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Exploring national support mechanisms for European reference network centres

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ABSTRACT

Integrating European Reference Networks (ERNs) into national health systems is crucial for rare disease care but remains challenging due to inconsistent support structures across countries. This study used a 2024–2025 multi-stakeholder survey of ERN clinical centre leads, hospital administrators, and national health authorities (JARDIN Joint Action, Work Package 9) to evaluate national support for ERN centres across six domains: staffing, education, formal recognition, funding, quality assurance, and strategic planning. Survey results revealed inconsistent national legal frameworks for recognizing ERN centres, major staffing deficits, and limited dedicated funding for ERN activities. Strategic planning for rare disease networks was often lacking, and institutional support for ERN-related quality assurance and continuing education remained low. Notably, ERN membership was associated with increased educational activities for health professionals, but these initiatives often lacked sustainability due to insufficient protected time and resources. Overall, the findings highlight that embedding ERNs into national health systems will require formal recognition of ERN centres in policy, consistent funding, stronger institutional backing, and structured support mechanisms to address workforce and quality gaps, ensuring long-term sustainability of this collaborative rare disease network.

1. Introduction

European Reference Networks (ERNs) were established in 2017 under Directive 2011/24/EU to improve access to highly specialised care for people with rare or complex diseases, which – although individually rare – collectively affect 6–8% of the EU population (about 30 million people) (Nguengang Wakap et al., 2019; European Commission, 2026; European Union, 2011). By connecting over 1000 specialised units across the EU and Norway, ERNs address geographical and expertise gaps through the "mobility of knowledge" – allowing expertise, rather than patients, to travel (Montserrat and Taruscio, 2019). Early analyses anticipated that such pooling would accelerate diagnosis and care for rare conditions by overcoming the inherent obstacles of scattered patients and expert clinicians (Julkowska et al., 2017; Evangelista et al., 2016).

Despite their potential, ERN integration into national systems is complex. As healthcare is nationally organised and funded, national support is what will unlock the full potential of ERNs – enabling legal recognition and integration into reimbursement, referral, and data systems. The ERN Board of Member States has urged stronger alignment with national policies to enable effective two-way knowledge exchange (Hedley et al., 2021a,b). Making ERNs operational requires integrating their providers into routine care, yet consistent support – covering funding, staffing, training, and data infrastructure – remains elusive. As the EU does not fund core clinical activities, this responsibility falls on Member States (Hollak et al., 2016).

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National support has been uneven: many countries lack dedicated funding or face administrative hurdles, and human resources remain a significant challenge (Sánchez-González et al., 2025; Tumiené et al., 2022). This is particularly concerning given the high complexity and specialised expertise required to adequately care for patients with rare conditions, and the additional coordination demands of effective ERN participation. Competency gaps in rare disease (RD) healthcare are well documented (Tumiené et al., 2022), and similar structural requirements – multidisciplinary staffing, institutional backing, dedicated roles such as clinical coordinators and data managers – have been highlighted in disease-specific frameworks (Conway et al., 2014). Without these, ERN-related tasks overburden teams and long-term sustainability remains at risk (Hedley et al., 2023).

Recognizing these challenges, a new Joint Action on Integration of ERNs into National Healthcare Systems (JARDIN) launched in early 2024 aims to support the integration of ERNs into national health systems. Within the JARDIN Joint Action, Work Package 9 (WP9) focuses on mapping and evaluating national support mechanisms for ERN-associated healthcare providers. Its goal is to identify current practices, highlight best examples, and propose policy options for sustainable integration.

This article presents key findings from the survey assessing the operability of ERN centres across three perspectives – ERN clinical units, ERN-hosting healthcare providers, and national/regional authorities – and aims to inform policy recommendations for their sustainable integration into national healthcare systems.

2. Methods

Survey questions were role-specific, though respondents, if applicable, were able to select multiple roles and required to complete separate surveys for each country/hospital/ERN centre they represented. Depending on responsibilities, respondents answered 1–36 questions. The full Survey text is available in the Supplementary Material.

Three stakeholder groups were targeted:

- ERN clinical centres (centre leads including ERN coordinators);
- Hospital administration representatives;
- National authorities from 27 EU Member States and Norway (Countries).

The numbers reported below reflect the number of stakeholders listed in the contact database to whom the survey invitation was disseminated:

– 867 ERN centre representatives (60.8% from existing 1425 ERN full-member clinical centres);
– 1240 healthcare provider (HCP)-level stakeholders from 213 hospitals (60% from existing 355 ERN-hosting hospitals);
– 207 national authority representatives (covering all 28 Countries).

The survey ran from June to December 2024, with reopenings to increase response rates. In early 2025, a validation round to confirm national data was conducted. Data were collected via the EU Survey platform (https://ec.europa.eu/eusurvey/home/welcome). The following reported numbers correspond to responses obtained from stakeholders included in the contact list.

3. Results

3.1. General survey results

When aggregating responses at the level of stakeholder groups, and counting multi-role respondents as providing one response for each role they reported, the following values were obtained:

- Clinical centres: Total of 488 out of 867 individuals in the contact list responded to the Survey (56.3%). Response rate to individual questions ranged between 84 and 99%.
- Hospital (HCP) administration: Total of 423 out of 2785 individuals in the contact list responded (15.2%) covering 213 out of 355 ERN-hosting hospitals (60%).
- National health authority: A total of 91 out of 268 individuals in the contact list responded (34.0%) covering all 28 Countries.

Response rates at hospital administration level ranged from 22% to 100% across countries.

3.1.1. Working conditions of an ERN centre

3.1.1.1. Staffing requirements and legal recognition of ERN centres. According to responses provided by national authority representatives, staff requirements for ERN clinical centres are defined in 6 out of 27 countries (22%) that responded to this question. The legal/organisational background includes national regulations or institutional policies in following countries: Austria, Croatia, Denmark, Lithuania, Slovakia, and Spain.

3.1.1.2. Number of RD patients in ERN clinical centres. The median number of patients per centre was 500/year, with an interquartile range (IQR) of 237–1100 and up to hundredfold variation between countries. The median number of RD patients per expert physician full-time equivalent (FTE) was 108 (IQR 46–250).

3.1.1.3. Adequacy of staff composition and FTE in ERN clinical centres. Many clinical centres reported challenges in maintaining adequate staff and FTEs for RD care. Consequences included unpaid overtime, task redistribution, and service limitation. Only 209 centres (43%) were satisfied with their staffing. Country-level data are shown in Fig. 1.

Proportion of clinical centres that reported lack of staff (total number = 274) is shown for individual staff roles in Fig. 2. Approximately 60% of clinical centres reported insufficient staffing across all professional groups, with expert physicians being inadequately available in over 84% of centres.Table 1 summarises reported strategies to manage FTE shortages by role (N (%)).

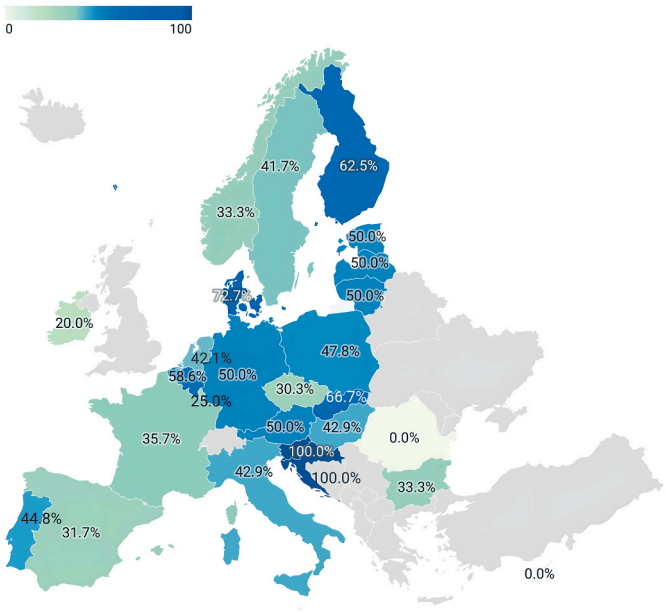


Fig. 1. Proportion of ERN clinical centres that are satisfied with their staff composition and FTE by Country.

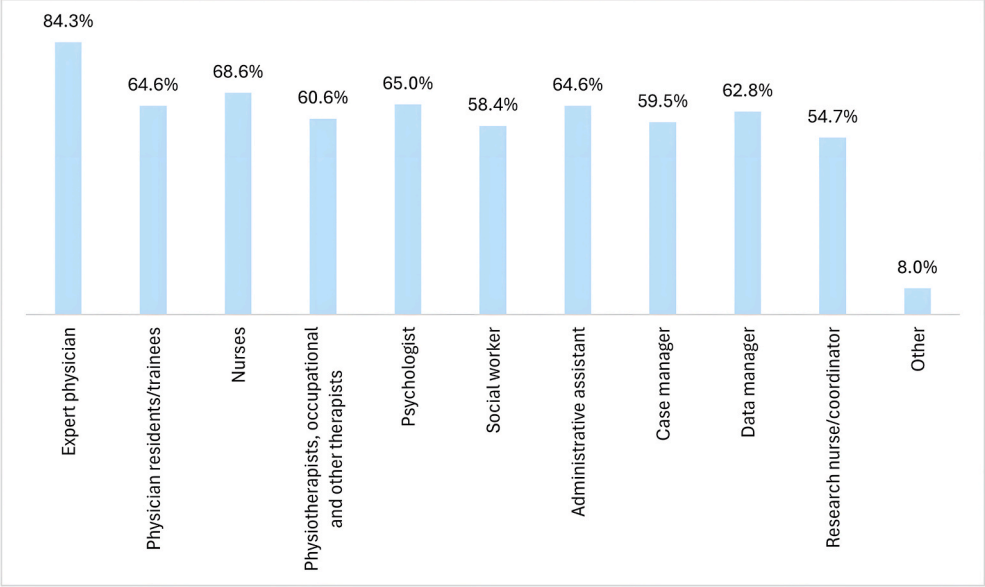


Fig. 2. Proportion of ERN clinical centres reporting insufficient staffing by professional role.

Table 1
Reported strategies to manage FTE shortages per MDT role – number and % of respondents by approach used.

	Service limit	OT paid	OT unpaid	Other team	Other unit	External	Other	Total
Expert physician	90 (23.1)	26 (6.7)	182 (46.7)	38 (9.7)	26 (6.7)	14 (3.6)	14 (3.6)	390
Physician trainees	76 (28.5)	20 (7.5)	110 (41.2)	36 (13.5)	13 (4.9)	2 (0.7)	10 (3.7)	267
Nurses	114 (39.6)	31 (10.8)	68 (23.6)	27 (9.4)	24 (8.3)	14 (4.9)	10 (3.5)	288
Rehab therapists	105 (46.7)	11 (4.9)	19 (8.4)	7 (3.1)	40 (17.8)	29 (12.9)	14 (6.2)	225
Psychologist	121 (49.2)	11 (4.5)	28 (11.4)	14 (5.7)	31 (12.6)	28 (11.4)	13 (5.3)	246
Social worker	97 (46.2)	10 (4.8)	21 (10.0)	14 (6.7)	39 (18.6)	17 (8.1)	12 (5.7)	210
Admin staff	115 (46.0)	18 (7.2)	35 (14.0)	39 (15.6)	25 (10.0)	1 (0.4)	17 (6.8)	250
Case manager	97 (42.2)	10 (4.3)	36 (15.7)	43 (18.7)	15 (6.5)	2 (0.9)	27 (11.7)	230
Data manager	97 (39.0)	9 (3.6)	46 (18.5)	49 (19.7)	20 (8.0)	3 (1.2)	25 (10.0)	249
Research nurses	82 (40.0)	18 (8.8)	26 (12.7)	34 (16.6)	18 (8.8)	4 (2.0)	23 (11.2)	205

Abbreviations: *MDT – Multidisciplinary team; paid/unpaid OT* – paid/unpaid overtime; *Other team* – covered by team member; *Other unit* – by other unit/person; *External* – external provider.

3.1.2. Staff education and research activities

3.1.2.1. Participation in rare disease educational activities. Clinical centre leads reported participation across five educational formats, summarised in Table 2.

Participation in online and in-person educational activities was high across respondents, although the frequency of engagement differed between formats. Out of 480 respondents, 474 reported attending webinars, with 15% participating rarely, 43% occasionally, and 40% regularly. Participation in in-person events (conferences, symposia, and workshops) was similarly widespread: among 482 respondents, 478 (99%) reported attendance, including 7% rarely, 28% occasionally, and 64% regularly. Country-level variation was more pronounced for webinars, where more than one quarter of respondents reported rare participation in five countries, compared with only one country for in-person events.

Table 2
Frequencies of attending educational activities.

Type of Activity	not at all	rarely	occasionally	regularly	Total
Webinars	6 (1%)	74 (15%)	208 (43%)	192 (40%)	480
Workshops, symposia, conferences	4 (1%)	34 (7%)	134 (28%)	310 (64%)	482
ERN postgraduate education programs	96 (20%)	124 (26%)	175 (37%)	82 (17%)	477
Exchange programs	148 (31%)	132 (28%)	150 (31%)	49 (10%)	479
Training with universities/non-governmental organisations (NGOs)	110 (23%)	110 (23%)	153 (32%)	102 (21%)	475

Among respondents who reported rarely or never attending webinars (n = 74), the most frequently cited barriers were scheduling constraints (86%) and insufficient institutional support (46%), while fewer respondents reported disinterest (16%) or other reasons (3%). Similar patterns were observed for in-person events: among 35 respondents with low participation, 80% cited time conflicts and 74% lack of resources, whereas 14% reported disinterest and 3% other reasons.

Participation in other ERN-related educational formats was more variable. Exchange programmes were reported by 331 of 479 respondents (69%), although regular participation was relatively limited (10%), with most respondents indicating rare (28%) or occasional (31%) involvement. Reported barriers included insufficient support (72%), scheduling conflicts (50%), and limited availability of programmes (8%). ERN postgraduate educational programmes showed higher overall participation, with 381 of 477 respondents (80%) reporting involvement; however, engagement was predominantly occasional (37%) or rare (26%), while only 17% participated regularly. Among respondents with low participation (n = 185), insufficient institutional support (58%) and scheduling issues (48%) were the most common barriers, followed by limited offer or awareness (14%) and disinterest (8%).

3.1.2.2. Impact of ERN membership on education within multidisciplinary teams. ERN membership was most frequently associated with a slight increase in educational activities (57%), whereas 25% reported no change and 18% reported a substantial increase (Fig. 3). This pattern was consistent across most ERNs, except for ERN RARE-LIVER and ERN ReCONNET, where all respondents reported increased educational activity and none reported no change.

3.1.2.3. Perceived priorities for improving rare disease education. Clinical centre leads were asked to evaluate a set of potential measures to sustainably improve their teams' RD-related education, using a 1–5 scale (with 5 indicating the highest perceived efficiency). The listed options included various formats such as internal training, webinars, structured curricula, and protected time for educational activities. Results are shown in Fig. 4.

3.1.3. ERN centre recognition

3.1.3.1. Official status of ERN clinical centres. The official status of ERN clinical centres was assessed based solely on responses from national authority representatives, using a yes/no question on whether ERN clinical centres hold official recognition as national or regional RD centres (see Fig. 5). Of the 27 responding countries, 17 (63%) confirmed such recognition.

3.1.3.2. Hospital-Level Support for ERN-related activities. Clinical centre leads were asked if their hospitals provide support for ERN tasks and 320 (66%) reported some support (Fig. 6), including assistance with the 5-year ERN evaluation (61%), annual monitoring reports (42%), other administrative support (40%), teleconferencing facilities (36%), and registry data entry (26%), while 164 (34%) reported none.

3.1.3.3. Hospital-reported support for ERN centres. Hospital representatives were asked about support for ERN activities. From 132 hospitals 94 (71%) reported providing support (Fig. 6), 27 (21%) reported none, and in 11 hospitals (8%) responses differed between respondents.

3.1.3.4. Patient referrals after ERN membership. Total of 188 clinical centres (39%) reported that their new patient referrals have increased since they became ERN members. Only 37/188 (20%) of those who increased their patient load reported that this was acknowledged by their HCP resulting in better support. This support was further specified by free text explanation which could be grouped in the following categories: Increased staff, funding or resources (15+ answers), project-based or indirect support (5 answers), acknowledgement expressed, but no additional support provided (10+ answers)

3.1.3.5. Challenges faced by clinical centres within the ERNs. A total of 365 ERN clinical centres that responded to this question (75% of the sample), from 187/355 hospitals (53%), identified key challenges linked to ERN involvement. Most frequently cited were time constraints (32%), administrative burden including paperwork and lack of automation (23%), lack of funding or reimbursement (e.g. for ERN tasks, travel, the Clinical Patient Management System (CPMS), and registries), insufficient staff or dedicated personnel, and lack of protected time for ERN activities. Additional issues included heavy data workload, weak institutional support, legal and regulatory barriers (General Data Protection Regulation [GDPR], ethics), outdated IT systems, organisational

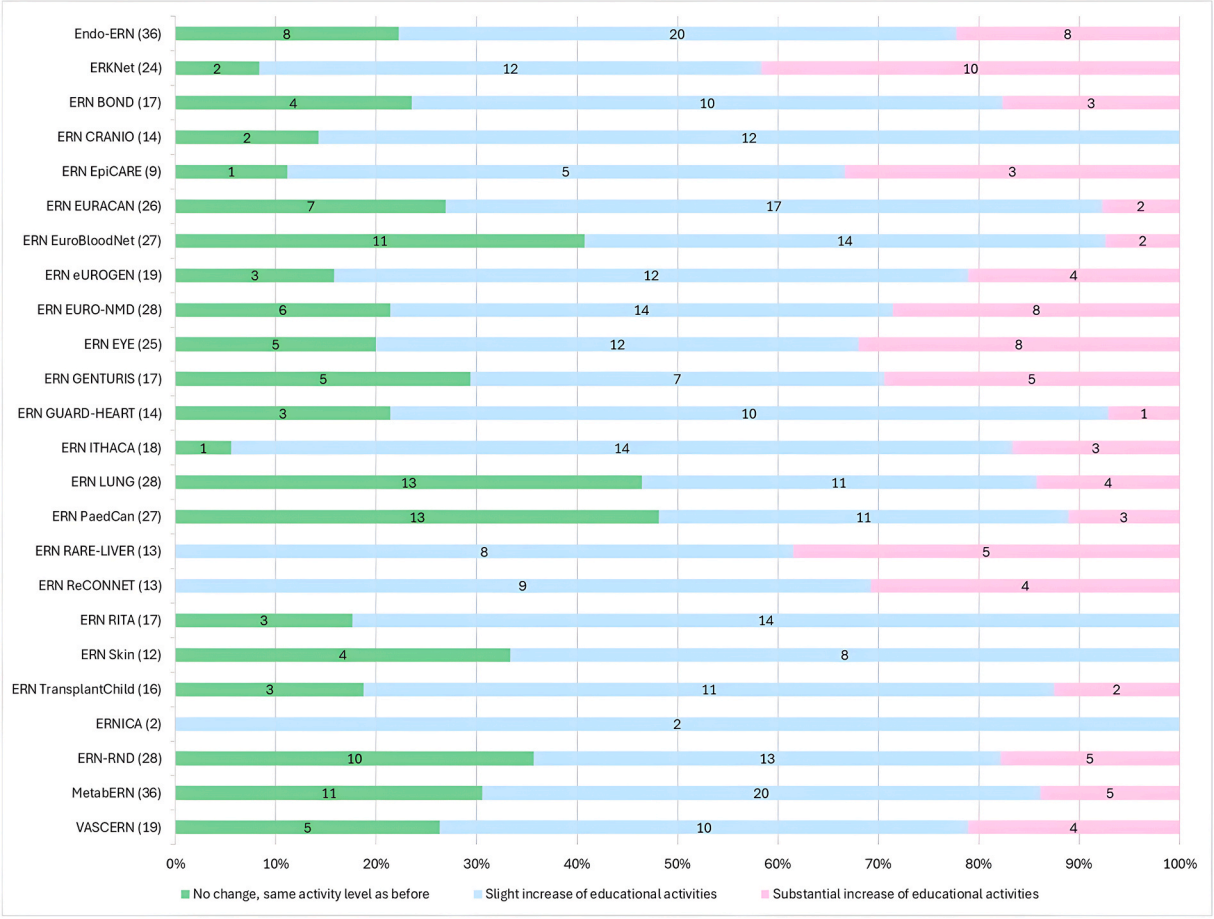


Fig. 3. Impact of ERN membership on RD-related educational activities.

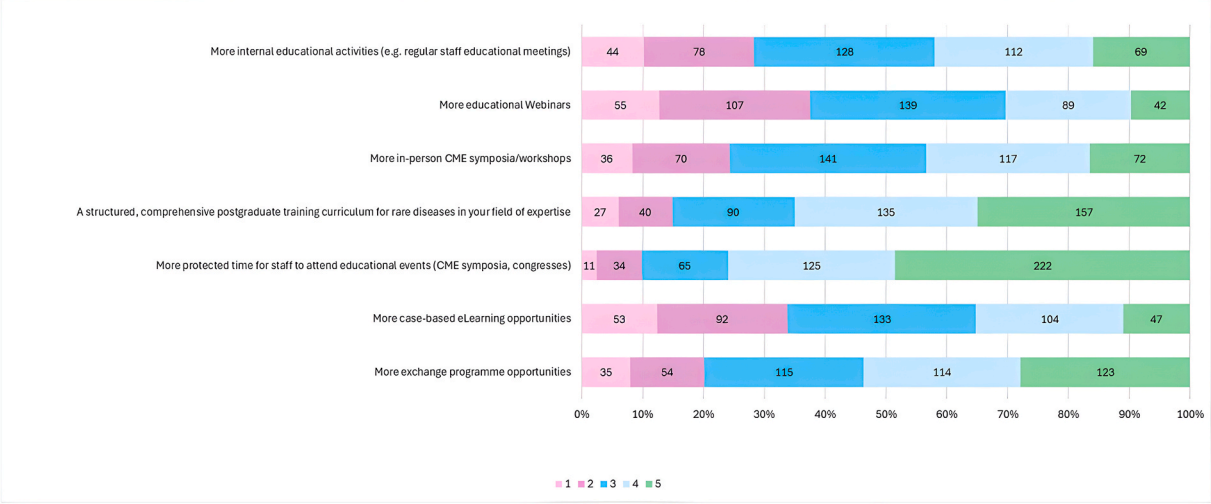


Fig. 4. Perceived efficiency of measures to sustainably improve RD-related education (1 = least efficient, 5 = most efficient).

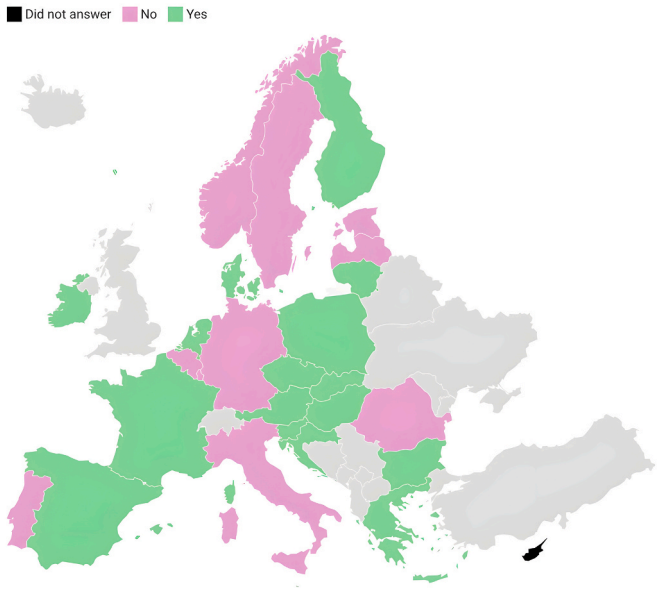


Fig. 5. Official recognition of ERN clinical centres as national or regional RD centres across EU Member States, based on responses from national authority representatives (27/28 countries; Yes/No).

complexity, and language or cross-border differences.

3.1.4. *FUNDING model*

3.1.4.1. Availability of public funding for hospitals hosting ERN centres. Of 27 Countries that responded at the national level questions only 7 (Czechia, France, Italy, Latvia, Luxembourg, Slovenia, Spain) confirmed additional public funding for ERN-hosting hospitals.

From clinical centre leads representing 211 (59.4%) hospitals, 90% reported no such funding recognised at the centre level including 91 (25.6%) from whom funding allocation was confirmed at the national level. From hospital administration perspective 89% hospitals confirmed no ERN-specific funding received, 7% reported some, and 4% gave conflicting answers. Among 110 hospitals where both clinical centre and institution representatives responded, 78% confirmed no funding; remaining cases showed inconsistencies due to unclear or selective allocation.

3.1.4.2. Link between ERN funding and national rare disease strategies. Of 7 countries reporting ERN-related public funding, six (France, Italy, Latvia, Luxembourg, Slovenia, Spain) tied it to a national RD plan. Funding models varied: Czechia offers lump sums and per-patient Orphacode bonuses; France and Luxembourg fund via RD plans; Latvia covers specific costs; Slovenia allocated a lump sum in years 2022–2023; Spain funds CSURs (Centros, Servicios y Unidades de Referencia - Spanish nationally designated reference centres for highly specialised care) through its strategy.

3.1.4.3. Non-public funding sources for ERN activities. Hospital representatives were also asked whether their institutions receive any additional ERN-related funding from non-public sources, such as private foundations, charities, or industry partners. From 130 hospitals that provided a response 115 (88%) did not receive any other extra funding specifically related to ERN activities, whereas 9 (7%) indicated that such funding was in place. For 6 hospitals (5%), respondents provided conflicting answers, preventing a clear determination (Fig. 7). Among hospitals where at least one representative reported receiving additional funding, reported uses included research (60%), patient care pathways (27%), coordination (20%), production of deliverables (18%), non-specified purposes (18%), and other (27%) (Fig. 8).

3.1.4.4. Additional non-public funding at ERN centre level. Total of 18 (87%) ERN centre representatives stated that their centre does not receive any other non-public funding specifically related to ERN activities, only 61 (13%) centre leads reported that such funding is in place. Among ERN centre leads reporting additional non-public funding, 58 specified its origin, which clustered into five main categories: industry sponsorship, charity or patient-organisation support, research grants and internal or private contributions.

3.1.5. *Quality of care*

3.1.5.1. Existence of national quality assurance models specifically for rare disease care. Of 27 responding Countries, 9 (33.3%) confirmed having a national quality assurance model: Austria, Bulgaria, Finland, Germany, Greece, Hungary, Italy, Netherlands, and Spain. In 7 of them (Austria, Germany, Greece, Hungary, Italy, Netherlands, Spain), the model is integrated into national strategies and regularly reassessed (e.g. every 4–5 years).

Five countries (Austria, Germany, Hungary, Italy, Netherlands) align their models with European Union Committee of Experts on Rare Diseases (EUCERD) criteria; four (Germany, Greece, Netherlands, Spain)

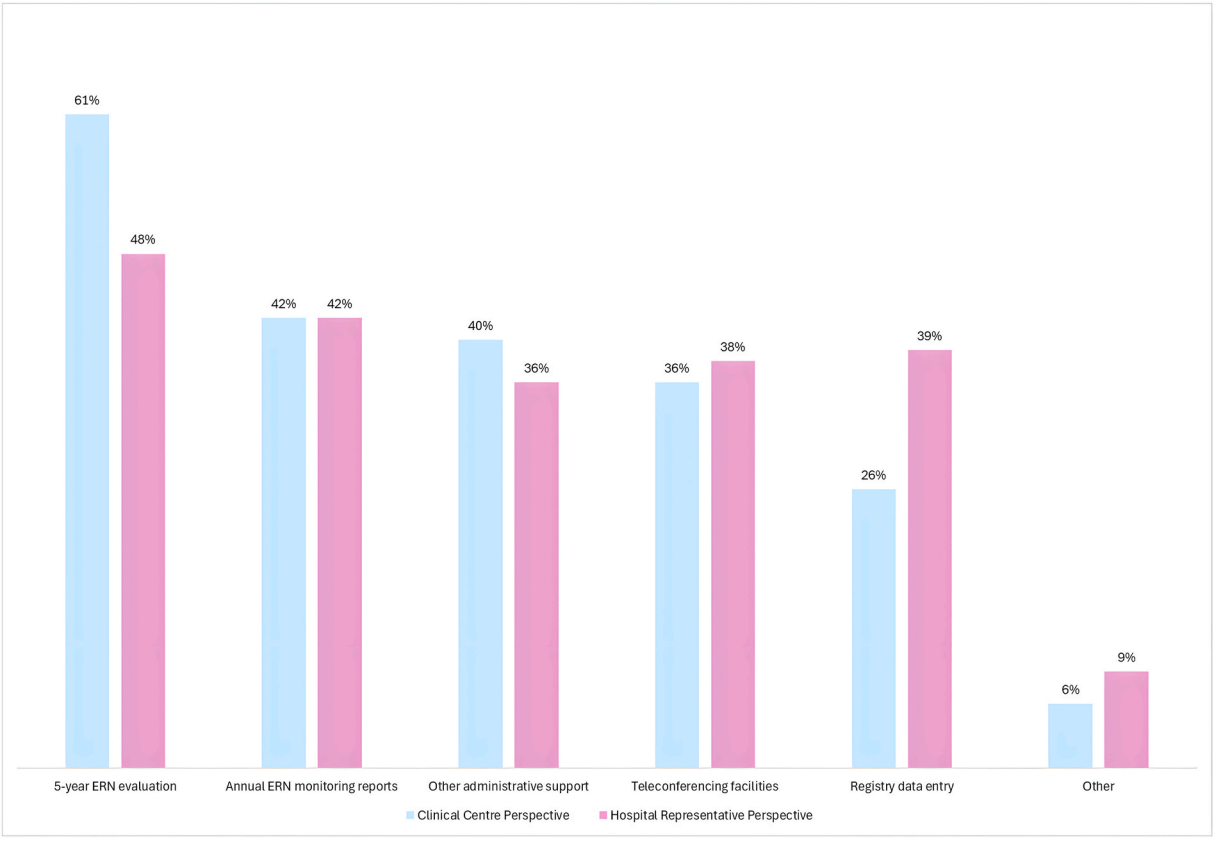


Fig. 6. Hospital-level support for ERN-Related activities (clinical centre perspective and hospital representative perspective).

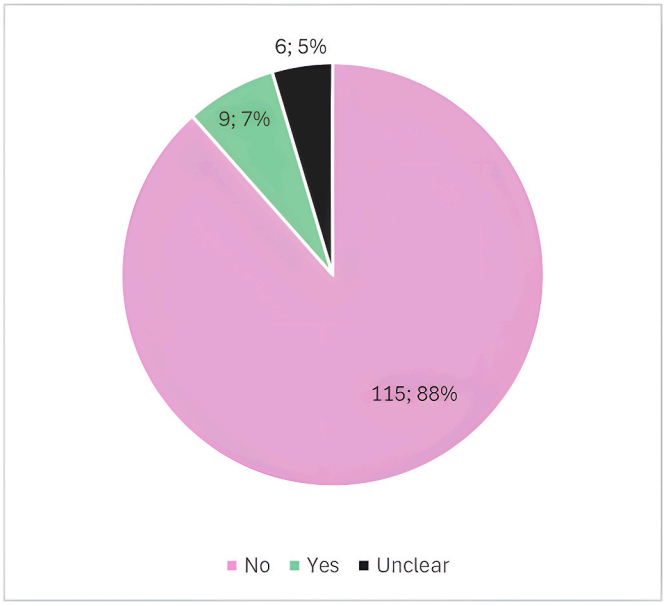


Fig. 7. Proportion of hospitals receiving additional funding (e.g. private, charity, industry) specifically related to ERN activities.

also use national frameworks. Certification is a funding prerequisite in Greece, Hungary, and Spain.

3.1.5.2. Hospital-Level Support for quality of care. As part of the survey, clinical centres were asked whether their healthcare providers offered institutional support for quality of care (e.g. quality management structures or RD offices). Responses were received from 476 clinical centre leads representing 208 hospitals (33.5% of all centres) and from 163 hospital representatives representing 124 of 355 hospitals (35%), across 24 countries.

Data from both respondent groups were available for 104 hospitals (29.3%). Among these, consistent quality-of-care support was confirmed in 64 hospitals (51.6%), while inconsistent responses were reported in 8 hospitals (6.5%). Overall, 214 of 476 clinical centres (44.9%), corresponding to 101 hospitals, reported receiving some form of institutional quality-of-care support.

More detailed information on the type of support was provided by 79 hospital representatives and 198 clinical centre leads from 60 to 100 hospitals, respectively. The most frequently reported support mechanisms were quality management structures (40%), RD offices (24%), RD coordinators (11%), standard operating procedures, care pathways or audits (10%), and data, information technology or reporting support (7%), while other or unclear forms of support accounted for 8%.

3.1.5.3. Continuity of care between childhood, adolescence and adulthood (transition). Hospital representatives and clinical centre leads were asked about the existence, scope, and barriers of defined transition processes. Out of 355 ERN hospitals, 129 (36%) responded: 60% confirmed a transition process, 28% did not, and 12% gave unclear answers. In 90 hospitals, 58% applied the process to all RDs, 34% did not, and 8% were inconsistent.

A standardised transition process was confirmed by respondents from 46 of 93 hospitals (49%) – either by all or at least some representatives – and by 312 of 476 clinical centre representatives (66%), covering all RDs managed at the centre in 216 cases (69%; representing 208 of 355 hospitals).

Where a transition process existed but was not yet fully implemented – reported by 26 healthcare providers and 149 clinical centres – barriers

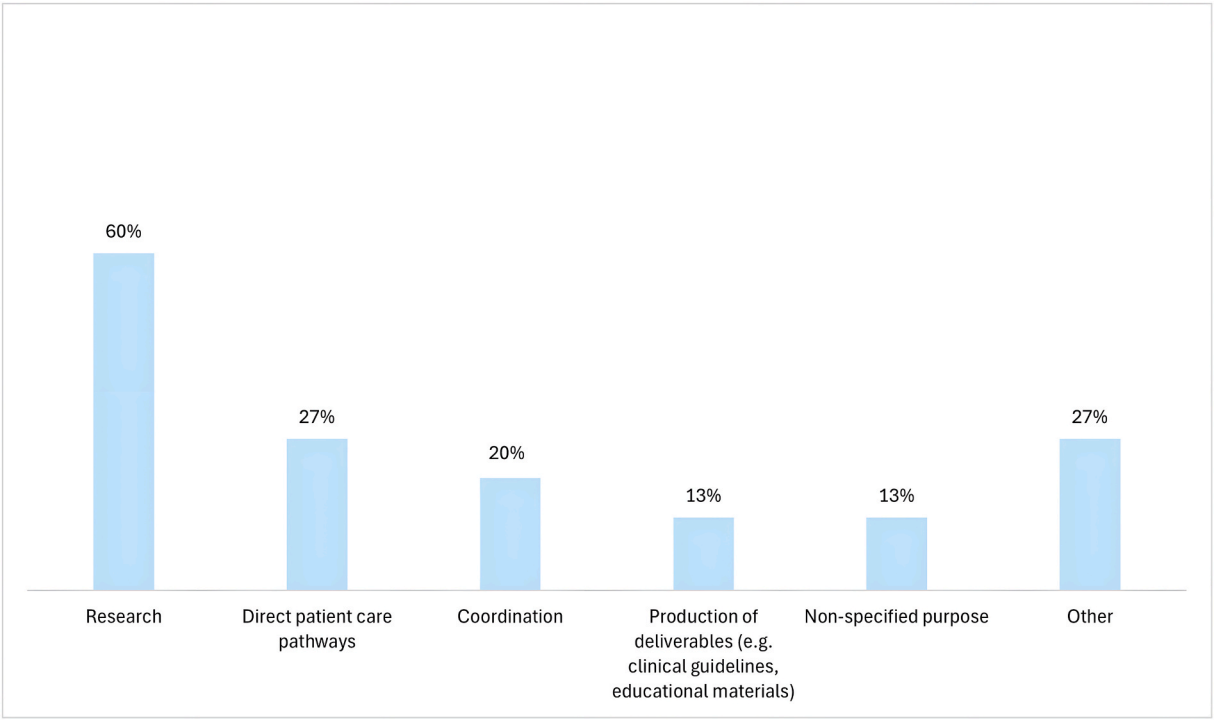


Fig. 8. Specific ERN-related activities funded among HCPs reporting additional funding.

were consistent across both perspectives: insufficient capacity on the adult care side to accept new patients (hospitals: 52%; centres: 45%), partial applicability to only a subset of RDs covered (hospitals: 48%; centres: 62%), limited paediatric capacity to prepare transfer documentation (hospitals: 44%; centres: 31%), and other reasons (hospitals: 7%; centres: 14%).

3.1.6. Centre Development strategies

3.1.6.1. Strategic planning mechanisms for ERN clinical centres. From 133 hospitals (38%) in 24 countries 188 representatives responded to the question whether there are mechanisms established for strategic planning of health services provided by their ERN clinical centre(s). Country-level distribution is shown in Fig. 9. Such a strategic planning was confirmed in 59 hospitals (44.3%) and absent in 56 (42.1%) and 18 hospitals (13.5%) gave conflicting answers. In 51% of cases, planning was part of departmental strategy; in 45%, part of overall HCP strategy.

3.1.6.2. Strategic planning for rare disease services at the centre level. Total of 475 ERN clinical centres across 209 hospitals in 27 EU countries answered the question. Rare disease-specific strategic planning mechanisms were reported by 237 centres (49.8%). Where present, planning was part of a departmental strategy (25%), integrated into the overall HCP strategy (25%), aligned with national RD plans (30%), or involved patient representatives (19%).

Responses from both hospital managers and clinical centre representatives were consistently available for 103/355 (29%). Full agreement between both groups was found in 39 hospitals (38%), while in 44

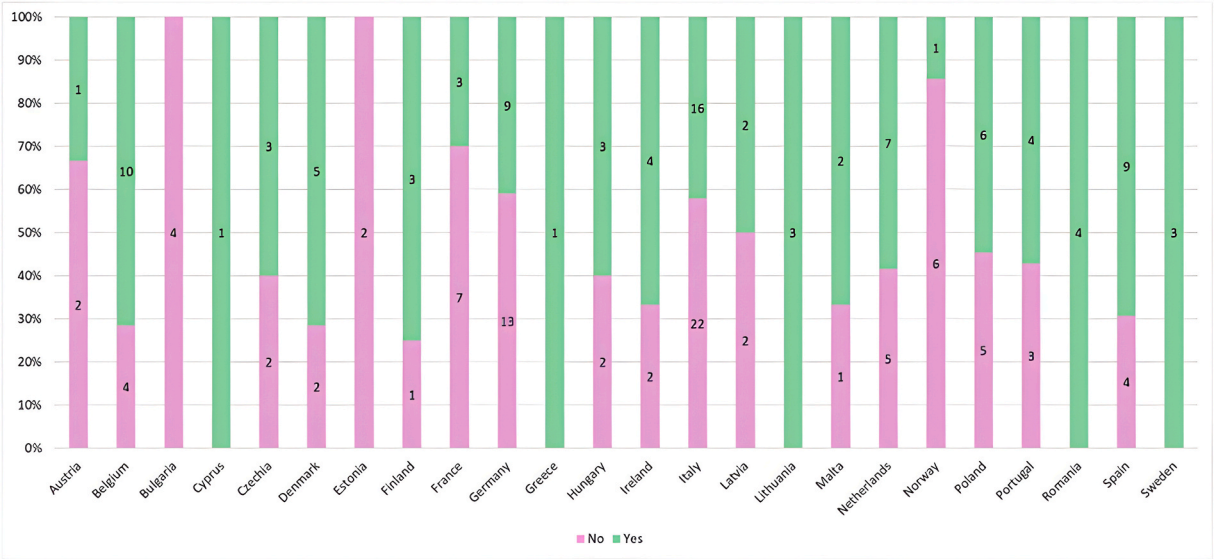


Fig. 9. HCP respondents reporting established mechanisms for strategic planning of health services in ERN clinical centres.

(43%) clinical centres within the same hospital gave differing answers.

In 53/103 hospitals (51.5%) the absence of strategic planning was acknowledged; however, in 28 of these, at least one clinical centre reported its presence. Conversely, in 36 hospitals, at least one centre denied what hospital management had claimed.

4. Discussion

This study assessed ERN centre operability across three stakeholder perspectives – clinical units, hospitals, and national authorities – covering six domains, at a time of rising policy focus on RDs (e.g. 2019 EU Council Recommendation, 2021 UN Resolution). The findings reveal substantial gaps across all six domains – workforce, recognition, funding, quality, and strategic planning – indicating that the main barriers to ERN sustainability lie not in a lack of professional commitment, but in system-level limitations: fragmented governance, inadequate staffing support, and absent dedicated funding. Despite strong clinical engagement, ERN activities remain insufficiently embedded in national regulatory, financial, and organisational frameworks.

A striking finding is the frequent misalignment between national authorities, hospital management, and ERN clinical centres: while national representatives often report formal recognition or support mechanisms, these are not consistently reflected at hospital or clinical unit level. This governance gap – characterised by unclear ownership of ERN responsibilities, weak internal communication, and absent accountability structures – means ERN activities are treated as optional rather than integral to routine care. Our data bear this out: only 20% of centres reporting increased patient load received corresponding institutional support, strategic planning responses differed between hospital management and clinical centres in 43% of cases, and only around 60% of EU countries formally designate ERN-affiliated hospitals as RD centres, with managers frequently failing to recognise the time clinicians dedicate to ERN activities (Independent Evaluation Body, 2024). Without a shift in how ERN participation is institutionally valued, it will continue to rest on individual commitment rather than systemic support.

Our results show crucial shortcomings in the staffing of ERNs, with many centres suffering from understaffing and legislative measures defining minimum numbers of specialists existing in only a few countries. This is in line with broader European trends – the Organisation for Economic Co-operation and Development (OECD) estimates a deficit of approximately 1.26 million healthcare workers, leading to chronic staff overload and burnout (Standing Committee of European Doctors [CPME], 2024). However, this situation is particularly acute in the field of RDs: training highly specialised professionals takes much longer than for common diagnoses, so the problem of staff shortages is more pronounced for these patients (Tumiené et al., 2022).

ERN membership has a clear and positive impact on RD education: 75% of clinical centres reported an increase in educational activities following ERN affiliation, with 57% reporting a slight and 18% a substantial increase. Participation in webinars and in-person events was high, though structured postgraduate programmes and exchange schemes remain underused – primarily due to insufficient institutional support and scheduling constraints rather than lack of interest, cited by only 14–16% of respondents – consistent with broader evidence of documented competency gaps and demand for mandatory training across Europe (Tumiené et al., 2022). To address this, stakeholders should prioritise protected time, structured curricula, and stable funding for ERN-led training, with webinars and case-based e-learning representing cost-effective options suited to busy clinical schedules; given considerable cross-country variation in paid education days, the median value across ERN centres could serve as a benchmark for minimum standards.

Our analysis shows that as a result, roughly two-thirds of ERN clinical units report some hospital support for ERN tasks, but typically only for periodic evaluations or reporting; core needs like registry data entry and protected time for rising patient referrals remain chronically under-resourced. This mismatch – clinicians bearing growing caseloads with no formal workload recognition, while ERN activities are not consistently embedded in institutional resource planning – threatens long-term sustainability. The clear policy fix is formal institutional backing: Member States should codify ERN centres of expertise in health plans and explicitly fund and staff ERN duties. Only with such hospital-level commitment and coherent national policy can ERN networks handle growing demand and fully deliver on their promise (EURORDIS, 2024a, b).

Of all the domains assessed, inadequate and unpredictable financing emerged as one of the most consistent and cross-cutting barriers, underlying many of the other structural gaps identified in this study. ERN funding remains a patchwork: the EU4Health programme provides ~€77.4 million (2023–2027) across all 24 ERNs, yet only a handful of national RD plans earmark additional support, and grants for core tasks have been widely viewed as inadequate – each ERN received just €200,000 over three years to build registries (Hedley et al., 2023; European Commission, 2023). The divergence between how clinical centres and host hospitals justify ERN activities likely reflects this fragmented reality, and our findings of wide country-level disparities align with calls for more coherent, sustained financing integrated within national RD strategies (Hedley et al., 2021a,b). Similarly, dedicated quality-assurance models for RDs remain scarce and unevenly applied, with a recent independent ERN evaluation identifying quality and patient safety as key areas requiring concerted policy support and closer coordination between health system leaders and ERN clinicians (Stoesz et al., 2024; EURORDIS, 2024a,b).

Strategic planning for RD services remains underdeveloped: fewer than half of hospitals (44.3%) and clinical centres (49.8%) reported a dedicated RD strategy, and where plans existed, they were rarely linked to national RD strategies (30%) or involved patient representatives (19%), being mostly limited to departmental or general hospital strategies. The lack of patient engagement in strategic planning (present in fewer than one in five cases) is a particularly striking gap for networks explicitly built around a patient-centred model. EU evaluators found that managers are frequently unaware of ERN activities and fail to allocate corresponding resources (European Commission DG SANTE, 2024), while hospital executives have elsewhere embraced ERN membership as an opportunity to leverage innovation (European Commission DG SANTE, 2019) – a gap in perception that leaves institutional planning for ERN centres fragmented and uneven.

Although these findings are descriptive, the cross-country variation they capture also points to transferable lessons. The systems that appear most integrated are those that have anchored ERN support within a binding national RD plan: in France, ERN clinical centres are funded directly through the National Plan for Rare Diseases, while the Netherlands has embedded its RD quality-of-care model within national strategy, including periodic re-assessment. The common denominator is not greater individual goodwill but the formal codification of ERN activities within national policy and financing instruments. Converting such isolated national practices into shared, EU-wide standards is precisely the aim of the JARDIN Joint Action, which provides the coordinating framework to move ERNs from project-based networks towards durable, adequately resourced components of national RD infrastructures.

This survey-based study has several limitations. Response rates varied across stakeholder groups, countries and ERNs, and incomplete responses may have introduced non-response bias. Overlapping questions addressed to different respondent groups occasionally resulted in inconsistent answers, reflecting differences in institutional roles or access to information. Representation was uneven across all three respondent levels. At hospital administration level, participation ranged from 22% (Romania) to 100% (Ireland, Lithuania, Luxembourg, Norway, Sweden and Slovenia); although approximately 60% of ERN-hosting hospitals participated overall, all countries except Romania reached at least 40% coverage. Representation was considerably more

variable at ERN clinical centre level (34% overall), where several large-volume Member States were markedly underrepresented – Romania (15%), France (19%), Belgium (20%), Germany (21%) and the Netherlands (24%) – so that the centres of some of the largest national networks are underweighted relative to their share of ERN membership. At network level, response rates similarly ranged from 5% (ERNICA) to 51% (ERN-EYE), with ERN-SKIN (23%), ReCONNET and EpiCARE (24% each) and RARE-LIVER (25%) among the least represented. Because the domains assessed – staffing, recognition, funding, quality assurance and strategic planning – are likely to differ systematically between better- and less-resourced systems, this uneven and fluctuating response may bias the aggregate estimates: countries and networks with greater institutional capacity, and therefore more staff available to complete the survey, are plausibly overrepresented, which could lead the true extent of unmet support needs to be underestimated. In addition, responses from individuals holding multiple roles required aggregation and, in rare cases, exclusion of contradictory data. Interpretation of the findings is further constrained by differences in national definitions and organisational contexts, as key concepts such as official recognition, institutional support and funding mechanisms are not uniformly defined across healthcare systems. Finally, the substantial heterogeneity observed across countries and ERNs, combined with potential misunderstandings or differing interpretations of survey questions, limits direct comparability and generalisability; therefore, the results should be interpreted as descriptive rather than fully comparative.

5. Conclusion

This study provides the most comprehensive overview to date of the challenges faced by ERN centres across Europe. Substantial heterogeneity in staffing, education, recognition, funding, quality assurance, and strategic planning was observed, alongside persistent misalignment between clinical centres, their host hospitals, and national authorities. Although ERNs have strengthened RD care by pooling expertise and stimulating cross-border collaboration, their integration into national health systems still remains to be established and will remain fragile, constrained by weak legal recognition, limited institutional support, and fragmented financing.

To secure sustainability, ERNs must be fully embedded in national RD plans and reimbursement frameworks, with dedicated funding streams that extend beyond patient care to cover registries, telemedicine, and cross-border consultation. At the same time, harmonised staffing standards, protected time for education, and structured post-graduate curricula are needed to build lasting capacity. Aligning national and institutional quality assurance systems with EU-level frameworks would provide consistency and accountability, while systematically engaging both patients and hospital leadership in strategic planning is essential to bridge the divide between clinical and managerial perspectives. If these steps are taken, ERNs can move beyond their current fragile position and evolve into a durable pillar of European healthcare – capable of delivering equitable, high-quality, and sustainable care for people living with RDs.

CRediT authorship contribution statement

Vojtěch Šimka: Conceptualization, Data curation, Formal analysis, Methodology, Project administration, Validation, Visualization, Writing – original draft. **Jana Jedličková:** Formal analysis, Methodology, Project administration, Validation, Visualization, Writing – review & editing. **Nela Navrátilová:** Formal analysis, Methodology, Project administration, Validation, Visualization, Writing – review & editing. **Ondřej Hynek:** Project administration, Writing – review & editing. **Valentina Sand:** Formal analysis, Validation, Visualization, Writing – review & editing. **Mari Murel:** Writing – review & editing. **Alberto M. Pereira:** Writing – review & editing. **Pavla Doležalová:** Conceptualization, Methodology, Project administration, Supervision, Writing – review & editing. **Franz Schaefer:** Methodology, Supervision, Writing – review & editing.

Declaration of competing interest

The authors of the manuscript entitled "Exploring National Support Mechanisms for European Reference Network Centres: An Overview from JARDIN Work Package 9" declare no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejmg.2026.105099.

Data availability

Data will be made available on request.

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