



EURORDIS
Rare Diseases Europe

Workshop 2

Patient Databases and Registries

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Patient Databases and Registries **Issues**

- Share expertise on RD data bases
- Do not repeatedly reinvent the wheel
- Diseases specific versus ALL RD databases
- Governance and Consent
- Good practice : setting up, data handling, dissemination,..
- Integrating clinical data and patient self reporting
- Sustainability

Recommendations

- The need for a position paper from Eurordis
- The need for Working Group linked to the European Committee On Rare Diseases, on registries & databases at a EU level: subsequent implementation by MS
 - Public/private partnership for funding
 - European Research Ethics Committee for rare diseases database
 - Developing a common software
 - Reviewing existing practices; create guidelines; linking to Centres of Expertise
- Information and involvement of patients and families
- Empowerment and experience sharing of PO representatives