

MINUTES
Ethics Working Group
European Academy of Paediatrics (EAP)
UEMS Section of Paediatrics

Bruxelles, Hotel Windsor, Hall A
Friday, January 29, 2016
14.00 – 15.45

1. Attendance: 11 members and Francis Crawley, GCPA, Bruxelles and apologies: Stefan Grosek
2. David explained that the **last manuscript**: Age determination of asylum seekers was now published in EJP as Editorial

(Sauer PJ, Nicholson A, Neubauer D; Advocacy and Ethics Group of the European Academy of Paediatrics. Age determination in asylum seekers: physicians should not be implicated. Eur J Pediatr. 2015 Sep 18. [Epub ahead of print])

and there were **4 others abandoned** (Ethics of electronic files, Consent of minor parents, Communication with children with disabilities and their families and Circumcision in boys - newborns and infants) while there was no reply from Inez who promised to write a framework on:

Is there any usefulness of respiratory support in disabled children? (Azuvedo I)

So David propose to move on and Francis presented three possible future topics (PPT presentations attached)

3. Manuscripts in preparation:
 - i) Data for Child Health – Promoting and Protecting Child Health through Data Stewardship (presented by Crawley F)

Decision: To revise and extend the already published paper of CESP/EAP Guidelines for informed consent and Guideline for research in children: 5 members agreed to help Francis and David to rewrite it: Carsten, Martin, Pieter, Isabel, Artur

4. Manuscripts/topics for consideration:
 - i) Ethical issues regarding microdosing (presented by Crawley F)
Decision: maybe in few steps: Francis will send the original publication(s) and David will send already done framework on Phase 1 studies in children from Pieter Sauer
 - ii) Promoting health, leisure and sports in children and some adverse points of it (doping, competitiveness and abuse)

Decision:

4 members are ready to help Francis to make manuscript until Dublin meeting: Joe, Max, Artur and Liesbeth (David will also ask Stefan Grosek if he would participate)

David will include the framework in word as well

(Health, Integrity, and Doping in Sports
for Children and Young Adults

Proposal for European Academy of Paediatrics Resolution
Ethics Working Group, Version 1.0)

5. Information about the documents on the web:

- i) Making decisions to limit treatment (Larcher V, et al. Arch Dis Child 2015;100(Suppl 2):s1-s26. doi:10.1136/archdischild-2014-306666)
- ii) Millenium development goals progress report (ADC, February 2015)
- iii) Nuffield Council of Bioethics - Children and clinical research: ethical issues

5. Useful links: David presented link to ENPR-EMA website where Consent/assent toolkit can be found:

http://www.ema.europa.eu/docs/en_GB/document_library/Other/2015/12/WC500199234.pdf

and will also be put on website

6. AOB: Max commented that more effort should be done to stress the problems of the »migrant children«. David will send the original paper written by Stefan Mjones on behalf of EAP about the Refugee children (available at: http://www.eapaediatrics.eu/Ethics_Documents.ehtml

under **Refugee Children - a Concern for European Paediatricians**)

See you in Dublin 3-5 June 2016

David

Attachments: 3 PPT presentations from Francis Crawley

Word file for the framework of Promoting health, leisure and sports in children (Version 1.0)

Already published articles to be revised - see 3i above):

Guidelines for informed consent in biomedical research involving paediatric populations as research participants **Eur J Pediatr (2003) 162:455-45**

Ethical principles and operational guidelines for good clinical practice in paediatric research. Recommendations of the Ethics Working Group of the Confederation of European Specialists in Paediatrics (CESP) **Eur J Pediatr (2004)163: 53-5**

Informed consent/assent in children. Statement of the Ethics Working Group of the Confederation of European Specialists in Paediatrics (CESP). **Eur J Pediatr (2003) 162:629-633**

All available at:

http://www.eapaediatrics.eu/Ethics_Documents.ehtml