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European Joint Programme on Rare Diseases

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Del 3.1
Dynamic catalogue of EJP-RD sustainable resources including Service Roadmap Database

Organisation name of lead beneficiary for this deliverable:

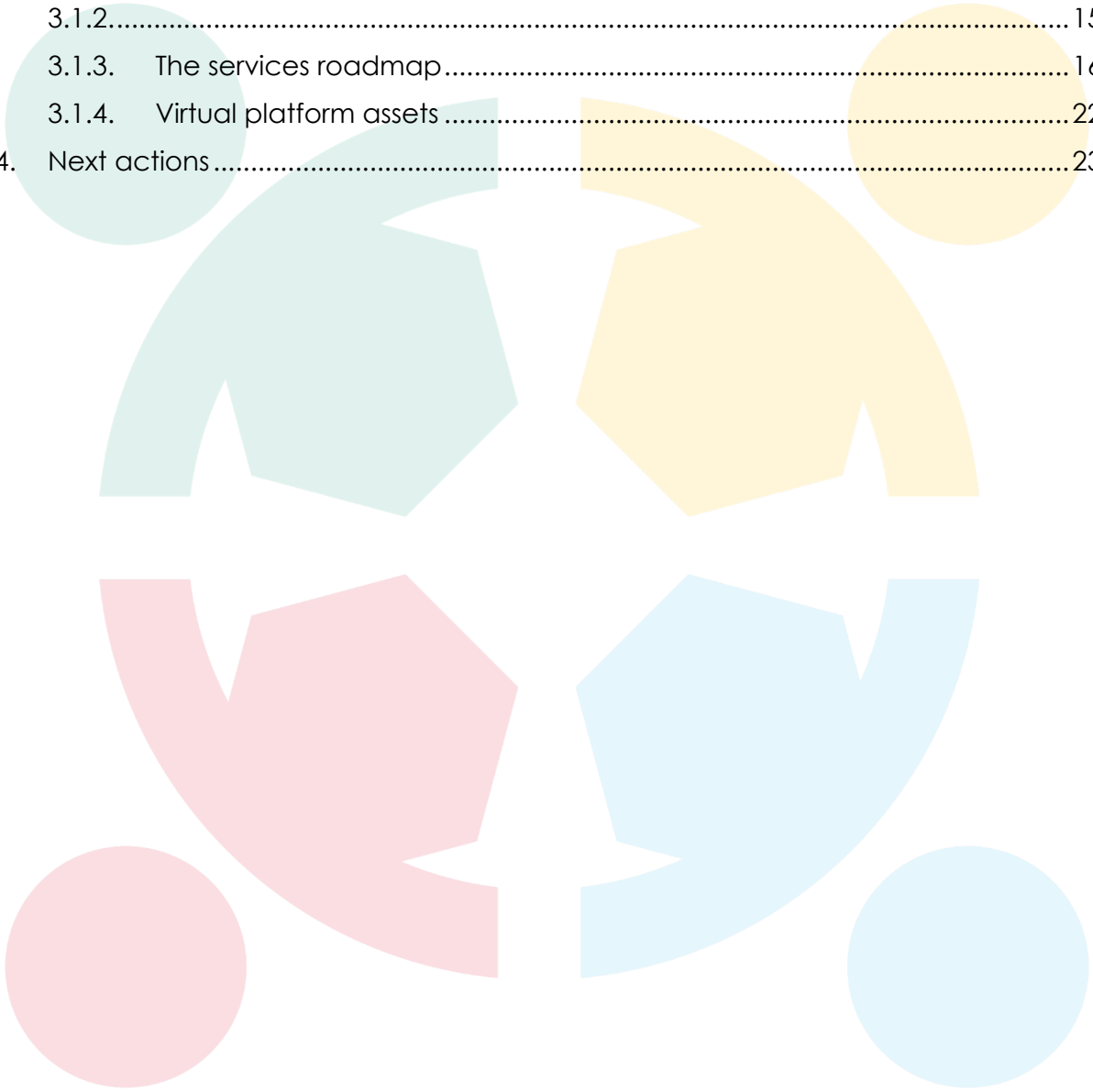**Contributors:** ISCIII; INSERM Coo; EATRIS; DTLS (ELIXIR-NL)

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1. Introduction

Sustainability, as a key factor for maintaining the rare diseases (RD) research ecosystem envisaged by the European Joint Programme on Rare Diseases (EJP RD), has been addressed since the programme's inception.

Work package (WP) 3 of the transversal pillar of the project is dedicated to this topic, with the aim to support all WPs on sustainability issues, while designing a suitable sustainability plan for the generated resources, activities, services, and outputs that contribute to the advancement in RD research, namely EJP RD elements or assets. The sustainability plan consists of the detailed strategic, operational, and financial plans that enable the optimal ongoing exploitation of these elements or assets. This relates to the exploitation, maintenance, and further development of the useful mentioned products, beyond the duration of the EJP RD funding. One key part of this is an analysis of the benefit to stakeholders.

One of the tasks in WP3, *"Task 3.2: Preparation of the sustainable EJP RD services catalogue, supporting the EJP RD dissemination and communication activities",* is specifically designated to identify and build a catalogue, dynamic, of these elements and assets, which helps dissemination too.

The Catalogue showcases the added value of EJP RD's activities and services, and illustrates how the elements connect with anticipated customers, partners, and resources, obtaining a conception of the key value propositions and activities. It also improves the communication to the interested stakeholders, as a tool for approaching target users, increasing return of value, which increases interest, and thus sustainability options.

The catalogue was subject to the evolution of the activities in the programme. The initial identified elements were changing through time, and this reflected on the results. These results have been also the basis for the sustainability roadmap (Task 3.3) which aims to pave the way towards the sustainability of each of the elements and assets produced or improved by EJP RD that would need a business plan, without losing the overall vision.

The Catalogue, after validation by the responsibles of the elements and services (WPs and tasks leaders) will be disseminated by WP5. Also, given this catalogue is a living document, dynamic in nature with expansive functionalities, WP3 will oversee any required update(s), until the end of the Programme.

2. Methods

Several approaches were taken to identify, develop, and refine the final elements included in this first[1] version of the dynamic catalogue, as seen in figure 1. The detailed

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[1] We call this the *first* version since it is the official presentation of the dynamic catalogue. Due to its nature, changes may be expected along evolution of elements and assets.

methodology and results of each step are depicted in the **Deliverable 3.4**. *"Proposal of structure, governance and financial model and global sustainability roadmap"* due in M46.
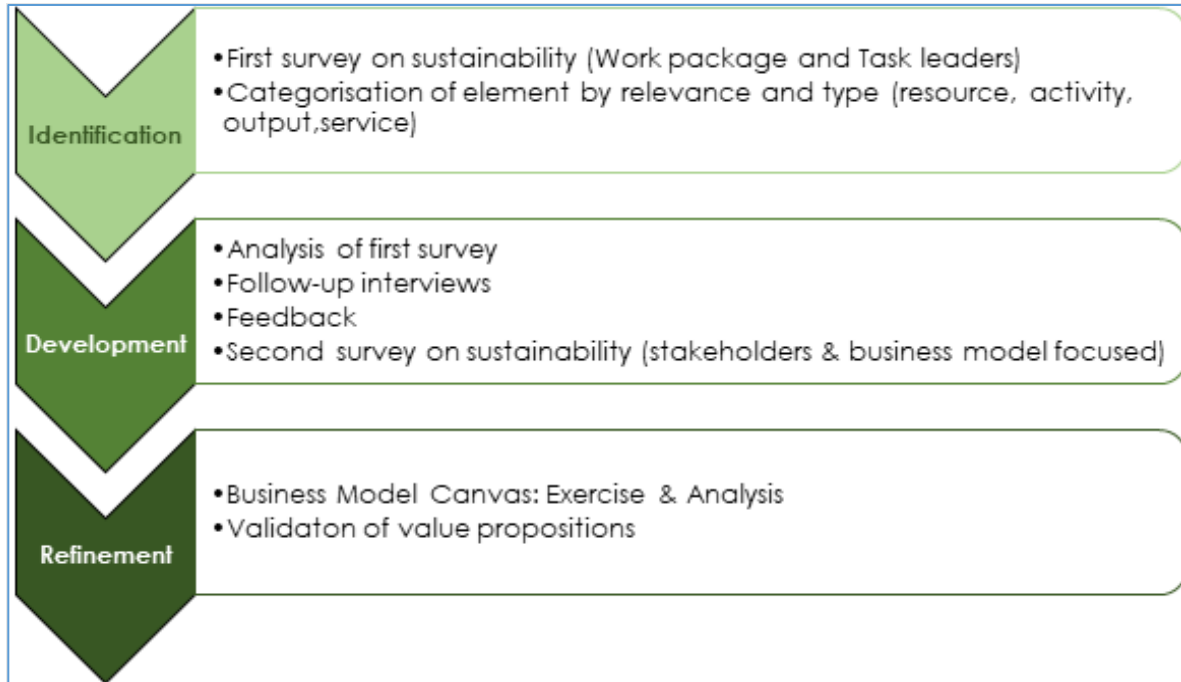

Identification
- First survey on sustainability (Work package and Task leaders)
- Categorisation of element by relevance and type (resource, activity, output,service)

Development
- Analysis of first survey
- Follow-up interviews
- Feedback
- Second survey on sustainability (stakeholders & business model focused)

Refinement
- Business Model Canvas: Exercise & Analysis
- Validaton of value propositions

Figure 1. Dynamic catalogue elements and assets pathway

3. Outcomes

Not all elements and assets identified in 2020 have landed in this version of the dynamic catalogue, as shown in Figure 2 on changes in number of elements. After several rounds of deliberations and follow-up, based upon the guidance and prioritisation criteria established in the **Sustainability Handbook**[2], the final list of elements and assets in the dynamic catalogue differs from the initial identification. Mergers of elements, inclusion of elements in packages or in larger ones, or the translation of the ever-changing challenge involved in building the virtual platform (VP), are the reasons for these modifications. Specifically, transversal activities and Pillar 2 assets underwent the greatest changes through the period, and only when the VP assets had enough maturity, the refinement could begin. Modifications also occurred due to the general evolution of the activities within EJP RD, which are dependent on the RD community needs.

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[2] The Sustainability Handbook (AD 20) prepared by WP3 contains the criteria and key sustainability factors and criteria for prioritising. The dissemination of information and education about broad sustainability issues, specific resources and plans will include participation at dedicated events and sharing of the handbook and written resources as well as inclusion of relevant materials within the online toolbox.
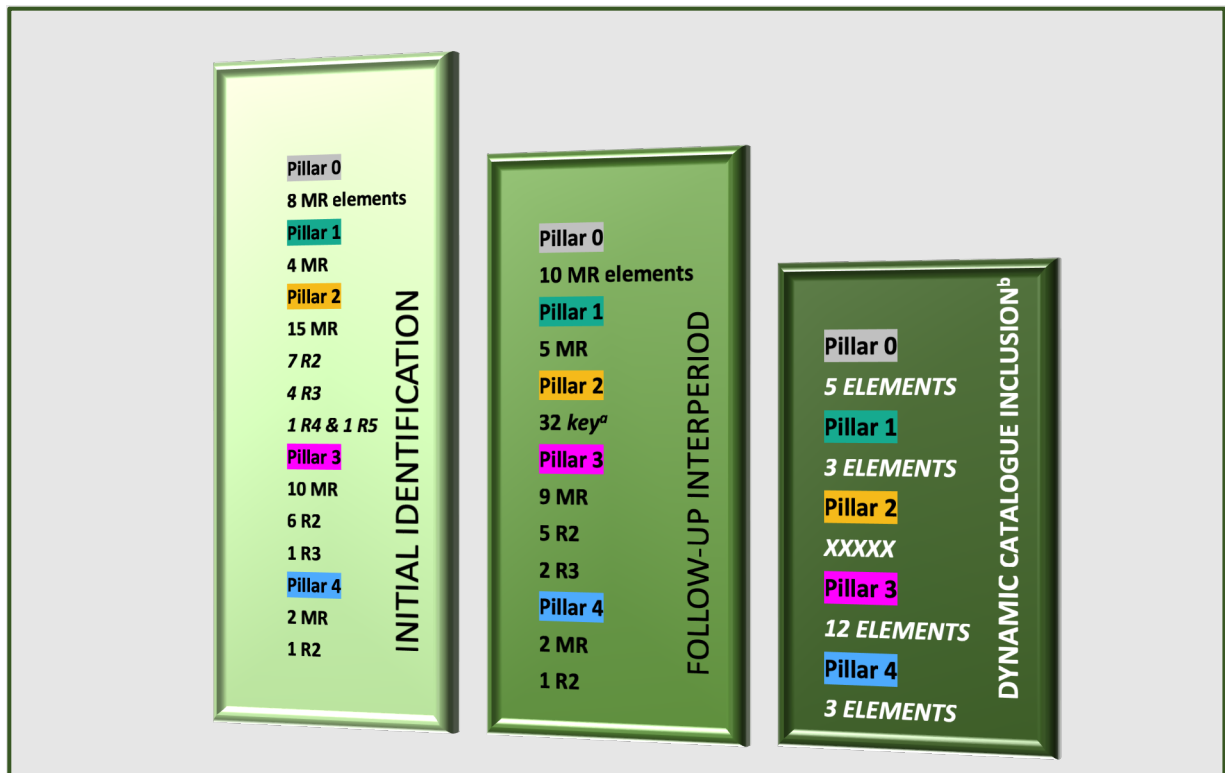
Figure 2. Changes in numbers of elements through the period:

MR: most relevant; R2: second in relevance; R3: third in relevance; R4: Fourth in relevance; R5: Fifth in relevance.

ᵃ With the maturity of the P2 elements initially identified, the elements came to be called assets and prioritized into *key assets* for the VP, although subject to change based on evolution of the VP.

ᵇ Please note that in the dynamic catalogue relevance is not shown. This is because relevance was only utilised for prioritisation purposes. However, a MR element could be removed instead one with other degree of relevance, after deliberation of the WP and Task leaders, due to other factors.

3.1. The Dynamic Catalogue

3.1.1. The activities, resources, and outputs collection

This part of the catalogue shows the activities, resources and outputs that contribute to the advancement towards the research ecosystem that EJP RD pursues to satisfy the needs of the RD Community.

The elements follow the pillar-order, besides being colored according to which pillar they belonged[3]. The type of element is displayed in the left (vertical text), and added value and activities in rows, with contact details.

The following elements are included:

- Sustainability Handbook
- Re(ACT) Congress and IRDIRC Conference
- Networking Support Scheme
- Research Challenges Scheme

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[3] Pillar 0: Coordination, Transversal Activities & Communication, in grey colour; Pillar 1: Fundings and Calls, showed in green; Pillar 2: Coordinated Access to Data and Services, in orange; Pillar 3: Training and Empowerment, in fuchsia colour; and in blue, the Pillar 4: Innovation and Clinical Trials Support

- Training activities

Detailed information on processes and characteristics may be found in **Del 3.4.**

Sustainability Handbook

OUTPUT	**VALUE PROPOSITIONS**	The general guidance on sustainability key factors helps the RD Community and other areas to plan and operate in a sustainable manner
	ACTIVITIES	Expansion-dissemination of knowledge State of the Art of Best Practices on Sustainability
	CONTACT	Ben Lydall benlydall@eatris.eu

Re(ACT) congress - IRDiRC conference

ACTIVITY	**VALUE PROPOSITIONS**	Presentation cutting-edge research. Networking / exchange ideas. Discussion of policies related to rare diseases research. Share experiences and perspectives from patients. Promotion of scientific cooperation and research on rare and orphan diseases. Increased visibility for industry involved customer and its solutions
	ACTIVITIES	Organisation of the Unique F2F congress that fosters RD Research and Policy independently on medical domain. Timely preparation & dissemination of Communication campaigns. Establishment of Scientific Committees. Topics definition and speakers' selection. Set a Business Plan for the Lobbying strategy & Sponsorship. Statistical analysis on participation & Feedback survey for congress improvement. Dissemination of congress material (recordings, presentations, etc.) to participants and upon purchase for some elements.

CONTACT	congress@react-congress.org

Networking Support Scheme

ACTIVITY	VALUE PROPOSITIONS	Organisation of networking events that involve RD research's stakeholders in countries involved in the EJP RD. Emphasis on involvement of PAOs, Early Career Scientists from all EJP RD involved countries and stakeholders from usually underrepresented countries in RD research networks. These involvements encourage multidisciplinarity in all EU, associated and third countries, and improve research efficiency and faster progress from lab to patients, also in future through the involvement of ECS. International, multistakeholder networking is key for RD research to move forward. No other European networking funding scheme for RD research exists as far as we know RD research community building
	ACTIVITIES	Provision of funding for organising a Networking event while encouraging the involvement of underrepresented stakeholders and countries. Budget, application and evaluation procedures and documents, evaluators and a secretariat are required.
	CONTACT	nsss@zonmw.nl

Research Challenges Scheme *(Public Private Partnerships)*

ACTIVITY	VALUE PROPOSITIONS	RDR Challenges call through PPPs allow an innovative funding scheme involving multiple contributors: consortia of applicants (Academia, SME, and Patient Advocacy Organizations) on one hand and industry sponsors on the other hand. This call is a milestone in improving public-private partnerships in the pre-competitive space and as such, it contributes to find a sustainable model for the next EU's research and innovation funding programmes. First lessons to be learnt already are the need for a

		neutral and trusted third party to help build a trust relationship facilitating negotiations between public and private stakeholders.
	ACTIVITIES	Identification of challenges and agreements with industry for sponsorship of part of the budget needed by the applicants with a defined process: Call for projects, eligibility criteria and evaluation; Implementation and initiation of selected projects; Management of the funding resources, establishment of contracts and distribution of funding to selected projects.
	CONTACT	Christine Fetro christine.fetro@ejprd-project.eu

Training material & module (Orphanet)

ACTIVITY	**VALUE PROPOSITIONS**	A training for trainers (TfT) session and a trainer's toolkit: Reserved to Orphanet Network members in order to empower them to be ambassadors of the Orphanet Nomenclature and ontology in their country and to deliver trainings in their countries in local languages.
	ACTIVITIES	Basic Module (videos, presentations, hands-on) that allow the participants to be able to: 1- Explain what the Orphanet nomenclature and the Rare Disease Ontology (ORDO) are. 2- Access Orphanet data that is relevant to their rare disease research activities dedicated forms and helpdesks.
	CONTACT	

Training quality assurance NGS

ACTIVITY	**VALUE PROPOSITIONS**	The course is a mixture of lectures, discussions and hands-on sessions, with a large scope on Next Generation Sequencing (NGS) diagnostics, with yearly updates. The course builds on expertise gained within EuroGentest and helps in the translation of research tools to diagnostic applications (in line with the IRDiRC objectives). The impact on the quality and reliability of NGS results, obtained through rare disease research.

		Expert trainers from different countries guarantee up-to-date trainings at international level, and selecting trainees from different countries and institutes make sure that knowledge will be used all over.
	ACTIVITIES	Key activities: *During the preparatory phase*: put together the programme, dissemination, selection process of the trainees in collaboration with international experts. *During the course*: daily coordination, contacts and discussions between trainers and trainees, to gather feedback from participants Other activities during the course: plenary sessions by experts in the field, space for Q&A and discussions, practical hands-on sessions. After the course: feedback is collected and evaluated.
	CONTACT	Liliane Geyskens Geyskens.liliane@ejprd-project.eu

FAIR Registries & undiagnosed Courses

ACTIVITY, RESOURCE	**VALUE PROPOSITIONS**	Focus on specific needs of the RD Community, updated yearly. Hand on exercises, use cases and demos. Material and contact to speakers available. Promotion of further interaction & collaborations. It represents the opportunity to meet international speakers and create networking among professionals involved in (i) the FAIRification of RD Data (ii) RD Registries (iii) undiagnosed rare conditions.
	ACTIVITIES	During the courses participants will learn: (i) the resources needed for the establishment and maintenance of a high-quality registry, (ii) the legal and ethical issues in compliance with the EU General Data Protection Regulation, (iii) the main steps and the latest useful tools, for the FAIRification of data and (iv) the newest strategies and tools to foster solutions of undiagnosed RD cases.
	CONTACT	Claudio Carta claudio.carta@iss.it

Trainings on biobanks & samples

<table>
<tr>
<td rowspan="3">ACTIVITY, OUTPUT</td>
<td>VALUE PROPOSITIONS</td>
<td>Delivery of training workshops on RD biobanking.
To favour communication and knowledge exchange about RD research biobanking and related operating procedures.
It increases visibility-interest on sustaining.
Delivery of preparatory material and training materials:
To ameliorate sharing of available templates and preparatory materials.
To have a dedicated person from the training funding programme/organisation to support secretarial activities, harmonizing and aligning all the workshops materials.</td>
</tr>
<tr>
<td>ACTIVITIES</td>
<td>To train junior and senior researchers, healthcare professionals to manage RD samples and their handling and sharing.
To favour networking among stakeholders of the RD community.
To share knowledge and news on the topic with associations of patients and patients. Surveys are key for feedbacks on workshops
To improve the sharing of training materials:
Preparing scientific programs, guidelines and certificates for attendants and speakers, using an online collaborative platform, logistic and instructions, confirmations emails for attendants/speakers, presentations template, feedbacks questionnaires, registration forms, participants evaluation criteria
Training materials: To collect and organize training materials and share via the online collaborative platform with all the attendants; to prepare and send instructions for accessing the training materials.</td>
</tr>
<tr>
<td>CONTACT</td>
<td></td>
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</table>

Programme delivery for the 3 schools

ACTIVITY	VALUE PROPOSITIONS	Empower rare disease patient advocates with knowledge and skills to take part in patient engagement roles side-by-side with researchers, regulators, and industry and policy makers. Increase the leadership capacities of patient advocates to advocate for rare diseases at EU and National level. Build a strong community of alumni who act on behalf of and for the benefit of the RD community. Patient-led and independent trainings. Quality: learning from experts Variety: topics, diseases, countries, cross-generational Open access: for the community, experts and alumni at the same level. Future-oriented: engage youth and innovative delivery methods. Accessible/inclusive for all rare diseases, across borders and levels of disability
	ACTIVITIES	Training: F2F training, online training, webinars, e-learning courses. Mentoring and problem solving.
	CONTACT	openacademy@eurordis.org

Workshops & training contents for paediatric patients

ACTIVITY, OUTPUT	VALUE PROPOSITIONS	Training is crucial to facilitate the implementation of children rights to participation in decision regarding their health. Training is important to facilitate the involvement of paediatric patients in ethically sound rare diseases research. Training helps to solve the lack of engagement of children in decision-making process regarding their health. Many challenges have to be faced for the engagement of children. It applies specifically tailored methods to the training and empowerment process of paediatric patients. They will allow to give them the skills needed to be involved as advocate.

	ACTIVITIES	Many challenges have to be faced to foster for the engagement of children. Training helps in increasing the awareness of children about main issues contributing to empower and engage children and solve the lack of children participation in advocacy activities in the field of rare diseases. Age-appropriate methods, including child-friendly materials, are applied within the training and empowerment process of paediatric patients. They allow to provide them the skills needed to be involved as advocates. Organisation of face-to face workshops, which may be adapted to online format when needed. Design and develop the training workshops aimed at increasing knowledge and providing young rare disease patients with skills, enabling them to get involved in rare diseases biomedical research and play a role in improving healthcare services for all patients by contributing with their specific experiences.
	CONTACT	info@teddynetwork.net

Online academic course (MOOC)

ACTIVITY, OUTPUT	**VALUE PROPOSITIONS**	Cover the lack of transversal training on rare diseases easily accessed by a wide audience, by delivering free, easily accessed and ergonomic MOOCs on transversal rare diseases research topics, with scalable content. Increase the awareness level on rare diseases research at a global level. Complement to already existing "traditional" studies programs in the universities. Stimulation of different stakeholders' interest to develop collaborations/new projects focusing on RD. No pre-requisite to access the online training: MOOCs are developed in priority for graduate students, PhD and young researchers, but is of equal interest and relevance for clinicians, patients, industry staff or lay public who wants to know about the subjects. MOOCs are continuously open for enrollment, but they can be freely attended for the duration of the course. Two mentoring windows per year are planned in order to facilitate the learning experience of participants, by answering to their question and stimulating discussions within the learners' community.

ACTIVITIES	**MOOC updating:** check if the information given (i.e., contents but also links to external publications/relevant websites) are up-to-date, if not they must be reviewed and modified accordingly; Identify if there is a specific need raised by the participants/developers to include a content that was not previously incorporated; define who can elaborate it and implement it in the platform; managing the copyright. **Managing the communication campaign for each MOOC,** by contacting organisations/institutions/associations throughout the world that fall in the target of the MOOC. **MOOC mentoring (2 facilitation windows are foreseen each year):** providing personal and timely support to MOOC participants, facilitating the interactivity among the participants and also with the formation itself, stimulating the maintenance of the interests of the participants. **Managing communication and interface** between course developers and the FutureLearn platform.	
CONTACT	Magda Granata magda.granata@fondation-maladiesrares.com	

ERN Workshops (Training multiplicators, researcher and clinicians)

ACTIVITY, OUTPUT	**VALUE PROPOSITIONS**	Sharing of up-to-date multidisciplinary knowledge and methodologies applicable for several different RD related research areas, highly relevant for ERNs and involved sites, at the European level, with option of accreditation if clinicians are a significant participant group.
	ACTIVITIES	Establishing and implementing calls for training activities Organisation of workshops (Procedures) Collaboration with selected workshop organisers
	CONTACT	info@ern-rnd.eu

ERN Workshops (Material)

OUTPUT		
	VALUE PROPOSITIONS	ERNs Workshops (Training multiplicators, researcher and clinicians) material. This training material comprehend research concepts and topics that are cutting edge and of cross-ERN benefit
	ACTIVITIES	Materials organisation and Standard Operating Procedures (SOP) for workshops
	CONTACT	info@ern-rnd.eu

Secondments (Mobility fellowships)

ACTIVITY, OUTPUT		
	VALUE PROPOSITIONS	The fellows have based on a specific research project/aim the possibility to perform research that is of benefit for the fellow, the host and home institution as well as involved ERNs, obtain a highly specific and tailored training, acquiring research experiences in a new environment and learning new methodologies, through exchanges between institutions.
	ACTIVITIES	Establishing and implementing calls for researcher exchanges Organisation of the mobility fellowships
	CONTACT	info@ern-rnd.eu

3.1.2. The services roadmap

This part of the catalogue shows those elements that are identified as services[4]. These services may be interrelated and share characteristics, channels and necessary resources. This possibility facilitates their disposition as a bundle of services, if needed.

The elements follow the pillar-order, besides being colored according to which pillar they belonged[5]. The type of element is displayed in the left (vertical text), and added value and activities in rows, with contact details.

The following elements[6] are included:

- Coordination services EJP RD & IRDiRC SciSec.

- Central Helpdesk.

- Advisory Regulatory Ethics Board (AREB).

- Monitoring.

- Innovation Management Toolbox.

- Mentoring services.

- Clinical Trials Support Office.

Detailed information on processes and characteristics may be found in **Del 3.4.**

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[4] Please, note that services in here are referring to a category of elements that provide assistance, support or backing to users, independently of the model of sustainability applicable and it does not represent necessarily payments.

[5] Pillar 0: Coordination, Transversal Activities & Communication, in grey colour; Pillar 1: Fundings and Calls, showed in green; Pillar 2: Coordinated Access to Data and Services, in orange; Pillar 3: Training and Empowerment, in fuchsia colour; and in blue, the Pillar 4: Innovation and Clinical Trials Support

[6] Support services are envisaged in this group. In the case of FAIRIfication Services, they will be presented along the VP assets

Coordination services EJP RD & IRDiRC SciSec

SERVICE, RESOURCE	VALUE PROPOSITIONS	Contribution to efficient programme/initiative planning, execution, monitoring and, issue solving to meet optimal quality result within deadlines. Proactive & adaptable (Hybrid/Agile) coordination of activities and information linkage including with external initiatives (outreach). Optimisation of the use of resources. Providing targeted professional multi-domain expertise matched with program/initiative segments. Proactive, stakeholder-targeted and adaptable. Communication & dissemination strategy and planning. Multiple skills and intercultural awareness (with excellence, professionalism, and kindness). Raise awareness and foster links with other initiatives/programs, (sharing common or aligned targets) allowing for efficient resource use & synergistic action. Facilitating the multi-stakeholder governance and decision making.
	ACTIVITIES	Ensure smooth and efficient programme execution according to validated planning. Continuous support of involved partners and EC single entry point to the consortium. Financial and administrative management of the programme. Communication and dissemination strategy and implementation. Preparation, organisation and follow up of consortium meetings. Quality follow-up and monitoring of the activities. Coordinate the development of Key Performance Indicators and enforce them. Efficiently guide, and support the network of RD stakeholders to achieve the objectives of the project and beyond. Guidance and contribution to strategic planning.
	CONTACT	coordination@ejprarediseases.org scisec-irdirc@ejprarediseases.org

Central Helpdesk

SERVICE, RESOURCE	VALUE PROPOSITIONS	Provision of centralised easy access to RD expertise. Tracked request processing with expedited appropriate time to address (RD research) request. Opportunity to build/expand own RD network. Opportunity to form/integrate multi-disciplinary/multi-stakeholder teams (networking service?). Increased awareness of RD resources/services and opportunities. Access to a large number of experts in multiple fields and topics. Tailored services & FAQ. Awareness & Analysis of the need of RD community. High value case studies that inspire customers for generating ideas (research questions, think about networking possibilities, discover resource use, etc.).
	ACTIVITIES	Analyse and translate the request. Match appropriate expertise to address the request. Contact matched experts to provide a feedback/solution and liaise with the requester. Ensure that an outcome is identified/obtained for each request. Update experts/expertise database (contacting involved experts). Outreach to uses through dissemination (increase visibility) Propose a tree structure/ontology of the services offered by EJP RD Generate answer to the most frequently asked questions. Stablish a multi-stage process for addressing a request. Creation of request database. Semi-automated/automated process to match requests with experts & services. Timeline follow-up for request processing. Tailored price estimation for specific requests.
	CONTACT	helpdesk@ejprarediseases.org

Advisory Regulatory Ethics Board (AREB) *(ELSI SERVICES)*

SERVICE, RESOURCE		
	VALUE PROPOSITIONS	Addressing the need of experts in the ELSI/regulatory field through a reference single contact point easily identified. Provision of quality and time-efficient ethics review of RD research proposals submitted ensuring ethically-sounded researches and accelerating their implementation. Increase the awareness on ELSI/regulatory topics and requirements for compliant RD research. ELSI/regulatory training & dissemination hub providing ad-hoc advice for specific topics. Optimised resource use and completeness of information through active collaboration with other ELSI/regulatory support services. FAQ Tracked request processing with expedited appropriate time to address (ELSI/ regulatory RD research) request.
	ACTIVITIES	ELSI/regulatory, support and advice (Analyse and translate the request/need; Match appropriate expertise to address the request; Contact matched experts to provide a feedback/solution and liaise with the requester if needed; Ensure that an outcome is identified/obtained for each request). Perform ethics review processes of RD research projects/activities to accelerate/facilitate the implementation of such projects in compliance with the ethics requirements and regulatory provisions. Disseminate news and advancements in the ELSI/regulatory field and outreach to users (increase visibility). Collect available and develop and execute training on identified ELSI/regulatory topics with a Rare Diseases Focus. Provide communication & support channel to ensure ELSI/regulatory office is efficiently connected with support services from other organisations/ programmes/ initiatives. Perform ELSI/regulatory watch to keep knowledge up to date. Initiate and maintain collaboration with other ELSI support services. Update experts/expertise Knowledge (contacting experts, collecting, and categorising type of request, indicating process followed & outcomes for each request). Develop semi-automated/automated process to match requests with experts, services, and possible process to follow and answer to provide (including proposal of a tree structure/ontology of the ELSI/regulatory service).
	CONTACT	areb@ejprarediseases.org

Monitoring

SERVICE	VALUE PROPOSITIONS	Tool that permits the centralisation and analysis of monitored funded projects. Reinforced by feedback from experts. The dissemination of Projects Best-Practices (design, execution, etc.) identified from monitoring activities includes the communication of main results to the general public.
	ACTIVITIES	Annual collection of information from projects. Analysis of advancement of individual project (in term of progress and outcomes). Analysis of impact of the funding opportunity as a whole evaluation of the funding tools (as scheme). Ensure projects are progressing towards their objectives. Analyse use of EJP RD/ (and the coming Rare Diseases Partnership) tools & standards by funded projects. Organisation of mid-term monitoring meetings. Continuous collection of monitoring information sub-set from projects. Development of final monitoring reports.
	CONTACT	helpdesk@ejprarediseases.org

Innovation Management Toolbox (IMT)

SERVICE , RESOURCE	VALUE PROPOSITIONS	Centralised repository of resources that provides searchability Answers to specific questions. Reactiveness. It does not require registration and free of charge.
	ACTIVITIES	Curation and update the list of resources. Website hosting maintenance. Customers or researchers' helpdesk. Website updating.
	CONTACT	Ben Lydall benlydall@eatris.eu

Mentoring

SERVICE	**VALUE PROPOSITIONS**	To address lack of access to specialist expertise, of awareness and unknowns. Easy access to full gamut of therapy development expertise. Opportunity to increase success rates in translational research projects of individual researchers. Systemic benefits: opportunity to increase robustness, improve outcomes, reduce failure rates in translational research projects, by stimulating interdisciplinarity and building capacities.
	ACTIVITIES	To provide free of charge expert mentoring services to researchers in Rare Diseases, utilising multi-disciplinary high-level expertise. To recruit mentors, get users, maintain portfolio of projects and mentor database. Outreach: onboarding mentors and mentees, onboarding projects (legal and coordination workflows). To manage mentor/mentee relationships and contact's moments. To report.
	CONTACT	Ben Lydall benlydall@eatris.eu

Clinical Trials Support Office

SERVICE	**VALUE PROPOSITIONS**	Support/advice for the planning and design of clinical studies for Rare Diseases (RD), with special focus in multinational research. Need for methodological and operational support to set up multinational research studies. By providing support/advice through the expertise of: a) Methodologist specialized in rare diseases/small populations (Aachen University), b) ECRIN, specialized in operational support for multinational clinical studies Investigators interested in the setup of multinational clinical studies for rare diseases. There is no similar service free of charge for the Rare Diseases community. It is built up on the expertise of partners with years of experience in their respective fields.
	ACTIVITIES	Support and advice (Analyse and translate the request/need; Match appropriate expertise to address the request.

	Contact matched experts to provide a feedback/solution and liaise with the requester if needed; Ensure that an outcome is identified/obtained for each request). Supporting and advising RD clinical studies to accelerate/facilitate the implementation of such projects. Key activities will be performed according to a procedure described in a Terms of reference document: processing of the requests relies in a secretariat and the expertise of the partners involved. The development and good performance of the activities rely on the expertise of the main partners involved.
CONTACT	Marta del Alamo marta.delalamo@ecrin.org

3.1.3. Virtual platform assets

The virtual platform will be presented separately. Although it could be considered a bundle of services, its unique configuration, with several assets that may fall in any of the categories (services, outputs, resources, or activities) requires a specific evaluation which is ongoing. The first set of VP value propositions and activities will be provided in Q4 2022.

4. Next actions

The dynamic catalogue is one of the tools to give visibility to EJP RD results and constitutes a relevant tool for dissemination, including the approach to interested stakeholders. The approach to stakeholders begun with the identification and posterior confirmation. A preliminary identification has been carried out during the processes to identify and assess the elements by the WP and Task Leaders.

To do so, the aim is to identify, for each element mentioned within each Pillar as well as for the supporting services, a stakeholder able to contribute to the sustainability of this element in the long term.

The confirmation of stakeholders is taken place in two steps:

- First, to complete the pre-identification of potential stakeholders, carried out by the WP3 coordination team

- On the basis of this pre-identification, a contractor specialised in business plans and project sustainability will finalise the identification and provide with different alternatives of stakeholders that could be a potential funder for the element. Potential agreements might be done after the approach to the identified stakeholders.

Regarding dissemination, WP5 will publish a dynamic digital content in the EJP RD website, as a digital catalogue, and the deliverable, which is public, after the approval by the Ex-Com.

Finally, the elements included in this catalogue, as well as the Virtual Platform assets, will be part of the Proposal of structure, governance and financial model and global sustainability roadmap, detailed in Deliverables 3.4 and 3.5, where sustainability plans are detailed.