twice in the previous week. Burnout symptoms (aMBI): 44% reported emotional exhaustion at a high level; 17% reported a high level of depersonalization.

The 25% of staff considering leaving PICU reported higher burnout (emotional exhaustion) scores ($p=0.001$); higher post-traumatic stress scores ($p=0.04$) and were also less likely to feel supported in relation to moral distress ($p=0.010$).

Conclusions These findings highlight the impact of changing PICU outcomes on staff, with increased survival of children with severe disability or technologically-dependent; and death following prolonged PICU admission sometimes after disagreements about cessation of LST, occasionally with public campaigns. They illustrate that the dimension of moral distress is one which needs to be acknowledged, along with burnout and post-traumatic stress² in a comprehensive assessment of staff well-being.

REFERENCES

1. Hamric AB, Borchers CT, Epstein EG. Development and testing of an instrument to measure moral distress in healthcare professionals. *AJOB Prim Res* 2012;**3**:1–9.
2. Colville GA, Smith JG, Brierley J, et al. Coping with staff burnout and work-related posttraumatic stress in intensive care. *Pediatr Crit Care Med* 2017;**18**:e267–e273.

G472 YOUNG PEOPLE'S VIEWS ON ACCESSING AND USING PERSONAL RECORDS FOR RESEARCH PURPOSES

¹R Mistry, ^{1,2}M Emonts, ^{1,2}R Agbeko, ³Young Person's Advisory Group, ⁴L Wilson, ¹M Walsh, ¹EJ Lim. ¹Paediatrics, Great North Children's Hospital, Newcastle upon Tyne, UK; ²Institute of Cellular Medicine, University of Newcastle, Newcastle upon Tyne, UK; ³Young Person's Advisory Group North East, Newcastle upon Tyne, UK; ⁴Connected Health Cities, Newcastle upon Tyne, UK

10.1136/archdischild-2018-rcpch.460

Aim Modernisation of records, coupled with advances in informatics, is making analyses of electronic records an increasingly rich source for researchers to help form evidence-based policy and treatments.

We aimed to review the public's views on health research from electronic records and databases, with a focus on children and young people (CYP).

Method

- A literature search on the public's perceptions of research from health records, data linkage, and acceptability of different modes of consent.
- Two focus groups using semi-structured discussions, to explore young people's perceptions of access to healthcare data, were held with our Young Person's Advisory Group. YPAG consists of 30 12–17 year-olds from diverse socio-economic and ethnic backgrounds.

Results Published research is primarily in adults. There is widespread unawareness and misunderstanding of research using health records. The public wish to be informed when their data is used for research as a matter of courtesy and to allow control of their participation. Opt-in consent was preferred. Opt-out consent is deemed potentially acceptable, with some studies demonstrating increased acceptability when participation bias is explained. Only one study explored CYP's views (17–19 year-olds). This broadly mirrored adults' views, including attitudes towards opt-out consent. No studies were found involving younger adolescents.

Our focus groups highlighted young peoples' strong sense of ownership of their data and desire to be informed.

Acceptability of access to data varies depending on exactly what is being used, by whom and for what purpose. A high degree of precision and flexibility in permission-granting was desired, alluding to dynamic consent. A distrust in the security of their data co-existed with a misunderstanding of the protection anonymization provides.

Conclusion CYP are clear in their desire for active engagement when it comes to using their data for research and show appreciation for balancing one's privacy against the 'greater good' for society. Further work is needed to explore how best to inform CYP of data use, allow informed participation, tackle misconceptions and maximise their partnership in this type of research. This is required to increase researchers' transparency and accountability with the public and maintain public trust in clinical research.

G473 A REVIEW OF THE NEUROLOGY CONSULTS OF THE CLINICAL ETHICS SERVICE AT A TERTIARY CHILDREN'S HOSPITAL

¹A Horne, ²P Prabhakar, ³J Brierley, ^{2,3}S Aylett. ¹University College London, London, UK; ²Department of Paediatric Neurology, Great Ormond Street Hospital, London, UK; ³Department of Paediatric Bioethics, Great Ormond Street Hospital, London, UK

10.1136/archdischild-2018-rcpch.461

Background The medical care of children with severe neurological disease, poses a number of ethical challenges; perhaps due to the lack of a cure, use of experimental treatment, and life limiting nature. When such ethical dilemmas arise, the clinical team and family may benefit from Clinical Ethics Support to help a consensus emerge on the best course of action for the child.

At this centre, a Rapid Case Review Service (RCRS) can occur within hours, but frequently days to review issues with the child's multidisciplinary team and parents. Little research has been carried out on this cohort's ethical challenges, and use ethics.

Objectives Understand medical, ethical and legal aspects of neurology RCRS consult and its role in addressing ethical problems faced

Methods Of 44 RCRS between 2012–2016, 11 were identified as having had a primary neurological disorder

Data obtained from RCRS referral form; Meeting minutes and Electronic patient records then categorised into 4 main variables: Demographics, Medical, Ethical and Legal. Confidentiality upheld by removing any patient identifiers

Results Demographics: Age 1–16 years (median 9); Medical: Average of 4 clinical diagnoses (range 2–5) Main categories: Neurological (5) (cerebral palsy and hydrocephalus); Neuro-metabolic (Leigh's syndrome, Pompe disease); neuro-muscular (DMD, SMA 1). Support teams: Palliative Care (10); External (8); Social Care (8); Psychology (6). Other concurrent conditions: Epilepsy (4); Neurodevelopmental delay (2); Learning disability (3). All had life limiting conditions. 4 had died by time of review (3 treatment withdrawal); 6 returned home of which 2 were now attending school.

Ethical issues:

- Conflicts between the clinical team and parents (6)
- RCRS recommendations: Involve palliative care and discuss DNAR; Seek second opinions regarding management; create a care plan with parents' involvement

- 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

¹M Aktas, ²R Kazmi, ³J Brierley. ¹Durham University, Durham, UK; ²Chaplaincy Department, Great Ormond Street Hospital, London, UK; ³Department of Paediatric Bioethics, Great Ormond Street Hospital, London, UK

10.1136/archdischild-2018-rcpch.462

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

^{1,2}AJ Shehadeh, ¹G Bull, ¹A Crouch, ¹S Hambrook, ¹A Samejeu, ¹D Zeitlin. ¹Paediatric Critical Care Unit, Royal London Hospital, Barts Healthcare Trust, London, UK; ²Paediatric Emergency Department, West Middlesex University Hospital, Chelsea and Westminster NHS Foundation Trust, London, UK

10.1136/archdischild-2018-rcpch.463

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.