EURORDIS EMM 2021

BREAKOUT 3
PARALLEL SESSION
TAKING ACTION ON ERNs AT NATIONAL AND EUROPEAN LEVEL

14th May 2021

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PART 1: Taking action on ERNs at national level. EURORDIS Toolkit 10.00-10.50

10.00-10.20 - Introduction, Matt Bolz-Johnson, ERN and Healthcare Advisor, EURORDIS

10.20-10.50 - Presentation of EURORDIS toolkit to support action at national level on ERNs, Inés Hernando, ERN and Healthcare Director, EURORDIS

10.50-11.10 – Comfort break

PART 2: Best practices 11.10-11.50

11.10-11.30 - Taking action at national level: Connecting patient organizations to Centres of Expertise through a legal role in the designation process. Cor Oosterwijk. Director National Patient Alliance for Rare and Genetic Diseases (VSOP, The Netherlands)

11.30-11.50 - Improving access to care and treatment for Huntington's Disease patients and families, Astri Arnesen, President European Huntington Association

PART 3: Discussion 11.50-12.30

11.50-12.10 – Questions

12.10-12.30 - Listening from you

- Identify together other best practices – have you organised or participated in any action on ERNs at national or at European level?
- Is the toolkit useful or are we missing something?

Introduction

Workshop Objective:

Learn how to use some of EURORDIS resources to take action on ERNs at national and European level.

RARE 2030 **GOAL** 3

All citizens can exercise their right to access a timely diagnosis, high quality essential healthcare, and safe, effective and affordable medicines and treatment, as close to home as possible or else have easy access to physical or remote cross-border healthcare, without unnecessary delay, under an EU "whole-system" approach for rare diseases.

Rare 2030
Foresight in Rare Disease Policy

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Shift from geographic coverage to improve ERNs connectedness at national level

Improving health outcomes of the 30 million people living with a RD requires adopting ERNs knowledge assets to improve the capacities of NHS and not just of a few CoE

Support expert teams to be active at EU level, within the ERN, as well as within their national health system

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	Patient Community	Health authorities	Healthcare providers	Hospital managers
EU Level	• ePAG advocates are the voice of the patient community in the ERNs Collect feedback from the community to represent their interests/views	• Strategic development (BoMs) • Endorsement of HCPs as a pre-requisite for application	• Active in ERNs collaborative activities	• Support clinician's activities in ERN (time and in kind support, infrastructure, financial/French Coordination Centres)
National Level	• Connect the national patient community to the ERNs • Raise awareness of ERNs and sharing information	• Organisation of referral pathways into ERN • Development of National Networks of CoE • Accreditation of CoE and adoption of ERN guidelines and other CDSTs, including care pathways	• National coordination role/liaise at local level with other HCPs, disseminate information • Effect change in their own organisation/ implementation of CPG, for example	• Support adoption of ERN assets within the hospital • Data monitoring and infrastructure

Taking Action on ERNs at national level

EURORDIS TOOLKIT

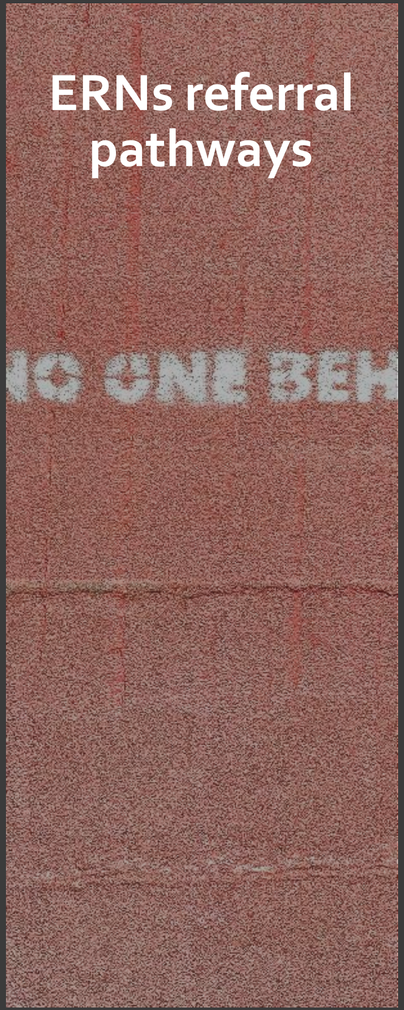
1

National RD plans and legal framework

2

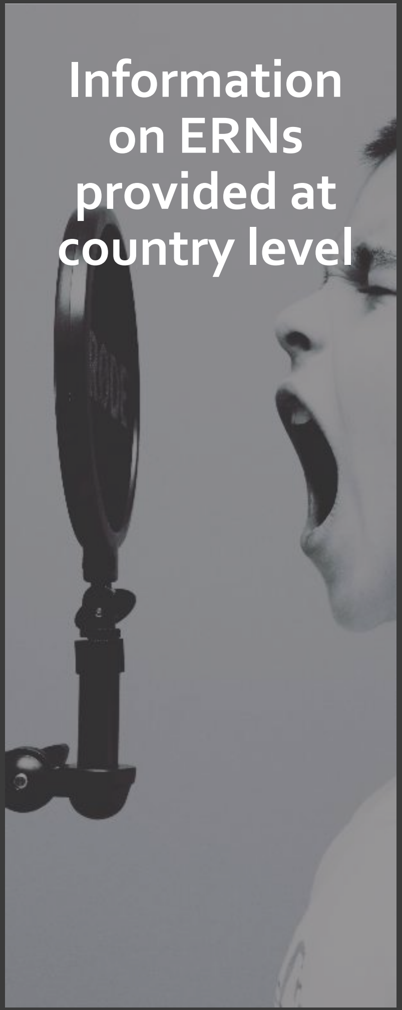
Patient care pathways

3



ERNs referral pathways

4



Information on ERNs provided at country level

5

Support by national governments to ERN members

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Chapters' Structure

1. Topic introduction

TODAY

2. Tools and Templates
3. Methodology and processes
4. Best practices

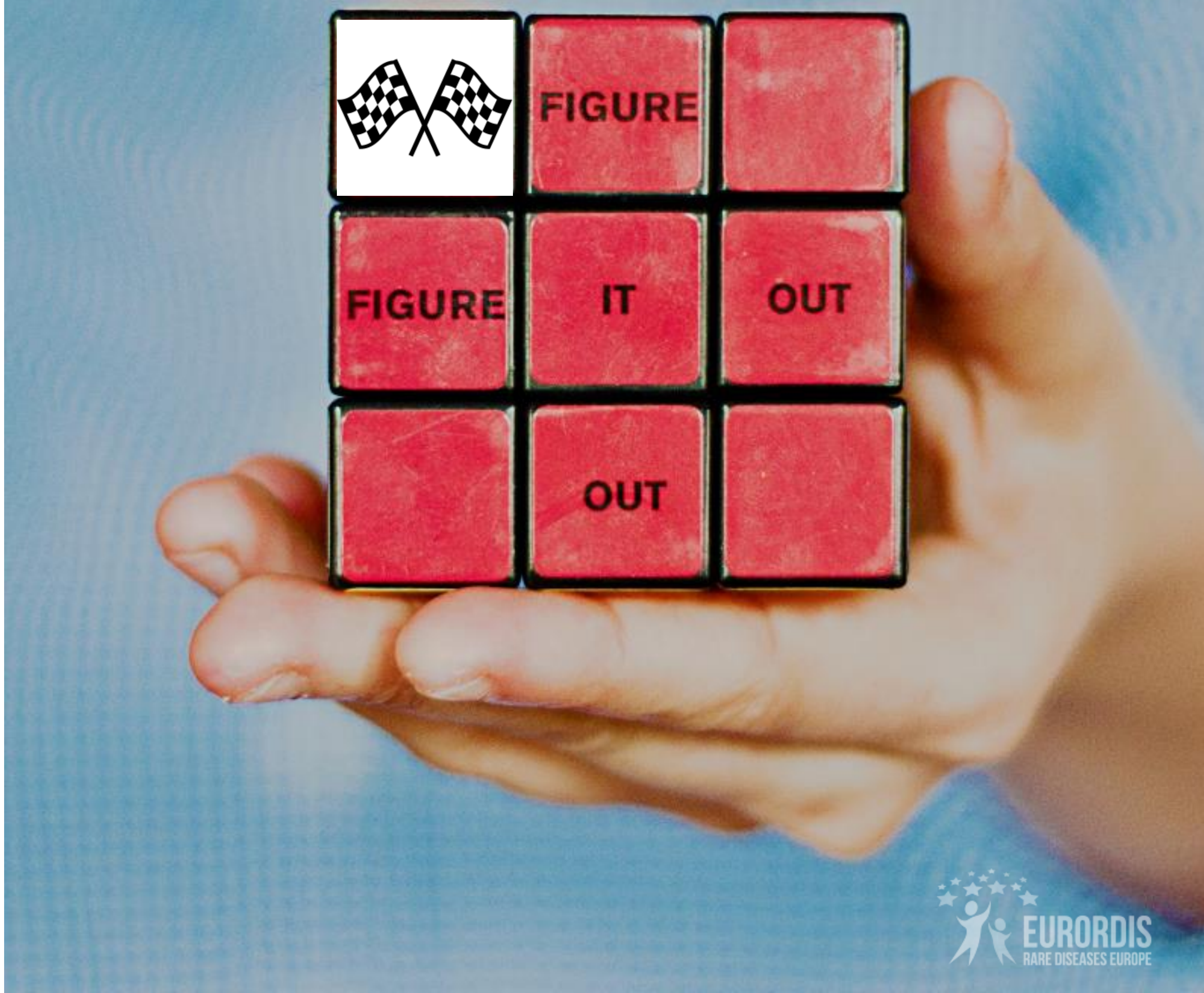
SERIES OF WEBINARS IN JULY AND OCTOBER

1. National RD plans and legal framework

- **RD plans** should define the mechanisms that a country will use to connect the national and EU levels, including changing role of HCPs/ERN members in their own country or how ERN knowledge assets will be adopted and implemented at national level.

- MS should adopt or amend **legislative instruments** to enable seamless integration of ERNs.

- Clear and, if necessary, legally defined procedures for the **identification and designation** of national Centers of Expertise – best practice The Netherlands.



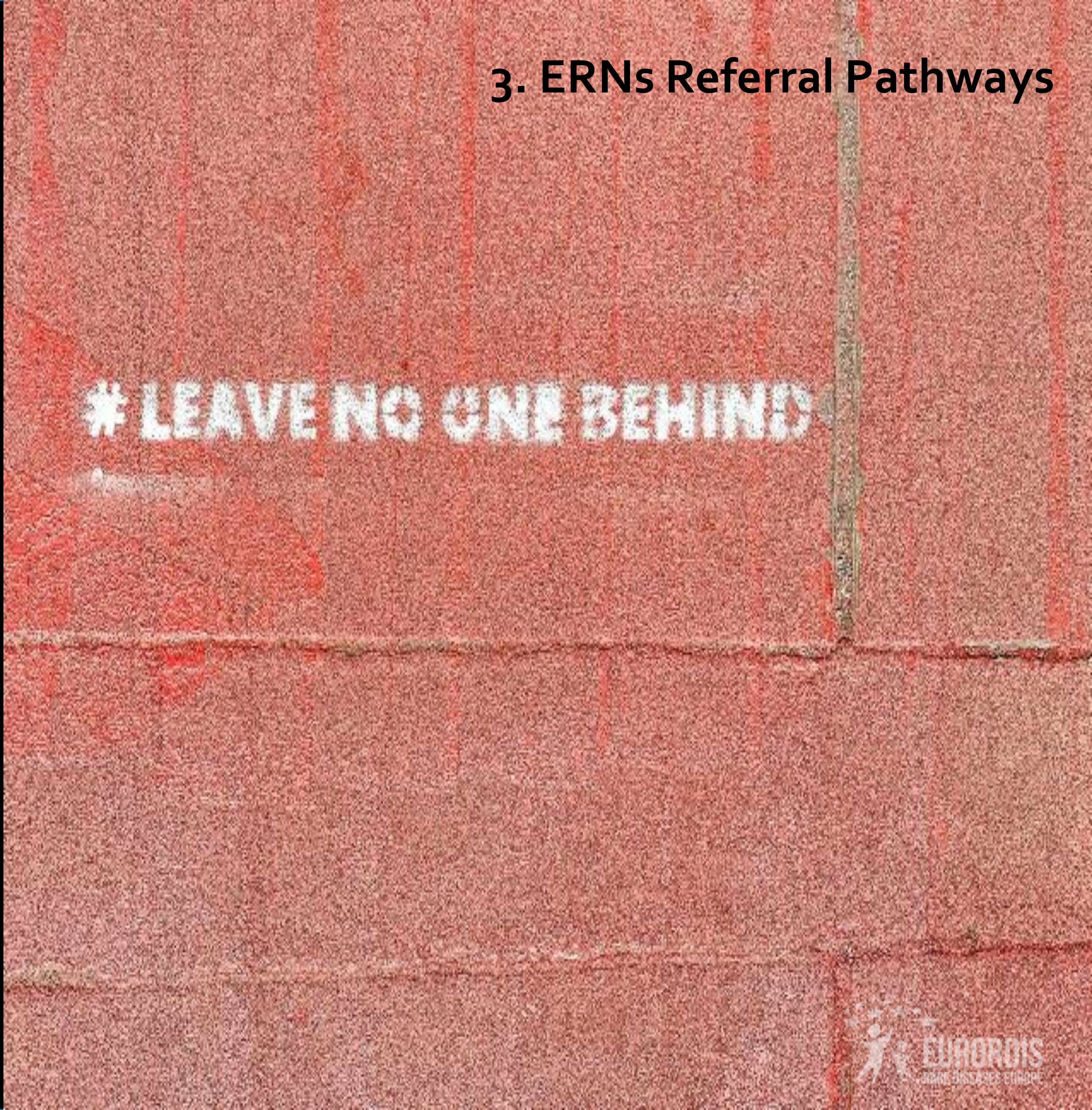
2. Patient care Pathways

Review ERN care pathways and explore how they can be implemented nationally:

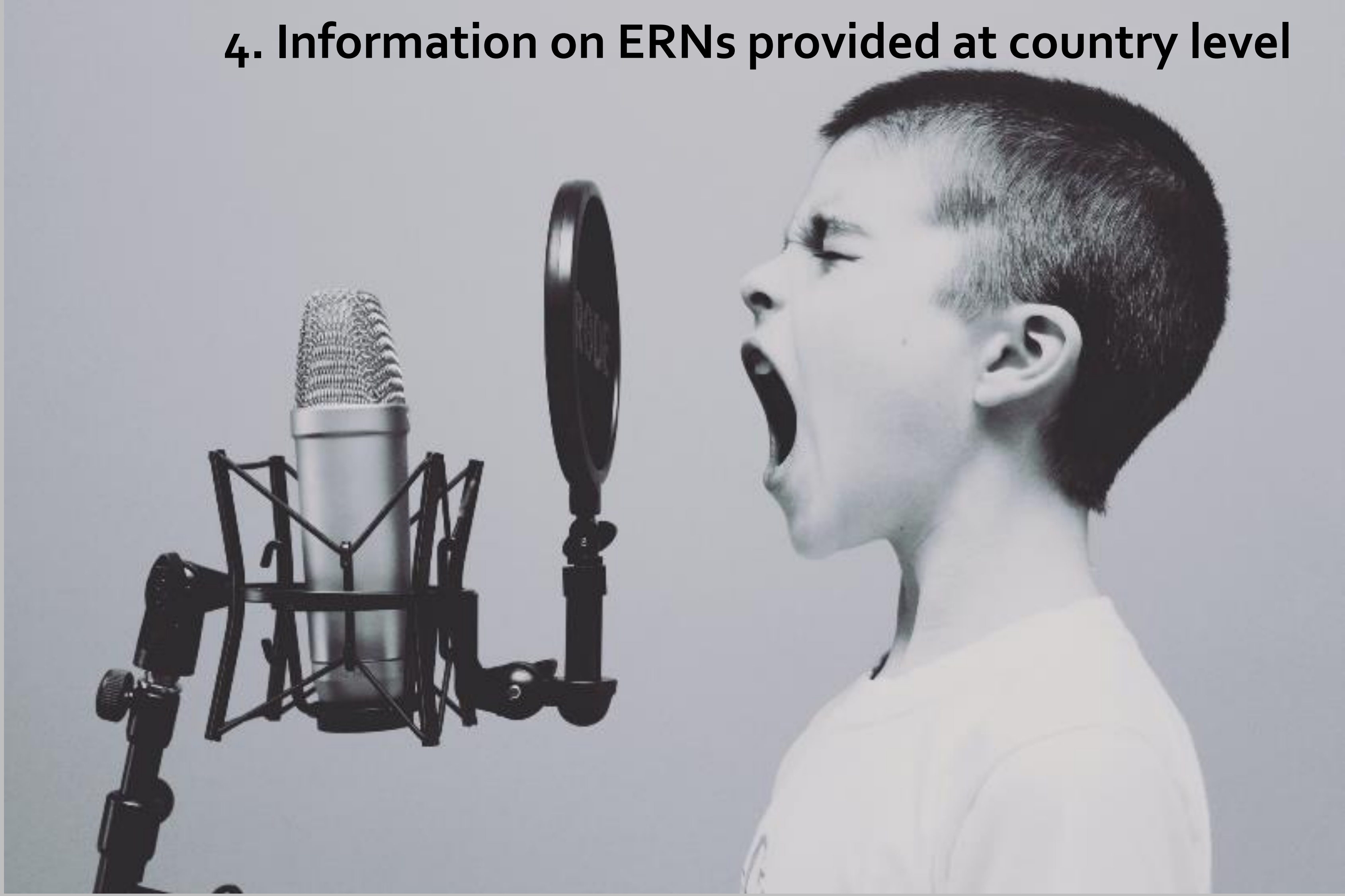
1. **Service mapping** (consider the path of the patient from an organisational point of view from referral to follow-up)
2. **Benchmark national care pathways against patients' needs**
3. **Assess alignment** of existing national care pathways with the ERN care pathways
4. **Evaluate economic burden** and the resources use to treat RD patients (first, you need to identify/code patients!)
5. **Service re-design**, in the light of patients' needs, the ERN care pathway and the economic burden.
6. **Monitor care pathways** for constant improvement

3. ERNs Referral Pathways

1. **Define clear referral pathways** to ensure access to ERNs services.
    - who can be referred?
    - who makes the referral?
    - what information is required?
    - is prior-authorisation needed?
    - how is follow-up organised?
    - what organisation manages the referral process?
2. **Train** professionals and patient community on the ERN referral system.
3. **Establish national/regional networks** of CoE to ensure timely access to ERN services. These networks should also translate into a more strategic engagement of national CEs with ERNs, via a limited number of full member HCPs.



4. Information on ERNs provided at country level



1. **Increase awareness of the general pub**lic on ERNs;

2. **Connecting ERNs to the national RD health ecosystem** – facilitating healthcare professionals, scientific societies, researchers and the RD patient community access to the services and knowledge generated/curated by the ERNs/, including medical education and other training activities

5. Support by national governments to ERN members

Support experts and clinical teams to have the capacity to participate in the Networks as well as to coordinate activities at national level (support can be admin, financial, organisational…)

Best practice 1: Designation of CoE in The Netherlands

Best practice 2: Improving access to care and treatment for Huntington's Disease patients and families