ERDERA

European Rare Diseases Research Alliance

Networking Support Scheme

Small support scheme for networking initiatives to share knowledge on rare diseases and rare cancers

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Call Text
Including guidelines for applicants

May 2025

Submission on a continuous basis
Collection of applications every 6 months, starting from October 7, 2025

For further information,
The application template, the Frequently Asked Questions (FAQ), and the link to the ERDERA electronic submission platform can be found at the ERDERA website.

For questions concerning content:
Read the Frequently Asked Questions (FAQ) on: ERDERA website
Or contact the Networking Support Scheme Secretariat:
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THE NETWORKING SUPPORT SCHEME IN SUMMARY

AIMS

The first aim of the Networking Support Scheme (NSS) in the European Rare Diseases Research Alliance (ERDERA) is to encourage scientific knowledge exchange on rare diseases or rare cancers between clinicians, researchers, research managers and patients in new and in expanding research networks by funding networking events.

The second aim of the Networking Support Scheme is to enable or increase the participation of usually underrepresented countries in Europe (listed in Annex 1) in new and in expanding research networks on rare diseases or rare cancers.

The focus of the networking events should be on research results and their implications, as well as on innovative solutions. The outcomes of these networking events may lead to future collaborative and novel research efforts.

PRACTICAL INFORMATION

In this Networking Support Scheme (NSS), applicants from all countries participating in ERDERA (see Annex 1 for eligible countries) are invited to apply for funding of up to 30,000€ per networking event to organize **transnational** European/international events focused on sharing and disseminating research knowledge on rare diseases. The flowchart illustrating the NSS funding process is depicted below (Fig.1). Please note that the principal applicant will have to use two online systems during the process if positively selected by the Networking Evaluation Committee: one system for application and scientific reporting (the ERDERA NSS online platform), and a second system for granting and financial reporting (provided by ZonMw).

Applicants can choose between a face-to-face meeting or a hybrid meeting, where a group gathers at one location while additional participants join online. To participate in this competitive call, a specific application template has to be completed and uploaded with some additional documents onto the online ERDERA NSS submission platform, along with some additional information in an online form on the platform. The call is open continuously from May 2025 till April 2029, unless the entire budget is exhausted. Applications are collected every six months, and the eligibility is checked. The collection dates, a word template representing the online form and an application template are present on the ERDERA website. Eligible applications are competitively evaluated by an independent Networking Evaluation Committee based on predefined criteria, in accordance with the rules of the European Union's Horizon Europe Research and Innovation programme.

Previous networking events, selected under the former rare disease programme EJP RD, are published in a Dashboard on the EJP RD website. These may be used as inspiration for building consortia or defining topics for the applications. At a later stage, this

Dashboard will be transferred to the ERDERA website and selected networking events in ERDERA will be added into this Dashboard.

The administrative management of the Networking Support Scheme is handled by the Networking Support Scheme Secretariat (NSSS), comprised of Research Council of Lithuania (LMT), Lithuania and The Netherlands Organisation for Health Research and Development (ZonMw), The Netherlands.
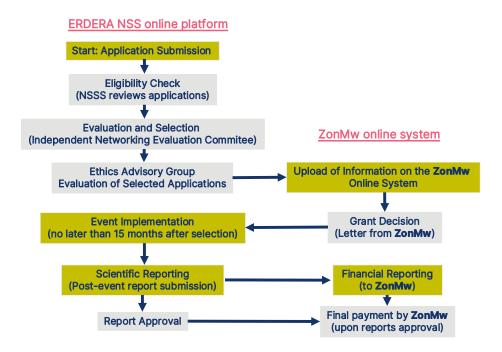
Figure 1 NSS selection and funding process. Funding will only take place if the application is positively selected by the Networking Evaluation Committee and subsequently positively evaluated by the Ethics Advisory Group and if enough funding is available.

LIST OF ABBREVIATIONS

EAG	Ethics Advisory Group
EC	European Commission
ECR	Early Career Researcher
EJP RD	European Joint Programme on Rare Diseases
ERDERA	European Rare Diseases Research Alliance
EU	European Union
GDPR	General Data Protection Regulation
IRDiRC	International Rare Diseases Research Consortium
LMT	Lietuvos mokslo taryba (Research Council of Lithuania)
NSS	Networking Support Scheme
NSSS	Networking Support Scheme Secretariat (ZonMw, LMT)
PAO	Patient Advocacy Organization
UCs	Underrepresented countries
ZonMw	The Netherlands Organisation for Health Research and Development

1. MOTIVATION

Rare diseases, primarily genetic, number over 7,000 and affect between 26 and 30 million Europeans. Despite their rarity, they pose significant and unique health challenges, often leading to early onset, reduced quality of life, and chronic illnesses impacting patients, caregivers, and healthcare systems.

Rare diseases research is crucial for prevention, diagnosis, and better care but faces hurdles: limited researchers and patients per disease, dispersed patient populations, fragmented databases, and the need for interdisciplinary collaboration. These challenges make rare diseases a unique domain requiring transnational cooperation.

To address these needs, the European Joint Programme on Rare Diseases (EJP RD) launched the NSS in 2019, promoting collaboration and knowledge sharing in rare disease (including rare cancer) research. Building on its success, the European Rare Disease Research Alliance (ERDERA) will continue the NSS initiative.

2. AIMS AND THE FOCUS OF THE CALL

The Networking Support Scheme (NSS) provides funding to organize workshops or conferences aiming at:

1. Encouraging scientific knowledge exchange among clinicians, researchers, research managers and patients/patient advocacy organizations (PAOs) in new and expanding transnational (clinical) research networks focused on rare disease(s), rare cancer(s), or cohorts of undiagnosed patients suspected of suffering from rare disease(s).
2. Enabling or increasing the participation of usually underrepresented countries in Europe in research networks on rare diseases or rare cancers.

The applicants should address both aims of the NSS.

The events should focus on research results and their implications, as well as on innovative solutions. The outcomes of the events should foster collaboration, promote patient-oriented research, and increase the uptake of research results in the rare disease and rare cancer communities.

The Networking Support Scheme aligns with ERDERA's vision and goals, as defined by the International Rare Diseases Research Consortium (IRDiRC), which promotes global collaboration in rare disease research. IRDiRC's vision is to ensure that all people living with a rare disease receive an accurate diagnosis, care, and therapy within one year of seeking medical attention.

For more information see IRDiRC website: https://irdirc.org/about-us/vision-goals/.

3. FORMAT OF THE NETWORKING EVENT

Applicants can choose one of the following formats for their networking event:

- **Face-to-face meeting** (in-person)
- **Hybrid meeting** (with a group onsite and additional participants joining online)

The choice of the format may depend on the aim of the networking event and the profile of participants. Since the Networking Support Scheme prioritizes collaboration and participant networking, applicants must carefully consider how to facilitate meaningful interactions, particularly in hybrid meetings. Networking events should go beyond lectures or webinars, incorporating dynamic and interactive sessions that actively involve participants and enhance the networking experience.

In the application, applicants have to justify the chosen format and the required budget. See Annex 3 for the suggested items and costs.

4. APPLICATION

4.1   ELIGIBILITY AND NON-ELIGIBILITY CRITERIA

4.1.1 ELIGIBILITY OF APPLICANTS

Eligible applicants for funding include:

- Rare disease or rare cancer researchers
- Clinicians
- Research managers working at universities, other higher education institutions, public research institutes[1], or in the clinical/public health sector (hospitals/public health and/or other healthcare settings and health organizations)
- Rare disease or rare cancer Patient Advocacy Organizations (PAOs) that have a legal entity.

Only **transnational networks** are eligible for funding. Consortia applying for a networking budget must include a minimum of **three** and a maximum of **ten eligible co-applicants** (including the principal applicant) from at least **three different countries.** One of these countries should be an **underrepresented country** mentioned in Annex 1**.** One of the co-applicants will be designated as the **principal applicant**. The organization of the principal applicant has to be a legal entity and established in an eligible country mentioned in **Annex 1.** Other co-applicants can come from the eligible countries from the list (Annex 1) and from Australia, Canada, United Kingdom, and Switzerland.

Applications that fail to meet these conditions will be rejected without further review.

Patient Advocacy Organizations:

An eligible rare disease or rare cancer Patient Advocacy Organization which may receive funding is defined as a not-for-profit organization organized under private law, which is, according to their articles of association (also: articles of incorporation and their by-laws) patient-focused, where patients and/or carers and/or family members of patients represent a majority of members in governing bodies and are financially independent, particularly from the pharmaceutical industry (max. 49 % of funding from several companies). More information on the eligibility of Patient Advocacy Organizations is mentioned in **Annex 2.**

PAOs may serve as principal applicants as long as the event focuses on sharing research-related knowledge. PAOs may ask researchers or clinicians to be co-

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[1] Funded by the government for at least 50%

applicants in an application, depending on the kind of knowledge that will be shared. Non-research-focused gatherings (e.g., family meetings) are not eligible.

The **role** of the **principal applicant** and contributions of the **co-applicants** are described in **sections 4.3 and 4.4.**

4.1.2 ELIGIBILITY OF DISEASES

Diseases are eligible if the definitions mentioned below are applicable:

- A rare disease or group of rare diseases is defined as one affecting no more than five in 10,000 persons in the European Community, EC-associated states, and Canada.
- A rare cancer is defined as one with an incidence of less than 6 cases per 100,000 persons per year. For the list of rare cancers see:
  https://web.archive.org/web/20240715025337/https://www.rarecarenet.eu/rarecarenet/cancerlist

- Cohorts of undiagnosed patients who are suspected of suffering from a rare disease/rare cancer. Undiagnosed patients have symptoms or a set of symptoms that are seen in other rare diseases or rare cancers, have no diagnosis after a significant time period and have visited several kinds of medical specialists. These diseases may be unusual presentations of known rare diseases/rare cancers or a disease that is yet to be characterized. ORPHAcode 616874: Rare disorder without a determined diagnosis after full investigation.

The following rare diseases are **NOT eligible**:

- **Rare infectious diseases are excluded**, as the scheme focuses on rare, complex conditions requiring specialized healthcare within the scope of European Reference Networks (https://ec.europa.eu/health/ern_en).

4.1.3 ELIGIBILITY OF THE COUNTRY WHERE THE NETWORKING EVENT MAY TAKE PLACE

The networking event must be held in one of the eligible countries listed in Annex 1. Organizing the networking event in an underrepresented European country can be an effective way to enhance participation from these countries, provided it adds clear value to the event. The local organizer of the event must always be a member of the applying consortium.

4.2   BUDGET PER NETWORKING EVENT

The maximum budget for a single networking event is € 30,000, inclusive of VAT, regardless of the chosen format (face-to-face or hybrid). It is not possible to apply for multiple networking events on a single application.

Costs must be clearly specified in the submitted budget plan, and only expenses directly related to the organization of the networking event are eligible. If ineligible costs are included, the budget will be adjusted accordingly. **Hiring an external organization to organize the event is not permitted.** Information for budget estimation is provided in Annex 3.

Co-funding is allowed (e.g., through registration fees or financial contributions from industry partners), but generating a profit from the event is not permitted. In the case of co-funding by a private-for-profit organization, the applicants must ensure that the content of the networking event is not influenced by this private-for-profit organization. The Networking Support Scheme cannot cover expenses for the participation of a private-for-profit organization.

Satellite events held back-to-back with larger conferences or symposia are allowed, provided the satellite events have a specific goal aligned with the Networking Support Scheme. Only the additional costs of the satellite meeting will be eligible (e.g., meeting room, audio-visual equipment, additional hotel night(s), travel costs of those participants that will come specifically to this satellite event, additional technical support, etc.).

The Networking Support Scheme does not cover research costs or personnel costs for event preparation. However, technical support costs at the event, such as managing the online component of a hybrid meeting or ensuring proper audio-visual setup, are eligible.

4.2.1 SPECIFICATION OF COSTS AFTER THE EVENT

The costs for the networking event must be specified and justified in a detailed budget plan submitted after the event to the Networking Support Scheme Secretariat (NSSS). This submission should include all necessary documentation (including electronic invoices, tickets, participant registration lists, etc.) to allow the secretariat to verify the expenses incurred. Costs that cannot be properly justified will not be reimbursed.

Reimbursement of costs resulting from 'no-shows' of participants or speakers (e.g., costs for hotel, catering, or travel expenses) is not possible and should be otherwise insured. In cases of force majeure, such as illness, last minute travel issues, or other unforeseen circumstances, claims must be substantiated with supporting proof.

4.3   ROLE OF THE PRINCIPAL APPLICANT

The **principal applicant** must be a **researcher, clinician, research manager, or representative of a legal PAO** (Annex 2) from an eligible country (Annex 1). The principal applicant will represent the network externally and serve as the sole contact person for the NSSS. The principal applicant is responsible for passing on all relevant information from the NSSS to the co-applicants.

The organization of the principal applicant will receive the allocated budget on behalf of the network if the networking event is selected for funding. The principal applicant will be accountable for managing the expenses, justifying the expenditure, and submitting both a financial report and an outcomes report for the networking event.

4.4   CONTRIBUTION FROM THE CO-APPLICANT

The applying consortium should consist of partners who will develop the scientific programme of the networking event, as well as the logistic organizer(s)/local organizer(s) of the networking event. Additionally, partners involved in communication and/or finances may also take part in the consortium. The division of this work for organizing the networking event is the responsibility of the co-applicants together with the principal applicant.

4.5   OTHER PARTICIPANTS

The applying consortium is allowed to invite other participants to join the networking event. There is no limit to the number of participants.

Researchers, clinicians, and research managers working in institutes that are established in eligible **countries,** and PAOs that are legally established in eligible **countries** are eligible to receive funds for travel and hotel costs to attend the networking event.

Researchers, clinicians, and research managers working in institutes that are established in **non-eligible** countries, and PAOs that are established in **non-eligible countries** must secure their own funding to attend the networking event, unless the applying consortium invites them as speakers or chairs at the meeting.

4.6   INCLUSION OF UNDERREPRESENTED COUNTRIES, ENCOURAGEMENT OF EARLY CAREER RESEARCHERS AND PATIENT ADVOCACY ORGANIZATIONS

INCLUSION OF UCs

It is mandatory to include in the consortia researchers and/or clinicians and/or research managers and/or PAOs from ERDERA participating countries usually underrepresented in rare disease networks or rare cancer networks (Bulgaria, Cyprus, Czechia, Estonia, Georgia, Greece, Hungary, Iceland, Latvia, Lithuania, Morocco, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, and Türkiye) as (co)-applicants.

Please note that active involvement of applicants from underrepresented countries, PAOs, ECRs and young researchers is an advantage as it is part of the impact evaluation criteria (see section 5.2).

ENCOURAGEMENTS

Consortia are encouraged to involve **Early Career Researchers** (ECRs) in their network, e.g., as (co)organizers. Furthermore, networks are also encouraged to involve **young researchers** (PhD and master students) and young clinicians (residents) in the programme, e.g., for event preparation, poster sessions, etc. For further information on the definition of an Early Career Researcher, see 4.6.1.

The involvement of **PAOs** is highly encouraged. For more information on strategies to involve patient representatives and PAOs in the event, please consult the EJP RD Short Guide on patient partnerships in rare disease research projects. If PAO involvement is not deemed appropriate within a specific event, this should be explained and justified.

Resources for finding patient representatives and PAOs willing to be involved in research:

- Orphanet portal for rare diseases and drugs patient organization directory
- Rare Diseases Europe (EURORDIS)
- European Reference Networks (ERNs)
- European Patient's Academy on Therapeutic Innovation (EUPATI)
- National patient alliance on rare diseases
- European Patient Cancer Coalition and rare cancers.

4.6.1 DEFINITION OF EARLY CAREER RESEARCHER (ECR)

A consortium is strongly encouraged to include ECRs as (co-)applicants in the application. For the NSS, ECRs are defined as:

PhD holders
Scientists who have received their PhD no more than seven years prior to the collection date of the application.

Medical doctors
Physicians who have completed specialist medical training no more than seven years prior to the collection date of the application. For physicians with a PhD, the date of the completed specialist medical training remains the relevant date.

Extensions to this period of seven years are allowed in case of reasonably justified career breaks: absence for parental leave, family care leave, long-term sickness leave, and compulsory military service.

ECR applicants must include the information (dates) in their CV:
- **PhD holders**: *Date of PhD certificate*
- **Medical doctors**: *Date of medical specialist certificate*
- **Extensions, if applicable:** Total months for parental leave, career breaks, or military service, etc.

4.7 REAPPLICATIONS AND FOLLOW-UP MEETINGS WITH NSS FUNDING

Applicants may apply for funding for a networking event more than once, but not in the same selection round.

An application not selected in a competitive round (of EJP RD NSS or ERDERA NSS) may be resubmitted once under the ERDERA Networking Support Scheme, provided it incorporates the feedback from the first evaluation. The revised application will compete on equal terms with the other submissions. If the revised application is not selected for the second time, it cannot be resubmitted.

Funding for a follow-up networking event may be requested only once after a previous selection. Applicants must clearly demonstrate the success of the first event and justify the need for a follow-up event. The wish to organize a (bi)yearly meeting is not sufficient. The applications for a follow-up event will compete on equal terms as applications for new networking events.

Consortia previously funded under the NSS can apply for a new event with different objectives or focus on a different rare disease or rare cancer. These applications must clearly demonstrate the success of the earlier event and will compete on equal terms with other submissions.

4.8 COMMUNICATION ON SELECTED NETWORKING EVENTS AND DISSEMINATION OF OUTCOMES

COMMUNICATION OF SELECTED NETWORKING EVENTS

The title of the networking event, names of the applicants, and the lay summary of the application will be published on the ERDERA website immediately after the application is selected for funding.

Applicants are encouraged to promote their events through their own communication channels.

DISSEMINATION OF NETWORKING EVENTS OUTCOMES

The outcomes of networking events should be publicly available. Exceptions to this general rule must be justified by the principal applicant (e.g., information related to competitive research grants applications).

The principal applicant must submit a final report using a specific online reporting form within 2 months of the event, including a public lay summary with a description of the content, the outcomes, and the next steps. The public lay summary of the outcomes of the networking event will be published on the ERDERA website together with the general slides of the networking event (with sensitive unpublished data or ideas removed).

It is also expected that the outcomes of the networking event will be disseminated through scientific publications, articles for PAOs and the public, newsletters, presentations at other meetings, information on their own websites, etc.

4.9   SUBMISSION OF APPLICATIONS

4.9.1 ADVICE BEFORE SUBMITTING THE APPLICATION

- Carefully read this call text, including the aims of the NSS and the evaluation criteria (see 5.2);
- Complete the application template (downloadable from the ERDERA website);
- Ensure your application aligns with the aims and scope of the NSS;
- Verify that all eligibility criteria are met;
- Follow the instructions in the ERDERA electronic submission platform;
- Adhere to the length limitations of each section.

4.9.2 REGISTRATION

Consortia intending to submit an application must register early on the ERDERA NSS electronic submission platform, as incorporating applicant details may take time. Instructions for registration and application are available on the ERDERA website.

4.9.3 APPLICATION SUBMISSION PROCESS

Applications (in English) must be submitted through a **one-stage submission procedure** by the principal applicant through the ERDERA online submission platform with this link.

Applications can be submitted continuously from May 2025 and are evaluated competitively after collection dates every six months. A calendar of collection dates is provided on the ERDERA website.

The application must be in English and consists of several parts: the online form on the ERDERA submission platform, and additional documents: application template, draft programme of the networking event, ethics self-assessment, signature page and, in case the Principal applicant is a PAO, a Declaration of Honour. The online form and the additional documents jointly include the following information:

- **Event details:** Title of the event, type of application (e.g., new, resubmission, satellite event), and chosen format (face-to-face/hybrid).
- **Public lay summary**: Max. 2000 characters including spaces, describing the event's details, including objectives, target group, medical domain, and potential impact. This summary will be published on the public part of the ERDERA website.
  - Write in plain English using short sentences, ensuring accessibility to a non-specialist audience.
  - Ask a layperson to read the summary and revise if needed.

- **The (group of) rare disease(s) or rare cancer(s) concerned**, including ORPHAcode.
- **Medical domain**.
- Name of **ERN** (if applicable).
- **Keywords** to describe the content of the networking event (3-7).
- **Keywords** from the EC.
- **Event logistics:** Location (city, country), proposed date(s)/month/year and number of participants expected. The event can be planned no later than 15 months after selection. The selection takes up to six months from the collection date.
- **Scope of the networking event**:
  - Objectives, background, unmet medical and patient needs addressed.
  - Transnational collaboration value and participants selection rationale.
  - Industry involvement (if applicable).
  - Expected outcomes and dissemination of outcomes.
  - Risk management plan for unmet objectives.
  - Sustainability or extension of the research network following the event and future use of the expected results.
- **(Draft) programme/agenda** including topics, session types (break-out sessions, other sessions, round tables discussions, presentations, posters sessions, case studies, etc.) and potential speakers. This should be uploaded as a separate document on the ERDERA online submission system.
- **Networking**: Explanation on the choice of format of the event (face-to-face or hybrid). Description of tools or strategies to ensure efficient networking.
- **Contribution to the research field:** How does this event make a difference in comparison to previously organized meetings?
- **Applicant information:**
  - Principal applicants: brief CV, contact details and description of their role in the networking event.
  - Co-applicants: information on **at least two** and **a maximum of nine** co-applicants, including a brief CV and description of their individual roles in the networking event.
- In principle, the networking event should be open for other interested parties. The applicants may provide an URL for further information to be published online on the ERDERA website after the application is selected.
- **Ethics self-assessment** (for further information, see 5.3.3). This should be uploaded as a separate document on the ERDERA online submission platform.
- **Budget plan:** Detailed expenses, co-funding in cash, and requested budget from the NSS.
- Number at the **Chamber of Commerce** of the institute/organization of the principal applicant or other official registration number of the institute/organization.

- A document with dates, names, and **signatures** of the principal applicant and the co-applicants. This should be uploaded as a separate document on the ERDERA online submission platform.
- **When the principal applicant is a patient advocacy organization (PAO), it must complete the Declaration of Honour, downloadable from the ERDERA website. See Annex 2 for the applicable conditions for the PAOs.**

5. EVALUATION

5.1   NETWORKING EVALUATION CRITERIA

The Networking Evaluation Committee (NEC) is a panel of independent experts issued by funding agencies and EURORDIS and is responsible for the evaluation of the submitted applications. NEC members must sign a confidentiality agreement and a statement to confirm that they will adhere to the ZonMw's and LMT's Code for Dealing with Personal Interests.

5.2   EVALUATION CRITERIA

Applications will be assessed according to specific evaluation criteria aligned with Horizon Europe rules (see below), using a common evaluation form. A scoring system from 0 to 5 will be used to evaluate the application's performance with respect to the different evaluation criteria.

Scoring system:

0: Failure.   The application fails to address the criterion in question or cannot be judged because of missing or incomplete information.

1: Poor.   The application shows serious weaknesses in relation to the criterion in question.

2: Fair.   The application generally addresses the criterion, but there are significant weaknesses that need corrections.

3: Good.   The application addresses the criterion in question well, but certain improvements are necessary.

4: Very good. The application addresses the criterion very well, but small improvements are possible.

5: Excellent.   The application successfully addresses all aspects of the criterion in question.

Evaluation Criteria:

Applications will be evaluated based on three main criteria: Excellence, Impact, and Quality and Efficiency of the Implementation. Each criterion will be scored on a 5-point scale, with a threshold of 3 for individual criteria and an overall threshold of 12 out of a maximum of 15 points. The sub criteria listed under each main criterion provide specific aspects for consideration but will not be scored individually. Instead, they guide the overall evaluation of each main criterion.

A. Excellence

  a. Clarity, focus and relevance of the vision for the event and its objectives.
  b. Justification of the networking event as the best approach to achieve the objectives.
  c. Soundness of the programme/agenda for achieving the objectives of the event, including choice of topics/speakers.
  d. Competence and experience of each applicant in relation to the event's objectives.

B. Impact

  Making a difference with:
  a. **Expected outcomes:** Potential for innovation, knowledge dissemination, and socio-economic, public-health or clinical impact.
  b. **Transnational collaboration:** Added value of transnational collaboration, including critical mass of information, harmonization of data, data sharing, etc.
  c. **Inclusivity and equity:** Gender balance, involvement of underrepresented groups and countries, Early Career Researchers (ECRs), patient advocacy organizations (PAOs), and other key stakeholders, such as industry (when relevant).
  d. **Sustainability**: Potential extension of the research network after the event, as well as the effectiveness of the proposed networking event in exploiting, disseminating, and communicating its results.

C. Quality and efficiency of the implementation

  a. Complementarity of the applicants within the consortium in relation to the event's organization.
  b. Appropriateness of the choice of format (face-to-face or hybrid) and engagement methods for networking.
  c. Appropriate event management, including risk management and contingency plans.
  d. Feasibility and cost-efficiency of the event, including the time schedule and requested resources.

5.3   PROCEDURE FOR EVALUATION OF APPLICATIONS

5.3.1 ELIGIBILITY CHECK

The Networking Support Scheme Secretariat (NSSS) will check all applications to ensure that they meet the call's formal eligibility criteria outlined in section 4.1. The NSSS will notify the principal applicant of the eligibility check results via e-mail.

Please note that applications failing to meet these criteria **will be declined without further review**.

5.3.2 PEER REVIEW OF APPLICATIONS

Applications passing the eligibility check will proceed to the Networking Evaluation Committee (NEC) for a remote evaluation based on the evaluation criteria in section 5.2. The NEC members will review each application, assigning scores and providing comments for each criterion on the evaluation form.

Each application will be assessed by 2-3 NEC members with a clinical or research background and a PAO/patient background. The evaluation reports for each application will be discussed in a remote plenary meeting of the NEC members, where final recommendations will be made. The NEC will validate a ranking list of the evaluated applications and the summary reports.

5.3.3 ETHICS ASSESSMENT

Applicants must complete a pre-filled ethics self-assessment table according to the Horizon Europe guidelines and attach it to their application. Dedicated members of the Ethics Advisory Group (EAG) of ERDERA will review the ethics self-assessments to identify tasks that need to be done and documents that need to be set up and/or retained by the principal applicant to ensure compliance with applicable ethics provisions and standards in case that the application is selected. All required ethics documents have to be made available to ERDERA EAG upon request.

According to Horizon Europe rules, an ethical assessment is required to ensure that European projects are ethics-compliant especially when personal data are processed in the context of research. For more information on how to complete the ethics self-assessment table, please have a look at the information provided in the explanatory video material on the ERDERA website. The principal applicant is responsible for ensuring compliance with ethics standards. Personal data, including contact details of the participants of the networking event collected in registration forms, shall be processed properly and the minimization principle shall apply. Participants have to be informed upfront of the purposes for which their contact details are used (e.g., through the statement "Your contact details are solely processed for the purpose of this workshop and its proceedings"). If the contact details will be used for other purposes (e.g., sending newsletters, or sharing them with others), the principal applicant needs to obtain the participants' consent. No personal data of patients shall be disseminated in the presentations shown in the event. Of additional relevance for the ethics assessment is to determine whether patients are invited to participate in the event and whether the meeting will be conducted in a hybrid mode, with some participants joining online.

5.4 FUNDING DECISION

Funding decisions will be based on the ranking list established by the NEC, the ethics assessment conducted by the EAG, and the available budget in the Networking Support Scheme.

The NSSS will determine the maximum budget for each selected networking event, taking into account the recommendations of the NEC on the requested budget.

If applications receive the same score and the maximum budget for the round is reached, the following prioritization criteria will apply:

- Applications addressing diseases not otherwise covered by higher-ranked ones.
- Applications with more co-applicants from UCs.

The budget per round is approximately € 375.000, with two collection dates per year. The total budget for the NSS over seven years is 3M€. Once the budget is exhausted, no further rounds of the NSS will be organized.

The NSSS will notify the principal applicant of the final evaluation decision via email, including the scientific evaluation summary report and, for selected applications, the ethics assessment report from the EAG.

5.5   REDRESS PROCEDURE

The principal applicant may submit a request for redress **within seven (7) calendar days** of receiving the eligibility result or the final decision of the evaluation procedure. Appeals are permitted if there is a suspected breach of eligibility or evaluation procedures. The redress procedure addresses only procedural aspects and will not call into question the scientific or technical judgement of qualified experts/evaluators. The application outcome email containing the results of the evaluation will include information on the appeals procedure, which is described below.

Admissibility of appeals
For an appeal to be admissible the following conditions must be met:

- The appeal must be submitted by the principal applicant of the application in question.
- Only one appeal per application will be considered for the eligibility procedure and only one appeal per application for the evaluation procedure.
- The appeal must be submitted via email to the ERDERA coordination within the seven (7) calendar days deadline and include:
  - the name of the call (ERDERA NSS);
  - the title and the acronym of the application;
  - a description of the alleged shortcomings of the eligibility or evaluation procedure.

The appeal must clearly demonstrate a procedural irregularity or a factual error. Appeals that fail to meet the above conditions do not relate to the eligibility or the evaluation of a specific application, or express mere disagreement with the evaluation results will not be considered.

Processing of appeals

Upon receipt of an appeal, an acknowledgement of receipt will be sent by the ERDERA coordination within seven (7) calendar days. The acknowledgement will outline the redress procedure and provide an anticipated decision timeline. All appeals received by the seven (7) calendar days deadline will be processed together, and the decision will be communicated to the appellant by the NSSS within seven (7) calendar days after the decision is made.

6 FINANCIAL AND LEGAL ISSUES

6.1 SUBMISSION OF THE TO BE FUNDED APPLICATIONS

The principal applicants of selected applications have to download their application as a PDF from the ERDERA electronic submission platform and upload it onto the electronic submission system of ZonMw, along with answers to additional required questions. Failure to complete this step will result in the application not being funded.

6.2 FUNDING ORDER

For this Networking Support Scheme, ZonMw (one of the funding agencies acting as the Networking Support Scheme Secretariat - NSSS) will send a letter containing the grant decision, obligations and applicable terms and conditions in relation to the execution of the proposed activities. This letter will be sent as an email to the principal applicant.

The principal applicant is solely responsible towards ZonMw for fulfilling all the conditions described in the grant decision letter.

The principal applicant of the selected network will be the contact person for the NSSS. Grants are always awarded in the form of a guarantee budget up to a maximum amount. It is possible to receive up to 50% of the budget indicated in the letter with the grant decision before the networking event. In case a representative of a PAO is the principal applicant it is possible to ask for a guarantee budget of 80% before the networking event.

The final financial settlement by the NSSS takes place after receiving a copy of the report with outcomes of the networking event (PDF of the information on the online monitoring platform of ERDERA that can be downloaded by the principal applicant from the ERDERA NSS online platform) and the financial report with relevant supporting documents (see "Specification of costs after the event", 4.2.1) (electronic invoices, tickets, etc.) within 3 months after the event has taken place.

The principal applicant is accountable for the expenses of the networking event. The principal applicant may choose whether their organization pays for all activities related to the networking event or sends budget for hotel, travel, and/or meeting costs to co-applicants. The costs have to be accounted for in the final financial report. (see "Specification of costs after the event", 4.2.1).

Changes to the composition of the applicants of the Networking Support Scheme or changes in the requested budget are not allowed, unless agreed by the NSSS. The principal applicant shall inform the NSSS of any minor or major changes to the event that might affect its implementation. In case of major changes, an independent expert can be consulted to help with the final decision.

6.3   IRDIRC POLICIES AND GUIDELINES AND IRDIRC RECOGNIZED RESOURCES

The applicants are expected to follow IRDiRC policies and guidelines. For more information see http://www.irdirc.org/.

Outcomes of a networking event may be considered for an application to become an IRDiRC Recognized Resource. IRDiRC Recognized Resources is a quality indicator, based on a specific set of criteria, created to highlight key resources which, if used more broadly, would accelerate the pace of translating discoveries into clinical applications. Any resource compliant with the criteria may apply for the label. For more information see http://www.irdirc.org/research/irdirc-recognized-resources/.

6.4   RESPECT FOR RELEVANT EUROPEAN AND INTERNATIONAL STANDARDS

Submitted applications must comply with relevant European and international standards, including:

- The General Data Protection Regulation (GDPR): the EC Regulation (EC 2016/679) on the protection of natural persons with regard to the processing of personal data and the free movement of such data: https://publications.europa.eu/en/publication-detail/-/publication/3e485e15-11bd-11e6-ba9a-01aa75ed71a1/language-en);
- European Research Council Guidelines on Implementation of Open Access to Scientific Publications and Research Data: referred to in Open access & Data management – Horizon Europe Online Manual (europa.eu).

Ethical and legal requirements:

Ethics is an integral part of research, and ERDERA requires all applications to meet legal and ethical standards at the international, EU, national, and institutional levels. Special attention will be paid to ethical issues such as research involving humans or animals, privacy of data and biomaterials, and informed consent. Only projects that fulfil the legal and ethical international/EU and national and institutional standards will be funded. See also section 5.3.3 Ethics assessment.

7 RESPONSIBILITIES, REPORTING REQUIREMENTS AND DISSEMINATION

Reporting Requirements

- The principal applicants of all funded networking events must submit a report on the outcomes within two months of the event.
- Reports must be in English and completed using a standardized (online) form provided by ERDERA.
- A public lay summary of the outcomes will be published on the ERDERA website.
- All reports will be monitored and assessed by responsible agencies within ERDERA, with monitoring led by CSO-MOH, Israel.
- Information from the reports may be used for dissemination and communication purposes of ERDERA.

The principal applicants may be contacted up to a year after submitting their report by CSO-MOH, to provide updates on further results, such as published papers, the formation of working groups, or applications for (research) grants.

Open Access and Acknowledgement

Applicants must ensure open access (free and online) to all peer-reviewed scientific publications relating to the networking event's results, in accordance with EC regulations.

Applicants must ensure that all outcomes (publications, presentations, etc.) of networking events include a proper acknowledgement of ERDERA and EC funding, including the display of the ERDERA logo when possible.

In addition, unless the EC requests or agrees otherwise or unless it is impossible, any dissemination of results (in any form, including electronic) **must display the EU emblem and include the following text:**

"This project has received funding from the European Union's Horizon Europe research and innovation programme under ERDERA programme GA N° 101156595".

*When displayed alongside another logo, the EU emblem must have appropriate prominence.

For the purposes of the obligations under this section, the applicants may use the EU emblem without first obtaining approval. This does not, however, give it the right to exclusive use. Moreover, the applicants may not inappropriately use the EU emblem or any similar trademark or logo, either by registration or by any other means.

8 CONTACT AND FURTHER INFORMATION

The administrative management of the Networking Support Scheme is handled by the NSSS, comprised of LMT, Lithuania and ZonMw, The Netherlands. The NSSS is responsible for: collecting the applications at each deadline, supporting the NEC and communicating with the principal applicants. ZonMw will be responsible for transferring the budget for the events to the organizations of the selected principal applicants. The principal applicant serves as the primary contact for the NSSS during the application and selection procedure, so they must share relevant information with the co-applicants.

Further information on ERDERA and the Networking Support Scheme is available at the ERDERA website.

9 ANNEXES

ANNEX 1: ELIGIBILITY IN COUNTRIES PARTICIPATING IN ERDERA

Eligible countries. The organization **of the principal applicant** has to be located in the following eligible countries that participate in ERDERA:

COUNTRY	COUNTRY
Austria	Belgium
Bulgaria	Cyprus
Czechia	Denmark
Estonia	Finland
France	Germany
Georgia	Greece
Hungary	Iceland
Ireland	Israel
Italy	Latvia
Lithuania	Luxembourg
Morocco	Norway
Poland	Portugal
Romania	Serbia
Slovakia	Slovenia
Spain	Sweden
Türkiye	The Netherlands

The Networking event may take place in the countries listed in the table above.

List of eligible usually underrepresented countries (UCs): Bulgaria, Cyprus, Czechia, Estonia, Georgia, Greece, Hungary, Iceland, Latvia, Lithuania, Morocco, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, and Türkiye.

The organizations of co-applicants may be located in the countries listed in the table above **AND in Australia, Canada, United Kingdom, and Switzerland** which also take part in ERDERA.

ANNEX 2: ELIGIBILITY OF PATIENT ADVOCACY ORGANIZATION (PAO)

The Patient Advocacy Organizations should fulfil the following criteria to be eligible to receive funding:

Legitimacy:

- Represent diseases that are in the scope of the call according to the information in 4.1 (eligibility and non-eligibility of diseases and topics).
- The organization should be formally established and registered as a not-for-profit organization for more than 1 year in one of the countries involved in ERDERA. See Annex 1 for the countries involved.

Mission/objectives:

- The organization shall have its mission/objectives clearly defined and should agree to have it/them published on ERDERA website.

Activities:

- The organization shall have, as part of its activities, a specific interest in rare diseases or rare cancers which should be documented (e.g., through a report published on the organization website).

Representation:

- The organization shall be representative of rare disease patients or rare cancer patients within
    - o EU Member States
    - o EU/EEA states
    - o ERDERA partner countries next to EU Member States and EU/EEA states

    The list of countries is indicated in the table in Annex 1.

Structure:

- The organization should have governing bodies which include a majority of rare disease patients or their family members OR rare cancer patients or their family members.
- The organization's governing structure should Include a legal financial representative for signing a financial report.

Accountability:

- The organization should have proven activities such as rare disease patient support, rare cancer patient support, advocacy activities, and/or rare disease/rare cancer research.
- Statements and opinions of the organization should reflect the views and opinions of its members and adequate consultation procedures with those members should be in place. In particular, the organization should ensure that the appropriate flow of information is in place to allow dialogue both ways: from and towards its members.
- The organization can demonstrate that its account system is able to trace all costs related to the project and archive these costs for a duration of 5 years after the last payment received from the funder.

Transparency:

- The organization shall be financially independent, particularly from the pharmaceutical industry (max. 49 % of funding from several companies) and disclose to ERDERA its sources of funding both public and private by providing the name of the bodies and their individual financial contribution, both in absolute terms and in terms of the overall percentage of the organization budget. Any relationship with corporate sponsorship should be clear and transparent. This information shall be communicated to ERDERA on an annual basis.
- The organization shall publish on its website the articles of association, sources of funding, and information on their activities.

ANNEX 3: INFORMATION FOR BUDGET ESTIMATION OF NETWORKING EVENT

The principal applicant must justify the costs for the Networking event, ensuring they are reasonable and adhere to the rules of their institution (e.g., if institutional policies require obtaining three quotes for a service, this must be followed).

The Networking Support Scheme does not cover research costs or personnel costs related to preparing the networking event. However, technical support for hybrid events is considered an eligible cost.

The table on the following page provides **indications** for eligible components for face-to-face or hybrid networking events.

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the European Union

Average costs for organization of meetings/workshops		Average costs in Euro (VAT included)	Remarks
Other Goods and services	Meeting room	700	Per day
	Lunch	35	Per person / day
	Dinner	45	Per person / workshop
	Coffee break	9	Per person / break
	Audio/video equipment for a non-hybrid meeting (screen, video projector, etc.)	200	Per day
	Audio/video equipment (screen, video-projector, etc.) for a hybrid meeting	600	Per day
Travel and accommodation	Travel in Europe	600	Round trip
	Travel Israel or Türkiye to Europe	1000	Round trip
	Traveling from US/CA to Europe	2000	Round trip
	Hotel with breakfast	120	Per person/night