



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

Medical Research Infrastructures & Users – feedback on activities and services

This report is part of Work Package 3:

“Community Driven Cross-Infrastructure joint research – Medical”

(Work Package Leader: ECRIN)

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Grant agreement no. 654248

Horizon 2020

H2020-INFRADEV-1-2014

Type of action: RIA



Funded by the H2020
Framework Programme
of the European Union

Summary

The H2020-funded project CORBEL aims to establish a collaborative and sustained framework of shared services between the ESFRI Biological & Medical Research Infrastructures (RIs).

A questionnaire was created to collect the needs and expectations of medical research communities and overall users of RIs. The responses have been collected and analysed and will be used as input to gather recommendations for continuous improvement and development of new, transversal services.

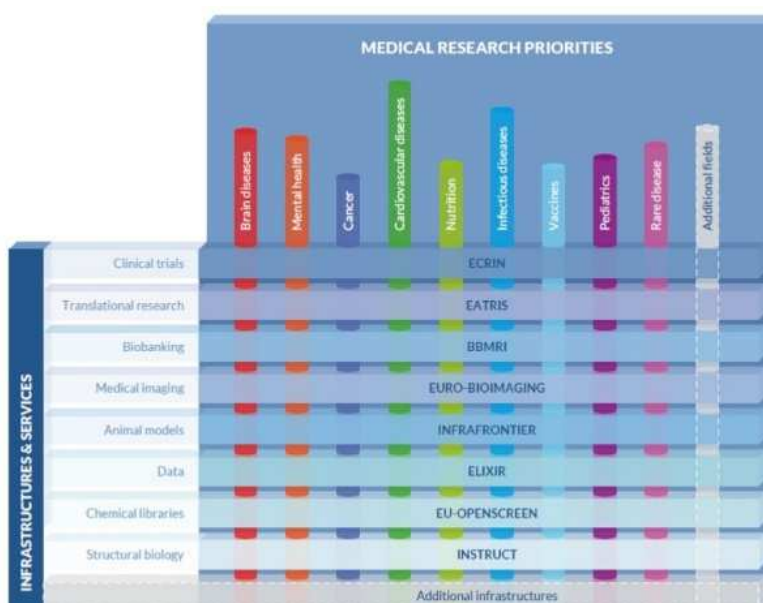
The main findings of the survey are:

- 1) Overall, RIs are acknowledged as scientific service providers. The added value for users in collaborating with RIs was greatly appreciated by most of the survey participants
- 2) The scientific coverage and the quality of services provided by RIs were found consistent with the expectations and the needs of the medical research community
- 3) The access procedures were found to be rather efficient and the websites were evaluated as quite informative
- 4) Suggestions were made to improve the dissemination of information related to services available as well as the visibility of RIs both at national and international level

Introduction

The concept of biomedical Research Infrastructures (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 instrument 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 effective alignment of the infrastructure capabilities and services to the needs of the different medical user communities in Europe.

In the context of the H2020-funded project CORBEL a “Medical Infrastructure/Users Forum - MIUF” (Table 1) was established as a key instrument for efficient development and use of biomedical RIs in Europe; it combines the ESFRI Biomedical RIs with scientific expertise in various medical research areas, bringing together expertise covering all clinical and pre-clinical aspects, including pan-European users’ communities as well as patient associations.



Capturing needs and expectations of scientific communities and funders is a prerequisite for the continuous improvement of current and future RI activities and provides a basis for long-term strategy.

To that end, a survey was conducted between May and July 2016, using an online questionnaire collecting feedback from RI users and medical researchers from various medical disciplines. The survey was distributed by the MIUF members through different communications means: CORBEL and RI websites, RI newsletters, mailing lists, national contact points, etc.

The responses were collated and analysed to meet the survey goals and were summarised as recommendations for improvement of practices and services.

Research Infrastructures:

- **BBMRI** (Biobanking and BioMolecular resources Research Infrastructure) www.bbmri-eric.eu
- **EATRIS** (European Infrastructure for Translational Medicine) www.eatris.eu
- **ECRIN** (European Clinical Research Infrastructure Network) www.ecrin.org
- **ELIXIR** (bioinformatics and research data integration) www.elixir-europe.org
- **EPCTRI** (European Paediatrics Clinical Trials Research Infrastructure)
- **EU-Openscreen** (European Infrastructure of Open Screening Platforms for Chemical Biology) www.eu-openscreen.eu
- **EuroBioImaging** (biomedical imaging infrastructure) www.eurobioimaging.eu
- **INFRAFRONTIER** (European research infrastructure for the development, phenotyping, archiving and distribution of mammalian models) www.infrafrontier.eu
- **INSTRUCT** (Integrated Structural Biology Infrastructure) www.structuralbiology.eu
- **ISBE** (Infrastructure for Systems Biology Europe) <http://project.isbe.eu>
- **MIRRI** (Microbial Resource Research Infrastructure) www.mirri.org

ERA-Nets (European research Area Network):

- **ERA-CVD** (Cardiovascular Diseases) www.era-cvd.eu
- **ERARE3** (Rare Diseases) www.erare.eu
- **NEURON** (Neuroscience research) www.neuron-eranet.org
- **TRANSCAN2** (Cancer) www.transcanfp7.eu

JPIs (Joint Programming Initiative):

- **AMR** (Antimicrobial Resistance) www.jpiamr.eu
- **HDHL** (Healthy Diet for healthy Life) www.healthydietforhealthylife.eu
- **JPND** (Neurodegenerative Disease) www.neurodegenerationresearch.eu

Other:

- **EURORDIS** (Rare Diseases Patients organisation) www.eurordis.org
- **OECI** (Organisation of European Cancer Institutes) www.oeci.eu
- **ROAMER** (A Roadmap for mental Health Research in Europe) www.roamer-mh.org
- **TRANSVAC** (European Network of Vaccine Research and Development) www.transvac.org

Table 1 – Composition of the Medical Infrastructure/Users Forum (by January 1st, 2017)

The ERA-Net EuroNanoMed3 (nanomedicine – www.euronanomed.eu) is expected to join

Feedback highlights

1. Statistics

Most of the countries hosting one or more RI coordination or nodes were represented in the survey (Fig. 1a), in spite of some bias in disseminating the survey (overrepresentation of one country).

The medical research area / activities of participants were well represented and balanced (Fig. 1b).

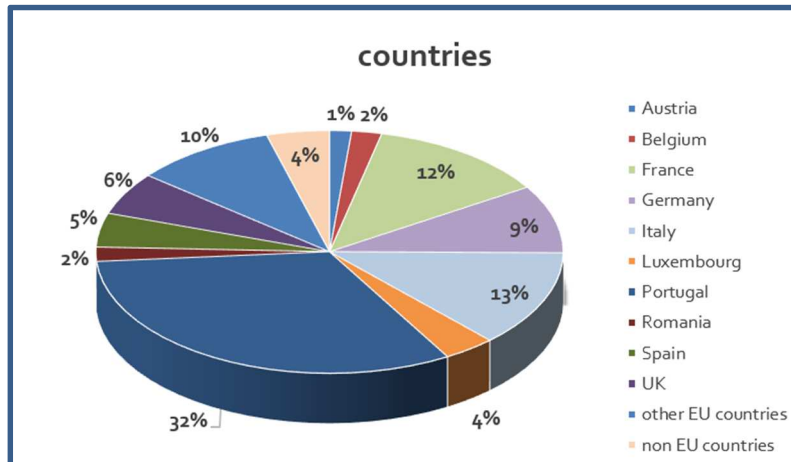


Fig.1a – Respondents: geographical distribution

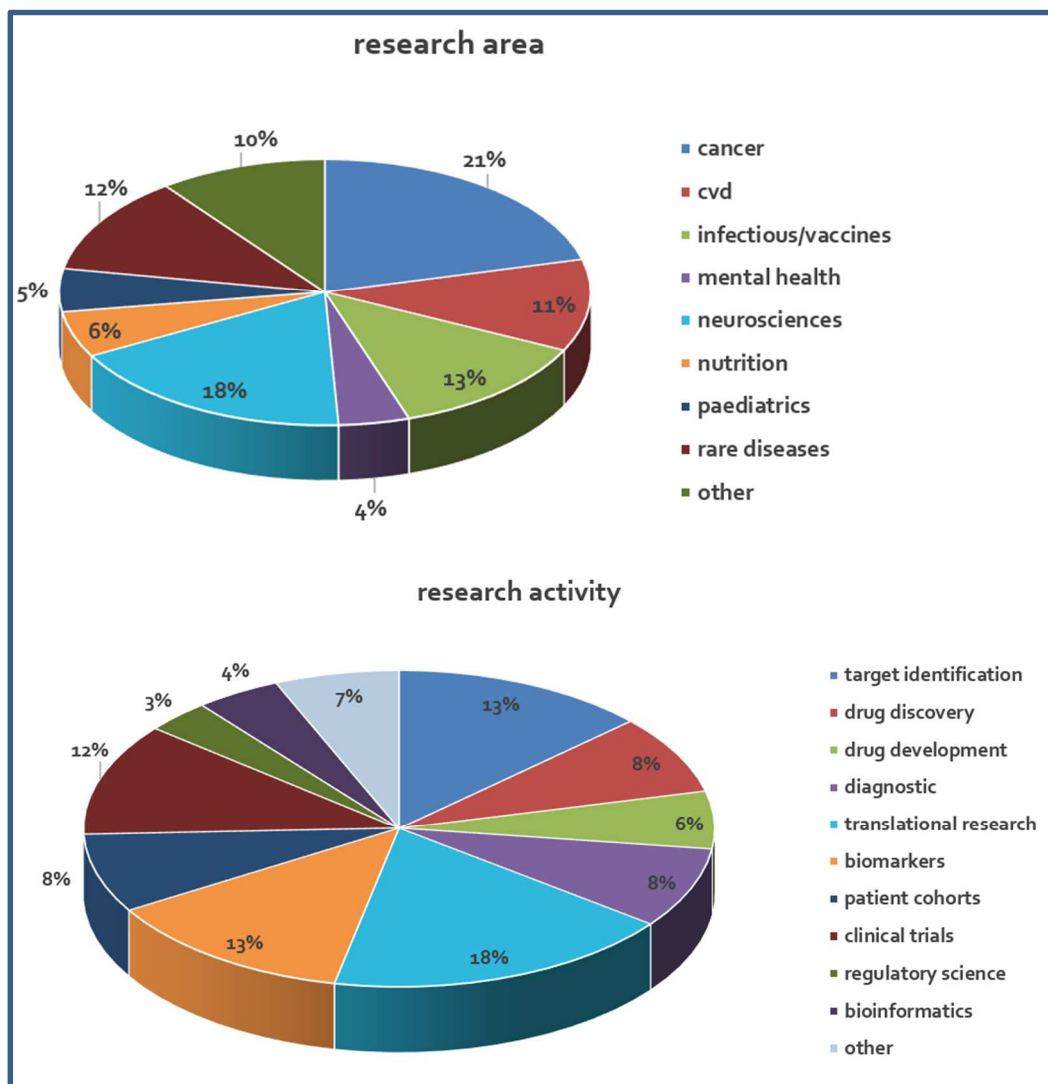


Fig.1b – Respondents: scientific profile

2. Research Infrastructures services

About **70%** of respondents declared to be aware of at least one Biomedical RI (Fig. 2), even though some discrepancies in the visibility of the RIs were observed, likely due to dissemination issues.

The majority of respondents (59.6%) estimated the coverage of their scientific area by RIs as good or very good (43.9% and 15.7% respectively). Nevertheless, suggestions were made to develop both OMIC services (genomics, proteomics, metabolomics...) and biostatistics, Big Data and computational analysis services.

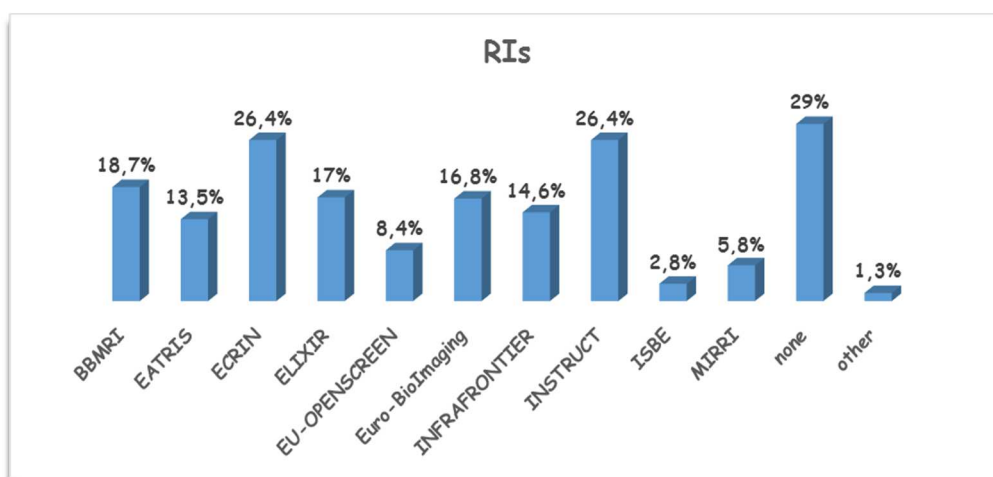


Fig. 2a – Awareness of Research Infrastructure services

Among those aware of RIs, **46.3%** of them applied for services and were asked to rate their satisfaction (Fig. 2b); according to the results, the overall appreciation rate could be summarised as “good”.

Appreciation of services	Average value for all RIs concerned (1= poor; 2= fair; 3= good; 4= very good)	Range (min – max value)
Efficacy of the RI contact	3.2	2.7 - 4
Access criteria / administrative procedures	3	2.3 – 3.4
Quality of services	3.3	2.3 - 4

Fig. 2b – Overall satisfaction about RIs’ services

The main expectations of collaborating with an RI (Fig. 2c) were the opportunity to have access to technical expertise and instruments and technologies (49% and 48% of respondents respectively), followed by the possibility to have access to samples (34.7%) and to start new collaborations (21.4%). All the expectations were globally met (average satisfaction rate: 3.4), with a good added value for the projects on the whole (average satisfaction rate: 3.3). However, it can be noted that quality of services and data was not regarded as a major driver for using RI services.

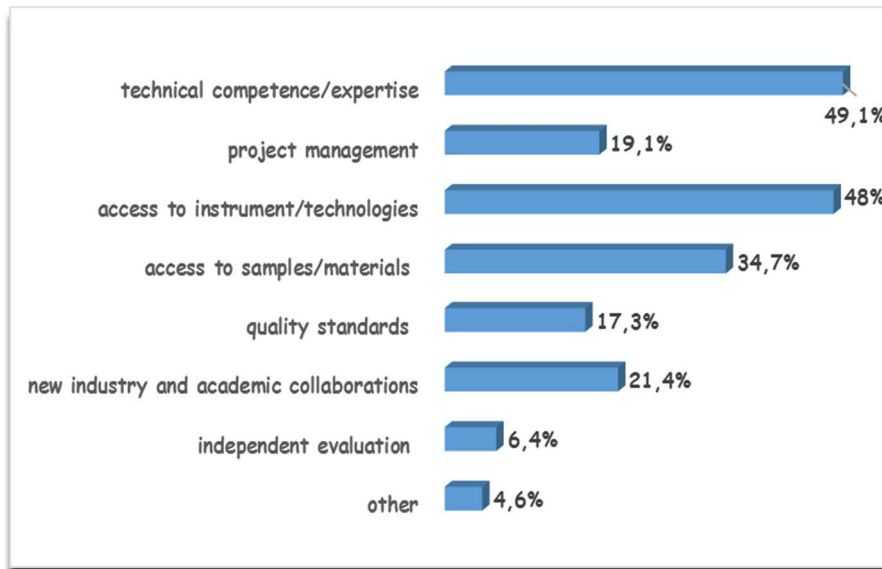


Fig. 2c – Expectations by accessing a RI

The survey participants that declared not having applied for services (46.3%) were asked to give the main reasons (Fig. 2d): in most cases, they were not aware of the services available and the access criteria were not clear (36.9% and 34.8% respectively).

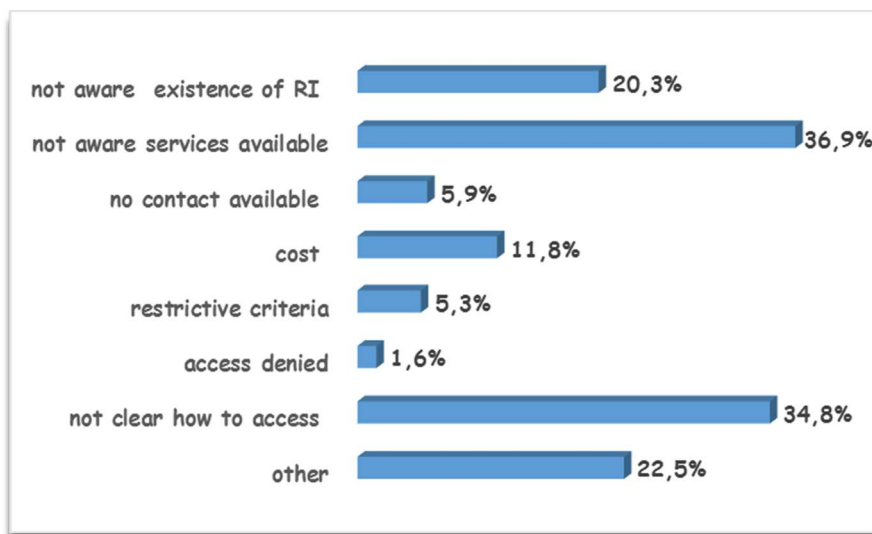


Fig. 2d – Reasons not to apply

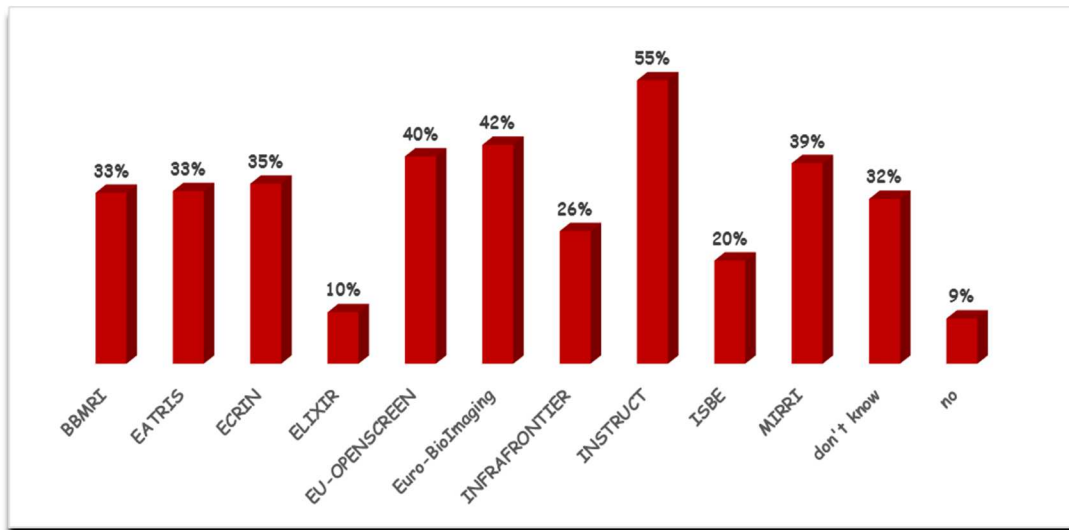


Fig. 2e – Plan to apply

Finally, all the participants were asked whether or not they have plans to apply in the future for services provided by one or more RIs (Fig. 2e): although some discrepancies are still evident, globally there is a clear interest in collaborating with RIs.

3. Communication

From the survey’s findings it appears that currently, users learn about RIs (Fig. 3a) mainly through personal communication (54.8%) and RI websites (38.4%) rather than through funding programs (29.5%) or conferences (25%).

As a principal source of information, the websites were however assessed as unclear, with a global appreciation rate just below the “good” threshold (Fig. 3b).

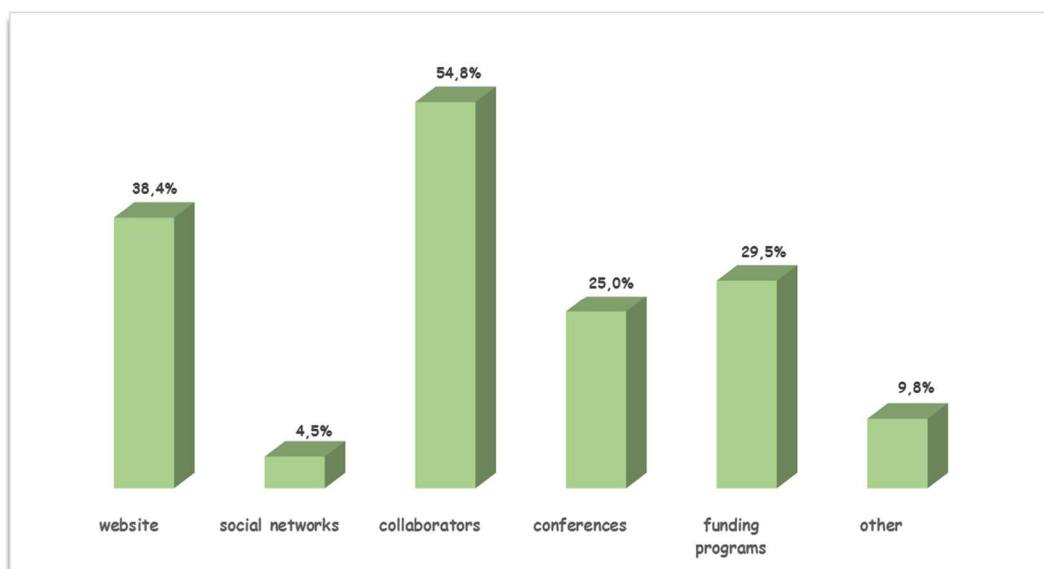


Fig. 3a - communication

Appreciation of websites	Average value for all RIs concerned (1= poor; 2= fair; 3= good; 4= very good)	Range (min – max value)
Global appreciation	2.96	2.8 – 3.1
Easy to find out information	2.8	2.6 – 3.1
Description of services	2.8	2.5 – 3.2

Fig. 3b – overall satisfaction about RIs' websites

As means of communication to raise awareness of RIs, respondents identified periodic newsletters (42.5%), participation in scientific conferences (47.8%), and publication in scientific literature (42.6%) as “good”. Social networks (Twitter and Facebook) were viewed as poor communication means (34.2% and 30.4% respectively); LinkedIn was an exception with a “good” rating from 35.7% of respondents. Finally, annual workshops organised by RIs were rated as “very good”.

Recommendations

Along with the positive feedback on the essence of RI activities, respondents also pointed to some improvements they wish to see:

- 1) Communication strategies should be improved to raise the visibility of RIs: first of all, services available should be presented with a customer-oriented approach (i.e. time schedule, prices) and in a clearer manner, with concrete examples of collaborative projects, in order to highlight the feasibility and the added value of collaborating with RIs. The RIs presence at both international and national scientific conferences should also be increased, and dedicated workshops are strongly encouraged.

RIs should provide national nodes and funders with several communication tools (brochures, fact sheets) that can be easily published and distributed. E-learning courses and webinars should also be developed.

- 2) Access criteria and procedures should be simplified and harmonised between the different RIs.

One of the major expected achievement of CORBEL is the creation of a common portal, with a more federated and users-friendly approach.