TRANSPERFECT 3 SUMMIT
CONVERSATIONS ON CLINICAL CONTENT

PAYERS DEMAND IT, SCIENCE REQUIRES IT:

How Can We Ensure the True Impact on HRQoL is Captured?

MODERATOR

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THE PANEL

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Health-Related Quality of Life (HRQoL) has become a focal point in the assessment of therapies, but are current tools truly capturing what matters most to patients? This panel brought together experts in outcomes research, market access, and patient advocacy to examine the evolving role of HRQoL evidence in regulatory submissions, payer negotiations, and scientific innovation.

Standard tools like EQ-5D have notable limitations, and the panelists believe that the future lays in disease-specific, patient-developed measures that better reflect real-world impact. While instruments like EQ-5D are often mandated for HTAs due to their role in generating quality-adjusted life year (QALY) calculations, many panelists argued these tools often fail to reflect the lived experiences of patients. Qualitative data and narrative supplements are increasingly being accepted by organizations like NICE, offering an avenue for richer, more nuanced perspectives on HRQoL.

Several speakers also stressed the importance of early patient involvement in the development and selection of patient recorded outcome (PRO) measures. Instruments that are meaningful, comprehensive, and accessible to patients—especially in rare or complex diseases—require collaboration with patients from the outset. That includes involving people with lived experience in research teams to guide the development, testing, and evaluation of new tools.

Minimizing patient burden, incorporating qualitative evidence, and prioritizing real-world data are absolutely mission-critical to proper HRQoL, especially in the case of rare and chronic conditions.

KEY TAKEAWAYS

Standardized tools alone are insufficient:
Instruments like EQ-5D are not always sensitive or relevant for specific conditions; disease-specific and qualitative measures must supplement them.

Early patient involvement is essential:
Patients should contribute to PRO development from the start to ensure tools are truly reflective of their experiences.

HRQoL data should be fit-for-purpose:
Regulators and payers need evidence that is methodologically sound and patient-centered.

Real-world data complements clinical trials:
Especially for rare or chronic diseases, real-world evidence can fill gaps left by rigid trial protocols.

Quality matters more than quantity:
Overloading patients with multiple PROs reduces engagement and data integrity; brevity and clarity should guide instrument selection.

Frameworks for qualitative evidence are evolving:
Bodies like NICE are becoming more receptive to patient narratives, but consistency and transparency are still needed.

Patient burden must be minimized:
Instruments must be acceptable, relevant, and not overly taxing for patients, especially those experiencing disease progression.

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