- Ethical challenges Limitation of treatment 3; Withdrawal of treatment 2; Discharging home with TPN 2; Refusal of consent for surgery 1; Escalation of pain medication 1; Burden of treatment 1; Experimental treatment 1.

Legal issues:

- One case was taken to court, seeking approval to withdraw artificial hydration on the grounds of child's best interest

Discussion Neurology consults made up 25% of the RCRS. They pose a particular challenge, with complex, often incurable disease, with either no evidence-based treatments or only palliative therapies available. So, ethical dilemmas regarding treatment and end of life decisions are common.

The associated neuro-disability, and life-limiting aspect means social care and palliative care should be involved early on. Furthermore, discussions around care plans and DNAR should be prioritised.

The RCRS has a vital role in helping resolve conflict between the clinical team and parents, and supporting them to come to a consensus on management. It is rare that a court application is required.

Future improvements may involve routine referrals to the RCRS, focused ethics' training for neurology clinicians, and prerequisite criteria for referral (e.g. having a second opinion and care plan).

G474

CHILDREN, ORGAN DONATION AND ISLAM: A REPORT OF A MULTI-DISCIPLINARY DAY

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Purpose The day was established to look at organ donation in the Muslim community from deceased children. The BAME population has a lower rate of organ donation, but an increased need for transplantation – though this is known in children. Anecdotally, some Muslim parents and academics have suggested that organ donation is forbidden whereas other Muslim scholars think it acceptable: Two main sects: Shia – Many scholars think organ donation and receipt permissible, though some suggest it's only permissible if organs go to Muslims. Sunni – some scholars do not accept brain death as human death. Re donation there are three main groups: donation permissible, not permitted or it is a 'grey area.'

Methods We explored these views in a multi-disciplinary and faith dialogue day with religious scholars, organ donation/transplant specialities, young people, and hospital chaplains.

Themes in child- donation/transplantation emerged: need for organs; the demographics of child death and donation; the respectful process of donation in the setting of end-of-life care; retrieval and transplant of organs; paradox between families agreeing to transplant who would not agree to donation. Both Sunni and Shia scholars explored their faith views about these issues and particularly the voice of the Prophet that forbade desecration of enemies after death was discussed, along with the appropriateness of its extension to the organ donation situation.

Results A panel convened to review the issues and find a way forward: (i) In general all felt the decision about whether to accept brain death as a definition of death was for the law

for country to determine. (ii) Organ donation was a matter that should be decided by the parents of the child. (iii) No attendees felt organ donation to be forbidden by any religious orthodoxy, and that as Islam is a way of life represented by generosity, organ donation is acceptable – not least as most people will accept a transplant if they need one for them, or their child

Conclusions A leaflet for families about the Islamic views of donation is to be made. Muslim children who have received a transplant and the chaplains/scholars present together with donation/transplant staff will arrange education sessions in Mosques for families and the community.

G475(P)

NHS STAFF ATTITUDES AND OPINIONS TOWARDS THE USE OF SOCIAL MEDIA BY PATIENTS, FAMILY AND FRIENDS IN RELATION TO THEIR HOSPITAL EXPERIENCE

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Intro 'Over 60% of 13–17 year olds have at least one profile on a social networking site, many spending more than two hours per day on social networking sites.'

American Academy of Child and Adolescent Psychiatry, February 2017.

Social media is increasingly employed by patients, families and friends (PFF/SM) to publicly express their thoughts and feelings about their hospital experience. It is well recognised that social media changes the way users communicate. Its unchecked use can disrupt established and effective communication channels such as PALS and face-to-face interactions.

Aim Primary survey of acute paediatric NHS Staff perceptions on the use PFF/SM to publicly document their hospital experience.

Methods Questionnaires were given to all staff, in the paediatric department at an inner London Children's Hospital.

The specifically constructed questionnaire looked at possible positive and negative impacts of social media use on aspects of a patient's attendance as outlined by the GMC Good medical practice (patient-staff relationships, clinical management, confidentiality and patient safety).

Results 94% of respondents had previous personal-use experience with some format of social media. 75% had been involved in a situation where a patient's hospital experience had been documented on social media. Of this 75%, one third reported that it was a positive experience and one third felt that it had been an overall negative experience.

Half of responders felt strongly that PFF/SM use would have an impact on clinical decision-making and interventions. However, whilst 41% were concerned that PFF/SM use would affect patient safety, only 22% felt that it could cause a breach of patient confidentiality.

Discussion Social media etiquette and governance are still emerging. Unchecked public comments, about professionals or the services they provide, present evolving challenges for trusts. Our staff survey has shown significant concern about the impact of PFF/SM on patient safety and the perception that it could impact on clinical decision making.