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DELIVERABLE REPORT

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REGISTRY/ BIOBANK SUPPORT SERVICE/ HELP-DESK FACILITY

Executive Summary

Transnational efforts are essential to make optimal use of resources and are more critical for research development on rare diseases than for other disease entities for which resources can be made more readily accessible. BBMRI-ERIC will develop the concept for a Common Service for Rare Diseases, which should provide a long-term "home" for these valuable initiatives.

One of the main initiatives for the implementation of a RD common service is to establish a Help-desk facility to provide real time support to RD biobanks and/or registries to meet requirements for participation to BBMRI-ERIC.

Help-desk service will be planned aiming to assist already existing and emerging RD biobanks in addressing various questions related to biobanking issues.
Moreover, RD helpdesk can be a test bed for the realization of similar facilities for diseases with a high probability of incidence on the population.

Registry/biobank Help-desk facility (HDf) develops selecting as a model Tiered Structure-Generalist Model and it provides for a layered structure with requests to three possible levels, and three possible levels of assistance.

HDf will provide services in collaboration with BBMRI-ERIC common services IT and ELSI and BBMRI-ERIC-HQ Quality Service to provide support to RD biobanks.

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Document log

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D7.2_Rev1	2017-09-05	Inclusion of details on results, added discussion section and next steps.	Luca Sangiorgi, Matias De La Calle, Marina Mordenti, Manuela Locatelli
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1. Background

Rare diseases are a large, heterogeneous category, affecting no less than 30 million Europeans. Today many patients with rare diseases still lack accurate diagnosis and appropriate treatments with a negative impact on survival and on quality of life. Transnational efforts are essential to make optimal use of resources and are more critical for research development on rare diseases than for other disease entities for which resources can be made more readily accessible.

Therefore, BBMRI-ERIC will develop the concept for a Common Service for Rare Diseases, which should provide a long-term "home" for these valuable initiatives.

The challenge is to maintain, on the one hand, well-established infrastructures, tools and procedures developed by the RD community (e.g., patient registries, research- and clinician-driven biobanks, platforms etc) and on the other hand, integrate and harmonise them with BBMRI-ERIC standards and procedures.

One of the main initiatives for the implementation of a RD common service is to establish a Help-desk facility to provide real time support to RD biobanks and/or registries to meet requirements for participation to BBMRI-ERIC.
Help-desk service will be planned aiming to assist already existing and emerging RD biobanks in addressing various questions related to biobanking issues.

Moreover, RD helpdesk can be a test bed for the realization of similar facilities for diseases with a high probability of incidence on the population.
In the literature there are several models help desk, the main ones are:

1.1 Gatekeeper Model

Some traditional Help Desks route all calls through a central call group. The advantage is that the internal customer (e.g. Biobank affiliated to BBMRI, Registry affiliated to Rd-Connect) does not have to know a dozen phone numbers and pick the correct phone number for the problem they are having. They only have to know one number. The function that this model provides can be called the dispatch group, the help desk, call screeners or a dozen other names. The function can be staffed with a single person or several. The common theme is that this group is not supposed to solve the customer's problem and serves only to link or direct the customer to the proper individual or group. Sometimes the call is first registered before dispatching. Sometimes the phone calls are simply transferred to someone else without being registered. When the registered call is transferred, someone else must call the customer back.

In most instances, the Gatekeeper model causes more problems than it solves. First, it places a barrier between the customer with the problem and the person with the solution. At the very least, it causes a minor delay while the gatekeeper transfers the call and in most cases results in a significant delay.

1.2 Call Sorting Model

The second basic model is to sort calls into special groups using technology rather than people. This sort might be by product, platform, problem, etc. Sometimes this is combined with the dispatch strategy or it is done electronically.

1.3 Tiered Structure - Specialist Model

The third strategy is the filtering of calls, typically known as a tiered specialist structure. In this model, one "specialist" group receives the calls. The most common form is to have the Desktop Support group play this role. Their job is to answer the phones when they ring, log the call into the call tracking system and try to help the customer with their call while they are on the phone. If there is a problem that is beyond their ability or responsibility, then they dispatch the call to another second level group.

The reason for this strategy is to solve more customer problems on the first call. In fact, it often causes reduced service levels. As a result of payroll expense and scheduling difficulties, the phones are not manned 100% of the time during business hours and therefore customers do not get to talk to a "live" help desk person. This means that customers must leave a message.

1.4 Tiered Structure - Generalist Model

The fourth basic strategy is a variation of the tiered structure. Instead of a Desktop Specialist answering the phone, there is a "generalist" group that answers all call types (phone, Web, email and etc.), logs the call, resolves what they can and transfers the balance to the second level. There can be several first level support tiers in this model, but usually three levels are normal. The routing and resolution priority is often set using a predefined severity & escalation procedure. The procedure is intended to ensure that the most important customers or the most serious issues are processed first.(1)

This process is similar to the hospital emergency room (ER) triage process. This is a process for sorting the injured people into groups based on their need for or likely benefit from immediate medical treatment.
As for the help-desk models three possible levels of support have been identified, based on the type of issues, problems and complexity. We shall classify the Support as follows:

1.5 Support Level 0

This is the basic level of support. Very simple problems being faced by the user or requests on general issues, normally being handled by the local help desk itself. In this case, the help desk operator would identify a user's needs and provide tips on how to manage a problem.

Typically, these solutions are in a FAQ or a knowledge base. Staff at this level use a knowledge base in a majority of users' requests. When a Level 0 support operator is not able to resolve the issue or answer to the request, they classify the problem and pass it on to the appropriate Support Level 1 operator. At this point, an issue tracking ticket is issued to the user.

1.6 Support Level 1

Support Level 1 involves technical knowledge and is staffed by experts who specific technical knowledge beyond the Support Level 0 operator. The help desk opens a Request Ticket for every user issue and is responsible for tracking it to closure. The experts then determine which expertise best matches the user's needs before delivering assistance. If their technical specialization is one that can help the user, the expert operator then determines whether this problem is a new issue or an existing one. Advanced diagnostic tools and data analysis may be done at this point.

1.7 Support Level 2

This Level requires a person who has specialized skills over and above the work the techs do in Support Level 2. This support is usually provided by the specialists involved in product development. They deal with complex issues. To solve the problem, they will collect as much data as possible from the staff at Support Level 0 and 1.(2)

2. Approaches (Methods)

2.1 Description of work and efforts

At first the main activity was focused on the study of literature on models Help-desk.
We have made staff meetings and conference calls with the project partners and representatives of the common IT service BBMRI-ERIC.

Registry/biobank Help-desk facility develops selecting as a model Tiered Structure - Generalist Model and it provides for a layered structure with requests to three possible levels, and three possible levels of assistance.

2.2 RD-Connect Biobank Criteria

Support will be delivered according with RD-Connect biobank assessment criteria, to ensure adherence to minimal entry conditions and the adoption of any standardisation and harmonisation measures needed for a successful biobank.

2.3 Assessment criteria

2.3.1 Disease(s) of interest

Interested biobanks must already store collections of rare disease biological samples.

2.3.2 Quality Standards (QS)

Biobanks should have a quality system in place for the operational management, including quality assessment/quality control for sample and data management. QS for sample management should follow best practice guidelines such as those of the OECD, BBMRI Quality Policy and applicable European standards for pre-analytical treatment of biological samples.

2.3.3 Standard Operating Procedures (SOPs)

The biobank should have adopted SOPs regulating:
- sample (and data) acquisition

- testing to ensure sample (and data) integrity

- sample processing and storage(3)

2.3.4 Ethical, Legal and Social Implications (ELSI)

The biobank should adhere to the following ELSI principles:
- samples are collected only if an appropriate informed consent has been previously obtained by the donor

- the consent can be withdrawn and sample (and data) removed anytime by the donor

- Contact person is available for donor enquiries regarding ethical and legal issues, such as informed consent, its withdrawal, or the use of the samples.

- confidentiality issues need to be dealt with in compliance with the local government laws

- specific rules and policies for distributing samples (and data) are clearly defined

2.3.5 Informatics set-up

The biobank should meet the following minimum system requirements:
- centralised or distributed data repository

- information Management system to manage biobank repositories, resources, samples and data in a structured way

- data identification capabilities (local persistent unique identifiers for samples and sample data)

- data transfer capabilities (exportability of data from the management system to a file format and secure data transfer through the internet)

3. Results

3.1 Schedule

The deliverable is aligned with the schedule (see WP7 Timeline 2016-2018 p.)

3.2 HELP-DESK MODEL

Level 1
Wiki system
Frequently Asked Questions (FAQs)
Guideline Repository

Level 2
Ticketing
Data collected from questions/answers in a repository – user experience
Video FAQs (from different biobanks)

Level 3
On particular aspects such as the Ethics Legal and Social Issues (ELSI), the help desk aims to manage directly the site or service interest:
- BBMRI-ERIC Directory to individuate biobanks typology and main information
- The Common Service ELSI BBMRI-ERIC, to manage potential questions on ELSI
- The BBMRI-ERIC-HQ Quality Service to solve problems related to Quality Management
- For all questions on Rare Disease, a bridge of knowledge and competences among RD-Connect and the beginning RD ERNs.

3.3 Deliverables

Common Service IT as a part of collaboration between WP3 (IT) and WP7 of ADOPT has installed a Helpdesk application -- Request Tracking system. This system allows users from both inside and outside of BBMRI-ERIC to submit their requests and assign these requests to the responsible people and monitor progress of their completion. A dedicated queue for RD has been setup within the HelpDesk, together with introductory training.
The Help Desk model was proposed and circulated among all participants for contribution in specific issue and further development.
Then, the HD model was revised and contributions were harmonized, proceeding with the implementation of a preliminary version of HD:

- Help Desk Request Tracker accessible by administrators at: https://helpdesk.bbmri-eric.eu/.
- To submit a request to Help Desk <rd@helpdesk.bbmri-eric.eu>
- A HelpDesk wiki web page is available:
- https://helpdesk-wiki.bbmri-eric.eu/. Content of the web page will be released by M26.

The Request Tracker System comprehends additional Services for monitoring the following KPIs:
• Customer service email
• Customer service phone call
• Average resolution time
• Request classification

3.4 Help Desk source of information

- BBMRI Directory http://old.bbmri-eric.eu/bbmri-eric-directory-2.0

- The Common Service ELSI, BBMRI. http://www.bbmri-eric.eu/bbmri-eric/

- Common Minimum Technical Standards and Protocols for Biological Resource Centres dedicated to Cancer Research, http://www.bbmri-eric.eu/services/standardisation/

- BBMRI Quality Policy http://old.bbmri-eric.eu/standards

- OECD Best Practice Guidelines for Biological Resource Centres http://www.oecd.org/sti/biotech/38777417.pdf

- BBMRI Tools http://www.bbmri-eric.eu/services/other-services/

- ID-Cards online catalogue listing biobanks and patient registries connected to RD-Connect. http://catalogue.rd-connect.eu/

3.5 Registry/biobank RD Help Desk Model
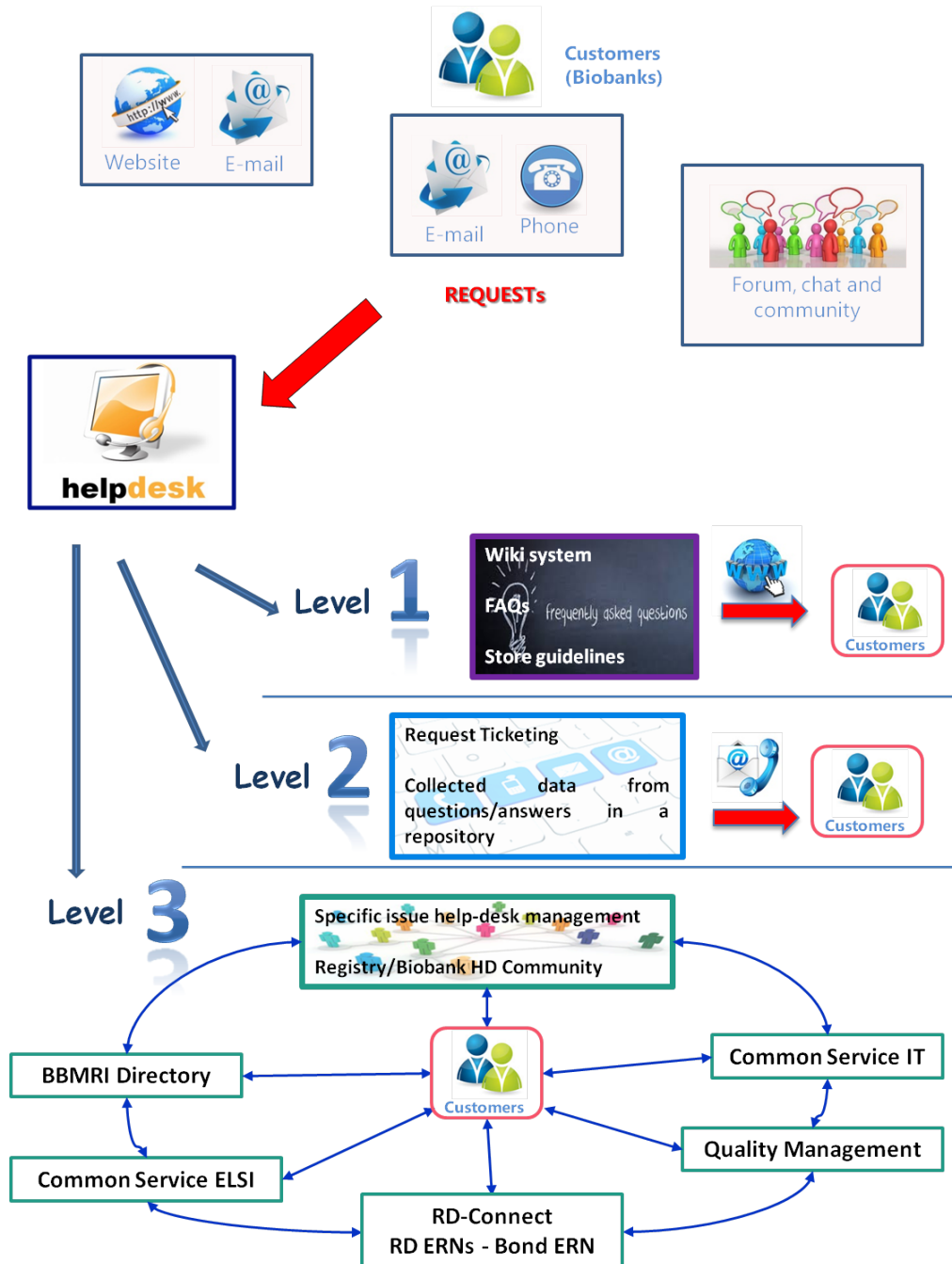
4. Discussion and Conclusions

The structured monitoring of Help Desk Services KPIs, together with RD Working Group meetings will allow a continuous improvement of the HD, beyond ADOPT, since, on one hand, the HD will be added as a permanent Service of BBMRI-ERIC, on the other hand, RD Working Group is comprehensive of several actors, beyond BBMRI-ERIC, belonging to the RD Community. Specifically, the RD Working Group, together with BBMRI-ERIC, will represent the organ guarantee the continuity of the HD efficiency after the end of ADOPT Project.

5. Next Steps

After sharing the Help-desk model with the project partners and carried out a needs mapping, and implanting the tools described in the Deliverables section, a testing phase and analysis will be approached.

Next step, will be kicked-off the implementation of Registry/biobank Help-desk model in IT facility, in collaboration with WP3.
The three different levels of support of Registry/biobank HD facility will be achieved in successive steps.
At the beginning, the first implemented level will consist of a web service composed of a) a wiki system, b) FAQs system with a repository that will populate gradually, and c) a guideline Repository (linked with BBMRI-ERIC website).

Hereinafter they will be implemented the second and finally the third level of Help Desk facility (above mentioned).

The HD will finally be tested as a transversal service on ERN on Rare Bone Diseases: as a common service between BBMRI-ERIC and RD- Connect.

During the testing phase, the following KPIs will be monitored through Request Tracker System, by frequency analysis:
• Customer service email
• Customer service phone call
• Average resolution time
• Request classification

The result of the KPIs analysis will help developing, fine tuning and improving the HD and the IT related tools.

5.1 Networking and Synergies

Help Desk Service for European Reference Networks

An ERN is a network of healthcare providers/centres of expertise which seeks to improve access to diagnosis, treatment and high-quality healthcare in highly specialised domains, particularly RD.

As soon as ERNs will be approved, an inter-ERN approach will provide a bridge of knowledge and competences among RD ERNs.
This inter-ERN approach will facilitate testing and further developing already existing tools and services. Specifically, Help Desk Service, developed within ADOPT will be made available as a transversal service for all ERNs.
*ERN on Rare Bone Diseases*

Dr Sangiorgi, from Istituto Ortopedico Rizzoli submitted, as coordinator, a ERN proposal on Rare Bone Diseases, together with other 38 Healthcare providers from 10 EU countries. the Scientific activity of BOND ERN is structured in Working Groups (WG).

The Help Desk facility implemented within BBMRI-ERIC and ADOPT project will be further tested by Working Group "Multidisciplinary Care-eHealth Tools" and by Working Group "Research" in BOND ERN.

Future Call for Projects
1. HORIZON 2020 - Work Programme 2016 - 2017 Health, demographic change and well-being. Call SC1-PM-03-2017: "Diagnostic characterisation of rare diseases", in collaboration, among others, with Orphanet.
2. HORIZON 2020 - Work Programme 2016, Call for ERNs Rare diseases – Support for new registries.

5.2 WP7 Timeline for 2016-2018
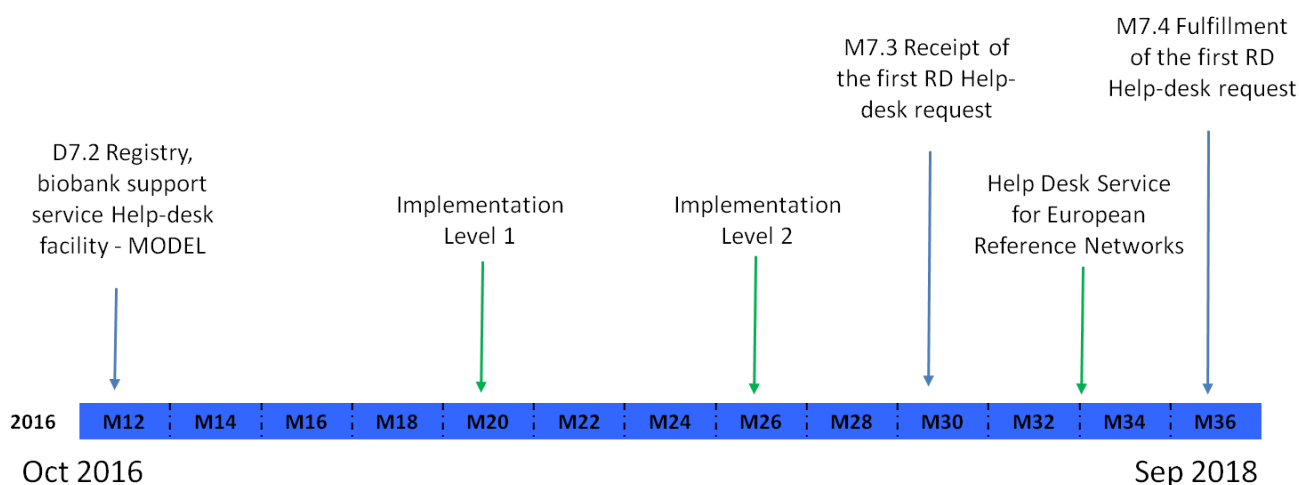
6. References

(1)Giva White Paper, *"Help Desk Staffing Models". https://www.givainc.com/wp/help-desk-staffing-models-simple-analysis-save-money.cfm*

(2) Understanding The Different Levels of Help Desk Support by Balaji Viswanathan · September 2, 2016. http://project-management.com/understanding-the-different-levels-of-help-desk-support/

(3) MIABIS-QMS-attributesV3