Introduction

Good governance is largely invisible; no one notices the errors that were avoided or the mistakes that did not happen. Instead, everyone focuses on what went wrong. One of the unsung highlights of the London Olympics was that no one died during the construction of the Olympic Stadium (Greece reported 14 fatalities in 2004 and Beijing reported 10 in 2008). The success in 2012 was no accident but the result of a concerted approach which, no doubt, was greeted by many with scepticism and the inevitable comments on ‘health and safety’. Certainly, there are all too many examples of people taking the rules to often ridiculous extremes and wrongly blaming health and safety legislation: such examples include children being banned from playing conkers unless they are wearing goggles, or hanging baskets being banned in case people trip and bang their heads. These and others are included in the Health and Safety Executive list ‘Top 10 worst myths’ on www.hse.gov.uk/myth/top10myths.htm

You get the drift of this. Governance is clearly important and is much more than just avoiding errors and mistakes. Processes, in the majority, have been developed to improve patient safety, and even if they feel unnecessary, can prove vital. Two deceased donors with the same blood group in the same hospital on the same day - likely? No. A recent incident however occurred following this exact situation. Those involved did not think this was likely either and an incorrect assumption was made leading to a ‘mix up’ in donor information. So please remember to use three points for patient identification and bear with the SNODs and Duty Officers if they seem pedantic and ask you to check. We know that at 4am with lack of sleep everyone wants to get things done, but this one minute check could prevent incidents that would have potential devastating consequences.

https://www.organdonation.nhs.uk/IncidentSubmission/Pages/IncidentSubmissionForm.aspx

Transparency of SAEARs Reporting

The HTA currently publish on their website details of Serious Adverse Events and Reactions (SAEARs) from all sectors they regulate. Whilst previously SAEARs reported by ODT to the HTA have not been published, to come in line with all other sectors these will now also be included.

ODT have worked closely with the HTA to ensure that the information in the public domain does not include any information that is identifiable to the area where the SAEAR occurred, be it Transplant Centre, Laboratory or ODT site. The information will be provided as a table in an annex within the HTA regulatory activity report, part of a series of reports which make up the HTA Authority meeting papers. An example of this table can be found on the HTA website here:
https://www.hta.gov.uk/sites/default/files/Papers_for_the_27_January_2015_Authority_Meeting_0.pdf

This change will not be publicised as such by the HTA, and the aim is to simply ensure clear transparency regarding reporting.
Pregnancy and Organ Donation

In a recent case, a pregnant woman who was 24 weeks pregnant suffered a catastrophic, non-survivable brain injury following a spontaneous intracranial haemorrhage. After careful deliberations involving the ICU team, the on-call obstetric staff and her close family, it was agreed not to attempt to deliver the baby or support the pregnancy. Rather, it was concluded that the patient's interests would be best served by treatment withdrawal. The patient had registered on the organ donor register, and her family were keen that organ donation should proceed. Although it was likely that the mother was brain stem dead, in light of the gestational age of the foetus a DCD pathway was considered most appropriate. After full discussion, life-sustaining treatment was withdrawn and maternal death was confirmed using circulatory criteria in the usual fashion. An obstetrician was present and confirmed foetal death by abdominal ultrasound approximately 30 minutes later, where after the retrieval procedure started.

The pregnancy guidance is being reviewed but the current process (MPD891) still stands.

Learning points

- Where possible, pregnancy should be diagnosed before organ and tissue donation is considered.
- Where a pregnancy is known, before organ/tissue donation is considered and the SNOD is involved, the clinicians must agree with the obstetricians and the family the most appropriate management for the mother and baby.
- If neurological death has been confirmed or if it has been agreed to withdraw life-sustaining treatment in the mother, then organ/tissue donation may be considered.
- If consent/authorisation is given for donation, the donation should proceed only as a DCD donation unless the foetus is already dead.
- An obstetrician should confirm foetal death before retrieval starts. The team may wish to observe a period of silence after foetal death has occurred.
- Any specific wishes of the family should be ascertained in regards to last offices with respect to both the mother and baby.
- All those involved should be made aware of the clinical situation and offered support during and after the retrieval.

Benefits and perils arising from the use of social media

Public support for organ donation comes from many sources: Increasingly we are seeing both families and friends of deceased organ donors and of recipients using social media to show how proud they are that their loved one has donated, and the benefits that solid organ transplantation gives to the recipient and their family.

Sometimes however, the content or timing of these public sharing of justified pride and joy has unanticipated consequences. For example, one donor family was recently upset when they received unexpected and unwanted press attention following a public thank you from the recipient of their loved one’s organs. In other cases, recipients were able to identify the donor family who then received information and comment that added to their grieving process.

NHSBT encourages good news stories to retain and improve support for organ donation but not if this causes distress to donor families or recipients. We know that no one ‘posts’ on social media or engages with the press consciously to upset others, however, the potential to do this needs to be highlighted by those health care professionals who support both recipients and donor families.
Working with the Coroner

Coroners and Procurators Fiscal (PF) have a clear jurisdiction to determine how and where an individual died. There are clear guidelines to when a patient should be referred to the Coroner/PF, and these include violent and unnatural deaths. Potential organ donors often die in these circumstances, and in these cases, whilst the actual cause of death is clear, such as a gun shot causing an unsurvivable brain injury, a referral to the coroner/PF would still be required because of the unnatural cause of the death. Please remember that the law governing referral to Coroner and PF differ across the four nations of the UK.

There have been a number of recent cases where the medical team did not feel the patient required referral to the Coroner as the cause of death was clear, despite the unnatural nature of the death. Organ donation proceeded and the Coroner became aware of the case at a later date and confirmed it fell within their jurisdiction. As well as impacting on the Coroner’s work, this late involvement of the coroner had potential to distress the family unnecessarily.

Most Coroners/PFs are keen to support a family or patients wish for organ donation to proceed, and whilst many cases require a post mortem and inquest to be held, they will agree to organ donation wherever possible. We are all keen to ensure that the important work of the Coroner/PF is not negatively impacted on by organ donation, and therefore it is important to ensure good communication at all times to enable organ donation to continue, and patients’ lives to continue to be saved, even when there is Coroner/PF involvement.

The responsibility of referring a death lies with the medical team caring for the patient, and not the SNOD. However, when discussing the referral with the SNOD, if appropriate, the SNOD may be able to facilitate the Coroner/PF referral.

Learning point

- The responsibility for referring the death to the Coroner/PF is with the medical team caring for the patient; it is not the responsibility of the SNOD although they can be asked to liaise with the Coroner/PF
- The SNOD should seek confirmation from the medical team regarding coroner/PF referral when donation is an option and may request the medical team to refer if it is felt the death falls into coroner/PF jurisdiction
- Even where a clear cause of death is present, if the cause falls into Coroners/PF jurisdiction, such as suspicious or unnatural, it is essential to discuss the case with the Coroner’s /PF office
- **When in doubt please refer!** It is better to discuss when unsure than for it to be highlighted following donation

Learning point

- Donor families and recipients have a right to have their privacy respected
- Recipients and their families should be made aware that social media and press coverage may cause inappropriate public attention and significant distress to the donor family during a very difficult time
- Recipient coordinators should advise recipients about the timing and content of postings on social media and of the potential unintended consequences for both the recipient and the donor families
- SNODs should work with donor families who wish to use social media to ensure that the timing and content would not cause harm or distress to recipients
- The Press Office in NHSBT is available 24/7 to support donor families and recipients who may be subject to unwanted media attention
The importance of utilising Patient Specific Points of ID

Reducing and, where possible, eliminating error in the matching of patients with their care is central to improving patient safety across the NHS. Errors that occur due to misidentification can have a range of consequences. Many of these will result in little or no harm, but some can result in serious, lasting harm and in some cases death.

The nature of the information communicated to and from all involved in the donation and transplantation pathway means that any incorrect data may result in serious harm to a potential transplant recipient.

There have been a number of incidents across the whole of the pathway that had the potential to have serious consequences for recipients if not identified. On all of these occasions the errors were noticed in time to ensure there was no impact, however, they all highlighted that the utilising of three points of adequate patient ID was not completed. One example of this was during urgent heart offering, when both parties confirmed the patient at the ‘top of the list’ had accepted. This led to the wrong patient being suspended from the urgent heart list as the Duty Office believed they had received an offer. This error was noticed within 24 hours, and on review the potential recipient, luckily, did not miss any offers.

To minimise the risk of misidentification, and therefore improve patient safety, all those involved in the donation and transplantation pathway should ensure that 3 points of ID are utilised to confirm either the potential recipient, actual recipient, organ or tissue donor’s identity to prevent any miss-communication or miss-understanding.

You may feel like a BT call centre on doing this, but the evidence is there to prove it works!

Learning point

- The National Patient Safety Agency (NPSA) has provided guidance on the approved core patient identifiers and how these should be utilised in practice

- All those in the donation and transplantation pathway should both be expected to provide and receive 3 points of patient ID at all times

If you have any comment, feedback or suggestion regarding the Cautionary Tales, please contact clinicalgovernance.odt@nhsbt.nhs.uk