

To the chair of European Commission Expert Group on Rare Diseases

November 7th 2016

The European Academy of Paediatrics (EAP) consider sustainable strategies to be essential to promoting child health, that build on multisectoral approaches for guaranteeing the rights of child. For all children early childhood provides an important window of opportunity to prepare the foundation of life-long learning and participation.^{1,2} Children are usually best cared for within their own family environment where specific (sub) specialist care and knowledge needs to be integrated .

Considering the EU Commission Expert Group on Rare Disease recommendations on social services *April 2016*, that:

- Member States should promote measures that facilitate multidisciplinary, holistic, continuous, person-centered and participative care provision to people living with rare diseases, supporting them in the full realization of their fundamental human rights,
- Member States should promote measures that support patients/families affected by rare diseases to participate in decisions regarding their care plan and their life project,
- Transfer of information between care providers, within the limits of data protection legal frameworks, should be promoted to support holistic care provision,
- Member State should promote coordination and networking between all parties involved in the care provision of persons affected by rare disease, including public, private and civil society organizations as well as between providers and patient/disability organizations,
- Rare diseases specificities should be integrated into national systems assessing a person's level of functioning, in line with the United Nations Convention on the Rights of Persons with Disabilities.

Considering that

- most health data today is vendor-dependent, tied to the application that produced it. IT Systems were not designed for data outliving the application, making lifelong health records difficult. When a change of application occurs, a lot of data is lost. Since this data must be shared between applications and kept for the lifetime of the patient, it must also become open and independent of the application and vendor.
- the principles of universal data collections, have great advantages for shared and community care, and health records cannot be simply shared but must be regarded as definitive entities.

We request the European Commission to take necessary actions to guarantee that data on child health and social care are collected in interoperable, open and independent applications to provide a lifelong personal health record.

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Of behalf of
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¹Early Childhood Developmental and Disability: a discussion
paper http://apps.who.int/iris/bitstream/10665/75355/1/9789241504065_eng.pdf

² <http://www.thelancet.com/series/ECD2016>

³ http://www2.openehr.org/resources/white_paper_docs/openEHR_vendor_independent_platform.pdf