

Renal Disease in Scotland

**Cross Party Group on Kidney Disease
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Consulting with Patients

A supplement to the Second Report of the
Cross Party Group on Kidney Disease
The Scottish Parliament April 2004

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1 Introduction

The Scottish Parliament Cross Party Group on Kidney Disease (CPG) was formed in response to growing concerns about the ability of the NHS to treat the increasing amount of renal disease in the Scottish population, together with evidence that the situation is likely to deteriorate markedly unless strategic plans are made to prevent it. The CPG published an analysis of the current situation, highlighting 22 challenges for the future in February 2003. The second report “Renal Disease in Scotland - A Strategy for Future Management” (April 2004) makes recommendations as to how these challenges might be met.

The CPG was concerned from the start of its work to understand how effectively renal services in Scotland addressed the needs of patients. The group was keen to consult with patients, giving them the opportunity to comment on deficiencies as well as improvements, and ultimately allowing patients to help shape the CPG’s recommendations for a patient-centred service. Accordingly, it undertook two pieces of research to ascertain patients’ attitudes to renal services. Both pieces of research are outlined in this report which is a supplement to the main report from the CPG “Renal Disease in Scotland - A Strategy for Future Management”.

The initial research comprised an extensive survey of renal replacement services, inviting over 2000 patients from across Scotland, to express their views on all aspects of dialysis through a questionnaire (*Appendix 1*). The results from this survey are outlined in Section 2 of this report. (*Further detail is available in Appendix 2*).

The second piece of research was implemented through an “Open Space” event with focus groups. The report from this event is reproduced in Section 3.

2 Dialysis Questionnaire

2.1 Background

During the period Sept 2003-Jan 2004, over 2,000 questionnaires were distributed to all renal units in Scotland. These questionnaires were designed to investigate the experience of both hospital and home dialysis patients using renal services in Scotland. The questionnaire investigated 5 specific areas; treatment, transport, environment, holidays and information (see Appendix 1). Staff within each renal unit distributed questionnaires. Patients were given the choice of returning their completed questionnaire to staff or returning it directly to the CPG in a stamped addressed envelope.

2.2 Response

A total of 663 patients responded (response rate = 33%) with representation from units across Scotland. This has resulted in one of the largest surveys of dialysis patients in Scotland to date, and has given the CPG an invaluable, detailed impression of patients’ experience. The most pertinent points from the survey are highlighted in Sections 2.3-2.8. Full data is available in Appendix 2.

The response to the dialysis questionnaire can be broken down as follows;

Unit	No. of responses
Gartnavel General Hospital, Glasgow	44
Western Infirmary, Glasgow	48
Inverclyde Royal, Greenock	17
Glasgow Royal Infirmary	31
Stobhill Hospital, Glasgow	62
Falkirk & District Royal Infirmary	23
Royal Hospital for Sick Children, Yorkhill, Glasgow	2
Dumfries & Galloway Royal Infirmary	36
Queen Margaret's Hospital, Dunfermline	38
Victoria Hospital, Kirkaldy	9
Aberdeen Royal Infirmary	67
Crosshouse Hospital, Kilmarnock	33
Raigmore Hospital, Inverness	47
Caithness General Hospital, Wick	1
Ninewells Hospital, Dundee	53
Monklands General Hospital, Airdrie	29
Borders General Hospital	5
Dr Gray's Hospital, Elgin	5
Royal Infirmary of Edinburgh	63
Western General Hospital, Edinburgh	37
Unit not identified	13

2.3 Treatment

Of the patients who responded, 81% were treated via hospital-based dialysis, the remainder received home-based treatments. Exactly half of the respondents had been receiving dialysis for between one and five years; 27% were relatively new patients having been on dialysis for less than a year, with 16% falling into the 5-10 year category. The remaining seven percent of respondents had been receiving dialysis for over ten years. The majority (86%) of haemodialysis patients received dialysis three times a week, between four to five hours per session.

When asked “what did you imagine dialysis would involve when you were first told you would need the treatment”, over 43% of the patients responded that they “had no idea”. Others believed it to be a very restrictive treatment, and “a lot of hassle”. Some patients had family members who already received dialysis and therefore had a clearer picture of what to expect.

Upon being told that dialysis treatment was going to be needed, just over a third of the patients surveyed felt they needed to know in detail, exactly what would be involved. Others wanted to know how it would affect their day-to-day life (22%) as well as what the possible side-effects might be (14%).

In answer to the question “were there support services that you feel should have been available to you at this point [pre-dialysis], but were not” 44% of patients surveyed felt that support services were lacking at the pre-dialysis stage. Many said that they would have liked to have had access to social workers (particularly for advice on benefits entitlements) and psychologists/counsellors.

Some of the comments provided by patients are detailed below;

<i>“I feel we need support services for financial issues and [assistance] with form filling” (Patient from Crosshouse Hospital, Kilmarnock)</i>
<i>“One centralised point of contact for [advice on] allowances” (Patient from Stobhill Hospital, Glasgow)</i>
<i>“More advice on benefits as I had to give up work” (Patient from Aberdeen Royal Infirmary)</i>
<i>“We need support financially [even] just to cover daily expenses” (Patient from Ninewells Hospital, Dundee)</i>

The provision of support for carers seems to vary from unit to unit with some patients citing access to carer support as “easy” or only a “telephone call away”, whilst others were less satisfied. When questioned on carer support, 44% of patients felt that the support offered to carers was insufficient.

Patients were also asked “with hindsight, what it would have been useful to know that you weren’t told at that [about to commence dialysis] time?” The issues most frequently identified were;

- More information about the types of dialysis available
- Being made aware of possible complications, side effects and long-term effects of dialysis including tiredness, the different emotional, mental and physical stages throughout and the physical effects on one’s body and possible weight loss
- Transport issues
- More information about support services and how to access them as well as contacts in an emergency
- Transplants
- Implications for the family and social aspects
- Other health problems associated with kidney disease
- Diet and fluid restrictions
- Financial problems.

Specific comments include;

<i>“I did not know it would change my life so much”, “did not fully appreciate that my life would revolve around dialysis”, “just how much dialysis interferes with normal life”(Patients from Stobhill Hospital, Glasgow and Monklands Hospital, Airdrie)</i>
<i>“I would like to have known it was not the end of the world” (Patient from Falkirk Royal Infirmary)</i>
<i>“That there is no back up in Orkney” (Patient from Aberdeen Royal Infirmary)</i>
<i>“How traumatic it is. The use of needles every session” (Patient from Crosshouse Hospital, Kilmarnock)</i>
<i>“How long have I got to live?” (Anonymous)</i>

A total of 28% of respondents felt that they had been inadequately prepared for dialysis. They reported that they would have liked more basic literature on the process of dialysis as well as the opportunity to see the treatment in action prior to commencing dialysis. However, 72% felt that they were well prepared, often citing staff as “excellent/caring/informative/patient”. Many of those who felt well prepared had been taken for a tour of the unit and had been given the opportunity to speak to patients already on dialysis. Some comments provided were;

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

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

Two thirds of patients said they were happy with staffing levels, whereas one third were not. Furthermore, whilst 79% of patients were happy with the dialysis shift they had been given, just over one fifth would have preferred a different shift but were unable to get the shift they wanted because of a lack of available space.

When asked, “what are the most important elements for you associated with dialysis”, *staff, transport and information* (in order of priority) were cited as patients’ top three priorities. When questioned on what the main drawbacks of dialysis were, the most commonly cited responses were;

- amount of time dedicated to receiving treatment
- effects on their working life
- restrictions on physical activity/tiredness
- lack of freedom and independence.

Patients were also asked to consider how their experience of dialysis could be improved. The most frequently cited suggestion was to reduce the amount of time spent receiving treatment. “A transplant” was suggested by 6% of respondents as something that would make their experience somewhat better.

2.4 **Transport**

Seventy percent of patients felt that their unit was close enough to home; 37% lived less than 5 miles away, 21% lived 5-10 miles away and 13% faced a journey of between 10-15 miles. However, 29% of respondents lived over 15 miles away.

In terms of travel time, the survey reports that just over half of respondents lived on average, less than 30mins away from their dialysis unit, with 34% living within one hour. The remaining 15% lived more than an hour away. Furthermore, about one quarter (24%) of patients could not make a direct journey to their unit, and so experienced prolonged journey times.

The questions relating to patient transport generated a 52% response rate, suggesting that over half of respondents rely on patient transport to get them to and from dialysis sessions. Patients have reported unacceptable delays in transport, particularly when waiting to be collected from the unit to return home. In some extreme cases this has been delays of between seven and ten hours. The average longest wait for patients using patient transport is 99 minutes, with some patients reporting two to three hours as common. However, the provision of transport does seem to vary from unit to unit with some “longest average wait” times coming in under 60 minutes, whereas in others it was over three hours. In addition to this, when questioned on shortest wait times, some patients reported their transport to be awaiting them, upon completing their dialysis session.

When asked “how could your transport arrangements be improved” the most common responses were;

- Better communication between various departments - medical, ambulance etc.
- Direct travelling. Limit the number of patients being picked up. Better organisation of pick-ups / pooling of patients
- Private tender
- Same regular driver.

2.5 **Environment**

The surroundings in which patients dialyse were deemed to be moderately or very important to 86% of the patients surveyed, particularly given the amount of time they have to spend in this environment each week. Just over one third (35%) of patients described their surroundings as good, 29% as excellent and 30% as adequate. They expected their dialysing environment to be bright, clean and comfortable and for over 80%, their environment lived up to or exceeded expectations. However 20% of patients were not as happy. Requests for less noise, more comfortable chairs and more blankets were commonplace from those dissatisfied.

When asked how their dialysis environment might be improved some responses given were;

“Peace and quiet”, “Heating to always work throughout the winter, well ventilated in summer” (Patients from Gartnavel Hospital, Glasgow)

“More comfortable chairs and beds” (Patient from the Western General, Edinburgh)

“More chairs, pillows, blankets, proper ventilation, better lighting” (Patient from Ninewells Hospital, Dundee)

Television with individual headphones would be considered an improvement by 66% of respondents. It was felt by 43% of respondents that access to the internet would also be an improvement.

“Earphones for individual TV’s, with radio channels, bookstands for reading, comfortable chairs, plants, quiet and comfortable waiting areas” (Patient from Raigmore Hospital, Inverness)

“Comfortable chairs with some kind of personal audio system” (Patient from Western Infirmary, Glasgow)

2.6 Holidays

The patients voiced strongly their concerns at the difficulty in taking holidays. More than half (59%) of patients on dialysis had not been on holiday since starting their treatment and in some cases this was over 10 years ago. Many of the 41% who had managed to take holidays, reported that it was easier to arrange holidays abroad than in the UK. The majority of those who had taken holidays were extremely happy with the services provided for them, as illustrated by the following comments;

- “Benidorm & Cyprus - excellent. First class attention” (Patient from Monklands Hospital, Airdrie)*
- “Tenerife & Australia. Service & facilities excellent”(Patient from Royal Infirmary of Edinburgh)*
- “Lanzarote, first class service. No delays. Why can’t the UK offer the same?”
“Majorca, Innsbruck, Ibiza, Sorrento. All fine. Main problem in UK is getting booked”
(Patients from the Western General, Edinburgh)*
- “Only been able to go abroad” (Patient from Victoria Hospital, Kirkaldy)*

When asked how holiday dialysis might be improved, many patients suggested that the NHS should make dialysis stations available within existing units to provide holiday dialysis spaces. Lack of information about holiday dialysis and the length of time to get blood tests checked and forwarded were also reported as major stumbling blocks preventing patients from taking holidays.

- “It would be easier if there was more information on holiday dialysis available”
(Patient from Dumfries & Galloway Royal Infirmary)*
- “Problems getting travel and medical insurance” (Patient Crosshouse Hospital, Kilmarnock)*
- “At present, 2 months minimum notice is needed for bloods when going abroad. If this could be shortened it would be beneficial” “Taking of bloods and swabs must be timely, so that any problems can be treated and not have to cancel holidays” (Patients from Inverclyde Royal, Greenock and Royal Infirmary of Edinburgh)*
- “More spaces in Scotland and England” “We need to make more beds available for holiday dialysis in the UK” (Patients from Monklands Hospital, Airdrie and Falkirk Royal Infirmary)*

2.7 Information

Good information was very important to 94% of respondents, with 70% of patients stating that the information they currently received was adequate. However, over one quarter felt that it could be improved.

Suggested improvements included;

- More regular, frank contact with consultants - with time and space to talk privately
- Easier access to support networks, literature and internet
- Regular, automatic discussion of blood test results, quality of dialysis fluid, any concerns, progress etc. Regular discussion of trends / patterns
- Updates on new drugs, research or treatments, better information about medication
- Contact with a dietician.

- “Any info, no matter how little, helps patients understand their treatment” “Need educated on medical terms to understand the questions staff ask me” “Easy access to results on PC - using username / password system.” (Patients from Ninewells Hospital, Dundee)*
- “More info on what test results mean. Layman’s terms would be good” (Patient from Aberdeen Royal Infirmary)*
- “Leaflets are not always best option, staff are very good, but under pressure” “Better patient oriented info on internet” “Getting life assurance” “If unit was properly staffed, perhaps home visits to patients could be improved” (Patients from Crosshouse Hospital, Kilmarnock)*
- “Audio information for the blind” (Patient from Falkirk Royal Infirmary)*

Patients emphasised the need for information to be presented in different ways and the need for their family and carers also to have access to information. Literature with various levels of detail; internet or electronically based information or access to a library resource containing publications or leaflets with the main aspects of their disease explained to them, were all deemed appropriate. However, it was emphasised that none of these could substitute for personal contact with appropriate staff - “a member of staff” was the most popular choice in answer to the question “how would you like to access this information”.

2.8 Conclusions from patient survey

As previously stated the patient survey has resulted in one of the largest surveys of dialysis patients in Scotland to date, giving the CPG an invaluable, detailed impression of patients’ experience. The results and suggestions contained within the patient survey have been incorporated into the CPG’s second report and have informed many of the patient-centred recommendations put forward.

3 Open Space Event and Focus Groups

3.1 Background

In order to give more depth to the CPG’s understanding of patient experience, and to supplement the data collected via the patient survey, an “open space” event was held in February 2004 involving 34 dialysis and transplant patients, and carers from across Scotland. This event invited a random, stratified sample of patients to nominate a list of topics important to them and then allowed for smaller group discussions to further investigate these topics. Following these discussions a series of bullet points were drawn up by each group, outlining why the issue was important. Participants were then invited to vote on each topic so that a prioritised list could be drawn up.

The report resulting from the Open Space event is reproduced in part below and includes;

- initial observations from all participants when nominating topics important to them
- detailed points put forward by each focus group
- 16 priorities identified by participants.

3.2 Report from an “Open Space” meeting for people who use Renal Services in Scotland - Informing the Scottish Parliament Cross Party Group on Kidney Disease

3.2.1 What is an Open Space Event?

An Open Space event is an opportunity for participants to identify what is important to them and discuss topics of immediate relevance to them. Participants identify the topics on the day itself and form themselves into small focus groups to identify the main facts, themes or actions for consideration. Participants self-organise into groups and can move from one to another when they feel they have had enough of one discussion or have made their point. Participants can also self organise into another group completely.

3.2.2 Background

Eighty people who use renal services in Scotland were invited to attend an “open space” event. Through a stratified, random sample generated by the Scottish Renal Registry, participants were selected from all units in Scotland and included current haemodialysis and peritoneal dialysis patients as well as those who have had a kidney transplant. Upon the reply deadline being reached, it was decided that additional recruitment should take place in order to supplement the 33 people from the random sample who had already expressed an interest in attending, as well as to try and ensure a more even geographical spread. A total of seven additional participants were recruited through the random selection of completed dialysis questionnaires (stratified by unit and type of treatment), through contacting the Scottish Federation of Kidney Patient Associations, the Highlands and Islands Kidney Patient Association and by direct approaches to some under-represented units.

A total of forty people were expected, with 34 people actually attending on the day, from most renal units in Scotland. The breakdown of units and participants were as follows;

Unit	Haemodialysis	Peritoneal Dialysis	Transplant	Carer
Western Infirmary, Glasgow		1	10	2
Gartnavel Hospital, Glasgow	1			
Glasgow Royal Infirmary	1			
Stobhill Hospital, Glasgow	2		1	1
Crosshouse Hospital, Kilmarnock		1	1	2
Raigmore Hospital, Inverness	1		1	
Ninewells Hospital, Dundee	1		1	
Aberdeen Royal Infirmary	1		1	
Royal Infirmary of Edinburgh			3	
Monklands Hospital, Airdrie	2			
Totals	9	2	18	5

3.2.3 Topics Identified - Initial Observations & Focus Group Summaries

This section documents the initial observations of individuals when identifying topics to be discussed during the Open Space event. The initial observations are then followed by the focus group summary for each topic.

TOPIC 1: STAFFING

Initial observations; shortage of staff, patients have less confidence in “agency” staff, medical back-up during the dialysis period, consistency in follow-up by nurses and doctors, the need for a government drive to train more specialist renal nurses, staff attitude - lack of understanding of patients needs, need for multi-disciplinary teams, continuity of staff and patient care, doctor availability, more staffing of twilight shift, staff training availability.

Focus group summary;

- Doctors should carry out regular rounds of the RDU (monthly)
- The shortage of nurses requires serious addressing by using semi-skilled persons on home dialysis
- Renal social worker required to cover each RDU
- Great need for a renal counsellor.

TOPIC 2: TRANSPORT

Initial observations; travel to dialysis unit - better transport service needed, length of time between leaving the house and going onto a machine, excess travel, communication between ambulance service and medical staff,

Focus group summary;

- In-house transport between various units
- Communication between various departments -medical, ambulance etc.
- Better programming of patient drivers
- Ferries - distance from facilities - hazardous
- Direct travelling - no Cook’s Tour.

TOPIC 3: ORGAN DONATION

Initial observations; change to transplant services to allow pre-dialysis patients transplantation, donor cards- opt out system, live transplant build-up procedure, organ availability, transplant waiting list and pre-emptive transplants, need to raise awareness at UK Government level and publicise to public to allay their fears.

Focus group summary;

- Awareness of potential of non-heart beating donors
- Education starting at school level (Spanish example)
- Change of law to make donor registration a legal document so that next of kin are not required to make the final decision

- Inequality of treatment across the country - different approach to live donors process in different places
- Need to raise awareness in general about what transplantation means - sensitive political issue.

TOPIC 4: POST-TRANSPLANT CARE

Initial observations; transplantation drug maintenance improvement in order to reduce the side effects, need for post-transplant testing.

Focus group summary;

- Patient care plans - shared with patients
- Drug regimes - discussion of side effects, suited to lifestyles
- Communication with GP's/general wards
- Consistency of care - best practice (e.g. skin care)
- Anxiety about length of time between clinic visits and length of time to obtain results.

TOPIC 5: PRESCRIPTIONS

Initial observations; paying for prescriptions - chronic diseases should be covered by exemption.

Focus group summary;

- Repeat prescriptions - usually for long periods, need to cut down time spent on collection
- Advice on taking of medicine - e.g. different times, benefits of certain medicines
- Changing medicine - passing on of information to doctor/patient - 3 way process
- Need to rationalise the drugs - inadequate amount dispensed causes continual visits to surgery and chemists
- Information - too much comes with medicine which causes worry, need for clarification and simplification.

TOPIC 6: BENEFITS SYSTEM

Initial observations; help with benefit claims, better consideration of incapacity benefits, many patients are unaware of what benefits they may be entitled to and liaison with the Benefits Agency would be useful, confusion over entitlement to free prescriptions.

Focus group summary;

- Better advice about benefits - solution is a forum of health professionals and Benefit Agency Officials
- Rigidity of examination process - should be relaxed/changed. Solution - hospital consultants/doctors report should carry more weight in the process
- Government should recognise long-term renal failure as a specific illness and give more weight to this
- Recognition for carers and appropriate allowance in recognition
- Reduction of benefits without thorough assessment

- Benefits that can be claimed
- Incapacity benefit - 60 years of age
- Disability living allowance - over 65 years of age
- Attendance allowance - over 65 years of age
- Patients should be informed of entitlements rather than having to seek such information
- Expert assistance should be given to fill in forms.

TOPIC 7: COUNSELLING AND MENTAL HEALTH

Initial observations; patient/carers counsellors, bereavement counselling, the role of the social worker should be bigger, disablement counselling, the need for contact with other patients who have been through treatment counselling in order to understand the psychological impact.

Focus group summary;

- Recognition of mental health issues
- Counsellors attached to all units
- Support and recognition of what is the role of the carer
- Routine referral to counselling and psychological services
- Information on how and where to access services.

TOPIC 8: QUALITY OF LIFE

Initial observations; importance of leading a “normal” life whilst on dialysis, impact on young patients - social, sexual, employment, aids to make life easier - a simple transporter, lifter for boxes of fluid and a portable/flexible stand for CAPD fluid, respite care, retirement options, pool of individuals who are prepared to visit patients.

Focus group summary;

- Resuming work - feeling useful and contributing and flexibility of renal units and employers
- Time taken up - social life disrupted
- Difficulty in establishing a balance in life between dialysis demands and maintaining good life
- Respite care - home dialysis
- Holistic approach
- Holidays “normalisation”
- Accessibility/information/technology
- Dialyse to live not live to dialyse.

TOPIC 9: HOLIDAYS

Initial observations; adopting the expectation that renal patients and carers should be able to enjoy holidays, information on insurance companies willing to cover renal conditions at a reasonable price, holiday dialysis - difficulty of getting it.

Focus group summary;

- Great difficulty experienced by Haemodialysis patients when deciding where to go. Need to find out who will accept them for six sessions. Package holidays are particularly awkward
- More emphasis to be placed upon access to cruising
- More information required through service of NEFCO
- Cost of holiday insurance and premiums.

TOPIC 10: INFORMATION

Initial observations; communication between patients, GP's, consultants and renal units, continuity of renal units, information in Braille, poor information regarding transplants, frank discussion of side effects, one-to-one advice from patients, more information needed at initial stages and pre-dialysis, information on consequences - financial, lifestyle change, personal, employment etc, patient representation on forums, education to enable informed choices, patient must be informed regarding replacement of consultants.

Focus group summary;

- Inform the public to improve awareness and perception
- Improve it!
- Fund it!
- Awareness

TOPIC 11: EQUIPMENT

Initial observations; audio equipment for blind people, need for replacement dialysis machines in Inverness.

Focus group summary;

- Adapted equipment should be made more accessible for different disabilities
- National Framework for financial funding of equipment - e.g. purchase of dialysis machines
- Equipment should have a useful life and then be replaced without compromise to patient safety.

TOPIC 12: SATELLITE DIALYSIS UNITS

Initial observations; more satellite units needed, the Victoria Infirmary in Glasgow has a new Ambulatory Unit but no renal department, no dialysis in South Glasgow, need for a new satellite unit in the Western Isles.

Focus group summary;

- Dialysis must be as close to the population as possibly by the use of a satellite unit - especially in the rural areas and islands
- Satellite units could be managed by a nurse with the help of semi-skilled personnel as in home dialysis
- The Health Executive should collectively be responsible for renal services and not individual health boards thus creating more equity in services.

TOPIC 13: GOVERNMENT ISSUES AND FUNDING

Initial observations; lack of major funding from the Government, the way in which renal illness is regarded in the NHS, need to raise profile of renal care in Scotland - how? And who can do this? Momentum of improvement in services needs to be maintained and where possible improved further, planning for increase in renal patients - physical plant, nursing, consultants and other staff.

Focus group summary;

- Need for public debate regarding opt out/in and publicise within schools
- Why charity? Should be mainstream
- End to postcode prescribing
- Patient funding - choice and flexibility
- Negative misleading popular publications
- Improved Government funding towards publicity in order to raise awareness and improve public perception
- Need for a political sponsor
- Joined up working with a common purpose between various voluntary organisations working in rural areas. The Government should promote this
- Encourage specialised nursing and nurse led care.

TOPIC 14: FACILITIES IN DIALYSIS UNITS

Initial observations; TV's without earphones, lack of things to do- 4-5 hours is a long time, comfort of dialysis patients - particularly on night shift, haemodialysis units are overcrowded and under funded which means patients suffer.

Focus group summary;

- Basics in place before additional resources made available e.g. comfortable chairs, clean blankets, curtains that fit - e.g. during night dialysis
- Lack of staff continuity - e.g. agency staff not able to give personal care. Agency staff vs permanent staff resentment building up means patient confidence falls
- Additional facilities - pay for use e.g. internet, access, telephones, personal TV's. DVD library, videos
- Each patient needs a buzzer to get attention from nurses stationed several rooms away

- Refreshments available when patients would like them not when regimented teatimes dictate
- Lack of cleanliness needs to be addressed
- Lighting/reading lights
- In some units, staff attitude towards patients could be improved.

TOPIC 15: SCREENING AND PRE-DIALYSIS ISSUES

Initial observations; testing by GP’s for renal function, diabetes and hypertension, comfort, dialysis availability- times, pre-dialysis treatment - preparation, donor list and information.

Focus group summary;

- Improvements in information for patients
- More education evenings - one-to-one with patients and former patients
- Individual screening early in the process
- Recognise the massive impact on life of the patient and their family
- Preparation for the psychological, emotional effects
- Better control of medicines and treatment so that the process could be delayed e.g. checks on blood pressure and other preventative measures.

TOPIC 16: QUALITY VS CONVENIENCE/ACCESS TO CARE

Initial observations; expertise vs convenience - international dimension, non-centralisation of transplant services.

Focus group summary;

- Giving people choice
- General opinion - centres of excellence in Scotland are better
- Hotel/residence facilities for families.

3.2.4 *Prioritising the topics*

Following the focus group discussions, each participant was given 12 ‘sticky, colour coded dots’ to place as they wished on each topic summary sheet. In this way, participants were able to indicate topics of most importance to them. Haemodialysis, peritoneal dialysis, transplant patients and carers were given separate colours.

The results, in order of priority are shown in the table below;

		Haemo	PD	Transplant	Carers/Others	Totals
Priority	Number of people voting	9	2	18	5	34
1	Staffing	25	1	12	11	49
2	Government issues & funding	5	1	29	4	39
3	Organ Donation	9	4	20	2	35
4	Information	11	3	13	5	32
5	Satellite dialysis units	18	4	1	5	28
6	Post transplant care	1	1	23	0	25
7	Equipment	2	0	11	12	25
8	Counselling & Mental Health	1	2	11	7	21
9	Screening and pre-dialysis issues	2	2	13	4	21
10	Facilities in dialysis units	9	0	10	0	19
11	Transport	9	0	7	0	16
12	Benefits system	2	3	7	2	14
13	Quality of Life	6	2	3	3	14
14	Holidays	6	1	1	3	11
15	Quality v convenience	1	0	6	0	7
16	Prescriptions	1	0	3	1	5
	Totals	108	24	170	59	361

3.3 **Conclusions**

All participants contributed to the “Open Space” event and a large number of topics were explored. The most important issues to emerge from the voting are listed, in order of priority, above. Many of these issues mirror those raised within the patient questionnaire and have been incorporated within the recommendations of the second report from the Cross Party Group on Kidney Disease, where appropriate.

Appendix 1 Dialysis Questionnaire

The Scottish Parliament Cross Party Group on Kidney Disease Dialysis Questionnaire

The Scottish Parliament Cross Party Group on Kidney Disease is currently drafting a report that will look to make recommendations on how to improve renal services in Scotland. As part of this report, the group is very keen to consult with dialysis patients and their carers from across Scotland on their needs. The group wants to ensure that you are given the opportunity to communicate your views on the process of dialysis, the treatment you receive and the ways in which your experience of dialysis might be improved.

It is proposed that the consultation will be carried out in three ways; using the paper-based questionnaire (attached), conducting a series of face-to-face interviews and possibly, at a later stage, a couple of focus groups. The results from these enquiries will then advise the recommendations to be incorporated into the Cross Party Group's second (solutions) report that is due to be published late autumn. It is anticipated that this report will make a central contribution towards improving your experience of dialysis and for others receiving this treatment.

As part of the questionnaire you are asked to fill in your name and the hospital at which you receive treatment. If you would prefer your response to remain anonymous please leave these lines blank. If you would be willing to take part in an interview, please complete this section along with some contact details and times it would be good for us to contact you. Please feel free to complete the questionnaire along with your carer if you wish. All completed questionnaires will be treated with the strictest confidence. If you have any queries regarding this questionnaire, the consultation process or the Cross Party Group on Kidney Disease please do not hesitate to contact a member of the secretariat listed below;

Katie Ronald - Public Affairs Manager (Scotland)
The National Kidney Research Fund
Tel: 01560 48 68 68
Email: kationeronald@nkrf.org.uk

CONTACT DETAILS

Name:

Hospital:

Contact telephone number & suitable contact times:

TREATMENT

1. Do you receive hospital or home-based dialysis?

2. How long have you been on dialysis?

3. How many times a week do you have dialysis?

4. How long is each of your dialysis sessions?

5. What did you imagine dialysis would involve when you were first told that you would need to have the treatment?

6. What did you feel you particularly needed to know about the whole dialysis process at this point?

7. Were there any support services you feel should have been available to you at this point, but were not?

8. Do you feel that sufficient support is offered/provided for carers?

9. Are there any information and support services available to those who care for you?

10. If yes, how easy is it for your carer(s) to access these information and support services?

11. With hindsight what would it have been useful to know that you weren't told at that time?

12. Do you feel that you were well prepared for dialysis by various staff and other information sources? ☐ Yes ☐ No

If yes, please detail how staff helped to prepare you. If not, how could this process have been improved?

13. Are you happy with the general staffing levels that you have seen?

14. Would you have preferred a different dialysis shift to the one you were given and were unable to get the shift you wanted because of lack of available space? ☐ Yes ☐ No

15. Other than treatment what are the most important elements for you associated with dialysis?
Please prioritise the following list from 1 to 6, putting a 1 against the item that is most important and 6 for least important.

Staff Information Transport Surroundings/environment What you do whilst dialysing Holidays

Other – please provide details

16. Other than the fact that you need to have the treatment at all, what are the main drawbacks of dialysis for you? For instance what are the main indoor or work-related activities that dialysis prevents you from undertaking?

17. What would help to make your experience of dialysis, somewhat better?

Markedly better?

TRANSPORT

18. Is the dialysis unit close enough to home? ☐ Yes ☐ No

19. How far do you have to travel to reach the unit?

20. How long does this take you on average?

21. Are you able to make a direct journey to the unit? ☐ Yes ☐ No

22. If you rely on patient transport...

What is the longest time you have had to wait before being collected to go home?

What is the shortest time you have had to wait before being collected to go home?

How could your transport arrangements be improved?

ENVIRONMENT

23. How important are your surroundings to you when you are having dialysis?

24. How do you rate your existing surroundings? Give further comment if you wish. ☐ Excellent ☐ Good ☐ Adequate ☐ Poor

25. What did you expect your dialysis environment to be like?

26. Has this lived up to your expectations or exceeded them?

27. Would having your own TV set whilst having dialysis be an improvement on your current situation? ☐ Yes ☐ No

28. Would having access to the internet or to a personal telephone line be useful? ☐ Yes ☐ No

29. If these were available, would you make a point of using them? Please provide further comment if appropriate. ☐ Yes ☐ No

30. How else could your surroundings be improved?

HOLIDAYS

31. Has holiday dialysis been possible for you in the past? ☐ Yes ☐ No
If yes, where did you go and were you pleased with the service available to you? If not, why not? What problems have you encountered?

32. How could holiday dialysis be improved?

33. How many holidays have you managed to take since beginning your treatment? (Holiday being 4 days or longer)

INFORMATION

34. How important is having good information about your treatment, etc, to you?

35. Do you feel the information you currently receive is... ☐ Too much ☐ Adequate ☐ Could be improved
If "could be improved" please explain how.

36. How would you like to access this information? (Please tick)
☐ Leaflet ☐ From a member of staff ☐ The internet ☐ The internet whilst being treated ☐ Interactive information points in the unit
☐ Having access to a paper-based information resource in the unit

Thank you for taking the time to complete this questionnaire. Your experience and views are of great value to us and will be incorporated within the next Cross Party Group report. If there any areas of concern that you would like to alert the CPG to and which you have not had the opportunity to highlight within this questionnaire, please do contact Katie Ronald (contact details on the front page of this questionnaire).

The National Kidney Helpline:

0845 300 1499

A Helpline for kidney patients, carers and all those with an interest in kidney disease.

Appendix 2 Results From Dialysis Questionnaire

No.	Question	Answer	Number	Total Responses	%
TREATMENT					
1	Do you receive hospital or home dialysis?	Hospital Home	536 127	663	81% 19%
2	How long have you been on dialysis?	< 1 year 1-5yrs 5-10yrs >10yrs	177 329 104 43	653	27% 50% 16% 7%
3	How many times a week do you have dialysis?	3 x week 4 x week	544 87	631	86% 14%
4	How long is each of your dialysis sessions?	3-4hrs 4-5hrs 5+hrs	122 368 99	589	21% 62% 17%
5	What did you imagine dialysis would involve when you were first told you would need to have the treatment?	Had no idea A very restrictive treatment A lot of hassle No. of other text responses given	272 80 33 245	630	43% 13% 5% 39%
6	What did you feel you particularly needed to know about the dialysis process at this point? (Multi-response)	What is involved Side effects How if would affect my life No. of other text responses given	296 115 184 240	835	35% 14% 22% 29%
7	Were there any support services you feel should have been available to you at this point but were not?	Agree, not available Disagree, were available NB: Additional comments were given	237 307	544	44% 56%
8	Do you feel sufficient support is offered/provided for carers?	Yes No NB: Additional comments were given	313 243	556	56% 44%
9	Are there any information and support services available to those who care for you?	Available Not available	239 208	447	53% 47%
10	If yes, how easy is it for your carers to access these information and support services?	Difficult/not very easy By telephone Easy No. of other text responses given	38 75 133 43	289	13% 26% 46% 15%
11	With hindsight what would it have been useful to know that you weren't told at that time?	Better basic literature on process To see treatment in action Benefits entitlement No. of other text responses given	49 25 19 245	338	15% 7% 6% 72%
12	Do you feel you were well prepared for dialysis?	Yes No NB: Additional comments were given	450 178	628	72% 28%
13	Are you happy with the general staffing levels you have seen?	Yes No	432 218	650	66% 34%
14	Would you have preferred a different shift to the one you were given and were unable to get the shift you wanted because of lack of available space?	Yes No	123 452	575	21% 79%
15	Other than treatment what are the most important elements for you associated with dialysis? (Prioritise from list)	Staff Info Transport Environment What to do Holidays No. of other text responses given	590 350 402 277 192 87 43	1941	30% 18% 21% 14% 10% 5% 2%

No.	Question	Answer	Number	Total Responses	%
16	Other than the fact you need to have treatment at all, what are the main drawbacks of dialysis for you?	Working life affected Lack of freedom/independence Has restricted my physical activity No. of other text responses given	166 228 261 281	936	18% 24% 28% 30%
17a	What would help your experience of dialysis somewhat better?	Less time on dialysis Transplant Fewer needles No. of other text responses given	93 28 10 296	427	22% 6% 2% 70%
17b	What would make your experience of dialysis markedly better?	Transplant No. of other text responses given	22 120	142	15% 85%
TRANSPORT					
18	Is the dialysis unit close enough to home?	Yes No	434 183	617	70% 30%
19	How far do you travel to reach the unit?	< 5 miles 5-10 miles 10-15 miles > 15 miles	201 118 72 161	552	37% 21% 13% 29%
20	How long does this take you on average?	< 30mins 30mins-1hr >1hr	301 200 85	586	51% 34% 15%
21	Are you able to make a direct journey to the unit?	Yes No	460 148	608	76% 24%
22a	If you rely on patient transport what is the longest time you have had to wait before being collected to go home?	No. of patients responded Average longest wait Longest wait	343 99mins 10hrs		52%
22b	If you rely on patient transport what is the shortest time you have had to wait before being collected to go home?	No of patients responded Shortest time - no wait	134		20%
22c	How could your transport arrangements be improved?	Couldn't be improved Direct Travelling Private tender No. of other text responses given	84 26 26 182	318	27% 8% 8% 57%
ENVIRONMENT					
23	How important are your surroundings to you when you are having dialysis?	Very Important Moderately Important Not Important	317 136 73	526	60% 26% 14%
24	How do you rate your existing surroundings?	Excellent Good Adequate Poor	177 208 183 33	601	29% 35% 30% 6%
25	What did you expect your dialysis environment to be like?	Had no idea Hospital Ward Bright/Clean/Comfortable	161 99 92	352	46% 28% 26%
26	Has this lived up to your expectations or exceeded them?	Lived up to/exceeded expectations Not lived up to/exceeded expectations	316 77	393	80% 20%
27	Would having your own TV set whilst dialysing be an improvement on your current situation?	Yes No	358 182	540	66% 34%
28	Would having access to the internet or to a personal telephone line be useful?	Yes No	247 332	579	43% 57%
29	If these were available, would you make a point of using them?	Yes No NB: Additional comments were given	356 180	536	66% 34%

No.	Question	Answer	Number	Total Responses	%
30	How else could your surroundings be improved?	Less Noise Extra staff More Comfortable Chairs No. of other text responses given	5 22 15 173	215	2% 10% 7% 81%
HOLIDAYS					
31	Has holiday dialysis been possible for you in the past?	Yes No NB: Additional comments were given	239 347	586	41% 59%
32	How could holiday dialysis be improved?	Satisfied More spaces More information No. of other text responses given	86 42 25 95	248	35% 17% 10% 38%
33	How many holidays have you managed to take since beginning your treatment? (Holidays being 4 days or longer)	None One Two Three or more	330 74 56 96	556	59% 13% 10% 18%
INFORMATION					
34	How important is having good information about your treatment?	Very important Moderately important Not important	563 27 8	598	94% 5% 1%
35	Do you feel the information you currently receive is...	Too much Adequate Could be improved NB: Additional comments were given	4 461 187	652	1% 70% 29%
36	How would you like to access this information?	Leaflet Member of staff Internet Internet whilst treated Interactive info Paper-based	233 442 59 42 56 154	986	24% 45% 6% 4% 5% 16%
2,000 patients invited to complete questionnaire				663	33%

