

# Awareness, Knowledge, and Preferences of United States (US) Patients with Chronic Lymphocytic Leukemia (CLL) and Their Caregivers Related to Finite Duration (FD) Therapy and Minimal (Measurable) Residual Disease (MRD)

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## BACKGROUND & INTRODUCTION

- Until the introduction of novel agents, such as Bruton tyrosine kinase inhibitors (BTKi), the management of CLL patients primarily utilized limited duration chemoimmunotherapy (CIT). The use of BTKi significantly changed the CLL treatment paradigm to include continuous single-agent oral therapy delivered until disease progression or intolerance.
- More recently, similar to past CIT protocols, new combinations of non-CIT agents are being used that can be given over a finite duration (AKA fixed or limited duration). In addition, measurable (minimal) residual disease (MRD) assessment is emerging as an important clinical tool. Understanding the patients' perspective on these trends is critical to providing best care.
- CLL Society, a patient-facing, physician-curated nonprofit organization focused on the unmet needs of the CLL community, sought to understand patients' self-assessed awareness, understanding and preferences related to this changing therapeutic landscape with the addition of finite duration non-CIT options and MRD testing, and to research how they influence patients' decisions around treatment.

## OBJECTIVES

- Understand patients' self-assessed awareness, understanding and preferences related to finite therapies and MRD testing in the present treatment era.
- Assess how these influence their decisions related to therapy.
- Identify gaps and misconceptions in awareness and understanding that can be addressed through improved patient education and shared decision making.

## METHODS

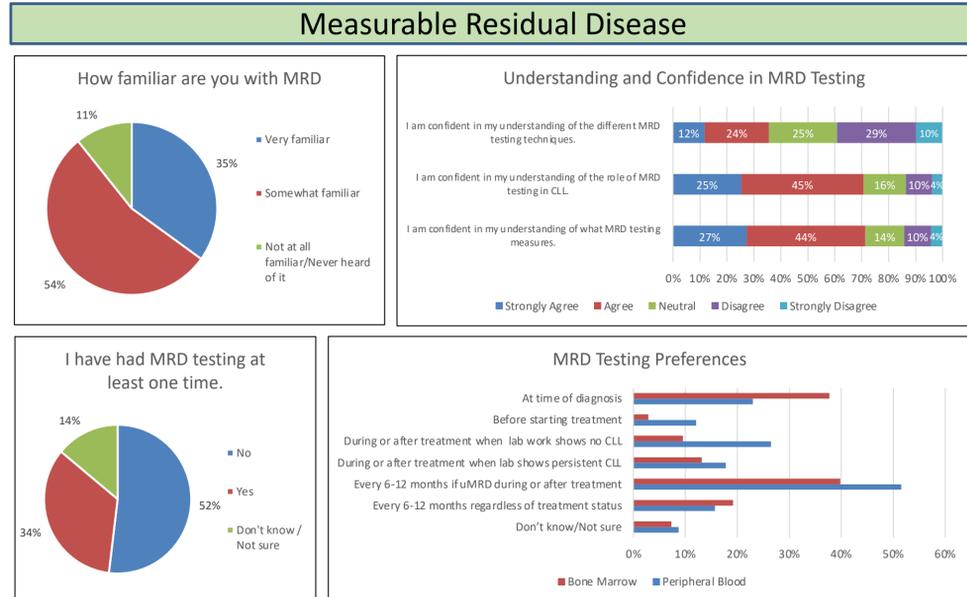
**Study Design**  
CLL Society developed a survey instrument to assess patient and caregiver awareness, understanding, and preferences associated with the concepts of MRD and finite duration therapies. The opt-in survey was conducted via a web-based data collection mode.

- Inclusion criteria**
- Respondents must be age 18 or older,
  - Have a diagnosis of CLL/SLL or be caring for someone with CLL/SLL,
  - Be an American resident with a working knowledge of English.

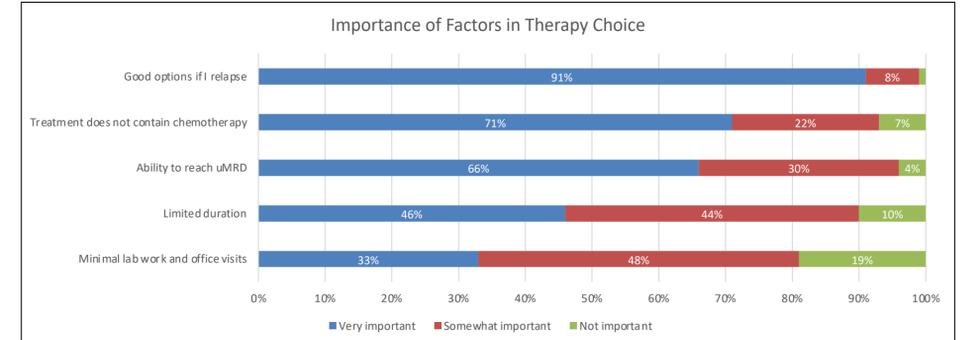
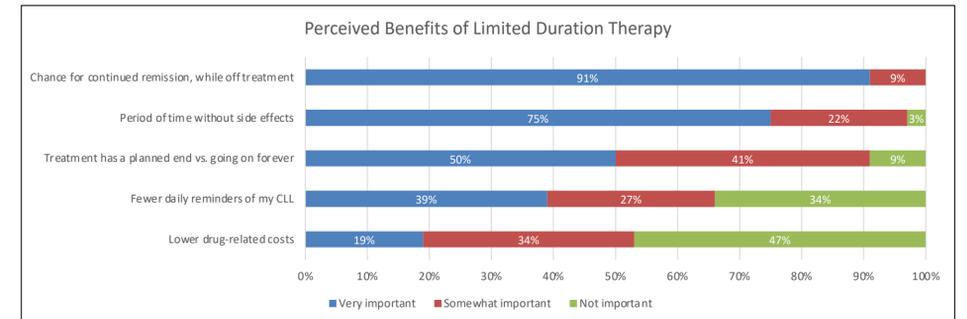
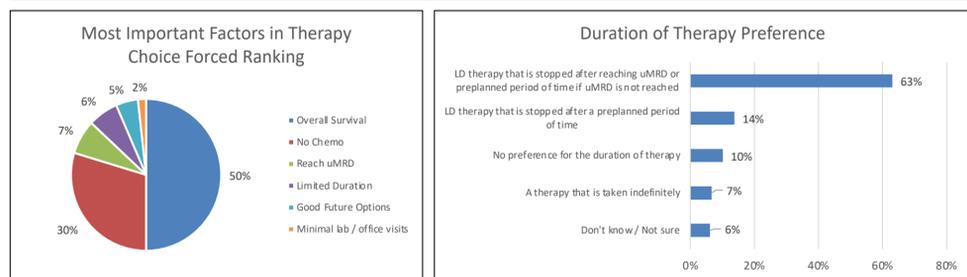
**Survey Recruitment**  
Patients and caregivers were invited by CLL Society via message boards, CLL Society website, emails, and multiple online communities. The survey was administered anonymously.

**Statistical Analysis**  
Data were analyzed using descriptive methods. Answers in individual surveys were cross checked for validity.

## RESULTS (CONTINUED)



## Limited Duration Therapy and Treatment Choice



## RESULTS (CONTINUED)

### Highlights: Awareness, Understanding, and Preferences

Areas of higher awareness, understanding and positive preferences	CLL Disease and Treatment Awareness	I am aware that some novel therapies may be prescribed continuously. Examples include ibrutinib, acalabrutinib, idelalisib and duvelisib).	Yes - 93%
	CLL Disease and Treatment Awareness	I am aware that some novel drug therapies may be prescribed for a limited duration. Examples include venetoclax, obinutuzumab, and others.	Yes - 90%
	Measurable Residual Disease (MRD)	Familiar about MRD's role in CLL.	Highly Confident / Confident 70%
		Confident in their understanding of what MRD measures.	Highly Confident / Confident 71%
Areas of lower awareness, understanding and preferences	Measurable Residual Disease (MRD)	If I became MRD detectable after being undetectable on a previous test, I would ask my doctor to consider:	Frequent monitoring, but no treatment change - 58%
		If I tested MRD detectable at the end of treatment, I would ask my doctor to consider:	Frequent monitoring, but no treatment change - 63%
	Factors Effecting Duration of Therapy	Factors when considering benefits of a limited duration treatment: Chance for continued remission, while off treatment	Very Important - 92%
		Factors when considering benefits of a limited duration treatment: Period of time without side effects	Very Important - 76%
CLL Disease and Treatment Awareness	CLL Disease and Treatment Awareness	Regarding awareness of their own prognostic and predictive factors (del 17p, TP53 mutation, del 11q, IgVH status, Notch1 mutation)	TP53 (38%) Complex Karyotype (36%) Mean (29%) Didn't know / not sure
		I am confident in my understanding of the different MRD testing techniques.	Neutral / Disagree / Strongly Disagree - 29%
	Minimal Residual Disease (MRD)	I would be satisfied with testing for MRD that looked for a specific of sensitivity (E.g. uMRD-6, uMRD-5, uMRD-4):	Don't know / not sure - 44%
Minimal Residual Disease (MRD)	Regarding understanding which treatments can achieve uMRD (BCL2, BTKi, Chemoimmunotherapy)	Don't know / not sure - 33%	

## RESULTS

**630 Responses**  
608 CLL patients  
22 CLL Caregivers

**5 Months**  
The survey was administered from SEP-2020 to FEB-2021

**2 Formats**  
Options to respond via PC or mobile device

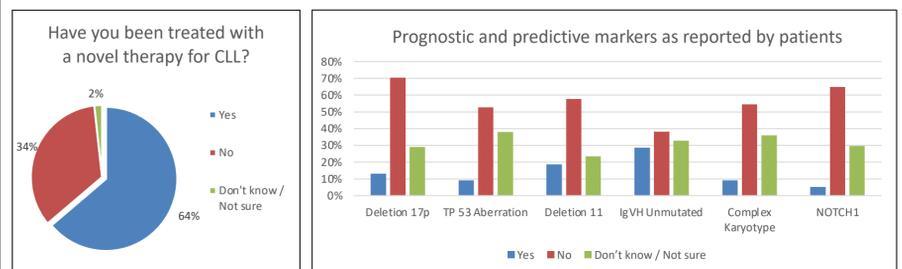
**Patient Demographics**

Age, Median (range)	63 (30-90)
Age, >70	35%
Sex, Female	55%
Does not have caregiver	48%
Treatment Status	
Watch and Wait	27%
Received of completed 1st treatment	38%
Received of completed 2nd or later treatment	34%

**630 Respondents** throughout every state in the USA

**19% (122)** From California  
**0.1% (1)** from Delaware and Mississippi

## CLL Disease and Treatment Status and Awareness



## CONCLUSIONS

- Overall survival (OS) and preserving future options were the 1st and 2nd very or somewhat important factors respectively in choosing a treatment. Ability to reach uMRD was rated more important than the duration of therapy. When forced to rank treatment preference on a fixed scale, OS was ranked 1st by 50%. Continued remission post-treatment was the major perceived benefit of finite therapy, followed by time without side effects off medication.
- Despite high levels of self reported confidence in understanding MRD, some patients had preferences for MRD testing when it was not indicated such as 18% of respondents wanting testing of peripheral blood when routine labs demonstrated persistent CLL. Regarding understanding of which treatments (BCL2, BTKi, Chemoimmunotherapy) can achieve uMRD about one third of patients were unsure.
- Given its opt-in nature and with nearly 1 in 5 who completed the survey coming from California, the results may not be reflective of all patients and caregivers.
- As the importance of MRD and finite therapy grows in CLL management, it will be incumbent upon providers to better understand and consider their patients' awareness, understanding, and preferences and to help patients become more informed about evolving practices so patients can make more informed therapeutic decisions.

## ABOUT CLL SOCIETY

CLL Society is a USA-based 501(c)3 nonprofit with a global reach. It is focused on patient education, support, advocacy and research to address the unmet needs of the CLL community through:

- CLL Society website <https://cllsociety.org> which contains up-to-date, accurate and patient-friendly information with >1,000,000 pageviews a year.
- The CLL Tribune, a quarterly online newsletter with patient, physician and related experts as authors.
- 39 CLL-specific local patient support and education groups with members in 3 continents.
- Virtual educational forums and webinars presenting expert speakers and patient advocates.
- Free virtual Expert Access™ to CLL experts providing consults to patients who would otherwise have no such access.
- Research on the patient journey and sharing results in major congresses and peer reviewed journals.

CLL Society wishes to thank the patients and caregivers who participated in this research.  
For questions or comments, please contact [research@cllsociety.org](mailto:research@cllsociety.org)



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