

Scottish Renal Patient Experience Survey

Dialysis Report

Your service - your views



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First published January 2010

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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 SRR, 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.



Photo courtesy of Diana Noble

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.

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 failure¹. 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; over 1,600 are on hospital dialysis. Most people on dialysis need 3 sessions a week, with each session lasting about 4 hours. During dialysis people can sit or lie down and can read, watch television, use a laptop, or sleep. It is not a painful process, but due to the rapid changes in blood fluid levels, it can cause nausea and muscle cramps. People on dialysis have to pay particular attention to their fluid intake and diet.

Renal replacement therapy in Scotland

The first person was dialysed for ERF in Scotland in 1960. About 500 new patients start RRT each year and there are now 10 adult and one paediatric renal units in Scotland, with 22 satellite dialysis units. There are two transplant centres. The SRR was set up in 1991 and every unit contributes agreed data to the Registry. Analyses of the data collected by the SRR 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 Plan², 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 dialysis 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 only the second time a survey of this scale has been carried out on patient experience of renal dialysis services, the first being for the Cross Party Working Group on Kidney Disease in 2004³. The response rate to the survey was 62% (1294/2076). The results are presented by main unit (sometimes referred to as parent unit) or, where

appropriate, by parent and satellite unit, except where numbers are too small. Most respondents were aged between 46–75 (66%). The median age for onset of ERF in Scotland is 61 years⁴. The median age for prevalent patients receiving haemodialysis in Scotland is 65 years and for those receiving peritoneal dialysis is 58 yrs¹. Just over 80% of respondents receive hospital dialysis and we are confident that the high response rate paints an accurate picture of their views.

The detailed findings are provided in Sections 4–13 of this report and key elements of these are presented in this summary.

Some of the findings echo those of the NHS QIS Adult Renal Services National Overview (2003)⁵ as well as those of the Cross Party Working Group on Kidney Disease in 2004³. In addition, 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*, published in 2008⁶.

Information about treatment and options

Generally respondents expressed high levels of satisfaction with most elements of services they received. They reported good levels of information about their treatment and options, particularly when they had been referred to renal services 3 months before starting dialysis. Those receiving hospital haemodialysis were more likely to report that they had not been offered a choice in the mode of dialysis (51%) than those receiving peritoneal dialysis (79%). Over 75% reported that transplantation was discussed with them, although when broken down into age groups, the percentage declined by age. While there appears to be good access to information generally, information sessions where people could meet staff and existing patients were not widespread. Over 80% confirmed that the purpose of their medication was explained, although only 60% had an awareness of the side effects.

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 48% said they used it; however, this represents only 12.5% of the total number of respondents. This raises issues of access, education and training. It is important that we invest in these support aspects if we are to maximise future use and value of this tool.

Communication and access to staff

There were high levels of satisfaction regarding the time staff have to answer questions and respond to any problems. Most people reported they would contact a nurse in the first instance which reflects the nurse-led nature of dialysis treatment. Over 85% reported that they felt they could contact their unit from home if they had anxieties or worries about their treatment. Overall, 80% reported that they could access renal medical staff when they were ill, although this varied amongst units, perhaps a reflection of the availability of on-site renal medical staff. There appeared to be issues with access to some other professionals should they be required, for example psychological services.

Communication between health services and across health and social services was not as highly rated as communication within unit teams. This was particularly evident to communications between renal units and GPs, and has been flagged as an improvement area.

Dialysis away from home

We asked people about their experience of travelling away from home for more than 3 days – either on holiday or on business – and access to dialysis during this time. About 44% reported they had done this and access to dialysis was rarely cited as an issue. It was interesting that 61% of respondents reported that they did not want to travel. A variety of reasons for this were given and it is clear that people need to be confident about their condition and the services they need. Those who had travelled, particularly those who had travelled on over three occasions, had travelled to Europe and worldwide, as well as within the UK.

The dialysis environment

This was the issue that generated most comments and the general view was that it could be improved. Comfort, choice of food, access to TV and radio were all given as examples of little things that can make a big difference to an experience that occurs 3 times a week for up to 4 hours at a time. There was a marked difference between the comments made about smaller and newer units and those made about the older, busier units, with patient satisfaction generally higher at smaller, newer units. At the time of publishing this report, one of the large Glasgow centres had moved to a newly built unit, and the other was about to transfer to another newly built unit. Some very practical examples of how better organisation would help were also provided – the need for co-ordination between hospital transport and dialysis services so that people do not have to wait up to 1.5 hours to start dialysis was one striking example. Another stark example was access only to pay-by-view TV proving expensive for people. Patient and family involvement in designing and maintaining the dialysis environment needs to be at the forefront of this aspect of renal services.

Improvements patients requested

Respondents were asked to tell us three ways in which their experience could be improved and the following themes were the areas drawing the most requested improvements:

- the dialysis unit environment
- co-ordination of sessions and better co-ordination between the patient transport and dialysis services to reduce waiting times for patients, and
- staffing levels. While many positive comments were received about the quality and commitment of renal unit staff, many patients said that they would like to see higher levels of trained staff on duty.

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 available to patients and, where appropriate, their family and carers, throughout the patient journey.
- there should be good co-ordination between patient transport services and the dialysis unit in order to minimise waiting times for haemodialysis patients. In addition, patients should begin and end dialysis without undue delay.
- patients should have access to members of the multidisciplinary team when required.
- communication between the renal unit and GP should be improved.

The full recommendations from this report can be found in Section 14.

While there is always scope for improvement, patient satisfaction with renal services 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 conditions 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'¹⁷. 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 in February 2002⁸. 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 Management⁹), entitled Renal Disease in Scotland: Consulting with Patients³.

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 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 take place in or are supported by the 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 established renal failure. 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 with 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 adult renal units

- use the information generated to support renal services in finding and implementing solutions to challenging 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 dialysis survey. The results of the transplant 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 dialysis survey was in two parts. In the first part, we asked patients to tell us about their experience at the beginning of their treatment. Their responses to these questions have been analysed according to the unit where they started their treatment. In the second part of the survey, we asked patients to tell us of the care they receive now. 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.

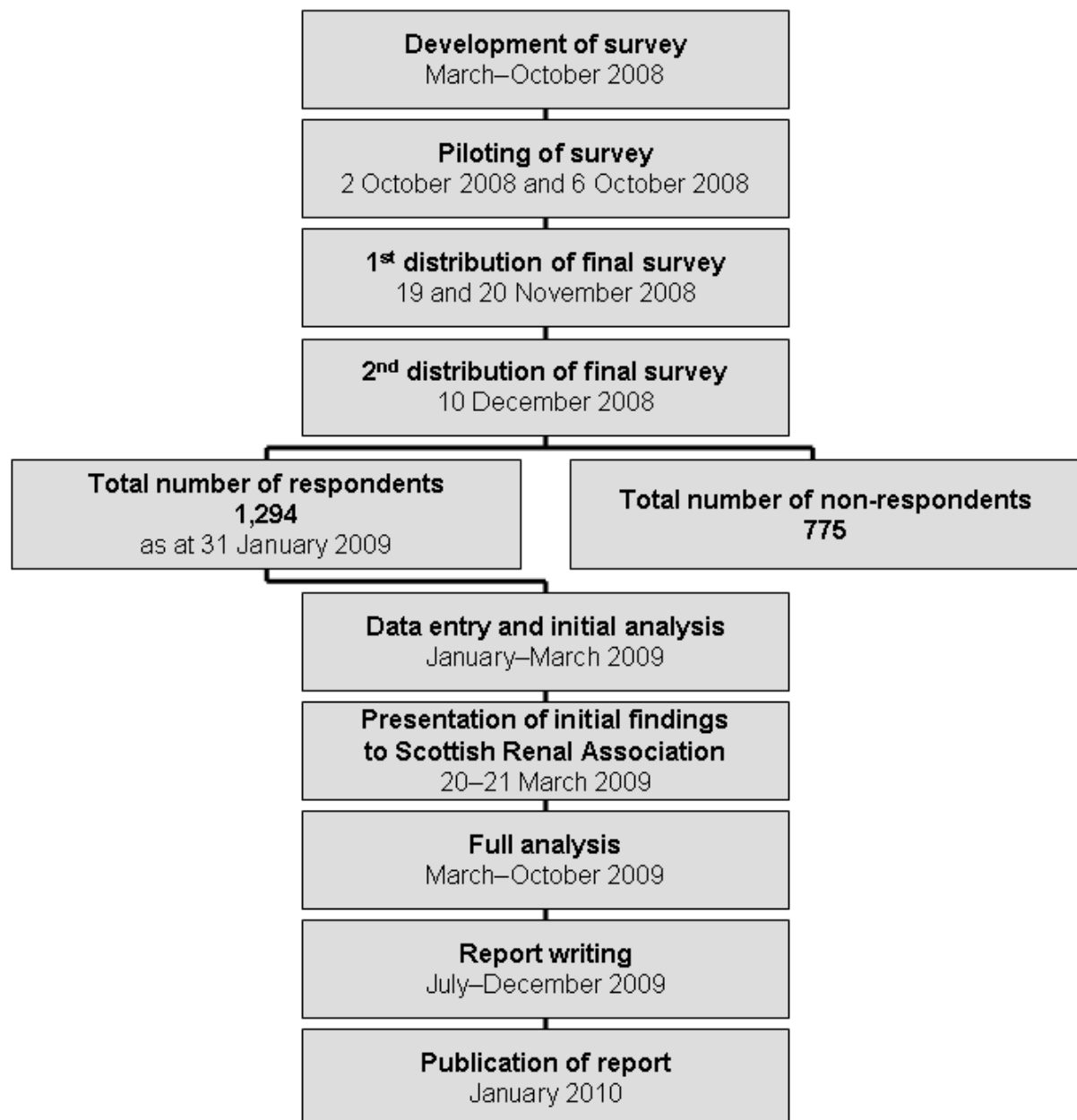
Statistical analysis was by comparison of observed and expected frequencies of responses in each unit (chi-squared test). Low numbers of responses of yes, no or not sure to some questions in some units meant that it was not always possible to make this comparison. We have indicated this in the text by recording 'It was not possible to tell whether differences exist among the units due to the small number of responses in some subgroups'.

Statistical analysis of responses is available upon request.

2.5 Ethical approval

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

Flow chart of dialysis survey



3 Response rates

3.1 Responses by unit attended before starting dialysis

Table 1 shows the unit attended before the start of dialysis treatment for all 1,294 patients who responded to the survey. The figures in this table were used as the basis for the analysis of Section 4 of this report.

Table 1: Responses by unit attended before starting dialysis

Dialysis unit (key for tables)	Number of respondents	% of all respondents in Scotland
Aberdeen Royal Infirmary (ARI)	161	13.8
Crosshouse Hospital, Kilmarnock (XH)	81	6.9
Dumfries & Galloway Royal Infirmary (DGRI)	37	3.2
Glasgow Royal Infirmary (GRI)	194	16.6
Monklands Hospital, Airdrie (MONK)	80	6.8
Ninewells Hospital, Dundee (NINE)	97	8.3
Queen Margaret Hospital, Dunfermline (QMH)	79	6.8
Raigmore Hospital, Inverness (RAIG)	69	5.9
Royal Infirmary of Edinburgh (RIE)	192	16.4
Western Infirmary, Glasgow (WIG)	179	15.3
TOTAL VALID RESPONSES	1,169	100.0
Outside Scotland	121	
Unit not identified	4	
TOTAL	1,294	

3.2 Responses by unit currently attended

Table 2 shows response rates by the unit in which patients were receiving treatment at the time of the survey. Response varied from 53.1% in the Western Infirmary to 76.8% in Dumfries & Galloway Royal Infirmary. The overall response rate was 62.3%. In sections 5–13, responses have been analysed by the 10 parent units or, where appropriate, by all 24 units in which there were more than 10 respondents. This latter group comprises all 10 parent renal units and 14 satellite units. Responses from satellite units in which there were 10 or fewer respondents have been grouped with their parent unit.

The table below also provides the key for unit names that has been used in the tables and graphs throughout the report.

Table 2: Responses by unit currently attended

Main/parent renal unit (key for tables) Dialysis satellite unit (key for tables)	Total number of attempted contacts ⁱ	Responses by individual unit ⁱⁱ	Total response rate %
Aberdeen Royal Infirmary (ARI) Peterhead Community Hospital (ARI – Peterhead) Dr Gray's Hospital, Elgin (ARI – Dr Gray's) Inverurie Dialysis Unit (ARI – Inverurie) Campbell Hospital, Portsoy Balfour Hospital, Kirkwall, Orkney Gilbert Bain Hospital, Lerwick, Shetland Chalmers Hospital, Banff ARI Total	241	111 17 15 11 6 5 3 1 169	70.1
Crosshouse Hospital, Kilmarnock (XH) XH Total	157	102 102	65.0
Dumfries & Galloway Royal Infirmary, Dumfries (DGRI) Galloway Community Hospital, Stranraer DGRI Total	56	36 7 43	76.8
Glasgow Royal Infirmary (GRI) Stobhill Hospital, Glasgow (GRI – Stobhill) Falkirk & District Royal Infirmary (GRI – FDRI) GRI Total	342	77 77 59 213	62.3
Monklands Hospital, Airdrie (MONK) MONK Total	175	106 106	60.6

ⁱ Figures provided by SRR on 11 November 2008

ⁱⁱ Number of respondents based on the unit that respondents reported they attend

Table 2 continued

Main/parent renal unit (key for tables) Dialysis satellite unit (key for tables)	Total number of attempted contactsⁱ	Responses by individual unitⁱⁱ	Total response rate %
Ninewells Hospital, Dundee (NINE) Perth Royal Infirmary (NINE – PRI) NINE Total	192	96 18 114	59.4
Queen Margaret Hospital, Dunfermline (QMH) Victoria Hospital, Kirkcaldy (QMH – VHK) QMH Total	140	56 29 85	60.7
Raigmore Hospital, Inverness (RAIG) Caithness General Hospital, Wick (RAIG – Caithness) Belford Hospital, Fort William Western Isles Hospital, Stornoway RAIG Total	111	60 11 5 4 80	72.1
Royal Infirmary of Edinburgh (RIE) Western General Hospital, Edinburgh (RIE – WGH) St John's Hospital, Livingston (RIE – St John's) Borders General Hospital, Melrose (RIE – BGH) RIE Total	340	122 39 26 24 211	62.1
Western Infirmary Glasgow (WIG) Gartnavel General Hospital, Glasgow (WIG – GGH) Inverclyde Royal Hospital, Greenock (WIG – IRH) Vale of Leven District General Hospital, Alexandria (WIG – VOL) Glasgow Holiday Dialysis Centre WIG Total	322	49 59 40 19 4 171	53.1
TOTAL	2,076	1,294	62.3

3.3 Age range, type of dialysis and year dialysis started

Table 3 gives the age range, type of dialysis and year dialysis started for respondents and non-respondents. Overall, 46.7% of Scottish dialysis patients were 65 or older at the time of the survey. 81.3% were receiving hospital haemodialysis and 77.1% had started dialysis after 2004. Respondents tended to be older than non-respondents and to have been receiving dialysis for longer, but otherwise it would appear that respondents were representative of the population from which they were drawn.

Table 3: Profile of respondents and non-respondents

	Respondents		Non-respondents ⁱⁱⁱ		Total	
	Numbers	%	Numbers	%	Numbers	%
Dialysis patients	1,294	62.5	775	37.5	2,069	100
Age range						
15–45	149	11.5	218	28.1	367	17.7
46–64	456	35.2	279	36.0	735	35.5
65–75	400	30.9	160	20.7	560	27.1
76+	287	22.2	118	15.2	405	19.6
Not recorded	2	0.2			2	0.1
TOTAL	1,294	100.0	775	100.0	2,069	100.0
Mode of dialysis						
Hospital haemodialysis	1043	80.6	640	82.6	1683	81.3
Home haemodialysis	47	3.6	17	2.2	64	3.1
Peritoneal dialysis	186	14.4	118	15.2	304	14.7
Not recorded	18	1.4			18	0.9
TOTAL	1,294	100.0	775	100.0	2,069	100.0
Year dialysis started						
Pre-1999	75	5.8	22	2.8	97	4.7
1999–2003	196	15.2	115	14.8	311	15.0
Post 2003	957	73.9	638	82.3	1595	77.1
Not recorded	66	5.1			66	3.1
TOTAL	1,294	100.0	775	99.9	2,069	100.0

ⁱⁱⁱ Figures provided by SRR as at December 2008. When added to the respondents, there is a slight difference of 6 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 result of duplicate responses which we were unable to identify and remove.

4 Experience at start of treatment

4.1 Organisation of kidney dialysis services

There are 10 main (sometimes referred to as parent) renal units in Scotland. Eight of these support up to seven satellite dialysis units each. The parent units and their 22 satellite units are listed in Table 2 in Section 3.2.

Only patients who reported starting their treatment at a Scottish renal unit were included in the analysis of this section, ie 1169/1294 respondents (see Table 1 in Section 3.1). For the purposes of analysis in this section of the report, we divided respondents into those seen at clinic for more or less than 3 months before starting dialysis, in order to determine the effect of having more time to explain treatment options. Some patients are not seen more than 3 months before starting dialysis due to the acute nature of their kidney failure or because they were referred late by their GP.

4.2 Respondents seen for more than 3 months before treatment

Overall, 88.7% (842/949) of respondents who were seen for more than 3 months before starting dialysis said that the options of haemodialysis and peritoneal dialysis were explained to them at or near the start of treatment. 816/961 (84.9%) felt they had received enough information about their condition or treatment before starting dialysis and 859/951 (90.3%) said that this information was given in a way that they could understand. There was no statistically significant difference amongst units for these factors.

4.3 Respondents seen for less than 3 months before treatment

68.2% (122/179) of respondents who were seen for less than 3 months prior to dialysis said that someone explained the options of dialysis to them at or near the start of treatment. 61.4% (113/184) felt they had been given enough information while 74.3% (127/171) said the information was given in a way they could understand. It was not possible to tell whether differences exist amongst units for these factors due to the small number of responses in some subgroups.

4.4 Information provided for family and carers

When asked about information provided for family and carers, 74.1% (678/915) of those seen for more than 3 months before starting dialysis indicated that enough information was given. There was no significant difference amongst units. The percentage was lower (58.2% - 106/182) for those seen less than 3 months before starting dialysis. Those seen for more than 3 months were more likely to say their family and carers were given enough information ($p < 0.001$). It was not possible to tell whether differences exist amongst units due to the small number of responses in some subgroups.

5 Treatment options

The remaining sections of this report were analysed according to the renal unit respondents told us they currently attend (see Table 2 in Section 3.2).

5.1 Choice of dialysis treatment

Only 50.8% (492/968) of respondents currently receiving hospital haemodialysis could recall being given a choice between home and hospital haemodialysis. Glasgow Royal Infirmary (59.8%) and Crosshouse Hospital (59.2%) were most likely and Monklands Hospital (36.9%) least likely to offer this choice of treatment ($p=0.026$ for differences among parent units). By contrast, 79.3% (138/174) of respondents currently receiving peritoneal dialysis said they had been offered a choice between automated peritoneal dialysis (APD) and continuous ambulatory peritoneal dialysis (CAPD). It was not possible to tell whether differences exist amongst units due to the small number of responses in some subgroups.

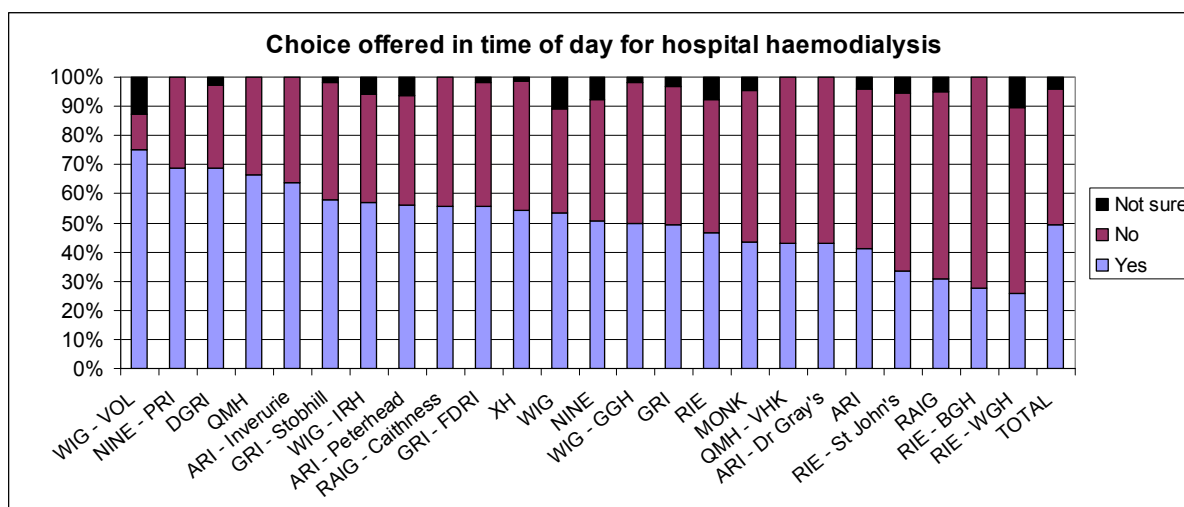
5.2 Would more people have preferred home haemodialysis?

12.6% (54/427) of respondents receiving hospital haemodialysis who could not recall being given a choice between home and hospital treatment said they would have preferred home haemodialysis. It is not known for how many of these home haemodialysis would have been a feasible option. It was not possible to tell whether differences exist amongst units due to the small number of responses in some subgroups.

5.3 Were hospital dialysis patients offered a choice in the time of dialysis?

49.3% (478/970) of respondents reported being offered a choice in the time of day they received their treatment ($p=0.003$ for differences amongst all units). It seems likely that units will only be able to offer a choice of dialysis times while they are not running at full capacity.

Figure 1: Hospital dialysis patients offered a choice in time of dialysis



For key to Figure 1, please see pages 13/14.

5.4 Discussion of kidney transplantation

We asked respondents to indicate whether the option of kidney transplantation had been discussed with them. As transplant is not generally considered to be a treatment option for those over the age of 75, these respondents were excluded from the main analysis. However, the responses were examined separately.

Overall 78.4% (764/975) of respondents aged 75 years and under said that kidney transplantation had been discussed. There were no significant differences among the units. Respondents aged 15–45 were more likely to have discussed transplantation (92.4%) than those aged 46–64 (85.7%) and 65–75 (64.3%) ($p < 0.001$ for comparison among these three age groups). Fewer (38.6%) respondents aged over 75 could recall discussing transplantation.

5.5 Kidney transplantation waiting list

39.5% (386/977) of respondents aged 75 years and under thought they were on the waiting list to receive a kidney transplant. Respondents aged 15–45 were more likely to be on the transplant waiting list (63.6%) than those aged 46–64 (47.7%) and 65–75 (21.2%) ($p < 0.001$ for comparison among these three age groups), but there were no significant differences amongst units. As expected, only 3% of those over the age of 75 reported being on the transplant waiting list.

Table 4: Numbers/percentages by age group of people who reported having a discussion about transplantation and of people who report being on the transplant waiting list

Age group	Transplant discussed	On waiting list
15-45	134/145 (92.4%)	91/143 (63.6%)
46-64	385/449 (85.7%)	213/447 (47.7%)
65-75	245/381 (64.3%)	82/387 (21.2%)
76+	102/264 (38.6%)	8/266 (3.0%)
TOTAL	866/1,239 (69.9%)	394/1,243 (31.7%)

5.6 Comments about the choice of treatment options

251/1294 respondents provided 253 comments about the choice of treatment options. Of these, 84 were factual and 44 positive. A further 92 comments were around information of treatment options; 45 respondents commented on the lack of information provided about the options for dialysis, and a further 47 provided comments about transplantation. Around a quarter of these were from people who thought they were unsuitable for transplantation, but would have liked to have had a discussion about it. A number of comments were received from respondents who understood why they were unsuitable for particular treatment options, indicating that a discussion of the options had taken place.

6 Patient information

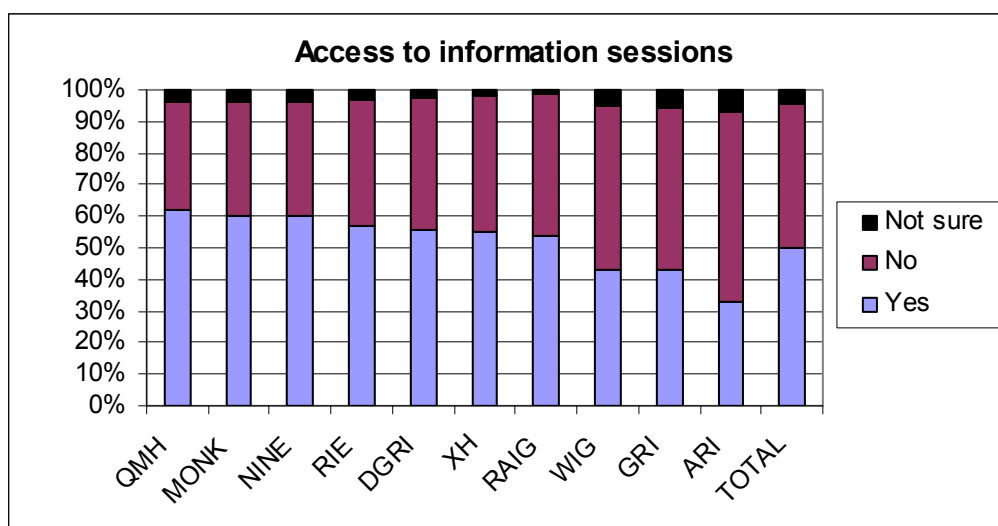
6.1 Access to written information

Across Scotland, 67.8% (835/1232) of respondents felt that their unit provided access to written information about dialysis and other aspects of treatment. There was no statistically significant difference among the units.

6.2 Access to information sessions

By contrast, only half of respondents (618/1233) had access to sessions where they could meet staff and patients and ask questions (Figure 2). There was a significant difference among the units ($p < 0.001$).

Figure 2: Access to information sessions

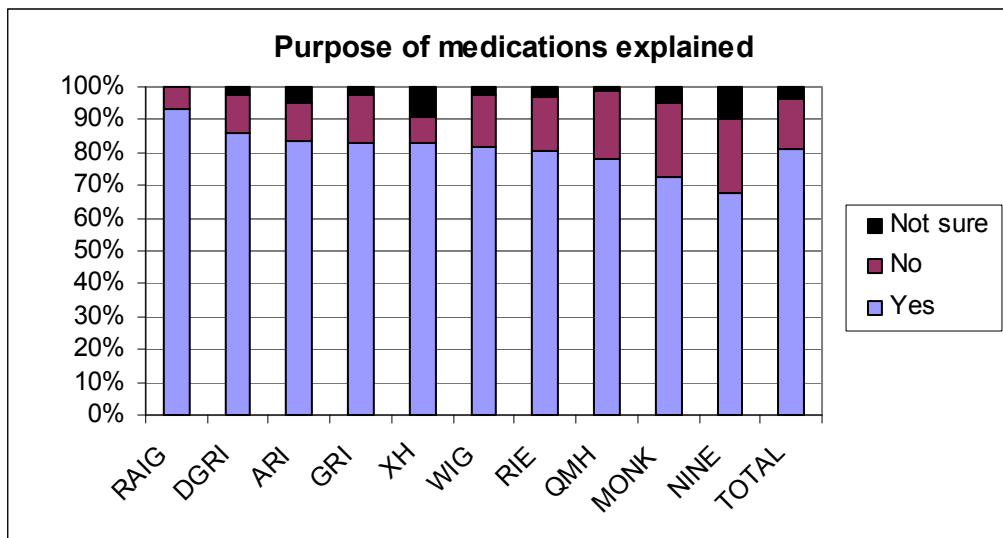


For key to Figure 2, please see pages 13/14.

6.3 Information provided about medications

Overall, 1006/1245 (80.8%) respondents reported that a member of staff had explained the purpose of medications they were prescribed. Patient satisfaction ranged from 68–93.5% (Figure 3). There was a significant difference amongst units ($p = 0.002$).

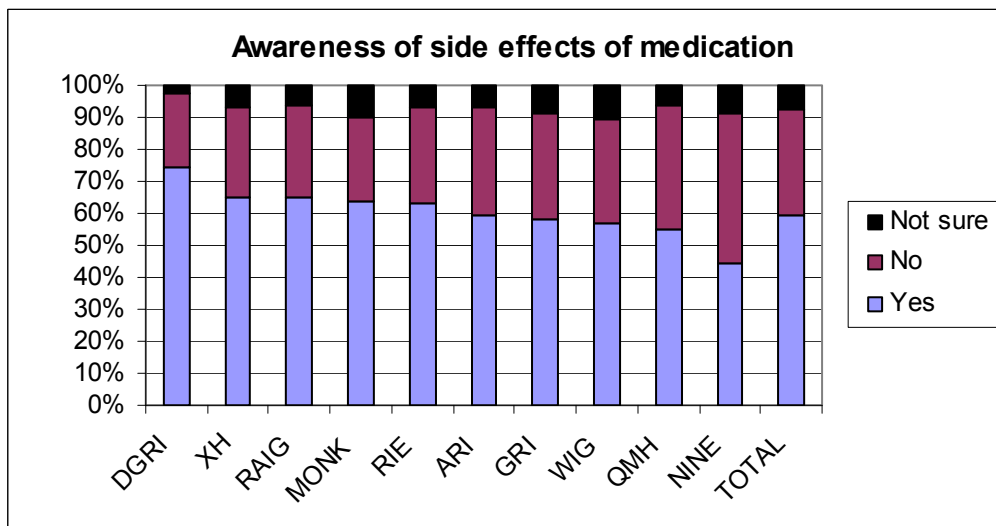
Figure 3: Purpose of medications explained



6.4 Awareness of side effects of medications

59.5% (737/1238) of people reported being aware of the side effects of their medications. Patient satisfaction ranged from 44.2–74.4% (Figure 4). There was a significant difference amongst units ($p=0.022$).

Figure 4: Awareness of side effects of medication



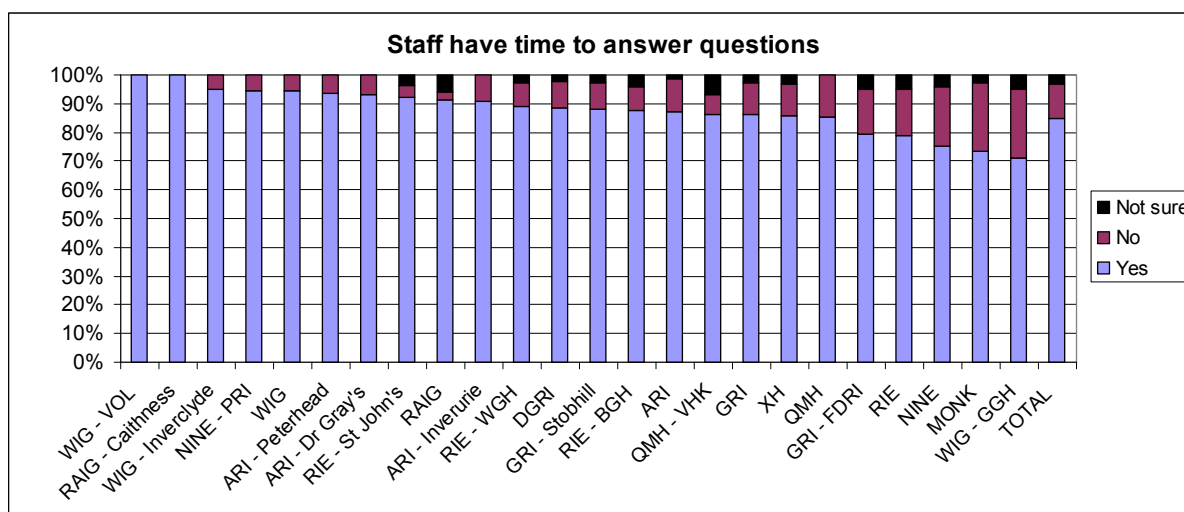
For key to Figures 3/4, please see pages 13/14.

7 Relationship with staff

7.1 Staff having time

Of 1,272 respondents, 1,077 (84.7%) felt that staff have time to answer their questions and deal with any problems they have with their condition or treatment. Patient satisfaction ranged from 71.2–100% (Figure 5). There was a significant difference amongst units ($p=0.001$), with smaller units in general receiving a more positive response.

Figure 5: Staff have time to answer questions



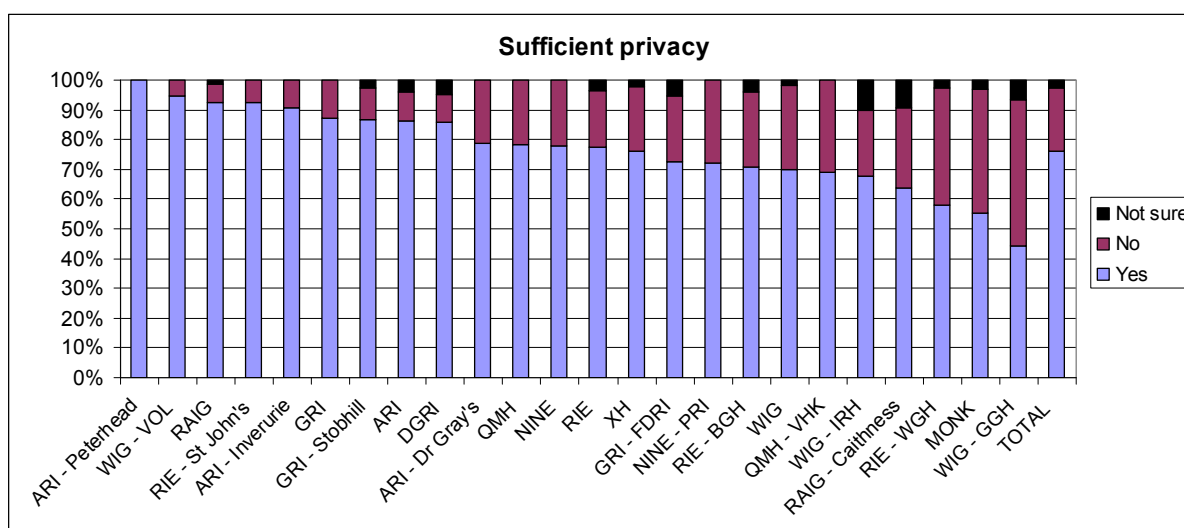
For key to Figure 5, please see pages 13/14.

Of those who felt that staff had time to answer their questions, 67.5% reported that they would usually ask a nurse, with a further 21.7% saying that they would ask either a nurse or consultant, or both. Only 10.6% reported that they would ask a consultant in the first instance. This reflects the nurse-led nature of renal dialysis treatment. It was not possible to tell whether differences exist among the units due to the small number of responses in some subgroups.

7.2 Sufficient privacy

Overall, 76.1% (965/1268) of respondents felt that they are given sufficient privacy when discussing their condition or treatment. Patient satisfaction ranged from 44.1–100% (Figure 6). There was a significant difference among the units ($p<0.001$).

Figure 6: Sufficient privacy



For key to Figure 6, please see pages 13/14.

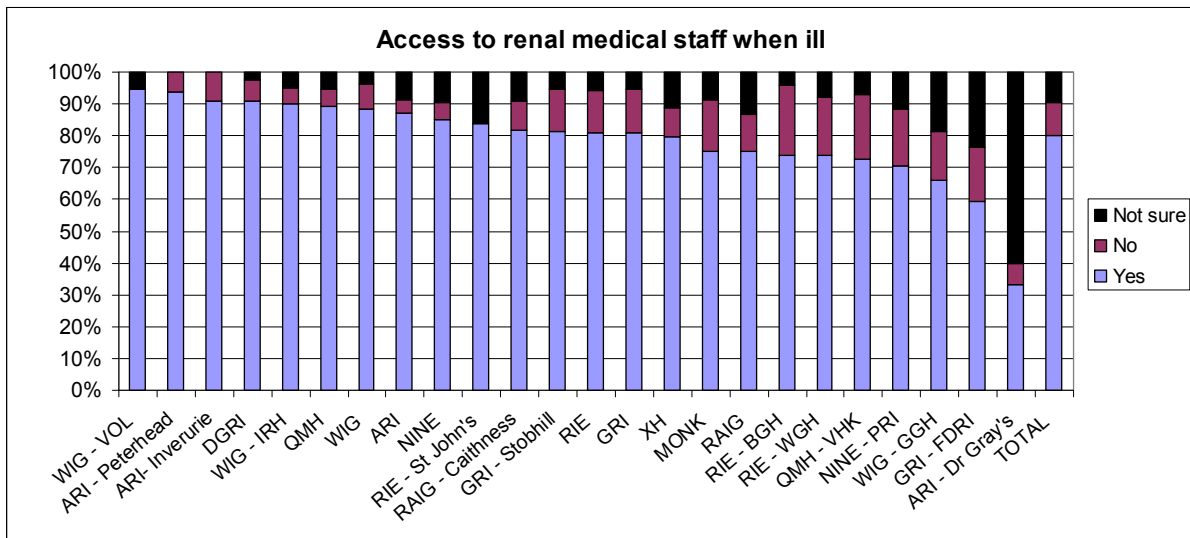
7.3 Contacting the unit

1,135 out of 1,272 people (89.2%) felt that they could contact renal unit staff from home when they have any anxieties or worries about their condition or treatment. Patient satisfaction ranged from 66.7–100%. It was not possible to tell whether differences exist among the units due to the small number of responses in some subgroups.

7.4 Access to medical staff when ill

Overall, 79.9% (1013/1268) of respondents felt that they could access renal medical staff if they are ill. Patient satisfaction ranged from 33.3–94.7% (Figure 7). There was a significant difference among the units ($p < 0.001$). Some of these differences may reflect the availability of on-site renal medical staff. In some units, particularly satellite units, renal medical staff may visit on a regular basis rather than have a permanent presence.

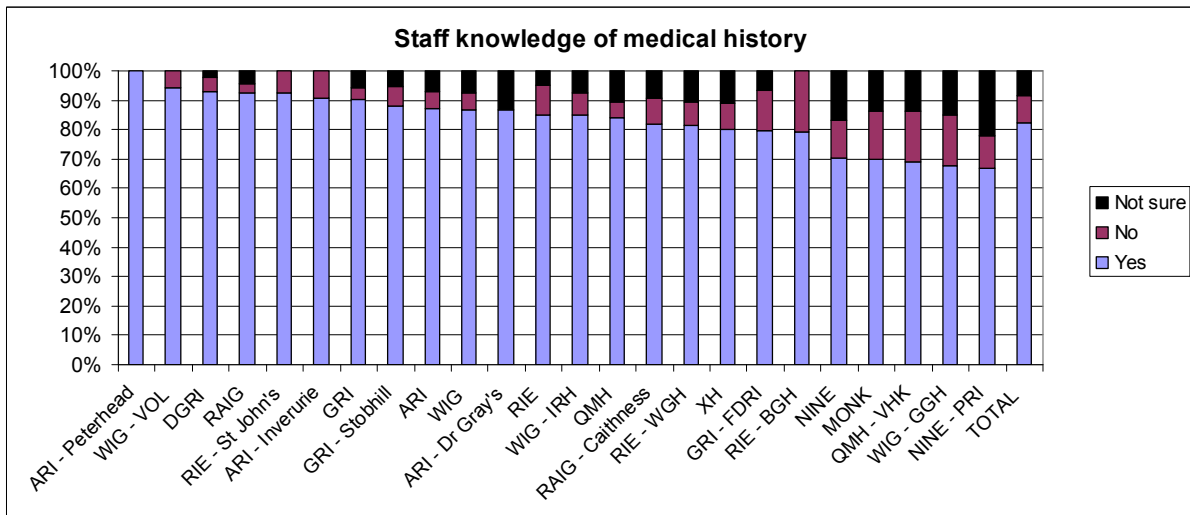
Figure 7: Access to renal medical staff when ill



7.5 Knowledge of medical history

Overall, 82.4% (1050/1275) of respondents felt that staff in the renal unit had a good knowledge of their medical history. Patient satisfaction ranged from 66.7–100% (Figure 8). There was a significant difference amongst units ($p < 0.001$).

Figure 8: Staff knowledge of medical history



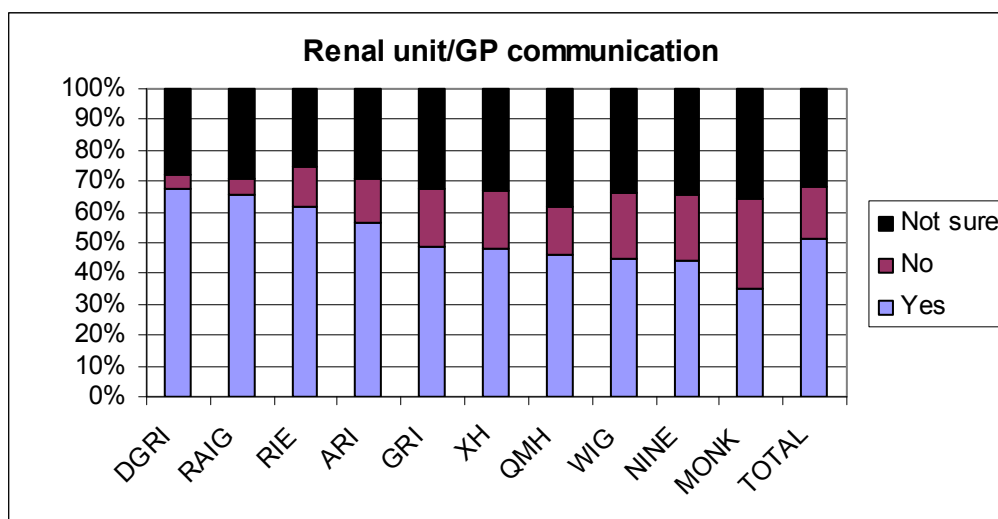
For key to Figures 7/8, please see pages 13/14.

8 Team working

8.1 Communication between renal unit and GP

51.3% (654/1274) of respondents felt there was good communication between the renal unit and their GP. Patient satisfaction ranged from 35–67.4% (Figure 9). There was a significant difference amongst units ($p < 0.001$).

Figure 9: Renal unit/GP communication



For key to Figure 9, please see pages 13/14.

8.2 Communication between renal unit and other services

37.5% (464/1236) of respondents felt that there was good communication between the renal unit and other healthcare services. A similar proportion, 35.3% (424/1202), felt there was good communication between the renal unit and non-healthcare services, eg social work, housing, voluntary organisations. However, a difficulty is that just over half of respondents did not know whether the communication was good or not. For this reason we did not attempt to analyse differences amongst units.

8.3 Access to other professionals

While most respondents said could see a dietitian and pharmacist if needed, only 53% felt they had access to a social worker if they had needed one, and fewer than 50% felt they would be able to see a physiotherapist, occupational therapist or psychologist (Table 5). Some of the written responses we received raised the possibility that this question may not have been clear. 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.

Table 5: Number of respondents who reported having access to members of the multidisciplinary team

	Number of Yes responses	Total number of respondents	%
Dietitian	1,210	1,267	95.5
Pharmacist	887	1145	77.5
Physiotherapist	411	830	49.5
Occupational therapist	331	776	42.7
Social worker	461	868	53.1
Psychological services	213	696	30.6

8.4 Comments on relationship with staff and access to other professionals

151/1294 people provided 152 comments about access to other professionals. The most frequent of these (just under a third of all comments) related to problems accessing other professionals; most frequently respondents requested better access to psychological, social work and physiotherapy services.

9 Hand hygiene

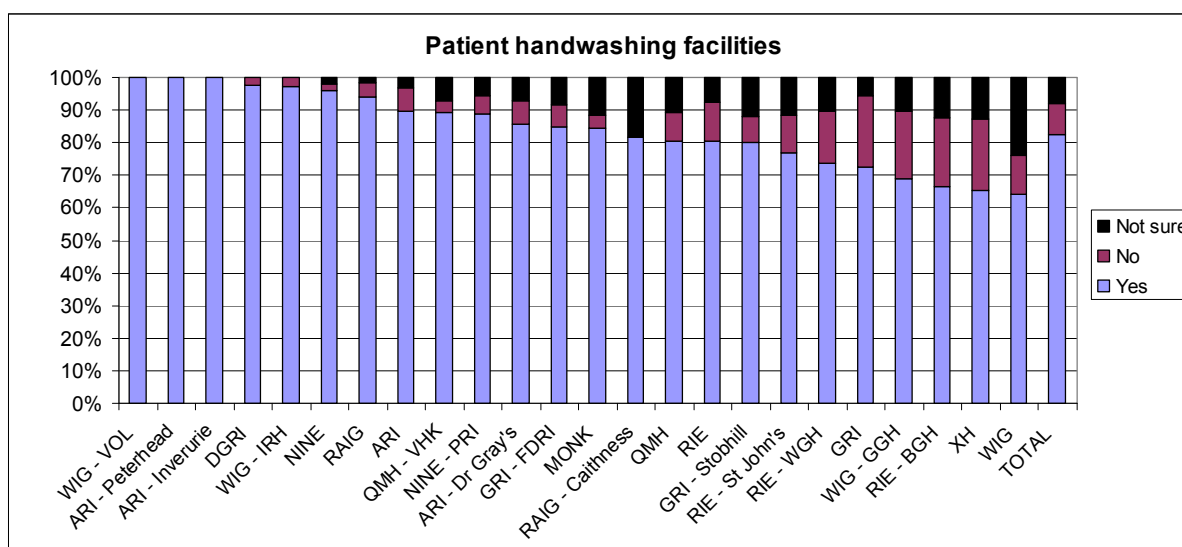
9.1 Staff hand hygiene

1215/1276 (95.2%) respondents indicated that staff usually cleaned their hands, either by washing them with soap and water or using alcohol gel, before treating them. Only 18 (1.4%) respondents said they did not, while 43 (3.4%) were unsure. It was not possible to tell whether differences exist amongst units due to the small number of responses in some subgroups.

9.2 Handwashing facilities

Overall, 1047/1268 (82.6%) people said that handwashing facilities were available for patients other than in the toilet area. There was a significant difference among the units ($p < 0.001$).

Figure 10: Patient handwashing facilities outwith the toilet area

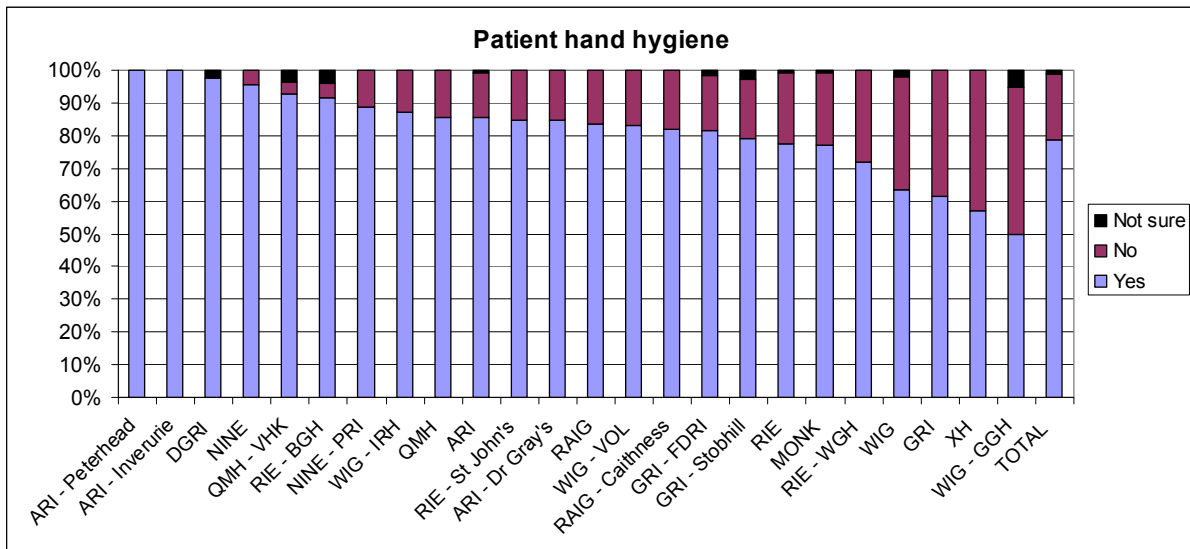


For key to Figure 10, please see pages 13/14.

9.3 Patient hand hygiene

977 (78.7%) of 1,241 respondents said that they usually washed their hands with soap and water or alcohol gel before entering the dialysis unit. There was a significant difference among the units ($p < 0.001$). This equates to 93.3% of those who said that patient handwashing facilities were available in their unit outwith the toilet areas.

Figure 11: Patient hand hygiene



For key to Figure 11, please see pages 13/14.

9.4 Comments about hand hygiene

187/1294 respondents provided 189 comments about hand hygiene. Just under a third of these were positive. Of the remaining comments, patient and staff hand hygiene drew the most comments (85), with the vast majority highlighting the variability in compliance among both staff and patients alike. Some raised concerns about visitors to the dialysis ward not following hand hygiene procedures.

10 Renal PatientView

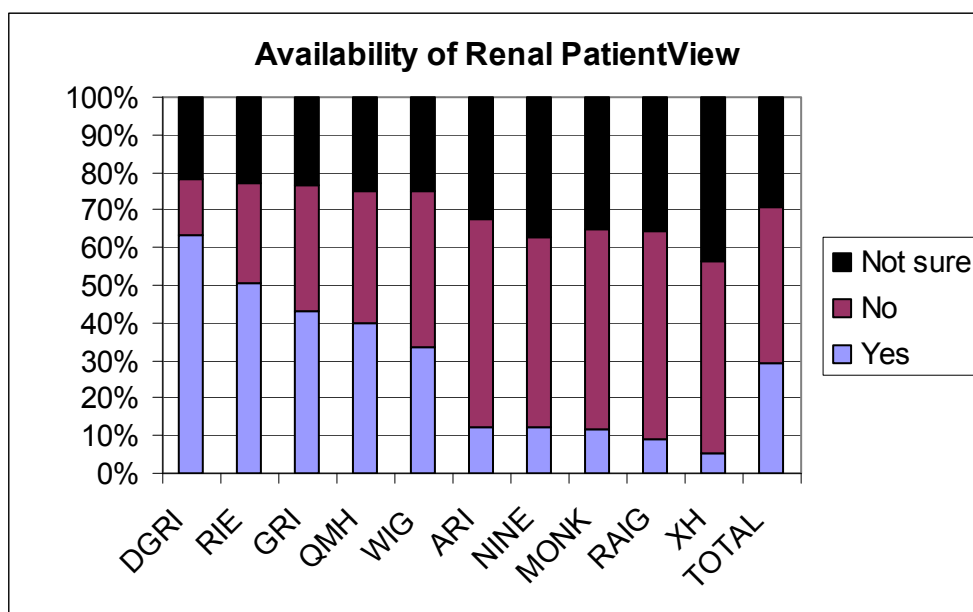
10.1 Description of Renal PatientView

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

10.2 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 359/1234 (29.1%) said that Renal PatientView was available and an almost equal number were not sure (Figure 12). 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 12: Availability of Renal PatientView



For key to Figure 12, please see pages 13/14.

Indeed at the time of the survey, Renal PatientView had not been installed in three of the units (Aberdeen Royal Infirmary, Monklands Hospital and Raigmore Hospital), and at Ninewells Hospital it had only recently become available^{iv}.

10.3 Use of Renal PatientView

Of the 359 who said Renal PatientView was available, 162/339 (47.8%) said they used it. This represents only 12.5% of the total number of respondents. It was not possible to

^{iv} Details taken from the Renal PatientView website in November 2009 - <http://www.renal.org/pages/pages/joint-activities/rixg/rpv/where.php>

see if there were differences in units due to the low number of people who use Renal PatientView in some units. This raises issues of access, education, awareness raising and training for patients in the use of this tool. Younger patients were more likely to use Renal PatientView (Table 6) ($p=0.002$). These findings differed from those of the transplant survey¹⁰.

Table 6: Use of Renal PatientView by age group

Use of Renal PatientView by age group				
	Yes	No	Not sure	Total
15-45	35 (68.6%)	16 (31.4%)	0 (0%)	51
46-64	75 (49.7%)	74 (49%)	2 (1.3%)	151
65-75	35 (35.7%)	60 (61.2%)	3 (3.1%)	98
76+	17 (43.6%)	21 (53.8%)	1 (2.6%)	39
Total	162 (47.8%)	171 (50.4%)	6 (1.8%)	339

10.4 Training on Renal PatientView

Considering only those respondents who said that Renal PatientView was available and that they used it, 74/154 (48.1%) reported having been trained in its use. It was not possible to see if any differences exist amongst units due to the low numbers who use Renal PatientView in some units.

10.5 Reasons why Renal PatientView is not used

398 respondents gave a variety of reasons why they did not use Renal PatientView. Some said they did not know about it, that it was not available, that they had difficulty accessing it (either due to login issues or due to lack of access to a computer/internet) or that they had no training. Others said they did not want to use it, or that they preferred to talk to staff.

11 Travelling away from home

11.1 Travelling away for more than 3 days

Respondents were asked to indicate how often they had been able to travel away from home for more than 3 days for either a holiday or business purposes. Overall, 43.6% (551/1264) respondents had been away from home at least once for more than 3 days. Patients attending Raigmore Hospital were most likely to travel (68%) while those attending Aberdeen Royal Infirmary were least likely (34.1%). The differences among the units were significant ($p=0.022$). 50.5% of those travelling away had done so only once or twice, while 49.5% had travelled 3 or more times. 532 respondents indicated their travel destinations. Of these, 49.8% have travelled within the UK only, 37.8% to Europe and 12.4% worldwide.

11.2 Travelling away by type of dialysis

Further analysis of the data by type of dialysis indicated that those receiving hospital haemodialysis were least likely to travel (only 40.1% overall), and least likely to travel frequently (only 18.1% travelled 3 times or more). Although numbers were much smaller, our findings showed that those receiving home haemodialysis were most likely to travel (68.2%), followed by those on peritoneal dialysis (59.3%) ($p<0.001$). Respondents receiving continuous ambulatory peritoneal dialysis (CAPD) travelled most frequently (41.6% went away more than 3 times).

11.3 Reasons for not travelling away from home

Of the 713 respondents who had not travelled away from home for more than 3 days, 660 provided a reason for not doing so (Table 7). Reassuringly most (61.1%) had not wanted to travel with only 65 (9.8%) indicating that they had been unable to arrange dialysis away from home.

Table 7: Reasons for not travelling away from home

	Number of respondents	%
Did not want to	403	61.1
Not well enough	112	17.0
Could not arrange dialysis	65	9.8
Other	80	12.1

Reasons given under 'Other' related mainly to those who had started dialysis more recently and who were not able to travel for this reason, for whom the need had not yet arisen, or who were unsure of how to go about organising dialysis away from home.

12 The environment

12.1 Grading of dialysis area/clinic

Respondents were asked to grade aspects of their outpatient dialysis area or peritoneal dialysis unit/clinic as good, average, poor. The following tables show patient responses to questions on the standard of catering, cleanliness, comfort, accessibility, entertainment, general surroundings, toilets/showers and clinic or ward waiting areas.

12.2 Best experience overall

The smaller units, which also tended to be those most recently built, at the Vale of Leven District General Hospital, Perth Royal Infirmary, Caithness General Hospital and Inverurie Dialysis Unit, offered the best overall experience, while the respondents attending Gartnavel General Hospital were least satisfied. It was noted that some Glasgow patients had recently transferred to new hospital haemodialysis facilities at the new Victoria Hospital. Others were due to transfer to the new Stobhill Hospital, which had not yet opened at the time of publication.

For each of the eight domains shown below, there were statistically significant differences among the units ($p < 0.001$).

For key to Figures 13–20, please see pages 13/14.

Figure 13: Standard of catering

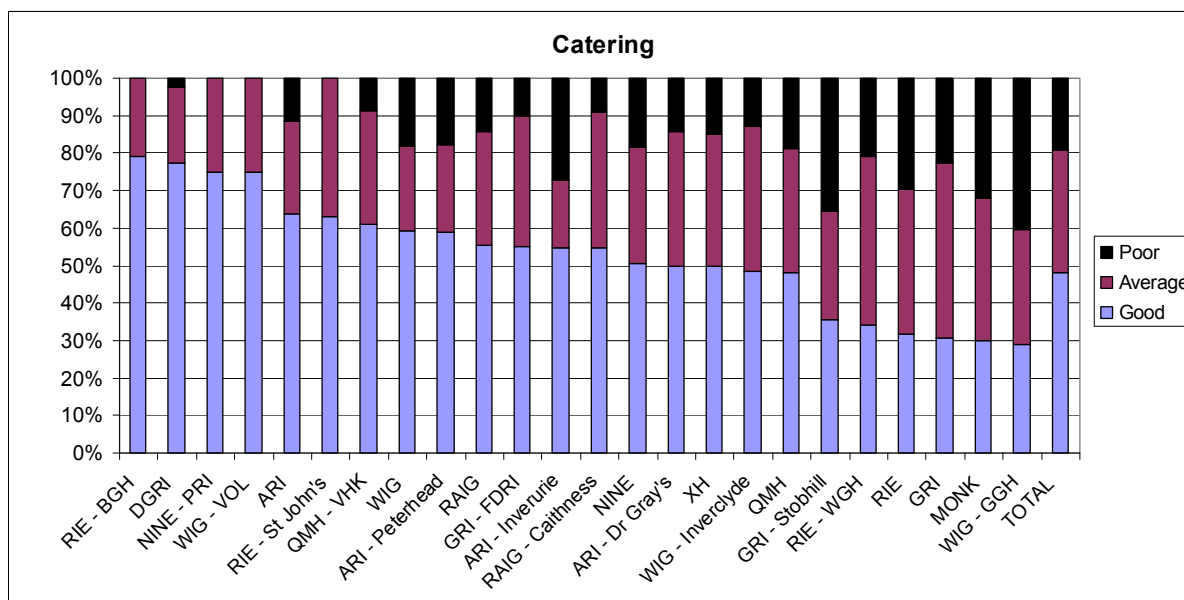


Figure 14: Standard of cleanliness

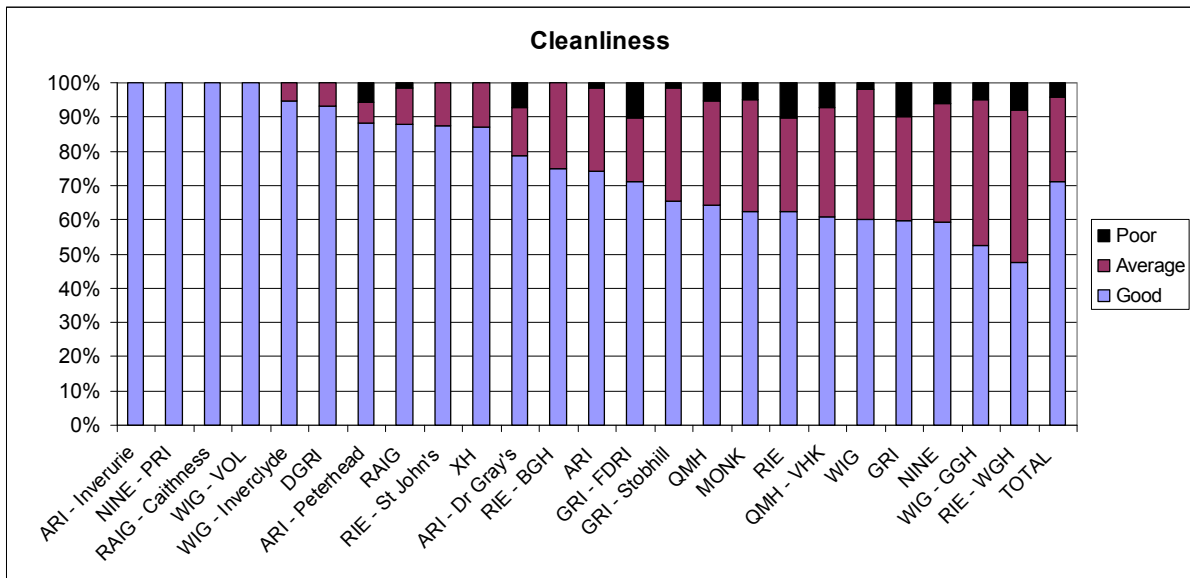


Figure 15: Standard of comfort

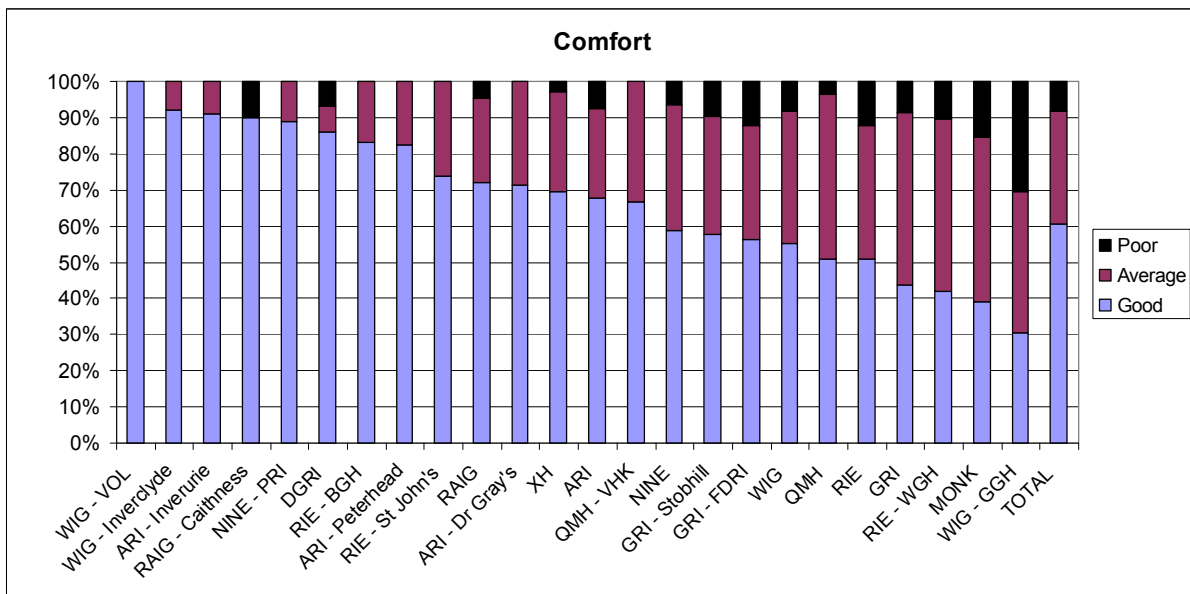


Figure 16: Standard of accessibility

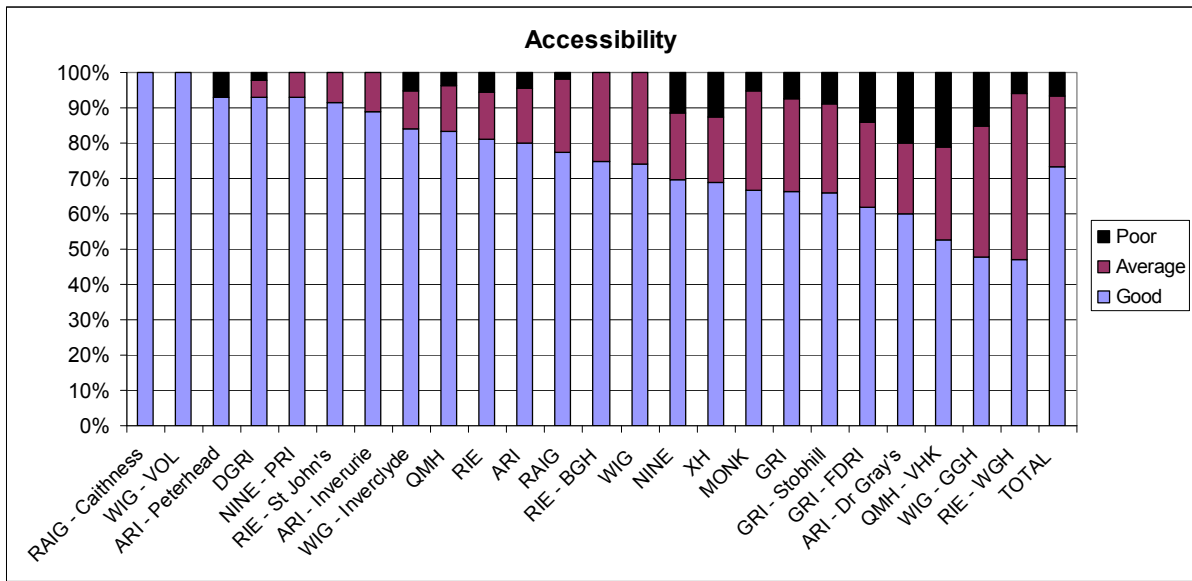


Figure 17: Standard of entertainment

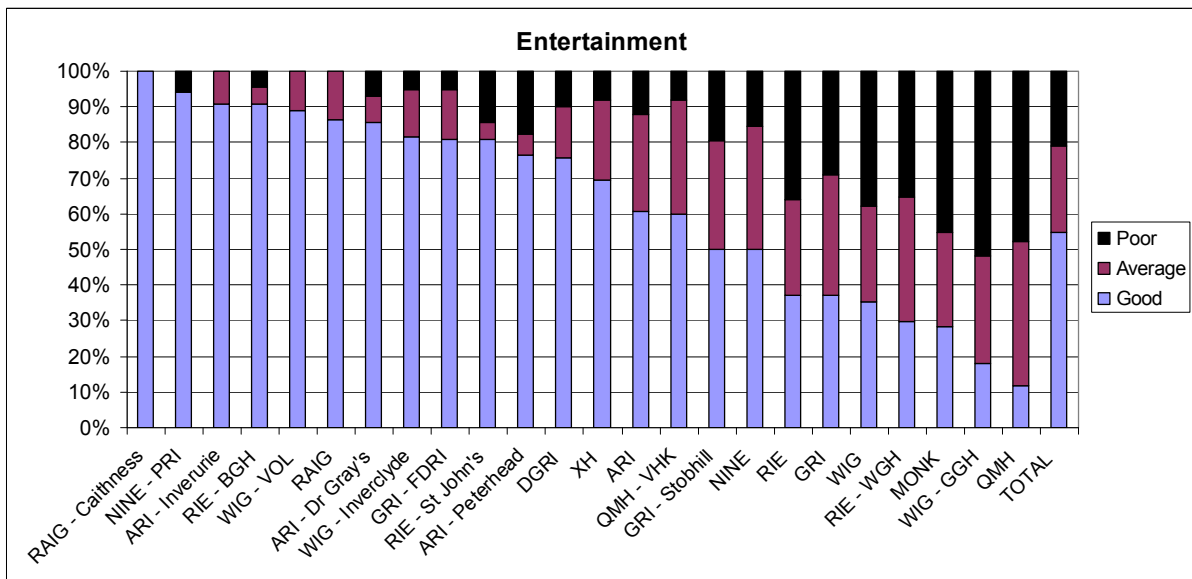


Figure 18: Standard of general surroundings

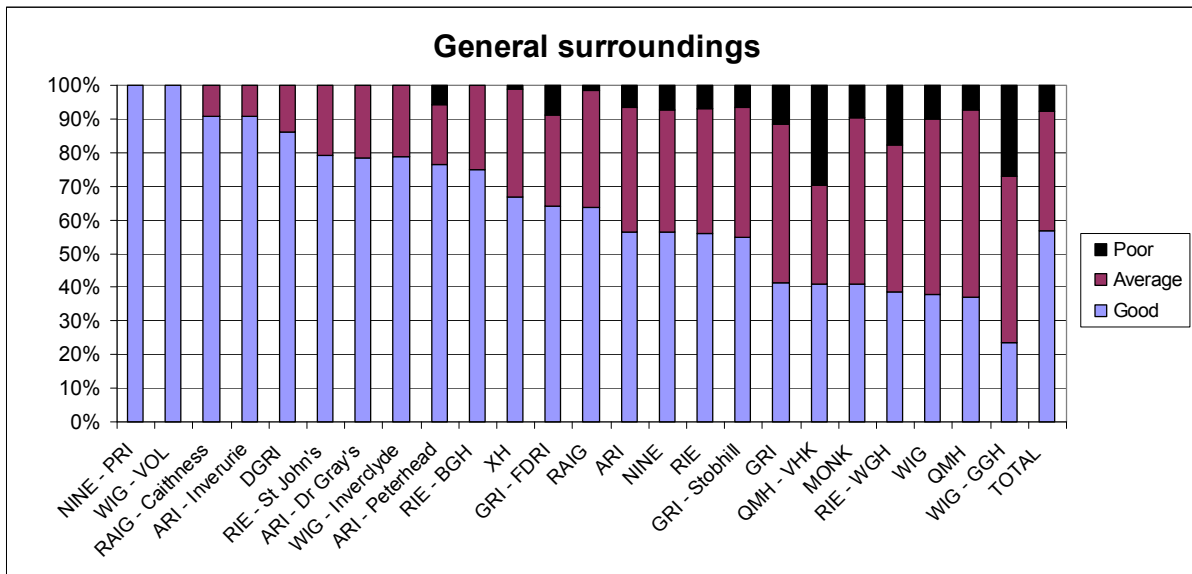


Figure 19: Standard of toilets/showers

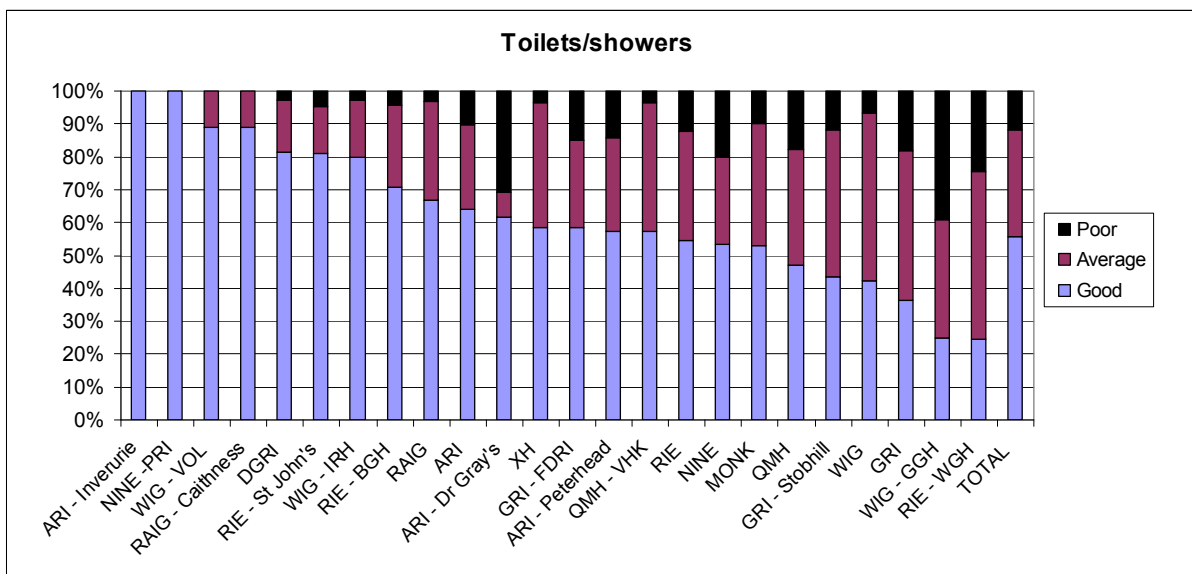
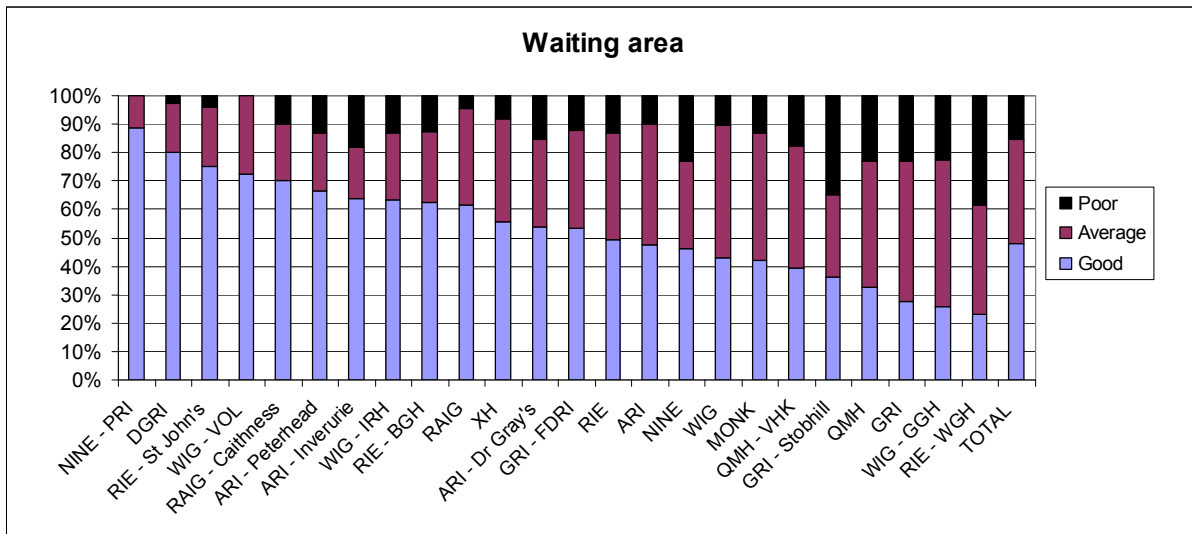


Figure 20: Standard of waiting area



13 Satisfaction with overall care and treatment

13.1 Grading of the quality of care

Respondents were asked to grade their experience of their current renal unit on a 10-point scale from 1 (very unsatisfied) to 10 (very satisfied). 1,263 (97.6%) of all respondents provided a score in this section. Satisfaction scores ranged from 7.1 at Gartnavel General Hospital to 9.4 at the Vale of Leven District General Hospital. The mean score was 8.1. There was a significant difference among the units ($p < 0.001$). Patients dialysing in smaller units, which in many cases were also the most recently built, tended to rate these units more highly than those who were being treated in larger dialysis centres.

Figure 21: Patient satisfaction



For key to Figure 21, please see pages 13/14.

13.2 Comments on the patient experience

We asked people to tell us three ways in which their experience of the service could be improved. 892/1294 (68.9%) people recorded 1,747 comments. Some of these comments echo those made by patients in the 2004 Scottish Parliament Cross Party Group on Kidney Disease supplement to the Second Report, Renal Disease in Scotland: Consulting with Patients³.

13.2.1 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 104 comments which were positive, a selection of which are below.

What patients praised...

'It's a new unit. There's not much more they can do. There's a TV for every patient.'
(Inverurie Dialysis Unit)

'All the staff in this unit do a wonderful job.' (Crosshouse Hospital)

'Service is excellent with no need for change.' (Dumfries & Galloway Royal Infirmary)

'Quality of care is excellent. Nurses have a genuine sense of care for patients.'
(Glasgow Royal Infirmary)

'I am very satisfied with the service I receive.'
(Vale of Leven District General Hospital)

'I honestly can't think of anything that I could suggest to improve anything. The staff are totally professional and very friendly and helpful.'
(Raigmore Hospital)

'Do not see how it could be any better. Am more than satisfied and grateful.'
(Borders General Hospital)

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

13.2.2 Dialysis unit environment

This topic drew 499 comments from people receiving hospital haemodialysis. The highest number of comments (128) was around entertainment, in particular the provision of televisions – better and free access, and better and individual televisions. 94 comments were made about improving the quality of catering and more choice of food. Other comments concerned seating (85 comments), temperature of the ward (most often too cold because of air conditioning) (54 comments), and privacy (14 comments), as well as a number of general comments which could not easily be themed.

What patients said they wanted...

'Bed side TV sets to help pass 5 hours.'
(Aberdeen Royal Infirmary)

'NHS to replace patientline with the provision of [free] TV. They do supply radio – it's good. More patient input into radio and TV programmes would be welcome.'
(Royal Infirmary of Edinburgh)

'The availability of radio for patients with poor sight or who do not care for TV all the time.'
(Dumfries & Galloway Royal Infirmary)

'Continue art classes.'
(Inverclyde Royal Hospital)

'...Better choice of breakfast for renal diet.'
(Queen Margaret Hospital)

'I would like to see better food and menu.' (Falkirk & District Royal Infirmary)

'Poor choice/problems with temp[erature] control of food....' (Monklands Hospital)

'Better comfort while on dialysis and blankets and pillows.' (Monklands Hospital)

'Chairs at waiting area could be more comfortable especially for older patients who at times have to wait ages on transport.' (Western Infirmary)

'Heating, ie extremely poor heating in waiting area and ward.' (Stobhill Hospital)

'Privacy to ask questions.' (Falkirk & District Royal Infirmary)

'More waiting room space. Too crowded for wheelchairs.' (Western General Hospital)

'Automated doors needed everywhere on the unit.' (Crosshouse Hospital)

13.2.3 Dialysis organisation and management

The organisation and management of dialysis treatment received 228 comments. More than half of these were around waiting times, due either to organisation of start times or to a lack of co-ordination between the local dialysis unit and patient transportation service. Some respondents indicated that they were not put on a dialysis machine at their allocated time, or delays in being taken off the machine. Monklands Hospital in particular drew a disproportionate number of comments around the organisation of dialysis start times (30.5% of all Monklands respondents).

What patients said they wanted...

'Being put on the machine quicker – we wait too long.' (Falkirk & District Royal Infirmary)

'The only complaint I have is the time wasted between arriving at the hospital and actual dialysis starting. This can be up to 1.5hrs in some cases.' Monklands Hospital)

'At times staff take too long to take patients off dialysis – this could be improved.' (Aberdeen Royal Infirmary)

'Would like to see time which is allocated to patient for connection to machine being adhered to.' (Queen Margaret Hospital)

'Joined up thinking between on/off time [for dialysis] and transport.' (Monklands Hospital)

13.2.4 Medical and nursing care

We received 231 comments about medical and nursing care, including staffing. The most common of these related to the need for additional staff. A few related to having more trained nursing staff available. Other comments were around having better access to medical staff and seeing the same doctor at clinics, having access to a named nurse and having the same nurse from start to finish of dialysis. A few

comments related to having access to other professionals, for example social worker, physiotherapist.

What patients said they wanted...

'Ensure adequate trained staff are on duty.' (Aberdeen Royal Infirmary)

'More qualified staff...' (Glasgow Royal Infirmary)

'Specified member of staff who could be approached with questions and concerns.' (Crosshouse Hospital)

'Easier access to doctor/consultant.' (Monklands Hospital)

'Consultant should visit patient monthly.' (Stobhill Hospital)

'More continuity when attending clinics prior to dialysis eg seeing same doctor and not a different one on each appointment.' (Glasgow Royal Infirmary)

13.2.5 Transport

Transport was an issue for a number of respondents. Many of the 205 comments were non-specific, whilst others specified that prompt pick-up times would improve their experience of the service.

What patients said they wanted...

'That I don't have as long to wait for an ambulance after dialysis.' (Crosshouse Hospital)

'Better [patient] transport arrangements.' (Dumfries & Galloway Royal Infirmary)

'Transport picking me up on time.' (Western Infirmary)

'More efficient transport/timekeeping.' (Royal Infirmary of Edinburgh)

13.2.6 Communication

Most of the 181 comments under this theme related to the provision of information (60 comments) and the attitude of staff towards patients (65 comments). A very small number of people commented on poor communication between the hospital and GP, and between patients and staff.

What patients said they wanted...

'More information – remember not everyone knows there is a question to be asked.' (Aberdeen Royal Infirmary)

'Treatment options discussed, not dismissed.' (Raigmore Hospital)

'More information about transplant lists.' (Monklands Hospital)

'More information for carers/families.' (Dr Gray's Hospital)

'[Being] made aware of when tablets have been changed.' (Ninewells Hospital)

'More understanding of how I feel.' (Crosshouse Hospital)

'A greater interest in me and my welfare on the part of staff.' (Aberdeen Royal Infirmary)

'Remembering you are not a name and number but a person.' (Stobhill Hospital)

'Better communication from non-medical services (transport, holidays etc).'

(Royal Infirmary of Edinburgh)

'GP/renal staff co-ordination.' (Western General Hospital)

'Someone to listen who has time.' (Ninewells Hospital)

'Limited access to dietitian.' (Victoria Hospital)

'More social work input, financial advice.' (Inverclyde Royal Hospital)

'...I would like to see more input from psychological services to help in coping with the emotional side of dialysis – support in coping with the depression that has accompanied the illness...' (Raigmore Hospital)

13.2.7 Other

Other themes which drew a smaller number of comments were parking; unit preference; hygiene; holidays; clinic environment; and, clinic organisation. In addition, 104 positive comments were provided.

What patients said they wanted...

'Better parking facilities.' (Aberdeen Royal Infirmary)

'Better monitoring of disabled parking.' (Royal Infirmary of Edinburgh)

'Facilities near home.' (Crosshouse Hospital)

'Improved toilet facilities.' (Western General Hospital)

'General ward cleanliness especially floors.' (Ninewells Hospital)

'Physical surroundings at outpatient clinic need to be improved.' (Western Infirmary)

'Accessibility of renal clinic.' (Glasgow Royal Infirmary)

'More availability of UK-wide dialysis to allow me to attend vocational training, visit family, holidays, etc.' (Stobhill Hospital)

14 Recommendations

The findings of the report indicate that patients are largely satisfied with the treatment and care they receive from renal units. This may be because for many, dialysis is a long-term treatment, impacting significantly on daily life. In addition, for those receiving treatment, it is necessary and life-saving unless they are able to receive a kidney transplant. Due to the long-term nature of treatment, patients are often able to build up a good relationship with clinical staff, and may, therefore, be reluctant to criticise⁷. 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 dialysis patients and would improve their experience. Some of these recommendations echo those in the NHS QIS Adult Renal Services National Overview (2003)⁵, indicating that while much progress has been made, some areas require further work.

Information:

- 1 Good quality information should be available to patients and, where appropriate, their family and carers, throughout the patient journey. This relates to Standard 12 of the Adult Renal Services Standards (2002)⁸ which states that: 'All people with chronic renal failure or on renal replacement therapy, and carers where appropriate, are given information to help them make informed choices'. In particular:
 - 1.1 provision of adequate information to patients and their family and carers before starting dialysis treatment, regardless of the timing of their referral to renal services. This should include an explanation of the dialysis options available to them, including home haemodialysis
 - 1.2 access to sessions where patients can meet staff and other patients in order to ask questions about their condition and treatment, and
 - 1.3 ongoing access to written information about dialysis and other aspects of treatment, including medications and their side effects.
- 2 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.
- 3 NHS boards should ensure that information about travelling away from home whilst on dialysis is provided to patients, and that adequate assistance is given in organising dialysis away from home for patients who wish or need to travel.

Treatment options:

- 4 Where capacity allows, hospital haemodialysis patients should be offered a choice in the time of day for their treatment.
- 5 The issue of renal transplantation should be discussed with all patients, regardless of suitability or age. Where patients might not be suitable for transplantation, an explanation of this should be provided.

Continuing care and treatment:

- 6 NHS boards should ensure compliance with Standard 13 of the Adult Renal Services Standards (2002)⁸. This will involve working in partnership with patient transport services to ensure good co-ordination with the dialysis unit so that waiting times for hospital haemodialysis patients at each end of their dialysis treatment are minimised. In addition, patients should begin and end dialysis without undue delay. These issues were highlighted in the NHS QIS Adult Renal Services National Overview (2003)⁵, and the results of this survey indicate that they remain issues for many patients.
- 7 All patients should be offered privacy when discussing their condition or treatment. For some units, this may involve consideration being given to offering haemodialysis patients an appointment to see the consultant at a clinic rather than discussing their treatment while receiving dialysis in the ward.
- 8 NHS boards should ensure that patients have access to the members of the multidisciplinary team they need when required. In particular ensuring:
 - 8.1 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.
 - 8.2 access to other healthcare professionals, including dietitians, pharmacists, social workers, physiotherapists and psychologists as required. This issue is outstanding from the recommendations in the Adult Renal Services National Overview (2003)⁵.
 - 8.3 sufficient trained nursing staff to put patients onto the dialysis machine at the start of their session and to remove them at the end of their session, and sufficient staff to ensure that patients' questions and problems are appropriately dealt with.
- 9 Communication between the renal unit and GP should be improved through ensuring compliance with Standard 11.2 of the NHS QIS Adult Renal Standards⁸, 'Clinic letters are sent to the GP within 2 weeks of being seen by a nephrologist'.

Quality of the environment:

- 10 **Quality of catering.** This includes widening the choice and temperature of food, and providing a menu suitable for patients on a renal diet. NHS boards should ensure compliance with Standard 4 of the NHS QIS Clinical Standards for Food, Fluid and Nutritional Care in Hospitals (2003)¹¹ which states 'Food and fluid are provided in a way that is acceptable to patients'.
- 11 **Renal wards and waiting areas.** Those units which have been most recently opened generally scored higher for overall patient satisfaction. Whilst it is acknowledged that the environment in many older renal units is not ideal, consideration should be given to making basic improvements to these environments. Examples should include reconfiguration of the waiting areas, provision of comfortable seating for people receiving hospital haemodialysis.
- 12 **Entertainment for hospital haemodialysis patients.** This should include replacement of Patientline with free TV, wider provision of books and other activities suitable for patients on dialysis.

Healthcare associated infection:

- 13 **Hand hygiene.** While this topic received a largely positive response, NHS boards should continue to ensure compliance with the World Health Organisation's^v moments for hand hygiene which is being implemented as part of the National Hand Hygiene Campaign (co-ordinated by Health Protection Scotland)^{vi}.
- 14 **Cleanliness.** NHS boards should ensure compliance with the NHS QIS Standards for Healthcare Associated Infection (2008)¹², particularly in relation to Standard 4a1, in all hospital renal environments, including toilet facilities.

^v <http://www.who.int/gpsc/5may/background/5moments/en/index.html>

^{vi} <http://www.washyourhandsofthem.com/index.html>
<http://www.washyourhandsofthem.com/support/5moments-support.html>

15 Limitations and lessons learned

15.1 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 Services⁸ 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.

15.2 Piloting the survey

A number of changes were made to the survey forms following piloting. The wording of some questions was changed for clarity. In some questions, the number of tick box options was increased to include a 'Not applicable' option. One section was added to the form to collection information about 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.

15.3 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 for staff involved.

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 62% of dialysis 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.

15.4 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 mean 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'¹³. 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).

15.5 Analysis

Most questions were well understood and well completed. However, from the responses it became apparent that one or two of the questions lacked clarity and had been interpreted differently by some participants (questions 6.4 and 2.11). 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

Appendix 2: References

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Appendix 3: Kidney dialysis patient survey



Scottish Kidney Federation
A Scottish Charity
Charity No. SC007914



Kidney dialysis patient survey Your service – your view

The Scottish Renal Registry and the Scottish Renal Association, in collaboration with NHS Quality Improvement Scotland, carried out a dialysis patient transport audit in all renal and satellite units in Scotland in September 2008. We now wish to capture your views on issues, other than patient transport, which affect the quality of your care.

Please return the survey by Wednesday 31 December 2008.

1. About you

1.1 Please indicate (✓) which **age group** you are in:

Age	15–45	46–64	65–75	76 and above
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1.2 In **which year** did you start dialysis?

1.3 What **type of dialysis** do you currently receive?

For the purposes of this survey, the term 'dialysis' relates to peritoneal dialysis as well as haemodialysis.

- | | |
|--------------------------------------------------------|--------------------------|
| 1.3.1 Hospital haemodialysis | <input type="checkbox"/> |
| 1.3.2 Home haemodialysis | <input type="checkbox"/> |
| 1.3.3 Continuous ambulatory peritoneal dialysis (CAPD) | <input type="checkbox"/> |
| 1.3.4 Automated peritoneal dialysis (APD) | <input type="checkbox"/> |


1.4 In **which year** did you begin receiving your **current** treatment?

1.5 Which **renal unit/satellite unit** do you **currently** attend?



2. Treatment options

- | | | | | |
|-----------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|---------------------------------------------------------|
| | Yes | No | Not sure | |
| 2.1 Were you being seen at a renal clinic for at least 3 months before you started your treatment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input style="width: 50px; height: 30px;" type="text"/> |


2.2 If you answered Yes to 2.1, **where was** that clinic?  _____

2.3 If you answered No to 2.1, at which renal unit/satellite unit did you **start** dialysis?  _____

	Yes	No	Not sure	Not applicable
2.4 At or near the beginning of your treatment, were the various options of haemodialysis and peritoneal dialysis explained to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.5 If you are on hospital haemodialysis now, were you offered a choice between home and hospital haemodialysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.6 If you answered No to 2.5, would you have preferred home haemodialysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.7 If you are on hospital/satellite haemodialysis , were you offered a choice in the time of day you receive dialysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.8 If you are on peritoneal dialysis , were you offered a choice between automated peritoneal dialysis (APD) or continuous ambulatory peritoneal dialysis (CAPD) ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.9 Was the option of renal transplantation discussed with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.10 Are you on the transplant waiting list ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.11 Do you feel staff have given you enough information about this?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2.12 Do you have **any other comments** about the choice of treatment options?


3. Patient information


		Yes	No	Not sure	
3.1	Before you started dialysis treatment, do you feel you were given enough information about your condition or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.2	Was the information you received in a way that you could understand ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.3	If you answered No to 3.2, would any of the following have helped?				<input type="checkbox"/>
3.3.1	Large print <input type="checkbox"/>				<input type="checkbox"/>
3.3.2	Languages other than English <input type="checkbox"/>				<input type="checkbox"/>
3.3.3	Audio tape <input type="checkbox"/>				<input type="checkbox"/>
3.3.4	Braille <input type="checkbox"/>				<input type="checkbox"/>
3.3.5	Other (please specify) 				
3.4	Do you feel your family/carers received enough information?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.5	Does your unit provide access to written information about dialysis and other aspects of your treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.6	Have you had access to sessions where you can meet staff and patients and ask questions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.7	Has a member of staff explained the purpose of the medications you are prescribed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.8	Do you know about any side effects you should watch for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.9 Do you have **any other comments** about the information you have received about your condition or treatment?




4. Renal Patient View

Renal Patient View, which is accessed through a computer, allows you to see your test results and provides information about diagnosis and treatment.

	Yes	No	Not sure	
4.1 Is Renal Patient View available to you? (If you answered No or Not sure to 4.1, please go to Section 5; if you answered Yes, go to 4.2)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4.2 If it is available, do you use Renal Patient View?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4.3 If you use Renal Patient View, were you given adequate training ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4.4 If you do not use Renal Patient View, please tell us why: 				

5. Your relationship with staff

	Yes	No	Not sure	
5.1 Do you feel the staff have time to answer questions and deal with any problems you may have about your condition or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5.2 If you answered Yes to 5.1, who are you most likely to ask?				
5.2.1 Consultant			<input type="checkbox"/>	
5.2.2 Nurse			<input type="checkbox"/>	
5.2.3 Other (please specify) 				
5.3 Do you feel you are given sufficient privacy when discussing your condition or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5.4 Do you feel you can contact the renal unit staff from home when you have any anxieties or worries about your condition or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5.5 Do you feel you have access to renal medical staff when you are ill?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

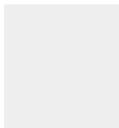
	Yes	No	Not sure	
5.6 Do you feel that the people you see in the renal unit or dialysis outpatient clinic have a good knowledge of your medical history?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

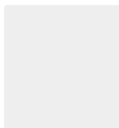
5.7 Do you have **any other comments** about your relationship or communication with staff at the renal unit?



6. Teamworking

	Yes	No	Not sure	
6.1 Do you feel there is good communication between the renal unit and your GP ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

6.2 The renal unit often has to work with other healthcare services , such as hospital, home care and nursing. Do you feel these services communicate well?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
--------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------	--------------------------	--------------------------	---------------------------------------------------------------------------------------

6.3 Do you feel that the renal unit works well with other non-healthcare services you may need, eg social work, housing, voluntary organisations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
----------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------	--------------------------	--------------------------	---------------------------------------------------------------------------------------

6.4 Do you feel you have access to the following professionals if you have needed them?	Yes	No	Not sure	Not applicable
6.4.1 Dietitian	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.4.2 Pharmacist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.4.3 Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.4.4 Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.4.5 Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.4.6 Psychological services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6.5 Do you have **any other comments** about how the different services you need work together?

7. Travelling away from home

7.1 While receiving haemodialysis or peritoneal dialysis, how many times have you been **away from home**, for example on holiday or on business, for more than 3 days?

None	1-2	3-4	5-6	7+
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7.2 If you answered None to 7.1, please indicate the **reason(s)** why:

7.2.1	I did not want to go away from home	<input type="checkbox"/>
7.2.2	I was not well enough to travel	<input type="checkbox"/>
7.2.3	I could not arrange dialysis away from home	<input type="checkbox"/>

Other (please specify):



7.3 If you have been away from home whilst on haemodialysis or peritoneal dialysis, for example on holiday or on business, **where** did you go?

UK	Europe	Worldwide
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7.4 Please tell us about any **difficulties** you face when trying to organise time away from home:



7.5 Please tell us what could be done to **help you organise** dialysis away from home:



8. The environment


8.1	When you attend the hospital, how would you grade the following aspects of your outpatient dialysis area or peritoneal dialysis unit/clinic?	Good	Average	Poor	Not applicable
	8.1.1 Catering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	8.1.2 Cleanliness of area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	8.1.3 Comfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	8.1.4 Accessibility (e.g. lifts, ramps, automatic doors)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	8.1.5 Entertainment (TV, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	8.1.6 General surroundings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	8.1.7 Toilets, showers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	8.1.8 Waiting area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	8.1.9 Other (please specify)				
	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Hand hygiene

When you attend hospital for dialysis or clinic appointments		Yes	No	Not sure	Not applicable
9.1	Do the staff usually clean their hands, either by washing them with soap and water or using alcohol gel , before treating you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9.2	Other than in the toilet areas, are there handwashing facilities for patients?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9.3	Do you usually wash your hands with soap and water or use alcohol gel before entering the dialysis unit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.4	Do you have any other comments about hand hygiene in the renal unit?				

10. In general

10.1 Please list, in order, the **3 things** that would make the biggest improvement to your experience of the service?

 1. _____

 2. _____

 3. _____

10.2 Please indicate by circling on the scale below **how satisfied you are overall** with the quality of care provided in your unit?

For example, ① = very unsatisfied ⇔ ⑩ = very satisfied

1	2	3	4	5	6	7	8	9	10
Very unsatisfied								Very satisfied	

Thank you for your time

Please post the survey back to NHS Quality Improvement Scotland in the **Freepost envelope provided**. No stamp is required.

Please return the survey by Wednesday 31 December 2008

NHS Quality Improvement Scotland
 FREEPOST SCO5432
 EDINBURGH
 EH7 0BR

www.nhshealthquality.org

Appendix 4: Glossary

acute kidney injury	The rapid loss of kidney function over a few hours or days (previously known as acute renal failure)
APD	See automated peritoneal dialysis.
automated peritoneal dialysis (APD)	A form of peritoneal dialysis that requires a machine to control the movement of fluid into and out of the peritoneal cavity. APD is carried out at home each night while the patient sleeps.
CAPD	See continuous ambulatory peritoneal dialysis
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 renal failure	The slow and progressive deterioration of kidney function.
clinical governance	<p>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.</p> <p>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.</p>
Clinical Standards Board for Scotland (CSBS)	The Clinical Standards Board for Scotland was a statutory body, established as a Special Health Board in April 1999. Its role was to develop and run a system of quality control of clinical services designed to "promote public confidence that the services provided by the NHS met nationally agreed standards, and to demonstrate that, within the resources available, the NHS was delivering the highest possible standards of care". On 1 January 2003, CSBS was merged, along with four other clinical effectiveness bodies, to form NHS Quality Improvement Scotland. See NHS Quality Improvement Scotland.

continuous ambulatory peritoneal dialysis (CAPD)	A form of peritoneal dialysis in which dialysis fluid is exchanged at regular intervals throughout the day.
dialysis	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.
established renal failure (ERF)	A loss of kidney function to a point where this becomes life threatening.
ERF	See established renal failure.
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.
home dialysis	Dialysis treatment that is carried out at home rather than in a hospital.
hospital dialysis	Dialysis that is carried out in a hospital renal unit.
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.
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 clinical practice; setting standards; driving and supporting implementation of improvements in quality; and assessing the performance of the NHS, reporting and publishing the findings. NHS QIS also has central responsibility for patient safety and clinical governance across NHSScotland. Website address: www.nhshealthquality.org
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.
PD	See peritoneal dialysis.
peritoneal dialysis (PD)	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 (RRT)	Treatment to replace the function of the kidneys in a person whose kidneys no longer work. Treatment is usually in the form of dialysis or transplant.
Renal 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.scotkidneyfederation.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 and 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.
transplantation	The act of transferring an organ or tissue from one individual to another.

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- in community languages.

Edinburgh Office
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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.