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Building Consensus and Maintaining Flexibility in Measurement Science for AYAs with Cancer

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We greatly appreciate the thoughtful letter from Drs. Husson, Sodergren and Darlington. They highlighted the many advantages of the European Organisation for Research and Treatment of

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Cancer's (EORTC) QLQ-C30¹, including their important work to develop adolescent and young adult (AYA) specific health-related quality of life (HRQOL) measures within the EORTC framework.² Research by EORTC, PROMIS, and related measurement science efforts internationally are essential to advance knowledge, improve care, and foster 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 multi-national AYA research studies to maximize 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 (NCORP) 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,⁵ providing a potential blueprint for achieving international consensus on important HRQOL domains for AYAs.

Any large-scale collaborative approach would also benefit from incorporating flexibility into AYA PRO measurement. As noted in our commentary, 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 that may vary by nation and/or culture, underscoring the need for country-specific calibrations and norms. For example items about financial burden may be less relevant within countries that have universal healthcare and fewer barriers to quality care,⁶ and items about body image or fertility may be answered differently depending upon norms that encourage (or discourage) body positivity⁷ or impact the expression of fertility concerns⁸, respectively.

On the measurement side, it may be unrealistic for the international community to come to 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.^{9,10} This allows researchers to continue to use measures they are comfortable with; but provide the mechanism to compare or combine results across clinical trials to examine 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 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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