



Measuring research impact on Patient Reported dimension



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Multi-Act
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MULTI-ACT EXPECTED OUTCOMES



A new **governance model** that can support MSRIs in improving their governance and better evaluate collective impact



Guidelines for capturing “**patient experiential knowledge**” across the health research and innovation path



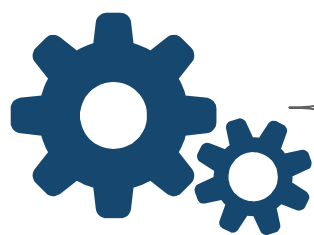
A new model for the assessment of the research impact across different dimensions (mission, excellence, economic, social and **patient-reported impacts**).



A digital **toolbox** that can support users from a multi-stakeholder perspective and the impact of research according to the patient's perspective

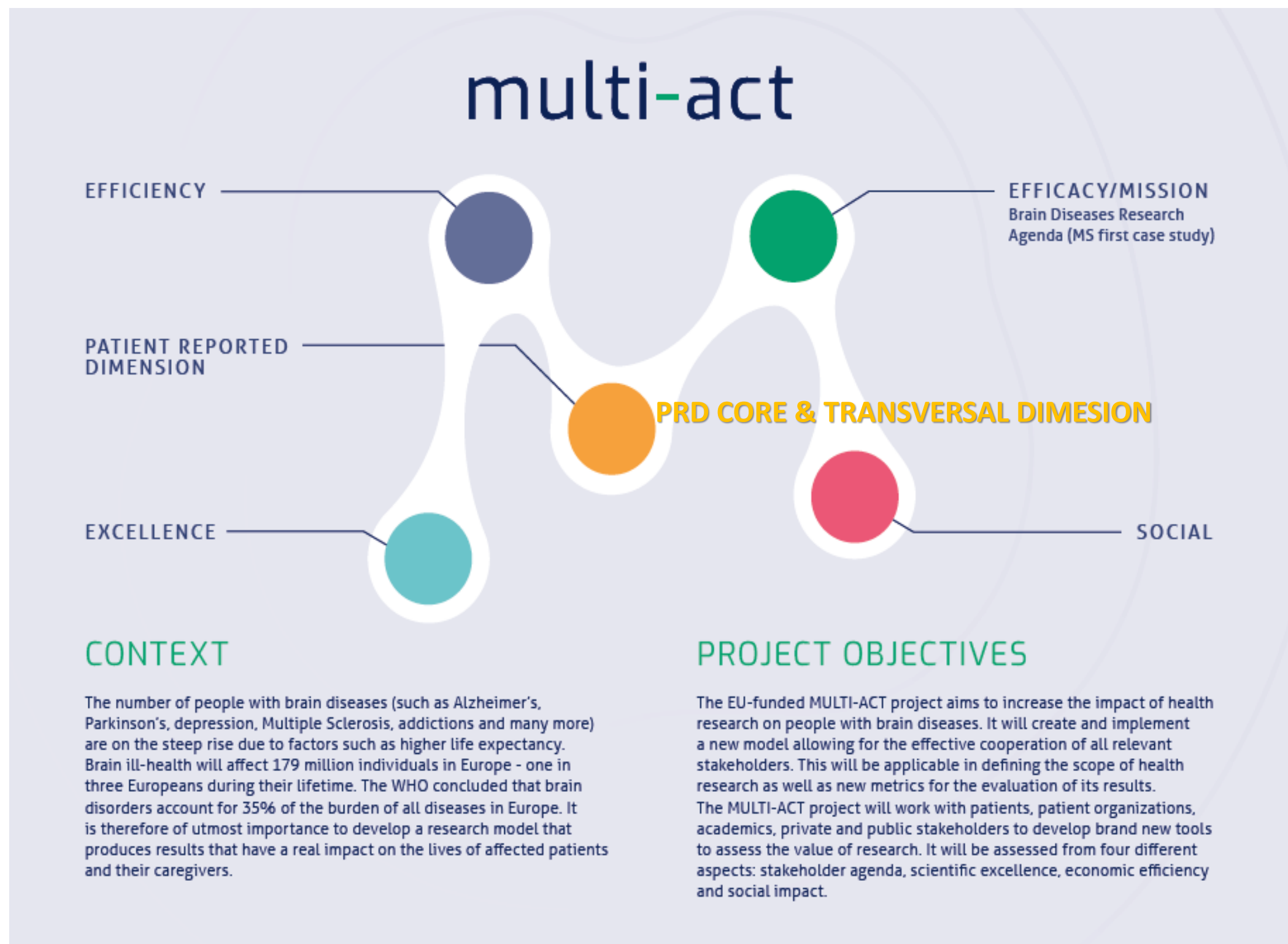


A set of **guidelines** to help in the use of the **Integrated collective research impact framework**, that can assist the users in applying the MULTI-ACT framework



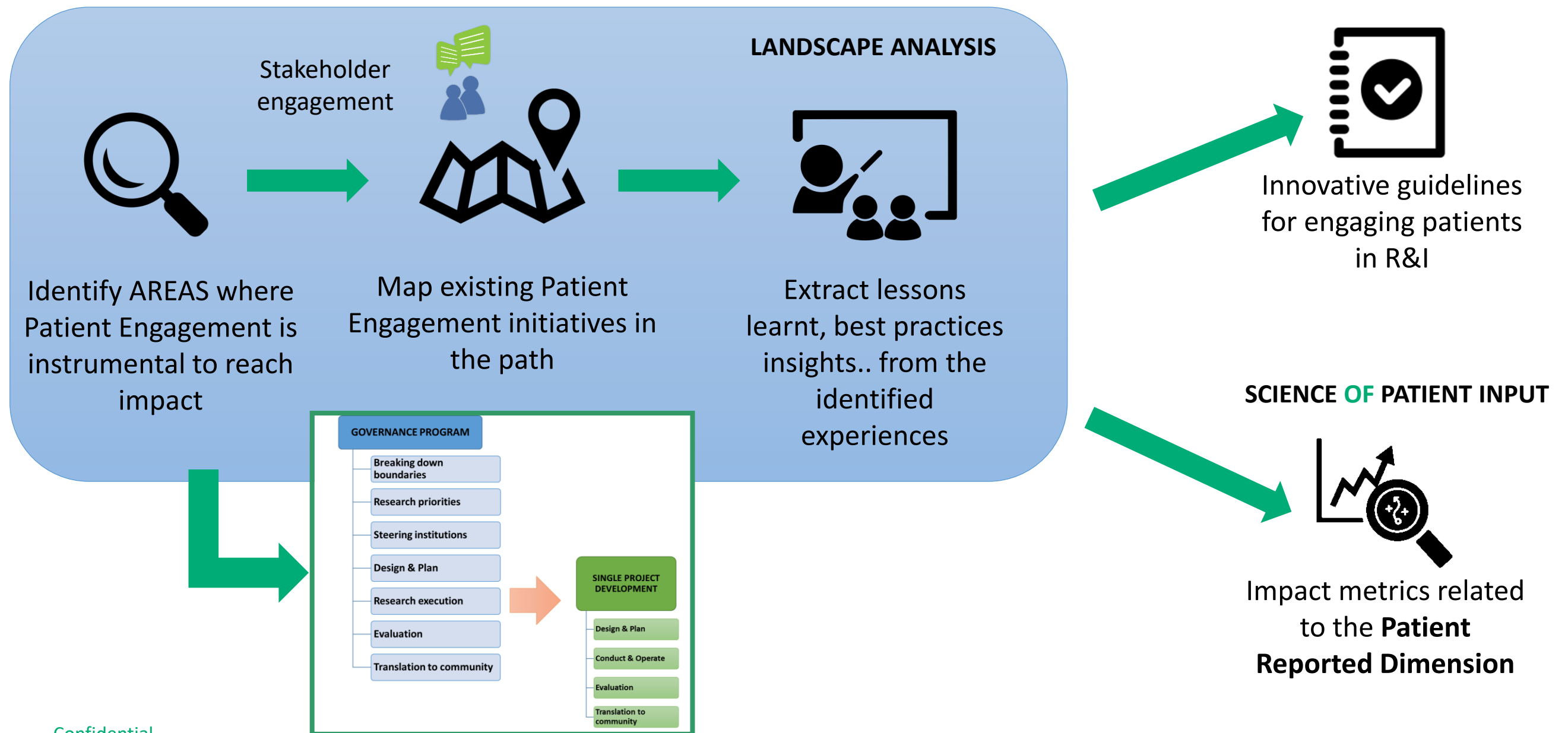
**SCIENCE
WITH PATIENTS INPUTS**
*Patients are the
ultimate recipients of
research findings,
and thereby
a key stakeholder*

**SCIENCE
OF PATIENTS INPUTS**
*Measuring **impact** of
health research on
**Patient Reported
Dimension** will maintain
patients engaged as key
stakeholder*



Enabling the Science WITH/OF Patient Input

Process & outputs of the “Building Knowledge” phase



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The 7-steps R&I path

MULTI-ACT & PEG studied **where** patients need to be engaged in the health R&I process to maximize its impact:



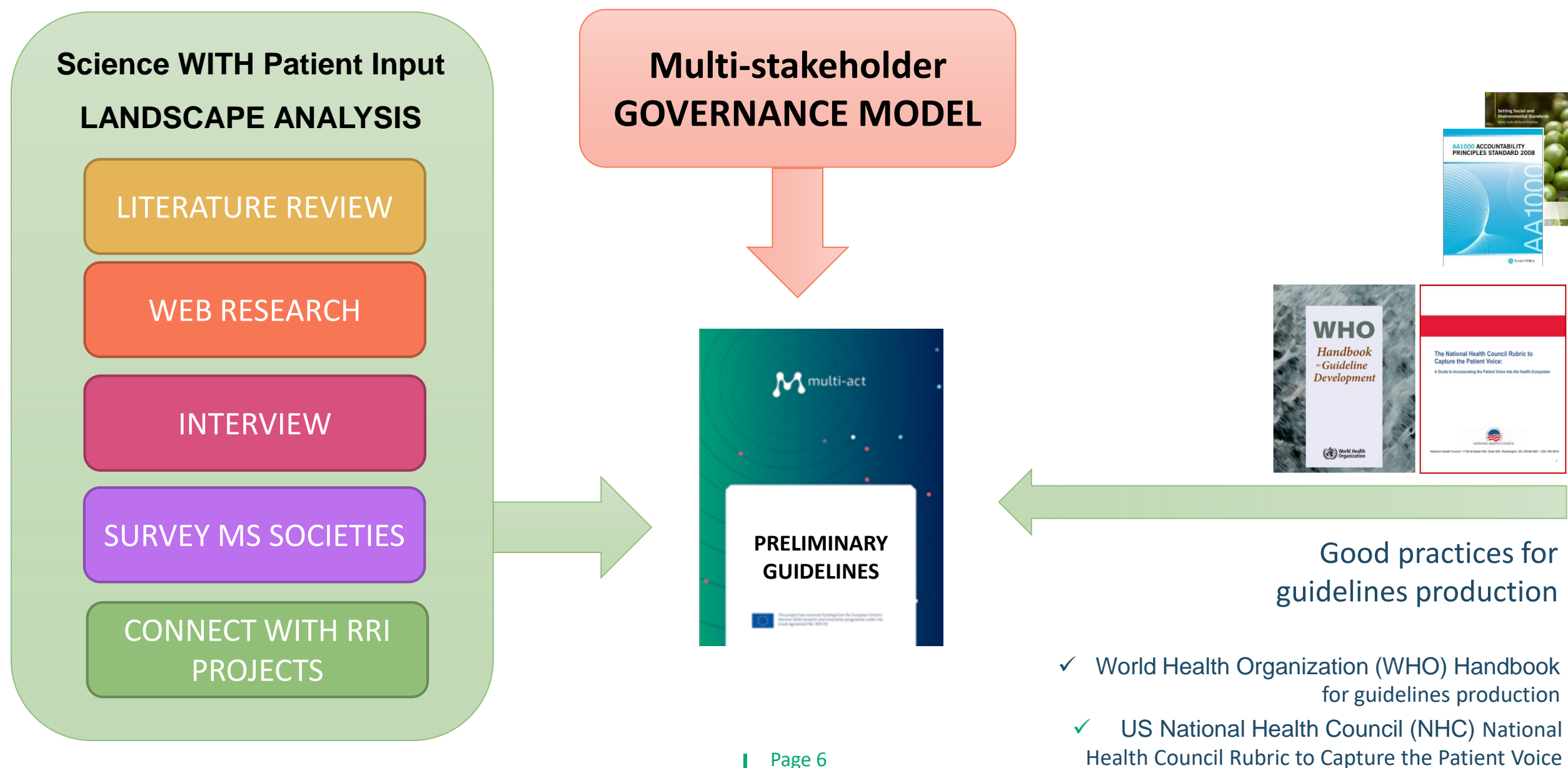
- ✓ 1. Boundary conditions
- ✓ 2. Research priorities
- ✓ 3. Steer institutions
- ✓ 4. Design & plan
- ✓ 5. Research Execution
- ✓ 6. Evaluation
- ✓ 7. Translation to community



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Preliminary MULTI-ACT Patients Engagement Guidelines

Expectations, criteria and rules for patient engagement co-developed by R&I Stakeholders



Insights from the Landscape Analysis

- Experiences of involvement mainly concern **adherence to medical treatments**, participation in **clinical trials** but very rarely the governance of R&I
- Need for **clear and evidence-based methods** and **quality criteria** for guidance on how to engage patients and public at all stages of R&I
- Limited evidence of the value of engagement demands for clear **methodologies to assess the value, impact** and **(cost-) effectiveness** of PE in R&I
- Importance of clear and **constructive communication and professional management** of all stakeholders

Empowering patients' "Experiential Knowledge"

Life experience of patients leads to knowledge escapes and complements the expertise of researchers.

*Meaningful patient involvement requires that the **difference between scientific and clinical expertise and patients' experiential knowledge**, is acknowledged and made productive, instead of erased.*

(Van de Bovenkamp et al. 2009).

Take home messages

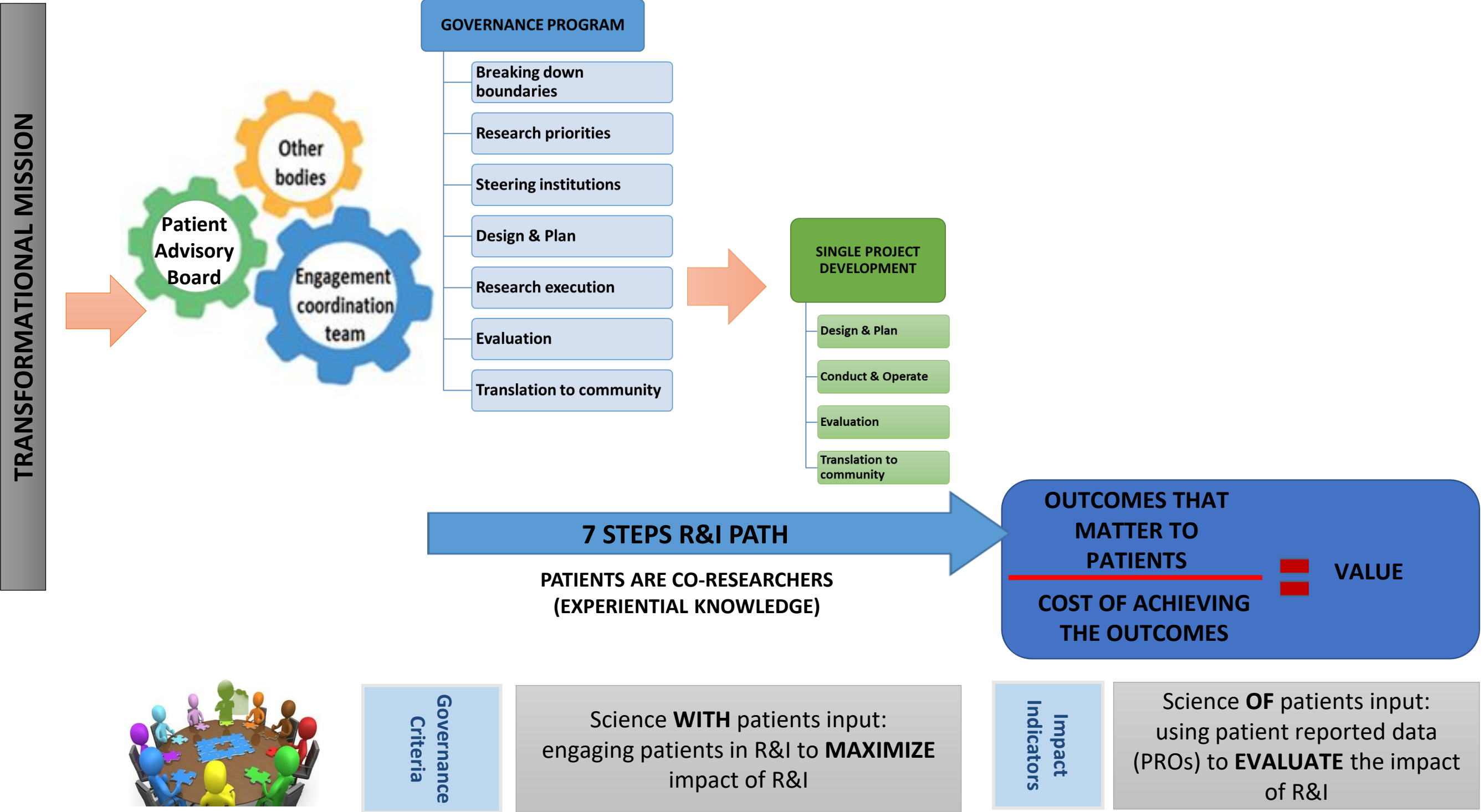
- The **patients' experiential knowledge** should not be contrasted with scientific/clinical knowledge, as it provides relevant and different insights.
- Patients with **equal power, co-creation and decision making role** in R&I have the potential to maximize the impact of R&I and to evaluate it on the outcomes that matter most to them.
- **Patients organization play a pivotal role** in enabling the transition from individual to collective patients' experiential knowledge.
- **Professional management** of all stakeholders is effective in empowering patients' experiential knowledge in R&I, to better prioritize the needs of patients and society.

Key aspects of the MULTI-ACT Patient Engagement Strategy:

- **Engagement Coordination Team** and governance model: ensuring representativeness
- **Training** focused on how to **empower patients to bring their “experiential knowledge” into the R&I continuum**, complementing existing training to make patients “experts”
- The importance to **understand and measure the impact** of R&I on **outcomes that matter to patients** (e.g. PROMS initiative)

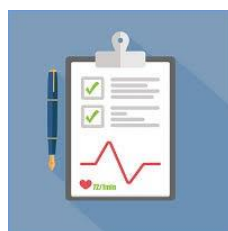
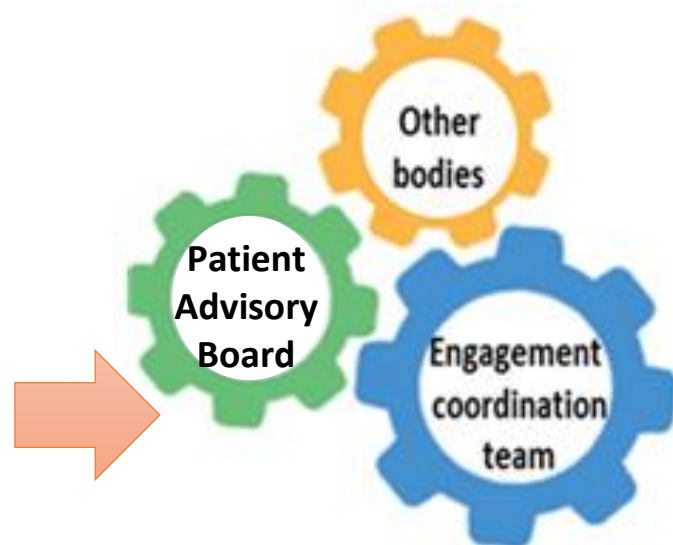


The value of Patient Engagement



The value of Patient Engagement

TRANSFORMATIONAL MISSION



Governance
Criteria

WP5

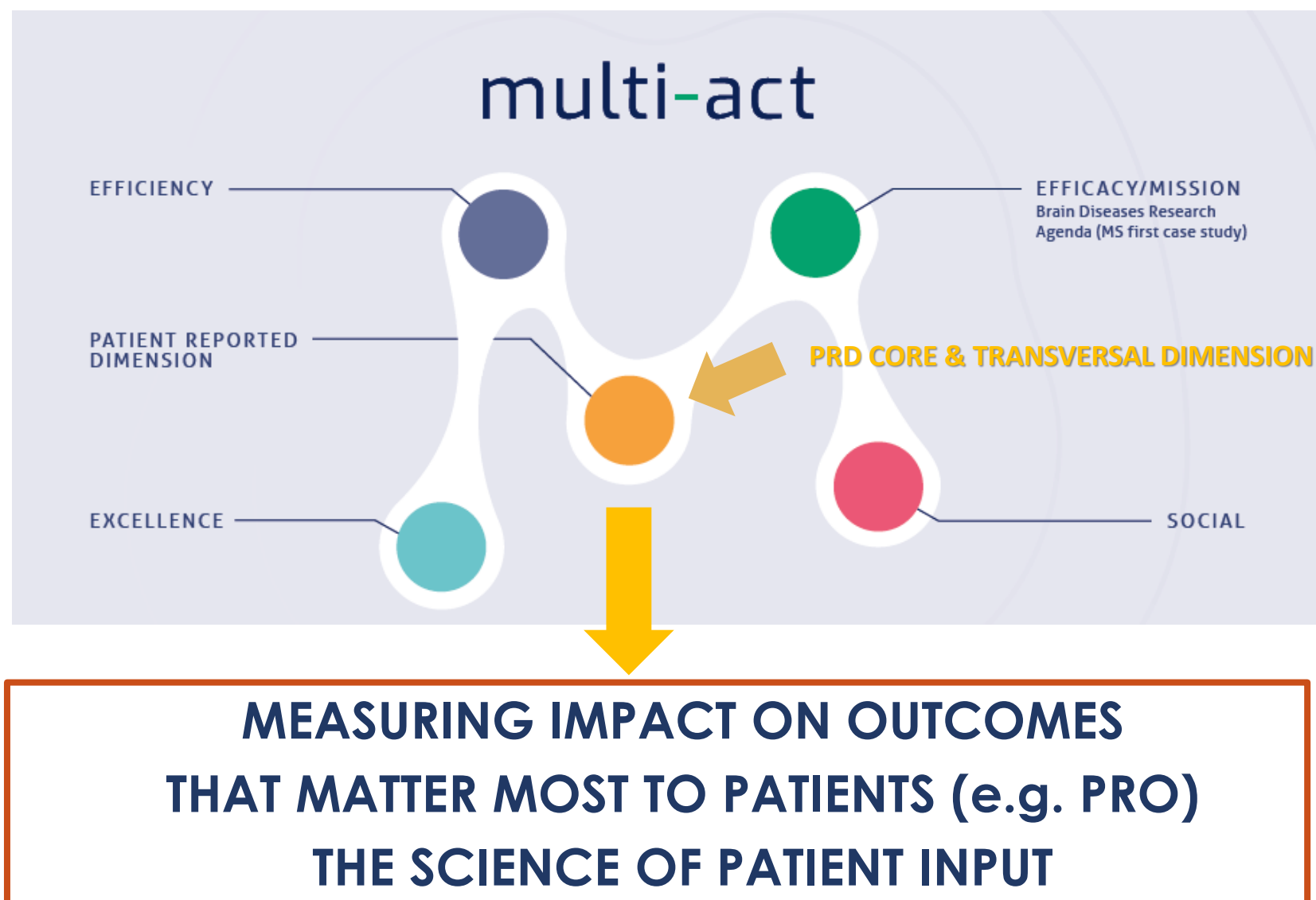
Science **WITH** patients input:
engaging patients in R&I to
MAXIMIZE impact of R&I

Impact
Indicators

WP3

Science **OF** patients input:
using patient reported data
(PROs) to **EVALUATE** the impact
of R&I

Enabling multi-stakeholder initiatives to increase co-accountability by grounding its impact assessment in the outcomes that matter most to patients

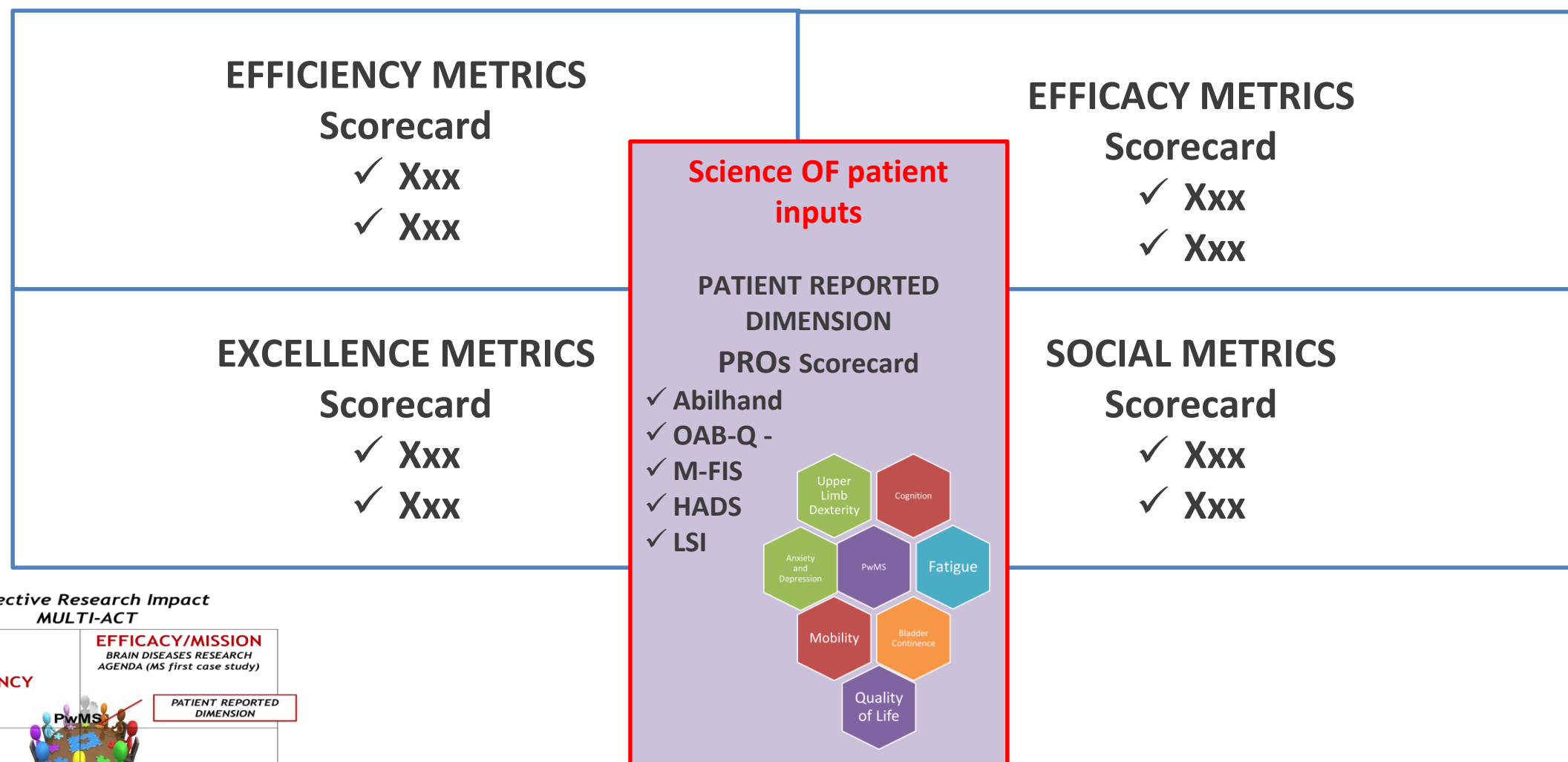


Patient Reported Outcomes

Evaluate the impact toward a transformational mission on the outcomes that matter most to patients:

- **Abilhand** - Manual ability for adults with upper limb impairment - Upper-limb disfunction reported in more than **60% PwMS**
- **OAB-Q** - Overactive Bladder Questionnaire - Bladder problems are reported in more than **70% PwMS**
- **M-FIS** - Modified-Fatigue-Impact-Scale. Fatigue is reported in more than **90% PwMS**
- **HADS** - Hospital Anxiety and Depression Scale. Anxiety and depression reported in more than **80% PwMS**
- **LSI** - Life Satisfaction Index. evaluate life satisfaction and quality of life with respect to the deseases

Collective Research Impact Scorecard: Patient Reported Dimension metrics: PROs



Collective Research Impact
MULTI-ACT



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EFFICIENCY

EFFICACY/MISSION
Brain Diseases Research
Agenda (MS first case study)

PATIENT REPORTED
DIMENSION

EXCELLENCE

SOCIAL

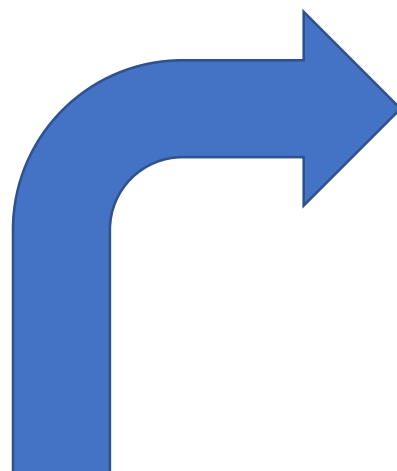
iConquerMS
PROMOPRO-MS

CONTEXT

The number of people with brain diseases (such as Alzheimer's, Parkinson's, depression, Multiple Sclerosis, addictions and many more) are on the steep rise due to factors such as higher life expectancy. Brain ill-health will affect 179 million individuals in Europe - one in three Europeans during their lifetime. The WHO concluded that brain disorders account for 35% of the burden of all diseases in Europe. It is therefore of utmost importance to develop a research model that produces results that have a real impact on the lives of affected patients and their caregivers.

PROJECT OBJECTIVES

The EU-funded MULTI-ACT project aims to increase the impact of health research on people with brain diseases. It will create and implement a new model allowing for the effective cooperation of all relevant stakeholders. This will be applicable in defining the scope of health research as well as new metrics for the evaluation of its results. The MULTI-ACT project will work with patients, patient organizations, academics, private and public stakeholders to develop brand new tools to assess the value of research. It will be assessed from four different aspects: stakeholder agenda, scientific excellence, economic efficiency and social impact.



METADATA IDENTIFICATION

- **EDSS** – Expanded Disability Status Scale
- **FIM™** - Functional Independence Measure
- **Abilhand** - (perceived manual ability in daily life)
- **OAB-Q** - Overactive Bladder Questionnaire
- **M-FIS** – Modified-Fatigue Impact Scale
- **SDMT** - Symbol Digit Modality Test
- **MoCA** Questionnaire
- **PASAT** - Paced Auditory Serial Addition Test
- **HADS** - Hospital Anxiety and Depression Scale
- **LSI** - Life Satisfaction Index

CLINICIAN ASSESSED OUTCOME

CLINICIAN ASSESSED OUTCOME

PATIENT REPORTED OUTCOME

PATIENT REPORTED OUTCOME

PATIENT REPORTED OUTCOME

CLINICIAN ASSESSED OUTCOME

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PATIENT REPORTED OUTCOME

PATIENT REPORTED OUTCOME

Rank Order	Neuro-QoL Domain (5-point Likert scale questions) Scored: 1[worst], 2, 3, 4 , 5[best]	Average Score (N = ~1,400)
1	Fatigue	2.89
2	Satisfaction with Social Roles and Activities	3.09
3	Sleep Disturbance	3.59
4	Positive Affect and Well Being	3.59
5	Ability to Participate in Social Roles and Activities	3.60
6	Anxiety	3.67
7	Cognitive Function	3.71
8	Emotional and Behavioral Dyscontrol	3.92
9	Lower Extremity Functional Mobility	3.93
10	Depression	4.11
11	Stigma	4.17
12	Communication	4.41
13	Upper Extremity Function Fine Motor ADL	4.54

USER CASE STUDY: Anxiety and depression

Anxiety and
Depression

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Focusing on anxiety and depression could be relevant also for Major Depression

Next steps

- Merging of two data sets available by FISIM in order to facilitate patient reported dimension calculation
- Inclusion of the data in the digital tool box (to take into consideration the type of input data and characterization)
- Testing of the metadata analysis



Thank you!

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