Renal Disease in Scotland



Second Report April 2004 Cross Party Group on Kidney Disease The Scottish Parliament

Cross Party Group on Kidney Disease April 2004

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A strategy for future management

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Cross Party Group on Kidney Disease The Scottish Parliament April 2004

ISBN No: - 1-904227-08-2

The Cross Party Group on Kidney Disease would like to thank The National Kidney Research Fund for its kind contributions towards the funding both of the consultations with patients and the preparation and publication of this report.

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1 SUMMARY OF KEY RECOMMENDATIONS

The following are the key recommendations made by the Cross Party Group for the improvement of renal services in Scotland. Fuller recommendations, together with the timings for the delivery of these, are contained in the body of the report.

- The Scottish Executive Health Department should, within eighteen months, develop a National Plan for renal services. The plan should incorporate national standards and targets based on best evidence.
- The Scottish Executive Health Department should immediately establish a National Clinical Network for Renal Disease to develop the National Plan and oversee its implementation.
- NHS Boards should develop Local Renal Networks based initially on the 10 adult renal units. These networks should be directly responsible for developing and prosecuting plans in accordance with the standards and targets in the National Plan.
- An appropriately funded quality assurance programme should be established and monitored by the Scottish Renal Registry (SRR).
- All stakeholders including patients should be involved at all levels of service planning. and in the production and implementation of the National Plan.
- Sufficient support and education should be provided for all patients approaching established renal failure to enable them to make fully informed choices about treatment modality.
- All patients should be able to choose freely between different types of dialysis, and there should be flexibility about the choice of dialysis shifts for patients receiving hospital-based treatments.
- All units should have IT systems that can report data directly to the SRR for audit and quality improvement. This should be part of the integrated electronic records system.
- The length of the dialysis day should not be extended by avoidable delays before starting and after finishing dialysis. Patients should expect to start and finish dialysis at specified times.
- For those on hospital-based treatments, the length of the dialysis day should be minimised by efficient transport to and from the centre.
- · All renal units should provide an efficient service for access surgery capable of delivering surgery reliably on a pre-arranged day.
- · Patients on renal replacement therapy (RRT) should have ready access to the support provided by the multi-disciplinary team, including trained renal social workers.
- Hospital-based dialysis should be delivered in a pleasant non-institutional environment close to the patient's home.
- Scottish renal units should have sufficient hospital haemodialysis stations to provide visiting patients with dialysis. These stations should be available to patients who need to dialyse away from their base unit for reasons of work or pleasure.

- There should be a sustained increase in hospital dialysis stations sufficient to provide haemodialysis for all who would benefit from it, regardless of location. Dialysis units should be run at optimal operating levels, estimated to be 80% of available dialysis stations.
- There should be a regular national review of dialysis facilities by the National Clinical Network for Renal Disease.
- All provider organisations should establish outpatient clinics for patients approaching renal failure that provide integrated "one stop" access to services and staff.
- Patients should be given full educational, social and psychological support to ensure they are sufficiently informed about their condition to take an active part in management.
- All patients should be provided with a care plan containing objectives of treatment. This should meet all the Renal Association guidelines for control of anaemia and other consequences of kidney failure.
- All dialysis units should, within two years, have sufficient specialist renal social workers to meet the British Renal Society (BRS) guidelines.
- A non-heart beating cadaver organ donation programme should be initiated immediately.
- Sufficient specialised nephrologists, surgeons and renal recipient transplant coordinators should be available to deliver renal transplant services. This will require increases in all workforce areas.
- · Renal units should have sufficient consultant and non-consultant grade medical staff to deliver a patient-centred renal replacement therapy service.
- Staffing levels should be monitored by the National Clinical Network for Renal Disease as one of its quality assurance measures.
- A framework for renal nursing should immediately be developed for Scotland. Clinical competencies and training should be standardised.
- A comprehensive recruitment and retention strategy should immediately be developed to ensure renal nursing is featured at pre-registration stage and is recognised within general nursing.
- There should be greater flexibility in defining roles in renal nursing to allow some of the current activities of renal nurses to be undertaken by other appropriately trained staff.
- Local renal networks should document the workload required to treat patients with acute renal failure and integrate the results into the required dialysis services.
- The National Clinical Network for Renal Disease should immediately establish a working party to develop a National Plan for the identification and management of Chronic Kidney Disease (CKD).
- NHS Board-established Local Renal Networks should develop plans to implement the National Renal Strategy on CKD.
- A SIGN guideline should be developed to cover the identification and management of CKD.
- Funding should be provided for a small number of pilot projects for the management of CKD. These should link primary and secondary care and other relevant professionals.

- All patients known to have CKD should be entered into a locally-agreed disease care plan.
- All patients with CKD and an estimated creatinine clearance of less than 30 ml/min or with worsening kidney function should be referred to a nephrologist to avoid the risk of late referral.
- Information technology systems should allow automatic transfer of the results of blood tests on all patients known to the renal unit from the laboratory where that patient's blood tests are processed.
- The National Clinical Network for Renal Disease should develop a research strategy as an integral part of the National Plan.
- The National Clinical Network for Renal Disease should include the care of paediatric patients within its remit.
- An additional National Clinical Network for Paediatric Renal Disease should be established immediately. Its work should be integrated with the National Clinical Network for Renal Disease.

2 INTRODUCTION

- 2.1 response to growing concerns about the ability of the NHS to treat the increasing amount of renal disease in the Scottish population, together with evidence that the situation is likely to deteriorate markedly unless strategic plans are made to prevent it. The CPG published an analysis of the current situation, highlighting 22 challenges for the future in February 2003. Its key findings are set out in Box One overleaf. This second report makes recommendations as to how these challenges might be met.
- 2.2
- disease across Scotland. Even so, great care has been taken to ensure that the recommendations contained here are realistic, achievable and, where possible, evidencebased. There will be a need for increased resources but only within the context of improved efficiency of service delivery. This requires comprehensive staff training and a commitment to continuous quality improvement focused on the needs of the patients and those that care for them. The responsibility for achieving this will rest with staff, patients and those responsible for funding renal services.

2

The Cross Party Group on Kidney Disease (CPG) in the Scottish Parliament was formed in

The CPG is committed to the provision of excellent and equitable treatment of renal

Box 1 - CPG First Report Challenges

- Although the take-on rate for renal replacement programmes in Scotland is no longer less than many other European Countries, there is a failure to plan for the year-on-year increase in patient numbers
- Current services operate under such pressure that they are unable to deliver flexible patient-orientated treatment
- Patients consistently identify inefficient transport between home and the dialysis unit as being amongst their greatest problems
- Resources, manpower and facilities for access surgery for dialysis are inadequate. There is also a shortage of transplant surgeons
- Transplant numbers are limited by a shortage of donor organs. Consequently, the number of patients on the renal transplant waiting list increases annually
- There are large numbers of individuals with moderate and potentially progressive renal disease who have not been referred to specialist nephrology services
- There is a critical shortage of nurses who are trained in the care of adult or paediatric patients with renal disorders. More nurses will be required for the expansion of dialysis facilities
- Delayed referral of children with renal disease is well recognised. Over a third have established renal failure when referred to the specialist renal service
- There remains a shortfall in the provision of all aspects of care to patients.

3 BACKGROUND

3.1 Renal disease is a major challenge for healthcare delivery programmes throughout the world because of the steadily rising number of patients with established kidney failure and the enormous cost of treating them. The number of patients using renal replacement therapy (RRT) is increasing annually (see Table 1). In 1993, 432 patients per million population (pmp) were receiving renal replacement in Scotland, a figure that had increased to 694 pmp by 2003 and is expected to approach 1,000 pmp within the next ten years. The incidence of patients starting dialysis in Scotland is now close to the European average. An ageing population poses additional problems because the incidence of renal failure increases with age.

Table 1: Different Pro	oportions of Modes of	Treatment and the	Increasing N	umber of Patients
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Year	Hospital HD	Home HD	CAPD	APD	Transplant	Total
1966	22	0	0	0	6	28
1971	77	7	0	3	55	142
1976	115	96	0	3	137	351
1981	166	169	103	1	311	469
1986	277	133	234	0	642	1286
1991	400	89	432	31	1012	1964
1996	787	65	370	84	1293	2599
2001	1227	45	255	157	1602	3286

3.2

The NHS in Scotland has responded to challenges by expanding facilities for treating patients with established renal failure by dialysis and transplantation. The history of the current facilities and how they came to be developed were documented in the first CPG report. There are 11 renal units (one paediatric and 10 adult) in Scotland with 12 associated satellite dialysis units. Two of the adult renal units and the paediatric unit carry out transplantation.

Box 2: Renal Units in Scotland

Aberdeen Roval Infirmary Dumfries and Galloway Royal Infirmary Monklands Hospital Queen Margaret's Hospital Royal Infirmary of Edinburgh

A full list of the renal units and their associated satellites and outreach clinics is given on the Scottish Renal Registry website - http://www.show.scot.nhs.uk/srr/

3.3

Scottish renal units have always collaborated closely and in 1978, they established the Scottish Renal Association (SRA) and subsequently the Scottish Renal Registry (SRR). In 1994 the SRR began auditing performance of renal units against evidence-based standards developed by the UK Renal Association. In 1998 the Registry initiated peer review of renal units by teams that included patient representatives. This rigorous quality assurance system was subsequently formalised by NHS Quality Improvement Scotland (NHS OIS - formerly the CSBS) which introduced 14 specific standards for renal and transplant units to achieve. The Standard headings are set out in Box 3.

Box 3: QIS Scotland - Standards for Renal Services

Standard	1:	Haemodialysis
Standard	2:	Peritoneal Dialysis
Standard	3:	Haemoglobin in Patients on
Standard	4:	Dialysis Access
Standard	5:	Nutritional Status
Standard	6:	Drug Therapy
Standard	7:	Access to Multidisciplinary
Standard	8:	Assessment for Transplanta
Standard	9:	Kidney Retrieval
Standard	10:	Survival Rates
Standard	11:	Out-patients
Standard	12:	Provision of Patient Information
Standard	13:	Transportation for Haemodia
Standard	14:	Audit: Information/Data Coll

3.4

The NHS QIS published its report "Adult Renal Services: A National Overview" in March 2003. This documented the ability of the Scottish renal and transplant units to attain the 14 standards and provided clear evidence of both successes and failures. The full document may be found at: http://www.clinicalstandards.org/pdf/natoveriew/renal.pdf

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Crosshouse Hospital Glasgow Royal Infirmary Ninewells Hospital Raigmore Hospital Western Infirmary, Glasgow Royal Hospital for Sick Children, Glasgow

Dialysis

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- 35 Almost all units were able to provide an adequate quality of dialysis to meet the UK Renal Association standards for individual patients. Yet, despite this success, the NHS QIS report graphically illustrates the extent to which units are operating beyond their capacity. Consequently, most units were unable to deliver a flexible and patient-centred service, for example, in respect of treatment modality. Many patients and their carers did not receive sufficient support from multidisciplinary teams, who are working under intense pressure - causing difficulties with recruitment and retention of staff. There is evidence that Scottish services for renal failure still compare unfavourably with those in other developed countries - the numbers of patients starting dialysis with temporary dialysis lines and lacking other proper preparation, an increased death rate and inflexibility with holiday dialysis, are examples here. Scottish patients and their families are, therefore, still receiving a sub-standard service and enduring unnecessary suffering.
- 3.6 The need to concentrate on providing enough dialysis stations over the past ten years has necessarily, but regrettably, meant that prevention has taken a back seat. Many diseases, including hypertension, diabetes and urinary tract obstruction cause slow but progressive kidney damage. This state has been termed chronic kidney disease (CKD). Populationbased studies in Scotland and elsewhere in the UK show that at least 1 in 100 people have CKD, yet this often goes unnoticed. CKD is also a major risk factor for accelerated cardiovascular disease, including heart attacks and strokes. These factors provide compelling reasons to identify and appropriately manage patients with CKD.
- 3.7 There are currently no British evidence-based general guidelines for the management of CKD, except in certain conditions such as diabetes and hypertension in which guidelines describe effective treatments for slowing or preventing kidney damage (SIGN Numbers 49 and 51 http://www.sign.ac.uk/; British Hypertension Society - http://www.hyp.ac.uk/bhs/home.htm). Making these treatments generally available will require new streamlined strategies for initial diagnosis and subsequent follow up.
- 38 A key challenge in planning renal services is to identify patients early enough to prevent or delay progression of their kidney disease and the associated cardiovascular damage. Preserving renal function can substantially improve quality of life and reduce the associated risk to the cardiovascular system. This has clear potential to relieve the enormous burden of disease currently left unmanaged.
- 3.9 Renal failure can also occur suddenly in patients without previous kidney disease, a process that is often reversible. The incidence of acute renal failure requiring treatment by dialysis in Scotland is 225 pmp per year and there is at least the same number of patients with lesser degrees of acute renal failure that do not require dialysis. Acute renal failure represents an important component of the workload of renal and intensive therapy services. This has major implications for the multi-professional renal workforce and must be included in planning for renal services.
- 3.10 The CPG believes that there should be a sustained development of renal services in Scotland to meet the twin challenges of providing a patient-centred renal replacement service and a comprehensive service for the identification and management of CKD. The development will need to be carefully co-ordinated and subjected to a vigorous quality assurance programme, if the objectives are to be met in a cost effective manner.

The Scottish Executive Health Department should, within eighteen months, develop a National Plan for renal services that will provide a patient-centred service for individuals with established renal failure and for the management of people with chronic kidney disease. The plan should incorporate national standards and targets based on best evidence.

Recommendation

The Scottish Executive Health Department should immediately establish a National Clinical Network for Renal Disease with responsibility for developing the National Plan and with overall responsibility for ensuring it is implemented.

Recommendation

NHS Boards should develop Local Renal Networks based initially on the 10 adult renal units. These networks should be directly responsible for developing and prosecuting plans for the management of individuals with renal disease within their locality, in accordance with the standards and targets set out in the National Plan.

Recommendation

An appropriately funded quality assurance programme should be established and monitored by an organisation required to review and audit the work that is being undertaken. The CPG would suggest that the SRR is the appropriate body to do this.

Recommendation

4

All stakeholders including patients should be involved at all levels of service planning and in the production and implementation of the National Plan.

PLANNING RENAL SERVICES FOR SCOTLAND - The Evidence Base

- 4.1 Major changes are needed in renal services, if the NHS in Scotland is to meet the challenge of delivering a comprehensive patient-centred renal service over the next 10 years. The CPG believes that patients' views and needs should be central to this restructuring. For this reason, the CPG has undertaken an extensive consultation exercise with patients prior to making its recommendations. This included the largest survey of patients' views about dialysis services ever conducted in Scotland, an in-depth analysis of patients' views in a focus group and the collection of opinions from patients living in island, and other remote, communities,
- 4.2 foundation for any plan for developing renal services in Scotland. It not only provided a comprehensive description of present renal services but it also set out 14 standards for the renal replacement therapy (RRT) programme, all of which the CPG strongly endorses. This report extends the NHS QIS work in two ways: for the first time it includes a detailed consideration of chronic kidney disease; and it utilises additional information not available to the NHS QIS team. This comes from a number of publications from Scotland and elsewhere in the UK that provide further information to aid the planning of renal replacement programmes and in respect of the multidisciplinary workforce required. These are discussed below.
- 4.3 renal failure in Scotland (SRA 2003). A further study from the SRR highlights geographical areas that will require new dialysis facilities. Services required for acute renal failure are based on the detailed epidemiological study performed by Aberdeen University in collaboration with the SRR.

The NHS QIS report "Adult Renal Services: a National Overview", should provide the

The latest SRR Report provides comprehensive data on the epidemiology of established

- 4.4 Workforce planning is based on the British Renal Society (BRS) report "The Renal Team: A Multi-Professional Renal Workforce Plan For Adults and Children with Renal Disease". This report examined staffing needs for all members of the multi-disciplinary team required for renal replacement programmes and developed benchmarks for the numbers of each professional group required per hundred patients on RRT. Comparison with the actual numbers of the various professional groups in post in British renal units showed a current under-provision of 40% in most areas of staffing and an overall requirement for a further 30% increase in staffing by 2010. Whilst the situation is generally less severe here than in England, district general hospital renal units, that treat 40% of patients with RRT, are particularly poorly provided for in Scotland.
- 4.5 The National Service Framework (NSF) for England: Part 1 (January 2004) provides details of the 10 year plan for the development of dialysis and transplant services and enables comparisons to be made between renal services in England and Scotland. It sets out five standards for the care of adults and children with established renal failure. These standards are a step forward, but the document does not provide the detailed direction that is helpful when discussing service delivery with healthcare managers. Nonetheless, it remains an excellent review of shortfalls in services in England.
- 4.6 Finally, the report from the Scottish Transplant Group in June 2002 and the Transplant Framework for England - "Saving Lives, Valuing Donors" - (July 2003) have strongly influenced our recommendations on transplant services.

5 **CURRENT SERVICES FOR ESTABLISHED RENAL FAILURE**

5.1 **Defining a Patient-Centred Service**

- 511 Patients with chronic disease face daunting challenges both from the disease itself and from the unwanted side-effects and other restrictions imposed by the therapies used to treat it continuously for many years. Accordingly, the aims of management are much broader than those for acute reversible illness and extend beyond the strictly medical aspects of therapy.
- 512 Patients need considerable information about their disease and different treatment options before they can make informed choices about which treatment is best suited to their needs. Treatment should be delivered efficiently in pleasant surroundings in order to prevent complications and minimise the disruption of the patients' normal lifestyle. It should be provided by well-trained staff, familiar to the patient, thus maximising physical and psychological well-being. Lastly, many patients and their carers will need regular physical, psychological and social support.
- 5.1.3 The importance of these principles in medicine generally is universally agreed. The facilities to satisfy them have for many years been embedded in services in other disease areas such as cancer and - increasingly - with other chronic disorders such as heart disease. Yet the NHS OIS report showed how rarely these principles were satisfied in renal services in Scotland, despite the focused efforts of staff. This appears to be due to the overwhelming pressure on services to satisfy a constant and pressing need to create extra dialysis places, without which patients would die.
- 5.1.4 Patients developing renal failure need different types of service at different stages of their disease. RRT for most patients begins with a period on dialysis with the hope of a kidney transplant in the longer term - something that is medically feasible in only about 40% of cases.

- 5.1.5 There are two different types of dialysis, both equally effective at replacing kidney function. Haemodialysis is typically performed for four to six hours, three times each week, either in a hospital centre or in the patient's home. Peritoneal dialysis is performed continuously without the need for thrice weekly visits to hospital. Patients need to be thoroughly informed about their disease and the options available to treat it before they can make informed choices as to which type of dialysis is best suited to their needs and lifestyle.
- 5.1.6 The period before dialysis is important to the success of treatment because this is when many aspects of treatment are optimised, including modification of diet, correction of anaemia and control of blood pressure. In addition, all patients need a small but essential surgical operation before they can start dialysis, regardless of the type chosen. Regular dialysis involves considerable time commitment each week. This is especially true for hospital-based haemodialysis because the dialysis treatment sessions are prolonged by travel to and from the dialysis unit and potentially by delays before and after the dialysis session. The time spent travelling from any location in Scotland to the nearest renal unit is shown in a map on the Scottish renal registry website (www.show.scot.nhs.uk/srr) Many of the restrictions inherent in dialysis are removed by a successful renal transplant but patients still require careful monitoring to watch for rejection and other frequent complications including accelerated cardiovascular disease.
- 5.1.7 The CPG was concerned from the start of its work to understand whether renal services in Scotland fully addressed the needs of dialysis patients. Accordingly, it undertook an extensive survey in which the views of some 663 patients were solicited about all aspects of dialysis. The survey findings were given added depth by a focus group discussion involving a randomly selected and stratified sample of patients and carers. A full report of this work is published in a supplementary CPG document - "Renal Disease in Scotland -Consulting with Patients".

Individual Views of Pre-Dialysis 5.2

- 5.2.1 Patients have individual needs that vary during the time they approach dialysis and join a renal replacement programme. However, the results of the consultation exercise identify a number of key requirements for a patient-centred renal service that are relevant to all stages of the "journey of care".
- 5.2.2 Patients need clear and accurate information that can be discussed with an appropriately trained member of the care team familiar with their case. The care itself should also be delivered by such a team. Patients and their carers will sometimes need support and respite from the rigours of RRT, since this places a heavy burden on both.
- 5.2.3 Both the survey and focus group identified the provision of information and adequate education as being key needs from the pre-dialysis stage onwards.

5.2.4 Information and Education

5.2.4.1 The provision of good quality information is vital at the pre-dialysis stage both to enable patients to choose between the various treatment options available to them and so that they can come to terms with the restrictions imposed by RRT and make suitable adjustments to their lives to accommodate them. Almost all (94%) of the patients surveyed stated that good information was very important to them, not only at the predialysis stage but throughout their journey of care. Yet as many as 30% said that the information they currently received was inadequate.

- 5.2.4.2 When asked "what did you imagine dialysis would involve when you were first told you would need the treatment?", 43% of the patients surveyed responded that they "had no idea". Feedback from the focus group also rated information and choice as having great importance for patients, not least because the choice of dialysis modality is not usually based on strict medical criteria, but on which type of treatment will least disrupt the patient's life. Patients emphasised the need for information to be presented in different ways, for example literature with varying levels of detail; internet or electronically-based information or access to a library resource containing publications or leaflets.
- 5.2.4.3 However, paper-based information should not be regarded as a good substitute for personal contact with appropriate staff - "a member of staff" was the most popular choice in answer to the question "how would you like to access this information". Nearly a third (28%) of the patients surveyed felt that they had been inadequately prepared for dialysis. Of those that felt they were well prepared, many had been taken for a tour of the unit and had been given the opportunity to speak to patients already on dialysis.

Box 4: Patients' Comments

"I was given a folder with choices of dialysis and shown the renal unit. I was free to ask questions of staff and patients" (Patient from Ninewells Hospital, Dundee)

"Staff at the hospital were reassuring and showed me round the dialysis unit with information" (Patient from Glasgow Royal Infirmary)

- 5.2.4.4 Nearly half (44%) of the patients surveyed felt that support services that should have been available to them were lacking at the pre-dialysis stage. Many said, for example, that they needed, but did not have access to, social workers (particularly for advice on benefits entitlements) and psychologists/counsellors. This also came out strongly in the focus groups. Other suggestions for improvement included;
 - More education evenings including one-to-one meetings with other patients and former patients
 - Greater recognition of the massive impact on life of the patient and their family
 - Better preparation for the psychological and emotional effects of dialysis.
- As much information as possible should be made available ahead of a consultation so 5.2.4.5 that the patient has the chance to absorb some of the key information and is better able to ask detailed guestions of medical staff. Many patients will require all treatment options over time and this should be emphasised from the outset. The option of live donor transplantation should also be raised early enough to enable pre-emptive surgery before dialysis has to start.
- 5.2.4.6 Some patients want more extensive access to their laboratory results and other areas of their clinical notes. The CPG therefore believes that Scotland should collaborate in a UKwide project to allow patients to obtain remote secure access to agreed extracts from their electronic records across the internet. In order for this to be achieved efficiently and effectively, there should be a rapid move towards integrated electronic patient recordkeeping. This will also help to reduce the clerical workload and may have other advantages, such as allowing for the dissemination of patient information and other material.

The patient's partner and family should not be forgotten. Even if they are not involved 5.2.4.7 directly in treatment, the patient will certainly need their informed and continuing support. The provision of support for carers varies from unit to unit with some patients citing access to carer support as "easy" or only a "telephone call away. However, 44% of patients surveyed felt that support offered to carers was insufficient.

Recommendation

Sufficient support and education should be provided for all patients approaching established renal failure to enable them to make fully informed choices about treatment modality. This will often require access to all members of the multi-disciplinary workforce, different types of literature to suit different needs, access to the internet and the like.

Recommendation

All patients should be able to choose freely between the dialysis modalities that are medically suitable including home dialysis, hospital dialysis, continuous ambulatory peritoneal dialysis and automated peritoneal dialysis. This range of choice should be available routinely within two years.

Recommendation

All units should have IT systems that can report data directly to the SRR for audit and quality improvement. Ultimately, this should be part of the integrated electronic records system, linked to primary care and patients should have electronic access to their records as part of this system, within three years.

5.3 Life with Established Renal Failure

5.3.1 **Travel Time**

- 5.3.1.1 Once having progressed to dialysis, there are various areas where patients perceive that services are open to improvement. These include transportation issues, dialysis session flexibility - often a function of service capacity, staffing arrangements and the built environment of their unit.
- 5.3.1.2 For many patients on haemodialysis, the "dialysis day" may be much longer than the time taken to dialyse due to the travel time to and from the dialysis centre and delays before starting treatment. Patients feel strongly that the length of the dialysis day should be minimised by providing dialysis as close as possible to home, a view endorsed by NHS QIS Standard 13 that states that travel time should be no more than 30 minutes.
- 5.3.1.3 Although SRR data suggests that only 10 percent of patients live further than this time, the CPG patient survey suggested that 49% of patients live over 30 minutes travelling time away from their dialysis unit, with 15% of those patients living over an hour's travelling time away. One patient living six miles from his unit regularly finds himself away from home for seven hours to complete a four hour dialysis session, due to delays in transport, almost doubling his "dialysis day".
- 5.3.1.4 The situation is particularly bad for those who live in some of the remoter parts of the country - such as the island communities - or where there is low population density, or poor transport infrastructure.
- 5.3.1.5 On the Isle of Bute, for example, patients receiving hospital haemodialysis ordinarily face at least a nine hour dialysis day - of which nearly five hours is travel time - three times a week. Patients believe that the grind of travel is much worse than that of the treatment and that although the location of treatment may not be far away, travel times are often unacceptable.

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- **5.3.1.6** The Highland region covers a geographical area the size of Belgium and, together with the Western Isles, has some 160 renal patients. A number of mainland haemodialysis patients face travel times of up to four hours followed by four to five hours treatment and then three to four hours to return home, at least three times a week. Adverse weather conditions will extend these times further.
- There is currently no provision of renal services in the Western Isles. Hospital 5.3.1.7 haemodialysis patients from Lewis fly to Raigmore Hospital in Inverness for treatment, and potentially have to remain in Inverness during the week, only to return home at the weekend. Others have had to travel to Glasgow for treatment. There are also a number of home dialysis patients in the Western Isles whose access to professional support and advice exists only on the mainland.
- 5.3.1.8 Similarly there are no renal replacement services available in Orkney. Those requiring hospital haemodialysis must face a long journey to Aberdeen. Those treated by peritoneal dialysis rely heavily on the support of family and friends to allow them to do so, and must travel to Aberdeen regularly to attend clinics.
- 5.3.1.9 With a growing patient population noted in all the communities outlined above, demand for renal replacement services is increasing, as is the number of patients failing to receive optimum care as described by the 14 NHS QIS Standards for Adult Renal Services.
- 5.3.1.10 Patients whose travel to haemodialysis is much longer than 30 minutes may further compromise their health over time. More satellite dialysis units and better patient transport arrangements would help to alleviate many of the problems.
- **5.3.1.11** Transport to and from the dialysis unit is only one of the reasons why the dialysis day is prolonged. Many patients experience delays in starting dialysis after arriving in the unit because the previous shift has overrun. This is a direct result of the inflexibility that occurs when dialysis centres operate above optimal capacity and causes untold worry. The CPG feels that it should not present too much of a logistical challenge to work out ways of tackling this problem.

The length of the dialysis day should be minimised by efficient transport to and from the centre and by eliminating delays in commencing dialysis and waiting for transport after dialysis treatment has finished. Providers should develop plans to deliver the NHS QIS standards for transport and for patient waiting times pre and post-dialysis. These plans should be developed immediately and implemented within two years.

5.3.2 Capacity

- 5.3.2.1 Building life around dialysis necessitates some flexibility of dialysis schedules, particularly for the patient who is trying to continue working or who has family commitments. Just over one fifth of patients surveyed would have preferred a different dialysis shift but were unable to change because of lack of space at the unit. Furthermore, when questioned on what the main drawbacks of dialysis were for them, the most commonly cited responses were;
 - amount of time dedicated to receiving treatment including travel
 - effects on their working life
 - restrictions on physical activity/tiredness
 - lack of freedom and independence.

- 5.3.2.2 The CPG believes that such drawbacks should be considered when reviewing and planning dialysis services so that, where possible, efforts can be made to minimise their impact, allowing patients to maintain as reasonable a quality of life as possible.
- 5.3.2.3 Another critical issue relates to the minor but essential surgical procedure (access surgery) required to prepare patients for dialysis. These are often subject to considerable delay and cancellations. Although this was not specifically addressed in the survey, it is known from discussion with patients that they generally feel that these procedures should command a higher priority in theatre timetabling. In particular, it is felt that access surgery should be delayed only in exceptional circumstances since the repeated delays, that are the reality of current practice, add considerably to the pressure on a patient who may already be apprehensive about life on dialvsis.
- 5.3.2.4 These objectives can only be met in dialysis units that are adequately staffed and that run at optimal operating capacity, with an appropriate level of inbuilt flexibility.

Recommendation

Patients should expect to start and finish dialysis at specified times and, within two years, there should be flexibility about the choice of dialysis shifts a patient is offered.

Recommendation

All renal units should provide an efficient service for access surgery capable of delivering surgery reliably on a pre-arranged day.

5.3.3 Staffing

- 5.3.3.1 Staffing was the topic deemed most important by the CPG focus group and over one third of patients thought staffing levels were inadequate. Access to staff with particular types of knowledge was often missing. This included counsellors - including those for carers and advice about social security benefits.
- 5.3.3.2 Staff shift patterns should be organised so that each patient is dialysed in an adequately staffed environment by as few different nurses as possible. This often does not happen.
- 5.3.3.3 Patients beginning home-based treatments need home visits by dialysis nursing staff to allay anxieties and establish secure regimes. All patients and their families may benefit from visits from other members of the multidisciplinary team. A dietician can explain to whoever does the cooking how to include the patient's essential dietary needs in food preparation for the whole family. An occupational therapist can assess the need for aids and equipment at home. A trained renal social worker can explore potential benefit payments to which the patient is entitled. These are often needed to help to cushion loss of income suffered by the patient or their carer.
- 5.3.3.4 Patients need a 24-hour contact number for the renal unit, to ensure prompt, appropriate care for problems associated with renal failure. The NHS QIS document and Renal Association standards demand the presence of an appropriately trained multi-disciplinary team. In Scotland, for example, social workers and renal counsellors are very often missing from this team. Such teams are important in ensuring both a better holistic standard of care for patients and to improve the management of co-morbidity, which has also been identified as an issue by the CPG.

Recommendation

Patients on RRT should have ready access to the support provided by the multi-disciplinary team, including trained renal social workers. They should also expect to be treated by the same small team of nurses. This should be routinely provided within three years.

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5.3.4 **Environment and Equipment**

- 5.3.4.1 The vast majority of patients surveyed (86%) considered their dialysis surroundings to be moderately or very important to them, particularly given the amount of time they have to spend in this environment each week. They expected their dialysing environment to be bright, clean and comfortable. Whilst many patients, especially in newer units, were happy with their surroundings when dialysing, those in older units were generally less pleased and the CPG would therefore like to see closer attention paid, as a matter of urgency, to how the older units might be improved. Common requests were for comfortable chairs, more and clean blankets, for privacy curtains that fit and for a quieter environment.
- 5.3.4.2 Patients having to spend several hours on dialysis also appreciate television with individual headphones to preserve a peaceful background environment (66% stated that this would be an improvement on their current environment). The focus group further highlighted a desire for DVD and video libraries, for power points, telephone points and internet access to enable them to work with computers. These facilities could be easily and inexpensively provided and indeed, are already available in some of the more modern units. They should be routinely available in all units.

Recommendation

Hospital-based dialysis should be delivered in a pleasant non-institutional environment close to the patient's home by a multi-disciplinary workforce that is familiar with the patient and their individual needs.

5.3.5 **Holiday Dialysis**

- 5.3.5.1 The patients voiced their strong concern at the difficulty in taking holidays, or indeed taking short breaks to visit relatives, in Scotland or the UK. These are especially crucial for patients on RRT, relieving family stress and providing respite from the daily rigours of life with renal failure. Notably, 59% of patients on dialysis had not been on holiday since starting their treatment and in some cases this was over 10 years. Many of the 41% who had managed to take holidays reported that it was easier to arrange holidays abroad than in the UK. The majority of those who had taken holidays were extremely happy with the services provided for them.
- When asked how holiday dialysis facilities might be improved, many patients suggested 5.3.5.2 that the NHS should make dialysis stations available within existing units to provide holiday dialysis spaces. This is for the most part precluded because present dialysis facilities are operating beyond capacity.
- 5.3.5.3 Lack of information about holiday dialysis and the length of time to get blood tests checked and forwarded were also reported as major stumbling blocks preventing patients from taking holidays.
- 5.3.5.4 Lack of holidays is one of the most important remediable ways in which the life of a patient on dialysis is differentiated from other people. The trauma and perceived "hassle" involved in going on holiday is usually enough to put off most patients from even trying. Provision of more holiday dialysis places should be a priority for any patient-orientated renal replacement programme, helping patients to minimise the lack of freedom they feel; allowing them prolonged visits to family members elsewhere in the country and, in general, helping patients to maintain a reasonable quality of life whilst on dialysis. In collaboration with those responsible for tourism, NHS Scotland should expand facilities for visitors to Scotland who require dialysis.

Recommendation

There should be sufficient capacity in hospital haemodialysis programmes to provide visiting patients with dialysis. This provision should be available to patients who need to dialyse away from their base unit, for reasons of work or pleasure, and should be provided within two years.

5.3.6 Life After Transplantation

- 5.3.6.1 In almost all respects the life of the patient after renal transplantation is easier than that on dialysis but even the most successful transplant brings its own medical challenges.
- 5.3.6.2 Primary care physicians have relatively little experience of the drugs used to prevent rejection and of the long-term issues regarding kidney graft function. Transplant patients feel the need for more ready access to advice in these areas than most primary care physicians are able to deliver. Many transplant patients feel the need for more direct access to the transplant unit both as a way of obtaining their latest laboratory results and as a source of advice about their medication and other clinical issues.

5.3.7 Individual Views - Conclusion

6

5.3.7.1 The CPG was convinced that the views expressed by the patients raised justified concerns. NHS services for all chronic diseases should aspire to deliver the same standards of care regardless of diagnosis. In particular, the CPG believes that renal services could learn much from the outstanding example of cancer services. The CPG strongly believed that "disease code prescribing" is just as iniquitous as "post code prescribing".

DELIVERING A PATIENT-CENTRED DIALYSIS SERVICE

- 6.1 Although the incidence of kidney failure has remained static for the past few years in Scotland, its prevalence is rising in the population as new patients are added to renal replacement programmes. However, both are expected to rise dramatically in coming years, driven by the increase in diabetes. This will present a challenge to policy-makers, as they assess the additional services required.
- 6.2 It is of crucial importance that a formal assessment does take place since many of the problems currently faced in Scottish renal care relate to a failure to plan for capacity increases in response to rising demand in the past 10 to 20 years. The CPG is keen to ensure that, in future, there is pro-active planning of services rather than the current pattern of merely reacting to increases in demand.
- 6.3 The incidence of kidney failure rises steeply with age. Above the age of 65, it is nine times higher than for people aged 20 to 44 years (SRR 2001 report). The Registrar General for Scotland predicts that the number of older people will rise over the next twenty five years (RGO 2002) and a recent report from the European Renal Registry which included data from Scotland, showed that the numbers of patients above the age of 65 who start RRT rose five fold between 1985 and 1999. Taken together, these reports make it clear that we should plan facilities to treat larger numbers of older and possibly disabled people in the future.
- 6.4 Complex models using formulae derived from past patterns of treatment have been used to predict future requirements for RRT in many parts of the world. Data from the SRR enables us to use actual figures for new patients and deaths from a complete national registry of patients on RRT in Scotland. A simple model can be constructed of what would have happened if these rates had been in place from the beginning.

- 65 The distribution between modes of therapy is predicted by examining the trends over the last 15 years and the likely future trends - assuming no significant changes in treatment. An effective plateau level of around 900 per million population (some 4,500 patients) on RRT is predicted in the next 10 years. Approximately 400 people pmp will have functioning renal transplants with perhaps 80 pmp on home haemodialysis or peritoneal dialysis. The largest group will be around 420 pmp on hospital haemodialysis, a near doubling of current levels. At the end of 2003 there were 694 pmp on RRT. The number of patients on peritoneal dialysis has not risen in the last 10 years and the number of patients with a functioning transplant may be reaching a plateau.
- 6.6 Increases in numbers will therefore be largely confined to those on haemodialysis. Planning for the considerable increase in hospital dialysis facilities required should be driven and audited by national bodies and NHS boards, in conjunction with local renal networks. These latter bodies should be required to develop five year rolling plans to provide facilities for RRT for all patients needing them.

There should be a sustained increase in hospital dialysis stations sufficient to provide haemodialysis for all who would benefit from it, regardless of location. This process should begin immediately and reach optimal capacity within three years. Dialysis units should always run at optimal operating levels, to provide sufficient flexibility to prevent inefficiencies for patients and staff. We estimate optimal operating level to be 80% of available dialysis stations for both main and satellite units.

Recommendation

There should be a regular national review of dialysis facilities by the National Clinical Network for Renal Disease and a capital programme to ensure that patients are dialysed in pleasant non-institutional surroundings with access, for example, to telephones and the internet.

- 6.7 There is growing literature on the negative impact of "late referral" of patients with advanced renal impairment. Observational studies have uniformly shown increased morbidity, hospital stay and cost of treatment in patients starting long-term dialysis who were referred late (usually defined as within four months of needing dialysis), compared to those referred to a dialysis unit earlier. Recent studies have reported that late referral to a nephrologist is an independent risk factor for early death on dialysis. There is consensus that, for optimal management, preparation for dialysis should start a year before a patient needs it. This time is used to:
 - Assess the patient medically and treat complications including anaemia, hypertension and poor nutrition
 - Provide information and discussion for patients to make an informed and unpressured choice about the type of dialysis that would best suit their lifestyle as well as the options for renal transplantation
 - Create permanent vascular access for haemodialysis or place in-dwelling peritoneal dialysis catheters, so that dialysis can be introduced smoothly.
- 6.8 To achieve this, all patients need access to members of a full multidisciplinary team prior to an individual care plan being drawn up with them. Progress needs to be monitored regularly and plans reviewed.

6.9

These procedures are best performed in a clinic where the necessary staff and coordination are available. A 'low-clearance' or pre-dialysis clinic, is an ideal setting for developing novel work practices. Many aspects of the work could be performed by nurse specialists, and new ways of communicating with patients could be developed - either electronically or using staff with appropriate basic training and qualifications. The possibility of interleaving conventional out-patient visits with telemedicine consultations should be investigated. The latter could be organised from a patient's home or a health centre where other members of the community health care team, such as the GP, could be involved.

Recommendation

All provider Trusts should, within two years, establish outpatient clinics for patients approaching renal failure that provide integrated "one stop" access to all members of the renal multidisciplinary workforce.

Recommendation

Patients should be given full educational, social and psychological support to ensure they are sufficiently informed about their condition to take an active part in management, including choice of type of dialysis and suitability for transplantation. This recommendation should be implemented immediately.

Recommendation

All patients should be provided with a care plan containing objectives of treatment - that is to slow progression and optimise treatment and with a choice of dialysis modality. This should meet all the Renal Association guidelines for control of anaemia and other consequences of kidney failure. The effectiveness of the care plan should be audited by the SRR, as is currently the case for those on RRT.

Recommendation

Local Renal Networks working with Unified Boards should within three years ensure that arrangements are in place for all patients to have vascular access created in a timely way and without repeated cancellations.

6.10

Unless there are specific medical contraindications, all patients should be dialysed three times weekly to the Renal Association's evidence based standards for adequacy. Their anaemia should also be corrected to the Renal Association standard with appropriate doses of epoetin and iron. They should have full access to nutritional support as recommended by the NHS QIS. The full multidisciplinary team, including a dedicated renal social worker, should be available to support them.

Recommendation

All provider organisations should immediately undertake a staff audit to determine whether they meet the NHS QIS standards for the provision of the multidisciplinary workforce, staffed to the levels recommended in the BRS Guidelines. A plan should be developed to ensure these levels are met within two years.

Recommendation

All dialysis units should, within two years, have sufficient specialist renal social workers to meet the BRS guidelines. Trusts and local authorities should co-operate to ensure that this happens.

Second Report of the Cross Party Group on Kidney Disease

7 TRANSPLANTATION AND ORGAN DONATION

- 7.1 The only truly effective long-term solution for renal disease is a kidney transplant and the main challenge facing transplantation in Scotland is the shortage of donor organs.
- 7.2 Provisional figures from UK Transplant for 2002 report the cadaveric solid organ donation rate in the United Kingdom as 13 pmp, with an 11.4 pmp donation rate in Scotland. This difference may be attributed to the expansion of non-heartbeating donor programmes in England, something that is not currently undertaken in Scotland. We note that recent clarification of the legal aspects by the Crown Office in Scotland has allowed this area to be pursued. Even with non-heartbeating donation, the donor rate is considerably lower than is needed to keep step with demand for organs and is lower than in other European countries, notably Spain.
- 7.3 A significant improvement in the above donation rates will be required if the gap between demand and supply of organs is to be bridged. The waiting list in Scotland for a kidney transplant in January 2002 was 556. The CPG, backed by the strong endorsement of the patient focus group, supports the recommendations of the Scottish Transplant Group to increase the numbers of organs available for transplant. Its recommendations include:
 - A comprehensive and sustained national organ donation publicity campaign (this was due to commence in February 2004)
 - Expansion of live kidney donation. Scotland currently has only 7.8 pmp live donor transplant compared with 19.1 pmp in the United States and 17.1 pmp in Norway. This may involve legislative changes to allow 'cross-over' or 'paired' donation and altruistic live donation
 - Implementation of non-heart beating donation programmes under the auspices of the UKT initiative
 - Further consideration and debate on legislation around organ donation
 - Provision of adequate staff across the multi-disciplinary team.

7.4 Transplantation

- 7.4.1 Recruitment difficulties relating to transplant surgeons throughout the UK are mirrored in Scotland. This must be addressed as a matter of urgency, since centres require skilled transplant personnel to maintain the highest standard of care.
- 7.4.2 On a wider national basis the Scottish Transplant Group has recommended that there should be a single organ retrieval team for the whole of Scotland. This would be expected to reduce disruption at the donor hospitals and allow flexibility with operating times. Negotiations concerning the single organ retrieval team are approaching conclusion.
- 7.4.3 All transplant patients receive intensive follow-up, usually by the nephrologist in either the transplant centre or referring unit. This input is necessary to ensure long-term graft survival, thus avoiding the necessity for dialysis. In addition, due to the effects of immunosuppression and other medication, health promotion and early identification of complications is vital. With growing numbers of transplant patients, additional resources are required to facilitate this follow-up. At present one centre has a transplant co-ordinator (registered nurse) who performs annual health checks on all transplant patients.

7.5 **Presumed Consent**

- 7.5.1 The CPG debated the appropriateness of recommending in this report a move to a system of presumed consent in Scotland. Following that discussion, the CPG has decided that it cannot take a stance in either direction on this issue at this stage. Instead the Group wishes to focus on promoting the broad recommendations of the Scottish Transplant Group as set out above.
- The CPG would also like other ways of actively encouraging people to sign up to the organ 7.5.2 donation register to be explored. These include a system of mandated choice or schemes that require individuals, for example, to tick a box on their tax return or driving license forms. It is further suggested that asking patients whether they are on the register should be added to the list of standard questions that GPs ask when signing up a patient or undertaking one of their periodic health checks.

Recommendation

A non-heart beating cadaver organ donation programme should be initiated immediately.

Recommendation

Sufficient specialised nephrologists, surgeons and renal recipient transplant co-ordinators should be available in Scotland within three years to ensure all transplant patients receive adequate follow-up. This will require increases in all workforce areas.

8 **DELIVERING A MULTI-PROFESSIONAL WORKFORCE**

8.1 The management of patients with established renal failure requires a highly committed multi-professional workforce. Renal units in Scotland have far fewer staff across all the professions than is the case in other European countries. The British Renal Society (BRS), the society that represents all branches of the collective workforce, has recently published an authoritative report that produces benchmarks for the number of whole time equivalents (WTEs) required to treat 100 patients on RRT (see box 5). When related to a Scottish context the four key deficiencies are in; the medical workforce in District General Hospital (DGH) nephrology units; trained renal nurses employed in dialysis units; renal dieticians; and trained renal social workers.

8.2 **Medical Staff**

8.2.1 Medical staffing levels in renal units vary considerably across Scotland. In particular, the staffing of renal units located in DGHs requires urgent attention. The number of consultant nephrology WTEs is considerably below those recommended in the BRS report (see table 2), resulting in difficulty in providing satisfactory out-of-hours cover. These pressures are compounded by the paucity of junior doctors in training attached to DGH renal units. They will be further exacerbated by changes to junior doctors' hours and the introduction of the new consultant contract.

BOX 5: BRS Recommended Ratios - Specialist Renal Staff to RRT Patients

Professional Group	Recommended Workforce Ratios
Renal Physicians	1 WTE consultant nephrologist per 100 RRT patients
Transplant Surgeons	2 surgeons pmp (1.2-1.5 WTE pmp)
Dialysis access surgery	1 theatre session per week dedicated to dialysis access surgery for each 120 dialysis patients. A caseload of 350 vascular access procedures requires one WTE surgeon
Donor Transplant Co-ordinators	1.66 donor transplant co-ordinators pmp
Histocompatibility and Immunogenetics Scientists	$1\rm WTE$ consultant clinical scientist/medical consultant per 1200 RRT patients and $1\rm WTE$ healthcare scientist per 135 RRT patients
Renal Nurses and Health Care Assistants • Haemodialysis * Skill Mix	1 WTE per 4.5 haemodialysis patients 1.5 nurses: 1 Healthcare assistant (HCA)
 Peritoneal dialysis * Skill Mix 	1 WTE per 20 community dialysis patients 5 nurses: 1HCA
 Renal Wards (includes transplant wards) * Skill Mix 	1.4 WTE per bed 2.5 nurses: 1 HCA
Dieticians	1 WTE per 135 haemodialysis patients 1 WTE per 270 peritoneal dialysis patients 1 WTE per 180 low clearance patients 1 WTE per 540 transplant patients
Social Workers	1 WTE per 140 RRT patients
Clinical Psychologists	1 WTE per 1000 RRT patients
Clinical Technologists	$1{\rm WTE}$ per 50 maintenance haemodialysis plus $1{\rm WTE}$ per 20 home haemodialysis
Pharmacists	1 WTE per 250 RRT patients plus 1 WTE per 60 transplants per annum
Managers/Administrators	1 WTE per 150 dialysis patients

8.2.2 In view of the training opportunities available in the DGHs, there should be a positive move towards establishing specialist registrar posts in all DGHs with three or more consultants.

Table 2: Medical staff in non-training grades at DGH Renal Units

Unit	Consultant (WTE)	Staff Grade	Associate Specialist	Patients on RRT
Dunfermline	3 (2)	1	0	188
Raigmore	2 (1)	0	1	110
Monklands	3 (2)	1	1	176
Dumfries	1 (0.3)	1.4	0	112
Crosshouse	2 (1)	1	1	190

Recommendation

Renal units should within two years have sufficient consultant medical WTEs to deliver a patient-centred renal service, using the BRS benchmark as a guide.

Recommendation

There should also, within three years, be adequate non-consultant grade staff.

Recommendation

Staffing levels should be monitored by the National Clinical Network for Renal Disease as one of its quality assurance measures.

8.3 **Nursing Staff**

- 8.3.1 Surveys undertaken by the Scottish Renal Nurses Group have demonstrated a substantial shortage of dialysis nurses. This finding was highlighted by the NHS QIS report which provided clear evidence that all 10 Scottish adult renal units were currently operating suboptimally in this regard. A major challenge here is that there is a recognised national shortage of appropriately trained renal nurses. This is true across all areas of practice including nephrology; transplantation; haemodialysis and peritoneal dialysis.
- 8.3.2 The CPG recognises that more research is needed before this challenge can be met. A subgroup of the SRR is ideally placed to undertake such research in conjunction with the National Workforce Unit. The aim should be to offer patients on dialysis the same standard of care throughout Scotland regardless of geographical, economical and circumstantial situations.
- 8.3.3 are significant problems that need to be addressed. Renal nursing is a challenging area in which to work due to the heavy workload and related stress and this is especially true for newly qualified nurses. Recruitment and retention could be improved by a combination of solutions, including enhanced payment in recognition of the degree of specialisation and training requirements of the area; improving career prospects; removing blocks to promotion; and providing greater exposure to renal nursing in basic nurse training.
- 8.3.4 Renal nurses contribute at all stages of the patient journey in delivering safe and effective care. The value of this input could be greatly enhanced, if a clear template existed that provided a proper framework for nursing care across Scotland. This template should at the very least encompass professional practice; recruitment and retention; education; management; leadership and research.
- 8.3.5 Clinical competencies for trained nursing staff should be standardised, especially as the roles of a nurse working within the field of renal specialty are constantly diversifying and currently include: clinical nurse facilitator, anaemia nurse; pre-dialysis nurse; vascular access nurse; nurse consultant; palliative care nurse; and home dialysis training nurse.
- 8.3.6 Nurses have a diverse role within the renal service and the requirement for a renal nurse to be appropriately skilled to enable them to provide a complex and diverse service is obviously paramount. Training standards for renal nurses should also be made more uniform across Scotland.
- This should be facilitated by the appointment of a renal SVQ co-ordinator for each 8.3.7 provider; by defining a new role for non-qualified staff, such as the renal care assistants and clinical assistants; and by providing funding to allow the release of nurses to undertake the necessary studies whilst ensuring that adequate cover is in place for them when they do so. The essential and valued work undertaken by non-registered nurses within the service should also be explored, developed and utilised more effectively than is currently the case.

Recommendation

A framework for renal nursing should immediately be developed for Scotland. Clinical competencies and training should be standardised.

Recommendation

A comprehensive recruitment and retention strategy should immediately be developed to ensure renal nursing is featured at pre-registration stage and is recognised within general nursing.

This is at least partly a function of the problem of recruiting and retaining nurses where there

Optimal staffing ratios should be based on agreed benchmarks, such as the BRS guidelines. Research should be undertaken to establish what these ratios should be.

Recommendation

There should be greater flexibility in defining roles in renal nursing to allow some the current activities of renal nurses to be undertaken by other appropriately trained staff.

9 **ACUTE RENAL FAILURE**

- 9.1 Acute renal failure (ARF) is a devastating illness in which there is rapid, but often potentially reversible, reduction in renal function. It can be caused by a number of underlying diseases and may or may not require dialysis for a period of a few days to a few weeks.
- 9.2 Some patients recover renal function and return almost to their previous state of health or their health may deteriorate. In this case they often develop multi-organ failure and may die. A small number of these patients develop chronic renal failure. Patients with acute renal failure are cared for in hospital. Patients who require RRT (dialysis or haemofiltration) are normally transferred to a large hospital where they are cared for in either a renal or an intensive care unit. Huge resources are required for the short duration of this illness.
- 9.3 Until recently, there had been very few large studies of the epidemiology of acute renal failure. In 2001, the SRR undertook a pilot study of patients who were treated with RRT which is being followed up by a comprehensive study funded by the Office of the Chief Scientist for Scotland. The initial findings for these two studies give a very clear picture of what is currently happening in Scotland. The incidence of acute renal failure needing treatment by RRT is about 225 pmp per year, much higher than had previously been realised. Half the patients are cared for in an ICU and the death rate at 90 days is likely to be as high as 70%. Acute renal failure is to some extent a marker and a consequence of severe illness and not always the primary cause of the patient's death. These new data have been carefully collected in a comprehensive prospective survey.
- 9.4 In contrast to the situation with end stage renal disease, there is little difficulty in making a timely diagnosis for patients who develop acute renal failure in hospital or as a result of catastrophic illness. However, a minority of patients develop acute renal failure silently as a result of hypersensitivity to prescribed drugs or as a result of glomerulonephritis. Early diagnosis of these patients presents a challenge, especially in the primary care setting. The challenge is to identify those patients who may benefit from highly specialised treatment and to provide appropriate facilities and staff training for the large numbers of very ill patients involved. We can now at least predict the numbers of patients we are likely to encounter with ARF in Scotland each year, their location and the extent of the peaks and troughs in the rate of referral.

Recommendation

Local renal networks should document the workload required to treat patients with acute renal failure and integrate the results into the required dialysis services.

10 CHRONIC KIDNEY DISEASE

- 10.1 Recent surveys from England and Northern Ireland suggest that between 0.5 and 1% of the population have significant chronic kidney disease and that less than 20% of these are known to renal services. CKD should be diagnosed if a patient has one or more of microalbuminuria, persistent proteinuria, unexplained haematuria or serum creatinine of more than 150 mmol/L or estimated GFR < 60 ml/min. Clearly it is neither possible nor appropriate for all patients with CKD in Scotland to be seen and managed by a consultant nephrologist. The great majority of these patients have mild renal disease and are not destined to reach end-stage renal failure. If they are free from complications they may be appropriately managed in primary care.
- 10.2 Regular measurement of kidney function is logical in patients at risk of progressive renal disease because of the adverse effects of late presentation. Renal function should also be measured regularly in all patients with significant proteinuria or with conditions that put them at risk of developing CKD including those on angiotensin converting enzyme inhibitors (SIGN) and those with hypertension (British Hypertension Society), diabetes (SIGN) or proteinuria, or significant bladder outflow obstruction.
- 10.3 In addition to being a predictor of progressive renal failure, CKD is an important risk marker for cardiovascular and cerebrovascular disease. Proteinuria, including microalbuminuria in non-diabetics, is a powerful cardiovascular risk marker even if glomerular filtration rate is normal. There is compelling evidence that established treatable cardiovascular risk factors, such as smoking, hypertension and dyslipidaemia are also risk markers for progression of many forms of renal disease. Management of patients with CKD therefore essentially involves minimising cardiovascular risk.
- Evidence-based guidelines for management of CKD have been developed in other 10.4 countries, notably the USA, Australia and Canada. Many of the recommendations in these guidelines are directly applicable to the UK. However, these countries have very different health-care systems so, for this reason, we believe that new guidelines directly applicable to Scotland are necessary. These guidelines must address three separate issues: the practical strategies for the detection of CKD; evidence-based management strategies for patients with kidney disease and patients at risk of developing kidney disease; and ways to deliver best practice treatment.
- 10.5 "care plan" for CKD. This will require extra demands on time and resources both in primary care and in renal units. From the patient's perspective, what can safely and reliably be handled in primary care or what is better carried out in a hospital sector should be achieved in the appropriate setting.
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It is likely that various models will emerge, including conventional "shared care" between GPs and hospital-based nephrologists; geriatricians, diabetologists, and other secondary care physicians; specialist primary care physicians or nurses working in the primary care setting: and/or computer-based shared care. Optimal arrangements will vary depending on the geographical setting, services already established and other local factors. Decisions about service design and implementation should be made locally within the constraints of an overall National Plan.

Mild to moderate chronic kidney disease (CKD) is very common in the general population.

We have not addressed the question of which individuals should be responsible for the

- 107 The introduction of electronic patient records based on accepted standards, that would be used by all members of the health care team, could improve safety and efficiency. They would encourage better communication with the patient's GP and community nurse and allow the possibility of secure direct access by the patient. Quality assurance and improved service planning would also result. Renal units and the SRR have a long track record of innovation and excellence in this field. This experience and expertise should be fostered.
- 10.8 Many people who could benefit from these new services could initially be detected automatically through the utilisation of appropriate software in laboratories and electronic patient records. Strict guidelines for further investigation, treatment, monitoring and referral to a nurse or doctor could be implemented by staff with minimal training and assessment. This would allow large numbers of people to benefit from the effective treatments that are now available, thus changing the traditional role of doctors who would then concentrate on trouble shooting, problem solving and treatment of patients with more complex problems.

The National Clinical Network for Renal Disease should immediately establish a working party to develop a National Plan for the identification and management of CKD. In particular the Plan should address the practical strategies for the detection of CKD; the development of evidence-based management strategies for patients with kidney disease and patients at risk of developing kidney disease, as well as ways to deliver best practice treatment.

Recommendation

NHS Board-established Local Renal Networks with members from provider organisations and other stakeholders including patients, should develop plans to implement the National Plan for CKD. These should ensure that local systems are in place to deliver the SIGN guideline recommendations for the identification and subsequent management of patients with CKD in high risk groups, such as those with diabetes or hypertension.

Recommendation

A SIGN guideline covering the identification and management of CKD should be developed in the next two years. This would build on the recommendations in existing SIGN guidelines on diabetes, hypertension in the elderly and cardiovascular disease.

Recommendation

Funding should be provided for a small number of pilot projects for the management of CKD. These should link primary and secondary care and other relevant professionals and be supported by the deployment of appropriate information technology. These might be best integrated into local clinical renal networks designed to ensure appropriate management and audit of patients with CKD. Ideally, these would include projects in different geographical locations.

Recommendation

All patients known to have CKD should be entered into a locally agreed, regularly audited. disease care plan to ensure appropriate monitoring of renal function, introduction of optimal strategies to minimise the risk of worsening kidney disease and achieve optimal management of cardiovascular risk factors.

Recommendation

All patients with CKD and an estimated creatinine clearance of less than 30 ml/min or with worsening kidney function should be referred to a nephrologist to avoid the risk of late referral.

Recommendation

Information technology systems should allow automatic transfer of the results of blood tests on all patients known to the Renal Unit from the laboratory where that patient's blood tests are processed, together with a system for bringing these results to the attention of those responsible for monitoring the patient's progress.

11 RESEARCH

- 11.1 The Scottish renal community is fortunate to have an exceptionally strong research base with internationally recognised research groups working across a broad range of disciplines. These include the fundamental aspects of developmental and inherited disorders of the kidney; the genetics of susceptibility to CKD and its progression to renal failure; the pathogenic role of autoimmunity and inflammation in renal disease; and the application of applied health sciences (including epidemiology and health services research) to the renal disease and its management. Strong collaborative links have been established between research groups investigating similar problems but remain much weaker among groups investigating different areas.
- 11.2 The CPG recognises the value of renal research in Scotland and the magnitude of the potential benefits it can bring to the care of patients in the future. In the short term, expertise in applied health sciences will be of great benefit in developing new management guidelines for chronic kidney disease and in the design and evaluation of new ways to deliver best practice to those in need.
- 11.3 The CPG believes that Scottish expertise provides enormous opportunities to apply the insights provided by basic research into renal disease into clinical practice through the development of a program of "translational research". The expertise in research into the biology of renal disease, combined with the skill and organisational ability of Scottish nephrologists, should ensure the success of such a program. It should make a substantial impact in the longer term.

Recommendation

The National Clinical Network for Renal Disease should develop a research strategy as an integral part of the National Plan. The research strategy should take account of expertise in all aspects of renal research in Scotland and should set the development of "translational research" as a high priority.

12 PAEDIATRIC NEPHROLOGY

- 12.1 The journey of care for children with renal disease increasingly begins ante-natally with the diagnosis of renal disease in utero. There is a requirement for an integrated multidisciplinary approach to the perinatal care of these infants. Throughout childhood a deterioration in renal function is typically seen in those born with renal disease with passage through chronic renal failure to end stage renal failure and finally transplantation. This requires access to multidisciplinary specialist paediatric nephrology services, including medical and nursing staff, dieticians, social workers, psychologists, pharmacists, teachers and play therapists. The care of these children is predominantly undertaken at their local regional centre with input from one of the four paediatric nephrologists who undertake regional outreach clinics.
- 12.2 Clinical governance dictates that as a result of the relatively low incidence of renal disease in children compared to adults, optimal care of children with complex renal disease should be managed from a single centre supervising the management of children with acute renal failure and providing diagnostic renal biopsy and other specialised investigations, dialysis access, initiation of home dialysis, hospital based dialysis and transplantation capable of meeting published clinical standards.
- 12.3 Unlike adult services the challenge for those caring for children with renal disease is not the increase in numbers but the ability to deliver equity of care throughout Scotland. The provision of outreach services is hampered both by limitations in medical staffing compared to published guidelines, which precludes an expansion in outreach clinics with several regional areas unserved including Fife, the Highlands, the Borders and Lanarkshire. Where existing outreach clinics are undertaken these are underpinned by local paediatricians with an interest in nephrology serving as a local contact with the central service. Historically, senior general paediatricians in geographically remote areas have managed more complex renal patients onsite, but as these individuals retire, and with the implications of clinical governance, this will disappear, requiring an expansion in the outreach clinics already undertaken.
- The development of a managed clinical network for paediatric nephrology is essential to 124 serve the requirements of the paediatric renal population in Scotland, functioning to provide equity of access and delivery of renal services wherever possible at local level. At present, this need is unmet and in addition there remains a dependence on charitably funded posts supporting nursing, dietetic and social work provision both locally and centrally. Without an increase in consultant paediatric nephrologist numbers, there can be no expansion in outreach services, thus requiring increased travelling and isolation for patients with renal disease and their families.

Recommendation

The National Clinical Network for Renal Disease should include the care of paediatric patients within its remit.

Recommendation

An additional National Clinical Network for Paediatric Renal Disease should be established immediately to develop plans for the delivery of a co-ordinated and patient-centred Renal Service for children in Scotland. Its work should be integrated with the National Clinical Network for Renal Disease.

APPENDIX ONE: OFFICERS AND ADVISORY GROUP

The Officers of the Cross Party Group on Kidney Disease are:

Margaret Jamieson, MSP - Convenor

Professor Andrew Rees - Vice Convenor

Katie Ronald - Secretary

The advisory group to the Cross Party Group on Kidney Disease during the preparation of this report comprised:

Ippy Brown, Clinical Nurse Manager, Renal Services North Division, Greater Glasgow Health Board

Mr John Forsythe - Consultant Transplant Surgeon, Edinburgh; Chairman of the Scottish Transplant Group and Specialist Adviser to the CMO Scotland

Berkeley Greenwood - (Administrative Secretary); adviser to the National Kidney Research Fund and employed by Portcullis Public Affairs

Dr Andrew Innes - Consultant Physician and Nephrologist; Ayrshire & Arran, representing the Scottish Renal Association

Dr Chris Isles - Consultant Physician and Nephrologist; Dumfries and Galloway

Dr Brian Junor - Consultant Nephrologist, Glasgow

Dr Graham R Knox - Transplant patient

Jen Lumsdaine - Transplant Co-ordinator, Edinburgh

Dr Ian Ramage - Consultant Paediatric Nephrologist, Glasgow

Professor Andrew Rees - (Chair); Regius Professor of Medicine, University of Aberdeen and President of the Renal Association of Great Britain and Ireland

Katie Ronald - Public Affairs Manager (Scotland), The National Kidney Research Fund

Dr Keith Simpson - Consultant Nephrologist, Glasgow and Chair of the Scottish Renal Registry

Gil Small - Dialysis patient and Chair of the Scottish Federation of Kidney Patients Associations

Nick Turkentine - Head of Marketing and Communications, The National Kidney Research Fund

We are also grateful for the input of Dr Ian Mackay and Anne Marie Craig who have acted as replacements for colleagues during the production of the report and to Mrs Florence Small.

Second Report of the Cross Party Group on Kidney Disease