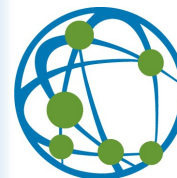


Establishing the first pan-European Registry for Rare Bone & Mineral Disorders



EuRR-Bone
European Registry for Rare
Bone and Mineral conditions

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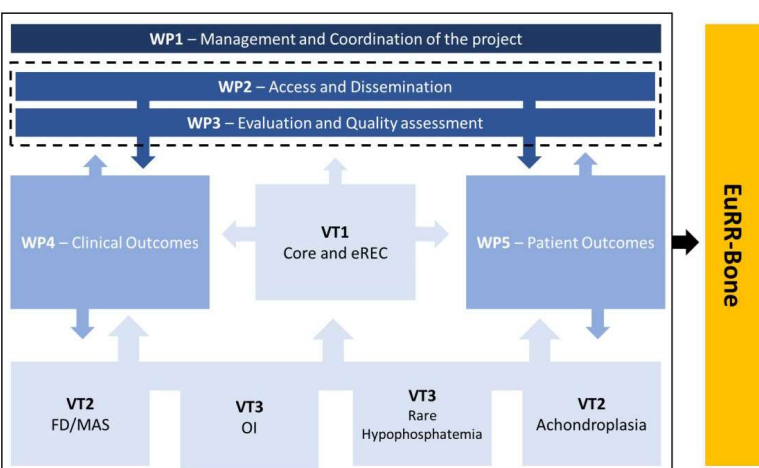
BACKGROUND

The lack of natural history data across rare bone diseases is significant, and the quality of care and expertise varies across regions and countries. A wide variety of specialists can be involved in the care and follow-up, but, until recently, the cross-disciplinary alignment was limited: each discipline had its own network, conference, guidelines and registries.

AIMS

The **European Registry for Rare Bone and Mineral Conditions (EuRR-Bone)** will be the first pan-European registry for Rare Bone and Mineral Conditions - a complex group of diseases for which the need of an adequate care and shared treatment pathways is pivotal. The focus will include **over 150 rare diseases affecting bones**, cartilage and dentin and more than **40 rare conditions affecting phosphate and calcium metabolism**.

WPs & VTs INTERACTIONS



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CONSORTIUM

A core group of the **European Reference Network on Rare Bone Diseases (ERN BOND)** healthcare providers, affiliated centres, experts and patients are involved in EuRR-Bone. This team will work closely with the **European Registry for Rare Endocrine Conditions project (EuRRECa)**.

ACTIONS

- Develop an **e-reporting programme** that will capture new clinical encounters
- Develop a centralised **core registry** aligned with **ERN BOND scope**
- Develop both **clinician and patient facing platforms**
- Develop **disease-specific modules** on Achondroplasia, Fibrous Dysplasia/McCune Albright syndrome, Osteogenesis Imperfecta and Hypophosphatemia
- Explore linkages **between EuRR-Bone and local, disease-specific registries**

CONCLUSION

The EuRR-Bone will take the lead to organise data, harmonise and improve healthcare for the four mentioned conditions and aim to scale this approach for all rare bone and calcium disorders, favouring both healthcare and research process.

more info



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