

## BACKGROUND

- Biomarker testing is becoming standard practice for many solid tumor cancers and is gaining momentum in hematologic cancers.
- Current NCCN guidelines recognize the importance of testing for mutations in AML and CML, given the potential therapeutic significance and impact on prognosis.
- Despite this, many patients still do not understand the biomarker testing process or implications for their care.

**Aims: This study aims to better understand AML and CML patients' experiences and unmet needs with biomarker testing.**

## METHODS

- We partnered with the Leukemia & Lymphoma Society to recruit patients with a history of any blood cancer into CSC's Cancer Experience Registry (CER).
- Participants who completed the CER and met study eligibility (18+, living in U.S., diagnosed with AML or CML in last 3 years) were recruited via email and completed a screener survey.
- Stratified sampling was then used to diversify the racial and socioeconomic background of the sample; eligible participants were invited for a virtual interview.
- Interviews were conducted via Zoom using a semi-structured interview guide, recorded and transcribed, prior to coding and analysis in NVivo 14. Interviews lasted an average of 93 minutes.

## PARTICIPANTS

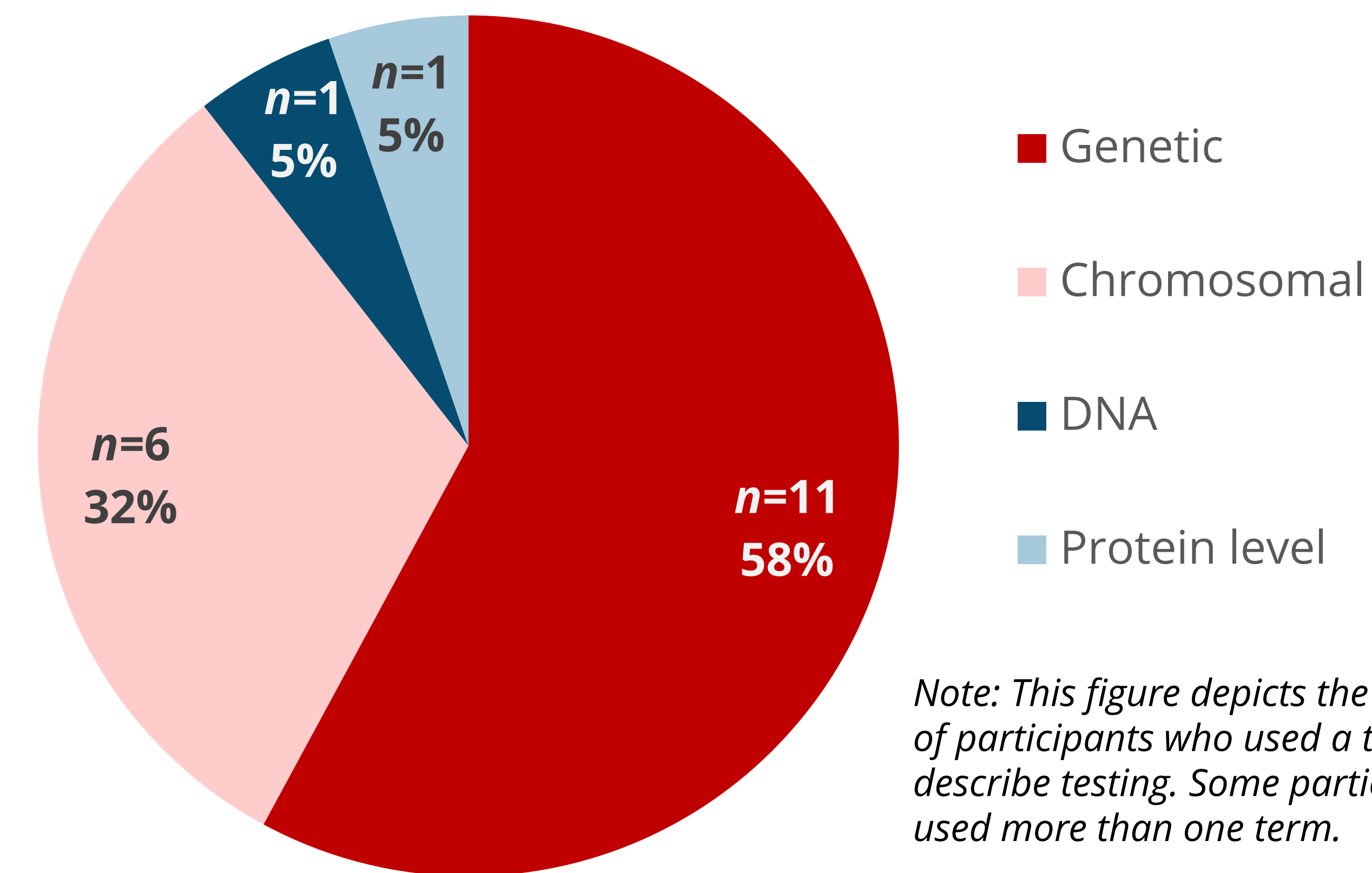
Participant Descriptives (N=15)	Mean/ n	SD/ %
<b>Age (years), range (33-72)</b>	M=53.8	SD=12.9
<b>Gender</b>		
Woman	7	47%
Man	8	53%
<b>Race &amp; Ethnicity</b>		
Non-Hispanic White	9	60%
Non-Hispanic Black / African American	2	13%
Non-Hispanic other/Multiracial	3	20%
Hispanic	1	6%
<b>Household Income</b>		
<\$40,000	5	33%
\$40,000 - \$79,999	5	33%
\$80,000+	5	33%
<b>Cancer Diagnosis</b>		
Acute Myeloid Leukemia (AML)	9	60%
Chronic Myeloid Leukemia (CML)	6	40%
<b>Year of Diagnosis</b>		
2020	4	27%
2021	6	40%
2022	5	33%
<b>Treatment Status</b>		
Currently receiving treatment	7	47%
Receiving maintenance therapy	3	20%
Completed treatment	3	20%
Other / I don't know	2	13%
<b>Care Setting</b>		
Community hospital or cancer center	4	27%
Academic or comprehensive care center	10	67%
Other	1	6%

Note. One person did not complete the interview; results reported out of 14 participants

## RESULTS

### What DO patients know about testing?

Figure 1. Language participants used to describe testing



Note: This figure depicts the number of participants who used a term to describe testing. Some participants used more than one term.

- **All participants received biomarker testing**, but there was discordance in the language used, with **only 3 out of 14 knowing the term "biomarker."**

"I know I had the **genetic testing** because I was able to go back and look at my test results from that, and they never really explained what the tests were for or what the mutations were. I had those mutations. They didn't explain it or how they affected me."

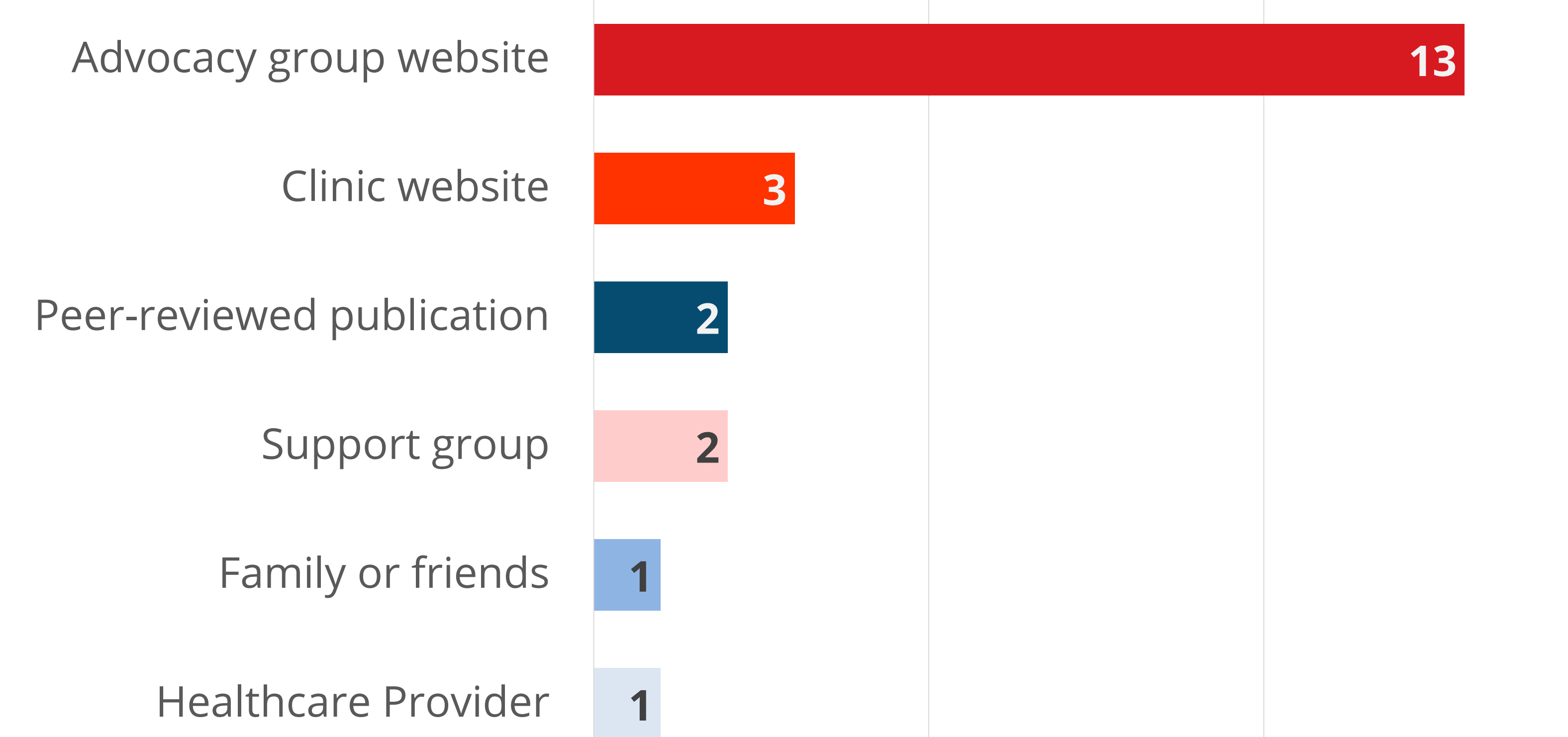
- Marcus (AML)

"I have not heard that term [biomarker] in my life. They [providers] just call it genetic testing. That was what it was."

- Michael (AML)

- Although most participants (12/14) understood the basic premise of testing and their mutations, all participants felt inadequately informed about the purpose of biomarker testing and their results.
- Knowledge around biomarkers was primarily self-sourced from independent research but **most participants (10/14) wanted to learn about the purpose and results of testing directly from a medical provider.**

Figure 2. How participants indicated they learned about testing



Note: This figure depicts the number of participants who reported learning about testing from this source. Some participants used more than one source to find information.

### What do patients WANT to know about testing?

- Participants were most interested in learning about the **specific details of their test results** and the **rationale** of testing beforehand, even for mutations that had no bearing on treatment, in order to feel informed about their diagnosis.
- **Poor patient-provider communication around testing was the participants' primary complaint**; half of the participants felt their providers had dismissed their questions or minimized their concerns.

"They're like, "You're doing good." I'm like, "But I wanna do more." But to reassure me, [he said], "You're doing what you need to be doing. You're progressing appropriately." **But just explain it [test results] to me!** I don't recall being explained like, what is this test? What is it for? What is it telling us? How does it direct your treatment?"

- Patricia (CML)

"It's [results] on my portal, so I can ask. But we don't know the intricacies or the details that you guys [providers] look for when you do a testing and what they each mean. I thought I could look it up. But it's too detailed to expect somebody to understand it all..."

**What is it [test] going to show? What's it looking for?"**

- Cheryl (AML)

- Participants expressed an interest in **clear, detailed** explanations from providers that spelled out the implications of testing.
- In addition to counseling from providers, participants want **accessible, trustworthy, and comprehensive online educational resources.**

"There needs to be more in-depth explanation upfront about the nature of testing and the rationale behind, and education on how to comprehend the results. ...For a normal person, it's totally mind boggling. And they need to get **a much better overall education at the very beginning**... If the physicians aren't going to do that, then they need to refer us to the support community."

- Linda (CML)

## CONCLUSIONS AND IMPLICATIONS

### Overall, we found that patients...

Know	Want to learn	Appreciated	Did not like
<ul style="list-style-type: none"> <li>• Specific <b>mutations</b> relevant to treatment</li> <li>• The <b>basic premise</b> of genetic testing of cancer cells</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Shared language</b> around testing (e.g., "genetic testing" or "biomarker?")</li> <li>• The <b>purpose</b> of testing and the <b>implications</b> of results</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Frank communication</b> about testing as it relates to their cancer</li> <li>• Opportunity for <b>follow-up questions</b></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Little to no</b> communication about the purpose of testing</li> <li>• <b>Minimal counseling</b> after receiving results</li> </ul>

- AML and CML patients have extensive experience with biomarker testing, but even highly educated patients **feel inadequately informed about the purpose, implications, and language around testing.**
- The quality of patient-provider communication before and after testing informs patients' overall experience with testing, suggesting the need for additional education and communication around testing from healthcare professionals and access to reliable information online.

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