

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

Deliverable D2.3
Report on user engagement activities

WP2 – Documentation, communication and outreach

Lead Beneficiary: DSMZ-German Collection of Microorganisms and Cell Cultures

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Contractual delivery date: 31 January 2020 Actual delivery date: 21 February 2020

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Grant agreement no. 654248 Horizon 2020 H2020-INFRADEV-1-2014

Type of action: RIA

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Executive Summary

This deliverable aims to give a comprehensive overview about the user engagement and user experience activities that were developed and executed by the CORBEL consortium in order to establish contacts to various scientific user communities and to support opening of the services developed in the project to a wide community. Based on the stakeholder analysis and the communication strategy that were developed at the beginning of the project, user engagement activities started right at the beginning of CORBEL. In order to ensure effective communication with all user communities, activities have been performed by all work packages.

The tools that were employed to engage with users were direct consultancy tools (e.g. face-to-face or virtual meetings, (feedback) workshops, exhibition/participation at relevant events, organisation of project-related events like the stakeholder meetings), the organisation of two Open Calls for advanced research projects, web-based communication tools (website, newsletter, social media, web-based tools and services), PR material, surveys/questionnaires, the Innovation Office web portal and an extensive webinar series.

User engagement activities will continue until the end of the project, and several activities will even be sustained beyond the project's lifetime, in order to maintain the established contacts to the user communities, to continuously provide information about (joint) RI services, and to offer user access to resources and services (e.g. via the Innovation Helpdesk).

Project objectives

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

- a) Development and execution of targeted user engagement and user experience activities to support opening of the services developed in the project to the wider community
- b) Dissemination of project results, e.g. through publications and presentations at relevant conferences
- c) Organisation of stakeholder meetings to provide ongoing opportunities for multi-way communication and feedback to the project partners

To a significant extent, the user engagement activities gave input for newsletter, website etc. and thus indirectly contributed to other WP2 objectives, such as the update of the project website, the production of a regular project newsletter and the execution of a social media strategy.

Detailed report on the deliverable

Background

The extensive stakeholder analysis that was performed at the beginning of the project (milestone MS4 'Stakeholder analysis roadmap to inform communication strategy', December 2015) identified the different user communities, the internal stakeholders and policy makers as the most important stakeholder groups for CORBEL. In the communication strategy¹ it was highlighted that collaborations with these groups should be set up and that they should be involved in discussions and, in specific cases, also in decision making processes. It was recommended to employ direct consultancy tools to engage with the users wherever possible, e.g. face-to-face or virtual meetings, (feedback) workshops, exhibition at or participation in relevant events, or organisation of project-related events like the stakeholder meetings. Also, web-based communication tools (website, newsletter, social media) and PR material were regarded as suitable for communicating to the various user groups. Moreover, in the Description of work surveys/questionnaires and the Innovation Office web portal were foreseen as other types of user engagement activities.

Task 2.2 of CORBEL WP2 is to develop and execute targeted user engagement and user experience activities to support opening of the services developed in the project to the wider community. In the Description of work, at least one activity per use case in WPs 3 and 4 and one for each common services work package was foreseen. Communication efforts were embedded in the use case WPs 3 and 4 to seek direct user feedback and to establish collaborations with e.g. ERA-NETs, IMI projects, e-infrastructures and industrial partners. This user engagement from the very beginning of the project was regarded as a critical step to tailor the services according to their needs and to develop the joint services with their assistance and recommendations.

With milestones MS6 ('Develop and implement targeted user engagement activities', September 2017) and MS7 ('Briefing paper on user engagement activities with focus on WP3, WP4 and the common services WPs', April 2019), crucial steps towards the execution of these activities were taken in the course of the project. The activities started right at the beginning and will continue until the end of the project. In order to ensure effective communication with all user communities, to seek user feedback also within other work packages and utilise existing experience within the project, the activities have been involving all work packages.

Description of Work

In order to ensure effective communication with all user communities, user engagement activities have been performed by all work packages. Usually, WP2 assisted with the announcement and promotion of the activities to the various stakeholders, employing the established CORBEL communication channels. A list of all outreach activities can be found in the CORBEL Outreach Archive.

WP2 (Documentation, communication and outreach)

Within WP2, the following user engagement activities were performed:

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¹ Deliverable D2.1 - Communication strategy based on stakeholder analysis: https://doi.org/10.5281/zenodo.154033

According to the CORBEL communication strategy, a number of communication channels were established and exploited: the CORBEL website, newsletter, social media accounts (Twitter, YouTube, ResearchGate) to target the users and the other CORBEL stakeholders.

The CORBEL website² experienced around 900 visits per month on average. Peak values were reached in November 2016 (2,889 visits), November 2017 (1,191 visits) and April and October 2018 (2,261 and 1,422 visits), most likely due to the launch of the Catalogue of services (Nov 2017) and the Open Calls (2016 and 2018) and the accompanying dissemination activities. In total, the website received around 43,000 visits until the end of December 2019.

The Catalogue of Services³, launched in November 2017, constitutes a means for user engagement on the CORBEL website and provides a basic overview about the services offered by the 13 research infrastructures (RIs) participating in CORBEL. Researchers looking for services they cannot access at their home institution can use the catalogue to identify RIs that offer the specific technology/expertise they need, contact the relevant RI and negotiate the access. Users can choose the technology or expertise the need from a drop-down list clustering the available services in five categories; subsequently, the RI(s) offering the requested resource is/are displayed.

The project newsletter 'CORBEL News' has been distributed twelve times since the project start4. Special issues were sent out to announce the CORBEL webinars, events and the Open Calls. In December 2019, the list of CORBEL newsletter recipients comprised 1,144 people.

The dissemination of project news and results was also supported by Social Media activities, especially via the Twitter account (@CORBEL_eu), resulting in 970 followers at the beginning of January 2020.

Project communication in general and especially cost-intensive activities like exhibitions and other face-to-face meetings were targeted at the most important stakeholder groups. Therefore, in close collaboration with other work packages, WP2 enabled exhibitions at several international conferences. The conferences that took place in 2018 focused on the announcement of the CORBEL 2nd Open Call among different user communities and were organised jointly with WP4.

- 3-5 October 2016: CORBEL exhibition at the International Conference on Research Infrastructures (ICRI) in Cape Town, South Africa. ICRI is a well-established international forum encouraging global cooperation and providing a unique opportunity to share views on matters of international relevance in the RIs' domain.
- 4-6 April 2017: CORBEL exhibited at the 12th BIOVISION (The World Life Sciences Forum) 'From Global health to One health' in Lyon, France, reaching about 1,200 stakeholders from academia and industry. The BIOVISION conference is a meeting place to discuss global health topics such as medical education, digital health and innovation, emerging viral diseases, cancer and metagenomics with stakeholders from all life science fields. BBMRI, EATRIS, ECRIN and ELIXIR jointly exhibited with CORBEL, informing the conference participants about individual and shared services of European Biological and Medical RIs.

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https://www.corbel-project.eu/home.html

³ https://www.corbel-project.eu/services.html

⁴ https://www.corbel-project.eu/newsletter.html

1-4 July 2018: CORBEL participated in the third biennial Core Technologies for Life Sciences (CTLS) conference in Ghent that targeted scientists and technical and administrative staff of shared resource laboratories. Information about CORBEL was distributed in several talks by CORBEL partners as well as via a poster. At the CORBEL booth, CORBEL outreach material, including information about the 2nd Open Call, and material from several RIs was displayed. In total, almost 300 people from the scientific community, industry and policy were reached by these means.

- 12-14 September 2018: CORBEL was present at the ICRI in Vienna. The conference was organised by the Austrian Federal Ministry of Education, Science and Research within the framework of the Austrian Presidency of the Council of the European Union and provided a forum for discussion about different aspects concerning national, pan-European as well as global RIs.
- 15-16 October 2018: CORBEL was present at the ELIXIR SME and Innovation Forum on 'Data Driven Innovation in Industrial Biotechnology' in Frankfurt/Main, Germany. In order to reach out to potential users from academia and industry and to advertise the 2nd Open Call, CORBEL was present with an exhibition booth, and the 2nd Open Call was advertised in a flash talk by WP4.
- 7 November 2018: CORBEL exhibition at the ENABLE (European Academy for Biomedical Science) initiative's 2nd European PhD and Postdoc symposium on 'The Promise of Future Medicine: From Research to Therapy', Copenhagen, Denmark. The event provided many opportunities to interact and network with early-career scientists from the biomedical field. The 2nd Open Call was presented in a flash talk and information about the RIs and CORBEL in general was given.
- 6-7 May 2019: CORBEL exhibition booth and poster presentation 'CORBEL Harmonising Access to Europe's Biomedical Research Infrastructures' at the LifeTime Launch Event 'Understanding cells to revolutionise health care'. CORBEL services were presented to the LifeTime community. The conference was attended by about 500 biomedical scientists, clinicians, patients, and stakeholders with a focus on single cell technologies and personalized medicine.
- 22-24 May 2019: CORBEL exhibition at the Instruct Biennial Structural Biology Conference in Alcalá de Henares, Madrid, Spain.
- 3-5 June 2019: CORBEL exhibition at the INFRAFRONTIER/IMPC Conference 2019 in Helsinki, Finland. The joint annual meeting of INFRAFRONTIER and the International Mouse Phenotyping Consortium (IMPC) focused on Genetic Variation, Big Data and Ageing. CORBEL was present with an exhibition stand, providing information about the project's work and the participating RIs.
- 6-11 July 2019: CORBEL exhibition at the 44th FEBS (Federation of European Biochemical Societies) Congress in Krakow, Poland. The congress aimed to provide an international forum in the area of Europe and neighbouring regions for the face-to-face exchange of knowledge and ideas across the molecular life sciences. CORBEL, Instruct, Euro-Biolmaging and EU-OPENSCREEN joined forces to raise awareness about the life science RIs among the 1,825 congress participants. The three RIs presented their fields of work and their offers in a special 'Using international research infrastructures to boost your science' session that attracted the

interest of around 150 participants. The joint exhibition booth of the three RIs and CORBEL provided a continuous space for encounters with the congress participants, who came from a large variety of research areas.

WP3 (Medical/Translational Research Use Cases)

Within WP3, the following user engagement activities were performed:

Establishment and sustainment of the Medical Infrastructure/Users Forum

The Medical Infrastructure/Users Forum (MIUF)⁵ brings together the RIs with scientific/technical expertise in different medical research areas, and medical research communities corresponding to European priorities, including pan-European users communities as well as patients associations. The MIUF is a key instrument for efficient development and use of biomedical research infrastructures in Europe, by promoting a culture of collaboration across the RIs 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.

Five face-to-face meetings were held so far, in order to gather input from various stakeholders (infrastructures, scientific communities, funding bodies) and to identify solutions for a long-lasting collaboration strategy: 25-26 January 2016, 12 October 2016, 19 April 2017, 24 October 2017, 15 October 2018. Another meeting was scheduled for 6 December 2019 in Brussels, but had to be cancelled due to a massive strike and the resulting transportation difficulties in France. Details are provided in the respective deliverables^{6,7,8} and the MIUF report⁹.

According to the MIUF recommendation to improve communication and visibility of RIs, the CORBEL Catalogue of Services was prepared in collaboration with WP2 (see WP2 section) and presented during the 4th MIUF meeting.

Establishment of a multistakeholder patient-level data task force

Transparency and access to research data is a key feature for research policies, impacting on data quality and robustness of results, and leading to optimal use of data generated by research projects. This is of particular importance in clinical research, where access to individual patient-level data would ensure data quality and robustness of analyses, improve the accuracy of estimates of benefits from a treatment and optimize the use of clinical trials data for re-analyses, secondary analyses and meta-analyses. Within CORBEL, a task force composed of experts¹⁰ covering different fields in data sharing was set-up to provide recommendations to make data sharing a reality. Three meetings were held (3-4 March 2016, 6-7 October 2016, 27-28 March 2017) to discuss multiple issues. For details, see D3.7¹¹ and multiple publications which resulted from this work (examples are provided in the footnotes 12,13).

⁵ http://www.corbel-project.eu/work-packages/wp3-medicaltranslational-research-use-cases/wp3-miuf.html

⁶ Deliverable D3.1 - 1st Medical Infrastructure/Users Forum (MIUF) Report: https://doi.org/10.5281/zenodo.154035

⁷ Deliverable D3.2 - 2nd Medical Infrastructure/Users Forum (MIUF) Report: https://doi.org/10.5281/zenodo.825054

⁸ Deliverable D3.3 - 3rd Medical Infrastructure/Users Forum (MIUF) Report: https://doi.org/10.5281/zenodo.2025792

⁹ MIUF report: https://www.corbel-project.eu/fileadmin/corbel/media/docs/170307_MIUF_Survey_Lay_Report.pdf

Website WP3 taskforce: https://www.corbel-project.eu/about-corbel/work-packages/wp3-medicaltranslationalresearch-use-cases/wp3-patient-level-data.html

Deliverable D3.7 - Report on conclusions from multi-stakeholder taskforce: https://doi.org/10.5281/zenodo.1409571

¹² Evaluation of repositories for sharing individual participant data from clinical studies (2019) Banzi R., Canham S., Kuchinke W., Krleza-Jeric K., Demotes-Mainard J., Ohmann C., Trials: https://doi.org/10.1186/s13063-019-3253-3

Participation in the CORBEL 2nd Open Call

Service providers from all medical RIs involved in WP3 participated in the 2nd Open Call which was launched in March 2018. A fifth Access Track 'Complex multimodal biomarker profiling' was developed and aimed at providing integrated access to biosamples, medical imaging and multimodal analysis to support the design and implementation of research projects in biomarker identification or validation (retrospective or prospective studies). Access Track 5 targeted external researchers from academia, industry and clinics and involved the hubs of BBMRI-ERIC, EATRIS and ECRIN as well as a node of Euro-Biolmaging, the European Population Imaging Infrastructure (EPI2).

WP4 (Bioscience Research Use Cases)

Within WP4, the following user engagement activities were performed:

Engagement with VIP users (pilot use cases)

VIP pilot projects drawn from the existing user base of the participating RIs were first identified to establish procedures of interaction between RIs when working together within the same project. The aim was to uncover technical and administrative hurdles for service providers and users, while at the same time providing premium support to the user by facility staff and WP4 management. Some of the VIP projects have made significant progress, however, a few VIP projects were also confronted with challenges and had to be terminated. More information is available in the respective deliverable ¹⁵.

Launch of two Open Calls for advanced research projects

WP4 launched two Open Calls^{16,17} to select research projects in an unbiased and merit-based fashion driven by the user, testing service pipelines along the way and to increase awareness for the CORBEL project and participating RIs and their services. The target audience were external researchers from academia, industry and clinics. Under the lead of WP4, other WPs contributed to the realisation of the Open Calls: WP2 supported with the outreach and communication activities and WP5 provided the application management system ARIA.

Within the 1st Open Call (5 October to 30 November 2016), 32 project proposals had been submitted, 30 of which fulfilled all CORBEL Open Call eligibility criteria. After scientific and technical evaluation, 21 projects were finally accepted as CORBEL user projects. In all steps, from proposal preparation to accepting the final projects, help and support from the WP4 project managers was regularly asked for and highly valued. Users, service providers and reviewers all made use of this resource and requested support in submitting proposals, handling the application management system, in establishing contact with users or service providers, etc.

After the success of the 1st Open Call which clearly demonstrated the high demand of cross-RI services, a 2nd Open Call for research projects was launched from 26 March to 31 December 2018. As an additional offer, service providers from all medical RIs involved in WP3 participated in the 2nd

¹³ Sharing individual participant data from clinical studies: a cross-sectional online survey among Italian patient and citizen groups (2019) Colombo, C., Anna Roberto, A., Krleza-Jeric, K., Parmelli, E., Banzi, R., BMJ Open: https://bmjopen.bmj.com/content/9/2/bmjopen-2018-024863

¹⁴ Website Access Track 5: https://www.corbel-project.eu/open-call/access-tracks/access-track-5-complex-multimodal-biomarker-profiling.html

Deliverable D4.1 - Strategy for enabling user access within pilot use cases: https://doi.org/10.5281/zenodo.154081

¹⁶ http://www.corbel-project.eu/1st-open-call.html

https://www.corbel-project.eu/open-call.html

Open Call. Additionally, WP8 assisted with outreach activities towards industry (SMEs and umbrella organisations) and gave input for a website subpage dedicated to potential industry users¹⁸. In total, 23 project applications from academia and industry covering all of the five offered Access Tracks were received. From all eligible projects, 16 applications were accepted as CORBEL user projects.

Organisation of two Open Call Service Operator & User Meetings

To better connect service providers from different RIs with each other, to exchange best practices for service provision and to discuss challenges in interactions with users, two face-to-face meetings were organised: 22-23 January 2018 (Berlin, Germany)¹⁹ and 1-2 October 2019 (Heidelberg, Germany).

The first meeting was attended by representatives from all RIs. Eleven VIP and 1st Open Call projects were presented jointly by service providers involved together with the users, who had also been invited. WP5 and WP6 also participated in the event to collect users and service providers' feedback regarding the ARIA infrastructure access management and needs of data management support, respectively. Other points on the agenda of the meeting included a presentation on the 'European Charter for Access to Research Infrastructures' by Federica Paina (Project manager, Euro-Biolmaging) as well as a panel discussion on 'Science, technology development and services in research infrastructures'. A training event for service providers, organised by WP9, concluded the meeting. Some key messages directly drawn from various discussions at the meeting emphasized how important frequent communication between all parties involved is. They also highlighted the necessity of careful project planning including timelines set out directly from the onset of a project. Most importantly, the key messages pointed out the invaluable role CORBEL played in realising several exciting cutting-edge research projects stimulating collaborations and driving technology development.

During the second meeting, twelve different research projects were presented jointly by the users and the service providers, presenting the scientific background and the progression of the projects, but also highlighting the benefit CORBEL support meant for the project or the service provider facility. The participants explained which hurdles they encountered and gave valuable recommendations for the future direction of joint service provision. The two RIS EMPHASIS and ERINHA that both joined the CORBEL consortium in 2017, presented their activities to the participants. In a session addressing 'Modern research and the data challenge', the EOSC-Life project was presented. Keynote speaker Caterina Strambio from the University of Massachusetts Medical School highlighted how data provenance, quality control and unified imaging pipelines increase reproducibility, data quality and fidelity in the field of biomedical imaging. A panel discussion addressed the challenges of modern research being carried out in large consortia in an interdisciplinary manner. Finally, companies presented needs and challenges from their collaborations with research infrastructures in a dedicated industry session.

In the course of the two meetings, interviews were conducted by WP2 with five scientists who successfully applied to the Open Calls. Recordings of the interviews are accessible on the CORBEL YouTube channel or via the CORBEL website²⁰.

 $\underline{https://drive.google.com/file/d/11wVbKeKTJ7NnOUboBtqCp1njQxhKXLkl/view?usp=sharing}\\$

https://www.corbel-project.eu/success-stories.html

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¹⁸ https://www.corbel-project.eu/open-call/application-from-industry.html

¹⁹ Agenda 1st Service Operator & User Meeting:

Survey among users and service providers of the 1st Open Call

Detailed feedback on the 1st Open Call application process was collected from all service providers and users via two surveys developed by WP4 and WP5 partners using ARIA²¹. Results of both surveys were circulated to other CORBEL partners across all WPs and used not only to improve the management and administrative support for on-going projects (including the access management platform ARIA) but also to inform the introduction of several crucial adaptations to launch the 2nd Open Call.

WP5 (Common Solutions for User Access)

Within WP5, the following user engagement activities were performed:

Refinement of the ARIA access management software after the Open Calls

After the 1st Open Call for research projects, two surveys were conducted to seek feedback on the employed access model from the applicants and service providers. This feedback was used to refine the ARIA software and to improve the proposal submission process to better meet the requirements of the users and other stakeholders. Many changes were implemented to support the opening of the 2nd Open Call (for details see Deliverable D4.2 and D5.2²²).

Following the 2nd Open Call two similar surveys were circulated, again to obtain feedback on the access model from applicants and service providers. Though this information collection is still ongoing, it will be used to inform future developments even those which might take place after the CORBEL project.

Provision of ARIA training measures and support

Support and training on ARIA was rated as being crucial in order for all users (end users, service providers, reviewers and project managers) to understand and get the most from the system and the features on offer. Therefore, a number of support materials and training webinars were compiled and shared with the CORBEL community. In December 2017 the ARIA help guide web pages²³ were launched. These pages gave information on how to complete common tasks in ARIA, and were organised by the role/type of user e.g. user applying for access, scientific reviewer, service provider, administrator. These pages have been disseminated within the CORBEL community in emails and presentations, and are also linked to from within the administration pages in ARIA. Additionally, a number of webinars about ARIA were held^{24, 25, 26}. Additionally individual user support enquiries from applicants to the Open Calls, scientists involved in review of proposals and CORBEL service providers were managed by a dialogue over email and/or telephone.

Webinars

WP5 delivered a webinar for the CORBEL webinar series about 'Quality Management in Distributed Research Infrastructures' (22 May 2018)²⁷.

https://youtu.be/arUJJNiGvc4

²¹ Deliverable D4.2 - Sustainable plan for user access to common RI services for 4 use case cross-ESFRI BMS research infrastructure pipelines: https://doi.org/10.5281/zenodo.2222358

²² Deliverable D5.2 - Report on Common Access Framework Concept: https://doi.org/10.5281/zenodo.2662133

https://instruct-eric.eu/help/collections

https://bit.ly/2U8tdc8

https://youtu.be/d7e_pXui2Ec

https://www.corbel-project.eu/webinars/quality-management-in-distributed-research-infrastructures.html

WP6 (Data Access, Management and Integration)

Within WP6, the following user engagement activities were performed:

The work conducted by WP6 on the standardisation of identifiers included the engagement of the biomedical RI communities and resulted in a community engagement roadmap²⁸. Further work addressed identifier recommendations and harmonisation in the context of the access by the RIs (coordinated through WP4)²⁹. This involved input from and collaboration across the 13 RIs, also engaging with CORBEL Open Call users and service providers regarding interoperability. A set of recommendations was given to improve interoperability potential in future cross-RI projects. Moreover, WP6 has engaged with globally aligned identifier standardisation activities, through existing initiatives such as Research Data Alliance, Force 11, FREYA, as well as emergent activities such as those convened by GEDE and the Australian Research Data Commons. In addition, the group has promoted identifier best practice and encouraged adoption, e.g. by publishers. Work towards providing a centralised Knowledge Hub has been conducted in collaboration with the ELIXIR Hub and will be reflected in the ELIXIR Knowledge Hub.

Moreover, WP6 has developed a suite of services supporting semantic standardisation for CORBEL, consisting of the Ontology Lookup Service (OLS)³⁰, an ontology repository, web interface and API, and BiobankConnect / MOLGENIS / connect / BiobankUniverse³¹, a matchmaking and harmonisation tool suite for biobank oriented datasets. These services address finding and identifying ontology terms (OLS), mapping between ontologies (Ontology Cross Reference (OxO)³²), and annotation-ontology mapping (Zooma and BioBankConnect). The service development has been driven requirements from the biomedical RIs (via CORBEL WPs 3 and 4) and international engagement. It is detailed in deliverable D6.3³³.

The ontology development pipeline was adopted by several user communities and has for example been used successfully to build three new CORBEL ontologies for EMBRC and also to extend existing ontologies that cover experimental variables and disease such as the Experimental Factor Ontology, The Sickle Cell Disease Ontology and the Human Cell Atlas Ontology.

WP6 has significantly contributed to the dissemination of OLS via several events, targeted to industry (big pharma / agrifood and SMEs) as well as academic.

BiobankUniverse, the matchmaking service for biobank/registry data sets on data item level, was published as part of the MOLGENIS web application for scientific data, facilitating the large scale matching and integration of disparate biobank datasets. This technology has been adopted by several of projects, including EU RD-connect, EU Solve-RD, BBMRI-ERIC, EU LifeCycle.

 $^{^{28}}$ Deliverable D6.1 - Review of identifier schemes, standards and interoperability maps and proposed harmonization strategy: https://doi.org/10.5281/zenodo.376236

Deliverable D6.2 - Access to Sustainable cross infrastructure identifier service(s) through ELIXIR service registry: https://doi.org/10.5281/zenodo.1441303

https://www.ebi.ac.uk/ols/index

https://biobankuniverse.com/

https://www.ebi.ac.uk/spot/oxo/

Deliverable D6.3 - Delivery of Toolkit supporting community ontology mapping and development: https://doi.org/10.5281/zenodo.2559160

WP7 (Common services providing support with ELSI):

Within WP7, the following activities were performed, targeting the participating RIs, thematic interest groups, researchers from academia, industry and clinics:

WP7 established working groups for ELSI support, regulatory frameworks, patient information and support materials. Additionally, especially legal experts of the WP7 working group have contributed substantially to the Code of Conduct for Health Research Initiative³⁴, which aims for a code of conduct under Article 40 GDPR, and ensured that the needs of research infrastructures are met appropriately. Most recently, the Initiative exchanged with other codes in the sector of health research and reached an agreement to align and cross-reference the codes as much as possible. The code will likely not be concluded within the CORBEL project, but has built ties with relevant stakeholders that will continue within EOSC-life.

Furthermore, under the responsibility of the Istituto di Ricerche Farmacologiche Mario Negri IRCCS, a multidisciplinary team has developed an Informed Consent Matrix for Clinical Trials³⁵. First, a protocol had been drafted and shared with other partners in order to define main aims, outcomes and activities. The final version was then discussed among partners in a meeting held in June 2016 in Milan. Furthermore, informed consent templates were collected from project partners and web research. In a next step, the characteristics of each template were assessed. Additionally, a literature review according to a protocol defined to search for relevant systematic reviews and guidelines, to inform the development of the template was finalised. The findings of the review were detailed in a report and concluded with a draft of the consent template matrix, shared with partners and tested by patient representatives. The final guide aims to provide a minimum set of requirements for informed consent aimed at adults in the context of multinational clinical trials. The matrix mainly refers to multicentre interventional randomized clinical trials, but some suggestions can also be applied to non-interventional research. However, it should be adapted to national settings and specific contexts. The guide covers the processing of information (context, language, setting), topics and proposed wording, as well as general suggestions on wording, format and length of the information sheet. In order to make it widely available and ensure sustainability beyond CORBEL, the guide is integrated in the BBMRI-ERIC ELSI Knowledge Base³⁶.

Webinars

WP7 has delivered several webinars for the CORBEL webinar series: 'Status Update on the Code of Conduct for Health Research Initiative' (5 June 2018)³⁷, 'The BBMRI-ERIC ELSI Helpdesk' (10 July 2018)³⁸, 'Towards a GDPR Code of Conduct for Health Research: where are we today?' (19 June 2019)³⁹.

³⁴ https://code-of-conduct-for-health-research.eu/

³⁵ http://www.bbmri-eric.eu/wp-content/uploads/informed-consent-matrix-for-clinical-trials-july-2019.pdf

http://www.bbmri-eric.eu/BBMRI-ERIC/elsi-knowledge-base/

Webinar 'Code of Conduct for Health Research Initiative': https://www.corbel-project.eu/webinars/status-update-onthe-code-of-conduct-for-health-research-initiative.html

https://www.corbel-project.eu/webinars/the-bbmri-eric-elsi-helpdesk-personalising-elsi-support.html

³⁹ https://www.corbel-project.eu/webinars/gdpr-code-of-conduct-for-health-research.html

WP8 (Accelerating Innovation)

Within WP8, the following user engagement activities were performed:

Establishment and maintenance of the Innovation Helpdesk

The CORBEL Innovation Office ⁴⁰ was started in 2016 and aims to increase the utilization of research data and resources through enhanced public-private collaboration and reduced length of matching and negotiation processes. At the CORBEL Innovation Office, a team of experienced business developers and legal experts provides free of charge advice and assistance to streamline research collaboration among Europe's biomedical RIs and the industry. Basically, the Innovation Office is set up to support RIs participating in CORBEL, but it is also open to requests from industrial clients aiming to establish a public-private collaboration. There has been a steady, if modest, demand for the services and it was particularly encouraging that both academia and industry made requests and that a wide range of topics was covered.

In addition, the Innovation Office web portal was supplied with content comprising guidelines and template documents for referral to by academic research staff. Included are a number of guideline documents on various aspects of research partnering and collaboration, including papers and presentations on Expert Centres, and downloadable template agreements or tools for designing agreements. The scope includes topics such as negotiation, IP, project budgeting and approaches to life sciences evaluation.

A comprehensive best practice guide for industry research collaboration, covering practically the entire range of likely issues was put together as a CORBEL deliverable⁴¹ and will be made available in brochure form. This guide aims to provide practical assistance to the academic researcher confronted with the need to establish effective and lasting collaboration with industry partners.

Organisation of the 'How European Biological and Medical Sciences Research Infrastructures boost Innovation by Open Access' meeting

On 20 June 2017, the national node BBMRI.at and EATRIS organized a meeting in Brussels⁴² within the framework of CORBEL to discuss how RIs can be utilised to support innovation. Speakers from a wide range of fields from the biomedical RIs, the European Commission, industry and other European organizations were invited. The speakers explored the topic of Open Innovation with particular emphasis on pre-competitive research cooperation models. The various RIs gave lectures and talked about how they are working to achieve the goal of Open Innovation. The meeting ended with a lively panel discussion between representatives of EMA, EFPIA and industry. Conclusions were that pre-competitive open access models are very valuable as an instrument for innovation, if issues such as intellectual property rights (IPR) are adequately addressed in the planning process.

Workshop: Best practices in Biomedical Public-Private Research Collaborations

From 12-13 December 2018, EATRIS organised a training workshop 'Best Practices in Biomedical Public-Private Research Collaborations: Network Development, Legal Planning & Project Management' in Ljubljana, Slovenia⁴³. The workshop aimed to offer practical tools and insights to

⁴⁰ https://www.corbel-project.eu/innovation-helpdesk.html

Deliverable D8.3 - Industry collaboration best practice guide: https://doi.org/10.5281/zenodo.2615364

⁴² http://www.corbel-project.eu/innovation-by-open-access-meeting.html

https://www.corbel-project.eu/events/event-articles/best-practice-workshop.html

academic groups as well as to staff from biological and medical RIs to accelerate their partnerships with industry and the innovation potential of their RI. The two-day training covered the many aspects of setting up public-private collaborations (business development strategy, legal frameworks, project management); it was followed by an interactive group exercise featuring a realistic case study. The programme and exercise were based on the perspective of the academic researcher, who is required to take an active role in setting up public-private collaborations. EATRIS and other biomedical infrastructures were invited to give highlights from their experience in reaching out to industry, and a pharmaceutical consultant gave a talk on the industry point of view. Judging by the high level of enthusiasm and the positive comments received, the workshop fulfilled a clear need in academia.

WP9 (Training)

Within WP9, the following user engagement activities were performed:

WP9 has organised a number of user engagement activities within the CORBEL training programme. The programme, comprised of a staff programme⁴⁴, a webinar series⁴⁵ and face-to-face training courses, is mainly targeted at technical operators of the RIs in the hubs and nodes, but also courses and workshops aiming at researchers from academia, industry and clinics have been organised.

To date, 15 webinars have been run successfully as part of the CORBEL webinar series and recordings were made available for future viewing on YouTube and embedded on the CORBEL website. Examples of face-to-face training courses that were run: Train the trainer workshop & course development hackathon (4-6 July 2018, Amsterdam), 'Machine Learning for Image Analysis' (29-31 October 2018) and 'Data Visualisation for Biology' (11-15 March 2019).

A detailed overview of the activities organised by the CORBEL Training Programme is provided in D9.4 Pilot Courses and Staff Exchange provided (due M55).

Next steps

More user engagement activities will be performed during the last months of the CORBEL project. These include:

- A workshop on 'Best practices in Biomedical Public-Private Research Collaborations', organised by WP8 (13-14 February 2020, Lisbon, Portugal)
- An ARIA workshop, organised by WP9 and WP5 (25 February 2020, Amsterdam, The Netherlands)
- The CORBEL Final Open Meeting48 (2 March 2020, Florence, Italy), organised by the whole consortium
- A workshop on 'Data visualisation for biology', organised by WP9 (16-20 March 2020, Hinxton, Cambridge, United Kingdom)

⁴⁴ https://www.corbel-project.eu/about-corbel/work-packages/wp9-training/wp9-staff-exchange.html

⁴⁵ https://www.corbel-project.eu/webinars.html

⁴⁶ https://www.corbel-project.eu/events/event-articles/machine-learning.html

⁴⁷ https://bit.ly/38ztJYs

⁴⁸ https://www.corbel-project.eu/events/event-articles/final-open-meeting.html

 A joint booth at the 15th European Molecular Imaging Meeting (24 - 27 March 2020, Thessaloniki), organized by 3-4 participating RIs (discussions ongoing). Euro-BioImaging secured also a slot in the scientific program and invited other RIs to contribute to a joint session.

- A workshop on 'Best practices in Biomedical Public-Private Research Collaborations', organised by WP8 (21-22 April 2020, Riga, Latvia)
- WP4 will organize a training workshop in Villefranche, 27-29 May 2020. This workshop originated from the very successful collaboration between two Open Call service providers (Euro-BioImaging EMBL-Node and EMBRC Villefranche) and their user. The workshop will be broadly advertised and invite participants internal and external to the consortium. WP2 will support the communication and outreach activities.
- Usability testing and review of ARIA is currently being undertaken by WP5 to improve the user experience and design to better meet the needs of different types of user. Usability testing is a technique used to evaluate the platform by testing it on real users. Participants are asked to perform a series of tasks and are encouraged to speak their mind as they do so. By observing how people interact with the platform and analysing the data, usability issues can be identified and a real understanding of user behaviour can be gained. Together this ensures that well informed design decisions are made.
- The CORBEL webinar series will be continued until the end of the project.
- Survey among the users and service providers of the 2nd Open Call (ongoing)
- A new website for the Life Science RIs is currently under development. This website aims to be a common source of comprehensive information about the 13 RIs, their activities, offers, news and funding opportunities and will serve as a single information portal for scientists and other stakeholders beyond the lifetime of CORBEL. Moreover, it is proposed to migrate the web contents of the CORBEL Innovation Helpdesk to the new site, and also provide information about the ELSI services.
- Initiated by WP4 as one of their measures for long-term sustainability of the developed common access pipelines, WP2 supported the development of a brochure highlighting the impact of the CORBEL Open Calls. Success stories on user projects illustrate the benefits CORBEL provided. The research infrastructures that committed themselves to continue with joint access provision are also introduced in the brochure. The brochure will be distributed at all upcoming relevant events during the lifetime of CORBEL and after.
- WP4/WP2 will be producing a series of animated videos, which will be used for the advertisement of joint service provision under CORBEL and beyond. The videos will be placed on the new Life Science RI website and will be available for presentations and other outreach activities. The focus of the first video will be on the concept of RIs and their service offers. The second video will highlight the impact of working with multiple RIs on the basis of selected success stories.

Abbreviations

CORBEL: Coordinated Research Infrastructures Building Enduring Life-science services

MIUF: Medical Infrastructure/Users Forum

OLS: Ontology Lookup Service

OxO: Ontology Cross Reference

RIs: Research Infrastructures

WP: Work Package

Delivery and schedule

The delivery is delayed: Yes. The slight delay was caused by the imminent maternity leave of the WP leader and the resulting time constraints.

Adjustments made

According to the Description of Action, the organisation of stakeholder meetings by WP2 was scheduled for the second and third reporting period of CORBEL. It was planned to organise the stakeholder meetings together with the Annual General Meetings (AGMs), starting with the second AGM in October 2017. However, in the 7th Executive Board Meeting on 2 February 2017 it was decided that instead of a meeting in October, the High Level 'Innovation by Open Access' meeting organised by WP8 in June 2017 should be regarded as the 2017 stakeholder meeting because it gathered participants from several of the CORBEL stakeholder groups.

Moreover, five MIUF meetings were held since the start of the project – as the MIUF is composed of participants from several CORBEL stakeholder groups (e.g. RIs and medical research communities), these events are also regarded as stakeholder meetings. Also, the two Service Operator & User meetings organised by WP4 in 2018 and 2019 constituted important CORBEL stakeholder meetings.

WP2 assisted with the announcement and promotion of the activities to the various stakeholders and conducted interviews with scientists during the Service Operator & User meetings.

Due to the extension of the CORBEL lifetime until 31 May 2020, the 4th AGM was postponed from autumn 2019 to 2 March 2020 (Florence, Italy). During this final CORBEL stakeholder meeting the consortium will present their solutions for harmonising user access to the RIs. Presentations by scientists from the biological and medical user communities will illustrate how concerted access to multiple RIs advanced their projects, thus demonstrating the benefit of CORBEL for European life science research. The meeting will be open to European scientists from the biological and medical field, potential users of the CORBEL common services as well as other stakeholders generally interested in CORBEL and the RIs and will thus be the final CORBEL stakeholder meeting.

As one objective within WP2, the organisation of an intensive user workshop during the last year of the project (back-to-back with the feedback workshop of the common services work packages) was scheduled. Because two user meetings (the MIUF meeting scheduled for 6 December 2019 (cancelled) and the Service Operator & User meeting in October 2019) had already been envisaged for the last year of CORBEL, and as the final CORBEL stakeholder meeting will also bring together many users, no additional user workshop will be organised by WP2.