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

Deliverable D3.3
3rd MIUF report

WP3 – Community-driven cross-infrastructure joint research - Medical

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Contributing partner(s): BBMRI, EATRIS, ELIXIR, Euro-BioImaging, EU-Openscreen, INFRAFRONTIER, Instruct, ISBE, ErasmusMC, Lygature, MIRRI

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Content

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) Establish a dialogue with funders and medical research communities to capture their expectations and needs
b) Implement strategic actions to encourage the cross-collaboration at pan-European level

Detailed report on the deliverable

Background

The CORBEL Medical Infrastructure/ Users Forum (MIUF, WP3.1) is designed to promote close collaboration, at the pan-EU level, between medical research communities, funding bodies, and medical research infrastructures. In particular, its mission is to

- promote the establishment of pan-European scientific communities, providing the scientific content and access to patients;
- define the respective roles of infrastructures vs. scientific communities, avoiding gaps, overlaps and fragmentation ;
- capture the needs of the scientific communities and of the funders in terms of infrastructure services ;
- ensure the appropriate development and deployment of these services by one or multiple research infrastructures.

Description of Work

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

A first meeting was held on January 2016, in Paris and its outcomes are part of the deliverable D3.1. Two other meetings were organised on October 12th, 2016 and April 19th, 2017 (Paris, ECRIN headquarters); the outcomes are described in the deliverable D3.2.

During the period covered by the present deliverable two meetings were organised: October 24th, 2017 in Amsterdam and October 15th, 2018 in Paris.

According to MIUF recommendation to improve communication and visibility of RIs, an interactive database was prepared in collaboration with WP2 listing all the available services offered by the RIs, as well as the access mechanisms. The online catalogue was published on CORBEL website (http://www.corbel-project.eu/services.html) and presented during the 4th MIUF meeting.

For the 5th MIUF it was decided to organise a larger event inviting medical research communities, SMEs and biotech to show and discuss what the added values in collaborating with RIs are (including success stories). The programme is presented in Appendix; four sessions were organised to discuss

- the structuring of medical research communities at the pan-European level
- the emerging needs of medical research projects in the context of the big data and personalised / stratified medicine approach
- and the challenges raised in terms of development and deployment of data services

1. Structuring medical research communities at the pan-European level: this session provided an overview of many recently-funded initiatives aiming to structure pan-European user communities in: infectious diseases (ECRAID), neurosciences (EBRA), vaccines (TRANSVAC-2), paediatrics (IMI C4C) and rare diseases (EPJ-RD).
RIs participate in these initiatives to optimise the use of resources and avoid duplication or fragmentation. In some cases, specific infrastructure-led projects have been designed to reinforce the infrastructure in a given domain (e.g. PedCRIN, coordinated by ECRIN, for the management of paediatric trials).
Some of the challenges noted during this session included: project sustainability, quality control, education/training (e.g. in vaccinology), information sharing and strategic vision.

2. New models for medical research in Europe: success stories: this session highlighted various 'success stories' in the context of the new medical research paradigm in Europe. In effect, MIUF/CORBEL partners are involved in diverse initiatives that incorporate cross-cutting technical expertise to address scientific questions.
Some of the challenges noted, e.g. for image analysis/machine learning, were data collection, anonymization, clean-up/structuring, storage, sharing, inspection/annotation, processing/analysis, and integration. The potential value of cross-cutting collaboration between academia and industry was underlined in a case study on EATRIS/NeurATRIS.

3. New approaches in personalised medicine and patient stratification: this session focused on two major issues facing the scientific community today: personalised medicine and patient stratification. These issues must be understood in the following context: multimodal data management and machine learning processing is now an essential component of personalised medicine. This allows the collection of marge sets of multimodal data from every single patient enrolled in observational or

interventional studies (clinical data, -omics data, imaging data). Speakers highlighted various issues such as the storage and sharing of data, and the optimisation of research to avoid lengthy (useless) trials.

4. Data sharing and reuse: this session continued the discussion on data challenges, with speakers detailing issues from the organisation/sorting of data to determining which repository to use. The key takeaway here was the following: sharing and reuse of (multimodal) data, images, and biosamples is essential to optimise the use of research data. Policies for data sharing and reuse are generally lacking, which hampers the reuse of sensitive data at a larger scale across national borders.

Next steps

A similar large stakeholders event will be organised also in 2019

Delivery and schedule

The delivery is delayed: Yes

As the 5th MIUF originally planned in Spring 2018 was postponed to Autumn 2018 (back to back with the CORBEL General Assembly) in order to organise a large stakeholder event, it was agreed to postpone the corresponding deliverable D3.3 and milestone MS11. This was approved and implemented in the frame of the 2nd Grant Agreement amendment.

Adjustments made

N/A

Appendices

Appendix 1: Programme 5th MIUF

Programme:

10:30 registration & coffee

11:00 Introduction *(J. Demotes)*

11:10 Structuring medical research communities at the pan-European level

- ECRAID – European Clinical Research Alliance on Infectious Diseases *(H. Goossens)*
- EBRA – European Brain Research Area *(H. Lichtenberg)*
- TRANSVAC2 - European Network of Vaccine Research and Development *(O. Leroy)*
- C4C – Conect4children *(L. Mangiarini)*
- European Joint Programme Rare Diseases *(D. Julkowska)*

12:45 lunch

13:45 New models for medical research in Europe: success stories

- Organic bioelectronics sensors for Point-of-Care: the ENM III project AMI *(F. Biscarini)*
- Image analysis and machine learning *(S. Klein)*
- Bridging the academia-industry divide with cutting-edge science: a case study *(B. Kuhnast)*

15:00 New approaches in personalised medicine and patient stratification

- R-Link: Optimizing response to Lithium treatment through personalized evaluation of individuals with bipolar I disorder *(F. Bellivier)*
- ImmunAID - Immunome project consortium for AutoInflammatory Disorders *(F. Fernandes)*
- NECESSITY - NEw Clinical Endpoints in primary Sjögren's Syndrome: an Interventional Trial based on stratifYing patients *(J-E. Gottenberg)*

16:00 coffee break

16:30 Data sharing and reuse

- Multimodal data management: TraIT *(J-W. Boiten)*
- Sharing and reuse of clinical trial data *(C. Ohmann)*
- Reuse of national health database for cohort follow-up: CONSTANCES (M. Goldberg)
- Sensitive data services of EOSC-Hub project *(G. Sipos)*

17:45 round table discussion

- *Distribution of roles between pan-European scientific communities and pan-European research infrastructures*
- *Role of funders in the pan-European structuring and multinational projects*
- *Reuse of health data for observational and interventional research*

18:30 end of the meeting