



Deliverable D3.6

MULTI-ACT Master Scorecard*



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:	MULTI-ACT Master Scorecard*	
REFERENCE NUMBER:	D3.6	
WORKPACKAGE CONTRIBUTING TO THE DOCUMENT:	WP3	
VERSION:	V0.2	
EXPECTED DELIVERY DATE:	31/07/2019	
DATE:	21/11/2019	
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Short description of the Deliverable (as in the DoA)*: The final result of WP3 is represented by this deliverable which provides a set of indicators which are able to measure different accountabilities (mission, excellence, economic and social) in multi-stakeholder-research initiatives and are selected for their relevance and robustness. Such indicators compose the MULTI-ACT Master sScorecard which then case by case is tailored to the specific multi-stakeholder research initiative by the MULTI-ACT



user who will select the most appropriate indicators following the guidance provided in further deliverables.

REVISION HISTORY				
REVISION	DATE	COMMENTS	AUTHOR (NAME AND ORGANISATION)	
V0.1	17/05/2019	First draft	University of Trento (Michele Andreaus, Ericka Costa & Carla Antonini). University of Burgos (Nicolás García-Torea, Carlos Larrinaga & Mercedes Luque). Tampere University (Eija Vinnari & Anna Kork).	
V0.2	18/06/2019	Second version including inputs from partners (namely the characterization of the specific fields used to describe each indicator in the scorecard) as weill as taking into account the guidance provided by the EAB.	Andreaus, Ericka Costa & Carla Antonini). University of Burgos (Nicolás García-Torea, Carlos Larrinaga	
V0.3	31/07/2019	Final edited and formatted version	Italian Foundation for Multiple Sclerosis (Danilo Devigili & Valentina Tageo)	

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V0.4	21/11/2019	New version resubmitted Michele Andreaus (UNITN),
		taking into account the Carlos Larrinaga (UBU),
		request for modification Valentina Tageo (FISM)
		included in the letter Ref.
		Ares(2019)6818091 -
		04/11/2019 received by the
		EC (see section 4 page 20 and
		excel file attached)

FILENAME: MULTI-ACT_D3.6_UNITN_20191121_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 health Research and Innovation (R&I) impact of multi-stakeholder initiatives. The rationale is the observation that most multi-stakeholder RRI initiatives have lacked shared measures of research impact and supporting infrastructures to enable the alignment of various actors' efforts. In particular, when assessing the impact of research on brain diseases such as multiple sclerosis (MS), it is fundamental to consider patients as a key stakeholder group, and focus on their needs and perspectives throughout the entire measurement process.

The CRIF is composed by the multi-stakeholder governance model developed in Work Package 5 (WP5) and the present Master Scorecard of indicators developed in WP3. The established framework applies a multi-stakeholder perspective to assess the impact of health research in the field of brain diseases, using MS research as case study. The Master Scorecard consists of five dimensions of accountability. The mission dimension refers to the capacity to fulfil the strategic priorities settled by the research initiative, while the excellence dimension concerns the quality of research. The social dimension considers the evaluation of direct and indirect effects of health research to the whole society, whereas the economic dimension refers to the assessment of the long-term economic sustainability of multi-stakeholder research initiatives. Finally, the patient reported dimension works as an overarching dimension and measures the impact of the research activities carried out by the initiative on those outcomes that most matter to patients.

In practice, the Master Scorecard of indicators can be adopted by multi-stakeholder research initiatives, including research funding and performing organizations. It aims to facilitate collaborative decision making for instance in the design of policies, agendas, funding programmes, evaluation procedures towards a concrete impact of research on people and society. 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.

This first public report of WP3 summarizes the work undertaken and presents a Master Scorecard consisting of relevant indicators for measuring the impact of health research. During the process of WP3 activities, the MULTI-ACT consortium has engaged with multiple stakeholders active in brain research in a co-creation process that involved extensive literature and multi-stakeholder initiatives reviews as well as interviews with External Advisory Board (EAB) members. This co-creation produced the WP3 Database, which comprises 1,556 unique indicators to measure the impact of research. The indicators were classified into 45 aspects of measurement considered as the most relevant. For each aspect, at least one core indicator, as well as additional indicators were selected based on their frequency in the literature and their relevance to the CRIF model and the values espoused by MULTI-ACT.

The Master Scorecard lists 115 indicators, providing a description, as well as additional information for each indicator. Nevertheless, the Master Scorecard illustrated in this document is a preliminary version presented in a report/table format. Next step will be translating it in an easy-to-consult catalogue of

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indicators accessible via the Digital Toolbox developed in WP2. Moreover, the consortium foresees the possibility to enrich and improve it following its validation in the MS case study (WP4) and eventually work further on its generalization to other brain diseases than MS (WP7), with the collaboration of MULTI-ACT partners.

To note, the present version of the document is a new one resubmitted taking into account the request for modification included in the letter Ref. Ares(2019)6818091 - 04/11/2019 received by the EC (see section 4 page 20 and excel file attached).



1 INTRODUCTION

The proposed multi-stakeholder framework will integrate the different perspectives of accountability, as well as the diverse (and often competing) interests of the different stakeholders involved in assessing the success of RRI initiatives. To meet the objective of generating the collective MULTI-ACT model, WP3 has developed a Master Scorecard of indicators that applies a multi-stakeholder perspective to assess the impact of health research in the field of brain diseases. The Master Scorecard consists of five dimensions of accountability. In line with RRI guidelines, the mission dimension focuses principally on better aligning R&I and its outcomes with the values, needs and expectations of stakeholders engaged in the research initiative while the excellence dimension considers the quality of research. The social dimension refers to the long-term impacts of MS research for the whole society, engaging different types of stakeholders. The economic dimension considers the long-term economic sustainability and the financial resources needed for pursuing the given mission. Finally, the patientreported dimension works as a core element guiding the research impact assessment on domains that matter most patients and acts as an overarching dimension in which the other four dimensions should be rooted. It emphasises the "science of people input": patients' needs, interests and involvement in the accountability process. The latter dimension will be extensively study in Task 1.5 (WP1) and integrated at a later stage in the digital version of the Master Scorecard included in the Toolbox (WP2).

Previous deliverables of WP3

To achieve its purposes, the MULTI-ACT project exploits synergies in the development of its framework and includes several work packages carrying out the different activities in parallel and reporting their key results in a set of deliverables. As this is the first public report of WP3, we shortly describe the previous work conducted and the main findings.

The first deliverable was **D3.1**: "List of multi-stakeholder accountability metrics according to the different dimensions". This report conceptualised the CRIF in a multi-stakeholder co-accountability framework by exploring the key theoretical concepts such as accountability. Moreover, based on academic literature and multi-stakeholder research initiatives review, the deliverable provided a list of indicators with their respective evaluation dimensions and frameworks currently used in assessing the impact of health research. The findings revealed that the majority of studies relies on a single stakeholder perspective to assess impact, instead of using a co-accountability approach that lies at the core of MULTI-ACT mission.

To respond to MULTI-ACT's overall objective regarding the multi-stakeholder accountability process, deliverable D3.2 ("Accountability steps for implementation to the selected mission") identified the methodology needed for implementing the co-selection of indicators. We explored the academic and grey literature from various research fields to identify the process used for selecting performance indicators in multi-stakeholder research initiatives. These accountability steps included: 1) establishment of scope and mapping of stakeholders, 2) development of conceptual framework, 3) co-selection of indicators, 4) measurement of indicators, and 5) reporting, monitoring and assessment in a continuous dialogue with the stakeholders.

Building on the landscape analysis of previous deliverables, **D3.3** ("Structure of the interviews to engage stakeholders") described the methodology to engage with relevant stakeholders by conducting



in-depth interviews. This report included a protocol for inductive, semi-structured interviews that seek to shed light on two specific topics: the stakeholders' perceptions of health research impact and co-accountability dimensions; and the aspects that should be considered when assessing the impact of RRI initiatives. The protocol contains 11 core and 22 additional questions as well as a method for analysing the interview data. The outcomes of these interviews were reported later in D3.5.

Since stakeholder engagement is the backbone of the MULTI-ACT, **deliverable D3.4** was entitled "Strategic working meeting to engage stakeholders". To build MULTI-ACT stakeholders network, the first online meeting was organized. The project invited an initial core group of stakeholders to contribute to the co-creation of the CRIF. The results of this meeting facilitated the identification process of potential key stakeholders and the discussion of background material to engage stakeholders.

Deliverable D3.5 "Basket of stakeholder-oriented metrics" presented a short-list of potential relevant indicators to elaborate the co-created basket of stakeholder-oriented indicators for assessing the impact of health research. This basket was constructed based on the findings from the eight stakeholder interviews (members of MULTI-ACT External Advisory Board) and the results of literature review concerning the impact indicators currently utilized by health sector organizations. The indicators were selected from the "WP3 Indicator Database 1.0", which contains 1,556 indicators identified through the literature review carried out throughout WP3 development. This database also served as the foundation for building the scorecard presented in this last deliverable D3.6.

This current D3.6 is the last deliverable of WP3 and provides the first release of the <u>Master Scorecard</u> in a report/table format. Next step will be translating it in an easy-to-consult catalogue of indicators accessible via the Digital Toolbox developed in WP2 as well as further enriching and improving after the validation of the overall framework in WP4.



Figure 1: Work Package 3 and the focus of deliverables.

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The MULTI-ACT framework supports that the indicators for each dimension need to be co-selected and co-developed in a collaborative process (presented in D3.2, D3.3 and D3.4). For co-creating the CRIF, we have engaged with different stakeholders related to MS and brain disease research to consider and integrate their diverse perceptions, interests and goals. In this deliverable, we utilised the participatory methods to complement the findings of the literature reviews and the stakeholder interviews (reported in D3.5). We engaged different stakeholders into the co-design of the Master Scorecard in order to find robust and suitable indicators for the MS and brain diseases research agenda. The engagement activities carried out through WP3 are part of the task "social impact measurement in the network". As a result, we will next introduce the Master Scorecard with a respective set of potential indicators for RRI initiatives, reflecting different accountability dimensions.

1.1 Purpose of this document

The purpose of this document is to present a preliminary Master Scorecard of indicators. The report draws on the collection of the WP3 Indicators Database developed through the previous stages of WP3. By continuing the tasks of previous deliverables (particularly D3.1 and D3.5) to identify the relevant indicators for assessing the impact of health research, this report especially focuses on the process of building the Master Scorecard. The task carried out for D3.6 consisted in exploring and selecting the indicators applicable to the different co-accountability dimensions in order to facilitate collaborative impact assessment and the alignment of multiple stakeholders according to their mission.

Furthermore, this version of the Master Scorecard continues the co-creation process through a participatory action research, where the multidisciplinary team of the consortium took part on a reflective process to select indicators. Collaborative action and critical reflection by all consortium members mean continuous refining and improving the research data, resembling the participatory action process comprised of a "circle of planning, action and fact-finding about the result of the action" (Lewin 1946, 38). To consolidate and identify the relevant indicators, the ultimate aim was to provide a first release of the Master Scorecard that can be further enriched. More in detail, the final structure of the master scorecard will be presented in WP2 in its digital version, the process of enrichment and fine-tuning for a selected MS case study will be carried in WP4 and a test of transferability to other brain diseases will be performed in WP7. Figure 2 represents the interrelated dimensions of MULTI-ACT co-accountability approach.

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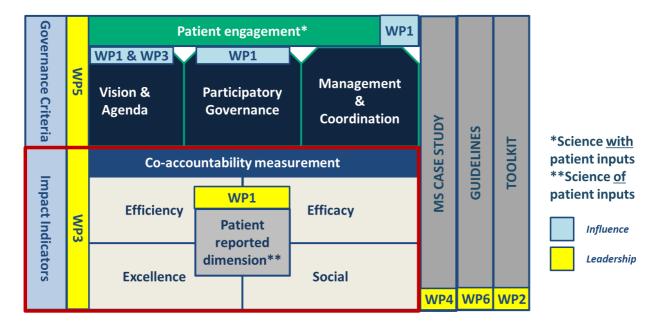


Figure 2 MULTI-ACT WP3 in the definition of the Collective Research Impact Framework (CRIF)

1.2 Structure of document

After the introduction, Section 2 describes the co-creation process by providing background material for scorecard.

Section 3 describes the methodology and the structure for building the scorecard. This section also reports how the selection of indicators was conducted.

Section 4 introduces the first release of the Master Scorecard with the proposal of indicators by the different dimensions.

1.3 Glossary

CRIF (Collective Research Impact Framework): conceptual framework that MULTI-ACT is developing to enable a new collective accountability approach to multi-stakeholder R&I initiatives in the field of brain diseases. There are five CRIF Dimensions: 1) Efficacy 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. 2) Excellence concerns the quality of research data and findings in health research. Only excellent research will have a positive impact on people and society. 3) 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. 4) Economic refers to the assessment of the long-term economic sustainability of health R&I. 5) Patient-reported 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.

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Indicator: A quantitative or qualitative factor or variable that provides a simple and reliable means to measure achievement, to reflect the changes connected to an intervention, or to help assess the performance of a development actor (OECD, 2010).

Master Scorecard: Set of indicators selected from the WP3 Indicator Database on the basis of literature and initiatives analysis. It works as an adaptive tool to help understanding and assessing the impact of health RRI. The scorecard consists of a long-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.

2 BACKGROUND OF THE MASTER SCORECARD

2.1 Development of collective research impact framework (CRIF)

The collective framework development starts from the reflections on health research outcomes and impact from a comprehensive perspective involving all the stakeholders, where research governance is expanding to a model of a 'quadruple helix' with patients and their community as a fifth strand. We believe that collective initiatives can be sustainable only if each involved part can evaluate their return on investment and alignment toward a given mission.

So far, most multi-stakeholder initiatives have lacked shared measurements of impact and supporting infrastructures to enable true alignment of efforts (Zaratin et al., 2014). In particular, when assessing the impact of MS health research organizations on brain diseases, it is fundamental to consider the patients, as key stakeholder, and their needs and perspectives throughout the entire measurement process.

Conventional measures related to the excellence of research need to be integrated with indicators related to the economic and financial dimension (efficiency), to the social dimension that relates to direct and indirect effects of health research to the whole society, and to the mission dimension (efficacy) which relates to the strategic priorities to focus on patient needs. The paradigm should **shift** from a single performance assessment system (top down accountability approach) to a new multi-dimensional model (toward a co-accountability approach).

The literature review revealed that the vast majority of studies that have assessed broader policy and practice impacts have relied on principal investigator interviews and/or peer review, instead of interviewing policy-makers and other important end-users of research. This represents a methodological weakness of previous research, as solely relying on principal investigator assessments, particularly of impacts of their own research, has an inherent bias, leaving the research impact assessment process open to 'gilding the lily' (Milat et al., 2015, Pedrini et al., 2017).

Considering the case of chronic brain diseases, the development of innovative and personalized care for people with such diseases can benefit from the CRIF, in which each interested party can have its return on investment aligned with the mission of developing effective care for patients. Building on

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the Integrated Accountability Model (IAM) proposed by Andreaus and Costa (2014), MULTI-ACT has developed a co-accountability approach with its five dimensions (mission, excellence, social, economic and patient reported) reflecting the multi-dimensional accountability that RRI initiatives need to align R&I and its outcomes with the values, needs and expectations of patients and society.

CRIF acts as a prospective model and as an accountability framework for evaluating health research impact. It can be implemented at the start or during the development of a research initiative to engage multiple stakeholders in defining impact indicators in a bottom-up approach, rather than applying traditional single performance assessment systems (Zaratin and Salvetti, 2018). Patients and their community are seen as new actors and key stakeholders in the RRI process. Indeed, the "science of people with MS inputs" will be applied in a transversal modality throughout the five dimensions (Anderson and McCleary, 2016).

Finally, the CRIF can be adopted by multistakeholder research initiatives, including funding and performing organizations, according to their mission towards better and collaborative decision making in the design of policies, agendas, funding programmes, evaluation procedures, etc. The validation of the CRIF in MS and other diseases will be performed in other work packages of MULTI-ACT (WP4 and WP7). This innovative approach will be instrumental to define a broader framework for collaborative initiatives in the health domain and for the evidence-based policies (Westrich, 2016; Salvetti et al., 2018).

2.2 The literature review for building the WP3 Indicator Database

This section presents a brief overview of the stages of the indicators collection for developing WP3 Indicator Database. It acts as a foundation on which the first release of the Master Scorecard is built.

The first stage was the creation of the database with an initial list of **indicators currently used to** account for the different categories of health research impact. It aimed at reaching a common understanding of health research accountability, considering the diversity of interests of multiple stakeholders. This first stage was carried out in D3.1 and yielded 342 indicators.

In the second stage, we added to the database the indicators coming from multi-stakeholder initiatives. This collection and literature review aimed to identify the required accountability steps to operationalize the co-selection of performance indicators. This phase responded to the MULTI-ACT's overall objective to ensure that indicators are selected through a participatory, multi-stakeholder process, and are the best approximation to measure the multi-dimensional nature of brain research impact. The accountability steps were identified following the theoretical arguments introduced in first deliverable and through a review of the academic and non-academic multi-stakeholder methodologies introducing co-development process of performance indicators. This second stage was carried out in D3.2 and yielded 218 indicators.

In the third stage, a comprehensive literature review of both academic research and non-academic initiatives on the measurement of impact of health sector organizations was conducted. This third stage was carried out in D3.5 and yielded 984 indicators. Figure 3 illustrates the overall literature



review and data collection stages of the WP3 Indicator Database development from which the Master Scorecard was built.

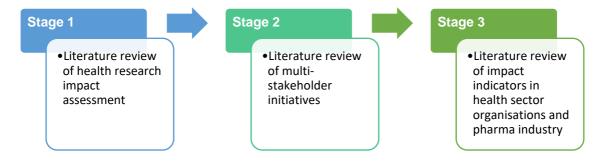


Figure 3. Development of WP3 Indicator Database

3 METHODOLOGY TO BUILD THE MASTER SCORECARD

3.1 Development of the Master Scorecard

Figure 4 represents the process of building the Master Scorecard and its potential uses in the next WPs (especially WP2, WP4 and WP7).

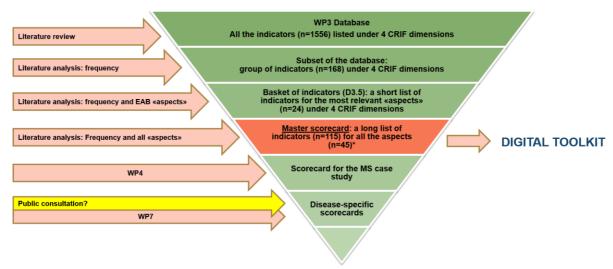


Figure 4. Construction of the Master Scorecard and use in future work packages.

The construction of the Master Scorecard is the main outcome of WP3. The first step to build the Master Scorecard was the development of the WP3 Indicator Database. As abovementioned, this database gathers the different indicators for evaluating health research impact and multi-stakeholder initiatives that were identified in the literature reviews (see section 2 for further details). Database includes as per the moment of submission a collection of 1,556 unique indicators.

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Secondly, the indicators were classified according to the four co-accountability dimensions (social, efficiency, efficacy and excellence) taken into account in the present report¹ and the stage of the research process to which they were related. The fifth dimension, i.e. the patient reported dimension of research impact, is the core topic of Task 1.5 which aims to contribute to development of the science of patient inputs by proposing the use of patient reported outcome measures capable to capture the impact of research on those outcomes that most matter to patients.

These classifications represent the Level 1 of the structural scheme of the database. To classify indicators, we followed an inductive approach to categorize them into a four-level hierarchy:

- Level 1 (accountability dimension and research stage)
- Level 2 (aspects of measurement)
- Level 3 (group of indicators based on the topic that they evaluate)
- Level 4 (definition of single indicator)

We applied a bottom-up approach and started from Level 4 (the individual indicators) to create groups of indicators (Level 3) that analyse the same or very similar issues using a common measurement approach. The groups were further combined to the aspects that measure similar topics (Level 2). Finally, these aspects were aggregated according to CRIF accountability dimension and stage of research process (Level 1). Four researchers worked on this task in an iterative process until agreement was reached on the most adequate classification for each indicator in the four-level hierarchy. Table 1 summarizes the distribution of indicators, groups of indicator and aspects at this stage.

Dimensions	Aspects of measurement	Groups of indicators	Indicators
Mission	10	42	433
Excellence	20	63	630
Economic	9	28	269
Social	6	35	224
Total	45	168	1,556

Table 1. Number of indicators, group of indicators and the aspects for each CRIF dimensions in WP 3 Database

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¹ Although the patient reported dimension is not included in the present analysis and selection of indicators, some of the indicators collected are related to patient-reported dimension too. Yet, at this point this dimension has not been considered in the first release of the Master Scorecard because patient-reported dimension is more thoroughly developed in WP1. Those indicators will be included in the next release of the Master Scorecard as well as into MULTI-ACT digital toolbox in future steps.



Thirdly, a preliminary set of indicators covering 24 relevant aspects of the WP3 Indicator Database were analysed to propose a basket of indicators (see D3.5). This short-list of indicators was selected considering the outcomes of analysis of the interviews performed with EAB members.

Fourthly, we extended the analysis to the whole WP3 Indicator Database and selected relevant indicators for each aspect. During this process, the database was revised and additional feedback was provided by other partners. As a consequence, the classification of aspects was simplified by merging some of them, ending up with 45 aspects. For each aspect, one core and two additional indicators were selected based on the following criteria:

- Core indicators were selected considering the frequency in which similar indicators cover the same topic within an aspect that appears in WP3 Indicator Database. Being the most frequent indicator mentioned by the literature implies that the issue that it evaluates is paramount within each aspect. Therefore, core indicators are expected to be implemented by all the initiatives that want to apply the MULTI-ACT framework.
- Additional indicators were selected considering their relevance based on the literature review, research expertise and frequency. After identifying the core one, two additional indicators were suggested from the remaining indicators of each aspects considering whether they were highly cited by the literature (even though they were not the most frequent) and they included relevant issues to evaluate a given dimension that were not contained in the core indicator. In some cases, as some aspects contain a low number of indicators, only one or none additional indicators were selected. Additional indicators are expected to be implemented by initiatives where staekholders regard an aspect as material when customizing the Master Scorecard or where the required information to provide the core indicator is lacking.

Given the dynamic nature of the Master Scorecard, further indicators were also classified and added to the Scorecard during the process of selecting core and additional indicators because of their high relevance for and connection to the CRIF dimensions and MULTI-ACT values.

3.2 Structure and information of the Master Scorecard

The Master Scorecard lists, at least, one core indicator for each aspect to be measured. As described above, it also includes additional indicators where it is appropriate. All core and additional indicators were studied in depth to collect information to develop the future steps of MULTI-ACT. More precisely, the information described in Table 2 is provided for each indicator. This information offers specific details for the construction and compilation of indicators. Additionally, the Master Scorecard structures the indicators in a way that allows the navigation among different dimensions, stage, aspect and group of indicators in an easy and manageable way.

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Name of the heading	Definition
Dimension according to the payback	PBM dimension to which the indicator belongs:
model (Level 1: adapted from PBM: Buxton & Hanney, 1996)	- Knowledge and research ("excellence")
,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	- Political and administrative ("social")
	- Health sector ("mission")
	- Broader economic ("economic")
Research stage indicator (Level 1: adapted from JPND)	- Input/Process/Output/Outcome/Impact
Aspect to be measured (Level 2: inductive classification)	The broader category into which similar gropus of indicators can be grouped
Group of indicators (Level 3: inductive classification)	The specific category into which similar indicators can be grouped
Description	Description of the indicator
Core/ Additional	Type of indicator within each aspect. CORE: expected to be provided by all initiatives; ADDITIONAL: recommended to increase accountability or because core is not possible to obtain
Advantages	Brief description of the advantages related to the adoption of the indicator
Disadvantages	Brief description of the disadvantages related to the adoption of the indicator
Quantitative/Qualitative	Qualitative: when the indicator consists in a narrative description or qualitative scale
	Quantitative: when the indicator is numerical (not necessarily in monetary units)
Additional information	Information to assist in compiling data and estimation of the indicator.

Table 2. Structure and information presented in the Master Scorecard



4 CRIF MASTER SCORECARD

The Master Scorecard translates MULTI-ACT mission and agenda into action. It is a catalogue that provides a long-list of top indicators assessing the impact of health RRI initiatives and considers key aspects of the four CRIF dimensions: mission, excellence, social and economic dimensions. It offers 115 indicators covering the 45 aspects of measurement that were identified across the accountability dimensions. Out of the 115 indicators, 46 are core and 69 are additional indicators. Such indicators will be complemented with a set of indicators related to the fifth CRIF dimension, i.e. the patient reported dimension, once the work which is being carried out in Task 1.5 will be completed.

Table 3 presents the distribution of indicators considering the dimension, aspect to be measured, whether they are core or additional and their research stage.

Dimension/Aspect	Core	Additional	Total selected	Total in WP3 Database
Mission dimension	10	13	23	433
Drug supply to patient	1	1	2	12
Governance	1		1	3
Health service assessment	1	2	3	33
Health services and products accessibility	1	2	3	75
Healthcare practitioners human capital	1	2	3	7
Improvement of health services	1	2	3	160
Influence on patient behaviour	1	1	2	8
Patient quality of life	1	2	3	111
Patient satisfaction	1		1	5
Stakeholder engagement	1	1	2	19
Excellence dimension	20	37	57	630
Academic production	1	2	3	76
Anticipatory design	1		1	1



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Bibliometric	1	2	3	60
Communication	1	2	3	28
Compliance	1	2	3	15
Ethics and integrity	1	2	3	9
Financial resources	1	2	3	64
Impact evaluation	1	2	3	20
Influence on public behaviour	1		1	3
Influence on subsequent research	1	2	3	41
Informing healthcare practice decision making	1	2	3	78
Intellectual property	1	2	3	22
Patient engagement & involvement	1	2	3	18
Products generated	1	3	4	37
Research partnership	1	2	3	32
Research recognition	1	1	2	11
Researchers' human capital	1	3	4	45
Resources allocated	1	2	3	15
Scientific input	1	2	3	33
Stakeholder engagement	1	2	3	22
Economic dimension	9	11	20	269
Anti-competitive behaviour	1		1	3
Control	1	1	2	63
Economic externalities	1	3	4	14



Financial performance	1	2	3	53
Improvement of health services	1		1	8
Intellectual property	1		1	3
Market	1	2	3	12
Organizational efficiency	1	2	3	85
Resources allocated	1	1	2	28
Social dimensions	7	8	15	224
Corporate reputation	1		1	2
Ethical marketing	1		1	5
Labour	1	3	4	27
Political externalities	1	2	3	15
Socio-environmental impacts	2	3	5	160
Stakeholder engagement	1		1	15
Total	46	69	115	1556

Table 3. Core and additional indicators selected per CRIF dimension

The complete Master Scorecard including the catalogue of indicators is attached to this deliverable as an Excel file (D3.6 Master Scorecard_with gender.xlsx). This file provides the information described in Table 2 (see section 3) for each indicator.

The Master Scorecard also pays attention to the monitoring of gender diversity, an essential element of RRI. When relevant, indicators are defined to consider the balance and the possible differences between women and men in measuring the impact of health research. Taking into account gender in relevant indicators has the aim of improving the societal relevance of health research in a RRI context. More specifically, twelve indicators are defined to be suitable to provide disaggregate data by sex (indicators number 19, 20, 25, 29, 32, 57, 88, 90, 91, 95, 105 and 106).

The Master Scorecard is paramount to the MULTI-ACT because it allows the project to establish the preliminary steps for developing a Digital Toolkit for health RRI. The Toolkit will offer health RRI initiatives the basis for the selection of appropriate indicators on the most relevant topics according to their mission and stakeholder interests. Therefore, the Master Scorecard will work as an adaptive



tool that enables evaluating, monitoring and understanding the impact and progress of research impact by customizing and tailoring the tool to different contexts and missions.

The Master Scorecard will be enriched, customized and implemented in the subsequent MULTI-ACT work packages. It will work as an input for developing the MULTI-ACT Digital Toolbox (WP2) and the disease specific scorecards delivered in other work packages (WP4, WP7). To enable these outcomes, the Master Scorecard possesses the following characteristics:

- Neutral and customizable. The Master Scorecard allows flexibility. It should not be used as a
 fixed set of indicators to assess the impact of health research of every RRI project/initiative. It
 offers a common starting point to be applied and tested to MS case study, to other brain
 diseases and multi-stakeholder RRI initiatives in general. As abovementioned, the indicators'
 relevance depends on the needs of the user and the specific mission of the initiatives.
- **Dynamic and open.** The Master Scorecard allows adaption. The initiatives using the Master Scorecard can add new indicators as per their specific needs.
- **Usable.** The Master Scorecards is constructed in a way that can be used, customized and applied by a broad range of users.
- **Comprehensive**. The Master Scorecard consists of a catalogue of core and additional indicators covering a wide range of aspects that could be relevant to assess the impact of health research. Therefore, it allows initiatives to select among a different topics and possibilities according to their needs.

The subsequent improvement of the preliminary Master Scorecard based on the feedback about its usability and applicability provided by the case study initiative in WP4 will reassure its consistency and robustness. Furthermore, Appendix 1 provides the final taxonomy or structure for the enrichment of the Master Scorecard and its translation in an online catalogue made available via the digital toolbox after the submission of this deliverable. The enrichment process aims to:

- (1) Add evidence for qualitative indicators (i.e declare if they have a code of conduct)
- (2) Add metrics for quantitative indicators
- (3) Indicate what are the indicators already in use (increase credibility)
- (4) Analyze the feasibility to obtain data to provide indicators.

In the next stages of the process, the final structure of the ultimate Master Scorecard will be demonstrated (in WP2), the enrichment and fine-tuning of indicators for a selected MS case study will be carried (in WP4) and a test of transferability to other brain diseases will be performed (in WP7).

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REFERENCES

Adam, P., Ovseiko, P. V., Grant, J., Graham, K. E., Boukhris, O. F., Dowd, A. M., & Sued, O. (2018). ISRIA statement: ten-point guidelines for an effective process of research impact assessment. *Health Research Policy and Systems*, 16(1), 8.

Anderson, M., & McCleary, K. K. (2016). On the path to a science of patient input. *Science translational medicine*, 8(336), 336ps11-336ps11.

Andreaus, M., & Costa, E. (2014). Toward an integrated accountability model for nonprofit organizations. In E. Costa, L. Parker, M. Andreaus *Accountability and social accounting for social and non-profit organizations* (pp. 153-176). Emerald Group Publishing Limited. Bradford, United Kingdom.

Banzi, R., Moja, L., Pistotti, V., Facchini, A., & Liberati, A. (2011). Conceptual frameworks and empirical approaches used to assess the impact of health research: an overview of reviews. *Health Research Policy and Systems*, 9(1), 26.

Barker, K. (2007). The UK Research Assessment Exercise: the evolution of a national research evaluation system. *Research evaluation*, 16(1), 3-12.

Bhattacharyya, A., & Cummings, L. (2013). Measuring corporate environmental performance—stakeholder engagement evaluation. *Business Strategy and the Environment*, *24*(5), 309-325.

Buxton, M., Hanney, S., Morris, S., Sundmacher, L., Mestre-Ferrandiz, J., Garau, M., et al. (2008). *Medical Research: What is it worth? Estimating the economic benefits from medical research in the UK.* In UK Evaluation Forum. Academy of Medical Sciences, London.

Canadian Academy of Health Sciences (CAHS 2009). *A Preferred Framework and Indicators to Measure Returns on Investment in Health Research*. Canadian Academy of Health Sciences, Ottawa.

Chan, A. P., & Chan, A. P. (2004). Key performance indicators for measuring construction success. Benchmarking: an international journal, 11(2), 203-221.

CHRODIS - Joint Action on Chronic Diseases. Diabetes: a case study on strengthening health care for people with chronic disease. http://chrodis.eu/wp-content/uploads/2017/02/wp7-deliverable-recommendations-final-draft.pdf

Department of Health and Human Services. Victoria State Government (DHHS). https://dhhs.vic.gov.au/

D'Este, P., Tribó, J. A., & García-Romero, A. (2008). Collaboration with universities and innovate activity in the Spanish pharmaceutical industry (2003-2005). *Medicina clinica*, 131, 66-70.

Era-Net Neuron. Development and advancement in methods and technologies towards the understanding of brain diseases' Joint Transnational Call 2009. Impact Report https://www.neuron-eranet.eu/ media/JTC2009 Impact-Report final.pdf

Gavi the global Vaccine Alliance. https://www.gavi.org



Global Reporting initiatives (GRI 2013). G4 sustainability reporting guidelines: Reporting principles and standard disclosures. *Global Reporting Initiative*, Amsterdam, 7-14.

Graham, K. E., Chorzempa, H. L., Valentine, P. A., & Magnan, J. (2012). Evaluating health research impact: Development and implementation of the Alberta Innovates – Health Solutions impact framework. *Research Evaluation*, 21(5), 354-367.

Innovative Medicines Initiative (IMI 2012). Bibliometric analysis of ongoing projects: Innovative Medicines Initiative Joint Undertaking (IMI). https://www.imi.europa.eu/sites/default/files/uploads/documents/reference-documents/IMI%20JU%20Bibliometric%20Report%201_FINAL.pdf

Innovative Medicines Initiative (IMI 2014). Bibliometric analysis of ongoing projects. https://www.imi.europa.eu/sites/default/files/uploads/documents/reference-documents/BibliometricsReport5.pdf

Innovative Medicines Initiative (IMI 2017). The Annual Activity Report. https://www.imi.europa.eu/sites/default/files/uploads/documents/About-IMI/Governance/Governing-Board/IMI2-GB-DEC-2018-17 Decision%20AAR%202017-GB%20Assessment_signed%2026JUN.pdf

Innovative Medicines Initiative (IMI 2018). Third amended annual work plan and budget for 2018. https://www.imi.europa.eu/sites/default/files/uploads/documents/reference-documents/IMI2-GB-DEC-2018-23 Annex 3rd amended AWP-Budget2018 ADOPTED 13JUL2018.pdf

Joint Programme – Neurodegenerative Disease Research (JPND 2016). Recalibrated Monitoring and Evaluation Framework for the EU Joint Programme – Neurodegenerative Disease Research (JPND). http://www.neurodegenerationresearch.eu/wp-content/uploads/2012/05/2016-JPND-Recalibrated-Monitoring-and-Evaluation-Framework.pdf

Kalucy, E. C., Jackson-Bowers, E., McIntyre, E., & Reed, R. (2009). The feasibility of determining the impact of primary health care research projects using the Payback Framework. *Health Research Policy and Systems*, 7(1), 11.

Krizanova, A., Gajanova, L., & Nadanyiova, M. (2018). Design of a CRM Level and Performance Measurement Model. *Sustainability*, 10(7), 2567.

Kuruvilla, S., Mays, N., Pleasant, A., & Walt, G. (2006). Describing the impact of health research: a Research Impact Framework. *BMC Health Services Research*, 6(1), 134.

Lewin, K. (1946). Action research and minority problems. Journal of social issues, 2(4), 34-46.

Liebow, E., Phelps, J., Van Houten, B., Rose, S., Orians, C., Cohen, J., et al. (2009). Toward the assessment of scientific and public health impacts of the National Institute of Environmental Health Sciences Extramural Asthma Research Program using available data. *Environmental Health Perspectives*, 117(7), 1147.

Loughney, D., Claus, B. L., & Johnson, S. R. (2011). To measure is to know: an approach to CADD performance metrics. *Drug Discovery Today*, 16(13-14), 548-554.

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Low, Y. S., Halim, I., Adhitya, A., Chew, W., & Sharratt, P. (2016). Systematic framework for design of environmentally sustainable pharmaceutical supply chain network. *Journal of Pharmaceutical Innovation*, 11(3), 250-263.

Mehrpouya, A., & Samiolo, R. (2016). Performance measurement in global governance: Ranking and the politics of variability. *Accounting, Organizations and Society,* 55, 12-31.

Milat, A. J., Bauman, A. E., & Redman, S. (2015). A narrative review of research impact assessment models and methods. *Health Research Policy and Systems*, 13(1), 18.

Monitoring the Evolution and Benefits of Responsible Research and Innovation (MoRRI 2018). The evolution of Responsible Research and Innovation in Europe: The MoRRI indicators report. https://www.technopolis-group.com/report/evolution-responsible-research-inovation-europe-morri-indicators-report-d4-3/

Ng, J., Scahill, S., & Harrison, J. (2018). Stakeholder views do matter: A conceptual framework for medication safety measurement. *Journal of Pharmaceutical Health Services Research*, 9(1), 21-31.

OECD (2010). *Glossary of Key Terms in Evaluation and Results Based Management*. OECD, France. Available at: https://www.oecd.org/dac/evaluation/2754804.pdf [Accessed: 13/05/2019]

Oortwijn, W. J., Hanney, S. R., Ligtvoet, A., Hoorens, S., Wooding, S., Grant, J., . . . Bouter, L. M. (2008). Assessing the impact of health technology assessment in the netherlands. *International Journal of Technology Assessment in Health Care*, 24(3), 259-269.

Ovseiko, P. V., Oancea, A., & Buchan, A. M. (2012). Assessing research impact in academic clinical medicine: a study using Research Excellence Framework pilot impact indicators. *BMC Health Services Research*, 12(1), 478

Parisi, C. (2013). The use of causal mapping in the design of sustainability performance measurement systems: Evidence from Novo Nordisk. In *Accounting and Control for Sustainability* (pp. 231-264). Emerald Group Publishing Limited.

Pedrini, M., Langella, V., Battaglia, M. A., & Zaratin, P. (2018). Assessing the health research's social impact: a systematic review. *Scientometrics*, *114*(3), 1227-1250.

Ramanathan, S., Reeves, P., Deeming, S., Bailie, R. S., Bailie, J., Bainbridge, R., . . . Searles, A. (2017). Encouraging translation and assessing impact of the centre for research excellence in integrated quality improvement: Rationale and protocol for a research impact assessment. *BMJ Open*, 7(12).

Ramanathan, S., Reeves, P., Deeming, S., Bernhardt, J., Nilsson, M., Cadilhac, D. A., . . . Searles, A. (2018). Implementing a protocol for a research impact assessment of the centre for research excellence in stroke rehabilitation and brain recovery. *Health Research Policy and Systems*, 16(1), 71.

Roundtable on Sustainable Biomaterials (RSB 2016). RSB Monitoring and Evaluation Impact Indicators, version 1.2. http://rsb.org/wp-content/uploads/2017/03/RSB-Impact-Indicators.pdf

Salton, R., & Jones, S. (2015). The corporate social responsibility reports of global pharmaceutical firms. *British Journal of Healthcare Management*, 21(1), 21-25.

24



Salvetti, M., Lubetzki, C., Kapoor, R., Ristori, G., Costa, E., Battaglia, M. A., ... & Zaratin, P. (2018). Steps towards Collective Sustainability in Biomedical Research. *Trends in molecular medicine*, *24*(5), 429-432.

Sarli, C. C., Dubinsky, E. K., & Holmes, K. L. (2010). Beyond citation analysis: A model for assessment of research impact. *Journal of the Medical Library Association*, 98(1), 17–23.

Searles, A., Doran, C., Attia, J., Knight, D., Wiggers, J., Deeming, S., . . . Nilsson, M. (2016). An approach to measuring and encouraging research translation and research impact. *Health Research Policy and Systems*, 14(1), 60.

Shabaninejad, H., Mirsalehian, M. H., & Mehralian, G. (2014). Development of an integrated performance measurement (PM) model for pharmaceutical industry. *Iranian Journal of Pharmaceutical Research*, 13, 207.

Sustainable Development Goals (SDG). Global indicator framework for the Sustainable Development Goals and targets of the 2030 Agenda for Sustainable Development. https://unstats.un.org/sdgs/indicators/Global%20Indicator%20Framework A.RES.71.313%20Annex. pdf

Torkko, M., Katajavuori, N., Linna, A., & Juppo, A. M. (2014). The utilization of quality KPIs in the pharmaceutical industry. *Journal of Pharmaceutical Innovation*, 9(3), 175-182.

Trimble, M., & Plummer, R. (2018). Participatory evaluation in times of governance transition: The case of small-scale fisheries in Uruguay. *Ocean & Coastal Management*, *161*, 74-83.

UN Statistics. Global indicator framework for the Sustainable Development Goals and targets of the 2030 Agenda for Sustainable Development https://unstats.un.org/sdgs/indicators/Global%20Indicator%20Framework%20after%20refinement.English.xlsx

Weiss, A. P. (2007). Measuring the impact of medical research: Moving from outputs to outcomes. *American Journal of Psychiatry*, 164(2). 206–14.

Westrich, K. D., Wilhelm, J. A., & Schur, C. L. (2016). Comparative effectiveness research in the USA: when will there be an impact on healthcare decision-making? *Journal of comparative effectiveness research*, 5(2), 207-216.

WHO Essential Medicines and Health Products Information Portal. http://apps.who.int/medicinedocs/en/d/Js2289e/8.5.html

Yaghmaei, E. (2018). Responsible research and innovation key performance indicators in industry: A case study in the ICT domain. *Journal of Information, Communication and Ethics in Society, 16*(2), 214-234.

Zaratin, P., & Salvetti, M. (2018). Evaluation woes: define metrics from the off. Nature, 559(7714), 331.

Zaratin, P., Battaglia, M. A., & Abbracchio, M. P. (2014). Nonprofit foundations spur translational research. *Trends in pharmacological sciences*, *35*(11), 552-555.

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APPENDIX 1. TAXONOMY FOR ENRICHMENT OF THE CRIF MASTER SCORECARD

Name of the heading	Definition
Name of the indicator	Short name of the indicator
Definition	Description of the indicator
Topic-Dimension	PBM dimension to which the indicator relates to:
	- Excellence
	- Social
	- Efficacy
	- Economic
Topic- Aspect to be measured	Indicate the overall aspect that the indicator evaluates within each dimension.
Rationale	Relevance of the indicator and advantages for its use.
Core/ Additional	Type of indicator within each aspect. Core indicators are key to evaluate each aspect. Additional indicators evaluate some areas which are not covered by the core indicators but that are relevant to provide a more in depth evaluation of the aspect. Additional indicators can also be provided when computing the core indicator is not feasible.
Data Type Representation	Type of indicator: Qualitative/Quantitative. For quantitative indicator, provide additional classification: percentage, ratio, absolute number.
Associated terms	Definition of associated terms that are relevant for understanding the definition of the indicator.
Preferred data sources	Datasources preferred for gathering the data required for elaborating the indicator. The initiative should provide information that indicate the accurateness of the data.

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Method of measurement	Description of method and/or process to elaborate and report the indicator.
Type of information to be reported by the initiatives	Indicate the type of information that the initiative must provide to disclose the indicator. This information helps to determine the input areas that the users will need to feed into the Toolbox.
Monitoring & Evaluation framework	Stages of the research process to which the indicator relates: - Input (resources used) - Process (if applicable) - Output (goods & services directly produced) - Impacts or final outcomes (long term changes)
Unit of measure	Indication of the unit in which the indicator is measured. Only in those cases where it is applicable.
Expected frequency of data dissemination	Indication of the frequency in which the data would be disseminated.
Expected frequency of data collection	Indication of the frequency in which the data would be collected.
Limitations	Main problems that could emerge when elaborating the indicators and potential disadvantages and/or shortcoming when using the indicators
Indicators in use	Indication of whether the indicator is currently being used: Yes/No
Example	Example of a report, webpage, etc on how to elaborate the indicator.
Links	Links of interest to either understand or compute the indicator.
Comments	Additional comments.



Feasibility	of elaborating the
indicator	

The initiative shall indicate whether it considers that it has access to the data needed to compute the indicator considering the data sources and additional information provided in the scorecard. To be filled by the initiative: Yes/No.