

A Patient/Provider Discussion Tool for Chronic Myeloid Leukemia

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Background

The Cancer Support Community (CSC) designed a patient/provider discussion tool for patients with Chronic Myeloid Leukemia (CML) with the goal to help patients and caregivers improve communication with their healthcare team. The purpose of this tool is to help patients assess their side effects, goals for treatment, and how treatment is affecting their lives, so that they can relay these issues to their provider.

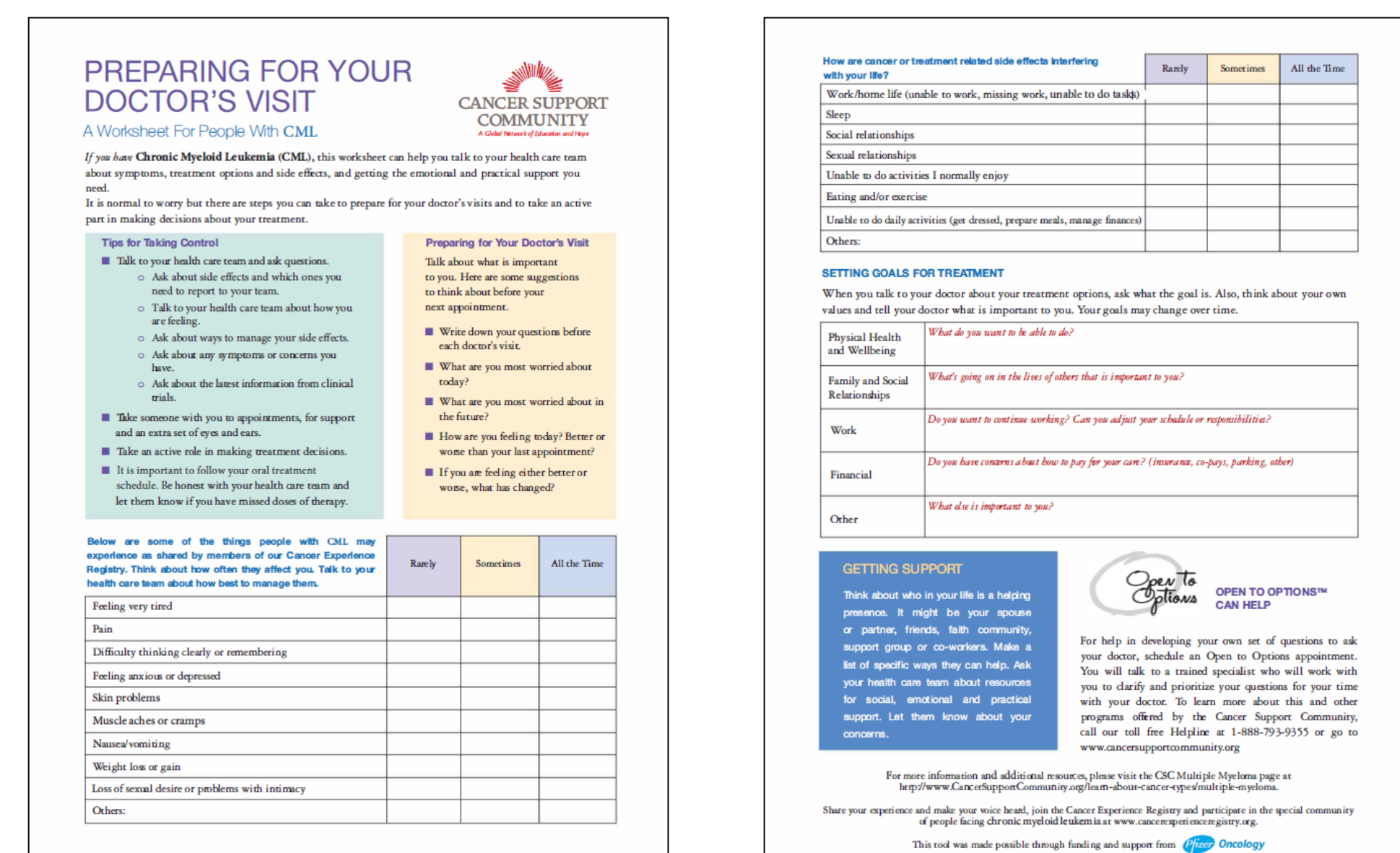
Aims

- Did the tool reflect the top issues CML patients and caregivers want to discuss with their providers?
- Was the tool useful for a wide range of CML patients and caregivers? How could it be made more useful?
- Did the tool help patients and caregivers articulate the broader impacts of CML to their providers?
- At what stage of illness is this tool useful? Does it have different uses at different stages?

Methods

CSC created a 2-page CML discussion tool using CSC's discussion tool for metastatic breast cancer as a template. CML-specific information from CSC's Cancer Experience Registry® was applied to the template to create a similar tool for CML. The Phase 1 draft of the CML tool was shown to the first wave of research participants, who provided qualitative feedback. The CML tool was then revised for Phase 2 and presented as stimuli for the second wave of research participants. Phase 2 qualitative feedback was used to create the final 4-page version of the tool. In total, CSC conducted 4 focus groups and 4 individual interviews with 16 CML patients and 3 caregivers.

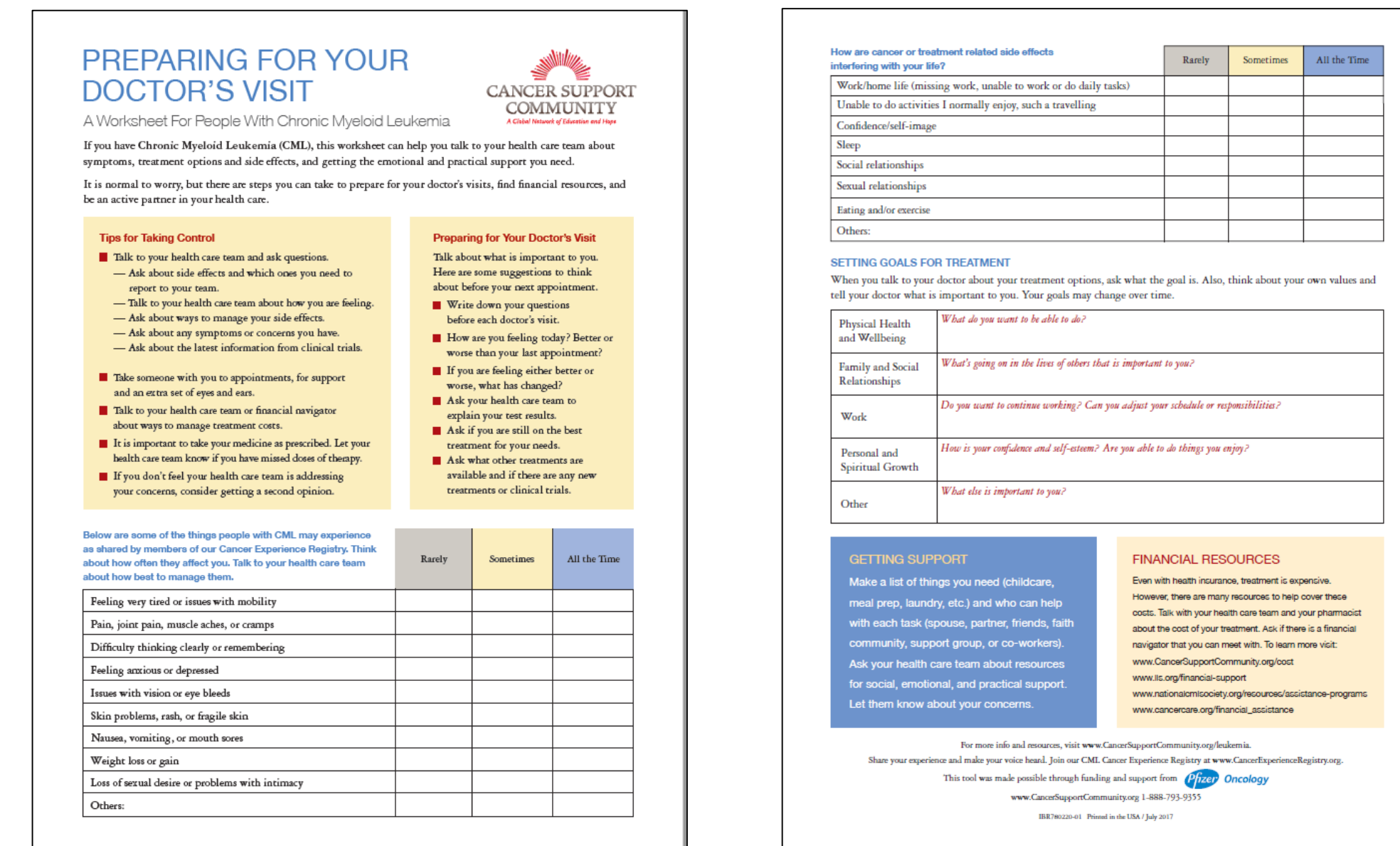
Phase 1 Participant Feedback



Participants wanted:

- Information about how to be advocates for themselves.
- Additional information about financial and social support.
- Additional side effects put in the *Side Effects and Symptoms* section.
- A line for confidence and self-image in the *Living with Side Effects* section.
- Recognition that others may not understand what living with CML is like.
- A line for personal and spiritual growth in the *Setting Goals* section.

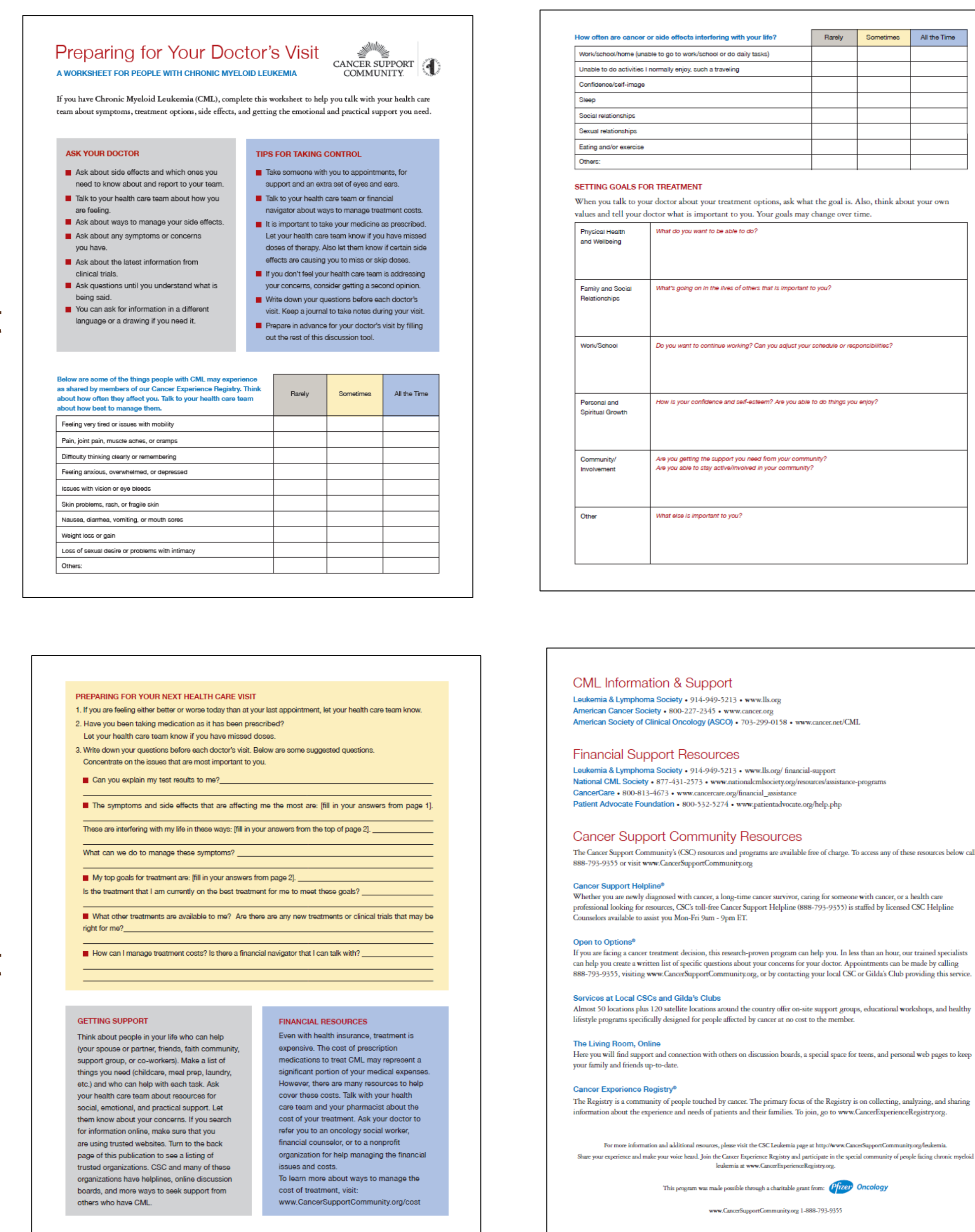
Phase 2 Participant Feedback



Participants wanted:

- A 4-page discussion tool (instead of the original 2-page tool) with more resources for support and room for taking notes prior to and during their doctor visits.
- Language suggesting that patients ask their doctor to clarify terms that are not understood.
- Additional side effects put in the *Side Effects and Symptoms* section.
- A line about giving back to the community/volunteering in the *Setting Goals* section.
- A list of specific financial and support resources.

Final CML Discussion Tool



Results

CML patients and caregivers reported that:

- Most of the top issues they wanted to address with their providers were captured in the initial version of the CML-specific tool. Additional issues requested included the impact of CML on their confidence/self-esteem and additional financial support services.
- This tool would be useful for newly diagnosed patients, patients switching to a new treatment or provider, and those who have infrequent visits to their oncologists. Participants felt that this tool would encourage newly diagnosed patients to ask for help early in their treatment.
- In the chronic stage of treatment, they can forget side effects that occurred months before their regular oncology visits. The tool can help them remember these details and organize their thoughts.
- They appreciated holistic approaches to managing their care in which treatment goals, life goals, and side effects are considered together. They report a lack of this understanding in the medical system overall.
- They often have difficulty expressing how CML influences their lives (family, work, spiritual, community, etc.) They thought this tool would help them think through the ways that health impacts other areas of life.
- Patients and caregivers want assistance in organizing their thoughts and preparing for oncology visits.
- Caregivers and patients 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.

Conclusions

- The intention is for patients and caregivers to use this CML discussion tool to assess their treatment goals and prepare for discussions during medical appointments. It also encourages them to discuss the impacts that CML has on their daily lives.
- Based on the research results, this tool would be most useful for newly diagnosed CML patients and patients switching to a new CML medication.
- This tool will also help patients identify and seek resources that can help them cope with finances and changes in quality of life related to CML.

Implementation

- CSC has a grant to distribute the CML discussion tool at no charge to CML 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.
- Our funder is also proposing to distribute the tool to CML health care providers via its salesforce.
- We would also like to make patient navigators aware of this tool and allow them to order/download it, at no charge, to help CML patients and caregivers improve their communication with health care providers.

Acknowledgments

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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, but also includes 11 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 11,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org

References

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