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1. Delivering training programmes through the ERNs

1.1. Calls for research workshop topics

In its objective to deliver training programs in the form of workshops, WP17 has continued to conduct calls in year 4. The aim of those calls is to identify the most suitable topics for the organization of research training workshops targeted to the ERNs. Selected research training workshops will have to train ERN researchers and clinicians in ERN relevant innovative training themes. Training themes may include innovative research methodologies, diagnostic research methodologies, interdisciplinary treatment approaches, such as gene therapy and transplantation, etc. Moreover, the workshops are aiming to provide a cross-ERN added value.
The successful applicant receives a financial support to organize a 2-day-workshop.
Two calls for workshop topics were launched in year 4. Table 1 below is summarizing the opening periods of the calls, the number of eligible proposals received, the number of selected applications and the final time point until which the applicants should hold their workshop.

Table 1 Summary of calls for research training in WP17: Workshop topics

	Opening period	Nr. of eligible proposals received	Date Final SEC evaluation	Nr. of selected applications	Last time point to conduct the Workshop/Fellowship
5. Call	23.03. – 25.04.2022	8	09.05.2022	5	18.06.2023
6. Call	01.09.-15. 10.2022	4	17.11.2022	4	31.10.2023

The received proposals are checked for eligibility (persons affiliated to any EJP RD beneficiary institution, ERN-full member or affiliated partner institution) and then evaluated in two steps by the Scientific Evaluation Committee. The first step includes remote evaluation by three members of the SEC and in the second step, the individual evaluations are presented by the three SEC members to the whole committee and a funding decision is made. The selection is based on the following criteria:

- Excellence
- Addressing cross-cutting issues relevant for ERNs
- Multidisciplinary aspects
- Fostering ERN collaboration
- No overlap with other EJP RD training activities

- Impact
- Relevance of the topic for the ERN(s)
- Will the topic induce or enhance collaboration within and between ERNs?
- Benefits the workshop will bring to the RD community

- Implementation

- Appropriate training methodology
- Appropriate venue of the workshop

28 workshop proposals have been selected for funding during the whole EJP-RD project duration.

When informing the selected workshop organizers about the attributed funding, the coordination offices at EKUT and LUMC are providing them with a detailed process description for the organization, containing all the steps going beyond the pure organization and including the reporting and reimbursement of the costs. The individual steps are linked to a responsible person/team who will carry out the work and can either be the workshop organizer, the project managers of the WP17 coordination team or the EJP RD coordination/communication team. Furthermore, the workshop organizer is receiving several templates (e.g. participants' registration form, website content templates, accreditation templates, satisfaction survey, etc.) who should be filled or adapted to the individual workshop. This process allows a uniform treatment of the ERN Workshops. In order to foster the most efficient collaborative work, all the documents are saved in a shared folder on MS Teams, to which all the three above mentioned parties have an access.
The EJP RD communication team is announcing the opening of the workshops through the EJP RD website and is preparing visual materials for communication via social media channels. Furthermore, the coordination offices of WP17 at EKUT and LUMC are disseminating the opening of the workshops through the ERN specific channels, so that all 24 ERNs can include the bespoken training event in their newsletter/events.

1.1.1. Completed workshops

The workshops that have been successfully conducted since the last reporting are summarized in Table 2. Reports of the completed workshops are available in the internal EJP RD database.

Table 2 Information on conducted workshops during reporting period (Including Call 2-6)

	Name Applicant	ERN	Institution	Country	Workshop Title	Date	Nb of on-site attendees	Nb of online attendees
Call 2	Giovanni Mosiello	eUROGEN, ITHACA	CHU Rennes	France	Trans-ERN Working Group for Spina Bifida Training: Workshop for future research on innovative diagnostic and interdisciplinary treatment."	31. 03. & 01. 04. 2022	33	0
	Barbara Jarzab	EndoERN	M. Sklodowska-Curie National Research Institute of Oncology, Gliwice ,	Poland	"Endocrine cancer - a challenge in adults and children"	04.05.2022	31	0
	Smail Hadj-Rabia	ERN SKIN	Hôpital Necker-Enfants Malades, APHP	France	The 8th international conference on Ectodermal dysplasias (ED)"	10.06.2022	no report	
	Cornelis D de Kroon	EURACAN	Leiden University Medical Center	Netherlands	ERN multidisciplinary research workshop on diagnostics and treatment of high grade endometrial cancer"	did not conduct the workshop		
Call 3	Sabrina Sacconi	EURO-NMD	University Hospital Nice	France	Contemporary	4-5. March 2022	52	39

					outcome measures in NeuroMuscular Diseases			
	Justine Bacchetta	BOND	Hospices Civils Lyon, Hôpital Mére- Enfant	France	Translational research workshop on bone impairment in rare diseases	9-10. June 2022	29	16
	Philippe Chevalier	GUARD-HEART	Hospices Civils Lyon	France	Functional studies of genetics variants found in patients with cardiac and neuromuscular diseases	14-15. June 2022	20	NA
	Donato Bonifazi	/	Consorzio per le Valutazioni Biologiche e Farmacologiche, Bari	Italy	Modelling & Simulation: Research Methodologies for Small Populations in Rare Diseases	4-5. July 2022	23	NA
	Pia Vihinen	EURACAN; GENTURIS	FICAN West Cancer Center, Turku University Central Hospital	Finland	Comprehensive gene profiling, molecular tumor board and artificial intelligence in the diagnosis and treatment of patients with rare adult cancers	29-30. September 2022	100	10
	Pascal Johann	PaedCAN	University Hospital Augsburg	Germany	Rhabdoid tumors in clinic and research: From basic biology to the patient bed	8. November 2022	20	0

	Maurizio Scarpa	MetabERN	Azienda Sanitaria Universitaria Friuli Centrale, Udine	Italy	The Blood-Brain Barrier: current research and novel therapeutic crossing approaches	8.-9. June 2023	23	0
Call 4	Isa Houwink	ERN Bloodnet	Leiden University Medical Center, the Netherlands. Dept. Public Health and Primary Care	Netherlands	Blended learning: Workshop how to design and evaluate an e-learning for rare diseases taking hemoglobinopathies as an example	did not conduct the workshop		
	Marielle E. van Gijn	ERN RITA	University Medical Center Groningen	Netherlands	From high throughput sequencing to diagnosis in immune mediated disorders	30-31. May 2022	42	99
	Arvid Irmejs	ERN GENTURIS	Pauls Stradins Clinical University Hospital	Latvia	Psychological, molecular and administration aspects of Hereditary breast and ovarian cancer genetic population screening (HBOC GPS)	27-28 April 2023	37	0
	Carolina Neves	Endo-ERN	Associação Protetora dos Diabéticos de Portugal (APDP)	Portugal	Genetics and precision medicine in rare diseases	18-19 May 2023	22	0

	David Gomez Andres	ERN-RND	Hospital Universitari Vall d'Hebron	Spain	Challenges and barriers for gene therapies in rare neurological disorders: preparing the next generation of clinicians and researchers	29-30 June 2023	44	80
Call 5	Cristina Haas	ERN-SKIN	University Hospital Freiburg	Germany	Epidermolysis bullosa (EB): from genes to translation into therapies	23-24. March 2023	54 (onsite and online)	
	Regina Rodrigo Nicolás	ERN-EYE	CIBER on Rare Diseases, Research Center Principe Felipe, Valencia	Spain	New Therapeutic Approaches for Inherited Retinal Dystrophies (NTAIRD)	27-28. March 2023	45	0
	Marco Vitellaro	GENTURIS; EURACAN	Fondazione IRCCS Istituto Nazionale dei Tumori, Milan	Italy	Desmoid tumors (DTs) in patients with Familial Adenomatous Polyposis (FAP): an interdisciplinary approach	22-23. May 2023	40	0
	Rosanne Smits	eUROGEN	Radboud University Medical Centre, Nijmegen	Netherlands	Psychosocial care for pediatric rare diseases: Common needs in uncommon conditions.	8-9. May 2023	23	0
	Giovanni Mosiello	ERKNet; ITHACA; TRANSPLANT-	Bambino Gesú Pediatric Hospital, Rome	Italy	Trans ERN training workshop on fetal and postnatal multidisciplinary	23-25. June 2023	54	0

		CHILD; eUROGEN;			management and multicentric research in in rare diseases.			
Call 6	Christoph Schramm	RARE-LIVER	University medical center Hamburg-Eppendorf	Germany	Young investigators' workshop for translational research in rare autoimmune liver diseases	25-26. May 2023	38	0
	Tanya Bisseling	GENTURIS	Radboud University Medical Centre, Nijmegen	Netherlands	CDH1 related hereditary diffuse type gastric cancer: optimizing surveillance	12-13 October 2023	37	0
	Wanda Lattanzi	CRANIO; ReCONNET	Fondazione Policlinico Universitario A. Gemelli Rome	Italy	Advances in regenerative medicine and tissue engineering for rare musculo-skeletal diseases	13-14 October 2023	25	0
	Petra de Graaf	eUROGEN	University Medical Center Utrecht	Netherlands	Urogenital Tissue Engineering from bedside to bench and back: What do clinicians need and what has basic science to offer	4-5 September 2023	22	0

1.1.2. Analysis of the quality and impact of the ERN workshops

Table 3: Analysis of the quality and impact of the ERN workshops

Workshop	Rating of the quality of the workshops	Rating of the usefulness of the workshop contents for the participants further reserch/professional activity
Trans-ERN Working Group for Spina Bifida Training: Workshop for future research on innovative diagnostic and interdisciplinary treatment."	50% excellent 38% very good	73% highly useful 23% useful
"Endocrine cancer - a challenge in adults and children"	82% excellent 18% very good	73% highly useful 27% useful
The 8th international conference on Ectodermal dysplasias (ED)"	No information	No information
ERN multidisciplinary research workshop on diagnostics and treatment of high grade endometrial cancer"	not applicable as this workshop didn´t take place	not applicable
Contemporary outcome measures in NeuroMuscular Diseases	No information	97,5% very useful or useful
Translational research workshop on bone impairment in rare diseases	83% excellent 17% good	78% extremely useful 22% useful
Functional studies of genetics variants found in patients with cardiac and neuromuscular diseases	No information	No information
Modelling & Simulation: Research Methodologies for Small Populations in Rare Diseases	68% excellent 32% good	36,4% highly useful 59% useful
Comprehensive gene profiling, molecular tumor board and artificial intelligence in the diagnosis and treatment of patients with rare adult cancers	50% excellent 50% good	42% extremely useful 58% useful
Rhabdoid tumors in clinic and research: From basic biology to the patient bed	100% excellent	50% extremely useful 50% useful
The Blood-Brain Barrier: current research and novel therapeutic crossing approaches	60% excellent 20% good 20% very poor	80% highly useful 20% useful
Blended learning: Workshop how to design and evaluate an e-learning for rare diseases taking hemoglobinopathies as an example	not applicable as this workshop didn´t take place	not applicable
From high throughput sequencing to diagnosis in immune mediated disorders	82% excellent 18% good	65% extremely useful 35% useful
Psychological, molecular and administration aspects of	85% excellent 15% good	95% extremely useful 5% useful

Hereditary breast and ovarian cancer genetic population screening (HBOC GPS)		
Genetics and precision medicine in rare diseases	65% excellent 35% very good	71% extremely useful 29% useful
Challenges and barriers for gene therapies in rare neurological disorders: preparing the next generation of clinicians and researchers	87% excellent 13% good	82% extremely useful 18% useful
Epidermolysis bullosa (EB): from genes to translation into therapies	85% excellent 10% good 5% fairly good	95% excellent 5% good
New Therapeutic Approaches for Inherited Retinal Dystrophies (NTAIRD)	93% excellent 7% good	100% extremely useful
Desmoid tumors (DTs) in patients with Familial Adenomatous Polyposis (FAP): an interdisciplinary approach	89% excellent 11% good	78% extremely useful 22% useful
Psychosocial care for pediatric rare diseases: Common needs in uncommon conditions.	50% excellent 43% good	72% excellent 28% good
Trans ERN training workshop on fetal and postnatal multidisciplinary management and multicentric research in in rare diseases.	89% excellent 12% good	78% extremely useful 22% useful
Young investigators' workshop for translational research in rare autoimmune liver diseases	96% excellent 4% good	100% highly useful
CDH1 related hereditary diffuse type gastric cancer: optimizing surveillance	75% very good 25% good	85% highly useful 15% useful
Advances in regenerative medicine and tissue engineering for rare musculo-skeletal diseases	82% excellent 18% very good	78% highly useful 22% useful
Urogenital Tissue Engineering from bedside to bench and back: What do clinicians need and what has basic science to offer	83% excellent 17% good	67% extremely useful 33% useful

1.1.3. Accreditation of workshops

EACCME (European Accreditation Council for Continuing Medical Education) - an institution of the UEMS has been identified as institutional body for the accreditation of ERN-Workshops.

First, the procedure for applying for accreditation has been well defined and subsequently applications for 3 workshops from Call 3 have been submitted. Among the different training formats EACCME accredits we have chosen the 'Live Educational Events (LEE)' for the accreditation of the ERN workshops. The minimal time required to obtain the review result of the application are 3 months.

The application for each LEE contains questions regarding:

- General information (nr. of participants, speciality, website, language)
- Format and duration of the event
- Detailed programme
- Target audience and internationality of the audience
- Means of monitoring for learners engagement (participants' attendance)
- Means for learners feedback (satisfaction survey)
- Educational needs assessment and list of identified needs
- List of educational outcomes
- Methods used to promote adult active learning during the event
- Source of funding
- Contacts of the scientific and administrative organizers and information about the provider institution
- COI
- Directors's declaration

Applications for accreditation of the following workshops have been submitted and all were positively evaluated:

1. Contemporary outcome measures in NeuroMuscular diseases - LEE22-00038 (10 CME points)
2. Translational research on bone impairment in rare diseases - LEE22-00350 (7 CME points)
3. Comprehensive gene profiling, Molecular Tumor Board and Artificial Intelligence in the diagnosis and treatment of patients with rare adult cancers - LEE22-00632 (11 CME points)

Depending on the duration of the event, the EACCME grants a certificate with certain number of CME (Continuous Medical Education) points per LEE.
Within one month after the end of the event a report needs to be uploaded on the EACCME website which is then reviewed by the correspondent administrator.
In order to evaluate the need and usefulness of the CME points granted for the attendance in an ERN workshop we have queried the opinion of the participants in the workshop "Clinical research – Basics and Beyond" from Call 1 prior to the start of the accreditation procedure. Out of 15 respondents, 1 scored CME point with 'important', 12 scored CME points with 'neutral' and for 2 of them CME points were 'irrelevant'.
In the course of the accreditation procedure, the satisfaction survey of the workshop "Translational research on bone impairment in rare diseases " contained the questions:

- "Do you have any supplementary added value of any kind by the fact you are attending an accredited event?"
- "CME points from UEMS-EACCME are recognized in my country/I can validate them for my personal training account."The results are represented in table 4.

Table 4. Answers from satisfaction survey on accreditation

Q: Do you have any supplementary added value of any kind by the fact you are attending an accredited event?	
14	No
1	This has led to a potential collaboration and grant submission between 3 centres
1	Meeting experts
1	No, but it adds to the value of the event
1	?
Q: CME points from UEMS-EACCME are recognized in my country/I can validate them for my personal training account.	
5	Yes
6	No
1	Probably
1	Don't know
2	NA
1	No interest in my situation as a patient representative
2	Irrelevant responses

The question "How important are CME points for you for this kind of training events?" in the satisfaction survey from the other two accredited workshops delivered low response rate.

However, the feedback obtained prior to the accreditation and the one post accreditation (s. Table 5) show that the CME points are not relevant and driving the attendance at such a workshop. This may be due to the national structure of continuous education, which is not obligatory, to the job assignment of the attendees (research rather than patient care/clinics), or due to the low awareness about European CME points and the procedure of recognition within its own country.

Combined with the time, human resources and financial investment in the accreditation procedure, this pilot procedure argued against continuing the accreditation with further workshops.

1.2. Calls for fellowships for research mobility

By the end of year 3, the 4th Call for research mobility fellowships have been launched. Initially, 16 new fellows were selected. In Q2 and Q4 of year 4 a 5th and 6th call have been launched, respectively. Table 5 is summarizing the opening periods of the calls, the number of eligible proposals received, the number of selected applicants and the number of fellows that retreated from their fellowship for various reasons (e.g. dropping out of the host group, change of job, health problems). For the purpose of completeness, the values of the 3rd call are also listed, as the fellows had until the end of year 4 to complete their research stay abroad.

Table 5 Overview of conducted fellowships WP17 from 2022 onwards

	Opening period	Nr. of eligible proposals received	Date Final SEC evaluation	Nr. of selected applications	Nr. of retreated fellows	Last time point to conduct the Fellowship
3rd Call	15.03.2021 – 26.04.2021	24	01.06.2021	18	2	31.12.2022
4th Call	18.10.2021 – 28.11.2021	19	21.01.2022 & 04.02.2022	16	6	30.09.2023
5th Call	02.05.2022 – 13.06.2022	21	05.07.2022 & 28.07.2022	16	0	30.09.2023
6th Call	03.10.2022 – 13.11.2022	32	07.12.2022 & 15.12.2022	27	2	31.03.2024

In order to improve the entire application and evaluation process, from the 5th call onwards, applicants had to submit the ethics statement with the application, so that the subsequent process could be accelerated by the Advisory Regulatory Ethics Board (AREB). We did not expect any more far-reaching restrictions due to COVID-19, so the fellows only had 12 months to complete their stay abroad. In the 6th call, the significantly increased number of fellows has led to a delay in the ethical assessment, which is why we have given the fellows time until 31.03.2024 to finish their residency. The significant increase in the number of applications is due to the fact that we used all available channels (EJPRD & ERN Websites, Twitter, LinkedIN, Newsletter, conferences and meetings) to increase visibility for what is expected to be the last call for applications.

1.2.1. Completed research mobilities

Out of the 91 fellowships selected for funding over the six calls, 73 have completed their fellowship since 2021, 4 will be finished by end of March 2024 and 14 had to

withdraw from their research stay abroad (Figure 1). Table 6 gives information on funded research mobility fellowships in the reporting period.

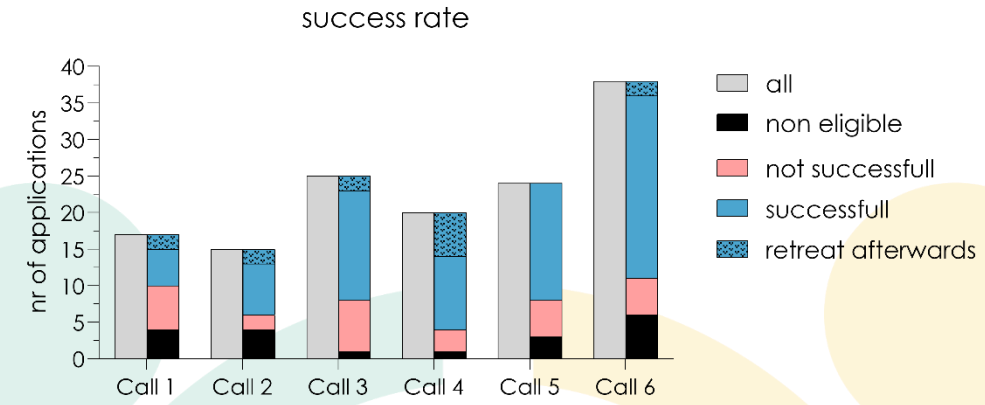

Figure 1 Success rate from all calls for research mobility fellowships

Table 6 Information on conducted fellowships during reporting period (Including Call 3-6)

Call	Name	ERN	Home institution	Host institution	Project title	Initial timing	Actual dates	status
Call 3	Francesco Missale	non-ERN (home), EUROCAN (host)	University of Brescia, Italy	Netherlands Cancer Institute – Antoni van Leeuwenhoek, Amsterdam, the Netherlands	Salivary gland tumours management and external validation of novel N category staging systems for malignant major salivary gland tumours	5 mo	09.12.2021 – 30.04.2022	finished
	Rebecca Pulvirenti	ERNICA	University Hospital of Padua, Italy	Erasmus Medical Centre – Sophia Children's Hospital, Rotterdam, the Netherlands	Towards a blueprint for transitional care in patients with congenital anatomical anomalies (CAA)	6 mo	01.09.2021 – 28.02.2022	finished
	Oana-Ofelia Dănilă	non-ERN (home), endo-ERN (host)	Carol Davila University of Medicine and Pharmacy Bu-charest, Romania	Leiden University Medical Centre, the Netherlands	The influence of Growth Hormone excess secretion on the evolution of Fibrous Dysplasia in patients	6 mo	16.08.2021 – 15.02.2022	finished
	Beste Ozsezen	LUNG	Hacettepe University School of Medicine Ankara, Turkey	Anna Meyer Paediatric University Hospital, Florence, Italy	Lung function in a cohort of teenagers born very preterm	6 mo	17.09.2022 – 15.12.2022	finished
	Eszter Lévai	ERKNet	Semmelweis University, Budapest, Hungary	Heidelberg University Hospital, Germany	The role of PARK7 in mesothelial and vascular endothelial barrier integrity and function in peritoneal dialysis	6 mo	01.10.2021 – 31.03.2022	finished
	Dmitrijs Rots	ITHACA (home), non-ERN (host)	Radboud University, Nijmegen, the Netherlands	Manchester University Hospitals NHS Trust, UK	Role of non-Mendelian genetics in Mendelian neurodevelopmental disorders	3 mo	01.11.2021 – 30.01.2022	finished

	Jeroen Kerstens	EURO-NMD (home), RITA (host)	University Hospital Antwerps, Belgium	Erasmus MC University Medical Center, Rotterdam, the Netherlands	Neuronal autoantibodies in patients with unexplained ataxia and/or parkinsonism	6 mo	18.01.2022 – 29.07.2022	finished
	Ana Filipa Duarte	CRANIO	Erasmus MC University Medical Center, Rotterdam, the Netherlands	King's College of London, UK	The FUZ gene in craniosynostosis: from a mouse knock-out model to understanding its contribution in human suture closure	6 mo	10.01.2022 – 07.08.2022	finished
	Elke de Boer	ITHACA	Radboud University, Nijmegen, the Netherlands	University of Burgundy, Dijon, France	Integrative analysis of NGS and transcriptome data to elucidate the genetic etiology of unexplained cases of ERN ITHACA	2 mo	24.09.2022 – 08.10.2022	finished
	Annalisa Allegorico	LUNG	Bambino Gesù Children's Hospital in Rome, Italy	University Hospital Münster, Germany	Immunofluorescence Technique to learn and spread knowledge in Italy	3 mo	28.08.2022 – 09.09.2022 & 26.11.2022 – 09.12.2022	finished
	Josias Bastian Grogg	non-ERN (home), eUROGEN (host)	The Christie NHS Foundation Trust, Manchester, UK	University Hospital Hamburg-Eppendorf, Germany & University Hospital Centre Zagreb, Croatia & Antoni van Leeuwenhoek Hospital Amsterdam, the Netherlands	The OprhAn-Testis-Histology Registry (OATH)	3 mo		cancelled
	Marija Miletić	eUROGEN	University Hospital Centre Sestre milosrdnice, Croatia	UZ Leuven, Belgium	Treatment patterns and real-world evidence for patients with penile cancer in specialized healthcare providers within ERN eUROGEN	3 mo	07.02.2022 – 30.04.2022	finished

	Giada de Lazzari	ERNICA (home), non-ERN (host)	University of Padua, Italy	INSERM, Institut national de la santé et de la recherche médicale, Toulouse, France	Patient-derived intestinal 3D model for studying rare disorders: the Tricho-Enteric Syndrome paradigm (TH3S)	6 mo	01.09.2021 – 28.02.2022	finished
	Eva Coop-mans	Endo-ERN (home), non-ERN (host)	Leiden University Medical Center, the Netherlands	Barts Cancer Institute London and The William Harvey Research Institute (WHRI), UK	GH-secreting pituitary tumours: nip therapy resistance in the bud (pilot-study)	6 mo		cancelled
	Benjamin Chaigne	reCONNET (home), RITA (host)	Centre de Référence Maladies Auto-immunes et Maladies Sytémiques Rares, Paris, France	Royal Free Hospital Campus – University College of London, UK	Integrated proteomic analysis of blood B cells and skin fibroblasts in systemic sclerosis: toward proteomic B/F signatures of SSc patients	6 mo	16.01.2022 – 16.07.2022	finished
Call 4	Aleksandre Tavadze	RITA	Medical Center Mrcheveli, Tiflis, Georgia	Instituto di Ricovero e Cura a Carattere scentifico Gaslini, Italy	The regulation of innate immunity and the pathogenesis or rare autoinflammatory diseases.	3 mo	01.04.2023 – 30.07.2023	finished
	Karin Wallander	GENTURIS	Karolinska Institutet, Stockholm, Sweden	Hospital Clínic, IDIBAPS, Barcelona, Spain	Translational study of the genetic cause for serrated polyposis syndrome and colorectal cancer.	6 mo	01.01.2023 – 30.06.2023	finished
	Stephanie Efthymiou	RND (home), endo-ERN (host)	UCL Institute of Neurology, London, UK	LUMC, Faculty of Medicine, Human Genetics, Leiden, the Netherlands	Improving our understanding of the global genetic architecture and phenotype of FSHD.	1 mo	01.05.2022 – 01.06.2022	finished
	Stefania Drovandi	ERKNet	Giannina Gaslini Institute, Genova, Italy	Heidelberg University Hospital, Paediatric Nephrology, Germany	Reverse phenotyping in steroid-resistant nephrotic syndrome.	6 mo		cancelled

	Valeria Aiello	ERKNet	IRCCS – Azienda Ospedaliero Universitaria di Bologna, University of Bologny, Italy	Hôpital Universitaire Necker, APHP.Centre, Université de Paris, France	Alport Syndrome: study of genetic, immunological and clinical factors related to post transplant outcomes	3 mo		cancelled
	Elad Shemesh	non-ERN (home), endo-ERN (host)	Carmel medical centre, Israel	Amsterdam UMC, Experimental Vascular Medicine, the Netherlands	Gut microbiome and derived metabolites in inherited metabolic disorders: Potential for bridging the genotype-phenotype gap	6 mo		cancelled
	Sarah Shalaby	RARE-LIVER	Department of Surgery, Oncology and Gastroenterology, Padua-University Hospital, Italy	Hepatic Hemodynamic and Liver Unit, Hospital Clinic, Barcelona, Spain	Portal and systemic inflammatory and endothelial dysfunction patterns in patients with portosynusoidal vascular disorder.	6 mo	01.03.2023 – 31.08.2023	finished
	Vesna Miladinovic	EUROCAN (home), non-ERN (host)	Leiden University Medical Centre, the Netherlands	Institute of Cancer Research, Royal Centre Hospital, London, UK	Quantitative functional MR imaging and correlation with pathology	3 mo	15.08.2022 – 15.11.2022	finished
	Cristian Ruiz Moreno	ERN PaedCan	Prinses Máxima Centrum, Utrecht, Netherlands	Helmholtz Munich, Germany	Developing deep learning methods for integration of single-cell multi-omics and spatially resolved datasets in diffuse midline gliomas.	3 mo	01.04.2023 – 30.06.2023	finished
	Maartje Meier	BOND (home), Endo-ERN (host)	Leiden University Medical Centre, the Netherlands	Aarhus University Hospital, Denmark	Epidemiology of fibrous dysplasia/McCune Al-bright syndrome (FD/MAS) in Denmark – a national registry-based study	4 mo	15.07.2022 – 30.09.2022	finished
	Ana Rita Matos	GENTURIS (home),	I3s - Institute for Research and Innovation in	Centre Léon Bérard, Lyon, France	The primary genetic cause and beyond: the life-time risk and	1 mo	01.02.2023 – 28.02.2023	finished

		non-ERN (host)	Health, Porto, Portugal		phenotype modifiers in HDGC.			
	Jane Murphy	GUARD-HEART	University College Dublin/Mater Misericordiae University Hospital, Ireland	Amsterdam University Medical Centres, the Netherlands	Clinical interpretation of cardiac gene variants identified in inherited cardiac condition patients from the Republic of Ireland	2 mo	02.05.2022 – 27.06.2022	finished
	Alberto Cossu	EpiCARE	Università degli Studi di Verona, AOUI, Italy	Filadelfia Epilepsy Hospitalet, Dianalund, Denmark	Application of Quantitative EEG analysis on data from children affected by Encephalopathy related to Status Epilepticus during Sleep	6 mo		cancelled
	Clarisse Sorato	non-ERN (home), EpiCARE (host)	Robert-Debré University Hospital, Paris, France	Royal Hospital for Children, Queen Elizabeth University Hospitals Glasgow, UK	Ring 20 Natural History and Biomarker Study.	3 mo		cancelled
	Eva Vrščaj	EURO-NMD (home), MetabERN (host)	Ljubljana University Medical Centre, Slovenia	University of Liège (CHU Liege), Belgium	Continuous movement monitoring in Duchenne Muscular Dystrophy.	4 mo	01.09.2022 – 31.12.2022	finished
	Safa Najidh	EuroBlood Net (home), non-ERN (host)	Leiden University Medical Centre, the Netherlands	Cancer Research Centre IBMCC, Salamanca, Spain	Design, development, and application of advanced multicolour flow cytometry in Cutaneous T-cell Lymphoma.	3 mo		cancelled
Call 5	Silvana Lobo	GENTU-RIS (home), non-ERN (host)	I3s - Institute for Research and Innovation in Health, Porto, Portugal	Hôpitaux de Paris and Sorbonne University, Paris, France	CTNNA1 in Hereditary Diffuse Gastric Cancer: unveiling 2nd hit mechanisms and somatic alterations.	3 mo	04.01.2023 – 03.04.2023	finished

	Andreea Cristian Bojoga	non-ERN (home), endo-ERN (host)	National Institute of Endocrinology, Bucharest, Romania	Radboud university medical centre, Nijmegen, Netherlands	Assessment of Pentraxin 3 as a potential novel prognostic marker in differentiated thyroid carcinoma.	3 mo	01.06.2023 – 03.08.2023	finished
	Tilde Kristensen	ERKNet	Aarhus University Hospital, Aarhus, Denmark	Radboud university medical centre, Nijmegen, Netherlands	Retrospective study on relapse treatment strategies in adult minimal change nephropathy.	3 mo	01.10.2022 – 16.12.2022	finished
	Isaac Maxi-miliano Bugueno	ERN CRANIO	Reference Centre for Rare Oral and Dental Diseases University Hospitals of Strasbourg, France	Radboud university medical centre, Nijmegen, Netherlands	To better understand and compare the clinical and research course of patients with rare diseases within the ERN orodental expert centres.	1.5 mo		finished
	Consiglia Longobardi	ERKNet (home), reCONNET (host)	University of Campania "Luigi Vanvitelli", Napoli, Italy	Ghent University Hospital, Belgium	Uremic toxins in severe combined immunodeficiency due to adenosine deaminase deficiency (ADA-SCID): the role of gut-kidney axis	3 mo	21.09.2022 – 20.12.2022	finished
	Anna-chiara Pastore	ERKNET (home), endo-ERN (host)	University of Campania "Luigi Vanvitelli", Napoli, Italy	RWTH Aachen University, Germany	Evaluation of variation in single-cell transcriptome of renal cortex following GLUT2 deletion.	6 mo	13.10.2022 – 12.04.2023	finished
	Ana Daniela de Oliveira e Silva	ITHACA (home), non-ERN (host)	Hospital Pediátrico de Coimbra, Portugal	Guy's and St Thomas' NHS Foundation Trust, London, UK	Clinical and molecular characterisation of BAF complex-related genetic syndromes.	6 mo	01.04.2023 – 30.09.2023	finished
	Carla Gaggiano	RITA	University of Siena and Azienda Ospedaliero, Italy	University Children's Hospital – University Medical Centre of Ljubljana, Slovenia	Systemic autoinflammatory manifestations in children with juvenile spondylarthrosis	3 mo	01.10.2022 – 31.12.2022	finished

	Guilia Mottadelli	ERNICA (home), non-ERN (host)	The Children Hospital, Alessandria, Italy	UCL Great Ormond Street Institute of Child Health, London, UK	The potential of Stem Cells in Intestinal Dysmotility and Intestinal Failure.	6 mo	01.04.2023 – 30.08.2023	finished
	Jonas Mellgren	CRANIO (home), non-ERN (host)	University of Gothenburg, Sweden	University College London, UK	Biomechanical Analyses and Simulations of Treatments of Unicoronal Craniosynostosis.	3 mo	08.04.2023 – 02.07.2023	finished
	Nora Pető	EpiCARE	National Institute of Mental Health, Neurology and Neurosurgery, Budapest, Hungary	University Hospital Freiburg, Germany	Epilepsy and Arousal Disorders	6 mo	05.04.2023 – 29.09.2023	finished
	Pinelopi Arvaniti	RARE-LIVER	University Hospital of Larissa, Greece	Hospital Clinic of Barcelona, Spain	Non-alcoholic fatty liver disease (NAFLD) in auto-immune hepatitis (AIH): how does metabolic liver injury affect immune response and disease progression?	6 mo	01.02.2023 – 31.07.2023	finished
	Hanna Lif	CRANIO	Uppsala Craniofacial centre, Uppsala, Sweden	Hôpital Necker, Craniofacial centre of Paris, France	Correlation between the skull base and orbit in unicoronal cranio-synostosis treated with fronto-orbital advancement.	6 mo	02.10.2022 – 06.11.2022& 15.01.2023 – 04.05.2023	finished
	Dominika Borselle	ERNICA (home), non-ERN (host)	Wroclaw Medical University and Hospital, Poland	UCL Great Ormond Street Institute of Child Health, London, UK	Regenerative medicine in the treatment of congenital long-gap oesophageal atresia.	3 mo	24.11.2022 – 04.02.2023	finished
	Eva Erzar	EURACAN (home), non-ERN (host)	Institute of Oncology Ljubljana, Slovenia	Institute of Medical Genetics and Pathology, University	In depth analysis of mature T-cell lymphomas from Slovenia: the	3 mo	01.10.2022 – 20.12.2022	finished

				Hospital Basel, Switzerland	Ljubljana-Basel T-cell lymphoma project.			
	Kirsten Nowlan	RITA (home), non-ERN (host)	HUS diagnostic centre/University of Helsinki, Finland	The Francis Crick Institute, London, UK	The role of inflammatory triggers in the manifestation of thymic abnormalities that lead to autoimmunity.	6 mo	01.02.2023 – 31.07.2023	finished
Call 6	Ilse Luyckx	VASCERN (home), non-ERN (host)	Antwerp University Hospital, Edegem, Belgium	LUMC, Anatomy & Embryology, Leiden, The Netherlands	In-depth characterisation of mice lacking SMAD6 expression using an immunohistological approach.	1.5 mo	01.03.2023 – 12.04.2023	finished
	Maria Giovanna Ruggiu	EpiCARE	Universita di Verona, UOC Neuropsichiatri a infantile, Italy	Hôpital Necker Paris, Service de Neuropédiatrie, France	Impact of early introduction of Ketogenic diet in patients with Epilepsy with myoclonic-atonic seizures (EMAS).	6 mo	01.03.2023 – 05.07.2023	finished
	Julie Bernardor	non-ERN (home), ERKNet (host)	University Hospital of Nice, Paediatric Nephrology Unit, France	University Hospital Heidelberg, Centre for Paediatric and Adolescent Medicine, Germany	Comprehensive molecular and functional understanding of early vascular calcifications in children with chronic kidney disease – building up an international paediatric CKD vascular disease research network.	3 mo	01.06.2023 – 31.08.2023	finished
	Ewa Sieliwon-czyk	GUARD-HEART (home), non-ERN (host)	Antwerp University Hospital, Edegem, Belgium	Imperial College London, Faculty of Medicine, National Heart & Lung Institute, UK	Exploration of novel electrocardiographic markers and genetic drivers of electrical dysfunction in dilated cardiomyopathy.	6 mo	01.04.2023 – 30.09.2023	finished
	Helena Pernice	EURO-NMD (home),	Charité Berlin, Department of	National Hospital for Neurology and Neurosurgery and	The genetics of complex Charcot-Marie-Tooth	6 mo	06.03.2023 – 30.08.2023	finished

		non-ERN (host)	Neurology, Germany	UCL Queen Square, London, UK	disease and inflammatory neuropathies.			
	Felix Kleefeld	EURO-NMD (home), non-ERN (host)	Charité Berlin, Department of Neurology, Germany	University of Cambridge, Dep. of Clinical Neurosciences, UK	The chicken or the egg: deciphering mitochon-drial pathology in inclusion body myositis spectrum disease (IBM-SD).	4 mo	23.01.2023 – 22.05.2023	finished
	Syna Miri	Euro-BloodNet	IRCCS Ca'Granda Foundation, Maggiore Policlinico Hospital of Milan, Italy	Leiden University Medical Centre, Dep. of Clinical Epidemiology, The Netherlands	Inhibitor development upon switch from plasma-derived to recombinant factor VIII in Previously Un-treated Patients with severe haemophilia A: the PUP-SWITCH study.	4 mo	28.09.2023 – 22.12.2023& 25.03.2024 – 31.03.2024	ongoing
	Marius Wits	BOND (home), non-ERN (host)	LUMC, Cell and Chemical Biology, Leiden, The Netherlands	University of Barcelona, Facultat de Medicina, Spain	Therapeutic Targeting of the Activator Protein 1 complex in Fibrodysplasia Ossificans Progressiva.	4 mo	30.08.2023 – 20.12.2023	finished
	Elisabetta Indelicato	RND (home), non-ERN (host)	Medical University of Innsbruck, Department of Neurology, Austria	TU Munich, Germany	A Multiomics Approach to unsolved Rare Movement Disorders.	6 mo	08.05.2023 – 31.10.2023	finished
	Kaisa Oja	ITHACA (home), non-ERN (host)	Tartu University Hospital, Institute of Clinical Medicine	TU Munich, Institute of Human Genetics, Germany	Improving diagnostic efficacy of rare diseases using multi-omics approach.	2 mo	05.03.2023 – 29.04.2023	finished
	Matthias de Wachter	RND (home), EpiCARE (host	Antwerp University Hospital, Paediatric Neurology, Edegem, Belgium	Danish Epilepsy Centre, Filadelfia, Dianalund, Denmark	Phenotype-genotype correlation in RORA-related neurodevelopmental disorders.	4 mo	02.10.2023 – 01.03.2024	ongoing
	Jeanesse Scerri	GUARD-HEART	Mater Dei Hospital, Malta	Amsterdam UMC, Department of Exp. Cardiology, The Netherlands	Cardiogenetics: Bridging the Gap.	1 mo	01.06.2023 – 30.06.2023	finished

	Valentina Di Micco	EpiCARE	Ospedale Padiatrico Bambino Gesù, Neuroscience Department, Rome, Italy	Danish Epilepsy Centre Filadelfia, Clinical Neuro-physiology, Dianalund, Denmark	Predicting epilepsy surgery outcome.	6 mo	Since 30.09.2023	ongoing
	Aleksan-dra Vujović	ERKNet	University Medical Centre Ljubljana, Paediatric Nephrology, Slovenia	University Hospital Heidelberg, Centre for Paediatric and Adolescent Medicine, Germany	Is antimicrobial prophylaxis required in addition to meningococcal vaccination in patients receiving complement inhibitors?	6 mo	01.04.2023 – 30.09.2023	finished
	Elisa Vegezzi	EpiCARE (home), non-ERN (host)	IRCCS Mondino Foundation, Neuro-oncology & Neuro-inflammation, Pavia, Italy	UCL Queen Square Institute of Neurology, London, UK	Genetic modifiers in hereditary ATTR amyloidosis.	6 mo	26.02.2023 – 03.09.2023	finished
	Karolina Tokarska	non-ERN (home), ERNICA (host)	University Children's Hospital in Cracow, Poland	Erasmus University Medical Centre, Dep. of Paediatric Surgery, Rotterdam, The Netherlands	The long-term consequences of repair operations for selected congenital malformations of the gastrointestinal tract in the aspect of transition to adult healthcare.	1 mo		cancelled
	Clarissa Becher	LUNG (home), non-ERN (host)	LUMC, Cell and Chemical Biology, The Netherlands	Technical Chemistry at the Vienna University of Technology TUW, Austria	Regulation of Activin signalling by shear stress in pulmonary arterial hypertension.	6 mo	11.06.2023 – 12.12.2023	finished

	Gizem Onder Sentürk	non-ERN (home), ITHACA (host)	University of Acıbadem Mehmet Ali Aydınlar, Dep. of Medical Genetics, Turkey	Karolinska Institutet, Dep. of Molecular Medicine and Surgery, Stockholm, Sweden	Investigation of predisposition to leukaemia and lymphoma.	3 mo	01.03.2023 – 30.05.2023	finished
	Martinica Garofalo	RND (home), non-ERN (host)	University Medical Centre Groningen (UMCG), Neurology, The Netherlands	IRCCS Fondazione Stella Maris, Developmental Neuroscience, Pisa, Italy	Are specific features of abnormal fidgety movements predictive for the develop-mental outcome? Retrospective qualitative assessment of early motor repertoire in school age children with cerebral palsy, neurodevelopmental disorders, or normal motor patterns.	3 mo	01.09.2023 – 30.11.2023	finished
	Hüseyin Örün	non-ERN (home), PaedCan (host)	Başkent University, Faculty of Medicine, Ankara, Turkey	IRCCS Instituto Giannina Gaslini, Paediatric Hematology and Oncology, Genova, Italy	Late mortality and causes of death among >5year survivors after bone tumour during childhood, diagnosed in the period 1960-1999 and registered in the Italian Off-Therapy Registry.	6 mo	19.06.2023 – 17.12.2023	finished
	Alexander Janssen	Euro-BloodNet (home), non-ERN (host)	Amsterdam University Medical Centre, Department of Pharmacy and Clinical Pharmacology, Netherlands	University of Cambridge, Dep. of Applied Mathematics and Theoretical Physics, UK	Personalising treatment for persons with haemophilia A based on bleeding risk using advanced machine learning based methods.	4 mo	n/a	ongoing

	Daniel López Domínguez	non-ERN (home), RND (host)	Josep Trueta University Hospital, Neurology, Girona, Spain	Sorbonne University, Paris Brain Institute, Salpêtrière Hospital, France	Neurofilament light chain as a biomarker for Spinocerebellar ataxias. Study of its correlations with motor, cognitive, and radio-logical parameters.	3 mo	01.09.2023 – 01.12.2023	finished
	Filippo Maria Panfili	GENTURIS	Ospedale Padiatrico Bambino Gesù, Neuroscience Department, Rome, Italy	Erasmus University Medical Centre, Dep. of General Paediatrics, Rotterdam, Netherlands	Follow up and clinical evolution of Plexiform Neurofibromas in NF1 paediatric patients treated with Selumetinib	3 mo	21.05.2023 – 20.07.2023	finished
	Viola D'Ambrosio	ERKNet (home), non-ERN (host)	Università Cattolica del Sacro Cuore di Roma, Italy	UCL, Department of Renal Medicine, London, UK	The role of oxalate in patients affected by End-Stage Kidney Disease.	6 mo	11.05.2023 – 19.10.2023	finished
	Barbora Piskláková	non-ERN (home), MetabERN (host)	University Hospital and Palacky University Olomouc, Czech Republic	Oslo University Hospital, Department of Medical Biochemistry, Norway	Study of the pathobiochemistry of selected inherited metabolic disorders by metabolomics	3 mo	04.03.2023 – 07.06.2023	finished
	Aleksandra Skibiak	ERKNet (home), non-ERN (host)	Medical University Gdansk, Dep. of Paediatrics, Nephrology and Hypertension	Newcastle University, National Renal Complement Therapeutics Centre	Genetic back-ground of atypical Haemolytic-Uremic Syndrome in a national cohort from East Europe - classification of variants of unknown significance.	4 mo		cancelled
	Romy Bouw-meester	ERKNet (home), non-ERN (host)	Radboud University Medical Centre, Nijmegen, the Netherlands	Newcastle University / Newcastle upon Tyne Hospitals NHS Foundation Trust, UK	A unique data registry collaboration; improving the clinical, genetic and biochemical characteri-sation of European aHUS patients	3 mo	n/a	ongoing

In total, the fellows came from 26 different countries. Figure 2A highlights the distribution of the fellows from the EU core countries (Belgium, France, Italy, Germany, Luxembourg, the Netherlands, Denmark, Ireland, Greece, Portugal, Spain, Austria, Finland and Sweden), EU expanded countries (Czech Republic, Estonia, Latvia, Lithuania, Hungary, Poland, Slovakia, Slovenia, Bulgaria, Romania, Croatia, Malta, Cyprus) and EJP beneficiaries (United Kingdom, Georgia, Israel, Turkey, Switzerland, Norway). Italy and the Netherlands were the countries that sent the most fellows abroad, with 16 and 12 fellows respectively.

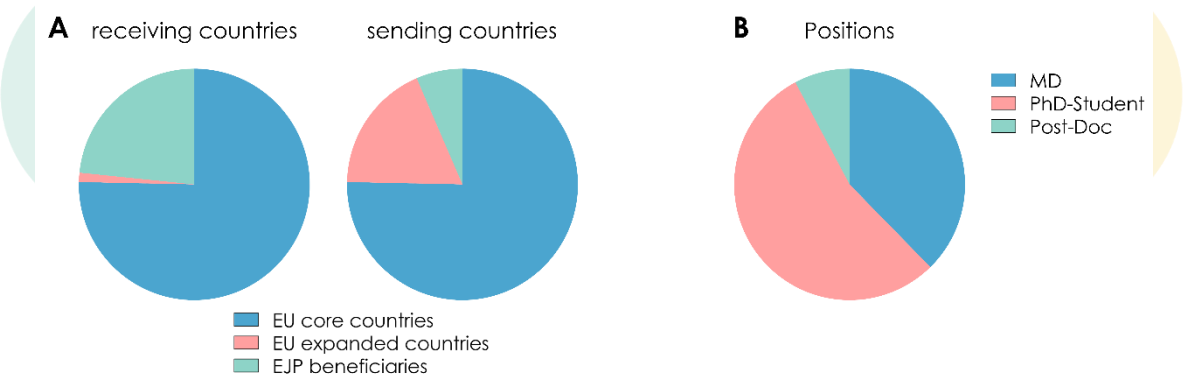

Figure 2 (A) Distribution of fellows from EU core and expanded countries and EJP beneficiaries. (B) Positions of the fellows.

The Netherlands and UK received the most fellows with 16 each and Germany with 15. Most of the fellows were PhD students (Figure 2B). Of the 24 ERNs, 23 ERNs were able to accept and/or send fellows (Figure 3). Unfortunately, there were no successful applications from the TRANSPLANT-CHILD ERN. With the later calls, more use was made of the fact that only either host or home institute must be an ERN. There were also some inter-ERN research stays (especially with BOND, ERKNet, EURO-NMD, reCONNET, RND, endo-ERN, EpiCARE, MetabERN and RITA), which emphasises the interdisciplinarity.

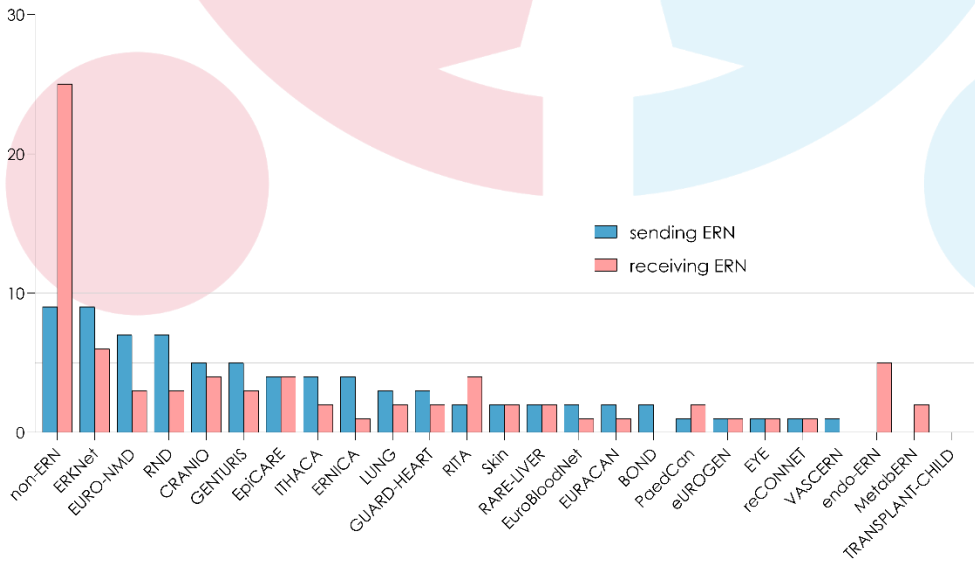

Figure 3 Overview of sending and receiving ERNs.

1.2.2. Summary of exploitable results

1.2.2.1. General feedback

To date 53 fellows completed the post-fellowship survey in which we asked them about their satisfaction after their stay abroad. All of them were very (7/8) to extremely (10) satisfied (Figure 4A) and were able to achieve most of their goals. They rated the quality of their stays as very good or excellent (Figure 4B).

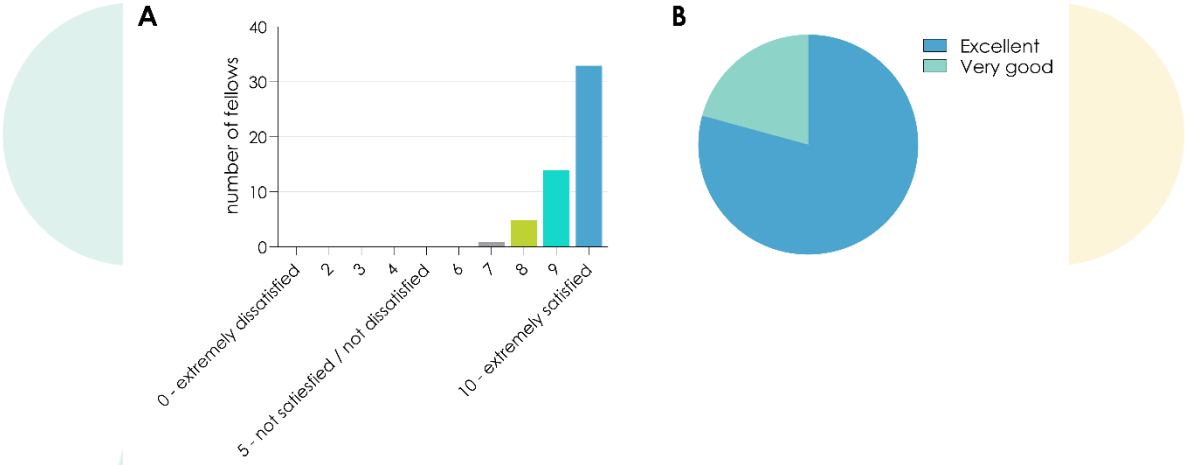

Figure 4 Fellowship experience and rating of quality

52 of the fellows stated that the guidance provided by their supervisor met their expectations. One fellow stated that she had no experience working in a laboratory or doing basic research and thus felt on her/his own for most time of her/his experience. The project didn't seem to be a priority to the supervisors.
The question "How useful is the exchange for your daily work and career?" was answered by 5 with "somewhat useful" and 48 with "very useful". Table 7 lists selectedstatements on the impact of the stay for the future research.

Table 7 Impact of research stay for future research

My research mobility fellowship stay from every aspect had a great positive impact on my future research, as learning variable new methods widened my methodical repertoire and will be extremely useful by planning my further experiments and projects and learning by highly established researchers of my field shaped my scientific thinking and view highly. I am sure this stay has had a trajectory-altering effect on my future research projects and career.
This project allowed me to understand better this disease, but also to see different manifestations of the disease due to high number of patients treated in this centre. In this regard, new questions arise over diagnosis and treatment of these patients.
Thanks to my stay, I am now able to start clinical projects on my own and possibly bring the experience to my home institution. Additionally, I am now focusing on long-term follow-up for patients with congenital diaphragmatic hernia and will continue my research in the field.

My cohort of patients is very large due to the possibility of collaborating with the host institution. We have planned to continue the collaboration in the future, which is of great value for me and my project.
The work developed during the fellowship has allowed us to centralize tumour samples from many European CTNNA1 germline variant carriers, which are very rare in a disease that is very aggressive. Thus, the knowledge generated from the results of the fellowship will pe pivotal to improve clinical management of CTNNA1 germline variant carriers. Furthermore, with the results obtained from this fellowship exchange we are planning to publish an original manuscript until the end of the year (2023)
This knowledge holds tremendous value for me, particularly if I choose to pursue a career in specialized diagnostics or research within the field of oncology or any other domain that extensively utilizes NGS technology in their daily practice. The proficiency I have gained through this fellowship equips me with a strong foundation to excel in these areas, opening doors to exciting opportunities and enabling me to contribute significantly to advancements in molecular diagnostics and scientific research.
This opportunity has greatly enhanced the paediatric rheumatology expertise at our centre (Slovenia) and provided us with valuable international connections.
This research fellowship has expanded both my knowledge ad my horizons. I have changed many things in my daily clinical practice, I have new ideas for research protocols that can be carried out at my home institution, and I have much more experience in analysing and presenting clinical and scientific data and results.
This experience has not only expanded my professional network but has also exposed me to different research methodologies and perspectives, enriching my understanding and approach to scientific inquiries. Observing the entirety and dynamics of a functional research facility was particularly fascinating. Witnessing the mentoring of young researchers and the interactions among scientists provided an invaluable source of inspiration. This comprehensive view of how a research environment thrives – through collaboration, mentorship, and the sharing of ideas – is something I hope to replicate and apply in Romania.

In the survey the fellows were asked whether the fellowship will be of profit for the host and home institution and whether the ERN as a whole will benefit from the exchange (Figure 5). The one response of "no" resulted from a misunderstanding of

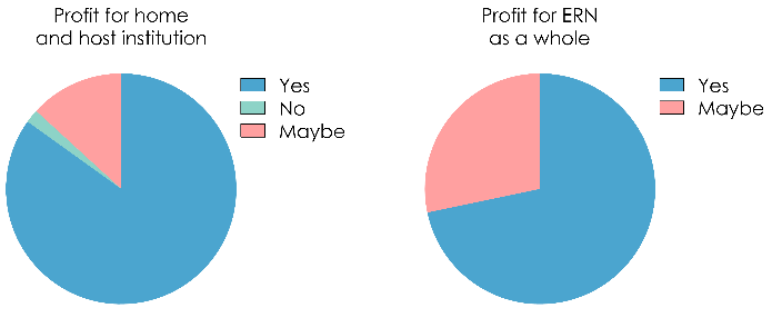

Figure 5 Expected profit for home and host institution and ERN as a whole.

the question and referred to the fact that neither the host nor the home institution received money from EJP RD.
Table 8 contains selected statements about whether there was anything else they would like to say about their experience of the exchange.

Table 8 Other remarks on the experience with the exchange

I would like to deeply thank the ERN for this opportunity and my supervisors and colleagues for giving me this opportunity of a lifetime to learn and gain so much both scientifically and on a personal level. (…) I gladly help with anything I can in this program, so more and more people can get this opportunity to improve and learn so much about various fields and methods of scientific research! Thank you!
It really is an amazing opportunity that besides learning new techniques, strengthens the band between researchers and fuels scientific discussions.
I am sincerely grateful for such a great opportunity. I have learned a lot, saw a lot of new therapeutic possibilities. The difference in the therapeutic possibilities in Croatia and Belgium is really huge. At the same time, I am happy because their patients have many great and new therapeutic options, but also sad because the situation in my country is so different.
I personally believe that sharing knowledge and expertise between centres is key to scientific and healthcare evolution. This research grant is the perfect opportunity to learn from one another and set the basis for further collaboration.
A great experience! I highly recommend this clinical and human experience.
I would like to thank again for ERN for this unique opportunity. It has been a very useful experience for me. It is very hard to fund ourselves wo are living in developing countries. I would never have a chance to learn lung function tests from a competent doctor if it wasn't for ERN.

Everything was perfect. The only thing I would consider for myself is that three months is too short period to be fully involved in a research project.
Certainly, I believe it's valuable to explore different perspectives ad insights, especially in the context of rare diseases. Sharing clinical cases fosters a richer understanding and enables collaborative problem-solving. This exchange has underscored the importance of cross-border cooperation in advancing our knowledge and expertise in the field.
Throughout the entire fellowship, I received close mentorship from both clinical and scientific perspectives. (…) The entire department staff was friendly and spoke English on a daily basis when I was present (sometimes even during interdepartmental rounds). They always made an effort to translate key concepts from patient consultations whenever families spoke in Slovenian. The Slovenian healthcare system has an efficient integrated software system for managing electronic medical records, laboratory data, and imaging, which made my work easier than expected. I was made to feel an integral part of the medical staff and was consistently engaged in clinical discussions and decision-making processes, making this fellowship a challenging and inspiring experience.
(…) Networking opportunities have opened up potential future collaborations, and living in a different country has fostered personal resilience, independence, and cultural appreciation. This experience has not only reinforced my passion for research but also underscored the critical role of international collaboration in advancing science and thus improving patient care. Thank you for this opportunity!