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Lessons from rheumatoid arthritis and inflammatory bowel disease: The importance of patient-centred outcomes in severe asthma

Joseph W. Lanario[1*], Matthew Masoli[2], Michael E. Hyland[1]

[1]Faculty of Health, University of Plymouth, PL6 8AA Plymouth, UK
[2]Department of Respiratory Medicine, Royal Devon and Exeter Hospital, EX2 5DW Exeter, UK

***Correspondence:** Joseph W. Lanario, Community and Primary Care Research Centre (CPCRC), Peninsula Medical School, Faculty of Health, University of Plymouth, PL6 8BU Plymouth, UK. joseph.lanario@plymouth.ac.uk
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Abstract

Biologic therapies have transformed care for people with severe asthma, yet treatment response has traditionally been assessed using clinician-derived measures, including lung function, exacerbation rates, and oral corticosteroid use. These metrics, while clinically important, frequently fail to capture what matters most to patients: their ability to participate in daily life, maintain relationships, and sustain work and social roles. The publication of the Core Outcome Measures Set for Severe Asthma (COMSA) and the subsequent CompOsite iNdexes For Response in asthMa (CONFiRM) composite score mark a shift towards patient-centred measurement of treatment response in severe asthma. Rheumatoid arthritis (RA) and inflammatory bowel disease (IBD) travelled this path decades earlier. Both conditions adopted composite scoring tools, such as the Disease Activity Score-28 (DAS28) and the Mayo Score, that incorporated Patient-Reported Outcome Measures (PROMs) alongside objective markers. Initiatives like Outcome Measures in Rheumatology (OMERACT) in RA and Selecting Therapeutic Targets in Inflammatory Bowel Disease (STRIDE) in IBD demonstrate that sustained, multidisciplinary collaboration between patients, clinicians, regulators, and industry can successfully embed PROMs into clinical trials and routine care. We argue that timely integration of health-related quality of life measures into clinical trials and practice requires electronic data collection, regulatory endorsement of PROMs as co-primary endpoints, and genuine patient partnership in research, beyond tokenism. By learning from parallel specialties, the asthma community can build a model of care that reflects what truly matters to those living with the disease.

Keywords

severe asthma, patient-reported outcomes, health-related quality of life, biologic therapy, composite outcome scores, COMSA

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Introduction

Biologic therapies have revolutionised the management of severe asthma, reducing exacerbation rates, improving lung function, and allowing many patients to reduce or eliminate their dependence on oral corticosteroids (OCS) [1]. However, how we define and measure treatment success has lagged behind this progress. Regulatory trials, clinical guidelines, and expert opinion have predominantly relied on clinician-derived endpoints, including forced expiratory volume in one second (FEV_1), exacerbation frequency, OCS dose, blood eosinophil count, and fractional exhaled nitric oxide (FeNO) [1]. These measures are objective and reproducible, but they may not reflect whether a patient can return to work, care for their family, exercise, or sleep through the night without fear of an attack [2, 3].

Recognising this gap, the Core Outcome Measures Set for Severe Asthma (COMSA) was published in 2023. This was the first multi-stakeholder consensus on which domains should define treatment response in severe asthma. Consistency of outcomes collected across trials will allow for meaningful comparisons between studies. COMSA established five core domains for measuring treatment response: health-related quality of life (HRQoL), exacerbation frequency, OCS use, lung function, and asthma control [4]. Building on COMSA, the CONFiRM (CompOsite iNdexes For Response in asthMa) score provides a numerical composite across these five domains, using domain weights guided by patient and clinician input. Exacerbations and OCS use were weighted most heavily, with HRQoL integrated alongside, not superseding, clinical measures [5].

This transition, from purely clinician-focused to patient-centred measurement, is not new to medicine. Rheumatoid arthritis (RA) and inflammatory bowel disease (IBD) underwent this change when biologic therapies arrived in their respective fields and did so before severe asthma. Their experience offers a source of comparison from which the asthma community can learn.

The current landscape in severe asthma

Despite the availability of validated HRQoL instruments, routine use of Patient-Reported Outcome Measures (PROMs) in clinical trials and practice remains inconsistent [6, 7]. A systematic review of clinical trials for severe asthma found that HRQoL was frequently omitted as an outcome measure [6]. Qualitative research confirms that the outcomes patients prioritise, including energy levels, emotional wellbeing, and social participation, are often not captured by standard clinical measures [3].

COMSA and CONFiRM represent the most meaningful steps yet taken to address this. By including HRQoL as one of five weighted domains, and by providing a practical scoring system to aggregate them, these tools create a framework that can be used both in trial design and in routine clinical practice [4, 5]. The question is no longer whether to include patient-centred measures in severe asthma, but how to ensure their adoption is consistent and meaningful, so that patients' experiences are included as part of any assessment. In this, asthma can take lessons from RA and IBD.

To date, uptake of COMSA and CONFiRM remains limited in part because both have only recently been published. A further barrier to their use is the lack of electronic infrastructure for routine HRQoL collection (see below).

Lessons from rheumatoid arthritis

RA was among the first chronic inflammatory diseases to gain access to biologic therapies, and one of the first to develop composite outcome scoring tools that incorporated the patient perspective. The Disease Activity Score-28 (DAS28) combined joint counts, an inflammatory marker, and a patient global assessment into a single index, providing an early example of how clinician and patient perspectives could be integrated [8]. Over time, it became apparent that the patient global assessment component captured something clinicians could not measure objectively, namely the lived burden of the disease.

The Outcome Measures in Rheumatology (OMERACT) initiative, established in 1992, became the primary means for developing and standardising outcome measures in RA through international consensus

involving patients, clinicians, regulators, and industry [9]. Crucially, it was not until 2002 that patients were invited as full delegates rather than observers, and not until 2006 that OMERACT formalised policies ensuring patient partners were involved in all working groups [10]. Genuine patient partnership requires explicit structures and policies, not simply an open invitation.

One product of this evolving patient partnership was the RAPID3 (Routine Assessment of Patient Index Data 3), an index based entirely on patient-reported data. It correlates well with more complex disease activity scores and can be completed in under two minutes in the clinic [11]. Experience implementing RAPID3 revealed an important practical lesson: collection rates increased from 9.3% and 36.2% at two clinic sites to a combined average of 79.5% when the questionnaire was administered electronically and integrated into patients' electronic health records, rather than via paper forms [12]. The mechanism of collection matters as much as the measure itself.

RA also demonstrates the persistence of established habits even after consensus-driven change. Despite decades of work through OMERACT, the DAS28 continues to be widely used, even though it is known to underestimate disease activity in patients with significant fatigue but minimal joint inflammation, a pattern that is common but invisible to the DAS28 [13, 14]. The existence of a better measure does not guarantee its adoption. Structural incentives, regulatory expectations, and clinical culture all shape what is measured in practice.

Lessons from inflammatory bowel disease

IBD has followed a broadly similar trajectory. The Mayo Score and the Crohn's Disease Activity Index (CDAI) were early composite tools that combined clinician-assessed and patient-reported elements to define disease activity and treatment response [15, 16]. Like DAS28 in RA, these instruments created a precedent for multidomain assessment, though they were primarily driven by clinicians and endoscopic findings.

The IBD Disk, developed through patient and clinician collaboration, was a step-change in thinking [17]. It was designed in response to the recognition that symptoms such as fatigue, urgency, and abdominal pain, which have a profound impact on daily life, were systematically underweighted or omitted from clinically derived measures. In a French validation cohort, the IBD Disk was found to be feasible and acceptable in routine clinical practice, and importantly, it prompted conversations between patients and physicians about which aspects of the disease were most burdensome to the individual patient [18].

The Selecting Therapeutic Targets in Inflammatory Bowel Disease (STRIDE) initiative, coordinated by the International Organization for the Study of IBD, represents the IBD equivalent of OMERACT. It is a sustained, multidisciplinary working group that has iteratively refined the definition of treatment targets and the outcomes used to measure them, including patient-reported symptom resolution as a therapeutic goal [19]. Regulatory bodies, including the European Medicines Agency and the US Food and Drug Administration, have progressively accepted PROMs as co-primary or secondary endpoints in IBD trials, a development that in turn legitimised the inclusion of patient experience in the formal evidence base [20].

Opportunities for severe asthma

The parallels between the trajectories of RA and IBD, and more recently severe asthma, suggest several concrete opportunities.

First, a HRQoL questionnaire should be reviewed as part of routine clinical encounters, not simply collected and filed. In RA, guidance for RAPID3 encourages clinicians to review the questionnaire with the patient during the consultation, enabling a shared understanding of which aspects of disease are most affecting their life [11]. The IBD Disk was similarly designed to facilitate patient-clinician dialogue rather than simply generate a score [17]. HRQoL data in severe asthma has the same potential: if clinicians are not routinely reviewing HRQoL questionnaire scores with patients, the measure becomes a bureaucratic exercise rather than a clinical tool.

Second, COMSA domains should be embedded as co-primary or secondary endpoints in future trials of biologic therapies for severe asthma, allowing for comparison of outcomes across trials. Regulatory acceptance of PROMs as endpoints in RA and IBD was both a driver and a consequence of their inclusion in trial design [21, 22]. Without proactive inclusion in pivotal trials, patient-centred outcomes will remain secondary to, and effectively subordinated by, traditional biomarkers in regulatory decision-making.

Third, there is a clear need for a sustained working group in severe asthma modelled on OMERACT and STRIDE, one that brings together patients, clinicians, researchers, regulators, and industry over the long term, with defined policies to ensure patient partners are genuine co-investigators rather than consultees. COMSA and CONFiRM are strong starting points, but the refinement and application of outcome measures requires ongoing governance, not a one-time consensus exercise.

Pitfalls to avoid

The experience of RA and IBD also highlights pitfalls that the asthma community should consciously work to avoid. Importantly, the comparisons drawn here are illustrative, not equivalent. RA and IBD are different diseases from severe asthma, with different underlying biology and different management challenges, and their outcome models cannot simply be transplanted unmodified. Severe asthma is heterogeneous in a way that RA and IBD are not to the same degree. Different phenotypes, such as eosinophilic and non-eosinophilic disease, can present differently, and symptoms fluctuate over short timescales, including asthma exacerbations, rather than the more gradual progression seen in RA and IBD. COMSA accounts for this by assessing response over a 12-month window, reflected in its inclusion of annual exacerbation frequency and OCS use, a timeframe that aligns with standard clinical practice for judging biologic response.

It is worth first acknowledging that the composite scores used in RA and IBD are themselves imperfect. The DAS28 underestimates disease activity in patients with significant fatigue but minimal joint inflammation [13, 14], while the Mayo Score has been criticised for relying heavily on endoscopic findings that do not always correspond to patient-reported symptom burden [22]. These limitations do not diminish the value of composite scoring, but they remind us that no index is perfect and refinement may be needed in the future. CONFiRM should be understood as a living tool, subject to ongoing refinement as evidence accumulates about which domains and weightings best reflect the lived experience of severe asthma. The lessons of RA and IBD are therefore not simply about adopting composite scores, but about building the structures needed to improve them over time.

There is a risk of tokenism, that is, involving patients as advisors who comment on decisions already made, rather than as partners who help shape the questions being asked in the first place. OMERACT illustrates how slowly this shift can happen. It operated for ten years before patients were full delegates, and a further four years before patient involvement was formally mandated across working groups [10]. Involving patients as advisors who comment on decisions already made is not the same as involving them as partners who shape the questions being asked. Genuine partnership, by contrast, requires structural commitment, including dedicated funding, protected roles, and training in research methodology, to make patient partnership meaningful.

The persistence of the DAS28 illustrates that consensus-derived improvements in measurement may be ignored in favour of established practice [13, 14]. In severe asthma, the risk is that COMSA and CONFiRM are widely endorsed but are implemented in a limited way, such as being acknowledged in guidelines but absent from clinical practice or trial outcomes.

Proactive integration into electronic health records, audit frameworks, and pay-for-performance structures will be needed to shift clinical behaviour, as the RAPID3/electronic-collection above demonstrates. Pay-for-performance schemes offer one plausible mechanism for embedding HRQoL measures alongside clinical metrics. The NHS Quality and Outcomes Framework (QOF) in the United Kingdom, for example, pays GP practices additional income for meeting defined quality indicators across clinical domains. France's Rémunération sur Objectifs de Santé Publique (ROSP) operates similarly, offering individual physicians financial bonuses for achieving public health and quality targets. However, neither

scheme currently includes HRQoL indicators for severe asthma, and this remains a proposal rather than established practice. The addition of HRQoL to any pay-for-performance scheme would need policy engagement and evidence of impact before adoption in severe asthma.

Electronic data collection is not optional but essential. The experience from RA, where electronic collection of RAPID3 transformed completion rates, should be applied to severe asthma from the outset [12]. Designing digital collection as an afterthought, retrofitting paper tools into electronic systems, risks recreating the same barriers that have historically limited PROM completion in clinic.

The lessons drawn here come from predominantly European and North American healthcare systems, but COMSA's constituent parts are not inherently resource-intensive: HRQoL questionnaires are inexpensive to administer on paper where a validated translation exists, exacerbation frequency and OCS use can be captured through patient recall or pharmacy records. Lung function assessment via spirometry may present a challenge, but peak expiratory flow can be used as an alternative where spirometry is unavailable, as recommended in current international guidance [23]. Measurement of these outcomes is achievable across resource settings even where biologic access itself is limited. The more significant barriers to wider adoption, as elsewhere in this piece, are electronic and regulatory rather than measurement-related. Without digital infrastructure for routine collection and regulatory frameworks that recognise these outcomes, uptake beyond high-resource settings is likely to lag regardless of how affordable the underlying measures are. However, this can be difficult as regulators do not move at the same pace, and a multi-country trial will meet the most conservative relevant regulatory framework, rather than the most progressive. Electronic record and regulatory adoption were barriers RA and IBD also faced before PROMs became normalised as endpoints [21, 22].

Conclusion

Severe asthma is at an inflection point. COMSA and CONFiRM reflect a growing recognition that clinical improvement, however robustly measured, does not capture whether patients feel better in their lives. The challenge now is implementation. This includes ensuring that patient-centred measures move from consensus documents into clinical trials, regulatory submissions, electronic health records, and, most importantly, into the clinical conversation between patient and clinician.

RA and IBD show that this is achievable, but that it requires sustained effort, structural commitment to patient partnership, regulatory engagement, and an awareness that old practices can be difficult to change. The asthma community does not need to repeat the missteps of its predecessors. By learning from them deliberately, severe asthma can establish a model of care in which what matters to patients is measured, valued, and acted upon.

Abbreviations

COMSA: Core Outcome Measures Set for Severe Asthma

CONFiRM: CompOsite iNdexes For Response in asthMa

DAS28: Disease Activity Score-28

HRQoL: health-related quality of life

IBD: inflammatory bowel disease

OCS: oral corticosteroids

OMERACT: Outcome Measures in Rheumatology

PROMs: Patient-Reported Outcome Measures

RA: rheumatoid arthritis

RAPID3: Routine Assessment of Patient Index Data 3

STRIDE: Selecting Therapeutic Targets in Inflammatory Bowel Disease

Declarations

Disclaimer

The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

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Author contributions

JWL: Conceptualization, Writing—original draft, Writing—review & editing. MM: Writing—review & editing. MEH: Writing—review & editing, Supervision. All authors read and approved the submitted version.

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JWL, MM, and MEH receive royalties for commercial use of the Severe Asthma Questionnaire (SAQ).

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