EJP RD

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Draft Content of the Online Academic Course

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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**
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.

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.

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-ordinators who will be in charge of the definition of the module content, lecturers’ choice and evaluation process for their module(s). Co-ordinators of the modules are bringing diverse expertise and include the following stakeholders: ERNs, Universities and Research Institutes (VUHSDK, 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).
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.
INTERACTIVITY BETWEEN LEARNERS

- To create possible contacts between different expertise
- 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
- Multidisciplinary activities will enrich the individual perspectives
- Exchange 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

EXCHANGES WITH EXPERTS

- 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

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**

People interviewed during the benchmark phase (Feb-June 2019)

<table>
<thead>
<tr>
<th>First name</th>
<th>Name</th>
<th>Position of interest for WP16</th>
<th>Organisation</th>
<th>Interview on</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laurence</td>
<td>FAIVRE</td>
<td>ANDDI RARE Coordinator (FR) ITHACA Training leader</td>
<td>Dijon University Hospital</td>
<td>2019-02-11</td>
</tr>
<tr>
<td>Jérôme</td>
<td>BERTHERAT</td>
<td>ENDO-ERN French representative</td>
<td>Paris University Hospital</td>
<td>2019-02-20</td>
</tr>
<tr>
<td>Michela</td>
<td>BERERO</td>
<td>Head of International and Scientific Affairs at the Centre for Genomic Regulation (CRG) in Barcelona, Spain</td>
<td>Centre for Genomic Regulation (CRG)</td>
<td>2019-02-26</td>
</tr>
<tr>
<td>Raquel</td>
<td>CASTRO</td>
<td>EURORDIS Open Academy</td>
<td>EURORDIS</td>
<td>2019-02-26</td>
</tr>
<tr>
<td>Alain</td>
<td>BERETZ</td>
<td>Mission on the EU Universities, attached to French Prime Minister</td>
<td>League of European Research Universites (LERU)</td>
<td>2019-03-01</td>
</tr>
<tr>
<td>Brane</td>
<td>LESCOSEF</td>
<td>ELIXIR Infrastructure</td>
<td>University of Ljubljana</td>
<td>2019-03-05</td>
</tr>
<tr>
<td>Claude</td>
<td>HOUDAYER</td>
<td>ERN GENTURIS French representative</td>
<td>Rouen University Hospital</td>
<td>2019-03-06</td>
</tr>
<tr>
<td>Karine</td>
<td>PALIN</td>
<td>Eu2P e-learning program manager</td>
<td>Bordeaux University</td>
<td>2019-03-12</td>
</tr>
<tr>
<td>Teresinha</td>
<td>EVANGELISTA</td>
<td>EURO-NMD ERN Coordinator</td>
<td>Institute of Myology (Paris Hospital)</td>
<td>2019-03-14</td>
</tr>
<tr>
<td>Birute</td>
<td>TUMIENE</td>
<td>ITHACA ERN Member</td>
<td>Vilnius University Hospital (VUH)</td>
<td>2019-03-14</td>
</tr>
<tr>
<td>Juan</td>
<td>TORRES</td>
<td>TRANSPLANTCHILD ERN Coordinator</td>
<td>La Paz University Hospital - IdiPaz</td>
<td>2019-03-14</td>
</tr>
<tr>
<td>Pierre</td>
<td>COCHAT</td>
<td>President, International Pediatric Nephrology Association (IPNA) Clinician involved in ERN and resp for RD reference centres</td>
<td>Lyon Univ Hospital</td>
<td>2019-03-18</td>
</tr>
<tr>
<td>Rick</td>
<td>THOMPSON</td>
<td>CEO</td>
<td>Findacure</td>
<td>2019-03-21</td>
</tr>
<tr>
<td>Rosan</td>
<td>VEGTER</td>
<td>Scientific and Education Manager</td>
<td>EATRIS</td>
<td>2019-03-25</td>
</tr>
<tr>
<td>Ariel</td>
<td>LINDNER</td>
<td>Research Director</td>
<td>Centre for Research and Interdisciplinarity (CRI)</td>
<td>2019-03-29</td>
</tr>
<tr>
<td>Eric</td>
<td>HACHULLA</td>
<td>Coordinator French Univ Diploma on RD research</td>
<td>Lille Univ Hospital</td>
<td>2019-04-09</td>
</tr>
<tr>
<td>Eva</td>
<td>VAN INGEN</td>
<td>Business Developer</td>
<td>ELEVATE</td>
<td>2019-04-17</td>
</tr>
<tr>
<td>Lucy</td>
<td>McKay</td>
<td>CEO</td>
<td>M4RD (Medics for Rare Diseases)</td>
<td>2019-04-17</td>
</tr>
<tr>
<td>Manuel</td>
<td>POSADA</td>
<td>Director Institute of Rare Diseases Research</td>
<td>ISCIII</td>
<td>2019-04-24</td>
</tr>
<tr>
<td>Viviana</td>
<td>GIANNIZI</td>
<td>Partner in WP16</td>
<td>FGB</td>
<td>2019-04-24</td>
</tr>
<tr>
<td>Edward</td>
<td>MEINERT</td>
<td>Chartered Engineer - digital technology in medicine</td>
<td>University of Oxford Healthcare Translation Research Group</td>
<td>2019-05-03</td>
</tr>
<tr>
<td>Lesley</td>
<td>HARRISON</td>
<td>Patient Support Manager</td>
<td>AKU Society</td>
<td>2019-05-03</td>
</tr>
</tbody>
</table>
### Annex 2 - List of existing online courses addressing RD research aspects

<table>
<thead>
<tr>
<th>Course Title</th>
<th>Target Audience</th>
<th>Country(ies)</th>
<th>Language(s)</th>
<th>Course Length</th>
<th>Course Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Genomic analysis quick and easy: RD-Connect Genome-Analysis</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>8hrs/week</td>
<td>Free</td>
</tr>
<tr>
<td>2. Finding registries and biosamples in just a few clicks: RD-Connect Bio</td>
<td>Researchers - health professionals, low countries physicians, caregivers, patients</td>
<td>France</td>
<td>English</td>
<td>3 courses for a total of 12 weeks</td>
<td>Free</td>
</tr>
<tr>
<td>3. Rhematology – Rheumatic Disease</td>
<td>Rheumatologists, healthcare professionals, patients, caregivers, health professionals, patient organisations</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>4. Angelman syndrome</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>20 min video</td>
<td>Free</td>
</tr>
<tr>
<td>5. Treatment and management of gastroenterology</td>
<td>Researchers - health professionals, low countries physicians, caregivers, patients</td>
<td>France</td>
<td>English</td>
<td>2 weeks</td>
<td>Free</td>
</tr>
<tr>
<td>6. French Network FISLAN</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>French</td>
<td>30 minutes</td>
<td>Free</td>
</tr>
<tr>
<td>7. Danish Universities</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>Denmark</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>8. St George’s, University of Liverpool</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>UK</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>9. Bioinformatic courses</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>10. Regulatory environments</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>11. Biomarkers and personalized medicine</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>12. Regulatory Frameworks</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>13. Medical Research</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>14. EMA</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>15. Socio-cultural educator</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>16. Socio-cultural training</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>17. Through Edubolirare platform, RPWA provides information and training to help the patients</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>18. Free access and unlimited courses</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>19. Using the right tools and techniques to develop improved rare disease education and services for researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>20. To develop improved rare disease education and services for researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>21. To provide knowledge about the use of augmentative and alternative communication methods (RDM)</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>6 months</td>
<td>Free</td>
</tr>
<tr>
<td>22. # 7th EULAR Online Course on Neuromuscular diseases</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>23. # 3rd EULAR Online Course for Health Professionals</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>24. # 12th EULAR Online Course on Rheumatic Diseases</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>25. # Online forums for networking with fellow students and tutors.</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>26. # Assessments and end of module assessment carrying EACCME credit.</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>27. # Working through clinical scenarios to make the experience accessible.</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>28. # Model on Rare Diseases, included in all training courses (partly)</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>29. # Methods and Techniques of Integration for People with Socio-cultural training, a difficult and comprehensive understanding of hyperammonaemia including anaemias</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>30. # Regenerative medicine</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>31. # Socio-cultural educator</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>32. # Socio-cultural training</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>33. # EMA</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
<tr>
<td>34. # Regulatory Frameworks</td>
<td>Researchers - health professionals, PhD students, researchers and medicines developers</td>
<td>France</td>
<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
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<td>35. # Medical Research</td>
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<td>France</td>
<td>English</td>
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<td>36. # Regulatory Frameworks</td>
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<td>37. # Biomarkers and personalized medicine</td>
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<td>English</td>
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<td>43. # Medical Research</td>
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<td>English</td>
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<td>English</td>
<td>2019</td>
<td>Free</td>
</tr>
</tbody>
</table>

**Notes:**
- Free access and unlimited courses are typically online platforms that allow users to access materials without cost, usually for a limited period or with some restrictions.
- Training cost depends on the training course, with some courses being completely free while others may have a nominal fee or require membership fees.
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 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
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 approximately 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**
- **# responses:** 189
- 25% Physicians
- 15% Clinical trial manager/project coordinator
- 15% Member of a Patients' organization
- 33% Other

**East EU**
- **# responses:** 16
- 57% Academic researcher

**Turkey**
- **# responses:** 142
- 31% Academic researcher

**Topics**
- Digital health
- Healthy economies
- Proof of concept to industry
- Regulatory affairs
- Translational research
- Information systems
- Biotechnology & biopharmaceuticals
- Innovative people and the role of one
- Managing play
- Introduction to context

**Targets**
- 29% Students (PhD or medicine)
- 18% Academic researchers
- 19% Physicians
- 13% Patients
- 29% Students (PhD or medicine)
- 20% Academic researchers
- 16% Physicians
- 13% Patients
- 25% Academic researchers
- 15% Physicians
- 10% Patients

**E-Learning Tools**
- Active learning exercises
- Lec / video 10 min
- Advanced Lec / video 30 min
- Annotated article
- PowerPoint (with subtitles or voice over)
- Webinar

**Results**
- 81% consider that interactivity between learners is important
- 88% consider that exchanges with experts are important
- 66% think accreditation is important
- 90% VS 81% VS 98%