

UCLH Trust response to PFD

The UCLH Trust response has been led by the Division of Infection, in recognition that the concerns raised by the coroner were principally about communication about the STEC outbreak investigation between UKHSA and the patient and family, a topic for which our Infection Prevention and Control (IPC) teams form the Trust's local expertise and point of contact, although a community outbreak investigation does not fall directly within their scope of practice.

We have sought input from microbiology and IPC colleagues as well as from our haematology team who lead on management of HUS/TTP and looked after the patient; and from the nursing leadership of the Intensive Care Unit.

We look forward to seeing the PFD response from UKHSA to understand if there is anything further that UCLH as a Trust can do in future to support issues to do with STEC outbreak investigations that involve our patients, as we are a national centre for TTP.

We recognise that it can be a challenge for patients and their families, as well as for the clinical teams looking after them, to provide to health protection teams the important information needed for an outbreak response. This is because the patients are ill, and because there are lots of inherent uncertainties in outbreak investigations. It is also important that there is some documentation in our electronic health records system (EHRs) that the health protection team have contacted the patient (see below). If the HP team visit then the UCLH nurses are generally happy to document this on EHRs and can certainly document a contact number for the HP team for ongoing queries; if it is a telephone contact that can be more difficult to implement as standard practice but we would endeavour to do so, hoping that the health protection team will encourage the UCLH staff to do so, in parallel

When patients are hospitalised, the health protection teams know to phone the nurse-in-charge of the ward (for HUS/TTP cases this is usually but not always ICU), to establish whether the patient is well enough to cope with a telephone call to go through the questions required for a timely outbreak investigation. Our nursing colleagues have reassured us that they always endeavour to support these consultations when they believe the patient is well enough to undertake the discussion, and exercise their expert judgment in supporting patients and their families as compassionate carers in this regard, if necessary involving the medical team in this decision.

Our IPC nurses' normal practice is to review actively infectious patients including e.g. with STEC on our wards and liaise with clinical ward staff. In addition, IPC nurses can explain what the infection means to patients and their families, especially if the patient/family requests such information, including how outbreak investigations generally proceed. This may include signposting them to the appropriate UKHSA patient info leaflets and how to contact the relevant health protection team for ongoing queries, and document this in the notes. We will reflect on this case and reinforce how we make relevant infection information available to patients and their next of kin, having clarified from UKHSA colleagues that the appropriate link to relevant patient information leaflets is on pages 59-66 of this document: <https://assets.publishing.service.gov.uk/media/63b84426d3bf7f26359c13b2/health-guidance-shiga-toxin-producing-escherichia-coli.pdf>