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General Remarks

We are concerned by the current proposals as we believe they risk undermining the introduction of GP commissioning - GPs will be required to commission not only services for which they have the best knowledge and understanding (technically and locally) but also services that are too complex and specialised for their technical knowledge and for which local knowledge is less important.

We believe that there should be national accountability for specialised services in order to prevent variation, that the current support system provided by the renal networks should be retained and that great care must be taken to ensure that patients with kidney failure see an improvement in their treatment choices.

Your views: Choice and competition

How can we best ensure that competition and patient choice drives NHS improvement?

Which are the types of services where choice of provider is most likely to improve quality?

In the case of specialist renal services, consistency of service to a high standard, provided to an adequate capacity, is key. There are some services where choice of provider does not necessarily result in the best quality, and providers for kidney dialysis and transplant patients must be specialist. The KA believes that renal services for those with or approaching kidney failure should be funded independently of GP Consortia and commissioned as national specialised services.

In these instances choice is more focused on the range of services provided (e.g. the ability to access home dialysis if appropriate). The highly specialised nature of the range of services that are required by kidney patients who have (or who are approaching) renal failure, or who have acute kidney injury means that introducing provider choice in this area (or even to a part of it) must be made with great care as failing to do so could seriously reduce quality.

Providers of renal replacement therapy should ensure that patients have equitable access to all options for renal replacement therapy. For example, patients should not have reduced choice as a



consequence of receiving haemodialysis from an in-centre provider, with a reduced chance of moving to a home based therapy,

What is the best way to ensure a level playing field between the different kinds of provider who could be involved?

The KA welcomes different kinds of provider where appropriate, so competition in specialist providers in provision of kidney dialysis units could, for example, be appropriate. However, such providers should be required to adhere to, and be measured against established Renal Association and NICE guidelines and Quality Standards, with a Service Level Specification which has included and taken account of patient views. Such services need therefore to be commissioned by specialists. Costs and tendering processes should be open and transparent to the public for interested patients, support groups and professional associations. A good recent example of this is the specification for procurement of renal services in the East of England.

This should be done in a timely fashion ensuring that patient services do not suffer damaging delays in provision.

What else can be done to make patient choice a reality?

It is not realistic to expect all patients to gather sufficient information to make informed choices, as many members of the public will not have the time, interest and ICT ability to make informed choices.

In primary care, patients with Chronic Kidney Disease should be told that they have the condition, and offered information on which to make lifestyle choices so that, if possible, they can become more involved with their care and possibly delay or prevent the progression of their condition. The variation of detected against expected prevalence of CKD in different parts of the country indicates that this choice is not yet available to a sufficient number of patients.

The Kidney Alliance supports choice of modality of treatment for end-stage renal failure patients. It believes it is essential for all choices to be carefully explained to the patient and their carers; such choices vary between types of dialysis, choosing not to have dialysis (conservative kidney management), and also whether to be considered for transplant if medically suitable. It notes that there is variation in services which can be offered to those with kidney failure in different parts of the country, and believe that this should be addressed to provide true choice for patients. (See comments in previous section).

Which are the types of services where choice of provider is most likely to improve quality?

Patient choice of provider exists in theory but professionals need to be encouraged to be open about alternatives when their own interests are vested. There could be a conflict of interest for patients who need referral into secondary care, but who attract income for GP consortia. It is critical for healthcare providers to collaborate in support of patients rather than compete with each other.

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Patients receiving care from a range of providers encounter different patient record systems which don't communicate with each other. Provision of patient record systems where information can be exchanged is likely to reduce duplication and improve quality. Such improvements can result in fewer visits to hospital and inappropriate referrals. The use of technology to enable patient data collected in primary care to be reviewed online so that the secondary care specialist can decide remotely whether a further consultation is needed would be a notable improvement.

Patient choice cannot be effectively implemented in the case of emergency services or emergency admissions to any hospital departments. Many patients will be unconscious or too traumatised to exercise choice – decisions made by expert professionals will often be the only options here.

Your views: Accountability and patients

How can we make the NHS properly accountable to the public, and make sure that patient involvement is at the heart of its decision making?

General remarks

The Kidney Alliance believes in NHS accountability to the patient. Local or national decisions, and the information on which they are based, should be transparent, open to scrutiny, but use a process whereby patients can have influence without introducing paralysing delays to decision making and unacceptable amounts of additional work.

It seems to us that a balance has to be struck between consultative decision making and permitted autonomous decision making where complex choices have to be made rapidly, for example to avoid unnecessary mortality.

There is a support system in place in the form of the **renal networks**, and the Kidney Alliance would like to see an assurance that these networks will continue. Where there are existing structures which work well for primary and secondary care, we cannot see any reason why they should be removed.

Imbalance between local and national accountability could undermine GP commissioning

Transparency and accountability do not automatically come from local decision-making and prioritisation. Although the perception might be that local decision-making will be more transparent because it takes place closer to the public, the reality is that it requires sophisticated communications systems, processes and safeguards to ensure that accountability is achieved (and is seen to be achieved). GP participation in clinical audits, such as the National Diabetes Audit, carried out in conjunction with the NHS Information Centre, is vital for accountability.

Some processes may be appropriate for many decisions on health services and priorities. However, there are some for which this will simply not work. We are encouraged by the fact that the Government has recognised this by maintaining a process of specialised commissioning, but we are very concerned that the balance between local GP-led decision-making and that at national level is



too heavily weighted towards GPs at present. We see that national accountability by the Secretary of State is necessary to ensure that the balance is weighted appropriately towards specialised services.

We believe the current proposals risk undermining the introduction of GP commissioning because it means that GPs will be required to commission not only services for which they have the best knowledge and understanding (technically and locally) but also services that are too complex and specialised for their technical knowledge and for which local knowledge is less important.

Specialised Kidney services are a good example of this. They comprise a complicated set of highly specialised services (including kidney transplantation and acute kidney injury as well as highly technical ones such as haemodialysis and home haemodialysis). Patients using services at this level often require rapid referral from one to another in life-threatening circumstance. For example a patient whose transplant is not successful must be immediately supported with dialysis. Therefore these services must be highly integrated and referrals made between services by specialist doctors. The involvement of GPs in this would be inappropriate as they would not have sufficient knowledge to contribute to decisions and such consultation would introduce life-threatening delays. Many rare conditions are being considered for commissioning in this way – simply because they affect small numbers of patients and detailed knowledge of the disease and its treatment is retained by a few specialists and not by GPs.

GPs should not be accountable for specialised services on which they have limited technical knowledge

Rarity of a disease is, however, not the only reason for taking such an approach. Complex, highly technical services, even when accessed relatively frequently, are managed by specialist clinicians and GP knowledge of how to provide and carry them out is limited. It seems to us that it would be unwise to make GPs accountable for such services when their knowledge and skills lie elsewhere.

The Kidney Alliance believes that transparency and accountability for these kinds of decisions is important but that, fundamentally, they should be lifted out of local, GP accountability where they would drain valuable time of GPs away from decisions on which they are far more qualified to make. This is one reason why the Kidney Alliance believes specialist kidney services should be commissioned at specialist level, funded by a direct budget.

Decisions on the NHS budget at local and national level must be informed by proper consultation with patient organisations

Patient organisations have a very important role to play in informing decision-making processes locally and nationally. The Kidney Alliance would like to see greater emphasis placed on all decision-making bodies to demonstrate that they carry out proper consultation with relevant patient organisations. We believe that local bodies should consult with local representatives of patient organisations where possible, but if this is not possible, they should approach these organisations through their national offices. We have noted comments during the listening exercise on a Citizens'

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Panel, but there has been no detail on how this may work and so we are unable to properly comment.

Local freedom in making decisions must be balanced not only by local accountability but also by a strategic overview of services to which local decisions must contribute and for which the Government remains accountable

The Kidney Alliance has concerns regarding the future consistency throughout the country in the level and quality of services commissioned by GP consortia. Whilst we are not against the principle of shaping services according to local requirements, we believe that some specialised services require a much more strategic approach to ensure that the current and future needs of patients can be met, particularly where there are associated significant costs for capital investment in technology.

Therefore the Kidney Alliance's concerns are both about whether or not sufficient has been done to enable to the NHS to take accountable decisions at local level and also about whether sufficient mechanisms have been planned to ensure that a national picture of services can be built up, identifying key strategic needs that should be addressed and thus helping to support the ultimate accountability of the Government for NHS services. This is different from the monitoring of performance via the Outcomes Framework. For some services, this issue will not arise, as they will be commissioned at national level.

Your views: Education and training

How can we make sure that NHS staff in the future have the right skills to meet changing patient needs? Are the arrangements we have proposed for education and training the best ones to ensure this?

Will the proposed changes to the education and training system support the aims of the modernisation process?

The proposed changes can support the aims of the modernisation agenda if a truly integrated system is created which will develop the whole workforce delivering high quality education and training. It is important that locally identified needs informing the education and training agenda are closely linked to the national picture.

The system has to have clear and transparent governance at all levels and the outcomes framework must be aligned to patient services required. There needs to be inclusion, engagement and participation from all stakeholders and that will include the independent and social care sectors.

It is essential that education and training are properly recognized and supported within the overall plan. To do so requires appropriate resourcing of training and education for all staff groups within the NHS. This includes funding and time for individuals to receive and deliver training and teaching. There needs to be a rebalancing between educational and training methodology. At present that

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balance is skewed towards educational methodology and is not valuing experiential learning and training.

How can health professionals themselves take greater ownership of the education and training of their own professions, whilst meeting the needs of healthcare employers?

It is important that the professionals themselves recognise that there is a great deal in the current system which works well and that they can be built on to improve the training and education agenda to even higher quality. Both the professionals and the employers need to work in partnership to develop the changes needed to ensure that a highly skilled well qualified workforce is produced. The development of a fully inclusive partnership can incentivise the professionals to take ownership. The development of silos within the professions must be prevented by partnership working between the professions. New roles developed by the professionals themselves that are meeting the needs of healthcare employers and ultimately the patient care pathways can also provide an incentive to take further ownership.

Training and education need to have better recognition within the job plans of health personnel. There should be a greater utilisation of 'bedside' training, incorporating training and teaching into regular clinical care.

How can we ensure that the values of the NHS are placed at the heart of our education and training arrangements?

The values of the NHS are also the values of healthcare providers across the healthcare and social care sectors and must be part of the culture of healthcare education and training. They should form the fundamental building blocks of the whole system of healthcare education and training. The proposed changes will fail if this is not achieved.

How can we best combine local and national knowledge and expertise to improve staff training and education?

There has to be clarity of policy, function and accountability of the Skills Networks and Health Education England (HEE) and the governance has to be transparent. There must be a close partnership working between them to ensure that there is a flow of knowledge and expertise both ways to facilitate access to both on local and national level. The sharing of the knowledge and expertise cannot happen if education and training is happening in isolation. A transparent system of sharing must be in place. It is important that the sharing is all inclusive of the independent sector. The representation of the independent sector on the Skills Networks as they are proposed to be legal entities needs further discussion as to how this will work in view of the diversity of the independent sector.

Your views: Advice and leadership



How can we ensure that advice and leadership from NHS staff themselves on improving services and tackling patient needs are at the heart of the health service?

What early action is being taken in your area to improve quality of services through clinically-led commissioning? What is working well?

It is absolutely essential for a complex pathway of care, such as renal disease, that clinically led networks (involving primary and secondary care) are maintained and enhanced. Renal networks across England have been successful in engaging secondary care, with perhaps less success in engagement of primary care. This is in part due to the gap between PCT management systems and GP themselves. However, they have been very successful in improving quality across the renal pathway – for example vascular access in East and West Midlands.

Within East Midlands, it is now proposed to merge the Cardiac, Stroke and Renal networks, with Diabetes involvement, into a single vascular network. This will be clinically driven, looking at both specific and cross cutting issues, and involve primary and secondary care.

How can commissioning consortia best engage and take on views from across the range of health professions in taking their commissioning decisions?

Within renal, the NICE CKD quality standards act as a template for the pathway and should form the bedrock to assist in commissioning decisions. However, GP consortia need to accept that some specialist clinical areas will require support. Clinical networks in the relevant areas should configure themselves to provide that support.

What more could we do to ensure that commissioners collaborate to join up services to fit around the lives of patients and carers, and the particular circumstances of certain conditions?

Support and enhance strategic networks particularly in areas of long term care, such as renal disease.