

31st December 2024

Mrs Linda Lee
Assistant Coroner
Warwickshire County Council

Dear Mrs Lee,

Re: Response to Regulation 28 Report to prevent future deaths following the inquest into the death of John Frederick Doyle.

Following your email request received on 12th November 2024, the UK Kidney Association (UKKA; formerly the Renal Association) and the British Transplantation Society (BTS) have collaborated and produced the following recommendations in response to your concerns.

Contacting off-site specialists and sharing information

- We recommend that all hospital switchboards, Emergency Departments and relevant personnel have a master copy of local specialist centre contact details so any query at any time can be appropriately directed.
- We recommend that all staff are advised of internal escalation routes. Relevant clinical colleagues should be aware of internal escalation routes to clarify whether off-site specialist input is required. We would expect this to be achieved by asking the Consultant responsible for the patient's care or their deputy.
- We advise that electronic information sharing in real-time should be the gold standard for information sharing. In the case of kidney patients, we would expect to be informed about all patients admitted for care in another hospital or elsewhere in our own hospital who have chronic kidney disease stage 5 (CKD G5) or who are receiving dialysis treatment or who have a kidney transplant.
- We advise that Trusts review their processes to ensure that CMV results are available in a timely fashion. This involves considering the transport and turnaround of samples with prompt reporting in specialist virology laboratories as well as how to ensure that blood is taken in the correct blood tubes.

Accessibility to Renal Care Guidelines

- As access to Guidelines could lead to a misunderstanding of the significance and urgency of required actions; the critical action in this case would be to contact the Specialist Centre.
- Whilst we acknowledge that being well-informed can help with communication and care delivery, in this case we would advise that care be delivered by a Specialist who should not necessarily need to refer to the Guidelines.

Transfer of responsibility, care coordination and decision-making for patient location

- We recommend that when a Specialist Team is managing the care of a particular condition at a distance or on-site, they assume responsibility for recommending the best location for

care delivery. This may require careful negotiation in cases where multiple conditions are being managed.

- We recommend that the responsible Specialist Team is from the local specialist renal centre rather than the renal centre usually caring for the patient. If necessary, local specialists can liaise directly with the relevant renal centre.

Action points for the UKKA and BTS

Each organisation is to take the following actions.

1. Share recommendations with the kidney care and transplant communities.
2. Contact patient associations to assist with considering the role of patients and their carers in highlighting where their specialist care is undertaken/provided and who to contact.
3. Share with the Royal College of Physicians Patient Safety Committee.

As the UKKA and BTS do not have responsibility for the care of patients with other conditions who will be similarly at risk, we recommend that the Coroner considers how to escalate issues of specialist care provision in hospitals at a national level.

Yours sincerely,

[Redacted signature]

[Redacted name]

Co-Chair UKKA Kidney Patient Safety Committee
Consultant Nephrologist Newcastle

[Redacted signature]

[Redacted name]

Co-Chair UKKA Kidney Patient Safety Committee
Renal Consultant Nurse East Kent Hospitals University NHS Trust

[Redacted signature]

[Redacted name] on behalf of the British Transplantation Society
Consultant Nephrologist, King's College Hospital