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1. Overview document

2. Approaches to identify what outcomes matter most to patients & families

Global Patient Experience Data Navigator

3. Tools for measuring outcomes that matter to patients & families | 4. PED use throughout the product development cycle

4. Patient Experience Data Navigator  Data use throughout the Healthcare process	The Stakeholder matrix helps you understand how Patient Experience Data is used in the product development process and the healthcare process. The matrix gives you the opportunity to see the collective value behind PED use. This view would support stakeholders' alignment to avoid duplication and inefficiencies.								
	Real World Data	Symptoms identification	Diagnosis	Treatment choices	Therapy cycles	Disease progression or survivorship			
Stakeholder		•			•				
Patients, caregivers	Measure improvements in health outcomes or quality of life	Enhanced understanding of the natural history of the disease or condition, including progression, severity, chronicity	Personalized medicine/ biomarkers	Enrich treatment information guidance (6)					
Patient advocate	Inform research, policy, education initiatives Unmet medical needs Defining patient-relevant added values and outcomes Enhanced understanding of the natural history of the disease or condition					Inform research, policy, education initiatives Unmet medical needs			
Healthcare professionals	Inform healthcare priority setting  Performance monitoring and assurance  Unmet medical needs  Enhanced understanding of the natural history of the disease or condition (6)  Establish clinical guidelines (6)  Characterise disease (6)	Enhanced understanding of the natural history of the disease or condition (6)	Personalized medicine/biomarkers  Enhanced understanding of the natural history of the disease or condition			Inform healthcare priority setting Performance monitoring and assurance Unmet medical needs			

5. PED use throughout the Healthcare process



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Overview document

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PFMD Made WITH Patients	pfmd							
	Real World Data	Symptoms identification	Diagnosis	Treatment choices	Therapy cycles	Disease progression or survivorship		
Stakeholder								
Regulators								
Life sciences industry	Inform priority setting, value propositions, pipeline and business decisions Assessment of current treatments Product design					Ilnform priority setting, value propositions, pipeline and business decisions Assessment of current treatments		
HTAs organization								
Clinical practice			Diagnosis procedures	Quality improvement Shared decision making Relevant endpoints Risk/benefit balance	Quality improvement Shared decision making Relevant endpoints Risk/benefit balance			
Researchers	Augment real-world evidence Assessment of current treatments Unmet medical needs Defining patient-relevant added values and outcomes					Augment real-world evidence Assessment of current treatments Unmet medical needs Defining patient-relevant added values and outcomes		
Funders								
Payors								

## Resources

made with patients

<sup>(6)</sup> Patient involvement in the development, regulation and safe use of medicines CIOMS Working Group report Draft, 24 February 2022