PFMD.org
Made WITH Patients

Global
Patient Experience Data
Navigator

BETA

Patient Engagement and Patient Experience Data
Intro to The Global Patient Experience Data Navigator

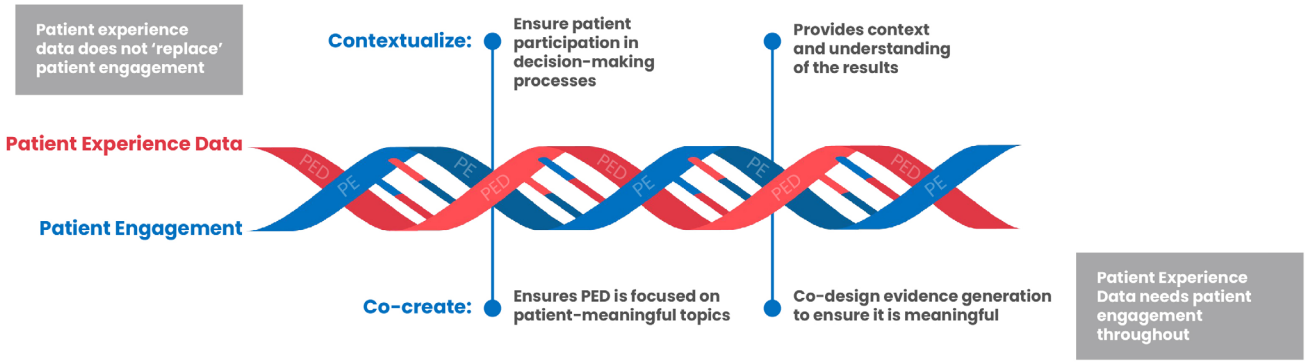
Why is this material important and how to use it

Patient engagement (PE) and the generation and collection of data from patients' experiences across all aspects of their lives (referred to as Patient Experience Data (PED)) is emerging as a critical aspect in research and healthcare to deliver evidence-based patient unmet needs, health outcomes and impact.

In addition to PE, **the generation and collection of data from patients' experiences across all aspects of their lives, referred to as Patient Experience Data (PED), is emerging as a critical aspect in research and healthcare. It can help identify unmet patient needs, desired health outcomes and impact.**

PE is essential for PED in order to build a patient-centered, comprehensive and robust data resource that can be used by all stakeholders in the health ecosystem.

PE & PED Fusion: Meaningful PED needs PE for co-creation and contextualization



Needs have been expressed by all stakeholders including the patient community, industry, regulators and healthcare professionals for a global PED Navigator to provide increased clarity and understanding on the generation and use of PED.

You can use this material to:

- ✓ **ensure that PED highlights the needs that are most important and meaningful to patients**
- ✓ **review the tools and methodologies available to measure these patient experiences and identify possible gaps**
- ✓ **identify what stakeholders are using PED, and how it is being used**
- ✓ **better understand how this data could be used to impact healthcare decision-making**

The Global Patient Experience Data navigator focuses on the impact of disease and treatment on patients.

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Who can use this tool

This tool aims at meeting the needs of multiple stakeholders and illustrates the potential use of PED in diverse contexts. The tool is disease agnostic. It has been developed starting from existing frameworks (like the FDA PFDD guidances and the National Health Council PC-CIS project), to avoid duplication of effort.

- Patient advocates
- Patients and caregivers
- Life sciences Industry
- HTAs organizations
- Payors
- Healthcare professionals
- Regulators
- Researchers
- Funders
- Clinical practice

How to explore and navigate this tool

This material has various sections. Click on each element to download the respective section. In each section you will have a link to the next element of the Global PED Navigator You can always refer back to this intro to continue exploring.

Global PED Navigator

Tools to help you navigate areas of impact as defined by patients and methods to capture PED

Tools to help you understand the various usage possibilities of PED for various health stakeholders and settings

Tool to identify *select approaches that could be used to determine what outcomes matter most to patients & families*

Use this tool to understand:

- what matters most to patients living with a disease or condition
- What tools *approaches* can be used to select *identify* areas of impact that are *most* important for your patient population or therapeutic area

DOWNLOAD THE TOOL

Click on this button to download the appropriate PDF

Tool to select appropriate measurement methods of outcomes that matter to patients & families

Use this tool to:

- Select the appropriate methods to analyze the areas of impact previously identified

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Tool to identify PED use per stakeholder throughout the *product* development cycle

Use this tool to better understand:

- WHEN are stakeholders using PED throughout the medicines development lifecycle
- WHY are stakeholders using PED throughout the medicines development lifecycle

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Tool to identify PED use per stakeholder throughout the healthcare process

Use this tool to better understand:

- WHEN are stakeholders using PED throughout the healthcare process
- WHY are stakeholders using PED throughout the healthcare process

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Glossary to provide clarity on the technical terminology and connect users with existing resources in this space.
Download the glossary

Find here the Excel version of the Global PED Navigator.

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How was this tool developed

This tool has been developed based on a co-creation model consisting of three main phases: co-development, validation and formalization.

Co-creation

Co-creation has been driven within a 30+ person working group of experts from diverse backgrounds.

This allowed the group to foster collective insights and intelligence from multi-stakeholder representatives and work towards building a common solution that would meet all needs. Ultimately, the goal was to design a solution which is de facto adopted since it has been 'co-created'.

Validation

Validation was a key moment in the co-creation process and it allowed us to identify the convergence point(s), show progress towards the project goal, and reach intermediary solutions that could facilitate broader understanding and a more agile adoption.

Formalization

Formalization then took place, with the collected insights from the working group.

This resource was co-developed in a multi-stakeholder working group representing patients, patient organizations, regulators, healthcare professionals, pharmaceutical companies, and external experts. Special thanks for drafting, editing, reviewing, and maintaining momentum to deliver the resource.

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