



NKF Campaigns Zone:
APPKG Dialysis Summit
July 2007



Text Only version

NKF Campaigns



Minutes of the Dialysis Summit held at the Thatcher Room, Portcullis House, Westminster on Thursday 12 July 2007

Present: Dr Evan Harris MP Chairman

Tim Statham, NKF APPKG Secretariat

Observers: Becky Purvis, Dr Harris Researcher

Authorities: Ms Monica Acheampong, Department of Health, James Woodhouse, Roche, N Karim, Roche, Y Bradburn, Renal Nutrition Group, Cathy Johnson, ANSA, Jon Gooch, B M Browne, C Alt, Br Braun Avitum, Miriam Barber, B Braun Avitum, Carol Hall, Ealing Primary Care Trust, Ray Mackey NKF, Colin Campbell, Westminster PCT, Nicky Coffey, South East Coast SCG, Paul Stevens, British Renal Society, Charles Kernahan, Kidney Research UK, Warwick Vaughan, Baxter, Amy Pott, Baxter, Liz Cropper, University Hospital North Staffordshire, Gerry Endall, Wessex Renal & Transplant Service (Portsmouth), Helen Laing, Healthcare Commission, Pynee Sanjivi, NKF, Susie Hackett, Roche, Frank Howarth, NKF, Donal O'Donoghue DOH, RW Dunn, NKF, David Macdonald, NKF, Deborah Duval, NKF, Janet Dean, MP, Paul Jennings, NHS, Jonathan Kwan, NHS, Brian Camilieu NHS, John Murray, SHCA, David Smith, Kingston PCT, Norman Lamb MP Lib Dem Health Spokesman,, Edwina Brown, West London Renal Transplant Centre, Alan Watson, Nottingham , Michelle Clemenger, Hammersmith Hospital, Sue Cox, Guy's & St Thomas' Hospital, Chris Winearls, Renal Association Vice President, Peter Mathieson, Renal Association (President), Jenny Scott, NWSCT (Spec. Comm Team), Caroline Ashley, UK Renal Pharmacy Group, Susan Mayo Medical Writer & Editor, P C Statham, PHD Research, Marion Higgins, NKF, Lewis Sander, NKF, Fiona Loud, Kidney Alliance, Roger Greenwood, Past Chair Kidney Alliance, Jason Raj, On behalf of Optimal Renal Care, Debbie Reece, Fresenius Medical Care, Leah Vaughan, Gambro, Peter Maxwell, Belfast City Hospital, Ken Tupling Co-Chair, NKF, Keith Simpson, RIXG, Glasgow Royal Infirmary, Steve Ashmore, Barnet PCT, Pearl Pai, Royal Liverpool University Hospital, Simon Wilson, Syner-Med, Teresa Howes, British Dietetic Association RNG, Gordon Nicholas, Patient, Karen Wilson Baxter Healthcare.

1. **Opening Address – Dr Donal O'Donoghue, Clinical Director for Renal Care:** Dr Donal O'Donoghue's presented the current issues facing the dialysis community.

Points of note:

- Dialysis away from the home unit is a big challenge.
- Key challenges 1 choice, 2 capacity 3 patient experiments and safety.
- There is a real issue with dialysis away from the home unit, which has to be looked at.
- It would be wrong to not think about dialysis in the same way as transplantation. A minority get on the transplant list. Why does it take so long to get on the transplant list? People who get transplants before they start dialysis fare much better.

- Renal Registry statistics illustrate there has been a huge increase in dialysis over 25 years. Less home haemodialysis and Peritoneal dialysis.
- The NSF says people should be able to get high quality dialysis designed around their individual needs. All methods should be available and interchangeable. Effective dialysis is not twice weekly dialysis. Dialysis should be available with low peritonitis rates, nephrology support adequate transport service and staff and service available should people require hospitalisation.
- What has happened over the last 5 or 6 years? 3 new units brought on line in the last 2 years. We have seen a big growth in satellite provision but none in the way of main unit development.
- The experience is not a pleasant and enjoyable one for patients. People are not allowed to exercise on dialysis in most units. To provide good service requires a good team approach. Patients need to be picked up at an early stage because this determines outcomes on dialysis. It is important to ensure people are allowed to make choices.
- Late detection has a high mortality risk. 20%-40% start as 'crash landers'. There is a big survival advantage to starting with an AV fistula. In Germany 95% will have an AV fistula fitted within 4 weeks. In UK 60% have not have not had one fitted in under 18 weeks.
- Access is a major issue in patient safety.
- Patient quality of life. Transport is an issue.
- Transplant list increasing. Currently 6480. Despite running hard we are only flat lining.
- Living donation improved year on year over the last 10 years.

Questions

Evan Harris. Do you have a chart that shows the number of people dying whilst waiting on the transplant list because this is the outcome measure that is most useful.

D O'D. I am sure it could be collected. There must be data on people removed from the transplant list but it would be approximate

Evan Harris. Is there an initiative to do this?

D. O'D. Sure UK Transplant would be able to provide that list but do not know whether it would be mortality on the list.

G Nicholas. It is on record that a lot of relatives are refusing permission for their loved ones organs to be donated. What is being done about this?

D. O'D The Organ Donor Task Force are investigating all aspects of organ donation. The results of their findings will be published in September. There has been action over the last 10 years but complete success has not been achieved. Cadaveric donor rates are low.

Janet Dean. How much is poor availability of holiday dialysis in this country related to capacity and how much to organisation?

D. O'D. Although it is important to be aware of cultural issues, the problem is a capacity issue. We cannot offer spaces for dialysis. Peritoneal dialysis patients are able to travel more freely but haemodialysis patients who travel away from base find it very difficult.

Dr Winearls. When is the NSF to be mandated? 18 week waits for vascular access is unacceptable.

Some of the things do not seem to be a priority.

D. O'D. I do not think we will see a number of things happening in the near future. We have to influence the local system of administration to look at quality issues and give a higher priority to them. 18 weeks for access is too long to wait. Some people are called in to hospital to sit in a bed to wait for 2 to 3 months whilst a dialysis slot becomes available.

Evan Harris. Hopes it will be identified how we could make best use of what is out there.

2. Overall dialysis capacity.

Evan Harris. Do clinicians believe that the current capacity is sufficient to meet the need without rationing?

C Winearls. No, we are constantly on red light full and we have to urge people to have peritoneal dialysis. We can never run the unit as planned. We do everything in reverse.

Jonathan Kwan. Managing dialysis is always crisis management. The problem is the way you determine capacity is how much capacity you have in the system. There is a dichotomy where capacity is limited by capital investment.

Prof Mathieson. It is everyone's experience that there is not adequate capacity. There is regional variation where capacity is not so serious in some parts as others. It is impossible to provide holiday dialysis without spare capacity.

Paul Jennings, West Midlands. We do not have the pressures described. We have variation across regions but some have more pressures than others. Through good planning on the need for dialysis it is possible for organisations to prepare themselves for increased capacity. We have prepared a model. There is no excuse for not having sufficient capacity in the region.

Gordon Nicholas. Following a failed transplant I have recently returned to dialysis and was appalled at the conditions on the main unit. It is not fit for purpose. It was built for 12 patients but now there are 21. It makes it worse because main units are not being funded.

Evan Harris. How does the DOH measure capacity - directly or indirectly? If there is a need for refurbishment money how is this capital funding accessed if this has been closed down?

D. O'D. There are parts of the country where people feel they have reasonable amounts of capacity, so it is possible to plan and get capacity right. DOH have outlined national capacity planning requirements within the NSF. It is for the local SHAs to manage local networks to prepare a local capacity plan because there are regional variations. For instance, the age profile should be the major driver in cities such as Birmingham which have a high ethnic population.

When the DOH wrote in November last year asking SHAs to provide capacity plans to 2013 the replies were patchy. It is important now Specialist Commissioners are in place to ask again for plans to 2013. Some are quite advanced and if only in progress we need to facilitate proper planning at SHA level. Regarding units which need refurbishment - Trusts have a responsibility to maintain units to a certain standard and they should put plans in place and money is in the system for this.

Evan Harris. How does DOH measure the number of people going on pre ESRF. Is there a direct measure of where there is capacity to meet the need now.

D. O'D. We do not have real time but we do have historic information from the Renal Registry but it is 15 months out of date. It is down to PCT level. It is obvious if you have a quarter of people on dialysis there is a problem in the area. The information the Registry has is extremely important to Commissioners and the Renal Registry have a new initiative to provide information which is accessible to patients. This information needs to be examined more.

Paul Stevens. It does not matter how good planning is. If you are doing 'catch up' as well as expand you are in trouble. They have a huge distance to come, despite planning they still have the same crisis. It destabilises the local Health Authority because of the revenue they take. How to catch up is dependant on the energy of the local unit to sort out problems and some do not have the energy. There is something needed to get motivation.

J Kwan. Capacity is more complex. Some units run two shifts and others four shifts and some have minimal care. One measure is the number of dialysis stations per million population but that is a crude measurement. What is needed is repeated growth of dialysis capacity. There was an undertaking in the NSF to expand to 500 stations but at the same time you have to address some of the capital investment problems which have to be designed to cater for this. So you would expect an expansion of 500 stations because at the end of the day it still gives the same cost if you enter into negotiations with providers. Funding in the end depends on therapy price allowed in capital investment and whether they are able to fund.

CEO Primary Care Chair. What we will see are a lot of issues that PCTs and Commissioners need to drive. Commissioners are being driven rather than driving. Commissioners need to set standards to drive.

Jenny Scott. Commissioners. The key thing is engagement with Commissioners. If they understand the issues they can work forward to address them. Patients, clinicians and Commissioners should work together to move forward. It is easily planned if people understand the issues and work together on this. Try to support Commissioners to understand the issues. The Renal Registry need to make their data accessible to Commissioners to enable them to understand the top 10 things they need to achieve. Commissioners are responsible for providing health services for the area they serve so it is their responsibility to address this.

Alan Watson, Nottingham. Wants to make the point that paediatrics have to dialyse children. Renal Paediatrics are organised into 12 units throughout the country and the biggest problem is that none of the Specialist Commissioners know what they are doing because they cross boundaries. Commissioners do not understand what they want. It needs to be done at a different level as when we need to transfer patients to adult units they say they have no capacity.

Commissioner. If Commissioners do not work in terms of a delivering quality and trying to work with Health Authorities then they should.

K Watson, Baxter. Where do Commissioners see the role of home based service therapies in this?

Roger Greenwood. Most capital allocation was stopped in 2006 but we need to keep units up to date and have a true mix of private and public. There is a huge priority on capital money. How can you access capital funds?

Commissioner. PCTs do not have a capital allocation. So you have to access capital through the Trust or through public/private partnership.

Home therapies Oxford. Home dialysis used to be popular but the majority of patients do not want home dialysis. There is a capital problem there too in that you have to buy a machine and modify a house and capital funding is not there.

Commissioner. We want patients to have choice. We set planning around choice. We think patients would want choice and we set things in place to offer people that choice.

Tim Statham, NKF. From the patient perspective it does matter. They want choice of Peritoneal dialysis, APD, Haemodialysis and home haemodialysis The choice is not there. They are told what they will have because of what is available locally.

Commissioner. You cannot have choice if you do not have facilities.

Edwina Brown, W London Hospital. There is capacity for PD. The Issue is that patients are not educated on the choice and the need to be trained. Old people may not be able to do it. In France home therapy has been regarded as the correct treatment for older people and it is possible for PD to be offered to patients over 70 years of age because they have community workers who give treatment at home.

Tim Statham, NKF. What are the financial restrictions to units of offering home treatment? What are the down sides?

C Winearls. So long as the treatment is right we can offer everything in Oxford but if everyone wanted home haemodialysis this could not be done because the capital is capped.

Gordon Nicholas. Choice cannot be offered because there are problems getting PCTs to fund home haemodialysis.

Tim Statham. Is there anyone who does not supply one of these choices because of financial reasons? No answer.

Pearl Pai. Commissioners do an excellent job but we still have capacity problems. We try to offer the whole range of options but Assisted Automated Peritoneal Dialysis (AAPD) is too expensive to offer to patients because it will be one treatment everyone will want in the future and I am not sure where the money will come from.

R Greenwood. You have to have good Commissioners. Home HD requires personal effort to build up nurses commitment but Commissioners do not want to spend money on training. We should think about AAPD because it is more cost effective than centred PD. We should do a business plan to include training. We can still be holistic. We should be optimistic. We have become lazy and have to invest in staff and put people on AAPD. We need investment also so the business plan stacks up.

Tim Statham. Can we consider the number of dialysis sessions on offer to patients? Are there many units offering less than the required number of sessions? Are outcomes suffering with two sessions being given instead of three?

C Winearls. If you do not have the capacity you have to dialyse twice instead of three times a week. This is usually for people starting dialysis, but if there is no capacity they will stay on twice instead of three times.

D.O'D. This is a patient safety issue. If a patient is put on twice weekly dialysis they become

accustomed to it and do not want to go on to three times a week dialysis. He does not know whether the patients have been told it is a more dangerous option. Good outcomes are about having good discussions beforehand.

J Kwan. AAPD is too expensive. We are the first unit to offer this treatment. If you take transport costs into consideration you can use this cost to offset the cost of AAPD. Transport costs should be taken into account.

Tim Statham. Who has got an ineffective solution to offer?

J Kwan. The closer to home units are situated the better as this means less transport costs. There should be more satellite units and more patients dialysing in them than in the main centre. This would give a transportation requirement of 10% to 16% whereas in-centre it would be 85%. This should be taken into consideration.

Evan Harris. I would like to know how the DOH monitor Commissioning because it has been a big complaint area for over 10 years.

D.O'D. I have not seen any data in the DOH that monitors this situation. It is back to a capacity issue. If there is a capacity problem it is impossible for units to offer places for people to dialyse away from the home unit.

C Winearls. DOH issued guidance. Units should try to provide places and it should be charged at the price the providing unit charge the local Commissioners. The current position is that the price charged is £ 350+ but this is not according to the DOH guidelines and the sending unit pay this. If units gave patients more than 2 weeks per year they would have to pay these very high prices and we do not have funding.

Evan Harris. Is there a compensatory method?

R Greenwood. I do not think this will be solved by capacity alone. There is no cash incentive. It is the right of patients to travel and this should also apply to dialysis patients. Units should be incentivised for patients on the move and it should be a support tariff for receiving travellers. In terms of PCTs it would not cost that much money. Only a relatively small number want to travel from the home unit and we should look for some incentive system.

D.O'D. It is not just capacity there is a cultural issue also. How we treat patients on dialysis is a fundamental issue. We cannot have a situation where local PCTs are losing money because of holiday dialysis. It is right that this should be incentivised. Patients should be told it is their right, the system should provide it and they should complain if they do not get it.

Evan Harris. Even if given the right some patient will not complain.

D.O'D. I would consider an incentive. We need to examine the tariff system and to get the HD tariff right and then make sure additional funds around this are created as well. Patients should be allowed to travel.

Evan Harris. What would your advice be to a unit who says we want to make stations available for visiting patients but it would mean moving patients to twice weekly. What is the best thing they can do?

D.O'D. We need to expand this question to the people in the room having this discussion. We need to seek alternatives. We need patient representatives and Commissioners to have a joined up approach. To put patients on twice weekly dialysis is terrible because this is a safety issue.

Fiona Loud. I have five years of dialysis experience. Patients in her unit never feel empowered to take their complaint further. I was able to get dialysis in France but cannot get dialysis in the UK.

J Kwan. Summarises issues regarding dialysis away from the home unit.

1. There should be one single price for dialysis across the country. What should be prohibited is for a unit to charge £ 250 rather than £ 150.
2. Capacity issue. When a patient returns to the unit infection control guidance states patients have to be quarantined for 3 months so you have to cater for this.
3. People going to the Indian subcontinent are happy to pay. People going to EEC never a problem because there are no capacity problems.
4. Outside EEC Countries. We have a bursary from the KPA to subsidise travel on a limited basis.

There is a huge cost for patients dialysing in the UK. Units cannot offer it because they cannot afford to pick up the costs.

A Watson. USA provides units where you can dialyse. If you can pay you can dialyse. Costs should be standardised because everyone agrees holiday dialysis is an essential component. We do not have enough social workers for patients to see they need this. In paediatric units we realise patients get burned out and need a break from dialysis units. We have a caravan and holiday home for this purpose. Why don't the DOH fund a couple of dialysis facilities in the UK where patients can choose to get a break. There should be equity of access in UK.

Bob Dunn, NKF. The situation on HHD has a disproportionate affect on low income people because they cannot afford to go abroad for holidays. The Trust does not pay for overseas dialysis - it is an inter-governmental arrangement. There are ways in which holiday HD can be done in this country - in the South West they offer a twilight shift and they don't mind. The costs are ridiculous. There is a big price difference across the country. Units closer to a place patients want to go have higher rates sometimes as high as £ 370.

We have been raising this with Rosie Winterton who has stated units should use the guideline costs but they do not do it. It is a very difficult area. There are units where it is planned. There is a limit on the places where patients want to go. It is something we need to face and find other innovative ways to overcome this. I would like to see everyone getting 4 weeks leave from dialysis a year.

3. **Starting Renal Replacement Therapy.**

Access

Evan Harris. Compared to other countries more patients start dialysis without a proper fistula and this has poor outcomes in terms of complications. What can be done to identify people early enough and then get surgery? Does the 18 week wait have an impact?

C Winearls. One of the problems is that it is done by a different type of surgeon and it involves a different discipline. There have been moves to create a body that takes a principal interest in vascular access and they have formed the Vascular Access Organisation to promote the needs of vascular access and the recognition for this area of surgical activity which has been not been recognised. The Renal Association and the Vascular Access Association have met to discuss how to get recognition

and the need for vascular surgeons

Evan Harris. Is there a tariff for a fistula? Is this set at a proper level?

? There is a tariff set for vascular access but it is not happening because of local variations and disorganisation because it is not identified as an area of expertise.

Paul Stevens: Physicians used to do vascular surgery but it is not straight forward. They cannot create good vascular access because it is complicated and requires training.

C Winearls. There are guidelines in place but they have to be put into action.

G Nicholas. The quicker a patient has a fistula put in the better it is. He had his put in 40 years ago and it is still functioning.

D.O'D. Vascular access remains a big issue. There is cause for some optimism that NHS have highlighted this. One of the five standards is vascular access and the NHS says people should have a fistula created six months before starting dialysis. We have a way of measuring this through the Renal Registry and the data shows variations across the country.

Vascular access one of the three themes in the renal audit. Good vascular access leads to a reduction in bed days, so it becomes self evident that if it is done well it is much cheaper.

We can get MRSA rates down but it is related to other infections with lines etc. so we need improved working practices with surgical colleagues and promoting the report that gives specific guidance in terms of expectations for 75% of patients starting dialysis.

Evan Harris. Do people think there is an issue on early identification? Is there anything else we should say about improving outcomes to prevent patients crash landing on to dialysis?

C Winearls. Education, education, education. It is as much for doctors as anyone else. To stop patients crash landing they need to be picked up early and when their eGFR is good, but there will always be crash landers. It is our job to educate people who have first sight of these people through education and pre-dialysis days in the clinics. When crash landers present to hospital they are given no education.

Edwina Brown, W London Renal Centre. We should give patients choice and put them on PD and then on AAPD and then should have education 2 to 3 weeks after dialysis.

Sue Cox. Since the introduction of eGFR we have had an influx of referrals from Primary Care. Other specialities in Secondary care should refer a lot of people to renal but hang on to them longer than they should and then come to pre-dialysis late. There is a need to educate physicians as well as patients.

? All crash landers should be channelled through the pre-dialysis programme in his clinic. It requires integrated working. Vascular access should not be an isolated procedure. There should be a whole patient pathway and we need to think of the whole package.

Pearl Pai. Where the patient is started is important. We do not have the money to appoint another nurse to take over when one left. We need to make sure there are resources available to ensure radiology support. In North of England they are trying to get resources to enable support nurses to be appointed. We need to get funding for all of this because patients fare better by education.

Evan Harris. Are there any comments on diet, diabetes or anaemia.

C Winearls. Where EPO is concerned GPs used to be asked to prescribe. We managed to get the PCT to appoint EPO nurses and we now prescribe from the unit. It is a fantastic success and has a cost saving of 40%. There is no restriction. We just invoice the PCT and it saved the system £ 600,000.

D.O'D Since the introduction of eGFR 500 people are not being picked up according to hospital records who are correlated to eGFR. It is an issue for people with chronic kidney disease if people are not in the system.

Evan Harris. If you have your own budgets are you rationed?

C Winearls. I recommend Payment By Results.

A Watson. There has been no mention of psycho/social care. No mention of social worker support and counselling. These are essential services as far as children are concerned as well as adults and too much is left on the shoulders of the nurse.

Bob Dunn, NKF. We are working on rates of social worker to patients and we have not yet achieved the 1991 level. Psycho/social aspect of pre-dialysis is incredibly important and absolutely essential. Only 37% of patients have Psycho/social care.

Teresa Howes. Phosphate control. There is evidence that where dieticians are involved with patients there are improved outcomes in the patient pathway, therefore progress needs to be made in allowing dieticians to become supplementary prescribers.

Dieticians have phosphate binders but cannot get hold of new phosphate drugs. There is also a need for a better integrated service between diabetes clinics and the renal team. Currently diabetic patients go to the diabetes clinic and receive separate support from the renal team but there is no communication between the two. Dieticians are trained to give advice in both cases. There is no integration in the two aspects.

Bob Dunn, NKF. It is crucial to agree plans together. We are starting to get patients identified on the Primary Care, Secondary Care and End of Life Care and we need to act together to integrate care pathways.

Teresa Howes. Diabetes - this situation has come about as a result of specialisation of provision. There are many kidney disease patients with diabetes and as dieticians we have a responsibility to make sure there is continuity of these conditions so we involve skills from all areas.

D.O'D. The key is the integration. We need to ask what people need at this stage. Look at how to do it. We need to get dieticians as supplementary prescribers and would support this.

T Howes to write to D.O'D about this. The first standard of Renal NSF says everyone should have an integrated care plan. All patients should have a care plan which is something you can carry and there are good examples of joined up IT which people can emulate but because many patients come to different specialities there is a major issue with a poor quality service offered, which is ultimately more expensive.

Psycho/Social – there is a lot of sharing of knowledge. The Renal Association are working with Diabetes UK on closer working to reduce crash landers.

Ironbinding medicines

D.O'D. West Midlands does have a forum within which discussions can take place.

Evan Harris. Should patients be able to get these treatments if doctors think they need them?

Commissioners. Clinical care pathways should be found first, not the other way around. They start by finding clinical care pathways and then look at funding.

P Mathieson. Because of the link between diabetes and renal disease there is a need to create a forum for joint consultation. Diabetes UK and Kidney Research UK are already working together on research. There is a huge need to integrate. It is being worked on.

J Kwan. The cost of new phosphate binders is a challenge. We need to offset the cost of the high price binder. It has been agreed we are 10 – 15 years behind the EPO argument. They are more costly than they used to be.

Tim Statham. We have heard that there is pressure on GPs to fall back to a phosphate binder like Calcichew which patients regard as an historic treatment as there are now better treatments such as calcimemetics available.

J Kwan. There are some patients who would not benefit from calcimemetics.

P Mathieson. EPO. The marketing companies have provided alternatives and renal units have been successful in getting prices down. All this has contributed to the success of EPO. Cinacalcet is not widely available because NICE ruled on access to it. We are a number of years behind on haemoglobin management and there are cost pressures in prescribing drugs which we think would be beneficial. We contribute to vascular problems by what we can prescribe.

D.O'D. This is an evidence free zone. Phosphate management is much better evidence based but we need to start to investigate through research why some people have such bad vascular disease. We should collect data but continue to do what we think is right. Evidence would give better information on how patients fare.

There may be an issue about whether NHS could consider research.

A Watson. Methods for assessing cardio-function require standardisation. Cardio-vascular trials have excluded people with kidney disease.

Pear Pai. We have conducted a survey about using more expensive drugs but the most important thing is to have a part time psychologist. Patients should be more involved with self care and receive more psychology support. Some patients would benefit from daily dialysis. They would find better quality of life and phosphate control would improve and I would like to get money allocated for patients who would benefit from more dialysis.

Bob Dunn. NKF. A Summit was held in London based on patient choice in renal services at which over 150 patients attended. Most could report in terms of what patients wanted from dialysis. The conclusion was that until dialysis capacity was resolved patients would never have choice.

Patient choice in West London is not alive and well because doctors think haemodialysis is the only option for patients. Patient choice has become worse but if patients could choose 50% would choose HD and 50% PD. There is too much depending on attitudes of doctors who look after patients. From a

commercial point of view, if you build all these units you have to fill them. In the USA you have less patients on PD because they have the units.

Evan Harris. A certain proportion would be on PD if given a free choice, whether this is the case because it is the doctor's preference or not.

D. O'D. Quality of choice is not good in most places despite best efforts. Studies show there are 50% or less on PD but 70% are on HD because PD does not last as long. I would question whether people are getting choice. There are certain geographical issues. There are some units where 5/6% is the figure for those on HHD, some units 10%-12% but NICE say 15%.

Some units are offering daily dialysis and people should talk to them who see what they are doing.

Evan Harris. Who is responsible for bringing units into line? Is it the Commissioners responsibility? Should the DOH be asking what is happening? Are the DOH powerless?

D.O'D. DOH is central to patient choice. The NSF mandated Registry returns because it exposes things. There is a place for Commissioners to pass on difficulties. The country is desperately short of HD capacity which makes it difficult to achieve choice. The need for HD capacity is the foundation stone. We need to have a balanced portfolio of options. We need to be able to offer PD with access to HD and other modalities. In Birmingham 70% need HD and until we have spare capacity I would be concerned at Commissioners delaying a start on dialysis because of capacity constraints. If we had capacity I would be more comfortable.

R Greenwood. You have to be cautious about how you expand dialysis. In private centres you lose choice because PD will diminish. We have to maintain all options and be cautious about excluding six times a week dialysis or PD or those options will disappear. There is too much emphasis on 'we must expand HD'. It also comprises of home HD we must maintain a mixed economy not just use private companies where there is a profit margin.

It is an appalling outcome for those people who never get transplanted and die within 3 years. Some people need to have freedom of choosing dialysis 6 times a week and we need to turn discussion from we need to expand HD. We need to be cautious on how we do this. Lets have Home HD, 6 times a week HD and PD and do not give it all to the private sector.

Evan Harris. As transplant rates continue to be inadequate and the median age of people going on dialysis increases is there evidence of ways of treating patients in a cost effective way, which will improve patient outcomes? If so shouldn't it be available?

Jenny Scott. Expansion of dialysis through the independent sector. What is the proportion of dialysis which we think patients would want and what form of dialysis. We are stressing choice for home HD and training and facilities to be in place, but we are not looking at personal choice for other modalities such as PD or Transplantation. We pay for what we get and the tariff is in line with NHS providers. If patients do not choose to go to a particular facility then the independent sector get paid for patients they treat.

Evan Harris. There is no direct obligation to put patients on the units. There is no indirect pressure to put patients on HD in new independent sector units?

Choice for Commissioners is making sure there is choice in each modality.

Debbie Reece, Fresenius. The perception is that companies have created a golden route, but they are only acting on what patients are getting offered. If there is a contract where patients want PD or home HD we would be prepared to listen and there are places where PD has been included. Companies are reacting to what has been asked for.

Evan Harris. I was under the impression you could not get NHS funding for a new build.

D'O'D. It is an option. I am aware of people coming into local hospital schemes to put in dialysis. This is core NHS PFI NHS. South Yorkshire and Cheshire are good examples and should be looked at to see how they have achieved this.

Ken Tupling, NKF. Elderly patients are being given the option of APD at home because it saves transport costs travelling to hospital and frees up capacity at the same time. If there is a problem during APD they ring the unit and ask to go in to hospital for a further top up session. I am concerned this is discrimination against elderly patients.

Fiona Loud. When a patient goes on dialysis they are very vulnerable and take what the doctor says as gospel so if steered to a particular modality they take this rather than other treatments on offer. Whatever a patient is told is best for them is the option they take but they may have been steered to a particular therapy because there was insufficient HD capacity etc.

Evan Harris. Has there been a survey asking patients if they were asked?

D.O'D. MRI did a survey some years ago which revealed 16% of patients felt choice was inappropriate because of their condition and 20% or less felt they did not have a part in the decision making process. Hopefully it is better now.

Looking at choice of home HD/Hospital HD offering self care, patients want to do some issues of dialysis then expand on that.

Marion Higgins, Home HD patient. I speak to patients at patient information days – usually around 40 new patients on dialysis a month. They are given demonstrations of PD and HD and at the end they have the choice but they are bewildered as to which one to choose. We are concerned about offering choice but some patients are at a vulnerable point and they find it difficult to make the choice.

A Watson. 20% do not have a choice if they crash land. Individual patients are able to absorb information at different rates and consideration should be given to small packages of information being given over a period of time. Choice is sometimes based on non medical factors and to service properly you need to have social support because patients cannot sustain the demand of PD at home without assistance.

J Kwan It is more important to quality assure the dialysis programme and then survey patients to see if they think they have been given choice. If it is still 80%/20% then quality assure further afield and seek their perceptions.

P Pai. The need is to provide more dialysis treatment choice. You would be surprised to find if a vote was taken from nephrologists it would be for home based treatment. If this is a good choice for nephrologists, why not for patients?

Bob Dunn. You should listen to patients if you want patient choice. In the South West we have

listening workshops. Get patients to workshops and listen to what they have to say and that way you get improved patient choice.

4. **Transplant Assessment**

Evan Harris. Is there an issue about transplant assessment? Can we rely on the transplant waiting list as a pointer of transplant demand?

D Duval. In 1992 I received a pancreas/kidney transplant when I was extremely poorly, yet if I was being transplanted now and assessed on the same criteria I would not be offered a transplant. I would like to know why.

Gordon Nicholas. I have just returned to dialysis following a failed transplant thinking I would be put on the transplant waiting list as I am otherwise fit and healthy. My nephrologist has told me I will not be put back on transplant list because I had skin cancer. Why should I be denied another transplant because I have had skin cancer? It is the end of the road for me.

J Kwan. There are nationally agreed entry grounds for entering the transplant programme. There should be national criteria for this.

D.O'D. The criteria should benefit patients. If you look at the Renal Registry data quite a lot of dialysis patients wait six months before being put on the transplant list. Why does it take so long to get people transplant listed and why is there such a large demographical difference? It may be something to do with investigations. It should be discussed with patients. We should listen to patients and provide psycho/social support so that they can make this choice. When approaching ESRF discussion needs to take place. Some clinics transplant 82 year olds and I suspect if we had sufficient organs more people would be listed. It varies up and down the country. There are a lot of factors which are unexplained.

van Harris. Is it reasonable to have a national criteria for listing or a national criteria for not listing that is evidence based. What is preventing this?

D.O'D. It would need to come from professional associations working with patient organisations and if we do a report such as vascular access that we could hand to everyone it would be good.

Tim Statham. I fully support this but think it would be difficult for UK Transplant. They say 400 people die on the transplant list each year. It cannot have been the same over 9 years. In the same years 3000 have died on dialysis. Some would have expected to have been waiting for a transplant. As soon as the figures are rectified it will show a huge increase in the number of people dying whilst waiting for a transplant.

P Mathieson. A drive to expand transplantation is closely supported by the Renal Association for an increase in living donor transplants and changes in the Human Tissue Act and use of non heart beating donors. There are no easy solutions for the gap in the number of people waiting and the number of organs available. There are agreed guidelines for the medical assessment of patients for listing, but they are not mandated or not enforced in terms of medical evidence. If this does not account for delays why are some listed pre-emptively and some not. There is a standard that patients are listed on cadaveric waiting list when they have been dialysed for 6 months but not practiced regionally as there are local variations.

A Watson. The biggest problems are ethical. I think there should be an ethical boundary which is open and transparent within medical reason.

Nephrologist. There should be a NICE guidance which should look at the evidence and make it open and transparent because this is the only way forward.

C Winearls. 5% of people die on dialysis, transplant patients are much lower. The 400 figure on list dying is misleading because people die anyway. Fewer would have died if they had been transplanted. If you have a transplant your chances are much lower if you are listed but do not have a transplant. This is a precious resource and a person transplanted for 10 years saves about £ 500,000. The question of equity comes in as we have to give to the person most likely to benefit. Clinicians should say the transplant should last about 5 years. Less is a waste. What about the patient who is high risk, ie someone who is less likely to survive and gets an offer from a member of their family. What should we do? We have a responsibility to the donor and the guidance for quality of life is over-riding. If we can see the donor is happy for a life expectancy of 2 years post transplant then we should be happy. The information given to people that they should choose transplant is not correct because this is a national resource we should husband it.

Evan Harris. To ask Alan Johnson if he agreed there was rationing and if so if it should be transparent.

J Kwan. South London does have a criteria. Audit once and look at why the patient is not listed.

C Winearls. The process is too slow. We should have a 'one stop shop' and most nephrologists agree.

Evan Harris. Asked D.O'D if he agreed to a proposal to have an audit across the country.

D.O'D. Think we need to spread good practice including an increase in cadaveric transplantation.

R Greenwood. The Patient View system where people can log into a computer to access their treatment results should be expanded. We are now in a position to do this and would expect DOH to give funding to get this started.

Gordon Nicholas. I would like to get my results before dialysis rather than post dialysis. I would like my pre-dialysis results sent to me so I can know what my dialysis requirements are.

R Greenwood. Renal Patient View can pick up results from the electronic patient record in the renal unit so if your results have not been given to you then it is up to your local renal unit.

Fiona Loud. Transport and parking. There is wide variation in standards. Is it a common experience for Trusts to charge dialysis patients to park and even blue badge holders. Is there something the DOH can do to bring Trusts into line.

Bob Dunn. Outlined the only ways to deal with parking costs.

1. Patients to pay, but this could amount to £12-15 per week.
2. KPA help to finance. It is a DOH cost generation scheme
3. Use them but get it free. Exeter now listen to patients and now going to change charges.
4. Patients who drive are recognised as subsidising transport and be paid per mile and get free parking.

This is being implemented in Cheshire & Merseyside. Other units should take the report from Cheshire & Merseyside and relate to their own plans. Gordon Brown said he was going to look into

parking charges.

Evan Harris. Any patients who are suffering difficulties with parking charges should write to their local MP and this will be brought up with the Minister.

Alan Watson. The transition in moving patients from paediatric to adult units is not handled well. Patients are well supported in paediatric units but are neglected in adult units. Paediatric units have to provide support but adult units are a psycho/social desert. It is a culture shock. These are young people who are still finding their way in the world and if they lose their transplant it is devastating. We are doing work on this but we need more help as this is a crucial point for young people. There should be more transition pathways developed.

Bob Dunn. Televisions/telephones. The recent report on this was a whitewash. The Minister claims patients get TVs at half price but this is not happening. This is still a problem for patients and they are still suffering. It is impossible to get meetings with the directors and Patientline.

D.O'D. Transition pathways. When units bring Patient View on line it will be good. It can be achieved and we need to push for this. We need to help with the local areas when there are issues and KPAs should be in discussion on what is provided for patients.

Transport. We need to get the report from Cheshire & Mersey supported by the DOH. Patients should not have to travel for more than 30 minutes. It is a challenging and complex area but there are examples of good practice. An audit system needs to be set up for faster access, transport, management of kidney disease and crash landing. It is about things patients want. Youth workers are fantastic I do not see why we cannot have pathways for young people. We need this type of model. Good work is happening in Birmingham and Gloucester which should produce good results.

Telephones. Being able to use mobile phones is good for patients. Since the Minister agreed it was OK to use mobile phones in hospital more should encourage them to do so.

Bob Dunn. One Trust is being sued because they are breaching the contract which states mobile phones are not allowed.

D,O'D. It is unacceptable and counter productive for people who come for regular haemodialysis to have to pay for parking. The same standard as in Cheshire & Merseyside should be adopted.

Evan Harris. Renal services are currently commissioned as a Specialist Service. There is some question as to whether some aspects of renal services are being taken out of Specialised Commissioning. He asked D.O'D to address this.

D.O'D. It is important to think of the full pathway. If we want to fix dialysis it is important there is sufficient volume of activity so that Commissioning can be uniform. It would be extremely challenging for Practice Based Commissioning. There is a general feeling if Carter is implemented we would be able to build on this. Carter has not been implemented to the same degree in every area.

Evan Harris. I am not enthusiastic for dialysis to be put in PCT commissioning.

D.O'D. Dialysis should not go outside of Specialist Care. A PCT cannot act on their own and in the interests of the population to do this for dialysis.

Commissioner. Look across London – 31 PCTs. We would have 31 PCTs commissioning. There are

5 PCTs in South West London for 1.7 million people. You need to get the right level of PCT. It would be stupid to get this across multiple PCTs. It is far better to have the appropriate expertise - you cannot replicate across all PCTs.

So what about Practice Based Commissioning? The money is within budgets held within individual practices. What is not been worked out is how to integrate commissioning to make sure everything is equal across the population. A practice may only have one or two patients with renal disease.

R Greenwood. I think it is important that renal maintains specialised status and we should have a strong opinion on this. I think we need a view on planning and investment. ESRF should remain a Specialist Service.

Concerned about 10% of CKD people on this. People on dialysis are very vulnerable and should maintain Specialised Service.

Specialist Health Care Alliance – John Murray. This was the subject of debate during the National Definition Set as to whether dialysis should remain a Specialised Renal Service. There was a scoping exercise. The view was that it should be excluded from Specialised Services but there are some strong views which means doubt remains. Part want to ensure that Commissioning Groups should have responsibility but in many cases the thought is that if dialysis remains a Specialised Service commissioning it should be done by PCT which will use Specialised Commissioning Group boundaries more effectively.

Sec SCG. We have been having this debate and there was some split. It is about commissioning and planning of services and if you get planning and commissioning right then as long as you work with local PCTs it could be successful. PCTs like the fact we will do the Commissioning for specialised services but for renal it spans Primary, Secondary and Tertiary care and you need someone to pull this together. What they were trying to get was equality across the country. What it is the population need and who procures what. If we commission renal services the total pathway should be considered. We as Commissioners have responsibility to look at totality.

Amy Potts, Baxter. We need a balanced style of care. It is still a complex area and if taken out of Specialist Services the expertise may be lost.

Barnet Lead in Specialist Commissioners. There are other advantages about not being a Specialist Commissioner – it is about getting the commissioning right. You can have different models to get the care of the patient right.

A Watson. What we want is people who can educate and understand the problems and stay in position long enough to understand the problems.

Alan Johnson said there would be no changes to PCTs for the foreseeable future.

Evan Harris. Asked if there was any merit in putting dialysis or some relatively predictable service considered Specialised into normal commissioning processes and then make sure it is being done properly by putting in an operating framework because it is a must do list for PCTs.

What is the time scale for the decision to be taken on whether some services are being pulled out from Specialised Services?

D.O'D. Does not know this.

We need to look at what is happening with growth of satellite dialysis, local services over and above dialysis which have not been troubled to the same extent and Pre-dialysis care and support for palliative care and getting Payment by Results right. If we do not have good quality care at patient level it is difficult to have the transparency you would want between commissioning and programmes.

Evan Harris. We cannot get into Payment by Results now because of shortage of time.

Thanks were given to Donal O'Donoghue for giving the time to come to the Summit and to NKF for their work.

Meeting closed at 5.00pm.

The National Kidney Federation is registered in England and Wales as a Company limited by guarantee (Company No 5272349) and awarded charitable status (**Charity Number 1106735**).

Give as You Earn contributions No. CAF GY511.

Registered Office:-

The Point
Coach Road
Shireoaks
Worksop
Notts
S81 8BW

Tel: (01909) 544999

Fax: (01909) 481723

Helpline: (0845) 601 02 09

E-mail: nkf@kidney.org.uk

[Top of Page](#)

Page created: 10 September 2008

Last updated: 10 September 2008



This website is intended for UK residents only.

If you have any comments about this site, please EMAIL the [webmaster](#)