

# Patient-reported goals in inflammatory bowel disease: what's the problem?

*Short title: PROMs: what's the problem?*

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A defining characteristic of the species *Homo sapiens* is that its members vocalise their diversity. None of us are alike when considering our concept of 'self', including cultural, socioeconomic, demographic, and experiential influences. In this context, how can we, as professionals managing the health of individuals, understand the lived experience of a chronic affliction such as inflammatory bowel disease (IBD)? The modern healthcare professional is trained to understand the measurement and treatment of disease from a quantitative perspective, where numbers conveying the probability of success and risk are primary considerations. Less often can we claim to have data that permit understanding of where an individual patient places their priorities, or what aspect of their care ought to be emphasised.

The therapeutic landscape for the management of IBD is widening, not only through increasing pharmacologic options, but also surgical and nutritional approaches. This is challenging for specialists to navigate and can be even more so for an individual with IBD when selecting a pathway that suits them. If a primary goal of medical care is to improve the quality of life of individual patients, then we need to listen to what patients have to say. It is therefore of paramount importance that shared decisions are made in the patient-physician interaction, which necessitates an understanding of the 'why' underlying the choices made by individual patients.

The report by van Deen *et al.* in this issue of the Journal [journal to insert ref] provides an insight into those factors that patients with IBD may prioritise (or not). A robust process of thematic content analysis, a qualitative research methodology, was mixed with quantitative statistical methods to encode a large sample of patient surveys. Qualitative research is often dismissed by scientifically trained clinicians as being of lesser value than quantitative measurement. That is to overlook the science: the goal of qualitative research is to gain insight into people's unique experiences and their interpretation of those experiences<sup>1</sup> and the understanding of social phenomena in natural, rather than experimental settings.<sup>2</sup> Such insights cannot be captured by quantitative studies, but they make a valuable contribution to health research.

Overall, the authors found that 70% of patients prioritised IBD-specific goals including symptoms or disease activity in general, or specific aspects around management of their illness. Interestingly, psychosocial goals were highlighted by only 12% of patients. Factors associated with the prioritisation of various disease or life goals were also identified following multivariate logistic regression. This included the association of age over 60 years with a desire to travel, and family planning for females and those aged between 30 to 40 years. Those hospitalised in the preceding 6 months had higher odds of being concerned about future surgery, and those with ulcerative colitis were more likely to be concerned about future disease

activity. In a subset of 637 patients with surveys collected at two consultations, only 20% reported the same goals or concerns at both timepoints. The message is that physicians need to check and re-check the goals of treatment with their patients, because the goal posts move.

The study focussed on a single open-ended question to prompt patient-responses, rather than a validated patient-reported outcome tool. This has the benefit of emulating 'real-world' clinical practice to identify a given patient's primary concern or goal. Conversely, one weakness of this approach is that examples of concerns may have led the patient, rather than being truly open-ended, although this was perhaps necessary. Additionally, the opportunity to report only a single concern or goal, rather than a ranked list, may have imposed artificial restrictions. The lack of validation is also likely to affect reproducibility and consistency. Regardless, this study is unique in the size and breadth of its sampling albeit including patients only from the United States. Whilst this may reduce the generalisability of the findings across global sociocultural groups, valuable insights and general principles can be derived.

Multiple survey-based studies have identified a disconnect between patient and physician expectations across various domains of living with IBD.<sup>3</sup> The IBD GAPPS multinational survey showed a significant difference between patients and physicians with regard to what constitutes disease remission, and the expected benefits and risks of various medical therapies.<sup>4</sup> Others have shown that physicians often underestimate the impact of specific IBD-related symptoms on quality of life and may thus fail to recognise issues that are important to patients.<sup>5,6</sup> Physical symptoms (including urgency and fatigue, among more commonly cited symptoms such as abdominal pain or diarrhoea) are one of the greatest difficulties facing patients living with IBD, which reduce psychosocial function, work, sexual activity and well-being.<sup>7</sup> The paradigm of managing IBD has changed, in concert with shifting epidemiology and an expanding therapeutic repertoire, which is beginning to take on board the views of patients and neglected symptoms such as urgency.<sup>8</sup>

A parallel concern is therefore the health economic impact of IBD as a chronic disease, attendant resource utilisation and cumulative burden on finite health resources. In this environment, a value-based health care model has growing appeal, aiming to place patient-centred, cost-effective care at its core, by prioritising the physical, mental, and social well-being of a patient.<sup>9</sup> Such a model requires accurate measurement of health outcomes after defining (and agreeing!) what those outcomes are, to which van Deen separately contributed.<sup>10</sup> Herein lies the strength of qualitative studies in IBD, which attempt to determine those aspects of holistic health that are most valued by patients living with disease.

Despite the difficulties of rigorous qualitative research, van Deen *et al.* have attempted to use this vital methodology to map out the answer to the elusive question of 'what do patients

want?'. The body of research to date reveals a concerning disconnect in patient-physician understanding, goals, and expectations. Whilst physicians are rightly trained to achieve important objective goals in the management of IBD, it is important not to forget the psychosocial organism in which the inflamed gastrointestinal tract resides. If we can understand how to treat-to-patient-*and*-physician-targets, we can move towards the shared goal of our patients living well with their disease.

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