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EBV-MS: Targeting Epstein-Barr Virus infection for treatment and prevention of multiple sclerosis

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Stakeholder Engagement Plan

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1. Glossary and Abbreviations

Co-Create: Stakeholders are engaged since the very beginning of the R&I processes with a decision making role, e.g. patients are asked to define a common/shared agenda and co-create research governance and sustainability.

Consult: Stakeholders are asked to provide feedback for decision-makers on their analysis and/or decisions. Stakeholders participate by being asked for advice and opinion, by expressing their views and having discussions. It does not usually include any share in decision-making.

CRIF (Collective Research Impact Framework): conceptual framework that MULTI-ACT developed to enable a new collective accountability approach to multi-stakeholder R&I initiatives in the field of brain diseases (Figure 1).

Digital ToolBox: a web-based tool with guidance functions towards participatory governance and stakeholder co-responsibility

EBV: Epstein Barr Virus

ECT: Engagement Coordination Team

Efficiency: refers the economic sustainability and the financial resources needed for pursuing the given mission

Efficacy/Mission: refers to the capacity of a given initiative or programme to achieve its mission, whereas the term mission entails all the strategic priorities settled via the stakeholder engagement process.

Excellence concerns the quality of research data and findings in health research. Only excellent research will have a positive impact on people and society.

Inform: Stakeholders are informed about research priorities, activities, outcomes and impact.

Involve: Stakeholders partnering in research design and development as co-researchers. Stakeholders are engaged in research project activities with active role by providing their perspective and data on a specific topic. However, the project is designed and initiated by the professionals and patients are not engaged in the co-creation of the project as direct decision-makers.

MS: Multiple Sclerosis

MULTI-ACT Master Scorecard: is a collection of 125 indicators which you can use to assess and monitor the impact of the research your initiative conducts. Through the Materiality Analysis, you and your stakeholders will create a customised scorecard.

PRD (Patient Reported Dimension): concerns patients as key stakeholder, whose needs, information and perspectives must be understood and incorporated into the process of health research impact evaluation. Thus, it works as an overarching dimension in which the other four dimensions should be rooted

PwMS: People with MS

RRI (Responsible Research and Innovation): is a term used by the European Union's Framework Programmes to describe scientific research and technological development processes that take into account effects and potential impacts on the environment and society

R&I: Research & Innovation

Social: considers the evaluation of direct and indirect effects of health research to the whole society, beyond the mission related dimension that for health R&I would typically focus on patient needs.

2. Executive Summary

This document is the Deliverable 1.4 of Work Package 1 (D5) for the Stakeholder engagement plan of the project EBV-MS: Targeting Epstein-Barr Virus infection for treatment and prevention of multiple sclerosis). This project has received funding from the European Union's Horizon Europe Research and Innovation Actions under grant no. 101136991 (EBV-MS).

The primary objective of the EBV-MS project is to understand the factors contributing to the development of multiple sclerosis (MS) in a small percentage of the individuals infected with Epstein-Barr virus (EBV) and define the underlying mechanisms of this process. Additionally, EBV-MS aims to investigate whether targeting the EBV infection with antiviral treatments can improve the disease trajectory or halt disease progression.

This document describes the stakeholder engagement strategy and activities applied to EBV-MS sub-projects being the backbone of the whole project and an essential part of its successful accomplishment. With Responsible Research Innovation (RRI) at its core, the EBV-MS projects will apply MULTI ACT model[1] to ensure co-responsibility of internal (consortium) and key stakeholders towards the achievement of the EBV-MS agenda (WPs objectives).

3. Introduction

If successful, the EBV-MS project will demonstrate how treating EBV infection could be integrated into MS prevention and treatment in different health systems to improve the quality of life for People with MS (PwMS) and their caregivers and lower the societal burden of disease. Importantly, this will also provide the framework for identifying individuals that would benefit the most from primary preventive strategies, in turn being an example applicable to other non-communicable infectious diseases.

The stakeholder engagement here proposed will ensure multidisciplinary, responsible and inclusive co-creation. EBV-MS will use a management model developed by Italian Multiple Sclerosis Society Foundation (FISM), the RRI "MULTI-ACT model" that aims to allow an efficient integration of multi-stakeholder perspectives into the EBV-MS project. MULTI-ACT stems from the acknowledgement that stakeholder engagement in health research and innovation is an important pathway to achieving impact[2] (Figure 1).

[1] Zaratin, P., Bertorello, D., Guglielmino, R. et al. The MULTI-ACT model: the path forward for participatory and anticipatory governance in health research and care. Health Res Policy Sys 20, 22 (2022). https://doi.org/10.1186/s12961-022-00825-2

[2] Kok M, Gyapong J, Wolffers I, Ofori-Adjei D, Ruitenberg J. Which health research gets used and why? An empirical analysis of 30 cases. Health Res Policy Syst. 2016;14:36. https://doi.org/10.1186/s12961-016-0107-2.

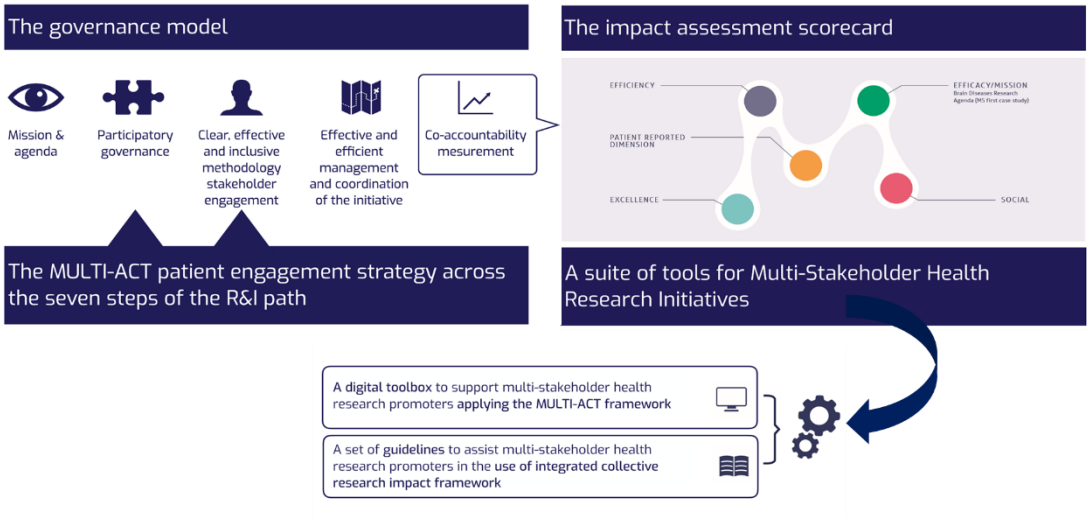

Figure 1. The MULTI-ACT Collective Research Impact Framework (CRIF). The mission-related dimension is one explicit driver for co-accountability approach developed by MULTI-ACT project. Conventional metrics related to the excellence dimension will be integrated with new measures related to the economic and financial dimension (efficiency) and to the social dimension that relates to achieving mission success (efficacy; one explicit driver of the MULTI-ACT co-accountability approach). The patient-reported dimension will be applied in a transversal modality throughout the dimensions of MULTI-ACT model..

With RRI at its core, a fundamental process that EBV-MS project should define relates to the engagement of stakeholders that will cooperate towards the achievement of the EBV-MS project agenda (WPs objectives). Considering this, the EBV-MS project aims at giving a step further in promoting research co-accountability towards its stakeholders. This document describes the different phases of the stakeholder engagement strategy applied to the EBV-MS consortium, which includes the following methodological steps: stakeholder mapping; levels of stakeholder engagement; Engagement Coordination Team (ECT) participatory governance; materiality analysis of EBV-MS shared agenda (WPs objectives); stakeholder engagement plan; feedback and improvement: co-accountability measurement.

4. Stakeholder engagement methodology

The stakeholder engagement plan is designed to shape and conduct the active involvement and participation of stakeholders in the implementation of a project. This plan considers the "Dissemination and Communication Plan" (D8.4 deliverable from WP8) document, a document that outlines the Communication and Dissemination Plan devised for the EBV-MS project, with reference on tools, phases, target groups of the action, timeline, format, and activities focused on outreaching external stakeholders. The methodology described below applies to MULTI-ACT model of RRI co-creation engagement and focused on internal (consortium) and key stakeholders.

4.1. Stakeholders mapping

EBV-MS convenes a unique collaboration of experts in the fields of neurology, virology, molecular biology, human population genetics, artificial intelligence, mathematical modelling, RRI, neuro-immunology, and patients' and user's associations. The consortium's work will be constantly subjected to input from other stakeholders to broaden the range of people involved and the viewpoints so that this important goal can be built in a shared way. The

design of an impact-driven stakeholder engagement strategy requires an accurate identification and analysis of the involved stakeholders. To this purpose, an in-depth mapping was carried out with consortium partners via a survey to identify the relevant stakeholders, the level of engagement and the expected impact.

When it comes to stakeholder classification, in the context of EBV-MS, the following general categories emerged from the questionnaire (Table 1):

INTERNAL STAKEHOLDERS
THE GROUPS AND/ OR INDIVIDUALS THAT ARE ALREADY PART OF THE PROJECT (COORDINATOR AND PARTNERS)
• WP1 leader - Project Management, MULTI-ACT Stakeholder engagement management & program manager • WP2 leader - Clinical Trials • WP4 leader - Immunological and Molecular Mechanisms and Biomarkers • WP5 leader - EBV and Host Genetics: EBV-VGWAS • WP6 leader - Prediction and Prevention • WP7 leader - Data Management • WP8 leader - Communication, Dissemination and Exploitation
KEY STAKEHOLDERS
REPRESENT A SUBSET OF ALL THE EXTERNAL STAKEHOLDERS THAT ARE EITHER HIGHLY IMPACTED BY THE PROJECT OR SPECIFICALLY INTERESTED IN THE ACCOMPLISHMENT OF ITS OBJECTIVES AND FOR THIS REASON DECIDE TO BE ACCOUNTABLE OF WPS ACTIVITIES
• Scientific Advisory Board members • EU research consortium on MS and EBV: BEHIND-MS consortium or new consortiums in the future • People with MS and their organizations (engaged by European MS Platform) • Citizens (engaged by European Citizens Association) • Gilead Sciences representative • Pharma Industry representatives (engaged by European Federation of Pharmaceutical Industries Associations)
External stakeholders
INDIVIDUALS OR GROUPS THAT ARE OUTSIDE THE PROJECT'S ENVIRONMENT. THEY HAVE SOME INTEREST IN THE PROJECT'S AIMS AND MIGHT INFLUENCE TO DIFFERENT EXTENT ITS EXECUTION AND THE ACCOMPLISHMENT OF ITS EXPECTED RESULTS. THE EXTERNAL STAKEHOLDERS THAT EMERGED FROM THE QUESTIONNAIRE:
• Advocacy groups: EPF (European Patients Forum) and EDF (European Disability Forum), EBC (European Brain Council), European Federation of Neurological Associations (EFNA) • Public health agencies representatives and health care providers: Centre for Disease and Control (CDC), European Centre for Disease and Control (ECDC), World Health Organization (WHO), Food and Drug Administration (FDA), European Medicines Agency (EMA) • European Academy of Neurology (EAN) • ECTRIMS/ACTRIMS • European Commission

Table 1: EBV-MS projects Internal, Key and External Stakeholders

4.2. Levels of stakeholder engagement

For the EBV MS project the main strategic objective of stakeholder engagement is to maximize the impact of the research by satisfying the expectations of the consortium members and of the other stakeholders. Another objective is to create consensus around the project necessary for its adoption by all the other stakeholders involved, both key and external ones. Considering this, for each group of stakeholders identified there will be different levels of engagement, as detailed below (Figure. 2):

- **Inform** is a one-way communication flow aimed at providing stakeholders with the right level of unbiased information about what is happening along the project's development or in the relevant scientific and technological field.
- **Consult** is first level of two-way communication exchange (interaction), done to obtain stakeholders' feedback on analysis, options and decisions.
- **Involve** is the second-level of two-way communication exchange, which differs from "consult" in its intensity, timing and depth. Involving stakeholders means working directly with them.
- **Co-create** is the third level of two-way interaction and the most intense. It will be an iterative process for the purposes of co-creating a shared WPs agenda and identifying aspects of interests and expected impact(s) by each stakeholder.

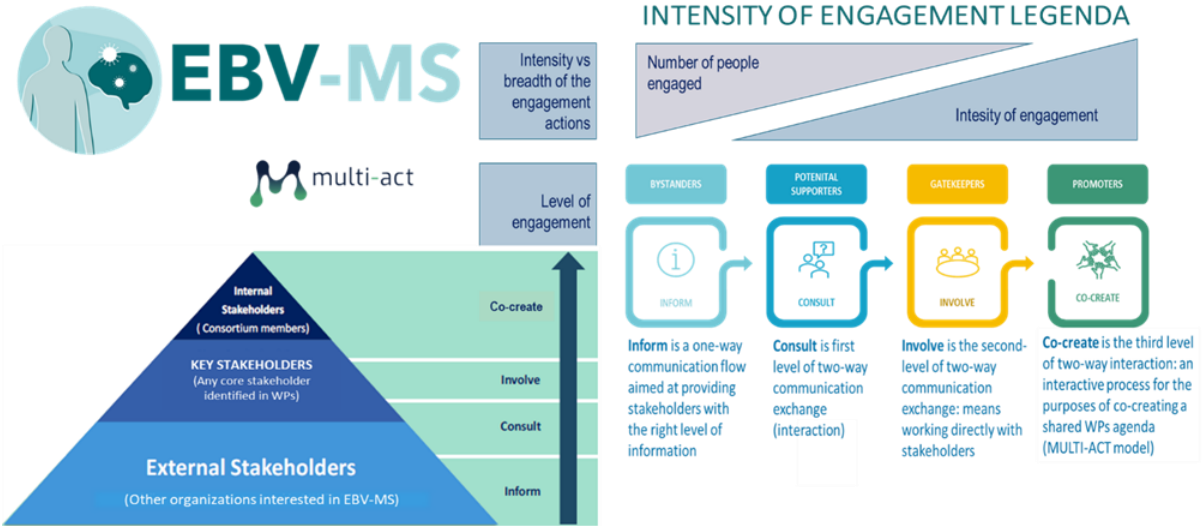

Figure 2. Stakeholders' classification and level of engagement

Internal and key stakeholders will be engaged by applying the MULTI-ACT co-create model, while the external stakeholders will be informed, consulted and involved using the main engagement channels reported in the D8.4 dissemination plan deliverable (Table1).

Stakholder	INFORM	CONSULT	INVOLVE
General public	website, social media		
People with MS, caregivers, Community Advisory Board (expert patients)	website social media newsletter EMSP conference	Online discussion w/ researchers Y4	CAB consultation, social campaign roundtable, policy brief event, advocacy days, development of social campaign
MS patient organisations, patient representatives, MSIF, MS advocates and groups	EMSP conference newsletter social media	Online discussion w/ researchers Y4 EMSP membership communication network (MCN) online meeting (joint with BEHIND-MS consortium) EMSP Young people's network (YPN) online meeting (joint with BEHIND-MS consortium)	Social campaign roundtable, policy brief event, advocacy days, development of social campaign
Scientists and researchers: ACTRIMS, ECTRIMS, academic institutions, ECF (European Charcot Foundation), American Academy of Neurology (AAN), European Brain Council (EBC), Genetics Society of America, EAN European Academy of Neurology, European Human Genetics Society, American Society of Human Genetics (ASHG), The Society of Molecular Biology and Evolution (SMBE), CSHL Biology of Genomes, GA4HG plenary meeting, ELIXIR, other universities (from network of consortium partners)	ECTRIMS EMSP booth Y4&5 Networking events (UiB?) BEHIND-MS consortium	Online discussion w/ researchers Y4	Social campaign roundtable, policy brief event, advocacy days
Healthcare professionals: EANN European Association of Neuroscience Nurses and MS Nurse Pro, EFNA (The European Federation of Neurological Associations), EAN, ECF, neurologists tied to member organisations and		Online discussion w/ researchers Y4	Social campaign roundtable, policy brief event, advocacy days
Advocacy groups: EPF (European Patients Forum) and EDF (European Disability Forum), EBC, EFNA		Online discussion w/ researchers Y4	Social campaign roundtable, policy brief event, advocacy days
Pharmaceutical industries and EFPIA (The European Federation of Pharmaceutical Industries and Associations EFPIA)		Online discussion w/ researchers Y4	Social campaign roundtable, policy brief event
Public health officials CDC, ECDC, WHO, FDA, EMA			Social campaign roundtable, policy brief event, advocacy days
Other similar projects	BEHIND-MS, Pathways to cures for MS		
Research funders (Horizon Europe, Gilead Sciences, others)			

Table 2: External stakeholders: level of engagement and related channels

4.3. ECT-Participatory Governance

The MULTI-ACT Governance Model aims to meet the different (and sometimes competing) needs of all the stakeholders involved in the EBV-MS projects, involving all interested stakeholders that want to be co-responsible of the WPs activities where their engagement will increase the impact of research. In line with above governance model, the EBV-MS consortium has created an Engagement Coordination Team (ECT). The ECT is a neutral body responsible for the management and monitoring of stakeholder engagement plans. Taking into consideration the result of the stakeholder mapping survey, the consortium will invite the stakeholders described in the Figure 2 below to act as members of the EBV-MS ECT:

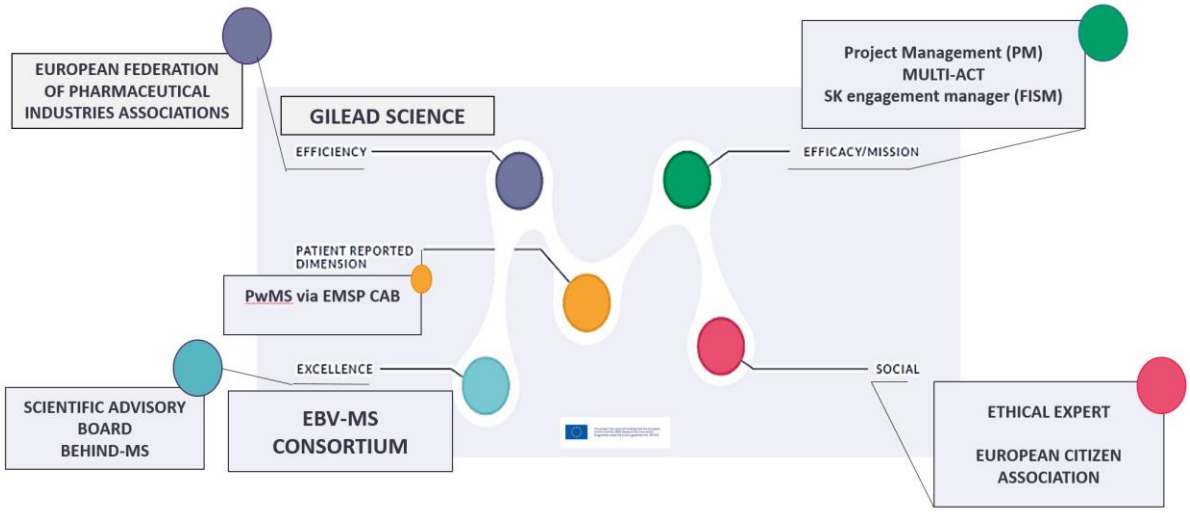

Figure 2: MULTI-ACT ECT: Internal and Key Stakeholders of the Engagement Coordination Team (ECT).

Each member of the ECT will ensure that the perspective of their stakeholder categories will be properly represented into the co-creation MULTI-ACT process in order to be accountable for the following dimensions of research impact:

- **the mission/efficacy dimension** will be entrusted by WP1 ECT through project management and coordination of stakeholder engagement activities;
- **the excellence dimension** will be entrusted by researchers and healthcare professionals of the consortium via WPs leaders (WP1, WP2, WP3, WP4, WP5 and WP6 leaders) that will also consult the Scientific Advisory Board and Behind-MS consortium;
- **the patient reported dimension** will be entrusted by EMSP through MULTI-ACT-CAB model that will be in charge to engage a representative people living with the disease community;
- **the social dimension** will be entrusted through the European Citizens Association representative and the ethical consortium manager.
- **The Efficiency dimension** will be entrusted through Gilead Science representative that will be in charge to consult European Federation of Pharmaceutical Industries Associations (EFPIA) and thus other Pharmaceutical Industries (e.g. Novartis, Roche, Sanofi, Merck, Moderna, ATARA Biotherapeutics).

4.4 ECT-Materiality analysis: EBV-MS expected outcomes and impacts

Another fundamental step, according to the MULTI ACT model, is to define the EBV-MS activities (shared agenda) towards which internal and key stakeholders (ECT members) undertake to be co-responsible towards the expected impact. Table 3 provides a list of the expected outcomes and impacts included in the grant agreement (page 26) that will be the focus of the materiality analysis and the related ECT aspects of co-responsibilities.

Table 3: Expected outcomes and impacts of EBV-MS project and ECT co-responsibilities.

OUTCOMES	IMPACTS	ECT CO-RESPONSABILITIES
The EBV-MS project mission achieved	**EFFICACY DIMENSION** • Target EBV in MS will guide healthcare decision-making on the best ways to treat PwMS and prevent individuals from developing the disease.	• Ensure the effective cooperation of all relevant stakeholders via a participatory governance model that takes into consideration the Responsible Research and Innovation (RRI) principles to increase the collective impact of EBV MS research project
Healthcare practitioners will have access to knowledge to guide them on preventive measures, on early identification of disease onset, and on the optimal treatment of pwMS. The effects of EBV on immune activation in people with MS as well as defining the requirements for a vaccine or treatment for preventing MS.	**EXCELLENCE DIMENSION** • New guidelines on preventive treatment or vaccination strategies against EBV from policy makers and public health • New treatment regimens for MS to be adopted by health professionals.	• Ensure true inclusion of patient's perspective (experiential knowledge) in clinical trial design and development (**engagement via EMSP CAB**) • Guarantee ethical acceptability and adequate information of the recruited patients (**via Ethical manager**) • Arrange regularly meeting with SAB and Behind-MS consortium to maximize the knowledge created in defining the risk of developing MS based on EBV infection and the response to anti-viral therapy (**engagement via WP leaders**).
Up-take of the AI models developed in the project: Implementation of the AI-based models for early MS-detection and identification of high-risk individuals at major MS-centres in Europe and worldwide.	**PATIENT REPORTED & SOCIAL DIMENSIONS** • Acceptability by PwMS and caregivers of the use of AI-based models for early MS-detection and treatments access.	• Arrange a survey-focus group with PwMS, their families and citizens to ensure true inclusion of their perspectives in AI-based models application in preventive treatments **(engagement via EMSP CAB)** • Arrange a survey-focus group with citizens perspectives to ensure true inclusion of their perspectives in AI-based models application in preventive treatments (**engagement via European Citizens Association**)

		• Guarantee ethical acceptability and adequate information by integrating ethical manager perspective **(via Ethical manager)**
New group of drugs used as prevention in susceptible individuals or as MS-treatment: Pharmaceutical companies will be given early access to the results from our research through their participation in advisory groups. This can facilitate new treatment paradigms of antiviral directed therapy, even if the results from our initial trials are negative. The results can be used to: • Develop vaccination strategies against EBV at population level or in high-risk individuals. • Develop antiviral or cell-based therapies of increased efficacy against EBV in in individuals with or at high-risk of MS or other EBV-associated diseases	**EFFICIENCY DIMENSION** • A new market for drugs for pharmaceutical industry and product manufacturers	• Set clear and transparent processes to speed up the translation of research findings into therapies development and access **(via Gilead science representative and EPFIA)** • Set clear and transparent processes for intellectual properties management (**all ECT members**)
Prevention in susceptible individuals: Use the best compound detected in phase 2a, emulated target trials and phase 2b trial as primary prevention of MS in susceptible individuals for developing the disease.	**SOCIAL DIMENSION** • Reduced risk of disability and mortality in vulnerable persons, with less requirement of health services and higher probability to remain in the work force.	• To propose a model to measure **positive impacts** on society

Table 4. provides a list of the EVB-MS WPs activities, stakeholders' engagement activities and expected outcomes that will be the focus of the collective materiality analysis. This table does not include activities related to the "Dissemination plan" (D8.4 deliverable) and Data management plan (D7.1 deliverable).

Table 4: EVB-MS WPs activities, stakeholders' engagement activities and expected outcomes

WPs	EVB-MS SHARED AGENDA	SK ENGAGEMENT ACTIVITIES	EXPECTED IMPACT
WP1 Project Management	1. Effective implementation, strategic management and quality control 2. Effective collaboration between consortium partners 3. Effective and coordinated engagement of all stakeholders that are involved in research so to consider their perspectives in the project development. 4. Responsible ethics issues management and risk management. 5. Effective implementation of materiality analysis and definition of impact aspects and indicators	1. Participate in ECT meetings to ensure the identification and development of common stakeholders' objectives 2. Guarantee an effective, cooperative and efficient coordination and alignment of the objectives and actions	1. Guarantee an inclusive and equitable governance model integrating the different perspectives
WP2 Clinical trials	1. To recruit participants into the clinical trials 2. To determine the safety, efficacy and an optimal dose of Tenofovir Alafenamide (TAF) on Epstein-Barr virus latent infection in pwRRMS (phase 2a trial). 3. To assess the efficacy of the optimal dose of TAF (or compound detected in emulated target trials) in reducing the inflammatory disease activity assessed by brain MRI compared to placebo in pwMS (phase 2b trial).	• Ensure true inclusion of patient's perspective (experiential knowledge) in clinical trial design and development (**engagement via EMSP CAB**) • Guarantee ethical acceptability and adequate information of the recruited patients (**via Ethical manager**)	1. Determine whether antiviral treatment can be used as a new class of drugs against MS according to the principles that require the application of patients' experiential knowledge and the guarantee of social ethics 2. Guarantee correct information on the results obtained by aligning the activities with the dissemination communication plan, according to ethical and social principles

WP3	**Epidemiology analyses** **1.** Characterize the interval between primary EBV infection and clinical MS onset. **2.** Identify drugs that predict the interval between primary EBV infection and clinical MS onset. **3.** Validate whether drugs predicting the interval between EBV infection and MS onset are also associated with disease progression in pwMS.	• Arrange regularly meeting with SAB and Behind-MS consortium (**engagement via WP leaders**).	To maximize the knowledge created in defining the risk of developing MS based on EBV infection and the response to anti-viral therapy Publications in major scientific journals (like Science, Nature, NEJM and The Lancet) and will be presented and discussed at major scientific congresses.
WP4	**Immunological and molecular mechanisms and biomarkers** 1. To evaluate the impact of antiviral therapies on T- and B-cell activation in a double blinded, placebo-controlled RCT (WP2). 2. To characterize cellular and molecular states of T- and B-cells that associate with MS and response to MS-therapies, and the impact of antiviral therapies on such states. 3. To define cellular biological markers that can be utilized to monitor current treatments and/or antiviral response.		

WP5	**EBV and host genetics: EBV-VGWAS.** 1) To gather blood and saliva samples from (a) pwMS and controls; and (b) healthy individuals from the general population and the rest of WPs of this proposal. 2) To genotype the host genome in the cohorts where this data is not already available. 3) To enrich, amplify, and sequence complete EBV genomes from individuals from objective 1 in order to generate a comprehensive catalogue of EBV variants. 4) To analyse EBV variabilities (performing EBV-VGWAS) together with the variants of the human donors (from GWAS data) to study whether EBV variability, either by itself or in combination with the host's affects MS risk, age of onset, the development of the disease, or treatment response. 5) To genotype the same cohorts for their HLA alleles and investigate their potential association with EBV genetic variants and risk of MS.		

WP6 Prevention and Prediction	1. to maximize the knowledge created from all the information collected by our consortium for defining the risk of developing MS based on EBV infection and the response to anti-viral therapy. 2. by using computational tools such as mathematical modelling and AI, we can test the relationship of multiple variables Along the time and identifying hidden relationships between EBV and MS. To this end, we are going to make use of several artificial intelligence (AI) tools for classification or prediction purposes (e.g., risk of developing MS, response to antiviral therapy) as well as mathematical models for creating digital twins and conducting in silico trials (anti-viral and anti-EBV vaccination trials). The long-term objective is to identify approaches and therapies aimed to the effects of EBV on immune activation in people with MS as well as defining the requirements for a vaccine or treatment for preventing MS.	• Arrange a survey-focus group with PwMS, their families and citizens to ensure true inclusion of their perspectives in AI-based models application in preventive treatments **(engagement via EMSP CAB)** • Arrange a survey-focus group with citizens perspectives to ensure true inclusion of their perspectives in AI-based models application in preventive treatments (**engagement via European Citizens Association**) • Guarantee ethical acceptability and adequate information by integrating ethical manager perspective **(via Ethical manager)**	• Acceptability by PwMS and caregivers of the use of AI-based models for early MS-detection and treatments access

An ECT workshop will be organized by M12 for the materiality analysis of the activities listed in the table 3. ECT members will be engaged in identifying the most relevant indicators for the above EBV-MS activities. The collective materiality analysis is the innovative managerial tool that FISM will make available through the MULTI-ACT digital toolbox (https://www.multiact.eu/wp-content/uploads/2021/05/MULTI-ACT-Digital-toolbox.pdf) in order to provide ECT members with the ability to jointly identify and co-select the aspects and indicators of impact. In order to constitute the dashboard of the initiative (shared measurement system), the toolbox recommends the use of a manageable number of indicators at least two from each of the 5 dimensions. The ECT will meet quarterly to monitor stakeholder engagement plans progresses using indicators of impact as identify by the materiality analysis. The circle closes with the publication of a progress report at M24.

The MULTI-ACT CRIF enables to conduct the Materiality Analysis on 5 dimensions via the digital Toolbox and finalize a tailored EBV-MS master Score Card:

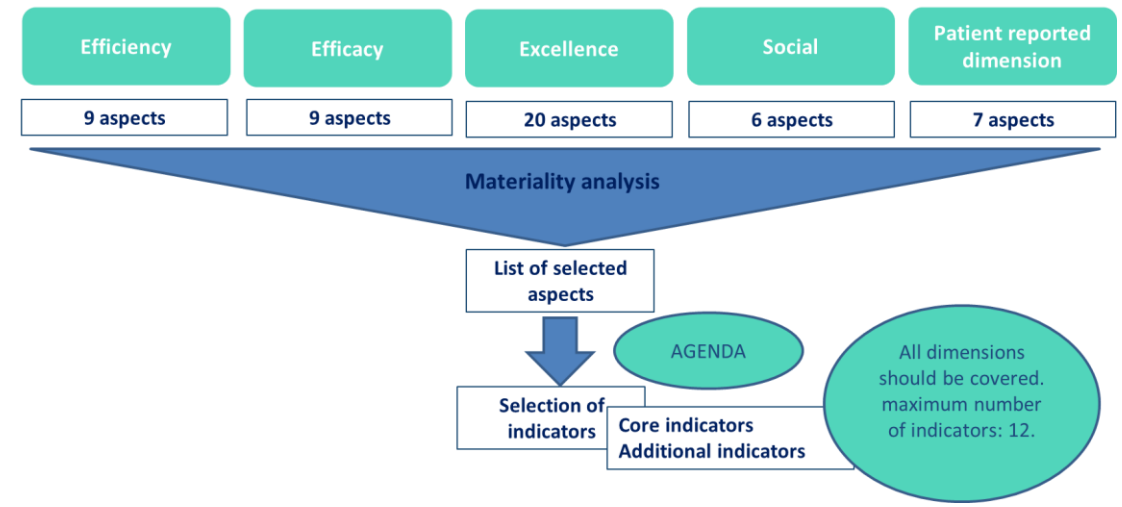

Figure 3: MULTI-ACT master scorecard for materiality analysis.

5 Key consultative bodies

An international Scientific Advisory Board (SAB) and collaboration with the Behind-MS Consortium have been established within the first project months to engage a larger set of experts in the fields of EBV research. We would like to note that via networking events of the European Health and digital executive agency, we have established contact with all other funded projects under the same program to share results, discuss way forward, and importantly best practices in advocating for policy changes.

5.1 Scientific Advisory Board

The Scientific Advisory Board was established in February 2024. Their mission is to provide scientific support, advice, and challenge the EBV-MS principal investigators on a range of scientific issues related to the progress in the project and in the field. They will meet annually in hybrid/physical format with the key researchers from the EBV-MS project.

5.2 Behind-MS Consortium

The Behind-MS consortium is funded through the same Horizon Europe program and has shared interests. An initial meeting was established in Spring of 2024 to introduce the two projects and discuss areas of shared interest and collaboration. A main priority is to collaborate instead of competing and sharing of data and results when relevant. It was agreed that regular meetings between the two consortiums will continue to take place minimum 2x yearly, in addition to physical meetings when possible. The two consortiums have already started shared dissemination activities towards scientific conferences, and we plan on continuing those throughout the project.

6 ECT next steps

Since the very beginning of the project the WP1 team has constituted the ECT to coordinate and monitor the stakeholders' engagement. The following actions will be:

- Nomination of the ECT members (as previously described in this document) and organization of the annual calendar meetings (M06).
- The ECT workshop will be organized by M12 for the materiality analysis. In-depth interviews will be carried out with the identified key and internal ECT stakeholders. The purpose of interviews is to prepare the subsequent materiality analysis workshop with the identified key and internal stakeholder to identify key indicators of impact and finalize the EBV-MS Master Scorecard (M12).
- Finalization of the external stakeholders plan through the dissemination (see deliverable D8.4).
- M24 stakeholder engagement plan report progresses.

7 Conclusion

This Stakeholder Engagement Plan is the main deliverable issued under the umbrella of WP1. It has been prepared by FISM with the contribution of all partners. The deliverable details the rules and procedures governing the stakeholder engagement plans, principles and main tools. The Plan originates from the provisions established in the Grant Agreement n.101136991 and in the Consortium Agreement signed by the partners. Any changes to the management issues described in this document will be reported through the progress reports scheduled at M24.

With continued dedication and collective expertise, we are poised to uncover new horizons in MS research and care.