



Deliverable D7.3

Set up of working groups focusing on specific BRAIN diseases



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Short description of the Deliverable:

This deliverable is linked to Task T7.2 which is to set-up working groups dedicated to translate MULTI-ACT to other brain diseases.

This task requires firstly to establish collaboration with (a) research consortium(s) in other brain disease areas than multiple sclerosis. This deliverable describes the process to set up working groups to interact with the MULTI-ACT consortium. As written in D7.1 we have already established collaboration with the EBRA cluster: EPI-Cluster. Therefore, this process of forming a working group in the EPI-Cluster will be used as the basis to potentially establish collaborations with other EBRA clusters in the future if relevant.

REVISION HISTORY			
REVISION	DATE	COMMENTS	AUTHOR (NAME AND ORGANISATION)
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V0.2	14/08/2020	Second version including additional input/feedback from UNITN (Michele Andreaus) and EY (Andrea Gavazzi) sent to all partners.	Elke De Witte, Françoise Van Hemelryck, EBC
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		by FISM (Deborah Bertorello), EY (Andrea Gavazzi), UNITN (Michele Andraeus, TAU (Anna Kork).	
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EXECUTIVE SUMMARY

The overall purpose of the MULTI-ACT project is to co-create a Collective Research Impact Framework (CRIF) that offers a more participatory and realistic evaluation of the health Research and Innovation (R&I) impact of multi-stakeholder initiatives.

Work Package 7 (WP7) aims to foster the application of the MULTI-ACT CRIF in multistakeholder research initiatives focused on other brain disease areas in addition to Multiple Sclerosis which an extensive case study is dedicated to in WP4. The objective is to explore the applicability and utility of the MULTI-ACT Collective Research Impact Framework (CRIF) in different brain disease research and innovation areas.

The first deliverable of WP7 reported on the identification and selection of another brain disease initiative and the establishment of the terms of the collaboration with the MULTI-ACT consortium.

The current deliverable reports on the setup of the working group which was established with one of the brain research clusters under the EU funded European Brain Research Area project (EBRA)¹: the EPI-Cluster².

The European Brain Research Area project — EBRA — is a H2020 funded Coordination and Support Action acting as a catalysing initiative for brain research stakeholders (researchers, clinicians, patients, governments, funders and public institutions) to streamline and better co-ordinate brain research across Europe while fostering global initiatives. Among other actions, EBRA has launched a Call for Clusters been launched to promote co-operation and exchange between brain research projects and networks, and thus enable or enhance international collaboration and the emergence of development of clusters in all areas of brain research. Within this frame a cluster is understood as an association of research projects that can be directed towards basic research, clinical research and/or methodological approaches under a common topic and disease area.

Based on the collaboration agreement established between MULTI-ACT and EBRA, the EPI-Cluster has been selected to setup a joint working group aimed at exploring the suitability of the MULTI-ACT CRIF in the cluster context. This working group can be also used as a basis to collaborate with other EBRA clusters in the future if relevant.

¹ <https://www.ebra.eu/about/the-mission/>

² <https://www.ebra.eu/existing-clusters/>

1 INTRODUCTION

The EU-funded MULTI-ACT project, in full “A Collective Research Impact Framework and multi-variate model to foster the true engagement of actors and stakeholders in Health Research and Innovation”, aims to increase the impact of health research of multi-stakeholder research initiatives and to better tie the research results to the mission of the initiatives.

To further develop and improve the MULTI-ACT CRIF, the MULTI-ACT Consortium already engaged in WP4 in a co-design effort with a potential user of the CRIF: The MS Care Unit initiative, a multi-stakeholder initiative in the disease area of Multiple Sclerosis (MS).

In WP7, the aim is to explore the applicability and utility of the MULTI-ACT CRIF in the context of other brain disease multi-stakeholder initiatives, guide research promoters on how to use the MULTI-ACT CRIF and take the most benefit from it. The purpose of WP7 is also to collect feedback on the usability of the framework in the specific brain disease area.

The first deliverable of WP7 reported on the identification and selection of a brain disease initiative and established the terms of reference for the collaboration between the cluster and the MULTI-ACT consortium. As described in Deliverable 7.1, a collaboration has been established with one of the EBRA clusters – EPI-Cluster. Therefore Deliverable 7.3 ‘Set up of working groups focusing on specific BRAIN diseases’ will start with the EPI-Cluster working group which can serve as an example for potential future collaborations with other EBRA clusters.

1.1 Background

The aim of this deliverable is to set up working groups dedicated to translate MULTI-ACT to other BRAIN diseases.

This task requires first of all to establish collaboration with research initiatives in other brain disease areas than multiple sclerosis (see Deliverable 7.1).

The EPI-Cluster, in the field of epilepsy, established under the EU funded European Brain Research Area project (EBRA)¹, was selected as best suited to collaborate with MULTI-ACT. As described in Deliverable 7.1, it appeared that a collaboration with the EBRA EPI-Cluster presents a timely opportunity as the EBRA epilepsy research community is looking to expand and engage with relevant stakeholders including patient groups.

This report introduces the EPI-Cluster and its MULTI-ACT dedicated working group with which the MULTI-ACT consortium will collaborate as well as the key steps of the collaboration.

1.2 Structure of this document

After the introduction, Section 2 describes the EPI-Cluster, the formation of the EPI-Cluster working group and opportunities for future working groups.

Section 3 provides the conclusions on the working groups set up process and introduces the next steps and deliverables under WP7.

1.3 Glossary

Co-accountability is the theoretical foundation of the overall MULTI-ACT framework. It refers to the approach of forming a broader and holistic expert knowledge and supports a plurality of perspectives in making decisions, not only in defining the performance indicators, but also in collecting data together and assessing the strategies in the long term. It represents an innovative form of democratic and participatory accountability, where a process of negotiation of interests and information is required. It promotes “multi-voiced” and tailored solutions that take into account the diversities of stakeholders’ value and interests. Co-accountability as a measurement framework promotes customized, qualitative and quantitative indicators that measure the accomplishments according the multiple stakeholders’ priorities.

CRIF is a conceptual framework developed by MULTI-ACT enabling a new collective accountability approach to managing and assessment multi-stakeholder R&I initiatives. This framework allows to consider different dimensions (excellence, efficacy, social, economic and patient reported dimension) in the research assessment, enabling a more effective multi-stakeholder approach, since it is naturally oriented to consider different interests and goals.

Multi-stakeholder initiative is a governance structure that seeks to bring different stakeholders together to participate in the dialogue, decision-making and implementation of solutions to the shared problems or goals.

Stakeholder refers to “any individual or group that is affected by, who can influence or may have an interest in the outcomes of an organization’s actions” (Freeman, 1984).

Stakeholder engagement refers to activities that can be done with stakeholders such as consult, listen, understand, communicate, influence, negotiate, etc., with the broader objectives of satisfying their needs, gaining approval and support, or at least minimizing their opposition or obstruction.

Master scorecard is an adaptive tool for assessing the research impact across the five CRIF dimensions. The scorecard consists of a list of indicators evaluating aspects of measurement linked to the different dimensions, that can be tailored into different contexts and missions. By facilitating assessing research impact, selection of appropriate indicators and monitoring progress, the Master Scorecard demonstrates how the organisation is producing impact in line with its mission.

Research & Innovation Path (R&I Path): sequence of processes and activities in R&I where patients can be engaged in order to maximize the impact of R&I.

2 The EBRA EPI-Cluster

MULTI-ACT was introduced to the first round of EBRA clusters: EPI-Cluster and PSMD Cluster. Interactions with the Prevention of Severe Mental Disorders (PSMD) cluster, revealed that in its current stage of development, they did not feel it was opportune to engage with MULTI-ACT but this could be reconsidered at a later stage. Therefore, this report focuses on the MULTI-ACT working group established with the EPI-Cluster which can serve as basis for potential collaboration with the new round of EBRA clusters (see section 2.3).

2.1 Organisation of the EPI-Cluster

EPI-cluster leadership



The EPI-Cluster² was established in 2019 under EBRA as a coordinating action for the European epilepsy research community. The consortium requested support for an EBRA Cluster based on the projects that participated in EpiXchange² and the main stakeholder (professional and patient) organisations including the European Alliance Epilepsy (EAE), the International Bureau for Epilepsy (IBE) and the International League against Epilepsy (ILAE). The leadership of EPI-Cluster comprises 10 internationally-recognized scientists and clinicians in the field and the leaders of the seven projects that came together under EpiXchange as well as leaders from patient and professional organisations. The EPI-cluster is led by a chair and a co-chair.

EPI-cluster' stakeholders

The EPI-Cluster intends to expand its membership to include affiliated members, other stakeholders and other projects with strong scientific synergies that were not able to participate in EpiXchange (H2020 ITN projects such as ECMED, EU-GliaPhD and SynaNET). The cluster seeks opportunities and interaction with other funded non-epilepsy projects within the Human Brain Project, JPND and ERA-NET and seeks to act at global level. The aim of such expansion is to ensure that all stakeholders perspectives are represented in the cluster such as:

- Academics/researchers: basic and translational science
- Clinicians/caregivers
- Infrastructure/data representatives
- Patient/patient representatives
- Industry representatives

² epiXchange 2018 brought together Europe's best-brains-to-pave-the-way-for-future-epilepsy-research

EPI-Cluster subgroups

EPI-Cluster plans to create 4 subgroups. These subgroups will coordinate the 3 remaining EBRA activities of the EPI-Cluster. The planned subgroups are:

- (1) Synthesis: Planning meetings and support the development of the programme for a European Forum on Epilepsy.
- (2) Policy & sustainability: Agreeing key research challenges, potential funding opportunities for EPI-Cluster community.
- (3) Innovation & industry: Responsible for contacting and engaging with SMEs and Pharma.
- (4) Data and research infrastructure: Coordinating interactions with partners such as HBP and supporting collaborations using our existing resources (e.g. biosamples).

Each subgroup will be led by 1 or 2 leadership members. This task is currently ongoing.

EPI-cluster priorities, objectives and perspectives

Six research and innovation priorities have been identified by the EPI-Cluster:

- Disease-modifying and personalised medicines for epilepsy and their delivery systems
- Target-led biomarker and diagnostics discovery and validation
- Innovative models for diagnostics and target development
- Digitalisation and personal monitoring for independent living in epilepsy
- Coordination of research infrastructures and the epilepsy data ecosystem
- Funding initiatives and integration to society, industry and regulatory space

The primary objective EPI-Cluster is to establish a collaborative framework for the coordinated actions of epilepsy research in Europe, based around the partnerships and research priorities. The proposed initiatives are to:

- Maintain, enhance and advance the existing collaboration and cooperation between multi-scale epilepsy research projects and their partner organisations in Europe.
- Expand the network, bringing in new European-led epilepsy-focused projects and non-epilepsy-focused
- Develop a global funding initiative on epilepsy research across agencies bringing in internationally outstanding academic, industry and other partners.
- Advance research on core topics including mechanisms, diagnosis, treatment and patient care.
- Increase and integrate the engagement of persons with epilepsy and their representatives in the design and execution of research activities.
- Enhance resource-sharing among research groups by establishing mechanisms for safe and effective exchange of resources, models and big data.
- Develop researcher exchange mechanisms to promote knowledge and training between groups.

- Develop an operational preclinical trial network and enhance clinical trial structures for epilepsy in Europe based on eHealth and genetic/clinical phenotyping tools to enable patient stratification.

The different stakeholder perspectives (ref. meeting June 2020) are the following:

- **All stakeholders:** Strong agreement for the value of the EPI-CLUSTER community and interest in being affiliated.
- **All stakeholders:** Epilepsy-related project coordinators supportive of joining forces.
- **Infrastructures:** Strong synergies and opportunities for EPI-CLUSTER to work with the Human Brain Project on human EEG/imaging and with QUEST on preclinical studies.
- **Industry:** Keen to see more small biotech/SMEs enter the area and potential to EPI-CLUSTER for preclinical trial “network”.
- **Patients:** Enthusiastic to contribute to EPI-CLUSTER through expert groups.

2.2 EPI-Cluster Working Group

Several engagement steps were needed to establish the EPI-Cluster working group that will collaborate with MULTI-ACT and define the plan of activities.

Step1: Which key aspects of the MULTI-ACT CRIF are of interest for the EPI-Cluster?

The mission, strategic intent and tools offered by MULTI-ACT CRIF were briefly presented by EBC to the EPI-Cluster during their meeting on 17th June 2020. All stakeholder categories mentioned above were present. The three key aspects of the MULTI-ACT CRIF were explained:

- (a) A new governance model made of a set of criteria allowing effective cooperation of all relevant stakeholders in multi-stakeholder research initiatives
- (b) Guidelines for capturing “patient experiential knowledge” across the health R&I path
- (c) A new tool (Master Scorecard) for the assessment of the research impact across different dimensions including excellence, efficacy, social, economic and patient-reported dimension and to better tie the research results to the objectives of the initiative.

Interest was expressed in exploring the use of MULTI-ACT tools and guidelines in particular to support the EPI-Cluster building its community, identify and engage with relevant stakeholders. Patient engagement guidelines (b) were seen as particularly valuable to the community as well as the governance criteria (a) to define the stakeholders and possibly better define the cluster’s priorities and agenda. This particular interest can be explained by the EPI-Cluster’s strategic priorities that were set in the cluster application for EBRA (mentioned in D7.1 and see Table 1).

Table 1. EPI-Cluster strategic priorities

EPI-Cluster strategic priorities
<ul style="list-style-type: none"> • Advance the existing collaboration • Expand the network

- Advance research on core topics
- Enhance resource-sharing
- Develop a preclinical trial network and enhance clinical trial structures
- Develop researcher exchange mechanisms
- **Increase engagement** of persons with epilepsy and their representatives
- Develop a global funding initiative on epilepsy research across agencies

Step 2: set-up of EPI-Cluster working group

Taking into account the 4 subgroups already defined (see 2.1) and their interest in the (a) governance criteria and (b) patient engagement of the CRIF, the WP7 leader, the EBRA cluster coordinator and the chair of the EPI-Cluster decided on the following criteria for setting up the working group :

- a minimum representation of 3 different stakeholders categories (incl. the patient as this was one of the main interests of the cluster)
- a maximum of 4 people in order to ensure the feasibility of meeting on a regular basis (bimonthly)
- main objective: to start the process of expanding the community (cluster' stakeholders) and defining the cluster's priorities and agenda by using the governance and patient engagement tools of MULTI-ACT CRIF.

The chair (basic researcher) already mentioned was interested in joining the working group. The co-chair (clinician), caregiver representative and a patient representative showed interest during the virtual meeting and were sent an e-mail to confirm their participation in the working group. Their participation was confirmed via mail.

The first dedicated Teleconference is planned mid September 2020.

Step 3: Plan of activities with the EPI-Cluster working group

We plan to have 2-3 dedicated virtual meetings over the course of September-November 2020 to go deeper into the MULTI-ACT CRIF in order to advise them on governance and patient engagement and to get feedback on the usability of the model in the Epilepsy disease area. The stepwise approach is described more in details in the next section.

2.3 Action Plan

2.3.1 More detailed information about MULTI-ACT framework – September 2020

This process will be guided by the WP7 leaders using the informational fact sheets that are currently under development.

The MULTI-ACT CRIF aims to allow for effective cooperation and accountability of all relevant stakeholders in health research initiatives by providing tools and guidelines for the implementation of a governance model enabling stakeholder engagement in defining accountability (co-accountability).

The reason behind is that considering stakeholders’ perspectives across different dimensions and thus ensuring their return on engagement, can foster and increase the impact of health research.

2.3.2 Use of the MULTI-ACT CRIF– September/October 2020

The EPI-cluster being a recent initiative, the CRIF will be used ‘ex-ante’ to help to set the initiative:

- EPI-Cluster’s governance (defining stakeholders).
- Mission, Strategic priorities and agenda

The use of the CRIF will follow some of the steps as per the MULTI-ACT CRIF workflow (see Figure 1 below):

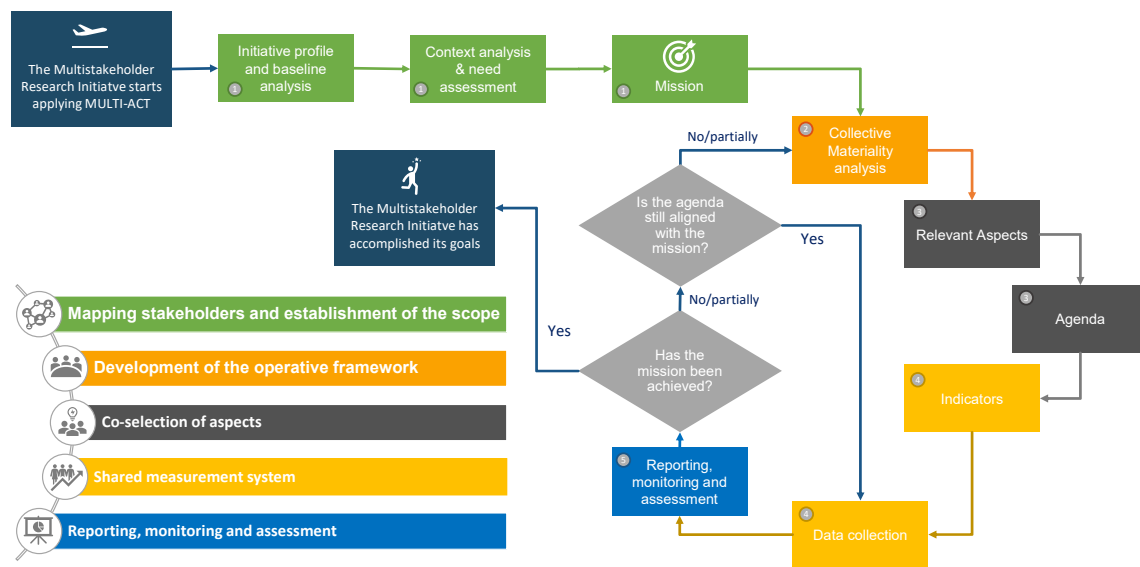


Figure 1. MULTI-ACT CRIF general workflow

EPI-Cluster governance

The first step will consist of applying some of the key features of the MULTI-ACT governance model. A baseline analysis of EPI-cluster will be performed (e.g., chair, co-chair, multi-stakeholder working groups) that will identify governance gaps and rooms for improvement as per the governance criteria. CRIF will provide a set of recommendations to address the governance gaps including, if applicable, how to ensure participatory governance, stakeholder engagement (including patient engagement), efficient management and coordination, leading to the definition of the accountability system.

EPI-Cluster’s stakeholders, strategic priorities and agenda

In order to set strategic priorities and to further refine EPI-Cluster’s mission and agenda, stakeholders expectations need to be assessed (ref. expected return on engagement). Therefore, suitable engagement approaches recommended by MULTI-ACT will be suggested to EPI-Cluster in order to explore demands of accountability. The EPI-Cluster will be invited to perform a materiality analysis. Upon completion, accountability indicators can then be used by the EPI-Cluster to assess performance and to demonstrate to which extent the EPI-Cluster produces impact in line with its mission.

2.3.3 Evaluation of the MULTI-ACT framework by EPI-cluster – November 2020

Following the analysis of EPI-Cluster’s actual governance, stakeholders and priorities, and MULTI-ACT’s recommendations to improve these, we will ask EPI-Cluster to evaluate the MULTI-ACT framework for their field of brain disease, epilepsy. We will ask them to assess the usability and applicability of the main components of MULTI-ACT:

- MULTI-ACT governance criteria/recommendations.
- MULTI-ACT recommendations for stakeholder engagement, with a focus on patient engagement.
- MULTI-ACT recommendations for setting priorities and agenda.

These aspects will be evaluated with the EPI-Cluster dedicated working group in order to get a concise feedback on the usability and applicability of the CRIF model (specifically governance, patient engagement guidelines) in the epilepsy field and will feed the exploitation plan.

The activities with the EPI-Cluster will be performed as per the Terms of Reference defined in D7.1. The action plan will constitute an annex to the Terms of Reference.

The action plan is summarized in Table 2 below with names of partners and individuals involved.

Table 2. Action Plan

Activity	Timeline/Deadline	MULTI-ACT Partners	Names
1) Baseline Analysis: completion of baseline analysis questionnaire in the MULTI-ACT toolbox.	EPI-Cluster working group meeting (1): 15 September	EBC to arrange meeting and support EPI-Cluster to complete a questionnaire EY: to produce results of baseline analysis from data submitted in the toolbox. To liaise with Intrasoft if needed EBC to share meeting material and minutes with all partners (invited to provide input as appropriate)	EBC : Elke De Witte, Françoise Van Hemelryck EY:Andrea Gavazzi Intrasoft: George Tsakirakis

<p>2) Presentation of baseline analysis key findings and recommendations</p> <p>+ recommendations on MULTI-ACT PE guidelines</p> <p>+ introduction to concepts of the materiality analysis</p> <p>(according to EPI-Cluster priorities)</p>	<p>EPI-Cluster working group meeting (2) (first half of October – date tbc)</p>	<p>EBC to arrange a meeting, share meeting material and minutes with all partners</p> <p>EY to share draft recommendations with all partners, prepare recommendations on PE with FISM and present recommendations to EPI-Cluster working group.</p> <p>(as per priorities)</p>	<p>EBC : Elke De Witte, Françoise Van Hemelryck</p> <p>EY:Andrea Gavazzi</p> <p>FISM: Deborah Bertorello</p> <p>UNITN: Michele Andreaus, Ericka Costa</p> <p>(observer or presenter capacity)</p>
<p>3) Engagement with EPI-Cluster working group members in order to refine stakeholders expectations and explore interests and demands of accountability</p> <p>(tentative according to interest and priorities of EPI-Cluster – alternatively as part of exploitation plan)</p>	<p>Second half of October/first half of November</p> <p>(tentative)</p>	<p>Academic team to suggest forms of engagement (e.g. interview, questionnaire) and prepare relevant material.</p> <p>EBC to coordinate engagement with EPI-Cluster working group members, share material and outcomes with all partners (invited to provide input as appropriate)</p>	<p>UNITN: Michele Andreaus, Ericka Costa</p> <p>TAU : Anna Kork</p> <p>UBU : Nicolás García-Torea, Carlos Larrinaga, Juliette Senn</p> <p>EBC: Elke De Witte, Françoise Van Hemelryck</p> <p>FISM : Bricchetto, Bertorello (PRD)</p>
<p>4) EPI-Cluster Materiality Analysis (MA)</p> <p>(tentative according to interest and priorities of EPI-Cluster – alternatively as part of exploitation plan)</p>	<p>First half of November</p> <p>(tentative)</p>	<p>If agreed by EPI-Cluster, EBC to send MA to working group and collect responses in liaison with EY and academic team</p> <p>EBC to share material and results with all partners invited to provide input as appropriate</p>	<p>EBC : Elke De Witte, Françoise Van Hemelryck</p> <p>EY: Andrea Gavazzi</p> <p>UNITN: Michele Andreaus, Ericka Costa</p> <p>UBU: Nicolás García-Torea, Carlos Larrinaga</p> <p>TAU: Anna Kork</p>

3 OPPORTUNITIES FOR FUTURE WORKING GROUPS

This process can serve as the basis for potential future collaborations with EBRA clusters. As a new round of EBRA clusters has just started, the same stepwise approach can be used to introduce the MULTI-ACT framework to the two new clusters: BRAINFOOD³, TRISOMY21⁴.



The overarching objective of the BRAINFOOD cluster is to ultimately positively impact on brain health by improving nutrition of European citizens based upon fundamental insights in the bidirectional links between brain health and nutrition. BRAINFOOD aims to:

- Stimulate the development of novel concepts that support design of foods/beverages for brain health.
- Provide new opportunities and incentives for scientists to bridge the gap in knowledge of how nutrition impacts on brain health.
- Stimulate the interest of funders (including industry) in supporting development of specific nutritions for target life stage groups (elderly, new-born, people at risk to develop mood (and other mental) disorders).
- Provide an exchange platform (knowledge and know-how) on how to address key questions and foster new collaborations based on the collective expertise of our group.
- Provide a knowledge base that can be used not only by the scientific community but also for all stakeholders that seek precise knowledge (separating fact from fiction) about the evidence base on how foods impact on brain health. These include the Food industry, Health care professionals, journalists, Public Health institutions, academia (seek funding for PhD students), policy makers and patient organizations. Social media will be exploited to develop targeted information that could reach all of the above mentioned categories, in addition to the general public (this could be achieved, e.g. by having an ad hoc twitter account that could be used as a platform to disseminate results and key messages on nutrition and health).



The primary objective the Trisomy 21 cluster is to establish a collaborative framework for the coordinated actions of Down syndrome research in Europe. Through EBRA cluster, we wish to expand existing European networks to promote coordination and collaboration among European scientists belonging to these research networks and share common

³ <https://www.ebra.eu/brainfood/>.

⁴ <https://www.ebra.eu/trisomy21/>.

projects with the goal of understanding disorders of the developing brain leading to intellectual disabilities such as DS.

The Trisomy 21 cluster aims at:

- Expand the network of DS researchers and initiate collaborative research on other intellectual disabilities and Alzheimer's disease.
- Harmonize and standardize protocols for DS (pre)clinical research, enabling better comparisons among studies.
- Co-ordinate efforts with research strategies across European and global brain initiatives.
- Enhance resource-sharing (experimental models, iPSc, clinical protocols, etc.).
- Develop a preclinical network and enhance clinical trial structures.
- Increase engagement in research of persons with Down syndrome and their representatives.
- Promote research on Down syndrome and Intellectual Disabilities by developing a funding initiative across agencies.
- Increase the visibility of the Down syndrome research community.

We are currently informing these EBRA clusters about the MULTI-ACT framework and assessing their interest to enter in the MULTI-ACT framework. If interested, we will guide them through the MULTI-ACT framework, implement it in their cluster and assess the relevance of MULTI-ACT for their particular field of brain research.

4 CONCLUSIONS

The set up of working groups to explore the applicability and utility of the MULTI-ACT framework on other brain disease areas than multiple sclerosis require a step-wise approach and takes time. The MULTI-ACT key aspects had to be explained for the cluster to grasp the potential value of the collaboration. As already mentioned, the time and resources required to incentivise research consortia to collaborate and use the MULTI-ACT tools should not be underestimated. User friendly material is required. Therefore the current development of user-friendly fact sheets on the key pillars of the CRIF will help to further collaborate with the working groups.

As the EBRA epilepsy research community is looking to expand and engage with relevant stakeholders including patient groups, they will be a good case to foster post-development action of the CRIF.

At the same time, the feedback from the different brain disease areas will be of instrumental value for the further development of the MULTI-ACT CRIF.

The next step will be to report on the specific engagement activities with the EPI-Cluster and potential further EBRA clusters.