

# Poster #2002: Improving information provision to enhance Chronic Lymphocytic Leukaemia (CLL) care in resource-limited countries (RLCs)

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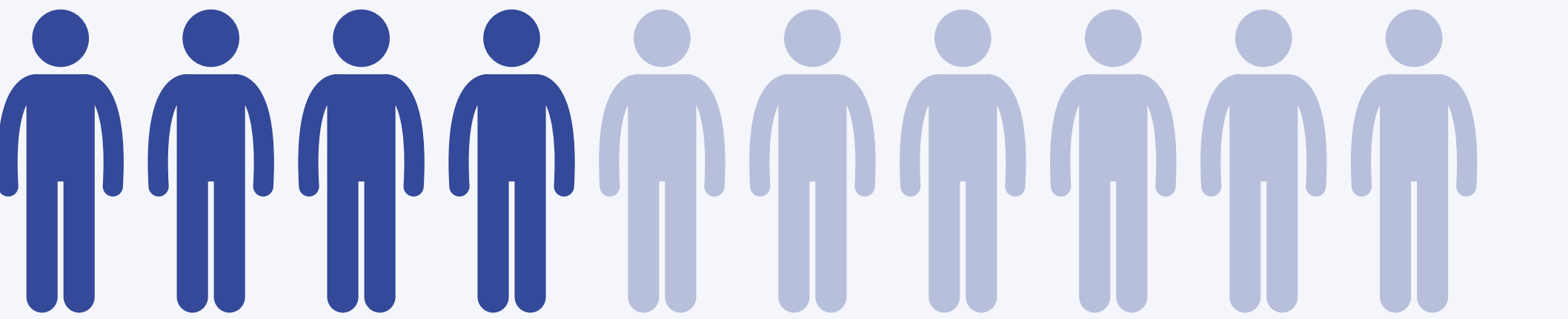
## Introduction

In many RLCs reported rates of CLL are rising, and death rates remain high, for example Ethiopia has the highest age standardised death rate globally.<sup>1</sup>

People living with CLL are often not provided with sufficient information to confidently navigate their own disease and care.

This problem is particularly pronounced in RLCs<sup>2</sup> - often referring to low- and middle-income settings - where shared decision-making (SDM) remains out of reach for many people living with CLL.

**41% of patients reported having inadequate information to make well-informed treatment decisions.<sup>3</sup>**

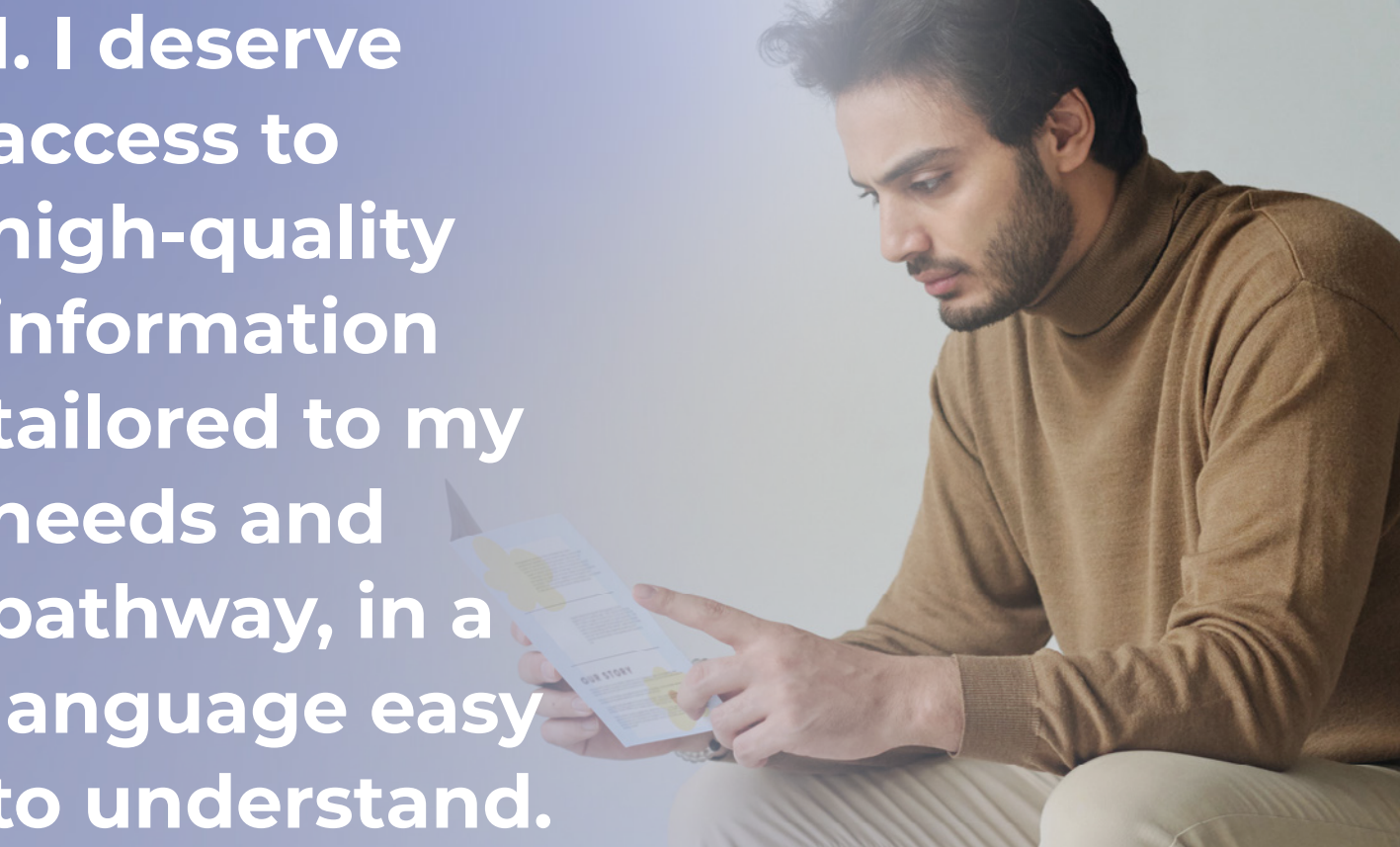


## Methodology

To address unmet needs such as information provision, the CLL Charter was developed, with continued input from 29 HCPs (Healthcare professionals) and PAGs (Patient Advocacy Groups). AstraZeneca initiated and funded the Charter following a roundtable with experts at the European Hematology Association 2024 Congress. The roundtable identified several unmet needs and recommended principles to address care gaps. These principles were further refined by a roundtable at the 2024 CLL Horizons conference. They were then expanded through a structured literature review and two rounds of offline feedback.



## Improving information provision is one of six consensus-driven principles in the CLL Charter



- 2. I deserve access to an accurate and definitive diagnosis.
- 3. I deserve access to shared decision-making throughout the care pathway.
- 4. I deserve access to affordable, effective care and a full range of specialists to support me throughout my journey.
- 5. I deserve emotional and psychological support from clinical, allied health professionals and support networks.
- 6. I deserve access to a care model that recognizes CLL's total impact, including its secondary effects and complications.

## References

1. Zhu, L., et al. 2021. Research Square. 2. CLL Advocacy Survey. 2021. [Internet]. [Accessed July 2025]. 3. Tam, C., et al. 2023. Blood Adv (2023) 7 (22): 6819–6828. 4. Montori, V. M., et al. 2022. BMJ Evidence-Based Medicine, 28(4), 213–217 5. Lymphoma Coalition (2024) 2024 Global Patient Survey on Lymphomas and CLL. Global Report. [Internet]. [Accessed July 2025]. 6. Eichhorst, B., et al. 2016. Hematology Am Soc Hematol Educ Program. 2016(1):149-155. 7. Howell. D.A., et al. 2024. European Journal of Cancer Care. 2024, 9999977. 8. Murthy, P. 2009. Health literacy and sustainable development. United Nations. [Internet] [Accessed July 2025]. 9. WHO. 2017. Strategic Communications Framework for Effective Communications. [Internet] [Accessed July 2025]. 10. Shaw, S. J., et al. 2008. Journal of Immigrant and Minority Health, 11(6), 460–467.



## Results

### A lack of information affects people with CLL and caregivers

- High-quality information is crucial for people living with CLL, carers and family members. It has been shown to improve quality of life and reduce anxiety and depression.<sup>4</sup>
- Many people living with CLL are unaware of their subtype,<sup>5</sup> which can help predict survival,<sup>6</sup> and they do not always understand the terms used to describe their disease.

### Information provision is key

- Appointments following initial diagnosis provide an important opportunity to understand a person's information preferences and needs for the future.
- Information can help people make informed decisions about their treatment options and to express their psychosocial needs.<sup>7</sup>

### Challenges with information provision within RLCs

- 1. People in RLCs are less likely to be able to access tailored information about their disease.<sup>2</sup>
- 2. There is often low functional literacy in these settings, so many people struggle to read and understand basic health information.<sup>8</sup>
- 3. RLCs can be very diverse<sup>9</sup> which can often mean significant cultural differences and specificities directly affecting how health information is received, understood, and acted upon, increasing health disparities.<sup>10</sup>
- 4. Specialists and people living with CLL should be able to access culturally appropriate information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations.<sup>9</sup>
- 5. People living with CLL prefer receiving information directly from a trusted HCP.<sup>2</sup> However, having the time and opportunity to have this dialogue with a HCP is not something everyone living with CLL has experienced, especially in RLCs where clinicians may be especially time poor.


### Recommendations to improve information provision for people living with CLL


- CLL information must be tailored to meet specific literacy and cultural needs in RLCs.
- People living with CLL must be able to access information specific to their disease in the local language.
- People living with CLL should receive good quality information from a trusted HCP, at the right time.




## Call to action

 Integrate health literacy improvement programmes into national cancer strategies.

 Embed CLL education at diagnosis throughout patient pathway.

 Leverage existing community and health networks to share tailored CLL information.

 Train HCPs to deliver clear, compassionate CLL information.

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