



EuRR-Bone

European Registry for Rare
Bone and Mineral conditions



European
Reference
Network

for rare or low prevalence
complex diseases

 Network
Bone Disorders (ERN BOND)

EuRR-Bone

is the first registry for all
**Rare Bone and Mineral
Conditions** in collaboration
with **ERN**

BOND and **Endo-ERN**.

Together with EuRECa,
EuRR-Bone aims to capture
clinical data from healthcare
professionals as well as the
needs and reported
outcomes of patients and
carers



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EuRR-Bone Structure

EuRR-Bone is composed of 5 Work
Packages and 5 Working Groups that in
synergy act to realize and implement the
Registry

WP1 - Management &
Coordination

WP2 - Dissemination & Access

WP3 - Quality Assurance &
Evaluation

WP4 - Clinical Outcomes

WP5 - Patient Outcomes & Patient
Platform

WG1 - Core and e-REC

WG2 - Rare Hypophosphatemia

WG3 - Fibrous Dysplasia/McCune
Albright Syndrome

WG4 - Achondroplasia

WG5 - Osteogenesis Imperfecta



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Endo-ERN

European Reference Network
on Rare Endocrine Conditions



EuRECa
European Registries For
Rare Endocrine Conditions

