



European **Rare Diseases**
Research Alliance

The European Rare Disease Research Alliance (ERDERA) and why New Zealand's membership as a National Mirror Group (NMG) matters

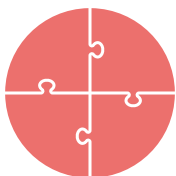
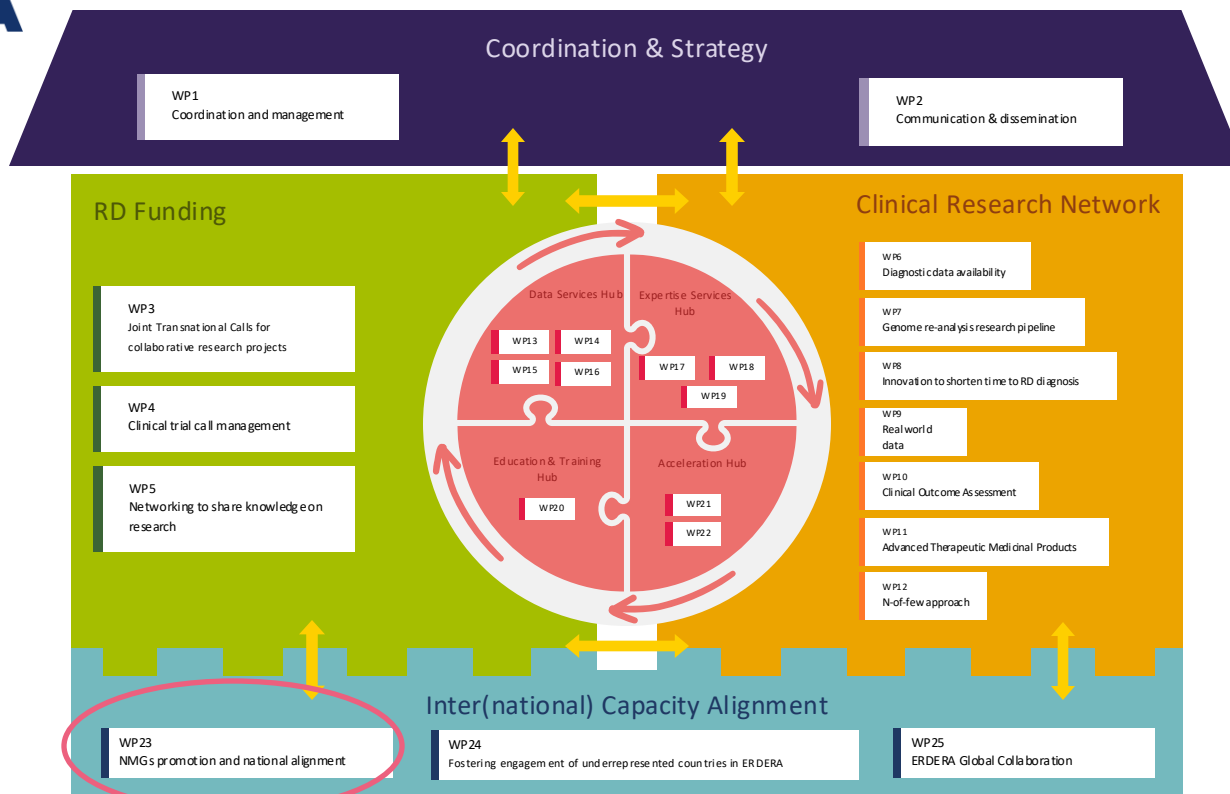
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WP13
Rare Diseases-Virtual Platform (RD-VP): Finding and accessing the data ecosystem

WP14
Data readiness services

WP15
Data sharing and analysis services

WP16
Knowledge bases and ontologies for RD research

WP17
Mentoring and consultancy

WP18
Regulatory support service

WP19
Methodological Support

WP20
Education and training in rare diseases research

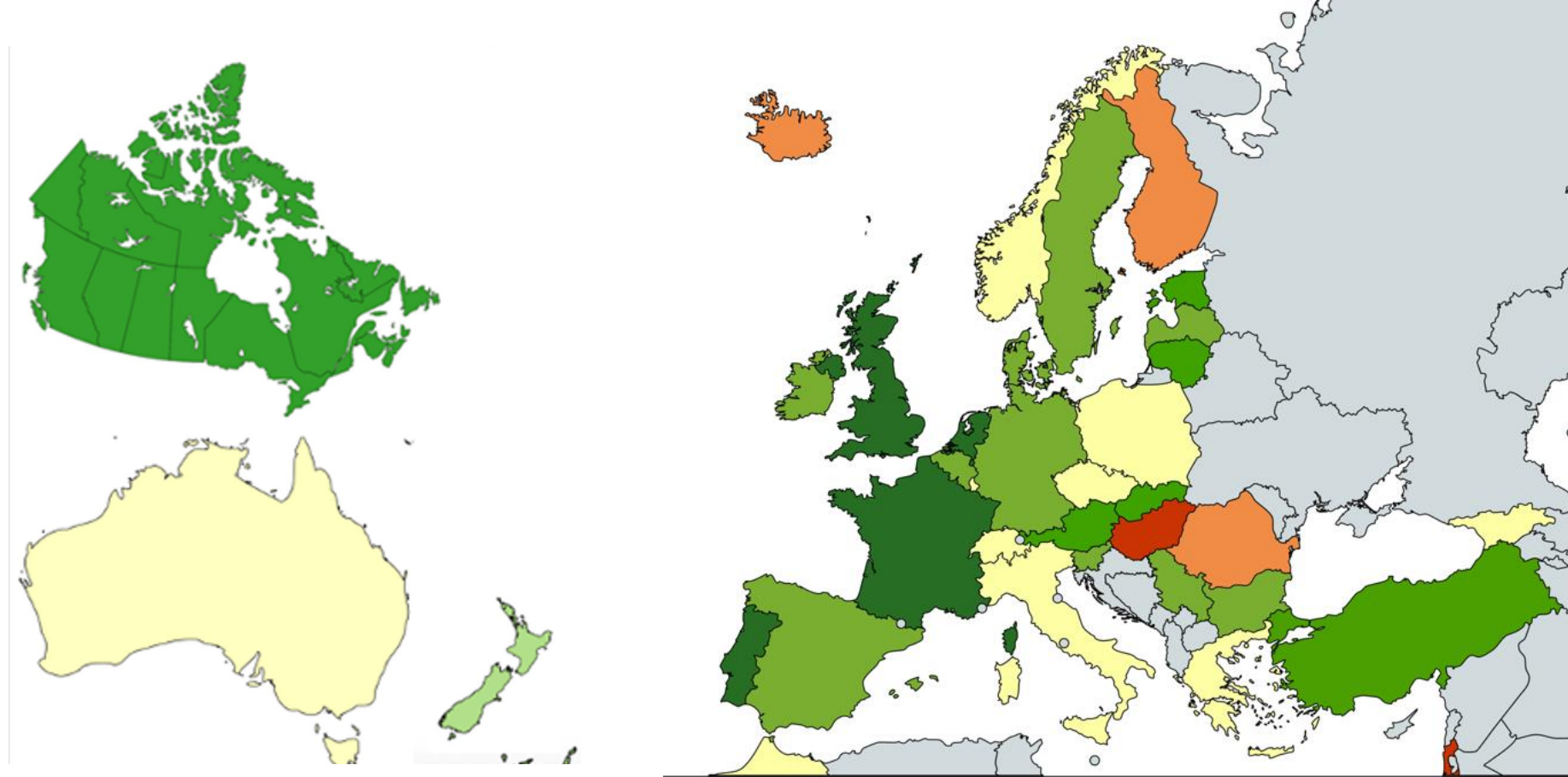
WP21
Technology accelerator

WP22
Public-Private Collaboration Accelerator

The purpose of NMGs

- Broadly speaking, NMGs should do 2 things:
 - Unite the RD research community in their national territory (& either integrate 'care' too, or else forge robust links to suitable groups/structures)
- Help bridge the gap between the European/International RD level, on the one hand, and national RD level on the other: effectively, this means
 - Furthermore, NMGs should enable more focused interactions and good practice sharing *between* countries





Key NMG Activities (1)

Coordinate/Bring cohesion to RD activities at national level



NMG

NMG General meetings and National Alignment Board (NAB) meetings

March '26

1-2-1 Meetings with the WP23 leads

Starting
Q2 '26

WP23 Topic Workshops

How to maximize the power of national plans for rare disease, and strengthen their capacity to foster rare disease research?

Riga, Latvia: 2nd – 3rd June 2025





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'Creating, evolving and utilising national registries to advance rare disease research'

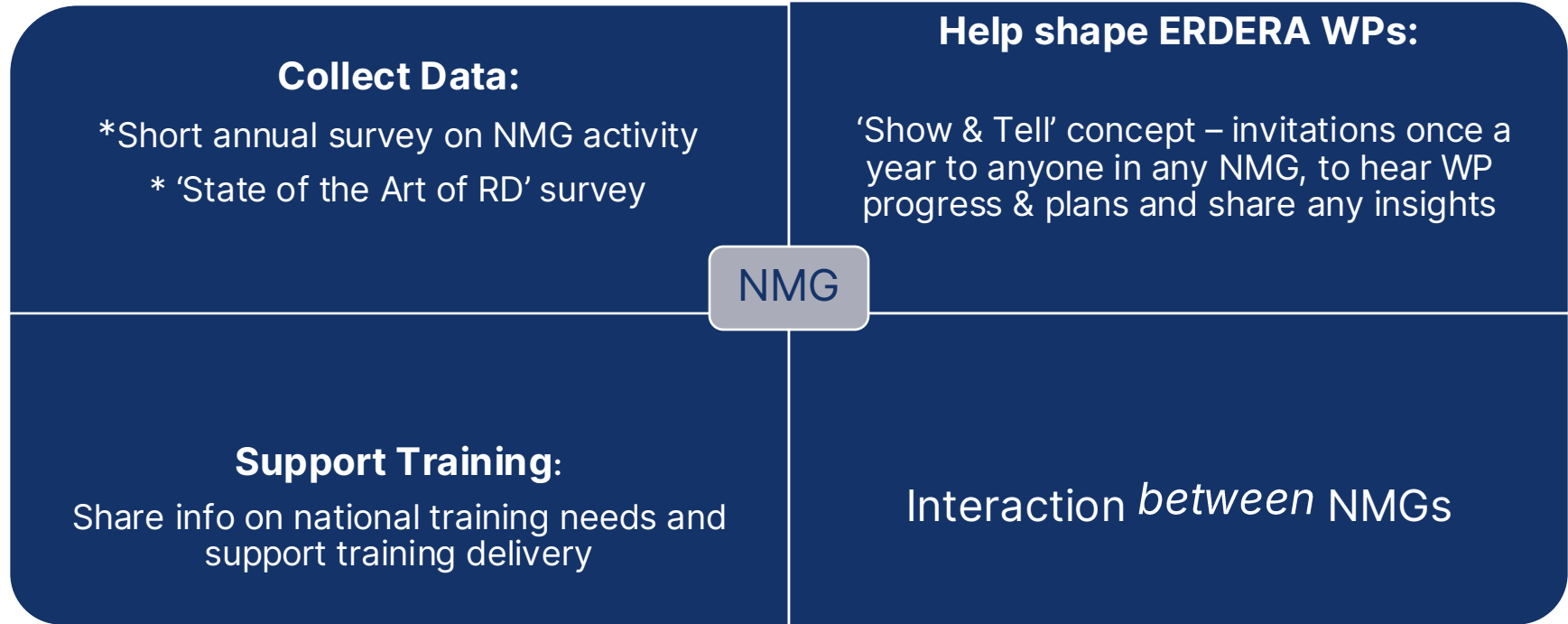
Riga, Latvia: 9th-10th June 2026



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Key NMG Activities(2)



Resource on the State of the Art of Rare Disease Activities

2025 Report for New Zealand

National Mirror Group

New Zealand has a National Mirror Group (NMG) in place, which was launched in December 2025. Rare Disorders New Zealand's (RDNZ) is the coordinator. The NMG utilises RDNZ working groups to reach across research, clinical and government spaces. The New Zealand NMG aims to work closely with the Australia NMG.

The collection of data from New Zealand for this report has been overseen via a data contributing committee. Contributors are listed at the end of the report.

Definition of a Rare Disease

New Zealand adopts the formal European Union (EU) definition of a rare disease (i.e. those with a prevalence of no more than 5 patients per 10,000 persons. This definition is laid down in Regulation EC no. 141/2000 on Orphan Medicinal Products, Directive 2011/24/EU on Cross Border Healthcare as well as in the Council Recommendation on an action in the field of rare diseases of 8 June 2009.). The National Strategy espouses this definition and there are no instances when a different definition is used.

Status Quo of any National Plan or Strategy for Rare Disease

What is the status quo?

New Zealand has a live, in-date, National Strategy for Rare Disease. The National Strategy is timebound, covering a period of ten years. This is New Zealand's first National Strategy for Rare Disease.

Elaboration and Adoption/How was the original strategy elaborated?

A dedicated group was in charge of overseeing the drafting and adoption of New Zealand's National Strategy for Rare Disease. The following stakeholder types were included in this group:



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<https://erdera.org/international-alignment/national-mirror-groups/>

NMG activities survey

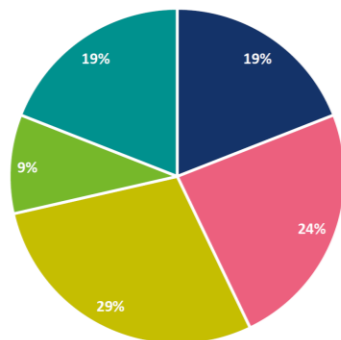


21 out of 21 NMGs completed the
NMG Activities survey



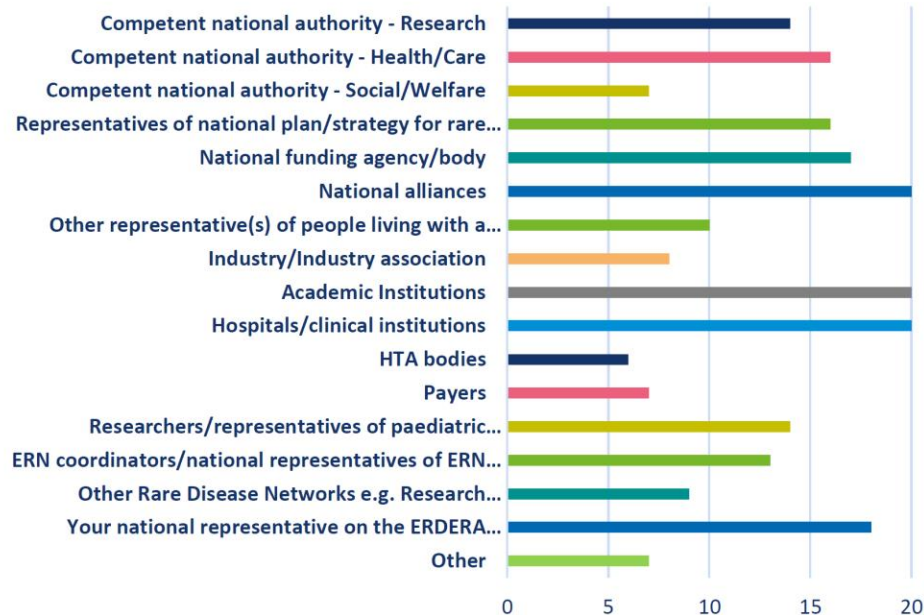
Approximately 369 organisations are
involved in NMGs in total

How many organisations are involved in your NMG?



■ Less than 10 organisations
 ■ 11-15 organisations
 ■ 16-20 organisations
 ■ 21-25 organisations
 ■ More than 26 organisations

Which of the following categories of stakeholders are part of your NMG?



Cyprus
Estonia
France
Germany
Ireland
Latvia
Lithuania
Netherlands
New Zealand



The National Mirror Group in New Zealand has been operational since 2025. Rare Disorders NZ serves as the primary national contact point.

Coordinate/Bring cohesion to RD activities at national level

NMG General meetings and National Alignment Board (NAB) meetings

- At least 1 virtual NMG Leads/Future Leads meetings per year,
- 1 in-person NAB meeting per year (through NAB role, NMG leads should support ERDERA planning each year)

NMG

1-2-1 Meetings with the WP23 leads

Each NMG will have an annual* meeting (virtual) with WP 23 leads, for us to better understand your needs, activities, realities, & assess how the NMG concept is working.

*we can arrange additional calls if requested, perhaps especially for UCs?

WP23 Topic Workshops

Each NMG should be represented in annual topic workshops, intended to share good/innovative practices, generate new knowledge, explore ERDERA advice, and optimise synergies for greater alignment.

Interact between NMGs:

Each NMG will have their own channel in MS Teams for internal communication as well as different channels for communication with other NMGs – we especially want to build synergies between countries with similar situations/geography, etc

NMG

Collect Data:

- *Short annual survey on NMG activity
- * 'State of the Art of RD' survey

Help shape ERDERA WPs:

'Show & Tell' concept – invitations once a year to anyone in any NMG, to hear WP progress & plans and share any insights

Support Training:

Share info on national training needs and support training delivery

3 Year Action Plans

There are several advantages to creating these action plans, e.g.

- crystallising thoughts in each NMG on where their real added-value lies, what specific actions they want to prioritise etc.
- Providing insight to WP23 on common goals and needs we can try to address, supporting country matchmaking etc

NMG three-year plans: example priority areas

Mapping the national rare disease landscape

The results of the mapping will serve as an evidence base for identifying gaps and opportunities for alignment

Engaging with national rare disease initiatives

NMGs plan to engage with other national RD or relevant initiatives, in an effort not to duplicate effort.

Rare disease awareness raising

To general public, patients, and healthcare professionals and other relevant national infrastructures

Influencing National Plans & Strategies for RD

5 NMGs are involved in drafting/revising NPs. Estonia and Bulgaria would like to advocate for developing NPs

Communication and dissemination

NMGs disseminating info by email but would like to increase web and social media presence. NMGs Would like to utilise Teams channels.

NMG three-year plans: Areas to exert NATIONAL influence

- **Diagnostics:** Latvia, France, Austria, Belgium, Türkiye, Slovakia plan to prioritise strengthening diagnostic strategies within their country. Specific plans include: standardising diagnostic lab procedures, ensuring diagnostic approaches are patient focussed and cost effective and aligning with other relevant initiatives.
- **Education and training:** 9 NMGs (France, Latvia, Belgium, Bulgaria, Türkiye, Estonia, Spain, Portugal, Slovakia) have identified training and education as a high priority area. Specific plans include: disseminating ERDERA training, developing a rare disease course for medical professionals, and integrating rare and undiagnosed diseases into undergraduate medical curricula.



Areas to exert NATIONAL influence Cont.

- **Data and patient registries:** Data and registries have been identified as high priority for the majority of NMGs, particularly for informing patient care and treatment pathways. Many NMGs specifically want to ensure interoperability with national infrastructures, ERN registries and the European Health Data Space (EHDS). Interest in coding of national registries, for instance, visibility, connection to VP
- **Research:** NMGs plan to boost RD research, as well as support clinical and basic research. In some, like UK, e.g. goal is maximising complimentary investments. Some NMGs identified research as an area to influence within their national plan/strategy.





**European Rare Diseases
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Thank you!



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