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DL 10.2 Implementation of the strategy to improve the OECl-TuBaFrost central database application

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Dissemination Level		
PU	Public	X
PP	Restricted to other programme participants (including the Commission Services)	
RE	Restricted to a group specified by the consortium (including the Commission Services)	
CO	Confidential, only for members of the consortium (including the Commission Services)	

DL10.2 Implementation of the strategy to improve the OECI-TuBaFrost central database application

Introduction

At the start of the WP10 biobanking the OECI-TuBaFrost sample exchange platform was selected from several well known biobanking sites as the only functional platform available at that time that was suitable to search and request samples. However, it was also noted that there was a lack of activity in the sample exchange on the platform. The cause of this lack was suspected to be due to the way the platform was set up. The site forms an integral part with the sites web pages that can be found at www.tubafrost.org.

There have been many changes since the launch of the TuBaFrost database management application to facilitate a virtual biobank. After the development of the application it was taken up by the OECI as a promising tool for virtual biobanking, as was proposed in the business plan of the project and in EuroBoNeT it was quite successful as a tool for exchanging samples which thus led to its proposal to serve as a base for further development of the virtual biobanks TuBaFrost. The restriction of only frozen samples/material? was banned and it was decided to create a similar environment in OECI-TuBaFrost database covering all the additions that were added on instigation of the users in the EuroBoNeT consortium. In addition, the tool made possible to have exchanges within not directly accessible project environments. A short description makes it possible to notice the activity and ask the project coordinator to join the community. In the BBMRI project a list of questions was designed for the characterization of hospital integrated biobanks in a biobank catalogue. This list was used to design a catalogue of biobanks that was added to the OECI-TuBaFrost database management application. Users are asked to fill out a questionnaire that was based completely on the BBMRI list. The data filled in the questionnaire fills the database with the characteristics of the biobank. The database which is an actual catalogue of biobanks is made completely searchable for registered users on the items used in the list. In this way biobanks can be selected on their attributes and kind of collection and it is possible to make a request to the contact person for the availability of certain types of samples. The requestor specifies what specific type of -, how many - and how much sample, is needed for the research. To complete the request should include a description of the planned research in which the samples are used. Although from the description of the database management application it looks already very comprehensive, however in practice it proved to be not very user friendly.

Strategy for improvement of the OECI-TuBaFrost database application

It was clear from the start that although the application had the potential of a sample exchange platform, it was not very intuitive and inviting to work with the application. Already in Deliverable 10.1 (Month 7) a strategy was set up to improve the application. As described there

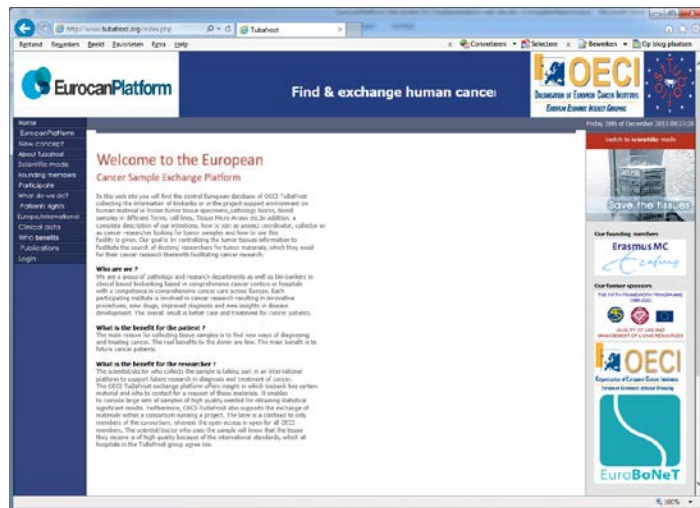
the WP10 participants were invited to give their comments while they were trying to work with the database applications. The suggestions and comments were taken seriously and the reported imperfections were translated into a series of updates. All participants were invited to report their comments by using the “Bug report”, which is a link that is included in the lower right corner of every page. The bug reporting tool is set up in such a way that the message is sent directly to the dedicated programmer and the tool reports the identity to the programmer of the PHP file generating the page the user is in. It is an ever returning agenda point on every meeting WP10 organizes. Therefore all active members of WP10 were involved in the process:

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Especially the report that was developed at the NKI by Jelle ten Hoeve and Sydney Cadot from NKI was very helpful. The generated report was evaluated in a team which gave resulted in major adaptations of the system. Whole parts were completely redesigned to improve the applications functionality and user friendliness for collectors and users in their many different roles. Roles that can even be changed by the super admin, admin and project coordinators in case the roles refer to project sample exchange platforms.

The website

The EurocanPlatform project was selected as the major contributor to the web site represented in the lay out and the sequence of the different buttons on left side of the site's pages. The name OECI-TuBaFrost was considered to be inappropriate in the current setting and not catching the website and database applications purpose. A new call text and name was considered to replace the old OECI-TuBaFrost name. The call text on top of the web site was changed into "Find & exchange human cancer samples for translational research" and the site is named: The European cancer sample exchange platform.



numbers to get an idea what can be expected in the database application concerning the numbers of biobanks and samples.

The database application biobank catalogue

Questionnaire:

The menus under "your catalogue", where the data of the logged in user can be made visible and edited, were completely changed from links to buttons and also the functionality and sequence were adapted to a much more logical flow when filling out the catalogue questionnaires. The buttons divide the questionnaire into more logical comprehensible parts or categories. When going from one category into the other, it is possible to save results of that part, which enables the user to pause or even logout, to come back later to continue the work without having lost previous work.

A special section was designed and implemented focusing on the EurocanPlatform WP10 biobanking efforts. Guidelines on best practices and standards that are important for biobanks to adhere to are presented in a [page](#) of links to these important documents. A tool was added to monitor the number of hits on the website.

The login page contains the normal username and password entry fields as well as instructions and links to other sites. In addition there is an overview in



There are also buttons that change color from grey to red if action is required from the user (see also screenshot). This can occur at the start when filling the questionnaire or when after a half a year, the attributes need to be reconfirmed or changed to the current time. In addition, after half a year e-mails are automatically sent out

asking the user to go over the data and reconfirm or adapt it. The data entered within the displayed different categories can be easily checked, updated and saved at any time.

A huge effort was made to hide questions in the questionnaire that are not of interest for the user depending on earlier given answers. Thus what questions are presented to the user when filling out the questionnaire depends on the type of collection or materials collected. This saves time for the user who avoids unnecessary questions and choices that need to be considered.

Search for biobanks:

This can be done under the top menu button "Search Catalogue". In first instance all attributes entered into the catalogue were searchable in a very large page. Severing and subsequent removal of "information only" attributes has made the page more accessible and presents a much nicer overview. In the upper right hand corner of the search page the number of hits is directly presented when data is entered in a field, making the entry of search attributes a lot more direct on the expected end result before even submitting a search to the database search engine. The biobanks that are presented as a result of a search can be selected and kept in basket.

Selected biobanks can be contacted either directly or through a questionnaire that aids to define the question more properly and text is generated in an e-mail which is automatically sent to the biobank contact person. In the direct form one gets to send an e-mail with own compilation of text to the contact persons of the biobanks.

Under the "Catalogue Actions" overviews are generated from the requests made as well as orders. In addition, the previously selected biobanks can be viewed. Last but not least, direct questions to all biobank managers can be launched.

From the catalogue basket the biobanks that want to share samples and cooperate in a research project can be entered in one of the user's active projects in the project sample exchange environment.

The database application project sample exchange support

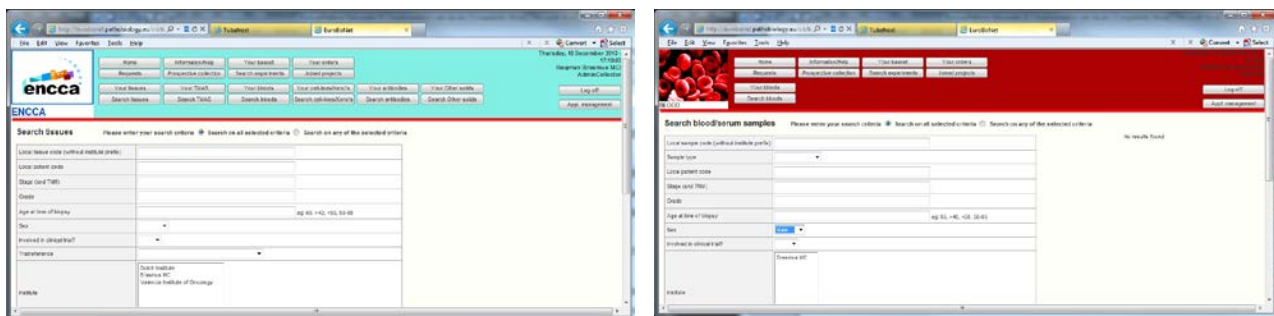
Here the workflows have been completely changed and the environments can even be adapted to any kind of sample to deal also with only those samples and datasets that are of interest in the project sample exchange.

Under the “Your Projects” button in the top menu bar, the user will find a listing of projects environments in which the user is participating. The list is split up into two different roles the user can be involved in the project sample exchange platforms: 1) The user is project coordinator, 2) The user is participant in a project exchange platform.

Under the “Join Projects” button a listing of all active projects environments can be found together with a short description. The user can request to become participant in such a project. The request mail is generated and sent to the project coordinator who can approve or disapprove the request. In addition, the coordinator can stop the collaboration with participants and stop the exchange platform of a complete project. To do this there are automatically generated mails sent out to the participants asking if they agree or willing to take over.

The role of the coordinator to change the exchange environment can be delegated to others in the project environment. Under the “Project Actions” button one can request the setup of a new project environment. An automatic mail is generated to the Super Admin, giving him the choice to permit or refuse this.

A new project setup enables an application management environment for the fresh project coordinator where the Top menu can be adapted even with a project logo and any specific top bar background color to match or contrast the project logo. This can be done in the “application management” of the project environment. The “Project lay out” button is offering all the necessary choices that change the project environment. The Top menu buttons can be de-activated and subject names adapted. Parts of the fields can be de-activated and also new fields



can be added with easy to define answer fields with choices in radio buttons (Yes/No), dropboxes (Fixed answers) or open fields. This enables reduction of the environment to only a collection of for instance earwax combined with the diagnosis and age.

The basic environment has been imported from the EuroBoNeT Project, so standard setup means it can deal with tissues (FFPE and Frozen), blood samples, cell lines, xenografts and tissue micro arrays. Also the sample request system has been taken over either through a form or directly to the presented e-mail address of the biobank contact person. Also there is a shopping cart called basket to make it more appropriate to human bio-materials.

ICD3 was replaced by ICD10 for diagnosis as well as topography. A tool was programmed to easily pick the proper code. The former alphabetic system was replaced with a tool that enables immediate type responsive finding of terms in the long list of ICD10 codes for diagnosis as well as topography. Once logged in the main exchange platform the entry through login to a project exchange environment is done under the same password and username. To switch back to the main exchange platform the button “joined projects” is used in the top menu of the project exchange platform.

Trial locator

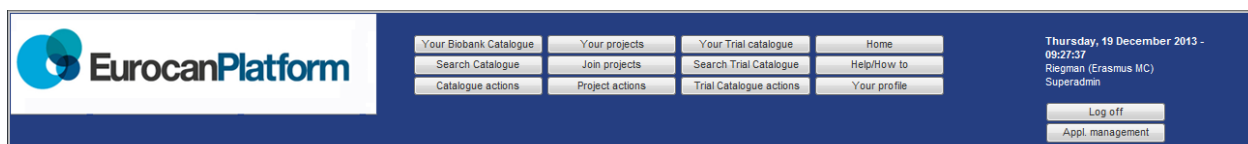
A trial locator was an idea that was presented by the EurocanPlatform coordinator and was coming from WP6 in the project. The idea was to have a simple dataset of trials that could identify those trials having biomaterials of interest for translational research purposes. The dataset was developed at first by proposals on what kind of data should be there put it in the database application and ask to evaluate the dataset. From the comments the final dataset was chosen.

Under the “Your trials” button the trials the user has entered are presented. The data of the trials can be edited and saved per trial. The “Search trials” button enables the entry of trial attributes that narrows down to the trial type the user is looking for. This way the search for well-defined biomaterials coupled to trials is facilitated. Also, when entering data the number of hits is presented after the data has been put in a field. This makes the search more direct and saves disappointment when actually seeing the result after submission of the search query. The trials identified can be selected and put in a basket and requests for samples can be made to the trial contact person.

The basket as well as well as other trial actions can be managed under the “Trial Actions” button in the top menu.

The main exchange platform:

For the main environment, it was considered important to create an environment where users would easily navigate their way, with as much as similarities and functionalities as possible. Therefore, a uniform set of buttons for the catalogue, the trial locator and the project sample



exchange platform, were designed forming a sort of matrix. The 3x3 matrix covers the three environments in the x-axis direction and the 'your search and action', in the y-axis direction. This is nicely put in the top menu, providing that the screen of the user is wide enough in pixel depth. Next to that the 'Home', 'Help/how to' and 'Your profile' also will follow this same y-axis direction. The 'Your profile' and 'Help/How To' have a search characteristic and 'Home' is used to take new action. In this way even a 4x3 matrix is formed if the last row is considered to be application specific.

On the right side there is 'Log off' and for those who have access, the 'Application management'.

Such a uniform approach makes the navigation through the different activities more natural and once you are used to one activity, it has a more natural feeling with the next activity.

The 'Help/How to' button was created to offer some assistance for those who are new to the site. In this page there is a listing of all buttons followed by an explanation which can be a text and sometimes also a document. The 'Admin' and 'Super admin' can add or edit text, as well as add or delete documents.

The addition of a data dictionary explains the different fields used in the different environments. Data dictionaries are accessible in the different environment explaining this environment.

A logical set of buttons in the application management are only visible for certain roles and the ability to make the same application buttons visible to selected users. This creates the opportunity to delegate the design to coworkers in the project.

Next to that, tools were designed for the project coordinator to control the type of sample and data asked to store, as well as activate and deactivate a series of preset questions with the ability to change the questions. There are also steering tools for the annotation of answers to own designed questions. The project coordinator can create questions and answer fields with choices in radio buttons (Yes/No), dropboxes (Fixed answers) or open fields.

Logistics in communications started by automatically generated e-mails between the Super Admin and the users have been redesigned and made more logical.

Discussion:

The EurocanPlatform WP10 biobanking group has together created a lean and effective tool for cancer sample exchange where a registered user can find biobanks that potentially have samples of interest, request them and exchange them in a dedicated project sample exchange platform. The database management application is not expensive to keep in the air. However, a caveat is to keep the program up to date. A programmer that knows all ins and outs of the application

financed on a project bases could lead to the loss of the programmer once the project ends and no updates or bugs can be fixed from that time onwards.

The advantages of the platform are that with a minimum of data sharing: 1) Biobank catalogue: The BBMRI list of characteristics of a hospital integrated biobank, 2) Trial locator: minimal trial characteristics 3) Project sample exchange platform: Sample data, but only those that need to be shared in the project. It is relatively cheap in exploitation costs.

The minimal amount of data means for the biobank manager that not a lot of time is lost when uploading or updating the data. In the catalogue section, the estimated data on numbers are even fit for purpose instead of the precise actual numbers. There is also less hassle with nomenclature of many fields, because the requestor has to specifically describe the typical required sample characteristics when requesting. The collector always stays in the driving seat and only needs to share the data of the samples that are suitable for the exchange once there is a collaboration. Collaboration is covered with a certain amount of privacy for competing groups, facilitating the chance to develop scientifically with keeping the Intellectual Property to the group.

Downsides are that the site is not well known and those who have visited and examined the site in the past are not aware of the improvements. Potential users are unfamiliar with the database application and do not see the benefits when joining. There are no real examples that show the benefits when using the application. It should become known under the flag of the BBMRI-ERIC to really have a European unified image. That is why WP10 has been trying to set up a connection to BBMRI, which has resulted in the taskforce called TAFLOX, in which an inventory was made of the metadata used in major hospital integrated biobank networks in Europe. TAFLOX started out as an initiative of WP10 EurocanPlatform between EuroCourse, EurocanPlatform (OECD-TuBaFrost) (EuroBoNeT), Spanish Biobanking Network, CRIP and BBMRI.SE, to raise the question who will take the lead in Cancer biobanking Networks and how it could best be organized. The TAFLOX inventory (added to this Deliverable as attached annex Excel file) has been separated in the attached excel file using colors in those fields that are common, ethically not possible without informed consent asking for permission and those that are typical for that kind of network. It could be used as a basis to standardize the annotations. Eric Jan Litton, director of BBMRI-ERIC, has recently opened the door for a proposal for further approach between BBMRI and the EurocanPlatform WP10 initiative, after WP leader Peter Riegman had made a statement that in BBMRI-LPC the hospital integrated biobanks are not getting a good opportunity to organize their field in BBMRI(-LPC). New health care research questions raised in genetic epidemiology however, can raise the importance of hospital collections enormously in the near future. Not well standardized or exchangeable collections could cost time when such collections need to be set up prospectively.

Now when the EurocanPlatform Cancer Sample Exchange Platform Application has been developed, it needs to get better known especially on its latest improvements. Therefore, dissemination of the platform and its improvements are key. The opportunity to organize a course in EurocanPlatform, which one of the deliverables, will help. However, it is very important to chose the moment as strategic as possible so many people can easily visit the

course. This is why the actual deliverable 10.11 has been asked to be postponed. Also mentioning the improvements in every lecture that is given on biobanking will help enormously.