SERVIZIO SANITARIO REGIONALE
EMILIA - ROMAGNA
Istituto Ortopedico Rizzoli di Bologna
Istituto di Ricovero e Cura a Carattere Scientifico

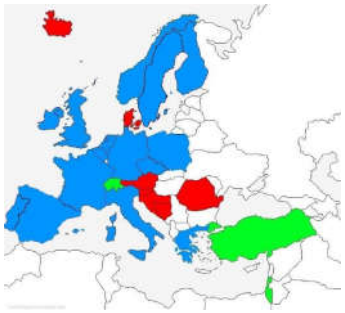
European Reference Network for rare or low prevalence complex diseases
Network Bone Disorders (ERN BOND)

Dipartimento RIZZOLI Research Innovation Technology
COSTRUIAMO INSIEME IL FUTURO

ERN-BOND Surveys on Diagnosis of Osteogenesis Imperfecta: the healthcare professional and patients experience

Matias de la Calle (1), Marina Mordenti (1), Manila Boarini (1), Maria Gnoli (1), Luca Sangiorgi (1)

(1) Medical Genetic Department, IRCCS Istituto Ortopedico Rizzoli



ERN-BOND is the **European Reference Network for Rare Bone Disorders.**

European Reference Networks

It brings together 38 highly specialised healthcare providers from 10 EU Member States.

-To foster holistic, multidisciplinary and patient-centred care

-To connect the best healthcare professionals with the best researchers, in order to improve access to cross-border medical expertise in line with Directive 2011/24/EU3.

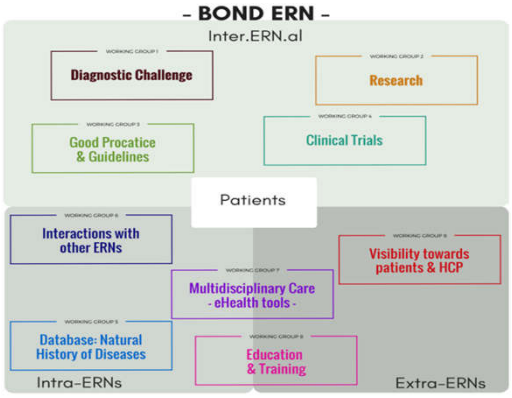
The network has selected one of the most common rare bone diseases, osteogenesis imperfecta, as an area of focus, to understand the common challenges in diagnosing rare bone diseases and to provide recommendations for improving referrals, reducing diagnostic errors and shortening diagnostic delays.

THE ERN-BOND WHITE PAPER ON DIAGNOSING OSTEOGENESIS IMPERFECTA

• Overview of the current situation relating to diagnosing *osteogenesis imperfecta*

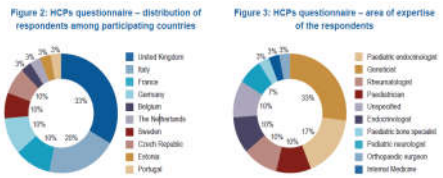
• Identify the **key challenges and potential solutions to further reduce these shortcomings, and improve the patient experience.**

Thematic Working Groups

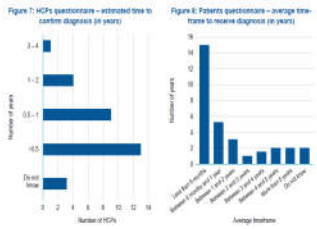


Results

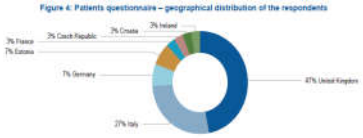
THE SAMPLE: QUESTIONNAIRE FOR HCPS



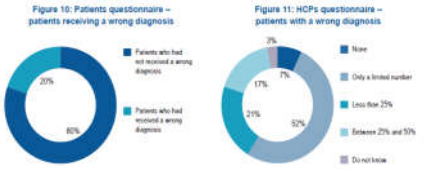
DIAGNOSTIC PATHWAY



THE SAMPLE: QUESTIONNAIRE FOR PATIENTS



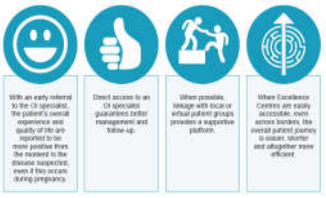
WRONG DIAGNOSIS



Conclusion

BARRIERS

SUCCESS FACTORS



POTENTIAL SOLUTIONS

For information:
matiasignacio.delacalle@ior.it

Rare Diseases 360
Collaborative Strategies to leave no-one behind
9th European Conference on Rare Diseases & Orphan Products
10-12 May 2018 Vienna