6TH EHEALTH NETWORK 18 NOVEMBER 2014
COVER NOTE BY SECRETARIAT

Topic 4:   **Patient registries guidelines –** *for discussion*

Issue at stake

Article 14 of the Directive on patients' rights in cross-border healthcare states that among the objectives of the eHealth Network will be to draw up **guidelines on effective methods for enabling the use of medical information for public health and research**.

The Joint Action on Cross Border PAtient REgistries iNiTiative (PARENT) was launched in 2012 and is led by the Slovenian National Institute of Public Health. PARENT aims to improve secondary use of data from patient registries in a cross-border setting for both public health and research needs. It is developing the Methodological Guidelines for efficient and rational governance of interoperable patient registries (Guidelines) and additional implementation tools and services.

The Guidelines should be endorsed by the eHealth Network in May 2015. The activity on the Guidelines is foreseen by the Multi-Annual Work Programme 2015-2018 of the eHN.

Summary of document

The document contains a discussion paper and a summary of the guidelines, including key chapters on methodological issues related to development, implementation, and governance of patient registries. The target population of the guidelines are registry holders, researchers, healthcare providers, developers, etc., who are aiming either to set up a new patient registry or to renovate the existing patient registry. The guidelines will be supported by WIKI tool to enable all users a quick and effective access of the information they need according their current activities.

Format of procedure in the eHN

The EC Chair will introduce the topic. PARENT representative (Metka Zaletel, Head of Health Data Centre, National Institute of Public Health) will make a presentation on the summary Guidelines and will propose some questions for discussion (listed in Discussion paper).

The eHealth Network members are requested to:
   – Discuss and comment on the Guidelines summary.