



# COMPASS: *FINDING OUR WAY* – ESTABLISHING MALAYSIA’S FIRST MPN SUPPORT AND ADVOCACY NETWORK

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## INTRODUCTION

Myeloproliferative neoplasms (MPNs) are a clinically significant group of chronic haematologic malignancies in Malaysia. Between 2009 and 2015, the national MPN registry identified 1,010 cases: essential thrombocythemia accounted for 40.4%, polycythemia vera for 38.1%, and primary myelofibrosis for 9.2%<sup>1</sup>. Despite well-documented evidence that patient advocacy and support groups enhance health literacy, treatment adherence, and psychosocial well-being<sup>2</sup>, no dedicated MPN patient advocacy or support network has been established in Malaysia to date. This initiative sought to establish a patient support network for individuals living with MPN in the southern Malaysian state of Johor, thereby pioneering the nation’s first MPN-specific advocacy and support organisation.

## METHODOLOGY

- **Patient Recruitment:** Clinician-led outreach was conducted during outpatient clinics and daycare treatment sessions at Sultanah Aminah Hospital, the regional haematology referral centre for Southern Malaysia. MPN patients were invited to participate in the network and attend the launch event.
- **Funding:** The establishment of the organisation was supported by initial funding from Sejati Initiative. Additional resources for the launch event, including venue, educational materials, and refreshments, were provided through sponsorship from industry partners.
- **Engagement Strategy:** Trilingual (English, Malay and Mandarin) educational materials were provided to ensure accessibility of information.
- **Evaluation:** Attendance records, participant feedback surveys, and support group membership growth were used to assess reach and impact.

## RESULTS

On 10 May 2025, more than 50 patients, caregivers, clinicians, and allied health professionals participated in an MPN patient-focused event, which featured educational talks and patient sharing sessions to foster knowledge exchange, connection, and empowerment. This event marked the official launch of COMPASS (**CO**mmunity for **MPN** **P**atient **A**wareness and **S**hared **S**upport), Malaysia’s first MPN patient support and advocacy network, representing an important milestone in building a more connected and supported MPN community.



## CONCLUSION

The launch of COMPASS demonstrates the value and feasibility of structured patient involvement in MPN care. The network now aims to transition to a patient-driven model, empowering those with lived experience to lead advocacy, support, and programme design for greater sustainability and relevance<sup>3</sup>.

## REFERENCES

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