

## Understanding patients' perspectives and preferences regarding first-line chronic lymphocytic leukemia (CLL) treatment across Europe

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**Background:** Following a cancer diagnosis, patients may turn to digital social community platforms to seek information and share their personal experiences, needs, and concerns. Valuable insights can be generated by systematically collecting and analyzing the patient voice on social media and online patient platforms. Artificial intelligence now enables the processing and extraction of meaningful insights from large volumes of unstructured online data. Digital listening leverages real-world insights by highlighting common themes and trends over time of topics important to patients.

**Aim:** This analysis aimed to understand patients' perspectives on the factors that most influenced treatment choice and the extent to which patients were involved in their treatment decision-making for first-line CLL using AI-based Semantic-NLP technology.

**Methods:** A multilingual ontology-based AI information extraction system (Semantic Hub) was used to identify the patient "voice" from online posts in France, Germany, Italy, Spain, and the United Kingdom (UK). Data related to patients and first-line treatments in CLL were collected from social community platforms and other online patient platforms (i.e. Facebook, Instagram, HealthUnlocked.com) between January 1, 2020 and December 31, 2025. Key medical concepts, including factors influencing treatment and how treatment decisions were made, were extracted from the data, grouped into thematic categories, and analyzed using both qualitative and quantitative approaches.

**Results:** A total of 44,451 messages from 2,699 individuals were detected across the five countries. The semantic analysis revealed that treatment decisions were generally guided by hematologists. In the UK and Germany, out of 1,090 and 629 authors, respectively, only 7% and 11% explicitly reported that they were involved in the decision-making for their choice of treatment. Of note, in Germany, patients posted that they were rarely asked about their personal priorities by their doctor. In terms of the factors that matter most to patients with CLL, safety and effectiveness were the primary drivers of treatment choice across the five countries

(Figure); these factors remained stable over time as the primary drivers of treatment choice. Treatment duration was the lowest ranking criteria influencing treatment choice across the five countries. Notably, in the UK, patients mentioned that those who chose a fixed-duration treatment were influenced by their hematologists' recommendation and the expectation of achieving a deep remission.

**Conclusion:** This analysis demonstrated that the safety and effectiveness of a treatment were the top priorities for patients, with treatment duration being the lowest priority, when discussing treatment choices for first-line CLL. Insights also revealed that shared decision-making between patients and their healthcare providers remains limited. Further research warrants validating these findings across a wide range of CLL patients beyond social community platforms as there may be a reporting bias from patients who are more motivated to share their experiences online.

**Figure. Insights from patients on factors influencing treatment choice, %**

