7TH EHEALTH NETWORK 12 MAY 2015 COVER NOTE BY SECRETARIAT

Topic 1: Recommendation on patients' registries in particular on use of knowledge gathered through Parent Joint Action

Issue at stake

At the eHealth Joint Action meeting in Brussels on 12 March 2015, it was requested that the context of PARENT Joint Action, its follow up, and the challenges ahead, would be presented at the eHealth Network meeting.

The purpose of this agenda topic is to solicit the eHealth Network members' comments as well as to raise awareness of the challenges faced by the registries and providing, through recommendations, solutions.

Summary of document

The paper with a set of recommendations provides a short overview of the key challenges faced by the Registries and through recommendations sets the scene for the next steps after the conclusion of the Parent Joint Action. The paper was prepared based on the input provided from the Parent Joint Action partners, by the European Commission and JRC.

Format of procedure in the eHN

The chair will introduce the topic and give the floor to Tapani Piha Head of Unit D3 at the European Commission who will present the document and open the floor for comments.

The eHealth Network members are requested to:

 Discuss and make general comments on the draft paper on patients' registries in particular on the use of knowledge gathered through the PARENT Joint Action.

The paper will be formally endorsed at the eHealth Network meeting in November. At the same occasion, note will be taken of the final PARENT Joint Action deliverables including the Parent Guidelines on the registries.

The HTA network meeting in autumn 2015 will also be informed of the paper and the Patent Joint Action deliverables.