Consider models of care which may safely enable shared decision-making in this population

Methods Review of literature with a focus on:
- Literature search of PubMed database focused on the effect of poor seizure control in adolescence on QOL and MH
- Adolescent psychological development, behaviour and goals and how they may impact decision-making in this population
- Strategies to support shared decision-making with high-risk treatments

Results Evidence demonstrates an association between poor seizure control in adolescence and adverse outcomes in MH and QOL.

Uncontrolled seizures cause higher perception of stigma and increase restrictions on participation. They further worsen social exclusion for adolescents.

Evidence suggests the risk of social exclusion by peers outweighs long-term health considerations in adolescence. There is evidence to suggest that adolescents’ own confidence in their ability to manage their epilepsy has a role to play in mental health resilience.

Close regulation of isotretinoin in dermatology demonstrates that highly teratogenic drugs can be used safely and effectively in this age group.

Conclusions Women and girls are missing out on optimal treatment of genetic generalised epilepsies due to concerns about potential adverse effects.

The current guidance may place disproportionate emphasis on the risk to a potential unborn child, without due consideration to the impact of poorly controlled seizures on an adolescent girl’s psychological and social development. Clinical decision-making currently overlooks factors which are important to adolescents and does not prioritise shared decision-making between adolescent girls and their clinicians. Evidence from developmental psychology, neuroscience and social medicine challenges our current decision-making paradigm.

Restricting access to a medication on the basis of sex without an equally effective substitute is unethical. Clinicians have an obligation to ensure that high quality and effective services are in place to enable women and girls to access valproate safely. Other specialties demonstrate that high-risk medications can be used safely in a well-designed service with informed consent.

Background Alder Hey Children's Hospital (AHCH) in northwest England provides regional specialist services and local general paediatric care. Paediatric multisystem inflammatory syndrome temporally associated with Covid-19 (PIMS-TS) is a new disease entity requiring paediatricians from District General Hospitals (DGHs) to seek advice from a number of specialists. During the first/second peak of the pandemic, patients with suspected PIMS-TS were transferred to AHCH under general paediatricians with subspecialist input.

To optimise patient care, during the 3rd peak of the pandemic (January 2021) an efficient virtual multidisciplinary team (MDT) consisting of rheumatology, cardiology, infectious disease and general paediatrics, was created to facilitate discussion of potential PIMS-TS cases. The MDT aimed to coordinate management of patients requiring specialist input, reduce unnecessary transfers whilst ensuring appropriate case management and utilisation of resources.

Daily (including weekends) virtual meetings were held to discuss all active referrals including the patient’s lead clinician, with the option of discussion on consecutive days until clinical improvement.

Objectives To analyse the cohort discussed at the MDT (January-March 2021), including demographics, outcomes, and need for transfer to AHCH.

Methods An online referral form using Microsoft SharePoint was distributed to regional DGHs for completion prior to the MDT. Discussion was documented on a database and outcome uploaded to AHCH patient records. These records were reviewed for this study.

Results 35 patients were referred over the 6 week study period. 14 (44%) were female. 21 referrals came from DGHs (66%), the remainder were internal. Age range was 4 months to 17 years; 9.3% <1 year, 25% 2–5 years, 40.6% 6–11 years and 25% 12–17 years. At time of discussion, six had a positive covid-19 PCR test and 13 had a confirmed positive household/family contact. PIMS-TS was diagnosed in 7 (20%) patients, three of whom were referred from DGHs. One required transfer to AHCH for inotropic support and one for echocardiogram. Two additional transfers to AHCH for surgical opinions were subsequently referred to the MDT. Of the remaining 25 patients (18 from DGHs), four were treated locally for Kawasaki’s disease. 19 of 21 (90.5%) DGH referrals to the MDT (majority without PIMS-TS) avoided unnecessary transfer to AHCH for assessment.

Conclusions The daily virtual MDT allowed efficient discussion with exchange of expertise and a collaborative approach from several specialties for suspected PIMS-TS cases across the region. It also enabled continuity across multiple discussions about individual cases. It provided the opportunity to discuss differentials in a new disease entity, empower DGH clinicians to start early treatment of PIMS-TS and recruit where appropriate to the RECOVERY trial. Unnecessary transfers were avoided in 90.5% of external cases. General paediatricians are key valued team members as the spectrum of disease and possible differential is wide. This MDT approach promoted the role of the general paediatrician in caring for these patients. Early treatment with a lower threshold to react and escalate has improved patient care. The use of better IT infrastructure helped bridge the gap of care delivery by geography. Feedback from DGH participants in the MDT was positive.