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.

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

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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

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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