# Uncovering the immune-related challenges facing people with chronic lymphocytic leukaemia (CLL)

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### Introduction



Infections are a leading cause of mortality and affect the management of day-to-day activities for people with chronic lymphocytic leukaemia (CLL).



COVID-19 has spotlighted the immune-related difficulties faced by people with CLL, which increases their vulnerability to COVID-19 infection and negatively impacts their daily lives.1

### Methodology

To address the immune-related challenges and gaps in guidelines and data available, a multidisciplinary steering committee was convened, comprising patient representatives, patient advocacy groups and leading clinicians, to review current evidence - including a literature review comprising over 84 publications - assess gaps and formulate recommendations aimed at enhancing the management of immune challenges experienced by people with CLL.

Discussions at the steering committee focused on the following



Recognition of the immune-related



Impact on day-to-day lives of people



Recommendations for change in managing CLL immune-related challenges.

#### References

1. York N, et al. Compromised: Uncovering the immune-related challenges facing people with chronic lymphocytic leukaemia. CLLAN. 2023. https://www.clladvocates.net/whitepaper-CLL-immune-challenges/.

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## Recognition of immune-related challenges

It is critical to recognise that for people with chronic lymphocytic leukemia,

pandemic<sup>1</sup>

However, it is important to remember that immune-related challenges were

present before the pandemic. There is an increased risk of severe infection due

treatment. However, low awareness of immune-related challenges among people

to the immunosuppression caused by the disease, and as a consequence of

The COVID-19 pandemic has drawn attention to immune-challenges, and for

people with CLL who face an increased vulnerability to COVID-19 infection and

an adverse impact on their day-to-day lives, taking advantage of this spotlight to

Individuals with CLL had fatality rates

up to 16.5 times higher than the global

Figure 2: HCP awareness of

immune-related challenges<sup>1</sup>

"Healthcare Professionals

approaches to manage the

increased risk of infection."

physicians are aware of the

unique immune challenges.

I'm not sure that my family

doctor is even aware I am

CLLAN working group members living

with CLL

immunocompromised."

can often fail to talk to

patients about immune

"In my experience, not

all primary healthcare

suppression and

median rate in the first wave of the

infections stand as a prominent contributor to mortality.1

with CLL and some healthcare professionals remain.

Figure 1: Infection risk<sup>1</sup>

The 5-year risk for

in CLL is 26% overall

Risk increases to 57%

Risk increases to 68%

for those with both low

disease progression

IgG levels and advanced

once antibody levels such

as immunoglobulin G (IgG)

severe infections

improve the lives of patients is critical.<sup>1</sup>



## Day-to-day impact





## Recommendations for change



Further Research is needed to build a stronger evidence base of the immune challenges facing people with CLL.

- Establishing the impact of vaccination status on CLL outcomes
- Quantifying and qualifying the impact of opportunistic infections that are not treatment-related
- Identifying research needed to inform planning and clarification of protective measures for immunocompromised people
- Understanding how people with CLL are affected by immune-related challenges with regard to their social life and mental health
- Specifically adding focus on immune challenges in CLL-specific groundwork, whether clinical research or patient experience surveys



Healthcare professionals should be supported to optimally manage people with CLL facing immune challenges. This could include:

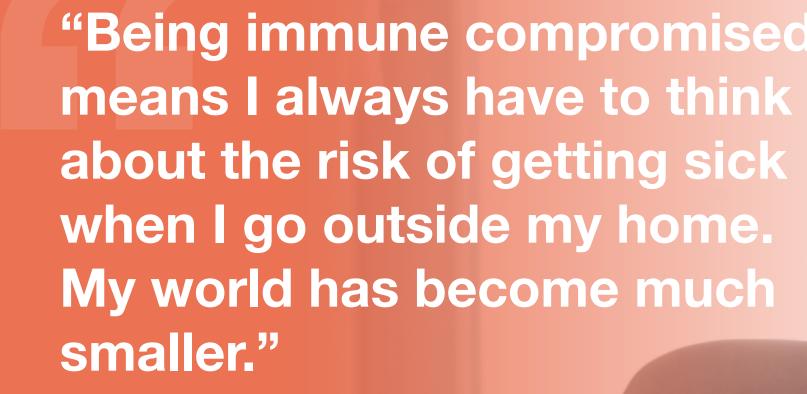
- Creating global clinical guidance for monitoring and managing immunosuppression in people with CLL
- Ensuring that immunocompromised status is flagged in the patient health records of people with CLL
- Instigating education and awareness raising activities amongst healthcare professionals, especially primary physicians
- Making shared decision-making and personalised approaches commonplace in the management and care of people with CLL



People with CLL should be supported with a range of information and resources to feel empowered, regardless of any immune challenges they may be facing.

Creating and sharing resources to educate and empower people with CLL (such as holistic self-assessments or information on the impact of certain lifestyle choices on infection risk)

## Patient voice:



"It creeps into most aspects of day-to-day activity changes lifestyle choices and [my] ability to interact with others safely."

CLLAN working group members living with CLL

Figure 3: Day-to-day impact of immune-related challenges



Research suggests that CLL has a significant impact on health-related quality of life (HRQoL).



People often lack general information on how to manage being immunocompromised and personalised information about their immunity status.



Quantifying the true impact of being immunocompromised on the day-to-day lives for people with CLL is challenging.



Only 52% of people with lymphoma or CLL are involved as much as they want to be in decisions about their care and treatment.

### Conclusion



People with CLL are at a higher risk of infection, which is the leading cause of mortality, yet preventing and managing immunosuppression is not always discussed with clinicians.



Immune-related challenges impact people living with CLL significantly, but there are evidence gaps that would help to quantify the real impact on day-to-day lives.



We call on the CLL community and health systems to improve the management of immune-related challenges by creating clinical guidelines for monitoring and managing immunosuppression; ensuring immunocompromised status is flagged; instigating education and awareness raising activities for HCPs; and making shared decision-making and personalised approaches commonplace.



Taking this opportunity to improve the lives of people with CLL who are immunocompromised by adopting these recommendations is paramount.



