Minutes

General Assembly Meeting

of the Coordination and Support Action BrainHealth

14.05.2024

9:00 – 13:00 Berlin/hybrid

**Annexes:** Agenda (I), List of Participants (II), Presentation Slides (III)

The meeting was opened by Tanja Fröhlich-Israng from the German Federal Ministry of Education and Research (BMBF), followed by a welcoming note from the CSA BrainHealth coordinator Ulrike Bußhoff (DLR-PT). The aim of the meeting was to inform the members of the Funders Forum about the process towards a future European Partnership for Brain Health as well as the progress that has been made since the start of the CSA BrainHealth in November 2023. The meeting was attended by 73 participants (48 on site and 25 online). All meeting attendees were invited to actively engage in the discussions and give feedback to what has been developed so far, in order to shape the future partnership according to the needs and priorities of national and regional funders.

Following the welcoming notes, Tim Raemaekers (European Commission, EC) gave an overview on the EC’s perspective for the future EP BrainHealth, including the expected objectives and the timeline for the next steps. Importantly, the request letters for preliminary financial commitments from member states and associated countries will be sent out shortly by the EC to the ministries in charge and must be completed by mid-September 2024. The expected cofunding rate from the EC will either equal 30% of the total contributions (same as in the existing networks in the brain health field), or can be upgraded up to 50%, depending on the type of the planned activities and the member states commitments. In the discussion it was emphasized towards the EC representative that a clarification on the funding rate is important for commitment decisions of national/regional funders and for the CSA in order to plan the activities of the future partnership accordingly. Regarding the role of the EC in the future EP the suggestion in the draft proposal (EC as an observer in the Governing Board) deemed suitable.

In the following, Astri Arnesen from the European Federation of Neurological Associations (EFNA) and Erik van der Eycken from the Global Alliance of Mental Illness Advocacy Network (GAMIAN) gave short insights into the patient perspectives on brain health and their views on what has been achieved so far. They emphasized the paramount importance of appropriate engagement of patients in all aspects of the future partnership, including a joint representation in the governance (“patients board”) as well as the availability of the necessary resources.

In the following four talks, CSA partners presented the progress that has been achieved in the major activities of the CSA, each followed by a feedback and discussion round.

## 1. Roadmap to a European Partnership for Brain Health

*Friederike Bathe (DLR-PT)*

In this presentation Friederike Bathe provided an overview on the aims and the process towards the European Partnership for Brain Health and in particular the progress that has been made in the generation of the proposal to be submitted to the EC. She outlined the scale of the problem with brain disorders being the major cause of death and disability in the EU and worldwide. Based on existing collaborations, the envisaged EP will foster alignment across European and global brain initiatives, develop an overarching ecosystem for brain health and generate the critical mass to create impact. She also presented the draft mission and vision statements as well as the general objectives of the partnership. The current version of the draft proposal (version V2) had been sent to the members of the Funders Forum in advance of the meeting.

**Feedback on Vision/Mission:**

* Everyone in general agrees on the vision statement, the mission, and the general objectives
* Focus on the healthy brain / healthy people, not only on people who are already affected by brain disorders should be more pronounced (also in the SRIA)

## 2. EP BrainHealth governance and structure

*Christina Müller (DLR-PT)*

This presentation focused on the governance and the structure of the future partnership, including the different modes of participation. Christina Müller outlined that four different areas of government are intended for the EP: strategic planning, advise/collaboration, management and an operational level. With regard to participation, three levels (partners, consortium and ecosystem) are envisaged, which are open for funders and stakeholders.

**Feedback on the governance:**

* The planned “patient advisory board” should be a permanent board and should also include care givers.
* Other sub-boards as part of the Collaboration Platform are currently under discussion e.g. for private sector representatives, health care providers, etc. The aim for creating sub-boards is, to have a defined contact point for different stakeholder groups and to encourage a consensus within each group before feedback is given to the Governing Board of the partnership.
* It was proposed that in addition to a patient advisory board, a permanent ethics boards could be installed. However, ethics experts will already be involved in the Scientific Advisory Board. Furthermore, it will be mandatory to form an ethics board for each call as well. Thus, having ethics experts forming an additional dedicated board might not be necessary.
* Chair of the Governing Board: The General assembly welcomed the idea to install the coordinator of the future partnership also as the chair of the Governing Board. In this way, continuity and efficient decision making can be assured. In addition, it was proposed to install a vice-chair, who should be elected by the partners. By this, functionality of the decision-making is guaranteed, also in case the chair is not available. In addition, the position of a vice-chair offers the opportunity for other countries to take on a highly visible position in the partnership.
* Voting right: For strategic decisions taken in the Governing Board, there was agreement on having one vote per country, in case of several funders from the same country. However, it has been suggested to include the possibility of one vote per partner for certain decisions. This could be the case for decisions taken in the Call Steering Committees, since here decisions are taken regarding funds from individual organisations. This aspect will be further elaborated in the Funders Forums Survey which will be circulated after the meeting.

**Feedback on modes of participation:**

* It was discussed how the looser group of "Stakeholders" (without legal binding contracts) are actually involved in the partnership.

Answer: They could be involved via the networking platform. In this way they are informed on a regular basis and their advice can be sought on demand. Since non-funding stakeholders can participate in three different categories they can titrate their level levels of commitment and participation within the partnership. If it is clear from the beginning that a higher level of commitment is desired, stakeholders can join as “Third Parties” (signature of CA only, small amount of work in WP obligatory), or even as “Non-funding Partners” (signature of the GA, significant amount of work in WP obligatory, e.g. as WP lead).

* There was a question, how ad hoc funders (not signing the General Agreement nor the Consortium Agreement, no voting right nor seat in the governing board) can actually be included in future calls of the partnership.

Answer: This is common practice in the predecessor networks (NEURON, JPND) and will probably also be possible in European Partnerships. However, this mode of participation should only be chosen in exceptional cases (e.g. in case new funders would like to get involved in the partnership). For all funders that are already members of the Funders Forum, participation as official partners (“Funders” or “Third Country Funders”) should be strived for, since only then they will be able to shape the strategy of the partnership (seat in the GB).

## 3. SRIA: Research Areas of the EP Brain Health

*Etienne Hirsch (INSERM)*

Etienne Hirsch (INSERM) outlined the process of SRIA development and the envisaged fields of actions. He stated that the SRIA will be derived from the WHO definition of brain health and comprise neurodegenerative and non-neurodegenerative as well as psychiatric conditions and functioning of sensory organs. The SRIA will be based on related former work from JPND, ERA-Net NEURON, HBP and EBRA. The development will be done in multiple steps, including several consultation steps, among them a general consultation in August which will be open to everybody. Five challenges need to be addressed: large-scale studies, brain health measures, efficacy of treatments, funding and regulatory aspects. They will be targeted by four research priorities and seven transversal fields of action. A portfolio of tools is available which will be matched to the priorities and actions and thus constitute the implementation plan.

**Feedback on SRIA development:**

* Analysing brain health in communities is important, including consideration of gender aspects and minorities
* Pre-clinical studies may be done multi-centric as is the case for clinical studies
* More interaction between students and the general public is needed
* The problem of losing young people to business instead of research careers may be addressed
* Performing clinical studies may be essential but may need to be addressed in collaboration with other EU-funding initiatives ; because providing funding for large-scale clinical studies within the partnership will pose a challenge.

## 4. International and global networking

*Frédéric Destrebecq (EBC) and Philippe Vernier (EBRAINS)*

Frédéric Destrebecq (EBC) and Philippe Vernier (EBRAINS) jointly introduced the current and planned international outreach activities. Connecting to ongoing initiatives in the area of brain health is important with regard to e.g. knowledge-sharing and capacity building. As of today, 103 relevant global organisations have been identified. Global partners will actively be invited to align with the CSA and the EP. Research infrastructures are needed to sustainably share data and material, however, researchers need to be convinced to share data and to make better use of existing infrastructures. This will help to avoid duplication and to increase reproducibility of results. A plan for a number of global activities and meetings is being drafted, including a 1-hour CSA introductory webinar on June 19, 2024, a networking reception at the FENS forum on June 27, 2024 as well as participation at the science summit at the UN General Assembly 79, the Brain Innovation Days 2024 [13-14 Nov 24] and a global conference at the Brain Innovation Days 2025.

**Feedback on global networking:**

* It will be essential to find partners that help solving the challenges.
* The potential of AI should be considered

## 5. Final Discussion and Closing Remarks

* *Need funds to be increased in comparison to usual amounts e.g. ERA-Net NEURON/JPND?*

Ulrike Bußhoff: If possible, yes

* *If many organisations are needed for the partnership, how can we attract all partners?*

Ulrike Bußhof: Every funder takes information provided back to their countries and communicates to relevant ministries, agencies, foundations etc. Also respond to survey and become a member of the Funders Forum.

* *Can other kind of actors be included in national commitments? Time is needed to find these actors and the question of 30% or 50% co-funding is important*.

Ulrike Bußhoff: Yes, other actors may be included. The ratio of co-funding is given by the EC and will depend on the type of action.

* *How many calls are planned per year?*

Ulrike Bußhoff: Needs to be discussed within the consortium, however, at the moment it is estimated that two biomedical calls per year will be envisaged, one in the thematic area that has so far been covered by JPND and one from the ERA-Net NEURON area. On top of that, there will be other call activities on additional topics (e.g. regular networking calls and calls for ELSA and/or innovation). A commitment is needed for the entire partnership (7 + 3 years run time of the projects of the last call). The currently envisaged call rythm would result in a maximum total number of 14 biomedical calls + additional non-biomedical calls.

* *What about “non-funding partners” in the Governing Board, e.g. research performing organisations? Or rather as stakeholders?*

Ulrike Bußhoff: Funders need to reflect on this. This aspect will be also be covered in the Funders Forum survey. There will likely be certain conditions for the participation as Non-Funding Partners (e.g. substantial contribution to work programme, in-kind contributions). Other options for participation in the EP BrainHealth, e.g. as Third Parties or Stakeholders, are foreseen.

Annex I: Agenda

CSA BrainHealth General Assembly

Tuesday, May 14th, Berlin *(morning session)*

9-13:00 CET

[*Connection link*](https://dlr-projekttraeger.webex.com/dlr-projekttraeger/j.php?MTID=m3ccd26cd4421150574f01832c118a3ab)

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| **9:00** | **Welcome**  *Tanja Fröhlich-Israng (BMBF), Ulrike Bußhoff (DLR-PT)* |
| **9:15** | **European perspective on the European Partnership for Brain Health**  *Tim Raemaekers (European Commission, DG Research & Innovation)* |
| **9:30** | **Patient Perspective on brain health**  *Astri Arnesen (EFNA), Erik van der Eycken (GAMIAN)* |
| **9:45** | **Roadmap to a European Partnership for Brain Health**  *Friederike Bathe (DLR-PT)*  *Vision, mission and expected impact of the future EP - feedback by funders* |
| **10:15** | **EP BrainHealth governance and structure**  *Christina Müller (DLR-PT)*  *Modes of participation, governance bodies - feedback by funders* |
| **10:45** | **Coffee break** |
| **11:15** | **SRIA: Research Areas of the EP Brain Health**  *Etienne Hirsch (INSERM)*  *Presentation of the SRIA priorities & mode of consultation – feedback by funders* |
| **12:00** | **International and global networking**  *Frédéric Destrebecq (EBC), Philippe Vernier (EBRAINS)*  *Concept for interaction with global initiatives - feedback by funders* |
| **12:45** | **Open questions and closing remarks**  *Ulrike Bußhoff (DLR-PT)* |
| **13:00** | **End of meeting and Lunch** |

Annex II: List of Attendees

Table 1 | List of Attendees in Berlin

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| Name | Country | Institution |
| Almeida Pereira, Carlos | PT | Agency for Clinical Research and Biomedical Innovation (AICIB) |
| Albanese, Federica | IT | Fondazione Regionale per la Ricerca Biomedica |
| Amouyel, Philippe | FR | Fondation-Alzheimer and L'Institut national de la santé et de la recherche médicale (Inserm) |
| Anderson, Sara | BE | EBRAINS |
| Arnesen, Astri | BE | EFNA/Eurohuntington |
| Bathe, Friederike | DE | German Aerospace Center (DLR) |
| Becker, Thomas | DE | German Aerospace Center (DLR) |
| Bibova, Katarina | SK | Slovak Academy of Sciences (SAS) |
| Bifolchi, Simona | IT | Ministry of Health |
| Bosnic, Mateo Ante | HR | Ministry of Science and Education of the Republic of Croatia |
| Bouvet, Philippe | FR | ANR |
| Breid, Sara | DE | German Aerospace Center (DLR) |
| Bußhoff, Ulrike | DE | German Aerospace Center (DLR) |
| Ciccarelli, Chiara | IT | IT MoH |
| Destrebecq, Frédéric | BE | European Brain Council (EBC) |
| Daly, Amanda | IE | HRB |
| Durrani, Abida | NL | MinVWS |
| Dorlöchter, Marlies | DE | German Aerospace Center (DLR) |
| Dutour Provenzano, Gaelle | FR | ANR |
| Frykman, Susanne | SE | Swedish Research Council |
| Gossen, Anna | DE | German Aerospace Center (DLR) |
| Grzybowska, Bozena | PL | NCBR |
| Hermantin, Hugo | BE | EBC |
| Hirsch, Etienne | FR | L'Institut national de la santé et de la recherche médicale (Inserm) |
| Horváth, Klára | HU | NKFIH |
| Hüttner, Katja | DE | German Aerospace Center (DLR) |
| Jurado Sanchez, Sandra | ES | Agencia Estatal de Investigación (AEI) |
| Anke Ley | DE | DFG |
| Lichtenberg, Hella | DE | German Aerospace Center (DLR) |
| Lorrio, Silvia | ES | Agencia Estatal de Investigación (AEI), Fundación Española para la Ciencia y Tecnología (FECYT) |
| Marquer, Catherine | FR | Agence Nationale de La Recherche (ANR), France |
| Müller, Christina | DE | German Aerospace Center (DLR) |
| Nelissen, Rosalie | NL | Netherlands Organisation for Health Research and Development (ZonMw) |
| Peeters, Kristien | BE | Research Foundation - Flanders (FWO) |
| Poulain, Bernard | FR | CNRS |
| Raemakers, Tim | BE | European Commission, DG Research & Innovation |
| Raulo, Erkki | FI | AKA |
| Rodrigues, Alexandra | PT | Innovation Fund Denmark |
| Rossignolo, Giulia Maria | IT | Fondazione Regionale per la Ricerca Biomedica |
| Ruzele, Zivilie | LT | Research Council of Lithuania |
| Salo, Aki | FI | Research Council of Finland |
| Schach, Sophia | DE | German Aerospace Center (DLR) |
| Schulte, Heidi | DE | German Aerospace Center (DLR) |
| Soon, Argo | EE | Estonian Research Council (ETAG) |
| Van der Eycen, Erik | BE | GAMIAN-Europe |
| Philippe Vernier |  | EBRAINS |
| Yeo, Karin | FR | JPND Secretariat, Communication office |

Table 2 | List of virtual attendees

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| Name | Country | Institution |
| Alexandra Bjørk-Skaflestad | NO | RCN |
| Alexandre Maurício | PT | FCT |
| Alicja Dyląg | PL | NCN |
| Annalisa Cartabia | MT | MCST |
| Candi Sanchez | ES | ISCIII |
| Ching-Mei Tang | TW | NSTC |
| Cristina Nieto | ES | ISCIII |
| Emma McGrath | IE | SFI |
| Emmanuel BROUILLET | FR | CNRS |
| Esther Chacón | ES | AEI |
| Jo Latimer | GB | MRC |
| Katrine Boeriis | DK | IFD |
| Kristien Aarts | BE | EBC |
| Magali Dumont | FR | FA |
| Maiken Engelstad | NO | Norwegian Ministry of Health and Care services |
| Marcin Chmielewski | PL | NCBR |
| Maria Azzopardi | MT | MCST |
| Mauricio Garcia-Franco | ES | ISCIII |
| Maxime Beaudoin | CA | FRQS |
| Päivi Kolu | FI | AKA |
| Sabrina Voß | DE | DLR-PT |
| Staffan Arvidsson | SE | FORTE |
| Vera Mönter-Telgen | DE | DLR-PT |

Annex III: Presentation Slides

