



Deliverable D7.2

Report on the questionnaires, interviews and focus groups conducted

Report illustrating the engagement activities performed with the selected working group: the EBRA EPICLUSTER



This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Grant Agreement No 787570

PROJECT ACRONYM:	A Collective Research Impact Framework and multi-variate models to foster the true engagement of actors and stakeholders in Health Research and Innovation
CONTRACT NUMBER:	787570
DISSEMINATION LEVEL:	Public
NATURE OF DOCUMENT:	Report

TITLE OF DOCUMENT:	Report on the questionnaires, interviews and focus groups conducted
REFERENCE NUMBER:	D7.2
WORKPACKAGE CONTRIBUTING TO THE DOCUMENT:	WP7
VERSION:	0.4
EXPECTED DELIVERY DATE:	30/11/2020
DATE:	18/12/2020
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Short description of the Deliverable (as in the DoA): This deliverable reports about the questionnaires, interviews and/or focus groups conducted with BRAIN diseases' stakeholders in order to explore the interests and demands of accountability of each selected stakeholder.

[Note: Specifically, this deliverable reports on the engagement activities conducted with brain diseases' stakeholders in order to explore the suitability of the MULTI-ACT CRIF in the EBRA EPICLUSTER context]

REVISION HISTORY			
REVISION	DATE	COMMENTS	AUTHOR (NAME AND ORGANISATION)
V0.1	25/11/2020	First draft	University of Trento (Michele Andreaus, Ericka Costa & Carla Antonini). University of Burgos (Nicolás García-Torea, Carlos Larrinaga, Juliette Senn & Mercedes Luque). Tampere University (Anna-Aurora Kork).
V0.2	26/11/2020	Second draft	University of Trento (Michele Andreaus, Ericka Costa & Carla Antonini). University of Burgos (Nicolás García-Torea, Carlos Larrinaga, Juliette Senn & Mercedes Luque). Tampere University (Anna-Aurora Kork). EBC (Françoise Van Hemelryck)
V0.3	30/11/20	Review	Integration of comments and modifications from partners EHMA, ARSEP, DiA, EY, and TUNI
V0.4	18/12/2020	Editing and submission	FISM (Paola Zaratin, Deborah Bertorello, Valentina Tago)

FILENAME: MULTI-ACT_D7.2_20201218_ v0.4

STATEMENT OF ORIGINALITY:

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

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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 impact of health Research and Innovation (R&I) of multi-stakeholder initiatives.

Work Package 7 (WP7) aims to support the implementation of the CRIF in other brain diseases and multi-stakeholder initiatives beyond Multiple Sclerosis, which has been identified as the specific case study of Work Package 4 (WP4). The purpose of the overall Work Package 7 is to explore the applicability of the CRIF and, at the same time, receive valuable feedback for further applications of the framework.

The second deliverable of WP7 (D7.2) describes the engagement activities carried out with the working group established under the European Brain Research Area project (EBRA), namely the EPICLUSTER, founded in 2019. The EPICLUSTER emerged following a major stakeholder meeting in Brussels in 2018, called EpiXchange, that brought together the coordinators of multiple EU-funded epilepsy projects and stakeholders from industry and patient representative groups. The aim of the cluster is to establish a collaborative framework that would facilitate research priorities, partnerships and coordination of the epilepsy research in Europe.

As the EPICLUSTER was recently established, the *'ex-ante'* implementation of the CRIF was perceived as potentially facilitating its management and governance, especially in selecting the key stakeholders as well as engaging them. The CRIF was seen as potentially beneficial in defining the mission, strategic priorities and agenda of the EPICLUSTER. The working group expressed their interest in exploring the use of the MULTI-ACT tools and guidelines, in particular to build the EPICLUSTER's community and identify and engage relevant stakeholders such as industry and patient representative groups.

Following the results of the EPICLUSTER's baseline analysis and the MULTI-ACT consortium's recommendations, in the next phases of engagement, we will enquire the EPICLUSTER to evaluate the usability and applicability of the CRIF for epilepsy. In particular, we will explore the cluster interest in and feasibility to adopt the MULTI-ACT Governance Model; strengthen the set of stakeholders engaged by also applying the MULTI-ACT Patient Engagement Strategy; and perform a Materiality Analysis leading to a tailored Master Scorecard.

1 INTRODUCTION

The goal of WP7 is to extend the MULTI-ACT approach and methodology of the Collective Research Impact Framework (CRIF) to a case study on another brain disease than Multiple Sclerosis (MS). WP7 aims to explore the applicability of the CRIF in multi-stakeholder research initiatives, guiding the CRIF users and promoters to achieve the stated mission of the initiative, but also collecting feedback from experience to be used for the ongoing improvement of the framework.

The previous deliverables of WP7 reported on the identification and selection of the EBRA EPICLUSTER and the set up of the working group that would interact with MULTI-ACT according to terms of collaboration outlined in D7.3¹. This deliverable (D7.2) describes on the engagement activities carried out according to the action plan stated in D7.3. In this sense, the goal of D7.3 is to report on the advancement of the engagement action plan. Therefore, the initial title of the deliverable has been changed from 'Report on the questionnaires, interviews and focus groups conducted' to 'Report on engagement activities with the selected working group: the EBRA EPICLUSTER' to better reflect the current phase of collaboration and thus the content of the report.

1.1 Purpose of this document

The purpose of this report is to:

- Provide a recap of the action plan of the EPICLUSTER working group;
- Describe the engagement activities carried out so far;
- Explain the next steps of the collaboration with the EPICLUSTER (results will be reported in the self-sustainability plan in D7.4).

1.2 Structure of the document

Section 2 presents the engagement activities performed with the working group, while Section 3 describes the plans after the engagement process based on initial feedback received.

¹ www.multiact/deliverables

1.3 Glossary

Collective Research Impact Framework (CRIF) is a conceptual framework developed by MULTI-ACT enabling a new collective accountability approach to managing and assessment multi-stakeholder R&I initiatives.

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)².

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.

² Freeman, R. E. (1984). Strategic management: A stakeholder approach. Boston: Pitman.

2 ENGAGEMENT WITH THE EPICLUSTER

As explained in D7.3, the EPICLUSTER is a cluster under the EBRA coordinating action for the European epilepsy research community. It includes as its main professional and patient stakeholder organisations the European Alliance Epilepsy (EAE); the International Bureau for Epilepsy (IBE); and the International League against Epilepsy (ILAE). The EPICLUSTER was chosen as a relevant case for MULTI-ACT due to its strategic priorities related to stakeholder engagement, collaboration and impact assessment. Moreover, it is a multi-stakeholder and multi-disciplinary initiative; therefore, it was considered as a suitable cluster to complement the brain disease context of MULTI-ACT.

The mission of MULTI-ACT and its developed tools were briefly presented to the EPICLUSTER in a virtual meeting in June 2020. The EPICLUSTER was interested in collaborating with MULTI-ACT and in applying its framework, especially because, having been established only in 2019, the cluster is still building its multi-stakeholder community to advance collaboration, and requires engagement with stakeholders. Both elements are included as part of the EPICLUSTER's strategic priorities (see Figure 1). Both MULTI-ACT and the EPICLUSTER agreed that a collaboration was a timely opportunity.



Figure 1: EPICLUSTER strategic priorities

An EPICLUSTER working group (see Deliverable 7.3) was established to interact with MULTI-ACT. The criteria for setting up the working group was a minimum representation of three different stakeholder categories (including patients) and a maximum of four people in the group to ensure bi-monthly meetings. The first dedicated teleconference of the working group was held in September 2020. The collaboration acts as a reciprocal effort to get feedback on the usability of the MULTI-ACT framework in the Epilepsy disease research context.

2.1 Engagement activities performed

This report focuses on the first engagement activities carried out until the end of November 2020 according to the working group's action plan stated in D7.3 (activities 1 & 2).

1. **Baseline Analysis: completion of baseline analysis questionnaire in the MULTI-ACT toolbox.**
 - EPICLUSTER working group first meeting on 15 September 2020, organized by EBC.
 - EPICLUSTER completed the baseline analysis questionnaire in the MULTI-ACT toolbox.
 - Results of baseline analysis, provided by EY.
 - Sharing the information with all partners.
2. **Presentation of baseline analysis key findings and recommendations, Patient Engagement (PE) guidelines + introduction to concepts of the Materiality Analysis (according to EPICLUSTER priorities).**
 - EPICLUSTER working group second meeting on 21st October 2020, organized by EBC
 - Draft recommendations for the EPICLUSTER, developed by the MULTI-ACT consortium

During the first **EPICLUSTER working group meeting** (15 September 2020) three partners from the MULTI-ACT consortium were present (EBC, FISM, Intrasoft). The purpose of the first meeting was to give more detailed information about the MULTI-ACT framework. After the EPICLUSTER working group meeting, the meeting material and the minutes were distributed and shared with all MULTI-ACT partners, asking for comments and feedback.

Before starting the process aimed at implementing the MULTI-ACT CRIF, the EPICLUSTER was requested to submit a baseline analysis in order to measure their initial level of coherence with the MULTI-ACT Governance Model. The MULTI-ACT Governance Model is one of the fundamental elements of the MULTI-ACT CRIF and it is composed of 5 criteria and 19 sub-criteria, detailed in 41 recommendations to be followed by the appliers of the model.

According to the original action plan, EBC arranged the second **EPICLUSTER working group meeting** on 21 October 2020 to discuss the application of the MULTI-ACT tools and to seek the interest of the cluster in performing the Materiality Analysis to tailor the Master Scorecard. The objective of the engagement activities was to share information, discuss the results of the baseline analysis submitted

by the EPICLUSTER and to present initial recommendations and improvements. Moreover, the purpose of these discussions was to incentivize the EPICLUSTER to use the MULTI-ACT CRIF in the long term by promoting the Materiality Analysis and impact assessment model.

Four participants from the EPICLUSTER and MULTI-ACT partners (EBC, EY, FISM, UNITN) attended the second working group meeting, which was recorded, as agreed with the EPICLUSTER. The programme consisted of the presentations of the MULTI-ACT tools to discuss their implementation:

- EPICLUSTER governance: baseline analysis results and MULTI-ACT recommendations – focus on ‘participatory governance’ and ‘stakeholder engagement’
- MULTI-ACT Patient Engagement Guidelines – tailored priority recommendations to the EPICLUSTER
- Introduction to the Materiality Analysis and impact assessment model (Master Scorecard)

First, the baseline analysis is a tool to assess the applicability of the MULTI-ACT framework in terms of the coherence of the EPICLUSTER initiative with the five criteria of the Governance Model (Mission and agenda, Participatory governance, Stakeholder engagement, Effective management, Co-accountability assessment). For each criterion, there are 4 evaluation levels, from fully coherent to lacking. The score of every criterion ranges from 0 to 20. Thus, the overall maximum score is 100. The EPICLUSTER’s baseline analysis was submitted on the MULTI-ACT toolbox and the results of the analysis were provided to the EPICLUSTER by the beginning of October 2020.

The results of the EPICLUSTER initiative baseline analysis were as depicted in Figure 2:

	SCORE	COMMENT
Criterion 1 - Mission and agenda	17,2	Fully coherent: the initiative is fully coherent with MULTI-ACT recommendations.
Criterion 2 - Participatory governance	3,3	Lacking: the initiative is not in line with MULTI-ACT recommendations.
Criterion 3 - Stakeholder engagement	4,3	Lacking: the initiative is not in line with MULTI-ACT recommendations.
Criterion 4 - Effective management	12,4	Coherent: the initiative is overall coherent with MULTI-ACT recommendations.
Criterion 5 - Co-accountability assessment	11,1	Coherent: the initiative is overall coherent with MULTI-ACT recommendations.
Total	48,3	

Figure 2: Results of the EPICLUSTER initiative baseline analysis

The baseline analysis questionnaire drew the attention of the EPICLUSTER to possible areas for improvement by explaining the gaps in meeting the participatory governance criteria and in engaging their stakeholders. Table 1 presents the main drivers to strengthen the coherence of the EPICLUSTER to the MULTI-ACT model and provide practical tools to support it.

Criteria	Strengths	Suggestions for areas of improvement	Relevant MULTI-ACT recommendations
1. Mission and agenda.	<p>The initiative has defined a mission shared with relevant stakeholders and a related agenda setting short, mid and long-term objectives, involving some of the relevant stakeholders.</p> <p>The initiative has identified intended beneficiaries.</p>	<p>There are not significant weaknesses for this criterion, however it could be strengthened the set of stakeholder categories involved.</p>	<p>1.2.1) Define a shared mission and a common agenda involving relevant stakeholders, thus tackling the intended issue with a unifying long-term vision and a clearly defined set of objectives and actions necessary to pursue the mission.</p>
2. Participatory governance.	<p>The initiative has defined a governance structure.</p>	<p>The initiative should implement a participatory governance guaranteeing an inclusive and equitable governance model, which allows the involvement of all interested parties through a co-design approach-</p> <p>The initiative should guarantee equity and mechanisms to avoid self-interest.</p>	<p>2.2.1) Prepare the initiative to implement co-creation processes by framing/reframing the composition of the initiative according to the new multi-stakeholder nature.</p> <p>2.3.1) Define a clear and agile backbone structure and define clear roles and responsibilities of all involved stakeholders, based on the mission and the agenda.</p> <p>2.4.1) Guarantee the support to and the meaningful participation of disadvantaged stakeholders (for financial, communication, language, cultural, age or mobility reasons) through appropriate mechanisms to give voice</p>

Criteria	Strengths	Suggestions for areas of improvement	Relevant MULTI-ACT recommendations
			to each of them and avoid marginalization.
3. Stakeholder engagement.	<p>The initiative has identified and mapped the stakeholders that might be influenced by or might influence the initiative, with a different level of engagement:</p> <p>Academics/researchers: basic and translational science</p> <p>Clinicians/caregivers</p> <p>Infrastructure/data representatives</p> <p>Patient/patient representatives</p> <p>Industry representatives</p> <p>The initiative performs a consultation process in order to understand the needs, expectations and challenges of the stakeholders involved in the initiative.</p>	<p>The initiative should define and approve a methodology to engage stakeholders.</p> <p>The initiative should define and implement a Patient Engagement Strategy, as patients are foreseen as a key stakeholder in the Health Research & Innovation process</p>	<p>3.1.1) Define a methodology to engage stakeholders, create and maintain an open dialogue with them and manage the engagement processes of participants throughout the entire design and implementation of the health research initiative.</p> <p>Within this context, specific attention should be addressed to the Patient Engagement Strategy</p>
4. Effective management.	<p>The initiative features an action plan in order to achieve its objective.</p> <p>In addition, it has a cost management process in place and maintains accountability over</p>	<p>To enhance the overall coherence to the model, further aspects should be defined in order to achieve clear and transparent processes and timeline:</p>	<p>4.2.1) Identify and negotiate with stakeholders a consistent program/project timeline and schedule, in order to assure that the progress is soundly implemented.</p>

Criteria	Strengths	Suggestions for areas of improvement	Relevant MULTI-ACT recommendations
	<p>time keeping track of expenses and revenues.</p> <p>Moreover, its internal team has solid skills, consistent with the activities.</p>	<p>Processes to ensure the balance between management and opportunities for engaging a wide range of participants.</p> <p>Contingency plan/risk management approach.</p>	<p>4.2.3) Guarantee a mechanism of review and evaluation, which allows to learn and improve the collaboration among stakeholders.</p> <p>4.3.1) Maintain flexibility, adjusting the goals and implementation actions to the changing reality and needs.</p>
5. Co-accountability assessment.	<p>The initiative has a monitoring system for the implementation of the actions of the initiative and the performance of the initiative itself.</p> <p>It also publishes a progress report and communicates with stakeholders about the progress of the initiative.</p> <p>Finally, there is a review process in place to improve the initiative's performance and practices and a process to gather feedback from external stakeholders and the public.</p>	<p>To enhance the overall coherence to the model, further aspects should be defined in order to achieve a shared and effective management system:</p> <p>Define an assessment system that allow to measuring initiative's "long-term impact" (ex-post).</p>	<p>5.1.2) Select appropriate indicators from the list of relevant aspects according to different impact dimensions and stakeholder perspectives in order to comprehensively assess the impact of health research.</p> <p>5.1.3) Ensure that the list of selected indicators consider the impact on patients.</p> <p>5.1.4) Establish a shared assessment system consisting of a set of indicators consistently tracked over time and a shared data collection process.</p>

Table 1: Recommendations based on the EPICLUSTER baseline analysis

Second, the presentation of the Patient Engagement Guidelines included the **MULTI-ACT Patient Engagement Roadmap**. It is based on four actions: Action 1 - Establishment of an Engagement Coordination Team; Action 2 - Selection of research steps where the patient engagement is instrumental to meet the mission; Action 3 – Design and implement a Patient Engagement Plan for each identified research priority and step; and Action 4 – Selection of the indicators to be used to measure the success and effectiveness of this engagement. Concrete examples of these actions were provided to the EPICLUSTER (see Figures 3-6).



Action 1: “Establishment of an Engagement Coordination Team”

EXAMPLE:

The Promoters (Governance Board) of EPICLUSTER establish an **Engagement Coordination Team** in charge of designing and implementing a Patient Engagement Plan in the EPICLUSTER activities.

→ **EPI-Cluster subgroup n.5: Engagement of people with Epilepsy Coordination Team**

The Team is a multi-stakeholder body with heterogeneous backgrounds and relevant skills such as **empathy, active listening, communication skills, and expertise in engagement strategies & methods (online and offline)**.

The Team is provided with a **training** to empower the ability of patients and stakeholders to **co-created and collaborate**, and **to ensure the representativeness** of the patients' community.

Figure 3: Action 1 - Establishment of an Engagement Coordination Team



Action 2: “Selection of research steps where patient engagement is instrumental to meet the Mission”

EXAMPLE:

Selected EPICLUSTER’s Strategic Priority: Increase and integrate the engagement of persons with epilepsy and their representatives in the design and execution of research activities.

Selected R&I step: Breaking down boundaries (e.g. policy, facilities, infrastructures, etc.)

Selected EPICLUSTER’s Research Priority topics:

Priority topic n.4: Digitalisation and personal monitoring for independent living in epilepsy

Selected R&I step: Execution (e.g. development and monitoring of research programmes/projects)

Priority topic n.6: Funding initiatives and integration to society, industry and regulatory space

Selected R&I step: Execution (e.g. development and monitoring of research programmes/projects)

Expected outcome: Capture and integrate the needs of people with Epilepsy in the activities of EPICLUSTER, engage them in the **strategy and research priorities** toward meeting the mission.

Figure 4: Action 2 - Selection of research steps where the patient engagement is instrumental to meet the mission



Action 3: “Design and implement a Patient Engagement Plan for each identified research priority and step”

Example on EPICLUSTER Research priority topic: Digitalisation and personal monitoring for independent living in epilepsy

Selected R&I step: Execution

Selected Patient Engagement activities:

- Patients are engaged in the development and monitoring of Epilepsy research at **Program Level** (e.g. release of call for proposals targeted Epilepsy and personalized medicine, selection of projects to be funded, monitoring and evaluation of funded projects, collaboration with Eranet-NEURON, etc.)
- Patients are engaged in the development and monitoring of research at **Project Development** (e.g. collaborating for ICT device development, in the enrolment to increase participation and decrease drop-down, to increase compliance with protocols and facilitate data collection, for writing and review of papers, etc.)

Figure 5: Action 3 – Design and implement a Patient Engagement Plan for each identified research priority and step

 **Action 4: “Selection of the indicators to be used to measure the success and effectiveness of this engagement”**

The ECT (sub-group n.5) defines metrics to monitor and evaluate the Patient Engagement Plan during and after its implementation.

Examples of metrics included in the Plan:

- ❖ *The analysis of expectation and satisfaction of patients for/with their engagement in EPICLUSTER, including identification of benefits and critical issues (pros and cons).*
- ❖ *The number of changes in the EPICLUSTER activities and processes (e.g. policies, composition of boards, objectives and priorities, strategic plan, evaluation of results, dissemination actions, etc.) according to the review made by patients*

Figure 6: Action 4 – Selection of the indicators to be used to measure the success and effectiveness of this engagement

Finally, the use of the **Materiality Analysis and impact assessment model (Master Scorecard)** was only shortly introduced to the EPICLUSTER to raise their interest in performing the Materiality Analysis and impact assessment on the later phases of the implementation process. The presentation connected the Baseline Analysis, with the selection of aspects (priority topics), the prioritization of aspects in the Materiality Analysis, and the identification of indicators from the Master Scorecard.

2.2 Feedback received

The EPICLUSTER working group gave their initial feedback on the MULTI-ACT model. The cluster was interested in the key aspects of the CRIF. The Patient Engagement Guidelines were seen as particularly valuable for approaching the stakeholder community as well as the governance criteria in defining the key stakeholder groups, the priorities and agenda of the cluster. However, it was also observed that an effective use of the MULTI-ACT model would require more user-friendly material. To this regard the working group was informed that the Digital Toolbox aims indeed to mitigate this aspect and to support the adoption of the model with specific functionalities that will direct the users (e.g. digital

functionality to design Patient Engagement Plan with suggestions provided in the form of drop-down menu).

One of the main challenges for the EPICLUSTER concerned essential questions, such as where to begin the implementation and how to do it. Additionally, many stakeholders would like to get involved in the multi-stakeholder exercise, but to do so in the most time-efficient and effective manner, avoiding the proliferation of meetings, for example. The working group considered the criteria of the Governance Model as an example of best practices but saw it mostly valid for large funded research initiatives. They suggested applying a 'lighter' version of the Governance Model.

The terminology used in stakeholder categories and the appropriate number of expert patients was perceived as too complex. The working group wondered, for instance, what might be a good balance for the representation of stakeholder categories in governance.

To respond to the points raised by the working group, a recommendations report with follow-up discussion to the 21st October meeting will be shared with EPICLUSTER in early January 2021. The discussion will provide MULTI-ACT insights on how to improve and customize the model, in particular for its exploitation phase.

3 FOSTERING THE POST-IMPLEMENTATION OF THE CRIF

Engagement activities with the EPICLUSTER were a timely opportunity. As the cluster is a newly established initiative, the implementation of the CRIF can facilitate ‘*ex-ante*’ the EPICLUSTER management and governance by selecting the key stakeholders as well as engaging with them. At that time, the CRIF was seen as beneficial in defining the mission, strategic priorities and agenda of the EPICLUSTER. The working group expressed its interest in exploring the use of MULTI-ACT tools and guidelines, in particular, to build the EPICLUSTER community and identify and engage with relevant stakeholders from industry and patient representative groups.

To continue the collaboration with the EPICLUSTER, the third meeting with the representatives of the cluster has been scheduled on 1 December 2020. The leadership meeting and its engagement activities will focus on the promotion of the adoption and implementation of the CRIF, and, in particular, in raising their interest to perform the Materiality Analysis leading to a tailored Master Scorecard and thus full adoption of the model that would indeed maximize its effectiveness and impact. The engagement with the EPICLUSTER working group members is an opportunity to explore their demands of accountabilities in order to refine stakeholder expectations (tentative according to interest and priorities of EPICLUSTER –alternatively as part of exploitation plan).

Following the results of the EPICLUSTER’s baseline analysis and the MULTI-ACT Consortium recommendations, in the next phases of the engagement, we will invite the EPICLUSTER to evaluate the usability and applicability of the CRIF for their field of brain disease, epilepsy. As their research community is looking to expand and engage with patients, their insights are valuable to foster the post-development action of the CRIF. The engagement activities will be performed as part of the exploitation activities and the results will be reported in D7.4 (plan for self-sustainability). The list of questions to be addressed are provided below.

3.1 Questions to be explored

As mentioned above, the next steps of the engagement with the EPICLUSTER will be described in the self-sustainability plan (D7.4). The plan will outline proposed actions to pursue the full implementation of the CRIF on the EPICLUSTER initiative including the Materiality Analysis and Master Scorecard. Moreover, it will include a plan for how to promote the CRIF further in the field of epilepsy and in other EBRA clusters:

- What is the added value expected by the EPICLUSTER in implementing the CRIF?
- The lighter Governance Model for smaller initiatives, will their implementation follow the CRIF governance flow? How suitable is it for the EPICLUSTER?
- How does the EPICLUSTER aim to measure its impact and define the demands of accountabilities of their stakeholders (tailored Master Scorecard could be useful)?
- How to strengthen the set of stakeholders involved in the definition of EPICLUSTER shared mission and common agenda?
- How can the EPICLUSTER governance structure be more participatory and guarantee equity and mechanisms to avoid self-interest?
- How can the EPICLUSTER define and implement a Patient Engagement Strategy to foster the Health Research & Innovation process?
- How can the EPICLUSTER implement a mechanism of review and evaluation, to learn and improve the collaboration among stakeholders?

4 CONCLUSIONS

The EPICLUSTER was recently established and, therefore, the *'ex-ante'* implementation of the CRIF was perceived as potentially facilitating the EPICLUSTER management and governance in selecting the key stakeholders as well as engaging them. The CRIF was seen as beneficial in helping to define the mission, strategic priorities and agenda of the EPICLUSTER. The working group expressed the interest in exploring the use of MULTI-ACT tools and guidelines, in particular to build the EPICLUSTER community and identify and engage with relevant stakeholders from industry and patient representative groups.

Following the results of the EPICLUSTER's baseline analysis and MULTI-ACT Consortium recommendations, in the next phases of engagement, we will invite the EPICLUSTER to evaluate the usability and applicability of the CRIF for their field of brain disease, epilepsy. In particular, the engagement will explore the cluster interest in using the most relevant parts of the CRIF at their stage of development, including strengthening the set of stakeholders engaged and performing a Materiality Analysis leading to a tailored Master Scorecard.