Thought Leaders Session
European Conference for Rare Diseases 2022

27 June 2022 | 16:30 to 18:00 (CET)

PREPARING THE FOUNDATIONS FOR A GLOBAL NETWORK FOR RARE DISEASES

Ines Hernando, ERN & Healthcare Programme
EURORDIS

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Agenda

- Introduction & Setting the Scene (Ines Hernando)
- Concept Model for the Global Network for Rare Diseases
- Addressing Patient Needs (Salman Saif, CureforU)
- European Region Readiness for the Pilot (Michelle Battye, ERN eUROGEN)
- Panel Discussion & Q&A (Ines Hernando)
- Closing Remarks (Ines)

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CONCEPT MODEL for the GLOBAL RARE DISEASE NETWORK

Matt Bolz-Johnson, Programme Director

Rare Diseases International

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Rare Diseases International & Members

Active in over

150 COUNTRIES

covering **6** continents

83

Member Organisations

RD National Alliances

Represent all RDs and one country

42

International Federations

Represent the same RD or disease area internationally or regionally

30

3

RD Regional Alliances

Represent all RDs in a geographical region

Europe (EURORDIS), Ibero-America (ALIBER) and Asia Pacific (APARDO)

8

Multi-stakeholder Platforms and Other RD Organisations

Associate Members

Rare Community has strength in unity, strength in diversity

RDI and RD Community come together to act on two levels:

- Shaping Global Environment: securing political recognition and support of RD as a global public health priority and included in global policy action in the United Nations and the World Health Organisation.
- Building Local Capacities: empowering our community to become strong advocates and strengthen healthcare systems capacities in rare diseases.

Policy Framework

2019 - UN Political Declaration on Universal Health Coverage: moving together to build a healthier world

- Stresses the need for a **comprehensive and people-centred** approach, with a view to leaving no one behind.
- Recognizes that UHC implies that all people have **access** to essential health services **without financial hardship, particularly for vulnerable populations.**
- Recognizes the need for **health systems that are strong** (…)
- Member States commit to scale up efforts and further implement the following actions:

  - strengthen efforts to address rare diseases as part of Universal Health Coverage

2021 - UN Resolution on addressing the challenges of Persons Living with a Rare Disease and their families:

OP1. Calls upon Member States to **strengthen health systems** in order to provide universal access to a wide range of healthcare services;

OP6. Encourages Member States (1) to foster the **creation of networks of experts and multidisciplinary specialized expert hubs** for rare diseases; and (2) to increase support for research by strengthening **international collaboration**, coordination of research efforts and sharing of data.

UN
RESOLUTION
PERSONS LIVING
WITH A RARE
DISEASE

Our Agreement

WHO and Rare Diseases:

- WHO Director General Statement on Rare Diseases, February 2018
- UN Political Declaration on Universal Health Coverage includes Rare Diseases, September 2019, and WHO is responsible for the implementation of UHC
- Memorandum of Understanding (MoU) signed between WHO and RDI, December 2019

World Health Organization

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“RD Gaining Momentum as a Key UN Policy Area”

H. E. Toshiya Hoshino - Ambassador and
Permanent Representative of Japan to
the UN, March 2021

“No country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases”

Helen Clark, United Nations Development Program (2016)

“WHO’s top priority is to support countries on the path towards universal health coverage, with the aim of ensuring that all people can access the health services they need. […] **This includes access to diagnosis and treatment for people who suffer from rare diseases**.”

Dr Tedros Adhanom Ghebreyesus, WHO Director General (2018)

“we must work together to ensure an **equitable and affordable access to quality health services and medicines for everyone** especially […] **people living with rare diseases** among others while ensuring that they **do not face financial hardship or fall back into poverty.**”

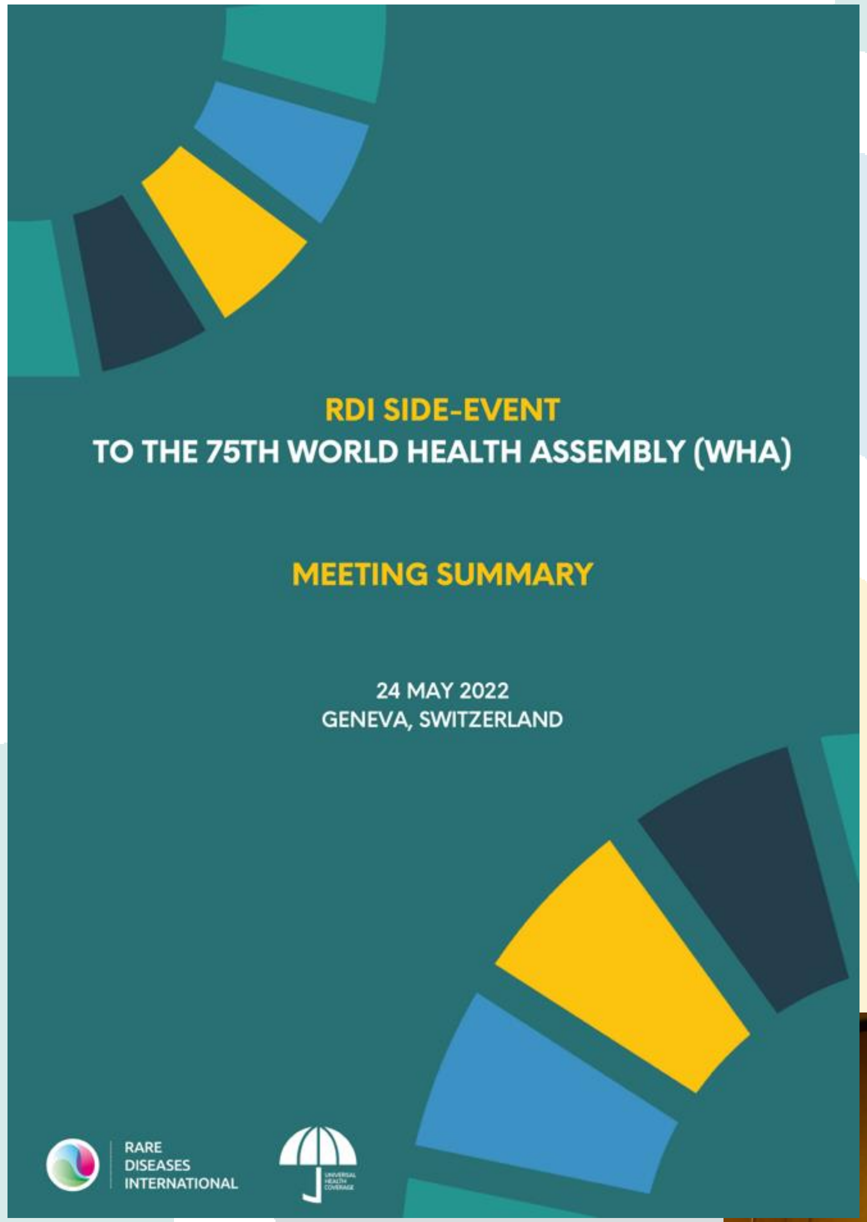
H. E. Vitavas Srivihok – Ambassador and Permanent Representative of Thailand to the UN (2021)

“As we are moving forward and putting the issues of RD on the political agenda of governments, it is **now time to follow with actions in health systems strengthening in rare diseases, for a Global Network on Rare Diseases**; therefore, implementing the governance measures against discrimination that we know would work best.

The **WHO will be moving along this road with you**.”

Dr Rüdiger Krech - WHO Director of Health Promotions, World Expo Dubai (2022)

WHO Informal Side-Event to the WHA



RDI SIDE-EVENT
TO THE 75TH WORLD HEALTH ASSEMBLY (WHA)

MEETING SUMMARY

24 MAY 2022
GENEVA, SWITZERLAND

RARE DISEASES INTERNATIONAL

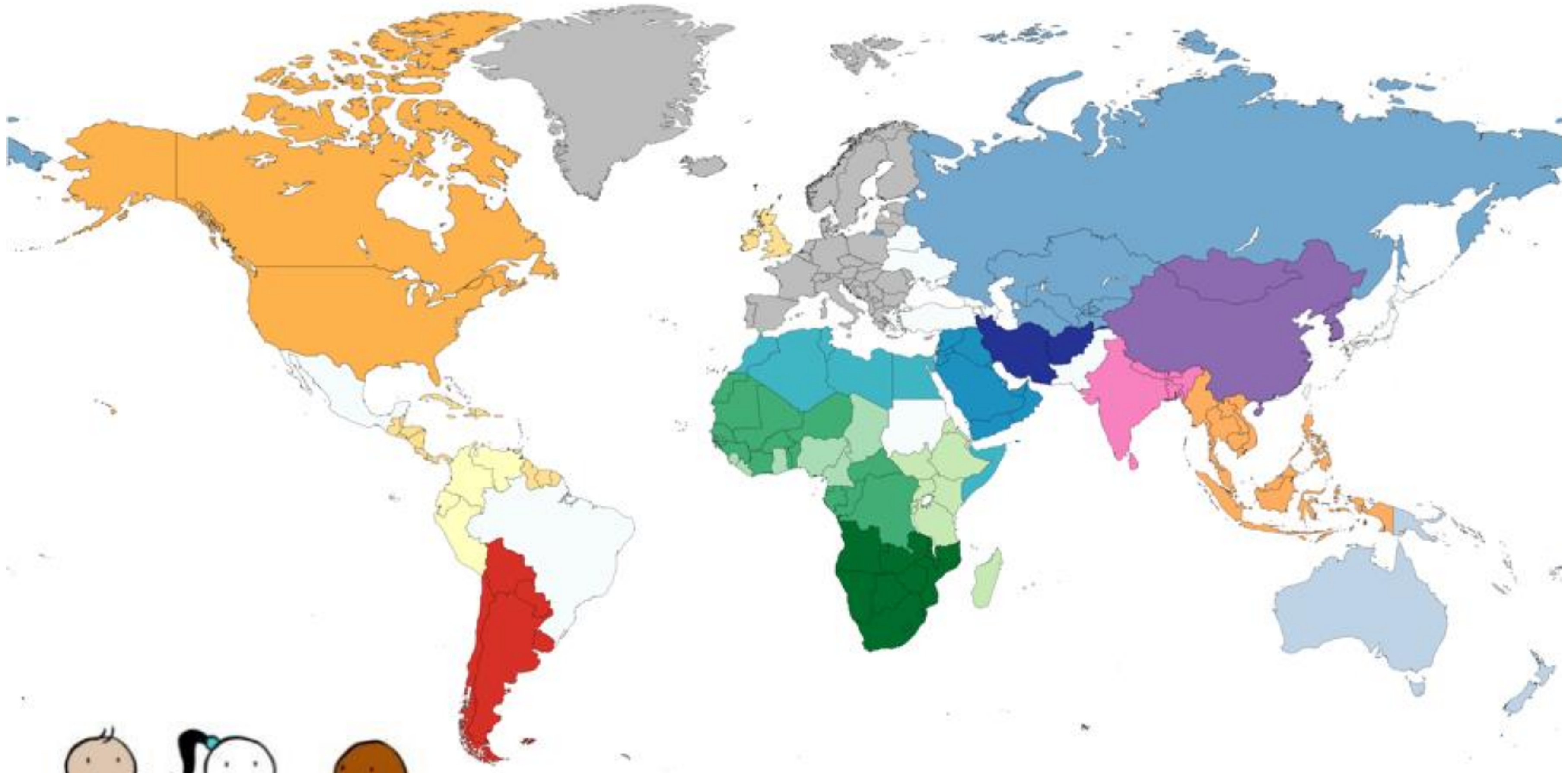
G24 May 2022, Geneva

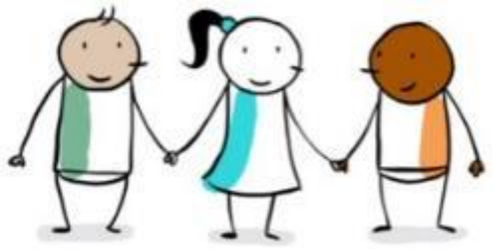
- Download Meeting Report
- 218 participants connecting on the digital platform
- over 80 countries
- over 600 viewings of the recorded event

Watch Recording: Click Here

Voice of All

Member States are encouraged to *foster the creation of networks of experts and multidisciplinary specialized expert hubs for rare diseases* and *strengthening international collaboration*.





- Engagement with an international Panel of Experts (>220 experts)
- 4 rounds of Global Workshops (totalling 20 workshops), 6 more rounds planned in 2022-23
- 3 rounds of Regional Workshops (totalling 13 workshops) in 2021-22, 4 more rounds planned in 2022-2023
- Consultation Workbook provided to all (available in Arabic, English, French and Spanish)
- Creating safe environments to understand and learn from each other
- Creating collective impact by building on the wisdom of all

Technical Documents

NEEDS ASSESSMENT

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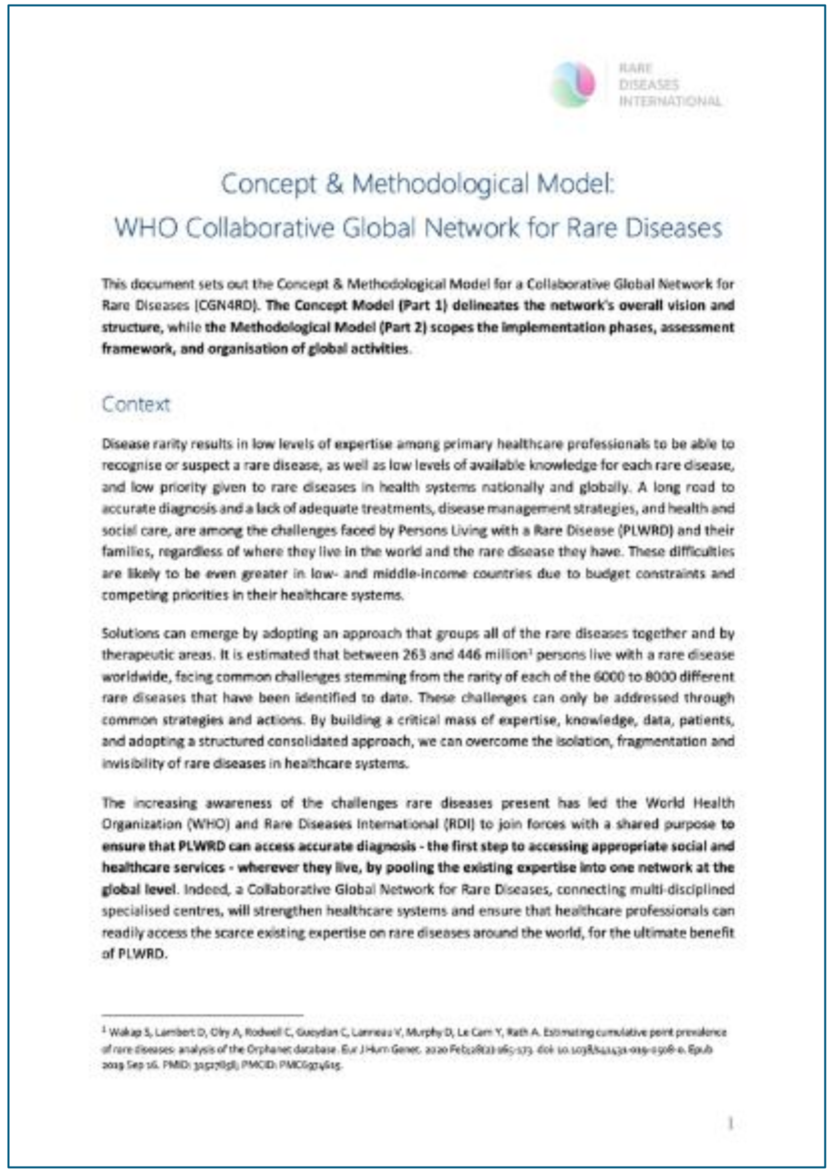
Rare Diseases Needs Assessment Study,
Conceptual and Methodological Model

to inform the development of

the WHO Collaborative Global Network
for Rare Diseases.

Population Needs Assessment Study
Report

CONCEPT MODEL



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Concept & Methodological Model:
WHO Collaborative Global Network for Rare Diseases

This document sets out the Concept & Methodological Model for a Collaborative Global Network for Rare Diseases (CGN4RD). **The Concept Model (Part 1) delineates the network's overall vision and structure**, while **the Methodological Model (Part 2) scopes the implementation phases, assessment framework, and organisation of global activities**.

Context

Disease rarity results in low levels of expertise among primary healthcare professionals to be able to recognise or suspect a rare disease, as well as low levels of available knowledge for each rare disease, and low priority given to rare diseases in health systems nationally and globally. A long road to accurate diagnosis and a lack of adequate treatments, disease management strategies, and health and social care, are among the challenges faced by Persons Living with a Rare Disease (PLWRD) and their families, regardless of where they live in the world and the rare disease they have. These difficulties are likely to be even greater in low- and middle-income countries due to budget constraints and competing priorities in their healthcare systems.

Solutions can emerge by adopting an approach that groups all of the rare diseases together and by therapeutic areas. It is estimated that between 263 and 446 million[1] persons live with a rare disease worldwide, facing common challenges stemming from the rarity of each of the 6000 to 8000 different rare diseases that have been identified to date. These challenges can only be addressed through common strategies and actions. By building a critical mass of expertise, knowledge, data, patients, and adopting a structured consolidated approach, we can overcome the isolation, fragmentation and invisibility of rare diseases in healthcare systems.

The increasing awareness of the challenges rare diseases present has led the World Health Organization (WHO) and Rare Diseases International (RDI) to join forces with a shared purpose **to ensure that PLWRD can access accurate diagnosis - the first step to accessing appropriate social and healthcare services - wherever they live, by pooling the existing expertise into one network at the global level**. Indeed, a Collaborative Global Network for Rare Diseases, connecting multi-disciplined specialised centres, will strengthen healthcare systems and ensure that healthcare professionals can readily access the scarce existing expertise on rare diseases around the world, for the ultimate benefit of PLWRD.

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[1] Wakap S, Lambert D, Olry A, Rodwell C, Gueydan C, Lanneau V, Murphy D, Le Cam Y, Rath A. Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. Eur J Hum Genet. 2020 Feb;28(2):165-173. doi: 10.1038/s41431-019-0508-0. Epub 2019 Sep 16. PMID: 31527858; PMCID: PMC6974615.

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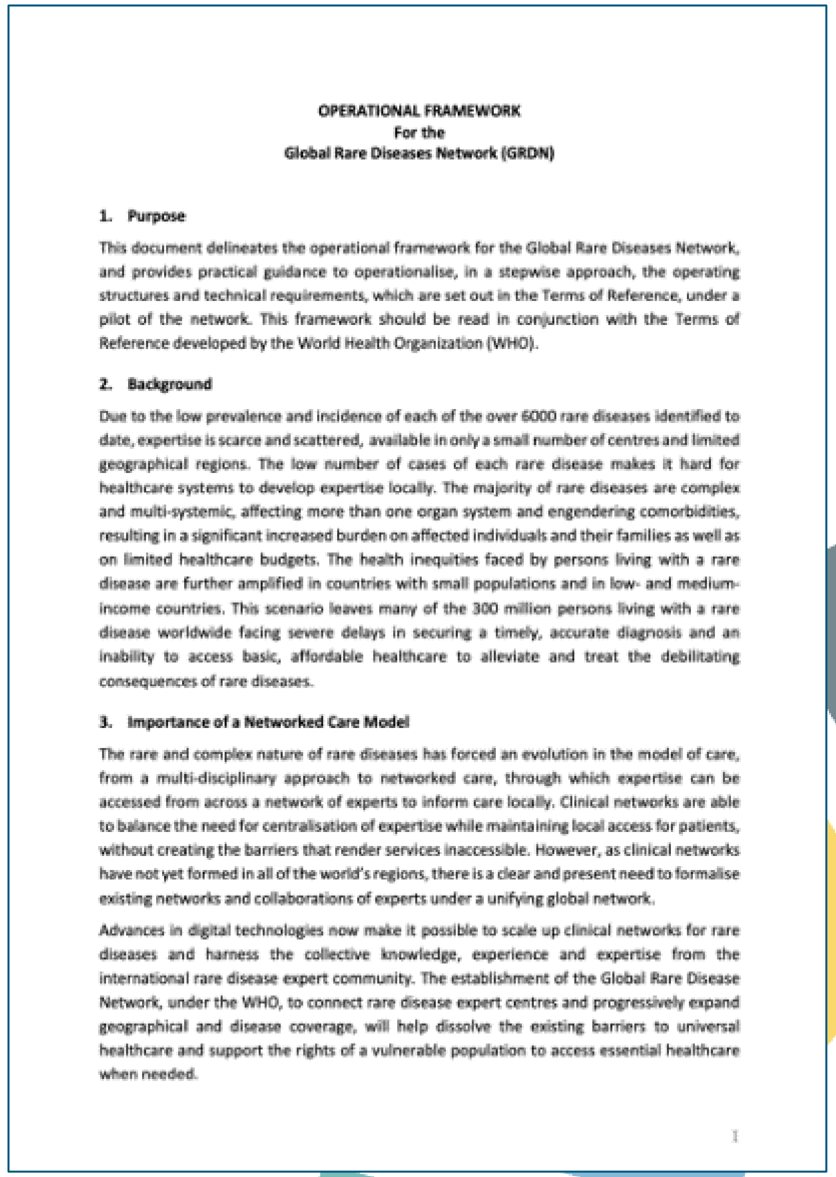
OPERATIONAL FRAMEWORK



OPERATIONAL FRAMEWORK
For the
Global Rare Diseases Network (GRDN)

1. Purpose

This document delineates the operational framework for the Global Rare Diseases Network, and provides practical guidance to operationalise, in a stepwise approach, the operating structures and technical requirements, which are set out in the Terms of Reference, under a pilot of the network. This framework should be read in conjunction with the Terms of Reference developed by the World Health Organization (WHO).

2. Background

Due to the low prevalence and incidence of each of the over 6000 rare diseases identified to date, expertise is scarce and scattered, available in only a small number of centres and limited geographical regions. The low number of cases of each rare disease makes it hard for healthcare systems to develop expertise locally. The majority of rare diseases are complex and multi-systemic, affecting more than one organ system and engendering comorbidities, resulting in a significant increased burden on affected individuals and their families as well as on limited healthcare budgets. The health inequities faced by persons living with a rare disease are further amplified in countries with small populations and in low- and medium-income countries. This scenario leaves many of the 300 million persons living with a rare disease worldwide facing severe delays in securing a timely, accurate diagnosis and an inability to access basic, affordable healthcare to alleviate and treat the debilitating consequences of rare diseases.

3. Importance of a Networked Care Model

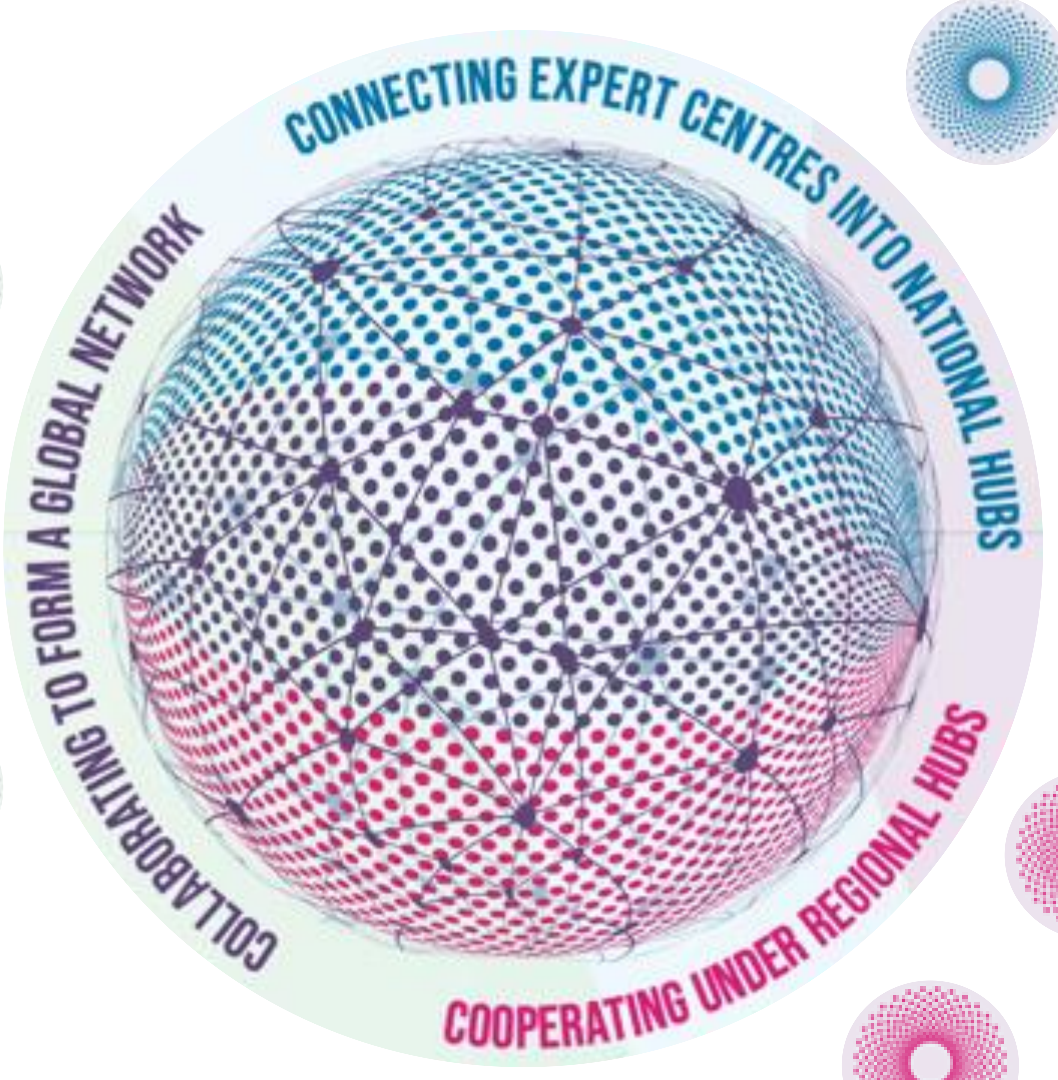
The rare and complex nature of rare diseases has forced an evolution in the model of care, from a multi-disciplinary approach to networked care, through which expertise can be accessed from across a network of experts to inform care locally. Clinical networks are able to balance the need for centralisation of expertise while maintaining local access for patients, without creating the barriers that render services inaccessible. However, as clinical networks have not yet formed in all of the world's regions, there is a clear and present need to formalise existing networks and collaborations of experts under a unifying global network.

Advances in digital technologies now make it possible to scale up clinical networks for rare diseases and harness the collective knowledge, experience and expertise from the international rare disease expert community. The establishment of the Global Rare Disease Network, under the WHO, to connect rare disease expert centres and progressively expand geographical and disease coverage, will help dissolve the existing barriers to universal healthcare and support the rights of a vulnerable population to access essential healthcare when needed.

1

Concept Model

Global Network is a “Network of Networks” that enables Persons Living with a Rare Disease - no matter where they live - to reach a network of expertise to access appropriate knowledge, diagnosis, and care.



Pooling expertise, access specialist advice and global knowledge through building a learning system

Leverage advancements in health and information technologies

Inform on global public health action

Knowledge ‘adaptors’ to access global knowledge to strengthen health systems

Connecting together under a hub and spoke model

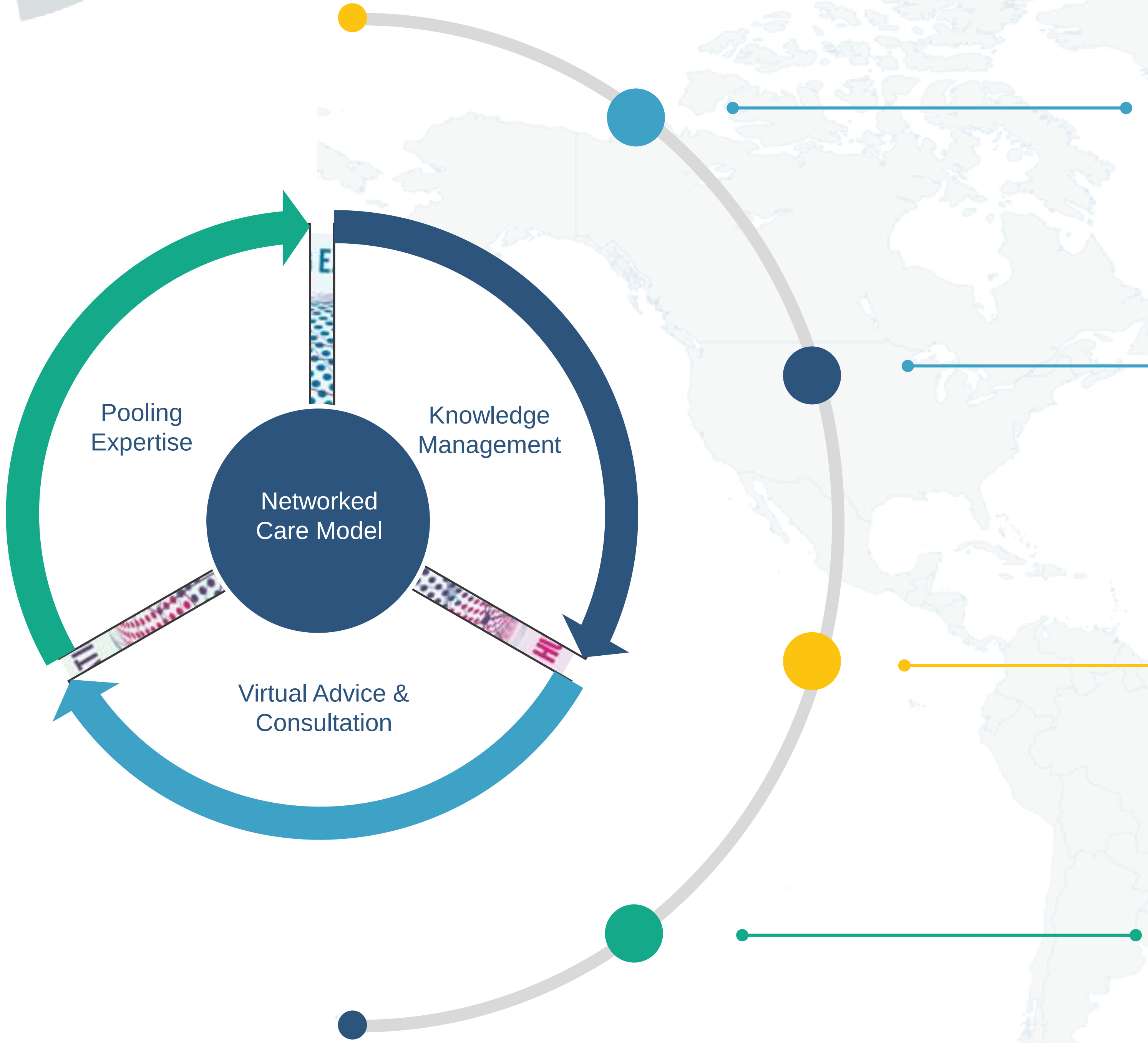
Nationally endorsed single or multi-centre National Hubs

Common digital platform to support collaboration and scale up diagnostic capacities

Shared experience and shared culture to build a shared vision

Virtual multi-centre networks of expert centres and patient organisations

Framework for Collaboration



NETWORK PARTICIPANTS

- Actively and internationally working in the field of rare diseases with proven experience and expertise in the subject matter
- Existing networks or collaborations of expert centres that have a good coverage of rare diseases and geography
- Member States, intergovernmental organizations, on-governmental organizations, patient associations, hospitals and academic institutions, private sector (incl. business associations) and philanthropic foundations

STEERING COMMITTEE

- Balanced representation of Network Participants e.g.: stakeholder groups, geographical areas and disease cluster
- Provide strategic direction for the Global Network and development of workplans and strategies

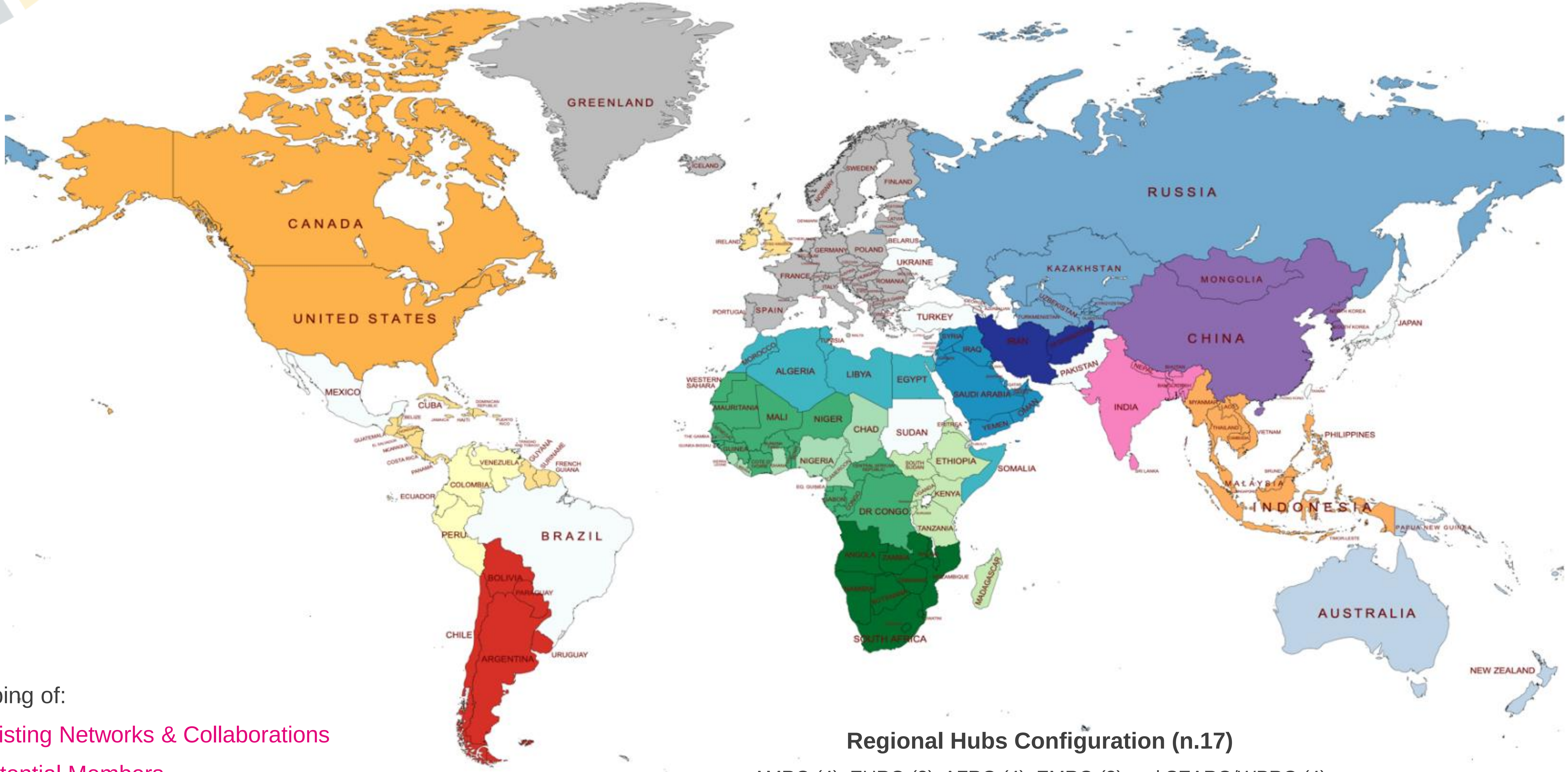
WORKING GROUPS

- Provide access to specialist advice, share information and coordinate joint activities.
- Initially established according to most relevant disease clusters: Need-led Dimension - grouping by common needs to build common strategies and action; Clinical-led Dimension - grouping to access a panel of experts for specialist advise and opinion

REGIONAL & GLOBAL HUB(S)

- The Global Network has the ambitious goal of increasing access to specialist experts through "**Regional and Global Hubs**"
- *Hubs of Expert Centres & Patient Organisations* to connect with healthcare systems under a "hub and spoke" model to support strengthening of local systems in rare diseases.
- Concept of Regional and Global Hubs will initially be co-developed and piloted under the Pilot Phase
- Prototypes will subsequently be organised in the Deployment Phase through the identification and designation of expert centres to form Regional and Global Hubs.

Foundation of the Global Network



Mapping of:

- Existing Networks & Collaborations
- Potential Members

Regional Hubs Configuration (n.17)

AMRO (4), EURO (2), AFRO (4), EMRO (3) and SEARO/WPRO (4)

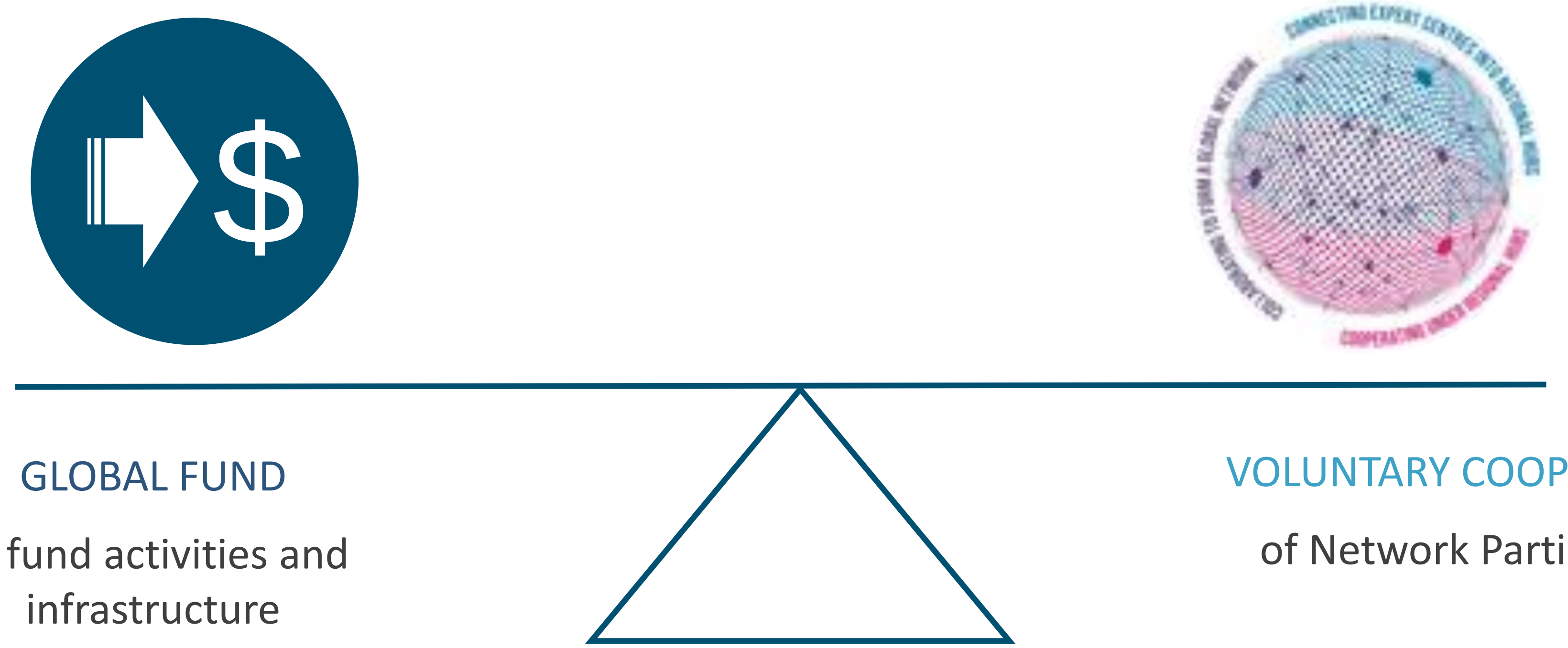
Resourcing & Sustainability

PILOT NETWORK

- Establish the Secretariat of the GRDN
- Explore the feasibility to create a “Global Rare Disease Fund” - charitable donations from multiple sources will be explored.
- Recognizing the contribution and investment of Network Participants
- Expert opinion and advice is based on voluntary contribution

NETWORK PARTICIPANTS

- Network Participants are endorsed to collaborate under the GRDN
- Participation in the Pilot Network is primarily based on voluntary contribution for activities that are agreed with the WHO
- Endorsement and support for Institutions to be a Network Participant.



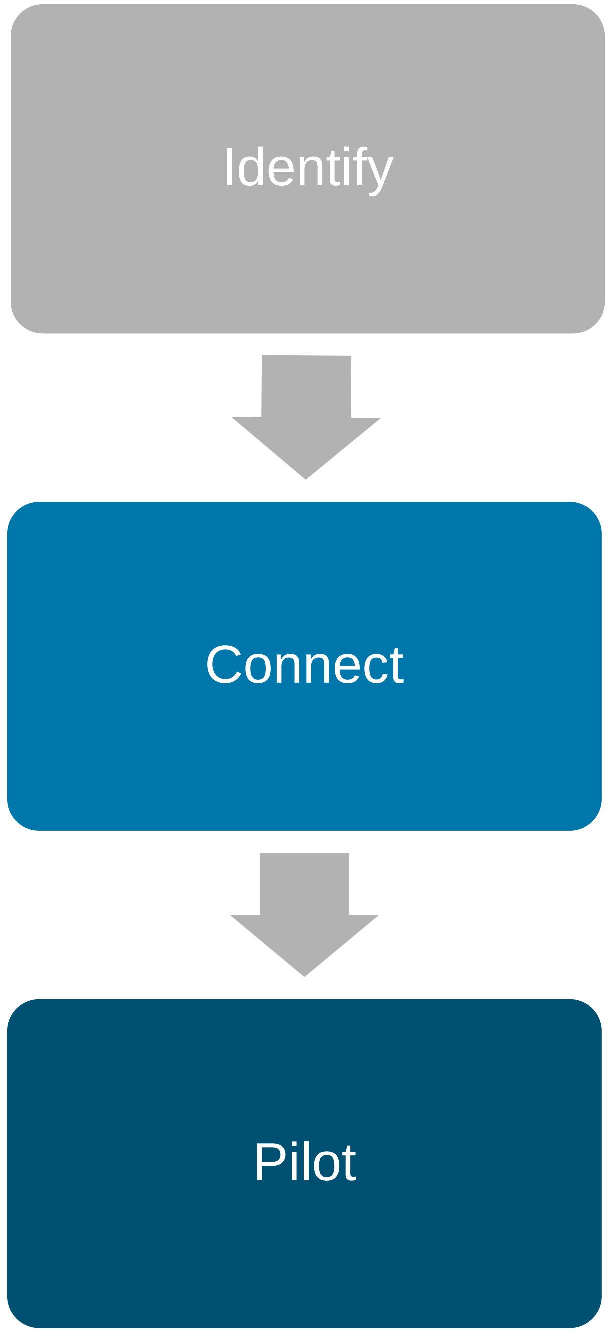
GLOBAL FUND

to fund activities and infrastructure

VOLUNTARY COOPERATION

of Network Participants

Identify Innovators & Early Adopters of Networked Care



Identify Potential Pilot Participants:

- Contribute significantly to the advancement of public health
- Actively and internationally working in the field of rare diseases
- Existing networks or collaborations of expert centres

Connect Innovators & Early Adopters Together:

- Define appraisal criteria and manage application process
- Member State endorsement & hospital support
- Launch pilot network and establish governments

Connect under the pilot:

- To experience on new approaches and build evidence base to support deployment
- Reflect on the Global & Regional Hub model and pilot model in each WHO region

THANK YOU

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Patient Perspective
GLOBAL RARE DISEASE NETWORK

cureforu

Salman Saif
Founder CureforU
www.cureforu.com

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Need for Global Rare Disease Network

- Fulfilling basic needs is already challenging in developing countries…………..and then having someone with RD in family would further complexify the situation……………………….Access to right expertise helping with right timely diagonose and treatment plan is not readily & easily available ……….which means patient with manageable and / or cureable RD are **LEFT BEHIND**

Hence Need for Clinical Networks to offer expertise anywhere in the world to help with right diagnose and treatment plan

A Project Inspired by Personal Experience of Parents

Vision - Facilitate better Cures for people living with Rare or Complex Disease by enabling health care professionals to Connect, Collaborate, and learn from each other

Shared Ownership — **Mutual Learning** — **Fit for Purpose Solution**

Dynamic Network of Medical Experts & Patient Organizations from Developing Countries & Developed Countries

1. To enable online expert opinion via case discussions on complex or rare medical cases to improve the chances of successful outcome for patients.
2. To share the information on complex medical cases, to foster medical learning .
3. To create conditions to enable institute level collaboration to improve the medical standards in Developing Countries.

1 Year of facilitating better Cures for Rare or Complex Diseases

Associations, Networks & Patient Organizations Providing Support & Guidance

APSP
(Association of Pediatric Surgeons Pakistan)
100+ Pediatric centers & Experts

Afghanistan Association of Pediatric Surgeons

15+ European Centers & Experts

Collaboration with ARM net

ARM net

MOU with ERN eUROGEN

European
Reference
Network

eUROGEN
Urogenital Diseases

Patient Organizations Helping us

SOMA e.V.

AIMAR

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1 Year of facilitating better Cures for Rare or Complex Diseases

Potentially Improving Outcomes of Patients living with Anorectal Malformations & Hirschsprung Disease

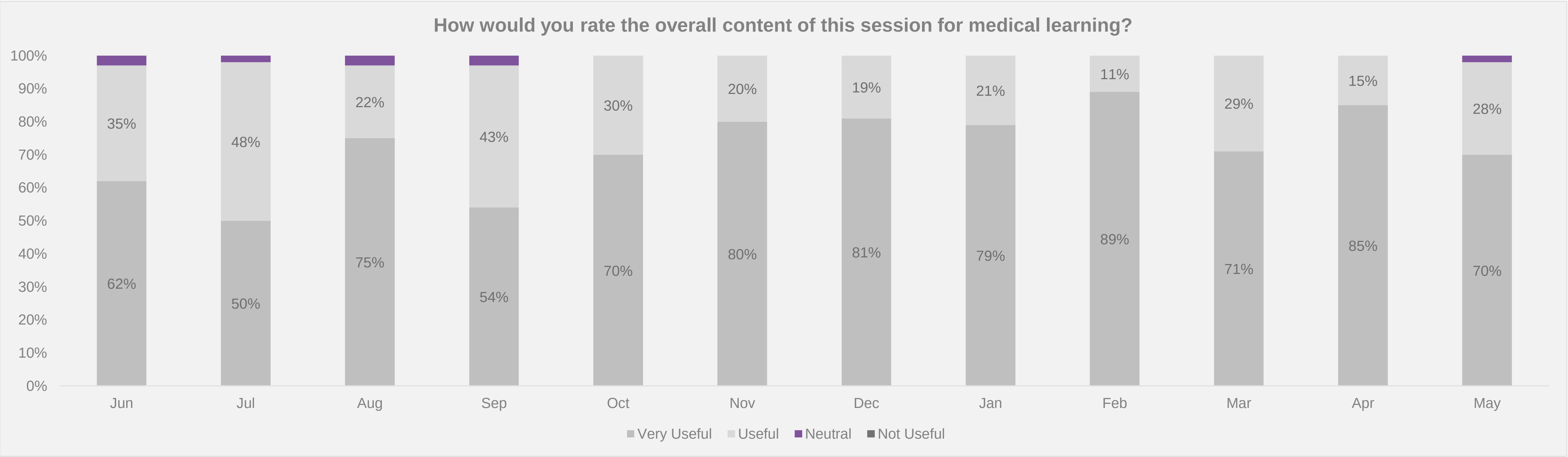
13 **Case Discussions**

26 **Case Discussed**

Fostering Medical Learning, across Community & Regions

❑ Each Case Discussion is attended by **70 to 100+** pediatric surgery professionals from **7+ Countries**

❑ **Over 98%** of attendees found case discussion content either **Very Useful** or **Useful** in terms of **Medical Learning**

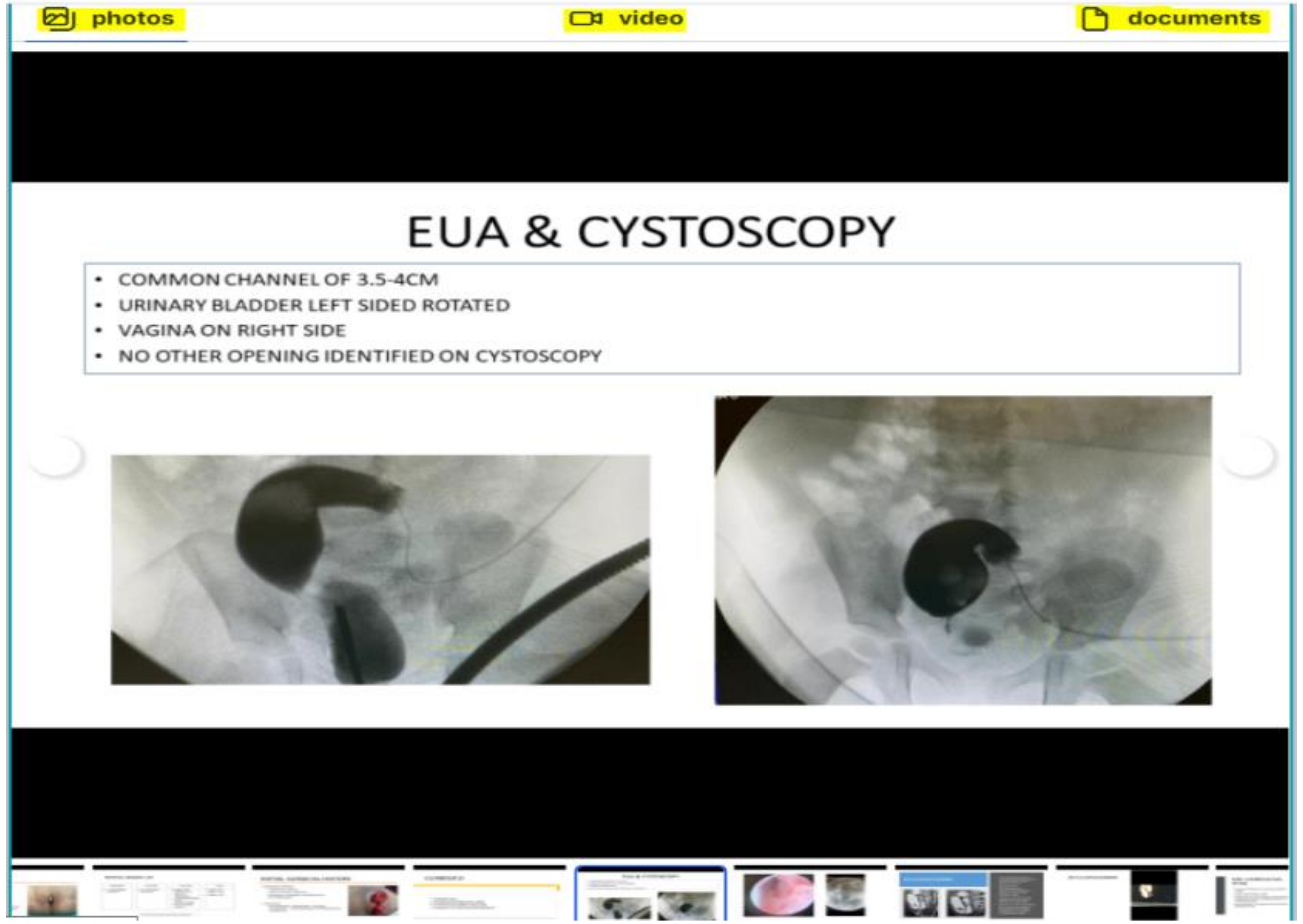

How would you rate the overall content of this session for medical learning?

1 Year of facilitating better Cures for Rare or Complex Diseases

Effective Knowledge Management via Central Digital Platform of Complex and Challenging Cases

www.cureforu.com

❑ **For Future Reference and follow up**, **All 26 cases** are systematically stored along case discussion video, case presentation, key discussion outcome, session chat and any relevant scientific publication



EUA & CYSTOSCOPY

- COMMON CHANNEL OF 3.5-4CM
- URINARY BLADDER LEFT SIDED ROTATED
- VAGINA ON RIGHT SIDE
- NO OTHER OPENING IDENTIFIED ON CYSTOSCOPY

1 Year of facilitating better Cures for Rare or Complex Diseases

Thanks to Medical Experts from Pakistan, Afghanistan, Turkey, Belgium, Germany, Austria, Italy and US

A big THANKS to Everyone who made it Possible so far

How could CureforU (or similar initiatives) contribute to Global Network RD pilot?

- **Confirming the Need and Potential positive impact of Global Clinical Network for Patients**
- **Confirming Global Network idea is very much possible to accomplish, as CureforU has demonstrated positive proof of concept**
- **Offering a good starting point / base for Global Network RD pilot to demonstrate further proof of value**
- **Offering learnings from ground experience which could increase likelihood of success of Pilot**
- **Piloting new collaboration approaches with existing networks i.e. ERNs (exploring with eUROGEN)**

What CureforU (or similar initiatives) Need to effectively contribute to Global Network RD pilot?

- Access to existing networks of expertise and other resources i.e. Collaborations with ERNs, ERN Academy, ERN CPMS… (work in progress with eUROGEN)
- Funding / Support Mechanisms to Scale up
  - CureforU did all so far based on volunteer work & self-support, availability of support & funding could increase the progress & impact significantly

Future Ambition

Near Term

- **Long term follow up** - Building mechanisms to ensure close long-term follow-up
- **Training & Knowledge Mgt** - Building customized training courses considering socio-economic conditions and potential self-learning/decision-making models.
- **Integrated Digital Platform -** All would be routed through/available via the digital collaboration portal and app.

Long-Term

Digital Virtual Hub of Rare & Complex diseases for Developing Countries, where healthcare professionals across regions can

- Collaborate & Discuss complex cases for better diagnose & treatment plan
- Offer / Receive assistance via mentorship & other collaboration programmes
- Provide / Receive customized training to improve skill set

And all being facilitated via **Digital hub** to ensure effective knowledge and data management.

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We are each of us angels with only one wing, and we can only fly by embracing one another

(Luciano De Crescenzo)

THANK YOU

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European Region Readiness for the Pilot

Michelle Battye, ERN eUROGEN

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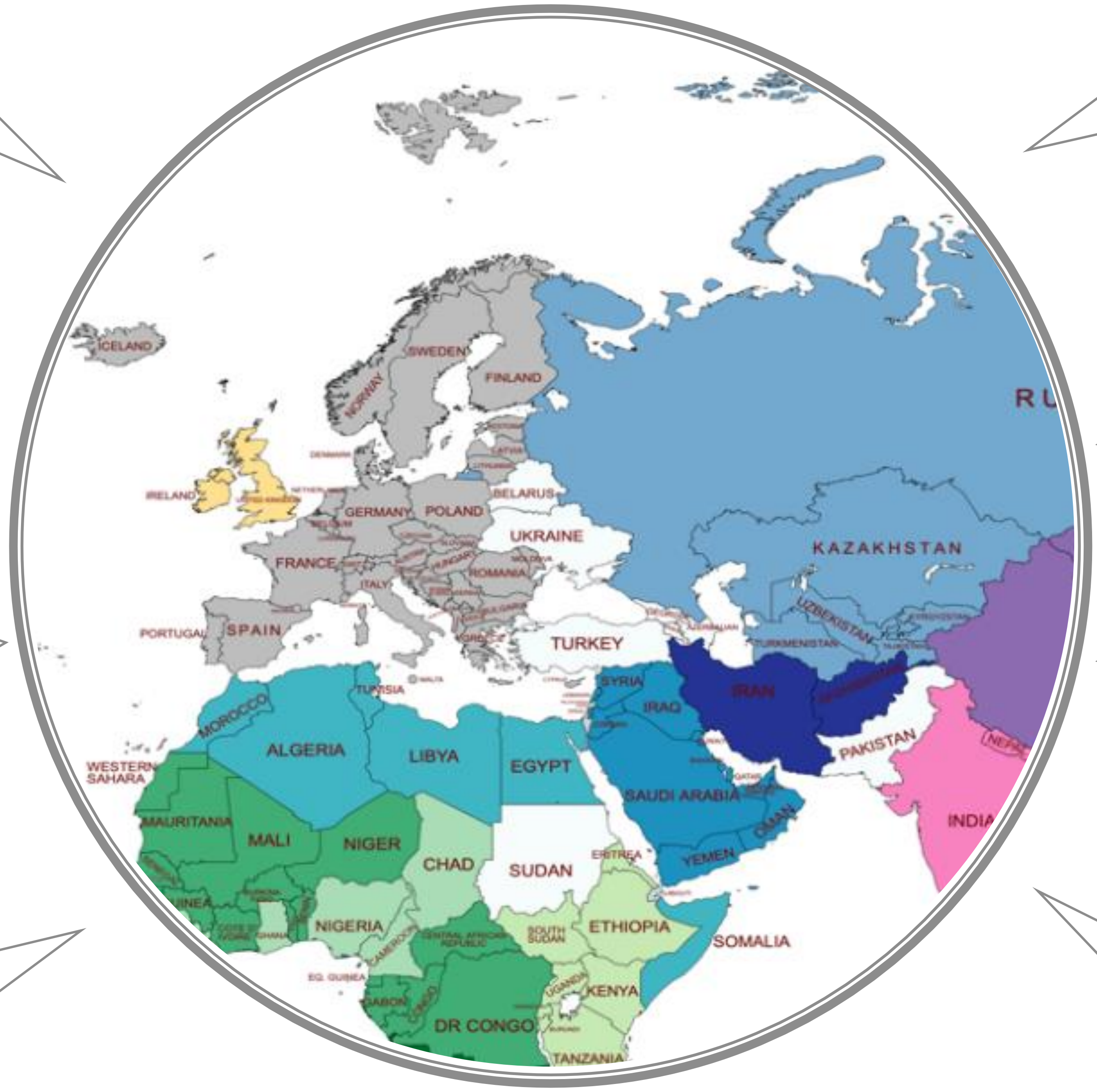
Overview of the European Region



The western parts of the European region, **27 countries are members of the European Union (EU) & more countries will join**

Population: 0,93 Billion (12,13%)
52 Countries (26.67%)
10,1 million square km (6%)

Overall mature HCS, with inequalities in patients' rights & access to diagnosis, care and treatment.

Orphan products approved by EMA, but **each country controls pricing and reimbursement → variations in availability and access** of medicines

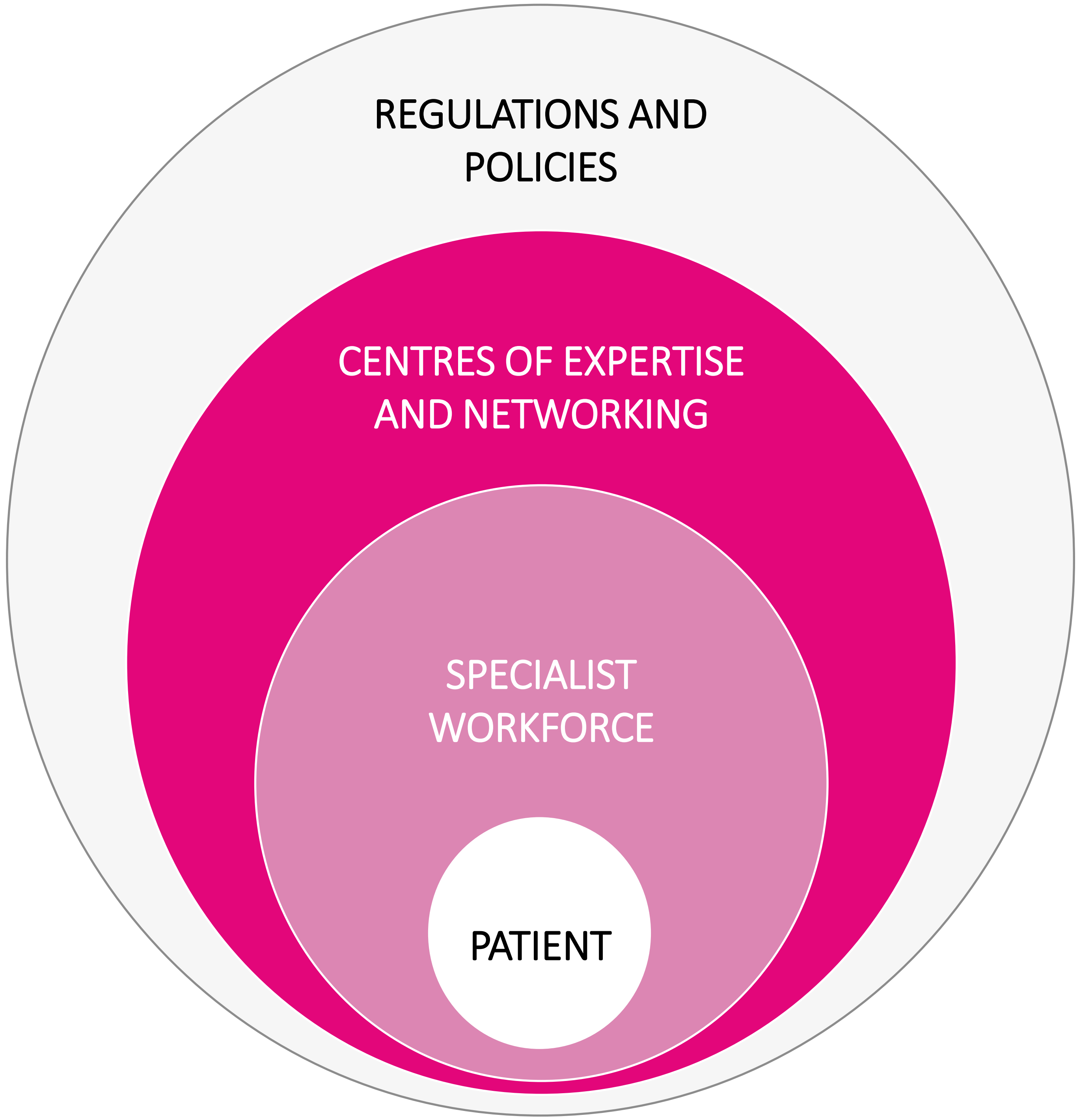
Russian Fed. has the **larger population,** 145.9M (15.6% of region) **& the biggest area,**
(39% of the continent land)

The **10 most populated countries** represent **the 71,8% of region** people

Estimated PLWARD in the Region is **between 32.7M and 55M** persons living with a rare

In **eastern Europe** 9 countries cooperate at **Commonwealth of Independent States (CIS)**; formed after the Soviet Union dissolution

How Healthcare is Organized for RD


REGULATIONS AND POLICIES

CENTRES OF EXPERTISE AND NETWORKING

SPECIALIST WORKFORCE

PATIENT

Regulations & Policies:

- Rare disease has been recognised as a public health priority in the EU and some Eastern European countries increasing the cross-border cooperation between States.
- Greater acknowledgement across the European region. Twenty-five EU MSs have a National RD Plan as well as outside the EU and under development (the former Yugoslav Republic of Macedonia, Norway). Some countries have none (Russian Federation, Island).
- Orphan medicine designation is coordinated under the European Medicine Agency (EMA) and regulated by the Orphan Medicine Regulation and Advance Therapies Regulation, encouraging investment in research and therapeutic development.

Centres of Expertise & Networking:

- Well-funded healthcare systems in some EU Member States, compared to other WHO Reg.
- An EU healthcare infrastructure is developing under the European Reference Networks, and there are a growing number of accredited national Centres of Excellence in the Member States. There is an opportunity to establish ERNs further and connect them throughout the WHO European Region. There is also a well-structured research infrastructure and collaboration under the European Joint Programme for RD, the ERNs research communities.
- HC 4RD is developing outside the EU, (Israel & Switzerland) with the recognition of Reference Centres, Centres of Expertise and Rare Disease Units.

Patient level:

- Patient community and representatives have been growing and is well organised and positioned to represent the community in developing strategy, policy, legislation, and operationalising front-line services. This facilitates the process of “incorporating” rare diseases into the national healthcare system.

The evolution of the ERNs

- A long process since 2004 with the first Rare Disease Task Force
- Council Recommendation in 2009
- Cross-Border Health Directive 2011/24/EU
- 2015: Implementation by the Commission
- 2017: Launch of 24 ERNs for five years (end March 23)
- 2019: ERNs enlarge to approximately 1600 specialised units
- 24 ERNs – wide fields – differing “natural histories” – heterogeneous entities

ERN Ecosystem

PATIENTS

NATIONAL HEALTH-CARE PROVIDERS

SPECIFIC ERN

TREATMENT

ADVICE

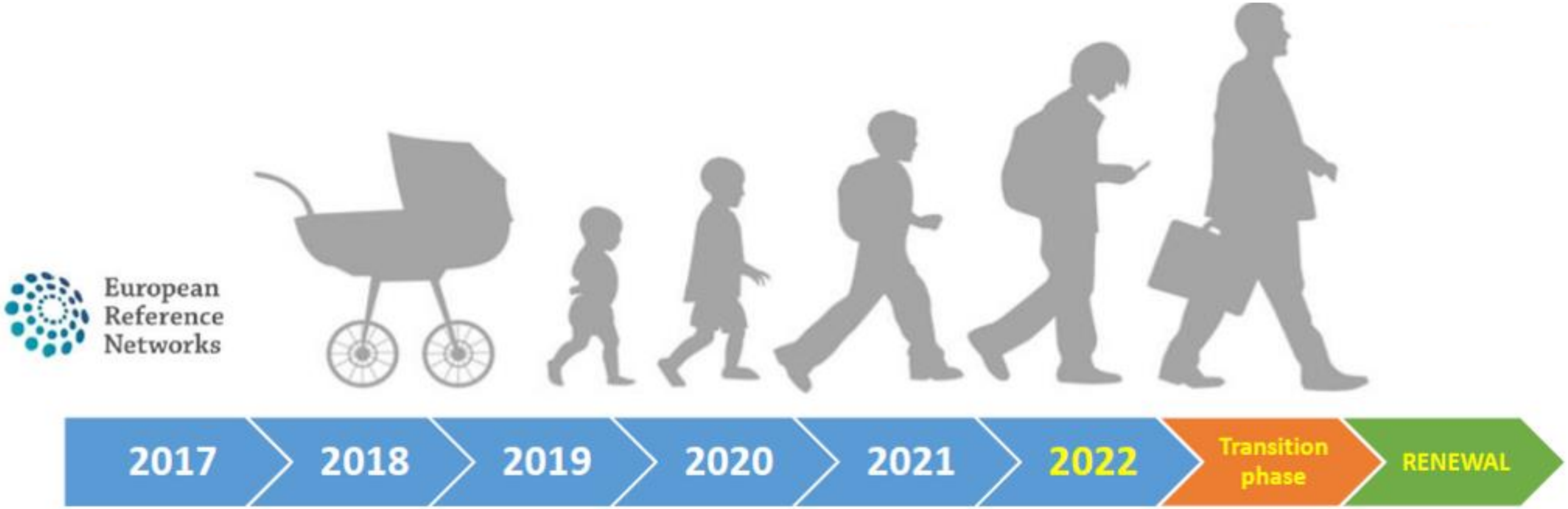
CLINICAL GUIDELINES

RESEARCH & INNOVATION KNOWLEDGE

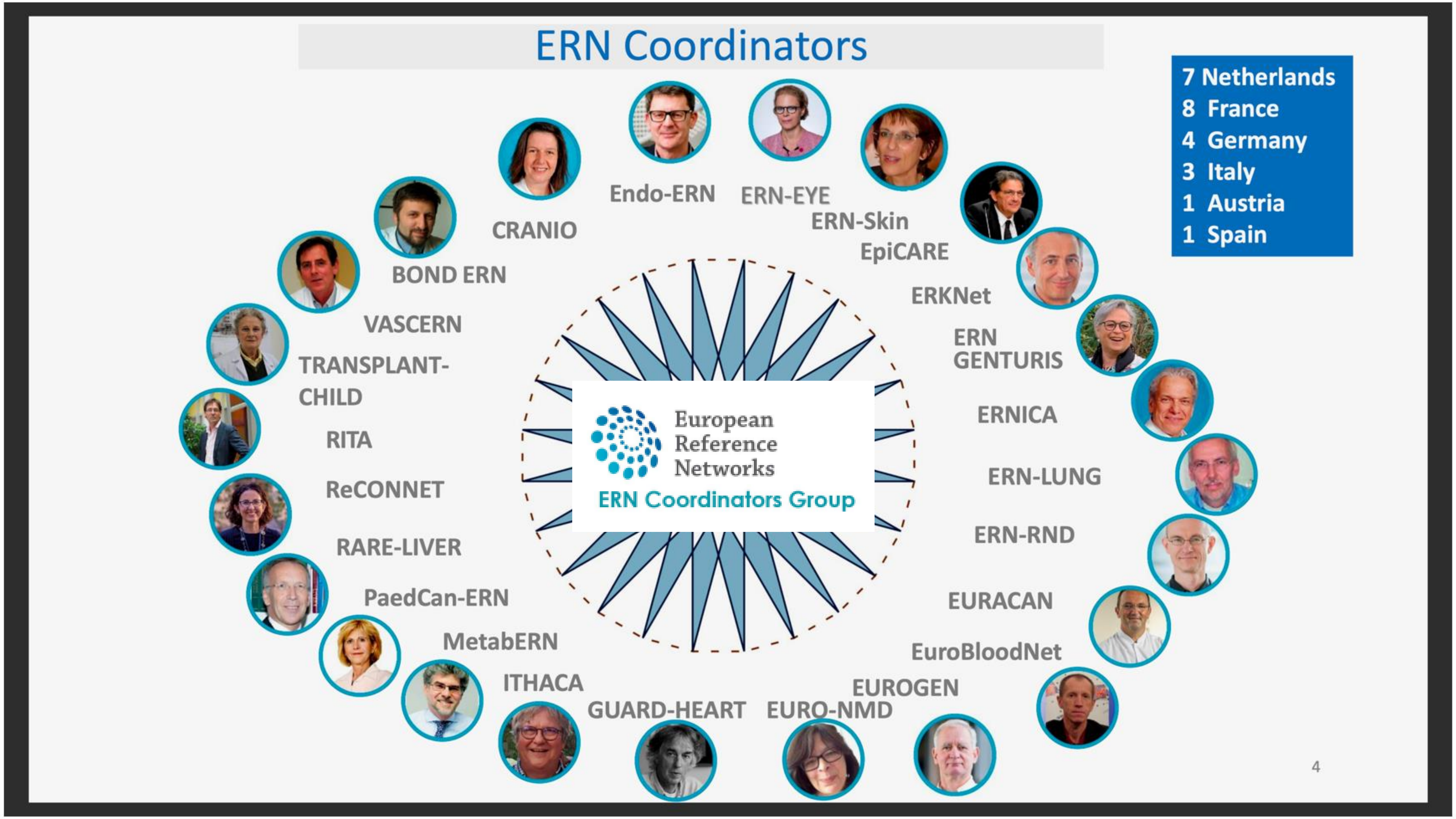
GENERATING & SHARING EVIDENCE

TRAINING & E-LEARNING

Share. Care. Cure.



24 ERNs



ERN Coordinators

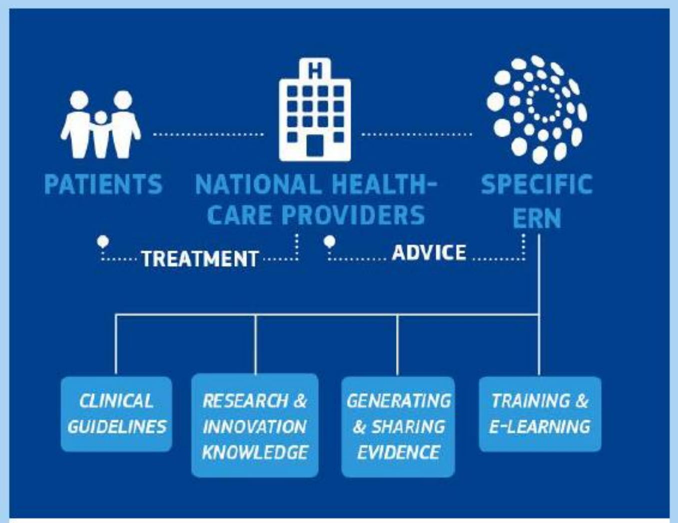
- 7 Netherlands
- 8 France
- 4 Germany
- 3 Italy
- 1 Austria
- 1 Spain

BOND ERN
CRANIO
Endo-ERN
ERN-EYE
ERN-Skin
EpiCARE
ERKNet
ERN GENTURIS
ERNICA
ERN-LUNG
ERN-RND
EURACAN
EuroBloodNet
EUROGEN
EURO-NMD
GUARD-HEART
ITHACA
MetabERN
PaedCan-ERN
RARE-LIVER
ReCONNET
RITA
TRANSPLANT-CHILD
VASCERN

European Reference Networks
ERN Coordinators Group

24 ERNs and ERN Units in 27 MS and Norway in 2022

ERN Ecosystem



Share. Care. Cure.

Enlargement of the Networks (from 01/01/2022)

843 Applications

630 Assessed by IAB

846 Old members

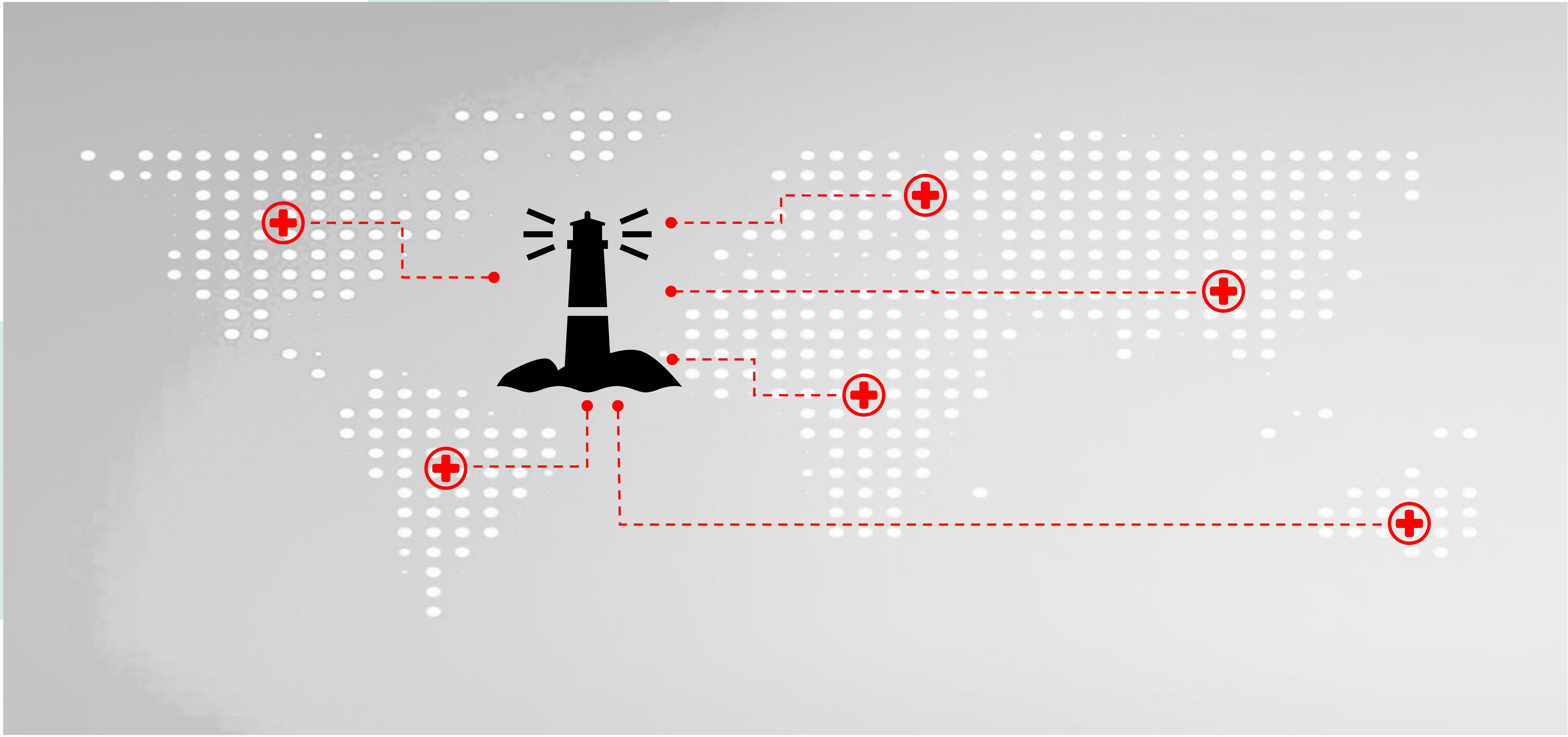
620 New members

1466 Full members + 288* Affiliated partners

~ 1600 HCP Units

All MS + Norway covered

Connecting networks with networks like ERNs
Are we ready?



How could EURO region contribute to Global Network RD pilot?

- Build on strengths of existing ERN network – collaboration and dissemination of information
- Virtual consultations on RD
- Knowledge sharing and exchange programmes (clinical and research)
- Data collection – interoperable global registries for RD

ERN eUROGEN Global Collaborations

- Developed a Global collaboration strategy

Partnerships

- Global: WHO Rare Diseases – Collaborative Global Network for RD (Active)
- Australia: ARM Registry, Melbourne, Australia (Signed 2022)
- Cure4U: Pakistan and regional Countries: ARM Patient Care and Organisation (Signed 2022)

EURO pilot readiness

Strengthens

- Maturity of Patient Organisations
- EC legislative framework - Comm in 2008, Council Recommendations 2009
- Maturity of networks (ERNs, Orphanet, Infrastructures)
- Legal base to collaborate with other international centres of expertise
- ERN registries and European Health Data Space
- Data collection – interoperable global registries for RD
- EC funding/ERN CG governance

Actions

- Linking into existing networks – how?
- Identification of “lighthouse“ HCPs, support
- Build on existing tools eg CPMS used in campaign to help rare disease doctors and patients in the Ukraine https://www.erncare4ua.com/
- GN4RD Regional Hubs define priority actions/disease areas – linked with existing networks eg knowledge sharing, clincial exchanges, virtual consultations
- No forum bringing national policy makers together (share best practice/peer review NAPs on RD

Key actions for pilot readiness

- Governance
- Lighthouse healthcare providers
- Agree priority areas
- Funding - WHO EC collaboration? EU4health and other programmes to stimulate ERN international collaboration?

THANK YOU

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Questions & Answers
& Panel Discussion

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Closing Remarks

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