



# ISPEP Voice 2 Value Study

Title: Translating patient advocacy group data into effective clinician education to improve patient care and outcomes

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## Problem Statement

Medscape Oncology Global, a provider of medical education for healthcare professionals, sought data to drive the development of educational activities on chronic lymphocytic leukaemia (CLL). Lymphoma Coalition, a global patient organisation, had access to relevant data through its [Global Patient Research Survey](#). A collaboration was established **to translate these data into effective clinician education** and address knowledge and confidence gaps to **improve patient care and outcomes**.

## Objectives

- Leverage the collaboration between Medscape Oncology Global and Lymphoma Coalition and results from Lymphoma Coalition's Global Patient Research Surveys to understand quality-of-life (QoL) issues (e.g., fatigue) and gaps in care (e.g., psychosocial support) experienced by patients throughout their treatment journey to inform accredited education for clinicians.
- Address clinicians' knowledge, skills, and confidence gaps regarding their ability to incorporate shared decision-making (SDM) into patients' care plans.

## Methodology

- **Training courses** were designed for clinicians providing guidance on how to integrate the patient perspective in treatment planning.
- Data from Lymphoma Coalition's 2022 global survey, with responses from 8637 patients/caregivers, were presented in an **online educational activity** in 2023 featuring Lymphoma Coalition's CEO, Lorna Warwick. Topics included patient/caregiver perspectives on SDM, side effects that affected patients most, and the psychosocial impact of CLL.
- A **symposium** presented at EHA 2024 featuring Lorna Warwick focused on the holistic care approach and the importance of SDM.

## Results (Outcomes and Impact)

- By increasing competency in integrating patient preferences into the healthcare decision-making process, participating haematologists/oncologists are now more confident in integrating SDM to individualise evidence-based therapy.
- Participant feedback revealed that the symposium increased clinicians' confidence (mostly or very much) in their ability to integrate effective communication strategies to facilitate SDM **from 21% pre-event to 38% post-event**.
- Translated education offered in multiple languages allowed clinicians access to information in their local language, fostering easier uptake of best practices globally.

## Triple Win

- **For Patients:** Clinicians who improve communication with their patients are better able to integrate patients' perspectives in treatment planning.
- **For Pharma:** Understanding patient perspectives and integrating their preferences into care plans are critical to unlocking the maximum potential from existing and new therapies with regards to improved treatment satisfaction, adherence and outcomes (see ROI section).
- **For Society:** Improving patient outcomes contributes to improved QoL, reduces avoidable healthcare resource utilisation and enhances productivity, thus reducing disease burden in society ([Marzban 2022](#)).

## Return on investment

- For **74%** of participating haematologists/oncologists, this medical education successfully improved (15%) or reinforced (59%) knowledge that patients' wishes and personal preferences are key factors informing treatment decision making.
- Results from medical education and advanced outcomes studies demonstrate that **clinicians are benefiting from guidance about how to integrate the patient's perspective into clinical decision making**, through enhanced knowledge and confidence that is exhibited in daily practice.

## Lessons Learned

- The collaboration between medical education providers and advocacy organisations offers an opportunity to explore areas of educational need for healthcare professionals and collectively design educational interventions to address those needs.
- Planning calls and frequent communication are critical to facilitate the integration of research findings from advocacy organisations (as well as clinical trial data) into meaningful educational interventions.

## Looking Ahead

- Further analysis of data from activity participants will continue to be evaluated and inform medical education to enhance patient care, satisfaction, QoL, and well-being.
- The collaboration model established between Medscape Oncology Global and the Lymphoma Coalition, through which data collected from patient surveys is shared to inform medical education, can be **replicated in other disease areas and contexts**.
- Future education should prioritise practical approaches for integrating novel therapies, including patient and treatment selection and incorporating the patient perspective, to enhance preparedness and confidence.

## Conclusion

Medical education, developed in collaboration with patient advocacy organisations, which effectively integrates patient needs and perspectives empowers clinicians to not only navigate treatment selection, but also successfully facilitate shared decision-making, resulting in improved patient care, outcomes, and wellbeing. In terms of 'ABC', this case study demonstrates the following:

- **Activation of patient voice:** inclusion of the patient experience data from the Lymphoma Coalition.
- **Behavioural change:** increased knowledge and confidence of HCPs.
- **Collaboration:** educational efforts through the collaboration between Medscape Oncology Global and the Lymphoma Coalition.