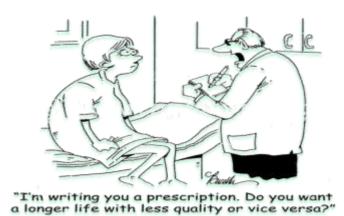


All acknowledge it is critical to ask patients what matters most to them, but are we doing it right?





And are we measuring it consistently?

- Only 6.7% of PROM development had patient involvement across all phases
- Only 10.9% included patients in assessing which outcome to measure
- In 25.9% of the PROM development studies, no patients were involved at all

	n	%
Patient involvement in	143	74.1
any phase of the development*		
Patient involvement in one phase	67	34.7
Patient involvement in two phases	63	32.6
Patient involvement in three phases	13	6.7
Establishing which outcome to measure	21	10.5
Unrestricted input from patients	2	1.0
Patient involvement in the	19	9.8
development of frameworks or domains		
Item development	113	58.5
Focus groups with patients	42	21.8
Interviews with patients	61	31.6
Other methods involving patients	27	14.0
Establishing the comprehensibility	98	50.8
of the questionnaire		
Cognitive interviews	48	24.9
Other methods involving patients	55	28.5
Patient involvement before 2005	53	73.6
Patient involvement between 2006 and 2010	46	65.7
Patient involvement after 2010	44	86.3

*Questionnaire development was divided into three development phases: establishing which outcome to measure, item development and testing for comprehensibility.

Wiering B, de Boer D, Delnoij D. Patient involvement in the development of patient reported outcome measures: a scoping review. Health expectations: an international journal of public participation in health care and health policy. 2017;20(1):11-23

Today's panel



Roman Casciano Executive Vice President & General Manager, Analytica Laser



Dean Spurden Associate Director for Rare Disease, Outcomes and Evidence, Global Health & Value, Pfizer



Bettina RyllFounder, and
Researcher, Melanoma
Patient Network Europe



Sheela Upadhyaya Associate Director -Highly Specialised Technologies, NICE

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