Kidney Alliance response to the NHS Commissioning Board Draft Mandate.

The Kidney Alliance is an umbrella organisation whose membership includes major patient, professional and research organisations in the kidney community. Our members include the British Renal Society, Renal Association, British Kidney Patient Association, Kidney Research UK, National Kidney Federation, British Association for Paediatric Nephrology, Association of Renal Managers, Renal Nutrition Group, Royal College of Nursing.

The Kidney Alliance aims to promote high quality treatment for all patients with kidney disease on an equal and uniform basis throughout the country. We work with patients, healthcare professionals and policymakers, within Government and the Department of Health, at the national and local level, to achieve this.

Our response focuses on core objective 21 and its associated question, which considers commissioning. It also includes other more general points which relate to outcomes for people with kidney disease. Our fundamental concern is that the strategic nature of the mandate does not provide sufficient detail to make an assessment of its likely impact on specific therapy areas. At this level it is at least possible that whilst an overarching outcome measure for the NHS could improve, its equivalent measure within some individual therapy areas might not. We would like to see a clearer safeguard to ensure that the performance of the NHS Commissioning Board will be assessed at this, as well as at overall NHS, level – whether commissioning is carried out nationally or through the CCGs.

Kidney disease is common, harmful, and can be treatable if detected early. It is estimated that up to 1 million people at risk of kidney disease have not been identified. People with kidney disease are very likely to be at risk from a range of cardiovascular conditions including stroke, heart disease and diabetes. Their care in total represents around £1.5bn per annum and has a significant potential impact on several domains both directly and indirectly because of its inherent risk factors.

Those who do progress to end stage kidney failure need to be treated by specialists in secondary and tertiary care who can not only provide the necessary treatment but also deal with complications as they arise; these specialists represent a multi-disciplinary team of professionals from nurses to dieticians, pharmacists, counsellors through to vascular surgeons and renal consultants. The integration of this team must be underpinned by appropriate specialised commissioning that facilitates seamless care.

After reading the mandate documents, we perceive that there is relatively little mention of specialised services and we remain concerned that this does not provide an effective safeguard against the complex pathway for kidney patients becoming

fragmented now or in the future as a result of changes to commissioning arrangements. There remains a risk that a gap will develop between CCG and specialised commissioning (both in knowledge and in practice) through which will fall essential elements of care.

We should like to suggest that more detail on long term conditions is provided, and that a clear definition of accountability for the work of the NHS Commissioning Board for the quality of the commissioning and delivery of consistent specialised services is built into the mandate.

Question 6. Do you agree that the mandate should be based around the NHS Outcomes Framework, and therefore avoid setting separate objectives for individual clinical conditions?

The mandate states that it should be 'based primarily around outcomes and the NHS Outcomes Framework – .... that there are other important objectives that the Government will want to set'. As the Outcomes Frameworks are still very new it is not possible to predict whether this approach is appropriate, but the principle is sensible. However it is not possible fully to respond to this statement without understanding what the other objectives are.

As the mandate links with the Outcomes Framework, the Alliance would like to see an assurance that reviews of not only the overall NHS outcomes but also therapy area-specific outcomes be undertaken in the same timescales.

Effective commissioning
Objective 21: As part of the work to improve healthcare outcomes, put in place arrangements to demonstrate transparently that the services commissioned by the Board are of high quality and represent value for money.

As kidney disease advances and people approach kidney failure, they require a complex set of highly specialised services including dialysis and transplantation. 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.

The Kidney Alliance strongly believes that all specialised kidney services as set out in the Specialised Services National Definitions Set (version 3) must 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.

Question 12. Should the mandate include objectives about how the Board implements reforms and establishes the new commissioning system?

The Alliance believes that this is a crucial question relating to specialised commissioning but we would need to have more information on this point in order to provide comment. We should like to see detail on accountability for commissioning against the 5 domains of care, using the more rigorous approach with which CCGs will be measured. We should like to see annual publication of a report on how the Board is performing in its commissioning duties; and the clear demonstration of how feedback will be sought from patient groups. We should like to understand how such commentary will be used to monitor performance and what mechanisms it will use to intervene if quality is falling.

We should also like to understand primary care responsibilities for long term conditions.

The mandate states that 'Although CCGs are not responsible for commissioning primary care, they will have an important role in supporting the Board to improve its quality.... The Board will need to consider how to harness their expertise and enthusiasm to secure continuous improvement in the quality of these services'

The Alliance feels that that this statement is incomplete as it gives no assurances on how such improvements may be made. Commissioning of kidney services for early kidney disease is essential - kidney diseases are a spectrum of disorders across a complex clinical pathway. In its early stages, kidney disease is commonly managed within primary care and the Kidney Alliance supports this approach for early stage disease.