



Agenda of Ethics WG (EAP, UEMS Section of Paediatrics)

ETHICS Working Group
Hotel Metropole
Bruxelles

Saturday, December 8, 2012; 11.30 -13.00

1. Attendance and apologies
2. NOTE: There was no Minutes' in Prague as there was a Workshop organized instead of the usual meeting
3. Manuscripts in preparation:
 - i. Information on declined and possible publication of manuscript of Female mutilation
 - ii. Final version of the paper: Determining bone age in asylum seekers (A Nicholson and P Sauer) - **attached**
 Ethically, we should not be involved in these legal aspects as we have a different "relationship" with these asylum seekers.
 There is not data on other countries, so the paper is based on the Dutch paediatric society.
 Discussing aspects of the paper.
 Could send a questionnaire amongst the presidents of the different countries in Europe – to make the paper more credible and powerful. If there's no need to publish the paper so urgently, it's possible to send an email to all national delegates and ask them for information or for a statement of their society. To make sure that this is a topic that was even discussed in their country.
 And then can add the data to the paper.
 Peter Sauer will prepare a short letter and will circulate it to the national delegates.
 This will be added to the Advocacy for Children and the Ethics Working Group.
 Added: some thoughts about ethics and legal aspects. Alf Nicholson has read the present paper and agrees with the present text
 - iii. Ethical issues on medical records and electronic files (results of the questionnaire)
 In Brussels last year, it was decided to send out a short questionnaire - Gabriela Kubatova prepared it and they circulated it to all the members, but received only from 8 country member: Belgium, czech, denmark, germany, poland, neterhlands, slovenia and UK.
 Showing the results: Later - should decide how to proceed with this material.
 7 of 8 people use electronic files.
 All or most of data is in electronic form.

Majority said that there is a special level to access the data for doctors and nurses, or doctors only.

The owner of the e-data is the hospital (4), the provider of health care (3) or the patients (1?)

Data is protected by data (6) and put separately on a double server (5 of these 6).

6 countries - stored on a special server.

5 countries - the data can be used for research studies.

Any groups that are excluded? In 2 countries - no; in 2 countries - psychiatric tests are excluded; 1 country - data with legal implications is excluded.

7 of 8 - no obligatory use of internet.

e-Health? 4 for ministry;

4 countries - the doctors decide about the record.

In 4 countries - it is necessary to have also a paper record.

Sauer - it's important to be able to save this data and these records for a really long period, like 400 years, especially for rare children's diseases and genetic findings and so on. We need to have data for the last 100 years or so because there is important data.

Trying to see how to get more people involved and engaged - agreeing that this is an important matter.

The topic is interesting but we cannot design a whole technological system to enable this option, but there are several issues that are specific to children and are problematic with these files - what goes in the charts and what doesn't? What is open only to the child and what is open also to the parents? These are issues particularly important children. For example, can you or your parents demand to destroy or change the records? We need to focus on these matters and not so much on the technical matters.

What about a decision to not do nothing in order to treat a child - where do you keep that on record?

Paper files were not perfect, they kept getting lost. The ethical issues are still there but we are all going towards a paper-less hospital.

There will be a new questionnaire - All national delegates should be involved and should give their input.

To summarize: will ask Gabriela to help with the minutes and then will add 5 more questions to the questionnaire and will make them a bit clearer so that the answers will be clear - such as what is the upper limit of years it should be kept, and can parents keep the records and so on.

4. New topics:

- i. Multidisciplinary care in children with rare diseases (Liesbeth Siderius)
Liesbeth went further from the last year to talk about the possibility of disabled children to be cared for at home.

A paper was circulated - a draft of a comment by the EAP.

WHO has launched a draft paper in September (on WHO website), which is in line with what we have agreed on last year, so we should react to this statement.

We, as EAP should collaborate with WHO and UNICEF on disabled children (usually also rare disease).

We want to make a short statement by EAP which is in line with this paper, so that we can be involved with this initiative.

The question is - do we just make a statement, or should we send it somewhere? What's the next step of our statement. We should send it to WHO and the people who made the document, but first we need to see how it is accepted in EAP.

When we come to a consensus - all these statements should be visible on our website in a very visible place, and new ones should be more highlighted. And when we have the statement - we need to send it to the national delegates to circulate it amongst their national paediatricians, because European doctors do not visit the WHO website. It should be visible on the Homepage.

Paragon - also to refresh the data on the ETHICS group.
Should be accessible only by password.

ii. Male circumcision

Peter wrote the first draft which was circulated, and there was a comment by Jose Ramet - who is in disagreement with the text in the paper. Also - it is not the role of paediatricians to take such a big decision involving the prevention of large communities.

Advocating to withdraw this potential article on male circumcision from the EAP statement.

The paper can still be published just by a group of paediatricians who support this article, but not on behalf of EAP. All mention of the EAP in the paper will be taken out.

Some people didn't receive it (maybe it was blocked by hospital servers because of certain terminology).

Peter Sauer - this statement should not divide us as EAP, but I invite everybody to read it and comment, and if you feel you can agree with it - you will be on the list of people supporting the paper and trying to send it to a journal.

Jose Ramet commented about the HIV issue in Africa, and this issue is mentioned in the article, but still - not all people can agree with the paper, so let's not make it an issue within EAP, but we'd like to get comments and see who can support it.

iii. Any other business

Proposals for future debate issues:

Cross Border Issues

Childhood prostitution (and Facebook profiles and so on)

Health immigrants

Futile treatment in the ICU - Neonatal and Paediatric

The ethics in getting sponsored by drug and pharma companies

Reminder: a long time ago there was a paper by CESP written by Chambers - referring to this last topic.

Looking forward to meet you in Hotel Metropole, Bruxelles
on December 8, 2012 at 11.30

David