

Letter to the Editor

Remote Monitoring of Inflammatory Bowel Disease: What Kind of Patient-Reported Questionnaires Should We Use?

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We read with interest the review by Van Andel *et al.* regarding the content validity of inflammatory bowel disease [IBD]-specific patient-reported outcome measures [PROMs] using the COnsensus-based Standards for the selection of health Measurement INstruments [COSMIN] methodology.¹ We compliment the authors for this extensive assessment and agree that adequately validated PROMs that measure the patient perspective are essential to guarantee high-quality care. However, we believe that one should differentiate between PROMs reflecting the patient perspective and patient-reported questionnaires quantifying outcomes prioritized by healthcare professionals.

As telemedicine has rapidly evolved, especially in 2020 due to the COVID-19 pandemic, remote monitoring has been increasingly integrated into daily clinical practice and emerged to be safe, [cost-] effective and accepted in meeting the growing demand for complex IBD care.² PROMs are classically defined as any report of the status of a patient's health condition that comes directly from the patient and should measure outcomes that matter most to patients.³ In line with this definition, the COSMIN guideline promotes development of high-quality PROMs by providing standards and criteria for assessment.⁴ The patient's perspective of their health status reflects what patients consider important in living with IBD, and should be part of routine care. We agree that it is essential for patients to be involved in PROM development and validation studies, as only patients can determine which health outcomes are relevant to them and whether questionnaires are comprehensive and comprehensible. On the other hand, Rubin *et al.* have demonstrated the presence of a significant perception gap between physicians and IBD patients with regard to disease activity.⁵ Therefore, to prevent disease progression and complications, safe remote monitoring also warrants monitoring of clinical endpoints. To enable remote monitoring of constructs such as disease activity in terms of mucosal inflammation and risk of [infectious] side effects, validation against a gold standard, such as endoscopy, is required. This

implies that development and validation of questionnaires aiming at successful remote monitoring of clinical endpoints necessitate guidelines that focus particularly on relevance and item generation valuable to healthcare professionals. Nevertheless, patient involvement in assessment of comprehensiveness and comprehensibility remains indispensable.

The review by Van Andel *et al.* has demonstrated the lack of sufficient content validity in a substantial proportion of the included IBD-specific PROMs. The discrepancy between the intended use of some PROMs aiming at remote monitoring of clinical outcomes and the COSMIN methodology probably explains part of the insufficient scores consequent to assessment. Hence, we challenge clinicians and researchers to reflect on the constructs of interest and reserve the use of the term PROMs for questionnaires in which the patient perspective is central, and we propose the term remote monitoring tools for patient-reported questionnaires which aim to capture clinical outcomes important to healthcare professionals.

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Author Contributions

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