

Enhancing CSC's Patient/Provider Discussion Tool for Metastatic Breast Cancer

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Background

In 2006, the Cancer Support Community (CSC) launched its *Frankly Speaking About Cancer: Metastatic Breast Cancer* (MBC) patient education program. This program raises awareness among patients and caregivers about MBC, current treatment options, managing side effects, psychosocial impacts, and fostering an open dialogue with their health care team. One of the components of this program is a patient-provider discussion tool to help patients better communicate with their health care team. In 2018, CSC revised and updated its MBC patient/provider discussion tool with patient and caregiver input to ensure it met their needs and incorporated more step-by-step instructions to improve their communications with health care providers.

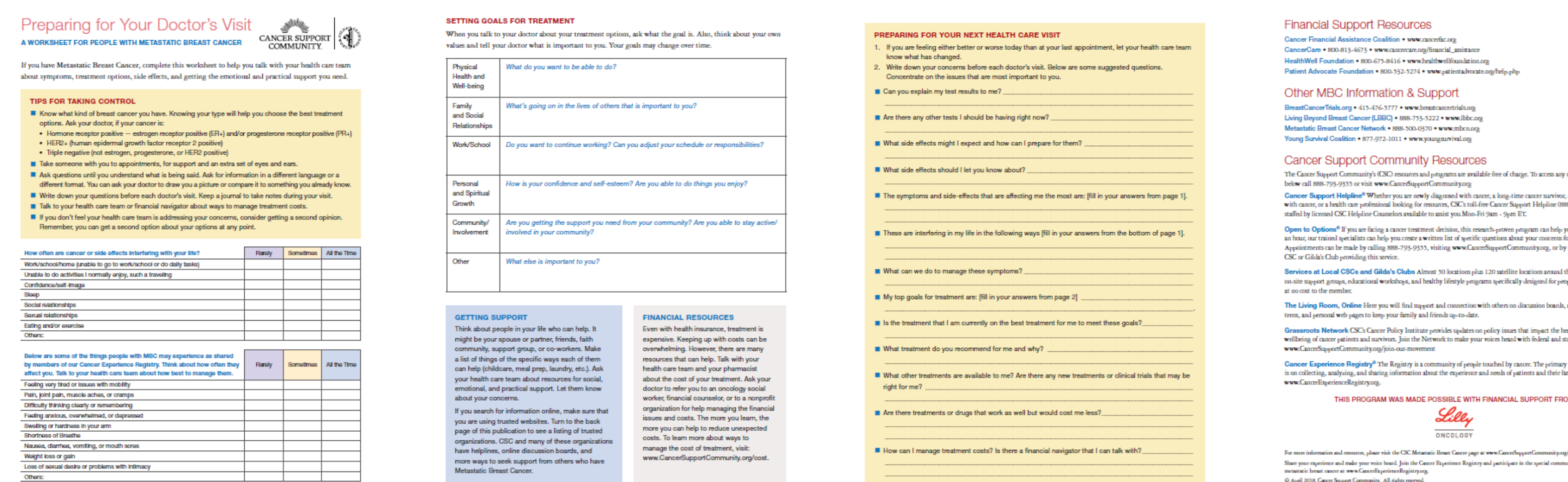
Aims

Update and improve a patient/provider discussion support tool to address MBC patients' specific challenges related to discussing their personal goals for treatment and the impact of symptoms and side effects on their everyday life.

Methods

- The methods to update this MBC patient/provider discussion tool were informed by our past work in updating a CML discussion tool.
- The existing MBC discussion tool was enhanced by incorporating step-by-step directions to starting discussions with health care providers about side effects, impact on daily life, and goals for treatment.
- The enhanced MBC was tested with MBC patients and caregivers.
- A two-wave iterative process was used, where qualitative findings from phase 1 were used to inform additional tool enhancements, with the further refined tool evaluated in phase 2.
- In total, CSC conducted 4 focus groups with 15 MBC patients and 3 caregivers.

Enhanced MBC Discussion Tool



The enhanced tool was shown to research participants, who provided feedback about:

- Whether the tool reflect the top issues MBC patients and caregivers want to discuss with their providers.
- Whether the tool is useful for starting a conversation with their health care providers about managing symptoms and side effects and treatment goals.
- Whether the tool could help patients articulate the broader impacts of MBC to their providers.

Acknowledgments

This enhanced discussion tool was made possible with generous support from Lilly Oncology. The original discussion tool was developed with generous support from Pfizer Oncology.



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

- The Registry is for all cancer survivors and caregivers and also includes 13 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

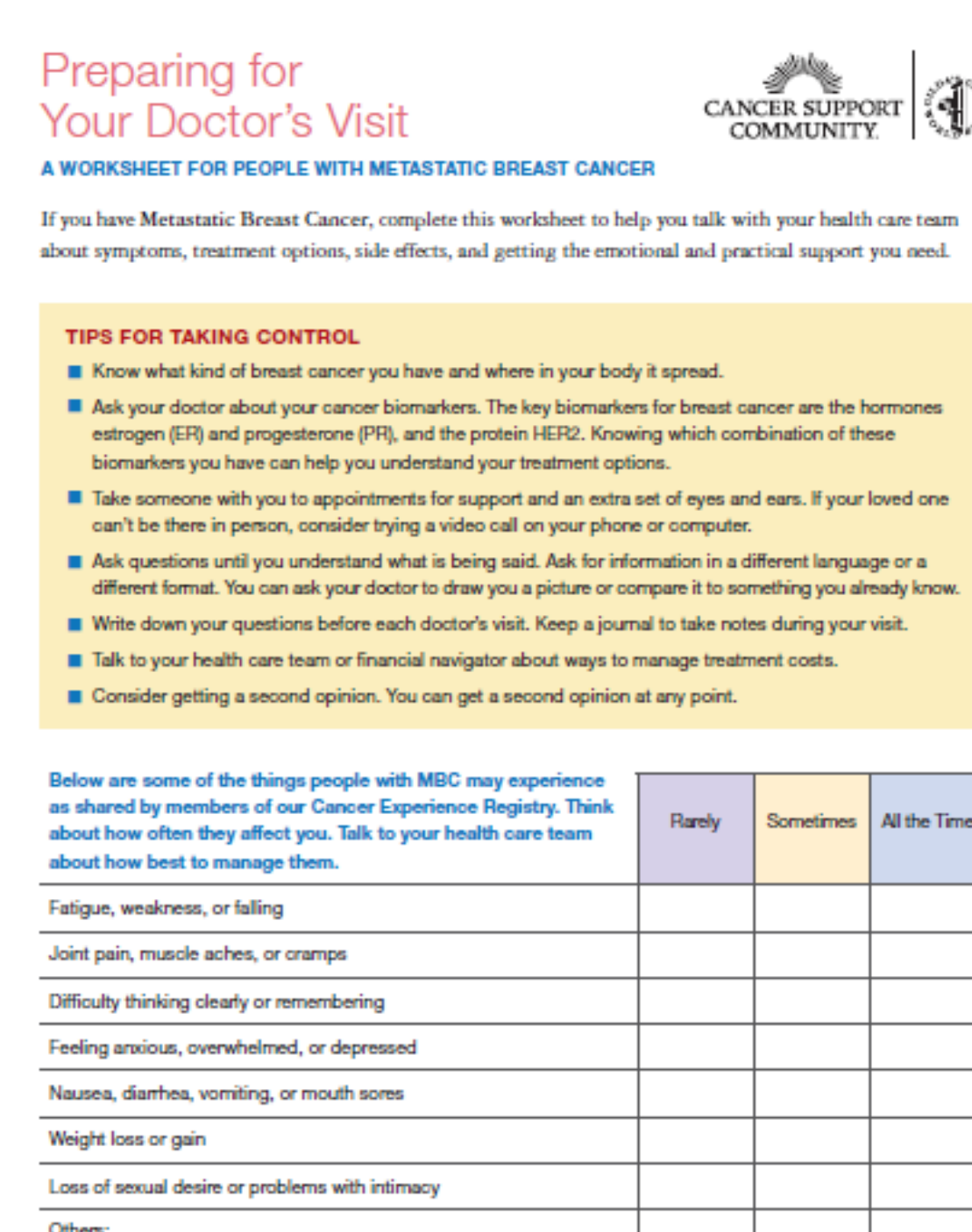
Participants Feedback

Participants suggested adding:

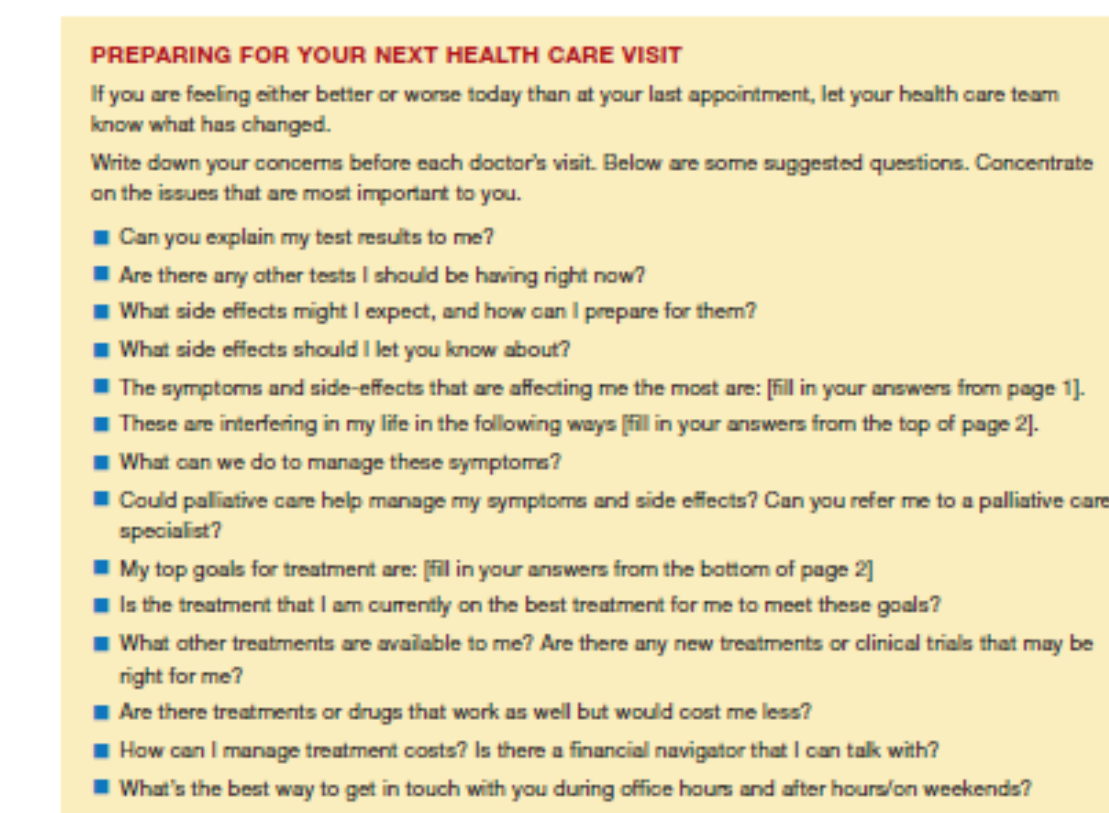
- Language addressing the importance that patients speak with social workers or patient navigators and to keep collecting information until they understand their condition and options for treatment.
- Additional side effects such as constipation, headaches, blood clots, bruising, hair loss, dehydration, and swelling or hardness in your arms or legs.
- Questions for the health care team about coping with side effects and financial resources, such as "Do you know of a drug company program that can help offset the costs of medications?"
- Information about how to be advocates for themselves, resources for managing the cost of care, and finding social support.

Final MBC Discussion Tool

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



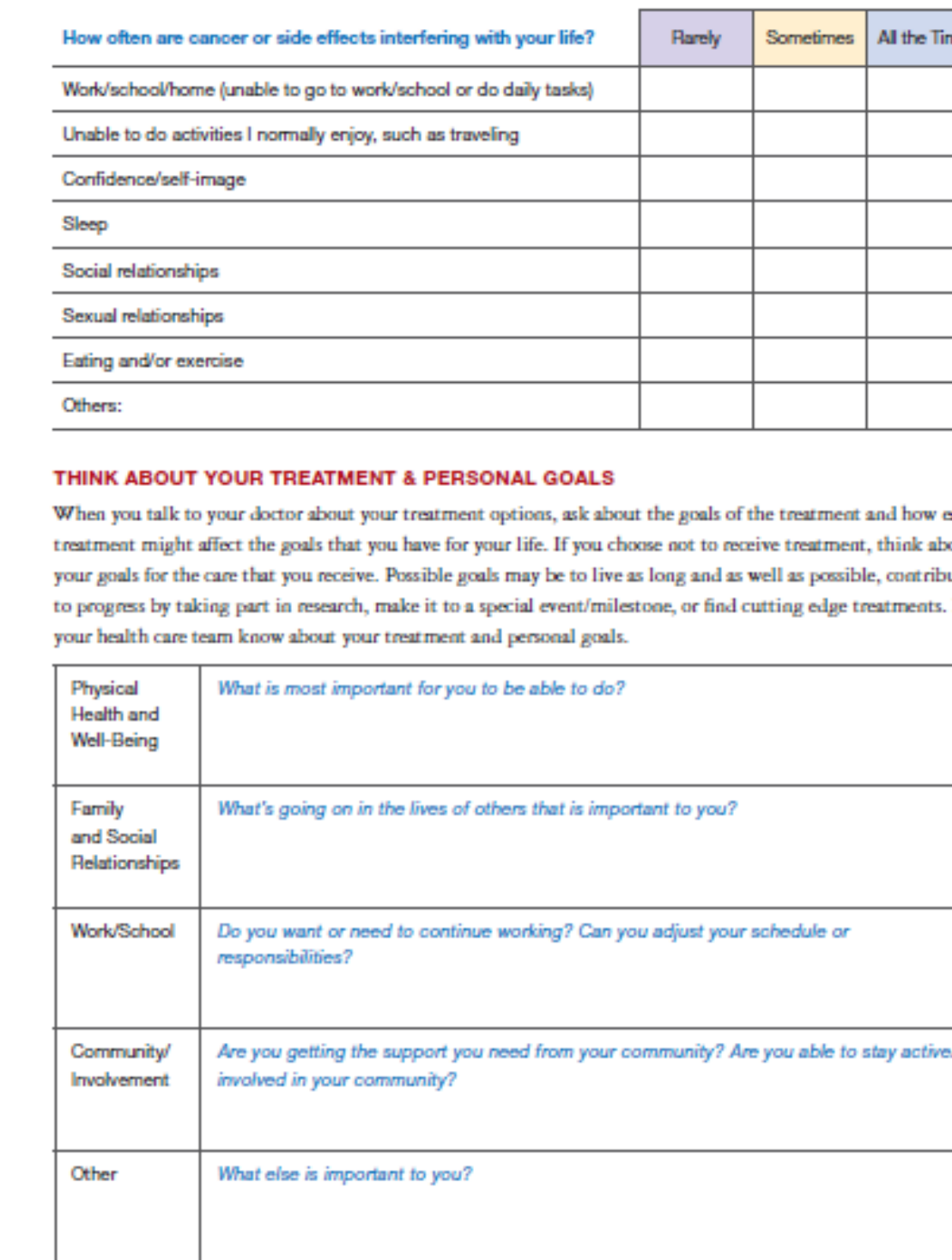
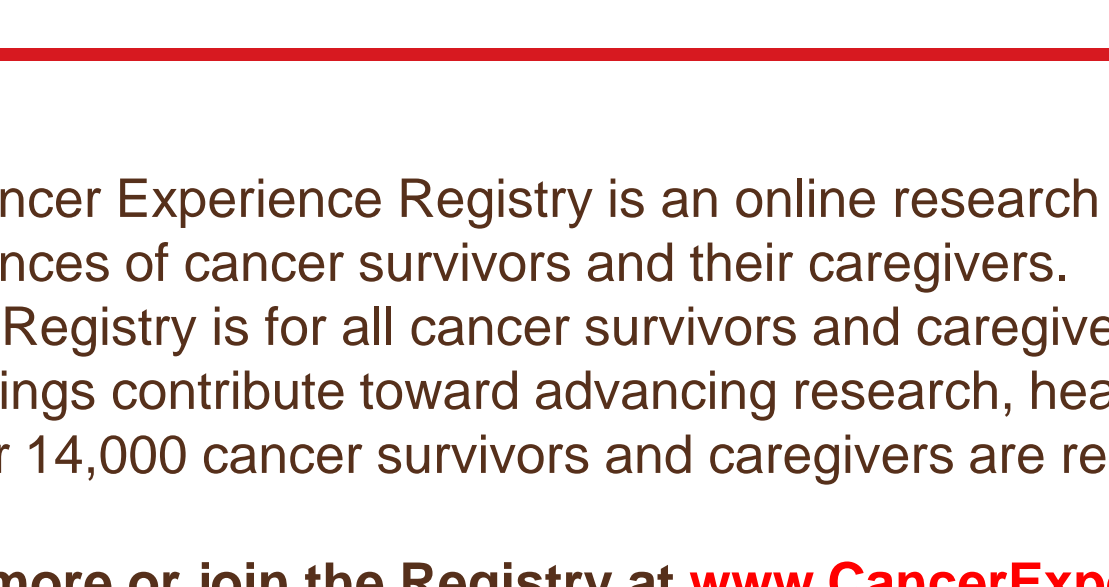
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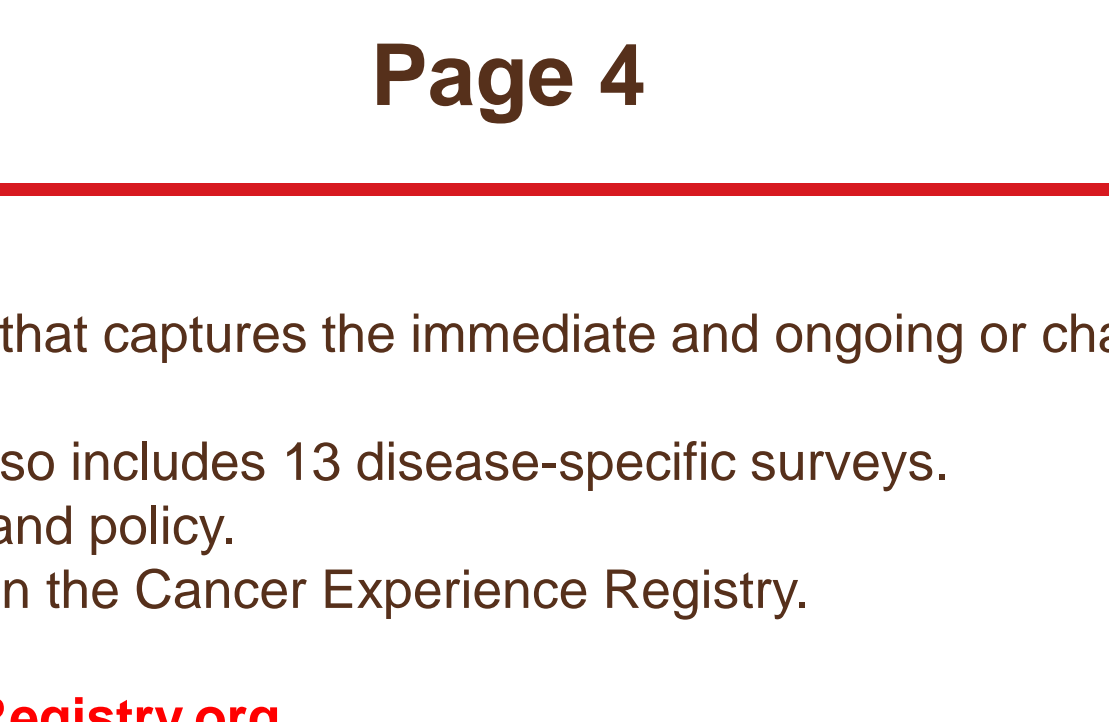
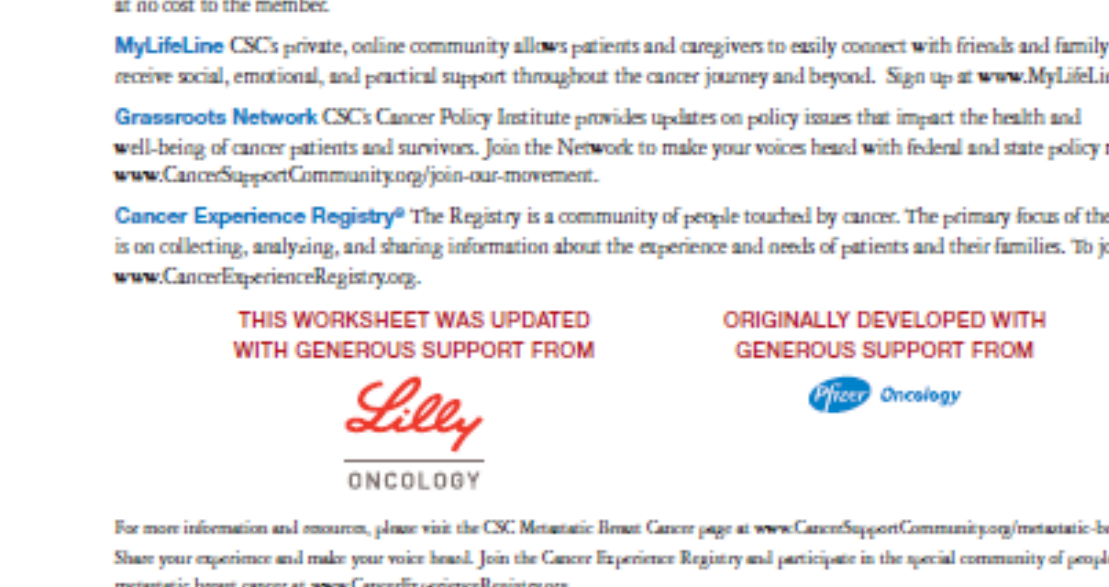
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Findings

- Patients regarded the MBC patient-provider tool as useful and liked the different areas of concern that it addresses.
- Patients reported that this tool would help them to communicate more effectively with their health care team and prompt discussions about their treatment goals and the impact of MBC on their daily life. They also believed it would help them to seek resources to cope with changes in quality of life related to MBC.
- Patients and caregivers viewed the side effects tracking worksheet as an appropriate tool to use at any point during the MBC journey.
- Patients and caregivers appreciated the holistic approaches to managing their care in which treatment goals, life goals, symptoms, and side effects are considered together.

Summary

Findings suggest that the enhanced MBC discussion tool can support patients and caregivers in their interactions with their health care team and empower patients to become active participants in their treatment decisions. CSC distributes the tool at no cost to MBC patients and caregivers via its internal network of more than 50 affiliates worldwide, the CancerSupportCommunity.org webpage and social media accounts, the *Frankly Speaking About Cancer* radio show, and partner patient advocacy groups. We also work to make health care providers and patient navigators aware of this educational book so they may help make it available to those impacted by a MBC diagnosis.

Frankly Speaking About Cancer Program

Frankly Speaking About Cancer (FSAC) is CSC's award-winning cancer education series, that provides evidence-based information on a variety of topics important to people affected by cancer. FSAC offers a number of publications in both print and electronic formats at no charge to patients and caregivers to help address MBC specific challenges during treatment and survivorship. For more information visit www.CancerSupportCommunity.org.



References

- Cancer Support Community (2018) Frankly Speaking About Cancer: Chronic Myeloid Leukemia (CML). Retrieved from: <https://www.cancersupportcommunity.org/chronic-myeloid-leukemia> and bit.ly/2k5S5Ce
- Ha, J. F., & Longnecker, N. (2010). Doctor-Patient Communication: A Review. *The Ochsner Journal*, 10(1), 38-43.