

Patient engagement in the development and extension of value frameworks

How to do it right?

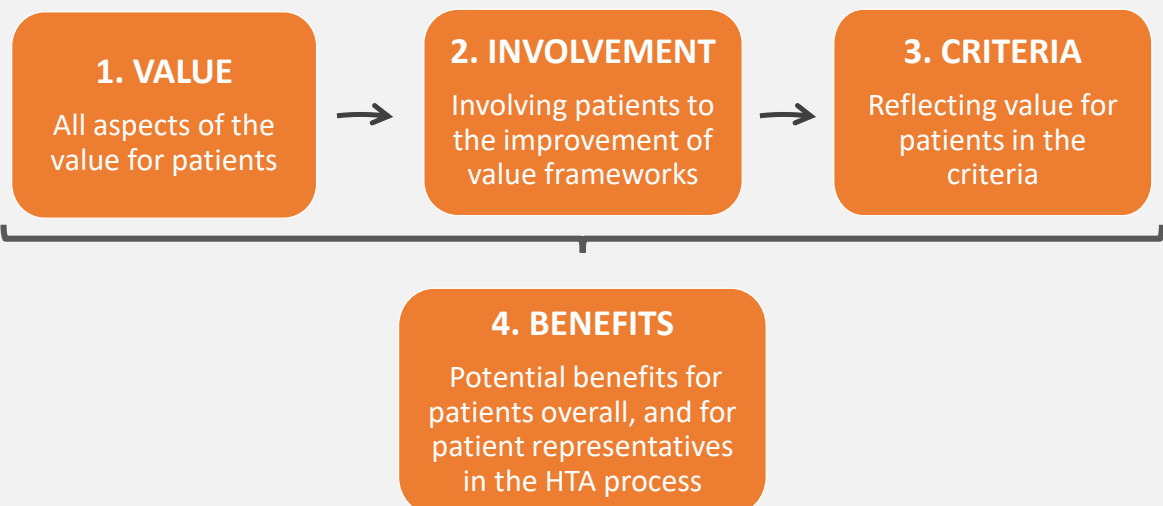
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Disclosure: The views and opinions expressed in this presentation are those of the presenter and do not necessarily reflect the official policy or position of the affiliated organizations

Improving value frameworks **WITH** patients - **FOR** patients



1. VALUE

2. INVOLVEMENT

3. CRITERIA

4. BENEFITS

What do we know about the **value for patients?**

- Originates from the patient experience
- Differs from patient to patient (depends on culture, age, social status, risk tolerance, medical parameters etc.)
- Both societal and individual perspectives have to be captured
- Differs from that of clinicians' and decision makers' perception of the value for patients



How to capture these values for patients?

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2. INVOLVEMENT

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4. BENEFITS

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Patient involvement in current value framework development

- **How patients are involved in the development of value frameworks?**
 - **No patients involved** (e.g. countries with less developed patient advocacy culture)
 - **Open call** for comments on the already developed value framework
 - **Small expert panel** (e.g. all stakeholder represented by one person)
 - **(Online) questionnaire** with elicitation tasks distributed to patients
 - **Separate workshop** for patient representatives (e.g. for validation)
 - **Patients as a part of multi-stakeholder workshops** (proportion of patients varies heavily)
- **Guidance needed on the target proportion of different stakeholders** (thereby patients) in multi-stakeholder workshops (Marsh, 2017; Kolasa, 2018) → **potential role of ISPOR?**

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Fair and representative involvement of patients

GENERAL PATIENT INVOLVEMENT PRINCIPLES APPLY

- **Avoid symbolic gestures:** choose meaningful patient involvement, not only ticking boxes
- **Early and often:** involve patients as early as possible, into all steps of the development
- **Representativeness:** involve a heterogeneous group of patient representatives with different perspectives
- **Use lay language:** “If you cannot explain it to a 3-year-old, you don’t understand it enough.”
- **As easy as possible:** minimize the cognitive challenges when designing MCDAs (e.g. reduce the number of questions posed, choose face-to-face elicitation) (Marsh, 2017)
- **Make sure they understand:** participant training, piloting elicitation tasks and validating that the results are consistent with participants’ understanding (Marsh, 2017)

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Patient-relevant criteria in current value frameworks

Systematic literature review on pricing and reimbursement level VFs (Jan 2013-March 2019) containing at least one criterion from the specified categories*

ALL VFs	TREATMENT-RELATED	DISEASE-RELATED	SOCIETAL	PATIENT EXPERIENCE
e.g.	<ul style="list-style-type: none"> • Efficacy • Safety • Strength of evidence 	<ul style="list-style-type: none"> • Severity of disease • Size of affected population • Unmet need 	<ul style="list-style-type: none"> • Equity • Productivity • Caregiver burden 	<ul style="list-style-type: none"> • Patient convenience • Patient adherence
N=36	100% (n=36)	80% (n=29)	61% (n=22)	39% (n=14)

*“Economic” and “Uniqueness and complexity of treatment” criteria not listed as considered not patient-relevant

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Extending value frameworks with patient experience

Examples of patient-relevant criteria in value frameworks

Traditional elements

Efficacy

Safety

Severity of the disease

Equity

Extended patient experience elements

Responsiveness to individual needs

Household's financial burden

Improved access for vulnerable and neglected patients

PROs and CROs

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Potential benefits of extended value frameworks for patients

- Can support **non-traditionally evaluated elements of the patient experience to be systematically assessed** at reimbursement decisions
- **May incentivize manufacturers** to design new technologies accordingly and gather evidence on these outcomes
- An explicit set of patient-relevant criteria may **enable patients to provide standardized input** to support reimbursement decisions
 - Guidance for patient representatives involved in the deliberative process
 - Evidence gathered from patients (survey, focus group) as a measurement of certain criteria
- A clear set of criteria explicitly incorporating patient experience has the potential to improve the **transparency of decision making thereby increase the acceptance of the decision in patient communities**

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Call for action for value framework developers

- 1 Allocate resources for engaging patients** throughout the development process from early on and in a meaningful and representative way
- 2 Guidance needed on the target proportion of different stakeholders** (thereby patients) in the development process
- 3 Consider including non-traditional elements of the patient experience** into the criteria to
 - capture a broader aspect of the real value for patients
 - facilitate evidence generation on these outcomes
 - incentivize the development of health technologies taking into consideration these aspects

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EPF Youth Group – representing young patients' voice in Europe



European Patients' Forum (EPF) Youth Group members, 2019 Budapest

“ A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE ”

EPF Youth Group – representing young patients' voice in Europe



EPF Summer Training for Young Patient Advocates (STYPA), 2019 Vienna

“ A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE ”

Make **meaningful** patient engagement
a reality in the development and
improvement of value frameworks

Thank you for you attention!

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