Engaging Patients in the Design, Generation, and Use of Patient Experience Data, including Real World Data

GetReal Institute Summit

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PFMD Purpose:

PFMD's goal is to improve global health by co-designing the future of healthcare for patients **WITH** patients.

46 Active Partners

Global Multi-stakeholder Reach

Scaling Patient Engagement Deeper & Wider

Build the Conditions and Enablers of Patient Engagement

Build Patient Engagement in Digital Health & Data

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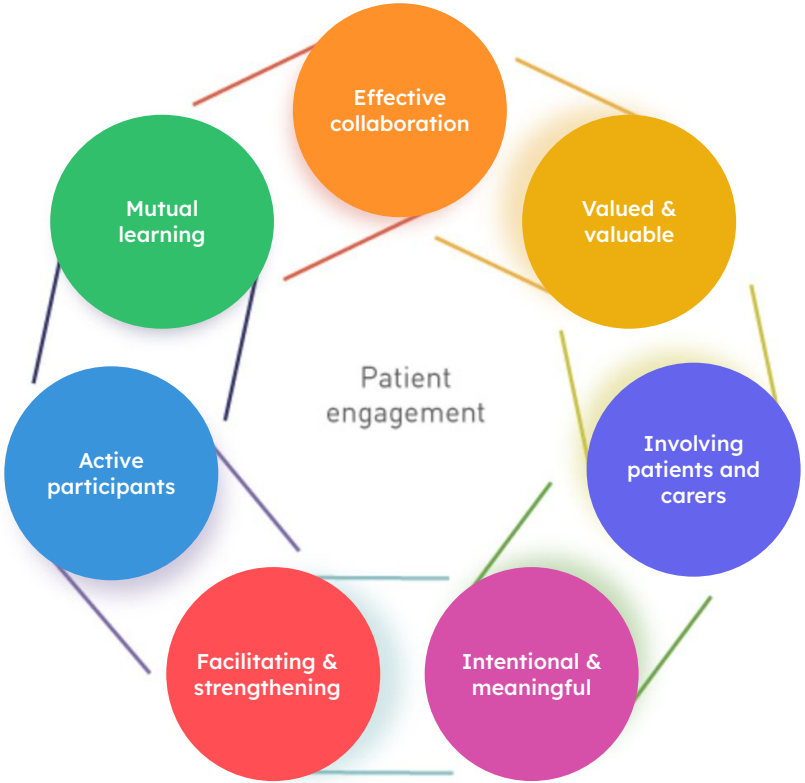
Patient Engagement & Patient Experience Data Project

Clarifying, integrating and streamlining the design, generation, analysis and decision-making about patient experience data (PED) through, and with, patient engagement (PE)

Objectives				
1. Provide **clarity, structure** and alignment of PED	2. Create a **common understanding** and language	3. Ensure **relevance and accessibility for all stakeholders** in healthcare decision-making	4. **Integrates PE through co-creation**, as POs and patient experts contribute to development	5. Emphasizes the need to **prioritize what is most important and meaningful for patients**

Please find here the link for the PE & PED Project.

Patient engagement needs to be active and meaningful



Regulator's Definition of **Patient Experience Data (PED)**

Data collected by any individual or organization

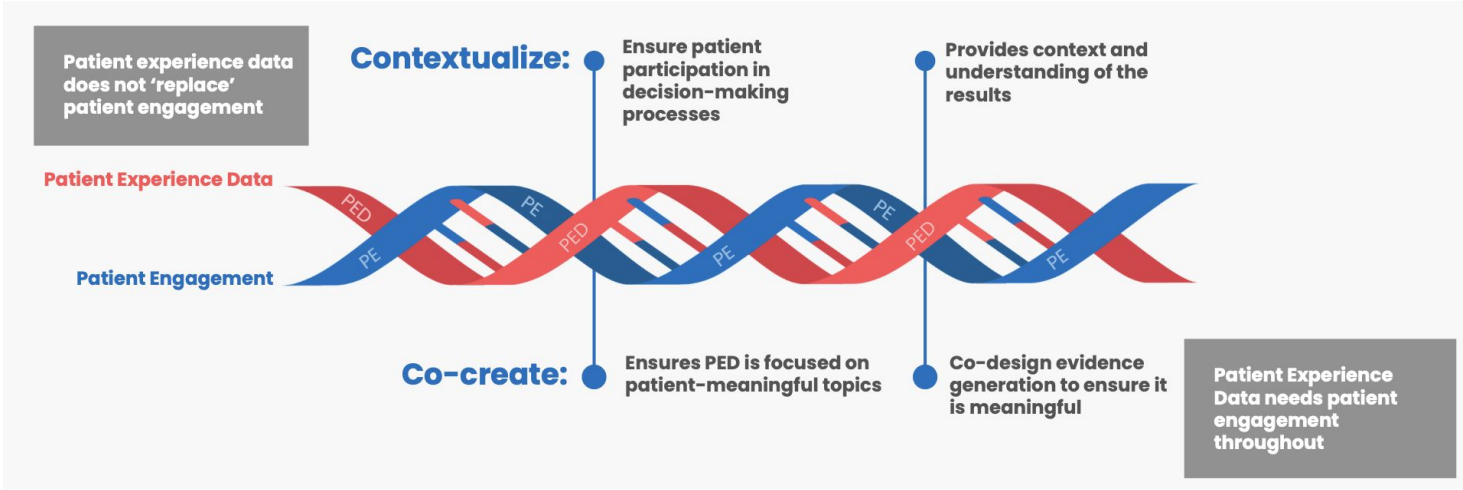
- "**Input on which outcomes** are important to them"
- "**Patient preferences** for outcomes and treatments"
- "**The relative importance** of any issue as defined by patients"

Captures patients' experiences, perspectives, needs, and priorities related to (but not limited to):

- "**The symptoms** of their condition and its natural history"
- "**The impact** of the conditions on their functioning and **quality of life**"
- "**Their experience** with treatments"

Source: *Section 569C of the Federal Food, Drug, and Cosmetic Act (21 U.S.C. 360bbb-8c).*

All must understand that patient experience data does not replace patient engagement

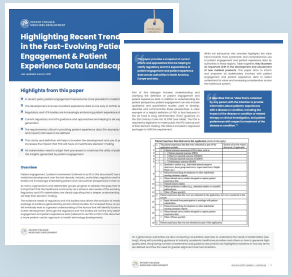


> *PE can support PED to ensure patient-centricity of measurement, contextualization of data, increased understanding of the evidence generated, and the co-creation of the design, generation, collection and analysis of PED.*

Co-creation with 300+ individuals, from 45+ organizations, with 600+ insights

2021-2022, PE & PED resources and tools increased awareness and provoked change

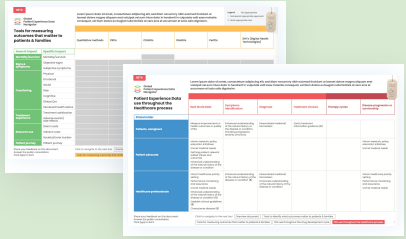
Landscape Paper v.1



Collective Value Publication

Landscape Paper v.2

Global PED Navigator



Please find here the links for the Landscape Paper v1, Collective Value Publication, and Global PED Navigator

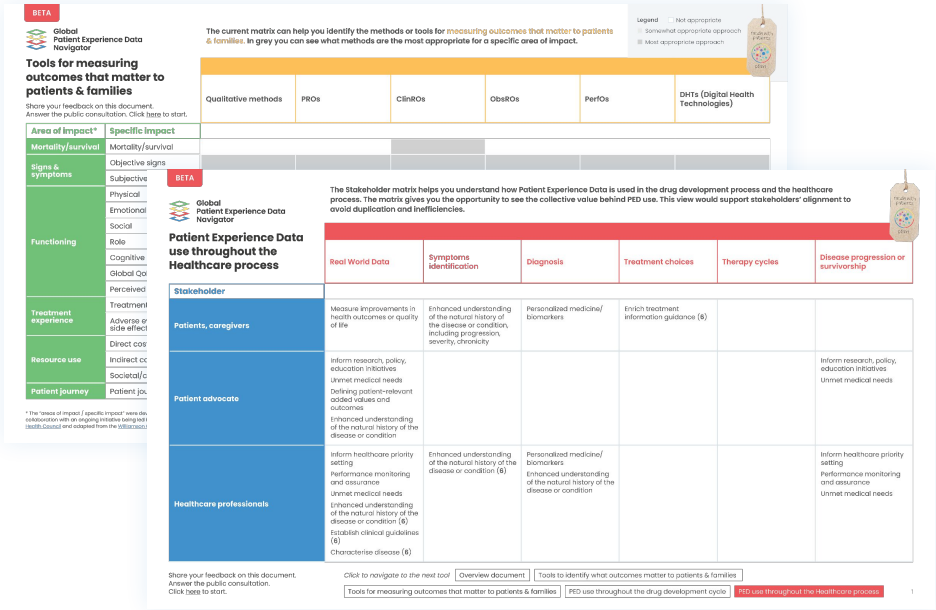
Global PED Navigator responds to 5 key questions resulting in 2 comprehensive and integrated templates

1. **WHAT:**
   Highlight the needs that are most important to patients

2. **HOW:**
   Review the approaches and methodologies available (and identify gaps) to measure these patient experiences

3. **WHEN:**
   Consider when stakeholders are using this data and **4. WHY**

5. **WHO:**
   Identify the stakeholders that are using PED



Patient experience data relevant for many stakeholders

Healthcare systems

- Healthcare priorities
- Performance monitoring
- Benchmarking
- Service improvement

Patient advocacy

- Identify patient needs
- Shape new patient services
- Inform research
- Inform health policy argumentation

Patients, caregivers

- Inform shared decision-making
- Contextualize choices
- Understand experiences of others

Regulators

- Inform regulatory decisions
- Contextualize clinical evidence
- Post-marketing data
- Revise product labelling

Life sciences industry

- Inform priority setting
- Pipeline and business decisions
- Value propositions
- Trial design

HTAs organization

- Inform value assessments
- Input into scoping and early dialogues
- Broaden scope of evaluations

Clinical practice

- Quality improvement
- Shared decision making
- Identification of gaps in care and support

Researchers

- Inform priority setting
- Identification of meaningful outcomes
- Study design

Funders

- Informing funding priorities
- Input into grant assessment criteria
- Input into research progress assessments

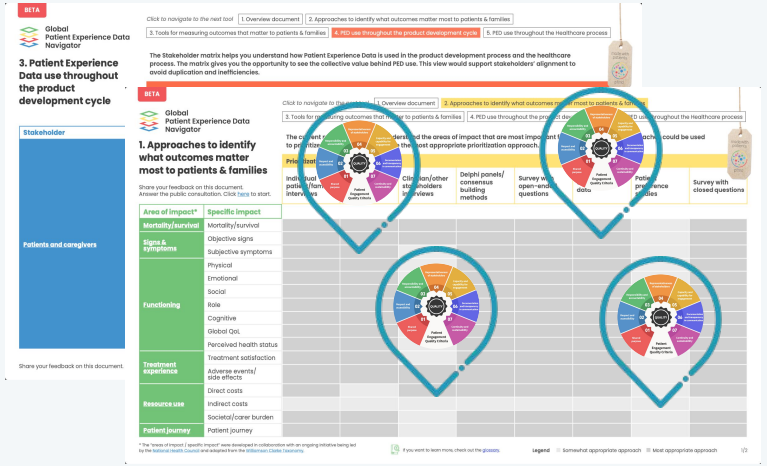
Payors

- Inform priority setting
- Budget allocation
- Reimbursement decision-making

2023 - Co-creating first version of multi-stakeholder Global PE & PED Navigator

Patient Engagement Quality Criteria

PE & PED Navigator (Phase II)



2023 – Exploring opportunities to consider Real World Data in relation to Patient Experience Data

Real-world data

1. Provide guidance on the "how and when" of PE for the generation and use of RWD
2. Capacity building tools/resources for patient organizations to collect RWD
3. Develop tools to increase awareness of importance of contributing data amongst HCPs and patients
4. Provide recommendations on the inclusion of patient experience data in the collection of RWD

PE and Patient Experience Data
Questions? Want to chat?

Please provide your email address

bit.ly/3h8gkAm