Focusing on people living with rare bone diseases

People living with rare bone diseases have many challenges to deal with including debilitating and painful symptoms and psychological and social impact.

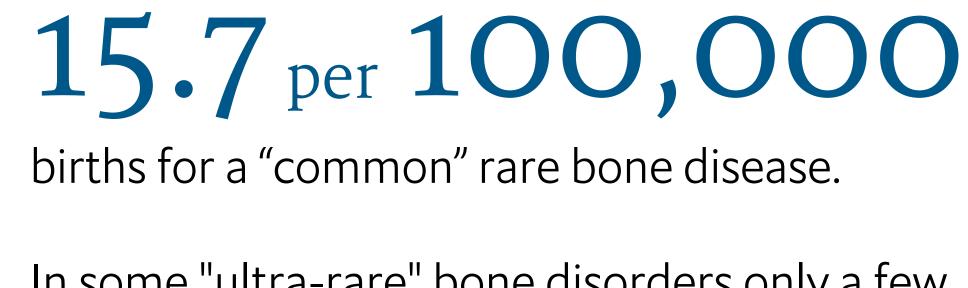






known rare bone diseases, affecting millions of people around the world





In some "ultra-rare" bone disorders only a few

people are affected.



of known rare diseases are rare bone diseases

Other rare diseases

Rare bone disease fall into 4 categories



Altered





involving genes

microenvironment

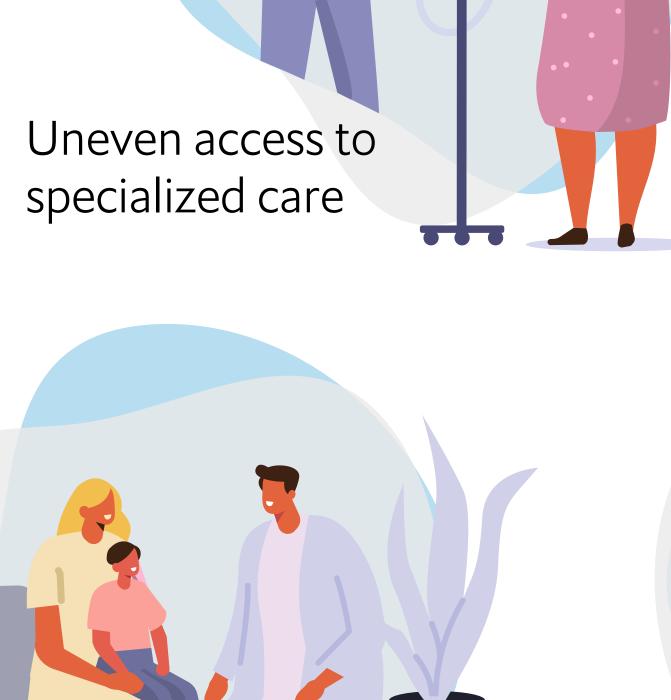


What are the challenges for patients, caregivers



and healthcare providers?

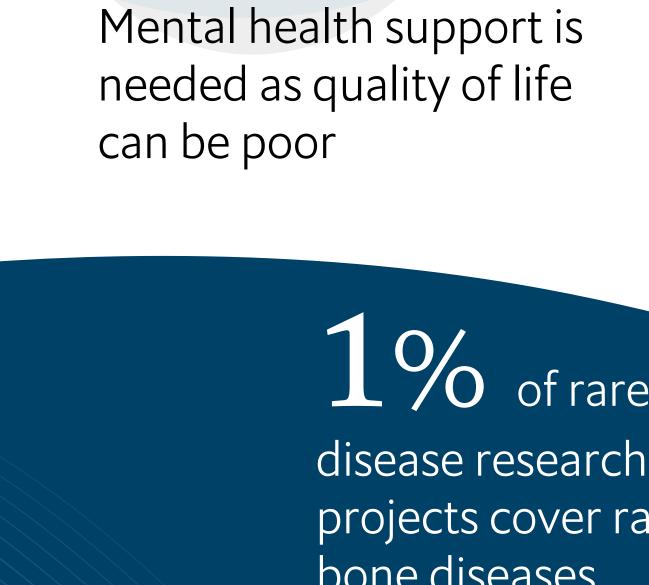




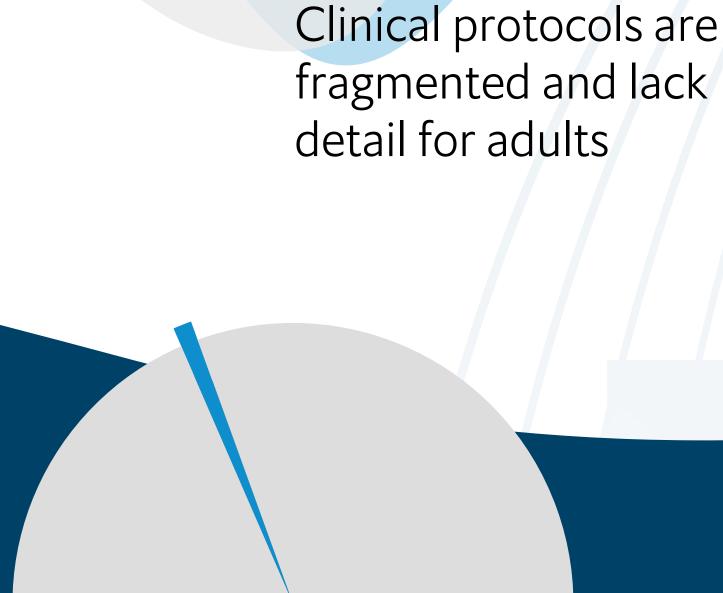
projects cover rare bone diseases





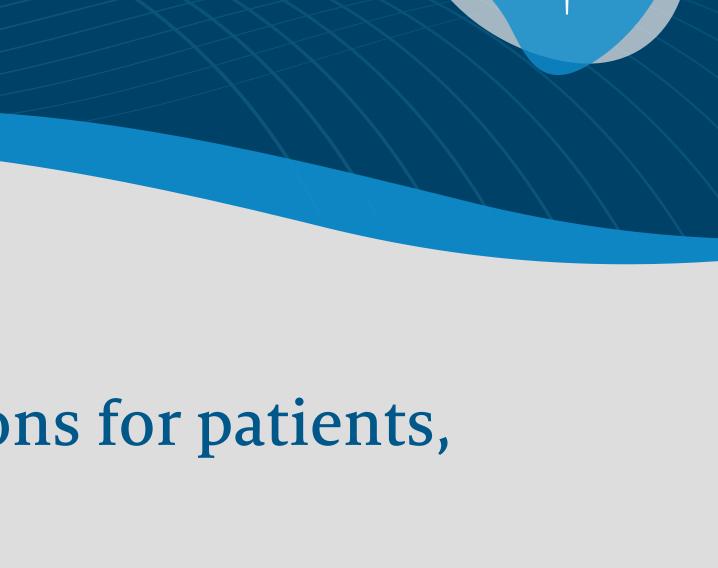






Other rare

diseases

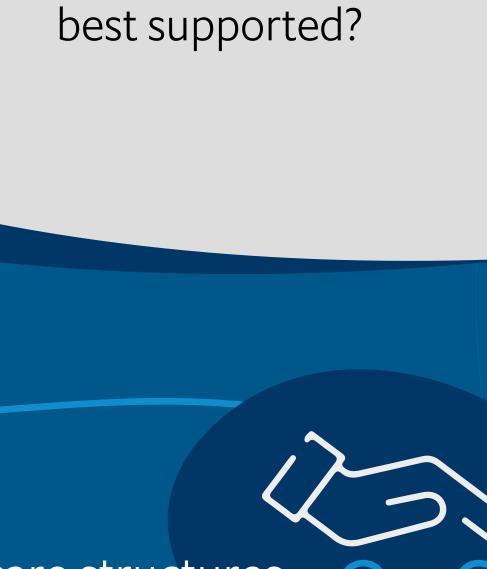


What is a good What is the psychological What is the cause outcome of treatment? impact and how can of pain?

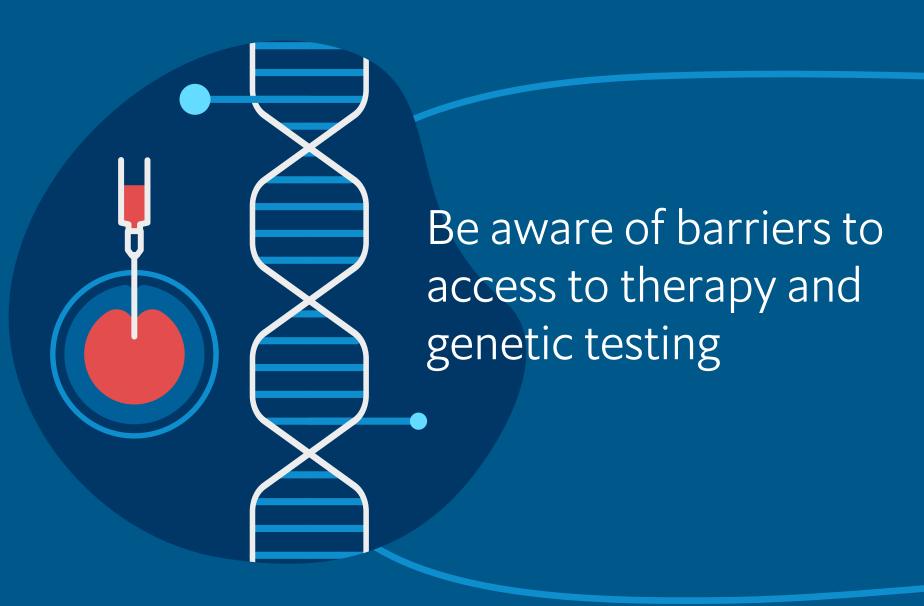
02

What can be done for the future?

Build transitional care structures



patients and families be

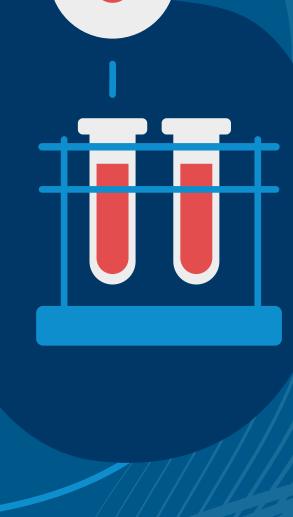


Drive forward patient-driven research and ensure registries are standardised

as patients become adults and

for patients and families

integrate mental health services



engagement with patients