



MDS Global Survey Report

Improving MDS patient quality of life and access to care

October, 2022



CONTENTS

EXECUTIVE SUMMARY	3
MDS GLOBAL SURVEY OVERVIEW	5
SURVEY DESIGN PROCESS	6
METHODOLOGY	9
SURVEY COMPLETION AND ABANDONMENT RATES	13
DEMOGRAPHICS OF RESPONDENTS INCLUDED IN ANALYSES	16
DESCRIPTIVE RESEARCH FINDINGS	19
REFERENCES	70
APPENDIX	71

Executive Summary

Purpose

The *MDS Global Survey* serves to better understand and raise awareness of issues experienced by individuals living with MDS and to use this understanding to make evidence-based decisions about how to improve quality of life and access to care.

The current report includes a summary of responses to each *MDS Global Survey* question, as well as select sub-group analyses.

Survey Design

Based on input from the MDS Alliance Steering Committee and general membership, a survey plan was developed to operationally define what the *MDS Global Survey* would measure. Based on the survey plan, broad research questions were documented to help organize the survey and guide reporting of results. Survey questions were written from the plan, pre-tested and revised based on expert reviewer recommendations and cognitive interview results, translated into 10 languages, and then programmed for online data collection.

Methodology

Data were collected between November 2021 and April 2022. With assistance from the MDS Alliance general member organizations and *MDS Global Survey* steering committee members, requests for participation, including a link to the survey, were posted on the MDS Alliance website and social media channels. Individuals living with MDS and who provided informed consent – agreeing to the processing of their personal data – were provided access to an anonymous online survey in English and 10 other languages.

Completion Rate

While 994 individuals accessed the online survey, 946 provided consent to the processing of their personal data and were provided access to the first section of the survey. Of the 946 consenting individuals, 788 (83%) proceeded to answer some or all demographic questions, 659 (70%) proceeded to answer some or all topic-related questions, and 509 (65%) completed the entire survey. The results in this report are based on the 659 individuals who completed more than the demographic questions.

Respondent Demographics

Over two-thirds of respondents reported living in an urban area (68.6%), with a spouse or partner (66.6%), and having a higher-education degree (77.0%). Just over half self-identified as female (56.9%). Reported total household income varied, from 10.3% of respondents having an income below \$23,800 to 14.3% having an income of \$118,883 or above. The majority reported having health insurance (85.4%), with the most commonly reported distance travelled to their primary care facility of 16.1 kilometers.

Key Findings

Key findings from the *MDS Global Survey* are summarized below.

Disease History/Current Status	
Before diagnosis, the physical symptom experienced by the greatest percentage of respondents was fatigue/tiredness (62.8%) followed by anemia (47.9%).	62.8% <i>EXPERIENCED FATIGUE/TIREDNESS</i>

Overall Health	
<i>FROM</i> 53.5% <i>TO</i> 85.8%	While 53.3% of respondents rated their overall health today as <i>good, very good, or excellent</i> , 85.8% reported their overall health would be <i>good, very good, or excellent</i> if no symptoms were present.

Mental Health and Wellbeing	
While 68.1% of respondents rated their mental health and wellbeing prior to their diagnosis as <i>excellent or very good</i> , 30.2% rated their mental health and wellbeing currently as <i>excellent or very good</i> .	<i>FROM</i> 68.1% <i>TO</i> 30.2%

Quality of Life	
52.8 <i>MEAN MDS-RELATED QOL</i>	Overall MDS-related quality of life, measured by the QUALMS, was 52.8, with the highest quality of life for the Benefit Finding (62.5) subscale and lowest quality of life for Emotional Burden (48.9) subscale.

Access to Care	
Almost 25% of respondents reported it taking more than 6 months to be evaluated for MDS after onset of MDS symptoms.	24.5% <i>WAITED > 6 MONTHS TO BE EVALUATED FOR MDS</i>

COVID-19 Effects	
79.6% <i>NOT AFFECTED BY COVID- 19</i>	Over three-quarters of respondents reported that COVID-19 did not affect them.

Improving Quality of Life and Access to Care	
The wish list items reported by the greatest percentage of respondents were <i>access to quality information / resources</i> (16.2%) and <i>emotional, social, and psychological support</i> (15.4%).	16.2% <i>WISHED FOR QUALITY INFORMATION/RESOURCES</i>



MDS Global Survey Overview

Background and Survey Purpose

Myelodysplastic syndromes (MDS) are a rare group of disorders where an individual's body can no longer make enough healthy blood cells in the bone marrow. While MDS can sometimes be cured with a stem cell transplant, or very rarely with intensive chemotherapy, usually MDS cannot be cured. However, MDS can be controlled and often improved with treatment to help those with MDS live longer, higher-quality lives.

Typically affecting older individuals (age 65+), MDS is rare, with an estimated 87,000 new cases each year worldwide (MDS Foundation, 2021). Accessing needed care and maintaining quality of life can be a huge challenge for many individuals living with MDS.

To address the challenges individuals living with MDS face, the MDS Alliance's vision is optimal care for all patients with MDS, worldwide. Their mission is to better serve patients with MDS and the caregiver communities, globally. The MDS Alliance has a comprehensive focus on the common experience of patients living with MDS and on serving that population as an advocacy community.

As an umbrella organization, the MDS Alliance has 40 general members across 32 countries. General members of the MDS Alliance are established non-profit/non-governmental organizations who are focused on meeting the needs of patients and caregivers living with MDS.

Between 2021–2022, the MDS Alliance developed and implemented the *MDS Global Survey* to better understand the issues and needs of individuals living with MDS so they could make evidence-based decisions about how to improve their quality of life and access to care.



Survey Design Process

The *MDS Global Survey* was developed systematically following a 6-step process.

1. Administer MDS Alliance Questionnaire



A questionnaire was administered to the MDS Alliance Steering Committee (made up of patient advocates, healthcare professionals, and patients) and the general membership to determine the constructs to measure, the respondent demographics to gather, the survey distribution methods, and the most beneficial survey outputs.

2. Create Survey Plan

Leveraging the questionnaire results, a survey plan was created to document and operationally define the constructs to be measured. For each construct, the plan included sub-constructs to be measured, the data collection instrument for gathering data on each construct (e.g., researcher designed questions, proprietary instruments), question types (e.g., multiple-choice, Likert-type, open-ended), and the anticipated number of questions.

3. Document Research Questions

Based on the survey plan, broad research questions were documented to help organize the survey and guide reporting of results.

- | | | |
|---|---|---|
| 1. What is the disease history/experience and current state of individuals living with MDS? | 2. What treatments have individuals living with MDS received? | 3. What perspectives do individuals living with MDS have regarding support they are receiving? |
| 4. What perspectives do individuals living with MDS have about their overall health? | 5. What perspectives do individuals living with MDS have about their mental health and wellbeing? | 6. What perspectives do individuals living with MDS have about their quality of life? |
| 7. What perspectives do individuals living with MDS have about their access to care? | 8. What perspectives do individuals living with MDS have about the effect of the COVID-19 pandemic? | 9. What perspectives do individuals living with MDS have about what's needed to improve their quality of life and access to care? |

4. Develop Survey

The survey was then developed following the survey plan. The [final survey](#) included 8 sections, with the survey items in each section used to answer one or more research question.

Section number	Section	Research questions (RQ)
1	Demographics	
2	Disease history/current status	RQ 1, RQ 2, RQ 3
3	Overall health	RQ 4
4	Mental health and wellbeing	RQ 5
5	Quality of life	RQ 6
6	Access to care	RQ 7
7	COVID-19 effects	RQ 8
8	Improving quality of life/access to care	RQ 9

5. Pre-Test Survey

The survey was pre-tested to identify and correct challenges that may have affected data quality. The pretesting process involved using two evidence-based methods: expert review and virtual cognitive interviews.

Expert Review

The purpose of the expert review was to have a “fresh set of eyes” critically evaluate the survey to identify and suggest ways for addressing any survey instruction, question wording, question sequencing, or potential respondent burden issues (e.g., the degree to which respondents might perceive participation as difficult, time consuming, or emotionally stressful) that may have led to measurement errors or may have hindered the question answering process.

The expert reviewer was an external, PhD-level organizational psychologist with 20+ years of survey design experience. Prior to conducting the review, the expert received an email with a copy of the paper-based, English-language version of the *MDS Global Survey*, as well as a second document describing the review purpose, instructions for completing the review, and space to document review results. In the provided space, the expert was asked to briefly explain each specific issue identified, as well as recommendations for ways to address any identified issues.

Prior to proceeding with the virtual cognitive interviews, the *MDS Global Survey* was updated to address the expert reviewer’s recommendations.

Virtual Cognitive Interviews

The purpose of the virtual cognitive interviews was to determine if (a) the survey instructions were clear, (b) the survey items were clear and measured what the developers intended, (c) individuals interpreted all survey items in the same way, (d) closed-ended questions provided at least one response option that would apply to every individual living with MDS, and (e) individuals understood critical terms.

The participants were 5 English speaking individuals living with MDS (2 from the United Kingdom, 2 from the United States, and 1 from Germany) and 1 MDS caregiver from the United States. Prior to participating in the interview, participants received an email containing an overview of the *MDS Global Survey* purpose and directions for completing the survey before the interview. At the beginning of the interview, after confirming participants completed the survey, participants were thanked for their participation, reminded of the purpose of the *MDS Global Survey*, and asked a series of questions, including the following:

- In general, how was your experience completing the survey?
- Were the instructions easy to understand? If not, what was difficult?
- Did the questions seem to flow logically? If not, where did you find difficulties with the flow?
- Were any of the questions worded in a way that was offensive to you? If yes, which ones?
- Were there any questions that were hard for you to answer due to confusing wording or terms you were unfamiliar with? If yes, which ones?
- At any time when you were completing the survey, did you feel frustrated? If yes, where, and why?
- Were there any questions that an individual may have problems answering because they don't see an option that fits their situation? [*Individuals were directed to specific questions in the survey that had "Other, please specify" options. The response options were carefully reviewed to ensure they were inclusive to minimize number of "Other (please specify)" responses*].
- Are there any additional questions you feel should be added to the survey which you would expect to see in a quality of life and access to care survey? If yes, what questions would you add?
- Is there any other feedback you'd like to share with us? If yes, what would you like us to know?

6. Translate and Program

Linguists employed by a professional translation agency translated the English version of the survey into 10 languages: Arabic, Dutch, French, German, Hebrew, Italian, Korean, Portuguese, Russian, and Spanish. These languages were selected because MDS-specific quality of life, within the *MDS Global Survey*, was measured using the QUALMS validated tool that is available in these languages. All translators and proofreaders were skilled, native linguists who specialized in the medical industry and had a minimum of 10 years' experience. All translators and proofreaders belonged to translation bodies such as the Chartered Institute of Linguists (CIOL) or Institute of Translators and Interpreters (ITI). Upon completing each initial translation, an independent proofreader checked the accuracy of all translations.



Methodology

Study Population

The target population for the *MDS Global Survey* was any individual living with MDS. Given the method for soliciting survey participants (described later in this report), survey respondents likely were those living in countries with MDS support groups and who were members of a support group. As these individuals may be better informed about, curious about, and more engaged with their condition; or they may have felt more isolated or unhappy with their care, their views may not be completely representative of the entire population of individuals living with MDS.

Data Collection Instrument

The data collection instrument was an online survey beginning with an informed consent question, followed by 8 sections consisting of 51 survey items: 50 multiple choice, multiple textbox, and Likert-type items; and 1 open-ended question. Two sections contained items from existing, validated instruments. Level of social support (Section 2C) was measured using the *Multidimensional Scale of Perceived Social Support* (Zimet et al. 1988). Quality of life (Section 5) was measured using the *Quality of Life in Myelodysplasia Scale* (QUALMS¹).

Section	Number of questions	Question type
Informed consent	1	Multiple choice
1. Demographics	10	Multiple choice, multiple textbox
2A. Disease history/current status	13	Multiple choice, date/time, Likert-type
2B. Treatments received	3	
2C. Support receiving	4	
3. Overall health	3	Multiple choice, Likert-type
4. Mental health and wellbeing	3	Multiple choice, Likert-type
5. Quality of life	3	Likert-type
6. Access to care	10	Multiple choice
7. COVID-19 affects	1	Multiple choice, Likert-type
8. Improving quality of life/access to care	1	Open-ended
Total	52	

¹ Copyright 2013 Dana-Farber Cancer Institute, Inc. and CHEO Research Institute, Inc. All rights reserved. Used with permission.



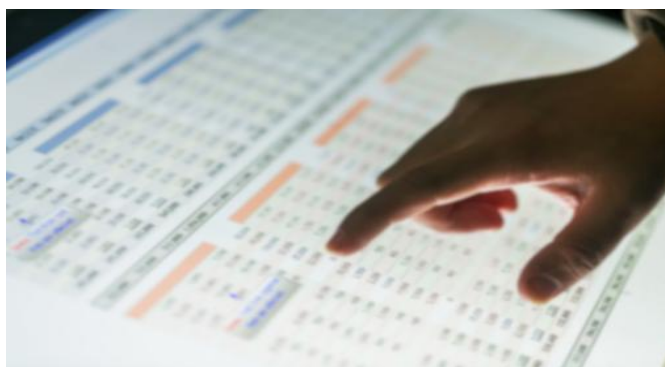
Participant Solicitation and Data Collection

Between November 2021 and April 2022, eligible participants were sought using multiple methods. These included support from the MDS Alliance general member organizations and *MDS Global Survey* steering committee members, as well as using MDS Alliance website features and social media channels.

1. ***MDS Alliance Members:*** MDS Alliance members received a communication requesting their support by sharing the survey with patient groups -- consisting of 40 general membership organizations across 32 countries -- and encouraging participation. Each member organization received details on the survey purpose and objectives, a draft email they could send to their networks, and editable social media graphics members could create in their required language and share on social media. Included in the provided request for participation were links to the survey in 11 different languages.
2. ***MDS Global Survey Steering Committee Members:*** The *MDS Global Survey* steering committee also received details of the survey purpose and objectives, a draft email they could send to their own networks, and editable social media graphics to be shared on social media to further the reach and distribution.
3. ***Social Media Campaign:*** To further encourage participation, a social media campaign was launched across the MDS Alliance Facebook, Instagram, LinkedIn, and Twitter channels. This involved the sharing of graphics with a call to action, and a link to the *MDS Global Survey* page on the MDS Alliance website. Additionally, the Facebook, Twitter, and LinkedIn page banners were updated to promote participation in the survey.
4. ***MDS Alliance Website:*** On the MDS Alliance website, a page was created to share information about the survey, including the purpose and objectives of the resulting report and guidance on completing the survey. Included in the provided request for participation were links to the survey in 11 different languages. A homepage banner was also created, where users could click through directly to the survey page. Within requests for participation, individuals who clicked on the survey link were taken to the first question on the survey, where they were asked if they consented to the processing of their personal data for the purposes of the survey. Individuals who selected "Yes" were then taken to Section 1 of the survey where they answered a series of demographic questions. Individuals who selected "No" were exited from the survey.

Data Cleaning

Upon completing data collection, all open-ended responses were back-translated into English and the raw data were cleaned to prepare for analysis. The data cleaning process involved reviewing all raw survey data to detect and correct errors that could affect the quality of analyzed data and reported results. A summary of the most significant steps in the data cleaning process is below:



- **Records were deleted** for those respondents who responded "No" to the processing of their personal data and who agreed to the processing of their personal data but did not proceed to answer any survey questions. Records were also deleted for 5 participants who consistently chose "Other" as the response but did not add additional information, limiting the usefulness of their responses.
- **Data were deleted** for those variables where the data did not fall within the expected range/response type (e.g., a numeral for city/town of residence, "I don't know" for mileage, invalid dates, and future date for date of symptom onset and diagnosis).
- **Values were corrected** where respondents were to provide the distance traveled to their primary care facility in either kilometers or miles, by changing all mileage and kilometer values to numbers only (e.g., 25 km to 25), using averages where two numbers were provided (e.g., 3-4 to 3.5), moving indicated miles placed in kilometers field to proper miles field, and deleting data when two values were provided for mileage (km and miles) that did not align.



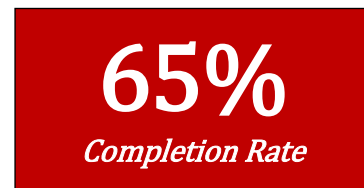
Survey Completion Rates



Survey Completion and Abandonment Rates

Overall Completion Rate

While 994 individuals accessed the online survey, 946 provided consent to the processing of their personal data and were provided access to the survey questions. Of the 946 consenting individuals, 788 (83%) respondents proceeded to answer the demographic questions (Section 1) and 659 (70%) proceeded to answer some or all the topic-related questions (Sections 2–8). A total of 509 respondents completed the entire survey, for a completion rate² of 65%.



Who Completed the Survey (N = 659)

Of the 659 respondents who proceeded to answer some or all the topic-related questions (Sections 2–8), most surveys were completed by individuals living with MDS (80.3%). The most frequently reported “Someone else” who completed the survey was spouses ($n = 6$), children ($n = 5$), and parents ($n = 3$).

▪ A patient with MDS	80.3% ($n = 529$)
▪ Caregiver of a patient with MDS	16.2% ($n = 107$)
▪ Someone else	3.5% ($n = 23$)

Overall Abandonment/Dropout Rates

Conducting a dropout analysis is helpful for future users of the *MDS Global Survey*. A dropout analysis provides future users a better understanding of where respondents abandoned the survey so they can make changes to improve future completion rates. The dropout rate³ for each survey item, by section, is displayed in [Appendix A](#). Complete questions are located in the [MDS Global Survey](#).

There were 9 areas where respondents abandoned the survey, with dropout rates ranging between 2% and 17%. The greatest dropout occurred just prior to answering Q10 (17%) and Q29 (14%), with the greatest percentage of respondents abandoning the survey within Section 2.

Researchers desiring to use the *MDS Global Survey* for future research are encouraged to consult additional scholarly resources to explore options for enhancing completion rates. One finding that is consistent within the literature is the negative relationship between completion rate and survey length. At a minimum, future users of the MDS Global Survey should consider

² Completion rate was calculated by dividing number of respondents who completed all required questions by number of consenting respondents who began survey.

³ The dropout rate (rounded to the nearest whole number) was calculated by dividing the number of respondents who did not answer a question by the number who should have answered the question (after data cleaning and taking into account skip patterns).

looking for opportunities to shorten the survey, retaining only those questions most critical to achieving desired objectives.

Completion Rate by Region and Country

Survey completion rates varied by region and country. Completion rates from 6 continents ranged from 67% to 100%. Country completion rates for respondents representing 32 countries ranged from 25% (for 1 country) to 100% (for 15 countries).

Most respondents ($n = 576$; 87%) were from North America ($n = 336$) and Europe ($n = 240$), where the regional completion rates were 79% and 70%, respectively. Within North America, the highest completion rates were from Canada (81%, $n = 39$) and the United States (80%, $n = 227$). Within Europe, the country-level completion rates ranged from a low 50% (Greece and Portugal) to a high of 100% (Belgium, Croatia, Finland, Hungary, Ireland, N. Macedonia, Spain, and Sweden); however, these countries had very small sample sizes. The European countries with the highest representation of respondents who completed the entire survey were France ($n = 42$), United Kingdom ($n = 32$), Germany ($n = 29$), and Italy ($n = 25$).

Region/Country	Completion Rate	Region/Country	Completion Rate
Africa	1/1 (100%)	Ireland	5/5 (100%)
South Africa	1/1 (100%)	Italy	25/38 (66%)
Asia	46/47 (98%)	N. Macedonia	2/2 (100%)
India	1/2 (50%)	Portugal	1/2 (50%)
Indonesia	1/1 (100%)	Spain	6/6 (100%)
Israel	1/1 (100%)	Sweden	3/3 (100%)
Korea	40/41 (98%)	Switzerland	7/10 (70%)
Malaysia	2/2 (100%)	United Kingdom	32/37 (86%)
Philippines	1/1 (100%)	North America	267/336 (79%)
Europe	167/240 (70%)	Canada	39/48 (81%)
Austria	3/4 (75%)	Mexico	1/4 (25%)
Belgium	1/1 (100%)	United States	227/284 (80%)
Croatia	2/2 (100%)	Oceania	20/23 (87%)
Denmark	5/8 (63%)	Australia	18/21 (86%)
Finland	2/2 (100%)	New Zealand	2/2 (100%)
France	42/69 (61%)	South America	8/12 (67%)
Germany	29/48 (60%)	Argentina	4/6 (67%)
Greece	1/2 (50%)	Brazil	1/3 (33%)
Hungary	1/1 (100%)	Peru	3/3 (100%)



Respondent Demographics



Demographics of Respondents Included in Analyses

Section 1 of the *MDS Global Survey* included questions to gather demographic information about the survey respondents. The demographic characteristics of the 659 individuals who proceeded to answer the topic-related questions, and who are included in subsequent analyses, are displayed below.

Geographic Location (*N* = 659)

The greatest percentage of respondents reported living in an urban area (68.6%).

Urban	68.6% (<i>n</i> = 452)
Rural	31.4% (<i>n</i> = 207)

Gender (*N* = 659)

Over half of the respondents self-identified as female (56.9%). The two individuals who preferred to self-describe identified as gender fluid.

Female	56.9% (<i>n</i> = 375)
Male	42.5% (<i>n</i> = 280)
Self-describe	0.3% (<i>n</i> = 2)
Prefer not to say	0.3% (<i>n</i> = 2)

Total Household Income⁴ (*N* = 659)

Almost one-quarter of respondents preferred not to share their total household income (23.7%), and of those who did, the income range differed from 10.3% having an income below \$23,800 to 14.3% having an income of \$118,883 or above.

Below €20,000 (Below \$23,800)	€20,000 to €44,999 (\$23,800 to \$53,493)	€45,000 to €69,999 (\$53,494 to \$83,208)	€70,000 to €84,999 (\$83,209 to \$101,043)	€85,000 to €99,999 (\$101,044 to \$118,882)	€100,000 and above (\$118,883 and above)	I prefer not to say
10.3% (<i>n</i> = 68)	22.2% (<i>n</i> = 146)	14.9% (<i>n</i> = 98)	9.0% (<i>n</i> = 59)	5.8% (<i>n</i> = 38)	14.3% (<i>n</i> = 94)	23.7% (<i>n</i> = 156)

Current Living Situation (*N* = 659)

The greatest percentage of respondents reported living with a spouse/partner (66.6%).

66.6% With spouse/partner (<i>n</i> = 439)	18.8% Alone (<i>n</i> = 124)	12.0% With immediate family (<i>n</i> = 79)	0.9% In a different setting (<i>n</i> = 6)
0.8% With extended family (<i>n</i> = 5)	0.6% In a residential facility (<i>n</i> = 4)	0.3% With friends (<i>n</i> = 2)	

⁴ U.S. dollar and Euro equivalents were based on the conversion rate at time of survey administration.

Highest Level of Education (N= 659)

Over three-quarters of respondents reported having a higher education degree (77.1%), with most respondents reporting a bachelor's degree (29.1%).

0.3%	Preprimary education (<i>n</i> = 2)
0.6%	Primary education (<i>n</i> = 4)
3.6%	Lower secondary education (<i>n</i> = 24)
17.6%	Upper secondary education (<i>n</i> = 116)
20.2%	Higher education (associate's/vocational degree) (<i>n</i> = 133)
29.1%	Higher education (bachelor's degree) (<i>n</i> = 192)
27.8%	Higher education (master's/doctoral degree) (<i>n</i> = 183)
0.8%	Prefer not to say (<i>n</i> = 5)

Distance Travelled to Primary Care (N= 659)

The most commonly reported distance travelled to their primary care facility (and the midpoint) was 16.1 kilometers (km), with the average distance travelled, due to a few extreme

Mean km • 32.5	Median km • 16.1	Mode km • 16.1	Range km • 0.1–1045.9
--------------------------	----------------------------	--------------------------	---------------------------------

outliers, being 32.5 kilometers.

Health Insurance (N= 659)

Most respondents reported having health insurance (85.4%). Of those who reported having health insurance, the greatest percentage of respondents reported coverage for on-site visits to specialists (91.7%) and primary care physicians (86.9%), as well as testing (84.3%). The smallest percentage reported coverage for clinical trials/experimental treatments (28.6%).

YES (has health insurance)
85.4% (*n* = 563)

NO (does not have health insurance)
14.6% (*n* = 96)

Which of the following does your health insurance cover?	
86.9% (<i>n</i> = 493)	On-site visits to primary care physician/GP
62.3% (<i>n</i> = 353)	Virtual visits to primary care physician/GP
91.7% (<i>n</i> = 520)	On-site visits to specialists
58.7% (<i>n</i> = 333)	Virtual visits to specialists
51.9% (<i>n</i> = 294)	On-site visits to mental health counselor/psychologist
37.6% (<i>n</i> = 213)	Virtual visits to mental health counselor/psychologist
84.3% (<i>n</i> = 478)	Testing
77.6% (<i>n</i> = 440)	Transfusions
55.0% (<i>n</i> = 312)	Facility charges
28.6% (<i>n</i> = 162)	Clinical trials/experimental treatments
34.4% (<i>n</i> = 195)	Other treatments



Descriptive Findings



Descriptive Research Findings

Disease History/Current State

What is the disease history/experience and current state of individuals living with MDS?

Section 2A of the *MDS Global Survey* included 13 questions to better understand the disease history/experience and current state of individuals living with MDS.

Time Between Symptom Onset and Diagnosis (N = 604)

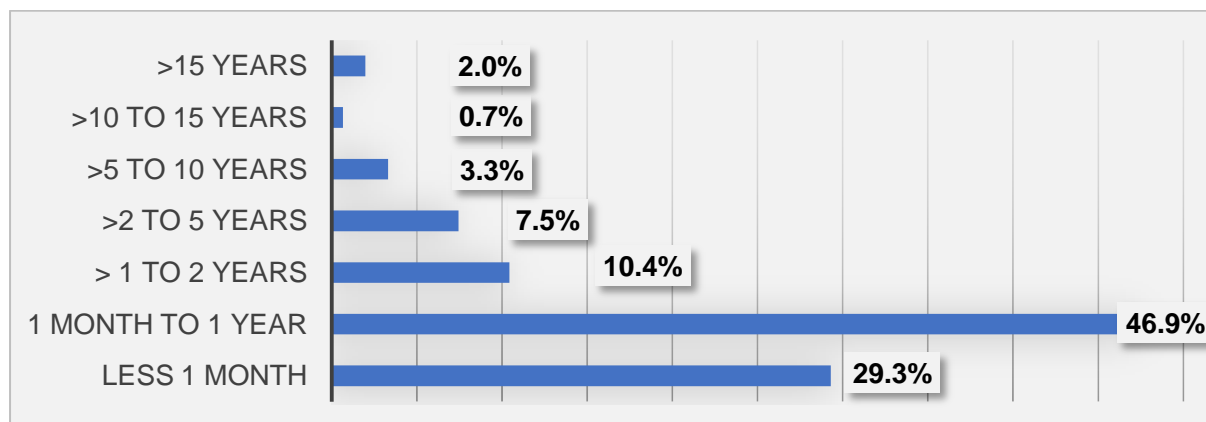
Respondents were asked 2 questions to determine the length of time between symptom onset and MDS diagnosis:

- “On what date did you begin showing symptoms of MDS (DD/MM/YYYY)”
- “On what date were you diagnosed with MDS (DD/MM/YYYY)?”

Excluding the 55 respondents who reported receiving a diagnosis prior to the onset of symptoms or who provided invalid dates, the mean number of months from symptom onset to time of diagnosis was 22 months (due to some extremely high outliers). The median number of months between symptom onset and MDS diagnosis was 3 months. The number of months varied from less than 1 month to greater than 1231 months, with calculations showing that most respondents (76.2%) were diagnosed within 1 year after onset of symptoms.

3

Median number of months between symptom onset and MDS diagnosis for those respondents who reported having symptoms prior to diagnosis



Interpretation of these results should take into account the following:

- 10 respondents reported the same date for onset of symptoms and date of MDS diagnoses.
- 46 respondents reported extreme delays between onset of symptoms date and date of diagnosis, ranging from 634 to 1231 months (or approximately 53 years and 103 years).

Physical Symptoms Prior to Diagnosis (N = 659)

Respondents were asked “*Before you were diagnosed, what physical symptoms, if any, were you having that were subsequently attributed to MDS?*”

The top 2 symptoms experienced by the greatest percentage of respondents were fatigue/tiredness (62.8%) and anemia (47.9%), with approximately one-fifth (18.4%) of respondents reporting they were not having any physical symptoms when diagnosed. The physical symptoms experienced by the smallest percentage of respondents were ascites (0.3%) – fluid collection within the abdomen – and an enlarged spleen (4.2%).

62.8%
Percent of respondents reporting fatigue/tiredness before diagnosis

	Percent of Respondents	<i>n</i>
Fatigue/tiredness	62.8%	413
Anemia	47.9%	315
Shortness of breath/trouble breathing	31.6%	208
Weakness	25.1%	165
Easy or unusual bruising/bleeding	22.5%	148
Dizziness	19.4%	128
I was not having any physical symptoms	18.4%	121
Unusual paleness	18.2%	120
Joint or bone pain	16.2%	107
Other (please specify)	12.0%	79
Weight loss	11.2%	74
Headache	10.8%	71
Frequent infections	9.7%	64
Loss of appetite	9.7%	64
Fever	5.0%	33
Nausea/vomiting	4.7%	31
Enlarged spleen	4.2%	28
Ascites	0.3%	2

Respondents reported having a significant number of “Other” symptoms at the time of diagnosis:

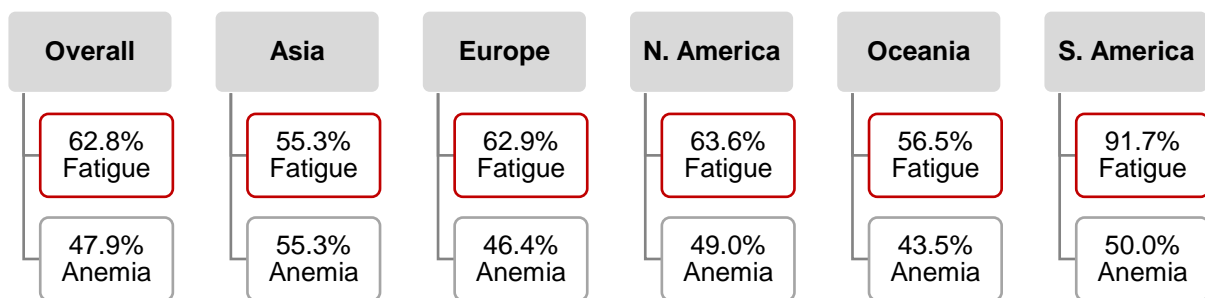
- High and low RBC counts (*n* = 2) and WBC counts (*n* = 5)
- High and low platelet counts (*n* = 11), as well as pancytopenia (low RBC, WBC, and platelet counts) (*n* = 1)
- Skin/extremity issues (*n* = 12), including easy bruising/hematomas, itching, rashes, slow healing wounds, and swelling/pain in extremities
- Sleeping issues (*n* = 5), including insomnia and night sweats
- Mouth issues (*n* = 4), including bleeding and pale gums, canker sores, and ulcers
- Internal organ issues (*n* = 4), including kidney problems and stomach/abdominal pains
- Fast beating heart (*n* = 3)
- Memory issues (*n* = 2)

- Other isolated issues⁵ included ringing ears, myasthenia gravis (weakness and muscle fatigue), inflamed blood vessels, collapsing when walking, failure to thrive, difficulty stopping bleeding, systemic lupus erythematosus, and low iron levels

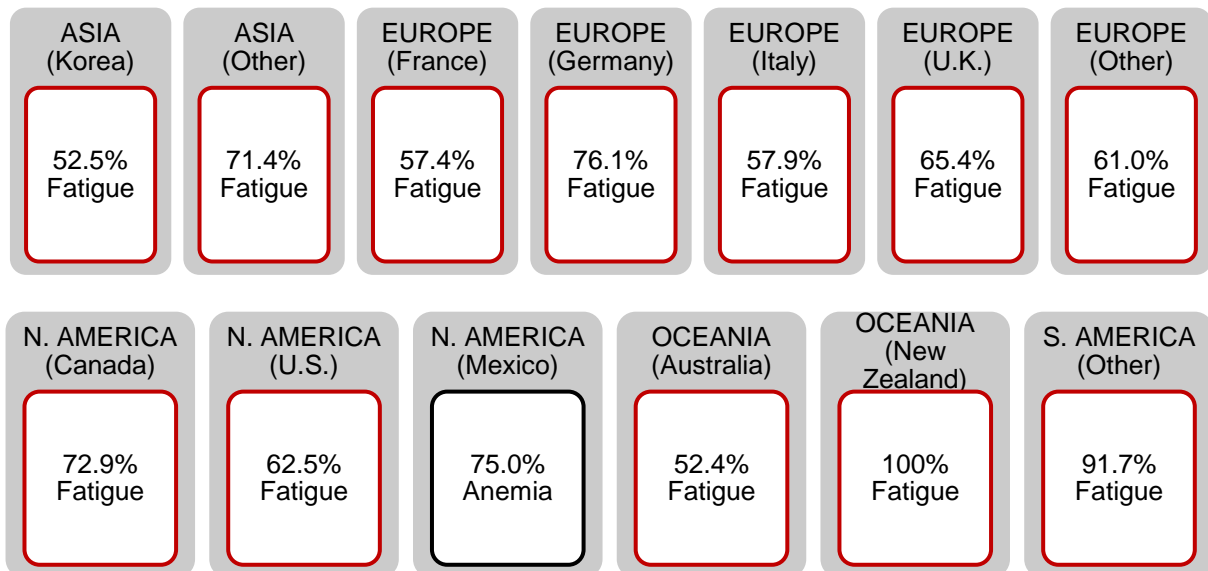
Physical Symptoms Prior to Diagnosis by Region and Country (N= 655)

Additional analyses were conducted to determine if the top 2 symptoms experienced by the greatest percentage of respondents prior to diagnosis – fatigue/tiredness and anemia -- were similar findings at the region and country level. The percent of respondents experiencing each physical symptom, by region and country, is displayed in [Appendix B](#). Results for countries with fewer than 20 respondents were grouped into one percentage in the region’s “Other” category.

As shown below, regional results were similar to the overall results. For 5 of the 6 regions (excluding Africa), the symptoms experienced by the greatest percentage of respondents prior to their diagnosis were fatigue/tiredness and anemia.



At the country level, fatigue was again the physical symptom experienced by the greatest percentage of respondents from all countries in the 5 regions excluding Mexico (N. America), where the greatest percentage of respondents reported experiencing anemia.



⁵ Isolated issues reported here and in other parts of the report are those reported by a single respondent.

Types of Testing (N = 659)

Respondents were asked “What types of testing did you undergo prior to your final diagnosis of MDS?”

While 4% of respondents did not recall the types of testing they underwent, the testing experienced by the greatest percentage of respondents were blood tests (96.0%) and bone marrow tests (89.8%). The smallest percentage of respondents reported flow cytometry/immunocytochemistry (17.0%) and molecular tests (9.1%).

Blood tests (96.0%)
Bone marrow tests (89.8%)
Tests experienced by the greatest percentage of respondents prior to final diagnosis

	Percent of Respondents	n
Blood tests	96.0%	632
Bone marrow tests (aspiration and biopsy)	89.8%	591
Chromosome tests (genetic testing)	36.6%	241
Flow cytometry and immunocytochemistry	17.0%	112
Molecular tests	9.1%	60
I do not remember	4.0%	26
Other (please specify)	3.5%	23

Respondents reported undergoing “Other” types of tests prior to their final MDS diagnosis:

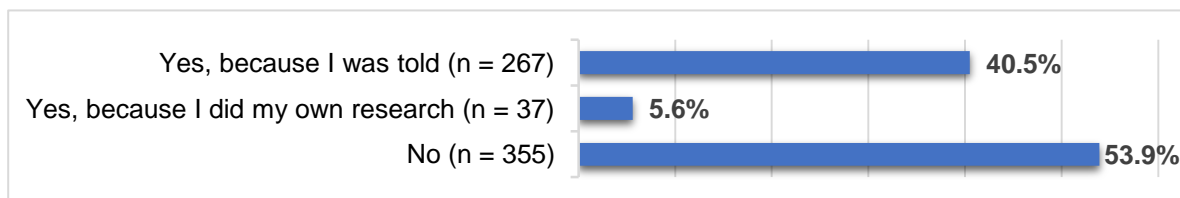
- Imaging (n = 12), including CT scans, PET scans, MRIs (cerebral, head), ultrasound of internal organs, and x-rays (lung)
- Colonoscopy (n = 4), endoscopy (n = 1), and gastroscopy (n = 1)
- Cardiac tests (n = 2), including echocardiogram
- Other isolated tests, such as stool analysis, rheumatological exams, immunophenotyping, next-generation sequencing, and testing for internal bleeding

Risk Level/Category and Subtype at Time of Diagnosis (N = 659)

Respondents were asked “Did you know your IPSS or IPSS-R risk level/category at the time you were diagnosed with MDS?”

More than half (53.9%) reported *not* knowing their IPSS or IPSS-R risk level/category at the time of diagnosis. Of the 46.1% who reported knowing their IPSS or IPSS-R risk level/category at the time of diagnosis, a small percentage (5.6%) only knew because they had performed their own research.

53.9%
Percent of respondents who DID NOT know their IPSS risk level at the time of diagnosis



Respondents who reported knowing their risk level/category were then asked, “What was your IPSS or IPSS-R risk level/category at the time you were diagnosed with MDS?”

While just over half (55.5%) reported a very low or low-risk MDS IPSS/IPSS-R level at the time of their diagnosis, 18.9% reported a high or very high-risk level.

	Percent of Respondents	<i>n</i>
IPSS Score		
IPSS score: Low-risk MDS	41.3%	116
IPSS score: Intermediate - 1	9.6%	27
IPSS score: Intermediate - 2	6.4%	18
IPSS score: High-risk MDS	10.7%	30
IPSS-R Score		
IPSS-R score: Very low-risk MDS	2.1%	6
IPSS-R score: Low-risk MDS	12.1%	34
IPSS-R score: Intermediate risk	3.6%	10
IPSS-R score: High-risk MDS	4.3%	12
IPSS-R score: Very high-risk MDS	3.9%	11
Other		
I don't remember	6.0%	17

Respondents were also asked “*What was your MDS subtype at the time you were diagnosed with MDS?*”

	Percent of Respondents (<i>N</i> = 610)	<i>n</i>
MDS-SLD with ring sideroblasts (MDS-RS) OR Refractory anemia with ringed sideroblasts (RARS)	16.0%	98
MDS with multilineage dysplasia (MDS-MLD) OR Refractory cytopenia with multilineage dysplasia (RCMD)	13.6%	83
MDS with isolated del(5q)	8.5%	52
MDS with excess blasts (MDS-EB2) OR Refractory anemia with excess blasts-2 (RAEB-2)	6.4%	39
MDS with single lineage dysplasia (MDS-SLD) OR Refractory cytopenia with unilineage dysplasia (RCUD)	6.4%	39
MDS with excess blasts (MDS-EB1) OR Refractory anemia with excess blasts-1 (RAEB-1)	5.9%	36
MDS, unclassifiable (MDS-U)	5.9%	36
Chronic myelomonocytic leukemia (CMML)	2.8%	17
MDS with thrombocytosis (MDS/MPN crossover)	2.0%	12
Secondary AML	0.5%	3
MDS with excess blasts (MDS-EB2) OR Refractory anemia with excess blasts - 2 (RAEB-2)	0.2%	1
I don't know	29.8%	182
Other (please specify)	2.0%	12

Of the 610 respondents who answered the question, approximately 30% did not know their MDS subtype at the time of diagnosis. The greatest percentage of respondents reported 2 subtypes:

- MDS-SLD with ring sideroblasts (MDS-RS) OR Refractory anemia with ringed sideroblasts (RARS) (16.0%)
- MDS with multilineage dysplasia (MDS-MLD) OR Refractory cytopenia with multilineage dysplasia (RCMD) (13.6%)

29.8%
Percent of respondents who DID NOT know their subtype at the time of diagnosis

The smallest percentage of respondents reported 2 subtypes at the time of their diagnosis:

- Secondary AML (0.5%)
- MDS with excess blasts (MDS-EB2) OR Refractory anemia with excess blasts – 2 (RAEB-2) (0.2%).

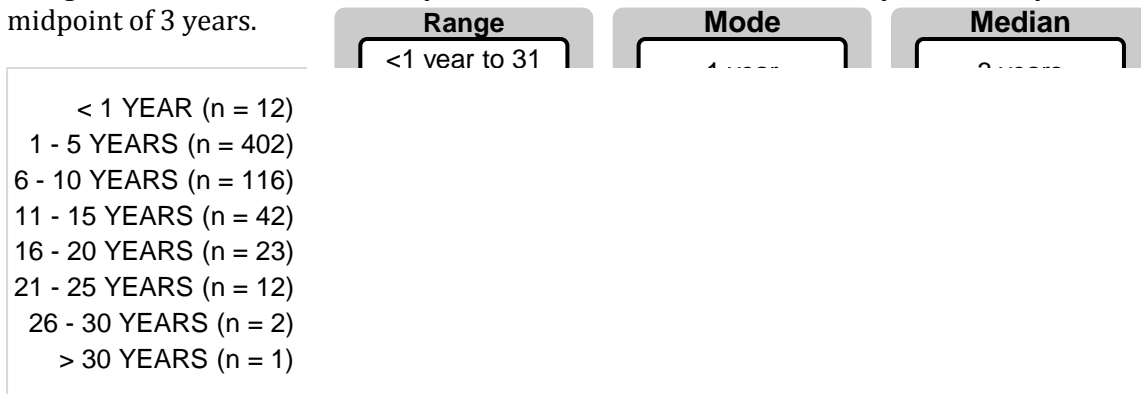
Of those who responded to the “Other (please specify)” option, none reported other actual MDS subtypes. The most relevant “Other” responses are below:

- C85.9 non-Hodgkin lymphoma
- Disorder in maturation of granulopoiesis 3-4% blasts
- Hypoplastic MDS
- Refractory cytopenia in childhood

Years Living with MDS (N = 610)

Respondents were asked “How many years have you been living with MDS?”

With a range of less than 1 year to 31 years, most (65.9%) respondents reported they had been living with MDS between 1 and 5 years. The most common number of years was 1 year, with a midpoint of 3 years.



Current Physical Symptoms (N = 610)

Respondents were asked “What physical symptoms attributed to MDS, if any, are you currently having?”

While 14.3% of respondents reported they were not currently experiencing any physical symptoms, the greatest percentage who was experiencing symptoms reported fatigue/tiredness (70.5%) and anemia (59.5%). While these are the same 2 symptoms the greatest percentage of respondents reported experiencing prior to their MDS diagnosis, the percentage of respondents reporting these symptoms increased. Similar to the physical symptoms experienced prior to MDS diagnosis, the smallest percentage of respondents reported currently experiencing ascites (1.3%).

70.5%
Percent of respondents who reported currently experiencing fatigue/tiredness

	Percent of Respondents	<i>n</i>
Fatigue/tiredness	70.5%	430
Anemia	59.5%	363
Weakness	39.3%	240
Shortness of breath/trouble breathing	36.1%	220
Joint or bone pain	35.6%	217
Easy or unusual bruising/bleeding	30.2%	184
Unusual paleness	20.0%	122
Loss of appetite	16.6%	101
Weight loss	14.3%	87
Headache	13.4%	82
Frequent infections	10.2%	62
Nausea/vomiting	8.7%	53
Fever	3.8%	23
Ascites	1.3%	8
Other (please specify)	11.0%	67
I am not having any physical symptoms	14.3%	87

Respondents reported a variety of “Other” physical symptoms attributed to MDS:

- Dizziness (*n* = 8)
- Skin issues (*n* = 9), including itchiness, blotchiness, petechiae, pins and needs, ulcers, and Sweet’s syndrome
- Cognitive issues (*n* = 4), including brain fog, memory issues, difficulty starting/completing tasks
- Blood cell count issues (*n* = 4)
- Graft-versus-host disease (*n* = 3)
- Enlarged spleen (*n* = 3)
- Swelling (*n* = 3) of feet, toes, and hands
- Sleep issues (*n* = 2) including excessive sleep and insomnia
- Gastric and kidney pain (*n* = 2)
- Eye issues (*n* = 2), including blurred vision, dryness, and inflammation
- Other isolated symptoms, including depression, trichotillomania, ankylosing spondylitis, degenerative bone disease, Grade 2 spondylolisthesis, pancreatic infection, instability when walking, a lingual fundus tumor, iron build up, heart palpitations/leakage in heart valves diarrhea, and mouth ulcers

Most Bothersome Physical Symptoms (N = 610)

Respondents were also asked “*What physical symptoms attributed to MDS, if any, are currently most bothersome to you?*”

The top 2 most bothersome physical symptoms reported by respondents were fatigue/tiredness (62.2%) and anemia (36.6%).



	Percent of Respondents	<i>n</i>
Fatigue/tiredness	62.2%	379
Anemia	36.6%	223
Shortness of breath/trouble breathing	28.1%	171
Weakness	27.1%	165
Joint or bone pain	23.2%	141
Easy or unusual bruising/bleeding	16.1%	98
Dizziness	14.4%	88
Headache	8.4%	51
Loss of appetite	7.2%	44
Frequent infections	7.1%	43
Weight loss	6.2%	38
Unusual paleness	5.4%	33
Nausea/vomiting	5.3%	32
Fever	2.1%	13
Ascites	0.5%	3
I am not having any physical symptoms	14.1%	86
Other (please specify)	9.0%	55

Respondents reported a variety of “Other” bothersome physical symptoms:

- Skin issues (*n* = 7), including blotchiness, edema, itching, petechiae, pins and needs, skin outbreaks that do not heal, and skin ulcers
- Cognitive issues (*n* = 6), including brain fog, depression, memory loss, mental problems/anxiety, and poor concentration
- Blood issues (*n* = 5), including low blood counts, low platelets, and platelet dysfunction
- Pain (*n* = 4), including gastric pain, bone pain, and stomach pain from injecting
- Sleep issues (*n* = 3), including excessive sleep, fatigue, and insomnia
- Stool issues (*n* = 2), including diarrhea and unformed feces
- Graft-versus-host disease (*n* = 2)
- Breathlessness (*n* = 2)
- Other isolated symptoms, such as dizziness, eye issues, tachycardia, infections/mouth ulcers, muscle spasms, enlarged spleen, loss of libido, swollen feet, and blurred vision

Most Recent Risk Level/Category and Subtype (N = 610)

Respondents were asked “*If known, what is your most recent IPSS or IPSS-R risk level/category?*”

While approximately one-third (34.0%) of respondents reported their most recent MDS IPSS/IPSS-R risk level was very low or low risk, 10.5% reported a high or very high risk level. These percentages are smaller than those respondents reported at the time of their diagnosis (55.5% reported a very low or low risk level and 18.9% reported a high or very high risk level at the time of their diagnosis).

10.5%
Percent of respondents whose most recent IPSS/IPSS-R risk level was HIGH or VERY HIGH

	Percent of Respondents	n
IPSS Score		
IPSS score: Low-risk MDS	22.8%	139
IPSS score: Intermediate - 1	7.7%	47
IPSS score: Intermediate - 2	4.6%	28
IPSS score: High-risk MDS	4.1%	25
IPSS-R Score		
IPSS-R score: Very low-risk MDS	2.0%	12
IPSS-R score: Low-risk MDS	9.2%	56
IPSS-R score: Intermediate risk	4.3%	26
IPSS-R score: High-risk MDS	3.6%	22
IPSS-R score: Very high-risk MDS	2.8%	17
Other		
I was told, but do not remember	14.2%	87
I was never told	24.8%	151

Respondents were asked “*What MDS subtype do you have now?*”

Of the 610 respondents who answered the question, over one-third (34.9%) reported not knowing their current MDS subtype. The greatest percentage of respondents reported the same 2 subtypes reported at the time of diagnosis:

- MDS-SLD with ring sideroblasts (MDS-RS) OR Refractory anemia with ringed sideroblasts (RARS) (14.3%)
- MDS with multilineage dysplasia (MDS-MLD) OR Refractory cytopenia with multilineage dysplasia (12.6%)

34.9%
Percent of respondents who DID NOT know their current subtype

	Percent of Respondents	n
MDS-SLD with ring sideroblasts (MDS-RS) OR Refractory anemia with ringed sideroblasts (RARS)	14.3%	87
MDS with multilineage dysplasia (MDS-MLD) OR Refractory cytopenia with multilineage dysplasia (RCMD)	12.6%	77
MDS with isolated del(5q)	8.4%	51
MDS with single lineage dysplasia (MDS-SLD) OR Refractory cytopenia with unilineage dysplasia (RCUD)	4.1%	25
Chronic myelomonocytic leukemia (CMML)	3.9%	24
MDS with excess blasts (MDS-EB1) OR Refractory anemia with excess blasts-1 (RAEB-1)	3.9%	24
MDS, unclassifiable (MDS-U)	3.8%	23
MDS with excess blasts (MDS-EB2) OR Refractory anemia with excess blasts-2 (RAEB-2)	3.0%	18
Secondary AML	2.8%	17
MDS with thrombocytosis (MDS/MPN crossover)	1.8%	11
MDS with multilineage dysplasia (MDS-MLD) OR Refractory cytopenia with multilineage dysplasia (RCMD)	0.2%	1
I don't know	34.9%	213
Other (please specify)	6.4%	39

The smallest percentage of respondents reported 2 subtypes, which differed from the subtypes reported when first diagnosed.

- MDS with thrombocytosis (MDS/MPN crossover) (1.8%)
- MDS with multilineage dysplasia (MDS-MLD) OR Refractory cytopenia with multilineage dysplasia (RCMD) (0.2%)

Of the 39 respondents who did not identify a subtype from the provided list, 48.7% ($n = 19$) reported they were in remission. Other relevant responses are below.

>1 applicable subtype

- MDS RAEB (D.46.7)
- MDS-EBS plus myelofibrosis
- Mixed types

Other

- C85.9G lymphoma
- Hypoplastic MDS
- Refractory cytopenia in childhood t-MDS

Other Medical Conditions (N = 610)

Respondents were asked “*What other medical conditions, if any, do you have besides MDS?* (Select all that apply). If you do not have any other medical conditions, please only select “I don’t have any other medical conditions.”

Over one-third of respondents (38.9%) reported not having any other medical conditions. Of the listed medical conditions, the greatest percentage of respondents reported having arthritis (23.1%), and the smallest percentage reported having hepatic disease (2.8%).

24.9%
Percent of respondents who reported having other cancers or medical conditions in addition to MDS

	Percent of Respondents	<i>n</i>
I don't have any other medical conditions	38.9%	237
Other cancers or medical conditions (please specify)	24.3%	148
Arthritis	23.1%	141
Heart disease	14.8%	90
Diabetes	12.5%	76
Autoimmune disease	9.5%	58
Pulmonary (lung) disease	6.4%	39
Renal (kidney) disease	5.7%	35
Hepatic (liver) disease	2.8%	17

Respondents reported having one or more cancers or medical conditions:

	<i>n</i> ⁶	<i>n</i>
Other Cancers	39	
• Breast cancer	13	• Cervical cancer 1
• Prostate cancer	8	• Double-hit lymphoma 1
• Skin cancer	6	• Liver cancer 1
• Multiple Myeloma	3	• Oral cancer 1
• Lung cancer	2	• Glandular prostate cancer 1
• Pancreatic cancer	1	• Thyroid cancer 1

⁶ Two respondents reported having other cancers or medical conditions but did not specify cancer/condition.

	<i>n</i>		<i>n</i>
Other Medical Conditions	11	Other Medical Conditions	
	1		
• High blood pressure/hypertension	12	• Endometriosis	1
• Hypothyroidism/hyperthyroidism	9	• Enlarged ascending aorta	1
• Osteoporosis/osteopenia	9	• Enlarged spleen	1
• Atrial fibrillation (AFIB)	6	• Erythropoietic protoporphyria	1
• Glaucoma	4	• Eventration following hemorrhage	1
• Graft-versus-host disease	4	• Flexibility (loss of)	1
• Fibromyalgia	3	• Gout	1
• Herpes zoster	3	• Growth hormone deficiency	1
• Irritable bowel syndrome	3	• Hepatitis B	1
• Sleep apnea	3	• Hip and knee surgeries and aches	1
• Pacemaker	2	• HIV/Aids	1
• Paroxysmal nocturnal hemoglobinuria	2	• Hyperlipidemia	1
• Polyps (bladder, colon)	2	• Increased risk of blood clots	1
• Restless leg syndrome	2	• Insomnia	1
• Addison's disease	1	• Iron overload	1
• Amyloidosis	1	• Lung nodules	1
• Aortic dissection	1	• Lupus	1
• Benign prostatic hyperplasia	1	• Monoclonal gammopathy of unknown significance	1
• Benign tumor behind eye	1	• Multifocal motor neuropathy	1
• Bone degeneration of spine	1	• Multiple endocrine neoplasia Type 1	1
• Cerebral ischemia	1	• Myelofibrosis	1
• Chronic progressive external ophthalmoplegia	1	• Parkinson's disease	1
• CIN2 (abnormal cervical cells)	1	• Peripheral artery/vascular disease	1
• Colostomy	1	• Pulmonary veno-occlusive disease	1
• COVID (Long term complications)	1	• Spinal stenosis	1
• Degenerative disk disease	1	• Stroke	1
• Depression	1	• Trigeminal neuralgia	1
• Displacement of lumbar vertebra	1	• Urinary incontinence	1
• Dizziness	1	• Vascular disease	1
• Down syndrome	1	• Vertigo (Benign paroxysmal positional)	1
• Edema	1		

Treatments Received

What treatments have individuals living with MDS received?

Section 2B of the *MDS Global Survey* included 3 questions to better understand the treatments individuals living with MDS may have received for their MDS. The results presented below must be interpreted with caution as not all available MDS treatments are accessible in all regions and

countries.

Treatments Received Since Being Diagnosed with MDS (N = 610)

Respondents were asked “Which of the following treatments, if any, have you received since being diagnosed with MDS?” If you have not received any of the following treatments, please only select “I have not had any of the above treatments.”

20.5%
Percent of respondents who reported not receiving any of the provided treatments since being diagnosed with MDS

The treatments respondents reported receiving are displayed below, categorized following completion of data analysis. While 20.5% of respondents reported not receiving any of the listed treatments, the categories of treatment received by the greatest percentage of respondents were blood transfusion (52.6%) and erythropoiesis-stimulating agents (45.6%).

Category (Treatment)	Percent of Respondents	<i>n</i>
Blood transfusions	52.6%	321
• Blood transfusion	52.6%	321
Erythropoiesis-stimulating agents	45.6%	278
• Epoetin (for example, Epogen, Procrit, Binocrit)	25.1%	153
• Darbepoetin alfa (for example, Aranesp)	13.8%	84
• Luspatercept (for example, Reblozyl)	6.7%	41
HMAs (Hypomethylating agents)	30.0%	183
• Azacitidine (oral or injectable)	22.1%	135
• Decitabine (Dacogen)	7.9%	48
Lenalidomide	11.0%	67
• Lenalidomide (Revlimid)	11.0%	67
G-CSF Drug Types	10.2%	62
• Granulocyte colony-stimulating factor (G-CSF; for example, filgrastim [Neupogen])	10.2%	62
Chemotherapies	4.2%	26
• Cytarabine (Ara-C) + daunorubicin	0.8%	5
• Cytarabine (Ara-C)	1.3%	8
• Decitabine & Cedazuridine (INQOVI)	2.1%	13
Other	14%	85
• Cyclosporine	6.1%	37
• Anti-thymocyte globulin (ATG)	2.8%	17
• Eltrombopag (for example, Promacta)	1.5%	9
• Pegfilgrastim (for example, Neulasta)	1.1%	7
• Romiplostim (for example, Nplate)	0.8%	5

• Granulocyte macrophage-colony stimulating factor (GM-CSF; Sargramostim or Leukine)	1.3%	8
• Alemtuzumab (Lemtrada)	0.2%	1
• Oprelvekin (IL-11; Neumega)	0.2%	1
None of the above	20.5%	125
• I have not had any of the above treatments	20.5%	125
I don't know	4.1%	25
• I don't know	4.1%	25
Other	13.6%	83
• Other (please specify)	13.6%	83

The “other” treatments reported by 83 respondents are below, again in categories identified after completing data analysis. Some respondents reported chemotherapies and erythropoiesis-stimulating agents -- that when combined with the results in the table above -- reveal that 6.9% ($n = 42$) reported receiving chemotherapy treatments and 46% ($n = 282$) reported receiving erythropoiesis-stimulating agent treatment since being diagnosed with MDS.

<p>Chemotherapies ($n = 16$)</p> <ul style="list-style-type: none"> • Busulfan and fludarabine ($n = 1$) • Fludarabine, amsacrine, and hydroxyurea ($n = 1$) • Fludarabine and busulfan ($n = 1$) • Multi-agent chemotherapy ($n = 1$) • Pevonedistat ($n = 1$) • Venetoclax ($n = 11$) <p>Targeted anti-cancer agents ($n = 8$)</p> <ul style="list-style-type: none"> • Fedratinib ($n = 1$) • Ivosidenib ($n = 1$) • Jakafi ($n = 3$) • Ruxolitinib ($n = 1$) • Tagraxofusp ($n = 1$) • Tibsovo ($n = 1$) <p>Antibody therapies ($n = 2$)</p> <ul style="list-style-type: none"> • Infliximab and rituximab ($n = 1$) • Ultomiris ($n = 1$) <p>Immunosuppressants ($n = 7$)</p> <ul style="list-style-type: none"> • Corticoids $n = 1$ • Cortisone ($n = 2$) • Patch/pump ($n = 1$) • Prednisone ($n = 3$) <p>Stem cell treatments ($n = 21$)</p> <ul style="list-style-type: none"> • Stem cell hormone ($n = 2$) • Stem cell transplantation ($n = 19$) <p>Erythropoiesis-stimulating agents ($n = 4$)</p> <ul style="list-style-type: none"> • Roxadustat ($n = 3$) • Sotatercept ($n = 1$) 	<p>Androgens ($n = 2$)</p> <ul style="list-style-type: none"> • Danazol ($n = 2$) <p>ECP ($n = 1$)</p> <ul style="list-style-type: none"> • Extracorporeal photopheresis ($n = 1$) <p>Iron overload treatments ($n = 7$)</p> <ul style="list-style-type: none"> • Deferasirox ($n = 4$) • Desferrioxamine ($n = 1$) • Exjade ($n = 1$) • Ferriprox ($n = 1$) <p>Other supportive care ($n = 5$)</p> <ul style="list-style-type: none"> • Antibiotics, broad spectrum, and others ($n = 1$) • B12 injections ($n = 1$) • Gamma globulin infusions ($n = 1$) • Iron ($n = 2$) <p>Clinical trials ($n = 2$)</p> <ul style="list-style-type: none"> • Clinical trial ($n = 2$) <p>Infusions ($n = 2$)</p> <ul style="list-style-type: none"> • Type unknown ($n = 2$) <p>Unrelated treatments ($n = 4$)</p> <ul style="list-style-type: none"> • Accutane ($n = 1$) • Blood Chromium ($n = 1$) • Treatment for myasthenia gravis and thymoma cancer ($n = 1$) • Zelitrex ($n = 1$)
--	--

Bone Marrow (Stem Cell) Transplant Treatments Received (N = 610)

Respondents were asked “Which of the following bone marrow (stem cell) transplant treatments, if any, have you received since being diagnosed with MDS?” (Select all that apply). If you have not received any of the following treatments, please only select “I have not had any of the above treatments.”

While most respondents (81.4%) reported not having had any bone marrow transplant treatments, of those listed, the most reported was an allogeneic donor stem cell transplant (14.6%).

	Percent of Respondents	n
I have not had bone marrow transplant treatments	81.8%	499
Donor stem cell transplant (allogeneic)	14.6%	89
My own cells stem cell transplant (autologous)	0.2%	1
Other (please specify)	0.8%	5
I don't know	3.0%	18

“Other” bone marrow transplant treatments respondents reported receiving were:

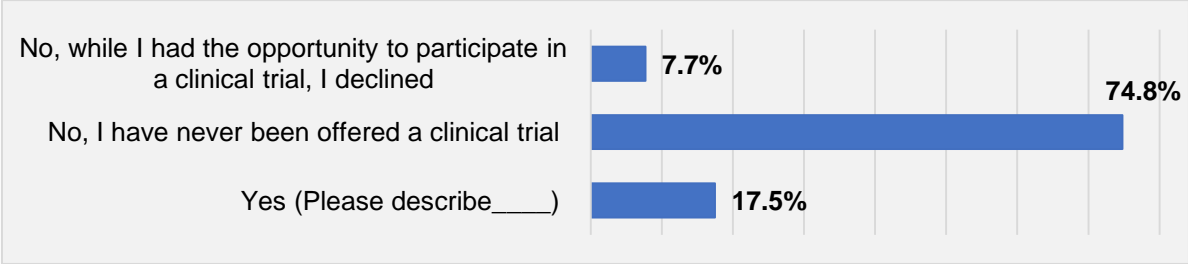
- Azacitidine (Vidaza) (n = 1)
- Donor lymphocyte infusion (DLI) (n = 1)
- Allogeneic stem cell transplant (scheduled for the future) (n = 2)
- BMT allogeneic for ALL, but not MDS, which is forthcoming (n = 1)

Participation in Clinical Trials (N = 610)

Respondents were also asked, “Have you participated in any clinical trials?”

While 82.5% of respondents reported they have not participated in a clinical trial, over three-quarters (74.8%) reported they had never been offered a clinical trial.

74.8%
Percent of respondents reporting they have NEVER been offered a clinical trial



Respondents reported participating in numerous other clinical trials and studies:

Anti-cancer agent trial	6	Thrombopoiesis-stimulating agent trial	2
• Pevonedistat	1	• Eltrombopag	1
• Vidaza and pracinostat	1	• Romiplostim	1
• IDHIFA	1	Vitamin C supplementation	3
• Jakafi	2	• EVI-3	1
• Tagraxofusp	1	• Vitamin C	1
		• Vitamin C in LR-MDS	1

Chemotherapy trial	5	COVID-19 related	5
• CPX-351 for remission	1	• COVID vaccine trial for blood cancer patients by LLS	1
• Dosage chemotherapy	3	• COVID-19 vaccine for post-HSCT	1
• Medication dosing	1	• Efficacy of covid 19 immunizations in HSCT patients	1
CAR T-cell trial	1	• For COVID	1
• Virus specific t-cell therapy	1	• C-SMART trial for covid prevention, post-transplant	1
Monoclonal antibody trial	2	Exercise, sport, and mind-body studies	4
• Alemtuzumab	1	• Sport/MDS register	1
• Azacitidine with placebo/sabatolimab	1	• Sports programme in SCT	1
Antivirals trial	1	• Sport, psycho-oncological studies	1
• Letermovir	1	• Sport in MDS	1
Fusion proteins	1	Other (insufficient details)	3
• Della porta	1	• NHLBI-MDS: Collection of samples for study	1
Lenalidomide trial	7	• Post-transplant regimen	1
• Azacitidine	1	• Shared care (Dana Farber)	1
• Lenalidomide	3	Trial halted	1
• Revlimid	1	• Was referred but due to COVID study was closed	1
• Revlimid	1	Excluded from trial	2
• SINTRA study	1	• Luspatercept but refused because of Gilbert illness	1
HMA trial	9	• Just the paperwork	1
• Black raspberry powder	1	Unrelated responses	7
• Enhance	1	• BK virus	1
• Jakafi	1	• Breast cancer clinical trial	1
• Luspatercept	1	• Charm study	1
• Oral decitabine	1	• Chase Clinical Trial	1
• Venetoclax	1	• CKD study	1
• Vidaza	3	• Esthemax transplant	1
Erythropoiesis-stimulating agent trial	17	• PPMI, a trial involving Parkinson's disease	1
• Epoetin	1	Unknown/Don't remember	37
• Exjade	2		
• Fibrogen sponsored trial	1		
• Luspatercept	6		
• Medalist trial	1		
• Oral decitabine	1		
• Aranesp	1		
• Roxadustat	3		
• Sotatercept	1		

Support Received

What perspectives do individuals living with MDS have regarding support they are receiving?

Section 2C of the *MDS Global Survey* included 7 final questions to better understand the support individuals living with MDS might be receiving for their MDS.

Help from Paid/Unpaid Caregiver (N = 610)

Respondents were asked “*In the past year, did you receive any regular help from any paid or unpaid caregiver because of your MDS?*”

Approximately three-quarters of respondents (73.0%) reported **not** receiving regular help from any paid or unpaid caregiver because of their MDS.



The respondents who reported they were receiving help were asked 2 questions:

- “Which of the following best describes the caregiver(s) who provided the help?”
- “What type of support did you receive from your caregiver(s)?”

Of those receiving regular help ($N = 142$), the greatest percent of respondents reported receiving help from a spouse (69.0%) or family member (37.3%), such as a parent, child, sibling, or cousin.

	Percent of Respondents	<i>n</i>
Spouse	69.0%	98
Family member (parent, child, sibling, cousin, etc.)	37.3%	53
Licensed/paid caregiver	12.7%	18
Friend	7.0%	10
Significant other	4.2%	6
Neighbor	3.5%	5
Other (Please specify)	4.9%	7

Respondents also reported receiving help from “Other” isolated sources:

- Cancer aid
- Housekeeper
- Nurse for injections
- Psychologist
- Registered dietitian nutritionists
- Red Cross
- *My Aged Care* (help available through Australian Government Department of Health)
- SA Pathology (an organization that provides diagnostic and clinical pathology services throughout South Australia)

The type of support the greatest percentage of respondents reported receiving from their caregivers was cooking/cleaning (74.1%), transportation (64.0%), shopping (63.3%), and care coordination (56.1%).

	Percent of Respondents	<i>n</i>
Cooking/cleaning	74.1%	103
Transportation	64.7%	90
Shopping	63.3%	88
Care coordination (e.g., medication/appointment management)	56.1%	78
Finances/home management	34.5%	48
Bathing/grooming/dressing	23.0%	32
Other (please specify)	12.9%	18

Respondents also reported one or more “Other” types of support, with the most commonly reported being psychological support (*n* = 11), such as companionship, emotional, mental, moral support and encouragement. Other isolated types of support included the following:

- Gardening
- Hooking up to IV
- Managing of health condition, treatments, talking to doctors, etc.
- Snow shoveling
- Therapy
- Dog walking

Perceived Adequacy of Social Support (N = 542)

The [Multidimensional Scale of Perceived Social Support](#) (Zimet et al., 1988) was included in Section 2C to better understand the perceived adequacy of social support from three sources (family, friends, and significant others). The instrument consists of 12 Likert-type items using a 7-point agreement scale (*1 = Very Strongly Disagree, 2 = Strongly Disagree, 3 = Mildly Disagree, 4 = Neutral, 5 = Mildly Agree, 6 = Strongly Agree, and 7 = Very Strongly Agree*).

Respondents were asked, “Please indicate the extent to which you agree with each of the following statements.”

A perceived adequacy of social support mean score was calculated for each statement. The average score for each item is displayed in the table below. The lowest rated items were related to perceived support from friends (Items 6, 7, 9, and 12). On average, respondents tended to *mildly agree* that their friends provided support.

	Mean (SD)
1. There is a special person who is around when I am in need	5.7 (1.8)
2. There is a special person with whom I can share my joys and sorrows	5.8 (1.7)
3. My family really tries to help me	5.8 (1.7)
4. I get the emotional help and support I need from my family	5.5 (1.8)
5. I have a special person who is a real source of comfort to me	5.6 (1.7)
6. My friends really try to help me	4.9 (1.6)
7. I can count on my friends when things go wrong	5.0 (1.7)
8. I can talk about my problems with my family	5.5 (1.7)
9. I have friends with whom I can share my joys and sorrows	5.0 (1.7)
10. There is a special person in my life who cares about my feelings	5.7 (1.8)
11. My family is willing to help me make decisions	5.6 (1.7)
12. I can talk about problems with my friends	5.0 (1.7)

Overall and Subscale Results

Following Zimet et al.'s (1988) scoring guidelines, responses to the 12 items were used to calculate an overall perceived support score, as well as scores for three subscales (a 4-item significant other subscale, a 4-item family subscale, and a 4-item friends' subscale). Mean scale scores were then calculated overall and for each subscale.

The mean perceived adequacy of social support scores, overall and for each subscale are below. Respondents perceived high social support from significant others and family (with a score range of 5.1 to 7) and moderate social support from friends (with a score range of 3 to 5).

Overall	Significant Other	Family	Friends
5.4	5.7	5.6	5.0
<i>High Social Support</i>	<i>High Social Support</i>	<i>High Social Support</i>	<i>Moderate Social Support</i>

Overall Health

What perspectives do individuals living with MDS have about their overall health?

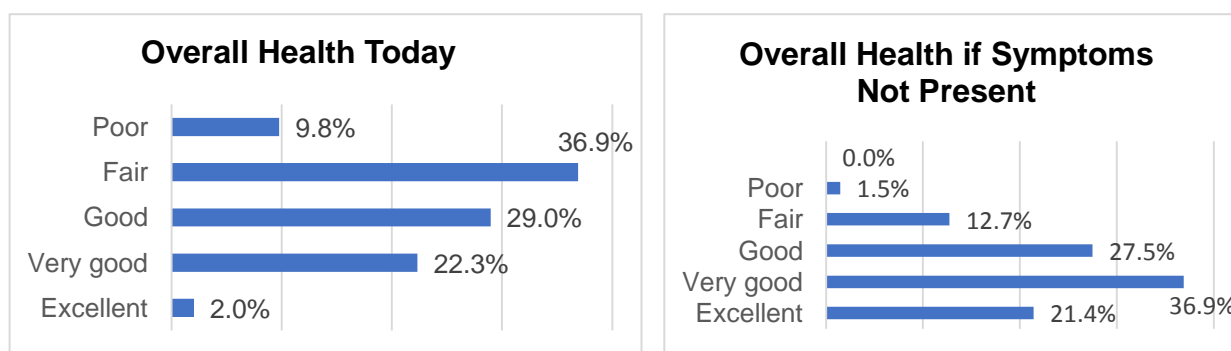
Section 3 of the *MDS Global Survey* included 3 questions to better understand the perspectives individuals living with MDS have about their overall health.

Overall Health Today and if MDS Symptoms Were Not Present (N = 542)

Respondents were asked two initial questions:

- “In general, how would you rate your overall health today?”
- “How would you rate your overall health if your MDS symptoms were not present?”

The greatest percentage of respondents (36.9%) reported their overall health today was *fair*; however, without their MDS symptoms, this same percentage (36.9%) reported their overall health would be *very good*. While fewer than 25% of respondents reported being in *very good* (22.3%) or *excellent* (2.0%) health today, over 58% reported they’d be in *very good* (36.9%) or



excellent (21.4%) health if it were not for their current MDS symptoms.

Based on respondent perspectives, overall health would be greatly improved if their symptoms were not present.

OVERALL HEALTH TODAY

53.3%

of respondents rated their overall health today as **Good, Very good, or Excellent.**

OVERALL HEALTH IF NO SYMPTOMS PRESENT

85.8%

of respondents rated their overall health, if no symptoms were present, as **Good, Very good, or Excellent.**

Overall Health by Access to Health Insurance, Educational Level, and Total Household Income

Additional analyses were conducted to determine if perceptions about overall health were related to (a) access to health insurance, (b) educational level, and (c) total household income.

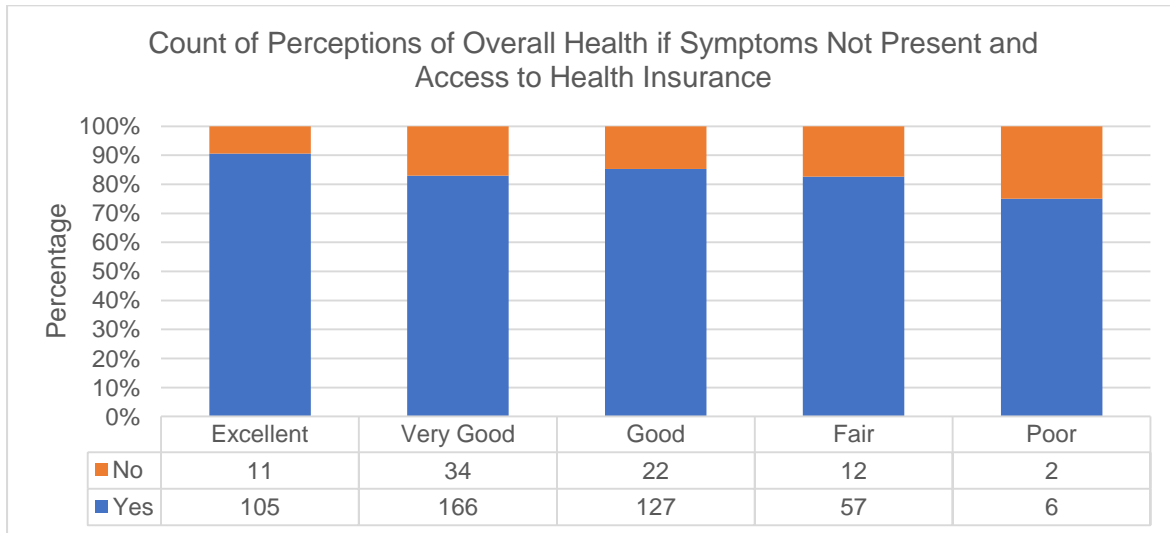
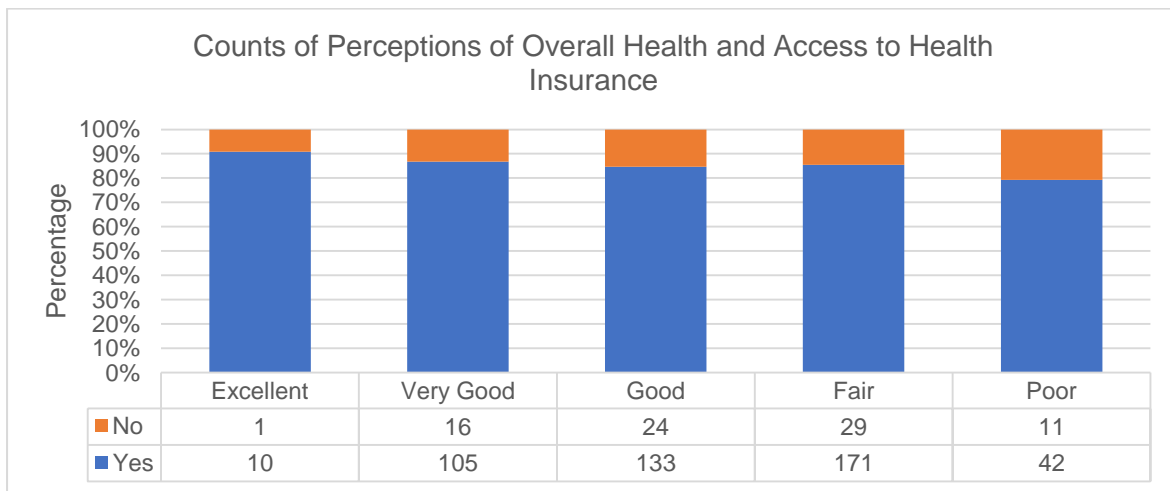
Access to Health Insurance

The table and charts below display how respondents rated their overall health for those who reported having (“Yes”) and not having (“No”) health insurance. As shown in the table, a greater percentage of respondents without health insurance (13.6%) than with health insurance (9.1%) reported being in *poor* overall health today. A greater percentage of respondents with health insurance (22.8%) than without health insurance (13.6%) reported their overall health would be *excellent* if their MDS symptoms were not present.

Two Mann-Whitney U tests ($N = 542$) were performed to determine whether there was a statistically significant difference in perceptions of overall health today and perceptions of

health if MDS symptoms were not present between those *with* and *without* health insurance. The results indicated a non-significant difference between both groups [$U = 17468.5, p = .333; U = 16978.5, p = .174$].

	Overall Health Today				Overall Health if Symptoms Not Present			
	Yes		No		Yes		No	
	%	<i>N</i>	%	<i>N</i>	%	<i>n</i>	%	<i>n</i>
Excellent	2.2%	10	1.2%	1	22.8%	105	13.6%	11
Very good	22.8%	105	19.8%	16	36.0%	166	42.0%	34
Good	28.9%	133	29.6%	24	27.5%	127	27.2%	22
Fair	37.1%	171	35.8%	29	12.4%	57	14.8%	12
Poor	9.1%	42	13.6%	11	1.3%	6	2.5%	2
Total		461		81		461		81



Education Level

The tables below display respondent ratings of overall health today and their overall health if MDS symptoms were not present – by highest level of education completed. Two Spearman rank correlations ($N = 539$) were computed to assess the relationship between educational level and respondent health ratings. There was a very weak, positive correlation between education level and overall health today ($r(537) = .095, p = .027$), with no significant

correlation between education level and perceptions of health if MDS symptoms were not present ($r(537) = .056, p = .195$).

Education Level	Overall Health Today					Total
	Poor	Fair	Good	Very good	Excellent	
Preprimary education (kindergarten and below)	0 (0.0%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	1 (50.0%)	2
Primary education (1st-6th grade)	0 (0.0%)	1 (100%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1
Lower secondary education (7th-9th grade)	4 (20.0%)	10 (50.0%)	3 (15.0%)	3 (15.0%)	0 (0.0%)	20
Upper secondary education (10th-12th grade or first three years of vocational education)	9 (9.5%)	41 (43.2%)	22 (23.2%)	21 (22.1%)	2 (2.1%)	95
Higher education (community or junior college, or vocational technical institute (non-university) leading to an associate's degree)	14 (13.2%)	38 (35.8%)	34 (32.1%)	19 (17.9%)	1 (0.9%)	106
Higher education (university or other educational institution leading to a bachelor's degree)	15 (9.4%)	49 (30.8%)	52 (32.7%)	40 (25.2%)	3 (1.9%)	159
Higher education (university or professional institute leading to a master's or doctorate degree)	9 (5.8%)	60 (38.5%)	45 (28.8%)	38 (24.4%)	4 (2.6%)	156
I prefer not to say	2 (66.7%)	1 (33.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	3
Grand Total	53	200	157	121	11	542

Education Level	Overall Health if Symptoms Were Not Present					Total
	Poor	Fair	Good	Very good	Excellent	
Preprimary education (kindergarten and below)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (50.0%)	1 (50.0%)	2
Primary education (1st-6th grade)	0 (0.0%)	0 (0.0%)	1 (100%)	0 (0.0%)	0 (0.0%)	1
Lower secondary education (7th-9th grade)	0 (0.0%)	5 (25.0%)	5 (25.0%)	5 (25.0%)	5 (25.0%)	20
Upper secondary education (10th-12th grade or first three years of vocational education)	2 (2.1%)	15 (15.8%)	21 (22.1%)	38 (40.0%)	19 (20.0%)	95
Higher education (community or junior college, or vocational technical institute (non-university) leading to an associate's degree)	2 (1.9%)	12 (11.3%)	36 (34.0%)	37 (34.9%)	19 (17.9%)	106
Higher education (university or other educational institution leading to a bachelor's degree)	4 (2.5%)	17 (10.7%)	45 (28.3%)	60 (37.7%)	33 (20.8%)	159
Higher education (university or professional institute leading to a master's or doctorate degree)	0 (0.0%)	20 (12.8%)	39 (25.0%)	59 (37.8%)	38 (24.4%)	156
I prefer not to say	0 (0.0%)	0 (0.0%)	2 (66.7%)	0 (0.0%)	1 (33.3%)	3
Grand Total	8	69	149	200	116	542

Total Household Income

The table below displays how respondents rated their overall health today and their overall health if their MDS symptoms were not present – by total household income. Two Spearman rank correlations ($N = 420$) were computed to assess the relationship between income level and respondent ratings of health. There was a moderate positive correlation between *income*

and overall health today ($r(418) = .219, p < .001$), and between *income* and *health if symptoms were not present* ($r(418) = .226, p < .001$).

Overall Health Today						
Total Household Income	Poor	Fair	Good	Very good	Excellent	Total
Below €20,000 (Below \$23,800)	6 (10.3%)	28 (48.3%)	15 (25.9%)	9 (15.5%)	0 (0.0%)	58
€20,000 to €44,999 (\$23,800 to \$53,493)	17 (14.2%)	45 (37.55%)	35 (29.2%)	22 (18.3%)	1 (0.8%)	120
€45,000 to €69,999 (\$53,494 to \$83,208)	5 (6.7%)	28 (37.3%)	26 (34.7%)	14 (18.7%)	2 (2.7%)	75
€70,000 to €84,999 (\$83,209 to \$101,043)	3 (5.6%)	23 (42.6%)	15 (27.8%)	12 (22.2%)	1 (1.9%)	54
€85,000 to €99,999 (\$101,044 to \$118,882)	1 (3.1%)	14 (43.8%)	9 (28.1%)	8 (25.0%)	0 (0.0%)	32
€100,000 and above (\$118,883 and above)	4 (4.9%)	17 (21.0%)	27 (33.3%)	27 (33.3%)	6 (7.4%)	81
I prefer to not say	17 (13.9%)	45 (36.9%)	29 (23.8%)	30 (24.6%)	1 (0.8%)	122
Grand Total	53	200	157	121	11	542

Overall Health if Symptoms Were Not Present						
Total Household Income	Poor	Fair	Good	Very good	Excellent	Total
Below €20,000 (Below \$23,800)	2 (3.4%)	13 (22.4%)	20 (34.5%)	15 (25.9%)	8 (13.8%)	58
€20,000 to €44,999 (\$23,800 to \$53,493)	3 (2.5%)	21 (17.5%)	30 (25.0%)	42 (35.0%)	24 (20.0%)	120
€45,000 to €69,999 (\$53,494 to \$83,208)	1 (1.3%)	9 (12.0%)	17 (22.7%)	31 (41.3%)	17 (22.7%)	75
€70,000 to €84,999 (\$83,209 to \$101,043)	0 (0.0%)	4 (7.4%)	15 (27.8%)	24 (44.4%)	11 (20.4%)	54
€85,000 to €99,999 (\$101,044 to \$118,882)	0 (0.0%)	1 (3.1%)	13 (40.6%)	11 (34.4%)	7 (21.9%)	32
€100,000 and above (\$118,883 and above)	0 (0.0%)	3 (3.7%)	19 (23.5%)	30 (37.0%)	29 (35.8%)	81
I prefer to not say	2 (1.6%)	18 (14.8%)	35 (28.7%)	47 (38.5%)	20 (16.4%)	122
Grand Total	8	69	149	200	116	542

Physical, Emotional, Social, Spiritual, and Intellectual Health (N = 542)

Respondents were also asked “*In general, how would you rate the following today?*”

Overall, respondents reported feeling the most positive (*excellent* or *very good*) about their intellectual (49.6%) and spiritual (39.9%) health, and least positive (*poor*) about their physical health (9.8%), emotional (9.8%), and social (10.1%) health.

	Excellent	Very good	Good	Fair	Poor
Your physical health (e.g., keeping your body healthy now and in the future)	5.0% (n = 27)	20.8% (n = 113)	32.1% (n = 174)	32.3% (n = 175)	9.8% (n = 53)
Your emotional health (e.g., feeling positive an enthusiastic about your life)	9.2% (n = 50)	24.7% (n = 134)	29.7% (n = 161)	26.6% (n = 144)	9.8% (n = 53)

Your social health (e.g., having your social needs met)	10.5% (n = 57)	21.0% (n = 114)	32.5% (n = 176)	25.8% (n = 140)	10.1% (n = 55)
Your spiritual health (e.g., having purpose, value, and meaning in your life with or without organized religion)	15.5% (n = 84)	24.4% (n = 132)	31.2% (n = 169)	21.0% (n = 114)	7.9% (n = 43)
Your intellectual health (e.g., continuing to expand your knowledge and skills)	17.9% (n = 97)	31.7% (n = 172)	26.8% (n = 145)	18.5% (n = 100)	5.2% (n = 28)

Over 45% of respondents rated all five types of health as only **fair** or **good**.

PHYSICAL HEALTH

64.4%

of respondents rated their physical health as **Fair** or **Good**.

EMOTIONAL HEALTH

56.3%

of respondents rated their emotional health as **Fair** or **Good**.

SOCIAL HEALTH

58.3%

of respondents rated their social health as **Fair** or **Good**.

SPIRITUAL HEALTH

52.2%

of respondents rated their spiritual health as **Fair** or **Good**.

INTELLECTUAL HEALTH

45.3%

of respondents rated their intellectual health as **Fair** or **Good**.

Mental Health and Wellbeing

What perspectives do individuals living with MDS have about their mental health and wellbeing?

Section 4 of the *MDS Global Survey* included 3 questions to better understand the perspectives individuals living with MDS have about their mental health and wellbeing.

Overall Mental Health and Wellbeing (N = 542)

Respondents were asked “*In general, how would you rate your mental health and wellbeing....prior to your MDS diagnosis....at the time of your MDS diagnosis...currently?*”

A greater percentage of respondents were more positive about their mental health and wellbeing prior to their MDS diagnosis than after. A much greater percentage of respondents reported being in *excellent* or *very good* health prior to their diagnosis (68.1%) than at the time of their diagnosis (32.8%) and currently (30.2%).

	Excellent	Very good	Good	Fair	Poor	Don't know
....prior to your MDS diagnosis?	30.6% (n = 166)	37.5% (n = 203)	19.2% (n = 104)	10.7% (n = 58)	1.8% (n = 10)	0.2% (n = 1)
....at the time of your MDS diagnosis?	11.6% (n = 63)	21.2% (n = 115)	24.7% (n = 134)	20.1% (n = 109)	21.4% (n = 116)	0.9% (n = 5)
...currently?	9.2% (n = 50)	21.0% (n = 114)	26.2% (n = 142)	27.9% (n = 151)	14.2% (n = 77)	1.5% (n = 8)

PRIOR TO MDS DIAGNOSIS	AT TIME OF MDS DIAGNOSIS	CURRENTLY
68.1%	32.8%	30.2%
of respondents rated their mental health and wellbeing prior to their MDS diagnosis as Excellent or Very good .	of respondents rated their mental health and wellbeing at the time of their MDS diagnosis as Excellent or Very good .	of respondents rated their mental health and wellbeing currently as Excellent or Very good .

Overall Mental Health and Wellbeing by Access to Health Insurance, Educational Level, and Total Household Income

Additional analyses were conducted to determine if respondent perceptions about mental health and wellbeing were related to (a) access to health insurance, (b) education level, and (c) total household income.

Access to Health Insurance

The table below displays how respondent ratings of mental health and wellbeing compare between those without (“No”) and with (“Yes”) health insurance. Three Mann-Whitney U tests were performed to determine whether there was a statistically significant difference in perceptions of mental health and wellbeing (prior to MDS diagnosis, at time of MDS diagnosis, and current) between those with and without health insurance.

The results indicated a non-significant difference between those with and without health insurance:

- Prior to MDS diagnosis [$N = 541$, $U = 16655.5$, $p = .111$]
- At time of MDS diagnosis [$N = 537$, $U = 17899.5$, $p = .761$]
- Current [$N = 534$, $U = 17685.0$, $p = .815$]

		Access to Health Insurance	
		No	Yes
		Percent of Respondents	Percent of Respondents
Mental health and wellbeing prior to MDS diagnosis	Excellent	22.2% ($n = 18$)	32.1% ($n = 148$)
	Very good	42.0% ($n = 34$)	36.7% ($n = 169$)
	Good	19.8% ($n = 16$)	19.1% ($n = 88$)
	Fair	14.8% ($n = 12$)	10.0% ($n = 46$)
	Poor	1.2% ($n = 1$)	2.0% ($n = 9$)
	I don't know	0.0% ($n = 0$)	0.2% ($n = 1$)
		Percent of Respondents	Percent of Respondents
Mental health and wellbeing at the time of MDS diagnosis	Excellent	11.1% ($n = 9$)	11.7% ($n = 54$)
	Very good	19.8% ($n = 16$)	21.5% ($n = 99$)
	Good	23.5% ($n = 19$)	24.9% ($n = 115$)
	Fair	24.7% ($n = 20$)	19.3% ($n = 89$)
	Poor	19.8% ($n = 16$)	21.7% ($n = 100$)
	I don't know	1.2% ($n = 1$)	0.9% ($n = 4$)
		Percent of Respondents	Percent of Respondents
Mental health and wellbeing currently	Excellent	7.4% ($n = 6$)	9.5% ($n = 44$)
	Very good	27.2% ($n = 22$)	20.0% ($n = 92$)
	Good	22.2% ($n = 18$)	26.9% ($n = 124$)
	Fair	24.7% ($n = 20$)	28.4% ($n = 131$)
	Poor	16.0% ($n = 13$)	13.9% ($n = 64$)
	I don't know	2.5% ($n = 2$)	1.3% ($n = 6$)

Educational Level

The table below displays respondent ratings of mental health and wellbeing at three points in time (prior to their diagnosis, at the time of diagnosis, and currently) by highest level of education obtained. Three Spearman rank correlations were computed to assess the relationship between educational level and respondent ratings of health and wellbeing (prior to MDS diagnosis, at time of MDS diagnosis, and current).

There were weak, yet positive correlations between educational level and health and wellbeing prior to MDS diagnosis ($r(538) = .099$, $p = .022$), at time of diagnosis ($r(534) = .120$, $p = .005$), and currently ($r(531) = .088$, $p = .043$).

Educational Level							
	Pre-primary	Primary	Lower secondary	Upper secondary	Higher ed 1 ⁷	Higher ed 2	Higher ed 3
Mental health and wellbeing prior to MDS diagnosis							
	Percent (n)	Percent (n)	Percent (n)	Percent (n)	Percent (n)	Percent (n)	Percent (n)
Excellent	50.0% (1)	0.0% (0)	20.0% (4)	27.4% (26)	27.4% (29)	30.8% (49)	35.9% (56)
Very good	50.0% (1)	100.0% (1)	25.0% (5)	41.1% (39)	36.8% (39)	39.0% (62)	34.6% (54)
Good	0.0% (0)	0.0% (0)	10.0% (2)	16.8% (16)	22.6% (24)	18.9% (30)	20.5% (32)
Fair	0.0% (0)	0.0% (0)	40.0% (8)	11.6% (11)	13.2% (14)	9.4% (15)	6.4% (10)
Poor	0.0% (0)	0.0% (0)	0.5% (1)	3.2% (3)	0.0% (0)	1.9% (3)	1.9% (3)
Don't know	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.6% (1)
Mental health and wellbeing at the time of MDS diagnosis							
	Percent (n)	Percent (n)	Percent (n)	Percent (n)	Percent (n)	Percent (n)	Percent (n)
Excellent	50.0% (1)	0.0% (0)	10.0 (2)	7.4% (7)	11.3% (12)	9.4% (15)	16.7% (26)
Very good	0.0% (0)	0.0% (0)	15% (3)	16.8% (16)	18.9% (20)	24.5% (39)	23.7% (37)
Good	50.0% (1)	0.0% (0)	20.0% (4)	22.1% (21)	31.1% (33)	24.5% (39)	22.4% (35)
Fair	0.0% (0)	0.0% (0)	25.0% (5)	26.3% (25)	17.9% (19)	18.2% (29)	19.9% (31)
Poor	0.0% (0)	100.0% (1)	30.0% (6)	25.3% (24)	18.9% (20)	23.3% (37)	16.7% (26)
Don't know	0.0% (0)	0.0% (0)	0.0% (0)	2.1% (2)	1.9% (2)	0.0% (0)	0.6% (1)
Mental health and wellbeing currently							
	Percent (n)	Percent (n)	Percent (n)	Percent (n)	Percent (n)	Percent (n)	Percent (n)
Excellent	50.0% (1)	0.0% (0)	0.0% (0)	9.5% (9)	8.5% (9)	10.1% (16)	9.6% (15)
Very good	50.0% (1)	0.0% (0)	15.0% (3)	22.1% (21)	15.1% (16)	21.4% (34)	25.0% (39)
Good	0.0% (0)	0.0% (0)	20.0% (4)	18.9% (18)	28.3% (30)	33.3% (53)	23.7% (37)
Fair	0.0% (0)	100.0% (1)	35.0% (7)	35.8% (34)	25.5% (27)	23.9% (38)	27.6% (43)
Poor	0.0% (0)	0.0% (0)	30.0% (6)	12.6% (12)	18.9% (20)	11.3% (18)	12.2% (19)
Don't know	0.0% (0)	0.0% (0)	0.0% (0)	1.1% (1)	3.8% (4)	0.0% (0)	1.9% (3)

Total Household Income

The table below displays respondent ratings of mental health and wellbeing at three points in time (prior to their diagnosis, at the time of diagnosis, and currently) by total household income. Three Spearman rank correlations were computed to assess the relationship between total household income and respondent ratings of health and wellbeing (prior to MDS diagnosis, at time of MDS diagnosis, and current).

There were moderate positive correlations between total household income and health and wellbeing prior to MDS diagnosis ($r(420) = .258, p < .001$), at time of diagnosis ($r(417) = .201, p < .001$), and currently ($r(415) = .228, p < .001$).

⁷ Higher ed 1 = associate's/vocational degree; Higher ed 2 = bachelor's degree; Higher ed 3 = master's/doctoral degree.

Total Household Income						
	Below €20,000 (Below \$23,800)	€20,000 to €44,999 (\$23,800 to \$53,493)	€45,000 to €69,999 (\$53,494 to \$83,208)	€70,000 to €84,999 (\$83,209 to \$101,043)	€85,000 to €99,999 (\$101,044 to \$118,882)	€100,000 and above (\$118,883 and above)
Mental health and wellbeing prior to MDS diagnosis						
	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)
Excellent	19.0% (11)	30.8% (37)	26.7% (20)	25.9% (14)	37.5% (12)	49.4% (40)
Very good	27.6% (16)	31.7% (38)	46.7% (35)	51.9% (28)	31.3% (10)	35.8% (29)
Good	24.1% (14)	21.7% (26)	16.0% (12)	14.8% (8)	25.0% (8)	13.6% (11)
Fair	25.9% (15)	13.3% (16)	8.0% (6)	7.4% (4)	6.3% (2)	1.2% (1)
Poor	3.4% (2)	2.5% (3)	2.7% (2)	0.0% (0)	0.0% (0)	0.0% (0)
Don't know	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Mental health and wellbeing at the time of MDS diagnosis						
	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)
Excellent	6.9% (4)	12.5% (15)	9.3% (7)	11.1% (6)	9.4% (3)	17.3% (14)
Very good	15.5% (9)	14.2% (17)	17.3% (13)	25.9% (14)	21.9% (7)	29.6% (24)
Good	22.4% (13)	20.0% (24)	32.0% (24)	22.2% (12)	31.3 (10)	24.7% (20)
Fair	22.4% (13)	24.2% (29)	21.3% (16)	24.1% (13)	18.8% (6)	14.8% (12)
Poor	31.0 (18)	29.2% (35)	18.7% (14)	14.8% (8)	18.8% (6)	13.6% (11)
Don't know	1.7% (1)	0.0% (0)	1.3% (1)	1.9% (1)	0.0% (0)	0.0% (0)
Mental health and wellbeing currently						
	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)	Percent (<i>n</i>)
Excellent	6.9% (4)	8.3% (10)	9.3% (7)	7.4% (4)	9.4% (3)	16.0% (13)
Very good	12.1% (7)	13.3% (16)	22.7% (17)	18.5% (10)	9.4% (3)	35.8% (29)
Good	20.7% (12)	30.0% (36)	22.7% (17)	35.2% (19)	34.4% (11)	21.0% (17)
Fair	32.8% (19)	32.5% (39)	28.0% (21)	29.6% (16)	28.1% (9)	22.2% (18)
Poor	27.6% (16)	14.2% (17)	16.0% (12)	7.4% (4)	15.6% (5)	4.9% (4)
Don't know	0.0% (0)	1.7% (2)	1.3% (1)	1.9% (1)	3.1% (1)	0.0% (0)

Referrals to a Counselor/Psychologist or Support Group (N = 542)

Respondents were asked "At the time of your MDS diagnosis, were you referred to a counselor/psychologist or support group?"

Most respondents (84.3%) reported they were not referred to a counselor/psychologist or support group at the time of their diagnosis.



Mental Health and Wellbeing Support (N = 542)

Finally, respondents were asked “*How frequently did you/do you rely on counselors, psychologists, or group therapy for your mental health and wellbeing...*”

Most respondents reported never relying on counselors, psychologists, or group therapy for their mental health and wellbeing – prior to their diagnosis (93.7%), at the time of their diagnosis (84.5%), and currently (85.4%). However, at the time of their MDS diagnosis, the percentage of respondents relying on these groups increased over 5%.

	Never	Weekly	Monthly
...prior to your MDS diagnosis?	93.7% (<i>n</i> = 508)	1.3% (<i>n</i> = 7)	5.0% (<i>n</i> = 27)
...at the time of your MDS diagnosis?	84.5% (<i>n</i> = 458)	4.6% (<i>n</i> = 25)	10.9% (<i>n</i> = 59)
...currently?	85.4% (<i>n</i> = 463)	3.1% (<i>n</i> = 17)	11.4% (<i>n</i> = 62)

Quality of Life

What perspectives do individuals living with MDS have about their quality of life?

Section 5 of the *MDS Global Survey* included [The QUALMS](#), a widely used instrument designed to measure MDS-specific quality of life. Consisting of 38 Likert-type items, respondents indicated how often, during the past week, they had specific feelings and experiences using the following scale: *Never, Rarely, Sometimes, Often, Always*.

Always.

Following Dana-Farber Cancer Institute (2013) scoring guidelines, responses to the first 33 items were used to calculate a total quality of life score, as well as scores for 3 sub-scales (a 14-item physical burden scale, a 3-item benefit-finding scale, and an 11-item emotional burden scale).

Prior to analysis, responses to all items were re-coded by assigning numerical values corresponding to the 5 response options: *Never* (100), *Rarely* (75), *Sometimes* (50), *Often* (25), *Always* (0), with 4 items being reversed scored. Final quality of life scores could range from 0 to 100, with higher scores representing better MDS-related quality of life.

Item-Level Results (N = 542)

Respondents were asked, “During the past week, how often....” The average quality of life score and standard deviation for each of the 33 items is displayed in the table below.

	Mean (SD)
1. ...did you feel as though there was a lack of clear information about your disease?	58.6 (29.6)
2. ...have you felt there was limited emotional support available for patients with MDS beyond their families?	53.6 (31.5)
3. ...did you feel as though you couldn't do anything about your disease?	40.0 (30.8)
4. ...did you feel the course of your disease was unpredictable?	34.0 (30.8)
5. ...did you have difficulty explaining MDS to your friends or family?	51.6 (31.7)
6. ...did you have trouble concentrating?	53.3 (28.3)
7. ...have you considered changing long-term plans due to health concerns?	46.7 (32.1)
8. ...have you experienced shortness of breath?	52.5 (30.5)
9. ...did low energy levels cause you to change your schedule?	45.9 (30.7)
10. ...did you feel as though your life was organized around medical appointments?	42.5 (31.7)
11. ...have you felt a sense of hopelessness?	58.2 (29.6)
12. ...have you been worried about getting an infection?	47.8 (29.7)
13. ...have you had sufficient energy for routine tasks?	56.4 (27.0)
14. ...were you afraid of dying?	58.6 (30.4)
15. ...did you feel angry about your diagnosis?	62.2 (32.2)
16. ...were you worried about bleeding?	65.7 (31.6)
17. ...did you feel a sense of gratitude for a part of life that you took for granted before?	60.7 (28.6)
18. ...did you feel nauseated?	73.6 (28.9)
19. ...did you worry about your MDS progressing or developing into leukemia?	42.3 (29.6)
20. ...did you take into account that you might be fatigued when planning your activities?	39.5 (30.5)
21. ...were you concerned that your MDS caused a financial burden for you or your family?	64.9 (33.5)
22. ...did you feel your family relationships were strained by your disease?	68.7 (30.7)
23. ...have you felt weak?	44.1 (29.5)
24. ...have you been too tired to take on the responsibilities you used to have?	48.0 (31.0)
25. ...did you worry about becoming a burden to your friends or family?	51.4 (31.6)
26. ...were you unable to participate in activities you are used to doing?	45.9 (31.5)
27. ...have you felt anxious about test or lab results?	47.6 (30.3)
28. ...did you avoid crowds because of fear of getting an infection?	38.1 (34.0)
29. ...did you find yourself grateful for tomorrow?	67.3 (29.1)

30. ...did you feel you were able to find quality information about MDS treatments?	59.6 (28.1)
31. ...were you concerned about bruising?	63.2 (32.0)
32. ...did you feel as though there were a lack of concrete answers about what will happen with your MDS?	41.6 (30.1)
33. ...did you experience a change in bowel habits?	57.6 (32.0)

Overall and Sub-Scale Results (N = 542)

MDS-related quality of life scores, overall and for each of the 3 sub-scales were calculated using the Dana-Farber Cancer Institute (2013) scoring guidelines:

- **Overall:** Calculated by averaging scores on items 1-33, with a potential range from 0–100, with higher scores meaning better quality of life
- **Physical Burden Scale:** Calculated by averaging scores on items 6, 7, 8, 9, 10, 11, 13(R), 18, 20, 23, 24, 25, 26, and 33
- **Benefit-Finding Scale:** Calculated by averaging scores on items 17, 29, and 30 (all reverse-scored)
- **Emotional Burden Scale:** Calculated by averaging scores on items 1, 2, 3, 4, 5, 12, 14, 15, 19, 27, and 32

The mean MDS-related quality of life scores, overall and for each of the three sub-scales are below.

	OVERALL	PHYSICAL BURDEN	BENEFIT FINDING	EMOTIONAL BURDEN
Mean	52.8	51.1	62.5	48.9
Range	10.6 – 96.2	3.57 – 100.0	0.0 – 100.0	0.0 – 100.0
Std dev.	15.9	20.0	20.9	19.9

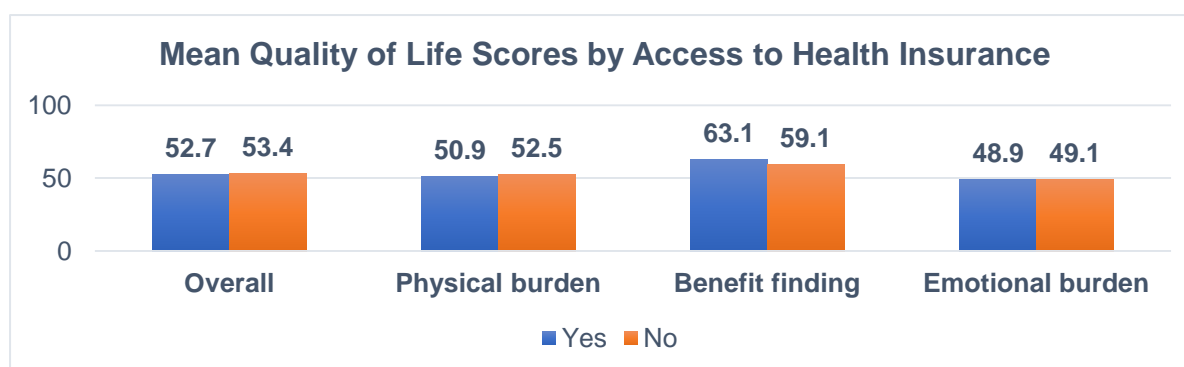
Respondents reported the highest MDS-related quality of life for *Benefit Finding* and the lowest MDS-related quality of life for *Emotional Burden*.

Quality of Life by Access to Health Insurance, Educational Level, and Total Household Income

Additional analyses were conducted to determine if respondent perceptions about their quality of life differed by (a) access to health insurance, (b) educational, and (c) total household income.

Access to Health Insurance

The chart below displays the mean quality of life scores (overall and for each sub-scale) for those who reported having (“Yes”) and not having (“No”) health insurance. Respondents with health insurance had a slightly higher benefit finding quality of life score (63.1) than those without health insurance (59.1). Independent samples t-tests revealed no statistically significant differences in mean quality of life scores (overall and for each sub-scale) between



those who reported having and not having health insurance.

Educational Level

The chart below displays the mean quality of life scores (overall and for each sub-scale) by highest level of education obtained.

Educational level	Mean Quality of Life (QOL) Score			
	Overall QOL	Emotional burden	Benefit finding	Physical burden
Preprimary	58.0	53.4	79.1	66.1
Primary	38.6	29.5	66.7	30.4
Lower secondary	57.0	55.1	45.0	56.1
Upper secondary	48.6	43.7	63.2	46.6
Higher education (associate's/vocational degree)	51.7	46.3	60.3	51.5
Higher education (bachelor's degree)	53.9	51.1	65.2	51.9
Higher education (master's / doctoral degree)	54.6	51.0	62.9	52.4

A Kruskal-Wallis H test ($N = 539$) was conducted to determine if overall quality of life scores differed by educational level. Results revealed a statistically significant difference in overall quality of life scores between educational levels, $H(6) = 13.215$, $p = 0.04$.

To identify where the differences existed, post-hoc pairwise comparisons (using Dunn's test) were conducted. The initial post-hoc results revealed statistically significant differences between educational levels for 3 of 21 comparisons. After making Bonferroni corrections due to the number of pairwise comparisons made, the results revealed no significant differences in mean quality of life scores between educational levels.

Educational level pairwise comparison	Post-hoc significance (p)	Bonferroni adjusted significance (p)	<p style="text-align: center;">Mean ranks</p>
Upper secondary education <u>and</u> higher education (bachelor's degree)	.004	.093	
Upper secondary education <u>and</u> higher education (master's/doctoral degree)	.003	.071	
Upper secondary education <u>and</u> lower secondary education	.026	.537	

Total Household Income

The chart below displays the mean quality of life scores (overall and for each sub-scale) by total household income.

Total household income	Mean Quality of Life (QOL) Score			
	Overall QOL	Emotional burden	Benefit finding	Physical burden
Below €20,000 (Below \$23,800)	47.5	42.2	66.1	46.1
€20,000 to €44,999 (\$23,800 to \$53,493)	53.0	49.1	60.0	51.8
€45,000 to €69,999 (\$53,494 to \$83,208)	54.6	50.9	61.4	54.0
€70,000 to €84,999 (\$83,209 to \$101,043)	55.8	52.6	64.0	53.3
€85,000 to €99,999 (\$101,044 to \$118,882)	48.9	46.1	66.7	43.8
€100,000 and above (\$118,883 and above)	44.1	52.4	63.7	55.8

A Kruskal-Wallis H test ($N = 420$) was conducted to determine if overall quality of life scores differed by household income. Results revealed a statistically significant difference in overall quality of life scores between income levels $H(5) = 14.089$, $p = 0.015$.

To identify where the differences existed, post-hoc pairwise comparisons (using Dunn's test) were conducted. The initial post-hoc results revealed statistically significant differences in overall quality of life for 5 of 15 comparisons. After making Bonferroni corrections due to the number of pairwise comparisons made, the results revealed a statistically significant difference in the mean overall quality of life scores between respondents with a household income below €20,000 (Below \$23,800) and €100,000 and above (\$118,883 and above).

Educational level pairwise comparison	Post-hoc significance (p)	Bonferroni adjusted significance (p)	Mean ranks
Below €20,000 <u>and</u> €20,000 to €44,999	.040	.594	
Below €20,000 <u>and</u> €45,000 to €69,999	.016	.239	
Below €20,000 <u>and</u> €70,000 to €84,999	.015	.231	
Below €20,000 <u>and</u> €100,000 and above	.001	.018	
€85,000 to €99,999 <u>and</u> €100,000 and above	.020	.300	

Access to Care

What perspectives do individuals living with MDS have about their access to care?

Section 6 of the *MDS Global Survey* included 10 questions to better understand the perspectives individuals living with MDS have regarding their access to care.

Time Between Onset of MDS Symptoms and Referral for Evaluation (N = 542)

Respondents were asked, “How much time passed between onset of your MDS symptoms (or abnormal blood test results) and referral for evaluation of possible MDS?”

While more than half of the respondents (55.4%) reported a timespan of less than 3 months, almost one-quarter of respondents (24.5%) reported it taking more than 6 months to be evaluated for MDS.

<3 months	4–6 months	7–9 months	10–12 months	>12 months	Don't know
55.4% (n = 300)	12.4% (n = 67)	6.1% (n = 33)	4.8% (n = 26)	14.0% (n = 76)	7.4% (n = 40)

Respondents who reported a time lapse of 3 months or greater were asked, “Which of the following contributed to your diagnosis taking more than 3 months? (Select all that apply).”

The top 3 reasons reported by the greatest percentage of respondents were due to inconclusive results (35.5%), GP/PCPs lack of understanding (27.6%), and receiving a different initial diagnosis (25.3%).

N= 217	Percent of Respondents (n)
Inconclusive results/no diagnosis given	35.5% (n = 77)
GPs/PCPs lack of understanding	27.6% (n = 60)
Different diagnosis initially received	25.3% (n = 55)
Difficulty scheduling appointment with physician	11.5% (n = 25)
Unable to locate and/or schedule appointment with MDS expert	11.1% (n = 24)
Testing delayed	10.6% (n = 23)
Distance to testing facilities was too great	3.2% (n = 7)
Inadequate transportation to/from medical appointments	1.4% (n = 3)
Cost of testing	0.9% (n = 2)
Other (please specify)	21.7% (n = 47)

Respondents reported a variety of “Other” reasons that contributed to the diagnosis taking more than 3 months:

- **The doctor did not suspect MDS** (n = 13), due to reasons such as not believing there was anything wrong with the individual, young age of individual, desire to watch for trends in blood tests, failure to do yearly bloodwork at annual physical, not seeing a problem with abnormal blood results, desire to rule out other causes of issues, and not wanting to do a bone marrow biopsy until hemoglobin level was at a certain level
- **Focus on treating other diagnoses** (n = 5), for example treating for breast cancer versus focusing on anemia, and treating for prostate cancer and Behcet’s disease
- **Testing issues** (n = 4), for example a focus on other tests, a delay in blood testing, and a delay in receiving genetic test results to confirm diagnosis
- **Not having symptoms** (n = 3)
- **Desire not to have testing** (n = 2) such as a bone marrow biopsy
- **Other** isolated reasons, such as choice of doctor, death of husband, wait time to see hematologist, and slow progression of anemia

Diagnosing Physician (N = 509)

Respondents were asked, “*What type of physician diagnosed you with MDS?*”

Most respondents (82.3%) reported being diagnosed by a physician who specializes in diagnosing and treating blood diseases (hematologist, 62.9%) or blood cancer (oncologist, 19.4%).

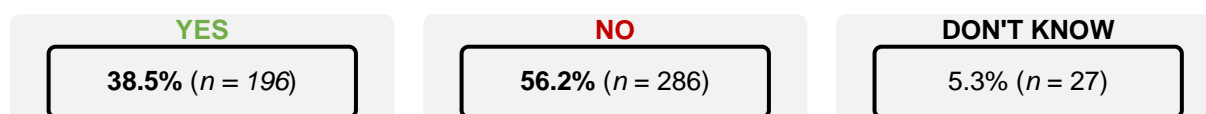
	Percent of Respondents (n)
Hematologist	62.9% (n = 320)
Oncologist	19.4% (n = 99)
MDS expert	9.0% (n = 46)
Primary care physician or general practitioner	4.9% (n = 25)
I don't know	1.4% (n = 7)
Other (please specify)	2.4% (n = 12)

The most commonly reported “Other” type of physician who diagnosed respondents was a hematologist/oncologist (n = 5) and interns (n = 4). Other isolated types of physicians included:

- Epidemiologist (n = 1)
- Medical specialist (n = 1)
- Neurosurgeon (n = 1)

Respondents were asked, “*Did the physician you initially saw about your symptoms, or who found abnormal blood results, diagnose you with MDS?*”

More than half of the respondents (56.2%) reported the physician they originally saw about their symptoms (or who found their abnormal blood results) was not the same physician who diagnosed them with MDS.



Multidisciplinary Team (N = 509)

Respondents were then asked, “*MDS patients often have a group of health professionals (a multidisciplinary team) they rely on to help manage their overall health. Which health professionals, if any, do you rely on? (Select all that apply).*”

The top 4 health professionals respondents reported being a member of their multidisciplinary team were hematologists (48.5%), hemato-oncologists (40.9%), MDS experts (38.3%), and primary care physicians/general practitioners (37.1%).

	Percent of Respondents (n)
Hematologist	48.5% (247)
Hemato-oncologist	40.9% (208)
MDS expert	38.3% (195)
Primary care physician or general practitioner	37.1% (189)
Nurse	24.4% (124)
Nurse practitioner	20.0% (102)
Oncologist	18.5% (94)
Pharmacist	11.8% (60)
Counselor/psychologist	8.6% (44)
Nutritionist	6.7% (34)
Physician assistant	6.7% (34)
Physical therapist	5.1% (26)
Social worker	4.5% (23)
I don't rely on healthcare professionals	3.9% (n = 20)
Other (please specify)	5.3% (n = 27)

The most commonly reported “Other” type of health care professional respondents reported as a member of their interdisciplinary team was **Specialists** ($n = 14$), including cardiologists, neurologists, gastroenterologists, endocrinologists, internists, dermatologists MDS specialists, ophthalmologists, pathologists, psychotherapists, rheumatologists, and gynecologists.

Other types of healthcare professionals reported included:

- Interns ($n = 3$)
- A case manager ($n = 1$)
- A doctor’s assistant ($n = 1$)
- A naturopath ($n = 1$)
- A holistic nutritionist ($n = 1$)
- A palliative care specialist ($n = 1$)

Some participants also reported non-healthcare professionals including:

- Professional associations ($n = 3$), such as Asleuval Association, Association of patients, Fundaleu
- A lifecare community ($n = 1$)
- A non-medical practitioner ($n = 1$)
- A personal trainer ($n = 1$)
- A mom ($n = 1$)
- The person living with MDS themselves ($n = 1$)

Healthcare Professional Primarily Relied On (N = 509)

Respondents were asked, “Which health care professional do you primarily rely on to manage your MDS?”

The top 3 healthcare professionals respondents reported primarily relying on were the same top 3 they reported being a member of their multidisciplinary team: hematologists (33.4%), hemato-oncologists (31.0%), and MDS experts (21.8%).

	Percent of Respondents (n)
Hematologist	33.6% (171)
Hemato-oncologist	31.0% (158)
MDS expert	21.8% (111)
Oncologist	7.9% (40)
Nurse	1.0% (5)
Primary care physician or general practitioner	1.0% (5)
Physician assistant	0.6% (3)
Nurse practitioner	0.4% (2)
Counselor/psychologist	0.2% (1)
Other (please specify)	1.4% (7)
I don't rely on any healthcare professionals	1.2% (6)

Respondents also reported “Other” types of health care professionals they primarily relied on:

- Interns ($n = 2$)
- Psychotherapists ($n = 1$)
- Rheumatologist ($n = 1$)
- Variety due to frequent change of doctors ($n = 1$)

Factors Limiting Ability to Access Care (N = 509)

Respondents were asked, “During the last 12 months, have any of the following limited your ability to access the care you need for your MDS? (Select all that apply).”

While over two-thirds of respondents (67.2%) reported that none of the factors listed limited their ability to access needed care, the limiting factor reported by the greatest percentage of respondents was COVID-19 (15.1%).

	Percent of Respondents (n)
COVID-19	15.1% (77)
Transportation	7.7% (39)
Distance to provider/treatment center	7.3% (37)
Access to MDS specialist	4.9% (25)
Wait times at provider office	4.3% (22)
Difficulty in appointment scheduling	4.3% (22)
Insurance coverage limitations/no insurance	4.1% (21)
Cost of treatment/services	2.9% (15)
Cost of travel	1.6% (8)
Cost of caregiver support	1.4% (7)
Lack of caregiver support	1.4% (7)
Decided not to go	1.0% (5)
Language barriers	0.6% (3)
None of the above	67.2% (342)
Other (please specify)	3.7% (19)

Respondents reported some “Other” isolated factors limiting their access to needed care:

- Difficulty getting needed transfusions ($n = 3$) for reasons such as blood shortage
- Insurance issues ($n = 2$), such as clerical errors
- Lack of physician follow-up care ($n = 2$), for example transplant oncologist providing little interest in follow-up care
- Online appointments ($n = 2$) making it difficult to meet face-to-face
- Adequacy of care issues ($n = 2$), specifically easy explanations that non-experts could understand
- A focus on other health conditions ($n = 1$)
- Frequency of medical appointments interfering with work ($n = 1$)
- Frequent doctor changes ($n = 1$)
- Indifference and disorganization of the public health facility to which they were entrusted ($n = 1$)
- Lack of access to drug trials in Canada ($n = 1$)
- Not knowing the disease had occurred even after a variety of testing (e.g., liver blood tests, MRIs) ($n = 1$)

Respondents were also asked, “*During the last 12 months, have you experienced a significant delay (not directly related to COVID) in accessing any of the following? (Select all that apply).*”

While over three-quarters of respondents (78.6%) reported not experiencing any significant delays, the delay reported by the greatest percentage of respondents was getting an appointment with a specialist (9.4%).

	Percent of Respondents (<i>n</i>)
I have not experienced any significant delays	78.6% (400)
An appointment with a specialist (oncologist, hematologist, or MDS expert)	9.4% (48)
A treatment intervention, such as a blood transfusion or chemotherapy	6.9% (35)
An appointment with a primary care doctor (e.g., a general practitioner)	5.7% (29)
A diagnosis test	4.5% (23)
Needed medications	4.3% (22)
Help/support from social services	1.6% (8)
Other (please specify)	1.8% (9)

Respondents reported “Other” significant delays accessing the following:

- Other specialists ($n = 3$), such as rheumatologist, allergist, dermatologist, urologist, and a mental health provider
- Needed treatment ($n = 3$), including surgery, blood, and newly-released medications

Overall Satisfaction with Access to Care ($N = 509$)

Respondents were asked “Overall, how satisfied are you with each of the following?” questions. Consisting of 7 Likert-type items, respondents indicated their satisfaction level using the following scale: *Very dissatisfied*, *Dissatisfied*, *Neutral*, *Satisfied*, and *Very Satisfied*.

Item-Level Results

The percent (and number) of respondents choosing each response option for all 7 items is displayed below. More than two-thirds of respondents reported being *satisfied* or *very satisfied* with each of the 7 items respectively (64.7%, 69.6%, 64.4%, 75.6%, 79.0%, 75.3%, and 71.0%).

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
Information received from healthcare providers about my treatment options	3.3% ($n = 17$)	6.9% ($n = 35$)	25.1% ($n = 128$)	35.8% ($n = 182$)	28.9% ($n = 147$)
My level of involvement in decisions regarding my care by my healthcare providers	2.2% ($n = 11$)	3.7% ($n = 19$)	24.6% ($n = 125$)	35.2% ($n = 179$)	34.4% ($n = 175$)
Information received about the safety of my treatment	2.8% ($n = 14$)	7.3% ($n = 37$)	25.5% ($n = 130$)	36.7% ($n = 187$)	27.7% ($n = 141$)
Quality of care according to the standard/guidelines or best practices available for my condition	2.0% ($n = 10$)	3.5% ($n = 18$)	18.9% ($n = 96$)	39.5% ($n = 201$)	36.1% ($n = 184$)
The safety of care provided to me	1.0% ($n = 5$)	3.1% ($n = 16$)	16.9% ($n = 86$)	40.7% ($n = 207$)	38.3% ($n = 195$)
The continuity in my care over time	2.4% ($n = 12$)	3.5% ($n = 18$)	18.9% ($n = 96$)	39.7% ($n = 202$)	35.6% ($n = 181$)
How well my healthcare provider adapts my care according to my changing needs	2.2% ($n = 11$)	4.1% ($n = 21$)	22.8% ($n = 116$)	35.6% ($n = 181$)	35.4% ($n = 180$)

Respondents were most dissatisfied with information received from healthcare providers about treatment options (10.2%) and information received about the safety of treatment (10.1%).

#1 MOST DISSATISFIED	#2 MOST DISSATISFIED
10.2%	10.1%
of respondents rated they were Very Dissatisfied or Dissatisfied with information received from healthcare providers about treatment options	of respondents rated they were Very Dissatisfied or Dissatisfied with information received about the safety of treatment

Responses were used to calculate an overall access to care score, as well as 2 access to care sub-scale scores (a 3-item information/involvement subscale and a 4-item quality/safety subscale). Responses to all items were re-coded by assigning numerical values corresponding to the 5 response options: *Very Dissatisfied* (0), *Dissatisfied* (25), *Neutral* (50), *Satisfied* (75), *Very Satisfied* (100). Final access to care scores could range from 0 to 100, with higher scores representing better access to care.

The mean and standard deviation for each of the 7 items is displayed below. Respondents reported having better access to safe care (78.0) and quality care (76.1), and less access to information about treatment options (70.0) and information about safety of treatment (69.8).

	Mean (SD)
The safety of care provided to me	78.0 (21.7)
Quality of care according to the standard/guidelines or best practices available for my condition	76.1 (23.3)
The continuity in my care over time	75.6 (23.7)
How well my healthcare provider adapts my care according to my changing needs	74.5 (24.3)
My level of involvement in decisions regarding my care by my healthcare providers	74.0 (24.1)
Information received from healthcare providers about my treatment options	70.0 (25.9)
Information received about the safety of my treatment	69.8 (25.3)

Overall and Subscale Results

The access to care scores, overall and for the 2 sub-scales is below. Overall, respondents reported being more satisfied with the quality/safety of care (mean = 76.1) than information received about treatment options and care involvement (mean = 71.3).

OVERALL	ACCESS TO CARE (INFORMATION/INVOLVEMENT)	ACCESS TO CARE (QUALITY/SAFETY)
74.0	71.3	76.1

COVID-19 Effects (N= 509)

What perspectives do individuals living with MDS have about the effect of the COVID-19 pandemic?

Section 7 of the *MDS Global Survey* included 1 question to better understand the perspectives individuals living with MDS have regarding the perceived effect of the COVID-19 pandemic.

Respondents were asked, “*Has COVID-19 affected any of the following?* (Select all that apply). If COVID-19 has not affected your care or treatment, please only select “COVID-19 has not affected me.”

Over three-quarters of the

79.6%
*Reported COVID-19
DID NOT
affect them*

	Percent of Respondents	n
COVID-19 has not affected me	79.6%	405
The care you’ve received for MDS	8.8%	45
Your ability to continue treatment for MDS	6.7%	34
Your ability to seek initial treatments for MDS	5.3%	27
Other (Please specify)	9.0%	46

respondents (79.6%) reported that COVID-19 did not affect them.

The most commonly reported “Other” way COVID-19 affected respondents was by affecting their **access to care** ($n = 19$). For example, respondents reported that COVID-19 caused difficulties accessing basic and emergency follow-up care/treatments and obtaining needed transfusions and chemotherapies. Respondents also reported other ways COVID-19 affected them:

- Inability to physically access doctors, requiring telehealth visits ($n = 10$)
- Lack of caregiver support, primarily inability to have caregivers with them during office/treatment visits ($n = 3$)
- Vaccine-related ($n = 2$), where some were unable to receive the vaccine due to thrombocytopenia and another believing the vaccine may have facilitated their MDS turning into AML

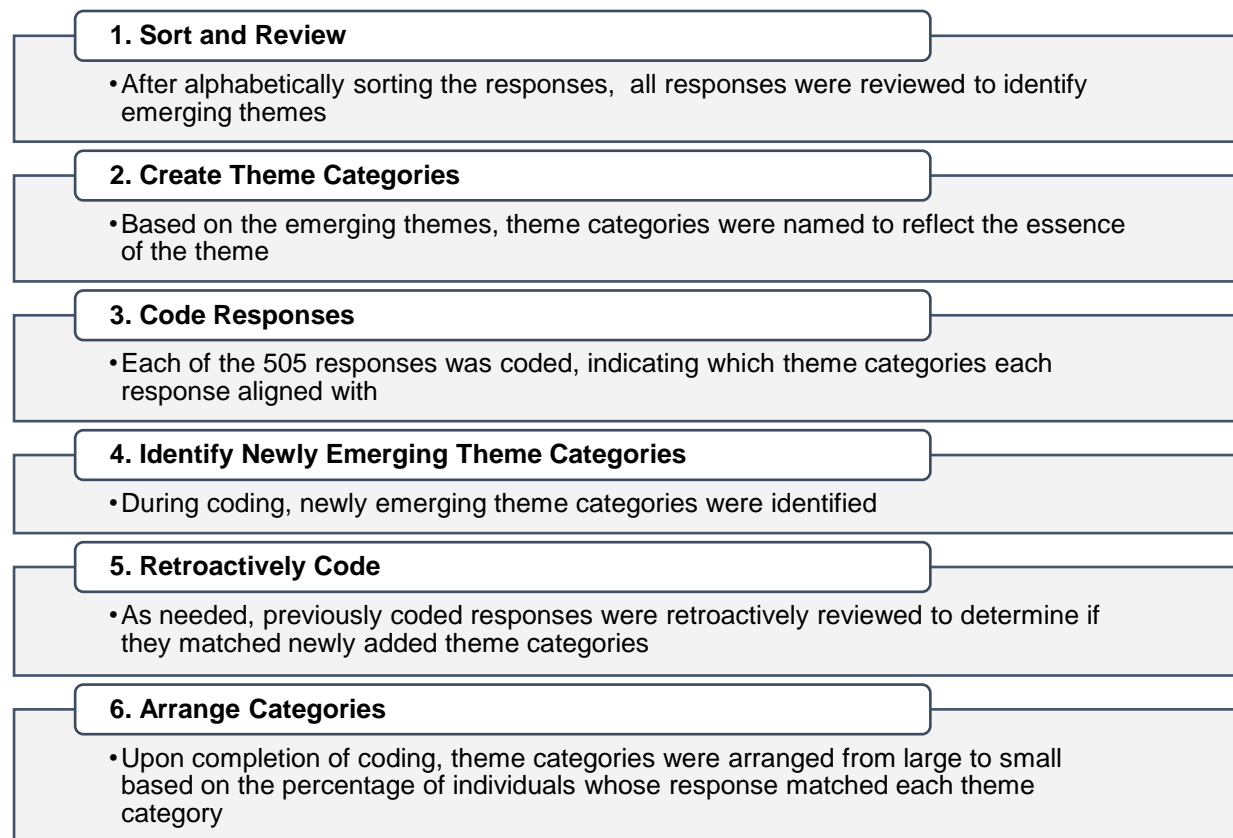
Improving Quality of Life/Access to Care (N= 505)

What perspectives do individuals living with MDS have about what's needed to improve their quality of life and access to

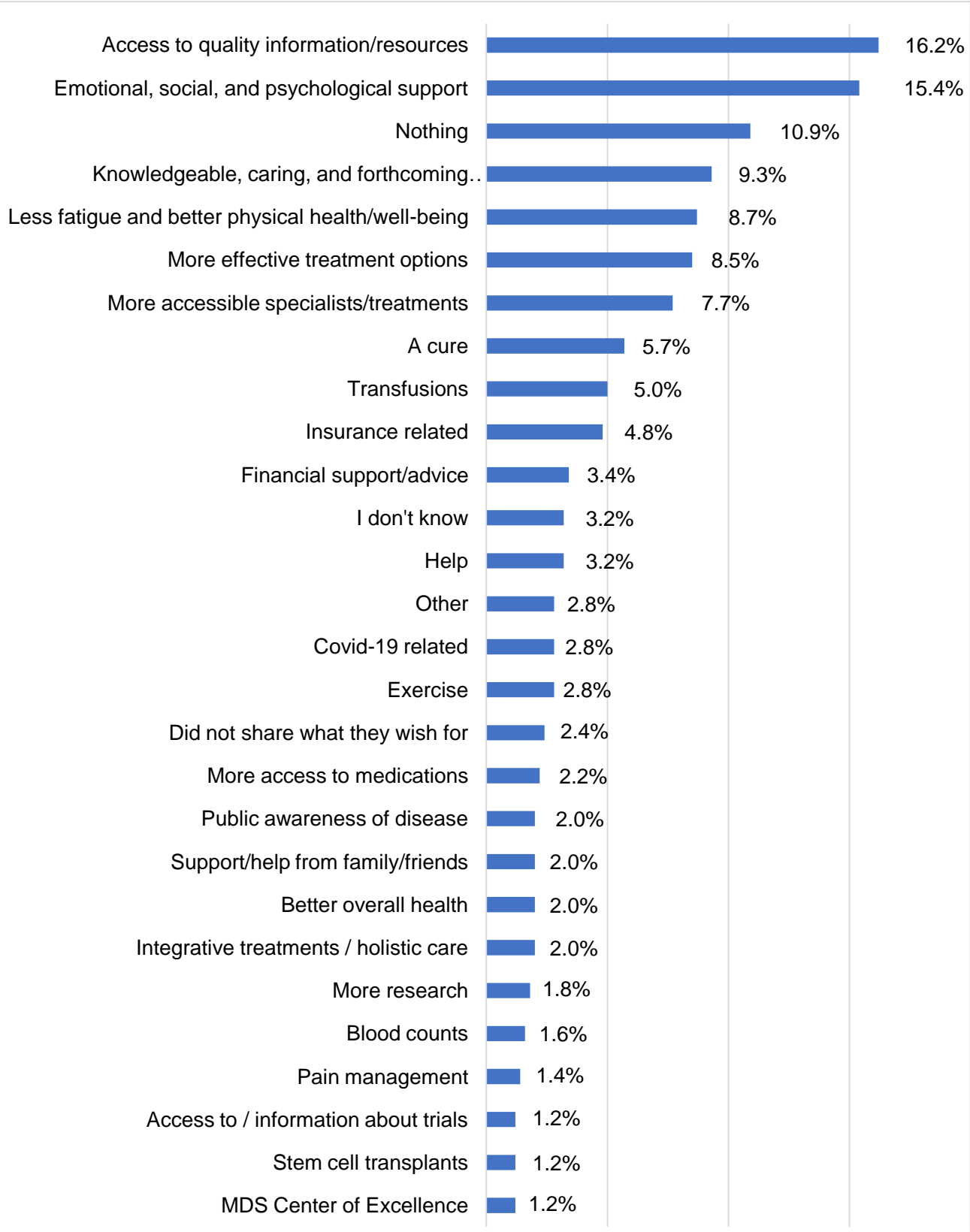
Section 8 of the *MDS Global Survey* included 1 optional, open-ended question to better understand the perspectives individuals living with MDS have regarding what's needed to improve their quality of life and access to care.

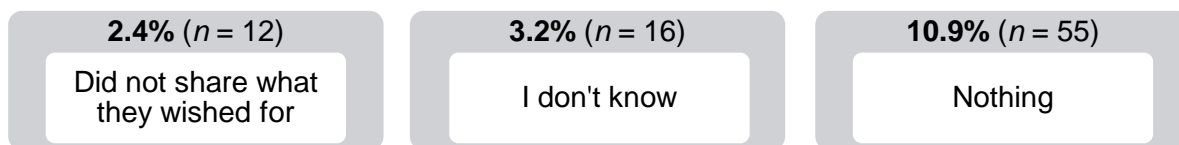
Respondents were asked, "What 2 things would you wish for to help maintain or improve your quality of life (your physical, mental, and social well-being and happiness) and/or improve your ability to access the personal healthcare you need to achieve the best health outcomes?"

Responses from 505 respondents were analyzed using a 6-step process:



The percent and number of responses that aligned with each of the theme categories is displayed in the chart on the next page.





While 2.4% of respondents *did not share what they wished for* and 3.2% indicated they *did not know* what could be done, a greater percentage of respondents (10.9%) reported there was *nothing* that could be done.

"I'm blessed with all of my needs. I have an excellent doctor, and life is good."

Respondents who reported that nothing could be done often elaborated, sharing that nothing could be done because they were receiving excellent care and currently had no issues. For example, one respondent shared, *"I'm blessed with all of my needs. I have an excellent doctor, and life is good."* Other respondents felt similarly, stating *"I have had great care! Having MDS at my stage there is nothing that can be improved on,"* *"My health care team are the best,"* and *"I could not have asked for more or better help than what I received from my doctors and Stanford Health."* Others elaborated on not currently having any issues, sharing *"I am doing alright,"* *"I do not feel there is any more I need to improve my health care,"* and *"There is nothing I have particular concerns about wanting to change."*

The wish list items reported by the greatest percentage of respondents were related to *Access to Quality Information/ Resources* and *Emotional, Social, and Psychological Support*.



ACCESS TO QUALITY INFORMATION / RESOURCES: 16.2% of respondents reported wishing they had more quality information and resources about MDS in general, MDS treatments, and their own prognosis and what they would likely experience.

I need "resources to help find methods to beat or control the disease"

Some respondents wished for access to general information about MDS. For example, one respondent wished they had access to critical information someone should know when first diagnosed - information about the disease. Other respondents wished for *"Resources to help find methods to beat or control the disease,"* and resources with *"...clear instructions as to which medical provider to call with medical problems which are impacted by MDS (e.g., skin infection, UTI)."*

One respondent wished for more information for young individuals living with MDS, stating *"All of the resources are directed at people over 60 who are in a very different life stage."*

Numerous respondents wished for more consistent information/updates, likely from their healthcare providers, about how to interpret their lab results, the possibility of re-trying previous medications, their current disease status, how their disease has changed, changes in treatments, as well as alternative and future treatment plans. One respondent also wished for more information on the reason for specific symptoms, sharing a desire to find out *"...why I have shortness of breath and extreme fatigue even though my hemoglobin is in the 9 to 10s."* One respondent made the point that they wished for *"better access to lay information."*

Many respondents wished for more in-depth information/knowledge about on their own prognosis, life expectancy, what they would be likely to experience over time, and how to

prepare for death. For example, one respondent said they wished for information on “*how much time I have left and how bad the end of my life will be.*” Another shared a desire for “*more explanation of where I am, what are the likely developments, [and] what treatment options remain.*” Similarly, other respondents desired “*a clearer understanding of what is likely to happen,*” and “*to be better informed about my current score and prognosis, I have too many unknowns in my life.*”

Some respondents expressed wishes for other types of information such as “*...scientific evidence to guide decision making about present and future treatment, extending life expectancy,*” and information on healthy eating, new developments related to a cure, and active support groups “*that can provide relevant information based on my condition.*”

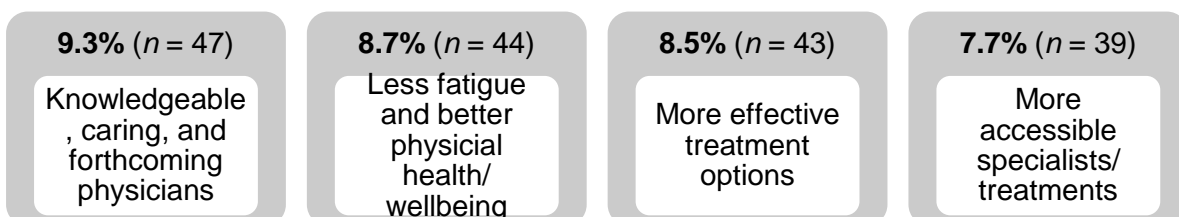
EMOTIONAL, SOCIAL, AND PSYCHOLOGICAL SUPPORT: 15.4% of respondents reported wishing they had more emotional, social, and psychological support.

I need “*a support team to get me through these tough times.*”

A significant number of respondents wished for more contact/interaction with other patients and the desire to talk with and compare notes with other patients. Specifically mentioned were desires to participate in an MDS support group and have access to an MDS patient blog. Several respondents expressed a specific desire for local MDS support groups, “*not just online*” and “*other than Zoom.*” Another respondent expressed a desire for an “*MDS patient blog to share their actual experience with treatments and side effect[s] from treatments, and [the] financial burden from different treatments.*”

Numerous respondents also wished for better and easier access to emotional and psychological support from counselors, mental health professionals such as psychologists, and therapy groups. For example, one respondent wrote about really needing someone to talk to about what’s going on in their life, while another expressed the need for a “*support team to get me through these times.*”

Another respondent shared, “*My experience ... leads me to say that I lacked assistance for mental well-being, a diagnosis like this should certainly be assisted by a team specialized in psychological care but perhaps this aspect derives from my way of approaching illness.*”



The wish list items reported by 7.7% to 9.3% of respondents were related to *Knowledgeable, Caring, and Forthcoming Physicians; Less Fatigue and Better Physical Health/Well-Being; More Effective Treatment Options; and More Accessible Specialists/Treatments.*

KNOWLEDGEABLE, CARING, AND FORTHCOMING PHYSICIANS: 9.3% of respondents reported wishing for more knowledgeable, caring, and forthcoming physicians.

I need “a knowledgeable doctor who cares about me and treats me as more than a 10-minute appointment every 3 months.”

Referring to the need for more knowledge, one respondent reported wishing for “*Hematologists and doctors at a local level (rather than primarily at centers of excellence) having the knowledge of MDS to recommend the necessary support and information at the time of initial diagnosis.*” The desire for knowledge

was also supported by other respondents who shared a desire for “*better information from doctors,*” and “*better understanding of MDS by my caregivers.*” Another respondent expressed a wish that providers “*better explained where I am: what are the likely developments, what treatment options remain.*”

Various respondents wrote about a desire for their healthcare professionals to spend more time with them. For example, one respondent wrote about a desire for “*more contact and visits with [my] MD,*” while another respondent wrote about healthcare professionals “*who do all they can, but don't have the time to sit and talk with us at length.*”

Yet another respondent reported wishing “*to actually have a conversation with a medical professional who can tell me which stage I am at and what to expect going forward with my MDS.*” Two respondents referred directly to the minimal amount of time spent with their healthcare provider, sharing “*[my] hematologist-oncologist only gives me 1/4 of an hour every 3 months!!!*” and a desire for “*consultations with [my] hematologist more frequently and longer because 15 minutes every 8 months is not enough to receive information and proper care.*”

Other respondents directly referred to the need for more caring healthcare providers. For example, one respondent wrote about a need for a “*primary medical provider who cares for and who communicates with me,*” while another wrote about how “*some specialists, hematologists and oncologists and 'personal' nurses could be more caring.*” Other respondents referred to the need for “*more optimism, empathetic optimistic doctors/nurses,*” and “*professionals who listen more and are more empathetic.*”

Other respondents wished for healthcare providers to be more forthcoming – proactively and honestly providing information. Respondents wished for things such as “*transparency [and] honesty,*” “*honesty with prognosis and discussion of end of life,*” “*clear explanations about my illness and the stage,*” and “*...a lot more honest information about my condition and where this going in the future with a timeline.*” Some respondents also referred to the need for “*more transparency in the decisions made by doctors when making a decision about a stem cell transplant,*” and a request “*that I am told with more precision about the possible treatments and am involved in the treatment decisions.*”

Other respondents reinforced the need for more knowledgeable, caring, and forthcoming physicians. For example, two respondents shared their desire for “*better communication with provider and return of calls,*” and “*...a knowledgeable doctor who cares about me and treats me as more than a 10-minute appointment every 3 months.*” Yet another shared, “*I wish my health care providers cared more, gave more information, and expanded my options. I feel like they don't know how to treat me...like I'm just an appointment in their busy day. I feel very insignificant.*”

LESS FATIGUE AND BETTER PHYSICAL HEALTH / WELL-BEING: 8.7% of respondents reported wishes related to having less fatigue and better physical health and well-being.

I "I wish that I had more energy and strength so that at 45 years old, I didn't always feel like I was in my 70's"

In terms of fatigue, respondents expressed wishes related to their energy and tiredness. As written by one respondent, "I am so tired of being tired all the time." Supporting the need for less fatigue, another respondent wrote, "I wish that I had more energy and strength so that at 45 years old, I didn't always feel like I was in my 70's." Another respondent wished for "an additional treatment to improve this fatigue which stops me from enjoying a normal life and which is often demoralizing."

Yet another respondent wrote, "before MDS I was always so active and, on the go, and doing things. I want to be able to do those things, but now I just do not care anymore." Other respondents expressed similar fatigue issues, expressing a desire to "have more energy to do things I would like to do," and "boost my energy because I am weak," wanting "anything to help alleviate the crushing fatigue," and to "find a drug to alleviate fatigue and being short on breath."

Other respondents referred to a desire for better physical health and wellbeing. For example, one respondent wished for their "physical well-being by proactively augmenting white blood cells reducing infection probabilities." Other respondents referred to improving their physical health, sharing a desire "to be able to partake in physical activity, and a therapy group with other MSD patients."

MORE EFFECTIVE TREATMENT OPTIONS: 8.5% of respondents reported wishing there were more effective treatment options available for MDS.

I need "some sort of treatment that would benefit my conditions. A . . ."

Some respondents wished for treatment options other than bone marrow transplants and transfusions. For example, expressing desire for a treatment option other than a bone marrow transplant, one respondent shared "I'm too old and overweight for a bone marrow transplant." Another expressed the need for "more treatments that last longer when a transplant is not an option." Expressing desires for treatment options other than transfusions, other respondents expressed the need for, "a treatment for anemia that reduces the need for transfusion and the constant travel (and long waits) to the hospital," new treatment options allowing them to "space out blood transfusions (currently 2 bags every 15 days)," and "to have effective alternative treatment to avoid regular transfusions and reduce the ferritine." Yet another respondent wrote about their desire for "control of anemia without having to periodically resort to blood transfusions (about once a month)..." which "would significantly improve my health but also the quality of life would benefit from it."

A few respondents expressed a desire for more effective treatments for those initially diagnosed with low risk MDS. For example, one mother of an individual living with MDS wrote, "my otherwise healthy son (age 40) went from low risk MDS diagnosis to AML in less than 3 months and died within 10 days of AML diagnosis. There seemed to be no options for treatment to keep him low risk and treatment was administered when counts were out of control, and it was too late."

Other respondents wished for more effective treatment options that worked for them personally. For example, one respondent wrote, "I need therapeutic treatments that work." Yet another wrote about the need for "some sort of treatment that would benefit my conditions. A miracle."

Other respondents wished for more effective treatment options in the form of drugs. For example, one respondent expressed a desire for “*new effective drugs [to] be released quickly,*” and “*hope that [a] new medicine will be developed and helpful to me and everyone.*”

Other respondents wished for more effective off-label use of treatments/drugs. For example, one respondent expressed desire for “*accessibility to drugs [for] compassionate use,*” while another expressed the need for “*including off label drugs, 'alternative' successful treatments.*”

MORE ACCESSIBLE SPECIALISTS / TREATMENTS: 7.7% of respondents reported wishing that MDS specialists and treatments were more accessible to them.

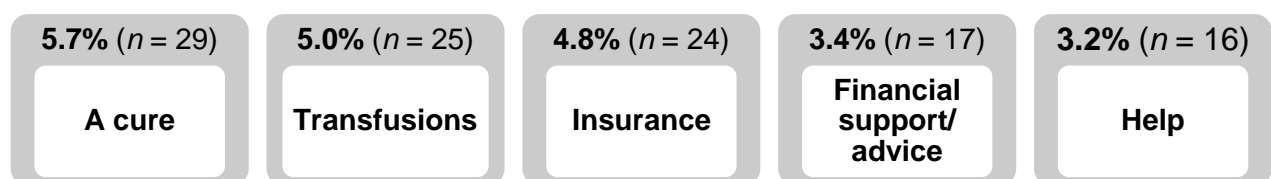
“Wish I could have help in finding a way to move closer to the city where my main MDS doctor is located (3 hours away)”

Some respondents wrote about a desire for specialists and treatment facilities to be geographically closer. For example, respondents wished for “*better local options for treatment,*” and access to “*a nurse specialist,*” “*a local hematologist,*” and “*qualified MDS experts and staff in Colorado.*” Other respondents expressed desire to be “*closer distance to [the] transplant center,*” a “*shorter travel distance to [the] hospital which provides treatment,*”

and that they have “*an MDS Center of Excellence that is closer (currently 150 miles away)...*” Two respondents reinforced the desire for local access, stating “*wish I could have help in finding a way to move closer to the city where my main MDS doctor is located (3 hours away),*” and “*I wish that when the time comes for me to have an SCT that it is available in the city that I live, and not 3 hours away by ferry. It will be very difficult to have to spend four months away from my family in Vancouver.*” One respondent even reported “*[There’s no] MDS specialist in my country.*”

Other respondents wrote about desired access to therapies not regionally approved. For example, one respondent wished for “*access to treatments not approved in Canada.*”

Yet other respondents wished for more timely access to healthcare. For example, one respondent wrote about the desire for “*access to healthcare that does not require long waits for prior authorization from health insurance. For example, I had to wait 5 months to see a nephrologis.*”



The wish list items reported by 3.2% to 5.7% of respondents were related to *A Cure, Transfusions, Insurance, Financial Support / Advice, and Help.*

A CURE: 5.7% of respondents reported wishing for a cure.

I need a “new cure for my MDS, as I’m too old and overweight for a bone marrow transplant”

In abbreviated responses, various respondents wished for a cure, stating their desire for “*better cures,*” “*a cure for MDS,*” “*a new cure,*” and “*more effective treatment leading to a cure.*” Various respondents also expressed their desire for a new cure, other than transplantation. For example, one respondent wished for a new cure due to age and weight, stating “*I’m too old and overweight for a bone marrow transplant.*” Another desired a new cure, wishing for “*a non-invasive cure besides a*

Stem Cell Transplant.”

TRANSFUSIONS: 5.0% of respondents reported wishes related to transfusions.

“My only wish would be that a treatment regime other than transfusion was available”

A few respondents expressed the desire for more spaced-out and less frequent transfusions. For example, one respondent expressed *“hope of a new treatment to space out blood transfusions (currently 2 bags every 15 days).”* Another expressed a desire for transfusions at home.

Various respondents expressed the desire to be transfusion independent, desiring treatments that eliminate or reduce the need for transfusions. For example, two respondents – one in Denmark and the other in France -- discussed Luspatercept as an option.

One of the respondents shared, *“I have had more than 1100 blood transfusions, and it would be nice, if they released Luspatercept in Denmark.”* The respondent from France stated, *“Luspatercept ... would help me to reduce or even eliminate transfusions.”* Yet another respondent shared, *“my only wish would be that a treatment regime other than transfusion was available. At this point based on my type of MDS I am transfusion dependent.”* Other respondents supported the desire to be transfusion independent requesting *“medication to get me off transfusions,”* and having *“effective alternative treatment{s} to avoid regular transfusions.”*

One respondent just wanted more flexibility in transfusion scheduling, desiring the *“ability to get blood transfusions on my schedule, rather than have to wait until I am in critical need. This is all because of the blood shortage in the US. I am transfusion dependent.”* Yet another respondent wished for better support of blood for transfusions, sharing *“currently [I’m] only getting one unit instead of 2 units per transfusion.”*

INSURANCE: 4.8% of respondents reported wishes related to insurance.

“Insurance approval of certain medications has been daunting and a source of frustration for myself and my doctor”

Various respondents shared insurance-related difficulties obtaining some MDS medications and treatments, and a desire to have these medications and treatments be more accessible. A respondent from Canada requested *“access to therapies not approved in Canada.”* Yet other respondents expressed a wish to obtain *“access to new drugs not presently approved by my health insurance”* and to *“get insurance to pay for treatments needed.”* One respondent expressed extreme frustration with insurance, writing *“insurance approval of certain medications has been daunting and a source of frustration for myself and my doctor. I feel the insurance companies do not adequately understand MDS.”*

A few other respondents expressed a more general concern about health insurance coverage. For example, one respondent indicated a desire for *“continued health insurance coverage upon my upcoming early retirement,”* while another expressed a need for more complete insurance coverage. Another shared, *“insurance coverage is very difficult because the cost is so high. Worrying about coverage is very stressful.”* Some other respondents expressed the need for more affordable and cheaper medication, while others expressed a desire to have *“specialized counselors who deal with cancer”* and *“local hematologists”* available in their insurance plan.

While one additional respondent expressed frustration with the process used by a specialty pharmacy, resulting in *“...delays in delivery resulting in missed doses,”* another reported just wanting *“less hassle navigating insurance.”*

FINANCIAL SUPPORT/ADVICE: 3.4% of respondents reported wishing they had more financial support and advice.

I wish for “clarity of financial aspects [related to MDS] and what is covered [by insurance].”

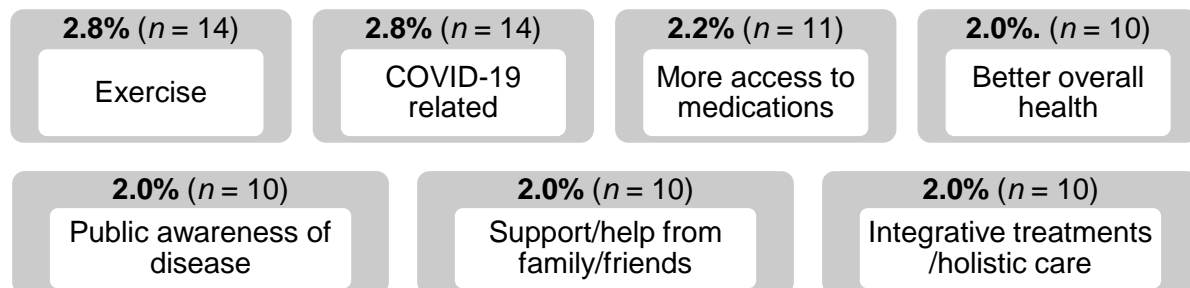
Numerous respondents indicated a need for financial/monetary support in general. Other respondents required a desire for specific financial help – for example, help with “*travel expenses to an MDS specialist;*” “*funds for in-home help;*” “*money for everyday home [expenses such as] yards [and] small jobs like cleaning gutters;*” and funds for medication cost relief. A few respondents requested support clarifying the financial aspects of MDS, including [insurance] coverage. A few others expressed a desire for financial advice while they are out of work and for “*clarity of financial aspects [related to MDS] and what is covered [by insurance].*”

HELP: 3.2% of respondents reported wishing they had help with things such as transportation, housework, meals, and care coordination.

I wish for “someone who could take me to appointments by car as I rely on a free ambulance service which is tiring and makes appointments much longer”

Regarding transportation, one respondent shared a need for “*transport to the care center;*” while another shared a need for “*...someone who could take me to appointments by car as I rely on a free ambulance service which is tiring and makes appointments much longer.*” Yet another shared “*...a continuous assistant for travel to and from the hospital would be useful.*”

In terms of housekeeping, one respondent made her case stating, “*I need help with taking care of my home, I can’t do it anymore. My husband tries but he has cancer too and has some dementia. Really need someone to talk to about what’s going on in my life and some help in the home.*” Other respondents shared they could use “*help with housecleaning [and] low cost prepared food*” and “*meals [being] provided for me and my caretaker daily.*” A few other respondents shared a need for “*help navigating the paperwork involved in replacing ...personal documents that were lost in a fire,*” and assistance with “*planning of medical examinations for related diseases.*”



The wish list items reported by 2.0% to 2.8% of respondents were related to *Exercise, COVID-19, More Access to Medications, Better Overall Health, Public Awareness of Disease, Support / Help from Family/Friends, and Integrative Treatments / Holistic Care.*

EXERCISE: 2.8% of respondents reported exercise-related wishes.

I wish for “advice and recommendations on exercise and diet”

In abbreviated responses, various respondents wished for exercise, sharing responses such as “*exercise;*” “*walking and fitness exercise;*” and “*regular exercise.*”

Other respondents had more specific requests. For example, one respondent wished for “*advice and recommendations on exercise and diet routines...*” to be available from their Kindle or audio book. Another wished for “*access to exercises classes...*”

COVID-19 RELATED: 2.8% of respondents reported wishes related to COVID-19.

“Once COVID eases, I look forward to traveling often and overseas”

While some respondents wished for more information related to the risks of COVID-19, others wished for more information on the efficacy of COVID-19 vaccinations for people with MDS. For example, one respondent wished *“to be able to obtain better information about the risks of Covid, efficacy of vaccinations etc. for people with MDS.”* Yet another respondent wished for *“an effective test to know our level of immunity in regard to covid and confidence that we could be effectively treated if we got it.”*

Others expressed general concerns about COVID and a desire to end the isolation/travel bans and the overall COVID-19 pandemic. For example, one respondent wrote, *“this pandemic has overwhelmed our healthcare system, leading to staff shortages and a crisis in our healthcare system.”* Yet another respondent expressed a desire for the *“lifting of bans for COVID -19 [sharing they] feel trapped.”*

One respondent wrote about the consequences of COVID-19, sharing *“I was locked in to avoid COVID and the sun...I used to be a very sociable person.”*

Other respondents expressed wishes related to vaccinations and tighter COVID restrictions. For example, one respondent wrote, *“my ability to safely go out into the community and interact is hugely held back by those who refuse to get vaccinated and pose dangers to my health. This has kept me in lockdown up to the present day. GET VACCINATED!!!!”* Another respondent wished for *“tighter COVID restrictions to allow me to visit venues, restaurants, etc.”*

Some respondents shared sentiments about life after COVID. For example, one respondent wrote, *“once COVID eases, I look forward to traveling often and overseas.”*

MORE ACCESS TO MEDICATIONS: 2.2% of respondents reported wishing they had more access to medications for treating MDS.

I need “easier and quicker access to relieving medications or those recently released”

While some respondents expressed a general desire for medications to address their health issues, others expressed a desire for *“easier and quicker access to relieving medications or those recently released,” “medicines to cure MDS,”* and *“medications to get [them] off the transfusions.”*

Some respondents reported wishing for access to specific medications. For example, one respondent wrote, *“I have had more than 1100 blood transfusions, and it would be nice, if they released Luspatercept in Denmark.”* Other respondents reported a desire for *“affordable access to Luspatercept”* and *“Exjade,”* and availability of generic Revlimid.

BETTER OVERALL HEALTH: 2.0% of respondents reported a general desire for better overall health.

I wish for “a chance to live a normal life again”

In abbreviated responses, various respondents wished for things such as *“health,” “better overall health,” “to get healthy,” “not to be unwell,”* for *“no deterioration in health,”* and *“a chance to live a normal life once again.”* One respondent reinforced the need for overall health, so that they could *“have a decent quality of life and not to be a burden to [their] family.”*

PUBLIC AWARENESS OF DISEASE: 2.0% of respondents reported wishing there was more public knowledge of MDS.

“It is a struggle constantly having to explain what it is. People know breast cancer, but [no] one knows what the hell MDS is”

One respondent who felt very strongly about the need for more public knowledge wrote, *“it is a struggle constantly having to explain what it is. People know breast cancer,*

but [no] one knows what the hell MDS is.” One respondent indicated there needs to be “public awareness and understanding of his invisible disease” because “you look fine.” Another respondent reported “I wish people would understand the rollercoaster ride...people don’t get it ...it gets lonely.”

SUPPORT/HELP FROM FAMILY/FRIENDS: 2.0% of respondents reported the importance of being supported by and receiving help from family and friends.

I need to be “surrounded by family and friends who care for me”

For example, one respondent reported the importance of being “surrounded by family and friends who care for me,” which was important to their social well-being. Another respondent indicated the need for “a husband who doesn’t give up easily and [is] emotionally there for me.”

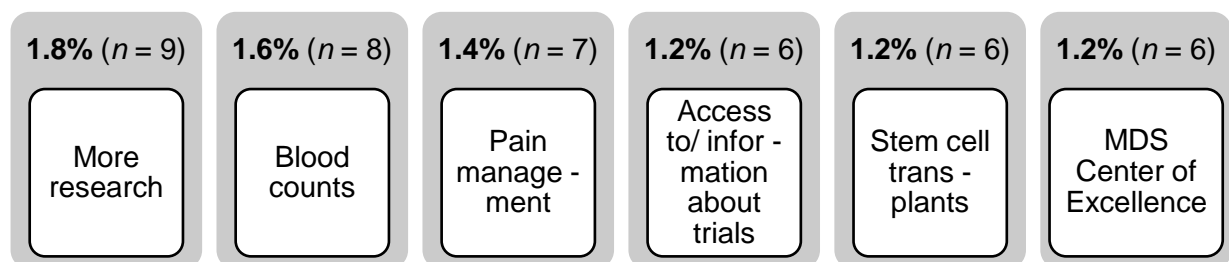
INTEGRATIVE TREATMENTS / HOLISTIC CARE: 2.0% of respondents reported wishing for more integrative and holistic treatments/care, as well as more collaboration/communication between their health professionals and treatment facilities.

“I wish that healthcare providers would have communicated better between each other and my family”

Some respondents expressed a desire for more information on integrative treatments, such as nutritional and homeopathic approaches, while others expressed a need for more holistic medical advice. For example, one respondent wished for a more “holistic approach from clinicians and healthcare teams, with access to counselling and dieticians.” Others expressed a desire to for treatments and care to include acupuncture, meditation, and counseling. Others

wished for better interaction between the health professionals treating them, such as between their “hemato-oncologist and other healthcare providers” and “increased communication between [their] hematologist and oncologist, [which] seems inhibited by high work-load demands of physicians.”

One respondent who felt very strongly about the importance of physician collaboration wrote, “I am moving to another state, so I hope that I’m able to find a primary care physician and a hematologist who work well together and that I can continue my current standard of care without interruption. That weighs heavily on my mind right now.” Another respondent who was reporting for her father, wrote, “I wish that healthcare providers would have communicated better between each other and my family.”



The wish list items reported by 1.2% to 1.8% of respondents were related to *More Research, Blood Counts, Pain Management, Access To / Information About Trials, Stem Cell Transplants, and MDS Center of Excellence.*

MORE RESEARCH: 1.8% of respondents reported wishing for more and better MDS research.

I wish for “better cures, better research on MDS”

For example, some respondents indicated the need for “more qualify of life research,” and research “...into stem cell therapy for people over 70 years of age.” An additional respondent wished for more “research to better treat and cure MDS,” and “better cures, better

research on MDS.”

BLOOD COUNTS: 1.6% of respondents reported wishing they had better blood counts.

“I wish I had the ability to raise my white blood cells and platelets”

For example, some respondents wished for better blood counts in general, stating a desire for “*higher blood counts*” and for their “*blood count to increase*.” Others referred to a desire for their WBC, RBC, or platelet counts to improve or remain the same. For example, one respondent shared, “*I wish I had the ability to raise my white blood cells and platelets*.” Another wished for “*...a treatment for my low number of platelets*.”

PAIN MANAGEMENT: 1.4% of respondents reported wishing for relief from general pain, bone pain, joint pain, and pain due to treatments.

I wish I had “relief from pains and aches”

For example, one respondent wished for “*relief from pains and aches*,” and another reported needing “*pain medication*.” Other respondents reported needing relief from a “*very painful myelogram every 18 months*” and “*...for the bone pain*.”

ACCESS TO / INFORMATION ABOUT TRIALS: 1.2% of respondents reported wishing they had better access to and information about clinical trials.

I wish I had “more information on possible trials I might qualify for”

For one respondent, access was a distance issue, wishing for “*access to trial treatments that did not involve long distance travel*.” Another respondent just wished for “*...more information on possible trials that I might qualify for*.”

STEM CELL TRANSPLANTS: 1.2% of respondents reported wishing for a successful stem cell transplant.

I wish I had “an improved overall success rate for stem cell transplant”

For example, a few respondents wished they could receive a stem cell transplant, with one caregiver reporting, “*I wish that my husband had been given the option of having a stem cell transplant*.” Others wished for “*...an improved overall success rate for stem cell transplant*” and “*more information on treatments for unsuccessful stem cell transplants*.”

MDS CENTER OF EXCELLENCE: 1.2% of respondents reported wishing they knew about and had an MDS Center of Excellence closer to them.

“I found out about the Centre of Excellence from Google”

For example, one respondent shared that their GP was “*clueless*” and they “*found out about the Centre of Excellence from Google*.” Other respondents wished they had “*an MDS Center of Excellence that [was] closer*” and “*... where I live*.”

References

- Dana-Farber Cancer Institute. (2013). *The QUALMS: Scoring instructions*. Boston, MA.
- MDS Foundation. (2021). *What is MDS?* <https://www.mds-foundation.org/what-is-mds/>
- Momentive. (2022). Tips for increasing survey completion rates. Retrieved August 31, 2022, from <https://www.surveymonkey.com/mp/tips-increasing-survey-completion-rates/>
- Perzynska, K. (2022, March 9). *How to get survey completion rate of over 80% (A real study)*. <https://survicate.com/surveys/survey-completion-rate/>
- Zimet, G.D., Dahlem, N.W., Zimet, S.G. & Farley, G.K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52, 30-41.

Appendix A

Section 1: Demographics

	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11
Completion #	788	788	788	788	788	788	760*	788	563	659
Dropout %	0%	0%	0%	0%	0%	0%	0%	0%	17%	2%

Section 2: Disease history and current status

	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22
Completion #	659	659	659	659	659	281	610	610	610	610	610
Dropout %	0%	0%	0%	0%	0%	8%	8%	0%	0%	9%	0%
	Q23	Q24	Q25	Q26	Q27	Q28	Q29	Q30	Q31		
Completion #	610	610	610	610	610	610	142	139	542		
Dropout %	0%	0%	0%	0%	0%	0%	14%	2%	7%		

Section 3: Overall health

Section 4: Mental health/wellbeing

Section 5: Quality of life

	Q32	Q33	Q34	Q35	Q36	Q37	Q38	Q39	Q40
Completion #	542	542	542	542	542	542	542	542	542
Dropout %	0%	0%	0%	0%	0%	0%	0%	0%	0%

Section 6: Access to care

	Q41	Q42	Q43	Q44	Q45	Q46	Q47	Q48	Q49	Q50
Completion #	542	217	509	509	509	509	509	509	509	509
Dropout %	0%	11%	6%	0%	0%	0%	0%	0%	0%	0%

Section 7: COVID-19 Affects

Section 8: Improving QOL/access to care

	Q51	Q52
Completion #	509	505
Dropout %	0%	NA ⁸

⁸ Q52 was the final, optional, open-ended question – not a required question.

Appendix B

The percent of respondents experiencing each physical symptom, by region, is displayed below. The top two symptoms experienced by the highest percentage of respondents are highlighted in green.

Symptom	Overall (n = 659)	Africa (n = 1)	Asia (n = 47)	Europe (n = 237)	N. America (n = 335)	Oceania (n = 23)	S. America (n = 12)
Fatigue/tiredness	62.8%	100%	55.3%	62.9%	63.6%	56.5%	91.7%
Anemia	47.9%	100%	55.3%	46.4%	49.0%	43.5%	50.0%
Shortness of breath/trouble breathing	31.6%	100%	17.0%	37.6%	30.4%	21.7%	33.3%
Weakness	25.1%	100%	27.7%	27.0%	23.0%	26.1%	41.7%
Easy or unusual bruising/bleeding	22.5%	100%	34.0%	22.8%	23.0%	13.0%	0.0%
Dizziness	19.4%	100%	40.4%	19.4%	15.8%	17.4%	41.7%
I was not having any physical symptoms	18.4%	0.0%	10.6%	18.6%	19.7%	26.1%	0.0%
Unusual paleness	18.2%	0.0%	19.1%	24.9%	13.4%	30.4%	8.3%
Joint or bone pain	16.2%	100%	6.4%	20.7%	13.4%	21.7%	33.3%
Other (please specify)	12.0%	0.0%	4.3%	11.0%	13.0%	13.0%	0.0%
Weight loss	11.2%	0.0%	23.4%	9.3%	10.4%	21.7%	8.3%
Headache	10.8%	100%	8.5%	12.2%	10.1%	4.3%	16.7%
Frequent infections	9.7%	100%	12.8%	12.2%	7.2%	8.7%	16.7%
Loss of appetite	9.7%	0.0%	19.1%	8.4%	9.9%	8.7%	0.0%
Fever	5.0%	100%	8.5%	5.1%	3.6%	8.7%	16.7%
Nausea/vomiting	4.7%	0.0%	8.5%	4.2%	4.5%	4.3%	8.3%
Enlarged spleen	4.2%	0.0%	2.1%	5.1%	3.9%	4.3%	8.3%
Ascites	0.3%	0.0%	0.0%	0.4%	0.3%	0.0%	0.0%

The percent of respondents experiencing each physical symptom, by country, is displayed below. For each region, included is the overall percentage and percentage by country. Regions where there were fewer than 20 respondents from multiple countries were grouped and are presented as one percentage in the “Other” category. The top two symptoms experienced by the highest percentage of respondents are highlighted in green.

Symptoms	Africa	Asia			Europe					
	South Africa (n = 1)	Overall Asia (n = 47)	Korea (n = 40)	Other ⁹ (n = 7)	Overall Europe (n = 237)	France (n = 68)	Germany (n = 46)	Italy (n = 38)	United Kingdom (n = 26)	Other ¹⁰ (n = 59)
Fatigue/tiredness	100%	55.3%	52.5%	71.4%	62.9%	57.4%	76.1%	57.9%	65.4%	61.0%
Anemia	100%	55.3%	60.0%	28.6%	46.4%	51.5%	60.9%	31.6%	46.2%	39.0%
Shortness of breath/trouble breathing	100%	17.0%	17.5%	14.3%	37.6%	42.6%	43.5%	39.5%	23.1%	32.2%
Weakness	100%	27.7%	25.0%	42.9%	27.0%	26.5%	39.1%	28.9%	15.4%	22.0%
Easy or unusual bruising/bleeding	100%	34.0%	40.0%	0.0%	22.8%	11.8%	23.9%	13.2%	23.1%	40.7%
Dizziness	100%	40.4%	42.5%	28.6%	19.4%	19.1%	21.7%	7.9%	26.9%	22.0%
I was not having any physical symptoms	0.0%	10.6%	7.5%	28.6%	18.6%	22.1%	17.4%	21.1%	7.7%	18.6%
Unusual paleness	0.0%	19.1%	17.5%	28.6%	24.9%	13.2%	50.0%	23.7%	19.2%	22.0%
Joint or bone pain	100%	6.4%	5.0%	14.3%	20.7%	14.7%	26.1%	28.9%	19.2%	18.6%
Other (please specify)	0.0%	4.3%	5.0%	0.0%	11.0%	5.9%	6.5%	10.5%	26.9%	13.6%
Weight loss	0.0%	23.4%	27.5%	0.0%	9.3%	8.8%	15.2%	7.9%	3.8%	8.5%
Headache	100%	8.5%	10.0%	0.0%	12.2%	11.8%	21.7%	10.5%	3.8%	10.2%
Frequent infections	100%	12.8%	15.0%	0.0%	12.2%	7.4%	15.2%	7.9%	26.9%	11.9%
Loss of appetite	0.0%	19.1%	20.0%	14.3%	8.4%	7.4%	19.5%	5.3%	0.0%	6.8%
Fever	100%	8.5%	7.5%	14.3%	5.1%	2.9%	6.5%	5.3%	0.0%	8.5%
Nausea/vomiting	0.0%	8.5%	10.0%	0.0%	4.2%	1.5%	6.5%	2.6%	7.7%	5.1%
Enlarged spleen	0.0%	2.1%	2.5%	0.0%	5.1%	2.9%	13.0%	0.0%	3.8%	5.1%
Ascites	0.0%	0.0%	0.0%	0.0%	0.4%	0.0%	0.0%	0.0%	3.8%	0.0%

Symptom	N. America				Oceania			S. America
	Overall N. America (n = 335)	Canada (n = 48)	U.S. (n = 283)	Mexico (n = 4)	Overall Oceania (n = 23)	Australia (n = 21)	New Zealand (n = 2)	Other ¹¹ (n = 12)
Fatigue/tiredness	63.6%	72.9%	62.5%	25.0%	56.5%	52.4%	100%	91.7%
Anemia	49.0%	47.9%	48.8%	75.0%	43.5%	47.6%	0.0%	50.0%
Shortness of breath/trouble breathing	30.4%	37.5%	29.3%	25.0%	21.7%	19.0%	50.0%	33.3%
Weakness	23.0%	33.3%	20.8%	50.0%	26.1%	23.8%	50.0%	41.7%
Easy or unusual bruising/bleeding	23.0%	14.6%	24.4%	25.0%	13.0%	14.3%	0.0%	0.0%
Dizziness	15.8%	25.0%	14.1%	25.0%	17.4%	14.3%	50.0%	41.7%
I was not having any physical symptoms	19.7%	12.5%	21.2%	0.0%	26.1%	28.6%	0.0%	0.0%
Unusual paleness	13.4%	20.8%	11.7%	50.0%	30.4%	33.3%	0.0%	8.3%
Joint or bone pain	13.4%	14.6%	13.1%	25.0%	21.7%	23.8%	0.0%	33.3%
Other (please specify)	13.0%	12.5%	9.9%	0.0%	13.0%	14.3%	0.0%	0.0%
Weight loss	10.4%	8.3%	10.2%	50.0%	21.7%	23.8%	0.0%	8.3%
Headache	10.1%	8.3%	10.2%	25.0%	4.3%	4.8%	0.0%	16.7%
Frequent infections	7.2%	4.2%	7.4%	25.0%	8.7%	9.5%	0.0%	16.7%
Loss of appetite	9.9%	10.4%	9.5%	25.0%	8.7%	9.5%	0.0%	0.0%
Fever	3.6%	6.3%	2.8%	25.0%	8.7%	9.5%	0.0%	16.7%
Nausea/vomiting	4.5%	6.3%	3.9%	25.0%	4.3%	4.8%	0.0%	8.3%
Enlarged spleen	3.9%	4.2%	3.5%	25.0%	4.3%	4.8%	0.0%	8.3%
Ascites	0.3%	0.0%	0.4%	0.0%	0.0%	0.0%	0.0%	0.0%

⁹ India, Indonesia, Israel, Malaysia, Philippines.

¹⁰ Austria, Belgium, Croatia, Denmark, Finland, Greece, Hungary, Ireland, N. Macedonia, Portugal, Spain, Sweden, Switzerland.

¹¹ Argentina, Brazil, Peru.