



European Academy of Paediatrics Research in Ambulatory Settings Network

EAPRASnet / Advocacy WG meeting Minutes Faro May 2017

EAPRASnet meeting

Stefano del Torso (I) opened the meeting by making last meeting's minutes approved.

DENTAL SURVEY

Adamos Hadjipanayis (CY) described the situation according the dental survey, as a Belgian dentist professor asked for 3000 EUR charge for editing the paper. Instead, a Cypriot expert would help make the paper completely free of any charge. The submission deadline for the manuscript for publication would be in June, finalisation of the paper is in progress.

As *Stefano* added for the future a clear agreement both on deadlines/timetable and costs needs to be discussed far beforehand.

VACCINATION HESITANCY STUDY:

Stefano introduced vaccination hesitancy study, the first of its kind of EAPRASNET 2.0, to produce more professional results, while making more demands on statistician. From the University of Padova, a statistician would be in help (who is also in the MOCHA project), and *Hans-Jürgen Dornbusch (A)* would also co-operate.

Zachi Grossman (IL) continued by offering the whole presentation to be sent to all coordinators participating in the project. He asked again to confirm which country representatives would participate. National EAPRASnet coordinators from the following countries indicated their willingness to participate:

Austria
Lithuania
Greece
Portugal
Poland
Belgium
France
Cyprus
Italy
Croatia
The Netherlands
Hungary
Israel
Germany
Slovenia
Spain



European Academy of Paediatrics Research in Ambulatory Settings Network

In the followings, he emphasised the importance of having a very close contact with the steering committee of this study. He also offered to send regular update by the steering committee to all participating coordinators, and vice versa, would need regular updates by participating coordinators; therefore, a frequent and fast communication is needed on every update made on the study.

There were some questions on the study design, such as:

- would the adding of countries with GP-based primary care paediatrics give extra value to the study?

As *Peter Altorjai (H)* added, implementing GP-based countries may bring some extra feature, as it would lead to an in-study comparison of PCP-based, mixed-system and GP-based countries. In his reply, *Adamos* stated that possible complications when adding a separate field for indexing GP/PCP office can be overcome and he would involve parents attending GPs' offices.

According to *Francis Rubel (F)*, there would be clear and definite differences between GPs and PCPs at the end of the study, if it would be run like that. The Croatian representative, *Aida Mujkic Klaric (HR)* also would find these differences important to be unfolded by the study.

Zachi continued by adding 3 issues to discuss about ethic committee approval:

- we, as country representatives should look for the appropriate ethic committee
- asking the committee beforehand if an informed consent is also required for this study
- translation of the questionnaire (Q), the protocol (P), informed consent (IC) is required

Arthur Mazur (PL) then added, the study has been already approved easily by the local Polish ethic committee. On the contrary, there are 9 separate provinces in Austria, with their own separate ethic committee approval business, so *Hans* would just be on time with connecting all committees from all provinces and get back answers. *Armando Barillari (B)* mentioned, study design would need to consider summer vacation as a period with usually low and slow access to any business authorities, so probably 4 months would work.

Translation of the Q, P and IC would take 1 month, as *Zachi* went on with his slides. Participating countries' representative should work closely with Lena group, as they will transform all material into digital form to the corresponding page of the Q website.

Then comes the period of recruitment:

- 15-20 reliable, engaged and enthusiastic paediatricians are needed
- deliver P, Q and IC to them
- make sure ALL participating paediatricians understand ALL questions of the Q, all issues with the P and IC
- then give them the link to the parental survey
- there are specific issues as when deliver the Q to parents:
 - a number of 15-20 eligible parents / participating paediatrician is needed, with at least 1 child between the age of 1-4 years





European Academy of Paediatrics Research in Ambulatory Settings Network

- exclude criteria is any ongoing acute illness
- 4 patients should be asked to participate each week / 5 week = all together 20

When it comes to the above timeframe, *Hans* was curious to know, whether it is only a draft or participating paediatricians need to follow strictly the above number?

Francis, based on his former experiences, said, usually there is too much to do on Mondays, so basically never make studies on Mondays, but on other days of the week.

Peter described the Hungarian situation, as well-child visits are managed by local municipalities not according to the PCP's will; that is once per week, on a dedicated day vary from praxis to praxis.

Adamos closed this discussion by saying that all country representatives will decide which is the most suitable and convenient day in their country .

By distributing the Q amongst parents, *Adamos* indicated, the probably the best idea would be to send the link directly to them. A frequent so-called infrastructure reminder is to be send to country representatives and probably to participating paediatricians to check the status of the study - as *Zachi* continued with this presentation.

It was *Peter's* thought to have a separate link per paediatrician not just per country to fully get access to the status data - and implementing this issue would also cover the issue of comparing GPs with PCPs very easily.

Back to the track, *Zachi* drew country delegate's attention to the importance of notifying Lena on official kick-off when all is ready in a country.

Francis highlighted, that EAPRASNET national coordinators usually work a lot with studies, this one would mean even bigger burden. Regarding this, *Adamos* cleared, that all participating coordinators will have authorship to the publication as a matter of reward.

Stefano continued by raising the interesting questions of designing new activities for EAPRASNET and also to build a new set of organisations for coordinators.

Back to the question of rewarding, the Greek representative, *Syridou Garyfallia (GR)* noted, a certificate may also be nice to have as a sort of acknowledgement to the participating paediatricians.

Hans's question was concerning financial refunds for the translation, and *Gabriela Kubatova (CZ)* suggested, *that* a financial motivation both for country representatives and participating paediatricians via a contract would be even more motivating and would raise the numbers of responses.

In addition it was discussed and agreed that whenever there is a tablet in the clinic, parents can fill in the Questionnaire directly in the waiting room.





European Academy of Paediatrics Research in Ambulatory Settings Network

ADVOCACY FOR CHILDREN

As in last December 2016, this working group's meeting was jointly held with EAPRASnet. Led by *Angel Carrasco (E)*, country delegates discussed the issue of a former study cooperation between the working groups, based on migrant's children health, originally titled as the survey on Child Health Inequalities among Migrant Children in the European Region.

As Angel described the situation of the paper of this study, there were difficulties with statistical analysis (too many data from certain countries, while less from other ones - how to compare?). There were also some technical and reference problems, nevertheless there also were unsuccessful attempts for publication. Currently it seems, that ESSOP (European Society for Social Paediatrics), a member of ISSOP (International Society for Social Paediatrics) would help this process to its official journal *Child: care, health and development*. *Nicholas Spencer (UK)*, the president of ISSOP also reviewed the paper, while *Zachi* is going to work on the finalisation - all taking just a few days now.

Angel continued reporting shortly on the annual spring meeting of ECPCP, this time hosted by Vienna.

He also notified the representatives again the annual ISSOP meeting would be in Budapest, this September. *Angel* would be on the plenary session, presenting the above paper on the EAPRASNET study.

Later he announced his step down from chairmanship. Corinne as CoChair will be chairing the WG til December.

Lenneke Schrier (NL) started her presentation by reporting on the project on migrant children guideline. The taskforce for this project consists of herself, *Corrine Wyder (CH)*, Stefano and *Nicole Ritz (CH - ESPID)*. Referencing the paper titled: The rights of children arriving in Europe from Lancet ([http://thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)00824-7/fulltext](http://thelancet.com/journals/lancet/article/PIIS0140-6736(15)00824-7/fulltext)), she continued with the obvious reasons to initiate working on this project:

- more than 300.000 (out of them 90.000 were accompanied) children were seeking asylum in 2015
- they may have specific needs and health risks
- access to migrant-friendly and high-quality services is very important

Referring to the UN Convention on the Rights of the Child, declaring the obligate needs of the same level of (health) care delivered to children, she found no EU recommendation for migrant children and adolescent care.

She continued with describing the way they achieved their goals: a temporary EAP working group was set up (Corinne, Lenneke and Stefano) with the collaboration of Nicole from ESPID. The aim was to collect country based guidelines in order to identify the minimal standard of health needs when in primary care (applicable for both PCP-based and GP-based systems) for migrant children at





European Academy of Paediatrics Research in Ambulatory Settings Network

first health care contact after arrival in any EU country. The checklist would be on EAP's website.

On the next slide Lenneke gave details on the actual method of data collection: email survey sent to 30 EU/EAA country representatives, with 83% response rate. Finally, 8 existing European and 3 overseas countries' (CAN, USA, AUS) guidelines were chosen for the comparison.

The method of consensus on recommendation was to identify a core group with conditions in at least 70% of the guidelines. Working group members also searched the MEDLINE intensively for data specific to migrant populations and indirect evidence from other populations. Then all these datasets were graded as high - moderate - low - very low.

The role of the expert panel was to determine the preferred clinical action, that is to consider balance between quality of evidence, (un)desirable effects, practical issues and costs, while recalling opinions from stakeholders, their possible values and preferences. Delphi method was used for the final recommendation.

The final guideline is about to have recommendation on:

- infectious diseases,
- mental health and physical / emotional maltreatment,
- chronic and non-communicable diseases,
- women's health and
- health promotion.

The next steps would be to collect all gradings on evidences, to get expert input (1st of June) from Anders Hjern (ISSOP, MOCHA), Ayesha Karid (ISSOP, mental health) and Uli von Both (ESPID).

The online checklist would be on EAP's website, finalizing publication is due in July to the EJP. A shared publication is likely to be with the WHO, the UNICEF and EU Santé.

Lenneke closed her presentations with specifying the final steps needed:

- input from Bulgaria, Denmark, Estonia, Ireland, Latvia and Malta
- and finally, the effort to distribute the minimum standard and checklist among paediatricians (and GPs)

Zachi asked whether the aim of this project was to review of existing guidelines to build a brand new EAP recommendation or to have a deep analysis of national guidelines . The answer from the working group members at present was to search Medline for a set of source documents, then grade evidences all found on a research, and build a unified recommendation.

Karoly Illy (NL) raised the question of the definition of migrant children used for this project. In her answer Lenneke cleared, that ISSOP definition was and is used in the whole process.

Peter also added that it would be nice to have it all presented at the ISSOP meeting, this fall in Budapest.





European Academy of Paediatrics Research in Ambulatory Settings Network

Stefano, by closing the meeting, said thanks to Angel for all he did in the advocacy working group as chairman. Corinne Wyder as co-chair will

National coordinators / country delegates present:

Peter Altorjai (H)
Armando Barillari (B)
Yevgeniya Bukharina (UA)
Sigita Burokiene (LT)
Angel Carrasco Sanz (E)
Liviana Da Dalt (I)
Stefano del Torso (I)
Hans Jürgen Dornbusch (A)
Karin Geitmann (D)
Zachi Grossman (IL)
Adamos Hadjipanayis (CY)
Karoly Illy (NL)
Wilhelm Kaulfersch (A)
Gabriela Kubatova (CZ)
Artur Mazur (PL)
Aida Mujkic Klaric (HR)
Ana Neves (P)
Francis Rubel (F)
Yoram Sandhaus (IL)
Lenneke Schrier (NL)
Paul Soler (M)
Garyfallia Syridou (GR)
Corinne Wyder (CH)
Jernej Završnik (SLO)

EAPRASnet EC is deeply indebted to *Peter Altorjai* for his precious, precise and timely preparation of the minutes

Stefano del Torso, Zachi Grossman, Diego Van Esso, Adamos Hadjipanayis

