Paper 2: NHS (Midlands) Renal Service Review letter and HWR response

(Received from NHS England/Improvement 5/8/20)

Renal Service Rapid Review

Over the last few weeks, clinicians, managers and commissioners working in renal services have reviewed every area of the service, and looked at opportunities to improve outcomes for patients.

COVID-19 impacted primary care, out-patient appointments and inpatient services. It also created the environment for better collaboration which will be a key requirement for service restoration and recovery.

Around half a million people aged 16+ in the Midlands have chronic kidney disease (CKD). The majority of these remain under primary care follow up, but each year, in England, an estimated 45,000 premature deaths occur in people with CKD. And for those people who identify as from Black, Asian and minority ethnic communities, they are five times as likely to develop CKD than people in other groups.

The rapid review makes a number of recommendations, which will now be developed in partnership with clinicians, managers and commissioners before system-wide agreement is sought.

1. **Formalisation of a funded Midlands Renal Network**

Clinically driven to support and implement innovation, the intention is for the Network to act as an enabler of integration throughout the renal pathway and with other related clinical services. It will also disseminate and implement best practice across the Midlands and reduce inequality of access.

2. **Transplant Capacity Model**

A number of potential models will be considered by the Real Network – to include a shared waiting list and passporting staff and patients (fulfilling all governance and protocols) to promote more equitable access as there are significant differences in waiting times throughout the region.

3. **Pathway Integration**

The Renal Network will consider how commissioners (CCG and Specialised) and providers can work more closely together to improve services and outcomes – for instance reduce the number of late presentations, the number of secondary care referrals and waiting times. A number of pilots will be reviewed – for instance the sharing of primary care medical care records and the funding of nurses to work out in the community. Commissioners support is needed to review options for transport and personalised budgets using Population Health Management methodology.

4. **Equitable Access to Home Therapies**

There is considerable variance in the utilisation of home therapies even though the infection risks are much less for home dialysis rather than in-centre. The intention is to develop models to share learning around home therapy services, and to create a dedicated team to improve education, support training and provide initial set up.

5. **Identification of Transplant Patients in Renal Centres**

The intention is to improve the identification of patients for transplant being treated in renal centres through access to staff with specialist transplant knowledge

6. **Providing patient centred care**

All of the recommendations being made in this review support patient centred care but this looks at the mental health support we can offer to patients. Multiple studies have found that transplant and dialysis patients have depression and anxiety and that these can reduce medical adherence and lead to less positive outcomes. It is our intention to develop a workforce strategy to ensure patients are at the centre of care.

7. **Recovery of Vascular Access Services and Diagnostic Services**

In order to improve access to vascular and diagnostic services, a range of measures are being considered to allow more patients to be prepared for either dialysis or transplants. Mutual aid and day case surgery are all being investigated. The review recommends that providers identify and protect capacity for vascular access so that no

patient experiences unnecessary delays. It is also recommended that transplant and CKD patient diagnostic requirements are included in trusts' plans for restoration of diagnostic services.

8. Renal Services in Adult Critical Care

Many COVID-19 patients required renal replacement therapy (RRT). It is our intention to ensure that workforce in adult critical care can support current and future capacity for RRT.
The network is developing a workplan to support the development of these recommendations which includes options appraisals, review of upcoming guidance (including GIRFT) and development of baseline capacity models.

We will be in touch with more updates as the review progresses.
Midlands Regional Renal Network
NHS England and NHS Improvement

Healthwatch Rutland email response, sent 6/8/20

Renal Services in the Midlands

Thank you for forwarding the results of the rapid review and associated letter to Healthwatch Rutland. We have several comments:

1. The recommendations do not mention any education or information programmes for those patients approaching end stage renal failure (ESRF) and the options, benefits and drawbacks of the different forms of renal replacement therapy. Such programs could also include lifestyle advice, including dietary restrictions, medications, exercise, state benefits etc.

2. We note that the aim is for patient-centred care. To further this, we would suggest a focus on better communications between primary and secondary care with the patient being kept fully informed along all care pathways, including proposed dates and venues for the commencement of dialysis. We have been told by a patient that existing communications are so lacking that his depression and anxieties increased as he was consistently 'left in the dark' and felt totally disempowered.

3. There is no mention of paediatric renal services. We understand that the University Hospitals of Leicester do not offer paediatric renal facilities so Rutland patients have to travel to Nottingham – a lengthy journey, particularly for those in the east of our county

4. We understand that there are no haemodialysis facilities in Rutland and adult patients must travel to Leicester, Corby or Loughborough – depending on the availability of 'slots'. Being a patient on a haemodialysis program is very arduous and restrictive. To travel 20-30 miles three times a week to then spend up to four hours on a dialysis machine, adds to physical and mental stresses. Could there be some consideration given to having satellite dialysis units in more rural areas as not everyone is able to or wishes to have home dialysis?

On a local note, we know that the University Hospitals of Leicester are reconfiguring their level 3 Intensive Care (ICU) services with the building phase now approaching completion. Part of this programme is to move the renal transplant services to Glenfield Hospital, with nephrology and outpatient services remaining for up to six months at Leicester General Hospital as 'a separate business case'. We are currently unaware of the progress of this 'separate business case' or the plans for co-locating nephrology services at Glenfield Hospital, adjacent to the new transplant ward. We are concerned that if the services remain in two hospitals, each on different sides of Leicester, there will be serious consequences for patient safety. As you will know, nephrology and transplant services are intrinsically linked and the Full Business Case (appendix 22) for the level 3 ICU reconfiguration states that the services should not be separated for longer than 6 months.

We hope that these comments are helpful to you in considering how best to shape renal services in the Midlands.

Best wishes
Dr Janet Underwood
Chair, Healthwatch Rutland