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# Adult Renal Dialysis Services In The UK: A Questionnaire Survey To Examine Providers And Commissioners Approaches To This Service

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## Abstract

**Background:** In the UK, the introduction of primary care trusts, changes in commissioning for adult renal dialysis services and the development of the National Service Framework for Renal Disease has implications for dialysis services for adult renal patients.

**Method:** To determine the number and type of adult renal dialysis services commissioned and provided a questionnaire survey was sent to all adult renal dialysis providers and commissioners of renal dialysis services.

**Results:** Response rates were 100% for provider units and 82% for commissioners. Overall a full range of modalities was both commissioned and provided. Differences occurred between the provision and commissioning of vascular access, recombinant human erythropoietin, conservative management programmes, dedicated transport services and multidisciplinary team members.

**Conclusion:** Considerable variation was seen between dialysis services provided and those commissioned. This variation has implications for patients and for successful delivery of UK Renal National Service Framework targets.

This work was conducted in the Section of Public Health, SchARR. The University of Sheffield, UK.

## Support

The study was commissioned and funded by The National Kidney Research Fund (<http://www.nkrf.org.uk>).

## INTRODUCTION

In the UK renal services are expanding; acceptance rates for treatment for end-stage renal disease rose from 22 to 96 patients per million population between 1982 and 1998.<sup>1</sup> Changing demographics: increasing numbers of elderly, many with Type 2 diabetes and associated renal complications; and higher incidence rates for renal replacement therapy in some ethnic minority populations, who are relatively young at present,<sup>2</sup> means further increases are inevitable. The prevalence of renal disease is lower than

many other conditions but costs for management and treatment are high. Renal replacement therapy consumed two percent of the UK National Health Service (NHS) budget in 2000 and is predicted to rise to three percent within five years.<sup>3</sup>

In the UK service provision for management of end stage renal failure is now defined in the National Service Framework (NSF) for Renal Disease.<sup>4</sup> Renal replacement therapy programmes in the UK in the 1960s and 1970s were provided by a small number of renal units based in teaching hospitals covering large catchment populations. From the 1980s renal services increased significantly, provided to some extent by increases in satellite units.<sup>5</sup> Options for renal replacement include renal transplantation or dialysis but patients may elect to be treated conservatively where institution of renal replacement therapy will be to further

detriment or with personal choice. Dialysis techniques provided include haemodialysis (HD), the majority of which is currently provided in centres, satellite and minimal care units, and peritoneal dialysis (continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD)), which is predominantly a home-based therapy. Less than two percent of patients are currently on home HD<sub>5</sub>.

UK health service budgets are now managed locally by primary care trusts (PCTs)<sub>6</sub> who commission or “buy in” services from the health care providers - in this case the renal dialysis units. Currently two groupings for specialised services are defined, covering planning populations of 1-2 million and 3-6 million<sub>7</sub>.

Given this changing background in commissioning and provision, a survey of commissioners (service planners) and providers (renal dialysis units) was commissioned by the National Kidney Research Fund to examine gaps between, and plans for, the commissioning and provision of adult renal dialysis services in the UK.

## **METHOD**

An advisory group of commissioners, providers, patient representatives, renal organisations, and other interest groups was established to inform the research. A questionnaire was designed to determine current adult renal dialysis status, but not to duplicate data already collected.<sub>5</sub> Open and closed questions common to commissioners and providers were used plus questions specific to each. Questionnaires were posted in July 2002, to named people in each provider unit /specialised commissioning group. Answers were collected by pre-booked telephone interview. Further telephone calls and emails were made where initial contact failed. Main provider units covered satellite units.

Questionnaire data accuracy was confirmed by posting copies of responses back for checking. Three corrections were made to original data. Data were analysed using SPSS and descriptive and frequency statistics obtained. Responses were compared between providers and commissioners.

## **RESULTS**

### **RESPONSE RATES**

Response rates were 100% for provider units (68), with two units based in each of three sites submitting combined data (Newcastle, Glasgow, and Leeds), and 82% (41/51) for commissioners.

## **TREATMENT**

### **DIALYSIS (TABLE 1)**

Commissioners were asked what services they commissioned whilst providers were asked for numbers of patients receiving treatment by modality. All (n=41) commissioning contracts for renal services included commissioning for unit haemodialysis. Three commissioners did not contract for home haemodialysis (HHD) and one for neither continuous ambulatory peritoneal dialysis (CAPD) nor ambulatory peritoneal dialysis (APD). A further three commissioners did not know if they commissioned APD. Provider responses showed 18,954 people receiving dialysis for treatment for end-stage renal disease. One provider unit had no patients on CAPD or APD and 16 units (27%) had no HHD (one non-response for each of CAPD and APD).

Patients with renal disease on regular haemodialysis, who go away for business, holiday or other domestic reasons, must continue their dialysis treatment. Two-thirds of commissioners (66%) always commission temporary out-of-area dialysis but seven percent of providers always have difficulties in making arrangements for out-of-area dialysis and 18% always have difficulty in accepting out-of-area patients. With permanent changes in residence, 88% and 76% respectively of commissioners never have a problem with changing service commissioning arrangements for patients when they either move out of, or into, an area. However 75% of providers sometimes or always have problems in transferring patients to another unit, or accepting patients into their unit. On the day of survey completion 58% of units had no staffed, functional, vacant haemodialysis slots.

### **VASCULAR ACCESS (TABLE 1)**

Adequate vascular access for haemodialysis is usually achieved by creation of an arterio-venous (AV) fistula using native blood vessels, although a substantial minority will use an AV graft constructed with synthetic material. Fifty-seven provider units had 30-100% of patients dialysing with an AV fistula/graft (missing n=11). Waiting times for elective fistula surgery ranged from 1-104 weeks (mean 13.7, median 9.5). Half (52%, 22) the commissioners had arrangements with at least one provider for vascular access but few (15%) specifically commission for renal interventional radiologists, and provision, whilst higher (49%), was limited.

**Figure 1**

Table 1: Provision and commissioning of adult renal dialysis services and support staff

	Provision	Commissioning
	N (%) adults receiving	N (%) commissioning
Unit haemodialysis	12903 (68.1)	41 (100)
Home haemodialysis	484 ( 2.6)	38 (92.7)
Continuous ambulatory peritoneal dialysis	3919 (20.7)	40 (97.6)
Automated peritoneal dialysis	1648 ( 8.7)	37 (90.2) <sup>1</sup>
	<b>Mean (%)</b>	<b>Mean (%)</b>
AV fistula or graft for dialysis (range)	69% (30-100) of patients	50% specify
Dedicated vascular access surgery sessions	73% of units	-
Dedicated vascular access surgical staff	71% of units	-
Dedicated renal interventional radiologist	49% of units	15% specify
	<b>Whole time equivalent/1000 dialysed</b>	<b>N (%) commissioning</b>
Renal technicians	11.2	15 (36)
Dieticians	7.8	15 (38)
Social workers	3.4	9 (21)
Pharmacists	3.0	13 (31)
Counsellors	0.8	9 (21)
Occupational therapists	0.6	7 (17)

<sup>1</sup>Assumed 3 'not known' were negative

## DRUGS

Various drug regimens are used in treatment of chronic renal disease and long-term haemodialysis, e.g. renal anaemia can be managed with recombinant human erythropoietin (EPO). Two thirds of commissioners (n=26) had agreed protocols for commissioning EPO, with restrictions on use by 21% (7). All provider units had agreed protocols for EPO, with 20 (30%) restricting its use.

## CONSERVATIVE MANAGEMENT

Conservative management is one option for end-stage renal disease. Most commissioners (n=36, 88%) do not specifically commission for this but 52% of provider units (n=32) have a programme.

## SUPPORT

### THE MULTIDISCIPLINARY TEAM (TABLE 1)

Management of patients with renal disease requires a multidisciplinary team. Commissioners were asked about commissioning for dieticians, pharmacists, social workers, counsellors, occupational therapists, and renal technicians, whilst providers were asked for their whole time equivalent (WTE) staff. Not all commissioners specifically commission support staff and those who do show considerable variation, as do providers.

Ten (24%) commissioners specify provision for a diabetes clinic, diabetologist or joint diabetic/ nephrology clinic in

their contracts, whilst 28 (45%) providers have formal shared care arrangements with diabetology. One provider has a joint diabetic clinic but no formal arrangement.

## TRANSPORT

Patients undergoing unit haemodialysis attend a provider unit or its satellite as outpatients usually three times a week, every week. Most commissioners commission dedicated transport services, either as part of a block contract with the Trust (24, 65%) or specifically for renal patients (5, 14%). A further eight use neither of these and four considered it not of relevance to them. Only 44% (30) of providers have dedicated transport services.

## THE COMMISSIONING PROCESS

Whilst 93% (39) of commissioners considered they had an effective and responsive commissioning process, under half (47%) of providers thought this. Albeit 74% (48) of providers considered that their commissioning process, whether effective or not, enabled them to change the number or range of services commissioned in response to demand, subject to physical capacity. Only 25 (39%) providers knew the total amount of income received from commissioners for renal services (3 non-responders) compared with 64% (27) of commissioners.

Providers and commissioners use similar methods to plan service requirements, such as locally developed models, usually with a built-in percentage of 8-10% for growth, or published models<sup>8,9</sup>, sometimes modified using local data.

## DISCUSSION

This survey covered those responsible for planning and commissioning for most of England, Wales and Northern Ireland. Identification of commissioners in Scotland was problematic because the word 'commissioner' is rarely used in the same context and the commissioning process is less structured. Whilst commissioner findings are partly limited by response rate, they also reflect the variation in roles and responsibilities seen within individual specialised commissioning groups. In some, the group takes full responsibility for policy issues and direct commissioning with provider units, whilst in others, the group has a policy role only and commissioning is done at a lower level. For those regions in which the former commissioning model applies we have full cover of the commissioning process where we have a response. For the latter, we had problems untangling the structures to identify all parties responsible for commissioning renal services. During implementation of

this survey it became clear that abolition of the UK health authorities and the move to PCTs<sub>4</sub> had caused some breakdown in identified roles and responsibilities for commissioning renal services in 2002. Changes in commissioning personnel over that year resulted in many commissioners being relatively new to the role, on a steep learning curve and not necessarily aware of the whole procedure.

The one area in which commissioners and providers agree relates to dialysis provision. Provision of a choice of treatments allows patients with renal failure to receive the most suitable care. Overall, both groups include all modalities except HHD. For this, provision may change following the National Institute for Clinical Excellence's recommendations on HHD.<sub>10</sub>

This survey has highlighted several areas where commissioners and providers are not in phase. For example, there is some variation with respect to vascular access with lower rates of specific commissioning compared to provision. On present showing, neither group will meet the proposed NSF standard whereby all patients approaching end-stage renal disease should undergo access surgery to create permanent access, for either peritoneal dialysis or haemodialysis. Discrepancies were also seen in prescribing EPO, transport services and conservative management.

Other major differences lie within the area of support staff. Renal technicians are essential for maintaining dialysis equipment and supplies yet only one third of commissioners specifically commission them. Similarly, providers tended to have better recognition of the role of social workers for this client group and were quite creative when lacking formally commissioned services. Actual provision may be lower than reported as some posts may be vacant, although these findings are supported.<sub>11</sub>

The less positive perception of providers concerning an effective and responsive commissioning service probably reflects changes in commissioning underway during the course of this survey. PCTs became responsible for commissioning although one provider unit commented that they had no lead PCT, no separate renal directorate, so there was no specific commissioning for renal services. Another reported that their commissioning group was new, had no chair, was at the information-gathering stage, had limited understanding, and no progress was being made. A third considered the commissioning process effective for

communication and commissioner-unit relationships but funding was insufficient. In contrast, one commissioner reported a good working relationship with clinicians, meeting monthly with them and local trust managers. Some imbalance may be due to commissioner perceptions: one commented that their commissioning was procurement in reaction to changes in need and demand rather than a planned, developed policy.

In summary, recent changes in commissioning for specialist services, including end-stage renal disease, are affecting performance, although some problems may have been ongoing. For providers, the structure is more stable. If patients are to get the best level of dialysis care and the renal NSF standards<sub>1</sub> are to be met, some change is essential, particularly on the commissioning side. A period of stability and consolidation would enable new commissioners to engage with the problem, with guidance,<sub>4,12</sub> and provide opportunity for more strategic planning.

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