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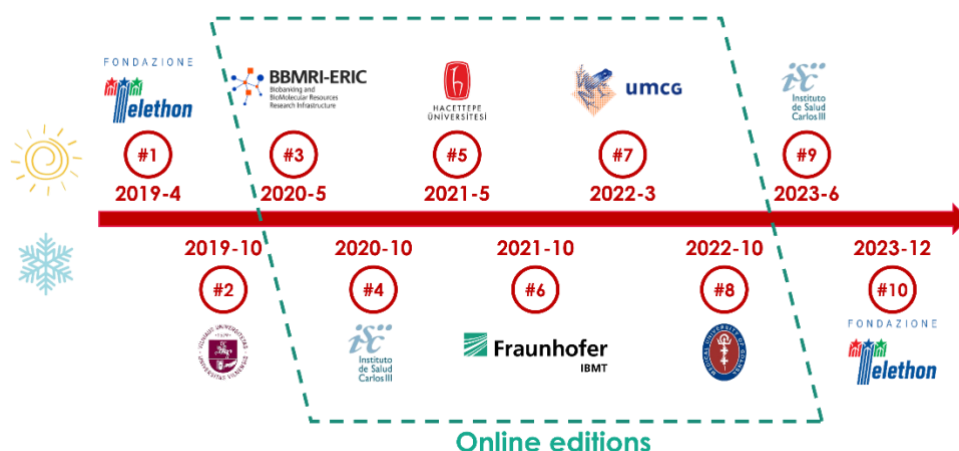
1. Introduction and Objective

Biological samples from rare disease (RD) patients are precious resources for research. Due to their intrinsic rarity, these samples are often dispersed in multiple biobanks and are difficult to locate. The accessibility of these biological samples underpins the development of new diagnostic techniques, biomarker development, identification of potential therapeutic targets and testing therapeutic response.

Biobanks are key research infrastructures that offer professional services to the research community for sample sourcing and management. They play an important role in maintaining the quality of the biological samples from time-of-collection to distribution, as well as conserving the privacy and wishes of the patients as indicated within the consent forms. Biobanks (eg. [EuroBioBank](#)) have begun to share RD sample datasets to centralised sample catalogue to facilitate sample access and support the change towards best practice with their special position interfacing patients, clinicians and researchers.

Therefore, upon the identification of such specific needs of training, Task 14.4, within Work Package (WP) 14 of Pillar 3 of the EJP RD, has developed during the period 2019-2023 a series of focused workshops to help the RD community with the experience of all actors around the biobanking activities. These training workshops are part of a capacity building programme put forth by the EJP RD Pillar 3. The goal of this training workshops was to develop the capacity on data management of biobanks, allowing them to optimise operations to support the need of RD research community. Through the workshops, we aimed to promote FAIRification of resources and research reproducibility^[1]. The training workshops gave researchers linked to biobanks the opportunity to learn how to harmonise and share their RD biological sample data and to encourage direct interactions between RD clinicians/researchers and biobanks, where researchers can exchange on how to leverage biobanks in their RD research. In 2019 and 2023 the training workshops were organised as in-person meetings. Due to the COVID-19 pandemic situation, from 2020 to 2022, the training workshops were held online (see Figure 1).

Figure 1: Online and in-person editions of the WP14.4 Biobank Training Workshops 2019-2023 highlighting the host organizer of the workshop

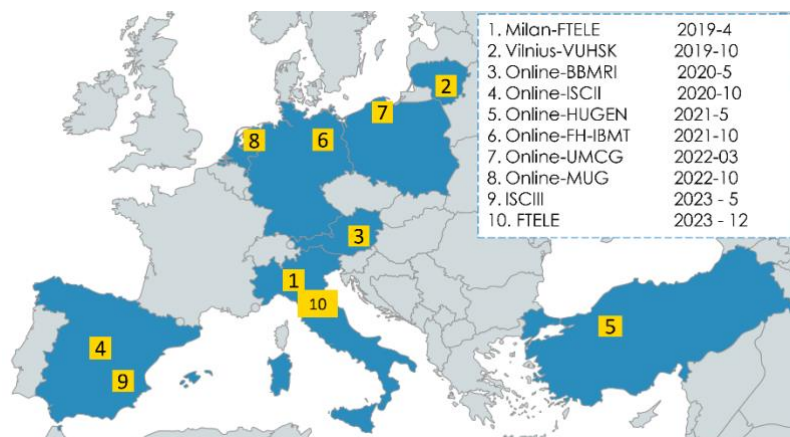


2. Methodology

Definition of Training programme

Over the course of EJP RD, 10 workshops, 2 per year, have been organized to offer capacity building opportunities for biobanks and stakeholders. Each training had a different host organizer which was in charge of organizing their workshop edition, supported in the organization by the Task Leader, FTELE, which was also in charge of supervising the whole training programme. The rotation of the host organizers, located in 9 different European cities (see Figure 2) allowed to maximize participation of stakeholders from different geographical regions in Europe. It was also the goal of the workshop to stimulate conversation and awareness in RD biobanking in different EU countries.

Figure 2: Locations of the Task14.4 Biobank Training Workshops 2019-2023



At the kickoff of the project, the task partners identified topics as relevant for the curriculum of EJP RD Biobank Training programme. The list of topics was discussed within the context of EJP RD goal, the focus of WP 14 and available resources to implement the workshops. The topics were prioritized as core curriculum or additional topics, that can be adapted to the workshops depending on country specific interests or themes on annual bases (Table 1). Approximately 20% of course contents were left to be adjusted according to local needs providing thus the opportunity to diversify the teaching programme.

Table 1: The core curriculum of the Biobank Training workshops and additional topics

Core Biobank Training Curriculum	Additional topics
<ul style="list-style-type: none"> Existing RD networks; EuroBioBank [2,3] FAIR principles, MIABIS [1,4] ELSI considerations for data sharing [5-8] Ontology & Orphanet Nomenclature Practical session on data harmonisation Tool Demos Catalogues and request management Country perspective in RD 	<ul style="list-style-type: none"> Data and sample sharing workflows Human pluripotent stem cell lines (iPSCs) annotation & registration How to set up a biobank Long term sustainability How to network and engage international collaboration How to write a biobank business plan

The in-person biobank training workshops contained plenary lectures and interactive small-group exercises, based on the *Problem-Based Learning* (PBL) method. PBL is a highly interactive and learner-centred approach where the learning occurs by working in a small group assisted by a facilitator to develop a solution of a Problem Case. Practical sessions on data management and demonstration of related tools were also part of the programme. Generally, the in-person workshops were divided in modules (or parts), the first part covered the general ELSI (ethics, legal and societal implications) and theoretical elements of the curriculum with group problem solving sessions, whereas the second one covered data and tool related practical sessions (Table 2). At the end of the workshops, the participants had the opportunity to present their group solutions and discoveries in plenary and discuss what they have learned with the trainers.

In the 2020 Spring edition, which we were able to deliver in May 2020 despite the difficulties of the pandemic we were facing, the PBL method was maintained, despite the online meetings limitation (see details below in 2020 workshops).

However, as the PBL is a highly interactive and learner-centred approach, it has been decided to suspend it until 2022, when the in-person workshops were restored. Therefore, online editions had a traditional learning method, maintaining anyway the module structure and covering the above described contents (Table 2).

Table 2: Workshop programme general outline

Part 1	Part 2
<ul style="list-style-type: none"> -Introduction to EJPRD and Biobank training - Problem Case & Problem Based Learning Breakout I: Case reading and problem analysis -Lecture -Lecture (topics from Core Curriculum) -Lecture -Breakout II: Problem solution -Solution presentations and review 	<ul style="list-style-type: none"> -Local RD biobanking activities -Lecture (Ontologies) -Tool Demonstrations -Practical session -Feedback

3. Workshops

3.1. 2019 Workshops

In 2019, the theme of the workshops was “**Organizing & maximizing rare disease biological sample data in biobanks**” (<https://www.ejprarediseases.org/training-orga-maxi-rd-biological-sample-data-biobanks/>). This was to take direct advantage of outcomes from previous EC-funded project RD-Connect, to leverage on previous investments and provide training on existing tools and concepts. The two workshops were held in **Milan, Italy (1-2 April 2019)** and **Vilnius, Lithuania (29-30 October 2019)**. The Milan workshop was the very first training workshop offered from the whole EJP RD capacity building programme since the start of the project. The two workshops had similar training contents and organisation.

The 2019 Problem Case described a general scenario and challenges biobanks may face while managing a RD biological sample collection. In particular, it focused on how to make RD biological findable and accessible using the current knowledge base, network, standards and tools. In order to make sure the participants focused the discussion on the specific challenges and came up with solutions, the problem case contained a few assumptions on the basic setup of the biobank.

For more details, see the EJP RD deliverable WP 14-D14.7 "Report on sample data management training workshops" submitted in M12.

3.2. 2020 Workshops

For year 2, the overarching goal was to implement new editions of biobank training workshop, building on the lessons learned in year 1. As planned, two training workshops were implemented between M13 – M24 despite the challenges of COVID-19 pandemic. The Spring training was initially planned to be a face-to-face workshop and was then adapted to the online format. GoToTraining platform was used to support the virtual training and parallel breakout sessions for allowing the PBL method.

The first workshop, jointly organised by the hosting partner BBMRI-ERIC with EASI-Genomics, BBMRI.at, CBmed GmbH and QIAGEN GmbH, took place online on 11 – 14 May 2020, entitled "Implementing Biomedical Research Projects: The Complete Workflow from Concept, ELSI and Privacy Considerations to High Quality Biobanking". The workshop was divided into two modules to address the key issues in research involving human subjects, biological samples and associated medical data. Module 1 covered ELSI aspects as well as the importance of data standardisation, whereas Module 2 (EASI-Genomics) covered the implementation of sample workflows in a clinical context that is compatible with the In Vitro Diagnostic Regulation. A new problem case to highlight the challenge of RD biosample management for research projects was designed by workshop organisers. The new Problem case focusing on the research project added a new perspective to the training and is in contrasts with the year 1 Problem case which focused on making sample collections in biobanks more findable and accessible. The new case presented a research project using DNA and/or cells from a patient affected by a RD for NGS genomics studies. EJP RD partners UMCG, ISCIII, FTELE, BBMRI-ERIC, CHARITE and CNAG-CRG contributed to the workshop with presentations and/or chairing of sessions.

The second workshop took place online on 29–30 October 2020, entitled "Toward Innovative Research Biobanks for Rare Diseases: Overcoming the Challenges". The training organiser was ISCIII, with the support of FTELE. The programme aimed at promoting the importance of biobanking activities in RD research. Therefore, it was addressed mainly to biomedical researchers, medical professionals and biobank managers who wanted to approach innovative biomedical research projects on human biological samples especially focusing on RDs. It contained 2 modules. Module 1 covered the role of the RD biobanks in research, especially considering the biobanking activity in the context of the ERNs, the unmet needs, the key role in unsolvable cases with rare diseases and, through specific biobanks' participation and reviewing some of their research outcomes, providing excellent experiences and practical issues on the activity, for instance, regarding biobanks for brain tissues, patient-derived organoids applied to treatment research, and myoblastoid cell lines. There were talks from EuroBioBank partners, hospital biobank holding samples from ERN affiliated centres, and a presentation on the concept of Pillar 2 Virtual Platform

including the biobank related tools (RD-Connect Sample Catalogue, Biobank Finder, BBRMI-ERIC Directory and Negotiator, Cellosaurus, hPSCreg, Orphanet Catalog). Module 2 covered innovative, complex disease models using such as induced pluripotent stem cells and organoids (in general, biobanking on advanced clinical materials for promoting clinical research on rare diseases), biobank in clinical trials and a dedicated session on ELSI, also including patients' perspective. Differing from the 2020 spring edition, the autumn workshop followed a webinar format with ample Q&A sessions. The content of the training was geared towards clinicians and researchers, to demonstrate the added value of rare disease biobanks. Partners ISCIII, FTELE, HUGEN, CHARITE, BBMRI-ERIC contributed presentations and/or chairing of sessions. The technical platform used for the live training was MS Teams.

3.3. 2021 Workshops

The first online course was organized by HACETTEPE, EJP-RD partner in Ankara, Turkey on May 11-14. Its theme was "Rare Disease Biobanks: Roles in Research Networks and International Collaborations". The workshop was focused on the description of local experiences in RD Biobanks in national plans, ELSI topics such as informed consent types, quality assurance programs and the new ISO standards, FAIR data principles for data sharing and General Data Protection Regulation (GDPR). Moreover, presentations provided examples of cross-border collaborations, biobanks in ERNs, virtual resources created for biobank research in EJP RD. Interactions between participants and lectures were facilitated by moderated question and answer sessions. Coordination team, and partners ISCIII, UMCG, FH-IBMT and FTELE contributed presentations and/or chairing of sessions.

The second workshop was organized by FH-IBMT, EJP-RD partner in Berlin, Germany on October 25-27. Its theme was "Pluripotent stem cells for rare disease research: banking, data, application". The training was aimed at biomedical researchers, medical professionals, and biobank managers who want to learn about the application of hPSC lines in RD research. hPSC data management and biobanking were introduced. hPSCreg and EBiSC described their operations and interactions with the RD community. RD researchers shared their experiences in the application of iPSC for disease modelling. Quality of PSC lines and methods used for developing the lines were also discussed. Moreover, representatives from EJP-RD discussed the quality of data in terms of interoperability and accessibility. Specific ethical considerations for hPSCs were described by an expert from the stem cell field. The future sustainability of iPSC biobanks was also discussed. The topics were addressed from diverse points of views, including representatives from biomedical ethics, patient organizations, applied research and industry. Coordination team, and partners ISCIII, UMCG and FTELE contributed presentations and/or chairing of sessions.

3.4. 2022 Workshops

The 2022 online training workshops were built on the experience and feedback gathered in Years 1-3 from Task 14.4 training activities, Pillar 2, ERNs and JTC-funded scientists. They were the 7th and 8th in the series of 10 workshops to be organized by Task 14.4. The 2022 training workshops were organised with partners UMCG and MUG as the main organisers, with the active support of FTELE. The workshops had a target

audience of professionals working in biobanks (subtask 14.4.1), RD researchers, and clinicians (ERNs). The workshops demonstrated the added value of biobanks for sample discovery and management in preclinical and clinical research. Collaboration with external relevant projects has been considered (e.g., ERICA) with the goal to synergise activities and increase the impact of the trainings. The content of the workshops has been fine-tuned to either gear towards beginner or more advanced-level participants. Workshops contained theoretical lectures on current best practices, technical/practical sessions on useful tools, data management, and privacy-preserving record linkage. Particular attention was made to incorporate Pillar 2 Virtual Platform-supported tools and services. Ample discussion time has been part of the program to encourage active discussion and exchanges between participants and trainers.

The first course was organized by UMCG, EJP RD partner in Groningen, Netherlands on June 14-15. Its theme was "Genetic biobanks for Rare Disease Research". The online workshop focused on the data management and tools, through the discussion of the EJP RD Virtual Platform as a discovery and research platform for rare disease research and the BBMRI-ERIC tools for biobanks and researchers as a discovery platform to make biobanks and their samples findable and accessible. Moreover, the FAIR data principles and data management were presented and discussed. It has been a focus on the use of ontologies such as Orphanet, OMIM and HPO for biobanked samples and the experiences of the EJP RD FAIR Data Stewards with some hands-on experience exercises. Moreover, the ELSI aspects of biobanking were covered, including the European privacy regulations (GDPR) and a special focus on ELSI considerations in Genetics. Further focus was on the sustainability of biobanks including a discussion on public-private collaborations. Coordination team and partner BBMRI-ERIC, contributed presentations and/or chairing of sessions.

The second workshop was organized by MUG in Gdansk, Poland on November 28-29. Its theme was "Biobanking in rare diseases: the Poland experience". The workshop was focused on the EJP RD Virtual Platform tool that enables access to extensive information about patient registries, biobanks, repositories, research analysis, and data for future studies. It has been a discussion on the issues related to the implementation of standard operating procedures referred to the collection, transportation, and provision of biological material developed by the members of the BBMRI.pl Consortium. It has been organised a closer look at the biobank and data management tools like the Biobank Management System (BBMS), the Central IT Platform of the Polish Biobanking Network (PBN) (<https://biobanks.pl>) or the Virtual Microscope a web application enabling access to digital histopathological slides for multiple users in Open Research Data system (<https://digitalpathology.pl>). Moreover, a virtual tour presenting robotic solutions applied in the biorepository of the Fahrenheit Biobank BBMRI.pl at the Medical University of Gdansk has been shown. Notably, a focus on Biobanking solutions applied in RD non-commercial clinical studies and the scientific potential of imaging techniques in translational studies has been done. ELSI aspects of the Polish data protection governed by the GDPR in biobanking, and data privacy rules for the health research sector including the perspective of a patient representative have been discussed. Coordination team, and partner FTELE contributed presentations and/or chairing of sessions.

3.5. 2023 Workshops

The first training workshop of 2023 “ERN biological samples in Rare Disease research: Added value and usefulness” was organized by ISCIII on June 12-14, in Madrid (Spain). This Spring edition, the first in-person after the pandemic, covered the high value of the ERN biological samples repositories in the RD research, and ways to enhance their benefit across research networks. The first day, starting in the afternoon, was dedicated to navigate through the ERNs experiences with biobanking, and the relationship with infrastructures as BBMRI and RD biobanking networks, like EuroBioBank. Trainees understood the particular context for collaboration when managing biosamples in the RD field. The second day was dedicated to the PBL, with work in groups for analysis of the problem, introductory and companion lectures to help the course of the exercise, and a session for solutions and discussion on the analysed problem. The third day, a morning session, served as wrap-up of the training, containing lessons learned, and steps to achieve a comprehensive RD research ecosystem. Coordination team, and partners FH-IBMT, BBMRI-ERIC and FTELE contributed presentations and/or chairing of sessions.

The second and last edition of the training workshop on biobanks “Managing RD biological sample data in Biobanks: lessons learned from the EJP RD training workshops” was organized by FTELE on December 13-14, in Milan (Italy). This face-to-face 2-day training workshop consisted of plenary lectures and interactive small-group exercises, based on the PBL method. The workshop focused on plenary introductory and companion lectures to help the course of the exercise, and a session for solutions and discussion on the analyzed problem followed by the PBL activity. The workshop contained lessons learned also from the past workshop editions, and steps to achieve a comprehensive RD research ecosystem. The first day, starting in the afternoon, focused on plenary introductory and companion lectures to help the course of the exercise, and a session for solutions and discussion on the analysed problem followed by the PBL activity. The second day, a morning session, served as wrap-up of the training, containing lessons learned also from the past workshop editions. Coordination team, and partners ISCIII, BBMRI-ERIC contributed presentations and/or chairing of sessions.

4. Webinars and preparatory materials

Preparatory webinar for training participants prior to the workshop were not required. Instead, a teleconference was necessary prior to the workshop to prepare the PBL facilitators, when PBL was included in the programme. The facilitators must be well prepared in PBL methodology as their role in assisting the group discussions is vital to the success of the workshop. With the help of WP14 leader Claudio Carta, we have developed a specific guide to prepare and help the facilitators to navigate the PBL discussion. The Facilitators Guide contains a detailed programme of the workshops, the problem case, the identified learning objectives, suggested questions to stimulate the group discussions, definition of terms and a list of relevant references from the lectures.

4.1. Selection of speakers

It was planned that the majority of the speakers/trainers would be EJP RD partners and/or WP14.4 partners, as it may increase interactions and interoperability between

WP and Tasks. This was indeed respected in all the editions. To provide the workshops with the flexibility to adapt the programme and to invite local speakers, the hosting organisers had the resources to invite 2-3 speakers in addition to the task partners. The facilitators for group discussions were part in some cases of the local RD community to stimulate engagement and their contributions to the workshops are in-kind. The speakers were representing in all workshops multiple perspectives, including the perspective of a patient representative in all the workshop programmes.

4.2. Dissemination

The workshops were mainly disseminated by partners and through the EJP RD communication manager via the project website, newsletters and social media channels.

4.3. Selection of participants

In principle, the biobank training workshop follows the Pillar 3 agreed criteria for participant selection. Participation of applicants from all stakeholders (clinicians, biobank management, basic researchers, patient organizations, ethicists, policymakers, etc.) was encouraged to facilitate communication between diverse viewpoints in RD. In particular, the small groups for the PBL learning exercises were composed of these different stakeholders to ensure different aspects of biobanking were brought together. In case of over-subscription, applicants already working in a biobank and/or working in the RD field were prioritized. In-person workshops has a maximum of 25 participants. For the online editions, we decided to include more participants, to give the possibility to a large number of persons (maximum 40) to participate and benefit from the online format.

4.4. Travel fellowships

For each of the training workshops, 2-4 travel fellowships were offered. The number of available fellowships reflected approximately 10% of the total participants in a workshop. Participants who wished to apply for travel fellowships were asked to submit a biosketch, a description of their current work, how attendance at the workshop would help them in their work/biobank, and whether their work location is in an EU-13 country or Turkey. The applications were evaluated by the workshop organizing committee composed of the local host organisers and task leaders. The selection and assessment of the fellowships took into account their geographical location, work relevance in RDs and biobanks, whether they represented patient organisations as well as whether they were young scientists.

2019 - Each of the workshops in 2019 offered 2 travel fellowships.

2023 - The Spring 2023 edition by ISCII offered 2 travel fellowships. The Fall 2023 edition by FTELE offered 3 travel fellowships.

5. Satisfaction questionnaire submitted to participants

Participants were asked to complete a feedback questionnaire at the end of the workshop.

5.1. Results and Discussion

Participant origins and profiles

In 2019, the biobank training workshop trained 22 participants in Milan and 24 participants in Vilnius (24). Both workshops had participants from different European countries, including EU-13 countries. Milan Workshop had participants from 9 different countries; EU-13: Lithuania, Estonia, Poland. Vilnius Workshop had participants from 7 different countries; EU-13: Poland, Turkey. Interestingly, the composition of the two workshops were quite different. Large percentage of the participants in Milan were biobank staff (Director, Manager, Data Manager, Technician or IT Administrator), whereas in Vilnius the participants were often research scientists and clinicians. The “other” profile types indicated by the participants included policymakers and students. The difference in the profile of the participants made a significant impact on the direction of the group discussions.

In 2020, during the spring workshop online edition, 40 out of the 69 registered persons were selected for participation; 35 of them participated at the end in the workshop. The participants had a good average of different backgrounds, about 50% were researchers and doctors, the other 50% were biobanks staff. People interested in the workshop came from 13 countries (7 from Italy, 7 from Israel, 6 from Spain, 6 from Turkey, 4 from Germany, 3 from Austria, 1 from Cyprus, 1 from Latvia, 1 from Malta, 1 from United Kingdom, 1 from France, 1 from Greece, 1 from Finland).

For the autumnal edition, 78 registrations were received, and 44 candidates were selected for participation, 29 of them persons attended the workshop. Based on the recommendations of the EJP RD Policy Board, participants involved in national plans for RDs were prioritised. Three participants came from EU-13 countries (Cyprus, Latvia, Malta).

The 2021 spring workshop in Ankara workshop was joined by 29 participants out of 41 persons registered, coming from 13 countries, 4 from EU-13 and 10 from Turkey. Two-thirds of them were researchers or clinicians, the other participants were biobanks staff. The second 2021-workshop organized by FH-IBMT was joined by 20 participants (out of 40 persons admitted and 72 registered), of whom 2 were from EU-13.

The spring edition of 2022 was organized by UMCG and was joined by 18 attendees out of 28 registrations, 1 from Poland (EU-13 country). Participants were researchers, biobank biologists, and clinicians. The autumnal edition organized by MUG was joined by 28 participants, out of 66 applicants, involving researchers, medical and biology students, biobanking staff members. 4 participants came from EU-13.

For the first 2023 face-to-face edition held in Madrid by ISCIII, 38 registered people, 24 participants (1 from EU-13). Biobankers, clinicians, research scientists and researchers participated. In the last training workshop organised face-to-face in Milan by FTELE, 13 trainees participated (1 from EU-13), out of 20 registered. Participants were biobank staff members, clinicians, researchers, and patient representatives.

For a detailed overview of each training workshop, see Table 3.

Table 3: Participant information

Workshop place	Persons registered	Participants	EU-13 + Turkey
Milan, 2019	27	22	3
Vilnius, 2019	29	24	2
Graz, 2020	69	40	26
Madrid, 2020	78	29	3
Ankara, 2021	41	29	14
Berlin, 2021	72	20	2
Groningen, 2022	28	18	1
Gdansk, 2022	66	28	4
Madrid, 2023	38	24	1
Milan, 2023	20	13	1

5.2. Analysis of the satisfaction questionnaire

Overall feedbacks

The details of the participant numbers and number of feedback questionnaires received from each of the workshops is shown in Table 4. Overall, the feedback from the participants were overall very positive, rating the workshops as very good or excellent, and meeting their expectations. More than 90% said they are likely or very likely to recommend the workshop to their colleagues. Here below some quotes from the feedback questionnaire:

"Now I know how to manage all this biobank things (e.g. where should I look for information, networking and so on), it'll really save my time in the future!"

"My key message from the WS is that sharing of samples is crucial part of successful biobanking either in rare disease field or other disease fields. This thinking will help me better consult stakeholders in the field as well as raises some new ideas for scientific publications."

Training methodology and course content

On the training approach, when organized, the PBL methodology was much appreciated by both the trainers and the participants. The participants indicated this method as effective. Many especially liked the informal atmosphere it created and the stimulating interactions between participants, trainers. Some quotes from the feedback questionnaire:

"Active interaction with the speakers and with other learners"

"Working on group with real problems"

"Working in groups is an excellent opportunity for intra and inter-national comparison"

Table 4: Feedback questionnaire results

Workshop place	Satisfaction rate good/excellent
Milan, 2019	93%
Vilnius, 2019	80%
Graz, 2020	94%

Madrid, 2020	94%
Ankara, 2021	86%
Berlin, 2021	93%
Groningen, 2022	90%
Gdansk, 2022	TBC*
Madrid, 2023	92%
Milan, 2023	100%

*TBC: To Be Collected

Training materials available

All the training material including presentation slides, reference papers, mock datasets and the solutions presented by the participant were shared directly with the participants at the end of the workshop through sharing a folder via Share Point of EJP RD MS Teams.

Dissemination of results

The activities of WP14.4 and the biobank training program was presented during the European Biobank Week conference 8-11 October 2019, Luebeck, Germany. EJP RD and WP14.4 were mentioned in the oral presentation on biobanking state-of-art during the Rare Disease Session (speaker: Chihui Mary Wang), and subsequently fully presented via a poster during the poster session (Annex 1). A paper reporting data from the training workshops on biobanking organised within Task 14.4 of Pillar 3 of the EJP-RD is under preparation and it is planned to be submitted by the end of the EJP-RD project (August 2024).

6. Conclusion and Next actions

Within the EJP RD, we have successfully organized 10 biobank training workshops to stimulate thinking and awareness in sharing RD biological samples and data, to teach the best practices in data management and the importance of networking for the rare disease field. We were able to leverage from existing tools and expertise of EJP RD partners to put together the brand-new comprehensive training programme. We were also able to adjust initial plans to face the emergency situation of COVID-19 and reach anyway our goals to have 2 editions each year. The feedback of the workshops were very positive, indicating the appropriateness of the curriculum, content and organization. We have gathered useful experiences and interesting observations from the workshops that will help the planning and organization future workshops in the field of RD biobanking.

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Annex I: Poster on WP14.4 Biobank Training Task presented during the European Biobank Week conference 8-11 October 2019, Luebeck, Germany

Promotion of rare disease biobank services, sample findability and accessibility through dedicated training workshops

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Rare Disease Challenge

A disease is defined as rare in Europe when it affects less than 5 people per 10,000. There are estimated 6000-8000 identified rare diseases. Access to rare disease (RD) biological samples is a challenge due to the intrinsic rarity and sparsity of patients.

Recent developments in the RD-Connect Sample Catalogue, a flagship platform listing over 66.500 RD samples, allow users worldwide to find specific specimens for research. Its subsequent link with BBMRI-ERIC Negotiator opens the way to initiate sample requests.

However, despite significant tool developments to improve access, biobanks did not have sufficient training opportunities to be able to exploit these technological advances. Similarly, researchers remain unfamiliar with biobank services and its potentials.

Capacity Building

Objectives

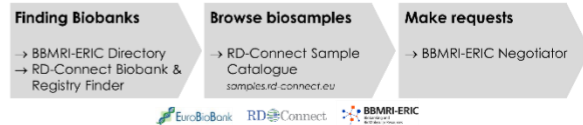
- Develop the biobank capacity on RD data management, harmonise and share RD biological sample data.
- Optimise biobank operations to support the need of RD research community.
- Encourage interactions between RD clinicians/researchers and biobanks, where researchers can learn on how to leverage biobanks in their research.
- Encourage involvement and conversation on RD biobanking in European countries.

Target

- Biobank managers and staff, researchers, clinicians, students, patient representatives.
- Travel fellowships to encourage participation from EU-13 countries.

2 workshops every year between 2019 – 2023; 10 workshops in total.

Ankara
Berlin
Gdansk
Graz (2020)
Groningen
Madrid (2020)
Milan (2019)
Rome
Vilnius (2019)



Curriculum & Problem Based Learning

Problem-Based Learning method: participants stimulated to discover and learn whilst working on a RD biobank problem case in groups.

Existing RD network: EuroBioBank
FAIR principles, MIABIS
Ethical considerations
Ontology & Orphanet Nomenclature
Country perspective

Practical session on data harmonisation
Tool Demos



Workshop outcomes

2019 theme: "Organizing & maximizing rare disease biological samples data in biobanks" in Milan 1-2 April and Vilnius 29-30 October. Feedback: 88% would strongly recommend it to their colleagues and 93% rated it as excellent or very good.

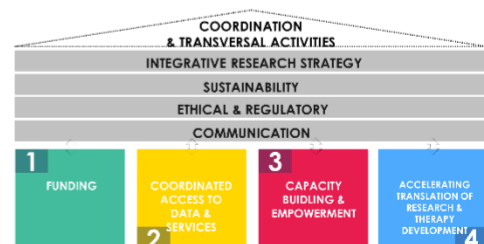
A rich, dedicated training program to promote biobank accessibility can moreover stimulate interactions between biobanks and its stakeholders.

What is EJP RD?

European Joint Programme on Rare Diseases is a 5-year project with the objective to "improve integration, efficacy, production and social impact of research on rare diseases through the development, demonstration and promotion of sharing of research and clinical data, materials, processes, knowledge and know-how, and an efficient model of financial support for research on rare diseases"

35 participating countries, 88 beneficiaries

www.ejprarediseases.org



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