

# **Scottish Renal Patient Experience Survey**

**Transplant Report** 

# Your service - your views



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## **Background and acknowledgements**

NHS Quality Improvement Scotland's (NHS QIS') vision is of an NHS that achieves excellence in the care of every patient every time. It leads the use of knowledge to promote improvement in the quality of healthcare for the people of Scotland and performs three key functions:

- providing advice and guidance on effective clinical practice, including setting standards
- driving and supporting implementation of improvements in quality, and
- assessing the performance of the NHS, reporting and publishing the findings.

In addition, NHS QIS also has central responsibility for patient safety and clinical governance across NHSScotland.

NHS QIS established a project steering group to oversee successful delivery of the project objectives. The steering group was established in May 2007 under the chairmanship of Dr Brian Junor, Consultant Nephrologist, NHS Greater Glasgow and Clyde (until August 2008) and Professor Chris Isles, Consultant Physician, NHS Dumfries & Galloway (August 2008–present). The steering group was tasked with overseeing the patient experience survey, given that both transplant and dialysis patient experience had not previously been captured on a national basis. The combination of multidisciplinary clinical expertise along with committed patient representatives on the steering group provided invaluable guidance and support to this project.

NHS QIS gratefully acknowledges the work of the renal services steering group members for their contribution to this project and the production of this report. The co-operation of the staff of the Scottish Renal Registry (SRR) was also crucial to the project as they co-ordinated the mailing of the questionnaires through their database.

The survey was endorsed by the Scottish Kidney Federation, a Scottish charity representing kidney patients' associations across Scotland. As well as permitting the use of its logo on the survey forms and posters, the Scottish Kidney Federation also promoted the survey on its website.

Statistical input to the project was provided by John Duffy, Deputy Director, Corporate Policy & Services, Scottish Funding Council; and Karen Ritchie and Joanne Abbotts from the Health Services Research and Effectiveness Unit, NHS QIS.

NHS QIS is especially grateful to those patients who took part in the two pilot exercises held in Dumfries & Galloway Royal Infirmary and in the Western Infirmary, Glasgow, in October 2008. Their constructive feedback was much appreciated and contributed greatly to the production of the final survey form.

Finally, NHS QIS wishes to record its thanks to all the respondents who took the time to complete the survey so thoroughly and return them promptly. Without such a high response rate, this report would not have been so comprehensive.



It was with great sadness that we learned of the death of Jane Bryce in June 2009. Jane was one of the public partners on the steering group. As a renal patient herself, Jane was committed to improving services for all renal patients in Scotland and helped us to ensure that the survey captured the issues of paramount importance to patients. From the outset, Jane was very keen to see a national patient experience survey for transplant and dialysis patients and we wish to dedicate this report to Jane's memory in recognition of her determination, courage and support for this project.

Photo courtesy of Diana Noble

# **Executive summary**

#### Introduction

Our kidneys are vital to our health. Every day they filter our blood, removing waste products and excess fluid using millions of tiny fibres called nephrons. If these become damaged, this can lead to a build-up of waste products in the blood and, if left untreated, this is fatal. The most common cause of kidney disease is damage caused by other long-term conditions such as diabetes or high blood pressure. In the UK, diabetic renal disease is the single most common cause of kidney failure<sup>1</sup>. Established renal failure (ERF) has to be treated by either dialysis (filtering of the blood) or a kidney transplant – known as renal replacement therapy (RRT). There are two types of dialysis: haemodialysis and peritoneal dialysis.

In Scotland, over 4,000 people receive RRT of which over 1,900 people have a functioning kidney transplant. Most of these people will have started dialysis treatment before receiving a transplant.

#### **Renal transplantation in Scotland**

The first successful kidney transplant to be carried out in the UK took place in Edinburgh in 1960. Almost 200 kidney transplants were carried out in Scotland in 2007–2008<sup>2</sup>. There are currently two transplant centres in Edinburgh and Glasgow. Kidney transplantation is no longer carried out in Dundee or Aberdeen. The SRR was set up in 1991 and every unit contributes agreed data to the Registry. Analyses of the data collected by the SSR are fully reviewed and are an essential element in monitoring the effectiveness of the clinical care provided for patients with ERF in Scotland.

#### Context

In the Better Health, Better Care Action Plan<sup>3</sup>, the Scottish Government committed to delivering an NHS based on a mutual ethos where staff and patients are co-owners of the NHS and have a greater say in the way services are delivered. Better Together, Scotland's national patient safety experience survey programme, takes forward this vision and aims to use the public's experiences of NHSScotland to improve health services and support staff in delivering high quality, equitable, patient-centred care. It is against this backdrop, and with these aims in mind, that NHS QIS agreed to undertake a transplant patient experience survey in collaboration with the SRR. Further information about the background to this work and the methods used to undertake the survey can be found in Sections 1 and 2 of this report. A copy of the survey form can be found in Appendix 3.

#### Our findings

This is the first time a survey of this scale has been carried out on patient experience of renal transplant services in Scotland and the response rate was 64% (1233/1938). Some results are presented by transplant unit and others by the parent unit responsible for the patients' long-term follow-up care. Most respondents were aged between 15–64 (82%). The median age for onset of ERF in Scotland is 61 years<sup>4</sup>. The median age for prevalent Scottish transplant patients is 50 years<sup>1</sup> and we are confident that the high response rate paints an accurate picture of their views.

The detailed findings are provided in Sections 4–11 of this report and key elements of these are presented in this summary.

Some of the concerns of patients fit into the themes identified by Better Together in their paper, Building on the Experiences of NHS Patients and Users<sup>5</sup>, published in 2008.

#### Information

Generally respondents expressed high levels of satisfaction with the information provided by the transplant unit. Over 95% felt the information had been provided in a way they understood. However, approximately 1 in 5 respondents would have liked more information for their families and carers at the time of their transplant.

One of the more recent self-management systems introduced for patients using renal services is Renal PatientView. It is a web-based system which allows patients to view their results and other information online. It is not yet available everywhere, but of those who reported access to Renal PatientView, only 54% said they used it; however, this represents only 21% of all respondents. This raises issues of access, education and training. It is important that we invest in these support resources if we are to maximise future use and value of this tool.

#### Communication

In the months after a transplant, shared care arrangements are often in place between the transplant unit and the patient's local renal unit. Good communication during this period is essential and we explored patients' views of how effective this was in these circumstances. Around 70% of respondents reported communication was good, although the remainder thought not or were unsure. This has been flagged as an area for improvement.

Co-ordination of care is especially important for transplant patients and our survey found that teamworking could be improved, specifically between the renal unit and the patient's GP.

#### Environment

Respondents indicated that the outpatient areas of some hospitals could be improved and indeed this was one of the few areas where there were differences in the levels of satisfaction amongst units.

#### Overall satisfaction at time of transplant

Overall satisfaction was rated very highly, scoring 8.7 (where 10 is the highest possible score). We recognise that these views relate to patients whose transplants were functioning at the time of the survey and may not reflect the views of patients whose transplant failed.

Patients were asked about the three main improvements to services that they thought would improve their experience and the following themes were the areas drawing the most requested improvements:

- the ward environment, particularly better standards of hygiene and cleanliness in ward areas. One of the biggest take-home messages was concern about the risk of infection as immunity is impaired by anti-rejection medication and respondents expressed the view that the standards of cleaning and hygiene in the ward environment could be better. They were also concerned about being moved during their stay or being nursed on a non-specialist ward. Whilst any risks associated with this will have been assessed by the local clinical teams, it is important that this information is shared with patients and their families.
- communication between transplant and renal units and more information, particularly about what to expect after the transplant, and
- staffing levels. While many positive comments were received about the quality and commitment of staff, many patients said that there should be more staff who were trained in renal care and listening skills.

#### Overall satisfaction with the quality of follow-up care

The average score of 8.8 out of a possible 10 demonstrated high levels of satisfaction with the quality of care after receiving a transplant. This finding was echoed in the many positive comments from patients praising their treatment or the staff who look after them.

People told us that follow-up care could be improved in three ways, namely by:

- better communication between patient and staff, between the renal unit and their GP and between departments
- clinics being better organised, most importantly to reduce the length of time they wait to be seen at the clinic, and
- making the clinic environment more comfortable for the patient, particularly waiting areas.

## Conclusion

Key recommendations focus on those areas which have been highlighted in other documents, and which the findings of this survey indicate are outstanding issues, namely:

- good quality information should be provided to patients' families and carers before transplantation
- communication between the renal unit and the patient's GP should be improved, and
- patients should have access to members of the multidisciplinary team when required.

The full recommendations from this report can be found in Section 12.

While there is always scope for improvement, patient experience of renal transplantation in Scotland is generally high. This has not been achieved by chance or by a few individuals but by a highly professional and systematic approach to delivering effective services to people with a life-threatening condition in a way that makes sure they are as independent and as well as possible. Renal services in Scotland are an exemplar for other long-term condition services to learn from.

We are well aware of the challenges and limitations of surveys; notably that 'patients remain reluctant to express critical comments about the care they have received from hospital. The reasons for this reluctance are complex and include a desire not to appear ungrateful as well as recognition of limitations of health care'6. Over 60% of those surveyed did respond which demonstrates their commitment to, and interest in, taking part in improving the services they use – we need to harness this and to build on it for the future, especially as many improvements relate to attitude and hearts and minds rather than to major financial investment.

# 1 Introduction

#### 1.1 Previous work in this area

The Clinical Standards Board for Scotland (now part of NHS QIS) published Clinical Standards for Adult Renal Services<sup>11</sup> in February 2002. During 2002, peer reviews took place in all 10 renal units and three transplant units in Scotland to assess performance against the standards. Local reports and a national overview detailing the findings of these reviews were published in March 2003. At that time NHS QIS committed to continuing to work closely with the SRR to follow up on key issues, notably patient experience.

From September 2003–January 2004, the Scottish Parliament Cross Party Working Group on Kidney Disease carried out a survey of Scottish renal replacement services. This comprised a patient survey and focus groups. The findings were published in a supplementary report to its Second Report (Renal Disease in Scotland: A Strategy for Future Management<sup>7</sup>), entitled Renal Disease in Scotland: Consulting with Patients<sup>8</sup>.

## 1.2 Taking this forward

In May 2007, the adult renal services steering group was established with a view to following up some of the issues highlighted in the 2003 reports. The group agreed that two patient experience surveys should be conducted: one of all kidney dialysis patients in Scotland; the other of all kidney transplant patients in Scotland.

## 1.3 Renal dialysis

The disruption to individuals' everyday life when they require regular dialysis treatment cannot be underestimated, given that for most this will affect the rest of their lives. Scottish patients with ERF who require renal RRT may choose to have haemodialysis in hospital or at home, or peritoneal dialysis at home. At the time of the survey, these treatments either took place in or were supported by 10 main (sometimes referred to as parent) and 22 satellite renal units in Scotland.

#### 1.4 Renal transplantation

A renal transplant is generally considered the best form of RRT for those considered fit enough to receive one, but is only suitable for 30–40% of patients with ERF. Most patients who receive a transplant will have spent a period of time on dialysis first. Maintenance of a successful transplant depends upon a clear understanding of two things: the need to take anti-rejection medication; and its possible side effects.

## 1.5 Aims of survey

Our brief was to conduct a survey of the experience of all patients in Scotland who are receiving RRT for ERF. Our objectives were to:

- gather and assess the views of RRT patients who are aged 15 and over on the delivery of renal care and services in renal units
- use the information generated to support renal services in finding and implementing solutions to deficient aspects of care

- highlight actions to be taken by NHS boards to improve the renal patient experience, and
- highlight areas of good practice.

# 2 Methodology and development of survey forms

## 2.1 Overview

The NHS QIS steering group designed two patient surveys – one for dialysis patients and one for kidney transplant patients. The surveys were based on the patient survey previously used by the SRR in 2001. To take forward development of the surveys, we formed a smaller subgroup comprising the chair of the steering group and two patient representatives, supported by NHS QIS staff.

## 2.2 Development of survey forms

The survey questions were written in plain English and printed in large font to enable those with sight-related problems to take part. A copy of the survey form can be found in Appendix 3. We received only one request for a translation which was provided.

We piloted the surveys in Dumfries and in the Western Infirmary in Glasgow in October 2008.

## 2.3 Conducting the survey

The SRR provided the names and postal addresses of all adult renal dialysis and transplant patients in Scotland in November 2008. We mailed survey forms to patients in two stages: a first mailing to all dialysis and transplant patients in November 2008 and a second mailing to non-respondents in December 2008. We encouraged participation through a consultant letter which accompanied the survey; in addition, posters were distributed to all renal units advertising the survey. All information which might identify patients was removed when the forms were returned, in order to preserve confidentiality. We included all responses returned up until 31 January 2009 in our analyses.

We report here the results of the transplant survey. The results of the dialysis survey will form the basis of a separate publication to be published at the same time as this report.

## 2.4 Data entry and statistical analysis

The transplant survey was in two parts. In the first part, we asked people to tell us about their experience at the time of their transplant. Their responses to these questions have been analysed according to the unit in which their transplant took place. In the second part of the survey, we asked patients to tell us about the care they had received during follow-up. These sections have been analysed according to the unit the patients were attending at the time of the survey. NHS QIS staff entered the anonymised data onto spreadsheets for analysis. Free text comments were also transcribed so that themes could be identified.

Numbers of non-respondents were extracted from the SRR database as at December 2008. Numbers of non-respondents should be regarded as approximate, given the constant addition of new patients and the removal of deceased patients.

Statistical analysis was generally by comparison of observed and expected frequencies of responses in each unit (chi-squared test). Low numbers of responses of yes, no or not sure to some questions in some units meant that it was not always possible to make this comparison. We have indicated this in the text by recording 'It was not possible to tell whether differences exist among the units due to the small number of responses in some subgroups'. Overall satisfaction scores (Sections 4.7 and 11.1) were analysed using Kruskal-Wallis one-way analysis of variance.

Statistical analysis of responses is available upon request.

## 2.5 Ethical approval

The Medical Research and Ethics Committee judged that this survey was a form of service evaluation that did not require ethical approval.

#### Flow chart of transplant survey



# 3 Response rates

## 3.1 Responses by unit in which transplant had taken place

Table 1 shows the unit in which the transplant had taken place for all 1,233 respondents. If a patient had more than one kidney transplant, we recorded the unit in which the latest transplant had been performed. 84.0% of respondents received their transplant in Glasgow or Edinburgh. The figures in this table were used as the basis for analysis of Section 4.

Transplant unit	Number of respondents	% of all respondents
Glasgow <sup>i</sup>	587	47.6
Edinburgh	449	36.4
Aberdeen	106	8.6
Dundee	27	2.2
Outside Scotland/Unknown	64	5.2
TOTAL	1,233	100.0

#### Table 1: Responses by transplant unit

<sup>&</sup>lt;sup>i</sup> This may include adults who received their transplant as children at the Royal Hospital for Sick Children, Yorkhill, Glasgow.

## 3.2 Responses by main/parent renal unit currently attended

Table 2 shows response rates by the renal unit with overall responsibility for the patients' long-term follow-up. Clinics may be provided at other sites. Response rate varied from 55.1% in Raigmore Hospital, Inverness, to 78.5% in Crosshouse Hospital. The overall response rate was 63.6%. The figures in this table were used as the basis for analysis of Sections 5–10.

Main/parent renal unit (key for tables)	Attempted contacts	Responses	Response Rate %
Aberdeen Royal Infirmary (ARI)	214	158	73.8
Crosshouse Hospital, Kilmarnock <b>(XH)</b>	65	51	78.5
Dumfries & Galloway Royal Infirmary (DGRI)	43	29	67.4
Monklands Hospital, Airdrie <b>(MONK)</b>	67	39	58.2
Ninewells Hospital, Dundee (NINE)	182	113	62.1
Queen Margaret Hospital, Dunfermline <b>(QMH)</b>	86	53	61.6
Raigmore Hospital, Inverness (RAIG)	89	49	55.1
Royal Infirmary of Edinburgh (RIE)	349	245	70.2
Western Infirmary, Glasgow (WIG)	843	496	58.8
Total	1,938	1,233	63.6

Table	2: Res	ponses b	v main	/parent i	unit cu	rrently	attended
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## 3.3 Age range, type and year of transplant

Table 3 gives the age range, type of transplant and year of transplant for respondents and non respondents. 97.8% of Scottish transplant patients were 75 years or under at the time of the survey, 73.6% had a deceased donor transplant (sometimes referred to as a cadaveric transplant) and 34.8% had their transplant for ten years or more. Respondents tended to be older than non-respondents and had their transplants for longer, but otherwise respondents were representative of the population from which they were drawn.

	Respond	dents	Non-respon	dents"	Tota	ıl
	Numbers	%	Numbers	%	Numbers	%
Transplant patients	1,233	63.6	712	36.6	1,945	100
Age range						
15–45	350	28.4	388	54.5	738	37.9
46–64	655	53.1	267	37.5	922	47.4
65–75	196	15.9	48	6.7	244	12.5
76+	30	2.4	9	1.3	39	2.0
Not recorded	2	0.2			2	0.2
Total	1,233	100.0	712	100.0	1,945	100.0
Type of transplant						
Cadaver (deceased donor)	919	74.5	513	72.1	1,432	73.6
Live	277	22.5	182	25.6	459	23.6
Not recorded	37	3.0	17	2.4	54	2.8
Total	1,233	100.0	712	100.0	1,945	100.0
Year of transplant						
Pre-1999	470	38.1	207	29.1	677	34.8
1999–2003	326	26.4	202	28.4	528	27.2
Post 2003	395	32.0	303	42.6	698	35.9
Not recorded	42	3.4			42	2.2
Total	1,233	100.0	712	100.0	1,945	100.0

Table 3: Age range, type of	transplant and year of transplant for respondents and
non-respondents	

<sup>&</sup>lt;sup>ii</sup> Figures provided by the SRR as at December 2008. When added to the respondents, there is a slight difference of 7 in the total from that in Table 2. This may be caused by the time difference in the Registry providing figures, and a minor change in total number of patients on the database, or as a result of duplicate responses which we were unable to identify and remove.

# 4 Experience at time of transplant

## 4.1 Organisation of kidney transplant services

Until 1998, there were four renal transplant units in Scotland, based in Glasgow, Edinburgh, Dundee and Aberdeen. The Dundee unit closed in 1998 and the Aberdeen unit in 2003. The first live donor transplant in the United Kingdom was carried out in the Royal Infirmary of Edinburgh in 1960. Consequently the transplant service moved to a purpose-built unit at the Western General Hospital in 1968. In 1995, the service returned to the Royal Infirmary, initially at the Lauriston Place site before moving to the New Royal Infirmary at Little France in 2002. Respondents to the survey received their transplants at these three sites. All adult renal transplants in Glasgow have been and continue to be undertaken at the Western Infirmary. Following surgery, patients are reviewed initially at the clinic of the unit in which they received their transplant before returning to their parent unit for long-term follow-up. The only exception to this rule is in Glasgow where the majority of transplant patients continue to attend the Western Infirmary.

## 4.2 Information provided by the transplant unit

Only respondents who reported having their transplant at a Scottish unit (1,169) have been included in the analysis of Section 4. Overall, 88.5% (1033/1167) of respondents recalled having received enough information about their transplant before their operation. There were no significant differences amongst units. Fewer patients, 85.3% (382/448) receiving a transplant before 1999, said they were given enough information than after 1999, 91.5% (279/305), though we have no way of telling whether this reflects lack of recall or an improvement in the information given. This difference was statistically significant (p=0.006).

## 4.3 Understanding of information provided

94.0% (1089/1158) of respondents reported that the information they received was in a way that they could understand. There were no significant differences amongst units. Fewer patients, 91.2% (403/442) receiving their transplant before 1999, said they could understand the information given to them than after 1999, 96.1% (293/305), though this may simply reflect lack of recall. This difference was statistically significant (p=0.002).

## 4.4 Provision of information in a different format

64/1158 (5.5%) respondents indicated they would have preferred the information they received to have been provided in a different format: 18 people (1.6%) would have liked large print with 10 (0.9%) requests for audio tape and 5 (0.4%) for another language. No-one expressed a preference for Braille.

## 4.5 Information provided for family/carers

78.9% (905/1147) of respondents felt that sufficient information had been given to their family or carers. There were no significant differences amongst units or by year of transplant. 247 respondents, who received their transplant in Scotland, submitted the same number of comments about the transplant information they received.

93 were positive comments and 92 of the remaining 154 comments were about lack of information, particularly about the side effects of medication (see Section 5.1).

# 4.6 Communication between the transplant unit and the parent renal unit

Respondents were asked whether they felt there was good communication between their transplant unit and their parent unit if these were different. We eliminated those who received their transplant in Dundee or Aberdeen from this analysis, given that transplantation is no longer carried out in these units. 345 respondents were eligible for analysis. For those transplanted in Glasgow, 93/128 (72.7%) felt the communication was good, whereas 35/128 (27.3%) thought not or were unsure. For those transplanted in Edinburgh, 148/217 (68.2%) indicated the communication was good, whereas 69/217 (31.8%) thought not or were unsure. There was no statistical difference between the two units.

## 4.7 Overall satisfaction

We asked respondents to grade overall satisfaction of their patient experience at the time of transplant using a 10-point scale with one representing very unsatisfactory and 10 very satisfactory. 1161/1169 (99.3%) of all respondents transplanted in Scotland provided a score in this section. Satisfaction scores ranged between 8.7 and 9.0 with no statistically significant differences amongst units. The average score across the four Scottish transplant units was 8.7. We recognise these responses relate to transplant patients whose transplants were functioning at the time of the survey and may not necessarily reflect the views of patients whose transplants had failed.

## 4.8 Comments on the patient experience

We asked respondents to tell us three ways in which their experience at the time of transplant could have been improved. Analysis was confined to the existing transplant units, Royal Infirmary of Edinburgh and Western Infirmary, as transplantation is no longer carried out in the Aberdeen and Dundee units. 422/1036 of respondents transplanted in Edinburgh or Glasgow submitted 746 comments. The themes that emerge from analysis of patient responses fall into three categories and the messages are the same for both units.

#### 4.8.1 Ward environment

Respondents felt their transplant experience would have been improved:

- with better and cleaner toilet/bathing/showering facilities
- with better standards of hygiene and cleanliness in ward areas
- had they been nursed in a ward specifically for transplant patients or in single rooms, rather than in a general ward, in order to reduce the risk of infection, and
- had they been moved less during their stay.

#### 4.8.2 Information and communication

Respondents asked for better communication between doctors, patients and families/carers; also more information on what to expect after the transplant including the side effects of medication.

#### 4.8.3 Staff levels and training

Respondents expressed a desire for better staffing levels, staff who are better trained in renal care and staff who had better listening skills.

# 5 Patient information

## 5.1 Information provided on medications

94.4% (1146/1214) of respondents reported that a member of staff had explained the purpose of the medications they were prescribed. Patient satisfaction ranged from 92.2–100% (Table 4). 98.3% (1196/1217) respondents reported knowing which medications were to prevent rejection of their transplant. Patient satisfaction ranged from 97.4–100%. For both of these questions, it was not possible to tell whether differences exist amongst units due to the small numbers of responses in some subgroups. A smaller proportion of respondents, 83.5% (1012/1212) said they knew about the side effects of their medications. Patient satisfaction ranged from 79.2– 89.3%. There were no statistically significant differences amongst units.

## 6 Relationship with staff

## 6.1 Clinic staff having time

93.7% (1132/1208) of respondents reported that clinic staff had time to answer questions and deal with problems they had with their transplant or treatment. Patient satisfaction ranged from 91.8–100% (Table 4). It was not possible to tell whether differences exist amongst units due to the small numbers of responses in some subgroups. Respondents indicated that they obtained information from a variety of sources including consultants, nurses, transplant co-ordinators or other members of staff. Overall, respondents were most likely to ask their consultant.

## 6.2 Sufficient privacy

97.7% (1176/1204) felt they had been given sufficient privacy when discussing their transplant or treatment. Patient satisfaction ranged from 94.1–100% (Table 4). It was not possible to tell whether differences exist amongst units due to the small numbers of responses in some subgroups.

## 6.3 Contacting the unit

89.8% (1079/1202) felt they could contact renal unit staff when they had anxieties or worries about their transplant or treatment. Patient satisfaction ranged from 83.7–96.6% (Table 4). There were no significant differences amongst units.

## 6.4 Knowledge of medical history

87.0% (1047/1203) felt that the staff they had seen in the renal unit or outpatient clinic had a good knowledge of their medical history. Patient satisfaction ranged from 83.1–100% (Table 4). There was a statistically significant difference amongst units (p=0.044).

Renal unit	Membe explained of medi	r of staff I purpose cations	Clinic havin	c staff g time	Sufficien	t privacy	Feel able the renal	to contact I unit staff	Good kno medica	wledge of I history	Go commu between and	ood nication renal unit I GP
	Number of yes responses	%	Number of yes responses	%	Number of yes responses	%	Number of yes responses	%	Number of yes responses	%	Number of yes responses	%
ARI	147	93.0	147	95.5	149	97.4	141	92.2	140	92.1	95	62.5
ХН	47	92.2	48	94.1	49	96.1	44	89.8	44	86.3	31	60.8
DGRI	28	100	29	100	28	96.6	28	96.6	29	100	24	82.8
MONK	37	97.4	36	94.7	37	97.4	32	86.5	33	86.8	24	63.2
NINE	109	97.3	105	94.6	107	95.5	106	94.6	100	89.3	70	64.2
QMH	49	92.5	49	92.5	48	94.1	43	86.0	44	89.8	31	63.3
RAIG	44	93.6	45	91.8	49	100	41	83.7	43	87.8	36	75.0
RIE	224	92.9	224	94.1	229	97.0	208	87.0	211	88.7	155	66.5
WIG	461	94.9	449	92.6	480	99.0	436	90.1	403	83.1	292	61.7
TOTAL	1146	94.4	1132	93.7	1176	97.7	1079	89.8	1047	87.0	758	64.1

# 7 Team working

## 7.1 Communication between renal unit and GP

Only 64.1% (758/1182) of respondents felt there was good communication between their renal unit and GP. Patient satisfaction ranged from 60.8–82.8% (Table 4). There were no statistical differences amongst units. It is likely that these results reflect delays in dictation and/or typing of hospital letters to GPs.

## 7.2 Access to other professionals

We asked patients whether they felt they had access to other professionals if needed. The results, which are shown in Table 5, suggest that while most felt they had access to a dietitian, pharmacist and dermatologist, fewer than 50% felt they would be able to see a physiotherapist, social worker, occupational therapist or psychologist. This is likely to reflect the fact that dietitians, pharmacists and dermatologists are typically part of the renal transplant follow-up team, whereas the other professionals are usually only accessed by referral. Some of the written responses we received raised the possibility that this question was not clearly worded. In particular, we felt some patients may have meant they had not seen a member of the multidisciplinary team, rather than that they would be unable to see one if needed. For this reason we did not analyse responses by unit.

	Number of Yes responses	Total number of responses	%
Dietitian	857	1,054	81.3
Pharmacist	814	1,029	79.1
Dermatologist	639	911	70.1
Physiotherapist	367	773	47.5
Social worker	290	689	42.1
Occupational therapist	250	687	36.4
Psychological services	230	665	34.6

#### Table 5: Access to other professionals

# 8 Hand hygiene

## 8.1 Hand hygiene

64.6% (769/1190) of respondents indicated that staff usually washed their hands at clinics. Upon reflection, we might have phased this question differently as an answer of 'no' or 'not sure' may simply have meant that patients did not see staff washing their hands.

186 respondents provided comments on hand hygiene in the outpatient clinic (186 respondents). Some comments related to staff hand hygiene, whilst others related to patient hand hygiene. Themes covered poor staff hand hygiene as well as poor patient hand hygiene and the availability and location of alcohol gel.

# 9 Renal PatientView

## 9.1 Description of Renal PatientView

Renal PatientView is a website which enables patients to view their results, diagnosis and relevant links to further information online. The website address is <u>www.renalpatientview.org</u>. Renal PatientView provides an opportunity for patients to share results and other information with family or carers.

## 9.2 Availability of Renal PatientView

We asked whether Renal PatientView was available and whether those who said they had access to it actually used it. Overall 508/1040 (48.8%) said that they had access to Renal PatientView, while 532/1040 (51.2%) thought they did not or were not sure. There was a significant difference amongst units (p<0.001), suggesting that some units may promote Renal PatientView more than others or that it had not been installed in every unit.



#### Figure 1: Availability of Renal PatientView

For key to Figure 1, please see page 14.

Indeed at the time of the survey, Renal PatientView had not been installed in three units (Aberdeen Royal Infirmary, Monklands Hospital and Raigmore Hospital) and at Ninewells Hospital, it had only recently become available<sup>III</sup>. We also gained the impression from analysis of free text comments that some people may have confused Renal PatientView with their hospital's patient management system (which also stores their results but which they cannot access).

<sup>&</sup>lt;sup>iii</sup> Details taken from the Renal PatientView website in November 2009 - <u>http://www.renal.org/pages/pages/joint-activities/rixg/rpv/where.php</u>

## 9.3 Use of Renal PatientView

260/483 (53.8%) who reported that Renal PatientView was available said they used it. This represents only 21.1% of the total number of respondents. It was not possible to tell whether differences exist among the units due to the small number of responses in some subgroups. This finding raises issues of access, education, awareness raising and training for patients in the use of this resource.

A comparison of those who use Renal PatientView by three age groups, 15–45, 46– 64 and 65 and over, demonstrated that there were no significant differences in its use by age. These findings contrast with those of the dialysis survey<sup>9</sup>.

#### 9.4 Training on Renal PatientView

Considering only those respondents who had access and used Renal PatientView, 127/215 (59.1%) respondents reported having training in its use. It was not possible to tell whether differences exist amongst units due to the small number of responses in some subgroups.

#### 9.5 Reasons why Renal PatientView is not used

427 respondents gave a variety of reasons why they did not use Renal PatientView. Some said they did not know about it, that they had difficulty accessing it or that they had no training. Others said they did not want to use it, preferring instead to talk to staff.

# 10 The clinic environment

#### 10.1 Grading of outpatient area

Respondents were asked to grade different aspects of their outpatient area as good, average, poor. The findings are shown in Figures 2–7. Units scoring highly in one environmental domain were likely to score highly in another and tended to maintain the same ranking in each domain.

## 10.2 Best experience overall

Dumfries & Galloway Royal Infirmary, Monklands Hospital and Crosshouse Hospital offered the best outpatient experience, while the respondents attending the Western Infirmary were least satisfied. We note that these patients, representing 40% of respondents in our survey, have since transferred to new transplant clinics at the new Victoria Hospital, Glasgow, and the new Stobhill Hospital, Glasgow.

For key to the following figures, please see page 14. For each of the six environmental domains shown on the next two pages, there is a statistically significant difference among responses from different units (p<0.001).

Figure 2: Standard of cleanliness of the area



Figure 3: Standard of comfort



Figure 4: Standard of accessibility



Figure 5: Standard of surroundings



Figure 6: Standard of toilets



Figure 7: Standard of waiting area



# 11 Satisfaction with follow-up care

## 11.1 Grading the quality of care

We asked patients to grade overall satisfaction of the quality of care provided during follow-up using a 10-point scale with one representing very unsatisfactory and 10 very satisfactory. 1208/1233 (98.0%) of all respondents provided a score in this section. Satisfaction scores ranged from 8.4–9.7. There were no statistically significant differences amongst units. The average score across the nine Scottish units was 8.8.

## 11.2 Comments on the patient experience

We asked patients to tell us three ways in which their experience during follow-up could have been improved. 578/1233 (48.9%) patients recorded 1,031 comments.

#### 11.2.1 Positive experiences

Whenever the survey invited free text comments, respondents often used this opportunity to praise their treatment or the staff at their local unit. For example, in this section we received 106 comments which were positive.

#### What patients praised...

'I have had nothing but excellent care and attention by all renal staff throughout my illness.' (Aberdeen Royal Infirmary)

'I have no complaints. The care I received from the transplant and renal units was first class.' (Crosshouse Hospital)

'I have the best team around ... I feel I am [a] very lucky person to have such a dedicated talent.' (Dumfries & Galloway Royal Infirmary)

'I am happy with the care I receive.' (Ninewells Hospital)

'I have had an excellent service - staff very professional.' (Victoria Hospital)

'... Staff are friendly, professional and efficient. I trust, respect and appreciate all of them.' (Royal Infirmary of Edinburgh)

'In all the years that I have attended both the renal unit and clinic, I am totally satisfied with the care provided.' (Western Infirmary)

The main themes of the remaining responses are outlined below. These themes were also reflected in free text comments throughout the survey responses.

#### 11.2.2 Communication

Better communication was the theme of 173 comments. Respondents expressed a desire to be treated more holistically by staff who can devote time to listening to them. Others requested better communication between the renal unit and their GP or between departments, so that there is improved follow-up and feedback on test

results. Related to this was a desire for more information and access to Renal PatientView.

#### What patients said they wanted...

'Better sharing of information between GP and clinic.' (Royal Infirmary of Edinburgh)

'Information on the renal journey would have been helpful at each stage.' (Monklands Hospital)

'Dealing with me as a 'person' with an illness.' (Western Infirmary)

'Having a little more time to discuss any worries.' (Western Infirmary)

'Better communication between departments.' (Ninewells Hospital)

'Getting results of tests ... quickly, ie not waiting till next appointment. By email better than by post. Availability of Renal PatientView might also be beneficial.' (Ninewells Hospital)

#### 11.2.3 Clinic organisation

There were 172 comments about clinic organisation. Most frequently, these related to waiting times at clinics (103 comments), however other topics included better administration and record-keeping; more choice about clinic days and times; and better arrangements for obtaining blood samples.

#### What patients said they wanted...

'Cut waiting times in clinics, more efficient routine needed.' (Queen Margaret Hospital)

'Clinic appointments outwith 9–5 working hours could help patients who work fulltime.' (Western Infirmary)

'Making sure my notes are always there.' (Western Infirmary)

'Improved appointments system.' (Royal Infirmary of Edinburgh)

'Improving blood sample procedure.' (Ninewells Hospital)

#### 11.2.4 Clinic environment

We received 171 comments about the clinic environment; the majority of these related to Aberdeen Royal Infirmary and the Western Infirmary. Improving waiting areas was the central theme, but better toilet facilities, better temperature control and the provision of sufficient comfortable seating, entertainment (such as reading materials/television) and refreshments were specifically mentioned.

#### What patients said they wanted...

'Waiting area could be more comfortable.' (Western Infirmary)

'Larger waiting area.' (Aberdeen Royal Infirmary)

'Easier access to toilets.' (Aberdeen Royal Infirmary)

'Refreshments.' (Ninewells Hospital)

'Improved waiting area with more seats.' (Western Infirmary)

#### 11.2.5 Continuing care and treatment

145 comments were related to continuing care and treatment. In 81 of these, respondents expressed a preference to see the same consultant/doctor at clinics; one who has a good knowledge of their medical history. Minor themes concerned being able to contact their renal unit directly for advice; and being able to access healthcare professional staff, eg dietitian, social worker.

#### What patients said they wanted...

'Seeing the same consultant on each visit.' (Crosshouse Hospital)

'Staff being aware of medical history.' (Western Infirmary)

'Easier access to a renal doctor if needed.' (Aberdeen Royal Infirmary)

'Social workers to help patients with financial problems.' (Edinburgh Royal Infirmary)

#### 11.2.6 Other

To a lesser extent, respondents also expressed a desire for better hospital parking facilities, better standards of hygiene and cleanliness in hospitals and higher staffing levels in renal units.

#### What patients said they wanted...

'Better parking at renal unit.' (Monklands Hospital)

'Better cleanliness.' Ninewells Hospital

'More nurses, therefore more time per patient.' (Ninewells Hospital)

'More trained staff.' (Western Infirmary)

## 12 Recommendations

The findings of the report indicate that people who responded were largely satisfied with their treatment and care, both at the time of their transplant and during continuing care and treatment. This may be because transplant patients are thankful to have received a life-saving organ which has resulted in an improved quality of life, compared to long-term dialysis which impacts significantly on daily life. However, inevitably there are areas of care and treatment which can be improved and this report highlights some of the areas of issue for patients. In making recommendations based on patients' views, we recognise that some patient concerns are easier to address than others, but trust that NHS boards and renal units will wish to improve services in order to make patients' experience better.

Based on what patients told us in the survey, we have made recommendations which aim to address the areas that are important to renal transplant patients and would improve their experience. Some of these recommendations echo those in the 2003 NHS QIS Adult Renal Services National Overview<sup>10</sup>, indicating that while there has been much progress, some areas require further work.

#### Information:

1 Good quality information should be provided to patients' families and carers and there should be good communication with both patients and their families and carers so that all are fully informed about the transplantation process. This relates to Standard 12 of the Adult Renal Standards (2002)<sup>11</sup> which states that: 'All people with chronic renal failure or on RRT, and carers where appropriate, are given information to help them make informed choices'.

#### At time of transplant:

- 2 Every effort should be made to minimise the number of times inpatients are moved within the hospital at the time of their transplant.
- 3 The transplant unit and the parent renal unit should ensure good communication and co-ordination of care during the post-transplantation period when shared care arrangements are in place.

#### Continuing care and treatment:

- 4 Communication between the renal unit and the patient's GP should be improved through ensuring compliance with Standard 11.2 of the Adult Renal Services Standards<sup>11</sup>, which states that: 'Clinic letters are sent to the GP within 2 weeks of being seen by a nephrologist'.
- 5 NHS boards should ensure that patients have access to the members of the multidisciplinary team when required. In particular ensuring:
  - 5.1 access to renal unit staff who can answer questions when they have concerns about their transplant or treatment, and
  - 5.2 access to renal medical staff with knowledge of the patient's medical history. Consideration should also be given to organising clinics, so that

patients who wish to see the same consultant about their treatment do so, where possible.

- 6 NHS boards should improve clinic organisation, so that waiting times are kept to a minimum.
- 7 Renal PatientView should be installed in all units where it is not yet available, and access, education, awareness raising and training on Renal PatientView should be provided for patients.

#### Quality of the environment:

8 Consideration should be given to making basic improvements to the outpatient clinic environment. Particular attention should be paid to improving waiting areas.

#### Healthcare associated infection:

9 NHS boards should ensure compliance with the prevention and control of infection standards within the NHS QIS standards for Healthcare Associated Infection (HAI)(March 2008)<sup>12</sup> and, in particular, minimise the risk of infection in ward areas.

# 13 Limitations and lessons learned

#### 13.1 Parameters of the survey

The survey did not include children and young people under the age of 15 years. As the NHS QIS Clinical Standards for Adult Renal Services relate to adults only, the steering group concluded that it was not feasible to include children in this written survey.

The survey was confined to those people who require RRT in the form of regular haemodialysis or peritoneal dialysis or a kidney transplant. Patients with acute kidney injury or those with chronic kidney disease not receiving RRT were not included.

#### 13.2 Piloting the survey

A number of changes were made to the survey forms after piloting. At the beginning of the survey form, we added guidance for those who regularly attend more than one renal unit. We made it clear that some questions related to the unit in which the transplant had taken place and others to the unit in which follow up was undertaken. The wording of some questions was changed for clarity. The number of tick box options was amended in some questions. Two sections were added to the form: a section on the environment taken from the dialysis survey; and a section on hand hygiene. Finally, we added an open format question at the end of each section. An average time for completing the survey was calculated from pilot feedback. This allowed us to give an average completion time in the guidance notes for the final survey.

#### 13.3 Conducting the survey

Conducting a national patient experience survey was a new venture for NHS QIS which required the development of new processes and skills.

The mailing of the survey, particularly the second mailing, coincided with the period of Christmas mail and initially there was some concern that many people would be too busy to complete and return the survey. However, given that 64% of transplant patients responded, scheduling the survey to take place at a busy time of year does not appear to have adversely affected the response rate. As the response was higher than anticipated, this resulted in a longer period for entering and analysing the data than originally foreseen.

The topics addressed in the survey were chosen by patient representatives, based on their knowledge of patients' concerns. The timescales for conducting the survey were short due to the requirement to report initial findings at the meeting of the Scottish Renal Association in March 2009 and ideally a longer time allocated to the pilot phase in order to test and refine the survey would have been beneficial.

There were a very small number of duplicates identified and eliminated from the analysis. Despite making every effort to ensure patient lists were up to date, regrettably a very small number of survey forms were returned indicating that the patient had died. In addition, a small number of surveys were returned indicating that data were incorrect, some details having changed in the preceding months.

## 13.4 Observations

In some of the questions, patients were asked to provide information about the start of their treatment. However, in some instances, treatment began a long time ago and powers of recall may have been impaired.

The subjective nature of patient experience surveys in general means that it is not possible to validate, verify or replicate the data. The experience is based on the patient's recollection and interpretation of events. However patient views provide valuable feedback to the service as 'knowledge of the experience, held only by the patient, is unique and precious'<sup>13</sup>. Results can assist NHS boards to develop patient-centred services by introducing small changes, often at minimal cost, which enhance the overall patient experience (eg clinic organisation/waiting times).

#### 13.5 Analysis

Most questions were well understood and well completed. However from the responses, a lack of clarity became apparent in one or two questions which were misunderstood by some participants (questions 6.2 and 8.1). This meant that it was not possible to draw clear conclusions from these questions.

The diversity of the survey in asking both open and closed format questions brought a level of complexity to the analysis phase. Overall, some valuable supporting evidence was obtained from free comments. Many free text comments reflected individual patients' unique experiences, nevertheless some common themes emerged which illuminated the quantitative data and allowed us to draw conclusions.

Care was taken to protect anonymity when interpreting the findings to ensure that no patients could be identified by renal unit staff, particularly in smaller units. To this end, steps were taken to amalgamate statistics from the satellite units with their parent unit, increasing the complexity of the analysis.

# Appendix 1: Membership of adult renal services steering group

**Professor Chris Isles**, Consultant Physician, NHS Dumfries & Galloway (Chair – from August 2008)

Sister Anne Allan, Clinical Ward Manager, NHS Highland

Ms Jane Bryce, Public Partner, NHS Highland (until June 2009)

Miss Laura Buist, Consultant Transplant Surgeon, NHS Greater Glasgow and Clyde

Mrs Margaret Christie, Public Partner, NHS Grampian

Mr James Dunleavy, Renal Pharmacist, NHS Lanarkshire

**Dr Jonathan Fox,** Consultant Nephrologist, NHS Greater Glasgow and Clyde (from October 2008)

Dr David Jenkins, Consultant Nephrologist, NHS Fife (until October 2008)

**Dr Brian Junor,** Consultant Nephrologist, NHS Greater Glasgow and Clyde (Chair - until August 2008)

Dr Wendy Metcalfe, Consultant Nephrologist, NHS Lothian

Ms Geraldine Ovens, Education Facilitator, NHS Ayrshire & Arran

Ms Jan Scott, Renal Dietitian, NHS Tayside

**Dr Caroline Whitworth**, Consultant Renal Physician, NHS Lothian (from May 2008–October 2009)

#### Support from NHS QIS was provided by:

Mrs Joanne Abbotts, Health Services Researcher

Mr Sean Doherty, Team Manager

Mrs Wendy Forbes, Project Officer

Mr Sam Poullain, Project Officer

Ms Vicky Rigley, Project Administrator

Dr Karen Ritchie, Lead Health Services Researcher

Mrs Fiona Russell, Programme Manager

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# Appendix 3: Kidney transplant patient survey

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2.6	Do you know which of these medications are to prevent your transplant being <b>rejected</b> ?					
2.7	Do you know about <b>the possible side</b> effects of these medications?					
2.8	Do you have <b>any other comments</b> about t about your transplant?	the <b>info</b>	ormatio	n you h	ave rec	eive
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~ •		Yes	Νο	sure	Not applicabl
3.4	communication between your renal unit and the transplant unit, if these were different?				
4. R	enal Patient View				
Ren you	al Patient View, which is accessed through t test results and provides information about	a comput t diagnosis	er, allov and tre	vs you eatmer	to see nt.
		Yes	No	sure	applicab
4.1	Is <b>kenal ratient View</b> available to you? (If no or not sure, please go to Section 5; if yes, go to 4.2)				
4.2	If it is available, do you <b>use</b> Renal Patient View?				
	If you use Depert Defient \/ievy were you	_	_	_	_
4.3 4.4	given adequate <b>training</b> ? If you do <b>not</b> use Renal Patient View,		Ш		
4.3 4.4 5. Y	if you use Renal Patient View, were you given adequate <b>training</b> ? If you do <b>not</b> use Renal Patient View, please tell us why:	ent renal	Unit		
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			Yes	No	Not	Not
5.3	Do you feel you <b>privacy</b> when d or treatment?	are given sufficient iscussing your transplant				
5.4	Do you feel you unit staff when y worries about yo treatment?	can <b>contact</b> the renal you have any anxieties or our transplant or				
5.5	Do you feel that the renal unit or <b>good knowledg</b> history?	t the people you see in outpatient clinic have a <b>e</b> of your medical				
5.6	Do you have <b>an</b>	y other comments about	your relati	ionship	with staff	at your
6. T	eam working				Not	Not
6. T	eam working		Yes	No	Not sure d	Not applicable
6. T	<b>eam working</b> Do you feel ther communication	re is good between the <b>renal unit</b>	Yes	No	Not sure	Not applicable
6. T 6.1 6.2	eam working Do you feel ther communication and your GP? Do you feel you following profes needed them?	re is good between the <b>renal unit</b> have <b>access to</b> the <b>sionals</b> if you have	Yes	No	Not sure d	Not applicable
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6. Tr 6.1 6.2	eam working Do you feel ther communication and your GP? Do you feel you following profes needed them? 6.2.1 6.2.2 6.2.3	re is good between the <b>renal unit</b> have <b>access to</b> the <b>sionals</b> if you have Dietitian Pharmacist Physiotherapist	Yes	N∘	Not sure	Not applic able
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6.1 6.2	eam working Do you feel ther communication and your GP? Do you feel you following profes needed them? 6.2.1 6.2.2 6.2.3 6.2.4 6.2.5 6.2.5	re is good between the <b>renal unit</b> have <b>access to</b> the <b>sionals</b> if you have Dietitian Pharmacist Physiotherapist Occupational therapist Dermatologist Social worker	Yes		Not sure	Not applicable

7. T	ne envire	onment				
7.1	How wo following outpatie	uld you grade the g aspects of your ent area?	Good	Average	Poor	Not applicabl
	7.1.1	Cleanliness of the area				
	7.1. <b>2</b>	Comfort				
	7.1.3	Accessibility (eg lifts, ramps, automatic doors)				
	7.1. <b>4</b>	General surroundings				
	7.1.5	Toilets				
	7.1.6	Waiting area				
	7.1.7	Other (please specify)				
	17					
0.11						
о. п		utactiont olinic		Yes N	Not	
8 1		utaff usually clean their ban	ds	res No	o sure	•
0.1	either by water or treating	y washing them with soap of using alcohol gel before you?	and			]
8.2	Do you clinic?	have any other comments	about har	nd hygiene	in the ou	utpatient

Please indicate by circling on the scale below how satisfied you are overall with the quality of care provided by your unit?
For example, $\mathbf{O}$ = very unsatisfied $\Leftrightarrow$ $\mathbf{O}$ = very satisfied
1 2 3 4 5 6 7 8 9 10
Very unsatisfied Very satisfied
Please list, in order, the <b>3 things</b> that would make the biggest improvement t your experience of the service.
2.
3.
Thank you for your time
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# Appendix 4: Glossary

acute kidney injury	The rapid loss of kidney function over a few hours or days (previously known as acute renal failure).
anti-rejection medication	Drugs to prevent organ rejection.
cadaver transplant	A kidney that has been donated by a previously healthy person who has died suddenly. Kidneys for donation are removed, with appropriate permission, when the donor's death has been confirmed by brain stem testing but the heart is still beating due to artificial ventilation. Now known as deceased donor transplant.
cadaveric	Relating to the body of dead person.
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.
chi-squared test	A test to see if a result is statistically significant. See statistically significant.
chronic	Present over a long period of time.
chronic renal failure	The slow and progressive deterioration of kidney function.
clinical governance	Ensures that patients receive the highest quality of care possible, putting each patient at the centre of his or her care. This is achieved by making certain that those providing services work in an environment that supports them, and that the organisation places safety and quality of care at the top of its agenda.
	Risk management at an organisational level is an important aspect of clinical governance. It 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 Standards Board for	The Clinical Standards Board for Scotland was a
Scotland (CSBS)	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 gareed 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
deceased donor transplant	See cadaver transplant.
dermatologist	A doctor who specialises in skin care.
dialvsis	A treatment for kidney failure that removes
	wastes and water from the blood artificially.
dietitian	An expert in nutrition who helps people with
	special health needs plan the kinds and
	amount of foods to eat.
ERF	See established renal failure.
established renal failure (ERF)	A loss of kidney function to a point where this
	becomes life threatening.
GP	general practitioner
haemodialysis	A treatment for kidney failure in which blood is
	purified by passing it across an artificial
	membrane to remove waste products.
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.
Kruskal-Wallis one-way analysis	A statistical test used for making simultaneous
of variance	comparison of more than two population
	means (averages) from independent groups,
	where those means are not normally
	distributed.
live transplant	An organ transplant between living persons.
medication	Drugs prescribed to treat a condition.
multidisciplinary team	A group of people from different disciplines
	(both healthcare and non-healthcare) who
	work together to provide care for patients with
	a particular condition.
nephrologist	A doctor who specialises in kidney disease.
NHS QIS	See NHS Quality Improvement Scotland.

NHS Quality Improvement Scotland (NHS QIS)	NHS QIS was established in 2003 and leads the use of knowledge to promote improvement in the quality of healthcare for the people of
	Scotland. It performs four key functions: providing advice and guidance on effective
	supporting implementation of improvements in
	NHS, reporting and publishing the findings.
	NHS QIS also has central responsibility for patient safety and clinical governance across NHSScotland. Website address:
occupational therapist	A health professional, also known as an OT, who finds ways to help people live at home and be independent, despite their illness.
outpatient	A patient reviewed in a hospital but who does not need to be admitted to hospital.
p value	The probability that at least as much statistical evidence would have been observed in an independent sample in which there was no real effect. This is the primary measure of statistical significance. Lower numbers are better. Traditionally a p value less than 0.05 is considered 'statistically significant'. (Cornell University - adapted)
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.
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.
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.
physiotherapist	A health professional, also known as a 'physio', who makes use of physical methods to promote healing, including the use of light, infrared and ultrasound, massage, hydrotherapy and remedial exercise etc.

psychological services	This type of service is provided by a wide range
	of professionals, for example:
	clinical/counselling psychologists; counsellors;
	psychiatrists; specialist and mental health
	nurses; psychotherapists; members of primary
	care teams; social workers; voluntary
	organisation workers with special skills, and a
	wide range of other mental health and non-
	mental health professionals working in a variety
	of services and settings.
referral	The process by which a patient is transferred
	from one professional to another, usually for
	specialist advice and/or treatment.
renal	Relating to the kidneys.
renal failure	An abnormality resulting from the inability of the
	kidneys to function and resulting in build-up of
	poisons in the body.
renal replacement therapy	Treatment to replace the function of the
(RRT)	kidneys in a person whose kidneys no longer
	work. Treatment is usually in the form of dialysis
	or transplant.
Renal PatientView	A website which enables patients to view their
	results, diagnosis, and links to further information
	online. Website address:
	www.renalpatientview.org.
renal unit	The part of a hospital which specialises in the
	treatment of people with kidney failure.
RRT	See renal replacement therapy.
Scottish Kidney Federation	A Scottish-based charity representing the voice
	of kidney patients across Scotland through
	kidney patients' associations. Website address:
	www.scotskidneyfederation.org
Scottish Renal Association	A group of healthcare professionals whose
	common purpose is to promote the highest
	standards of care for renal patients in Scotland.
	Website address: www.renal.org/sra/
Scottish Renal Registry (SRR)	A national database which records the clinical
	details of renal patients throughout Scotland.
	Reports are produced for: quality improvement
	including audit & peer review; research
	including basic demography and
	epidemiology; service planning, and teaching.
	Website address: www.srr.scot.nhs.uk
side effect	An effect of treatment in addition to its desired
	therapeutic effect. A side effect is usually
	unpleasant and unwanted.

social worker	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.
SRR	See Scottish Renal Registry.
statistically significant	A term used in statistics to describe a result that is unlikely to have occurred by chance.
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.
transplantation	The act of transferring an organ or tissue from one individual to another.

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The Scottish Health Council, the Scottish Intercollegiate Guidelines Network (SIGN) and the Healthcare Environment Inspectorate are also key components of our organisation.





