

CANCER SUPPORT COMMUNITY

A Global Network of Education and Hope

### 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



with your life?			Rarely	Sometimes	All the Time	
Work/home life (un	able to work, missing work, una	ible to do task\$)				
Sleep						
Social relationships						
Sexual relationships						
Unable to do activit	ies I normally enjoy					
Eating and/or exerci	se					
Unable to do daily act	tivities (get dressed, prepare meals,	manage finances)				
Others:						
	our doctor about your treatment doctor what is important to you What do you want to be able to do	u. Your goals may	<u> </u>		bout your own	
Family and Social Relationships	What's going on in the lives of others that is important to you?					
Work	Do you want to continue working? Can you adjust your schedule or responsibilities?					
Financial	Do you have concerns about how to pay for your care? (insurance, co-pays, parking, other)					
Other	What else is important to you?					
GETTING SUPPORT Think about who in your life is a helping presence. It might be your spouse or partner, friends, faith community, support group or co-workers. Make a list of specific ways they can help. Ask your health care team about resources for social, emotional and practical support. Let them know about your concerns.		For help in developing your own set of questions to as your doctor, schedule an Open to Options appointment You will talk to a trained specialist who will work wit you to clarify and prioritize your questions for your tim with your doctor. To learn more about this and othe programs offered by the Cancer Support Community call our toll free Helpline at 1-888-793-9355 or go t www.cancersupportcommunity.org				
list of specific w your health care for social, en support. Let th	e team about resources notional and practical	you to clarify with your do programs offe call our toll	and prioriti ctor. To lea red by the free Helplin	rn more about Cancer Supp e at 1-888-79	t this and othe ort Community	

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.

#### Acknowledgments

This project was supported by an unrestricted grant from Pfizer.



# A Patient/Provider Discussion Tool for Chronic Myeloid Leukemia

## Claire Saxton MBA\*, Heather Hollen MS\*, Jenny Karubian MA, Alexandra K Zaleta PhD\*\*

# \*Cancer Support Community, Washington, DC \*\*Cancer Support Community, Research and Training Institute, Philadelphia, PA

#### Phase 2 Participant Feedback

PREPARING FOR YOU DOCTOR'S VISIT A Worksheet For People With Chronic Myeloid L If you have Chronic Myeloid Leukemia (CML), this worksheet c symptoms, treatment options and side effects, and getting the em It is normal to worry, but there are steps you can take to prepare for be an active partner in your health care.	eukemia an help you tall otional and prad	COM A Chiefed Netwo to your health ca tical support you	need.
<ul> <li>Tips for Taking Control</li> <li>Talk to your health care team and ask questions.</li> <li>Ask about side effects and which ones you need to report to your team.</li> <li>Talk to your health care team about how you are feeling.</li> <li>Ask about ways to manage your side effects.</li> <li>Ask about ways to manage your side effects.</li> <li>Ask about ways to manage your side effects.</li> <li>Ask about the latest information from clinical trials.</li> <li>Take someone with you to appointments, for support and an ettra set of eyes and ears.</li> <li>Talk to your health care team or financial navigator about ways to manage treatment costs.</li> <li>It is important to take your medicine as prescribed. Let your health care team know if you have missed doses of therapy.</li> <li>If you don't feel your health care team is addressing your concerns, consider getting a second opinion.</li> </ul>	Talk ab Here au about b Wri befo Hov wor I fyo wor Ask expl Ask trea Ask avai	<ul> <li>Preparing for Your Doctor's Visit</li> <li>Talk about what is important to you.</li> <li>Here are some suggestions to think about before your next appointment.</li> <li>Write down your questions before each doctor's visit.</li> <li>How are you feeling today? Better or worse than your last appointment?</li> <li>If you are feeling either better or worse, what has changed?</li> <li>Ask your health care team to explain your test results.</li> <li>Ask if you are still on the best treatment for your needs.</li> <li>Ask what other treatments are available and if there are any new treatments or clinical trials.</li> </ul>	
Below are some of the things people with CML may experience as shared by members of our Cancer Experience Registry. Think about how often they affect you. Talk to your health care team about how best to manage them.	Rarely	Sometimes	All the Time
Feeling very tired or issues with mobility			
Pain, joint pain, muscle aches, or cramps			
Difficulty thinking clearly or remembering			L
Feeling anxious or depressed			
Issues with vision or eye bleeds			
Skin problems, rash, or fragile skin			
Nausea, vomiting, or mouth sores			
Weight loss or gain			

Participants wanted:

- 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 list of specific financial and support resources.

### Final CML Discussion Tool





Page 2 Front



#### CANCER EXPERIENCE REGISTRY. A PROGRAM of the CANCER SUPPORT COMMUNITY

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



• A 4-page discussion tool (instead of the original 2-page tool) with more resources for

• A line about giving back to the community/volunteering in the Setting Goals section.



Page 1 Back



Page 2 Back

### Results

CML patients and caregivers reported that:

- preparing for oncology visits.
- distress.

#### Conclusions

- on their daily lives.

#### Implementation

- advocacy groups.
- providers via its salesforce.

#### References

Breccia M, Graffigna G, Galimberti S, et al (2016). Personal history and quality of life in chronic myeloid leukemia patients: a crosssectional study using narrative medicine and quantitative analysis. Supportive Care in Cancer 24(11):4487–4493

Cancer Support Community (2017). Chronic Myeloid Leukemia (CML) Specialty Registry Report 2017. Retrieved from http://www.cancersupportcommunity.org/sites/default/files/uploads/our-research/2017\_Report/the\_cml\_specialty\_report\_7-10.pdf?v=1

Ha, J. F., & Longnecker, N. (2010). Doctor-Patient Communication: A Review. *The Ochsner Journal*, 10(1), 38–43.

• 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

• 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

• 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

• 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 with also help patients identify and seek resources that can help them cope with finances and changes in quality of life related to CML.

• 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

• Our funder is also proposing to distribute the tool to CML health care

• 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.