Report of the EJP RD kick-off meeting

30-31 January 2019, Paris

Agenda

DAY 1 (30 of January 2019)	
08:00 – 09:00	Registration
09:00 – 10:00	Opening ceremony: • Speech from president of INSERM • Speech from representative of FR Ministry of Research • Speech from representative of FR Ministry of Health • Speech from representative of EC (tbc) • General presentation of the EJP RD by the EJP RD coordinator
Presentation of the WPs	
Coordination and transversal activities	
10:00 – 10:15	Coordination and transversal activities general presentation
10:15 – 10:45	**WP1: Coordination**
	WP2: Integrative Research & Innovation Strategy
11:05 – 11:20	Coffee break
	WP3: Sustainability strategy & business plan
	WP4: Ethical, regulatory, legal and IPR framework of the EJP RD
	WP21: Ethics requirements
12:20 – 13:00	**WP5: Communication & dissemination**

13:00 – 14:00	Lunch
Pillar 1	
14:00	General presentation of the Pillar 1
	WP6: Joint transnational calls for collaborative research projects
	WP7: Networking to share knowledge of rare diseases
	WP8: Rare Diseases research Challenges
	WP9: Monitoring of funded projects
15:20 – 15:40	Coffee break
Pillar 2	
15:40	General presentation of Pillar 2
	WP10: User-driven strategic planning and transversal activities for Pillar 2 data ecosystem
	WP11: Common virtual platform for discoverable data and resources for RD research
	WP12: Enabling FAIRness and federation at the record level for RD data, patients and samples
	WP13: Enabling multidisciplinary, holistic approaches for RDs diagnostics and therapeutics
17:00 – 17:30	AOB of the day (buffering time)
17:30	Departure for the evening social event
19:00 – 22:00	Evening social event & dinner
DAY 2 (31 of January 2019)	
Pillar 3	
08:30	Pillar 3 general presentation

	WP14: Training on data management and quality
	WP15: Capacity building and training of patients and
	researchers in RDs research and processes
	WP16 : Online academic education course
	WP17: ERN RD training and support programme
	WP18: Development and adaptation of training activities

Pillar 4	
10:10	**Pillar 4 general presentation**
	WP19: Facilitating partnerships and accelerating translation for higher patient impact
	WP20: Accelerating the validation, use and development of innovative methodologies tailored for clinical trials in RDs
11:00 –11:20	**Coffee break**
11:20 – 12:30	**Free individual F2F networking/discussion time**
12:30 – 13:30	**Lunch**
13:30 – 14:15	**EJP RD Governance**
14:15 – 15:15	**Research & innovation prioritization strategy:** • **ERN research strategy** • **IRDiRC Roadmap 2019** • **EJP RD prioritisation process**

15:15 – 15:30	Coffee break
15:30 – 16:30	**EJP RD administrative & financial procedures** • **Budget and financial reporting** • **Update on the Consortium Agreement**
16:30 – 17:00	**Summary of the meeting:** • **Guidelines/recommendations for partners** • **Next steps (timeline)**
17:00	**Closing of the meeting**

Participants

Name	Surname	Institution
Allon	**Irit**	CSO-MOH
Altavilla	**Annagrazia**	Hôpital Timone
Amselem	**Serge**	RADICO
Beermejo-Sanchez	**Eva**	ISCIII
Beltrami	**Elena**	FTELE
Beltran	**Sergi**	CNAG
Birute	**Tumiene**	VUHSK
Bonnaud	**Emilie**	FFRD
Brookes	**Anthony**	ULEIC
Bross Facer	**Virginie**	EURORDIS
Carta	**Claudio**	ISS
Chrzanowska	**Krystyna**	MUW
D'Angelo	**Carla**	INSERM Coo
De Guerra	**Arnaud**	DGS/MSR
Eerola	**Iiro**	European Commission
Evelo	**Chris**	UM
Favresse	**Roseline**	FRRD
Fetro	**Christine**	FFRD
Giannuzzi	**Viviana**	FGB
Gueguen	**Sonia**	RADICO
Graessner	**Holm**	EKUT

Hanaver	**Mark**	Inserm
Halftermeyer	**Juliane**	Inserm transfert
Heard	**Jean - Michel**	Metab-ERn
Hilgers	**Ralf-Dieter**	UKA
Julkowska	**Daria**	INSERM Coo
Lapointe	**Anne-Sophie**	DGOS
Lydall	**Ben**	EATRIS
Monaco	**Lucia**	IRDiRC/FTELE
Nabbout	**Rima**	APHP
Nguyen	**Catherine**	INSERM ITMO GGBT
Pivet	**Laure**	DGOS
Posada	**Manuel**	ISCIII
Rath	**Ana**	INSERM- ORPHANET
Roos	**Marco**	LUMC
Schaefer	**Franz**	UKL-HD
Schuster	**Ralph**	DLR
Schwartz	**Bertrand**	Ministry of Research
Tzima	**Katerina**	INSERM Coo
Urbain	**François**	INSERM Coo
Ussi	**Anton**	EATRIS
Van Weely	**Sonja**	ZonMw
Weinbach	**Jérôme**	DGS/MAEI
Zanello	**Galliano**	INSERM Coo

Report

The present document reports different points discussed after each WP presentation. It does not describe the WPs presentations. For detailed presentation content, please refer to the kick-off meeting slideshow.

Opening ceremony

The representatives of the French ministry of Health – Arnaud de Guerra, French ministry of Research & Innovation – Bertrand Schwartz and the European Commission – Iiro Eerola, opened the EJP RD ExCom kick off meeting by underlining the importance of the EJP RD program in establishing a strategic and collaborative RD research, improving diagnostics, therapies and patient care, and empowering all stakeholders as well as giving Europe a leading role in the field of RD. The CEO of INSERM, Prof. Gilles Bloch presented the involvement and support for rare diseases of INSERM on Thursday 31st of Janaury.

Coordination and transversal activities – general presentation:

The coordinator of the EJP RD, Daria Julkowska presented the history of the program and the objectives of the meeting:

- Each WP presents the objectives, outputs and outcomes of each of the WPs.
- Identification of the nature and number of interactions
- Agreement on the governance structure of the program
- Preparation of the first steps of the EJP RD prioritization strategy

WP1 Coordination:

The following items were presented and agreed:

- EJP RD working environment: it cannot be developed using Google drive since the data storage is in the US, which is against current GDPR regulation. It is extremely important that EJP RD respects all legal and ethical regulations. Thus, the coordination explored the possibilities of use of another tool and it appears that Microsoft 365 (which is different from One Drive dedicated to general public) would be a good solution.
- EJP RD Calendar: common agenda for the whole EJP RD should be created. It will be divided into "general" part including all dates of EJP RD F2F meetings and TCs of the ExCom. The other part (more detailed) will be dedicated to Pillars/WPs with the possibility to add dates for the physical meetings and the Pillar teleconferences including dialling numbers. Each Pillar will have the possibility to create its own sub-agenda and agree on the level of granularity of the indicated events (only WPs or Task, etc…).

- Any "sensible" data will NOT be stored on the common EJP RD server (e.g. patient data or research project data). The server will be used to store relevant documents, surveys and collect templates, etc.
- The use of Survey Monkey is not possible due to data storage in the US. There is a need to find another option and any input is welcome.
  Post-meeting note: the coordination possesses a survey tool that is internally managed at INSERM and can be used by the EJP RD partners. The dedicated accounts (one per pillar or more of needed) can be created on demand.
- The use of Mail chimp for the newsletter also represents a problem due to data storage in the US. Another solution needs to be identified. In addition, the coordination team will verify if there is also a storage issue with Doodle.
- The collection of email coordinates of the EJP RD partners is very important for further contact and dissemination. EJP RD members need to complete the survey launched by the Coordination and provide a complete mailing list. If needed, the WP leaders have to collect the email contact from their collaborators and forward the information to the Coordination team.
- Each Pillar will get one Zoom account and one webinar account for dedicated conference calls and seminars
- The coordination team will support each Pillar in writing of the Pillar conference call minutes. There is no need (nor sufficient manpower at the coordination unit) to support writing of minutes for each WP or Task conference call.
- The Annual Work Plan has to be drafted by June and will be discussed at the start of July with the Policy Board. The final version of the AWP & Summary of Progress Report must be delivered in September. The EC shall review the AWP by October.

WP2 Integrative research & innovation strategy

- Connecting EJP RD with different RD stakeholders such as the RD National Plan representatives in the European countries, the EMA, and the National Mirror Groups, will be required to establish and develop an efficient research & innovation strategy plan.
- The following links refer to the EMA strategy plan
  https://www.ema.europa.eu/en/about-us/how-we-work/european-medicines-regulatory-network/eu-medicines-agencies-network-strategy-2020
  https://www.ema.europa.eu/en/about-us/how-we-work/regulatory-science-2025

WP3 Sustainability strategy & business plan

- WP3 will develop a tight collaboration with the Pillar 2 regarding the sustainability of the virtual platform (WP10). It will also interact with WP4 where the IP issues will be treated, and with WP16 in order to identify and built a sustainable E-learning programme after the 5 years of the EJP RD. WP3 will be essential to start lobbying (e.g. ensure the connection with EU parliament) by year 3.
- WP3 will develop workshops and seminars on sustainability exercise for academics.

- In order to efficiently run the sustainability plan it would be important to collect the sustainability models going beyond RD field (tax exemption, crowdfunding, etc.) as well as meet with structures who already achieved sustainability.
- The sustainability should be kept in mind and guide decisions in the running of all WPs.

WP4 Ethical, regulatory, legal and IPR framework of the EJP RD

- WP4 will closely work with WP21 and the independent Ethics Advisor to be established in the first months of the project.
- WP4 will be tightly connected to the coordinator and Pillars, including Pillar 2, regarding ethical issues. The resources to be gathered within Pillar 2 already have their own code of conduct. WP10 will need the support of WP4 to develop and harmonize their activities. Importantly, partners who are involved in this Pillar are also involved in AREB.
- With regards to data protection, the GDPR applies to all pillars and there should be an internal policy on how to create the database and store the data → the WP 4 will do this together with the Ethics Advisor.

WP5 Communication & dissemination

- All documents must be addressed to the Coordination unit and validated by WP5 prior to publication.
- The EJP RD Communication Manager will establish an interaction with the Communication Managers of the different EJP RD partners in order to facilitate the exchange of information and the communication.
- It was suggested that the 1st page of the EJP-RD website provides information on the 24 ERNs (link to their website). Articles related to EJP RD, ERNs or their partners might be published on the website to increase the visibility to the public.
- Previous project funded by E-Rare as well as Looking for Collaborations module will be transferred to the EJP RD website. Same can be done for E-Rare reports, etc. It should be verified whether the E-Rare information have to be maintained on the website for 5 years and more content transferred to the EJP RD website. In contrast, the IRDiRC website will not be integrated in the website of EJP RD. The EJP RD website will remain in English unless someone can translate it in another language for specific contents.
- EJP RD should integrate in its strategy the publication of statements and opinion papers. Specific journals should be targeted to give more visibility.
- Facebook and LinkedIn won't be used to advertise EJP RD (except individual LinkedIn account of EJP RD members) as they are not GDPR compliant.
- A WhatsApp account will be established so it is easier for partners to communicate and send the twitter news to the EJP RD communication manager
- The meeting schedule will be conserved in 2020 for RE(ACT) that is foreseen for March 2020 and always takes place in the same year as ECRD (Eurordis Congress). It is envisaged that the RE(ACT) 2020 can be organised as joint congress with IRDiRC congress. It is now being discussed by the IRDiRC Operating Committee.

PILLAR 1: Funding collaborative research on rare diseases

WP6 Joint transnational calls for collaborative research projects

- The recommendations and guidelines for JTC applications will always be described on the website.
- It has been agreed that Pillar 1 should be tightly linked to the Pillar 3 trainings: whenever needed the funded researchers should be encouraged to participate in the Pillar 3 trainings relevant to their project (e.g. FAIR data, ontologies, engagement of patients, etc.). The ExCom agreed that all JTC applicants can be informed about the trainings but the funded projects should be strongly encouraged to participate.
- Rare cancers and rare neurodegenerative diseases are excluded from the 1st JTC. However, a working group will be set up to discuss the funding of rare cancers and make sure that they are included in the coming years. Nevertheless, it should be underlined that rare cancers **are included** in the other funding WPs such as the Networking scheme or Rare Diseases Research Challenges.

WP7 Networking to share knowledge of rare diseases

- The networking scheme is open to any consortia including the ones from ERNs. The scope of networking can vary (can be overarching) and should not be limited only to subjects related to one RD or group of RDs. Thus, one can imagine that it will be also open to Pillar 2 members.
- The **maximum** grant contribution is of 30000 euros per event and will not be increased at least for the first 4 rounds of Networking scheme. It may be changed after thorough evaluation of the scheme at later stage.
- To avoid conflict of interest for the partners issued from the beneficiaries of the EJP RD it must be clear that the applications to the Networking scheme should be different/complementary to the activities planned and funded within the EJP RD or any other action already. If an application including EJP RD beneficiaries is granted it is extremely important to clearly separate the activities (and budget lines).

WP8 Rare Diseases Research Challenges

- The RDR challenges will support small public-private projects (e.g. proof of concept studies). The total budget for RDR challenges is of 1,5 M euros. WP8 will be connected to the Coordination and the EC for the validation of the calls before their publication.
- At present ERNs are not authorized to interact/collaborate with industry (until their code of conduct is agreed, which is now in hands of DG Santé and a dedicated working group from ERNs) so this should be taken into account as possible obstacle for RDR applications. One possibility is that ERN members participate with their university/research hat but this may lead to discredit of the ERNs position and value towards possible industrial partners.
- WP8 organises its first workshop on the 12 of February 2019 in Brussels. Several representatives of industry as well as WP8 members, Pillar 1 chair and VC and EJP RD coordinator will be present. None of the research or ERN

representatives were invited due to the possible conflict of interest – it is not possible to participate in the workshop and decision making and apply for RDR challenge funding after.
- WP8 and WP20 should be connected to jointly overcome the problem of ERN participation and interactions with industry.

WP9 Monitoring of funded projects

- It will be important to follow closely the development of indicators from ERA-LEARN as the EC will use them (or even impose them) at some moment for the evaluation of projects funded within Horizon 2020 and Horizon Europe Partnership initiatives (EJP RD is one of those).

PILLAR 2: Innovative coordinated access to data and services for transformative rare disease research

WP10 User-driven strategic planning and transversal activities for Pillar 2 data ecosystem

- No questions or specific comments to this WP.

WP11 Common virtual platform for discoverable data and resources for RD research

- There is a regulation regarding the access to resources - Some resources are open while others have a control mechanism. It is up to the WP11 to decide on the authorization of access. The ethical and legal issue will be addressed by WP10-GDPR and in collaboration with WP4. The Global Alliance is working on this too (e.g. Beacon project).
- The main questions regarding the use and storage of data are:
  - How we can ensure the deposit of the resources? → First need to map the capacity of the existing repositories to accommodate new or expand to accommodate.
  - How this (catalogue) will be integrated in the EJP RD entry point? Who will host it? → This is yet to be decided.
  - How are you going to normalize the data? → The idea is not to impose to different resources to use the same standards but to use standards that will provide coherent answers so the metadata could give coherent answers.
  - What is the role of the registries metadata that EJP RD will do and how it is connected to the work of JRC on registries metadata? → The teams from the University of Frankfurt, which work on this for JRC will also work in the EJP RD so there is an alignment.
- Understanding the meaning of metadata is very important: Metadata is the information about the data (where it is, how to access it, how to analyse it, what ontology to use for its analysis, etc;) but depending on the nature of the data, the metadata may be different.

WP12 Enabling FAIRness and federation at the record level for RD data, patients and

samples

- Data should be used even if they are not fully organized (completed database and standards). The data can be used while they are kept with the resources under specific conditions. This must not prevent the start of collaboration.
- For the WP12 and P2 in general there must be a clear communication structure so people know how to interact.

WP13 Enabling multidisciplinary, holistic approaches for RDs diagnostics and therapeutics

- For the call for projects on X-omics foreseen in this WP, process for partner identification should be installed and the projects will then have to be prioritized on the basis of transparent criteria.
- A survey should be sent to the ERNs in order to identify which data sets they have and which analysis they need. ERNs and researchers should also be trained to perform the analyses. This training will be connected to WP17 who will help setting up the training platform for the projects that would be interested in developing and using WP13 pathways.
- Different types of training can be considered: courses, workshops or even short-term stays. This will depend on the training material but the real-time stay is always useful. The WP16 & 18 will also be able to provide help.
- The integration of data from other species may be considered for the development of pathways: e.g. through the involvement of Infrafrontier or wikipathways? However, integrating data from different species is never easy. For wikipathways they already have mice data (more than for human!) and any pathway can be started as soon as data and homology conversion can be done. Nevertheless, this can be proposed only if at the end somebody will really look at it and use it.

PILLAR 3: Capacity building and empowerment

WP14 Training on data management and quality

- The possibility to organize courses during congress/conference will be explored for the next year. It may be valuable to link the courses with the big meetings in order to increase the number of participants and lower the costs of participation (since people will be already there for the congress).
- The courses will be disseminated through the EJP-RD and Partners website (interaction with WP5).
- Blueprints for some workshops will be developed and connected with WP3 for sustainability.

WP15 Capacity building and training of patients and researchers

- Regulatory and ethical needs e.g patient paediatric training, will be covered by the courses but further needs will come with time.
- Patient rights based on EU directives (consent, procedures) are covered in

these WP trainings.
- Any relevant connection related to training of paediatric patients and the relation between C4C and EJP RD will be established through Eurordis.
- The F2F training will be provided in English.

WP16 Online academic education course

- ELIXIR will not be used as a e-learning platform but will be involved in evaluation of the performance and monitoring of courses.
- It has not yet been defined which type of certification will be delivered in order to accredit the training course. Getting an accreditation will be very challenging since the EJP RD is not a legal entity. Therefore, it might be valuable to liaise to the EIT to learn on how the accreditations can be done.
- Since some of the contents to be integrated in the WP16 online course were already developed by an organization it will be important to capture correctly any possible IP issues. Due to this, sometimes it may be only possible to link these contents and not fully embed them in the e-learning course.

WP17 ERN RD training and support programme

- The number of surveys already run or received by the ERNs may represent a problem if we want to launch another survey to capture the training needs. It will be important to explain the benefit of these surveys and also identify the person(s) in charge to answer the surveys in the ERNs.
- A small group should be selected to gather information from the ERNs and integrate what is already available. However, we need to keep in mind that the ERN evaluation of training needs (already performed) was focused on needs in training for healthcare and not research.

WP18 Development and adaptation of training activities

- No specific questions or comments to this WP.

PILLAR 4: Accelerating the translation of high potential projects and improving outcomes of clinical studies in small populations

WP19 Facilitating partnerships and accelerating translation for higher patient impact

- There is a need for better informing the scientific community about the Translation tool and innovation manager support that will be provided by the WP.
- How can we avoid that WP19 compete with the private companies offering similar services (eg CROs)? → First of all, private companies will ask for money (as they are business oriented), while the WP19 wants to go for early pre-clinical research to derisk the projects that will be in advance of the CRO support (that focuses on more derisked projects). WP19 can also help to accelerate the access to companies supporting drug development and clinical trials when necessary (among which CROs). In addition, the WP19 has the specificity and knowledge on RD! (which is missing from regular CROs).

- The confidentiality issue and IP will be handled by the innovation manager so the researchers are aware of what level of caution they should have in the disclosure of their results and what to do ahead of any disclosure.
  To be taken into consideration: seek a mandate to act in the name of the host institution (to be defined how we can do this) in relation to the exploitation activities foreseen in task 2 of WP19.
- WP19 will interact with WP6 and WP9 for funding and monitoring of funded projects, and WP18 for development of new trainings.
- WP19 may have to liaise with the CCC of IRDiRC for the planned Task Force on common knowledge base to drive RD research. This will help in defining what are the needs of the pharma companies, and facilitate the development of the roadmap for the EU investment platform.
- The involvement of TACT committee (TRAT-NMD TACT) will be used to create a handbook on how to create an advisory committee for therapeutics to help other RDs groups interested in it.
- Since the support of innovation manager(s) from WP19 will be limited to the support to Pillar 1 projects or eventually some previous E-Rare funded projects we should keep in mind that scaling up is very important (for the future of this possible service and EJP RD).

WP20 Accelerating the validation, use and development of innovative methodologies tailored for clinical trials in RDs

- The outcomes of WP20 will be very important for the WP3 to ensure sustainability (and dissemination).
- What about the interaction with the EMA? → the ERN research group is in contact with the EMA and there is a link person at EMA to follow. However, the EMA contact point cannot be permanently represented in the Task Force Group of WP20 (but will be available to answer the questions or advise).

EJP RD Governance

- General Assembly: Highest level of decision within the project. One representative per beneficiary.
- Governing Board: 1 representative per country, 1 representative of ERN, 1 representative of EU infrastructure, 1 representative of Orphanet, 1 representative of patients, 1 representative of non-profit organisations. We may consider the integration of 1 representative of funders (representing the voice of all funders?).
- For the representative of a non-profit organization they can decide if they want to be considered as one group with one representative or if they prefer to be integrated in the groups of specific countries.
- GB prepares the recommendations for the GA final vote.
- Each participating (beneficiary) country decides on how to establish a common position on each element for the GB.
- Some serious concerns have been expressed regarding the possibility for GA members to file a veto as it is considered that the rules proposed in the Consortium Agreement are not clear enough to properly define "detrimental situation". Thus, veto could be raised also for minor reasons as long as the beneficiary considers the situation as "detrimental".

- How to express the "exceptional" position of a member of the GB? → There is a distinction between the position of a GB member (which is already a single voice of a country or group) and a position of a separate GA member (in case if two institutions from the same country cannot agree). The exceptional position of a GB member would be in that case a position different from other GB members (and not a position of a single GA member).
- Policy Board: One representative of each Ministry per member State (including countries represented only via the linked third parties), European Commission Directorates, Representative of regulatory authorities and other stakeholders such as the Chair and Vice Chair of IRDiRC, EFPIA, pharmaceutical industries. PB will discuss the strategy and sustainability of EJP RD.
- National Mirror Groups: NMG constitution is not mandatory but strongly advised.
- What about the integration of national representatives participating currently in the ERN board of Member States? → They should be listed as stakeholders to include in the NMG. This can be specified in the ToR of NMG.
- NMG will interact with the GB and bring the voice of additional representatives at the national level.

Research & Innovation prioritization strategy

ERN strategy

- Current internal discussion of ERNs: It has been suggested that ePAG members may serve as patient representatives in the research working group (RWG) of ERNs. However, this criterion should not be exclusive to ePAGs. It has not yet been decided how many representatives of patients should be present in the RWG.
- ERNs and EJP RD have common members (Chair of RWG and Chair of the ERN Coordinators are involved in EJP RD Operating Group). Consequently, there is an opportunity to develop the communication and better inform ERNs regarding on-going activities in order to avoid a duplication of work with EJP RD. Furthermore, it will be important to support the joint development of future projects between ERNs and EJP RD, and link the forthcoming needs of ERNs with EJP RD prioritization strategy.
- It has been suggested to introduce some flexibility in EJP RD in order to propose new activities more valuable than the one initially proposed. This flexibility is found in the Annual Work Programming. However, the EC does not expect that we will restructure the whole programme every year and any major changes must be well justified!

IRDiRC strategy

- The survey to the ERNs and their strategy will be very important for the identification of new Task Forces.
- It would be interesting to have a follow-up on completed IRDiRC Task Forces – update the recommendations and tools to keep it useful to the community.
- How can we ensure that the representatives of specific WPs of EJP RD are part of the TF so IRDiRC could profit from the inputs of the EJP RD? → EJP RD members can apply to participate to IRDiRC Task Forces when nominations

are open. But it will not be a granted position. A recommendation to maintain/reflect "diversity" in Task Force composition has been mentioned – IRDiRC should always keep its international character but the connection with the EJP RD is important.

EJP RD prioritization process

- In order to better reflect on the positions from the funders and from the research performing organisations it has been suggested to have 2 representatives per country in the GB: One for funding and one for the institution. However, there was no agreement that such process would be positive. What is more important is that the final part of the prioritisation of topics for calls and call management is independent from the research organisations involved in the EJP RD.

EJP RD administrative and financial procedures

Budget and Financial reporting

- The Budget Plan is now updated and will be sent to all beneficiaries. Each beneficiary should send a financial report once a year.
- In case if the institutions/teams which are beneficiaries of the EJP RD participate and are granted from Pillar 1, the project must be separated from the general EJP RD budget and the two budgets must be managed separately.
- The bank details of EJP RD partners will be collected and the budget will be transferred to the partners who signed the Grant Agreement.
- A workshop will be proposed to financial/administrative officers in May-June 2019.

Update on the Consortium Agreement

- The Consortium Agreement is divided in 3 parts: the framework, the sub-CAs for Pillars 1 and 2, the *Ad hoc* agreements will be developed on demand.
- The pre-final version of the framework CA will be delivered by mid-February.

AOB

- EJP RD received a positive response from GA4GH as Driver Project. As agreed previously, the coordination will put in place the vote of the General Assembly for final validation and will inform EJP RD partners on next steps.

Final conclusions of the kick off meeting:

- The WPs presented their expected outcomes and outputs; this will serve to define the KPIs and KRIs;
- The majority of interactions between WPs were identified and new ones appeared;

- The Coordination Unit will keep track of these interactions but each WP must also do its own work to keep them alive;
- The EJP RD governance was discussed and will be finalized through the CA;
- The Coordination will prepare the terms of reference and send invitation for nominations for GA, GB and PB;
- EJP RD strategy is highly dependent on the connexion with the ERNs and IRDiRC;
- ExCom members are key in the communication and work with involved partners.