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Adoption Brief



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This document will be released to promote the adoption of the Manual and the other project's outputs by the R&I actors and contain a number of proposed actions to foster their widespread use.

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EXECUTIVE SUMMARY

MULTI-ACT. Collective Research Impact Framework and multi-variate models to foster the true engagement of actors and stakeholders in Health Research and Innovation is an EU-funded project with a goal of increasing positive impact of health research on people living with brain disorders and society. It has created the Collective Research Impact Framework (CRIF). The CRIF offers a set of tools to establish participatory governance mechanisms and enable realistic evaluation of collective impact of health Research and Innovation (R&I) multi-stakeholder initiatives, namely the Baseline Analysis, Governance Criteria, Materiality Analysis, Patient Engagement Guidelines, and Master Scorecard. They are also made available and operationalised in the digital Toolbox which facilitates application of the CRIF and interaction among stakeholders. They were created and refined in work packages 1, 2, 3, 4 and 5.

The D6.3 *The Adoption Brief* is intended to promote the adoption of the *Integrated CRIF Manual* (D6.1) and the other project's outputs among the R&I actors. The MULTI-ACT Consortium collectively took a decision to focus on two categories of stakeholders i.e., the *Research Funding and Performing Organisations (RFPOs)* and the *Payers and Purchasers* (public or private entities responsible for underwriting the costs of health care). The message and its presentation are thus adopted to their interests. Additional goal of the document is to present proposed actions to foster the widespread use of the CRIF.

This document will be widely promoted among stakeholder in its leaflet version, containing information from the chapters 2-8. Such version is professionally designed with informative graphics, aesthetically pleasing and easy to read to capture the target audience's attention and persuade them to further explore the CRIF. It is freely downloadable from the MULTI-ACT website resources' section.

1 INTRODUCTION

The work package 6 is focused on gathering outputs of work packages 1, 2, 3, 4 and 5, and translating them into guidelines accessible to Research and Innovation (R&I) actors and specifically Research Funding and Performing Organisations (RFPOs) who wish to embrace a more participatory approach in designing, executing and evaluating the impact of their research programmes or projects and, thus, are the ultimate CRIF's Users.

The purpose of its final deliverable, *D6.3 Adoption Brief*, is to promote the adoption of CRIF and other project's outputs by the R&I actors. It contains several proposed actions to foster their widespread use, trigger the interest of the reader to explore the Manual and navigate through the Toolbox functionalities.

1.1 Purpose of this document

This document presents the deliverable *D6.3 Adoption Brief*. It is dedicated to any person or organisation interested in the MULTI-ACT project or the Collective Research Impact Framework (CRIF). However, it is written especially with two categories of stakeholders in mind: Payers and Purchasers¹ and Research Funding and Performing Organisations (RFPOs).

The *Adoption Brief* builds the case for organisations and initiatives to adopt the CRIF in their health research undertakings. It intends to persuade through the presentation of epidemiological, social and economic facts, as well as testimonials from first adopters of the framework. It also presents components of the CRIF, explaining how using them can improve the quality of the health research.

1.2 Structure of document

The document is divided into the following sections:

- 1) [NEUROLOGICAL DISEASES' BACKGROUND: TRENDS, EPIDEMIOLOGY, COSTS AND BURDEN](#) section explains the need for brain disease research that takes into account its social and economic impacts.
- 2) [THE MULTI-ACT COLLECTIVE RESEARCH IMPACT FRAMEWORK \(CRIF\)](#) presents the Framework and its parts, with an emphasis on ease of use and facilitation of stakeholder engagement.
- 3) [WHY MULTI-ACT? THE BENEFITS OF THE CRIF](#) presents benefits of adopting the CRIF.
- 4) [PROPOSED ACTIONS FOR THE WIDESPREAD USE OF THE CRIF](#) describe what actions will be undertaken to promote the CRIF and facilitate its adoption.

¹ As per MULTI-ACT classification of stakeholders (to be found in full in the CRIF Integrated Manual, D6.1), Payers and Purchaser are public or private entities responsible for underwriting the costs of health care. Examples of public entities include Polish Narodowy Fundusz Zdrowia (NFZ). In some countries, regions or central government may play this role. Depending on the system adopted in a given country, health insurance companies (AXA, Cigna) and health care providers may also fall into this category.

- 5) [TESTIMONIALS](#) present statements from the early Adopters of the CRIF, who cooperated with the MULTI-ACT project and co-created the framework by giving their feedback.

1.3 Acronyms

ARSEP	Fondation Pour L'Aide à La Recherche Sur La Sclerose En Plaques
CRIF	Collective Research Impact Framework
DiA	Dane-i-Analizy.pl sp. z o.o.
EBC	European Brain Council
EU	European Union
EHMA	European Health Management Association
EY SPA	Ernst & Young Financial Business Advisors
FISM	Fondazione Italiana Sclerosi Multipla FISM Onlus
INTRA	Intrasoft International
RFPO	Research Funding and Performing Organisation
TAU	Tampereen Yliopisto
UBU	Universidad De Burgos
UCP	Universidade Catolica Portuguesa
UNITN	Università Degli Studi Di Trento
WP	Working Package

2 NEUROLOGICAL DISEASES' BACKGROUND: TRENDS, EPIDEMIOLOGY, COSTS AND BURDEN

It is estimated that at least 1 in 3 Europeans is affected by a brain disorder each year – around 179 million people (DiLuca and Olesen, 2014). The WHO stated that brain disorders account for 35% of the burden of all diseases in Europe. In 2017, 307.9 million (Deuschl *et al.*, 2020) cases of brain diseases were counted in the 28 European Union member states (EU28), of which 74.5 million were newly diagnosed, including Alzheimer's disease and other dementias, epilepsy, headache (migraine and tension-type headache), multiple sclerosis, Parkinson's disease, brain cancer, motor neuron diseases, neuroinfectious diseases, and stroke.

Patients with brain disorders had a total number of disability-adjusted life-years (DALYs) of approximately 21 million and the total number of deaths was 1.1 million. (Deuschl *et al.*, 2020) DALYs are the sum of the years of lives lost and the years lived with disability by the patients because of the diseases. After cardiovascular diseases and cancer, neurological disorders' burden on DALYS and deaths in the member states was the third highest. Neurological disorders were responsible for 13.3% of total DALYs and 19.5% of total deaths, ranking third after cardiovascular diseases and cancers. (Deuschl *et al.*, 2020)

In addition to the negative impact on healthy life years and the quality of life, brain disorders also have consequences beyond the healthcare system by impacting the increasing costs of technological progress, prolonged impairment, great dependency and significant reduced productivity at work, as well as the burdens on health and social welfare systems (European Brain Council, 2017; Deuschl *et al.*, 2020).

The annual direct and indirect costs for the EU economy and national health budgets of these disorders are estimated at 800 billion euro, of which 60% is attributable to direct healthcare and non-medical costs and 40% is from the loss of productivity in the labour market (European Brain Council, 2017).

The MULTI-ACT project's Collective Research Impact Framework (CRIF) allows health research initiative to measure their impact not only in terms of purely scientific and academic results, but also in terms of social and economic long-term results, with the patients' well-being as the main focus.

The rise in the number of people with brain diseases (such as Alzheimer's, Parkinson's, depression, Multiple Sclerosis, addictions, and many more) and the high proportion of deaths and DALYs attributable to those diseases are due to factors such as higher life expectancy and the increasing incidence and duration of diseases related to ageing. (Deuschl *et al.*, 2020).

The European Union supports collaborative projects in neuroscience areas to translate research benefits to citizens. Despite the significant progress in terms of understanding of neurological diseases at the molecular, cellular and circuit levels, the translation of these discoveries into therapies remains a critical challenge. It is estimated that out of 10 people living with a disorder, 3 to 8 are untreated or inadequately treated, even when therapies exist (European Brain Council, 2017).

It is necessary to foster innovation by building effective collaboration in research by involvement of all stakeholders, including academia, government and regulatory agencies, patient and health foundations, biotechnological companies and the pharmaceutical industry. However, most multi-

stakeholder initiatives have lacked shared measurements of impact and supporting infrastructures to enable true alignment of efforts and accountability of results. The CRIF is specially designed to foster engagement of stakeholder from the very start of research, and allows the scientists to focus on the research topic which are key from the patients' perspective and thus have a higher chance of rendering high-impact results.

3 THE MULTI-ACT COLLECTIVE RESEARCH IMPACT FRAMEWORK (CRIF)

To increase positive impact of health research on people living with brain disorders and their loved and carers, the MULTI-ACT project has created the Collective Research Impact Framework (CRIF). The CRIF offers a participatory and realistic evaluation of the impact of health Research and Innovation (R&I) in multi-stakeholder initiatives. Distinguishing feature of the CRIF is enabling co-accountability: the initiative's different stakeholders, despite their competing interests, co-create their mission, agenda and impact assessment system. All relevant areas of impact are always taken into account. The CRIF is composed of several components:

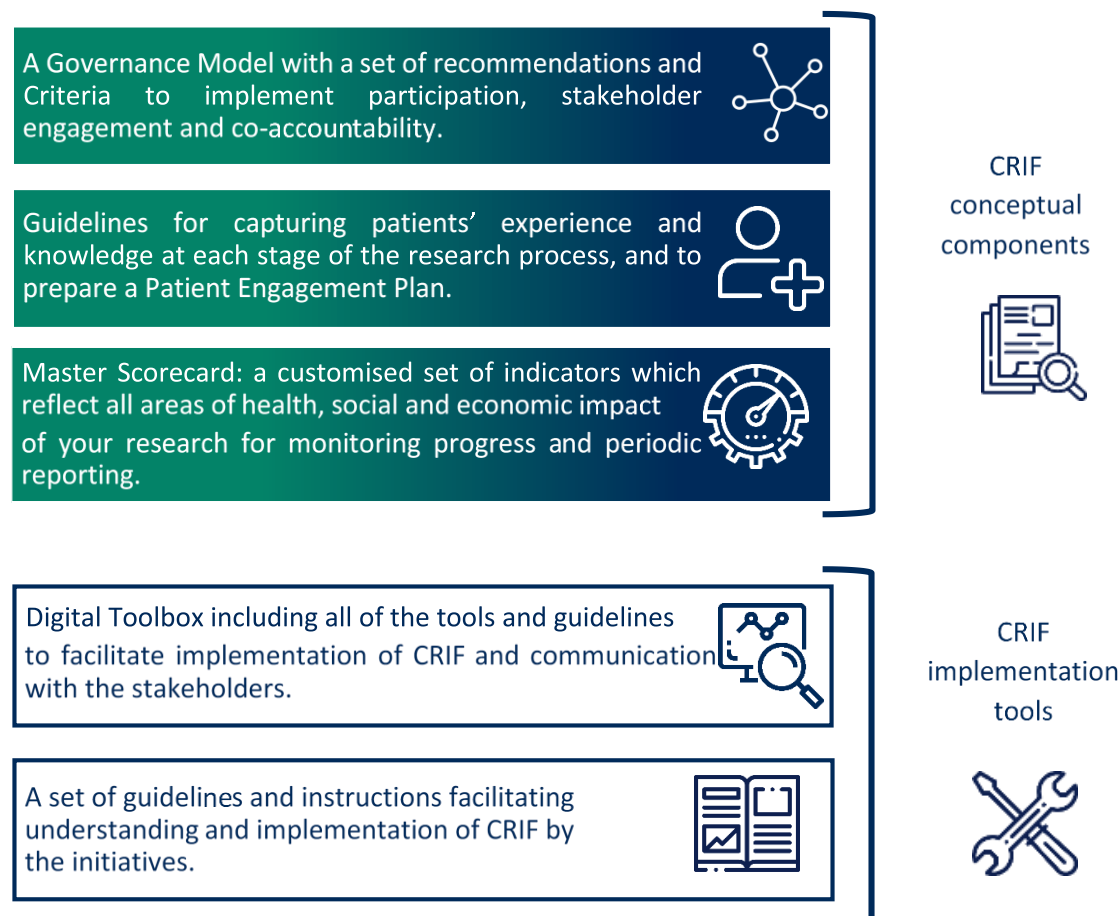


Figure 1 CRIF Concepts and Tools

3.1 Governance Model

The **Governance Model** provides a set of recommendations (Criteria) on how to organize an initiative's governance bodies, define its mission and agenda, and implement a monitoring and measurement system. Thanks to the Governance Model, the initiative can **define its mission and shared agenda** in accordance with the MULTI-ACT principles of stakeholder engagement and co-accountability. You will also find instructions on how to establish a **shared and effective assessment system** to understand if you are applying the model correctly.

The MULTI-ACT Governance Model is composed of 5 main criteria that your research initiative needs to meet. Those criteria are:



Figure 2 Governance Model: Governance Criteria

The Governance Criteria offer detailed yet flexible recommendations on how to achieve the above characteristics.

3.2 Patient Engagement Guidelines

Patient engagement is at the heart of CRIF, linking all its elements. MULTI-ACT developed specialised **Patient Engagement Guidelines**. The Guidelines provide methods to develop the Patient Engagement Plan and recommendations on how deep the engagement should be. They allow to capture patients' knowledge gained through lived experience of their disease and use it in order to increase positive social impact of the health research.

3.3 Master Scorecard

The Master Scorecard translates the MULTI-ACT philosophy and agenda into action, providing potential indicators to assess all the key aspects of impact of health RRI initiatives, with special focus on the benefits for patients, healthcare, and society. It provides a catalogue of indicators grouped into the five CRIF dimensions of accountability (see Figure 3). The Master Scorecard is an adaptive tool.

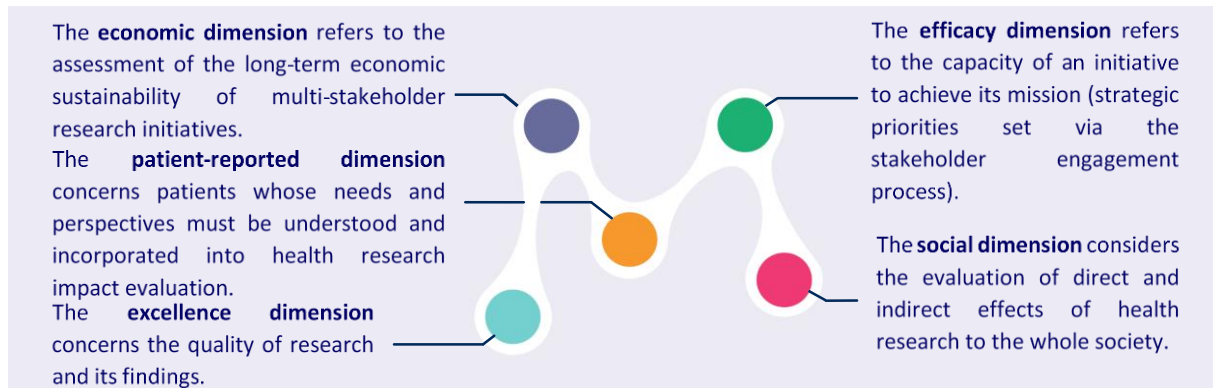


Figure 3 Five CRIF Dimensions

The initiative's internal and external stakeholders engage in a Materiality Analysis in order to select the indicators that are relevant for the vision and agenda of the research initiative. The Master Scorecard can be applied at the beginning or during the development of a research initiative, engaging multiple stakeholders in defining impact indicators towards a given mission through a collective bottom-up approach.

3.4 Digital Toolbox

Implementation of the CRIF is supported by the **digital Toolbox** – an online platform with all the functionalities needed for the process. The Toolbox provides all the results in a downloadable format. The tools are accompanied by tips, explanations and instructions at every step.

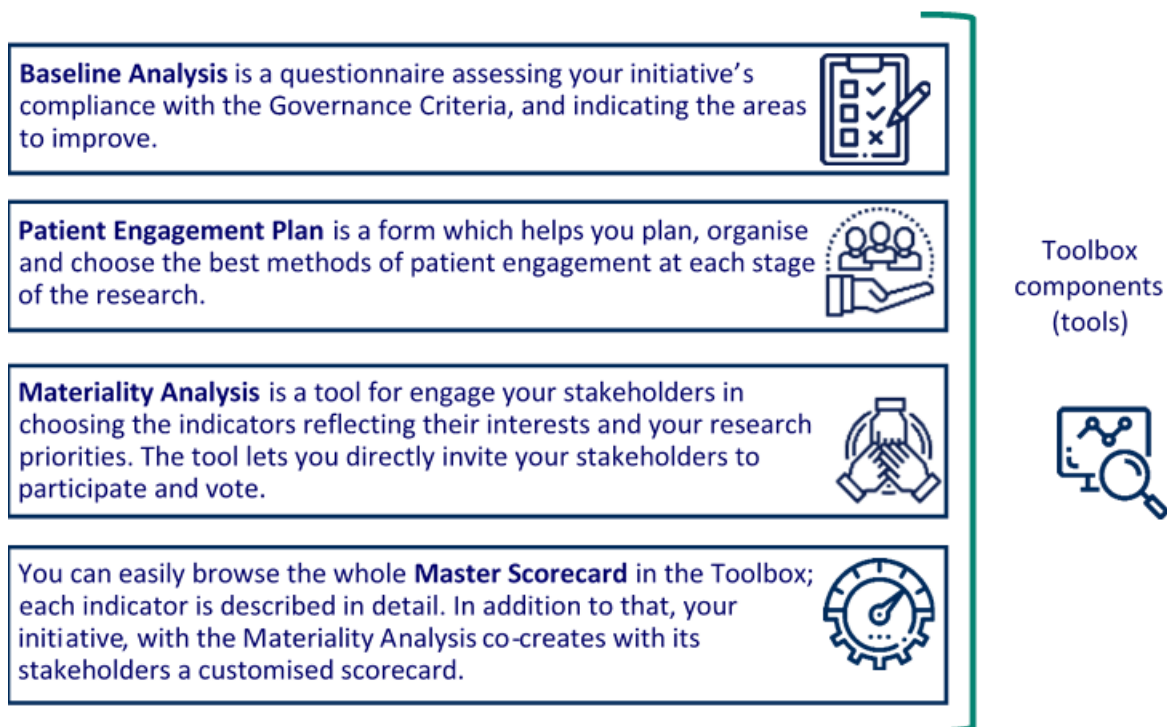


Figure 4 Components of the Toolbox

The Toolbox is accompanied by the **CRIF Manual** that explains the CRIF and guides the user through the implementation process.

4 WHY MULTI-ACT? THE BENEFITS OF THE CRIF

The CRIF is a management tool with strict requirements in terms of governance, co-accountability and patient engagement finalized to improve the impact of scientific research.

MULTI-ACT proposes to implement the during the beginning of a research initiative to engage stakeholders in defining metrics for the project's mission and agenda (Zaratin and Salvetti, 2018), but at the same time it allows a degree of flexibility that is important from the end-user's perspective.

The CRIF has been appreciated by initiatives who tested it: the MS Care Unit (the Charcot Foundation), the EPICLUSTER (EBRA) and the Global Initiatives International Progressive MS Alliance. They praised it for how well it captured patients' and other stakeholders' point of view and facilitated its integration into the initiative's mission and agenda. Its ability to identify gaps in the governance process and easy-to-implement recommendations were also noticed. The CRIF was created to address the particular case of research about multiple sclerosis, and then expanded to all brain diseases.

- The CRIF not only engages patients and other stakeholders, but it uses their knowledge to maximise impact of research on the society. With the CRIF, patients are not “taught” and then “interrogated”; they empowered and listened to.
- It enables participatory governance of health research and innovation initiatives
- It promotes co-accountability among research collaborators
- The CRIF offers a catalogue of impact indicators that cover all relevant areas of impact

5 PROPOSED ACTIONS FOR THE WIDESPREAD USE OF THE CRIF

The CRIF will be promoted to research initiatives focused on a variety of brain diseases. Promotional materials, from factsheets and brochures to videos, will be widely shared. The key element in the promotion of the CRIF is naturally the digital Toolbox. Additionally, a range of possible services to facilitate widespread use of the CRIF is considered:

- Multi-Stakeholder Engagement Academy: a service of training in implementing the CRIF within research initiatives.
- Certification: audit services assessing initiative's governance system with the CRIF.
- Consultancy: additional services supporting CRIF implementation.

Such services, to be developed beyond the end of the MULTI-ACT project, are explored more in depth in the Exploitation and Capitalization Plan (D8.5).

6 TESTIMONIALS

During the MULTI-ACT Final Conference (Multi-Act Project, 2021a, 2021b), the representatives of early adopter organisations discussed their experiences with the CRIF: how it benefitted their research and how they perceived the usefulness of the framework for other initiatives. Fragments of their statements were captured as testimonials for the Adoptions Brief.

“As soon as I was exposed to MULTI-ACT, I thought ‘Well, this is exactly what we need’.” Prof. Giancarlo Comi, Chair (European Charcot Foundation)

“What to me is fundamental, not only for our project, but for all the projects, is to test the project to see if – with this type of tool [...] – we may be able to define for each of the stakeholders the Return on Investment. And if we are able to satisfy all the five dimensions [...] of accountability.” Prof. Giancarlo Comi, Chair (European Charcot Foundation)

“... We’ve been actively working with MULTI-ACT to really think through – how do you set that strategy? And particularly for us – how do we do this when we want to ensure that the hopes and concerns and the aspects and **perspectives of the people affected by MS are heard** worldwide? And that [...] set the stage for our engagement with MULTI-ACT.” David Henshall, Professor of Molecular Physiology & Neuroscience (Royal College of Surgeons), Chair (EPICLUSTER – EBRA)

“Everyone embraces this concept of **Responsible Research and Innovation**, but the gap has been having a standard process, having a process that’s **consistent**, having a process that’s **measurable**, and – a particularly for us [...] patient engagement [...] in all aspects of research. And we just found that there’s a myriad of approaches around the world but none that were designed with that [...] thoughtful **methodology** that would be repeatable, measurable, that would be aligned to the **scientific** aspects [...].” David Henshall, Professor of Molecular Physiology & Neuroscience (Royal College of Surgeons), Chair (EPICLUSTER – EBRA)

“We were missing some key elements in terms of our mission. We all agreed that what is lacking in the epilepsy field in Europe at the moment is an **organised approach to public patient involvement** in research and co-design of research.” Graham McReynolds, Associate Vice President (Global Initiatives International Progressive MS Alliance)

“MULTI-ACT ran a **Baseline Analysis** on our cluster. And it was fantastic! And I was amazed at how good it was in terms of usability. They absolutely nailed everything that was missing from our naively put together consortium. [...] they laid out a **clear and an easy-to-follow** way to make changes.” Graham McReynolds, Associate Vice President (Global Initiatives International Progressive MS Alliance).

7 LITERATURE

Deuschl, G. *et al.* (2020) ‘The burden of neurological diseases in Europe: an analysis for the Global Burden of Disease Study 2017’, *The Lancet Public Health*, 5(10), pp. e551–e567. doi: 10.1016/S2468-2667(20)30190-0.

DiLuca, M. and Olesen, J. (2014) ‘The Cost of Brain Diseases: A Burden or a Challenge?’, *Neuron*. Elsevier Inc., 82(6), pp. 1205–1208. doi: 10.1016/j.neuron.2014.05.044.

European Brain Council (2017) *Early Intervention: Bridging the Early Diagnosis and Treatment Gap*. doi: 10.13140/RG.2.2.20145.07520.

Multi-Act Project (2021a) *EBC - Multi-Act*, *Vimeo.com*. Available at: <https://vimeo.com/527787491> (Accessed: 9 April 2021).

Multi-Act Project (2021b) *Event Report: MULTI-ACT Final Conference*. Available at: <https://www.multiact.eu/2021/03/26/event-report-multi-act-final-conference/> (Accessed: 9 April 2021).

Zaratin, P. and Salvetti, M. (2018) 'Evaluation woes: define metrics from the off', *Nature*, 559(7714), pp. 331–331. doi: 10.1038/d41586-018-05750-5.

8 LEARN MORE

MULTI-ACT Project: <https://www.multiact.eu>

MULTI-ACT Materials: <https://www.multiact.eu/publications>

MULTI-ACT Toolbox: <https://toolbox.multiact.eu>

MULTI-ACT on Twitter: <https://twitter.com/multiactproj>

MULTI-ACT on LinkedIn: <https://www.linkedin.com/in/multi-act-project-773074167>