



Deliverable D2.2

MULTI-ACT content and data collection manual

“It will specify the data and content collection procedures and the annotation of content based on common expert-generated vocabularies.

In this way, the relevant experts and stakeholders will continuously update the knowledge base of the project with the content that they collect.”



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Short description of the Deliverable (as in the DoA):

This document details the implementation of the acquired knowledge regarding the MULTI-ACT project, and more precisely the content collection, modelling and integration processes required to provide the MULTI-ACT toolbox with relevant, attractive and validated Collective Research Impact Framework related content.

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EXECUTIVE SUMMARY

Based on the outcomes of the Collective Research Impact Framework (CRIF) that was developed in WP3 and WP5, the initial version of the MULTI-ACT Toolbox v1 was created and its initial testing phase was commenced. This enabled further identification of all foreseen content that exceeds the strictly required data for the Toolbox use and core functionalities and aided to define the necessary mechanisms that will ensure the proper classification and annotation of all anticipated data and content.

These added functionalities will facilitate the ongoing enrichment of the Toolbox and the overall propagation of the Multiple Sclerosis (MS) Research Impact database, to later account for other brain diseases, guaranteeing the continuous enhancement of the Toolbox and its value in collecting valuable sources of information in its life course and making them available among its users.

The accumulation of all content will be done in parallel with the continuous updating of the expert vocabularies used for its annotation, ensuring that the users and stakeholders will benefit from the ongoing enrichment by the acquired knowledge.

1 INTRODUCTION

1.1 Purpose of this document

The purpose of this document is to present the overall data & content collection requirements and mechanisms related to MULTI-ACT Toolbox core functionalities as well as the organization of the content and data collection processes that will enable the accumulation of relevant Collective Research Impact Framework related structured content.

Furthermore, it provides the modelling and integration activities that were perceived, leading to the development of specific user roles and functionalities necessary for the collection and administration of all relevant data. This entails, apart from the procedures already identified in D2.1 Methodology & Design principles of the MULTI-ACT Toolbox deliverable, new sources and methods of data acquisition that will lead to creation and enrichment of a MS Research Impact database.

Finally, it analyses the manner in which all collected content is annotated based on the expert-generated vocabularies developed in the MULTI-ACT project which will ensure the proper classification of all the accumulated content so as to be validated and usable in the MULTI-ACT Toolbox.

1.2 Structure of document

Section 2 describes the data requirements and the relevant content collection functions that were implemented to support the core functionalities of the MULTI-ACT Toolbox v1. That includes all user data, the initiatives' collected information as well as all data related to the impact assessment indicators.

Section 3 describes the additional data collection mechanisms and functions that were defined and are currently being developed in order to collect additional Collective Research Impact Framework related content.

Section 4 portrays the enriched Taxonomy that was defined to enable the annotation of all collected content as well as the required user roles and functionalities that were implemented in the Toolbox in order to administer the Taxonomy enrichment and subsequent use.

1.3 Acronyms and Abbreviations

CMS	Content Management System
CRIF	Collective Research Impact Framework
EBC	European Brain Council
EY	Ernst & Young
FISM	Fondazione Italiana Sclerosi Multipla FISM Onlus
GUI	Graphical User Interface
MS	Multiple Sclerosis
RFPO	Research Funding and Performing Organizations

RRI	Responsible Research and Innovation
DiA	Dane i Analizy
UBU	University of Burgos
URL	Uniform Resource Locator

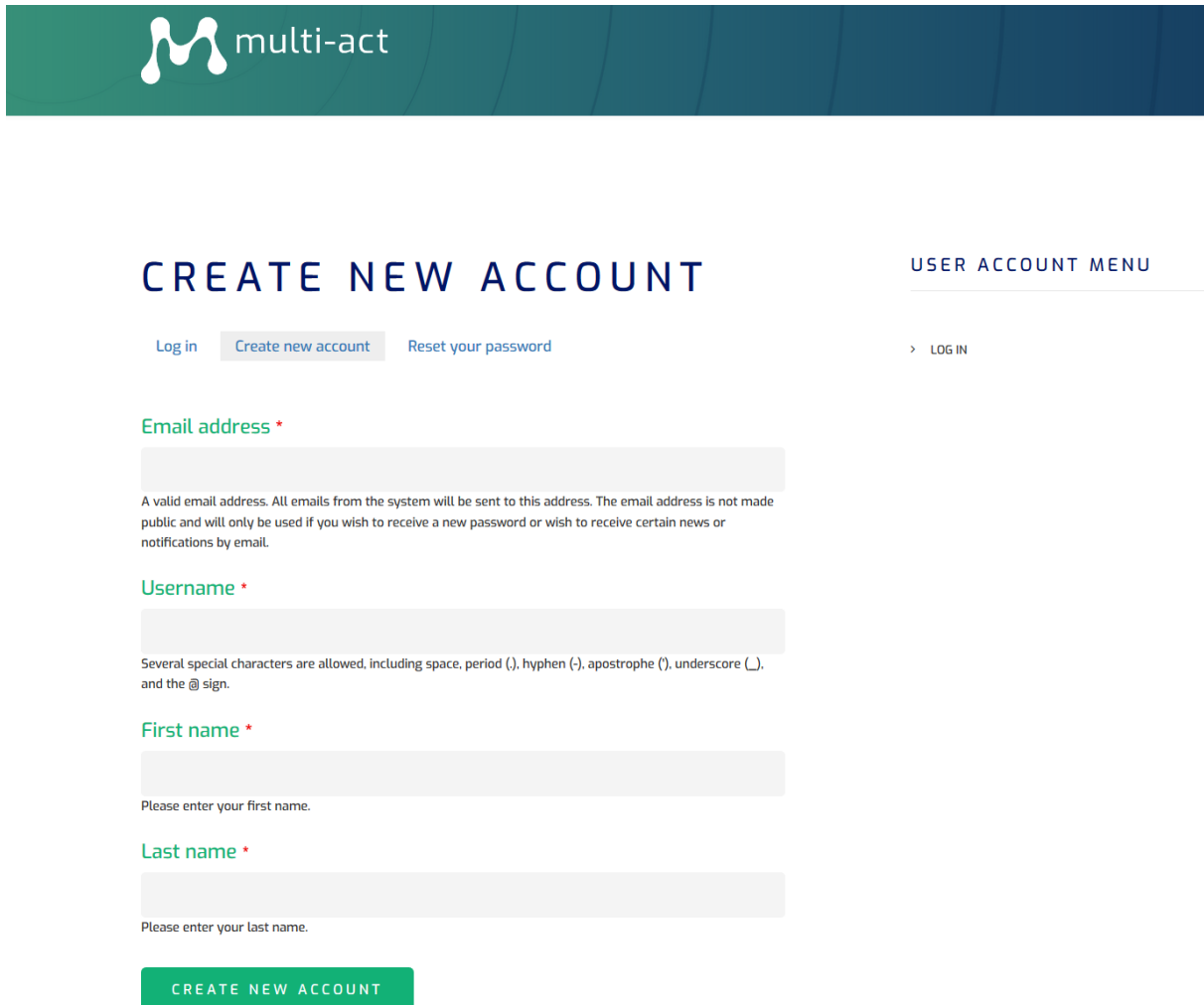
2 MULTI-ACT Toolbox Data Requirements and Content Collection Functions


The data required for the implemented functionalities of the MULTI-ACT Toolbox v1 is hereby described.

2.1 User-Promoter

Upon registering, a new user, acting as the promoter of a multi-stakeholder research initiative provides only basic information (Figure 1 – User-Promoter Information) that consists of:

- Name
- Surname
- Email address



 multi-act

CREATE NEW ACCOUNT

[Log in](#) [Create new account](#) [Reset your password](#)

[> LOG IN](#)

Email address *

A valid email address. All emails from the system will be sent to this address. The email address is not made public and will only be used if you wish to receive a new password or wish to receive certain news or notifications by email.

Username *

Several special characters are allowed, including space, period (.), hyphen (-), apostrophe ('), underscore (_), and the @ sign.

First name *

Please enter your first name.

Last name *

Please enter your last name.

[CREATE NEW ACCOUNT](#)

Figure 1 – User-Promoter Information

This minimum information is required to ensure the functionality of password recovery and can be updated at any point by the user using the profile editing option. (Figure 2 – User Information Edit)

MY INITIATIVES

MS INITIATIVE 01

MS Initiative 02b

TEST INITIATIVE
INTRA

SINGLE PROJECTS

Single Project

ADD CONTENT

+ Add Initiative

JOHN21

View Edit

Current password

Required if you want to change the *Email address* or *Password* below. [Reset your password.](#)

Email address *

john.smith@somewhere.com

A valid email address. All emails from the system will be sent to this address. The email address is not made public and will only be used if you wish to receive a new password or wish to receive certain news or notifications by email.

Password

Password strength:

Confirm password

Passwords match:

To change the current user password, enter the new password in both fields.

First name *

John

Please enter your first name.

Last name *

Smith

Please enter your last name.

SAVE

USER ACCOUNT MENU

> MY ACCOUNT

> LOG OUT

Figure 2 – User Information Edit

2.2 Initiatives

The Initiative's information collected upon its creation (Figure 3 – Initiative Information) consists of:

- Title
- Initiative Type
- Promoter's Stakeholder Type
 - the different stakeholder types are the same as the ones illustrated under "Stakeholder Member Types" in Figure 3 – Initiative Information.
- Starting Year
- Number of Organizations involved
- Core Activities

- Stakeholder member types
- Geographical Coverage
- Parent Initiative
 - If a parent Programme initiative has completed the assessment process, for every child Project initiative the user is asked if the new Project initiative inherits/shares the same features as the parent Programme. If the user confirms the inheritance, the child Project does not have to undergo the Assessment process and subsequently shares the assessment status & score of its parent Programme.

CREATE INITIATIVE

Title *

Initiative Type *

Your stakeholder Type

Starting Year

Number of Organizations involved *

Core Activities

STAKEHOLDER MEMBER TYPES *

Geographical Coverage *

Parent Initiative

☐ Inherits Parent's Assessment

SAVE **PREVIEW**

USER ACCOUNT MENU

- > MY ACCOUNT
- > LOG OUT

MULTI-ACT MODEL BASELINE ANALYSIS

Complete

IMPACT ASSESSMENT

Add impact assessment

INDICATORS IN USE

Projects deviation

Figure 3 – Initiative Information

2.3 Indicators

The impact assessment of an initiative is facilitated with the use of the Master Scorecard developed in WP3. The Master Scorecard is a catalogue that provides a long list of indicators assessing the impact of health RRI initiatives considering key aspects of the CRIF dimensions: efficacy, economic, excellence social and patient-reported dimensions.

2.3.1 *Indicator Automatic Importer*

Due to the massive content of the Master Scorecard and its subsequent effort in the relevant data entry, an importing mechanism was developed that diminishes the human effort that would be otherwise required.

This importing mechanism parses the Master Scorecard input that was provided in an Excel form and automatically populates all relevant fields, rapidly carrying out complex actions that would require immense time and human effort, while eliminating the probable expected human errors that would be otherwise anticipated.

A [sample video](#) to show the output of this functionality is hosted at the Toolbox hosting server.

2.3.2 *Indicator Editing – Author Role*

The continuous enrichment of the Master Scorecard indicators as well as the general need of editing their content demanded for a new user role to be defined to be able to facilitate this need.

This role was then appointed to Academic members of the MULTI-ACT Consortium empowering them in continuous enhancement and validation of the indicators content.

The users bearing the role of Author can search for a given indicator via:

- Search function (Figure 4 – Indicator Search A). The keyword-based search is performed into all text fields of the Master Scorecard.
- Dropdown Menus based on the Indicator's CRIF Taxonomy (Scorecard) reference. (Figure 5 – Indicator Search B)



SEARCH FOR LIFE SATISFACTION INDEX

[Content](#) [Indicators](#) [Users](#)

Enter your keywords: Life Satisfaction Index

SEARCH

[Search help](#)

Advanced search

SEARCH RESULTS

LIFE SATISFACTION INDEX

Life Satisfaction Index Indicator code 181 ... comparisons. Considering that the measurement of patient **satisfaction** is disease-specific, the measurement of the ...

USER ACCOUNT MENU

> MY ACCOUNT

> LOG OUT

Figure 4 – Indicator Search A

INDICATORS

[ADD CONTENT](#)
[+ Add Indicator](#)

Filter by Scorecard Reference

- Any -

- Any -

CRIF Dimensions

-Economic

--Resources allocated

---Employment

--Organizational efficiency

---Quality

---Employment

---Cost savings

---Cost

--Financial performance

---Financial stability

---Profitability

---Revenue

--Anti-competitive behaviour

---Anti-competitive behaviour

--Control

---Control process

--Economic externalities

---Indirect economic impact

Percentage change in how patients are satisfied with their level of functional domains evaluated by the scale after the care received (self reported)

HADS - Hospital Anxiety and Depression Scale


Percentage change in how patients are satisfied with their level of Anxiety and Depression after the care received (self reported)

Transparency in sustainability reporting

Disclosure of public reports about the economic, social and environmental impacts resulting from the initiative/project's research and how these impact are being managed.

Figure 5 – Indicator Search B

Upon selecting an indicator, the users are able to update its content through a GUI that offers rich HTML capabilities (Spelling Correction, Formatting, etc.) (Figure 6 – Indicator Editing).



multi-act

INDICATORS
INITIATIVES
PROFILE

EDIT INDICATOR

ABILHAND - MANUAL ABILITY FOR ADULTS WITH UPPER LIMB IMPAIRMENT

View
Edit

Title *

Abilhand - Manual ability for adults with upper limb impairment

Description *

Percentage change in how patients are satisfied with their level of upper-limb dexterity after the care received (self reported) |

Description of the indicator.

Rationale

The indicator facilitates comparisons. Considering that the measurement of patients' satisfaction with their level of upper-limb dexterity is disease-specific, the measurement of the percentage change provides a standardized measure of patient satisfaction.

Relevance of the indicator and advantages for its use.

Core/ Additional *

Core

Figure 6 – Indicator Editing

3 MULTI-ACT Toolbox Additional Data and Content Collection Functions

3.1 Baseline Analysis Uploaded Content

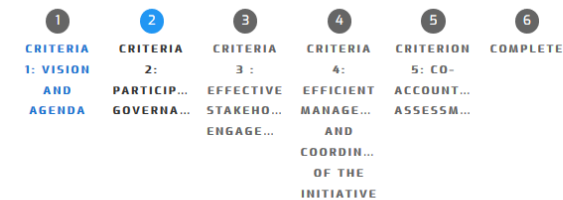
Prior to a user being able to undergo the Impact Assessment of their initiative, they must complete the Baseline Analysis Questionnaire which assesses the level of adherence of the initiative with MULTI-ACT Framework's Governance Model.

During this process a multitude of information is collected, addressing the initiative's governance, vision, management etc.). The questionnaire also entails several complex functionalities aiming to make the process as user friendly as possible i.e.

- Dynamic content based on previous answers given.
- Pagination and completion status/percentage.
- Draft submissions so that a user can return to complete the questionnaire at a future point in time.
- Etc.

MULTI-ACT FRAMEWORK BASELINE ANALYSIS

View Results



Page 2 of 6 (20%)

5) Have you established a governance structure for your research initiative?

Yes

5.1) Could you please describe the different bodies in your governance (e.g. boards committees, working groups, teams, others) in your research initiative and describe their functions and composition.

The different bodies in your governance have x,y,z

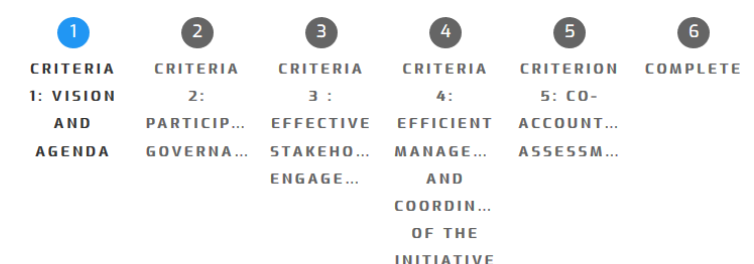
5.2) WHICH OF THE FOLLOWING STAKEHOLDERS ARE INVOLVED IN THE GOVERNANCE BOARD?

- ☐ Patients
(people with the diseases and affected by the diseases (i.e. relatives, caregivers))
- ☐ Patients organizations, patient associations, advocacy organizations, etc.
- ☐ Society individual citizens, civil society organizations and networks
- ☐ Payers and purchasers, public or private entities responsible for underwriting the costs of health care
- ☐ Care providers, health and social care organizations and professionals (doctors, nurses, etc.)
- ☐ Policy makers EU institutions; national, regional and local policy makers

Figure 7 – Baseline Analysis Questionnaire

Furthermore, a document collection functionality was implemented in the Baseline Analysis Questionnaire to assist with document uploading for a variety of supporting documents (Mission Statements, Initiative's Agendas, Documentation of Initiative's procedures and mechanisms).

The user is able to upload the requested documentation, while defining multiple rules regarding acceptable file attributes (number of files, file size, file types etc.) (Figure 8 – Baseline Analysis Content Uploads)



Page 1 of 6 (0%)

1) Have you developed a shared vision/mission for your initiative?

Yes
▼

Mission-Vision we mean the change you seek to achieve in the future

1.1) Please provide the mission statement and related documents to the mission.

Browse...

No files selected.

Maximum 5 files.
2 MB limit.
Allowed types: txt rtf pdf doc docx odt ppt pptx odp xls xlsx ods.

2) Do you have an agenda defining the priority areas, mid-term and long-term objectives and a set of actions to achieve the objectives of the initiative?

Yes
▼

2.1) Please provide the documents related to the agenda

Browse...

No files selected.

Maximum 5 files.
2 MB limit.
Allowed types: txt rtf pdf doc docx odt ppt pptx odp xls xlsx ods.

3) Could you please describe how you have defined the common objectives, priority areas and set of actions?

Figure 8 – Baseline Analysis Content Uploads

The accumulation of the Baseline Analysis results and documents provided by all the Toolbox users-initiatives, provides a major source of input of information for the population of the MULTI-ACT MS database.

3.2 Impact Assessment Support Documents

An additional source of user provided content that is currently being developed is document uploading as part of the Impact Assessment process. The users will be able to upload documents per selected indicator, properly annotating them with the use of the MULTI-ACT

Updated Taxonomy for Uploaded Content Annotation Use. The implemented content uploading and annotation functionalities will be documented in Deliverable D2.4 – MULTI-ACT Toolbox, v2.

3.3 Initiative Surveys

With the provided insight of the MS Care Unit that has commenced using the MULTI-ACT Toolbox, the specific need of an initiative to collect information from their stakeholders was revealed. The surveys present the first activity of the Research Initiative in order to collect vital inputs from their stakeholders, which are necessary for the governance of the research initiative as per the MULTI-ACT governance model. This presents the feasible setting for collecting and annotating content and data for the initiative’s purposes, and subsequently the MULTI-ACT goals.

To facilitate such need, three surveys of the MS Care Unit were implemented as part of the Toolbox functionalities, associated with the respective initiative “digital space” in the Toolbox, and are awaiting their finalization in order to be distributed among the initiative’s stakeholders. Through this process, crucial knowledge is to be gained as to the future needs of relevant research initiatives and their promoters in terms of required data for the governance of the research initiative as per the MULTI-ACT defined governance model.

The three surveys are to be addressed to Academic and non-academic Healthcare Units as well as to Practicing Neurologists and will enable the collection of various clinical data. (Figure 9 – MS Care Unit Survey)



Figure 9 – MS Care Unit Survey

The current designed implementation is that the initiative will initially populate their list of stakeholders in the Toolbox, so that it can then select the recipients that will undertake a survey.

Afterwards a unique survey web link (URL) will automatically be created for every stakeholder thus ensuring the valid identity of the participants enforcing the one-vote per stakeholder rule.

3.4 MULTI-ACT Guidelines

The outcome of the Baseline Analysis Questionnaire will result to a scoring assessment that will portray the initiative's adherence with the MULTI-ACT vision. Additionally, for every criterion or in some cases specific sets of questions per criterion that a passing score has not been achieved, specific guidelines will be given on how to achieve better adherence.

The Governance guidelines were delivered as the outcome of WP5 and are documented in Deliverable D5.4 *MULTI-ACT model for collaborative initiatives*, whereas the Patient Engagement Guidelines are documented in Deliverable D1.6 *Final version of the MULTI-ACT Patient Engagement in Health R&I guidelines*. The Toolbox will eventually present these guidelines in a user-friendly, contextualized and accessible manner, respecting at the same time any information that may be confidential or sensitive. The implementation of the guidelines as part of the Toolbox functionalities will be presented in D2.4 – MULTI-ACT Toolbox, v2.

4 Content Annotation Processes

4.1 Taxonomy Enrichment – Admin Role

In order to facilitate the need of the enrichment and overall editing of the MULTI-ACT Taxonomy after its initial definition in D2.1, the core Taxonomy module was installed on Drupal¹. This enables a user holding the role of Admin to administer all MULTI-ACT taxonomies by organising entities in categories and subcategories in a tree form. This has already been implemented in the *Master Scorecard* Taxonomy (Figure 10 – Master Scorecard Taxonomy)

Home » Administration » Structure » Taxonomy » Edit *Master Scorecard*

[+ Add term](#)

Master Scorecard contains terms grouped under parent terms. You can reorganize the terms in *Master Scorecard* using their drag-and-drop handles.

[Show row weights](#)














NAME	OPERATIONS
 CRIF Dimensions	Edit ▼
 Economic	Edit ▼
 Resources allocated	Edit ▼
 Employment	Edit ▼
 Organizational efficiency	Edit ▼
 Quality	Edit ▼
 Employment	Edit ▼
 Cost savings	Edit ▼
 Cost	Edit ▼
 Financial performance	Edit ▼
 Financial stability	Edit ▼
 Profitability	Edit ▼
 Revenue	Edit ▼

Figure 10 – Master Scorecard Taxonomy

The use of taxonomy enables regrouping and reorganizing of categories and subcategories by a simple drag and drop mouse movement, leading to the desired restructuring and automatically moving all the subsequent nodes.

¹ <https://www.drupal.org/>

4.2 Updated Taxonomy for Uploaded Content Annotation Use

For the document annotation needs, an annotation taxonomy has been collaboratively produced, which can be used in the classification of all collected documentation. A sample of the taxonomy outcome can be seen in Figure 14 - Content Annotation Taxonomy whereas the complete taxonomy is presented in APPENDIX 1 MULTI-ACT Annotation Taxonomy.

Content Annotation contains terms grouped under parent terms. You can reorganize the terms in *Content Annotation* using their drag-and-drop handles.

[Show row weights](#)

NAME	OPERATIONS
✚ Bibliometric	Edit ▼
✚ Academic search databases	Edit ▼
✚ Bibliometric datasources	Edit ▼
✚ Classification of journals with open access options, such as DOAJ list (Directory of Open Access Journals), PMC (PubMed Central), the ROAD list (Directory of Open Access scholarly Resources), CrossRef, and OpenAIRE	Edit ▼
✚ Google analytics or similar web engines.	Edit ▼
✚ Google scholar	Edit ▼
✚ Rankings of journals (e.g., JCR, SJR)	Edit ▼
✚ Scopus	Edit ▼
✚ Web of Science (WoS)	Edit ▼
✚ World Intellectual Property Organization Database	Edit ▼
✚ Codes And Guidelines	Edit ▼
✚ Code of conduct	Edit ▼
✚ Code of ethics	Edit ▼
✚ Community development plans	Edit ▼
✚ Guidelines	Edit ▼
✚ Official document containing evaluative criteria in the research proposal evaluation	Edit ▼

Figure 11 – Content Annotation Taxonomy

Subsequently, a user, upon uploading a document, will be able to easily annotate it, either via an auto-complete input field (Figure 12 – Auto-Complete Annotation) or by selecting a value in a tree like depiction of the annotation taxonomy. (Figure 13 – Annotation Tree-like Method)

Annotation

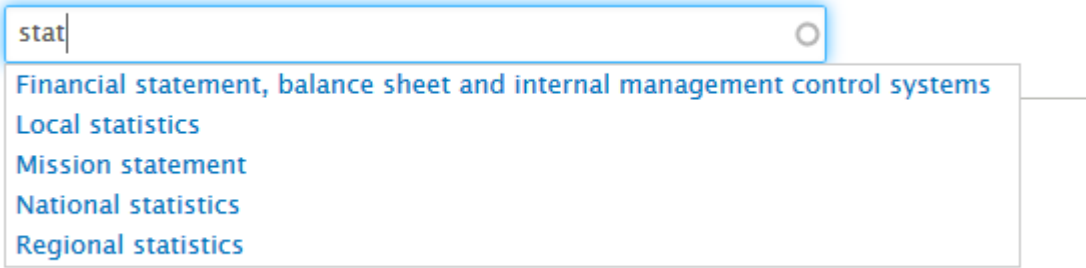


Figure 12 – Auto-Complete Annotation

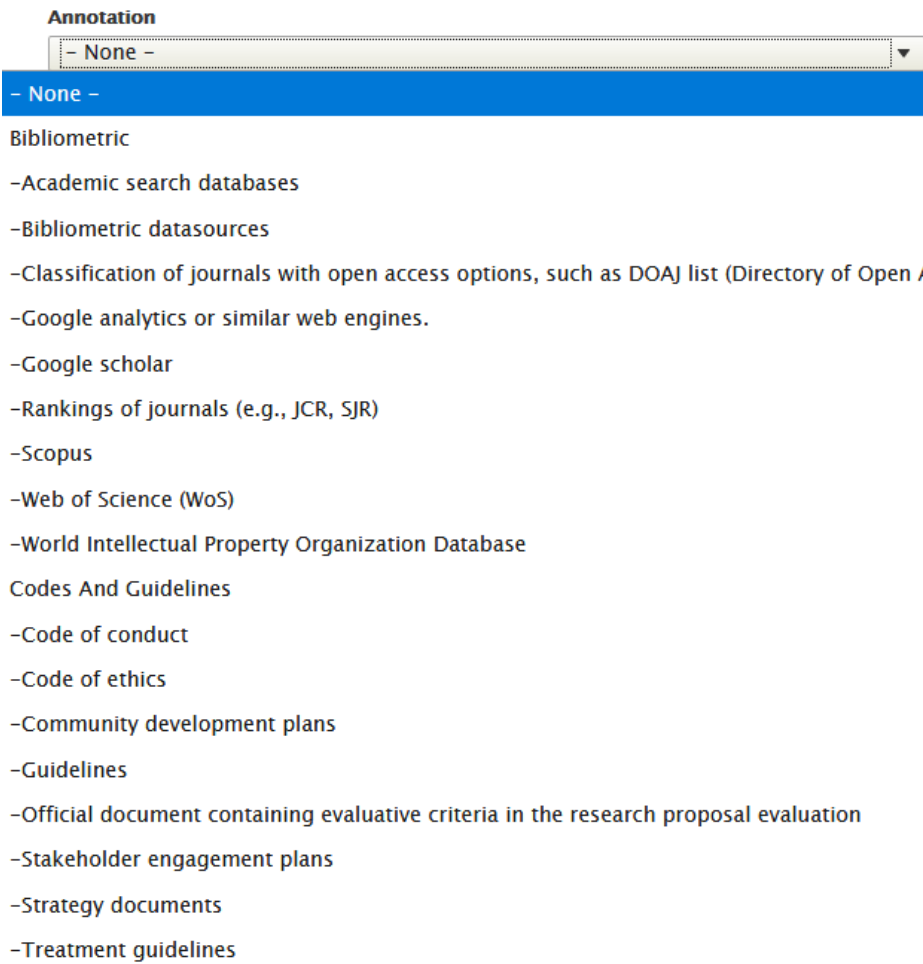


Figure 13 – Annotation Tree-like Method

5 CONCLUSIONS

Deliverable D2.2 has presented the data and content collection requirements and mechanisms related to MULTI-ACT Toolbox core functionalities as well as the organization of the content and data collection processes that will enable the accumulation of relevant Collective Research Impact Framework related structured content. It also described designed and in implementation Toolbox features and functions, supporting differentiated user roles and rights, introducing necessary author roles with content uploading, annotation and enrichment capabilities, as the feasible approach to collect and annotate content and data is through domain experts, users from relevant initiatives, etc.

In addition to capitalizing on internal consortium such domain expertise, in order to further and enrich the content and taxonomy related inputs and functionalities of the Toolbox, a first such activity has also been initiated with the first case study of MULTI-ACT, MS Care Unit. It has been agreed that respective surveys will be implemented in the Toolbox for use by the MS Care Unit and their users to fill in and collect vital information. This presents a first step towards knowledge acquisition of methods for data acquisition and in the long-term towards the creation and enrichment of an MS Research Impact database. Finally, the Deliverable further presented the enriched MULTI-ACT taxonomy for content annotation and the methods introduced in the Toolbox empowering users to easily annotate content and data, as well as easily enrich the taxonomy if necessary to ensure the proper classification of all the accumulated content so as to be validated and` usable in the MULTI-ACT Toolbox.

Figure 14 visually presents the graph of the Content Annotation Taxonomy for annotating uploaded Documents/Data to the MULTI-ACT Toolbox, whereas the subsequent table presents in more detail the Taxonomy dimensions and values/elements.

Figure 14 - Content Annotation Taxonomy

Bibliometric	
	Academic search databases
	Bibliometric data sources

Codes and Guidelines	Classification of journals with open access options, such as DOAJ list (Directory of Open Access Journals), PMC (PubMed Central), the ROAD list (Directory of Open Access scholarly Resources), CrossRef, and OpenAIRE
	Google analytics or similar web engines.
	Google scholar
	Rankings of journals (e.g., JCR, SJR)
	Scopus
	Web of Science (WoS)
	World Intellectual Property Organization Database
	Code of conduct
	Code of ethics
	Community development plans
	Guidelines
	Official document containing evaluative criteria in the research proposal evaluation
	Stakeholder engagement plans
	Strategy documents
	Treatment guidelines
	Clinical data
	Clinical information system
Health Records	Electronic health record system
	Electronic medical records
	Health care providers, clinics records
	Hospital data
	Hospital record information systems
	Medical costs
	Patient records
	Database and interviews
	Dedicated survey
	Expert survey
	Health surveys
	Interviews
	Interviews and/or surveys with practitioners/experts
	Interviews with practitioners/clinicians
	Market surveys
	Patient surveys and interviews
	Preference surveys
Interviews and Surveys	Public consultation
	Questionnaires used in trials

Reports	Questionnaires
	Surveys
	Annual reports
	Expected duration of life and degree of disability
	Financial statement, balance sheet and internal management control systems
	Human resource management report
	Initiative financial report
	Initiative scientific report
	Internal report
	Internal reports by press office
	Local data registries
	Local statistics
	Meeting reports of works councils
	Mission statement
	National statistics
	Policy report
	Records of service delivery
	Regional data registries
	Regional statistics
	Research report
	Scientific report
	Sustainability report
Other	
	Administrative data
	Billing and accounting systems, procurement or supply management department
	National registries
	Production and research sites of the company
	Professional association