

CHALLENGES FOR THE SUSTAINABILITY OF THE ERNs

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- Challenges for the sustainability of the ERNs
 - Added value of ERNs for people living with RD and member states
 - Building, maintaining and improving the high quality of the ERNs
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 - Integration of the ERNs in national healthcare systems
- Summary



WHY SUSTAINABILITY OF THE ERNs ?

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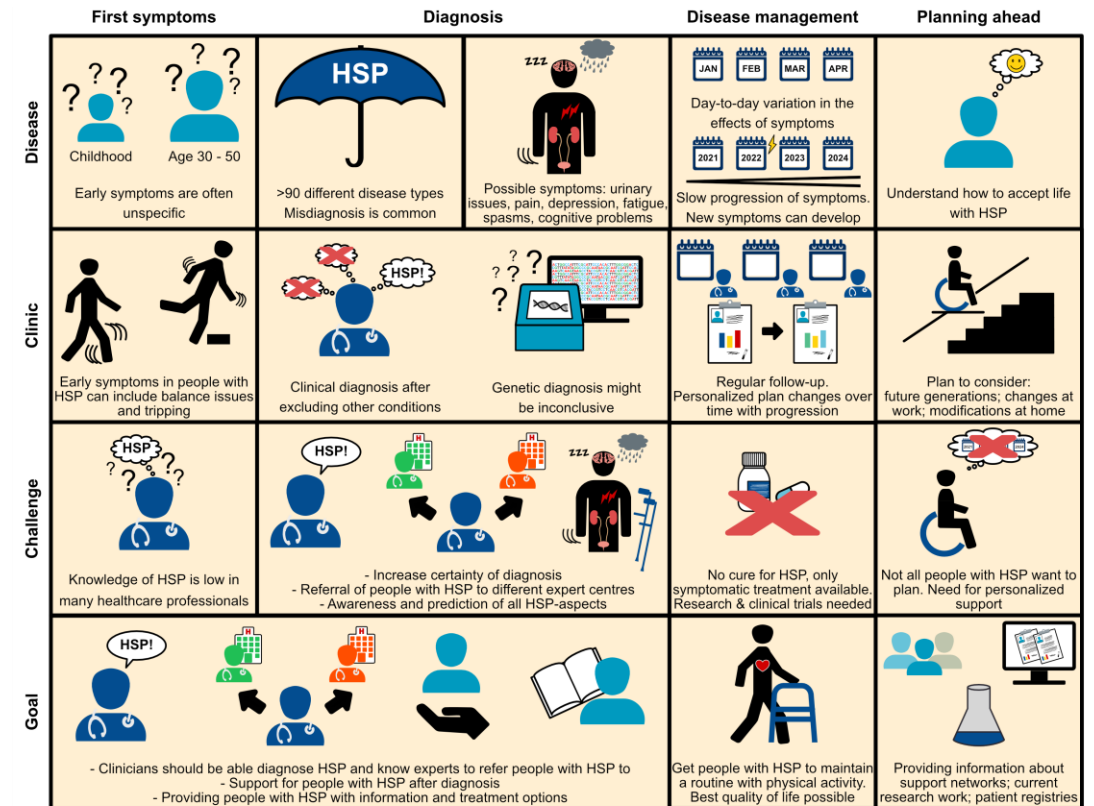
- ERNs are formal permanent infrastructure for knowledge creation and sharing, structured collaboration, partnership between experts and people living with a rare disease
- Disruptive successful innovation in the area of healthcare with a clear focus on highly specialised healthcare services
- ERNs provide added value through collaboration on EU level
- ERNs proved their ability to act efficient and flexible in times of crisis (COVID-19, Ukraine)



CHALLENGES FOR THE SUSTAINABILITY OF THE ERNs

ADDED VALUE OF ERNs FOR PEOPLE LIVING WITH RD AND MEMBER STATES

- Core activities of ERNs
 - Crossborder healthcare / CPMS
> 3,450 cases
- Training and education of health professionals
Structured and sustainable training programs and curricula are being established
- Patient journeys
- ERN registry
All ERNs, already >50,000 included patients
- Guidelines and Clinical Decision Support Tools
> 400 guidelines developed, appraised and endorsed



Example: Patient Journey for Hereditary Spastic Paraplegia

BUILDING, MAINTAINING AND IMPROVING THE HIGH QUALITY OF THE ERNs

Evaluation of all ERNs after first five years (2017-2022):

VERY GOOD RESULTS

Compliance with Criteria for Networks			
	2: Fully Developed (in %)	1: Partially Developed (in %)	0: No Activity / Not Developed (in %)
Endo-ERN	86,54	13,46	0
EpiCARE	96,15	3,85	0
GENTURIS	100	0	0
ERN RITA	94,23	5,77	0
ERN BOND	75	17,31	7,69
ERN EYE	78,85	15,38	5,77
ERN GUARD-HEART	94,23	5,77	0
ERN-LUNG	78,85	21,15	0
ERN-RND	90,62	4,69	3,12
EURACAN	69,23	23,08	7,69
EuroBloodNet	92,31	7,69	0
eUROGEN	82,69	11,54	5,77
Euro-NMD	73,08	19,23	7,69
ITHACA	88,46	11,54	0
RARE-LIVER	75	23,08	1,92
VASCERN	94,23	5,77	0
Average	85,6	11,8	2,5

Network Applicant Compliance by Area												
	Endo-ERN	EpiCARE	GENTURIS	ERN RITA	ERN-RND	EURACAN	Euro-NMD	ITHACA	RARE-LIVER	...	VASCERN	Average
1. Governance	1,93	1,93	2	2	2	1,6	1,73	1,87	1,93		2	1,9
2. Clinical care	1,89	2	2	1,67	1,89	1,89	1,33	1,67	1,44		1,67	1,7
3. Quality and patient safety	1,33	2	2	2	2	0,67	1	1,67	1		2	1,5
4. Patient centred care	1,67	2	2	2	1,71	1,67	1,33	2	1,33		2	1,8
5. Contribution to Research	1,86	2	2	2	1,56	1,43	2	2	1,86		2	1,9
6. Education and Training	2	1,83	2	2	2	1,67	2	2	2		2	1,9
7. Networking and Dissemination	2	2	2	2	2	1,83	1,83	2	2		2	2,0

BUILDING, MAINTAINING AND IMPROVING THE HIGH QUALITY OF THE ERNs

Generic conclusions from evaluations of ERNs

- Wide European coverage, wide disease coverage
- Patient-centred approach, active engagement of the patients
- Use of cross border healthcare to discuss complex cases
- Development and endorsement of guidelines and CDMT
- Act as hub for knowledge pooling and sharing
- Establishment of registries



PREPARATORY STEPS

- IEB sets up the evaluation process
- ERN Members information and task organisation



SELF-EVALUATION

- Self-evaluation by ERNs
- Self-evaluation by HCPs



IEB TECHNICAL EVALUATION

- Document review
- Virtual interviews with ERNs
- On-site audits in a sample of the HCPs



EVALUATION RESULTS

- Draft reports
- Comments and amendments
- Improvement plan (if needed)
- Final reports

MANAGEMENT OF THE ERNs

Large European networks of HCPs

European healthcare infrastructure

Networks of national expertise centres that are part of the national healthcare systems

EU funded projects in which not healthcare is funded but mainly central coordination activities

Research networks

Country	N members
Austria	1
Belgium	4
Bulgaria	1
Croatia	1
Cyprus	1
Czech Republic	4
Denmark	2
Finland	1
France	6
Germany	9

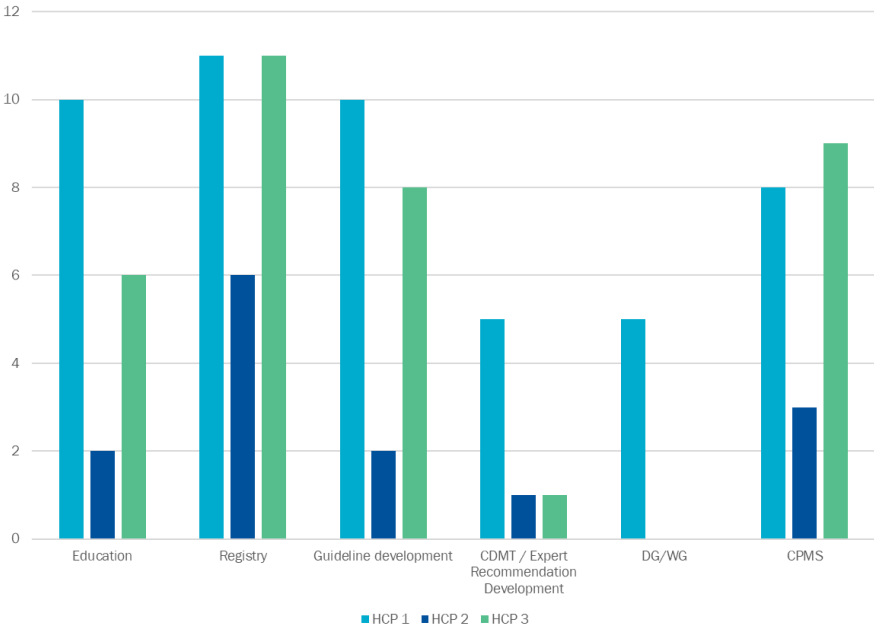
Country	N members
Estonia	1
Latvia	1
Luxembourg	1
Malta	1

Country	N members
Greece	1
Hungary	3
Ireland	1
Italy	9
Lithuania	1
Netherlands	6
Poland	2
Slovenia	1
Spain	8
Sweden	2



68 HCPs from 25 countries

Example: ERN-RND



Management tool: ERN score card

INTEGRATION OF THE ERNs IN NATIONAL HEALTHCARE SYSTEMS

JA for Integration of ERNs in national healthcare systems (JARDIN)

Work packages

- WP4: Sustainability
- WP5: National governance and quality assurance models
- WP6: National care pathways and ERN referral systems
- WP7: National reference networks and undiagnosed disease programs or equivalent
- WP8: Data management
- WP9: National support options for ERN-HCP

ERN perspective - expectations

Ad WP4: Sustainability of ERN integration on member state level

Ad WP5: Assign (large parts of the) appointment and evaluation of ERN members to national level

Ad WP6: Formal role of ERNs in EU cross-border healthcare decision-making

Ad WP7: Systematic and structural ties between ERN and national networks

Ad WP8: Interoperability of hospital information systems and/or national registries with ERN registries

Ad WP9: Adequate resource allocation for ERN services on national, regional and local level



SUMMARY

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President of the European Commission in a recent response to a letter from the European Parliament:

“at the very core of our efforts is the determination to ensure that all rare disease patients, including children, have access to the best possible knowledge, diagnosis, and treatment. **The European Reference Networks proved to be the most successful innovation in the area and key to achieving this goal.**”

ERN Letter (quotes)

- ERNs have the potential to harness EU solidarity for enhancing health equality across our countries and expanding our health systems' capabilities to diagnose, treat and manage rare and complex conditions.
- ERNs have not yet fully delivered on their potential and we know there is still a long way to go to achieve health equality and equity across the European Union for the vulnerable population they serve.
- The next EU political cycle must succeed in fully consolidating the Networks and their seamless integration into cross-border and national healthcare systems.
- **The time is ripe to move the ERNs from good to great and showcase this model of solidarity and cooperation as world-leading in highly specialised healthcare.**



THANK YOU