



Deliverable D6.2

Online accessible guidelines (within MULTI-ACT website)



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

This deliverable consists in the creation of a dedicated section of the MULTI-ACT website where the manual and the other project's outputs will be made available to be downloaded and/or easily consulted by R&I actors for free usage.

REVISION HISTORY			
REVISION	DATE	COMMENTS	AUTHOR (NAME AND ORGANISATION)

V0.1	28/04/2021	First draft	Marcin Kautsch (DiA), Natalia Matuszak (DiA)
V0.2	30/04/2021	Final edited version	Valentina Tageo (FISM)

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This deliverable contains original unpublished work except where clearly indicated otherwise.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

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 the 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. These tools and methods 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 *D6.2 Online accessible guidelines* explains how DiA contributed to the textual layers of the Digital Toolbox. Originally, the deliverable D6.2 consisted in creation of a dedicated section of the MULTIACT website where the *Integrated CRIF Manual for R&I Actors* (D6.1) and the other project's outputs will be made available to be downloaded and/or easily consulted by R&I actors for free usage. However, the task was expanded into text in the entirety of the Toolbox.

This document explains the process of creation of the text, the implemented solutions in all components of the Digital Toolbox.

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 R&I actors and specifically Research Funding and Performing Organisations (RFPOs) who wish to embrace a more participatory approach in designing, executing and evaluating their research programs or projects and, thus, are the ultimate CRIF's Users.

Originally, the deliverable D6.2 consisted in creation of a dedicated section of the MULTIACT website where the *Integrated CRIF Manual for R&I Actors* (D6.1) and the other project's outputs will be made available to be downloaded and/or easily consulted by R&I actors for free usage.

However, during the project, DiA's contribution to the textual layer and testing of the Toolbox expanded to include:

- Creation of explanatory texts for all sections of the Toolbox,
- Review of the whole text in the Toolbox to maintain coherence with the Manual,
- Review of hyperlinks to the Manual and the MULTI-ACT website,
- Creation of additional captions which increased Toolbox's accessibility for visually impaired users.

WP6 Leader, DiA, has led these activities securing terminological coherence across the different phases of the project's work and the development of the Toolbox. This work started earlier with the creation of the project inter-WP glossary and continue along the whole duration of the project as the CRIF kept evolving during the development of both the Digital Toolbox and the Manual (D6.1), so it was necessary to monitor consistency between these two deliverables. Particular attention was paid to always providing explanation of the terms with which a new CRIF user may not be familiar with – either by footnotes or by hyperlinks to the Manual.

1.1 Process of developing the textual layer

The process of developing the explanatory texts was continuous, occurring when technical development of the Toolbox functionalities dictated. The dedicated Manual section of the Digital Toolbox website was completed after the D6.1 was finalised. DiA and INTRA collaborated intensely throughout the process.

1.2 Purpose of this document

This document's purpose is to present briefly DiA's contribution to the textual layer of the Toolbox and the dedicated Manual section and explain the process of their creation and implementation.

1.3 Structure of document

The document presents parts of the Toolbox for which DiA created textual layer, together with the solutions employed and rational behind them.

- [HOME PAGE](#) present text created for the Home Page,
- [DEDICATED MANUAL SECTION](#) shows how the Manual's text was adapted to the website,

- [INITIATIVE OVERVIEW PAGE](#) gives an overview of how explanatory texts link the Toolbox functionalities to the Manual.
- [FUNCTIONALITIES](#) presents textual contribution inside specific functionalities of the Toolbox.

1.4 Acronyms

ARSEP	Fondation Pour L'aide A La Recherche Sur La Sclérose En Plaques
BA	Baseline Analysis
CRIF	Collective Research Impact Framework
DiA	Dane-i-Analizy.pl sp. z o.o.
EBC	European Brain Council
EC	European Commission
EHMA	European Health Management Association
EU	European Union
EY SPA	Ernst & Young Financial Business Advisors
FISM	Fondazione Italiana Sclerosi Multipla FISM Onlus
INTRA	Intrasoft International
MA	Materiality Analysis
MSC	Master Scorecard
PRD	Patient-reported dimension
PROMs	Patient Reported Outcomes Measures
PROs	Patient Reported Outcomes
R&I	Research and Innovation
RFPO	Research Funding and Performing Organization
RRI	Responsible Research & Innovation
TAU	Tampereen Yliopisto

UBU	Universidad De Burgos
UCP	Universidade Catolica Portuguesa
UNITN	Università Degli Studi Di Trento
WP	Work Package

2 HOME PAGE

The home page contains introductions to:

- The MULTI-ACT project,
- The Digital Toolbox,
- The Digital Toolbox's functionalities: Baseline Analysis, Patient Engagement Plan, Materiality Analysis, Master Scorecard.

The language is simple and aims to encourage (potential) user to explore the Toolbox and the CRIF further. To this end, it concentrates on benefits of adopting the CRIF, the Toolbox and each separate functionality. Hyperlinks to chapters of the Manual are provided as an easy way for an interested reader to learn more about each component of the CRIF.

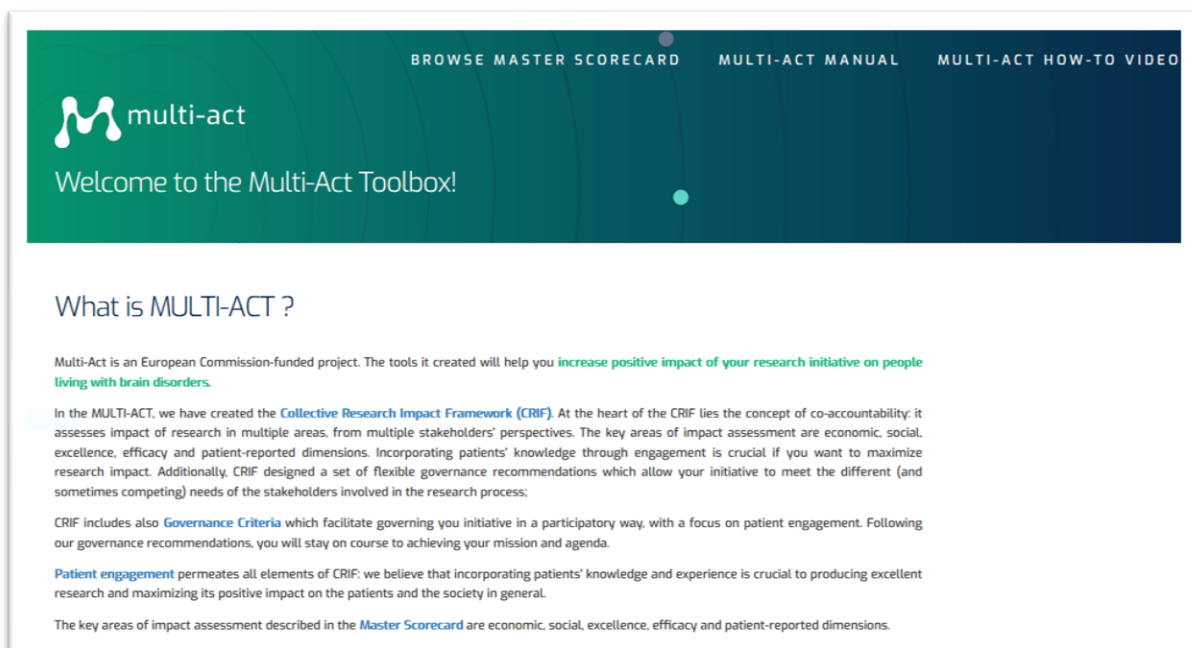


Figure 1 Home page: introduction to Multi-Act

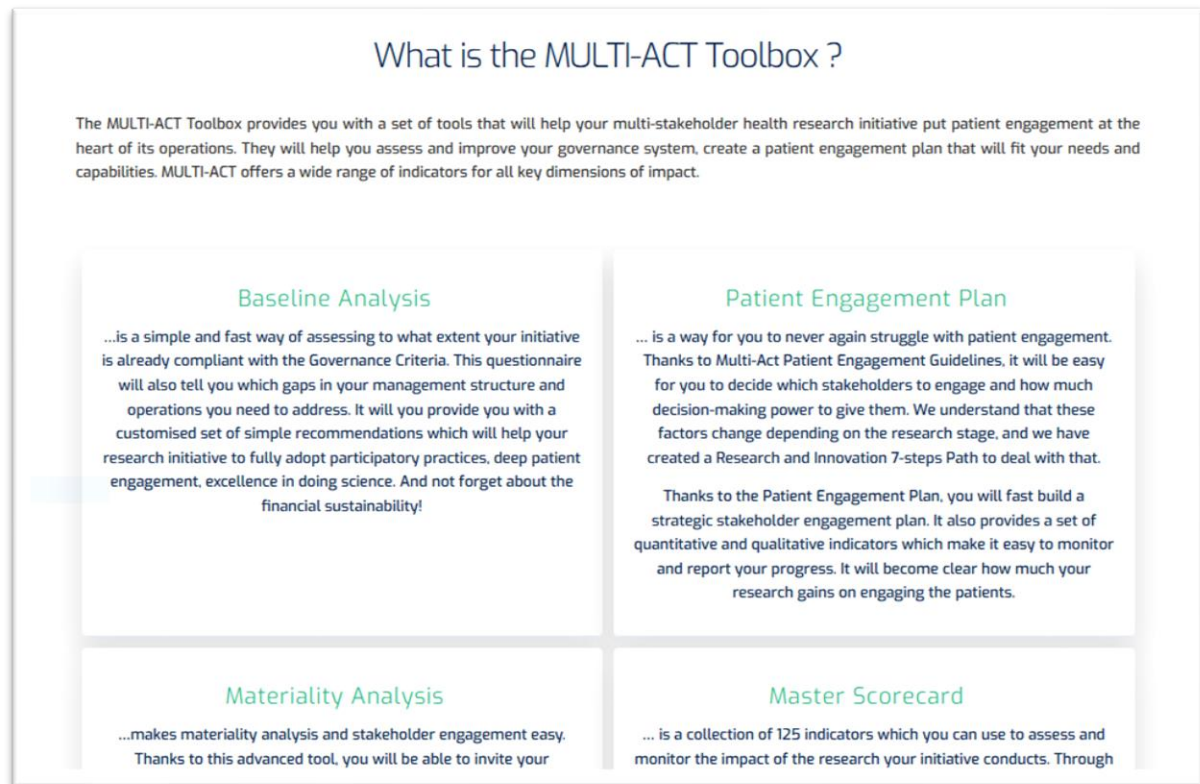


Figure 2 Home page: introduction to Toolbox functionalities

3 DEDICATED MANUAL SECTION

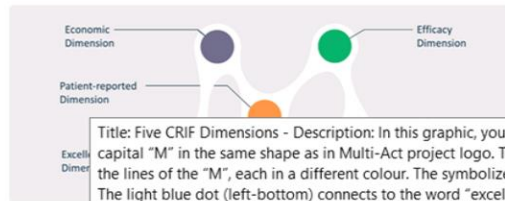
The dedicated Manual section of the Toolbox website contains the text of the D6.1 meant for the public (i.e. without the introduction meant solely for the EC reviewer), adapted to be used as a reference point by the Toolbox user.

The Manual makes full use of the hyperlinks interconnecting its different sections that are present also in the .pdf version. Elements typical to “book” form of the Manual, as page numbers, numbering of the headers, figures and tables captions were reduced to necessary minimum for technical reasons and simplify the structure.

At the same time, special attention was paid to increase accessibility of the Manual for visually impaired readers: DiA created long captions for each illustration, explaining its “unreadable” contents.

will choose the most relevant ones for, creating a customised scorecard. The indicators used in the Master Scorecard come from an extensive literature review and from a co-creation process (especially for the patient-reported dimension).

The scorecard is intended for monitoring the initiative's progress and assessing its impact. The selection is performed via the [Collective Materiality Analysis](#), an auxiliary operative tool which allows you to engage all relevant stakeholders in your initiative in selecting the indicators. There are **five dimensions of the Master Scorecard** which reflect different areas of impact but also different and often competing interests of stakeholders involved in the research and innovation process as shown below.



- **Efficacy:** refers to the capacity of a given initiative (process). For more, see [Efficacy dimension](#).
- **Excellence:** concerns the quality of research and its findings. For more, see [Excellence dimension](#).
- **Social:** considers the direct and indirect effects of health research for the whole society, going beyond patient needs. For more, see [Social dimension](#).
- **Economic:** refers to long-term financial sustainability of health R&I initiatives. For more, see [Economic dimension](#).
- **Patient-reported:** concerns patients whose needs and perspectives must be understood and incorporated into health research impact evaluation. For more, see [Patient-reported dimension \(PRD\)](#).

The dimensions are divided into 53 aspects, which are key topic areas.

Figure 3 Dedicated Manual section, CRIF dimensions figure: example of long captions for visually impaired readers

Information about functions, composition and significance of the governance bodies are described in the Governance Criteria. In the tables below, you can find condensed summaries of the functions, composition and appointment procedures for each governance body, with references to the Governance Criteria. It may prove useful later on when you decide to set up a governance body or compare characteristics of the bodies that already exist in your initiative with those set out by the CRIF.

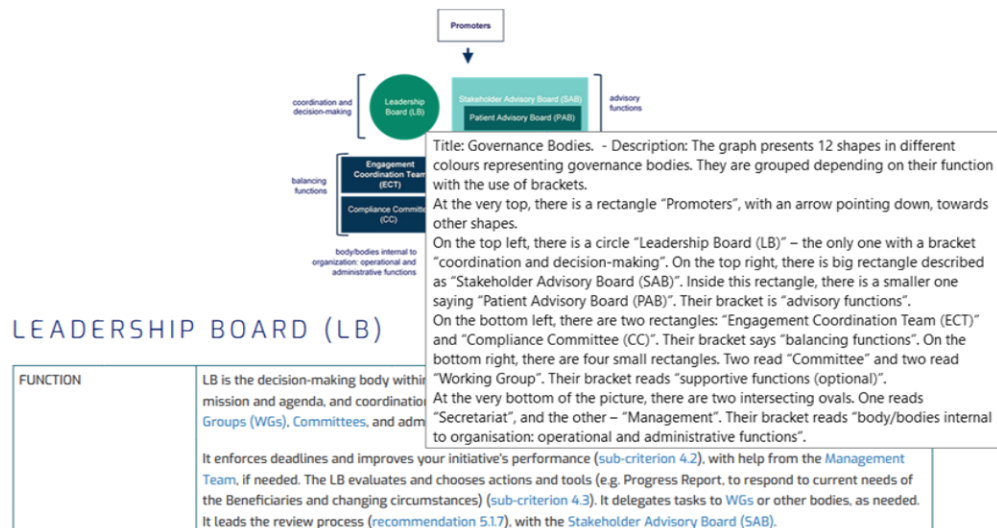


Figure 4 Dedicated Manual section, Governance Bodies figure: example of long captions for visually impaired readers

4 INITIATIVE OVERVIEW PAGE

Each initiative's Overview Page reveals Toolbox functionalities gradually, as the user completes them in a prescribed order. DiA and INTRA decided to work based on the assumption that the user who starts using the Toolbox has not read the Manual. Consequently, the effort was made to:

1. Avoid overwhelming the user with too much information, new terminology and long explanations.
2. Explain the flow of work at the very start.
3. Always provide easily-accessible hyperlinks to the parts of the Manual it is advisable for the user to read before using a functionality.

To keep the initiative Overview Page light, it was decided to create "Read more" roll-down sections.

To exemplify, at the very top of the Overview Page, there is a "CRIF Workflow" roll-down section explaining the steps in visual way, and directing the user towards relevant part of the Manual.

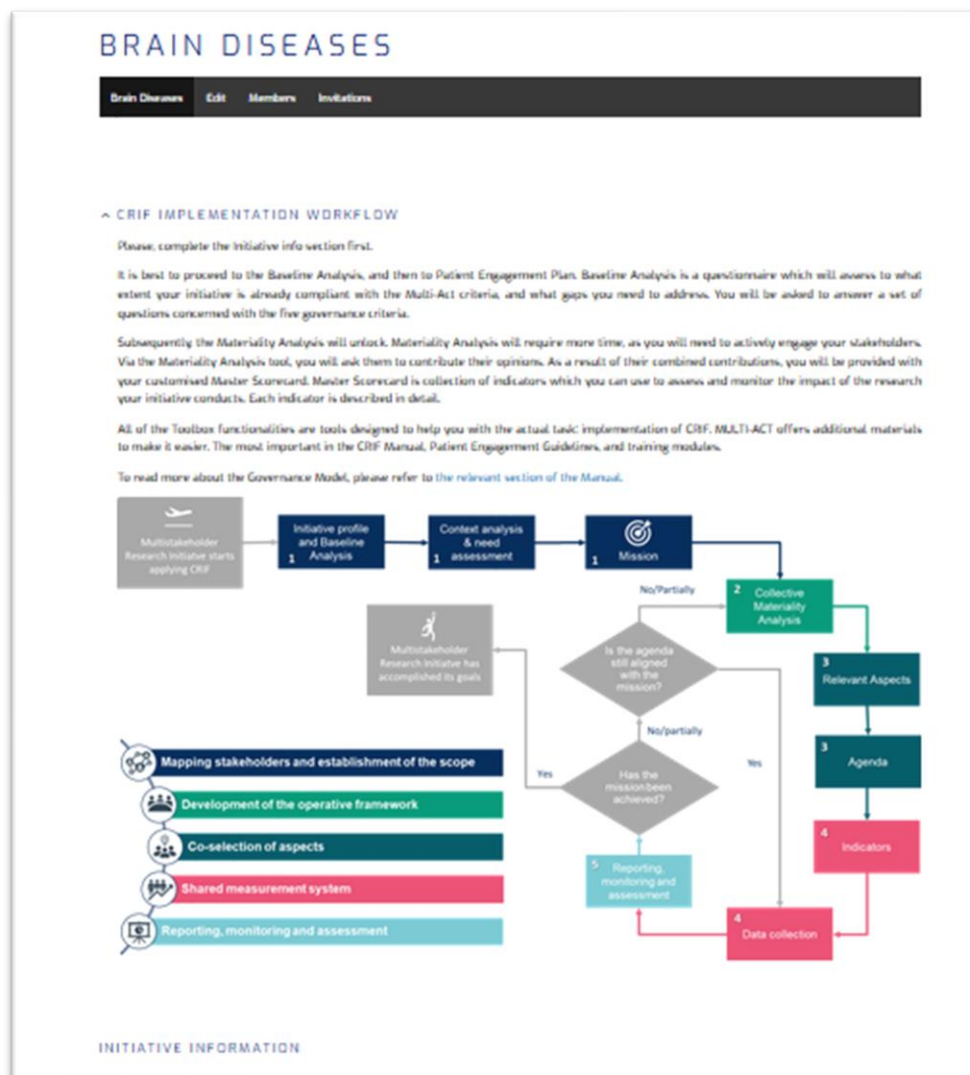


Figure 5 Initiative Overview Page: explanatory text for the CRIF

The same approach was used with every functionality appearing on the Overview Page.

BASELINE ANALYSIS

You have completed the Baseline Analysis. The results indicate which recommendations from the Governance Criteria you should look into and implement. We suggest you familiarize yourself with the whole [Governance Chapter of the Manual](#). Click on "Completed" to repeat the Baseline Analysis. Click on "Score" to get your report and learn which Governance recommendations your initiative should implement to become compliant with CRIF.

You can repeat the Baseline Analysis to monitor your progress towards compliance.

✓ Completed
☰ Score: 20.75%

^ Read More

Baseline Analysis is a questionnaire that measures the level of compliance of your initiative's governance and patient engagement with the [CRIF](#). It is recommended that you conduct the Baseline Analysis as soon as you decide to implement the MULTI-ACT Framework within your initiative. Learning the results of the Analysis has benefits regardless of how advanced the initiative is.

The Baseline Analysis tool provides customized governance recommendations based on the [Governance Model Guidelines](#) and [Patient Engagement Guidelines](#), indicating gaps to be addressed.

During the process of filling in the Baseline Analysis questionnaire, you will be asked to upload various documents: financial reports, yearly reports, sustainability reports, internal policies on patient engagement, mission and vision, ethical compliance, monitoring and evaluation, social and environmental impact assessment, governance bodies and management procedures, academic achievement etc.

Figure 6 Initiative Overview Page: explanatory text for the BA

5 FUNCTIONALITIES

The explanations within the functionalities (Baseline Analysis, Patient Engagement Plan, Materiality Analysis, Impact Assessment) were kept to a minimum, because hyperlinks to relevant sections of the Manual are already provided at the point of entry into functionalities on the initiative Overview Page.

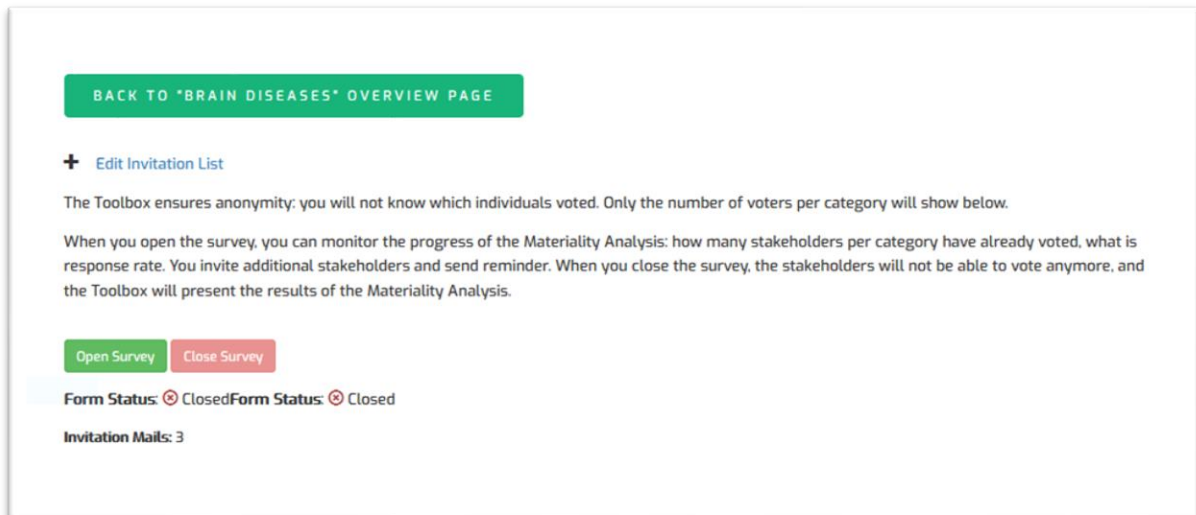
However, there were several instances where DiA opted for placing in-text explanations where difficult or non-intuitive terminology was present. Below is an example from the Baseline Analysis questions. The user may misunderstand the term "patient", which in common speech refers only to the people with a disease, which in the MULTI-ACT it refers also to their relatives and caregivers. An explanation was also provided for the term "Payers and Purchasers" as less-intuitive.

3.1) WHICH OF THE FOLLOWING STAKEHOLDERS TOOK PART IN DEFINING THE OBJECTIVES, PRIORITIES AND SET OF ACTIONS FOR YOUR INITIATIVE?

- ☐ 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.)

Figure 7 Baseline Analysis questions: in-text explanations

DiA also decided to include in-text explanations and instructions in the Materiality Analysis. It is the most complex functionality of the Toolbox. It also involves external stakeholders (participants), so the risk of mistakes and misunderstandings needed to be reduced. It was also important to explain to the user representing the initiative how the participants experience the functionality.



BACK TO "BRAIN DISEASES" OVERVIEW PAGE

+ Edit Invitation List

The Toolbox ensures anonymity; you will not know which individuals voted. Only the number of voters per category will show below.

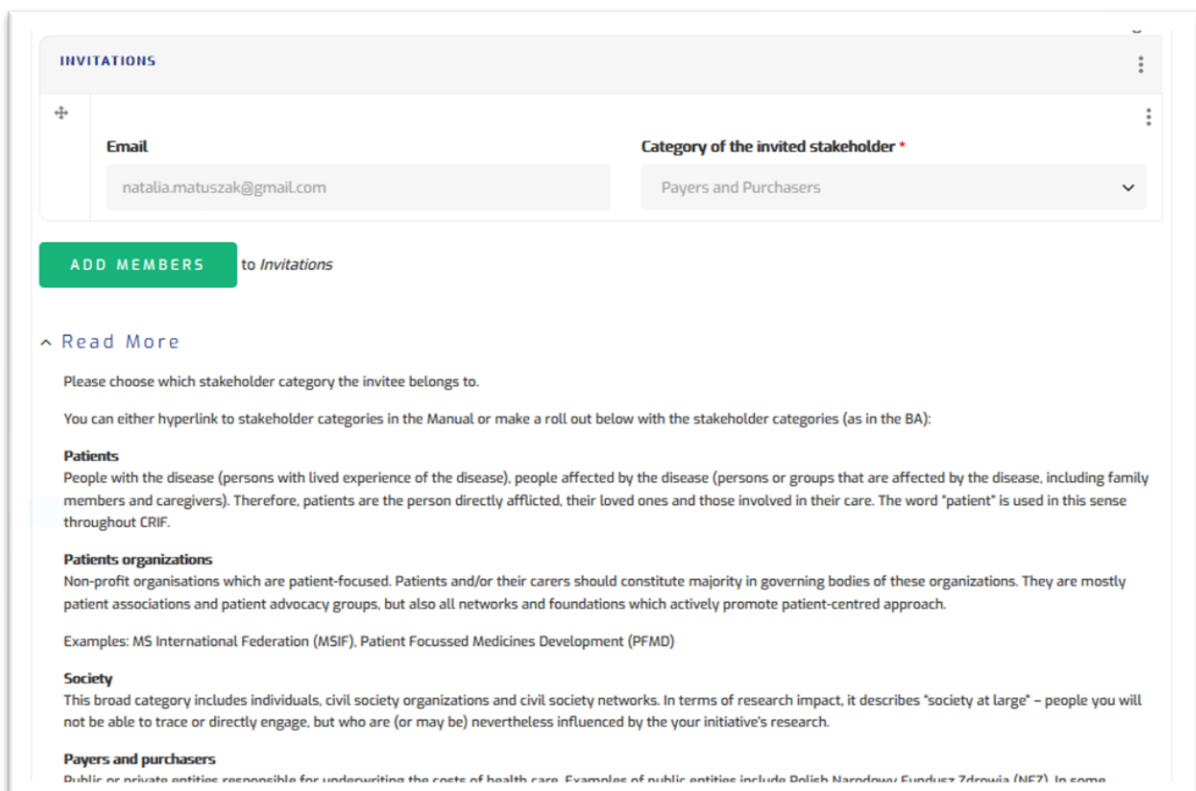
When you open the survey, you can monitor the progress of the Materiality Analysis: how many stakeholders per category have already voted, what is response rate. You invite additional stakeholders and send reminder. When you close the survey, the stakeholders will not be able to vote anymore, and the Toolbox will present the results of the Materiality Analysis.

Open Survey Close Survey

Form Status: Closed Form Status: Closed

Invitation Mails: 3

Figure 8 Materiality Analysis: explanatory text for invitations



INVITATIONS

+ Email Category of the invited stakeholder *

natalia.matuszak@gmail.com Payers and Purchasers

ADD MEMBERS to Invitations

^ Read More

Please choose which stakeholder category the invitee belongs to.

You can either hyperlink to stakeholder categories in the Manual or make a roll out below with the stakeholder categories (as in the BA):

Patients
People with the disease (persons with lived experience of the disease), people affected by the disease (persons or groups that are affected by the disease, including family members and caregivers). Therefore, patients are the person directly afflicted, their loved ones and those involved in their care. The word "patient" is used in this sense throughout CRIF.

Patients organizations
Non-profit organisations which are patient-focused. Patients and/or their carers should constitute majority in governing bodies of these organizations. They are mostly patient associations and patient advocacy groups, but also all networks and foundations which actively promote patient-centred approach.
Examples: MS International Federation (MSIF), Patient Focussed Medicines Development (PFMD)

Society
This broad category includes individuals, civil society organizations and civil society networks. In terms of research impact, it describes "society at large" – people you will not be able to trace or directly engage, but who are (or may be) nevertheless influenced by the your initiative's research.

Payers and purchasers
Public or private entities responsible for underwriting the costs of health care. Examples of public entities include Dolich Narodowy Fundusz Zdrowia (NFZ). In some

Figure 9 Materiality Analysis: explanatory text for stakeholder classification