

MINUTES

Ethics Working Group

European Academy of Paediatrics (EAP)

UEMS Section of Paediatrics

Algarve, Portugal

Hotel Tivoli Marina, Vilamoura, Hall Gemini 2

May 12, 2017 at 11.00 – 12.30

1. Attendance and apologies: Grosek (will attend in December 2017) and 13 members participated (see the list at the end)
2. Approval of the agenda

Approved

3. Approval of the Minutes, Bruxelles, December 2, 2016 <http://eapaediatrics.eu/wp-content/uploads/2016/12/Minutes-Ethics-Winter-Meeting-2016.pdf>

Approved

4. Manuscripts in press:

- i) Obesity in children and adolescents (Acta Paediatrica) – sent for consideration to Acta Pedaítrica – waiting for their reply
- ii) Health, Integrity, and Doping in Sports for Children and Young Adults (Resolution of European Academy of Paediatrics

Ethics Working Group) (published in EJP see at:

<http://link.springer.com/article/10.1007/s00431-017-2894-z>

However this is not the final step: it has been proposed a **Six-step Implementation Process**

1. A dedicated EAP Webpage for the Resolution
2. Translation into European and International Languages
3. Endorsement by leading European and International medical, political, and sports organizations
4. Putting the Resolution on the political and sports agenda for discussion
5. Adoption by national, regional, and local medical, political, and sports associations
6. Regular review, follow-up, and (when necessary) revision

Steps 1, 2, and 3 may be the immediate focus and can run in parallel. Step 4 will be strengthened by having Steps 1, 2, and 3 largely achieved.

Step 1:A dedicated EAP Webpage for the Resolution

This webpage could contain the following items:

The Resolution and a link to the EJP publication

Translations of the Resolution

Endorsements with logos from various organisations

A list of references and related documents

Eventually EAP revisions and supporting documents

Decision: David will refer this to EC to open a Webpage on EAP for such Resolutions. The webpage should have a good overhead, e.g. CHILD HEALTH.

Step 2: Translation into European and International Languages

We should attempt to achieve translations into major European and International Languages:

- German (Peter)
- French (Jean-Christophe)
- Spanish (Manuel)
- Portugese (Ines)
- Italian (? Francis will forward)
- Russian (? Francis will forward)
- Arabic (Ahmed)
- Chinese (Jean-Christophe will forward)

Decision: The translations will be done by ethics WG members (in brackets) as soon as possible.

Step 3: Endorsement by leading European and International medical, political, and sports organizations

Below is a list of European organizations that might be approached to officially endorse the Resolution. We could write to each of the organizations and ask them to officially endorse it. If they agree to endorse it, they could do so by sending an official letter of endorsement and/or by sending their logo for use on the EAP Webpage dedicated to the Resolution.

We do not need to achieve endorsements from all organizations. This will be for some, perhaps, a short process (yellow). For others, perhaps a longer process.

We should write to all of them, but particularly target a few (perhaps those highlighted). Some of these organizations will likely not endorse themselves, but lead others to do so. They will also contribute to Step 4: 'Putting the Resolution on the political and sports agenda for discussion'.

1. Standing Committee of European Doctors (CPMP) – of which EAP is a member
2. European Centre for Disease Prevention and Control (ECDC)
3. International Federation of Medical Students Association (IFMSA)
4. Medecins du Monde (MdM)
5. Organisation for Economic Co-operation and Development (OECD)
6. Platform for International Cooperation on Undocumented Immigrants (Picum)
7. World Health Organisation (WHO)
8. Council of Europe - Education, Youth, Culture and Sports Council (EYCS)
9. European Commission - Directorate General for Education and Culture (DG EAC)
10. WHO-Europe
11. World Medical Association (WMA)
12. European Union of General Practitioners/Family Physicians (UEMO)
13. European Junior Doctors (EJD)
14. European Medical Students Association (EMSA)
15. European Union of Medicine in Assurance and Social Security (EUMASS)

16. European Union of Medical Specialists (UEMS)
17. Council of European Dentists (CED)
18. European Federation of Nurses Associations (EFN)
19. European Patients Forum (EPF)
20. European Public Health Alliance (EPHA)
21. Pharmaceutical Group of the European Union (PGEU)
22. International Pediatric Association (IPA) – and their member societies
23. American Academy of Pediatrics (AAP)
24. International Olympic Committee (IOC) - Liesbeth will get in touch!
25. European Football Association (EUFA)
26. European Tennis Federation (ETF)
27. European Rugby Association
28. Union Cycliste Internationale (UCI)
29. European Cyclist Federation (ECF)
30. European Union's Cyclists' Group (EUCG)
31. European Tennis Federation (ETF)
32. A comprehensive listing of European and International Sports Associations
https://ec.europa.eu/sport/resources/networks-partners/sport-federations_en

Step 4: Putting the Resolution on the political and sports agenda for discussion

If the Resolution is to be a living document that impacts sports policy and achieves the benefits it seeks for children and young adults, it will benefit from wide discussion, input, and even criticism. The EAP should foster the promulgation of the Resolution in meetings of sports ministers and sporting organizations.

Step 5: Adoption by national, regional, and local medical, political, and sports associations

The EAP could work through its membership and those endorsing the Resolution to achieve the adoption of this by sports federations and clubs at the national, regional, and local levels. Our aim should be to see this used and implemented at the level closest to the child and their parents.

Step 6: Regular review, follow-up, and (when necessary) revision

The EAP might decide to regularly review the Resolution and, if beneficial, revise and update it. Perhaps after 3 or 5 years. In addition, other documents on sports and leisure for children from the EAP can be developed and linked to this Resolution.

Decision: It has been accepted that for ALL Resolutions, Guidelines, Statements, etc. after a period of 3 years a revision should be made, and EC should take care that these revisions will be done on time.

5. Manuscripts in preparation:

- iii) The performance enhancing drugs use in children in sport issue.
 (Brierley Joe) Please read outline at: <http://eapaediatrics.eu/wp-content/uploads/2016/11/Performance-enhancing-drugs-Brierly.pdf>

Postponed until Winter Meeting in Bruxelles

- iv) Sports in disabled children (Siderius Liesbeth) Please read outline at:
<http://eapaediatrics.eu/wp-content/uploads/2016/11/Sports-and-art-in-disabled-children.pdf>

Postponed until Winter Meeting in Bruxelles

6. New proposals of manuscripts/resolutions

- v) Statement of vulnerability in sports (Robert Ross-Russell, Martin White)

RRR has proposed to start with the table on Rights of the children and how they are really respected in the real world (attached). Everybody will look on it and make his own comments and suggestions. Francis commented that these are the rights of the children that go hand in hand with other rights, such as how we are dealing with the rights of migrants and those with disability – so we can maybe merge the three manuscripts in prep somehow together. It should also be stated somewhere that US never ratified the Declaration of Rights!

Decision: everybody will write the comments to the table and send them either to Rob and Martin or to David to complete it and then decide whether to write a statement or a manuscript out of the data.

- vi) *First-in-children Clinical studies of Medicines (Francis Crawley)*
Francis presented new possible topics for future (see attachment – PDF of presentation) The idea is to develop a pathway for first in children CT – a clear description of ethical guidelines with important input of pharmacokinetics. Jean-Christophe also mentioned that the Ethics WG should comment something on use of extremely expensive drugs for some (rare) neuromuscular diseases (such as certain types of Duchenne), as such therapies are prolonging life of these children but finally they die anyway. Peter commented that this topic should be regarded even broader – what is the benefit for the child and his whole family – a patient-centred approach.

Decision: David will send the PDF of the presentation to all the members to comment until next meeting, when Francis will present it again, maybe with inclusion of the above points.

- vii) *Microdosing in children (Francis Crawley)*
Francis presented this topic to the members (see attachment PDF) and commented also on Dutch organisation for innovation in science (David will send this document again to the members – PDF). After a discussion the decision was made: this topic is interesting from the scientific point of view for different subspecialities, for the ethics WG the ethical part should be extracted – for next meeting in Bruxelles.

- viii) Migrant children and young adults in Europe: ethical view on research, participation in studies and ethical guidances for medical workers (Neubauer, Crawley)

Due to lack of time the presentation was postponed to the next meeting.

7. AOB (Declaration of Geneva)

Francis informed everybody that WMA (World Medical Association) is reviewing the Declaration of Geneva:

The Declaration of Geneva was adopted by the World Medical Association (WMA) at its second General Assembly in 1948 and is considered one of the core documents of medical ethics. In 2016, the Declaration of Geneva was scheduled for revision. A workgroup was established by the WMA and given the mandate to assess the need for a revision and to develop a draft revised version of the Declaration of Geneva.

Experts, stakeholders and the WMA's national medical association members and are now invited to comment on the proposed changes which have been drawn up by the workgroup following a careful process of deliberation.

The proposed amendments are intended to incorporate important ethical principles which do not appear or are not stated explicitly in the current version of the Declaration of Geneva

To this end, a three-week public consultation will take place from **8 May to 29 May 2017**.

After the discussion the Decision was made that Peter will write a sentence or two on respect of the autonomy of the child and Francis will do the revision and then we send the comments to WMA on behalf of Ethics WG EAP.

The meeting ended at 12.45

D. N.

List of attending members (**please, check the e-mail addresses**):

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