



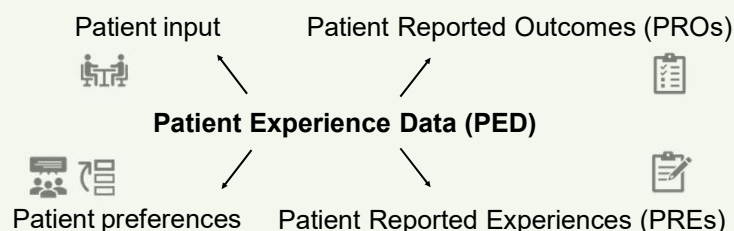
Challenges, opportunities and policy ways forward to systematically embed patient experience data in healthcare decision-making: insights from multi-stakeholder interviews

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Introduction



PED increasingly recognised by stakeholders as an important source of information that should be considered when making decisions

Challenges hamper the systematic collection and implementation of PED

More **patient-centred** healthcare decision-making

Objectives

This study aims to **elicit stakeholders' perspectives** on challenges, opportunities and concrete policy ways forward to systematically embed PED in healthcare decision-making

Methods



Semi-structured interviews (n=39) with:

- Healthcare industry
- Academia & non-profit organisations
- Regulatory authorities
- HTA bodies & payers
- Patient organisations



Interviews **transcribed** ad verbatim



Thematic framework analysis using NVivo Software

Results*

* Based on interim analysis (n=13)



Challenges

Healthcare industry	Regulators, HTA bodies & payers	Patient organisations
<ul style="list-style-type: none"> • Lack of guidance on requirements for the collection of PED • Lack of transparency on the assessment of PED in regulatory, HTA and payer decision-making 	<ul style="list-style-type: none"> • Lack of quality criteria for the collection and evaluation of PED • Lack of validated methods and tools for obtaining robust and high-quality PED • Limited experience and knowledge on the assessment of PED 	<ul style="list-style-type: none"> • Lack of knowledge on when and how to share patients' perspective • Lack of resources and capabilities to collect PED



Opportunities

Healthcare industry	Regulators, HTA bodies & payers	Patient organisations
<ul style="list-style-type: none"> • Standardisation on how to collect PED, particularly patient preferences • Raising awareness to better understand the value of PED 	<ul style="list-style-type: none"> • Guidelines on how to assess PED • Case studies to gain experience and knowledge • More research on validated methods and tools, such as fit-for-purpose PRO measures 	<ul style="list-style-type: none"> • Need for guidance on how to engage patients • Training and education on effective patient involvement

First, need for regulatory guidelines First, gain experience & best practices

Policy ways forward



- Concrete and practical guidelines on PED collection and evaluation
- Increased transparency on how PED are considered in decision-making
- Clear alignment on the expectations and responsibilities of each stakeholder group
- Multi-stakeholder interactions, e.g., workshops

Abbreviations

HTA: Health Technology Assessment,
PED: Patient Experience Data,
PRE: Patient Reported Experience
PRO: Patient Reported Outcome



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Conclusion*

Stimulating critical and constructive reflections on policy ways forward to address identified challenges



Tailor decision-making to meet patients' needs and preferences