

Breakout session 1: Digitalisation and data management

1. Interoperability and Resources

- Opportunity to connect and support data sharing

2. Coding and Registries

- Coherent vs heterogeneous coding: Orphacodes – specific for RD! (multilingual, computable and free), cooperation on data models
- Registry concerns: data collection, legal aspects, interoperability, secondary use, future integration in the EHDS, access to data

3. Non-clinical role of the Clinical Patient Management System

- Management decisions: recognize the work of the ERNs of the hospital
- Visibility and Integration: national collaboration, access to rural areas
- Sustainability: can help decisions on reimbursements