ITP Management: Bridging Clinician and Patient Perspectives

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> Immune thrombocytopenia (ITP) management presents a persistent clinical dilemma: balancing platelet count normalisation with patient-reported quality of life and treatment burden. The immediate takeaway from discussions at eha 2026 is that a more integrated approach, incorporating patient perspectives into treatment decisions, is essential for optimising outcomes beyond mere laboratory values.

KEY TAKEAWAYS

- The Pivot: ITP management is shifting from a purely platelet count-driven approach to one that integrates patient-reported outcomes and quality of life.
- The Data: While no specific trial data was presented, the consensus highlighted the discordance between clinician-perceived treatment success and patient-experienced burden.
- The Action: Clinicians should actively solicit and incorporate patient preferences and quality of life concerns when formulating ITP treatment plans, moving beyond isolated platelet count targets.

Immune thrombocytopenia (ITP) is an acquired autoimmune disorder characterised by a platelet count below 100 x 109/L, leading to an increased risk of bleeding.1 The primary goal of treatment has traditionally focused on achieving and maintaining a safe platelet count to prevent severe haemorrhage.2 However, the impact of ITP extends beyond bleeding risk, significantly affecting patients' quality of life (QoL) due to symptoms like fatigue, fear of bleeding, and the burden of treatment itself.3 Discussions at eha 2026 highlighted a persistent gap between clinician-defined treatment success, often measured by platelet counts, and patient-perceived well-being.4

Current guidelines for ITP management recommend various therapeutic options, including corticosteroids, intravenous immunoglobulin (IVIg), anti-D immunoglobulin, and thrombopoietin receptor agonists (TPO-RAs).2 Splenectomy remains an option for refractory cases.2 While these treatments are effective in raising platelet counts, they are associated with side effects that can diminish QoL. For example, corticosteroids can cause weight gain, mood changes, and bone density issues, while TPO-RAs require regular administration and monitoring.5 The eha 2026 sessions underscored that clinicians often prioritise platelet count normalisation, sometimes overlooking the cumulative impact of treatment-related adverse events and the psychological burden of living with a chronic condition.4

The ITP Conversation: Bridging Perspectives

The eha 2026 symposium, titled 'The Immune Thrombocytopenia (ITP) Conversation: Bringing Together Patient and Clinician Perspectives,' focused on identifying and addressing the disconnects in ITP management.4 The discussions involved haematologists, patient advocates, and individuals living with ITP. A key theme was the variability in what

constitutes 'success' from different viewpoints. Clinicians frequently define success as a sustained platelet count above 30-50 x 109/L with minimal bleeding.2 Patients, however, often define success by the absence of debilitating fatigue, the ability to maintain daily activities, and a reduction in anxiety related to their condition, even if their platelet count remains below the normal range.3,4

One significant point of divergence identified was the perception of treatment burden. Clinicians may view a treatment as effective if it achieves a target platelet count, while patients may find the frequency of hospital visits, the side effects of medication, or the constant monitoring to be highly disruptive to their lives.4 For instance, a patient might prefer a slightly lower, stable platelet count if it means avoiding the severe mood swings associated with high-dose corticosteroids.5 The symposium emphasised that shared decision-making, where treatment options are discussed in the context of individual patient values and lifestyle, is not consistently practiced.4

The discussions also highlighted the need for better patient education regarding ITP and its management. Patients often report feeling inadequately informed about their condition, the rationale behind treatment choices, and the potential long-term implications.3 This lack of understanding can lead to non-adherence and dissatisfaction with care.4 Conversely, clinicians expressed challenges in eliciting comprehensive patient perspectives during routine consultations, often due to time constraints and a focus on immediate clinical parameters.4

While no new clinical trial data was presented, the consensus among participants was that future research should incorporate patient-reported outcome measures (PROMs) more rigorously.4 PROMs, such as the ITP-Patient Assessment Questionnaire (ITP-PAQ), provide validated tools to assess fatigue, emotional well-being, and activity limitations.3 Integrating these measures into clinical trials and routine practice could offer a more holistic understanding of treatment efficacy. The symposium concluded that a paradigm shift towards patient-centred care, where QoL is given equal weight to platelet counts, is necessary to improve overall outcomes for individuals with ITP.4 This requires ongoing dialogue between patients and clinicians, facilitated by improved communication strategies and the systematic use of PROMs.

For further comprehensive understanding of haematological conditions, including ITP management, readers are directed to the authoritative Oxford Handbook of Clinical Haematology.

CLINICAL IMPLICATIONS

The eha 2026 discussions on ITP management underscore a persistent, yet often unaddressed, disconnect in chronic disease care: the chasm between objective clinical metrics and subjective patient experience. For haematologists, this means moving beyond the comfort of platelet count targets and engaging in a more nuanced dialogue about what 'living well' with ITP truly entails for each individual. It is not enough to achieve a platelet count of 50 x 109/L if the patient is debilitated by corticosteroid side effects or the anxiety of frequent monitoring. The onus is on clinicians to actively solicit patient preferences, even when time is a constraint, and to recognise that a 'successful' treatment outcome might involve a compromise on platelet numbers in favour of improved quality of life.

From an industry perspective, the emphasis on patient-reported outcomes (PROMs) should serve as a clear directive. Pharmaceutical companies developing new ITP therapies, whether novel TPO-RAs or other immunomodulators, must integrate validated PROMs into their clinical trial designs from phase II onwards. Simply demonstrating superior platelet response rates will become increasingly insufficient if those gains are offset by an unacceptable burden of side effects or administration. Payers and regulatory bodies, such as

> NICE or the FDA, should also consider mandating the inclusion and reporting of meaningful PROMs in drug approvals and reimbursement decisions for chronic conditions like ITP. This would incentivise a more holistic approach to drug development.
> Ultimately, the 'ITP Conversation' highlights that patient-centred care is not merely an aspirational concept but a clinical imperative. Patients with ITP are not just platelet counts; they are individuals with lives, jobs, and families. Their fear of bleeding, their fatigue, and the disruption caused by treatment are as real and impactful as any laboratory value. A truly effective management strategy must acknowledge and integrate these lived experiences, fostering a collaborative relationship where shared decision-making leads to outcomes that are both clinically sound and personally meaningful. Failure to do so risks suboptimal adherence, patient dissatisfaction, and a missed opportunity to genuinely improve lives.

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