

A VIEW OF UK NEPHROLOGY

Based on observations from visits to all UK renal units

May 2004 - May 2007

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INTRODUCTION

When I began my three year term as President of the Renal Association in May 2004, I proposed a plan that I would visit all renal units in the United Kingdom and my proposal was supported by the Executive Committee.

These visits to my mind had a number of goals

- A demonstration by action that the Renal Association was interested in all its members, clinicians or scientists, regardless of the size, style or geographical location of the renal unit in which they work.
- The need to understand the issues facing them in their daily clinical, managerial, research and training lives if I was properly to represent the very broad “constituency” which is the current membership of the Renal Association.
- The wish to compare and contrast the organisation and clinical practice in renal units around the country in order both to facilitate the sharing of ‘good practice’, and also to understand how progress and development in renal units has become so variable across the country.

This was a considerable undertaking and it would also be necessary to justify the cost of a programme of visits against these perceived benefits and to keep that cost to a minimum.

It would have been impossible to undertake these visits, as indeed it would be impossible to fulfil my role as President of the Renal Association, without the support, tolerance and patience of my colleagues in Leicester who have accepted my frequent absences.

Finally let me emphasise that the views expressed in this report are my own personal opinions. The report has been written primarily for the interest and information of members of the Renal Association. These views do not represent any approved policy of the Renal Association.

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March 2007

ARRANGEMENTS FOR THE VISITS

Arrangements were made to visit 71 adult renal units and 13 paediatric renal units in the UK by contacting clinical directors. Visits began in May 2004 and by summer 2006 all but one adult unit, and all but four paediatric units had been visited. The remaining few visits were completed by March 2007. Travel was kept to a minimum: whenever possible I visited groups of units over two or occasionally three days when it was not possible to make the visits as day trips from Leicester.

The initial communication to clinical directors outlined the goals set out above and emphasised the following points.

- I appreciated how busy units are on a day-to-day basis, and I wished to interfere with routine week as little as possible.
- Depending on the size of the unit and their own wishes, I would be happy to spend half a day and preferably most of a day with them.
- I was keen to hear about the unit's successes and achievements and also about its perceived challenges and frustrations.
- I would like to meet all medical staff including consultants, non-consultant career grades, and trainees singly or in groups.
- I would like to meet senior nursing staff and other key members of the multiprofessional clinical team
- I would like to meet research staff within the renal unit, and where appropriate collaborators beyond the units
- I would like to meet managerial staff within the unit, and if it was deemed appropriate would offer to meet senior Trust managers.
- I was happy to give a talk about the Renal Association and the role it is playing in the modern NHS if that was felt appropriate

STYLE AND CONTENT OF REPORT

The notes I have kept from my visits have enabled me to recall a detailed, and probably unique, picture of life and work in renal units in the UK. I will not in this report document or tabulate in detail the achievements and difficulties of individual named renal units. Comparisons are complex and invidious since they depend on a range of local and regional circumstances. In my view such tabulations invite over-simplification and false credit and discredit.

Nor in this report will I duplicate information about the demographics and performance of renal units, particularly with regard to renal replacement therapy. These data are of course freely available from the UK Renal Registry and UK Transplant, for all but the very small minority of units not yet returning data to the Registry.

Rather I have decided to make general observations over a wide range of renal unit activities, but will gladly provide any renal unit clinical director with additional information including specific comparisons to other units if it is so wished.

Because of the distinctive cultural and organisational features, I have commented separately on adult and paediatric units

My report inevitably is commenting on an evolving situation. As I write the report, well over two years have elapsed since some of my visits. New consultant staff have been appointed, satellite units and other major clinical facilities have opened, and the impact of the NSF in England continues to be felt.

I am also pleased that some of the key issues which emerge in this visit report have already been addressed by the Renal Association either alone or in partnership with other organisations in a number of working party reports and surveys which are either published or in preparation. These include:

- Vascular access – through the Renal Association/Kidney Research UK Vascular Access Survey 2005, and the Renal Association/Vascular Society/British Society for Interventional Radiology Working Party Report 2006.
- Peritoneal dialysis access – through a Renal Association Working Party commissioned in December 2006.
- Medical workforce development – through the Renal Association/Royal College of Physicians of London Working Party on ‘The Future of Renal Medicine in the UK’ published in March 2007.
- Inequity of access to kidney transplantation - through the Renal Association/ British Transplantation Society transplantation questionnaire to units planned for 2007

GENERAL OBSERVATIONS ON THE VISITS

The responses from Renal Association members before, during and after the visits suggested that the goals I had set for myself had merit, and the visits were well appreciated. If anything that appreciation was more markedly expressed in those units more geographically remote from middle England, and in smaller units away from major academic and transplant centres. In such units, it did indeed seem that there was sometimes uncertainty about the interest of the Renal Association in their affairs.

Hosts were unfailingly generous with their time and hospitality. I typically spent half a day in a unit, often a whole day in larger units. A number of colleagues put me up in their own homes, and I was able to enjoy a wide range of food and beverage in many settings. I learned much about the comparative quality of NHS sandwiches, although nobody could beat the buffet lunch provided in one unit from a local Italian restaurant.

I also learnt much about public transport in the UK, especially the rail network, and endured that remarkable alloy of excellent, indifferent and absurd which is the lot of the rail traveller in this country.

In many places I gave a talk about the Renal Association and particularly its current role in NHS service development. These talks were attended by large numbers of medical, nursing, and management staff, and provoked good discussion. Often people seemed encouraged and surprised at the extent of Renal Association involvement in the most topical issues.

Overall my visits confirmed the prejudice I have held for a long time that the United Kingdom has “renal services it does not deserve”. Despite facilities and staffing which have often been woefully inadequate over many years, UK renal units have provided a clinical service of remarkably high quality which by its coherence, integration and continuity of care is still the envy of much of the world. I attribute this to the very high quality leadership and commitment

of senior medical and nursing staff. There is still a real passion for the work and a deep-seated culture of philanthropy toward people with kidney disease which we should not underestimate, and which we lose at our peril.

These observations do not dilute the significance of the persisting shortage of physical and human resources in many of our units, although we do seem to be in a period of very significant growth, particularly in consultant numbers and haemodialysis facilities. Both of these are however long overdue and unless sustained will not enable us to make up lost ground. But I did find real optimism that step changes were being achieved in a number of units which could have a real impact on both quantity and quality of care.

It is of course important to note that my visits have also traversed a period of time characterised by substantial new investment in the NHS, the positive impact of the National Service Framework for Renal Services in England, and now the fragile uncertainty of NHS funding in late 2006 onwards. And all of this laced with a heady mixture of perpetual reorganisational uncertainty. These fluctuations inevitably mean that our progress is still fragile.

DEFINITIONS

For the purposes of this report I am using the following terms in the following way.

Renal Unit - a unit based in an acute hospital with inpatient beds, consultant nephrologists, and a multiprofessional clinical team. A renal unit has an outpatient haemodialysis facility on its own site and runs a CAPD programme. Most renal units are also responsible for the care of haemodialysis patients dialysing in one or more satellite units remote from the main unit site. Many renal units also run consultant-led nephrology clinics in smaller acute hospitals or community hospitals remote from the main unit site, often where a satellite unit is sited. Most renal units also now undertake the continuing care of transplant patients.

Satellite unit - a haemodialysis facility only offering maintenance outpatient haemodialysis on a site geographically separate from the main renal unit. Occasionally a satellite unit is on the main renal unit hospital site although geographically remote within the site from inpatient facilities; more commonly it is on another acute hospital site, attached to a community healthcare facility, or free standing. Satellite units are built and run by the NHS or by the private sector; all patients in satellite units continue to be under the direct care of a supervising consultant.

Renal and Transplant unit – a renal unit on the same site as a surgical service supporting renal transplantation, sometimes also with pancreas and liver transplantation.

Commissioning - the process by which the NHS agrees to provide capital and revenue to build, staff and run renal units. In using this term generically I recognise that not all parts of the UK use the term 'commissioner' in this specific sense, or have quite the same organisational structures for these key processes.

Acute Kidney Injury [AKI]

This clinical challenge has been known to most of us for as long as we can recall as acute renal failure [ARF]. Since the term AKI is rapidly gaining ground nationally and internationally and seems destined to be ubiquitous, I have taught myself to use it here.

GEOGRAPHY

Catchment populations served by renal units are very variable, in most cases appropriately reflecting geography and demographics.

There are 13 renal units in the UK with a catchment population of 350,000 or less, and three with a catchment population of 250,000 or less. Nine of those 13 units are in Scotland, Wales and Northern Ireland. Despite recent expansion in consultant numbers, six of those units still have only one or two consultant nephrologists.

By contrast there are 4 units, all in England, with a catchment population for nephrology in excess of two million. Catchment populations for transplantation are of course all considerably larger, between two and four million.

The evolution of renal units has been very variable in different parts of the country. The 'hub and spoke' model was the norm until about 10 years ago, the spokes typically consisting of district hospitals with a satellite dialysis unit supervised by consultants based at the main renal unit. In some parts of the UK this has offered the basis for a natural evolution to the establishment of renal units in hospitals which began by hosting satellite units, with the stepwise establishment of a full renal unit service. Such units gradually developed the critical mass to become independent of the 'mother' unit in providing nephrology services, although still part of a network for transplantation. Even when such evolution is the goal it is striking how variable is the rate at which these steps have been achieved, despite energetic engagement by local nephrologists. There are however few parts of the country where there is still a sense that further renal units needed to be established. The population covered and the need for a critical mass of staff and all relevant infrastructure, both suggest that existing renal units should be developed further rather than new renal units be established. In general the main pressure is on the establishment of sufficient satellite HD units, and of proper resources in main units, especially beds and medical and non-medical staff, as I will discuss later.

There are regrettably a couple of exceptions. There are at least two regions of England where planning failure has led to considerable "black holes" of inadequate coverage of renal services. Patients still travel inordinate distances. One district hospital which should undoubtedly support a renal unit has never been allowed to develop one. Even satellite HD facilities have not been available. In each case clinical directors and other leaders within the main renal units overseeing these areas are clear about the correct solution, and have repeatedly supplied the underpinning information necessary to make the case, backed up by external expert advice. But planning and commissioning failures have been sequential and additive. It is a matter of surprise and interest that combination of commissioning, the renal unit voice, and the patient voice has not yet had success in those areas. Local issues are complex and inevitably there are vested interests and alternative priorities so I will not discuss the details of these situations in this report. They are however manifestations of the failure of specialised commissioning in this country.

DIALYSIS

I will not repeat the detailed demographic and programme information available from the UK Renal Registry, but will make some observations.

Haemodialysis versus Peritoneal Dialysis

There is virtual universal agreement that PD was an over-used modality in much of the UK throughout the 1980s and 1990s. In many units the wide use of PD became a mechanism to assure treatment for people in the face of significant limitations in hospital and satellite HD facilities. In most places PD programmes have gradually shrunk and numbers have typically reached a plateau or continued to fall very slowly over the last five years. However opinion still varies significantly among nephrologists and nurses about the optimum size of a PD programme. The mainstream opinion is that about 20-25% of dialysis patients would appropriately be on some form of PD, and these patients would usually be early in their dialysis career, when there is still worthwhile residual renal function. However units which assured me they provided free choice of dialysis modality nevertheless had PD programmes varying between 5% and 30% of the total dialysis population. I have no doubt that this reflects the specific opinion of unit leaders, both nephrologists and nurses, and I was struck in the number of places that forceful leadership can maintain and increase the size of a PD programme, as well as restrict it. The great majority of pre-dialysis preparation and counselling in our units is led by senior nurses; in conversation with them I was typically assured that the patient was given absolutely free choice and neutral information, although I formed a clear view that this is not the case and that like it or not patient 'choice' is heavily modified by professional advice.

At one extreme there do still appear to be a small number of renal unit leaders who are close to sharing the view (to paraphrase the famous critique of Stanley Shaldon) that PD is 'a second rate treatment for second rate patients prescribed by second rate doctors'. However such opinions are in a very small minority.

Peritoneal Dialysis

Peritoneal Dialysis Techniques

Automated PD is gradually expanding and is the majority modality in many units. In some units patient choice drives treatment allocation. In others there is a restriction reflecting the way the PD contract has been negotiated.

Opportunities to use more expensive PD fluids, for example icodextrin and bicarbonate-based fluids, are also variable according to negotiated contracts. Considering there are only two PD suppliers in the UK, Baxter and Fresenius, and given the relative uniformity of needs of UK PD patients, it is curious to me how varied are the negotiated contracts. Clinical directors were typically satisfied that they had negotiated a 'good deal', but such local 'good deals' do seem to offer patients remarkable variation in access to the techniques of PD which many regard as the norm of modern treatment. Clinical directors and business managers also seem to spend substantial energies on contract negotiations, which might be reduced by a more interactive approach.

I have not had the opportunity to ask the suppliers their perception of these variations in contract.

PD continues to be offered as a self-care home-based therapy. In most units relatives are actively discouraged from becoming involved in the dialysis because of the time intensive burden this may impose on them if they become the primary dialysis deliver. Some units offer family-delivered care as a last resort.

Assisted PD in the home supported by helpers other than relatives is gaining some interest but it is too early to comment in its acceptability and cost-effectiveness.

PD delivered by nursing home carers has assumed an increasing role for older frailer PD patients. Units appear to struggle to make this an efficient approach. Often staff in one nursing home are trained to care for a patient for only a few months, and then the skills

atrophy. A number of units discussed with me proposals to identify a small number of nursing homes which could provide PD in a more sustained way to several patients, thus maximising return on training. Some PD teams seemed to me to have an unnecessarily conservative approach to PD training for carers in nursing homes, for example wanting to train only staff with nursing qualifications.

Peritoneal Dialysis Training

PD training facilities in renal units vary from windowless broom cupboards to pleasant airy rooms in appropriate clinical areas. Only in the very largest PD programmes are these rooms in full time use and they typically double or treble as day case units, clinical investigation rooms and so on. Many smaller units use commercially provided training schemes, which are in general viewed very positively.

Peritoneal Dialysis Programme Staffing

Pragmatic approaches are taken to optimal staff support for PD programmes. Most units recognise the merits of visiting people at home to understand their personal challenges in self-care for PD. But smaller more remote units must temper that advantage against the risk that inordinate amounts of expert professional time are lost in travelling.

Haemodialysis

Haemodialysis Facilities

The most measurable currency of sufficiency of physical resource in renal units is the number of haemodialysis stations available and their location with regard to patient population distribution. In most parts of the UK the situation remains one of "crisis management". It is typical that all haemodialysis facilities will be full and that makeshift strategies such as turning inpatient beds into outpatient haemodialysis stations, or renting portacabins in car parks, are needed before the next satellite unit is opened.

While all new units are built to the recent NHS Building Notes for Dialysis Units, thus ensuring adequacy of plant, there is still remarkable variation in the physical detail of such new builds. Practical planning can make it difficult to find an ideal site within a large hospital, so that adjacencies are less than ideal. A number of PFIs have new renal units but it has proved difficult to achieve ideal solutions in the context of big builds. For example I found it disappointing that a number of new units do not have outpatients HD units on the ground floor with immediate access to cars and ambulances.

Some new buildings are very well designed not only in core facilities. I saw attractive glass atria, large entrance lobbies, landscaped views - but only in a few places, not in most. Such variations are surprising when there is assumed to be tight control of NHS capital spending

There are important variations in planning assumptions in different areas. Most renal units are currently dialysing three shifts a day, but many report difficulty filling the 'twilight' shift, since only a minority of patients are willing to accept that shift or are deemed suitable to go home as late as 11pm even if transport can be reliably be offered. The changing demographics of those receiving unit or satellite HD mean there are very few working patients of the sort for whom evening [or the former night] shifts were originally intended as a positive social step. One unit in the UK was still dialysing 4 shifts a day in 2006 while awaiting the completion of a new build, creating almost intolerable pressure on patients and staff alike.

Typically satellite units are planned on the basis of two shifts a day. Some units have succeeded in having capacity for main units also planned on the basis of two shifts a day allowing the third shift to provide the necessary flexibility to optimise care. Others regrettably have been unable to resist pressure from commissioners to 'sweat assets' [both physical and human] by expecting three full shifts a day throughout. This is a false economy.

Haemodialysis or Haemodiafiltration?

I found a very wide range of opinion about the relative merits of different extracorporeal therapies for maintenance RRT, especially the relative virtues of HD and haemodiafiltration [HDF]. I am sure this reflects the paucity of substantial evidence in this area; allowing opinion and dogma considerable freedom. Simplified, I heard three views:

- On one hand there are clinical directors who see no proven benefit for HDF and therefore regard HD as the correct treatment for almost all patients.
- Others believe it is clinically useful for a minority of patients - criteria were very variable, sometimes patients with cardiovascular instability, sometimes younger 'untransplantable' patients.
- There are also some who are certain HDF is the right treatment for all and only resources deny them this right.

In many areas the increase in HDF is being driven by commercial satellite unit contracts which budget for a certain proportion of patients to receive HDF. Some sceptics were cynical about this development seeing it merely as a commercial move to sell more expensive machines and consumables.

Predicting and Planning Growth of HD

Predicting approximate growth rates for dialysis programmes remains an inexact science which is nevertheless helpful for renal units and commissioners. Given its inexactitude, it is perhaps surprising that there has not been national acceptance of a single modelling programme, and I suggest that 'wheel reinvention' has continued too long in this area. Regrettably over the last decade modelling has only served to emphasise that any proposed date when 'steady state' in the number requiring dialysis will be achieved continues to recede. Occasional surges in local transplantation rates, for example with the impact of the recent changes in UKT allocation criteria or a sudden expansion in live donation, can temporarily relieve pressure.

Predicted growth rates are more commonly exceeded, and new satellite units, more rapidly filled than predicted. This typically follows the opening of a new unit geographically remote from the main unit which in several instances has led to the identification of substantial numbers of those with ESRD not previously referred.

As a consequence of these many factors, only in a very few places in the UK has proper planning and commissioning been achieved - in such a system haemodialysis stations will be open before, not after they are needed (see below Regional Variations and Commissioning Arrangements).

Home Haemodialysis

Home HD remains the appropriate modality for a minority of patients and the size of the minority offered home HD has shrunk over the last decade. This is in response to a number of appropriate clinical factors including the rise of pre-emptive live donor transplantation in young fit people who would typically have been suitable for home HD, and the growth in satellite units increasing the opportunity to dialyse close to home without the need to commit to home HD. Most, but not all units, actively promote home HD as a modality, but increasingly training arrangements are localised to one unit in a large network, or provided commercially. Some units have not even offered home HD, justifying this on the basis that the particular demographics of their unit mean that such a small minority of patients are suitable for home HD that it no longer becomes a cost-effective opportunity. I doubt this is correct.

Frequent or daily HD is yet to make its mark, and there is no clarity about how the additional consumable costs will be resourced against the traditional thrice-weekly HD model. Many commissioners have specifically chosen not to fund home HD, or only to fund a very small number of patients, or only to fund thrice weekly consumable costs.

Some units have made the expansion of home haemodialysis a conscious priority. A training facility has been designated within the renal unit, consultant and nurse leads have been identified as champions, and this modality has been made a very positive part of pre-dialysis education programmes. However even with such commitment the results are still remarkably variable; units with this approach have a proportion of dialysis patients on home HD varying from 3-12%, median ~5%. This appears to be driven by patient choice; units typically report little success in promoting home HD among those well established on centre or satellite unit dialysis. Home HD as first modality at the beginning of RRT is a more fruitful area of development. Units vary in their view about the necessary staffing infrastructure to support a home HD programme. It is increasingly common that nursing support is wrapped up within a home care team providing support for PD patients and un-dialysed patients within the community. Technician support is undoubtedly cost ineffective with very small home HD programmes, but collaborative arrangements with adjacent units should be possible.

There is little evidence that “patient choice” is driving a demand for home HD to anything close to the unevidenced 15% of patients on RRT proposed by NICE, although one unit in 2007 has 12%. However the numerical information is often confused by variously expressing home HD as a denominator of all RRT patients, or all dialysis patients, or all HD patients. In response to the NICE home HD guidance, a number of units have surveyed their established haemodialysis populations and found very few patients who wished to move to home HD and were suitable for it. This includes some parts of the country which might have been characterised as “fertile” home HD territory – i.e. rural and semi-rural areas with favourable socio-economic demographics - where there was clear evidence that patient choice still favoured unit-based treatment, despite the need for significant regular travelling to a dialysis facility. The apparent paradox between this view against home HD and the undoubted truth that transport is the commonest dissatisfaction of the HD patient, is I suspect explained by the fact that many who could do home HD are also fit enough to drive to the unit, and economically secure enough to be able so to do, thus being protected from the frustrations of hospital transport.

Satellite HD Units

There still remains uncertainty about the definition of a satellite HD unit, but for my purposes I am taking it to mean a maintenance HD facility on a site remote from the renal unit’s inpatient beds, either away from a hospital, or on a hospital site which has no nephrology inpatient beds. The steady growth in satellite HD in the 1980’s and 1990’s has been followed by a more rapid expansion over the last few years, at least in part in response to the NHS capital made available around the time of the publication of Part 1 of the NSF for Renal Services in England. Tendering for such units has typically invoked bids both from the private sector and the NHS, and successful bids have been distributed between those two types of providers. It is clear there is to be no further NHS capital of this kind for satellite HD units in the foreseeable future. The optimistic view is that the emerging independent sector treatment centre (ISTC) programmes and the opportunities for NHS Foundation Trusts to generate capital by other means will allow us to maintain growth, but this is untested territory and a time of real uncertainty for clinical directors.

Expansion of satellite HD

In some places the siting of a satellite unit has undoubtedly provided the springboard to the establishment of a full renal unit in that hospital. The need to improve patient care by minimising travel becomes increasingly obvious when patients dialysing at satellite units have an acute complication requiring an inpatient stay and may have to travel an hour or two to the renal unit to be admitted. On the other hand I saw clear examples of the reverse with Trusts recognising from the siting of a satellite unit the likely scale of infrastructure, cost and support needed if a full renal unit were developed, and taking the view that they are very pleased that someone else will provide the service even if the geography and travel are inappropriate.

Models of care in satellite HD

While the principles of care in satellite units are clear, the practicalities of this are remarkably varied, particularly the ability of units to provide consultant-led care. Some satellite units are visited by a consultant weekly, some monthly, some rarely. Some units rely on remote support by phone and email for a largely nurse-led service. The opportunity for a patient in a satellite unit to see a nephrologist often contrasts sharply with opportunities available for a maintenance dialysis patient in the main renal unit. Both extremes may be inappropriate – i.e. the main renal unit patient may not need to see a doctor, but somehow it happens because there is someone on site; on the other hand even very experienced nurses in satellite units may not always be sufficiently supported. A key determinant here is adequate IT which I discuss further below.

A number of clinical directors expressed concern to me that the quality of service provided by their private provider in satellite HD units is deteriorating, increasingly stripped of any elements which might be described as the ‘softer’ side of the quality agenda, things which are noticeable to patients.

There is considerable concern that the relentless move towards a monopoly provider for satellite HD in the UK carries the risk that these trends will continue, and that the provider will ‘lose its edge’ with a reduction in standards.

Independent Sector Treatment Centres

The time period covered by my visits has seen the emergence of ISTCs as a model for expansion of HD facilities in England. The three units in the first phase of ISTCs were all able to demonstrate to me the major benefits to their service which they were confident ISTCs would provide by a predictable expansion of HD stations in parallel with demand. They were also able, within the limitations of confidentiality, to reassure me that they had taken the most rigorous approach to the governance and financial issues which have concerned many outside observers. At the time of writing contracts for the first phase of ISTCs have been awarded and a second phase is now being considered. The disquiet about this development is beyond the scope of this report. However if governance is secure and core renal unit facilities are neither organisationally nor financially challenged, then it seems inevitable that ISTCs will play a major role in our attempts to expand HD facilities in this country.

Nursing Home HD

The unrelenting increase in the number of older people receiving HD had led to growing interest in the notion of units identifying local nursing homes to which a small HD facility might be attached. The capital cost compared to nursing home delivered PD may prove prohibitive in times of cost constraint, but this deserves consideration as a treatment quality issue.

Transport for HD

This remains the single largest concern of HD patients. It has been the subject of recent DH Learning Sets whose reports provide templates for significant improvements in this vexing problem.

I shall therefore not comment in details except to say that few units had convincing solutions, but those who did had crucially gained control of transport within their own budget and management; local arrangements with ambulance services having uniformly failed to deliver an acceptable service.

It is however a major concern that some Trusts insist on offering hospital transport for dialysis patients on a basis no different to that offered to other outpatients; as though thrice weekly lifelong visits to hospital for dialysis could be compared to intermittent attendances to outpatient clinics. These approaches are consigning some dialysis patients to self-funded public transport. This is unacceptable.

Non-dialysis management of advanced CKD

This “movement” is rapidly gaining ground. There is strong conviction in renal units that there are substantial numbers of patients (typically older people) with stage 5 CKD who are optimally managed without dialysis. Some of these in earlier years might have received dialysis. Others did not but were followed by nephrologists, or by other specialists. In a rapidly emerging field this offers a number of challenges

- Terminology is still undefined and units use a variety of terms including palliative care, non-dialysis care, and conservative care; inevitably this creates some confusion for staff, patients, and commissioners.
- The cost of managing such patients is high including frequent clinic attendances, home visits, and high cost drugs such as EPO. Specific funding streams have not been identified.
- It is a form of clinical care still almost devoid of robust evidence
- The development of this model of care requires interactions with other services with which renal units have not previously worked closely, particularly palliative care services. These services although charged by government directives to expand beyond cancer care to non-clinical palliative care are very variable in the resources they can commit to working with renal units, and rate of development of services is very variable.
- Clinical leadership for these programmes varies from unit to unit, and in some is predominantly nurse led.
- The incorporation of non-dialysis care into counselling for patients with stage 4 and 5 CKD is creating additional challenges to the expectation that such counselling will provide bias-free information allowing patients unfamiliar with kidney disease to make informed choice. This is an area which challenges conventional audit and research approaches but where we may have much to learn about the provision of information, its transmission and receipt. I was disconcerted at the confidence which some staff appeared to show that decisions made by patients they had counselled were correct, independent and free from professional or inappropriate family influence.

Factors influencing take on rates for RRT

Registry data shows significant variations across the UK explicable in great part by differences in age and ethnicity of catchment populations. However the overall trend is that take on rate is stabilising in the UK at little more than 120-130 PMP. The statistic is typically used to fuel the view that we are significantly under-resourced for haemodialysis and that if *additional* stations opened up the take on rate would grow again and begin to match those seen in other parts of western Europe (if not the United States). Conflicting evidence relevant to this was put to me in many units:

- There has been a fairly stable take on rate for dialysis over the last five years despite increasing numbers of satellite stations
- Many clinicians have the view that non-dialysis care of stage 5 CKD has been under used, and that a significant number of patients who have started renal replacement therapy (particularly older people) have not been well served by that approach.
- The recent introduction of eGFR confirms that many older people with stage 4 and 5 CKD have not previously be identified to renal units, and growing experience dictates that the judgment of our clinical teams is that many of those individuals are not

suitable for renal replacement therapy, which argues against the view that our take on rate is being restrained.

- On the other hand there is experience in a number of localities that a new satellite unit is filled more rapidly than careful demand modelling predicted, implying false restraint of demand by geographical inconvenience.

There is however no support for the view that removal of all financial and planning restraints will take the UK close to the remarkable incidence rates of ESRD seen in countries with very high prevalence of type 2 diabetes such as Germany or the United States.

TRANSPLANTATION

Significant changes in the clinical practice of renal transplantation over the last decade are having a major impact on renal units. In general renal units report satisfaction with transplantation services and appreciate the close clinical interaction with transplant surgical teams. The overall quality of service provided is appreciated both in transplanting units, and in renal units remote from transplant centres. Nevertheless evolving practice identifies a number of significant inequities which must be addressed.

There is still marked variation in the proportion of patients from a dialysis programme who are listed for deceased donor transplantation. There are also delays in being listed. These issues are being addressed by a Renal Association/BTS questionnaire which renal units will receive in 2007. Areas of concern include

- Delays in getting necessary investigations done to complete work up for listing, the commonest problem being slow access to cardiac investigations.
- Variations in evaluation requirements; not uncommonly the perception of nephrologists that unnecessary investigations or referrals for further opinions are made by transplant surgeons.
- Delays in patients seeing transplant surgeons before listing either at a clinic at the transplant unit, or if the transplant surgeon visits another renal unit.

Each of these problems affects a significant minority of renal units.

The rapid growth of live donor transplantation is welcome but it remains uneven. Transplant units vary in their ability to be responsive in providing pre-emptive transplantation. As an informal test of the flexibility and responsiveness of live donor programmes, I presented the following scenario to most renal units I visited.

‘Suppose a 20 year old woman presents for the first time to your clinic tomorrow with reflux nephropathy, serum creatinine 3-400 μ mol/l who you expect would be on dialysis within three months. How likely is it that she could be pre-emptively transplanted if a family donor offered at that first visit?’

Only a small minority of units answered this question positively with confidence, and in some units it was expected that it would take 12 months to transplant such a patient. This is unsatisfactory.

There is also wide variation in the availability of laparoscopic donor nephrectomy. This inequity is being rapidly addressed by transplant surgeons gaining these skills but nevertheless at this time access to these services is incomplete. This is now seen by many renal units as a significant inequity

Where kidney-pancreas transplant programmes have been established they are well appreciated and in general the quality of service is highly regarded by nephrologists.

However there is concern that patients listed for kidney-pancreas transplantation will inevitably “jump the queue” for deceased donor kidneys.

Organisation of Transplant Services

A wide range of models for transplant care continues in the UK and these are usually pragmatic responses to local enthusiasms and personalities. Transplant surgeons vary between those who undertake all aspects of transplant care including primary responsibility for immunosuppressive regimens and medical management in the peri-operative period; compared to others who essentially offer a technical surgical service leaving all non-surgical aspects of care to the nephrologists. In general these arrangements, although very varied, work well and suit local environments.

One specific variation is the approach to transplant biopsies. In some transplant units these are undertaken by transplant surgical staff or radiologists, limiting opportunities for nephrology trainees to become expert in this procedure.

Return to Nephrology Care

Arrangements are also extremely variable for the return of patients from non-transplanting renal units to the care of that unit after transplantation. Some patients are returned to the parent renal unit on discharge from hospital, or at three months, or at 12 months, or never. Arrangements are usually by mutual consent, although in a number of places there is a perception and frustration in renal units that transplant units are unwilling to “let their patients go”. This not infrequently involves patients in very considerable amounts of travel for clinical attendance or hospital admission. The lack of any accepted criteria of competence in early post-operative transplant care mitigates against clear arrangements being developed.

Long Term Care of Transplant Patients

There is now wide acceptance that long term management of transplant patients is the province of the nephrologist, not only in manipulating immunosuppressive regimens and other strategies to maximise long term graft function, but also in management of cardiovascular and other post-transplant risk. There are now very few units left where such patients attend a transplant clinic and are reviewed by junior surgical staff. There is however wide variation in practice about the return of such patients to their parent renal unit if transplanted remotely. Competence in the long term care of such patients is regarded as mainstream nephrological expertise, but there are logistic problems which are often not adequately dealt with. Laboratory support, especially measurement of immunosuppressive drug levels, is still unsatisfactory, and it is not uncommon for blood samples to travel long distances, and a rapid results service not to be available. The cost of immunosuppressive drugs, particularly newer agents, is in many units not properly resourced. Non-transplanting renal units wish to take on the longterm care of these patients but cannot do it without resources, including drug costs, and specialist nursing time. Transplant units are often reluctant to release such resources from their budget. In some units nephrologists quite rightly wish for resources that will ensure transplant patients get the quality of service locally which they would get in the transplant unit. These tensions require work.

VASCULAR ACCESS

Historically transplant surgeons were the major providers of vascular access for haemodialysis. In most transplanting units, the volume of access work is now well beyond transplant surgeons to deliver alone. Involvement of vascular surgeons is increasing in these units but is by no means yet universal. I found no evidence that vascular access services are superior in transplanting units.

Deficiencies in the vascular access service in the UK are well known, and have been highlighted by the recent Vascular Access Survey and the Vascular Access Working Party. Vascular access provision remains remarkably variable. Those units with successful programmes with high prevalence of native AV fistulas are usually smaller units and typically

have derived their success from the strong commitment of an individual surgeon, working in close collaboration with a nephrologist, who have built a high-quality service by personal dedication. Such a model is excellent but must now be replaced by properly structured services based on a number of surgeons with appropriate support. I found evidence that this is beginning to happen and units typically were optimistic that they were turning the corner in the challenges of their vascular access service. This was usually based upon

- The involvement of recently appointed vascular surgeons, who were enthusiasts, or were required by job planning to undertake the work.
- The appointment of vascular access co-ordinators on renal units
- The increasing quality of interventional radiology – although regrettably this still remains very patchy. In well served units one or more interventional radiologists are offering semi-urgent and urgent fistula rescue work, and in some units are also placing all permanent dialysis catheters.

INPATIENT FACILITIES

The quality and quantity of inpatient facilities is an area of great variation and widespread frustration within renal units. Units typically report greater difficulty in getting adequately resourced inpatient facilities than expanding satellite haemodialysis, and this is a reflection of commissioning arrangements. In smaller units, where consultants typically have a practice in general internal medicine, it is common for renal patients to be admitted to general medical wards. Attempts are often made to cohort patients on specific wards to develop nursing expertise. Where there are committed renal wards, the nursing establishment is typically inadequate and units have great difficulty convincing Trust managers that the case mix of a typical renal ward is significantly more challenging than in unselected general medicine.

Renal High Dependency Beds

This is another area of great variation. Even larger units with dedicated renal wards may not have high dependency beds (even if a very loose definition of that term is used) and few have a properly established Renal High Dependency Unit [HDU]. Patients are frequently managed on general high dependency units in other parts of the hospital, but many hospitals do not have any sort of medical [as opposed to surgical] HDU. Such units are typically not plumbed for haemodialysis and patients may therefore receive sub-optimal renal replacement therapy (for example being required to remain on CVVH when intermittent haemodialysis and mobilisation would be the proper management at that stage of the illness) or are moved through the hospital to be dialysed on a maintenance unit from their inpatient bed. Much of this care is far from ideal

Inpatient haemodialysis on the renal ward

Views vary considerably about the optimal model for care. Many renal units do not have their ward plumbed for haemodialysis. Smaller units typically indicate that even if this were done, it is not realistic to suppose that sufficient staff with the appropriate competencies could be recruited to the ward area to support an acute inpatient haemodialysis service. Most regard an unplumbed ward as a realistic compromise. A minority argued otherwise – that it is “a good thing” for inpatients to move from the ward to the maintenance haemodialysis unit to be dialysed, since this provides for more stimulating clinical practice and more challenging work within the haemodialysis unit environment. I do not support that view, and prefer the solution to that particular issue being adequate staffing levels and the routine rotation of nursing staff between various elements of the renal unit including the HD unit and the renal ward to maintain and expand competence.

ACUTE KIDNEY INJURY

There is more variation in arrangements for the management of AKI in the UK than in any other aspect of the work of renal units. This reflects the absence of any clear commissioning arrangements and uncertainty about shared lines of responsibility particularly between critical care and renal units. This creates a real sense of pressure within renal units unable to deliver the service to which they rightly aspire.

The lack of renal HDU beds in the UK, and the lack of HD facilities in non-HDU renal beds have a significant negative impact on patient care. Patients wait too long to be admitted to the renal ward both from within and beyond the base hospital. They are often managed in inappropriate facilities (for example, ITU when they are fit apart from their requirement for renal replacement therapy to be on a general ward).

There are now large active intensive care units in most hospitals with intensivists increasingly trained and enthusiastic to manage AKI as part of multi-organ failure. Nephrologists struggle to provide a bedside consult service in these circumstances, and in some parts of the country it seems that telephone communications between critical care units and the responsible renal unit are less than ideal. Few nephrologists now undertake the role of “physician to the ITU” which was common in earlier days when nephrologists had a high presence in critical care units run by intensivists lacking in experience of renal disease, and acute renal replacement therapy was managed by the renal unit team. This inevitably has led to some de-skilling, and in many units a lack of exposure to AKI for nephrology trainees.

Attitudes vary significantly in this area. Some units regard this as an inevitable change and expect that nephrologists will increasingly become clinicians responsible for chronic disease rather than the acute critically ill. Others disagree and cling with enthusiasm to this element of their work, which can include not only regular and high intensity clinical input to the critical care unit in the main hospital but also frequent emergency visits when on call to other hospitals. Where it has been maintained this approach is valued by intensivists. This aspect of the work of renal units needs considerable attention and planning if appropriate patterns are to be identified and maintained.

One small newly established renal unit has chosen to commission renal replacement therapy for AKI from the commercial sector on a “per treatment” basis with a contract based on rapid response times. It is too early to know if this is a viable model.

Whilst most AKI in the context of multi-organ failure is “acute tubular necrosis”, concerns must always be raised that the increasing devolution of care of these patients to intensivists runs the risk of diagnostic error; one simple example would be the misdiagnosis of a patient with a pulmonary renal syndrome as having community acquired pneumonia with ATN rather than systemic vasculitis. In general, renal units seem satisfied that the available expertise in critical care and the level of liaison with the renal unit minimise this risk.

INFORMATION TECHNOLOGY

The very success of renal units in embracing electronic clinical information systems over many years has led to current difficulties. Renal units have long taken for granted that it is almost impossible to provide high quality clinical care without immediate electronic access to a wide range of clinical information; as a very minimum basic demographics and laboratory test results. Systems such as Proton have now developed a high degree of sophistication and remarkable functionality. The following risks must be highlighted.

- In many units the developmental expertise has come from individual enthusiasts, often an individual consultant taking the lead. Succession planning in renal units must ensure there is sufficient clinical leadership to develop this further.
- Non-clinical support has likewise developed on an *ad hoc* basis. Typically one individual, sometimes undertaking other roles in the unit, has become the maintainer of the system. There is no career structure or succession planning for such individuals.
- Trust IT departments are very variable in the quality of support they give. It is not untypical that they have “many other challenges to deal with” and regard the renal unit as IT competent and “the least of their problems”. This may even come down to a lack of proper cover for sickness or leave if the renal unit’s system manager is unavailable.
- The progressive growth and success of the Registry will place increasing demands on renal unit IT systems. Data routines will begin to include information which cannot come from automatic downloads and will require some manual input. This will inevitably involve further IT management time., as well as cultural and organisational change among clinicians. While the Registry capitation fee covers the Registry’s costs, renal units will need to fund from within their budgets proper local IT management support.
- During the period of my visits there were still a small minority of adult renal units not yet providing data to the Registry. The NSF for England provides a clear mandate that this should no longer be regarded as optional. In a small number of units the lack of a clinical information system is a major service weakness and significant difficulties in negotiating capital to purchase such a system reflect the negative impact of the National Programme for IT (NPfIT) - Connecting for Health[CfH].
- Renal units have not yet received any reassurance from CfH that the complex functionality of renal unit clinical information systems is understood, or any guarantees that this functionality will be reproduced by CfH as an absolute minimum. Nor have units received any reassurance that migration to new systems within CfH would secure all archived data as well as ensuring proper prospective data collection.
- There is a negative impact from much IT development being in limbo while CfH comes to life. Renal units have been significantly disadvantaged in this which has prevented a number of units purchasing the clinical information system they so badly need.

MEDICAL STAFF

Consultants

There has been an unprecedented growth in the number of consultant nephrologists in the UK over the past five years, who now number 370. Current growth rate is 8% per year. While all this growth is welcome, consultant numbers do not necessarily equate directly to an increase in consultant delivered patient care. A proper assessment of the number of whole time equivalent consultant posts in any unit is more accurate and will take into account significant variations such as commitments to general internal medicine, academic commitments, management commitments, leadership in teaching and education, and so on. A popular currency is the number of RRT patients per consultant; this again can easily give a misleading picture of workload unless the relative proportions of satellite and main unit HD patients, and the proportion of old and new transplant patients are also factored in.

However, any of these currencies of consultant resource are inadequate unless account is also taken of non-consultant career grade and SpR numbers contributing to the service in a unit.

Small renal units are being steadily expanded but there remain a few in which consultant numbers are inadequate. Workloads which were perhaps tolerable for single or double handed consultants when small renal units were being established in earlier times are now intolerable as RRT programmes increase in size. Let alone the additional burdens of returning transplant patients requiring long term care, the growing expectations of leadership in CKD education and awareness programmes, and the requirements of general [internal] medicine. Thankfully most such units are being supported within a managed clinical network, or have immediate plans for appointments of third and fourth consultants. Four consultants must be regarded as the minimum for any more units to become truly autonomous, especially when there is little or no middle grade cover out of hours.

I found plenty of evidence to support my view that the calibre of the consultant body in nephrology in the UK continues to be of very high quality. Senior trust managers who I met in a number of units spoke very highly of the commitment and delivery of consultant nephrologists. Nephrologists take a disproportionate burden of the major medical management responsibility in many trusts: including roles as clinical directors for services beyond nephrology, medical directors, clinical tutors, college tutors, directors of undergraduate teaching programmes, R&D directors, and so on.

Non-Consultant Career Grades

The Renal Association survey in 2004 identified 60 individuals with staff grade or associate specialist positions in UK renal units. There were also a number of unfilled posts. In a number of units the holders of these posts were individuals essential to the quality of care in the unit, typically with a major role in the management of patients on haemodialysis. Many of these individuals function at consultant level in terms of specialist expertise and commitment, and the advent of Article 14 of the new PMETB Regulations as an avenue for them to join the Specialist Register is very welcome. The extreme inefficiency of PMETB to this point and the slowness of the process is deprecated. However a number of other units have unfilled posts in these grades despite re-advertisements, and a number are being converted into consultant positions. It is clear that there are few high-quality candidates for non-consultant career grade posts and this may well reflect the rapid increase in training numbers over the last few years encouraging individuals who previously might have accepted a non-consultant career grade posts to enter specialist training. It seems unlikely that the number of NCCGs in renal units will increase but those in post are very highly valued.

SpRs

Despite the perceived decreasing interest in nephrology as a specialty and concern that it is regarded as unattractive set against many current life expectations of younger doctors, I met many excellent and highly committed SpRs during my visits. The great majority I met I would however regard as being "old school" in the good sense of that word indicating individuals who started their training under older regimens which recognised that long hours apprenticeship was an important and necessary part of clinical training; and that it is very difficult indeed to deliver continuity of care or experiential learning within a shift work culture. It remains to be seen how the newer generation of doctors just entering specialist training will come to terms with the difference between their work programme as trainees and expectations of them as consultants. There are many aspects to nephrology training beyond the remit of this report, but issues highlighted to me by trainees during my visits included

- The disproportionate time spent in large renal and transplant units which are the hub of their training, compared to smaller renal units within the same Deanery/Network. Trainees mostly reported excellent clinical experience in smaller units but spent little time there. Consultants in those units likewise regard the distribution of SpR time as less than fair enforcing a disproportionately high level of consultant delivered care in smaller units.

- Training in interventional nephrology is also threatened by the growing tendency for radiologists to undertake renal biopsies and dialysis catheter placement, and the emerging role of nurse practitioners in some units with a role in access placement.
- Decreasing exposure of trainees to critical care is also of significant concern to them.

NURSES AND OTHER HEALTH PROFESSIONALS

Renal units proved the importance of multiprofessional clinical working for many years before the current vogue of emphasising the enhanced role of this part of the healthcare workforce. Senior nursing staff in dialysis units have for more than 30 years been given remarkable and appropriate degrees of independence and responsibility, and have flourished in these roles. All the units I visited were absolutely dependent on highly committed and experienced senior nursing staff many of whom manage to maintain major clinical responsibilities despite the potential management demands. I met a range of nurse consultants, nurse practitioners, and nurse specialists with highly developed roles which are well respected. The recent financial stringencies in the NHS have put these roles under severe threat in a number of units and key senior staff have had their contracts terminated, putting a number of renal services at significant risk. A letter early in 2007 from the Presidents of the Renal Association and the British Renal Society to the Chief Nursing Officer for England pointing out the folly of this had an extremely bland response.

In many units I had opportunity to meet senior nursing staff individually or sometimes in a group without medical staff being present. These were often revealing discussions and I would like to highlight the following points.

- Senior nurses in general appreciated the extent of their clinical responsibility and felt valued by senior medical staff.
- A minority felt that some lip service was still being paid to nursing autonomy, and that some consultants were still somewhat paternalistic and controlling.
- There seems considerable variation among senior nurses about their perception of the comparative roles of nurses and doctors and the features in training experience and practice which distinguish medical from nursing staff.
- In this context there was much variation in the extent to which nurses wished roles to be enhanced and extended, for example in becoming independent prescribers, or in triaging newly referred patients with CKD. There was also great variation in their wish to gain technical expertise in the placement of haemodialysis or PD catheters.
- There is great variation in task distribution among specialist nurses. Some units have many specific roles - e.g. anaemia, vascular access, pre-dialysis education, transplant, and so on. Others prefer the concept of a multiskilled team where a 'named nurse' for the patient can deliver all of the above as needed. My visits strengthened my view that the latter of these two models is preferable for continuity of care and professional development. But I have no hard evidence to support this view.

There continues to be very marked variation in the resources available to renal units for other key health professional groups. Dietetics, pharmacy, psychology, social work are still often regarded as "extras" rather than as a core part of the clinical team, and are often the first element of a development to be 'squeezed' by commissioners when resources are stretched. Individual units have had considerable success in expanding some elements of the multiprofessional team, but no unit has full team staffing. It is remarkable and disappointing that a number of units should still be dependent on charitable [often BKPA] resources for such posts.

ADMINISTRATIVE STAFF AND MANAGERIAL SECTORS

Secretarial support

Provision of secretarial staff remains highly variable. In many units the secretarial support was excellent in quantity and quality, and many staff had worked in the unit for a long time, a testament to the positive working environment. On the other hand Trusts are increasingly devolving clinical typing to remote sources, often in other cities or other countries, and the key role of the medical secretary as an interface between patients and clinical staff was being rapidly eroded. This is of course not specific to renal units.

Business management

Most large renal units are separate “directorates” or “business units” and have a substantial degree of autonomy with good direct access to Board level decision making within the Trust. Smaller renal units are typically within general medicine or occasionally within surgical divisions. This has obvious risks, but in general clinical directors and their managers are confident that specialist commissioning allows them direct access at a senior level in their Trusts when needed.

Even with good working relationships it is not uncommon for the distribution within the Trust of income brought in to the hospital for renal services is opaque. It is a regular complaint that positive balances achieved by renal units are redistributed by the Trust to meet shortfalls in others clinical areas [most commonly general surgery and emergency medicine]. Opportunities given to renal units to re-invest resources are all too few.

COMMISSIONING

Dialysis station numbers and consultant numbers are two criteria indicating greater success of commissioning in Scotland and Northern Ireland [and at least until some years ago in Wales] over a sustained period. As best as I can tell this reflects sensible planning and commissioning on a country wide basis, which contrasts with the mantra for ‘local’ management of resources in England.

In England, specialised commissioning arrangements remain extremely variable. At its best, well established clinical networks have developed proper arrangements with a lead PCT [or equivalent] which drives the commitment of all PCTs to network decisions. I have made too few visits to units since the most recent realignments with further reductions in the number of PCTs to assess any further adverse effect from this most recent change. Continuity among senior management staff within specialised commissioning is a crucial asset and those regions working successfully have usually had the same senior individual in a SHA or regional role for some considerable time. In successful clinical networks, of which there are quite a few, consensus decision making among clinicians has become the norm and major decisions, for example the prioritisation of geographical sites within the network for new satellite units, are not a matter for destructive debate.

The exceptions to these successful arrangements are however extremely challenging. There are still places in the UK where rational stepwise development of renal services has proved almost impossible, where there has been no coherent regional decision making and where inevitably this has meant significant under-provision of renal services. There are examples of ill-informed decision making when choosing sites for new units or working out how inpatient and outpatient services should develop in parallel.

Remarkably there is still a completely unacceptable situation in one renal unit in the UK where there is no coherent programme of HD machine replacement, no identified budget for machine purchase, and where machines are still purchased with charitable funds.

Whilst a “managed clinical network” is the current preferred term for the organisation of renal services, arrangements have developed with sensible flexibility reflecting specific local circumstances. The 'managed clinical network' is described as being different from the old “hub and spoke” model but in reality it is local geography which has the major impact on delivery of services. The number of hospitals capable of maintaining an inpatient and outpatient renal unit, the distances to be travelled, the number of transplant units within a geographical patch will all have a major impact on planning. The relentless drive to provide services close to patients without compromising on quality is correct and is a challenge being well met in most parts of the UK. Developments would appear to have been slowest within 50 miles of the middle of London. There are local circumstances not appropriate for detailing in this report, but it is inescapable that there are still very substantial travelling distances and travelling times required of patients in this part of the UK; and that hospitals serving populations which would sustain a renal service in other parts of the UK, have in this region been slow to establish independent services.

The Carter Report on Specialised Commissioning contains very sensible proposals which *if implemented* should serve to rationalise and improve the variable picture I report above. Regrettably at the time of this report there is evidence of the varying enthusiasm with which local health communities are responding to the DH expectation of the Carter Report implementation.

RENAL PATHOLOGY

The shortage of histopathologists with special expertise in renal disease is a growing concern and there seem at present to be no specific training strategies to ensure that this highly specialised field is sufficiently staffed. Despite this most renal units report satisfactory arrangements ensuring clinically appropriate rapid reporting of renal biopsies. Many report a same day urgent reporting service using car transport of biopsy samples to the specialist unit. Video conferencing facilities for renal biopsy meetings are being developed and are a successful model for smaller units.

ACADEMIC NEPHROLOGY

It is a consistent “cri de coeur” that academic medicine is under threat in the UK, and nephrology feels itself as no exception to this.

It is easy to look back at the ‘golden days’ when almost all renal units had developed in teaching hospitals, and when consultant staff on a unit usually included a Professor of Renal Medicine, and quite often a Professor of Medicine. Inevitably that cannot be maintained, but given the enormous increase in consultant numbers over the last few years it still disappoints me that so few of these consultants have been able to sustain a significant research career, despite the lighter on-call rotas now required of many consultants. Most units which I visited said their staff would very much like to be more involved in research but the pressing realities of clinical responsibilities drown out enthusiasm and commitment.

Factors which need to be considered are

- The fading necessity that a period of full time research is a mandatory part of nephrology training.

- The increasing amount of time spent by trainees in busy clinical environments remote from academic centres.
- The great difficulty in obtaining “blue chip” research funding for clinical and translational research over the last decade. The majority of nephrologists with an academic reputation of the sort which satisfies university assessors are predominantly involved in laboratory research lacking immediate clinical application.
- Those academic nephrologists with the current greatest success are typically those with the lightest clinical commitments. The “renaissance” nephrologist who could turn his or her hand to clinical, teaching and research work and pursue all successfully unfettered by the need to justify time management to the hospital and university regulators may soon be an extinct species.
- There is a tension for nephrology more than for most other branches of internal medicine in this area. Clinical nephrology is built on continuity of care and longterm commitment to individuals with severe chronic disease. This does not sit well with the academic model in which “serious” clinical academics do occasional clinics or occasional months on the wards.
- Regrettably research skills and evidence of intellectual energy are not always considered necessary for consultant appointment

RESEARCH

Modern nephrological practice is awash with opportunities for translational clinical and health services research as well as laboratory research interests. The range of interests of the rapidly expanding consultant population is more and more varied, Large renal units in particular need to find ways to provide equal respect and encouragement to consultant staff whether they are predominantly working in a clinical, teaching or research track. This is clearly an increasingly difficult goal for clinical directors in the Trust job planning and PA counting environment brought to us by the current consultant contract.

Wherever I visited, nephrologists with full time clinical contracts were frustrated at their inability to achieve more in the way of effective and meaningful research. These frustrations take different guises. Smaller units typically had realistic goals: they wished to “pull their weight” in contributing patients to large national or international studies such as ASTRAL and SHARP, and also recognised that participation in industry-led trials remains a way to try and support some infrastructure. Nevertheless research nurses in these units typically were on short term salaries with uncertain funding streams; not a good basis for progress. Larger renal units, particularly with major academic elements, displayed the typical frustration of difficulty in obtaining “blue chip” research funding, particularly given the modest scale of resource available from Kidney Research UK by contrast for example with British Heart Foundation or Cancer Research UK.

For all renal units however research governance is a major detraction. Trust R&D Departments and Research Ethics Committees in particular, but also the whole wider research governance structure, is seen as anti-research. Clinicians are tired of being told that NHS R&D are determined to simplify application processes when manifestly they have made them ridiculously onerous with no evidence they have improved participant safety. Heavily pressed clinicians are simply losing the will to engage with this bureaucracy and as a consequence research opportunities are being lost.

VISITS TO PAEDIATRIC RENAL UNITS

Paediatric nephrology has of course many similarities to adult nephrology, but just as many cultural and organisational differences. I was fortunate from the time I was a research registrar to work with paediatric nephrologists, but I am aware that many adult nephrologists have little understanding of their work. This lack of understanding has sometimes been mutual. In the past this has polarised into ill-informed misunderstandings which could perhaps be parodied as:

Adult nephrologist's view – 'Paediatricians are always complaining they are busy, but they have hardly any patients and a huge multiprofessional team, so what do they do all day?'

Paediatrician's view – 'Adult nephrologists just practice production line medicine with vast numbers of patients, they have lost the personal touch. When our patients are transferred on to the adult service, they are unhappy, and then things go wrong.'

Such polarised parodies are almost eliminated, but in my experience not quite, which is precisely why I mention them here.

Geography

There are 13 paediatric renal units in the country offering specialist tertiary services including dialysis, of which 10 also undertake renal transplantation. The 13 units have catchment populations varying between 1.7 and 6 million [total] population. These large geographical areas inevitably mean that children and their families may travel very large distances for specialist care, and will also require paediatric nephrologists to travel extensively to support peripheral clinics. While much non-RRT care can be delivered by the specialist team travelling to peripheral clinics, RRT inevitably requires more travelling to the specialist centre. Excessive travelling by the clinical team may be 'patient-friendly' but can represent a major loss of specialist time to 'non-productive' travel.

Renal replacement therapy

Dialysis

Paediatric renal replacement therapy is *par excellence* a very low volume very high cost service.

For older children ideal renal replacement therapy is usually pre-emptive transplantation, but infants and small children will require dialysis until there has been sufficient growth to make transplantation an appropriate option. First choice dialysis therapy for most children is home APD. Hospital based haemodialysis is usually a fall back modality when transplantation and peritoneal dialysis cannot be achieved, although it may be a first choice therapy in a minority of young people in the teenage years. Paediatric renal units are currently supporting between 8 -30 PD patients, and 4-15 HD patients. HD can be a very challenging modality in children not least because of travelling distances.

Transplantation

Units perform between 8-25 paediatric transplants a year, with live donor transplants varying between 10-50% of the whole. This variation in live donation must represent significant differences in attitudes of paediatric nephrologists to live donor transplant which I could not tease out, but which would appear to be opinion-based.

Some paediatric nephrologists shared my view that even the present small number of paediatric units offering transplantation is unsustainable, mainly because specialist surgical skills cannot be maintained. A contraction of units offering paediatric renal transplantation seems almost inevitable, particularly for transplantation in smaller children. It would be much preferable if the specialty proactively promoted and directed such a contraction rather than having it imposed, perhaps in response to a future staffing crisis.

Medical Staff

Consultants

There are between 2 and 6 whole time equivalent consultant paediatric nephrologists in UK units. BAPN's stated recommendation has been 1 consultant per 6 million total population, i.e. 60 consultants nationwide, presently there are 61.

The present consultant numbers represent a very substantial expansion over the last five years. This expansion in turn was preceded by a period of workforce planning blight in which substantial numbers of SpR posts had been created but there was real uncertainty about sufficient consultant posts becoming available for those completing training. At one stage I think this seriously threatened the specialty in the UK since another generation of young trainees would never have entered paediatric nephrology having witnessed such a workforce planning failure. Fortunately the necessary consultant posts were created. Workforce planning will always be difficult in such a small specialty. But paediatric nephrology has particularly suffered at the hands of changing commissioning arrangements over the last few years. Negotiating new posts becomes almost impossibly challenging when 30 or more PCTs need to be consulted and persuaded. The new specialist commissioning arrangements proposed by the Carter Report are therefore of particular importance to paediatric nephrology.

There are particular problems in planning and resourcing paediatric renal services in small geographical areas which cannot naturally be supported in a larger network, for example Northern Ireland. It is difficult to plan for, or indeed recruit, the number of consultants sufficient to maintain reasonable on call rotas. In these circumstances rotas can be extremely burdensome, often requiring individuals to work 1 in 1 or 1 in 2 for many years.

Non-consultant career grades

Establishment of non-consultant career grades posts has not been a favoured approach to staffing issues in paediatric units; only one unit has such a post.

Trainees

Trainees attached to paediatric units are not always committed to a career in nephrology, and will often be involved in general paediatric on call.

The inevitable effect of these medical staffing issues is that paediatric nephrology is an almost exclusively consultant-delivered service. It is typified by periods of high intensity work involving consultants in day-to-day clinical work, a substantial part of which would in adult units typically be delegated to junior staff.

Surgical Support

Paediatric renal units are generally satisfied with the quality of surgical support their patients receive. There is some concern that surgical trainees coming through will struggle to get sufficient experience in paediatric transplantation. A number of units particularly rely on the expertise and commitment of a single senior transplant surgeon with a predominantly adult practice, with some uncertainty about succession planning. Other units have paediatric surgical expertise in which they have great confidence. There is concern about variable availability of laparoscopic donor nephrectomy. This is of great importance in promoting donation, especially if the donor is a family member involved in ongoing care of the patient or other siblings.

Non-Medical Clinical Staff

As in adult nephrology, senior nurses have highly developed specialist roles and are absolutely crucial to the delivery of the service, particularly given the lack of sustained input from junior medical staff. Specialist nurse roles include the management of urinary tract infections, incontinence, transplantation assessment and follow up, and home care. In most paediatric renal units the service would be unsustainable without these specialist roles. Regrettably many trusts have seen these nursing roles as a potential source for cost saving and this represents a major risk.

Recruitment and retention of paediatric haemodialysis nurses, especially in London, can be very difficult.

Dietetics plays a very major role in the care of paediatric renal patients, and most units seemed to have achieved sufficient expert staffing.

There are however a number of additional roles where provision is very variable and often frankly inadequate. This includes psycho-social expertise, and specialist pharmacy expertise (medicines management being a very major issue in paediatric renal practice).

There are other additional roles, for example play therapists and teachers, which might easily be wrongly viewed as “mere icing on the cake”. A number of units appear to have had great difficulty in making Trusts and commissioners understand that these are at the core of the overall care for children who will inevitably spend substantial parts of their early lives in hospital. It is of great concern that a number of units still rely on charitable funding (particularly from BKPA) to fund these core roles.

Transitional Care

Concern is often expressed that adult renal units, dominated as they are by older people, with an average age often approaching 70 years, are inappropriate environments for adolescents and young adults,. But paediatric wards seem to me equally inappropriate for these young people; often with décor typified by Mr Men pictures , and Duplo on the floor representing a potential health and safety hazard to the unobservant visitor. This has been addressed in a number of paediatric units by the provision of a resource room for the older age group with an environment which the young people can themselves dictate with culturally appropriate music and suitable computers, games, and the like.

Lack of understanding of the challenges of managing children with chronic kidney disease and supporting their families led in the past to an adult unit perspective that young people often transferred at a time when they were still emotionally immature and very dependent on their parents who had always taken responsibility for their illness. Paediatric renal units discussed with me a variety of models for trying to achieve good transition. Typically they now have excellent programmes helping young people take increasing responsibility for their illness starting in the early teenage years.

Although paediatric units do not look after any patients for more than 18 years it is clear that emotional and psychological ties between children, parents and the clinical team become extremely strong, which may explain some of the difficulties of transition.

When adjacent to large adult renal units, transition clinics are often in place; providing the opportunity for an adult nephrologist to join a paediatric nephrologist to see patients together soon before transfer. These are established in many paediatric units, are popular and appear to work well, although relying on the commitment of individual consultants on both sides. Transfer of young people to smaller adult renal units is organisationally more challenging. Some paediatric units reported to me reluctance of local adult units to accept transfers, particularly of adolescents who are on haemodialysis. Transfers appearing sometimes to rely on consultant goodwill rather than any recognised principle about transfer of care. A number of paediatric units have an established youth worker/transition worker model and this has strong support from enthusiasts, but others expressed to me concern that the evidence base is not yet robust enough to justify the investment this requires.

Paediatricians discussed wistfully with me the notion of an adolescent ward rather than an adult ward as a better environment for these young people when inpatient care is needed after transition. There are in practice no such wards in the UK with any clinical renal expertise, and it seems unlikely this will become a viable model of care.

Changing Case Load Complexity

The point was repeatedly made to me that the case mix of children with kidney failure continues to become more complex. Not only does this mean even more intense clinical input in both acute and outpatient settings, but increasingly requires difficult decisions to be made. This is inevitably very time-consuming in counselling. For example, children with neonatal pulmonary hypoplasia, those with complex inborn errors of metabolism, and children needing cardiac transplantation in very early life, are requiring acute or long term

renal support. In units covering large ethnic minority populations, children with complex genetic syndromes create a significant workload. The increasing breakdown of family structures means that psychosocial and educational support are often more demanding than before.

Paediatric nephrology in general hospitals

In addition there are changing attitudes among general paediatricians which is increasing the workload of paediatric nephrology units. For example few general paediatricians appear willing to manage children with steroid-sensitive nephrotic syndrome through more than one or two relapses, or indeed may refer a *de novo* nephrotic child. This is in contrast to past years when many nephrotic children would be managed through multiple relapses by a general paediatrician with telephone advice from a paediatric nephrologist. Some units suggested resolving this problem by developing a cadre of general paediatricians with an interest in nephrology who have spent some time training in a paediatric renal unit and who would then work in a district hospital supported by the paediatric renal unit. This model is not being introduced quickly enough.

Critical care

By contrast with adult units, there does not yet seem to have been any significant reduction in the role of paediatric nephrologists in ICU. There are few paediatric ICUs in the country and almost all are in large university hospitals which have a paediatric renal unit. In general network arrangements seem sound and no paediatric renal units voiced major concerns about clinical management or governance in this area.

Academics and Research

The UK has two paediatric renal units with an international academic reputation, both based on laboratory research. Paediatric nephrology was originally a more academic specialty with clinical research being a normal feature of all units' daily work. This pattern seems to have atrophied for two reasons. Firstly the excessive clinical pressure paediatric units had to carry particularly before the relatively recent consultant expansion. A second difficulty has been securing competitive funding for clinical or translational research. These two factors seem to have decreased the emphasis on research awareness and thinking during training. A number of units also reported to me on failures in negotiations with medical schools for maintenance or increase in academic posts in paediatric nephrology.

There is now an NHS Medicines for Children Research Network in which nephrology is taking a prominent part, and which may provide an important opportunity to expand the research profile.

Renal Pathology

In general paediatric renal units were satisfied with the renal pathology service they were receiving. However some units reported concern about lack of expertise in rare paediatric diagnoses among renal pathologists with a predominantly adult practice. Some units mooted a more structured approach to the discussion of challenging cases through a renal pathology national network.

Information Technology

This remains a major issue for paediatric renal units. Despite the NSF requiring renal units to make annual returns on all RRT patients to the UK Renal Registry, this is still far from being complete in paediatrics.

Although paediatric renal units report commitment to the principle, it has also been true that the small number of patients for whom they care has not in earlier years driven the necessity of developing IT for effective clinical care, as has been the case in adult renal units responsible for much larger numbers of patients..

The UK Renal Registry has had some money from the Department of Health to complete the implementation of paediatric clinical information systems, but it has not yet been possible to spend this. A significant issue is the lack of investment from Trust IT departments for both the necessary capital development, and also to support software development in an area which is inevitably seen as a low priority given the very small number of cases involved.

This issue needs to be given high priority, and it seems likely it will become increasingly difficult for paediatric units to make a case of need for resource expansion if they lack the nationally demonstrable audit data to support their case.

Conclusions

Paediatric nephrologists show remarkable commitment to continuity of care including demanding on call work. It seems unlikely that the new generation of consultants, will accept this work pattern with its perceived adverse effects on lifestyle and work-life balance. I hope that my concerns are not realised.