



## ***Commissioning of Renal Services***

**Kidney diseases are a spectrum of disorders across a complex clinical pathway. Early kidney disease is commonly managed within primary care. More complex kidney services (including dialysis, transplantation, acute kidney injury) are commissioned at a regional, specialised level in England. The expertise and resource to look after a vulnerable group requires specialised centres responsible for large populations. The current system of specialised commissioning allows strategic planning.**

**The Kidney Alliance regards the continuation of this national/regional approach to commissioning of specialist dialysis services as essential for the future care of people who have or who are approaching renal failure. Any moves away from this towards GP Consortium commissioning at local level will fragment the service, resulting in poorer outcomes, reduced efficiency and higher cost. Such fragmentation will be detrimental to care of long term patients and could affect mortality, thereby influencing key NHS outcomes and providing less value for money.**

**It is vital that dialysis retains its status as a specialist service and is commissioned effectively by the NHS Commissioning Board, under advice from the Advisory Group on National Specialised Services (AGNSS).**

### ***Kidney disease: the clinical pathway***

It should be emphasised that the Kidney Alliance is not advocating that all kidney care be commissioned as a specialist service. Whilst we believe that services currently provided in specialist units should be commissioned as specialist services, there is a major role for GPs in providing care for patients with Chronic Kidney Disease in which kidney function has not declined to the extent that specialist support is required. However, the care of such patients requires careful integration between GPs and specialist units.

Chronic kidney disease (CKD) is common in the general population, with about 10% being classified as having CKD. The common causes are diabetes and vascular disease, but rare conditions can also affect kidney function. For the majority of people with CKD, it will not lead to kidney failure, although it is associated with complications such as anaemia and an increased risk of cardiovascular events (heart attacks, stroke). In the last 5 years there has been considerable education delivered to primary care, most of which has come from specialist centres, about the diagnosis and early management of CKD. This has been to address three core issues:

1. The recognition of CKD
2. Optimal management of CKD to reduce the risk of kidney function declining
3. The recognition of more complex problems in association with kidney impairment, including those patients with declining function that might result in kidney failure

To put the demand for specialist renal care in perspective, for every 1000 patients that a GP is responsible for, 100 will have CKD. However, only 2 will have a potential need for dialysis and only 2 will have kidney failure. It is these patients that require more complex clinical care, for which primary care have neither expertise nor resource.

### ***Specialised services***

The planned reforms to the NHS as set out in the White Paper *Equity and Excellence: Liberating the NHS*, place great emphasis on decision-making and prioritisation at local level. Whilst the Kidney Alliance is not against this principle, we are concerned that this would not be suitable for some aspects of kidney care, notably specialist kidney services such as dialysis, and that these services should not be subjected to local prioritisation processes that could introduce unacceptable variation in provision and access.

We are concerned that insufficient attention is being paid to the specific requirements of people requiring or potentially requiring dialysis. This could result in continuity of care being replaced by a transactional arrangement that may be in a GP consortium's financial best interests, but which might not be in that of the patient.

Moreover, the care of a patient who is either on or is being prepared for dialysis is not just a matter of the performance of a single treatment, but a complex care package across many disciplines. For example, a single patient with kidney failure may, in their lifetime, have a transplant, need peritoneal dialysis and then following a second transplant require haemodialysis. During that entire time, medical, nursing, dietetic, pharmaceutical and social expertise would all be required.

Situations such as this require a high degree of vertical integration to ensure that patients have access to life-saving care when they need it. By far the most effective and efficient way of doing this is to maintain all of these specialised services within a nationally/regionally commissioned set of care that allows the flexibility required. If these services were to be fragmented by the introduction of GP commissioning, the Kidney Alliance is concerned that onward referrals would be slowed down, resulting not only in reductions in efficiency but potentially putting lives at risk.

The Kidney Alliance believes that it is essential that services for dialysis, acute kidney injury and kidney transplantation all remain within a specialised kidney care service, commissioned nationally, unless or until another arrangement is shown to deliver better quality, outcomes, continuity, capacity and efficiency.

The specialist nature of each service, combined with the complex, individual pathways followed by patients result in commissioning and funding requirements that are better-served by a central approach that is capable of dealing with the financial risks, can plan strategically over long periods and has the specialist knowledge to provide high quality services efficiently. These requirements include:

- Detailed long term strategic planning, beyond the scope and timescales that GP Consortia will need to follow to ensure the fiscal requirements placed on them are met. Despite a volume of opinion from pathfinder consortia that a move to biennial budgets would be beneficial rather than the current focus on an annual budget, there appears to be resistance from DH. However, even biennial budget planning would be much too short term for effective dialysis service planning.

- Significant capital investment in specialised equipment and facilities that, in order to achieve the best value for money, is likely to require an approach beyond the boundaries of GP Consortia (even where several work together).
- Careful geographical placement involving consideration and prioritisation at a higher level than an individual GP Consortium. NOTE: whilst the co-operation between several Consortia might appear to overcome this point, it should be remembered that such partnership is likely to be based on broader reasons existing between the member Consortia: whilst such reasons may be valid, they are likely to be different from those that need to be taken into consideration at a strategic level when designing a dialysis service. Therefore, placement of services geographically is likely to suffer unless carried out strategically and isolated from other more local influences.
- In light of the points above, the level of financial risk for individual or groups of GP Consortia would be too great. It is therefore important that the Government recognises the benefits of pooling financial risk across a region (and with a more strategic view) in order to be able to make long-term investment in a comprehensive set of services for kidney patients.

#### ***Need for integration with other kidney care***

Not all renal medicine falls under the category of specialist services; it is important to remember that chronic kidney disease (CKD) is dealt with in primary care. However, renal replacement treatment (the care of patients who are progressing towards or have actually reached total kidney failure) is a specialist service and has been so for many years for valid reasons.

The integration of specialist care for kidney failure alongside that provided by GPs for chronic kidney disease has been generally good. Likewise the vital services that provide direct support for dialysis, ensuring its benefits are maximised (such as patient counselling) have generally been accessible and integrated.

The Kidney Alliance strongly believes that the integration of both these elements of care must continue. We are concerned that the increased probability of local variations in services due to the effects of localism will place such integration under threat in some places. Therefore, where the outcomes of a specialist treatment depend (at least in part) on an additional service, we believe there must be some guarantees on the continuity of the additional services.

In addition, the complexity of specialist kidney services means they require a much greater degree of integration than many other equivalent services. This encompasses:

*Vertical integration* throughout the care package so that patients can switch between diverse but related services such as peritoneal dialysis, transplant and haemodialysis easily and as required. Since kidney disease is so closely linked to other major conditions such as diabetes and heart disease, there needs to be some consistency in the design, commissioning and placement of services across each of these. For example, a person who undergoes heart surgery may require dialysis, which cannot be provided if dialysis services have been fragmented and have moved outside the hospital specialist centre.

*Temporal integration* throughout the care pathway so that the progression of individual patients is carefully thought through. For example pre dialysis care for patients is very important and is best carried out by specialist units who will eventually look after the patient. Another example is end of life care. GPs do not have the skills to deal with this. Without such integration, there is a risk that patients will not be progressed when the need to be. Later referral generally means poorer outcomes and more expensive treatment

### ***Transplantation***

Specialist kidney care includes kidney transplantation along with dialysis and acute kidney care. There are 19 transplant centres in England. They are geographically co-located with dialysis and other specialist renal services; they share the same specialist staff and are provided from the same pool of hospital beds. They normally cover populations of approx 3 million. Care is multi-disciplinary and requires a number of highly specialised skills that are found in few PCTs. For example kidney transplantation involves a high proportion of live donors who are prepared to give one of their kidneys to a patient. This requires huge sensitivity and a lot of counselling support and specialist investigation of potential donors. Providing these specialised services via individual GP consortia would not be cost-effective. For example some types of dialysis programmes such as peritoneal dialysis and home haemodialysis require specialist training programmes and specialist nursing care.

The needs of a patient with progressive renal failure will vary throughout their lives and they may progress through several treatment modalities until they die. Thus the patient may start in a specialist pre dialysis clinic, progress to peritoneal dialysis, have a transplant after 2 years, have that transplant fail after 10 years, return to haemodialysis for 4 years, have a second transplant and die of a heart attack 8 years later, having spent a total of 22 years on renal replacement treatment. Therefore an adequate service for renal replacement treatment must be capable of providing all modalities: GP consortia will not be capable of doing so because the numbers of patients would be too small; they lack critical mass and thus unit costs would be prohibitively high.

The Kidney Alliance is an umbrella group of patient and professional organisations working in renal care - Association of Renal Industry, Association of Renal Managers, British Association for Paediatric Nephrology, British Kidney Patient Association, British Renal Society, British Transplant Society, Kidney Research UK, National Kidney Federation, Renal Association, Renal Nutrition Group, Royal College of Nursing.

### ***Decisions based on understanding the services, not on mathematical definitions***

Whilst many specialist services are intended for people with rare conditions, this is not always the case. For example, where patient numbers have grown (as in dialysis), the specialist characteristics of the services often do not change. Despite the increased numbers, the patient care package still has the same high level of complexity (as described above). Therefore, changing the way they are commissioned purely on the basis of numbers would be inappropriate.

Although the size of population from which commissioning takes place is one factor in the definition of a nationally commissioned specialised service, it is made clear that this should only be used indicatively and not prescriptively. Under the current definition, therefore, any use of the number of people who are likely to require the service in a rigid way as a decisive

factor in excluding a service from specialist status would be inappropriate. This could only be changed if the definition were to be revised and that would need to involve widespread consultation. Likewise, a prescriptive use of the number of provider units would be inappropriate.

The Government must not allow the rigid adherence to mathematical definitions such as population size and number of treatment centres to exclude services from specialist commissioning, whose past and continuing success is founded on the way specialist commissioning has provided a stable environment in which they have been able to develop. The needs of such services do not necessarily depend on patient numbers and could not be met by GP consortia commissioning.

It is very important to look carefully at the nature of specialist services in order to understand the factors affecting quality, outcomes, cost and efficiency that make them specialist services requiring regional or national commissioning and that would be detrimentally affected if they were to be commissioned in a different way.

When considering dialysis as a specialist service, the Department of Health should also place emphasis not only on the characteristics of the service, but also on the particular requirements of patients who have entered the pathway of renal replacement, a pathway that will continue until they die and which may last for decades.

The definition of a nationally commissioned, specialised service uses the size of population in the area from which commissioning takes place. The figure used as a guide is a population of 1 million, and services are considered specialised if the figure exceeds 1 million. This is often treated as a rigid threshold below which services should lose their specialist status. However, the figure is intended as a guide and interpreting it rigidly can lead to erroneous decisions. For example many central tertiary units currently manage more than one dialysis unit and many of them manage up to 5 satellite units often based in local DGHs. They operate as hub and spoke services with specialist services provided at the tertiary centre and nephrology and dialysis operated as an outreach service in the DGHs. They commission as a single provider and may cover a population which can often be as high as 2-3 million.

In addition, the number of units at national level providing services influences its specialist status. Notionally the crucial cut-off seems to be 50 units above which a service is no longer classed as specialist. The number of specialist renal units appears to stand close to this figure. However, since many commission as clusters, the actual denominator i.e. the number of units which are directly commissioned as providers of renal services to the PCTs is much lower than 50.

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