



# An Innovative Telemedicine Platform to Provide Expert Access to Patients with Chronic Lymphocytic Leukemia (CLL)



Brian Koffman<sup>1</sup>, John M. Pagel<sup>2</sup>, Neil Bailey<sup>2</sup>, Andy Kaempf<sup>3</sup>, Byung Park<sup>3</sup>, Liza Avruch<sup>1</sup>, Christopher Lee<sup>4</sup>, Babak Movassaghi<sup>4</sup>, John C. Byrd<sup>5</sup>, Alan P. Skarbnik<sup>6</sup>, Matthew S. Davids<sup>7</sup>, Alexey V. Danilov<sup>3</sup>

<sup>1</sup>CLL Society, Claremont, CA; <sup>2</sup>Center for Blood Disorders and Stem Cell Transplantation, Swedish Cancer Institute, Seattle, WA; <sup>3</sup>Knight Cancer Institute, Oregon Health and Science University, Portland, OR; <sup>4</sup>InfiniteMD, Boston, MA; <sup>5</sup>Division of Hematology, Department of Internal Medicine, The Ohio State University, Columbus, OH; <sup>6</sup> Division of Lymphoma and Chronic Lymphocytic Leukemia, Novant Health, Charlotte, NC; <sup>7</sup> Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA ;

## BACKGROUND & INTRODUCTION

### Background about CLL in Care in 2019

- Expert care can improve outcomes for CLL patients (pts).
- CLL treatment has rapidly changed over the past several years, making it challenging for healthcare providers (HCP) to keep pace with new therapies.
- Telemedicine can provide HIPAA-compliant access to experts.
- Many patients do not have access to CLL experts due to geography, insurance, or cost.
- The nonprofit CLL Society, working with 10 CLL experts and using a platform from an online 2nd opinion service (InfiniteMD), coordinated 105 telemedicine consults in 2017-19 as part of a free Expert Access Program (EAP).
- Here we report the impact of this service on a nationwide underserved CLL population.

## OBJECTIVES

- To establish feasibility of telemedicine (EAP) approach in CLL care and assess receptiveness of patients to online tools and telemedicine consults
- To conduct preliminary assessment whether telemedicine (EAP) consulting service impacts decision making in CLL care
- To identify potential gaps and barriers to EAP consulting service

## METHODS

### Study Design

- The EAP application was available online at CLLSociety.org with links on CLL forums and in weekly alerts sent to >5000 pts. It was promoted at CLL Society patient educational forums and 28 support groups.

### Inclusion criteria

- To qualify for EAP, participants needed to be US residents who had a CLL diagnosis but weren't seeing an expert physician (defined as a nationally recognized CLL research physician who primarily cares for CLL pts)

### Survey Recruitment

- Pts meeting inclusion criteria were asked to complete a pre-consult survey and had their electronic records synopsis reviewed by the consulting expert.
- Pts participated in a 30-minute online HIPAA-compliant video consult with the CLL expert.
- Following the consult, pts received a summary to share with their local HCP
- Pts completed a (post-) survey.

### Statistical Analysis

- Answers in individual surveys were cross checked for validity.
- Data were analyzed using descriptive statistics and Clopper-Pearson confidence intervals.

Additional information about the EAP program at <https://cllsociety.org/lll-society-expert-access>



## ABOUT THE CLL SOCIETY, INC.

The CLL Society Inc. is a 4 year old 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:

- The CLL Society website <https://cllsociety.org> contains up-to-date, accurate and patient-friendly information.
- The CLL Tribune, a quarterly online newsletter with patient, physician and related experts as authors.
- Launching and supporting .30 CLL-specific local patient support and education groups and hosting live educational forums on 3 different continents.
- Providing free virtual Expert Access™ to CLL experts to patients who would otherwise have no other such access.
- Providing free CLL Society Educational Toolkit to HCPs to aid in educating their patients.
- Surveying CLL patients and caregivers to inform patients and HCP about the patients' and caregivers' perspective.

## RESULTS

### Survey Response Rate:

- 116 patients registered
- 100% filled out pre-consult survey
- 105 pts. (90.5%) 105 had the EAP consult
- 84 pts. (72.4%) finished the post survey

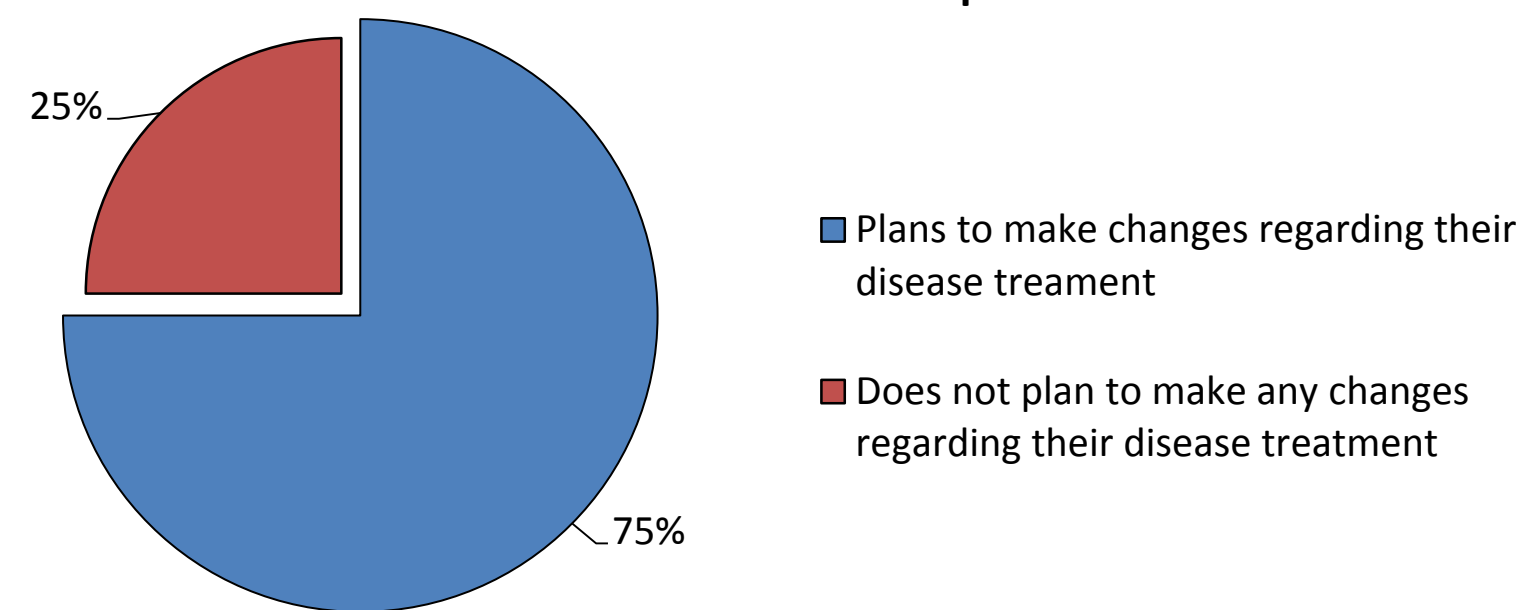
### Patient Characteristics (n=116)

- Age, median (range): 62 (28-88)
- Age, ≥ 65: 42
- Sex, Males: 53%

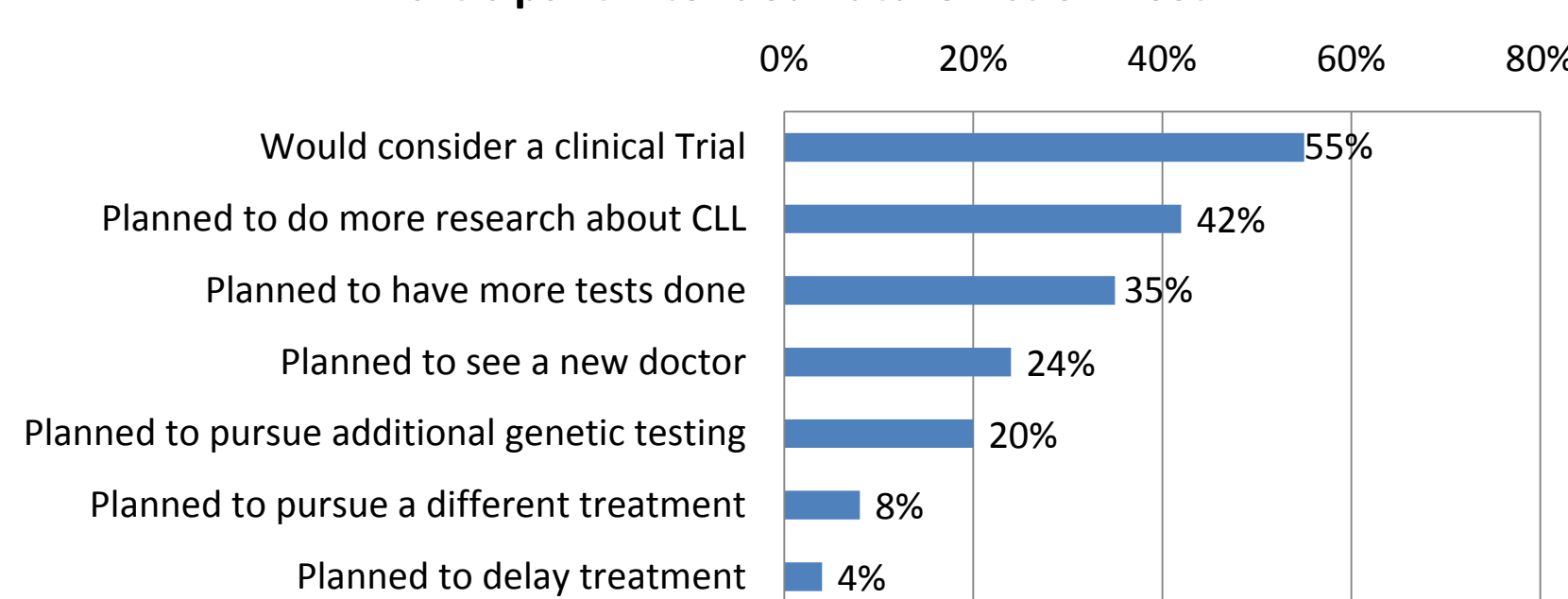
### Reasons patients didn't complete the EAP consult (n=11)

- Patient was able to see an expert in person
- Patient was unresponsive to email/phone calls to schedule
- Patient missed scheduled call and did not respond to rescheduling
- Patient wanted to wait until a later date, but never re-applied/was not responsive to emails/phone call to apply

Effect of EAP consult on future care plans



Participant Intended Future Action Post-EAP



95% of participants affirmed that the convenience of the online platform was important in their decision to participate in EAP

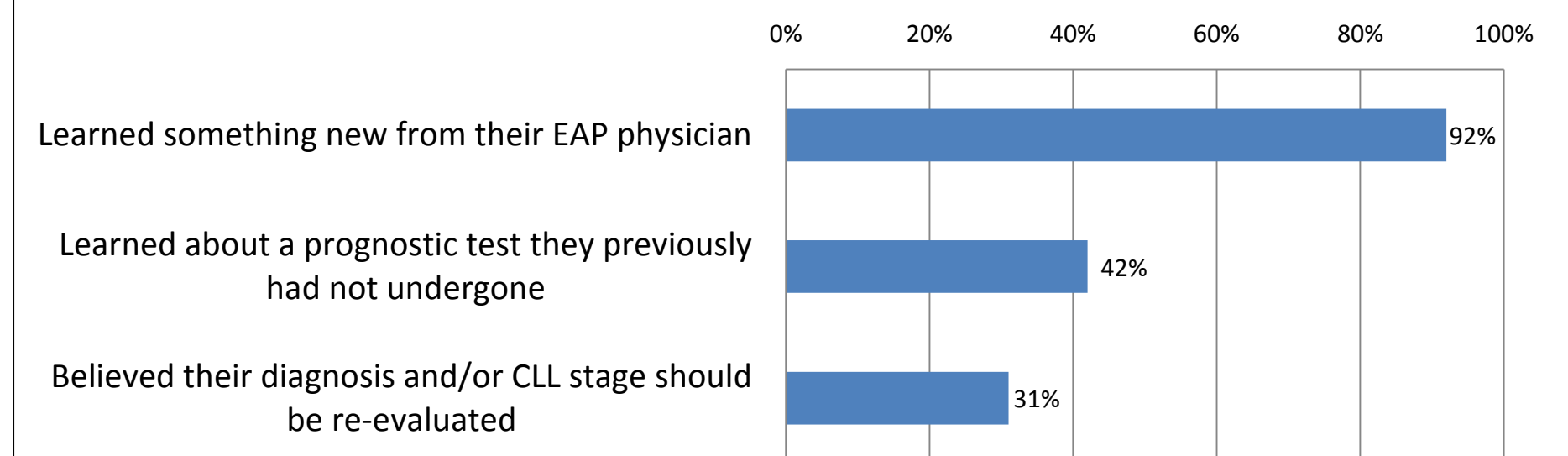
Only 2% of the 84 pts who completed the post-survey did not find the online consult easy, due to hearing trouble or video issues

83% of participants felt a greater peace of mind following their EAP call



## RESULTS

### What Participants Learned



"I was glad to get a 2nd opinion from a CLL specialist, who thoroughly evaluated my case before our video/phone appointment. My doctor contacted me immediately after reading the Expert Access expert's summary and went over all of the recommendations. We are currently moving forward with one of the recommendations."

"You pointed out that I had not had IGVH testing. You said those results would be key to making a final decision about treatment. Our interview was especially timely, since I was scheduled to begin FCR as prescribed by my local hometown oncologist. As it turned out, I was the first patient for whom he ever prescribed this test. My IGVH status is unmutated, so I began taking Imbruvica". I believe you played a key early role in my journey with CLL and I wanted you to know about the crucial positive impact you had in my life."

## Study Limitations:

- 21 of the 105 pts who had a consult did not complete the post-survey, raising the possibility of reporting bias if those who failed to follow-up did so because of a negative experience.
- Differences in the exact wording between the pre and post surveys limited the statistical analysis. Going forward we are using identical pre and post questions in our surveys for data collection so any future results will directly measure the impact of EAP.
- The revised intake will gather more demographics including treatment status.

## CONCLUSIONS

- Access to CLL experts through EAP provided important medical information and improved confidence in a patient's current HCP.
- 75% of pts (95% CI: 64% - 84%) planned to make changes regarding their CLL management.
- An online consult with an expert may benefit pts by both increasing their confidence in their local HCP and in their knowledge of CLL, while motivating them to act.
- This study is expanded and includes collection of additional medical data as well as harmonization of pre- and post-questionnaires

We thank the pts who took the initiative to try to improve their own care, the expert doctors who participated, InfiniteMD, an online second opinion service that uses live, synchronous video technology to match patients around the world with top medical specialists, for providing the platform, and Verastem Oncology for helping initiate and support EAP.

For questions or comments, please contact [research@cllsociety.org](mailto:research@cllsociety.org)

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