Patient Engagement

Monitoring and Evaluation Framework with metrics

About this tool

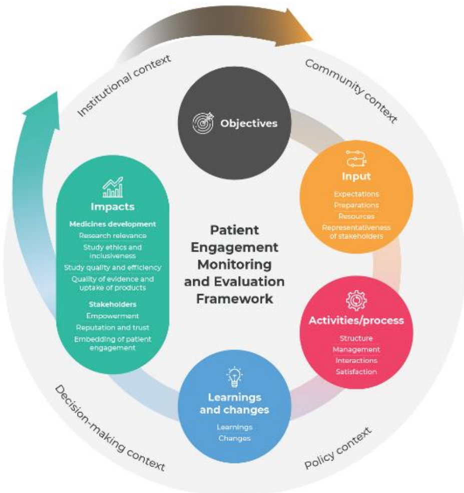
This Patient Engagement Monitoring and Evaluation Framework, with metrics, was created to help partnerships between patients and/or patient organisations, bio-pharmaceutical companies, regulators and health technology assessment (HTA) bodies to self-evaluate the progress and impacts of patient engagement in the medicines development lifecycle and thereby:

- Support learning to facilitate meaningful patient engagement
- Understand the pathway to impact of patient engagement
- Demonstrate better decision-making in medicines development
- Assess the return on engagement for all stakeholders

This Framework is part of the PARADIGM Toolkit that will be soon freely available on the PARADIGM Patient Engagment Toolbox: https://imi-paradigm.eu/petoolbox/.

Using this tool

Who should use this tool? The Framework will be most useful for those who directly plan, conduct and oversee patient engagement in the medicines development lifecycle.



What does this tool provide? The tool provides a map for monitoring and evaluation of patient engagement across multiple decision-points in medicines R&D, including 87 metrics organized across four key evaluation components:

1. *Input metrics* (n=13) show whether or not the conditions for meaningful and sustainable patient engagement are in place.
2. *Activities/process metrics* (n=16) show how the implementation of patient engagement is progressing and can elucidate areas for improvement.
3. *Learning and change metrics* (n=13) show the short-term, direct results of patient engagement which give an indication of the progress made towards impacts.
4. *Impact metrics* (n=45) show the long-term impacts for medicines development and stakeholders.

The context component allows users to understand what contextual factors (n=15) may facilitate or inhibit success. Each metric is accompanied by a description and possible methods for monitoring and evaluating its progress.

How can this tool be used? There is no 'one size fits all' set of metrics appropriate for every initiative or organisation. Therefore, this tool allows users to select metrics in order to develop a tailored set that aligns with their specific objectives and provides meaningful information in their context. Different metrics are grouped together in sample sets relevant to specific objectives of conducting patient engagement. These sets intend to guide users of the tool in creating an M&E strategy tailored to their patient engagement initiatives or programme.

Steps to evaluate impact

Partnerships can consider constructing a dashboard of key metrics, following the approach outlined below, to understand the progress and impact of their collaboration.

Step 1: Decide on the primary objectives

In deciding on the objectives, it is important to consider the goals of all stakeholders involved in the collaboration and their information needs. For example, the updates and feedback they like to receive on the progress achieved towards these set objectives and what they consider as success.

Step 2: Select metrics

In selecting metrics, it is important to discuss the expected path from input to impact and links between the steps that need to be taken. The tool will provide most value if metrics are selected by all involved in patient engagement and measured over time. The sample sets of metrics can be used as a starting point. A tailored set should include metrics that related to each of the four components of the Framework and found essential to gather information on the progress to achieve the main objectives of the initiative. Some are considered as meaningful but may not be feasible to measure in all organisations or may require adapted reporting structures, capacity and resources. All metrics provided in this Framework were identified as being related to patient engagement.

Step 3: Identify methods

Metrics can be measured with surveys, interviews, focus groups or other methods. The sample sets of metrics are accompanied with sample questions, methods and tools drawn from literature and evaluation documents which can be used as a starting point for measurement.

Step 4: Create a feedback loop

Data analysis and reflection on short-term results should be repeatedly undertaken to adapt the initiative and enhance learnings that set the stage for achieving impacts. Contextual factors that may facilitate or hinder the success of the collaboration should be considered.

When to measure?

Input and process metrics can often be measured before or directly after engagement, learning and change metrics within about 12 months and impact metrics in the years after engagement, at initiative, programme or study level. It should be taken into account that various contextual factors influence medicines development, therefore impacts cannot all easily be compared or linked to patient engagement.

More information: check-out the publication in the journal *Health Expectations* (Vat et al, forthcoming) or contact the developers (T.J.Schuitmaker@vu.nl). This tool was developed by PARADIGM – a multi-stakeholder consortium consisting of representatives of four European patient organisations, 15 biopharmaceutical companies and two academic institutions, and is based on literature, expert knowledge and case studies.