

To: Martin Seychell, Deputy Director General DG SANTE  
European Commission  
Brussels

To: the Members of Expert Panel on Effective ways of investing in Health

“ Benchmarking access to healthcare in the EU”

October 23, 2017

Dear Mr Seychell,  
Dear Members of Expert Panel,

Considering the right to access to highest standards of care, including the most vulnerable children, pediatricians and experts together at round table conference during European Academy of Paediatrics (EAP) conference in Ljubljana, Slovenia, October 14<sup>th</sup> would like to urge the European Commission to

- Encourage the use of harmonized European data set for surveillance of preventive child health schemes in an electronic health record including all children, disabled, migrants, Roma;
- Support an inclusive holistic medical and social approach for all children with rare and disabling conditions with semantic interoperability in medical practice where data sets can be exchanged between the different stakeholders.

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## Background

The European Academy of Paediatrics (EAP) considers sustainable strategies to be essential to promoting child health, that build on multi-sectoral approaches for guaranteeing the rights of child. 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. Most rare conditions involve diagnostic confirmation and a pro-active multidisciplinary approach. During the focus on specialty care for the child, fragmentation may occur in which the role of primary care may be neglected. Chronic and rare conditions require holistic, comprehensive and coordinated joint management among primary care, specialists, and families.

The World Health Organization states that a collaborative management approach at the primary health care level involving patients, their families and other health care providers may reduce the burden of disease for the child, family, and society.(EAP statement 2011)<sup>1</sup>.

The EU Commission Expert Group on Rare Disease on social services, stated in April 2016 that<sup>2</sup>:- Member States (MS) 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. MS should promote measures that support patients/families affected by rare diseases to participate in decisions regarding their care plan and their life project and transfer of information between care providers, within the limits of data protection legal frameworks.

The EAP's considers the promotion of digital innovation as a tool to enhance access to healthcare, prevention, a holistic approach of the child's health. The principles of universal data collections, have great advantages for shared and community care. In 2015 the Slovenian National Institute of Public Health (Nacionalni Inštitut za Javno Zdravje) launched the PARENT model for developing comparable and interoperable patient registries<sup>3</sup> in clinical fields of identified importance (e.g. chronic diseases, medical technology). Interoperability is the key prerequisite. In essence, the semantic interoperability is a highly structured, rule and standard-rich segment governing terminology, knowledge, standard interpretation and document interpretation, identifiers, etc. all agreements should aim to be compliant with standards or practices dominantly accepted for a particular area, particularly if determined at EU level.

In a holistic semantic structure of primary care, hospital care and integrated person centered care all stakeholder should include the use of the terminologies identified in the PARENT project. It is evident that these structures are not in place and /or locked in vendor dependent IT systems. The openEHR is an example of open, exchangeable, non-for-profit, vendor-independent platform.

Hearing experiences presented at the round table conference on October 14<sup>th</sup> 2017 the following should be addressed to facilitate a European holistic child health approach:

### *Primary Care*

Defining minimal European data screening and surveillance schedules to electronic health records in the different countries including communications between primary care, specialist care and patient's families

### *Multidisciplinary medical approach for rare and complex disabling conditions including:*

-General data collection for epidemiology and

-Support to implementation of standards for semantic interoperability in the EU that facilitate a mechanism of data sets exchange between the different stakeholder in specified rare and disabling conditions

### *Social Care*

Usage of electronic ICF-meta language tool for children with chronic disabling conditions.

1.<http://eapaediatrics.eu/wp-content/uploads/2015/12/EAP-Statement-11-12-2011-.pdf>

2.[https://ec.europa.eu/health/sites/health/files/rare\\_diseases/docs/recommendations\\_socialservices\\_policies\\_en.pdf](https://ec.europa.eu/health/sites/health/files/rare_diseases/docs/recommendations_socialservices_policies_en.pdf)

3.<http://patientregistries.eu/>