MINUTES
Ethics

EAP Winter Meeting Warwick Hotel, Bruxelles, December 7th 2024
14:45 - 15:45
Chair: Joe Brierley

1. Welcome

The Chair, Joe Brierley, opened the meeting and welcomed all attendees.

2. Approval of the Agenda and Previous Minutes

The agenda for the current meeting and the minutes from Porto, Portugal (12 April 2024) were reviewed and approved without changes.

3. Publications and Position Papers

The following key publications and statements were discussed:

- **EAP Code of Conduct: A modern framework for maintaining ethical integrity within paediatrics.**

This document addresses critical areas such as:

- Professional Integrity: Ensuring paediatric practice remains focused on the best interests of children.
- Collaboration with Industry: Establishing guidelines for working with industry partners while maintaining transparency and avoiding conflicts of interest.
- Ethical Decision-Making: Providing tools to support paediatricians in navigating ethical challenges in clinical and research settings.

The document has undergone several iterations and was submitted to the EAP Executive Committee (EC) for final approval. Once endorsed, the Code of Conduct will be published on the EAP website and disseminated to members.

- EAP Statement on Gender Dysphoria

The group discussed the EAP Statement on Gender Dysphoria, a document developed to guide paediatricians on providing ethical, evidence-based care for children and young people experiencing gender dysphoria. Key points included:

- **National Variability**: Acknowledgment of diverse national standards and practices across European countries.
- **Child-Centred Approach**: Emphasising the need to prioritise children's rights, autonomy, and well-being in all care decisions.

- **Guidance for Paediatricians**: Offering practical recommendations for respectful and supportive care, balancing ethical sensitivity with clinical judgement.

The statement has been published in *Frontiers in Paediatrics* and was well received at the EAPS Congress in Vienna. The group noted that the topic remains contentious in several European regions but affirmed its importance in addressing ethical care for this vulnerable group.

- **Climate and Air Quality Statement: Highlighting the urgent need to address air quality and its impact on children's health**

The Climate and Air Quality Statement represents a significant initiative advocating for the role of paediatricians in addressing environmental health. Key elements of the discussion included:

- **Focus on Air Quality**: Recognising air pollution as one of the most pressing health threats to children in Europe. The group referenced specific cases, such as a UK child's death attributed to air pollution, which underscored the urgency of the issue.
- **Empowering Families and Children**: Paediatricians were encouraged to discuss air quality with children and families to promote awareness and realistic actions for change. The group rejected the paternalistic notion that families are powerless in addressing environmental health issues.
- **Collaborative Efforts**: The statement aligns with global initiatives led by **UNICEF**, **WHO**, and **Longfonds** (a Dutch respiratory health organisation). The group expressed enthusiasm for further collaboration with these organisations to amplify their advocacy efforts.

Addressing air quality is not only a medical responsibility but also an ethical obligation. The group stressed the importance of integrating environmental health topics into the paediatric ethics curriculum.

Further collaboration with Longfonds, UNICEF, and WHO was mentioned as next steps to amplify impact.

4. Overview of 2024

Key highlights from 2024 were presented:

- EAPS Congress (Vienna): Ethics sessions on air quality and gender dysphoria were successfully delivered and well-received
- Web Development: The newly launched website will contain Ethics SAG-related documents which were previously not so visible..
- Ethics Curriculum: Progress made towards launching ethics webinars as part of the EAP educational strategy.

5. Work Plan for 2025

The following action items were outlined for 2025:

- Organ Transplantation Rights: Develop a position statement addressing discrimination against children with learning disabilities and chromosomal anomalies in organ transplantation, in collaboration with ESOT, ELPAT, and DTI.
- High-Expense Innovative Therapy: Explore consensus on ethically supporting innovative therapies for children, especially those with rare diseases.
- Transition of Complex Treatment: Focus on transitioning children on high-cost or ethically complex treatments into adult services.
- Ethics Support Questionnaire: Develop an exploratory questionnaire to assess ethical support systems in paediatrics.
- Children's Rights Standard: Align EAP's children's rights framework with Belgian standards, aiming to establish a European-wide benchmark.
- The IPA Children in Conflict Group collaboration was also mentioned.

6. AOB (Any Other Business)

- Challenges in research ethics regarding children were highlighted, particularly in ensuring their active participation in ethical reviews.
- A brief update on ongoing issues with hosting resources on the EAP website was provided.

7. Closing Remarks

The Chair thanked participants for their valuable input and encouraged continued involvement. The next steps include drafting position statements, progressing on planned webinars, and preparing the ethics curriculum launch in 2025.

Key Follow-Up Actions:

1. EAP Website Update: Ensure ethics documentation and position papers are accessible.
2. Organ Transplantation Project: Begin Delphi workshop and expert group selection.
3. Webinar Development: Launch initial ethics webinars in early 2025.
4. Children's Rights Adaptation: Collaborate with WHO Europe to advance work on a European standard.
5. Questionnaire Distribution: Develop and distribute ethics support questionnaire.