



*From: The President*

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#### RENAL ASSOCIATION RESPONSE TO WHITE PAPER CONSULTATIONS: Commissioning for Patients; Local Democratic Legitimacy

The Renal Association is the professional body for nephrologists and renal scientists in the UK. The great majority of consultant nephrologists in the UK are members. The Renal Association operates the UK Renal Registry, an electronic registry that collects data on all patients receiving Renal Replacement Therapy (RRT) in the UK and provides detailed annual reports, including several outcome measures. The number of patients with established renal failure requiring life-long expensive treatment with RRT is destined to continue to rise for at least the next decade, creating major financial pressures within the system; nephrologists therefore have a vested interest in ensuring that money is spent as efficiently and effectively as possible so as to optimise outcomes for this group of patients,.

We welcome the plans to remove waste and duplication from the commissioning process.  
We welcome the plans to transfer the major responsibility for the commissioning of healthcare from managers to clinicians.  
We welcome the proposals that local authorities have a formal role in commissioning consortia.

Many aspects of the care of patients with advanced kidney disease are complex, and are rightly seen as the province of specialists. Such aspects include the planning for, and provision of RRT (haemodialysis/haemodiafiltration, peritoneal dialysis, and kidney transplantation) and decision-making around whether or not a patient should undergo renal replacement therapy. For this reason we welcome the proposal that RRT remains within the Specialised Services National Definitions Set.

However, nephrologists also have expertise in the management of complex disorders affecting the kidney, including the differential diagnosis and management of disorders causing acute kidney injury, electrolyte disorders, and severe hypertension; renal vascular disease; glomerulonephritis; renal involvement in systemic diseases such as vasculitis, SLE, and myeloma; and tubular disorders, both genetic and acquired. Many of these conditions are not part of the Specialised Services National Definitions Set, and we have some concerns that GP consortia, particularly if relatively small, will not have sufficient experience to know how to manage these conditions; and also that consortia will mistakenly assume that, because RRT is commissioned centrally, they can safely ignore other aspects of the care of kidney patients. We are particularly concerned that adequate arrangements are in place to commission the pathway for care of patients who opt, as a result of shared decision-making, not to undergo

RRT. Lastly, nephrologists care for significant numbers of children and adults with rare disorders, many of which require life-long complex care. As the Chief Medical Officer pointed out in his 2009 Report, rare conditions are common, but each condition requires its own pathway. For these reasons we consider it essential to build in to the proposals an expectation that GP consortia will work in partnership with local specialist services. At present, there is scarcely a mention of specialists in the framework, and no proposal to replace the current requirement that PCTs consult with local specialist services during the between primary and secondary care.

Many secondary care paediatricians would not feel competent to manage children with complex disorders of the kidney as the conditions are rare and require highly specialised treatment and thus care is provided shared care arrangements between the secondary and tertiary centres. It is therefore difficult to imagine that GP consortia would have sufficient expertise and therefore it is extremely important that services are commissioned through children's kidney networks which incorporate community and hospital based teams both locally and at the tertiary centre.

Chronic kidney disease is a life-long condition which may shorten life and may be associated with progression to established renal failure, which by definition is fatal without RRT. Once RRT has been started, a patient may survive for many years (albeit with reduced life expectancy compared to those without kidney failure) and may undergo several transitions between modalities of treatment. During all of this time, a patient's care is shared between hospital-based and community-based settings. Many patients with kidney disease have other co-existent conditions, such as arterial hypertension, diabetes mellitus, atherosclerotic cardiovascular disease, and often require advice from specialists in other disciplines as well as from their GP. Because of the complexity of the patient pathway, there are numerous points at which information transfer can fail, and numerous opportunities for improvement, including financial savings, improved safety, greater patient empowerment, and improved clinical outcomes.

Our major concern is that the proposals in the supporting documents for the White Paper do not go far enough in describing how to achieve these gains. We are confident that the same considerations would be equally valid in other chronic diseases that require some specialist input.

Specifically, the present system of payment by results can provide perverse incentives to increase or maintain activity in secondary care settings. For instance, seeing patients in an outpatient clinic attracts a tariff, whereas providing advice to a GP or a community-based nurse specialist does not. Nephrologists are keen to be able to contribute to a system of care that provides the most effective interventions, at the lowest cost, in the setting most appropriate to the patient. To achieve this would require that the care pathway was commissioned across the spectrum of primary and secondary care, with the involvement of both community-based and hospital-based team nurses, doctors, and allied professions, as well as social care. Such a pathway would involve an integrated information system to ensure seamless transfer of information (for instance, relating to prescribing decisions and laboratory test results) and should be designed to maximise patient empowerment by provision of information to the patient to support shared decision-making. Some managed care networks are beginning to build such pathways. The present proposals, in which primary medical services are commissioned centrally by the NHS Commissioning Board, and secondary care is commissioned by GP consortia, will make the design of such an integrated pathway very difficult, and risks perpetuating the wasteful division between primary and secondary care.

We are very concerned about the absence of any mention of teaching or research in the proposals. Developing the next generation of clinicians, and developing new treatments and implementation strategies for existing treatments, is an essential part of healthcare. We are concerned that GP consortia, operating under severe financial constraints, will instead see research and teaching as optional extras.

Lastly, we are concerned about planning blight between now and the full operation of GP consortia.

We hope that these comments are helpful.

Yours sincerely

A handwritten signature in black ink, appearing to read 'CRV Tomson', is positioned above the typed name.

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