



- Increase **awareness** amongst general public and Health care professionals, health authorities and relevant stakeholders on inherited metabolic disease (IMDs)
- Disseminate of new information, **scientific publications** and revision of existing health-related information

- Facilitate and harmonise the **newborn screening** in EU
- Use of the Unified-IMD registry to study the **natural history** of asymptomatic and symptomatic state of diseases

- Enhance speedy **diagnosis** by promotion of diagnostic expert consultation (CPMS) and training sessions
- Improve access to the best diagnostics (biochemical/genetic) and to **genome-wide genetic investigations** through active collaboration with Orphanet and ERNDIM

- Revise/develop of Care pathways & Guidelines
- Facilitate **Clinical Trials/Research** (defining research priorities and disseminating research-related information)
- Create big databases with patients data
- Improve the Regulatory process for medicines
- Participate in the production of White papers and Recommendations

- Assess the effectiveness and efficiency of clinical processes
- Develop a common programme on **Transition** from childhood to adulthood

- Participate in and provide input and insights from patients and HCPs in **Education of patients**
- Instruct general practitioners on how to follow patients
- Promote the MetabERN Education website (<https://metab.ern-net.eu/>) dedicated to **capacity-building, education & training**.

- Share the **'Quality of Life'** surveys and outcomes measurement
- Facilitate the provision of social care services

- Continue collaboration with **other ERNs** through the ERN-Coordinators Platform (on a strategic level) and through ongoing consultations with overlapping networks (at a practical level)

- Recent achievements to start the journey:**
- A dedicated group on **patient empowerment** has been established
 - The **Patient Board governance structure** is up and running including the Patient Executive Committee (PEC). The PEC is the voice of all patient representatives involved in the subnetworks and Work Packages in order to improve their involvement and enable their feedback to be heard by HCPs.
 - Patients have been involved in addressing their **specific needs, preferences and priorities** (Survey, feedback systems, etc.)

