

2020-01-29

Wednesday, January 29, 2020 12:24 PM

<b>Date:</b>	29/01/20	<b>Place:</b>	TC
<b>Start:</b>	9.00 AM CET	<b>End:</b>	10.00 AM CET
<b>Topic:</b>	3 <sup>rd</sup> AREB TC		
<b>Participants:</b>	FGB: Annalisa Landi, Viviana Giannuzzi EJP RD coordination team: Yanis Mimouni BBMRI: Petr Holub ECRIN: Marta Del Alamo EMBL -DTL PROJECTS- ELIXIR/ELIXIR-NL: Rob Hooff EATRIS: Ben Lydall VUHSK: Biruté Tumiene ZonMw: Sonja van Weely		
<b>Apologizes:</b>	<p><u>Mandatory participation:</u></p> <ul style="list-style-type: none"> <li>➤ BBMRI: Michaela Th. Mayrhofer</li> <li>➤ CVBF: Giovanni Migliaccio</li> <li>➤ RaDiCo: Sonia Gueguen</li> </ul> <p><u>Facultative participation:</u></p> <ul style="list-style-type: none"> <li>➤ EJP RD coordination team: Daria Julkowska</li> <li>➤ INSERM: Eleonora Passeri</li> <li>➤ INSERM [Orpha]: Ana Rath</li> <li>➤ EURORDIS: Virginie Bros-Facer</li> <li>➤ REPRESENTATIVE OF THE ERN RESEARCH GROUP: Alberto M Pereira</li> <li>➤ EATRIS: Anton Ussi</li> <li>➤ UKL-HD: Franz Schaefer</li> <li>➤ AP-HP: Rima Nabbout</li> <li>➤ DLR: Katarzyna Saedler, Michaela Fersh (could not connect, IT issues).</li> </ul>		

TOPIC	DISCUSSION AND DECISIONS
1. Update on the Ethics Advisor appointment	<p>Y, Mimouni explains that the General Assembly partners, representing their institute in EJP RD have been invited to vote Yes/No/Abstain before 12th Feb 2020, for:</p> <ul style="list-style-type: none"> <li>• the change of the budget to address the estimated workload of the External Ethics Advisor and the Other Ethics Manager (WP4 partners, AREB members), for the duration of the program: it is proposed to distribute proportionally the cost of 197 526€ (i.e. 0.36% of the total EC contribution) over all beneficiaries' budget</li> <li>• and a second vote to validate the selected candidate.</li> </ul> <p>As specified in the Section 6.2.3 of the Framework Consortium Agreement, the voting rules are as follows:</p> <ul style="list-style-type: none"> <li>• The vote will be valid if two-thirds (2/3) of the members of the General Assembly have voted;</li> <li>• Each member of the General Assembly shall have one vote;</li> <li>• Decision shall be taken by a majority of two-thirds of the vote cast.</li> </ul> <p>A separate tool (ballotillo) has been used to support the vote.</p> <p><b>Action: None</b></p>
2. Inclusion of a legal member among AREB members	<p>AREB members have been asked to suggest a legal expert from their organisation to join the AREB. The person must be chosen among members of institutions joining the EJP RD Consortium, but does not have to be in WP4 already.</p>

	<p><b>Action:</b></p> <p><input type="checkbox"/> <b>All to provide suggestions before next week 7th February 2020</b></p>
<p>3. MS teams – AREB section</p>	<p>Y. Mimouni explains the AREB dedicated channel. P. Holub asks if he can be included in this channel as deputy of M. Mayrhofer. A. Landi replies that AREB deputies may be included in the channel. Petr will be added during coming night. There is also a discussion about the access of the OG to the minutes; to solve this, the minutes notebook will be moved to the WP4 general SharePoint folder.</p> <p><b>Actions:</b></p> <ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> 1. <b>Y. Mimouni to include P. Holub in AREB channel</b></li> <li><input checked="" type="checkbox"/> 2. <b>Minutes notebook to be moved to WP4 general</b></li> <li><input checked="" type="checkbox"/> 3. <b>Y. Mimouni to change the e-mail address of Michaela in teams to her usual work address</b></li> </ul>
<p>4. AREB section on the EJP RD website</p>	<p>E. Passeri is not able to join the TC. Y. Mimouni presented the website current organisation and proposes a section dedicated to AREB to be displayed. Sub-sections can be proposed.</p> <p><b>Action:</b></p> <ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> <b>A. Landi to create a folder with documents to be uploaded in the website and to get in touch with E. Passeri for the AREB Section</b></li> </ul>
<p>5. EJP RD JTC 2019 projects: Procedure for ethics monitoring</p>	<p>S.van Weely informs AREB members that Ethics in the JTC 2019 projects may have to be monitored separately by the institutions of each researcher in a consortium, in collaboration with their local ethics advisors. However, we will also need to check whether the entire ethic requests for the consortia do comply with the ethics norms set by EJP RD. A. Landi suggests to schedule a TC with Pillar 1 leaders involved in JTCs to discuss how to proceed and asks S. van Weely if Call Secretariat JTCs 2019 wants, in the meantime, to share with the AREB the projects with urgent ethics requirements to be fulfilled by the end of January by highlighting ethics sections to be implemented/revised by the AREB.</p> <p><b>Actions:</b></p> <ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> 1. <b>Ralph/Katarzyna (Call secretariat JTC 2019) to send the projects with the most urgent ethical requirements and information on this from their coordinators to Annalisa and Viviana in order to ask for AREB support</b></li> <li><input checked="" type="checkbox"/> 2. <b>A separate TC will be organised with Daria, Viviana, Annalisa, Katarzyna, Ralph and Sonja and people involved in JTCs 2019</b></li> </ul>
<p>6. Update on Data Transfer Agreement being generated for WP13 work</p>	<p>Following the feedback from the Data Provider (INSERM-Toulouse – ERN) the signature of the DTA will be outside from the scope of EJP RD. Inserm-Toulouse provided their DTA that will be used (already used for the same Data Transfer in their other activities). This DTA would be signed by the Provider (Inserm-Toulouse) and by the tenant of the Embassy Cloud that will host Data (UMCG partner). A code of conduct is being signed by the persons (scientists) involved in this activity. EMBL-EBI quote "The Embassy Cloud is considered to be part of EMBL territory and its status will not change at the end of the week (Brexit). All EMBL's activity is covered by the internal policy #68 relating to data protection and data privacy.".</p> <p>★ <b>For EJPRD please note that the entire EMBL, as international organisation is OUTSIDE of the GDPR!</b></p> <p>Discussions on the use of Embassy cloud are ongoing regarding:</p> <ul style="list-style-type: none"> <li>• the provision of this cloud for EJP RD activities (in-kind contribution)</li> <li>• EJP RD will not pay for any hardware</li> </ul> <p>P. Holub states that they will be considered third countries and they do not need to comply with any jurisdictions. Y. Mimouni asks P. Holub to join the next TC on this topic. P. Holub agreed and asked if M. Mayrhofer and Irene Schlünder a lawyer with expertise in GDPR may be invited as well.</p> <p>P.Holub: EJP should also be prepared for researchers using other cloud providers</p>

including commercial like amazon, google and microsoft. These providers have done a lot to show their GDPR compliance possibilities.

**Actions:**

- 1. **Y. Mimouni to update on the final decision**
- 2. **Y.Mimouni to invite P. Holub, M. Mayerhofer and I. Schlünder to join the next teleconference on this topic**

**7. Update on the ERN VASCERN REQUEST**

Y. Mimouni explains that Pillar 2 leaders decided to appoint two persons to be in contact with the AREB on this topic.

**Action:**

- Pillar 2 leaders to appoint persons to be in contact with the AREB**

**8. AOB**

✓ **Pillar 2 Use Case on informed consent**

The AREB members with declared expertise in Informed consent have been invited from Pillar 2 to contribute to the Use Case on Informed Consent in pillar 2 (for the virtual Platform development) . A. Landi informs Y. Mimouni that, among them, V. Giannuzzi, M. Del Alamo, M. Mayrhofer and her expressed their interested in being involved in this activity.

**Action:**

- Y. Mimouni to add Viviana Giannuzzi, Annalisa Landi, Marta Del Alamo and Michaela Mayrhofer to the Team "Use Cases".**

✓ **Technical report Y1**

A. Landi informs all that the WP4 report (Y1) is ready to be implemented in the General report (ExCom Team). She will also upload the file in the General channel of WP4 to collect comments/suggestions on Task 4.2 (if any) by Friday 31<sup>st</sup> January.

**Action:**

- A. Landi to upload in the centralised file (ExCom Team) and in the general WP4 channel the description of work (WP4) by Friday 31<sup>st</sup> January 2020**
- All (WP4) to provide her with comments/suggestions on Task 4.2 (if any) by Friday 31<sup>st</sup> January 2020**

✓ **RDR Challenge Call**

S.van Weely informs Annalisa and Viviana that she will send them the text on Rare Diseases Research Challenges (WP8) for an Ethics review and additional input.

**Action:**

- A. Landi to provide AREB feedback on the Rare Diseases Research Challenges call before the end of February 2020**

✓ **Cloud services and GDPR for the VP Development**

P. Holub raised the fact that we need to address the "GDPR" topic when a partner, in the framework of the VP development, is/will be using other cloud services (Amazon, etc.).