

Coordinated Research Infrastructures Building Enduring Life-science services - CORBEL -

Deliverable D3.1
1st MIUF Report

WP3 – Community Driven Cross-Infrastructure joint research - Medical

Lead Beneficiary: ECRIN -ERIC

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Contributing partner(s): BBMRI, EATRIS, ELIXIR, Euro-Biolmaging, EU-Openscreen, INFRAFRONTIER, INSTRUMENT, ISBE, MIRRI

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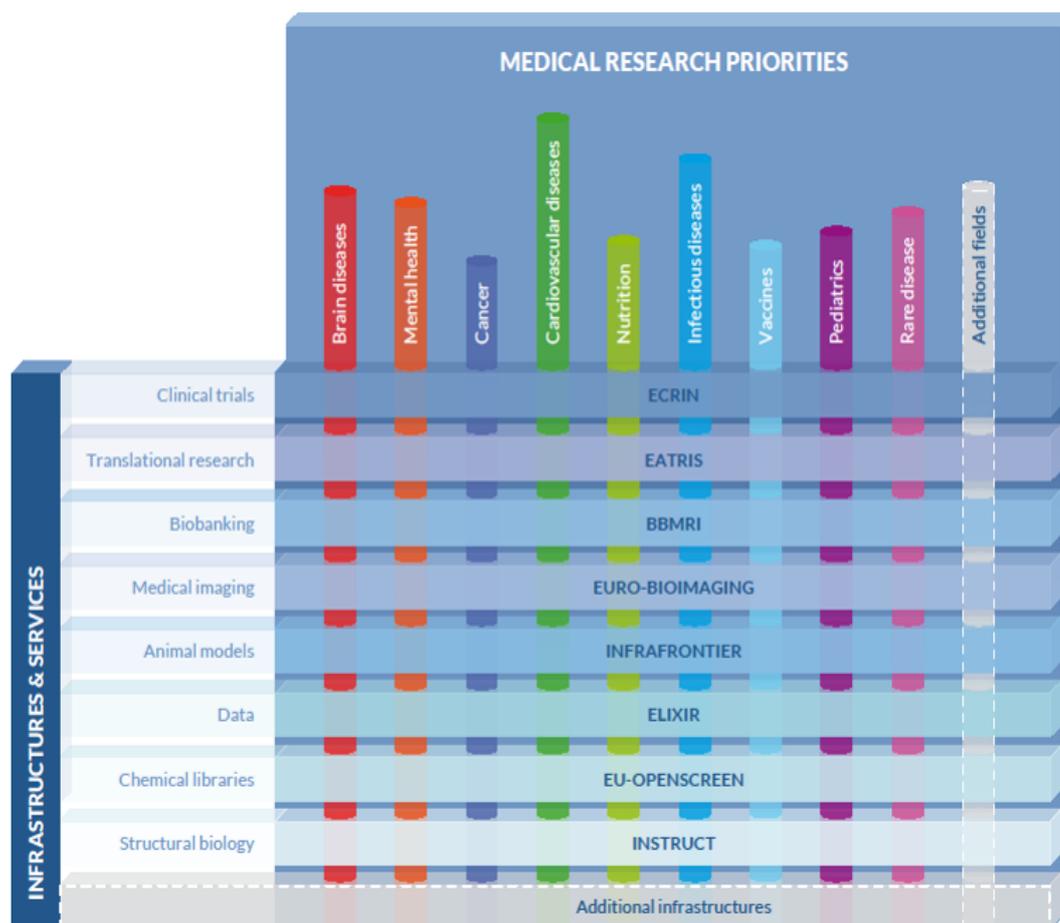
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Executive Summary

The “Medical Infrastructure/Users Forum (MIUF)” combines the BMs ESFRI RIs with scientific expertise in different medical research areas, bringing together medical research communities corresponding to European priorities, including pan-European users communities as well as patients associations. The MIUF will be a key instrument for efficient development and use of biomedical research infrastructures in Europe, by promoting a culture of collaboration across the ESFRI BMs infrastructures and capturing needs and expectations of scientific communities and funders, to drive the development of tools and services and to promote a consistent development strategy, avoiding gaps and overlaps.



Project objectives

With this deliverable, the project has reached/this deliverable has contributed to the following objectives:

- a) Effectively strengthen the communication between Bio-Medical Research Infrastructures and medical research communities

Detailed report on the deliverable

Background

Research facilities and infrastructures become increasingly expensive, due to the complexity of scientific and technical development. Research Infrastructures (RIs) play a pivotal role in advancement of knowledge and technology, and represent a powerful instrument to promote, facilitate and enhance regional, national and transnational collaborations by giving a shared access to facilities, resources, services and data. RIs represent the center of the knowledge triangle of research, education and innovation. However, close collaboration with medical research communities is needed to ensure appropriate development of tools and services, and open access for researchers to RIs across Europe.

Description of Work

To ensure a good coverage of medical priorities in Europe, both the coordinators of the ERA-Nets/ JPIs programs (as research priorities area) and representatives of main pan-European initiatives were invited to be part of the MIUF: ERA-Net TRANSCAN and OECl (cancer), ERA-Net ERARE3, IRDiRC and RD-connect (rare diseases), NEURON, JPND and ROAMER (neurosciences), EPCTRI (paediatrics), ERA-Net ERA-CVD (cardiovascular diseases), JPI HDHL (nutrition), JPI AMR and EVI (infectious diseases). A representative of EURORDIS (patients' organisation) and at least one representative of each BMs ESFRI RI are also members of the MIUF.

Several face to face meetings are planned during the whole project, in order to gather input from various stakeholders (infrastructures, scientific communities, funding programmes) and to identify solutions for a long-lasting collaboration strategy.

The first meeting was held on 25-26 January, in Paris (ECRIN headquarter).

The major issue raised during the discussion was the insufficient communication and visibility: Research Infrastructures (RIs) offer services and expertise in data collection, management and protection as well as in conducting specific research (translational, clinical trials etc.) but this capability remains unrecognized; on the other hand, the complexity of scientific and technical development, along with the high competition, require more collaboration with infrastructures, to perform high quality research, based on the independent quality standards provided by the RIs.

One possibility to strengthen the collaboration could be to integrate RIs in a research project as a full partner in charge of a dedicated task or step (ex. product development, monitoring etc.); to that end, users need to have an overview how to interact with RIs, and what is possible (or not) in terms of access and services available. A support service ("brokering approach") addressing the researcher to the right contact (i.e. relevant infrastructure) should be envisaged.

Therefore, two short- and middle-term actions were identified:

- 1) A joint survey should be performed by the RIs in order to identify the missing tools, modules and services, the potential missing infrastructure and the coverage gap (ex. are psychiatry and pediatrics underestimated? as pointed out during the discussion); obstacles to access and integration of infrastructures in research projects should also be included in the survey.
- 2) Following the recommendations raised by the research communities through that survey, a specific communication document on Research Infrastructures should be provided, listing the existing expertise (tools, resources, services and data) provided to the medical research communities and explaining the access modalities (criteria, fees etc.). To be successful, RIs should implement a new communication plan, by identifying their missions, the achievable goals and by assessing the environment (users). The final communication document will be published on both the CORBEL and funders websites and widely distributed to the users.

Based on those recommendations, CORBEL WP3 performed an online survey, which was sent out to real and potential RIs users, through several communication channels (CORBEL and RI websites, RI newsletters, national contact points, national hub, investigators involved in ERA-Net funded projects etc.). Several aspects related to RIs activity were explored: the current visibility of each RI, the efficacy of the communication strategy (website, literature, scientific conferences) as well as the quality of the services provided and the global appreciation of the collaboration with a Research Infrastructure. The text of the survey is presented in Appendix 2.

Next steps

The survey is currently still running; the outcomes will be analysed in summer 2016 and presented to the MIUF members during the second meeting, which will take place on 12th of October, in Paris.

Based on those results, the MIUF

- will propose recommendations to drive the development of new tools and services by RIs, based on specification documents;
- will start outlining a strategy plan to improve integration of medical research communities and medical RIs. The expansion to other medical research communities (e.g. nanomedicine) will also be considered.

Publications

Not applicable.

References

Not applicable.

Abbreviations

| | |
|----------|--|
| AMR | Anti-Microbial Resistance |
| EPCTRI | European Paediatric Clinical Trial Research Infrastructure |
| ERA-Net | European Research Area - Network |
| ERARE3 | ERA-Net on Rare Diseases |
| ERA-CVD | ERA-Net on Cardio-Vascular Diseases |
| EURORDIS | Rare Diseases Europe |
| EVI | European Vaccine Initiative |
| HDHL | Healthy Diet for a Healthy Life |
| IRDiRC | International Rare Diseases Research Consortium |
| JPI | Joint Programme Initiative |
| JPND | Joint programme on Neurodegenerative Diseases |
| MIUF | Medical Infrastructure/Users Forum |
| NEURON | ERA-Net on brain diseases |
| OECI | Organisation of European Cancer Institutes |
| ROAMER | A Roadmap for Mental Health Research in Europe |
| SAB | Scientific Advisory Board |
| TRANSCAN | ERA-Net on Translational Cancer Research |
| TRANSVAC | European Network of Vaccine Research and Development |

Delivery and schedule

The delivery is delayed: No

Adjustments made

No adjustment made

Appendices

Appendix 1

List of the external MIUF members

| Medical Area | Organisation | Name |
|-------------------------|----------------|-----------------------|
| Cancer | OECI | Claudio Lombardo |
| | TRANSCAN | Silvia Paradisi |
| Rare diseases | ERARE3 | Daria Julkowska |
| | IRDIRC | Petra Kaufmann |
| | RD-Connect | Kate Bushby |
| Neurosciences | NEURON | Marlies Dorlöchter |
| | JPND | Philippe Amouyel |
| | ROAMER | Josep-Maria Haro |
| Pediatrics | EPCTRI | Adriana Ceci |
| Cardiovascular diseases | ERA-CVD | Wolfgang Ballensiefen |
| | ERA-CVD SAB | Wiek van Gilst |
| Nutrition | JPI HDHL | Jolien Wenink |
| Infectious diseases | JPI AMR | Maria Starborg |
| | EVI & TRANSVAC | Odile Leroy |
| Patients | EURORDIS | Mathieu Boudes |

Appendix 2

First Medical Infrastructures/Users Forum (MIUF) meeting – Paris, 25-26 January 2016

Research Infrastructures Meet Scientific Communities

Monday, January 25th

- 17:00** **Welcome and Introduction**
- CORBEL project (*Andrew Smith, ELIXIR*)
 - Objectives of the MIUF (*Jacques Demotes, ECRIN*)
- 17:20** **Presentation of Medical Research Infrastructures: (5' each)**
Organisation, tools, services
- BBMRI (*Outi Törnwall*)
 - EATRIS (*Giovanni Migliaccio*)
 - ECRIN (*Jacques Demotes*)
 - ELIXIR (*Andrew Smith*)
 - EuroBioImaging (*Silvio Aime*)
 - EU-Openscreen (*Philip Gribban*)
 - Infrafrontier (*Michael Raess*)
 - INSTRUCT (*Alberto Podjarny*)
- 18:00** **Presentation of Users (5' each)**
Research community, scientific challenges, infrastructure and service needs
- **Cancer**
 - o OECI (*Claudio Lombardo*)
 - o ERA-Net TRANSCAN (*Silvia Paradisi*)
 - **Rare diseases**
 - o RD-Connect (*Emma Heslop*)
 - o ERA-Net ERARE (*Daria Julkowska*)
 - o EURORDIS (*Mathieu Boudes*)
 - **Pediatrics**
 - o EPCTRI (*Adriana Ceci*)
 - **Brain**
 - o JPND and ERA-Net NEURON (*Marlies Dorlöchter*)
 - **Cardiovascular**
 - o Cardiovascular diseases (*Wiek van Gilst*)
 - o ERA-CVD (*Hella Lichtenberg*)
 - **Infectious diseases**
 - o JPI AMR (*Maria Starborg*)
 - o Vaccines (*Odile Leroy*)
 - **Public-Private partnership**
 - o IMI2 (*Ann Martin*)
- 19 :30** **End of the meeting**
- 20 :00** **Dinner (*La Petite Casserole, 64 rue Cantagrel*)**

Tuesday, January 26th

Facilities become increasingly expensive, due to the complexity of scientific and technical development. Research Infrastructures (RIs) play a pivotal role in advancement of knowledge and technology, and represent a powerful instrument to promote, facilitate and enhance regional, national and transnational collaborations by giving a shared access to facilities. RIs could be seen as the center of the knowledge triangle of research, education and innovation. Close collaboration with medical research communities is needed to ensure appropriate development of tools and services, and open access for researchers to RIs across Europe.

8:30 1. How to capture the infrastructure needs of medical research communities?

Research Infrastructures have to adapt to the needs of their user's communities. On the other hand, medical research communities have conducted mapping and gap analysis of their infrastructure needs.

- Presentations (10 min each)
 - o *RI: How research infrastructures collect information on user's needs? (Giovanni Migliaccio, EATRIS)*
 - o *Medical research communities: how medical research communities establish priorities and strategies on specific infrastructures? (Josep Maria Haro, ROAMER – visio conference)*
- Discussion

9:30 2. How to foster communication and cooperation between RIs and users?

Communication, cooperation and commitment of research infrastructures, of scientific communities and of funders may result in consistent policies taking advantage of existing instruments to access services meeting the needs of researcher – rare diseases as a case study.

- Presentations (10 min each)
 - o *Infrastructure platform for rare diseases: the INNORARE MoU (Giovanni Migliaccio, EATRIS)*
 - o *Medical research communities (Emma Heslop, RD-Connect)*
 - o *Funding: E-RARE3 and IRDiRC (Daria Julkowska)*
- Discussion

10:30 Coffee break

10:50 3. How to cooperate on development of infrastructures and scientific communities?

A proactive pan-European structuring of medical research communities driven by research infrastructures is an option to attract users and to develop services and tools adapted to user's needs. On the other hand, scientific communities may develop specific services and instruments. In both cases, a strong coordination should avoid fragmentation or duplication.

- Presentations (10 min each)
 - o *RIs contributing to structuring users communities : the ECRIN-IA project (Christine Kubiak, ECRIN)*

- o *Scientific communities : development of specific infrastructure tools and services for vaccines (Odile Leroy, Transvac)*
 - Discussion
- 11:50 **4. How to establish a joint strategy for the development of new services?**

A large number of countries have prepared national roadmaps that establish the prioritisation of national and pan-European RIs, using the ESFRI Roadmap as a reference. This could help to define national budgets, facilitate political support and allow a long-term financial commitment.

 - Presentations (10 min each)
 - o RIs: how is the BMS RI strategy defined
 - At the level of a single infrastructure, or a group of infrastructures: strategy plan (*Michael Raess, INFRAFRONTIER*)
 - At national and EU level : national and European roadmaps (*Jacques Demotes, ECRIN*)
 - o *Medical research communities : how is the development strategy defined*
 - *JPIs and ERA-Nets: HDHL (Jolien Wenink)*
 - *Patient's perspective : EURORDIS (Mathieu Boudes)*
 - Discussion
- 13:00 **Lunch**
- 14:00 **5. General discussion**
- 15:00 **6. Next steps, work plan, working groups, deliverables, next meetings**
- 16:00 **End of the meeting**

Appendix 3

Text of the survey (the online link: <http://ecrin.limequery.com/index.php/689673/lang-en>)

The H2020-funded project CORBEL (Coordinated Research Infrastructure Building Enduring Life-science Services; GA n. 654248) will establish a collaborative and sustained framework of shared services between the ESFRI Biological & medical Research Infrastructures.

This aims to transform biomedical research in Europe - from the discovery of basic biological mechanisms to applied medical translation - through the provisioning of harmonised services.

The concept of biomedical RIs represents a major paradigm shift in the conduct of biomedical research. Whereas in the past researchers had to combine scientific and technical expertise, the complexity of technological development and the amount of generated data led to a partial dissociation between research questions, raised by thematic experts, and the instruments producing the data. Today RIs operate instruments, providing access to research projects whose scientific content is developed and analysed by the relevant scientific community. However, there is an urgent need to ensure the effective alignment of the infrastructures capabilities and services to the needs of the different medical user communities in Europe.

The following questionnaire aims to collect the needs and expectations of scientific communities and overall users of RIs to

- 1) harmonise and improve the services provided by the research infrastructures
- 2) define priorities and service development

The CORBEL partners would like to thank you in advance for participating in this survey: your input is highly appreciated!

- **Section A: General**

A1. Your Name

A2. Your Organisation

A3. Your Country

A4. email address

A5. Your profile:

Academic researcher

Clinician

Industry

Other

A6. Your disease-related area:

Cancer

Cardiovascular diseases

Infectious diseases / Vaccines

Mental health

Neurosciences

Nutrition

Paediatrics

Rare diseases

Other

A7. Your research activity:

Target identification

Drug discovery

Drug development

Translational research

Biomarkers

Patient Cohorts

Clinical Trials

Regulatory science

Bioinformatics

Other

• **Section B: Research Infrastructures**

B1. which RI are you aware of:

BBMRI

EATRIS

ECRIN

ELIXIR

EuOpenscreen

EuroBioImaging

INFRAFRONTIER

INSTRUCT

none

Other

B2. Have you already collaborated with one or more of them?

BBMRI

EATRIS

ECRIN

ELIXIR

EuOpenscreen

EuroBioImaging

INFRAFRONTIER

INSTRUCT

Other

No

B3. Why?

not aware about the existence of a RI in your research field

not aware about the services available

no contact available in your Country

cost (high/not eligible for funding coverage)

criteria to access too restrictive

access denied

not clear how to access the central coordination unit

Other

B4. What were your expectations by accessing to a RI?

technical competence/expertise not available in your group

support to project management

access to samples/materials not available in your institution/country

quality standards for your data/results

find new industry and academic collaborations

independent evaluation of your project

Other

B5. How were these expectations met?

(1 = poor 2 = fair 3 = good 4 = excellent)

technical competence/expertise not available in your group

support to project management

access to samples/materials not available in your institution/country

quality standards for your data/results

find new industry and academic collaborations

independent evaluation of your project

other

B6. How do you evaluate the added value for your project in collaborating with a RI (e.g. *successful collaboration, new collaborations generated...*)?

1 = poor

2 = fair

3 = good

4 = excellent

B7. Do you think your scientific area is well covered by RIs in terms of services?

1 = poor

2 = fair

3 = good

4 = excellent

B8. What existing services would you like to be improved/revised? *Free comment*

B9. In your opinion, what are the services missing? *Free comment*

- **Section C: Communication**

C1. How did you find out about the RIs?

website

social networks (LinkedIn, Facebook, Twitter)

collaborators

conferences

funding programs (national, transnational, European...)

Other

C2. For those websites you already visited, please evaluate how they look like

(1 = poor; 2 = fair; 3 = good; 4 = excellent)

global appreciation:

BBMRI

EATRIS

ECRIN

ELIXIR

EuOpenscreen

EuroBioImaging

INFRAFRONTIER

INSTRUCT

MIRRI

easy to find out information:

BBMRI

EATRIS

ECRIN

ELIXIR

EuOpenscreen

EuroBioImaging

INFRAFRONTIER

INSTRUCT

MIRRI

clear description of available services:

BBMRI

EATRIS

ECRIN

ELIXIR

EuOpenscreen

EuroBioImaging

INFRAFRONTIER

INSTRUCT

MIRRI

C3. In your opinion, could the following means of communication help to raise awareness and visibility of RIs?

(1 = poor 2 = fair 3 = good 4 = excellent)

periodic newsletter

participation of RI to scientific conferences (poster/oral presentation)

publication in scientific literature

annual workshop organised by the RI (what's new, success stories...)

LinkedIn

Facebook

Twitter

C4. Do you have any suggestions to improve the communication? *Free comment*

- **Section D: Access**

D1. Which services have you applied for: BBMRI

Data/metadata

Software/tools (directory, sample/data negotiator, sample locator)

expertise/management

D2. Which services have you applied for: EATRIS

translational (animal) models for drug target validation and vaccine production

transnational medicine: regulatory expertise/project management

industry or academic partners for collaboration

GXP produced radiopharmaceutical, ATMP or vaccines

molecular imaging technologies

biobank samples

biomarker validation

D3. Which services have you applied for: ECRIN

clinical trial management (operational support to multinational clinical trials)

clinical trial data management

outcome measures database for medical device

monitoring tools

regulatory database

D4. Which services have you applied for: ELIXIR

Standards (ontologies, identifier services)

Access to Open reference databases (e.g. Ensembl)

Data management services

Access to secure compute resources (cloud)

D5. Which services have you applied for: EuroBioImaging

image acquisition

image data repositories

image data processing

expertise/management

D6. Which services have you applied for: EuOpenscreen

compound collection

Data/metadata

expertise/management

D7. Which services have you applied for: INFRAFRONTIER

technologies (mouse model generation, systemic phenotyping)

mouse models

data/metadata

tools for finding mouse models

expertise/management

D8. Which services have you applied for: INSTRUCT

technologies (platforms)

software/tools (computational and data processing)

expertise/management

D9. For those services you already applied for, how do you evaluate the RIs in terms of

(1 = poor; 2 = fair; 3 = good; 4 = excellent)

efficacy of the RI contact to provide information and support:

BBMRI

EATRIS

ECRIN

ELIXIR

EuOpenscreen

EuroBioImaging

INFRAFRONTIER

INSTRUCT

access criteria/administrative procedures:

BBMRI

EATRIS

ECRIN

ELIXIR

EuOpenscreen

EuroBioImaging

INFRAFRONTIER

INSTRUCT

quality of the services provided:

BBMRI

EATRIS

ECRIN

ELIXIR

EuOpenscreen

EuroBioImaging

INFRAFRONTIER

INSTRUCT

D10. Do you have any suggestion to improve the quality of the services? *Free comment*

Thank you for completing the questionnaire!

To find out more about the CORBEL project, please visit our website and subscribe the newsletter:

www.corbel-project.eu

www.bbmri-eric.eu

www.eatris.eu

www.ecrin.org

www.elixir-europe.org

www.eu-openscreen.de

www.eurobioimaging.eu

www.infrafrontier.eu

www.structuralbiology.eu

www.project.isbe.eu

www.mirri.org