

POLICY BRIEF 2026

Ensuring equitable diagnosis, access, treatment and lifelong support for every person living with Chronic Lymphocytic Leukaemia (CLL)





Executive Summary

Across Europe, remarkable scientific discoveries have transformed **Chronic Lymphocytic Leukaemia (CLL)** from a condition managed primarily with chemotherapy into one where highly effective targeted therapies now offer longer survival, improved quality of life, and -for some people- treatment-free periods.

Yet this innovation is not reaching all people with CLL equally.

The country in which a person lives continues to influence whether they receive a timely diagnosis, access to recommended molecular testing, access to (including reimbursement of) innovative therapies, opportunities to participate in clinical trials, and opportunities to access specialist multidisciplinary care and appropriate psychosocial support.

To better understand these disparities, the European CLL Association (ECLLA) convened its first European Policy Roundtable in Dublin in 2026, bringing together people with lived experience, advocacy leaders, haematologists, psycho-oncology experts, researchers, industry, and policy specialists, from across Europe. The discussion confirmed that while healthcare systems differ considerably, many challenges are shared.

The Roundtable identified four priority areas for European action:

- 1. Improve diagnosis and referral pathways.**
- 2. Ensure equitable access to treatment.**
- 3. Expand access to clinical trials and innovation.**
- 4. Integrate psychosocial support throughout the CLL pathway.**

Together, these four priorities map onto the lived pathway for people with CLL – from diagnosis, through treatment decisions and access to research, to the psychosocial support needed at every stage.

This Policy Brief presents both high-level and more practical recommendations for European institutions, national governments, healthcare professionals and patient organisations, clustered around these 4 priorities. In addition, it highlights a number of core cross-cutting recommendations to drive progress in the CLL field and reduce the current inequalities and inequities. These recommendations are a starting point: as each annual ECLLA Roundtable delves deeper into the status quo across European countries, and advances efforts to agree on good practices and approaches that should be expanded across borders, it is anticipated that these recommendations will be expanded and elaborated.

Introduction – the impact and unmet needs of CLL

CLL is, in many ways, a condition marked by contradictions. These pose particular challenges to people with CLL, to families, and to society at large.

01

Rare yet common

CLL is a rare cancer, affecting only around 4-6 people per 100,000 per year - but is simultaneously the most common form of leukaemia in adults.

02

Primarily an older person's condition: but it can affect younger

people too - The average age at diagnosis is approximately 70, meaning this is primarily a condition affecting older adults. However, the picture is more complex, as much younger adults are also affected: less than 10% of diagnoses occur in the under 45s, but this is still a substantial population.¹

The connection with ageing means CLL is poised to become an even more significant healthcare issue in the future, as population ageing is a major trend in European countries. It is expected that CLL incidence will therefore continue to rise.

Compounding the issues, for a **‘later-life’ condition**, there is a major socio-economic impact; that **average age of diagnosis of ‘around 70’** means that it is not a condition facing people in their ‘twilight’ years: in the modern world, those affected by this condition are often going to be active members of society fulfilling key roles, either still in employment themselves, bolstering the voluntary sector, or else providing essential childcare support. An impact on these individuals will therefore have a broader societal and financial impact. For **younger people with CLL**, there are additional challenges. Here, the chances of the condition affecting daily life, employment, and social life, will arguably be higher. Affected individuals may well have young children to consider, complicating and increasing the impact on the wider family.

03

Incurable and typically slow-burning: but not always

In some respects, the outlook for people diagnosed with CLL has improved drastically in recent years. The majority will never need treatment, and those who do have more options than ever (IF they are realistically accessible). What this means is a **lifetime of ‘watching and waiting’**, which though typically now referred to as active monitoring, is nonetheless a lifetime of uncertainty. But crucially, in some cases the CLL will be more aggressive and require timely intervention, to optimise outcomes and quality of life. Health systems must be able to differentiate between these scenarios, and provide appropriate support to all people with CLL, despite the heterogeneity of the condition.

CLL is, by definition then, a condition of extremes, with bespoke needs. **In 2026, the CLL community has a good idea of what people should expect regarding referrals, diagnosis, treatment and access to trials.** Guidance exists to prompt clinicians on appropriate management. But the extent to which all people with CLL, in all European countries, can actually access the services, support and opportunities they need, leaving nobody behind, clearly varies from country to country.

Furthermore, the multistakeholder ECLLA Roundtable highlighted the fact that when it comes to agreeing what appropriate psychosocial and mental health support should look like, the community is less clear: the psychosocial impact and needs of CLL have only recently gained prominence as a topic of discussion, yet even here there are already key messages and clear recommendations are forthcoming.

As the manifestation of CLL can vary, so does the reality of affected individuals and families to be able to access the services and support and opportunities they need. Below, we outline key challenges and accompanying recommendations to enable everyone living with CLL to receive what they are entitled to.

Cross-Cutting Recommendations for the CLL Community

-  Work must be undertaken to elucidate more precisely the nature and extent of the challenges facing people with CLL in all European countries, via robust data collection.
-  Population surveys and additional workshops or roundtables should be organised, to build consensus on good practices adopted in certain countries and build a roadmap for their implementation in other settings.
-  A European framework for monitoring CLL inequalities should be created.
-  To amplify advocacy potential, the CLL community should explore the potential for collaborating across the wider blood cancer and rare cancer ecosystems, whilst maintaining a unique and essential focus on CLL, specifically.
-  National, Regional and European cancer plans and strategies should be examined, to assess the prospects for inclusion of measures to address CLL-specific challenges, with recommendations issued, where relevant.
-  ECLLA should examine and propose strategies to address the specific issues facing people with CLL in the European region in close collaboration with the broader global community.
-  The implications for people with CLL of key EU legislation and policy should be explored and clarified, assessing opportunities through the new General Pharmaceutical Legislation, the EU HTA Regulation and its Joint Clinical Assessments, the EU BioTech Act, and the shifting regulatory space, amongst others.
-  Recognising the particular challenges facing people with CLL and professionals in non-EU European countries, support should be provided to raise the level of provision and quality to that of EU states with regards to diagnosis, treatment, research, care, and social support for CLL, whilst exploring the wider options for collaboration in therapy development and access to clinical trials.
-  People with lived experience of CLL should be recognised as experts in their condition – they and the organisations which represent them, should be involved at every step of healthcare, research and psychosocial decision-making.

- The key role played by patient organisations in the CLL space should be recognised by national and European authorities, and support provided for individuals to engage in advocacy, education, policymaking, research, and data-collection activities, recognising people with CLL and patient organisations as partners. The unique support patient organisations bring must be acknowledged and supported, to ensure these groups can continue their vital work in partnership with health systems and research organisations, whilst recognising that these groups should never be a substitute for official services.

Topic-Specific Recommendations

1.

The referral and diagnosis processes must be improved, ensuring all people with CLL receive a timely diagnosis through appropriate diagnostic methods

- Primary care clinicians' awareness of CLL should be improved, to expedite appropriate testing and referral of both typical and atypical CLL presentations
- All people with suspected or confirmed CLL should have timely access to specialist haematology assessment, supported by clear national referral pathways and appropriate referral timeframes.
- Appropriate biomarker testing should be available at the clinically relevant timepoint to support evidence-based treatment decisions, including IGHV mutation status before first-line treatment and TP53 mutation and del(17p) testing before each treatment line, in line with EHA recommendations.
- At diagnosis, affected individuals and their care partners should be provided with reliable information about CLL and signposted to an appropriate national or local patient organisation for information, peer support and other available resources.
- People with CLL should be informed about appropriate opportunities to contribute to CLL registries, observational studies and other research initiatives where these are available.
- People with CLL entering active monitoring/surveillance should receive a clear follow-up and supportive-care plan, including information about monitoring, infection prevention and vaccination.
- People with CLL should receive coordinated care, with effective communication, appropriate data-sharing, and seamless referral pathways between primary care, haematology specialists, and all other professionals involved in the care pathway.

2.

Inequalities in access to evidence-based CLL care and treatment should be reduced through consistent implementation of European guidelines and transparent monitoring

- The [2026 EHA CLL Guidelines](#) should provide an important European benchmark for high-quality CLL care, supported by national clinical pathways and quality standards that translate recommendations into practice.
- Implementation of evidence-based CLL care should be systematically monitored across Europe, including variation in diagnostic testing, treatment availability, supportive care and outcomes.
- Delays and inequalities between regulatory approval, reimbursement and real-world access to guideline-recommended CLL treatments should be reduced across Europe. People with highly refractory CLL should also have equitable access to appropriate clinical trials and, where necessary, cross-border referral pathways.
- Equitable access to immunoglobulin replacement therapy should be ensured for people with CLL who meet evidence-based clinical criteria, alongside consistent infection prevention and management across Europe. Clinicians should also have appropriate training and support to recognise and manage treatment-related toxicities.
- Digital health tools should be explored as a means of improving access, monitoring, education and shared decision-making, while complementing rather than replacing person-centred care.

3.

All people with CLL should have equitable access to clinical trials and other research opportunities

- Eligible individuals should be informed about relevant clinical trials and research opportunities and supported to participate wherever appropriate, irrespective of geography, with particular attention to people with CLL in smaller countries and underserved regions.
- Public-private partnerships should support improved clinical trial opportunities in all European countries
- Validated patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) should be agreed and used more consistently across CLL care and research to capture quality of life, treatment burden, psychological wellbeing and care experience.

4.

The unmet psychosocial and mental health needs of CLL must be better explored, and support integrated across the CLL pathway

- Psychological support should become part of routine CLL care - not an 'optional extra' or a responsibility left solely to patient organisations.
- European data on the psychological, social and quality-of-life impact of CLL should be strengthened, including the effects of uncertainty, active surveillance, treatment, relapse, work, finances and family life.
- Validated quality-of-life and psychosocial measures should be incorporated at appropriate points in CLL care and research to better identify unmet needs and inform care.
- European CLL guidance should be complemented by more specific, actionable recommendations for psychosocial support and rehabilitation, co-created with people with CLL, care partners, healthcare professionals and patient organisations and responsive to different levels of individual need.
- The needs of care partners and families should be recognised alongside those of people with CLL, with appropriate information, support and signposting throughout the CLL pathway. This includes recognising the practical, emotional and often invisible burden that care partners carry – including impacts on their own employment, wellbeing and daily life – which frequently mirrors the challenges faced by people with CLL themselves.

Conclusion

In conclusion, CLL -as both an acute and chronic condition, a cancer and a rare disorder- poses unique challenges to people with CLL and their families, whilst also necessitating some fundamental shifts in terms of care, access to innovation, and holistic support. As the European population ages, a rethink in care provision becomes even more urgent, requiring an evolution from episodic treatment to integrated -yet still personalised- pathways through the health, research and psychosocial spheres. **The recommendations above offer a route to better understand the true extent of the inequalities facing people with CLL living in different parts of Europe, whilst also laying the foundations for real change.** Getting this right for CLL would improve quality of life for people affected by this condition, whilst simultaneously boosting European competitiveness and health-system sustainability.

Reference

ⁱ There is a major need for greater data collection on the experiences of people with CLL, as below. However, the core statistics highlighted here come from Hallek, M., 'Chronic Lymphocytic Leukemia: 2025 Update on the Epidemiology, Pathogenesis, Diagnosis, and Therapy', American Journal of Hematology, Vol .100, Issue 3, 2025 pp.450–480, <https://doi.org/10.1002/ajh.27546>. The following sources also provided important background for the creation of the ECLLA Roundtable and this Policy Brief:

- Eichhorst, B., Ghia, P., Bosch, F., Clifford, R., Gregor, M. et al., 'EHA Guidelines on management of chronic lymphocytic leukemia and Richter transformation', HemaSphere, Vol. 10, Issue 6, 2026, e70403. <https://doi.org/10.1002/hem3.70403>
- Monica M., Becirovic S., Bianchi-Manaila I., Duborija-Kovacevic, N., Draganic, P. et al. 'EUROCOVER-CLL: Reimbursement and accessibility of new treatments in relapsed/refractory chronic lymphocytic leukemia', Frontiers in pharmacology, Vol. 16, 1629465, 2025, <https://doi.org/10.3389/fphar.2025.1629465>

NB. The works above do not constitute an exhaustive bibliography - they are included here as a brief background selection.

