

# Developing a Patient/Provider Discussion Tool for Chronic Lymphocytic Leukemia (CLL)

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## Background

The National Cancer Institute estimates more than 20,000 people will be diagnosed and over 163,000 people will be living with Chronic Lymphocytic Leukemia (CLL) in the US in 2019. In 2017, nearly 40% of CLL patients that participated in the Cancer Support Community (CSC) Cancer Experience Registry® (CER) reported that they were not sufficiently prepared to make treatment decisions and communicate with their health care team. In 2018, CSC developed a patient/provider discussion tool to help patients better communicate with their health care team.

## Aims

Develop a patient/provider discussion support tool tailored to CLL patients' specific challenges related to making decisions about the risks vs. benefits of treatment, short and long term side effects of treatment, their stage of life, and the impact on family and friends.

## Methods

CSC created the draft tool for CLL patient-provider communication using CSC's discussion tool for CML ([bit.ly/2kiS5Ce](http://bit.ly/2kiS5Ce)) as a template.

The draft tool was tested in focus groups with CLL patients to assess whether it met their needs. The initial draft was shown to the first wave of research participants, who provided qualitative feedback. The CLL tool was then refined and presented as stimuli for the second wave of research.

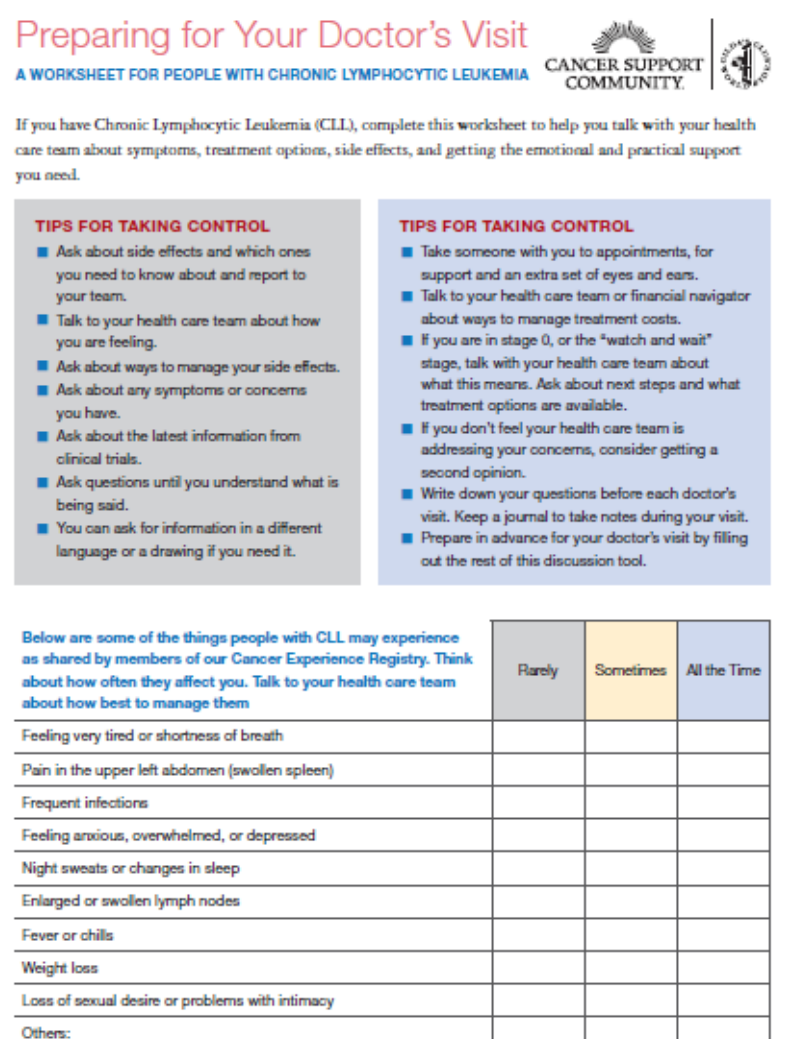
In total, CSC conducted 4 focus groups with 20 CLL patients.

Focus group participants were asked to give feedback about the following:

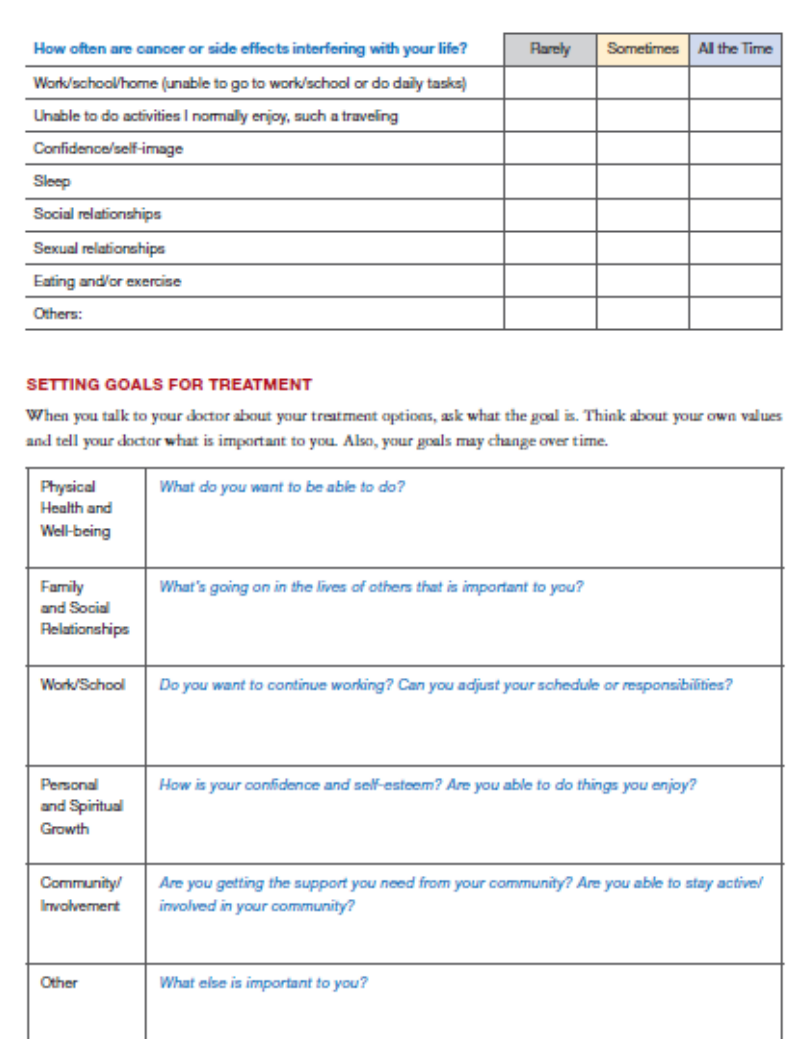
- Did the tool reflect the top issues CLL patients want to discuss with their providers?
- Was the tool useful for a wide range of CLL patients?
- Did the tool reflect how CLL affects patients' lives?
- Could the tool help patients articulate the broader?

## Initial Version of the CLL Discussion Tool

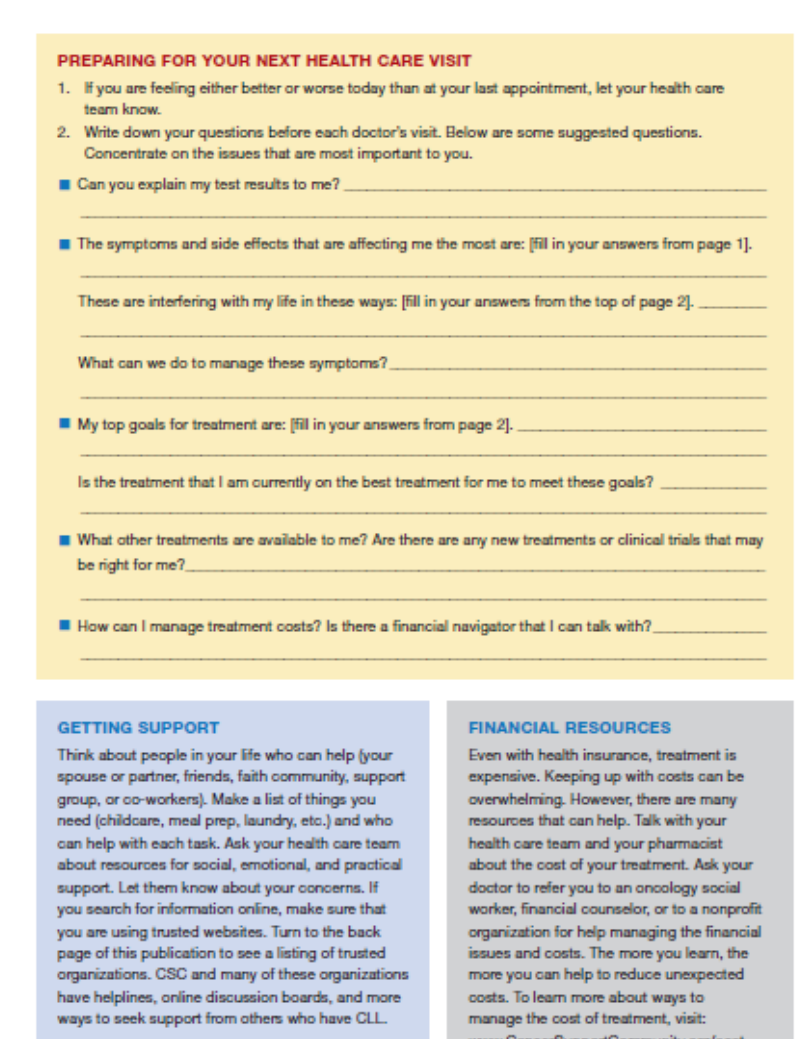
The initial draft was shown to the research participants, who provided qualitative feedback.



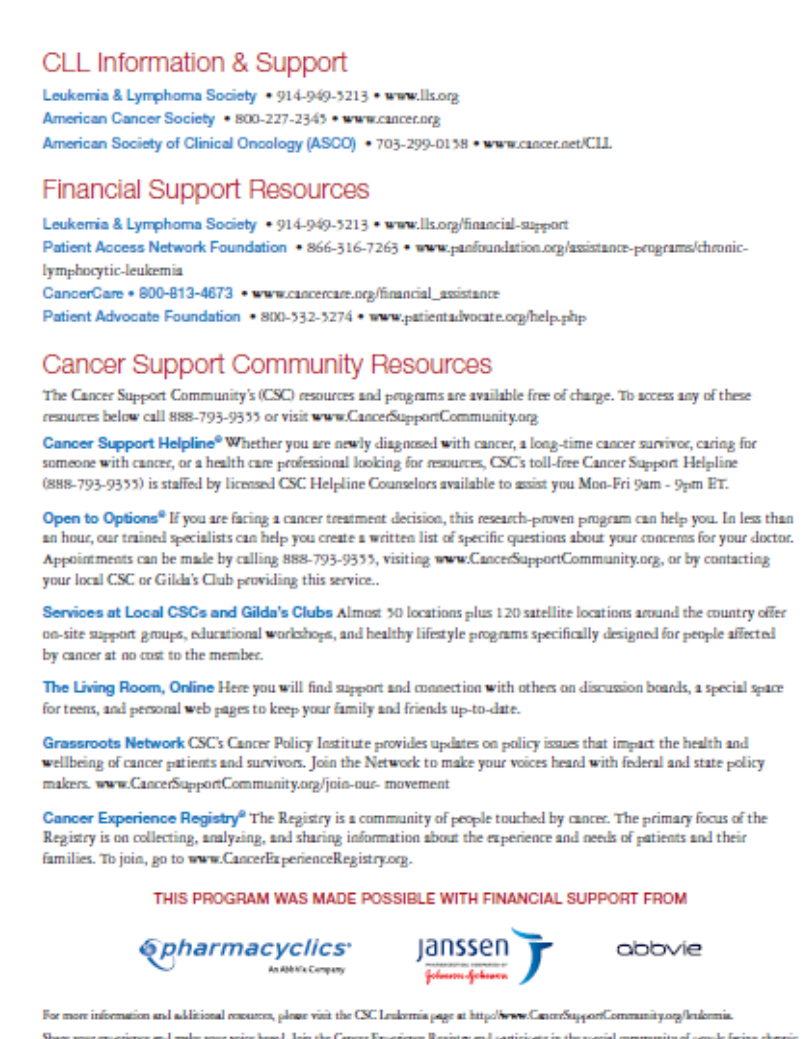
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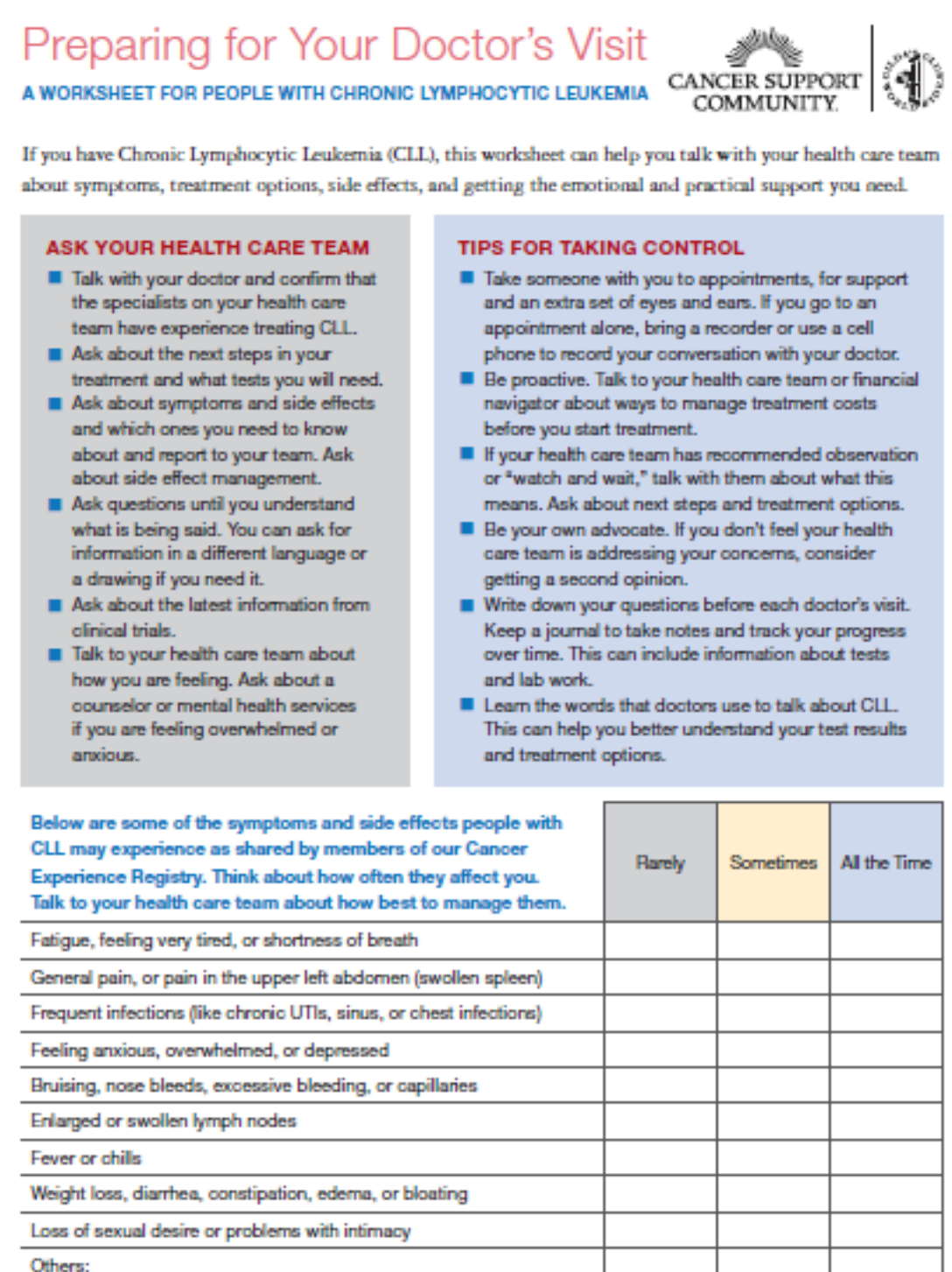
## Participants Feedback

Participants suggested adding:

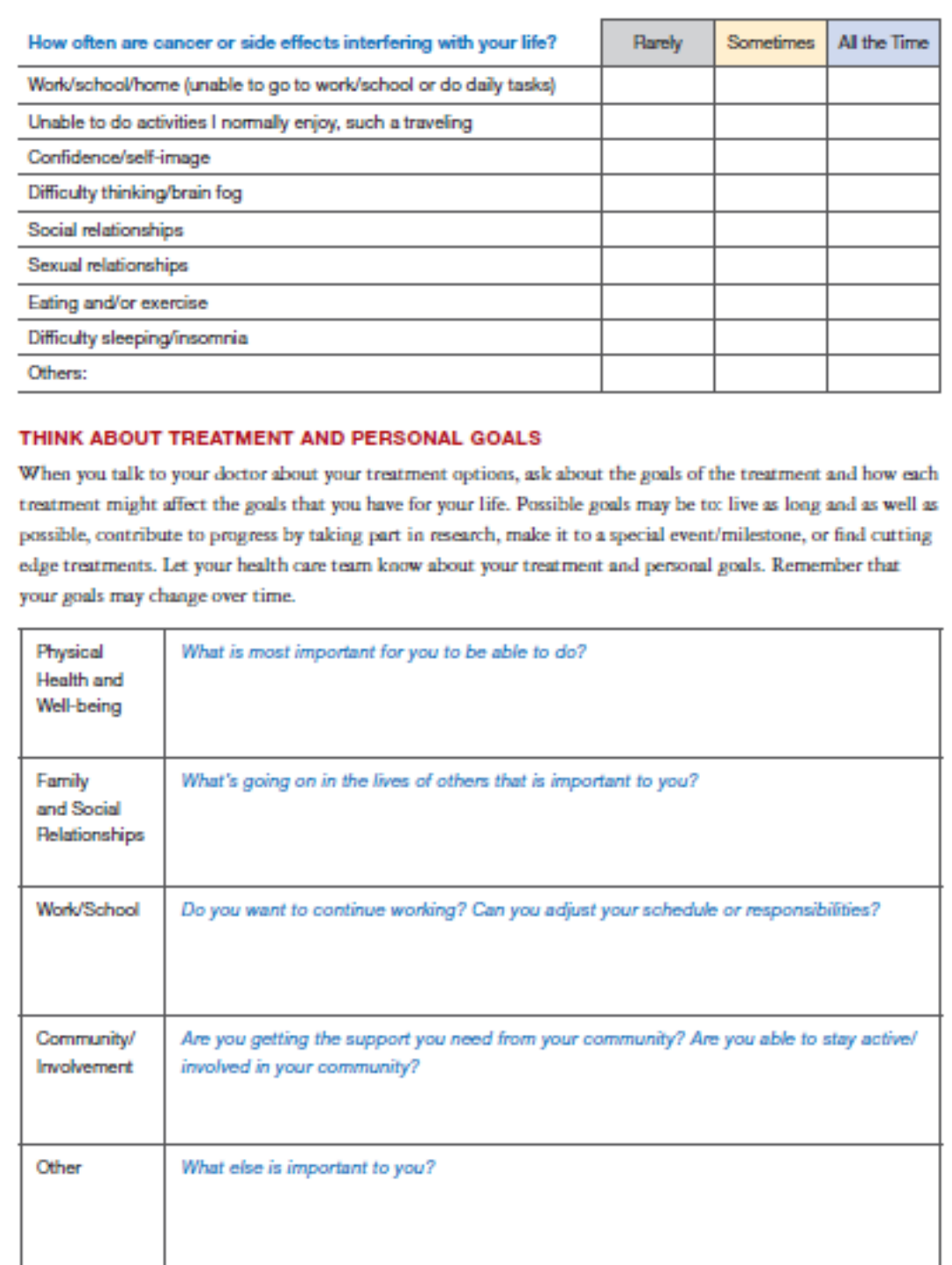
- Language addressing the importance that patients ask questions and communicate with their doctors, take notes and track their progress over time, including test results and lab work.
- Additional side effects, such as edema, bone pain, nose bleeds, fatigue, bloating, shingles, bruising, chronic UTIs, weight loss, sinus infections and pneumonia.
- Information about how to be advocates for themselves, resources for managing the cost of care and finding social support.
- Information to help explain CLL and recognition that others may not understand what living with CLL is like.

## Final Version of the CLL Discussion Tool

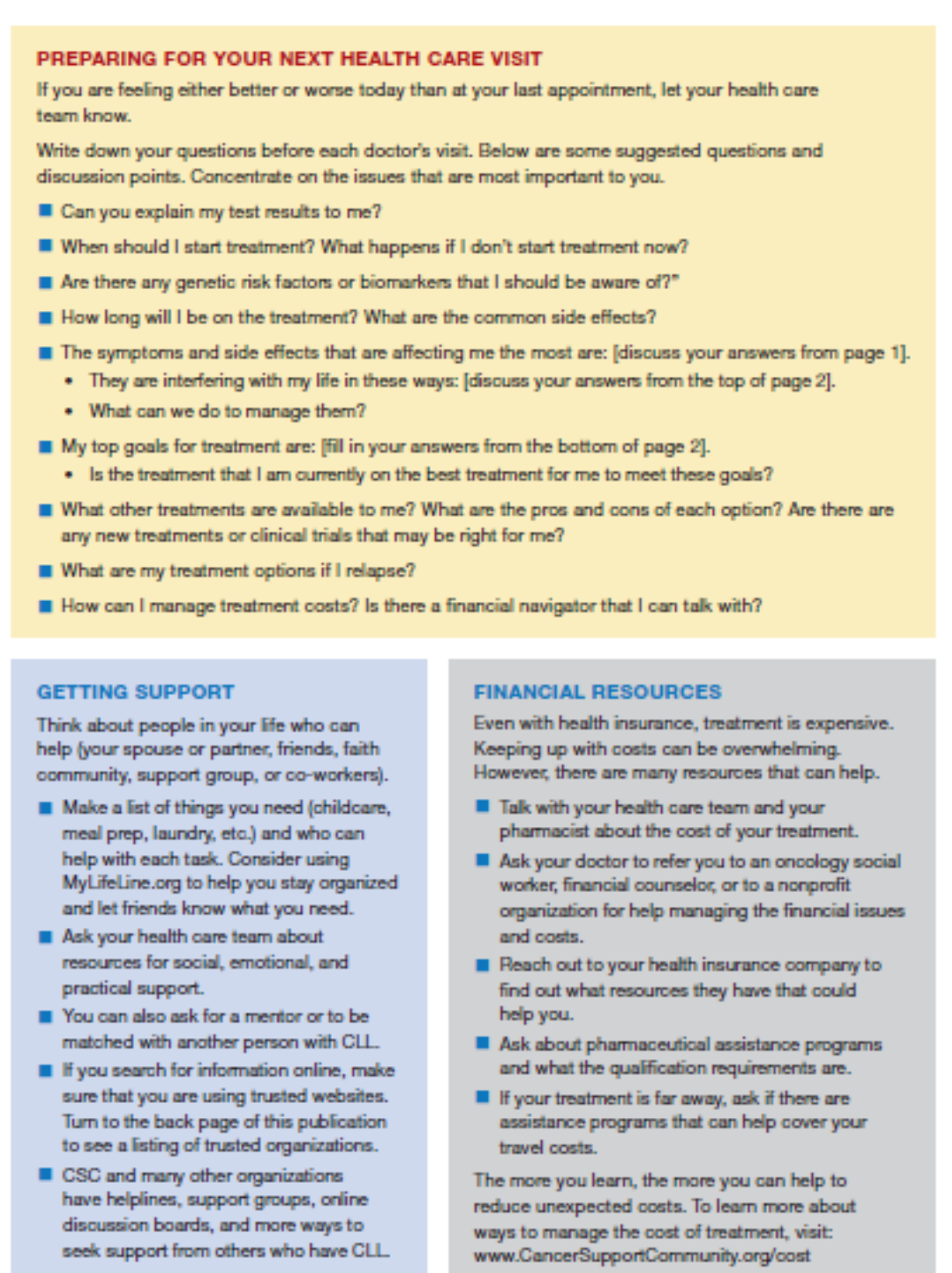
CSC implemented the feedback received by focus groups participants and updated the CLL discussion tool to ensure it meets their communication needs.



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## Findings

- Most of the top issues patients wanted to address with their providers were captured in the initial version of the CLL-specific tool.
- Additional feedback included adding a system to track side effects and changes in treatment goals over time and suggestions for additional financial and support resources.
- Participants believed this tool would be most useful for newly diagnosed patients with CLL, as well as CLL patients who were deciding whether to switch to a new treatment or provider.
- Patients were concerned about the cost of treatment and highlighted the importance of encouraging others to ask their health care team for referrals to patient advocates or nonprofit organizations for help and guidance.
- Participants reported appreciation for an integrated approach to managing their care in which treatment goals, life goals, and side effects are considered together. They view this tool as a way to empower patients to become active partners in their care and help them find ways to cope with their distress.

## Summary

Findings suggest that the CLL discussion tool can help patients communicate with their health care team and lead to fruitful conversations about their treatment goals, treatment decisions, and the impact of CLL on their daily life. Regarding implementation, CSC distributes the tool at no charge to CLL patients and caregivers via its internal network of almost 50 Cancer Support Communities and Gilda's Clubs worldwide, the CancerSupportCommunity.org webpage, the *Frankly Speaking About Cancer* radio show, and partner patient advocacy groups. We would also like to make patient navigators aware of this tool and allow them to order/download it, at no charge.

## Frankly Speaking About Cancer Program

*Frankly Speaking About Cancer* (FSAC) is CSC's award-winning FREE landmark cancer education series, that provides evidence-based information on a variety of topics important to people affected by cancer. *FSAC: Chronic Lymphocytic Leukemia* offers a number of publications in both print and electronic formats to help address CLL specific challenges during treatment and survivorship. For more information visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org).



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The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers.

- The Registry is for all cancer survivors and caregivers and also includes 12 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 14,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org)

## References

- Cancer Support Community (2017). Chronic Lymphocytic Leukemia (CLL) Specialty Registry Report 2017. Retrieved from [https://www.cancersupportcommunity.org/sites/default/files/uploads/our-research/2017\\_Report\\_the\\_cll\\_specialty\\_report\\_7-10-17.pdf](https://www.cancersupportcommunity.org/sites/default/files/uploads/our-research/2017_Report_the_cll_specialty_report_7-10-17.pdf)
- Cancer Support Community (2018) Frankly Speaking About Cancer: Chronic Myeloid Leukemia (CML). Retrieved from: <https://www.cancersupportcommunity.org/chronic-myeioid-leukemia> and bit.ly/2kiS5Ce
- Ha, J. F., & Longnecker, N. (2010). Doctor-Patient Communication: A Review. The Ochsner Journal, 10(1), 38–43.
- Shanafelt T D, Bowen D A, Venkat C, et al. (2009). The physician-patient relationship and quality of life: lessons from chronic lymphocytic leukemia. *Leukemia research*, 33(2), 263–270. doi:10.1016/j.leukres.2008.06.019
- Westbrook T D, Maddocks K, Andersen B L (2016). The relation of illness perceptions to stress, depression, and fatigue in patients with chronic lymphocytic leukaemia. *Psychology & health*, 31(7), 891–902. doi:10.1080/08870446.2016.1158259