



BETA

# Patient Engagement and Patient Experience Data

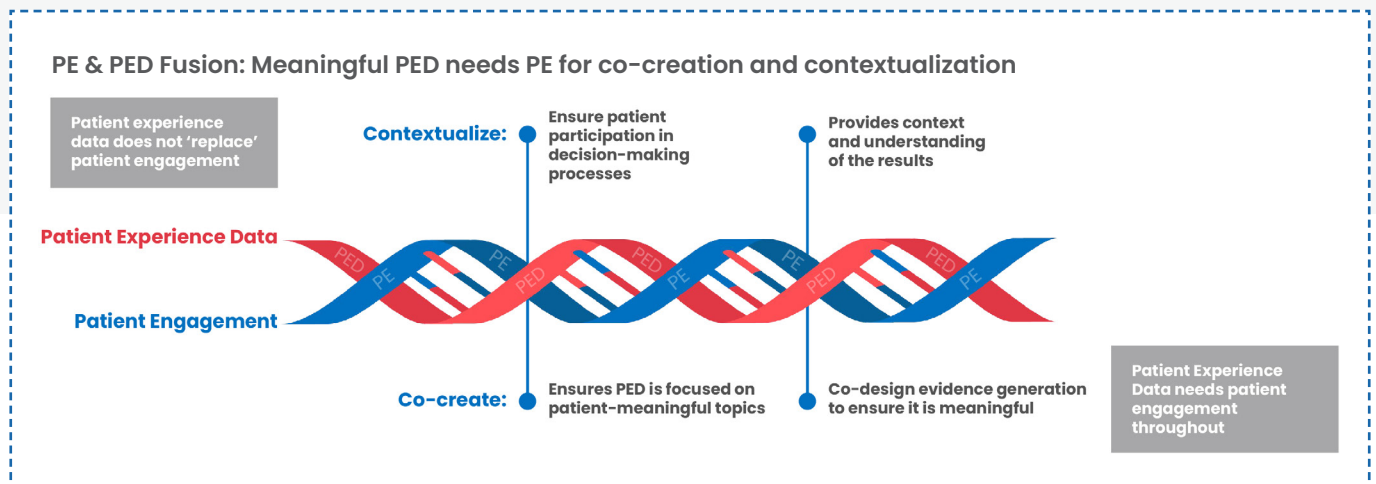
## Intro to The Global Patient Experience Data Navigator

### 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.



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.

## 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



Payors



Funders



Patients and caregivers



Healthcare professionals



Clinical practice



Life sciences Industry



Regulators



HTAs organizations



Researchers

## How to explore and navigate this tool

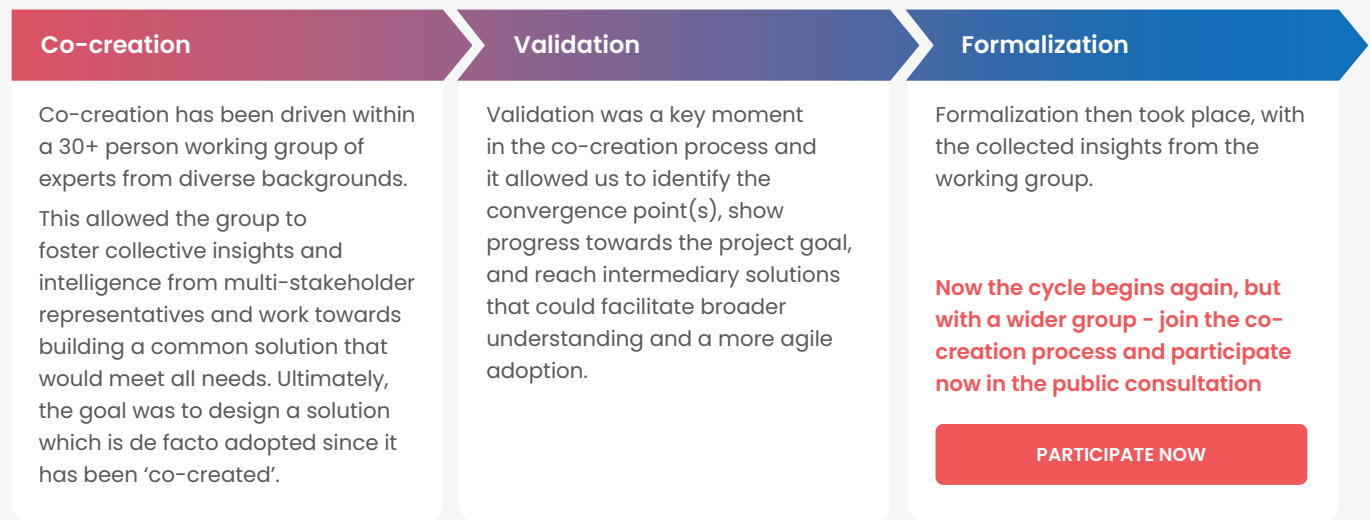
This material has various sections. Click on each element to download the respective section. In each section you will have a link to the next element of the Global PED Navigator. You can always refer back to this intro to continue exploring.

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	
<p><b>Tool to identify select approaches that could be used to determine what outcomes matter most to patients &amp; families</b></p> <p>Use this tool to understand:</p> <ul style="list-style-type: none"> <li>what matters most to patients living with a disease or condition</li> <li>What tools approaches can be used to select identify areas of impact that are most important for your patient population or therapeutic area</li> </ul> <p style="text-align: center;"><a href="#">DOWNLOAD THE TOOL</a></p> <p><small>Click on this button to download the appropriate PDF</small></p>	<p><b>Tool to select appropriate measurement methods of outcomes that matter to patients &amp; families</b></p> <p>Use this tool to:</p> <ul style="list-style-type: none"> <li>Select the appropriate methods to analyze the areas of impact previously identified</li> </ul> <p style="text-align: center;"><a href="#">DOWNLOAD THE TOOL</a></p> <p><small>Click on this button to download the appropriate PDF</small></p>	<p><b>Tool to identify PED use per stakeholder throughout the product development cycle</b></p> <p>Use this tool to better understand:</p> <ul style="list-style-type: none"> <li>WHEN are stakeholders using PED throughout the medicines development lifecycle</li> <li>WHY are stakeholders using PED throughout the medicines development lifecycle</li> </ul> <p style="text-align: center;"><a href="#">DOWNLOAD THE TOOL</a></p> <p><small>Click on this button to download the appropriate PDF</small></p>	<p><b>Tool to identify PED use per stakeholder throughout the healthcare process</b></p> <p>Use this tool to better understand:</p> <ul style="list-style-type: none"> <li>WHEN are stakeholders using PED throughout the healthcare process</li> <li>WHY are stakeholders using PED throughout the healthcare process</li> </ul> <p style="text-align: center;"><a href="#">DOWNLOAD THE TOOL</a></p> <p><small>Click on this button to download the appropriate PDF</small></p>
<p>Glossary to provide clarity on the technical terminology and connect users with existing resources in this space.</p> <p style="text-align: center;"><a href="#">Download the glossary</a></p>			

After you explore the Global PED Navigator don't forget to share your feedback on its usability and clarity. Click [here](#) to answer the survey.

## 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.



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.

Special acknowledgement to Tom Willgoss, Head of Clinical Outcome Assessment Development & Execution at Roche, for his contribution.

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