INTRODUCTION
The meeting of 10-11 June 2015 focused on progress towards the implementation of European Reference Networks (ERNs), cross border genetic testing, and social services for rare disease (RD) patients.

EUROPEAN REFERENCE NETWORKS
The group adopted an addendum to the 2013 recommendations on European Reference Networks for rare diseases. This addendum aims to address two areas with particular specificities for rare diseases: the necessity of patient involvement in RD ERNs, and an illustrative grouping of RDs as a possible approach to RD ERN planning and to eventually ensure coverage of all RD.

An progress update on the implementation of Article 12 of the Directive on patients’ rights in cross-border healthcare was given, including on the work towards the development of a manual and toolbox for the assessment of ERNs.

UPDATE ON ACTIVITIES IN THE MEMBER STATES
The latest advances in the adoption and implementation of national plans/strategies in the field of RDs were presented. 18 Member States have now adopted a national plan or strategy and many are in the stages of implementation, mostly with a focus on the designation of centres of expertise in preparation for the participation in the first ERNs.

GENETIC TESTING
The Expert Group discussed a draft recommendation on cross-border genetic testing, based on the work conducted by the EUCERD Joint Action in this area and the outcomes of two workshops in the field in 2012 and 2014. The Group agreed that a recommendation is needed in this evolving area, and decided to clarify in the text the scope of the document, to enhance the focus on cross-border issues and to include related areas of interest concerning genetic testing where there is consensus. The discussion on the draft recommendation will continue in the next meeting.

SPECIALISED SOCIAL SERVICES FOR RARE DISEASES
The outcomes of the work on specialised social services within the EUCERD Joint Action were presented and a draft recommendation on social care for rare diseases was discussed. It was decided to develop the document by clarifying the definition of social care and scope of the various terms used to ensure that the concepts are understood by all actors in the same way, as this is an area which often falls outside the competencies of health ministries. The document will be discussed at the next meeting and a decision will be made at that point as to the targeted timeline for adoption.

PROJECT AND JOINT ACTION UPDATES
An update on the EUCERD Joint Action, which will finish in August 2015, was presented. A final conference to disseminate the outputs of the Joint Action will be organised in Luxembourg on 15 September 2015, to be followed by the kick-off meeting of the new RD Joint Action.
This Joint Action will support the activities of the Orphanet database, the implementation of appropriate coding of rare diseases in Member States using Orpha codes, and support to the work on the development and implementation of policy recommendations by the Expert Group on Rare Diseases.
**Next Meeting**
The next meeting of the Expert Group will take place on 12-13 November 2015 in Luxembourg.