

months of the age boundary for their service. Baseline questionnaire was utilised to confirm the eligibility of the case, current treatment and comorbidity. Additional data were collected on the adult service to whom they were referred. Consultants were also asked to evaluate the different aspects of an optimal transition.

The BPSU reported 135 cases with 64 returned questionnaires and 51 eligible ADHD cases in transition. The CAPSS reported on 115 cases with 47 returned questionnaires and 39 eligible ADHD cases in need of transition were identified.

Results from the surveillance period which ended in November 2016 are very exciting. In general they indicate poor transition processes for young people with less than 25% of clinicians holding a transition planning meeting or having a handover period and less than 50% having the referral to an adult mental health service accepted.

Conclusions Both paediatricians and child psychiatrists are equally involved in the management of young children with ADHD. However, there are still gaps in the provision of transitions of ADHD adolescents across the lifespan in most UK regions.

National guidelines that aims to promote optimal transitions and reduce perceived barriers to transition of care for young people with ADHD out of children's to adult services should be established.

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G470

CO-OCCURRENCE AND CO-MORBIDITIES AMONG CHILDREN AND ADOLESCENTS WITH ADHD AND ASD IN A SCOTTISH LOCAL AUTHORITY

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ADHD is the commonest childhood neuro-behavioural disorder, affecting 5% to 12% of school-age children and about 1% of children meet the criteria for ASD. Co-occurrence of ASD and ADHD is increasingly recognised after introduction of DSM-5. They both share difficulties with emotional control, attention and high levels of negative affect, with differing underlying motivational and behavioural tendencies.

Objectives We analysed the clinical characteristics of children and young people with ADHD and ASD audited within two Community Child Health clinics of a Scottish NHS Trust over a 12 month period.

Methods A retrospective review of all patients seen in the out-patient clinics between June 2016 and May 2017 within an NHS Region was carried out. ADHD was diagnosed using validated Swanson, Nolan, and Pelham –IV Questionnaire (SNAP-IV). Sleep problems were diagnosed empirically from detailed clinical history provided by the parents/carers/patients. ASD was diagnosed by a multidisciplinary approach involving detailed assessment individually by the Educational Psychologist, Clinical Psychologist, Speech and Language Therapist and the Community Paediatrician, followed by group discussion, using the ICD-10 checklist criteria to confirm or refute a Diagnosis.

Results ASD and ADHD constituted 13% and 17% of the clinic caseloads respectively. They presented with similar

characteristics including male gender preponderance (4.3:1 and 4.5:1), proportion of new referrals (20% and 18%) and discharges (22% and 19%) respectively. 19% of ASD children had ADHD while 14% of ADHD children had ASD. They had a similar range of co-morbidities but sleep, emotional problems and DCD were commoner among ADHD patients (52%, 25% and 19% vs 44%, 17% and 9% respectively). CAMHS and General Paediatricians were more commonly involved with ADHD patients (33% and 14% vs 20% and 6%) than ASD children.

ASD patients were equally distributed between young (5–9 years) and older school age (10–14 years) children (20% and 18% respectively) while most ADHD patients were chiefly older (10–14 years). ADHD patients were on average 20 months older, attended more clinics (average 2.2 vs 1.6) and had higher number of co-morbidities (average 2.3 vs 1.6).

Table 1 summarises the clinical and epidemiological characteristics of children and adolescents with ADHD and ASD.

Child Health Ethics and Law Special Interest Group

G471

MORAL DISTRESS, TRAUMA AND BURNOUT IN STAFF IN RELATION TO CHANGES IN PICU OUTCOMES, CHALLENGING CASES AND MEDIA INVOLVEMENT IN DISAGREEMENTS ABOUT END-OF-LIFE CARE

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Background Technological advances have decreased PICU mortality but increased the number of children surviving with disability or technologically-dependent. Death in PICU most frequently follows withdrawal of life-sustaining therapy (LST), increasingly after prolonged admissions for invasive organ support. Disagreements with families about cessation of life-sustaining therapy (LST) can be protracted, distressing for everyone, harmful to the child and ultimately require court adjudication. Little is known about the impact of this, or of that of social/other media campaigns when families decides to involve the press, as is increasingly the case

Method 50 staff (39 nurses; 9 doctors and 2 AHPs) were surveyed using the Moral Distress Scale-Revised (MD-R) questionnaire¹; Trauma Screening Questionnaire (TSQ) and abbreviated Maslach Burnout Inventory (aMBI) together with several open-ended questions about their experiences and what they felt had been learned 3 months after the final court decision following one such high profile case.

Results Mean moral distress score (MDS-R) was 96, consistent with recent Canadian multi-centre PICU study and higher than average Adult ICU scores (57–83 in the literature). Specifically, in relation to the recent high profile case 15% scored in the clinically significant range for post-traumatic stress symptoms (TSQ); a significant number reported a number of sub-clinical symptoms; 68% reported being 'upset by reminders of the event' and 53% reported 'heightened awareness of potential danger' to themselves and others at least

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