

Perspectives on RD Coding National & EUHA

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“The European University Hospital Alliance is formed by leading European university hospitals with demonstrated excellence in healthcare, education and research”

EUHA – Strong Participation in ERNs

ERN BOND 4	ERN CRANIO 5	ENDO ERN 7	ERN EPICARE 2	ERKNET 4	ERN RND 4
ERNICA 4	ERN LUNG 6	ERN SKIN 4	ERN EURACAN 6	ERN EURO- BLOODNET 7	ERN EUROGEN 6
ERN EURO-NMD 5	ERN EYE 1	ERN GENTURIS 5	ERN GUARD- HEART 2	ERN ITHACA 4	MetabERN 6
ERN PaedCan 6	ERN RARE-LIVER 3	ERN ReCONNET 3	ERN RITA 6	ERN TRANS- PLANT-CHILD 3	VASCERN 5

Rare Diseases Classification and Coding

One of the network's strategic goals

- Inventory of the current coding systems in use in the different hospitals
- Identifying the challenges in introducing common tools
- Gap analysis – Why OrphaCodes!

Lessons learned on the national level

Classification and coding – Aims

Registries

- Epidemiology
- Statistic
- Clinical Trials
- Treatment

Personalized medicine

- Etiology
- New therapies

ERN

- CPMS / Consultation
- Registries
- Guidelines

Patient records

- Follow-up
- Evaluation
- Visibility of patient groups
- Emergency healthcare

Lab systems

- Statistics
- Research
- Development of diagnostics



Thank You!

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