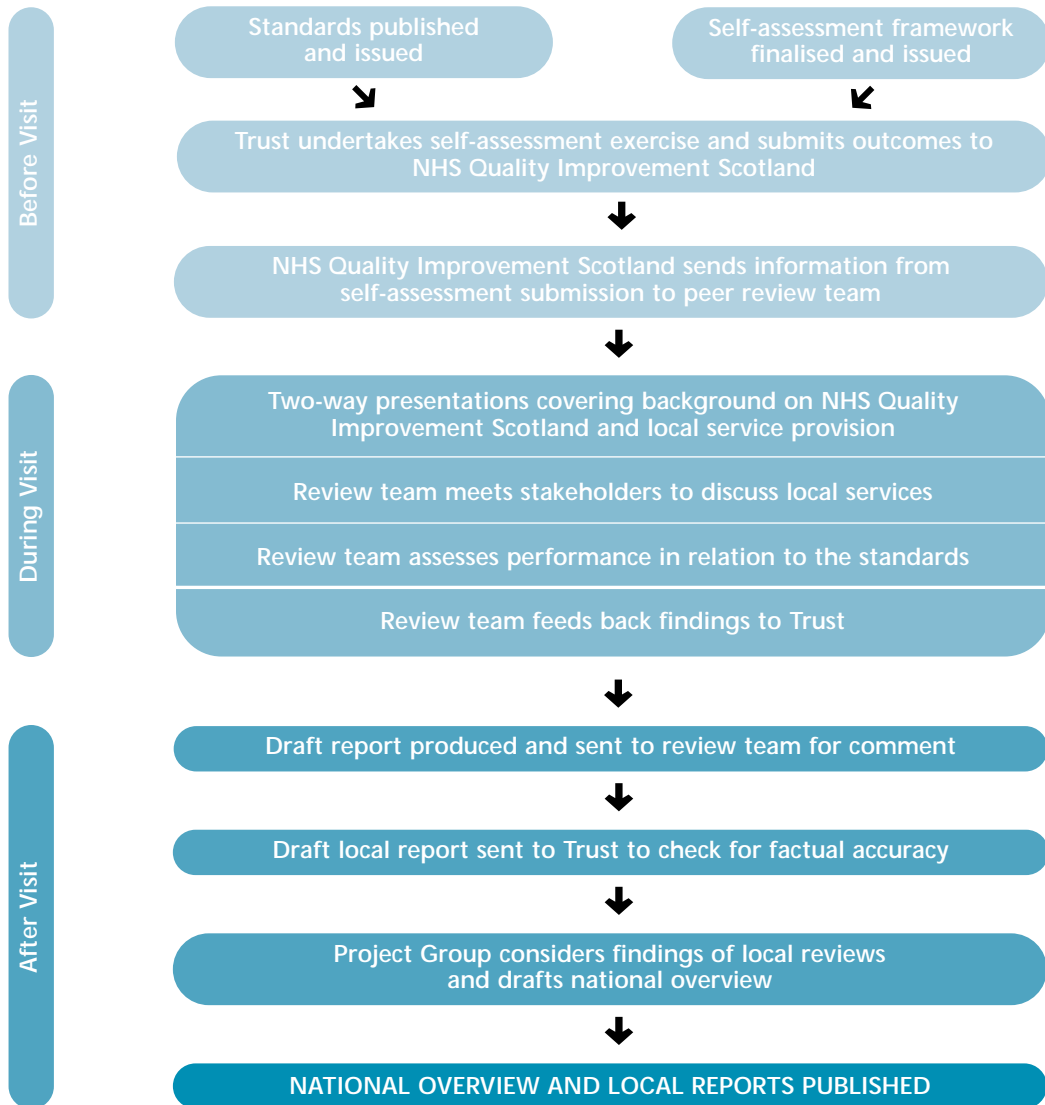
North Glasgow University Hospitals NHS Trust

The Board member specifically working with the Adult Renal Services Project Group was **Professor John Cromarty**.

Support from NHS Quality Improvement Scotland was provided by **Dr David Steel** (Chief Executive), **Mr Sean Doherty** (Review Team Manager), **Ms Rona Smith** (Senior Project Officer), **Mrs Fiona Russell** (nee Dymitrenko; Project Officer) and **Miss Josephine O'Sullivan** (Project Administrator).

Appendix 2

The Quality Assurance Process: Approach Used in this Review



Standards

All standards set by NHS Quality Improvement Scotland comprise a standard statement and related criteria.

Standard Statement

Describes the agreed performance for the specific area, determined by those who are involved in the delivery/receipt of the service.

Criteria

State exactly what must be done for the standard to be reached.

Some criteria are **essential** as it is expected that they will be met wherever a service is provided. Others are **desirable/aspirational** in that they will promote continuous quality improvement as they are being met in some parts of the service and demonstrate levels of quality which other providers of a similar service should strive to achieve.

Self-Assessment

Each set of clinical standards has an accompanying self-assessment framework. This framework gives guidance about the type of evidence required to demonstrate performance against the standards. It is completed and submitted to NHS Quality Improvement Scotland prior to a peer review visit, together with extensive additional documentation. The evidence obtained from this self-assessment exercise comprises the main source of written evidence considered by each peer review team.

Peer Review

Peer review is the process by which a multidisciplinary review team, including members of the public, carries out a renal unit visit to validate the quantitative data submitted through the self-assessment. This is done by means of gathering qualitative information both through discussions with staff in clinical areas, and observation.

During each review, the review team was guided by a team leader to ensure a multidisciplinary consensual assessment was reached. At the conclusion of the review, the review team provided feedback to the renal unit and Trust representatives giving a broad overview of its assessment, which was based on the written self-assessment, and evidence obtained during the review visit.

To enhance the consistency of the process, a NHS Quality Improvement Scotland manager and project officer accompany each visit, both of whom provide the secretariat and developmental support for the project group during the standard-setting phase of a project.

The schedule for an adult renal services external peer review visit included:

- initial meeting with key personnel responsible for the service under review;
- dialogue with clinicians, audit staff and managers based on the written evidence;
- scrutiny of documentation;
- interviews with staff members;
- regular team briefings throughout the day to assess progress and to compile the local report; and
- feedback to the renal unit and Trust representatives on conclusion of the visit.

In addition, the review team met with patient representatives, who were randomly selected by the Scottish Renal Registry, and patient group representatives from the area served by the renal unit.

The review team for each peer review visit comprised different people. Although this presents challenges in achieving consistency of process, it promotes sharing of good practice and ensures that each review team assesses the performance of a renal unit against the standards, not by comparing one unit with another.

In order to determine whether a particular criterion is 'met' or 'not met', each review team requires to identify evidence on a variety of levels. For example, to demonstrate that a particular issue is addressed in a local protocol, evidence is sought during the peer review process as follows:

- description of the issue and how it should be managed in a local written protocol (submitted as part of the self-assessment);
- confirmation of awareness of the location and content of the protocol through staff interviews;
- evidence of a process in place for the protocol to be regularly updated; and
- collection of data through an integrated care pathway/audit sheet, leading to provision of collated audit data confirming compliance with the local protocol.

Until a legal interpretation of the Data Protection Act is made as to whether patient records can be accessed for purposes other than managing patient care, review teams are not scrutinising individual patient records. Therefore, in cases where it is stated that information is recorded in individual patient case notes, and the claim is corroborated in staff interviews during the visit, an assessment of 'met' will be made.

The responsibilities of NHS Quality Improvement Scotland include reporting whether the services provided by NHSScotland, both nationally and locally, meet agreed standards, and do not include reviewing the work of individual healthcare professionals. In achieving this aim, variations in practice (and potential quality) within a service will be encountered. Where such variation exists between hospitals (eg between a main renal unit and its satellite unit(s)), this will be stated; treatment variations will also be reported, but will not identify patients or healthcare professionals.

Reports

A local written report was drafted at the time of each visit. Draft reports were then circulated to the review team for comment, and to the Trust concerned to allow a check for factual accuracy.

On conclusion of the peer review programme, the project group reconvened to study the findings and examine trends in order to draw conclusions and make recommendations to NHS Quality Improvement Scotland.

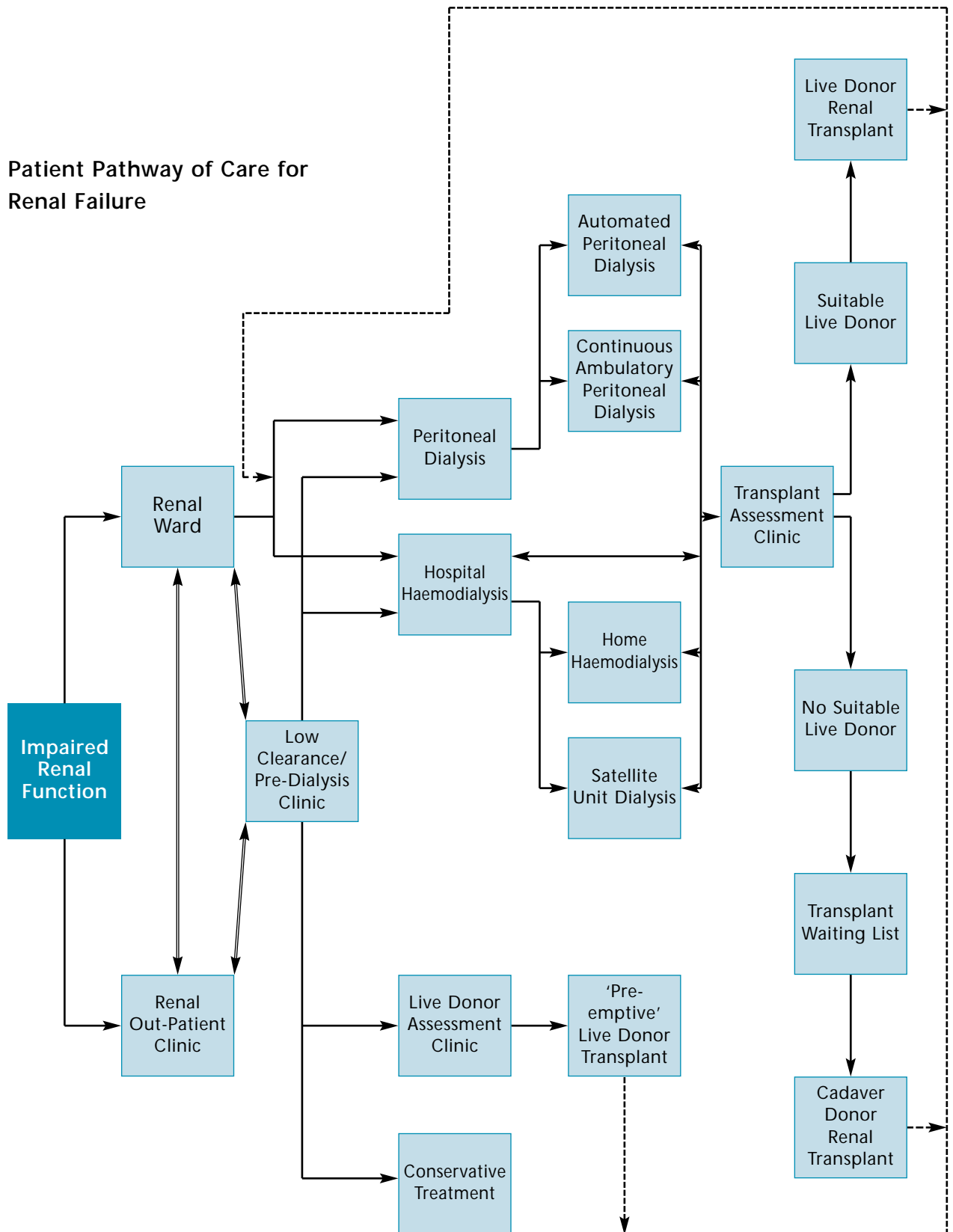
Appendix 3

Co-ordinating Adult Renal Services Care

Patient Pathway of Care for Renal Failure

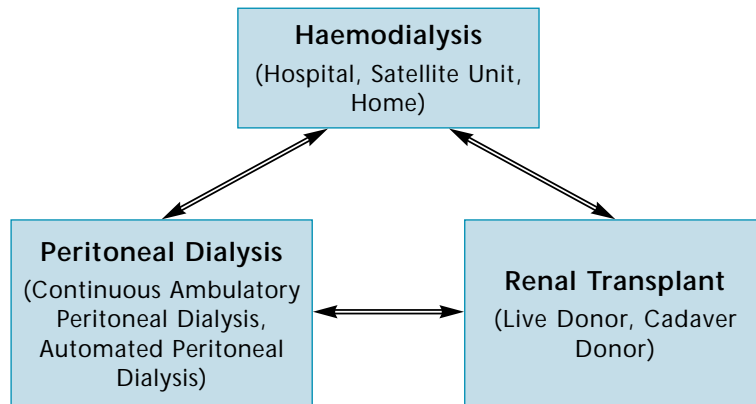
Stage	Initial Contact and Referral	Diagnosis and Options for Treatment	Treatment and Care	Monitoring and Follow-up
What might happen	<ul style="list-style-type: none"> • discussion of symptoms causing concern • routine screening tests • referral to hospital • sudden loss of renal function (eg due to injury, infection) 	<ul style="list-style-type: none"> • tests: <ul style="list-style-type: none"> – blood tests – ultrasound – CT scan – kidney biopsy • information and advice • discussion of options 	<ul style="list-style-type: none"> • reviewing diet • drugs • anaemia control • dialysis access surgery • peritoneal dialysis • haemodialysis • home haemodialysis • pre-emptive live donor transplant • live/cadaver donor renal transplant • information • counselling support • social work support 	<ul style="list-style-type: none"> • tests (eg haemodialysis and peritoneal dialysis adequacy, haemoglobin, iron status) • transplant assessment • check-up
Where	<ul style="list-style-type: none"> • GP surgery • out-patient clinic • A&E unit • renal ward 	<ul style="list-style-type: none"> • hospital • home visits by pre-dialysis nurse • other venues – renal information sessions 	<ul style="list-style-type: none"> • hospital (main or satellite renal unit) • clinics • GP surgery • home 	<ul style="list-style-type: none"> • hospital (main or satellite renal unit) • clinics • GP surgery
Who may be involved	<ul style="list-style-type: none"> • GP • practice nurse • A&E staff • nephrologist • specialist nurse 	<ul style="list-style-type: none"> • physician • nephrologist • urologist • GP • specialist nurse • radiologist • patient support organisations (eg Kidney Patients' Association) 	<ul style="list-style-type: none"> • dietician • pharmacist • surgeon • nephrologist • specialist nurse • transplant co-ordinator • social worker • GP • other health professionals (eg physiotherapist, psychologist) 	<ul style="list-style-type: none"> • nephrologist • surgeon • dietician • pharmacist • specialist nurse • GP

Patient Pathway of Care for Renal Failure



Patient Pathway of Care for Renal Failure

During a life-time of care on renal replacement therapy, patients may move between forms of therapy a number of times. It is possible to move between dialysis treatments, depending on which will be most effective for the patient in terms of their health and circumstances. For patients receiving a renal transplant, in some cases, this will last many years. However, in most cases, the patient will require a further period of dialysis treatment in the future.



Adult Renal Service Review Team Members

Sister Stella Adam

Sister, Grampian University Hospitals NHS Trust

Mr Murat Akyol

Consultant Transplant Surgeon, Lothian University Hospitals NHS Trust

Sister Anne Allan

Clinical Ward Manager, Highland Acute Hospitals NHS Trust

Ms Helen Anderson

Lay Representative, Lothian

Dr Mark Andrews

Consultant Nephrologist, Tayside University Hospitals NHS Trust

Mrs Caroline Arnott

Ward Manager, Fife Acute Hospitals NHS Trust

Dr Gordon Baird

General Practitioner, Dumfries & Galloway Primary Care NHS Trust

Mrs Doreen Bell

Lay Representative, Fife

Dr Carol Brunton

Consultant Nephrologist, Highland Acute Hospitals NHS Trust

Mrs Catherine Bryce

Lay Representative, Grampian

Ms Jane Bryce

Lay Representative, Highland

Ms Susan Christie

Renal Dietician, Lothian University Hospitals NHS Trust

Mr Tony Collins

Lay Representative, Grampian

Mrs Adele Cook

Lay Representative, Dumfries & Galloway

Miss Deborah Corner

Principal Clinical Pharmacist, Tayside University Hospitals NHS Trust

Miss Aileen Currie

Renal Pharmacist, Fife Acute Hospitals NHS Trust

Dr Conal Daly

Consultant Nephrologist, Grampian University Hospitals NHS Trust

Mrs Rhona Duncan

Renal Dietician, Ayrshire & Arran Acute Hospitals NHS Trust

Mr Jim Dunleavy

Renal Pharmacist, Lanarkshire Acute Hospitals NHS Trust

Mrs Ann Dunlop

Charge Nurse, Ayrshire & Arran Acute Hospitals NHS Trust

Mr Jetmund Engeset

Consultant Transplant Surgeon, Grampian University Hospitals NHS Trust

Professor Stewart Fleming

Professor of Cellular & Molecular Pathology

Tayside University Hospitals NHS Trust

Ms Fiona Gardiner

Renal Dietician

Dumfries & Galloway Acute & Maternity Hospitals NHS Trust

Mrs Marjorie Gaughan

Specialist in Public Health, NHS Ayrshire & Arran

Mr Sandy Glass

Lay Representative, Highland

Miss Alison Glover

Renal Nurse, Lothian University Hospitals NHS Trust

Dr Morag Gorrie

Associate Specialist, North Glasgow University Hospitals NHS Trust

Mr Ken Graham

Consultant Nephrologist, NHS Shetland

Dr Malcolm Hand

Consultant Nephrologist, Lanarkshire Acute Hospitals NHS Trust

Mr John Heaney

Lay Representative, Lanarkshire

Dr Iain Henderson

Consultant Nephrologist, Tayside University Hospitals NHS Trust

Mr William Hoare

Lay Representative, Tayside

Mrs Denise Hogarth

Lay Representative, Ayrshire & Arran

Dr Chris Isles

Consultant Physician/Nephrologist

Dumfries & Galloway Acute & Maternity Hospitals NHS Trust

Ms Leonora Johnston

Lay Representative, Glasgow

Dr Brian Junor

Consultant Nephrologist, North Glasgow University Hospitals NHS Trust

Mr Alistair Lawrie

Nurse - Renal, Fife Acute Hospitals NHS Trust

Ms Lesley Logan

Operations Manager, Renal Medicine, Transplant and Vascular Services,
Lothian University Hospitals NHS Trust (until November 2002)

Project Manager, National Services Division (current)

Ms Jen Lumsdaine

Transplant Co-ordinator, Lothian University Hospitals NHS Trust

Dr Ewan Macaulay

Consultant Vascular Surgeon, Grampian University Hospitals NHS Trust

Mrs Monica MacDonald

Lay Representative, Highland

Ms Alison McGilvray

Lay Representative, Forth Valley

Dr Eilon McGregor

Consultant Nephrologist, North Glasgow University Hospitals NHS Trust

Mr Scott McJarrow

Lay Representative, Grampian

Dr Ian McKay

Consultant Renal Physician, Ayrshire and Arran Acute Hospitals NHS Trust

Professor Alison MacLeod

Honorary Consultant Physician/Nephrologist and Chair of Renal Association Standards Group, Grampian University Hospitals NHS Trust

Mrs Jan McQuat

Renal Dietician, Tayside University Hospitals NHS Trust

Ms Sara Martin

Dietician, Fife Acute Hospitals NHS Trust

Rev Gillian Morton

Lay Representative, Borders

Mrs Elaine Nicol

Clinical Nurse Facilitator – Renal Services
Grampian University Hospitals NHS Trust

Miss Margaret Nicol

Pharmacy Manager, Ayrshire & Arran Acute Hospitals NHS Trust

Ms Maureen O'Neill

Lay Representative, Greater Glasgow

Mrs Geraldine Ovens

Charge Nurse, Ayrshire & Arran Acute Hospitals NHS Trust

Dr Nick Pace

Consultant Anaesthetist, North Glasgow University Hospitals NHS Trust

Mrs Maureen Perry

Specialist Nephrology Nurse, Tayside University Hospitals NHS Trust

Mr Brian Phillips

Lay Representative, Fife

Mr John Prentice

Lay Representative, Greater Glasgow

Miss Andrea Ridealgh

Renal Nurse Specialist, NHS Shetland

Dr Alison Severn

Locum Consultant Nephrologist, Tayside University Hospitals NHS Trust

Dr Keith Simpson

Consultant Physician and Chair of Scottish Renal Registry
North Glasgow University Hospitals NHS Trust

Mr Russell Smith

Lay Representative, Lanarkshire

Mrs Lorna Thomson

Renal Pharmacist, Lothian University Hospitals NHS Trust

Mrs Audrey Warden

Clinical Team Manager, Tayside University Hospitals NHS Trust

Mrs Patricia Weir

Lay Representative, Argyll & Clyde

Dr Caroline Whitworth

Consultant Nephrologist, Lothian University Hospitals NHS Trust

Ms Lindsey Wilson

Clinical Nurse Manager – Renal
Grampian University Hospitals NHS Trust

Dr Robin Winney

Consultant Renal Physician, Lothian University Hospitals NHS Trust

Appendix 5

Glossary of Terms

abdominal cavity	The space in the abdomen (the area between the chest and pelvic bone) that contains the intestines and other internal organs.
access	Entry to the bloodstream for haemodialysis or entry to the abdominal cavity for peritoneal dialysis.
accreditation	A process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.
acute renal failure	The rapid loss of kidney function over a few hours or days.
acute sector	Hospital-based health services which are provided on an in-patient or out-patient basis.
adequacy	Refers to how well dialysis replaces the function of the kidneys.
AHP	See allied health professions.
allied health professions (AHP)	Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dieticians, etc. Formerly known as professions allied to medicine (PAM).
allocation	The matching of an organ to a patient based on blood and tissue type.
anaemia	A reduction in the quality of the haemoglobin in the blood. The main symptoms are excessive tiredness, breathlessness on exertion, pallor and poor resistance to infection.
anthropometry	The measuring of the human body or a part of the human body.
antibiotic	A chemical substance produced synthetically or by a micro-organism which has the capacity to inhibit the growth of or to kill other microorganisms.
APD	See automated peritoneal dialysis.
arteries	Blood vessels which carry blood away from the heart to supply the tissues.
arteriovenous fistula	A connection between an artery and a vein (this excludes arteriovenous grafts using artificial vessels).

assessment	The process of measuring patients' needs and/or the quality of an activity, service or organisation.
assessment (for transplantation)	The physical examination, tests and studies required to check whether a person is suitable to receive an organ transplant.
audit	A process which allows for the systematic and critical analysis of the quality of care.
automated peritoneal dialysis (APD)	A form of peritoneal dialysis that requires a machine to control the movement of fluid into and out of the peritoneal cavity. APD is carried out at home each night while the patient sleeps.
biochemical	Relating to the chemistry of the body.
biopsy	The removal of a small piece of tissue from an organ or part of the body for histological analysis, microscopic study, or pathologic evaluation.
blood pressure	Blood pressure is related to the force of the heart pumping and the resistance to the flow of blood through the body. It is the pressure of the blood in the main arteries needed to push it through the smaller vessels of the circulation.
blood transfusion	The infusion of a volume of blood obtained from a healthy person into the bloodstream of a patient whose blood is deficient in quantity or quality, through accident or disease.
brain stem testing	A set of specific tests carried out by doctors to confirm death.
BTS	British Transplantation Society.
cadaver kidney	A kidney that has been donated by a previously healthy person who has died suddenly. Kidneys for donation are removed when the donor's death has been confirmed by brain stem testing but the heart is still beating due to artificial ventilation, and appropriate permission has been given for donation (see Section 1.4).
calcium	A chemical element obtained through diet that is essential in the formation of bones and teeth.
CAPD	See continuous ambulatory peritoneal dialysis.

care plan	A document which details the care and treatment that a patient/user receives, and identifies who delivers the care and treatment.
carer	A person who looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.
catheter	A hollow tube used to transport fluids to or from the body.
chronic	Present over a long period of time.
chronic renal failure	The slow and progressive deterioration of kidney function.
clinical governance	A framework through which NHS organisations are accountable for both continuously improving the quality of their services, and safeguarding high standards of care, by creating an environment in which excellence in clinical care will flourish. Management of clinical risk at an organisational level is an important aspect of clinical governance. Clinical risk management recognises that risk can arise at many points in a patient's journey, and that aspects of how organisations are managed can systematically influence the degree of risk.
Clinical Resource and Audit Group (CRAG)	CRAG was the lead body within the Scottish Executive Health Department promoting clinical effectiveness in Scotland. The main committee, together with its subcommittees provided advice to the Health Department, acted as a national forum to support and facilitate the implementation of the clinical effectiveness agenda and funded a number of clinical effectiveness programmes and projects. On 1 January 2003 CRAG was merged with four other clinical effectiveness bodies to create NHS Quality Improvement Scotland. See NHS Quality Improvement Scotland.
clinical service	Service provided by healthcare professionals.
Clinical Standards Board for Scotland (CSBS)	The Clinical Standards Board for Scotland was a statutory body, established as a Special Health Board in April 1999. Its role was to develop and run a system of quality control of clinical services designed to "promote public confidence that the services provided by the NHS met nationally agreed standards, and to demonstrate that, within the

	resources available, the NHS was delivering the highest possible standards of care". On 1 January 2003, CSBS was merged, along with four other clinical effectiveness bodies, to form NHS Quality Improvement Scotland. See NHS Quality Improvement Scotland.
clinical trial	Research study conducted with patients, usually to evaluate a new treatment or drug. Each trial is designed to answer scientific questions and to find better ways to treat individuals with a specific disease.
cold storage	The process that allows a donated organ to be kept cold in sterile conditions until it reaches the operating theatre for transplantation to the recipient.
community hospital	Local hospitals, units or centres providing an appropriate range and format of accessible health care facilities and resources. These will include in-patient and may include out-patient, diagnostic, day care, primary care and outreach services for patients provided by multidisciplinary teams. Medical care is normally led by GPs in liaison with consultants, nurses and allied health professional colleagues, as necessary. Consultant long-stay beds, primary care nurse-led and midwife services may also be incorporated.
computerised tomography (CT)	An X-ray imaging technique used in diagnosis that can reveal many soft tissue structures not shown by conventional radiography.
conservative management	The treatment of renal failure without dialysis.
continuous ambulatory peritoneal dialysis	A form of peritoneal dialysis in which dialysis fluid is exchanged at regular intervals throughout the day.
contra-indication	Any condition, past or present, which makes a particular line of treatment unsuitable or undesirable.
controlled trials	Studies in which treatments are compared - these may include inactive or placebo therapy.
core data set	The essential information related to a specific medical condition - may include demographic, clinical management and outcome data used for audit and research.

CRAG	See Clinical Resource and Audit Group.
creatinine	A waste product that is removed from the body by the kidneys, and excreted in the urine. A high level of creatinine in the blood indicates kidney damage.
creatinine clearance	A measure used by hospital staff to assess how well the kidneys are working or whether enough dialysis is being provided.
criterion(s)/ criteria(pl)	Provide the more detailed and practical information on how to achieve the standard, and relate to structure, process or outcome factors.
CSBS	See Clinical Standards Board for Scotland.
CT	See computerised tomography.
cytomegalovirus	A virus that can cause several severe infections in patients who have recently had a renal transplant.
data set	A list of required and specific information relating to a specific disease.
data source	The source of evidence to demonstrate whether a standard or criterion is being met.
delayed graft function	A kidney transplant that does not work immediately.
desirable (criterion/criteria)	Good practice that is being achieved in some parts of the service and demonstrates levels of quality to which other providers of a similar service should strive.
diabetes	A disorder characterised by high levels of glucose (sugar) in the bloodstream.
diabetic nephropathy	Kidney disease that has developed as a result of diabetes.
diagnosis	Identification of an illness or health problem by means of its signs and symptoms. This involves ruling out other illnesses and causal factors for the symptoms.
dialysate	A sterile fluid used in dialysis to facilitate the extraction of waste from the blood.
dialysis	A treatment for kidney failure that removes wastes and water from the blood artificially.
dialysis fluid	See dialysate

dietary assessment	An evaluation of the extent to which dietary intake is likely to meet nutritional needs. Factors assessed include current food and fluid intake, duration and severity of any changes in appetite and oral intake, and the presence of factors which may be affecting food and fluid intake.
dietician	An expert in nutrition who helps people with special health needs plan the kinds and amount of foods to eat.
discharge	A discharge marks the end of an episode of care. Types of discharge include in-patient discharge, day-case discharge, day-patient discharge, out-patient discharge and allied health professions (see AHP) discharge.
disconnect systems	A peritoneal dialysis system in which the dialysis bag is not connected to the patient between exchanges.
diuretic	A drug that increases the flow of urine.
donor	Someone who gives blood or an organ from their body to be used in another person's body (the recipient).
end stage renal failure	Kidney failure requiring treatment by dialysis or kidney transplantation.
erythropoietin (EPO)	A substance normally produced by the kidneys which stimulates the bone marrow to produce red blood cells. In renal failure less is formed resulting in anaemia, but it can be replaced by an injection of artificially produced erythropoietin.
essential (criterion/criteria)	A criterion that should be met wherever a service is provided.
European Dialysis and Transplant Association Registry	A registry of patients on renal replacement therapy throughout Europe organised by the professional body for European nephrologists.
evaluation	The study of the performance of a service (or element of treatment and care) with the aim of identifying successful and problem areas of activity.
evidence-based medicine	Evidence-based clinical practice is an approach to decision making in which the clinician uses the best evidence available, in consultation with the patient, to decide upon the option which suits that patient best.

function	The activity of an organ or part of the body.
generic standards	Standards that apply to most, if not all, clinical services.
genetic disorder	An illness or condition that has been inherited.
glomerulonephritis	The inflammation of the filtering units in the kidneys which alters their normal functions.
glomerulus	One of the tiny filtering units of the kidneys. Each kidney contains about one million glomeruli.
GP	General Practitioner.
graft	A transplanted organ or tissue.
guidelines	Statements which help in deciding how to treat particular conditions.
haematocrit	The ratio of the volume of red blood cells to the total volume of blood.
haematological	Relating to the blood.
haemodialysis	A treatment for kidney failure in which blood is purified by passing it across an artificial membrane to remove waste products.
haemoglobin	The part of red blood cells that carries oxygen around the body.
HDL	See Health Department Letter.
Health Council	Each NHS Board area has a Health Council, an organisation whose aim is to promote public consultation and participation in health-related matters. Sometimes referred to as a Local Health Council.
Health Department Letter (HDL)	Health Department Letter (formerly known as Management Executive Letter - MEL), formal communications from the Scottish Executive Health Department to NHSScotland.
healthcare professional	A person qualified in a health discipline.
home dialysis	Dialysis treatment that is carried out at home rather than in a hospital.
hospital dialysis	Dialysis that is carried out in a hospital renal unit.

hospital transportation	Hospital vehicles that are used to transport patients to and from hospital for treatment.
immediate function	A kidney transplant that works immediately.
immunosuppressive drug	A drug that suppresses the immune system of a patient in order to allow that patient to accept a transplant in the immediate and long term.
incidence	The number of new cases of a disease within a defined group of people over a period of time.
iron	A key component of haemoglobin. When red blood cells are lost, so is iron.
Island NHS Board	Island NHS Boards do the work of both NHS Boards and Trusts, in that they have a strategic and operational role. There are three Island NHS Boards: Shetland, Orkney, and the Western Isles.
kidney	One of two bean-shaped organs located near the middle of the back just under the ribcage. Kidneys filter waste from the blood, remove excess water from the body, maintain the proper balance of salts and acids in the body and produce essential hormones.
Kidney Alliance	An 'umbrella' body representing all organisations involved in renal services.
Kidney Patients' Association	A group or society whose aim is to support kidney patients and their carers.
Kt/v	A calculation used by hospital staff to assess the adequacy of dialysis.
LHCC	See Local Health Care Co-operative.
liaison psychiatry	Providing psychiatric consultation to patients with non-psychiatric medical disorders.
live donor	Someone who agrees to give one of their organs during life to another person.
Local Health Care Co-operative (LHCC)	In Scotland, Local Health Care Co-operatives are voluntary groupings of GPs and other local health care professionals intended to strengthen and support the primary health care team in delivering local care.

low clearance	When monitoring of renal patients shows increased levels of creatinine, this is described as low clearance. Patients may then be referred to what is known as a low clearance clinic, and this in turn can indicate they are in a pre-dialysis phase.
malnutrition	Insufficient nutrition or the wrong sort of nutrition.
Management Executive Letter (MEL)	Formal communications from the Scottish Executive Health Department to NHSScotland, now known as Health Department Letters (HDLs).
marginal donor	It is recognised that not all kidneys come from ideal donors, and that some donor characteristics, such as age or a history of high blood pressure, may result in a slightly higher likelihood of transplant failure. Current evidence suggests that patients who receive such a kidney still have a better outcome than had they remained on dialysis. Every kidney used for transplantation has to meet core criteria.
matching	The process by which a suitable kidney is found for transplantation.
medication	Drugs prescribed to treat a condition.
MEL	See Management Executive Letter.
microbial count	Relating to micro-organisms or germs.
molecular weight	A term used to describe the weight or mass of chemical compounds.
monitoring	The systematic process of collecting information on clinical and non-clinical performance. Monitoring may be intermittent or continuous. It may also be undertaken in relation to specific incidents of concern or to check key performance areas.
multidisciplinary	A multidisciplinary team is a group of people from different disciplines (both healthcare and non-healthcare) who work together to provide care for patients with a particular condition. The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition, the scale of the service being provided, and geographical/socio-economic factors in the local area.

National Service Standard	Standards that have been set by the Kidney Alliance. They form the core objectives of the strategic plan for renal services (2001-2006) that aims to ensure patients with end stage renal failure receive the best medical care.
nephritis	An inflammation of the kidneys.
nephrologist	A doctor who specialises in kidney disease.
nephrology	The branch of medical science that deals with the kidneys.
nephron	A term which refers to the million or so structures within each kidney that filter blood in order to make urine.
NHS Board	NHS Boards replaced the separate board structures of Health Boards and NHS Trusts. The NHS Boards cover the same geographical area as the old Health Boards. The overall purpose of NHS Boards is to ensure the efficient, effective and accountable governance of the local NHS system, and to provide strategic leadership and direction for the system as a whole, focusing on agreed outcomes.
NHS priorities	The three national clinical priorities are mental health; coronary heart disease and stroke; and cancer.
NHS QIS	See NHS Quality Improvement Scotland.
NHS Quality Improvement Scotland (NHS QIS)	NHS Quality Improvement Scotland is a statutory body, established as a Special Health Board in January 2003. Its role is to focus on improving the quality of patient care and the health of patients. It will have a particular emphasis on the quality of care and the patient journey for vulnerable groups. NHS Quality Improvement Scotland has been created by the merger of five organisations: Clinical Standards Board for Scotland (CSBS); Health Technology Board for Scotland (HTBS); Scottish Health Advisory Service (SHAS); Nursing and Midwifery Practice Development Unit (NMPDU), and the Clinical Resource and Audit Group (CRAG). Website address: www.nhshealthquality.org
NHSScotland	The National Health Service in Scotland.
nutrient	That which nourishes.
nutrition	All foods, the physical and chemical process by which food is converted into body tissue or energy.

nutritional intake	Dietary intake of healthy or nourishing foods.
nutritional status	A term that describes the extent to which an individual's nutritional needs are being met.
occupational therapy	The treatment of mental and physical health problems by encouraging people to participate in specific activities that will help them to reach their maximum level of function and independence in all aspects of their daily life. An occupational therapist is a person specially trained to provide such assessment and treatment.
organ	A part of the body that performs a particular function.
outcome	The end result of care and treatment and/or rehabilitation. In other words, the change in health, functional ability, symptoms or situation of a person, which can be used to measure the effectiveness of care and treatment, and/or rehabilitation.
out-patient	A patient reviewed in a hospital but who does not need to be admitted to the hospital.
PAM	See professions allied to medicine.
patient	A person who is receiving care or medical treatment. A person who is registered with a doctor, dentist, or other healthcare professional, and is treated by him/her when necessary. Sometimes referred to as a user.
patient journey	The pathway through the health services taken by the patient (the person who is receiving treatment), and as viewed by the patient.
patient survival rate	The number or proportion of patients who remain alive on renal replacement therapy during follow-up.
patient-month	A measure of follow-up which takes account of the number of patients treated and the time during which they have been observed.
PCRG	See Primary Care Reference Group.
PD	See peritoneal dialysis.
peer review	Review of a service by those with expertise and experience in that service, either as a provider, user or carer, but who are not involved in its provision in the area under review. In the NHS Quality Improvement Scotland approach, all members of a review team are equal.

peritoneal cavity	The space in the abdomen that contains the intestines and other internal organs.
peritoneal dialysis	A treatment for kidney failure in which dialysis fluid is introduced into the peritoneal cavity to remove wastes and water from the blood.
peritonitis	Inflammation of the peritoneum (the lining of the abdominal cavity).
pharmacist	A qualified professional who understands the nature and effect of medicines and how they are produced and used to prevent and treat illness, relieve symptoms or assist in the diagnosis of disease. Pharmacists use their expertise for the well-being and safety of users and the public.
phosphate	A mineral commonly found in food, especially dairy products, which binds to calcium to keep bones strong and healthy.
physiotherapy	The branch of treatment that employs physical methods to promote healing, including the use of light, infrared and ultraviolet rays, heat, electric current, massage, manipulation and remedial exercise.
planned patients	Patients for whom treatment or surgery is planned in advance.
pneumocystis infection	A severe form of pneumonia in patients who have recently had a renal transplant.
policy	An operational statement of intent in a given situation.
polycystic kidney disease	An inherited kidney disease in which cysts replace normal kidney tissue, causing the kidneys to fail.
postgraduate qualification	A degree or qualification that is awarded after a period of further training.
potassium	An essential mineral in the body found in many foods, especially fruit and vegetables. It is responsible for normal muscle function, including heart muscle, but excessively high levels in the blood can cause the heart to stop beating.
pre-dialysis	Before dialysis.
prescription	Usually a written recipe of treatment.

primary care	The conventional first point of contact between a patient and the NHS. This is the component of care delivered to patients outside hospitals and is typically, though by no means exclusively, delivered through general practices. Primary care services are the most frequently used of all services provided by the NHS.
Primary Care Reference Group (PCRG)	Established to help NHS Quality Improvement Scotland ensure that the component of care delivered to patients outside hospitals is included in its standards, and to promote the accreditation of general practices.
primary healthcare team	The primary healthcare team encompasses a range of family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners.
professions allied to medicine (PAM)	Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dieticians, etc. Now called allied health professionals (AHPs). See allied health professions.
prophylaxis	The prevention of disease; preventive treatment.
prospective studies	Studies that are carried out from the present to the future.
protein	One of the three main classes of food. Proteins are made of amino acids, which are called the building blocks of the cells. The cells need proteins to grow and to mend themselves. Protein is found in many foods such as meat, fish, poultry, and eggs.
protocol	A policy or strategy which defines appropriate action in specific circumstances. Protocols may be national, or agreed locally to take into account local requirements.
purification	Process where impurities are removed from the blood during dialysis.
quality assurance (QA)	Improving performance and preventing problems through planned and systematic activities including documentation, training and review.

Quality Assurance Manual	Document outlining the methods and procedures to be used in setting standards and reviewing services.
rationale	Scientific/objective reason for taking specific action.
recipient	A person who receives a new organ.
red blood cells	Cells in the bloodstream that contain haemoglobin which carries oxygen from the lungs to the tissues.
referral	The process whereby a patient is transferred from one professional to another, usually for specialist advice and/or treatment.
regimen	A course of treatment such as a prescribed combination of diet and drugs.
register	A collection of similar information from individuals used to compile an overview observation.
renal	A term that means relating to the kidneys.
Renal Association	The Renal Association is the professional body for United Kingdom nephrologists. The Standards Subcommittee of the Renal Association has produced recommended standards and audit measures for the treatment of adult patients with renal failure. Where evidence or recommendations exist in the Renal Association standards, for an area of renal services for which NHS Quality Improvement Scotland is taking forward standards, it is referenced.
renal failure	An abnormality resulting from the inability of the kidneys to function and resulting in a build-up of poisons in the body.
renal function	A measure of how well a person's kidneys are working to remove waste products from the body.
renal nutrition	Food and/or diet suitable for patients with kidney disease.
Renal Nutrition Group	A subgroup of the British Dietetic Association with special expertise in the nutritional aspects of renal failure.
renal replacement therapy	Treatment to replace the function of the kidneys in a person whose kidneys no longer work. Treatment is usually in the form of dialysis or transplant.

renal unit	The part of a hospital which specialises in the treatment of people with kidney failure.
renal vein	The blood vessel that returns filtered blood from the kidney to the rest of the circulation.
residual renal function	The remaining function of kidneys which are not working properly.
retrieval	A term used to describe the process by which organs are removed for the purposes of transplantation.
RRT	See renal replacement therapy.
Scottish Executive Health Department (SEHD)	The Scottish Executive Health Department is responsible for health policy and the administration of NHSScotland. Website address: www.show.scot.nhs.uk/sehd/
Scottish Intercollegiate Guidelines Network (SIGN)	SIGN was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland, to sponsor and support the development of evidence-based clinical guidelines for NHSScotland. Where a SIGN guideline exists for a specialty or service for which NHS Quality Improvement Scotland is taking forward standards, it will be referenced. For further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed, contact: SIGN Executive, Royal College of Physicians, 9 Queen Street, Edinburgh EH2 1JQ. Website address: www.sign.ac.uk/
Scottish Renal Association	A group of healthcare professionals whose common purpose is to promote the highest standards of care for renal patients in Scotland.
Scottish Renal Registry	A national database which records the clinical details of renal patients throughout Scotland for audit purposes, and the clinicians who manage the Registry.
SEHD	See Scottish Executive Health Department.
self-assessment	Assessment of performance against standards by individual/clinical team/Trust providing the service to which the standards are related.
sensitise	The process by which repeated blood transfusions and previous transplants can reduce the likelihood of finding a compatible kidney in patients with renal failure.

SIGN	See Scottish Intercollegiate Guidelines Network.
SIGN guideline	Scottish Intercollegiate Guidelines Network guideline.
social work	Social work services provide advice and practical help for problems resulting from social circumstances. A social worker is a person who has obtained a professional qualification in social work. A social worker supports vulnerable people and their carers with the aim of enhancing the quality of all aspects of their daily lives.
standard statement	An overall statement of desired performance.
symptom	A reported feeling or observable physical sign of a person's condition that indicates a physical or psychological abnormality.
therapy	A word often used to mean treatment.
thrombosis	The formation of a blood clot in an artery blocking the blood supply. For example, a clot in a coronary artery can cause a heart attack.
transplant	An organ or tissue that is transferred from one individual to another.
transplant co-ordinator	Someone who assists in co-ordinating organ retrieval and the necessary tests, studies and other activities to assess the suitability of a person to receive a transplantation.
transplant liaison nurse	A nurse working in a renal unit that does not offer transplantation, who liaises with the transplant co-ordinator to ensure that patients are referred for transplantation and have all the necessary tests before being accepted onto the transplant waiting list.
transplant surgeon	A doctor who specialises in performing operations to put an organ from one person (the donor) into another (the recipient).
transplant survival rate	The number or proportion of transplants which remain functional during follow-up.
transplantation	The act of transferring an organ or tissue from one individual to another.

Trust	A Trust is an NHS organisation responsible for providing a group of healthcare services for the local population. An Acute Hospital Trust provides hospital services. A Primary Care Trust delivers primary care/community health services. Mental health services (both hospital and community based) are now usually provided by Primary Care Trusts.
Type 1 (insulin-dependent) diabetes	Type 1 diabetes develops if the body is unable to produce any insulin. This type of diabetes usually appears before the age of 40. It is treated by insulin injections and diet.
UK Transplant	A Special Health Authority working within the NHS to support transplant units throughout the UK and Northern Ireland.
ultrasound	An imaging test that bounces sound waves off tissues and converts the echoes into pictures.
urea	A waste product which is formed when the body breaks down protein.
urea reduction ratio (URR)	A measurement used by hospital staff in haemodialysis to check that enough dialysis is being provided (dialysis adequacy).
URR	See urea reduction ratio.

Our Commitment

We will:

- involve NHS staff, patients and the public in all parts of our work;
- work with and support NHS staff in improving standards;
- assist NHSScotland in delivering the highest quality of NHS care to each patient;
- base conclusions and recommendations on the best evidence available;
- be open and transparent in all our work through wide circulation of reports written in language that can be understood by all and is jargon free;
- seek to avoid duplication of effort through working closely with other national organisations involved in improving the quality of care within the NHS; and
- ensure our own work is subject to quality assurance and evaluation.



NHS Quality Improvement Scotland (Edinburgh Office)
Elliott House 8-10 Hillside Crescent Edinburgh EH7 5EA
T: 0131 623 4300 F: 0131 623 4299

comments@nhshealthquality.org

www.nhshealthquality.org