# Reply to the Importance of a Collaborative Health-Related Quality of Life Measurement Strategy for Adolescents and Young Adults With Cancer

We greatly appreciate the thoughtful letter from Husson, Sodergren, and Darlington. They have highlighted the many advantages of the European Organisation for Research and Treatment of Cancer Quality-of-life Questionnaire Core 30,[1] including their important work on developing adolescent and young adult (AYA)–specific health-related quality of life (HRQOL) measures within the EORTC framework.[2] Research by the EORTC, the Patient-Reported Outcomes Measurement Information System, and related international measurement science efforts are essential for advancing knowledge, improving care, and fostering better outcomes for AYAs with cancer. We agree with their recommendations for collaboration and cooperation at the international level, the potential value of a consensus-based approach, and a clear need for flexible and dynamic approaches to capture the HRQOL of AYAs.

The total disease burden in AYAs accounts for approximately 6% of cancer cases both nationally and internationally.[3,4] Thus, there is a need to identify shared goals, collaborate, and develop multinational AYA research studies to maximize the yield from observational studies and clinical trials. Within the US-based National Clinical Trials Network and the National Cancer Institute's Community Oncology Research Program, there are efforts underway to foster cross-group collaborations and develop consensus recommendations for patient-reported outcome (PRO) assessments among AYAs. At the international level, Husson et al highlighted the International Consortium for Health Outcomes Measurement, which recently identified a core set of PROs for cancer survivorship research and provided a potential blueprint for achieving an international consensus on important HRQOL domains for AYAs.[5]

Any large-scale collaborative approach would also benefit from incorporating flexibility into AYA PRO measurements. As noted in our commentary,[6] the developmental and disease heterogeneity among AYAs makes a one-size-fits-all approach to PROs challenging. This may be particularly true for HRQOL domains, which may vary by nation and/or culture; this underscores the need for country-specific calibrations and norms. For example, items about financial burden may be less relevant within countries that have universal health care and fewer barriers to quality care,[7] and items about body image or fertility may be answered differently according to norms that encourage (or discourage) body positivity[8] or affect the expression of fertility concerns,[9] respectively.

On the measurement side, it may be unrealistic for the international community to come to a consensus on a single measurement system. There are many excellent universal and cancer-specific HRQOL measures with extensive evidence for their validity and reliability in a variety of cancer populations. Perhaps a more realistic endeavor is to use psychometric methods to create crosswalks among measures when possible.[10,11] This allows researchers to continue to use measures with which they are comfortable but provides a mechanism for comparing or combining results across clinical trials to examine the HRQOL impact of AYA populations.

We applaud the invitation by Husson et al for international collaboration to optimize HRQOL assessment in AYA oncology. We agree with the need to identify a consensus around PRO domains and support efforts for flexible measurement strategies. We look forward to continuing the conversation, improving measurement science, and catalyzing future patient-centered work among AYAs.

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## CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

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