European Academy of Paediatrics

Paediatric Section of U.E.M.S

Chair: Liesbeth Siderius

Agenda

1) Minutes Winter meeting 2018
   Minutes were approved

2) Gdansk IT network
   Jola Wierzba
   The University of Gdansk has developed an medical data management system for children with Duchenne. People with Duchenne need multidisciplinary care including cardiologist, pulmonologist, neurologist, geneticist, rehabilitation and very important psychologist. They want to connect with care at home. The data management system connects the families with the different (sub) specialties and can collect follow up data.

3) Rare Care World
   The Drupal 8 webbased providing application programming interface's
   Liesbeth Siderius
   Presentation is included
   Questions Questioning the group on the use of any of the terminologies most known is the ICD, second the ICF, the LOINC and the ATC are not known.

4) HL7 and interoperability
   Peter Altorjay
   The participant is the MOCHA project have become in contact with HL7. Founded in 1987, Health Level Seven International(HL7) is a not-for-profit, ANSI-accredited standards developing organization dedicated to proving a comprehensive framework and related standards for the exchange, integration, sharing and retrieval of electronic health information that supports clinical practice and management, delivery and evaluation of health services. There will be a meeting in IT and health in August where Peter is presenting on behalf of the EAP as part of collaboration on IT care plans and history summary.

5) Discussion: **What should we know/ train about IT**?
   In Israel the system holds lots of data. The data are not interoperable with other health systems. In Germany the Minister of Health has guidelines on medical apps, for example on allergy. In Finland there is (also) data, question is who owns the data. Companies may be very interested and offering money for data collections. These are ethical issues. Suggestion is to connect the ERN board, the ERN's are designing registries which are not compatible with each other. Germany (BK) urges interoperability is not only an issue for rare diseases. There is a concern on the data protection regulation. The DG Sante is moving forward. Regulations may be adopted for biomedical research. Belgium advocates for using the same IT language, the different terminologies. The Dutch minister of Health is advocating and facilitating personal health records based on the terminologies and classifications gathered

by the National Institute of IT in Health. Israel states that in general older persons are goldmines for the bigdata collection, as opposed the children, who are usually healthy. The children with a rare condition are the exception. There exist a structure MD clones producing synthetic data.

A statement will be produced on the need for interoperable data as well as dataprotection.

dd 17-5-2019

Attended by:

Peter Altorjai, Hungary
Ivan Bambir, Croatia
Koray Boduroglu, Turkey
Denys Boichuk, Ukraine
Sian Cooley, UK
Karen Daelin Holm, Norway
Ann De Guchtenaere, Belgium
Ulle Einberg, Estonia
Lars Gelander, Sweden
Yevgenii Grechukha, Ukraine
Zachi Grossman, Israel
Adamos Hadjipanayis, Cyprus
Wilhelm Kaulfersch, Austria
Berthold Koletzko, Germany
Larisa Kragelj, Slovenia
Risto Lapatto, Finland
Marina Mamenko, Ukraine
Artur Mazur, Poland
Vladimir Pilosoff, Bulgary
Chris Pruusild, Estonia
Joana Rios, Portugal
Ivanna Romankevych, Ukrain
Rob Ross Russell, UK
Liesbeth Siderius, The Netherlands
Thomas Siebler, Luxembourg
Milos Simov, Slovenia
Ketil Stoertal, Norway
Lia Syridou, Greece
Paul Torpiano, Malta
Meteja Vintar Spreitzer, Slovenia
Martin White, Ireland
Shin-Young Yim, South Korea
Gulay Sergin, Turkey