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IPI 5: A MODEST PROPOSAL: CAN WE EASE THE BURDEN OF MYRIAD MEASURES WITH A MINIMUM DATA SET THAT ACTUALLY MATTERS TO PATIENTS?

ISPOR Glasgow, November 7 2017

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



"I'm writing you a prescription. Do you want a longer life with less quality or vice versa?"
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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 any phase of the development*	143	74.1
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	10.9
Unrestricted input from patients	2	1.0
Patient involvement in the development of frameworks or domains	19	9.8
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 of the questionnaire	98	50.8
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
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Dean Spurden
Associate Director for
Rare Disease,
Outcomes and
Evidence, Global Health
& Value, Pfizer



Bettina Ryll
Founder, and
Researcher, Melanoma
Patient Network Europe



Sheela Upadhyaya
Associate Director -
Highly Specialised
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