

## BACKGROUND

Myelodysplastic Syndromes (MDS) are a heterogeneous group of marrow failure diseases whose prognosis and treatments are guided by marrow morphology, degrees of cytopenias, and genetic changes. Due to the complexity of the disorder, combined with the advanced age and frailty of most patients, conveying crucial information for shared decision-making poses challenges. Despite efforts designed to enhance communication, there is limited understanding of these initiatives' effectiveness.

**The aim of this study is to identify informational gaps of Cancer Experience Registry (CER) participants with an MDS diagnosis.**

## METHODS

- The CER is an ongoing online research study conducted by the Cancer Support Community that seeks to uncover the emotional, physical, and financial impact of cancer.
- In association with the MDS Foundation, **140 participants with MDS** enrolled from August 2021-March 2023 and provided sociodemographic and clinical history information.
- A subset ( $n=120$ ) also answered questions regarding whether they received additional assistance with MDS-related information and when this was provided.

## PARTICIPANTS

N = 140	Mean/n	SD/%
<b>Age (years) (range 34-93)</b>	M=69.6	SD=11.4
<b>Race &amp; Ethnicity</b>		
Non-Hispanic White	n=128	91%
Non-Hispanic other/Multiracial	n=8	6%
Hispanic	n=1	1%
<b>Gender Identity</b>		
Woman	n=72	51%
Man	n=66	47%
<b>Education</b>		
High school or less	n=26	19%
Some college, did not graduate	n=20	14%
Associate degree	n=7	5%
Bachelor degree	n=42	30%
Graduate degree or higher	n=44	31%
<b>Household Income</b>		
Less than \$40,000	n=25	18%
\$40,000 - \$79,999	n=38	27%
\$80,000 - \$119,999	n=22	16%
\$120,000 and above	n=19	14%
<b>Employment Status</b>		
Employed	n=21	15%
Retired	n=98	70%
Unemployed	n=18	13%
<b>Time Since Diagnosis</b>		
1 year or less	n=57	41%
1-2 years	n=26	19%
3-5 years	n=19	14%
6 or more years	n=34	24%
<b>Treatment Status</b>		
Currently receiving treatment	n=72	50%
Previously received treatment	n=25	18%
Never received treatment	n=37	26%

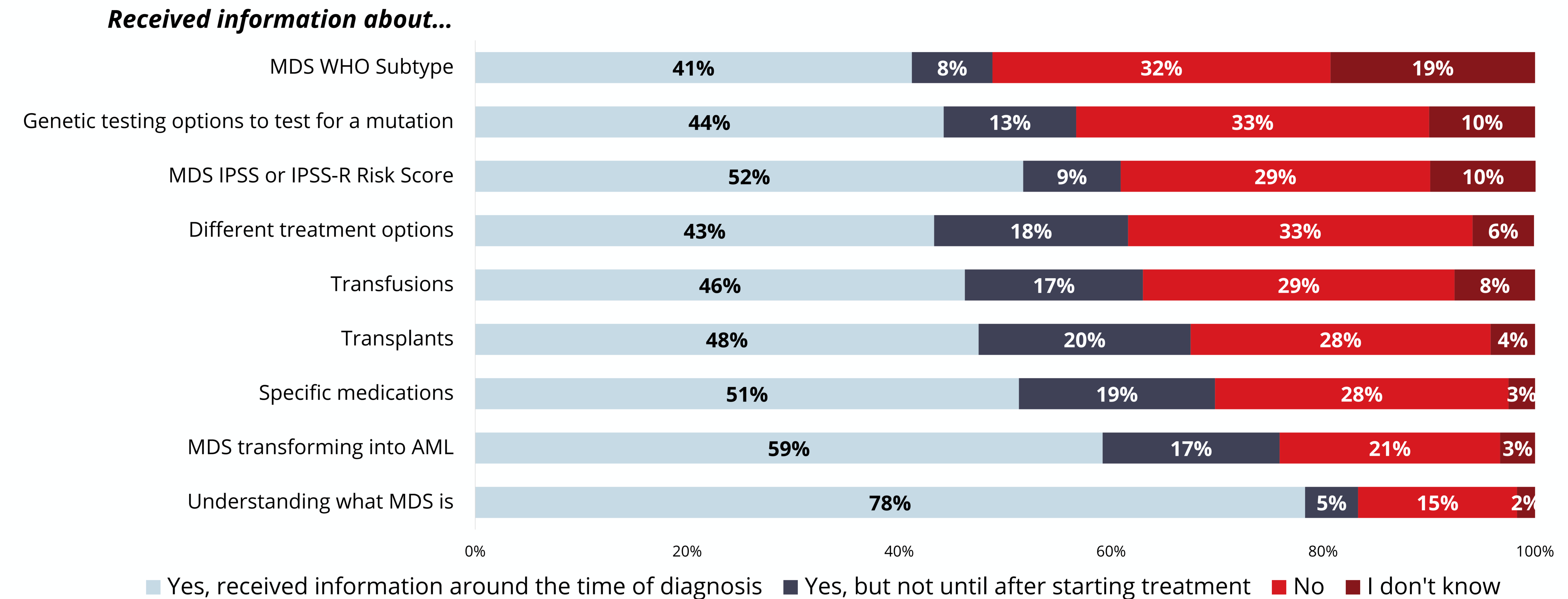
Note: Data for "I don't know" and "Prefer not to share" response options omitted from table.

## ACKNOWLEDGMENTS

Support for this study was provided by Acceleron, Bristol Myers Squibb, Genentech, Geron, Novartis, Taiho, and Takeda

## RESULTS

**MDS participants reported significant gaps in the information that they received about important topics related to their MDS diagnosis and treatment.**



**Figure 1. From the patient's perspective, was MDS-related information communicated and when was the timing of its delivery (N=120)**

**MDS participants reported gaps in receiving diagnostic information which are critical determinants of prognosis and are used to inform treatment decisions.**



**Figure 2. Gaps in knowledge about MDS diagnosis (N=140)**

## CONCLUSIONS AND IMPLICATIONS

- Based on the early results of the CER derived from a cohort of highly educated and motivated MDS patients, it appears that effective communication about MDS, risk classification, and treatment options is suboptimal.
- A significant proportion of respondents were unable to recall information about their diagnosis critical to informed shared decision-making.
- Given the complexities of an MDS diagnosis, additional efforts to educate patients are necessary. Patient support organizations, such as the Cancer Support Community and the MDS Foundation, can serve as valuable educational resources.