EJP RD

European Joint Programme on Rare Diseases

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Draft Content of the Online Academic Course

Organisation name of lead beneficiary for this deliverable:

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Goal & objectives

Most of the currently available online trainings and courses have so far either been focusing on a rare disease, a group of rare diseases (RD), a specific technology or developed for a national or very specific audience. The overall objective of the EJP-RD WP16 is to provide an EU-wide education programme on transversal RD research to all interested stakeholders, fully available online via an e-learning established service provider.

The course is aimed at providing transversal and multidisciplinary content on RD research. The objective is not only to develop a high-quality e-learning academic-like RD course but also an attractive content both accessible to a lay audience and a more expert audience. The whole course is meant to be developed around a number of different modules and topics that will rely partially on the existing content currently scattered and not always available in English. New and additional contents will be generated in tight coordination with top-tier RD experts. Whenever possible, a complimentary access to the e-learning platform facilities will be provided to ERNs since those networks are also developing e-learning materials. Similarly, all relevant online research training activities and educational material developed by the ERN will also be highlighted through this online course. Educational material developed within the context of WP16 is meant to be transversal and non-redundant with that of the ERNs.

In a nutshell, the expected impacts of the online academic course are to better inform and train the RD community at large, to increase awareness on RD research and specific translational issues and to foster innovative RD research.

Methodology

The objective of the first task of WP16 was to better define the targets of the course, to assess the needs of the potential trainers and to refine the main topics of the academic education course. To do so, several activities have been performed during the first 9 months of the project encompassing qualitative interviews, online surveys, comparison of e-learning platforms offers, mapping of the existing resources, etc.

Qualitative interviews

From January 2019 till April 2019, almost 30 qualitative interviews (approx. one to two hours each) have been led with representatives from the following stakeholders:
- EU Patients' Organisations (Eurordis, Findacure, M4RD, AKU Society),
- Research Centres (CRG and WP16 partners),
- E-learning platforms (Elevate, French CRI),
- Clinicians and ERN representatives (essentially WP16 partners),
- EU Infrastructures (ELIXIR, EATRIS),
- EU-funded programmes having developed MOOCs (EIT Inno Energy, through Oxford University, Eu2P e-learning program),
- the coordinators of the National French University Diploma on RD research,
- etc.

These interviews have been pivotal in order to define a draft-design for the global course structure and enabled us to refine the needs to be addressed together with the primary targets of the EJP-RD e-learning academic course. The list of interviewed representatives is available in Annex 1.

## Benchmarking of the existing and available resources

In parallel to qualitative interviews, a benchmarking of existing RD academic courses at EU level has been performed. This collection has been essentially compiled through online search, previously known resources, information feedbacked during interviews and through WP16 online survey (see below). This list contains approximately 30 online courses and is available in Annex 2. This collection is not exhaustive and a regular monitoring should be carried out. Approximately one third of the identified courses are specific to a specific rare disease/pathology, whereas the WP16 objective is to develop or highlight transversal and multidisciplinary content on RD research. Some of the courses (even though relevant) are no longer available.

Online surveys

Based on the outputs from a first qualitative stage of benchmarking, the needs of a huge group of learners have been surveyed through an online survey. This survey was run from early June till mid-July 2019. It was framed as a single comprehensive online survey to collect information. The following areas were questioned: types of training measures to foster and increase (RD) research; main targets for an e-learning course on RD research; most important research skills training domains to be addressed; knowledge of the existence (or under development) of similar or connected initiatives; e-learning preferred format; e-learning preferred tools; interactivity need; academic accreditation incentive. Importantly, this survey included a "priorization exercise" in order to identify the top priority topics to develop. Free text was also available under several questions and numerous and relevant feedbacks have been gathered that will be essential to frame the specific tools and contents. The outline of the survey is available in Annex 3.

Multiple channels have been used to disseminate the survey: interviewed organisations during the benchmarking activity, EJP-RD Partners themselves and their networks, EJP-RD communication channels, etc.

Previously, results from the ERN survey developed in the context of the EJP (Q1 2019) to survey ERN needs on a number of issues (including training needs) were also analyzed to refine the anticipated targets and current orientations of the EJP online academic course. The results show that the most important research skills training domains that need to be addressed for this specific community are "Scientific tools & methodologies" and "Technical skills". A preference was highlighted for face to face trainings. Students were identified as the main target to train. "
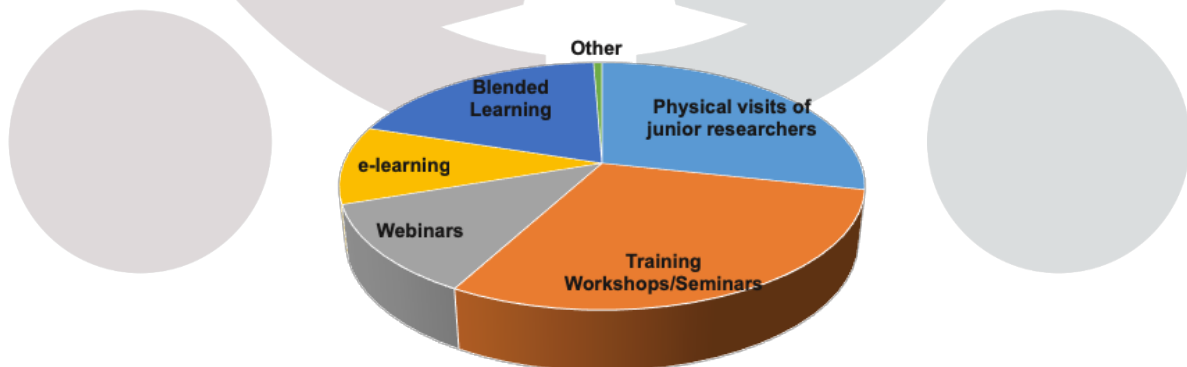
ERN Survey - Most efficient training measures according ERN needs
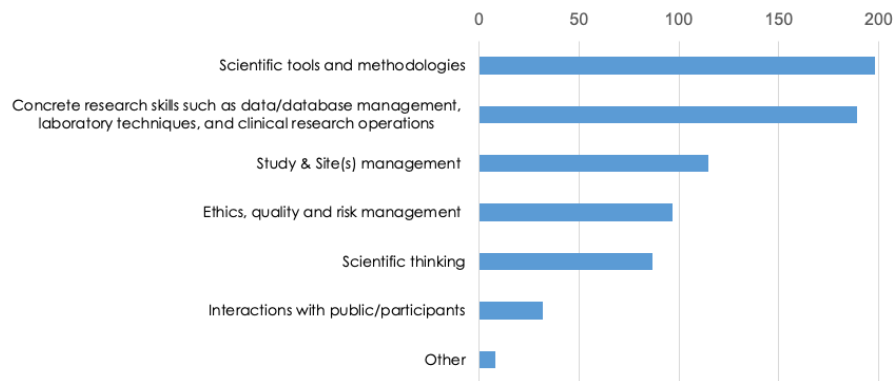
ERN Survey - Most important research skills training domains to help ERN Heath Clinical Professionals raise the level of their research

E-learning platforms benchmarking & discussions

In parallel to the assessment of the needs and targets, the technical solutions have been compared to host and develop the online course. A comparison of seven e-learning platforms (FutureLearn, Elevate, Coursera, EdX, CRI MOOC Factory, FUN-MOOC, OpenUpEd) has been performed over the first semester. Two e-learning platforms (FutureLearn and Elevate) have been shortlisted based on the following criteria:

- location of the platform and of its server (Europe vs US)
- topics usually addressed by the platform (familiarity with health/medical fields)
- platform language (English)
- learning tools/methodology
- reactivity/willingness to work with us
- recognition
- experience in working with EU consortia and EC-funded projects

A fruitful dialogue has been developed with the two short-listed platforms that has led to the refinement of both the content and size of the course. The results of this comparison exercise have been discussed at the EJP-RD General Assembly with all the partners and at month 9, the choice of the selected platform is almost finalized.

Critical analysis of the results

Refined targets

The targeted audience of the online academic course has been refined based on the benchmarking activities described above.

352 responders participated to the online survey as shown below.

Responders to WP16 online survey per country and per background
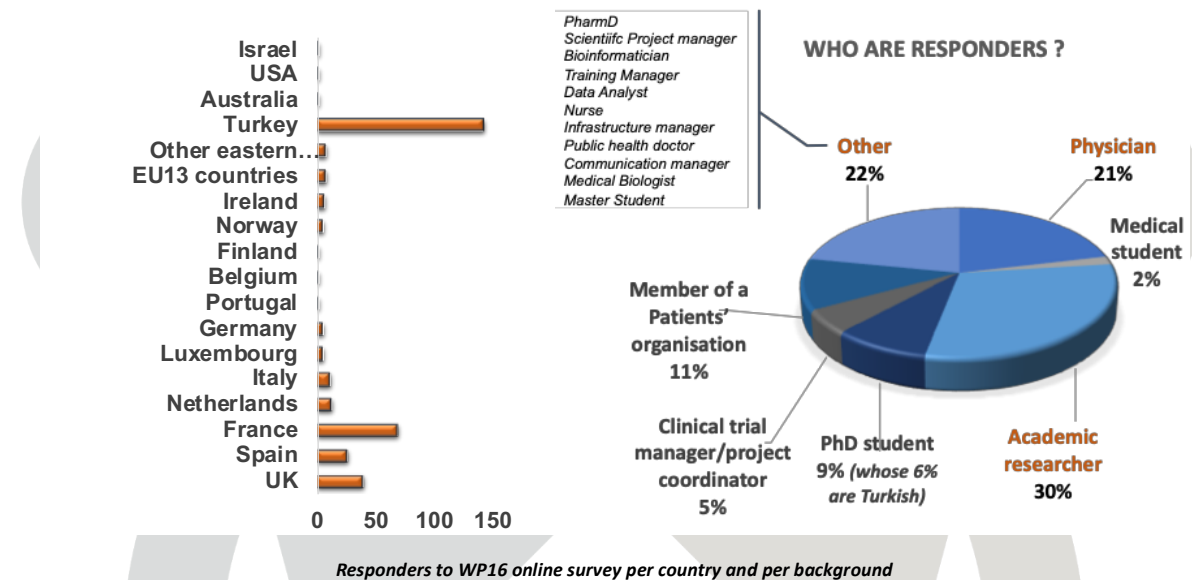
Accordingly, the online academic course will target (by expected order of priority): students (PhD/Post-doc, research and medical students), academic researchers looking for specific content on RD, Patients' Organizations representatives and practitioners. The audience is expected to be worldwide, not restricted to EU countries.

E-Learning Academic course on RD research: main targets / General consensus: Students will be the main target
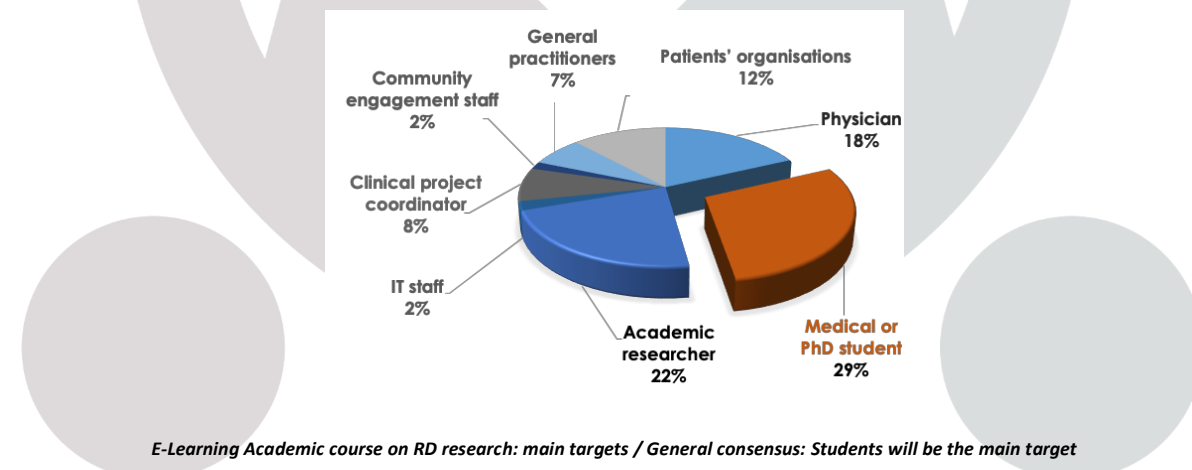
Targets being still quite heterogeneous, to address the different needs, two levels for each module will be implemented:

(i)   **level 1:** one short video addressing basic definitions and an overview of the subject. For this level, the targets (which are not exclusive) will primarily be: Patients' Organisations, general audience, undergraduate and MsC Students, GPs, paramedics, etc.

(ii)   **level 2**: an advanced session. For level 2, the targets will be: PhD/Post Doc students, medical students, academic researchers, practitioners.

No accreditation nor certification will be sought for level 1 content. Certification will be ensured for level 2 and accreditation will be an objective once the first contents are implemented and run at least one.

Given the fact that Turkish responders constituted almost half of the responders, a comparative analysis of their answers has been performed with regard to Western and Eastern EU countries responders. The comparative analysis has demonstrated that very few differences appeared should it be on the priority training targets or on the priority topics to develop. An overview of this comparative analysis is available in Annex 4.

Design of the modules

All along the benchmarking activities, the design for each module of the course has been worked and defined. It has been approved at WP level by all WP partners, 8 of them being representatives from ERNs. Each module of the online academic course will consist in:

(i)   one short video addressing basic definitions and an overview of the subject that would be accessible at any time for all and shareable on different supports;
(ii)   an advanced session with 5 to 10 units of advanced content and exercises (+/- 1h per unit).

Timeline of the course's modules development

The 10 to 12 modules envisioned at the incipit of the project have been challenged by the outputs of the surveys and discussions with the e-learning platforms. Topics have been ranked by priority order and given the budget and time constraints, a more pragmatic approach has been fostered to develop a high-quality content within a realistic amount of time.

Each module is to be built in close collaboration with two co-coordinators who will be in charge of the definition of the module content, lecturers' choice and evaluation process for their module(s). Co-coordinators of the modules are bringing diverse expertise and include the following stakeholders: ERNs, Universities and Research Institutes (VUHSK, ISCIII, INSERM (AMU), Patients' Organisations (EURORDIS), EU Infrastructures (EATRIS, ELIXIR), Charities (FFRD, FGB). All of them are involved in other WPs of the EJP RD, that will ensure the non-redundancy of the content to be developed internally as well as its optimal uptake under other activities, in particular within WP19 or by Pillar 1 funded projects.

A three-fold perspective will be followed within a specific module including patients' testimonies, clinicians' perspective and researchers' expertise

Modules will be launched progressively: two priority modules will be implemented by month 24 on the following topics: Diagnostic research and Innovative personalized therapies. A third one will be launched in 2021 on translational research in RD. Even though "management" was listed as a priority topic, further to discussion with ERNs held at the EJP-RD General Assembly, this topic seems more relevant for ERNs own e-learning modules and WP16 will better focus on other modules. Final choice on the 4th and 5th topics is to be discussed at the WP level by the end of 2019. Several sessions would be possible per year per module (based on audiences registered for the first modules).

Modules	Co-coordinator	Co-coordinator 2
Diagnosis of rare diseases	ERN ITHACA Prof. Laurence FAIVRE	ERN GENTURIS Dr.Chrystelle COLAS
Innovative personalised therapies for rare diseases	ERN TRANSPLANTChild Dr. Eduardo LOPEZ GRANADOS	MetabERN Dr. Nadia BELMATOUG
Translational research	EATRIS Rosan VEGTER	ERN EURO-NMD Dr. Teresinha EVANGELISTA

First 3 modules to be developed and their co-coordinators

Tools and pedagogy

Preferred tools have been surveyed within the online survey and also throughout qualitative interviews. There is a clear demand and need for formats such as webinars, active learning exercises, video from lecturers as well as more for more traditional formats such as PowerPoint presentations (see below). The survey results also clearly demonstrate that potential learners are expecting a high level of interactivity, not only between learners and teachers/experts but also between learners and peers. As a result, efforts will be made to develop fora, webinars and interactive contents all over the different modules to be developed.

WP16 Survey results - Preferred e-learning tools

Western-Central EU	Eastern EU	Turkey
# responses 189	16	142
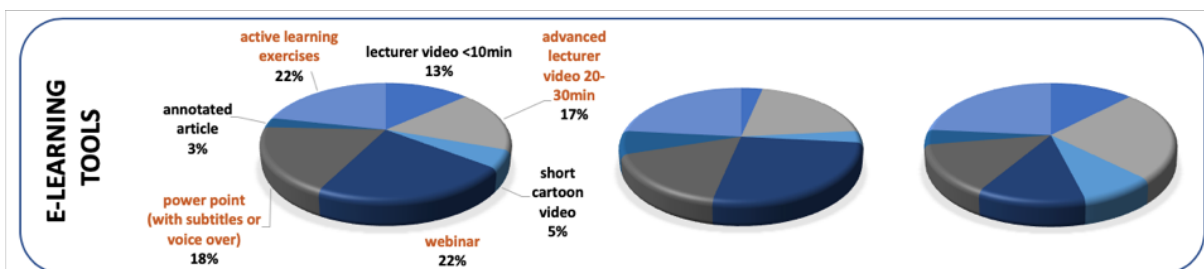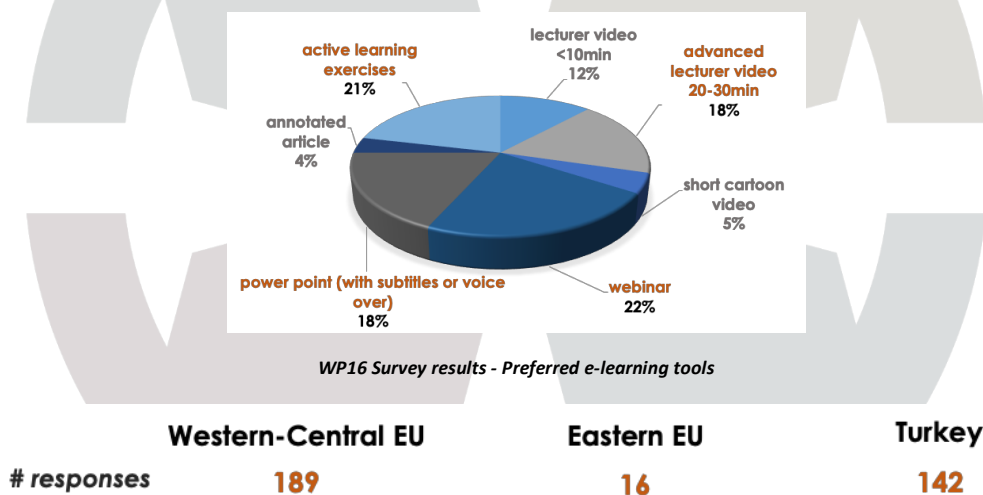
WP16 Survey results - Preferred e-learning tools – comparison over responders from different EU regions

IMPORTANCE OF INTERACTIVITY BETWEEN LEARNERS

« To create possible contacts between different expertises »
« A personal contact will facilitate the translation of the knowledge »
« It may add benefits through peer-to-peer learning and multiple solutions in problem-based learning »
« It helps engaging and generate discussion and cross fertilization »
« Multidisciplinar activies will enrich the individual perspectives »
« Exhange of mistakes and opinion allows a better understanding of the issues »
« Brainstorming usually opens your mind to other possibilities as normally you are biased by what you know »
« It may favor new collaborations »
« To avoid unnecessary movements for students »
« Methodological teaching needs interaction »
« It helps build a community of "alumni" »
« Important to build an archive (e.g. forum based) »
« Learners often have great, up to date information that they are happy to share with others »
« For a better understanding of the problems faced by different countries »

IMPORTANCE OF EXCHANGES WITH EXPERTS

YES 95%

« More comprehensive understanding »
« To have the opportunity to ask questions » « Because learners usually have questions, which need to be answered personally »
« It is of high importance: to elucidate unclear parts of e-learning material and deepen knowledge in certain areas that learner is interested in (provides more learner-centered approach) »
« Possibility to get feedback on special requests very important »
« Q&A sessions benefit to all students to improve understanding, memorising and transfer of concepts taught »
« Helps to embed reflective practice »
« Mentoring »
« In the absence of face-to-face meeting, it is useful »

- Not everyone has time to engage
- Difficult to achieve / depends on individual timing requirements
- Not necessarily interactivity / possibility to contact the experts per e-mail

Interaction and interconnection with ERN training activities

The EJP RD e-learning course will also be developed with the ability to link and flag ERN own research e-learning training activities as well as other relevant e-learning trainings developed by the RD community. This has been clearly requested by ERNs on the occasion of the EJP-RD General Assembly in Gdansk in September 2019. Mapping ERN online research training developments and ensuring a smooth and fluent communication with ERN training/research groups and representatives will be essential to avoid any duplication or redundancy as well as wasted efforts.

Conclusions and Next steps

Development of first modules' content

The draft content of the course being now defined such as the specific targets, the next steps include the development (in tight connection with modules' coordinators) of the content for the two first modules of the e-learning course with the selected platform providers. The two first modules should

be implemented and run at least once by the end of 2020. Work will also start in parallel on the content of two additional modules to be deployed in 2021. Defining specific learning objectives, students' assessment and course content evaluation are also short-term objectives for 2020. This will be done in collaboration with coordinators and lecturers from the initial stage to ensure quality assessment and impact is well taken into consideration from the start.

Foreseen steps include the following:

- September 2019: decision on which e-learning platform provider
- End of 2019: subcontractor agreement signed
- January 2020: start developing the first contents
- End of 2020: first two modules available and run.

Annex 1 - List of qualitative interviews

First name	Name	Position of interest for WP16	Organisaion	Interview on
People interviewed during the benchmark phase (Feb-June 2019)				
Laurence	FAIVRE	ANDDI RARE Coordinator (FR) ITHACA Training leader	Dijon University Hospital	2019-02-11
Jérôme	BERTHERAT	ENDO-ERN French representative	Paris University Hospital	2019-02-20
Michela	BERTERO	Head of International and Scientific Affairs at the Centre for Genomic Regulation (CRG) in Barcelona, Spain	Centre for Genomic Regulation (CRG)	2019-02-26
Raquel	CASTRO	EURORDIS Open Academy	EURORDIS	2019-02-26
Alain	BERETZ	Mission on the EU Universities, attached to French Prime Minister	League of European Research Universites (LERU)	2019-03-01
Brane	LESKOSEF	ELIXIR Infrastructure	University of Ljubljana	2019-03-05
Claude	HOUDAYER	ERN GENTURIS French reprentative	Rouen University Hospital	2019-03-06
Karine	PALIN	Eu2P e-learning program manager	Bordeaux University	2019-03-12
Teresinha	EVANGELISTA	EURO-NMD ERN Coordinator	Institute of Myology (Paris Hospital)	2019-03-14
Birute	TUMIENE	ITHACA ERN Member	Vilnius University Hospital (VUH)	2019-03-14
Juan	TORRES	TRANSPLANTCHILD ERN Coordinator	La Paz University Hospital - IdiPaz	2019-03-14
Pierre	COCHAT	President, International Pediatric Nephrology Association (IPNA) Clinician invoved in ERN and resp for RD reference centres	Lyon Univ Hospital	2019-03-18
Rick	THOMPSON	CEO	Findacure	2019-03-21
Rosan	VEGTER	Scientific and Education Manager	EATRIS	2019-03-25
Ariel	LINDNER	Research Director	Centre for Research and Interdisciplinarity (CRI)	2019-03-29
Eric	HACHULLA	Coordinator French Univ Diploma on RD research	Lille Univ Hospital	2019-04-09
Eva	VAN INGEN	Business Developer	ELEVATE	2019-04-17
Lucy	McKay	CEO	M4RD (Medics for Rare Diseases)	2019-04-17
Manuel	POSADA	Director Institute of Rare Diseases Research	ISCIII	2019-04-24
Viviana	GIANNIZI	Partner in WP16	FGB	2019-04-24
Edward	MEINERT	Chartered Engineer - digital technology in medicine	University of Oxford Healthcare Translation Research Group	2019-05-03
Lesley	HARRISON	Patient Support Manager	AKU Society	2019-05-03

Annex 2 - List of existing online courses addressing RD research aspects

Skateholders	Area	Rare disease domain covered	Main topics covered	Targeted audience	Type of e-learning	e-learning platform	Year of creation	Date last course	Duration	Country(ies)	language	web link
Findacure (UK charity)	Generic		a central hub of information and training to help the establishment and growth of rare disease patient groups	rare disease advocates, patients		Findacure	2015	Free access and illimited		UK	English	https://portal.findacure.org.uk/
Dipartimento di Biologia, Università Federico II, Italy	Generic		Bioinformatic tutorial using Fabry Disease as example	health professionals			2017	Free access and illimited		Italy	English	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5666731/
Rare Genomics Institute and the Organization for Rare Diseases India	Generic		to strengthen and optimize rare disease patient advocacy for pre-sequencing and post-sequencing support functions			Rare Gene Superheroes course (funded by Sanofi)	2017	Free		India	English	
Eurordis -Open Academy	Generic		Modules : # Medical Research # Ethics # Regulatory Frameworks # EMA # Benefit-Risk Assessment & Pharmacovigilance # Market Access # Setting the landscape of pre-clinical research # Genetic research to clinical diagnosis of Rare Diseases # Sharing patient data # From research to therapies # Genome editing	patient organisations		Managed by Eurordis		Free access to training tools (slide from Eurordis Summer School, webcasts, interactive training modules) + Full online modules will be developed following edition of the EURORDIS Winter School		UE	English	https://www.eurordis.org/online-training-modules
NORD - National Organization for Rare Disorders - & PCORI - Patient-Centered Outcomes Research Institute -	Generic		Tools and templates on the subject of "patient and research"	patients			2015	Free		USA	English	https://www.pcori.org/research-results/2015/pcori-training-program-rare-disease-patient-advocates
Utrecht University	Generic		This training course introduces you to key aspects of translational research and medicines development Course topics: Introduction to translational medicine Target validation Predictive models Biomarkers and personalized medicine Regulatory environments					Free	2weeks, 8hrs/we	Netherlands	English	https://elevatehealth.eu/online-medical-courses/translational-medicine-online
ELIXIR	Generic		Bioinformatic courses					Free			English	https://elixir.mf.uni-lj.si/
St George's, University of London	Generic		Genomic technologies across the breadth of medicine Over three online courses, you will explore a variety of clinical scenarios, to gain a deep insight into the potential of genomics in healthcare, and the clinical applications of molecular genetic techniques and next generation sequencing (NGS) technologies.	scientists and healthcare professionals at a postgraduate level		FutureLearn		Free	3 courses for a total of 10 weeks training, possibility of accreditation	UK	English	https://www.futurelearn.com/programs/genomics-in-healthcare
Danish Universities	Generic		eLearning course about the importance of good research data management (RDM) The course is divided into three independent modules: # Introduction # FAIR # Data Management Plans	PhD students, researchers and research support staff		Creative Commons Attribution 4.0 International License. The course is brought to you by the Danish National Forum for Data Management, and is funded by Denmark's Electronic Research Library (DEFF) and the Danish eInfrastructure Cooperation (DeIC).	2019	Free access and illimited open to all	3 modules of a 20 min video recording (including animations and interviews)	Denmark	English	https://vidensportal.deic.dk/en/RDMLearn
Eu2P	Generic		Eu2P stands for "European programme in Pharmacovigilance and Pharmacoepidemiology". It is currently offering an innovative web-based education & training offer in Pharmacovigilance and Pharmacoepidemiology	Academic student, healthcare professionals, non-specialists		Eu2P team at Bordeaux University manages an elearning platform with the Chamilo LMS tool	2011	Training cost depend on the formation, short courses, Certificate, Masters or PhD		UE	English	https://www.eu2p.org/
Romanian Prader Willi Association (RPWA)	Generic		EDUBOLIRARE PLATFORM Through Edubolirare platform, RPWA provides information and socio-medical training, a difficult and challenging sector, and at the same time, an area where there is a need for a professional approach to information and training. The information is publicly accessible. # Socio-cultural educator # Personal Assistant for Severely Disabled People # Art Therapist # Methods and Techniques of Integration for People with Disabilities # Model on Rare Diseases, included in all training courses (partly)	patients, caregivers, health professionals						Romania	Romanian	http://www.edubolirare.ro/
ERN TransplantChild	Generic		E-learning webinars on various pediatric transplantation items	medical students, health professionals	webinars	You Tube					English	https://www.transplantchild.eu/en/activities/working-groups-2/e-learning-webinars
ERN Euro-NMD & RD-Connect	Generic		1. Genomic analysis quick and easy: RD-Connect Genome-Phenome Analysis Platform, by Steven Laurie, Centro Nacional de Análisis Genómico, Barcelona, Spain 2. Finding registries and biosamples in just a few clicks: RD-Connect Registry & Biobank Finder and Sample Catalogue, by Mary Wang, Fondazione Telethon, Milan, Italy 3. Linking up all those data: why should we make data FAIR, by Marco Roos, Leiden University Medical Center, The Netherlands	health professionals, researchers	webinars	You Tube	September 2018				English	https://ern-euro-nmd.eu/rd-connect-webinars/
Orphanet	Generic		Old version of elearning project Orphaschool by Orphanet (not currently in use)	Large						France	French	https://www.orpha.net/orphaschool/elearn1.htm
Integrated DEsign and AnaLysis of clinical trials in small population group (IDeAl)	Generic		IDeAl Webinar Series (Introduction by Ralf-Dieter Hilgers)	Clinicians - geneticians- statistical methodologists	webinars	You Tube	2016	Free access and illimited		UE	English	https://www.ideal.rwth-aachen.de/?page_id=806#toggle-id-1-closed
Medics4RareDiseases	Generic		e-learning for medical students and doctors about the fundamentals of rare diseases	Large	expert lectures	You Tube	2019	Free access and illimited		UE	English	https://www.m4rd.org/video-library/
French Network FISLAN	RD Focused	ALS	key principles of care for patient at home	patients, caregivers, health professionals		?	2018	Free access and illimited		France	French	https://elearning.portail-sla.fr/login/index.php
French Network FAVA-MULTI	RD Focused	rare multisystemic vascular disease	Module 1: Marfan Syndrome Module 2: Ehlers-Danlos Vascular Syndrome Module 3: Fibro-Muscular Dysplasia Module 4: Rendu-Osler Disease Module 5: Lymphatic Diseases (primary lymphedema + lymphatic malformations) Module 6: Superficial Arteriovenous Malformations Module 7: Psychological and social repercussions of diseases.	health professionals			2018	Not openned yet		France	French	https://www.favamulti.fr/se-former/formation-medicale/e-learning/
European Network for Rare and Congenital Anaemias - e-ENERCA	RD Focused	haematology	initial and continuing medical education in the field of rare anaemias	health professionals						UE	English	https://www.enerca.org/e-healthservices/elearning.html
Royal College of General Practitioners	RD Focused	Motor Neurone Disease	resources to help genereal practitioners in the diagnosis and management of patients with any rare disease but with a primary focus on motor neurone disease	health professionals			2014 (updated 2018)		30 minutes	UK	English	http://elearning.rcgp.org.uk/course/info.php?popup=0&id=160
Frambu Resource Centre for Rare Disorders	RD Focused	Prader Willi Syndrome	learning goals for eight different themes, concerning different aspects of daily life of a person with PWS	caregivers						Norway	Norwegian	http://kurs.helsekompetanse.no/pws/hela
Orphan Europe Academy programme committee	RD Focused	hyperammonaemia	a comprehensive understanding of hyperammonaemia including its causes and clinical consequences Tools: # Working through clinical scenarios to make the experience interactive; questions can only be satisfactorily answered by reference to the literature or text books to obtain all the information required. # Downloadable .pdf written halfway between the formality of a book and the informality of a seminar to make them user-friendly and accessible. # Assessments and end of module assessment carrying EACCME credit. # Course specific webpages with electronic versions of study materials. # Online forums for networking with fellow students and tutors.	physicians		Recordati Rare Diseases Foundation	2013		6 months	UE	English	http://www.rrdacademy.org/en/course/e-learning-hyperammonaemia-module/71
Frambu Resource Centre for Rare Disorders	RD Focused	Angelman syndrome	To provide knowledge about the use of augmentative and alternative communication (ASK) for individuals with Angelman syndrome.				15 January 2019	Free		Norway		http://www.frambu.no/CourseDetail.aspx?t=6fa0e71e-ea7d-47e2-b4b8-ec116c825580&BookingId=2258dc50-7ee1-45b3-8ea9-20a3a702f5ad9&type=NettKurs
FYMCA	RD Focused	Gaucher Disease, Fabry Disease and MPS Disorders (Mucopolysaccharidosis)	To develop improved rare disease education and services for those in the developing world The learning path consists of three modules — one per disease — and there are about 10 courses (45 minutes each).	low countries physicians		iSpring				South Africa	English	https://www.ispringsolutions.com/blog/fymca-medical-with-ispring-we-deliver-rare-disease-education-to-low-income-countries/
EULAR	RD Focused	rheumatology	# 12th EULAR Online Course on Rheumatic Diseases # 4th EULAR Online Course in Paediatric Rheumatology # 3rd EULAR Online Course for Health Professionals # 7th EULAR Online Course on Systemic Sclerosis # 9th EULAR Online Course on Connective Tissue Diseases # 6th EULAR Online Introductory Ultrasound Course							UE	English	https://www.eular.org/education_training.cfm
ERN EuroNMD	RD Focused	Neuromuscular diseases		researchers - health professionals	webinars			Free access and illimited		UE	English	https://ern-euro-nmd.eu/webinars/

Annex 3 - WP16 online survey

EJPRD Survey on online training needs in the context of rare diseases research

Q1. You are a:

- Physician
- Medical student
- Academic researcher
- PhD student
- IT staff
- Clinical trial manager/project coordinator
- Community engagement staff
- General practitioner
- Member of a Patients' organisation
- Other:
  Additional Questions (for For Physician, Medical student, Academic researcher, PhD Student):
  Q1a: Are your institution related with a University? If yes, which one?
  Q1b: Are your University member of a Erasmus+ European Universities Alliance? If yes, which one?

Q2. Please, indicate the country where your institution is located

Q3. In order to raise the level of rare diseases (RD) research knowledge, which of the following types of training measures would address this topic most efficiently (choose top 2)?

- Physical visits of junior researchers in other laboratories/research groups
- Face-to-face training Workshops/Seminars
- Webinars (online collaborative seminars)
- e-learning course as MOOC
- Combination of campus-teaching and e-learning (Blended Learning)
- Other: (free text)
- Comments: (free text)

Q4. In your view, what would be the main target group for an e-learning course on RD research? Please pick your top 3

- Physicians
- Medical students
- Academic researchers
- PhD students
- IT staff

- Clinical trial manager/project coordinator
- Community engagement staff
- General practitioners
- Patients' organisations
- Other: (free text)
- Comments: (free text)

Q5. What, in your view, are the most important research skills training domains that need to be addressed in the context of RD research? Please pick your top 3

- Introduction to the RD general context
- Diagnosis of rare diseases
- Management of rare diseases
- Innovative personalised therapies for rare diseases
- Biotechnologies & bioinformatics
- Information Systems
- Translational research
- Regulatory affairs
- From innovation and Proof-of-concept to industry
- Health economics
- Social Sciences and Humanities applied to RD
- Environmental and participatory (digital) health technologies and information
- Other: (free text)
- Comments: (free text)

Q6. Do you have any existing or under development e-learning course organized by your University/Organisation in the field of rare diseases research?

- Please describe briefly the focus and topics addressed

Q7. Which e-learning course format matches with the time you would be willing to spend to train yourself?

- a basic course < 2H
- an advanced course from 10H to 15H (with approximatively 1 to 1.5H of work /week)
- Comments: (free text)

Q8. Which kind of e-learning tools would you prefer to use? Please pick your top 2

- lecturer video <10min
- advanced lecturer video 20-30min
- short cartoon video
- webinar
- power point (with subtitles or voice over)
- annotated article

- active learning exercises (ex : problem-based learning, Mind mapping activity, Online debates)
- Comments: (free text)

Q9. Do you think interactivity is important for an e-learning course?

- Between learners: Yes – No
- Between lecturers and learners: Yes – No
- Comments: (free text)

Q10. In your view, is academic accreditation an important goal for an e-learning course?

- Yes
- No
- Comments: (free text)

Annex 4 - WP16 survey - Comparative analysis of results per geographical origin

	West-Central EU	East EU	Turkey
# responses	189	16	142

FROM WHOM ?

West-Central EU: Physician 25%, Medical student 0%, Academic researcher 18%, PhD student 2%, Clinical trial manager/project coordinator 7%, Member of a Patients' organisation 15%, Other 33%

East EU: Academic researcher 57%

Turkey: Academic researcher 33%, Medical student 28%

TOPICS

DIGITAL HEALTH, SSH, HEALTH ECONOMICS, PROOF-OF-CONCEPT TO INDUSTRY, REGULATORY AFFAIRS, TRANSLATIONAL RESEARCH, INFORMATION SYSTEMS, BIOTECHNO & BIOINFORMATICS, INNOVATIVE PERSONALISED MEDICINE, MANAGEMENT, DIAGNOSIS, INTRODUCTION RD CONTEXT

TARGETS

West-Central EU:
29% Students (PhD or medecine)
18% Academic researchers
19% Physicians
13% Patients

East EU:
35% Students (PhD or medecine)
20% Academic researchers
16% Physicians
13% Patients

Turkey:
29% Students (PhD or medecine)
26% Academic researchers
15% Physicians
10% Patients

E-LEARNING TOOLS

West-Central EU: active learning exercises 22%, lecturer video <10min 13%, advanced lecturer video 20-30min 17%, short cartoon video 5%, webinar 22%, power point (with subtitles or voice over) 18%, annotated article 3%

	West-Central EU	East EU	Turkey
consider that **interactivity between learners** is important	81%	90%	86%
consider that **exchanges with experts** are important	93% VS	81% VS	98%
think accreditation is important	66%	80%	77%