MDS ALLIANCE GLOBAL SURVEY 2024

'A FOCUS ON ACCESS TO CARE'

GLOBAL REPORT

JULY 2025

MDS Alliance
Myelodysplasia Global Network

ACKNOWLEDGEMENTS

We would like to thank our MDS Alliance members community and all the patients and caregivers who took part in the MDS Alliance 2024 Global Survey. Without their input we would not have been able to develop this report. We would also like to thank our sponsors for funding the survey and Picker for supporting and delivering the survey.

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EXECUTIVE SUMMARY

BACKGROUND

The MDS Alliance is an international organization dedicated to supporting patients with myelodysplastic syndromes (MDS)—a group of blood disorders affecting bone marrow. Their mission is to ensure MDS patients worldwide receive the best possible multi-professional care, regardless of location. The alliance comprises 40 members from 32 countries and is led by a steering committee of 6 member organisations.

In 2022, MDS Alliance launched their first global patient survey, gathering responses from 659 MDS patients across 32 countries. Those findings were used to strengthen the MDS community by developing resources and tools for patients, caregivers, and healthcare professionals. It was decided that such surveys will run bi-annually and so in 2024, another MDS Global Survey was developed, completed and analysed. This report is a summary of this survey.

AIMS

The focus for ‘The MDS Global Survey 2024’ was ‘Access to care’ and this was to be delivered with the support of Picker, an international charity working across health and social care. The main survey topic was selected based on feedback from the MDS community, the MDS Alliance Steering Committee and findings from ‘The MDS Global Survey 2022’. As such, three key aims were identified:

1. To better understand patient access to medications, treatments, and care.
2. To identify barriers and facilitators to access across different health systems.
3. Based on the findings above, to develop clear, actionable recommendations for stakeholders.

METHODOLOGY

The survey was designed and developed by the MDS Alliance Steering Committee and reviewed. The MDS Alliance Steering Committee were responsible for designing and developing the purpose of the survey while Picker was responsible for delivering the survey and data analysis. The survey was available to view online in Qualtrics in 10 languages including English and remained active for completion for 4 months between 30th September 2024 to 31st January 2025. It was promoted and distributed by the MDS Alliance via email, online forums, social media, newsletters and through MDS Alliance member organisations and their networks. The survey was directed at patients and caregivers aged 18 and above, directly or indirectly, affected by a diagnosis of MDS.

The following summarizes the key findings from the MDS Global Survey 2024.

KEY FINDINGS

	Respondents
	• 628 respondents; 83% of these were MDS patients. • Respondents from 31 countries; 58% of these were in Europe. • 98% of respondents live in countries with a high GDP per capita. • 46% of respondents aged 66-80 years. • 48% of patients also have autoimmune or inflammatory disease. • Top 5 country respondents: France > Republic of Korea/ South Korea > United Kingdom > USA > Germany.

MDS Diagnosis

- Bone marrow biopsy is main method for confirming MDS.
- Age and/ or geographical location may influence the time from first experiencing symptoms to visiting a health professional.
- 45% of patients do not know their MDS subtype.
- Lack of clarity from healthcare professionals about quality-of-life issues, survival rates and suitability for stem cell transplants.

MDS Care and Support

- 39% of patients receive regular support.
- Spouses are the most common caregiver (70%).
- Emotional support and help with household duties are the main form of support given by carers to MDS patients.

MDS Treatment

- 1 in 10 patients do not feel involved with treatment decisions.
- Offers of a bone marrow transplant are low but more common in younger patients.
- Only half of MDS patients are looked after by multidisciplinary team.
- Access to care is variable.
- Number of visits to haematologists is higher in younger patients.
- Fatigue, joint pain and weight loss are most common side effects.
- Nearly one fifth (22%) reported it was difficult for the patient to access care from their MDS specialist.
- Nearly a quarter (23%) reported that patients' symptoms have gotten worse after treatment.
- Over half (57%) reported delays in accessing services with the biggest challenge being accessing appointments with specialists.

MDS Testing and Monitoring

- Younger patients take more bone marrow tests than older patients.

BACKGROUND

The MDS Alliance is a global umbrella organization dedicated to improving the lives of people affected by MDS - a group of rare blood disorders that impact the bone marrow's ability to produce healthy blood cells. The Alliance, which comprises 40 members from 32 countries, was founded with the goal of uniting patient advocacy groups, healthcare professionals, and researchers, and works to ensure that patients worldwide have access to optimal care, accurate information, and a supportive community.

One key mission of MDS Alliance is to provide connections. It brings together member organizations from across the globe to share resources, best practices, and the latest scientific developments. These member groups often provide direct support to patients and caregivers, including educational materials, helplines, and peer support networks. By fostering collaboration between countries and institutions, the Alliance helps bridge gaps in care and knowledge, especially in regions where MDS awareness and treatment options may be limited.

Another key mission of MDS Alliance is to raise awareness of MDS. Despite being relatively rare, MDS can have a profound impact on quality of life, often causing chronic fatigue, increased risk of infections, and bleeding complications due to low blood cell counts. The transition of MDS to Acute Myeloid Leukaemia is also often a worry for many patients. The Alliance supports campaigns and events - such as the MDS World Awareness Day (October 25th) - to educate the public and healthcare providers about the condition. These efforts aim to reduce delays in diagnosis and ensure that patients receive timely and appropriate treatment.

In addition, the MDS Alliance also plays a vital role in promoting research and innovation. It supports international surveys and studies that gather patient experiences, helping to shape future care strategies and influence policy. For example, the 2022 Global Patient Survey collected responses from nearly 659 individuals across 32 countries, offering valuable insights into the challenges faced by those living with MDS. This kind of data is crucial for identifying unmet needs and advocating for better healthcare services.

In summary, the MDS Alliance is more than just an organization – it is a lifeline for many. By uniting voices from around the world, it empowers patients, supports caregivers, and drives progress in the understanding and treatment of MDS. Whether someone is newly diagnosed, navigating treatment, or supporting a loved one, the Alliance offers a sense of solidarity and hope. For more information, please visit the MDS Alliance webpage: : https://www.mds-alliance.org

METHODOLOGY

Specific methodological details of the survey design, implementation and data analysis are described below.

QUESTIONNAIRE DEVELOPMENT

Based on feedback from the MDS Alliance Global Survey 2022 and the MDS Alliance Steering Committee, it was decided that any questions asked in the survey should fall within the following themes: (i) Patient demographics, (ii) Diagnosis, (iii) Care and support, (iv) Treatment and (v) Testing and Monitoring.

The survey included mainly closed-ended questions (e.g. multiple choice, dichotomous (yes/no) or demographic questions) and some open-ended short answer questions. All respondents were asked specific demographic questions (e.g. questions related to age, gender, country of residence, level or education) to get a better understanding of the collected sample group. Caregivers were asked additional questions that sought to get a better understanding about the person they were caring for. Where necessary, question rerouting was implemented to ensure that respondents only addressed subsequent questions that were relevant to them.

LANGUAGES

The survey was initially developed in English and then translated and proofread into 9 different languages by native speakers. Languages were selected by the MDSA Steering Committee based on the potential to reach the greatest number of respondents. The 10 languages that the survey was available online were as follows:

- Arabic
- Dutch
- English (UK)
- French
- German
- Hebrew
- Italian
- Korean
- Portuguese
- Russian

INCLUSION CRITERIA

To be eligible to complete the survey respondents had to be aged 18 years or over and be either an MDS patient or a current or former caregiver of an MDS patient (this could include, but is not limited to, spouse or child). Patient and caregiver respondents were required to have answered at least one question from Q13 onwards or C_Q8 onwards respectively.

DATA COLLECTION

The survey was hosted online using the third-party online survey platform Qualtrics. It was active for 4 months; from 30th September 2024 to 31st January 2025. There were no time constraints when completing the survey, and if respondents had cookies enabled in their web browser settings, they could leave the survey and return at the same place if accessing again on the same device and browser.

DISTRIBUTION OF SURVEY

To ensure the survey reached as many people as possible, various communication platforms were used. In the first instance the survey was shared with all members of the MDS Alliance. It was then added to the MDS Alliance website and social media platforms including X (Twitter), Instagram, LinkedIn and Facebook. To maximise engagement, additional communication and marketing materials were collaboratively developed between the MDS Alliance Steering Committee and Picker and distributed to Alliance members.

DATA CLEANING

Data were extracted from Qualtrics into Excel. Any responses that did not meet the specific inclusion criteria were removed. Any responses that were flagged by Qualtrics as potential bots were reviewed prior to data being aggregated. To streamline analysis, data were suppressed/ not analysed where there fewer than 30 respondents received at both the individual question level and across the results breakdown. As a result, the question that has not been included in this report due to suppression is described below (Q49). A total of 177 responses were removed from the dataset.

- *Q49. Please select which country you received your bone marrow transfusion in. To quickly find your country in the list below, please click on the box and start to type in the country.*

DATA ANALYSIS

Data were considered as a whole and/or grouped accordingly and analysed to address specific aims of the survey. This survey specifically focuses on unpicking trends in access to care. The effect of GDP per capita and gender on the results were specifically investigated. Where numerical data was collected, this is reported as a % and rounded to the nearest whole number. As a result, the total for a single-response question can appear slightly below or above 100%.

DATA PRIVACY

This was a voluntary survey with no financial incentive provided by the MDS Alliance for completion. Before starting the survey, respondents were informed of the purpose of the survey and how the results would be used. General Data Protection Regulations (GDPR) were followed and all data that was collected was anonymised. No personal identifiable or sensitive information was collected from respondents.

STATISTICAL ANALYSIS

The number of respondents to each question or response is indicated by n=(x), where x represents the number of respondents. Due to question routing within the survey, and because responding to all questions was not mandatory, the number of respondents varies across different questions. All data and graphs were analysed/ generated using Microsoft Excel and/or GraphPad Prism v10 software. Where possible, statistical analysis was completed using the software and is described in Figure/ Table legends. Where no statistical analysis was performed; any reported differences cannot assume statistical significance.

RESPONDENT DEMOGRAPHICS

- 628 respondents – 83% were patients.
- 31 countries – 58% in Europe.
- 98% of respondents lived in countries with a high
- GDP capita
- 71% of respondents had health insurance.

Section 1 of the MDS Global Survey 2024 included questions to gather demographic information about the respondents. A total of 628 people completed the survey, 520 of whom were patients and 108 were caregivers. The demographic characteristics of the 628 individuals who are included in subsequent analyses are described below.

GEOGRAPHIC LOCATION

The survey was completed by 628 respondents form 31 different countries. There were 2 respondents that preferred not to disclose the location. Of the 31 countries, 18 (58%) were in Europe, followed by 6 in Asia (19%), 3 in North America (10%) and 2 (6%) in Africa, Australasia and South America. The top 5 countries with the most respondents were; France (151) > Republic of South Korea (127) > United Kingdom (112) > United States of America (80) > Germany (71) (Figure 1). These countries will be provided with individual country reports of the MDS global survey.

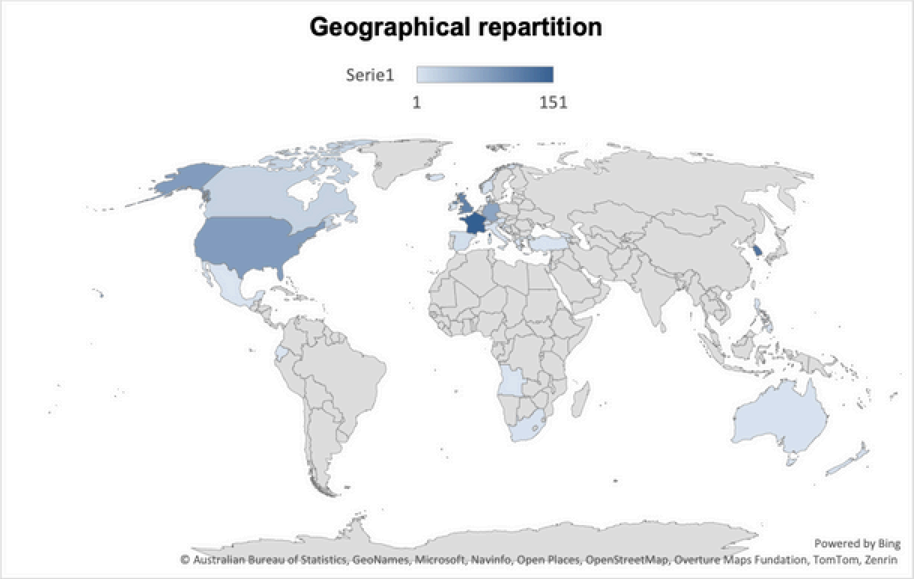


***Figure 1.* Geographical representation of countries that completed the survey.** *Dark orange represents the country with the highest respondents (France, n=151). Grey represents countries that did not respond to the survey.*

MDS patients consisted of 83% of the respondents (Figure 2A). This trend in respondent type was similar throughout the different continents (Figure 2B). Most respondents (77%), irrespective of continent, lived in urban areas with more than 5,000 inhabitants in their community, whilst the rest lived in communities with less than 5,000 inhabitants (Figure 3).

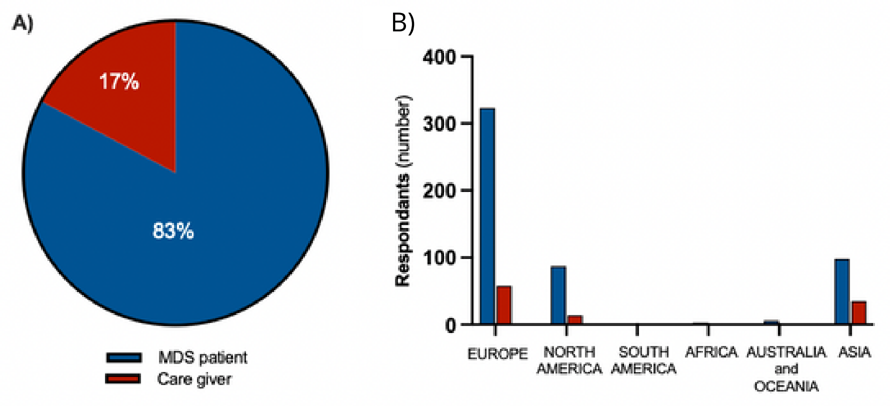


***Figure 2:* Distribution of MDS patients vs Care givers as overall numbers (A) and according to geographical location (B).** *Data are shown as a % from n=628 respondents.*

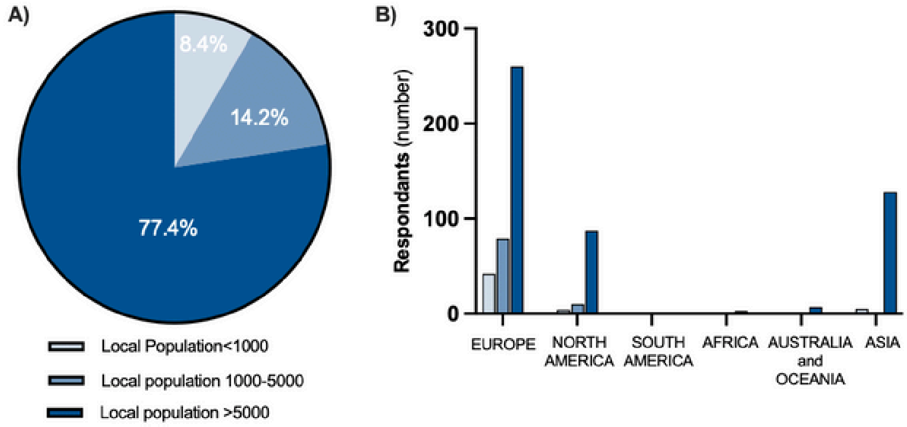
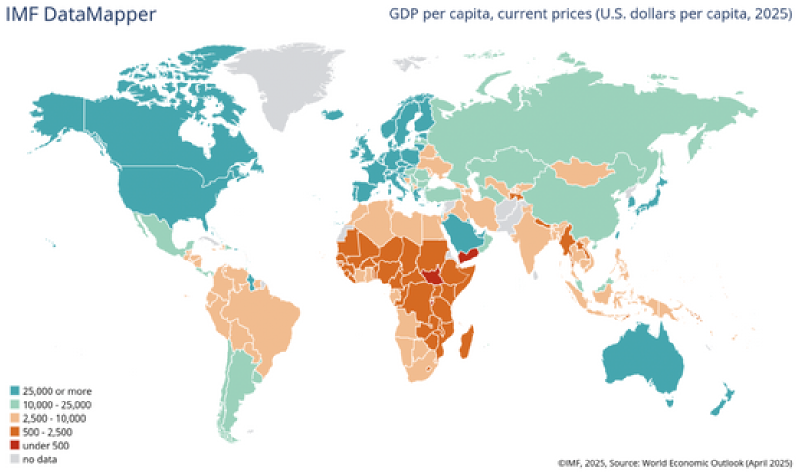


Figure 3:* *Local population size of area that respondents live in as an overall number (A) and according to geographical location (B). *Data are shown as a % from n=628 respondents.*

COUNTRY GDP AND HOUSEHOLD INCOME

A summary of all the respondent numbers and country of residence is shown in Table 1. A global map showing distribution of GDP per capita (in US dollars) shows that the continents Europe, North America and Australasia contain countries with the highest levels of GDP per capita in the world (Figure 4).
This is important to note as a total of 510 patients (98%) and 105 caregivers (97%) respondents live in countries with a GDP of $25,000 or more (Table 1).



©IMF, 2025, Source: World Economic Outlook (April 2025)

Figure 4 and Table 1:* *Map of global GDP per capital in 2025. *Countries are coloured according to their GDP (in US $) per capita ranging from red (under $500) to aqua ($25,000 or more). Data is taken from IMF website ((https://www.imf.org/external/datamapper/NGDPDPC@WEO/OEMDC/ADVEC/WEOWORLD/GUY).*

In line with this, respondents were questioned about their household income. Under half (41%) of patients surveyed had an income below $44,999, whilst 45% had an income higher than this. 15% of those surveyed preferred not to disclose their income.

Country	**Continent**	**Average income/ household (thousand $)**	**Patient**	**Caregiver**	**Total**
France	Europe	46.8	138	13	151
Republic of Korea / South Korea	Asia	34.6	95	32	127
United Kingdom of Great Britain and Northern Ireland	Europe	55.0	89	23	112
United States of America	North America	89.1	67	13	80
Germany	Europe	55.9	58	13	71
Canada	North America	53.6	18	1	19
Switzerland	Europe	104.9	12	0	12
Spain	Europe	36.2	6	1	7
Austria	Europe	58.2	4	2	6
New Zealand	Australasia	46.1	4	1	5
Norway	Europe	89.7	4	0	4
Luxembourg	Europe	140.9	3	0	3
Croatia	Europe	25.7	2	1	3
South Africa	Africa	6.4	2	1	3
Australia	Australasia	64.6	2	0	2

Country	Continent	Average income/ household (thousand $)	Patient	Caregiver	Total
Ireland	Europe	108.9	2	0	2
Denmark	Europe	75.0	1	1	2
Italy	Europe	41.1	1	1	2
Philippines	Asia	4.4	1	1	2
Andorra	Europe	45.3	0	2	2
Angola	Africa	2.9	1	0	1
Antigua and Barbuda	North America	22.6	1	0	1
Cyprus	Europe	41.1	1	0	1
Ecuador	South America	6.9	1	0	1
Georgia	Asia/ Europe	9.6	1	0	1
Greece	Europe	25.8	1	0	1
Iceland	Europe	90.3	1	0	1
Mexico	South America	12.7	1	0	1
Türkiye	Asia/ Europe	16.7	1	0	1
Armenia	Asia	8.9	0	1	1
Israel	Asia	57.8	0	1	1
Prefer not to say	N/A	N/A	2	0	2
		Total (as %)	**520 (83%)**	**108 (17%)**	**628 (100%)**

Table 1: Country respondents (both patient and caregiver) for the MSA Global Survey 2024. *A total of 628 people completed the survey which included 520 patients and 108 caregivers. Each country is coloured according to their GDP per capita, as shown in Figure 4. Countries are ranked in descending order of the number of their 'total respondents'.*

AGE AND GENDER

Just over half of survey respondents self-identified as females (56%), the rest identified as males (44%) (Table 2). Over half of those that completed the survey were aged 66 or over (54%). The rest were aged between 18-65 years of age.

Q5: Age group (years)	
Less than 18	0%
18-29	3%
30-45	10%
46-65	33%
66-80	46%
Over 80	8%

Table 2:* *Age group of respondents. *Data are shown as a % from n=628 respondents.*

LIVING SITUATION

Over two thirds of patients (68%) lived with a spouse or partner and the rest lived either alone (17%) or with immediate family (14%).

HIGHEST LEVEL OF EDUCATION

A total of 23% of patients had up to a secondary/ high school level of education whilst just under half (44%) had a post-secondary education (Table 3). A total of 28% had up to postgraduate qualifications. A small percentage (3%) preferred not to disclose or had another level of educational qualifications (2%) (Table 3).

Q6: Education level	
None, Primary/ Elementary School	23%
Post-Secondary (College/	44%
Postgraduate (Master's, PhD or	28%
Prefer not to say	3%
Other	2%

***Table 3.* Q6: What is the highest level of education you have completed?** *Data are shown as a % from n=520 respondents.*

HEALTH CONDITIONS

A total of 38% of those surveyed did not have any of the health conditions described (Figure 2). Autoimmune and/or inflammatory conditions, such as arthritis, autoimmune disease or chronic inflammation were a common symptom with nearly half of the respondents (48%). Other common health conditions included cardiovascular (20%) and respiratory (15%) diseases (Figure 5).

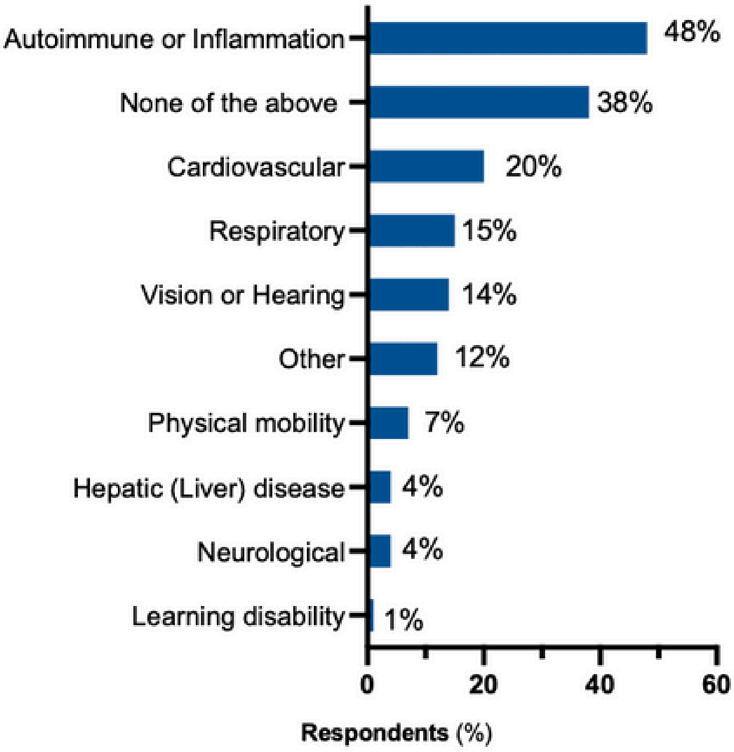


Figure 5: ***Q9: Do you have any of the following physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?*** *Data from the different conditions were grouped into relevant categories as shown above.*

HEALTH INSURANCE

Over two thirds of patients confirmed they had health insurance (71%). A quarter (25%) did not have any health insurance, 2% did not know and 2% preferred not to say. Of those that were covered, 89-90% were covered for healthcare visits to primary health professionals or specialists, 74% transfusions, 65% testing's and 56% to on-site visits to mental health counsellor/ psychologist (Table 4). Only 20% of patients surveyed had health insurance that covered clinical trials. To note, a total of 8 respondents were from countries with a GDP per capital of less than $25,000; 63% of those (5/8) had health insurance.

71% YES 25% NO

Q11: If you have health insurance, which of the following does it cover?	
Onsite visits to specialists	90%
Onsite visits to primary	89%
Transfusions	74%
Testing	65%
Onsite visits to mental	56%
Facility charges	55%
Virtual visits to primary	41%
Virtual visits to specialists	38%
Virtual visits to mental	24%
Clinical trials / experimental	20%
Other treatments (please	6%
Don't know / can't	5%

Table 4. Q11: Which of the following does your health insurance cover? Please select all that apply. Data are shown as a % from n=368 respondents.

SURVEY ANALYSIS: PATIENT RESPONSES

SECTION 1: MDS DIAGNOSIS

- 45% do not know their MDS subtype.
- Bone marrow biopsy remains main formal method of MDS detection.
- Household income and age influences ease of accessing diagnostic services.

A total of 520 patients completed the survey and 60% of these were diagnosed in the last 4 years that the survey conducted (2022 – present) (Figure 6). To better understand whether there were any trends in the way that MDS was diagnosed between different respondents, the patients were asked detailed questions about their diagnosis.

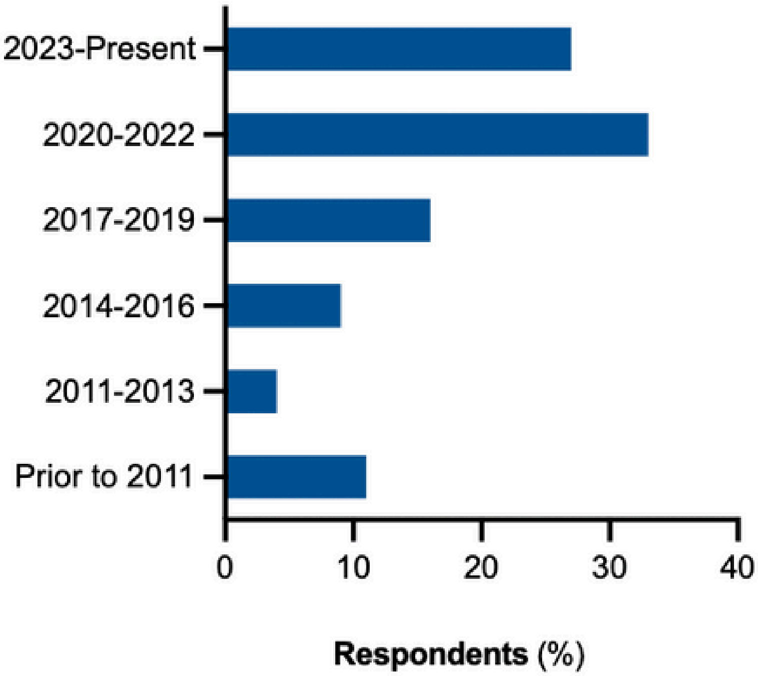


Figure 6: ***Q12: What year were you diagnosed with MDS?*** *Respondents were asked to provide information about when they were first diagnosed with MDS. Data are shown as a % from n=517 respondents.*

TIME FROM FIRST EXPERIENCING SYMPTOMS TO VISITING A HEALTH PROFESSIONAL

Over half of patients (51%) first spoke to a healthcare professional within 3 months of first experiencing symptoms (Figure 7). The age of respondents and where they lived (continent) seemed to influence some of the responses. Specifically, the likely age group to speak to healthcare professionals within 1 month were those aged 30-45 years (41%) (Figure 8). Those living in Asia-Pacific were most likely to speak to health professions within 3 months compared to other continents (Figure 9).

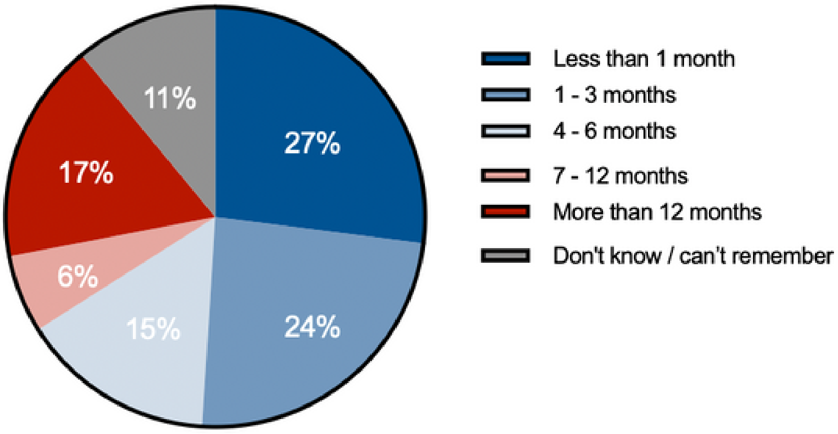


***Figure 7: Q13:* How long was it from the time you first experienced symptoms until you first spoke to a healthcare professional about them? By this we mean any healthcare professional you saw, this could be a GP / family doctor, hospital doctor, etc.** *Data are shown as a % from n=515 respondents.*

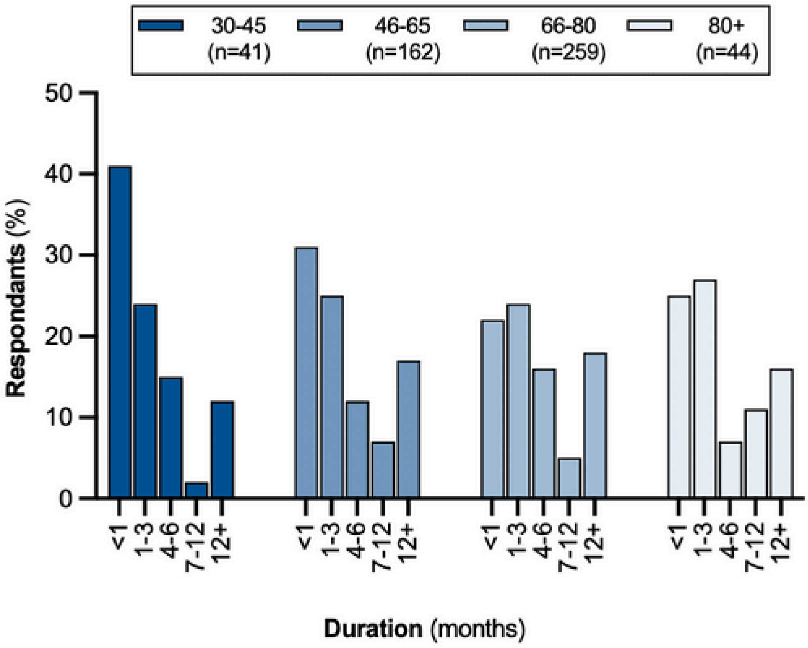


Figure 8: ***Effect of age on Q13: How long was it from the time you first experienced symptoms until you first spoke to a healthcare professional about them? By this we mean any healthcare professional you saw, this could be a GP / family doctor, hospital doctor, etc.*** *Data are shown as a % from n=515 respondents.*

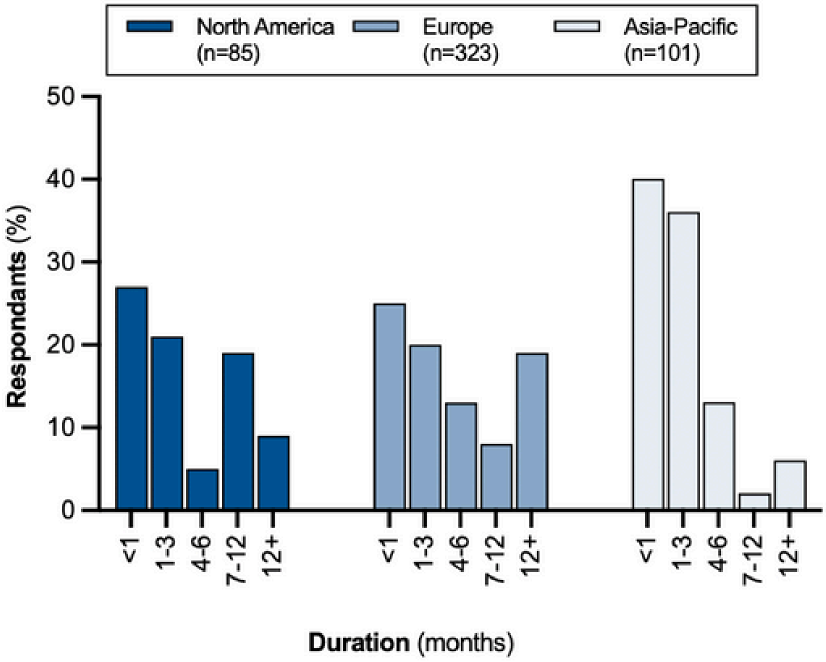


Figure 9: ***Effect of geographical location on Q13: How long was it from the time you first experienced symptoms until you first spoke to a healthcare professional about them? By this we mean any healthcare professional you saw, this could be a GP / family doctor, hospital doctor, etc.*** *Data are shown as a % from n=515 respondents.*

NUMBER OF HEALTHCARE VISITS BEFORE A BLOOD TEST

Just under half of patients (51%) visited a healthcare professional about their symptoms once, before they had blood tests (Figure 10). The age of patients, gender, geographical location and education level may influence the number of healthcare visits before a blood test.

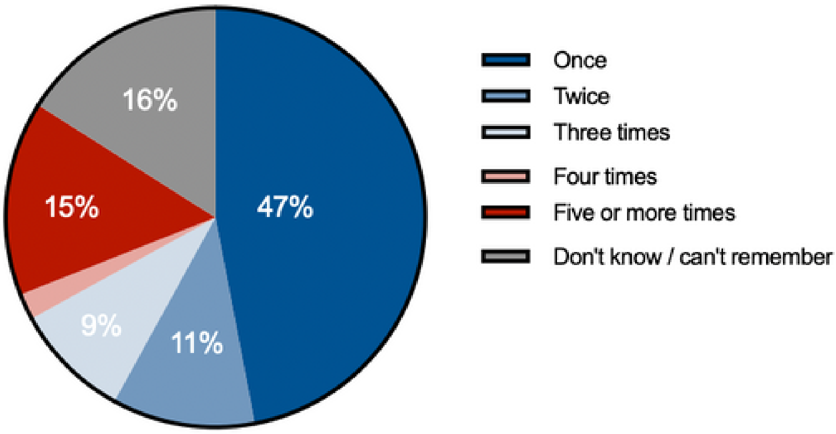


Figure 10.* *Q14: How many times did you see a healthcare professional about your symptoms before you had blood tests? By this we mean any healthcare professional you saw, this could be a GP / family doctor, hospital doctor. *Data are shown as a % from n=514 respondents.*

Although younger patients visited healthcare professional quicker than older patients, the number of visits needed prior to a blood test was greater. Only 34% of patients aged 30-45 years were likely to visit only once before blood tests compared to 57% of those aged 80+ years (Figure 11). One reason may be that MDS is more common in those aged over 60 years and so blood tests may be more routinely requested in this demographic group. Between 13-17% of respondents within the different age categories couldn't remember or didn't know the number of healthcare visits before blood tests.

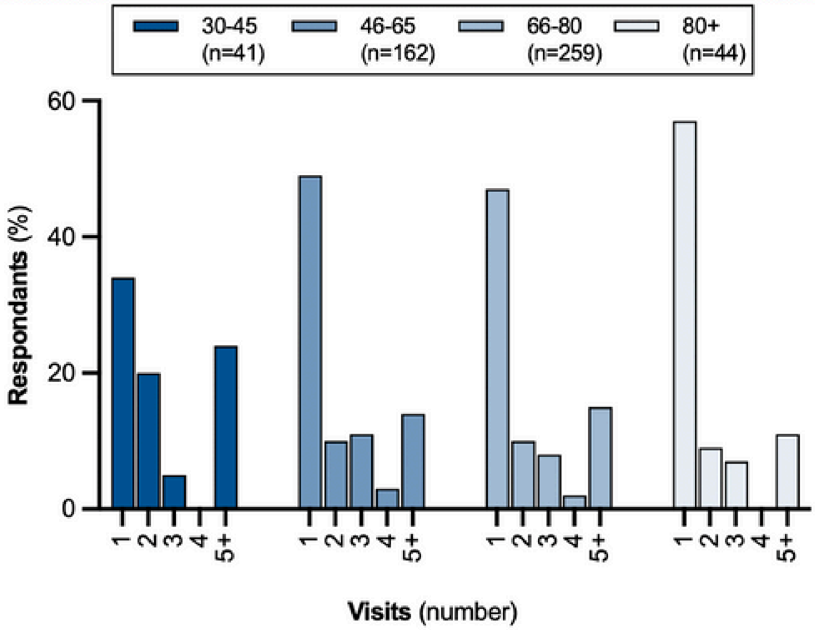


Figure 11. Effect of age on Q14: How many times did you see a healthcare professional about your symptoms before you had blood tests? By this we mean any healthcare professional you saw, this could be a GP / family doctor, hospital doctor. *Data are shown as a % from n=514 respondents.*

Patients living in North America (65%) were more likely to get blood tests after the first visit with a healthcare professionals compared to 46% in Europe and 34% in Asia-Pacific (Figure 10) (Figure 12). 11%, 15% and 24% of respondents living in North America, Europe and Asia-Pacific respectively couldn't remember or didn't know the number of healthcare visits before blood tests.

Males (51%) were slightly more likely to get blood tests after the first visit with a healthcare professional compared females (43%) (Figure 13). 16% of males and 16% of females couldn't remember the number of healthcare visits before blood tests.

Patients with a postgraduate qualification (53%) were more likely to get blood tests after the first visit with a healthcare professionals compared to those with secondary school, primary school or none (44%) (Figure 14). Between 12-20% of respondents within the different qualification categories couldn't remember or didn't know the number of healthcare visits before blood tests.

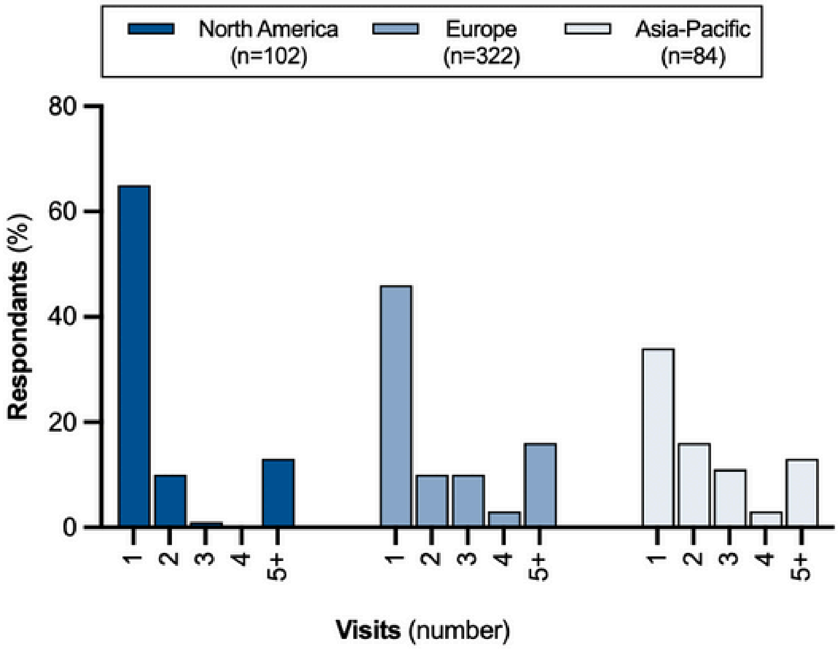


Figure 12. ***Effect of geographical location on Q14: How many times did you see a healthcare professional about your symptoms before you had blood tests? By this we mean any healthcare professional you saw, this could be a GP / family doctor, hospital doctor.*** *Data are shown as a % from n=514 respondents.*

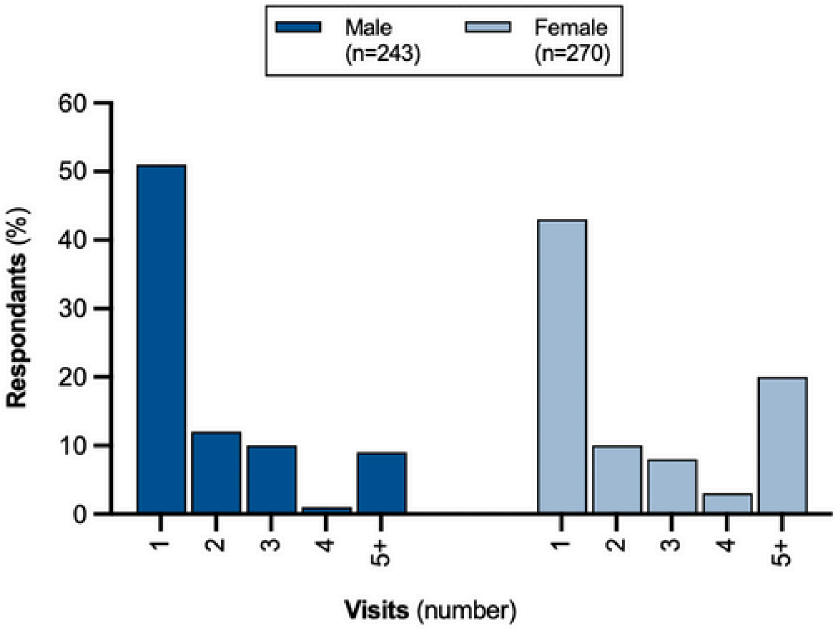


Figure 13. ***Effect of gender on Q14: How many times did you see a healthcare professional about your symptoms before you had blood tests? By this we mean any healthcare professional you saw, this could be a GP / family doctor, hospital doctor.*** *Data are shown as a % from n=514 respondents.*

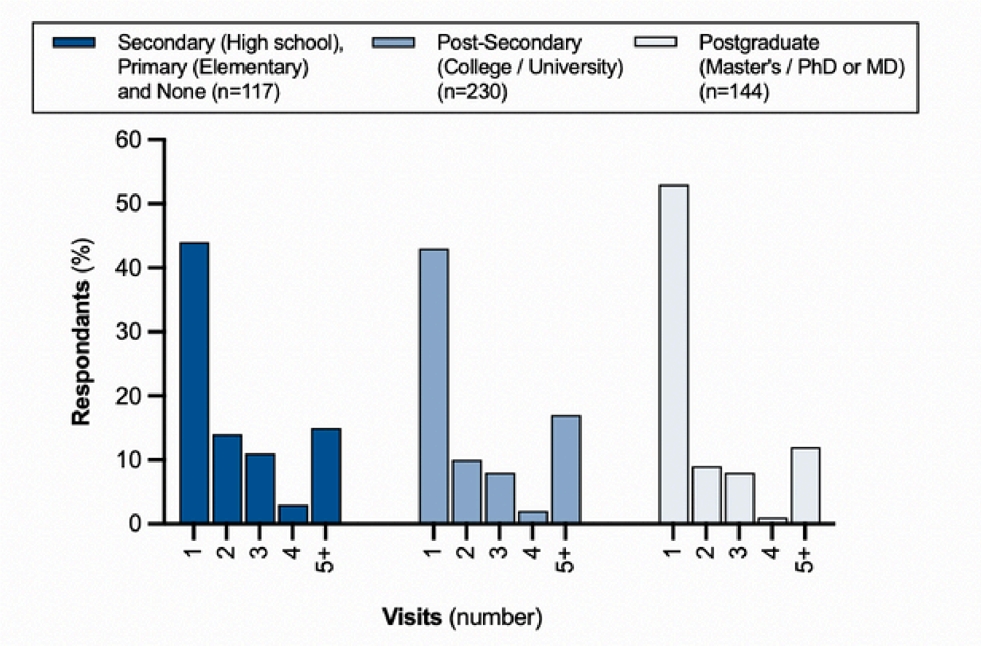


Figure 14. ***Effect of education on Q14: How many times did you see a healthcare professional about your symptoms before you had blood tests? By this we mean any healthcare professional you saw, this could be a GP / family doctor, hospital doctor.*** *Data are shown as a % from n=514 respondents.*

BONE MARROW BIOPSY

Globally, patients were most likely to report their MDS was initially detected by a routine blood test (50%) (Figure 15). 97% of patients received a bone marrow biopsy as a confirmation of their MDS (Figure 16). Globally, 59% of patients reported having a bone marrow biopsy within 3 months of having their initial blood test.

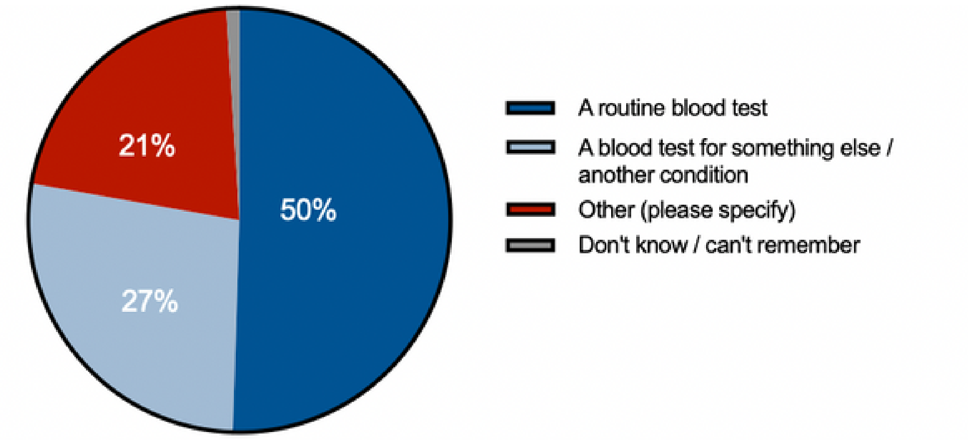


Figure 15: Q15: Was your MDS initially detected from one of the following? *Data are shown as a % from n=508 respondents.*

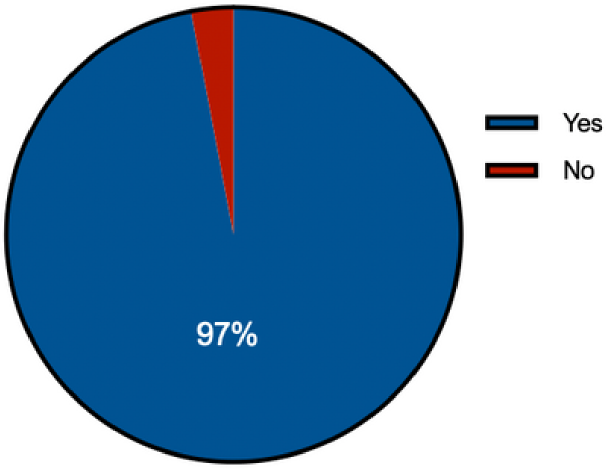


***Figure 16:* Q16: Did you have a bone marrow biopsy to diagnose your MDS?** *Data are from n=513 respondents.*

AVAILABILITY OF GENETIC TESTING

More than three-quarters (77%) of patients reported that genetic testing is available in their country (Figure 17). This was most common in Asia-Pacific (94%), while patients in Europe (30%) were most likely to report they did not know if genetic testing was available in their country (Figure 18).

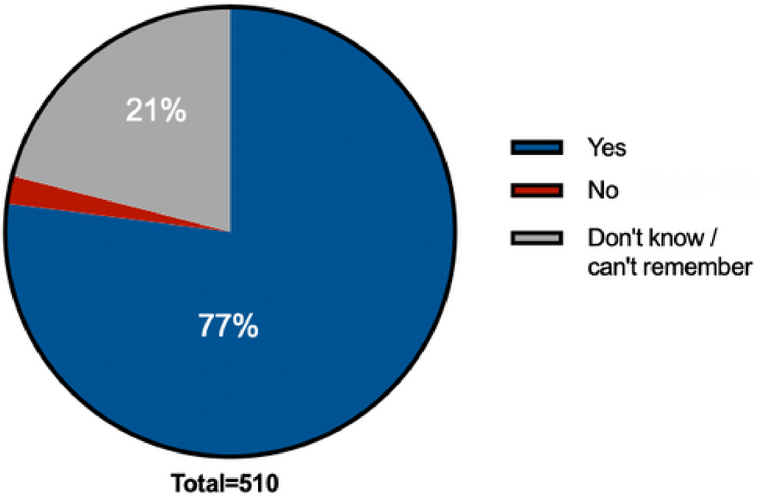


***Figure 17.* Q17. Is genetic testing available in your country?** *Data are shown as a % from n=510 respondents.*

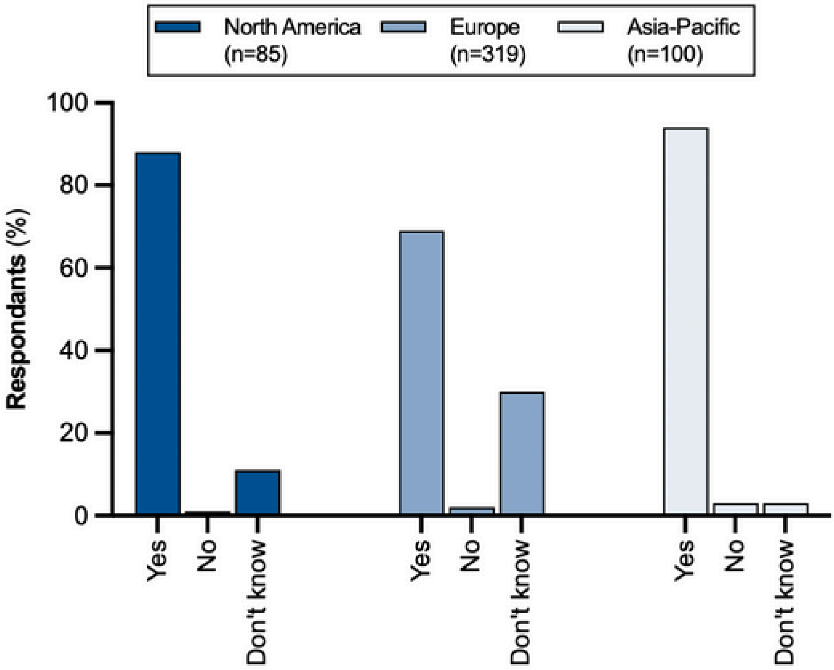


***Figure 18.* Effect of geographical location on Q17: Is genetic testing available in your country?** *Data are shown as a % from n=510 respondents.*

TESTING METHODS FOR MDS

Globally, the most received tests were (Figure 19):

- Complete blood count testing (87%)
- Chromosome tests (genetic testing) (58%)
- Gene mutation testing (51%)

Patients who had received chromosome tests (genetic testing) were asked how many genes were tested. Three-quarters (75% of patients reported that they did not know or could not remember (Figure 20).

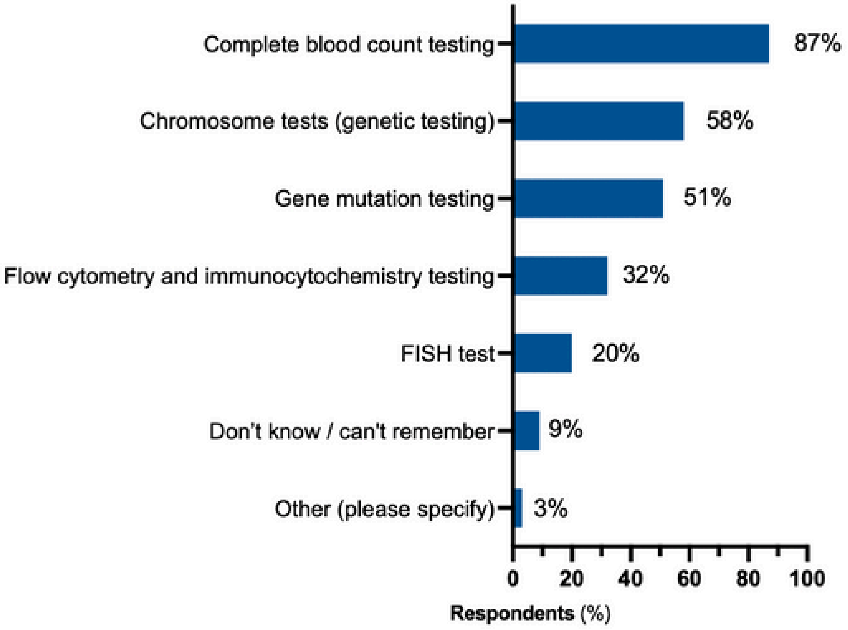


Figure 19: ***Q19: Have you had any of the following test(s)? Please select all that apply.*** *Data are shown as a % from n=507 respondents.*

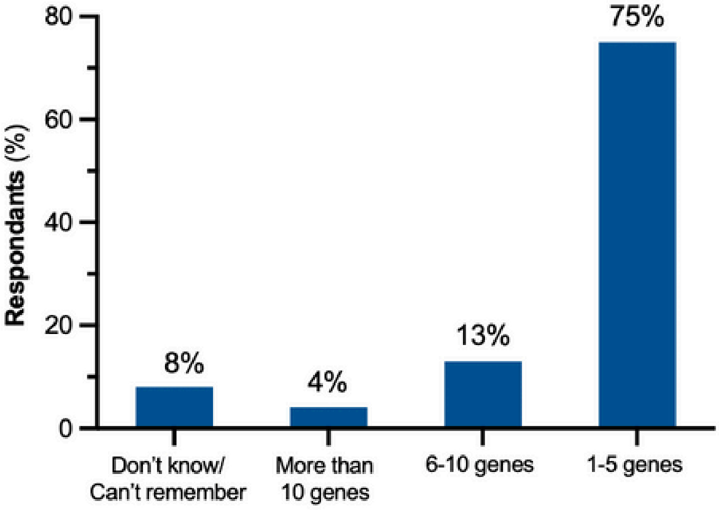


Figure 20: ***Q20: In your chromosome tests (genetic testing), how many genes were tested?*** *Data are shown as a % from n=290 respondents.*

DELAY IN MDS DIAGNOSIS

Nearly six in ten (58%) patients reported they waited less than 6 months from their first abnormal blood test to receiving their MDS diagnosis (Figure 21). Patients who waited six months or longer from their first abnormal blood test to receiving their MDS diagnosis were asked if there were any reasons for this delay. A total of 81% reported contributing factors to their delays. The most reported reasons were (Figure 21):

- Inconclusive results or no diagnosis given (39%)
- Lack of awareness or knowledge about MDS (33%)
- Misdiagnosis or incorrect initial diagnosis (25%)

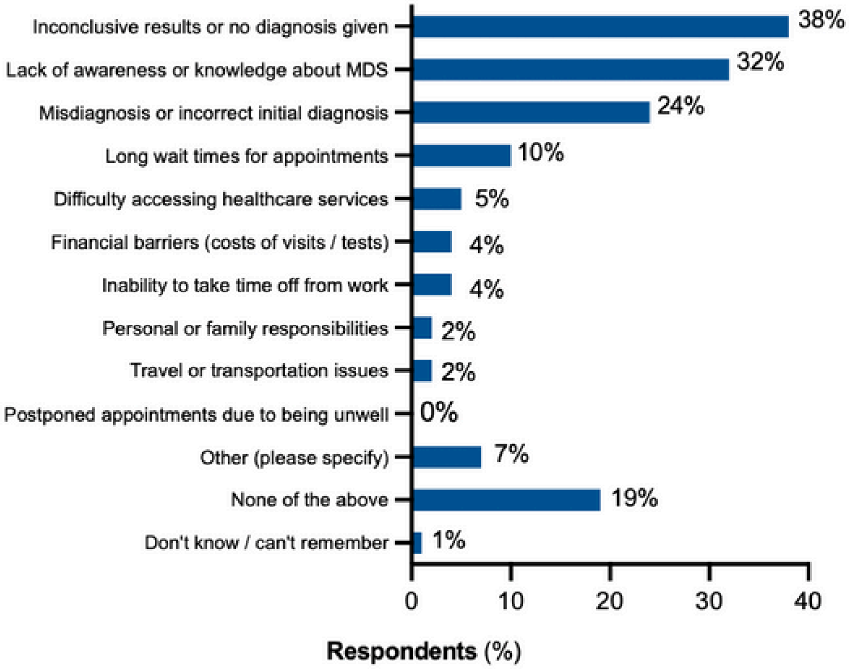
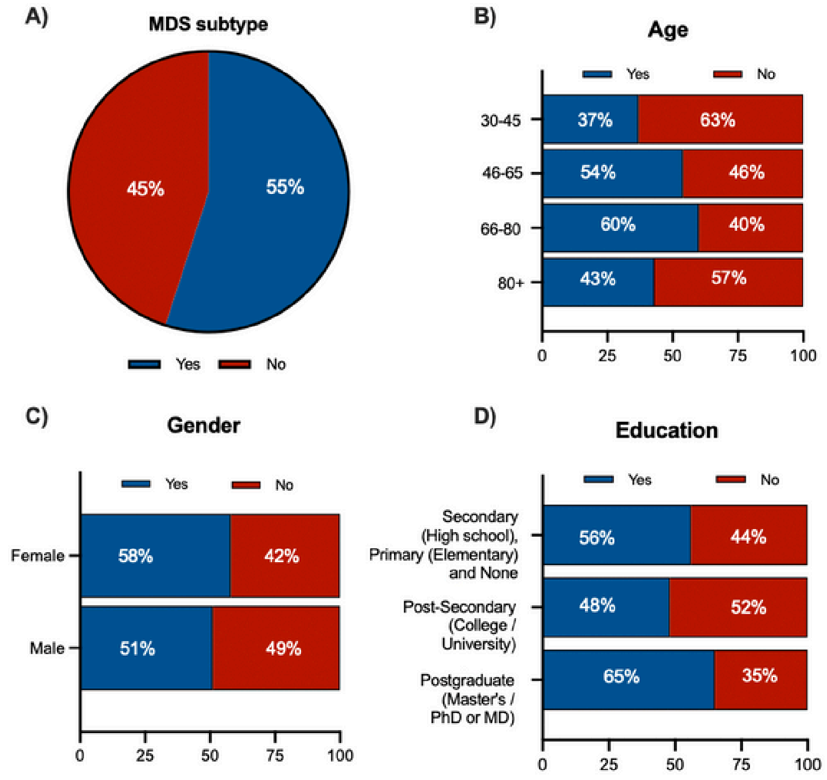


***Figure 21:* Q22: Did any of the following delay your MDS diagnosis? Please select all that apply.** *Data are shown as a % from n=207 respondents.*

MDS SUBTYPE AWARENESS

A major finding from this survey is that **nearly half of all respondents (45%) were unaware of their MDS subtype** (Figure 22A). Of those that were aware (55%), the most common MDS subtypes noted was MDS with; low blasts and isolated 5-q deletion (19%), multilineage dysplasia (18%), low blasts and SF3B1 mutation (12%) and low blasts with ring sideroblasts (10%).

Certain trends were observed when further unpicking this data. The 'youngest' (35-45 years) and 'oldest' (80+ years) age groups were least aware of their subtype (63% and 47% respectively compared to 46% and 40% compared to those aged between 45-60 years and 65-80 years) (Figure 22B). Women, those living in Asia-Pacific and those with less than €45,000 (Figure 22C, E and F). 48% of those with a post-secondary school education were aware of their MDS subtype compared to 65% of those with a postgraduate degree (Figure 22D). This suggests that age, gender, geographical location, level of education and income may all play a role in patients' awareness of their subtype.



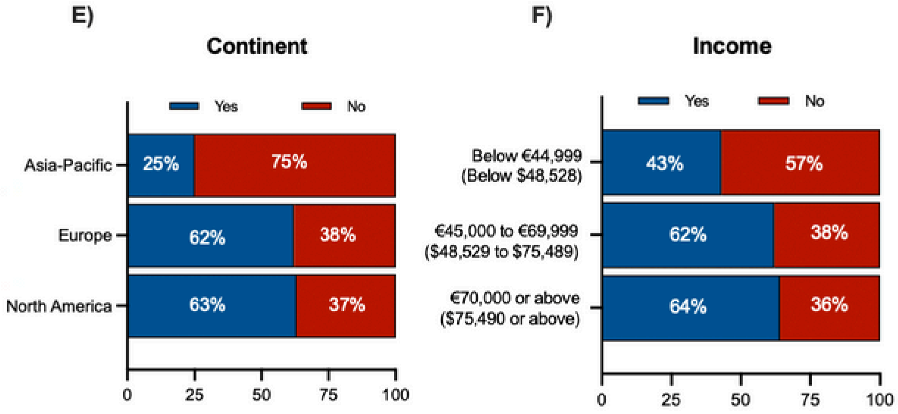


***Figure 22:* Q23: Do you know your MDS subtype? Patients were asked whether they knew their MDS subtype (A). Data was separated according to age (B), gender (C), education level (D), continent (E) and income (F).** *Data are shown as a % from n=512 respondents.*

To unpick this further, follow on questions about patients' opinions of the level of information provided by healthcare professionals at diagnosis were asked. This may help to determine whether the reason patients do not know their subtype is because they haven't been clearly informed by healthcare professionals.

IPSS-R AND IPPS-M AS SCORING SYSTEMS

The Patient 'International Prognostic Scoring System' (IPSS)-R and IPSS-M are risk stratification systems used to predict patient prognosis and guide treatment decisions. Patients were asked to provide details on the scoring system that determined their risk level at diagnosis or at the time of responding to the survey. It was noted that the IPSS-R scale was the main determinant scale of risk level for respondents at diagnosis and at the time of completing the survey. When looking at the IPSS-R risk score at diagnosis, it was noted that nearly half of patient respondents had very low - low risk MDS (48%) (Table 5). A total of 19% had intermediate risk MDS and 11% had high – very high risk MDS. Low risk MDS remained the most common risk level of patients at the time of completing the survey.

Importantly, nearly one in ten (9%) of patients claimed that they did not know or couldn’t remember their risk score at diagnosis whereas nearly **one in four (23%) did not know their risk score** at the time of responding to the survey. This significant number suggests that more may be done to inform patients of their subtype.

<table>
<tr><th colspan="5">Q26a: Patient IPPS-R risk level <i>at diagnosis</i></th></tr>
<tr><td>Very low
7%</td><td>Low
41%</td><td>Intermediate 19%</td><td>High
7%</td><td>Very high
4%</td></tr>
<tr><th colspan="5">Q26b: Patient IPPS-R risk level <i>at time of completing survey</i></th></tr>
<tr><td>Very low
6%</td><td>Low
27%</td><td>Intermediate 10%</td><td>High
3%</td><td>Very high
2%</td></tr>
</table>

<table>
<tr><th colspan="5">Q26a: Patient IPPS-M risk level <i>at diagnosis</i></th><th></th></tr>
<tr><td>Very low
1%</td><td>Low
4%</td><td>Moderate low
2%</td><td>Moderate high
2%</td><td>High
2%</td><td>Very high
1%</td></tr>
<tr><th colspan="6">Q26b: Patient IPPS-M risk level <i>at time of completing survey</i></th></tr>
<tr><td>Very low
2%</td><td>Low
9%</td><td>Moderate low
6%</td><td>Moderate high
4%</td><td>High
5%</td><td>Very high
2%</td></tr>
</table>

Table 5.* *Q26: What was your IPSS-R or IPSS-M risk level / category at diagnosis and at time of completing the survey? If you know both your IPSS-R or IPSS-M risk level / category, please provide your IPSS-M risk level / category. *Data are shown as a % from n=289 and n=284 respondents for at diagnosis and at time of completing the survey respectively.*

QUALITY-OF-LIFE ISSUES, SURVIVAL RATES AND SUITABILITY FOR STEM CELL TRANSPLANT

Patients were asked to what extent certain aspects were explained to them at diagnosis. Patients were most likely to report they received a complete explanation about MDS treatment options (56%), closely followed by how their MDS may progress (55%). In contrast, fewer patients reported receiving a complete explanation about the impact of MDS on their quality of life (35%) and average survival time (31%) (Figure 23).

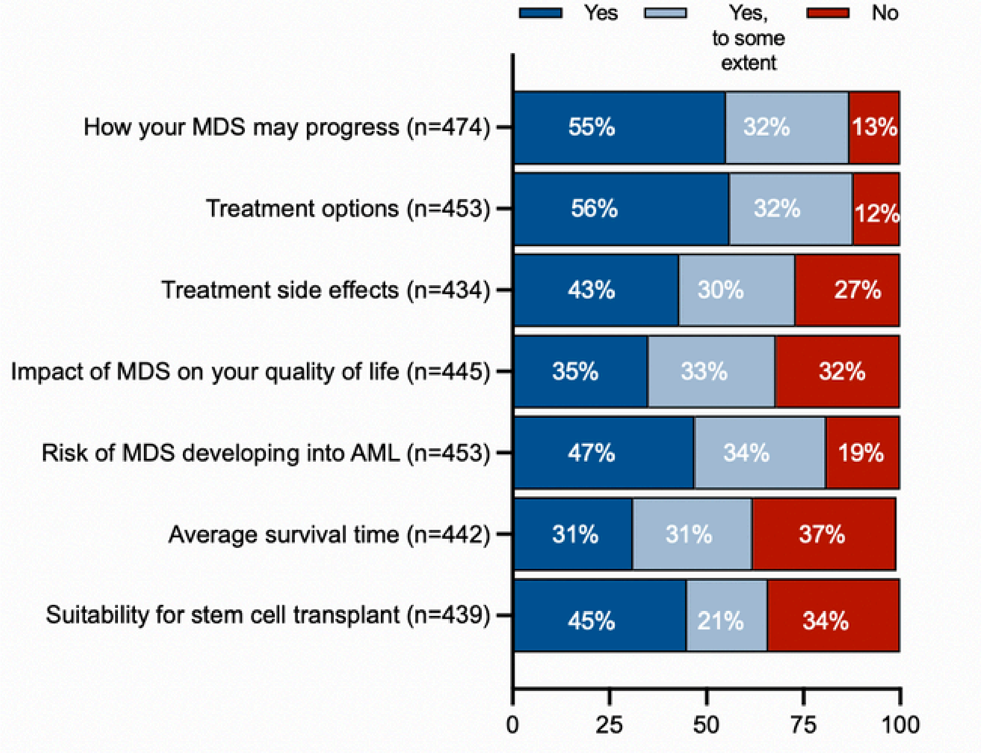


Figure 23: ***Q27: At diagnosis, did a healthcare professional explain the following to you in a way you could understand.****Data are shown as a % from n=434-474 respondents.*

Age was the biggest determinant as to how certain aspects were explained to them at diagnosis from healthcare professionals (Figure 24-27). A higher proportion of younger patients (aged 30-45 years) felt that they could understand the explanation from their healthcare professional regarding how their MDS may progress (Figure 24), their treatment options (Figure 25), treatment side-effects (Figure 26) and suitability for a stem cells transplant (Figure 27).

There was no obvious age trends related to how patients felt that they could understand the explanation from their healthcare professional regarding the impact of quality of life (Figure 28), risk of transition of MDS to AML (Figure 29) and average survival time (Figure 30).

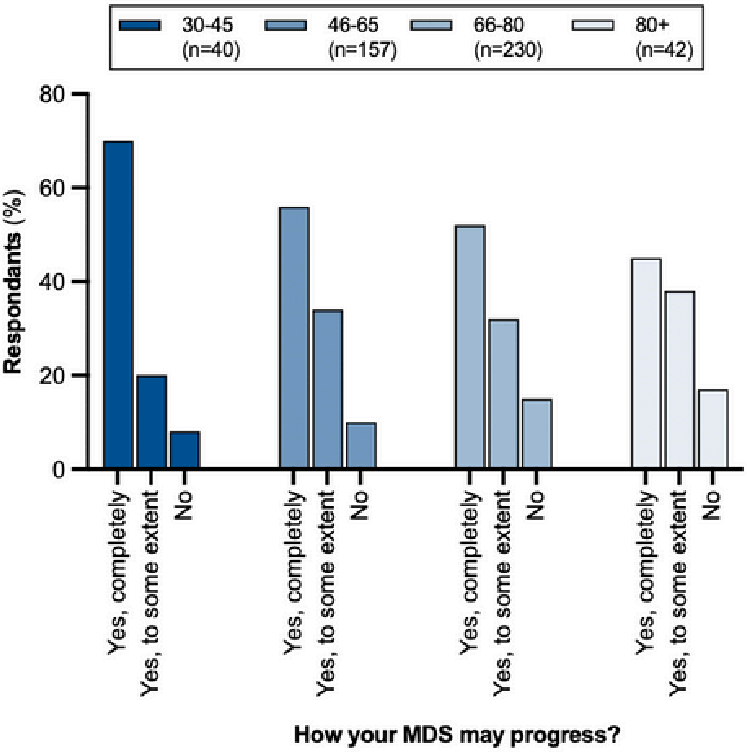


Figure 24: ***Effect of age on Q27: At diagnosis, did a healthcare professional explain the following to you in a way you could understand how your MDS may progress.*** *Data are shown as a % from n=477 respondents.*

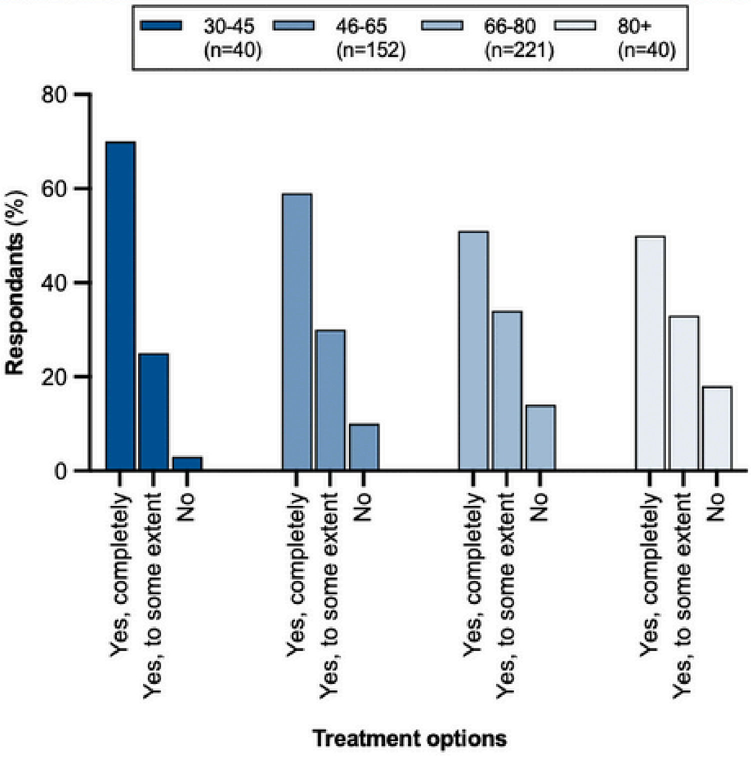


Figure 25: ***Effect of age on Q27: At diagnosis, did a healthcare professional explain the following to you in a way you could understand your treatment options.*** *Data are shown as a % from n=461 respondents.*

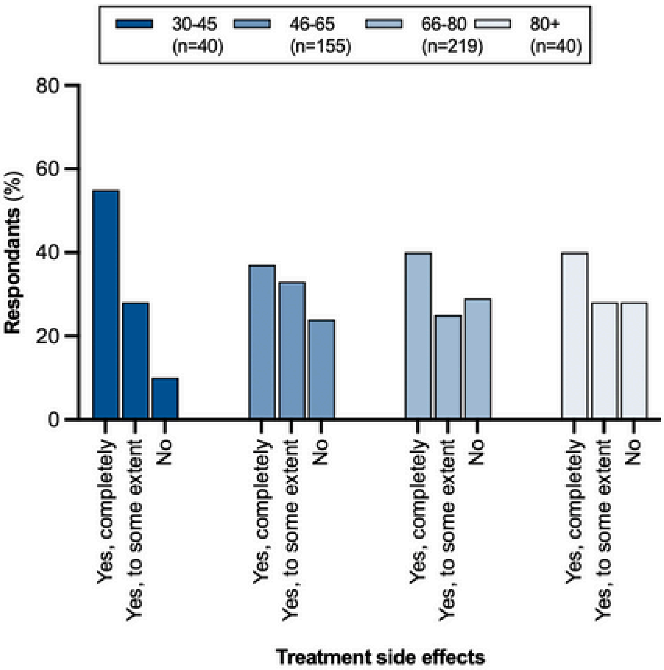


Figure 26: ***Effect of age on Q27: At diagnosis, did a healthcare professional explain the following to you in a way you could understand your treatment side effects.*** *Data are shown as a % from n=463 respondents.*

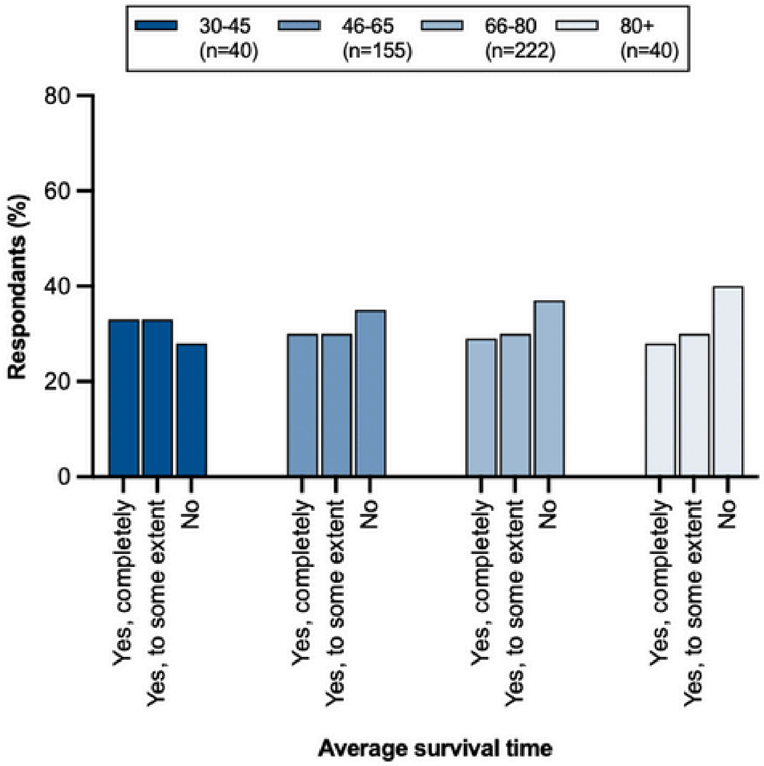


Figure 27: ***Effect of age on Q27: At diagnosis, did a healthcare professional explain the following to you in a way you could understand the average survival time.*** *Data are shown as a % from n=463 respondents.*

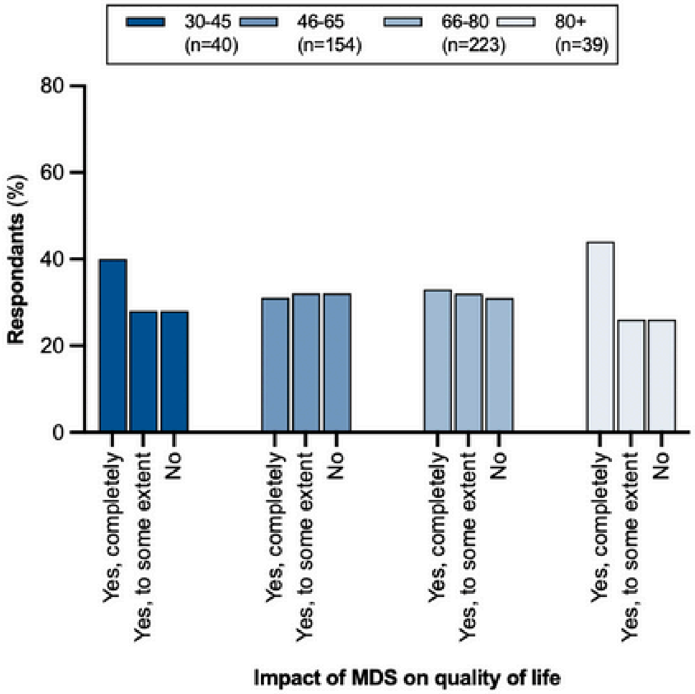


Figure 28: ***Effect of age on Q27: At diagnosis, did a healthcare professional explain the following to you in a way you could understand the impact of MDS on quality of life.*** *Data are shown as a % from n=464 respondents.*

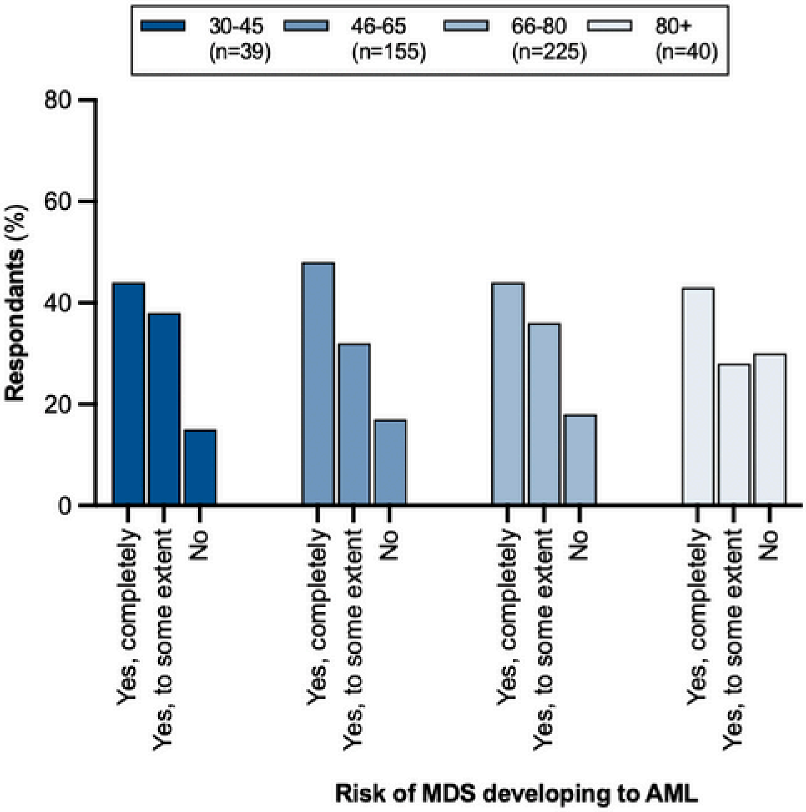


Figure 29: ***Effect of age on Q27: At diagnosis, did a healthcare professional explain the following to you in a way you could understand the risk of MDS developing to AML.*** *Data are shown as a % from n=467 respondents.*

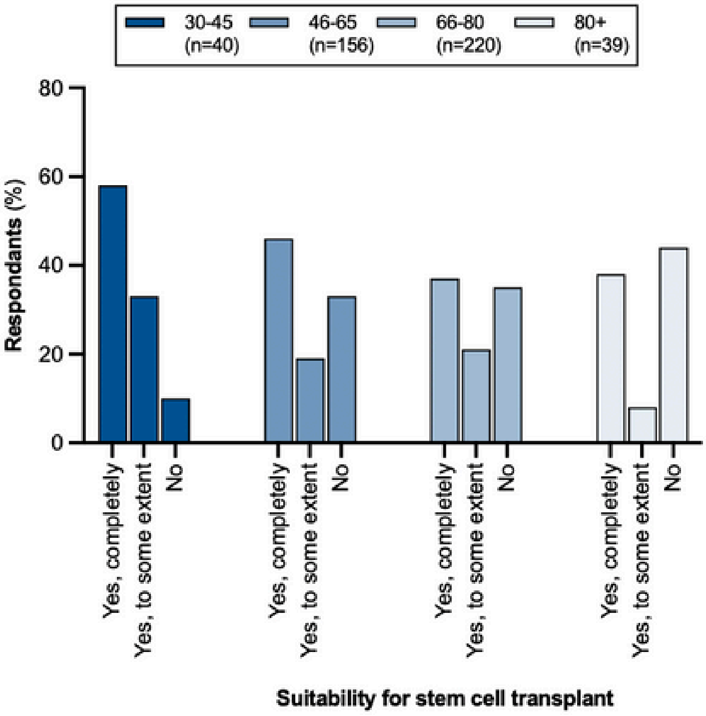


Figure 30: ***Effect of age on Q27: At diagnosis, did a healthcare professional explain the following to you in a way you could your suitability for a stem cell transplant.*** *Data are shown as a % from n=465 respondents.*

When comparing genders, there were little difference between males and females in their understanding of healthcare professionals explained to them how MDS may progress, the treatment options available, treatment side-effects, risk of MDS developing to AML, average survival times and suitability for stem cell transplant. However, more females were unaware of the impact of MDS on the quality of life; 35% of females compared to 26% of males. The levels of education and household income did not have any major impact on whether patients felt healthcare professional explained certain aspects of MDS to them well.

EASE OF ACCESSING DIAGNOSTIC SERVICES

Three-quarters of patients (72%) indicated that they found it either very easy or easy to access diagnostic services. Ease of accessing diagnostic services was higher in males (78%) than females (68%) (Figure 31), older (80+ years; 79%) patients than younger patients (30-45 years; 56%) (Figure 32) and in patients with a higher income (€70,000+; 74%) compared to <€45,000 (64%) (Figure 33).

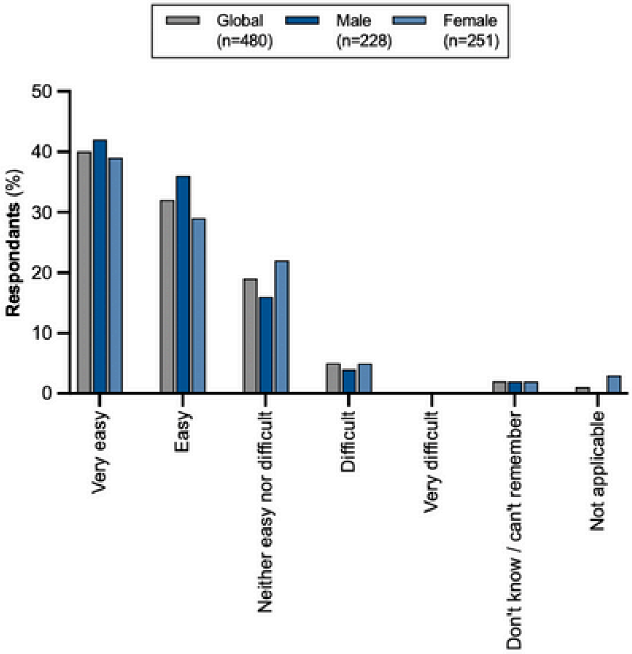


Figure 31:* Effect of gender on Q28+. How easy was it for you to access diagnostic services (such as testing, screening)?Data are shown as a % from n=480 respondents.*

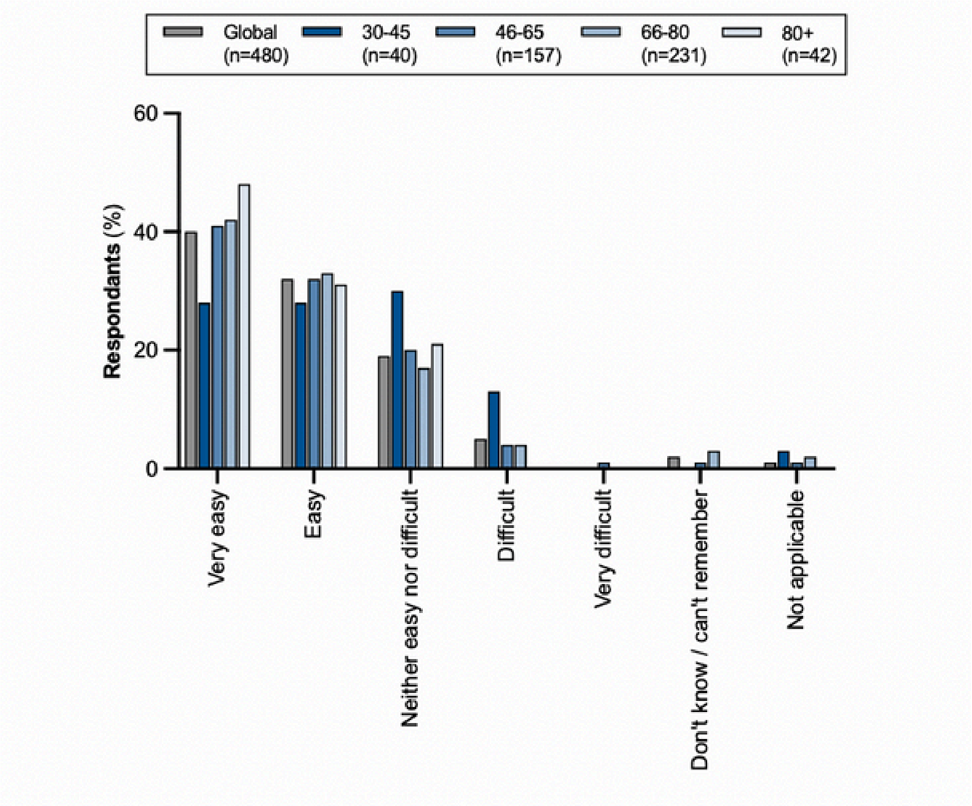


Figure 32: ***Effect of age on Q28+. How easy was it for you to access diagnostic services (such as testing, screening)?***

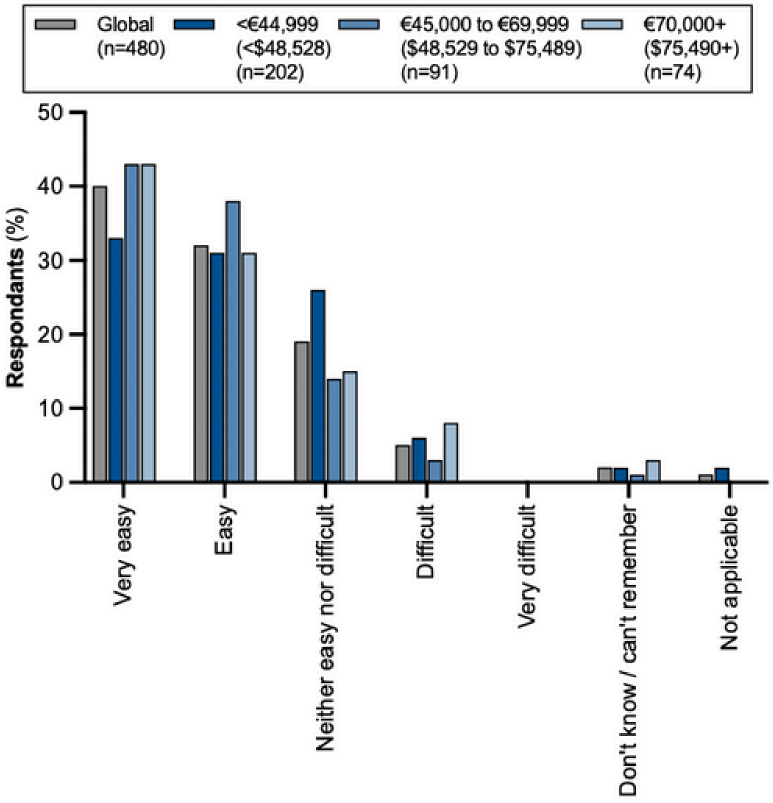


Figure 33: ***Effect of household income on Q28+. How easy was it for you to access diagnostic services (such as testing, screening)?*** *Data are shown as a % from n=480 respondents.*

SECTION 2: MDS CARE & SUPPORT

- 39% of patients receive regular support.
- Spouses – most common caregiver.
- Emotional support and help with household duties are the main form of support given by carer to patients.

The next section of questions focused around 'Care and Support'. Questions asked focused on the amount of support patients were getting, the type of support and who was providing it.

SUPPORT RECEIVED

Patients were asked about whether they received support, either paid or unpaid, in the last 12 months. Nearly four in ten (39%) patients reported receiving regular support from a paid or unpaid caregiver because of their MDS (Figure 34).

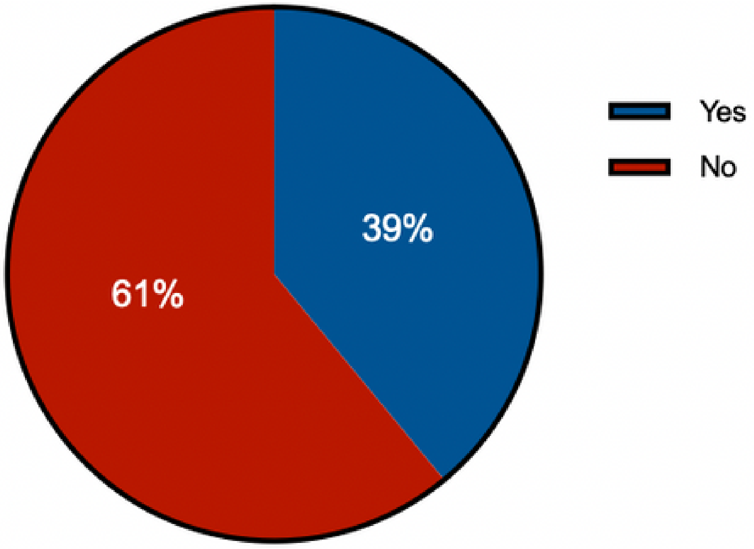


Figure 34. ***Q29 In the last 12 months, have you received regular support from a paid or unpaid caregiver, because of your MDS?*** *Data are shown as a % from n=480 respondents.*

Receipt of regular support from a paid or unpaid caregiver due to MDS varied by continent (Figure 35A). People living in Europe were least likely to receive support with 70% saying they have not received any support in the last 12 months. In contrast people living in Asia-Pacific received the most support; only 38% did not receive any support (Figure 35A). When looking at specific countries, patients in the Republic of Korea / South Korea (66%) were the most likely to report receiving support. Analysis by age shows that patients aged 30-45 (63%) were more than twice as likely to report receiving regular support from a paid or unpaid caregiver, than patients aged 66-80 (30%) (Figure 35B).

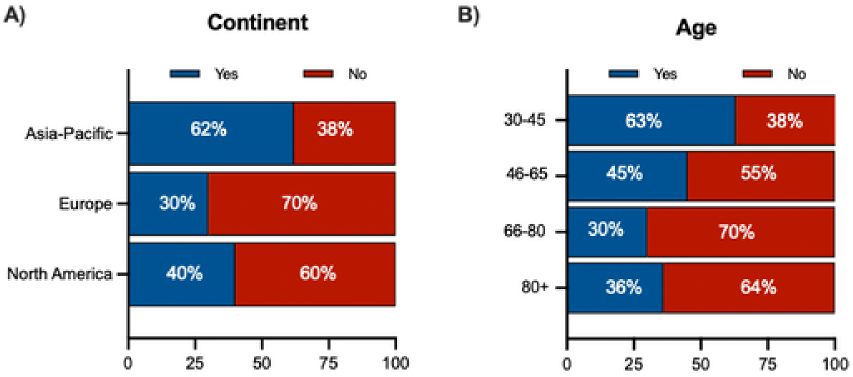


Figure 35: ***Q29: In the last 12 months, have you received regular support from a paid or unpaid caregiver, because of your MDS?*** *Data are shown as a % from n=480 respondents.*

SPOUSES/ PARTNERS ARE THE MOST COMMON CAREGIVERS THAT PROVIDE SUPPORT

Of patients who receive regular caregiver support, seven in ten (70%) reported being supported by their spouse / partner, while 43% were supported by a family member such as a parent, child, sibling or cousin (Figure 36).

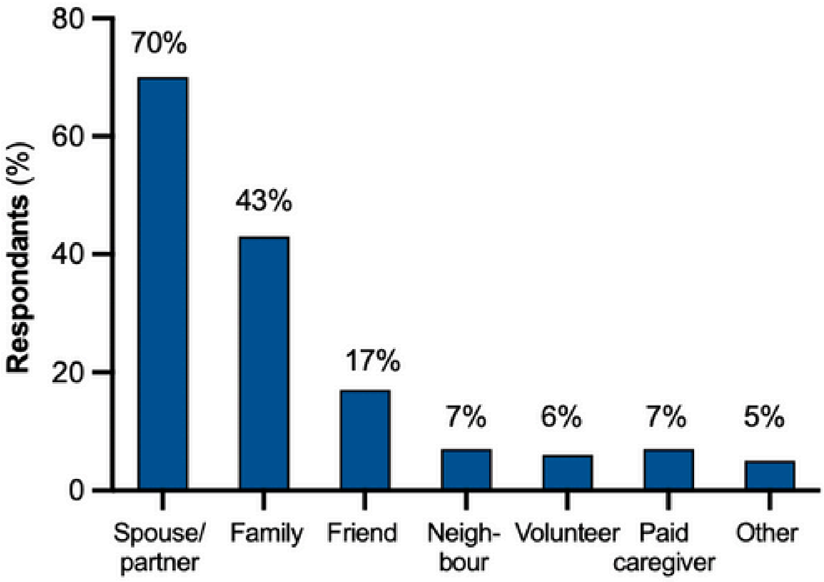


***Figure 36:* Q30: Which of the following best describes the caregiver(s) who provided support? Please select all that apply.** *Data are shown as a % from n=182 respondents.*

TYPE OF SUPPORT RECEIVED

The most reported types of support received by patients included (Figure 37):

- Companionship and emotional support (83%)
- Household tasks e.g. cooking, cleaning, other household chores (74%)
- Providing companionship during trips or appointments (51%)

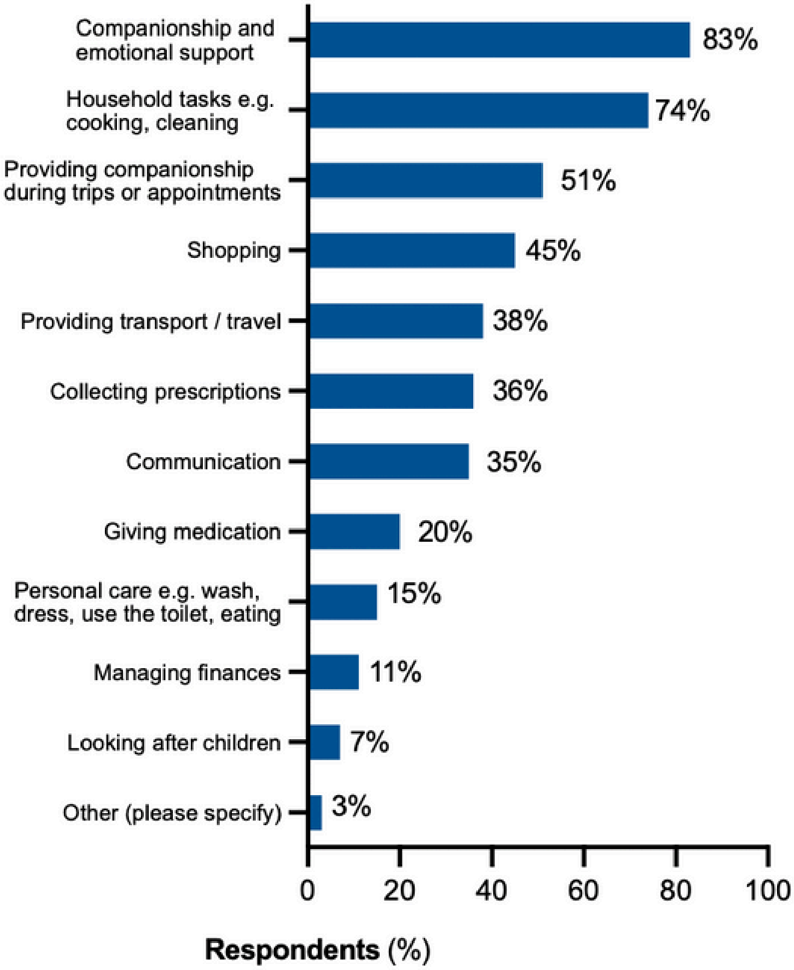


***Figure 37:* Q31: What type(s) of support did your caregiver(s) provide? Please select all that apply.** *Data are shown as a % from n=184 respondents.*

SECTION 3: MDS TREATMENT

- 1 in 10 – feel not involved in decisions.
- Centres of Excellence – variable access.
- Fatigue and joint pain - most common side effect.
- Treatment access is variable.
- Appointment cancellations are highest in younger patients.

The next section of questions focused around ‘Treatment’. Questions asked focused on issues related to treatment, including access to care and symptoms and side effects to treatments.

TIME TRAVELLED TO SEE A MDS SPECIALIST

Globally, 71% of patients travel 60 minutes or less to see their MDS specialist. Only 2% of patients globally reported not having an MDS specialist (Table 6).

Travel time varied by country and household income. Patients in North America were most likely to have a shorter journey time, with 77% travelling 60 minutes or less to their MDS specialist (Figure 38).

Similarly, patients living in a household with a higher income of €70,000 or above (80%) were more likely to travel 60 minutes or less to visit their MDS specialist, compared to 64% of patients with a total household income below €44,999, and 74% of patients with a total household income of €45,000 to €69,999 (Figure 39).

Time travelled	%
0-15 minutes	8%
16-30 minutes	26%
31-45 minutes	20%
46-60 minutes	17%
61-90 minutes	12%
90-120 minutes	8%
More than 2 hours	7%
I do not have an MDS specialist	2%

***Table 6.* Q32: On average, how long does it take you to travel to your MDS specialist?** *Data are shown as a % from n=472 respondents.*

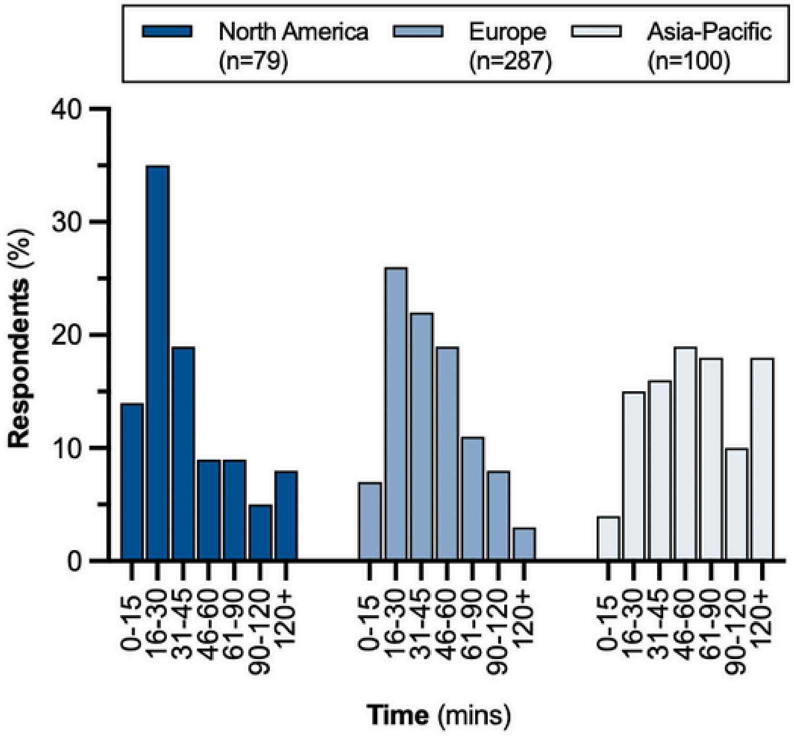


***Figure 38.* Effect of geographical location on Q32: On average, how long does it take you to travel to your MDS specialist?** *Data are shown as a % from n=472 respondents.*

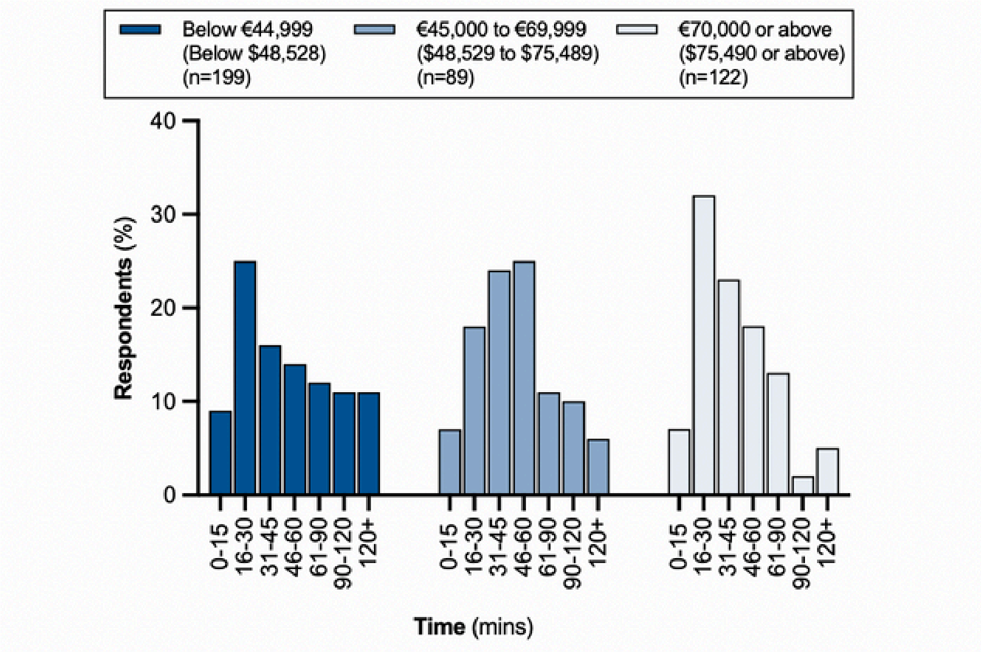


Figure 39. ***Effect of household income on Q32: On average, how long does it take you to travel to your MDS specialist?*** *Data are shown as a % from n=472 respondents.*

ACCESSING CARE FROM AN MDS SPECIALIST

Overall, 68% of patients surveyed who have a MDS specialist found it very easy or easy to access care from their specialist (Figure 40). However, this varied by geographical location, age, level of education and household income.

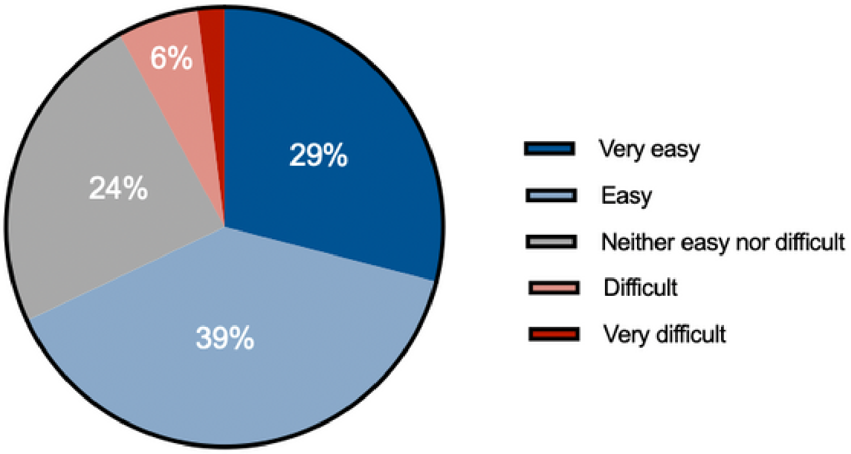


Figure 40. ***Q33: How easy is it for you to access care from your MDS specialist?*** *Data are shown as a % from n=454 respondents.*

Analysis by geographical location shows that **patients in North America (81%) were more like to find it very easy or easy to access care** from their MDS specialist, than patients in Europe (64%) or Asia-Pacific (40%) (Figure 41). Of all the patients that took part, patients living in the USA (84%) and France (79%) found it the easiest (either very easy or easy) to access care from their MDS specialist.

Analysis by age shows that **younger patients were more likely to have trouble in accessing care** from their MDS specialist. Nearly one-quarter (24%) of patients aged 30-45 found it very difficult or difficult to access care from their MDS specialist, compared to 0% (n=0) of patients aged 80+ (Figure 42).

Patients with a postgraduate degree (Master's / PHD or MD) (84%) were more likely to find it very easy or easy to access care from their MDS specialist, than patients with a post-secondary education (college / university) (59%) or those with a secondary education or less (64%) (Figure 43).

As total household income increases, ease of accessing care from a MDS specialist increases. A total of 57% of patients living in a household with a total income below €44,999 found it very easy or easy to access care from their MDS specialist, compared to 72% of patients with a total household income of €45,000 to €69,999 and 80% of those with a total household income of €70,000 or above (Figure 44).

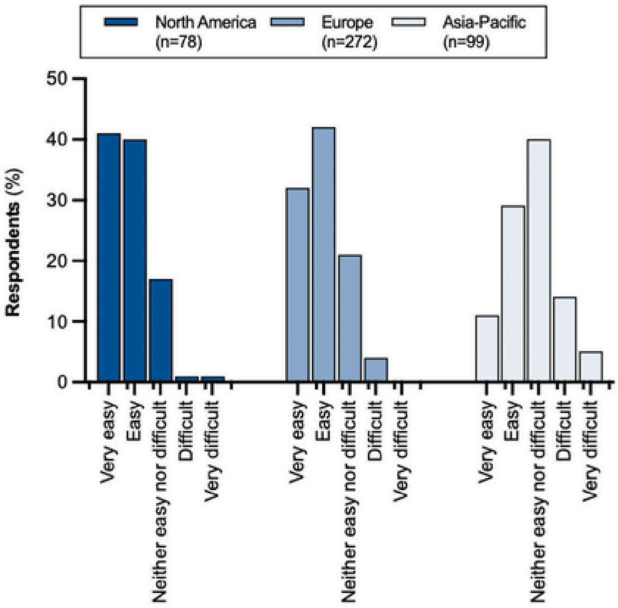


Figure 41: Effect of geographical location on Q33: How easy is it for you to access care from your MDS specialist? *Data are shown as a % from n=454 respondents.*

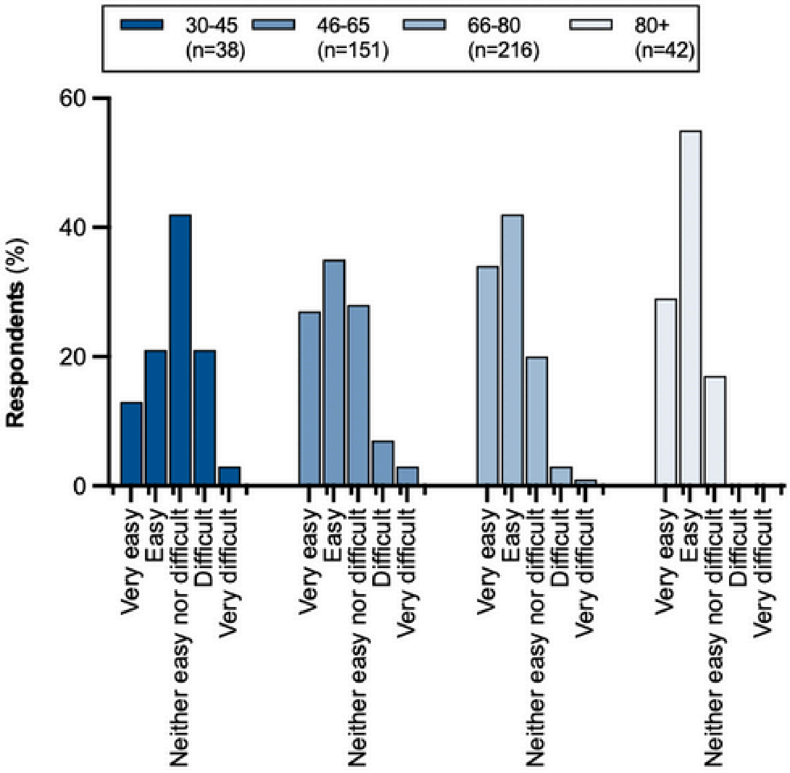


Figure 42: ***Effect of age on Q33: How easy is it for you to access care from your MDS specialist?*** *Data are shown as a % from n=454 respondents.*

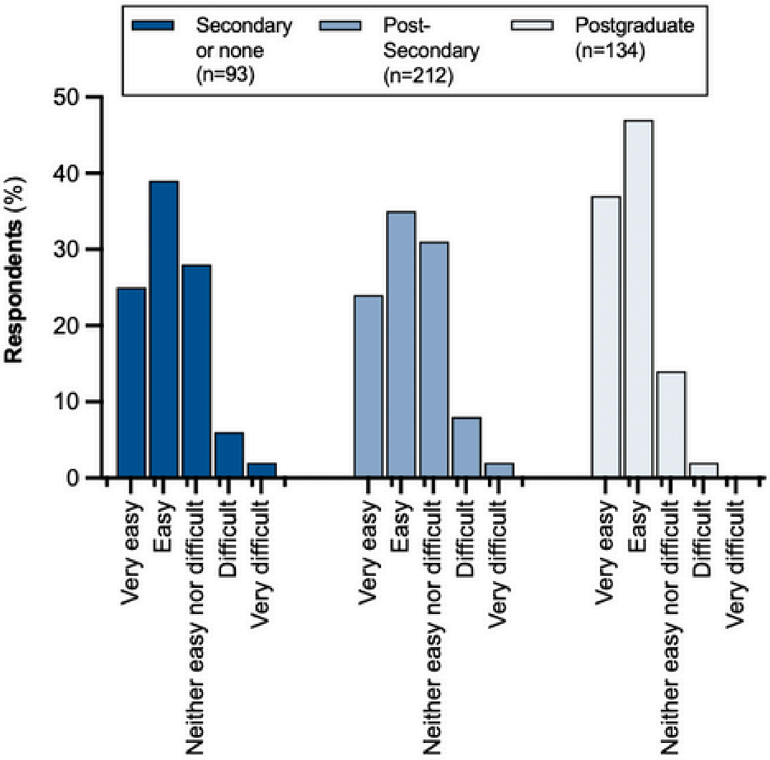


Figure 43: ***Effect of education on Q33: How easy is it for you to access care from your MDS specialist?*** *Data are shown as a % from n=454 respondents.*

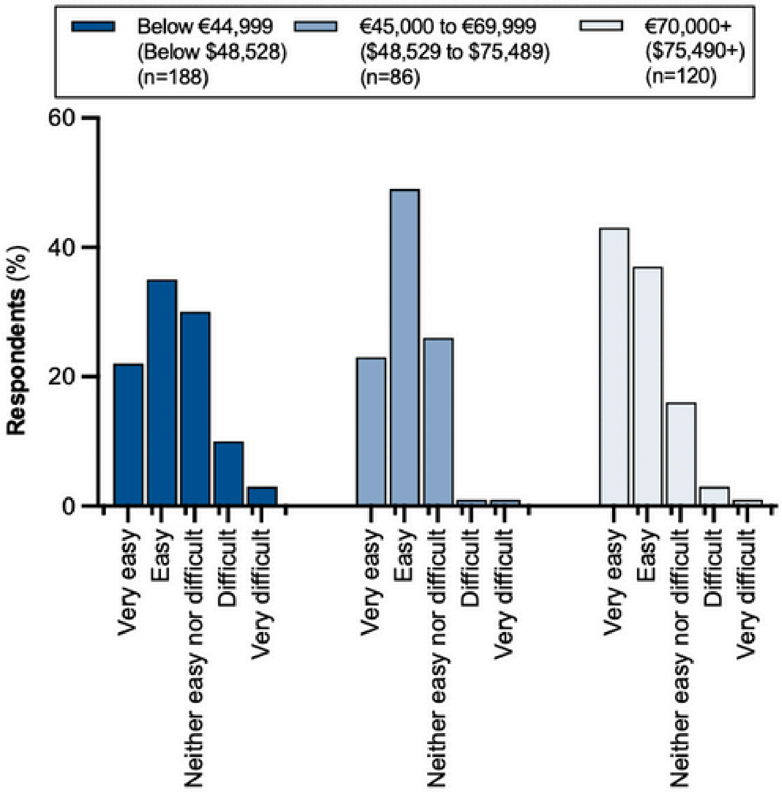


***Figure 44:* Effect of income on Q33: How easy is it for you to access care from your MDS specialist?**
Data are shown as a % from n=454 respondents.

ACCESS TO MDS CENTRES OF EXCELLENCE

MDS Centres of Excellence are specialized centres recognized for their expertise in diagnosing and treating MDS. These often provide advanced care, research opportunities, and a vast amount of patient support for MDS. A total of 157 MDS Centres of Excellence exist in the countries that completed the survey (Table 7). 50% of these are located in the United States. A total of 10 countries (32%) that took part in the survey do not have any Centres of Excellence.

Overall, more than six in ten (62%) patients have access to an MDS Centre of Excellence (Figure 45). Despite having a relatively low number of Centres of Excellence compared to other countries, access to a MDS Centre of Excellence was highest in the Republic of Korea / South Korea (92%, n=84). Analysis by continent shows patients in Europe (55%) had the least access to Centres of Excellence compared to other continents.

Country	**No. of Centres**
France	11
Republic of Korea / South Korea	3
United Kingdom of Great Britain and	9
United States of America	79
Germany	17
Canada	2
Switzerland	4
Spain	4
Austria	1
New Zealand	0
Norway	1
Luxembourg	0
Croatia	1
South Africa	1
Australia	6
Ireland	1
Denmark	2
Italy	6
Philippines	0
Andorra	0
Angola	0
Antigua and Barbuda	0
Cyprus	0
Ecuador	0
Georgia	0
Greece	4
Iceland	0
Mexico	1
Türkiye	1
Armenia	1
Israel	2

Table 7:* *MDS Centres of Excellence in the countries that respondents lived in. *Data is taken from MDS Foundation Website (https://www.mds-foundation.org/community/centers-of-excellence).*

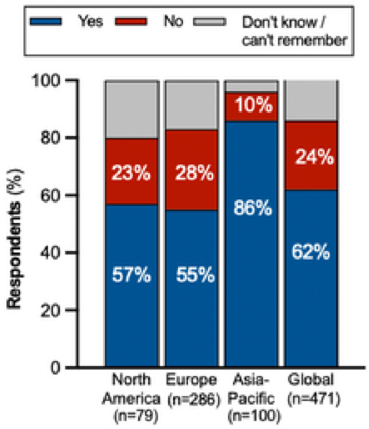


Figure 45:* *Q34: Do you have access to an MDS Centre of Excellence? *Data are shown as a % from n=471 respondents.*

APPOINTMENT SCHEDULING

Overall, 63% (n=293) of patients reported their appointments were definitely arranged on days and at times that work well for them. As age increases, the proportion of patients who felt appointments were definitely arranged on days and at times that work well for them increases (Figure 46A). Approximately one-third (36%) of patients aged 30-45 felt appointments were definitely arranged on days and at times that work well for them, compared to 56% of patients aged 46-65, 71% aged 66-80 and 74% aged 80+ (Figure 46A).

Of all the countries surveyed, the proportion of patients who felt appointments were arranged on days and at times that work well for them was highest in the USA (85%) (Figure 46B). As a result, a total of 77% of patients surveyed living in North America reported their appointments were definitely arranged on days and at times that work well for them. This was compared to 66% in Europe and 40% in Asia-Pacific (Figure 46B).

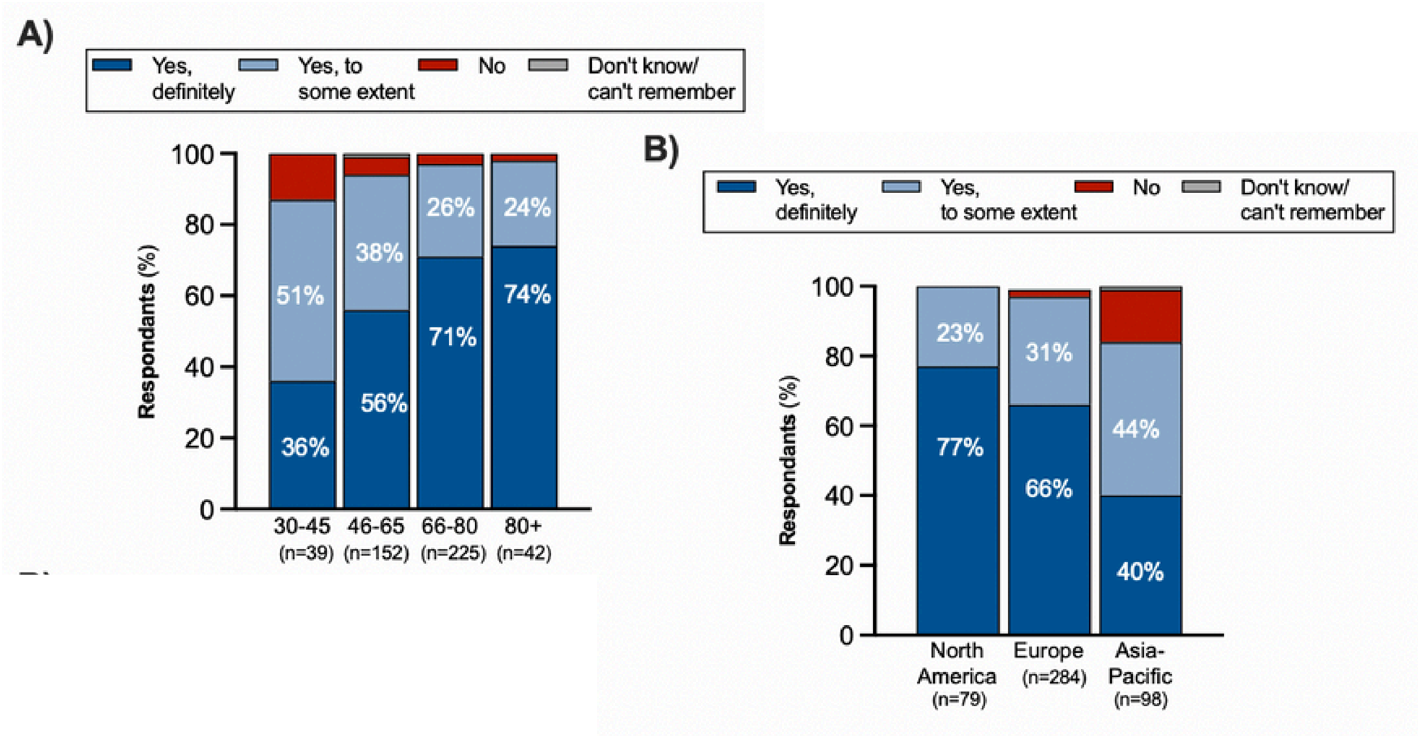


***Figure 46:* Effect of age (A) and geographical location (B) on Q35: Are your appointments arranged on days and at times that work well for you?** *Data are shown as a % from n=467 respondents.*

One reason for the above finding may be due to difficulties around arranging appointments. A total of 36% of patients aged 30-45 years compared to 4% of those aged 80+ years experienced some level of difficulty arranging appointments (Figure 47). When comparing geographical locations, 31% of patients living Asia-Pacific experienced some level of difficult arranging appointments compared to 12% in Europe and 13% in North America. As a result, levels of appointment cancelation/ re-arrangement because it was too difficult to get there were highest in patients aged 30-45 years and those living in Asia-Pacific (Figure 48).

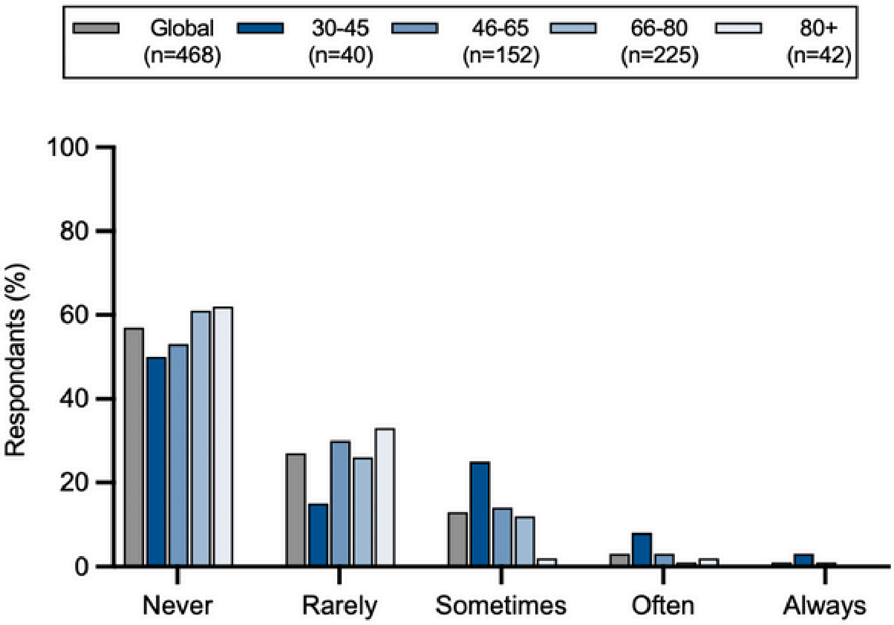


***Figure 47:* Effect of age on Q36: Do you have difficulty arranging appointments with your healthcare provider / MDS specialist?** *Data are shown as a % from n=468 respondents.*

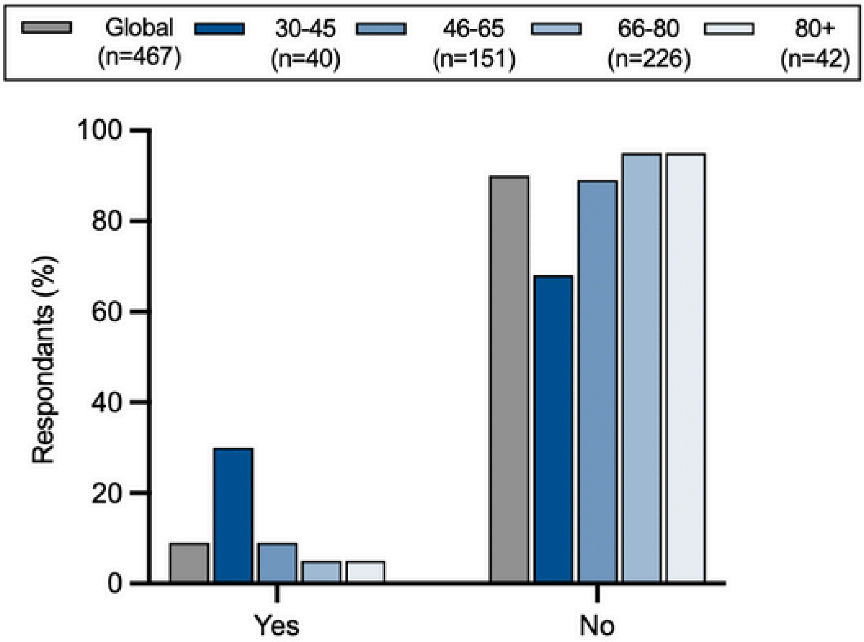
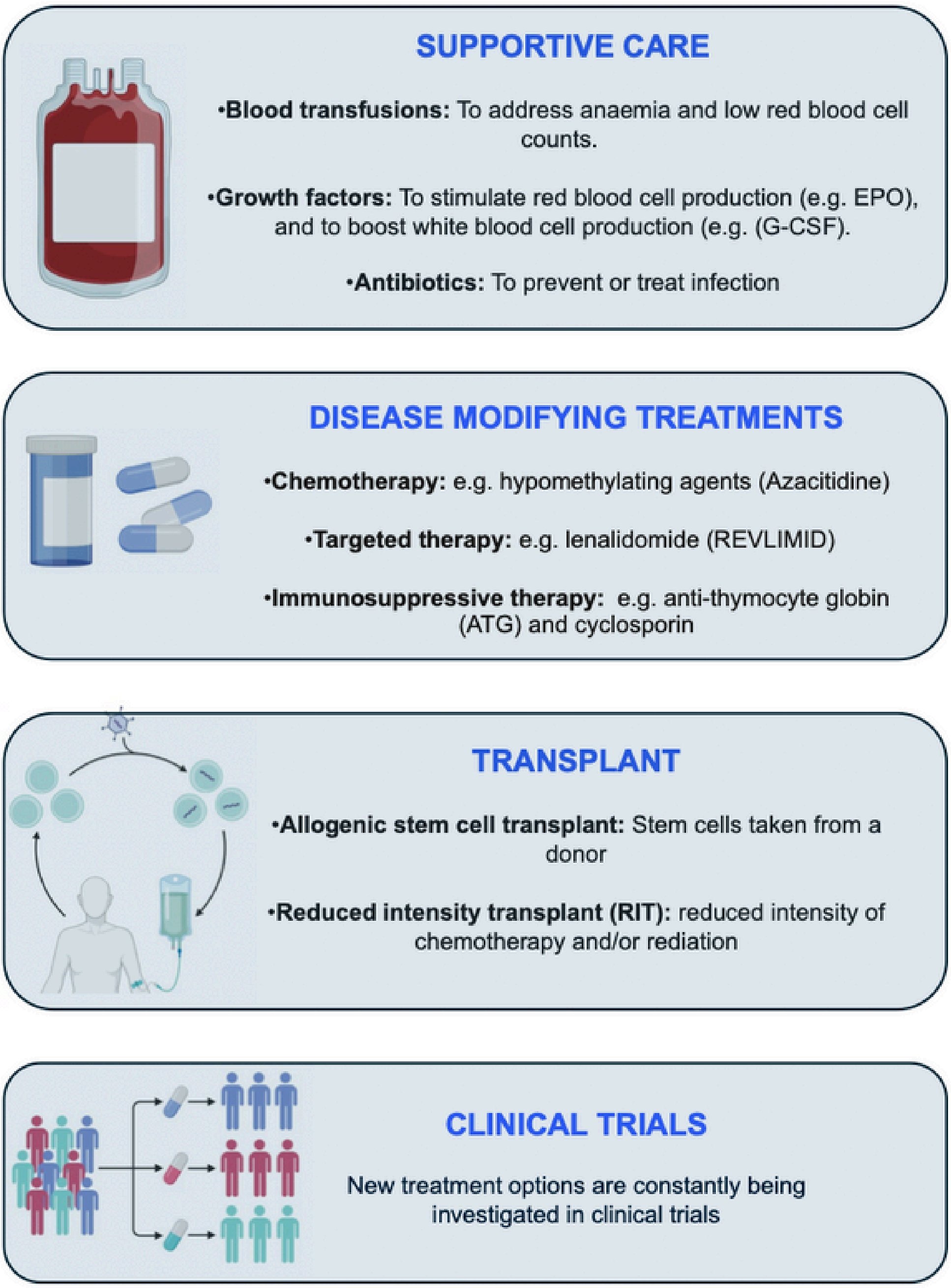


Figure 48: ***Q37: Have you ever had to rearrange or cancel your MDS treatment or appointments because it was too difficult to get there?*** *Data are shown as a % from n=467 respondents.*

TREATMENT FOR MDS

There are four main types of treatments for MDS. These include (1) supportive care, (2) disease modifying treatments, (3) transplants or (4) clinical trials (Figure 49). A summary of the types of treatments is highlighted below. In this survey, patients were asked if they were receiving any treatment and if so, what this was. It should be noted that the best treatment approach for MDS is highly individualized and depends on many factors, including the patient's age, overall health, specific characteristics of their MDS and geographical location.



SUPPORTIVE CARE

•**Blood transfusions:** To address anaemia and low red blood cell counts.

•**Growth factors:** To stimulate red blood cell production (e.g. EPO), and to boost white blood cell production (e.g. (G-CSF).

•**Antibiotics:** To prevent or treat infection

DISEASE MODIFYING TREATMENTS

•**Chemotherapy:** e.g. hypomethylating agents (Azacitidine)

•**Targeted therapy:** e.g. lenalidomide (REVLIMID)

•**Immunosuppressive therapy:** e.g. anti-thymocyte globin (ATG) and cyclosporin

TRANSPLANT

•**Allogenic stem cell transplant:** Stem cells taken from a donor

•**Reduced intensity transplant (RIT):** reduced intensity of chemotherapy and/or rediation

CLINICAL TRIALS

New treatment options are constantly being investigated in clinical trials

Figure 49. Treatment options available to patients with MDS. *Images created using Biorender®.*

Of the patients surveyed, 81% have received treatment for their MDS. The most common three treatments accessed by patients since being diagnosed with MDS were (Figure 50):

- Red blood cell transfusions (49%)
- Erythropoiesis-stimulating agents (37%)
- Platelet transfusions (24%)

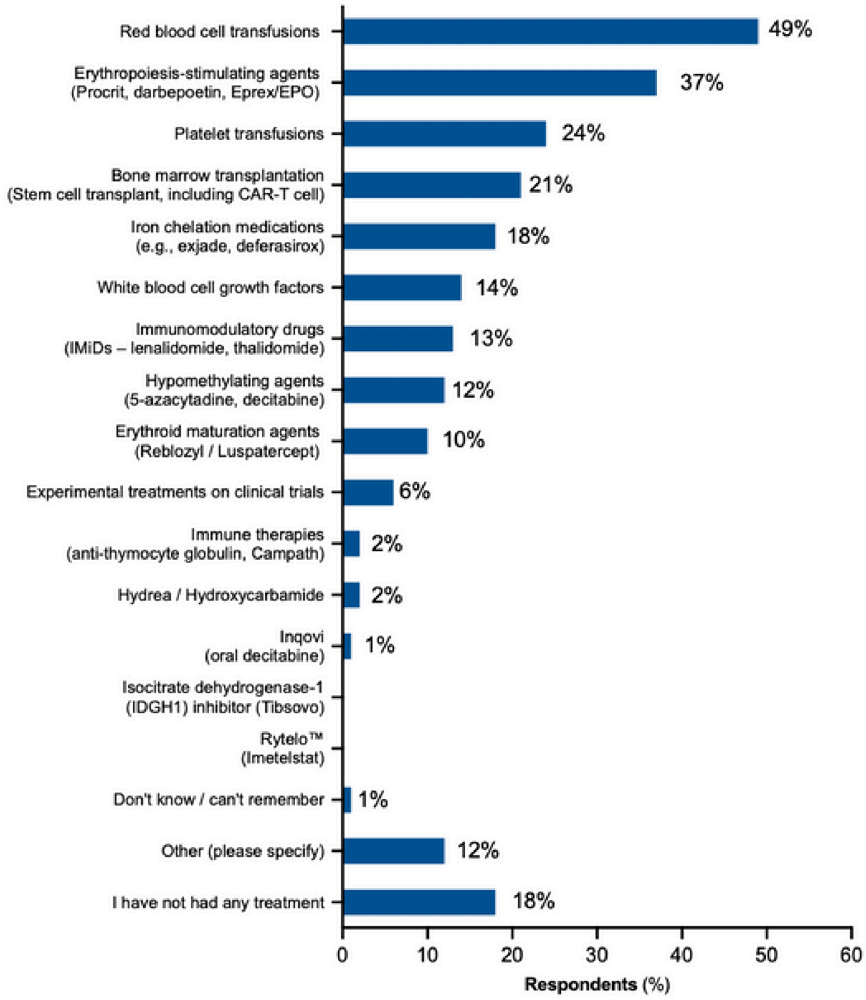


Figure 50. ***Q38: Which treatments have you received since being diagnosed with MDS? Please select all that apply.*** *Data are shown as a % from n=468 respondents.*

Age was a determining factor for what treatments patients received. Patients that were younger were more likely to have received certain treatments (Table 8):

- 51% of patients aged 30-45 have had a bone marrow transplantation, compared to 7% of patients aged 80+.
- 56% of patients aged 30-45 have had platelet transfusions, compared to 17% of patients aged 66-80 and 80+.

Treatment type	Overall	30-45	40-65	66-80	80+
Red blood cell transfusions	**49%**	69%	48%	45%	55%
Platelet transfusions	**24%**	56%	26%	17%	17%
White blood cell growth factors	**14%**	26%	16%	12%	2%
Erythropoiesis-stimulating agents (Procrit, darbepoetin, Eprex/EPO)	**37%**	21%	34%	40%	48%
Erythroid maturation agents (Reblozyl / Luspatercept)	**10%**	8%	7%	12%	14%
Inqovi (oral decitabine)	**1%**	0%	0%	2%	0%
Iron chelation medications (e.g., exjade, deferasirox)	**18%**	28%	16%	17%	24%
Immunomodulatory drugs (IMiDs – lenalidomide, thalidomide)	**13%**	28%	12%	12%	17%
Hydrea / Hydroxycarbamide	**2%**	8%	2%	2%	0%
Hypomethylating agents (5-azacytadine, decitabine)	**12%**	15%	9%	12%	12%
Immune therapies (anti-thymocyte globulin, Campath)	**2%**	8%	3%	1%	0%
Isocitrate dehydrogenase-1 (IDGH1) inhibitor (Tibsovo)	**0%**	0%	1%	0%	0%
Bone marrow transplantation (Stem cell transplant, including CAR-T cell)	**21%**	51%	28%	14%	7%
Rytelo™ (imetelstat)	**0%**	3%	0%	0%	0%
Experimental treatments on clinical trials	**6%**	5%	5%	5%	10%
Other (please specify)	**12%**	8%	11%	11%	19%
Don't know / can't remember	**1%**	3%	2%	0%	5%
I have not had any treatment	**18%**	10%	16%	22%	10%
Total	**468**	**39**	**152**	**227**	**42**

Table 8: ***Effect of geographical location on Q38: Which treatments have you received since being diagnosed with MDS? Please select all that apply.*** *Data are shown as a % from n=468 respondents.*

Geographical location was also a determining factor for what treatments patients received. Patients that lived in Asia-Pacific were more likely to have received certain treatments (Table 9):

- 41% of patients aged in Asia-Pacific have had a bone marrow transplantation, compared to 10% of patients in North America and 16% in Europe.
- 47% of patients aged 30-45 have had platelet transfusions, compared to 22% of patients in North America and 17% in Europe.

Treatment type	**Overall**	**North America**	**Europe**	**Asia-Pacific**
Red blood cell transfusions	**49%**	46%	47%	60%
Platelet transfusions	**24%**	22%	17%	47%
White blood cell growth factors	**14%**	13%	10%	24%
Erythropoiesis-stimulating agents (Procrit, darbepoetin, Eprex/EPO)	**37%**	43%	42%	16%
Erythroid maturation agents (Reblozyl / Luspatercept)	**10%**	11%	13%	0%
Inqovi (oral decitabine)	**1%**	5%	0%	0%
Iron chelation medications (e.g., exjade, deferasirox)	**18%**	11%	21%	16%
Immunomodulatory drugs (IMiDs – lenalidomide, thalidomide)	**13%**	9%	12%	21%
Hydrea / Hydroxycarbamide	**2%**	4%	2%	2%
Hypomethylating agents (5-azacytadine, decitabine)	**12%**	11%	8%	24%
Immune therapies (anti-thymocyte globulin, Campath)	**2%**	3%	1%	5%
Isocitrate dehydrogenase-1 (IDGH1) inhibitor (Tibsovo)	**0%**	0%	0%	0%
Bone marrow transplantation (Stem cell transplant, including CAR-T cell)	**21%**	10%	16%	41%

Rytelo™ (imetelstat)	**0%**	1%	0%	1%
Experimental treatments on clinical trials	**6%**	4%	8%	2%
Other (please specify)	**12%**	13%	13%	6%
Don't know / can't remember	**1%**	1%	1%	2%
I have not had any treatment	**18%**	20%	21%	7%
Total	**468**	**79**	**285**	**98**

Table 9:* *Effect of geographical location on Q38: Which treatments have you received since being diagnosed with MDS? Please select all that apply. *Data are shown as a % from n=468 respondents.*

Of patients who have received treatment, the most reported current or most recent treatment was bone marrow transplantation (23%) (Table 10). In this instance, this varied greatly by country. A total of 38% of patients in Asia-Pacific were currently on or most recently received a bone marrow transplantation. This was mainly driven by data from Republic of Korea / South Korea, where 40% (n=23) of patients surveyed in have currently or most recently received a bone marrow transplantation, compared to 10% (n=3) in the USA (Table 10).

Treatment type	Overall	North America	Europe	Asia-Pacific
Red blood cell transfusions	**15%**	5%	13%	25%
Platelet transfusions	**5%**	8%	2%	10%
White blood cell growth factors	**4%**	8%	4%	2%
Erythropoiesis-stimulating agents (Procrit, darbepoetin, Eprex/EPO)	**8%**	8%	11%	0%
Erythroid maturation agents (Reblozyl / Luspatercept)	**9%**	13%	12%	0%
Inqovi (oral decitabine)	**1%**	5%	0%	0%

Iron chelation medications (e.g., exjade, deferasirox)	**5%**	5%	7%	0%
Immunomodulatory drugs (IMiDs – lenalidomide, thalidomide)	**10%**	8%	11%	10%
Hydrea / Hydroxycarbamide	**1%**	3%	1%	0%
Hypomethylating agents (5-azacytadine, decitabine)	**6%**	8%	5%	10%
Immune therapies (anti-thymocyte globulin, Campath)	**1%**	0%	1%	2%
Isocitrate dehydrogenase-1 (IDGH1) inhibitor (Tibsovo)	**0%**	0%	0%	0%
Bone marrow transplantation (Stem cell transplant, including CAR-T cell)	**23%**	10%	19%	38%
Rytelo™ (imetelstat)	**0%**	3%	0%	0%
Experimental treatments on clinical trials	**2%**	3%	3%	0%
Other (please specify)	**11%**	15%	12%	5%
Total	**256**	**39**	**150**	**63**

Table 10:* *Effect of geographical location on Q39: Of the following treatments you have received, which is the current or most recent treatment? *Data are shown as a % from n=256 respondents.*

ACCESS TO MEDICINE

Globally, the majority (90%) of patients reported they have never or rarely had difficulty getting the medicine they needed for their MDS treatment (Figure 51A). The proportion of patients who never or rarely have had difficulty getting the medicine they needed for their MDS treatment was highest in France (95%, n=103). Age was the only variable which showed some differences between groups. As age increases, ease of accessing medicine for MDS treatment increases. 79% of patients aged 30-45 reported they have never or rarely had difficulty getting the medicine they needed for their MDS treatment compared to 93% of patients aged 66-80 and 80+ (Figure 51B).

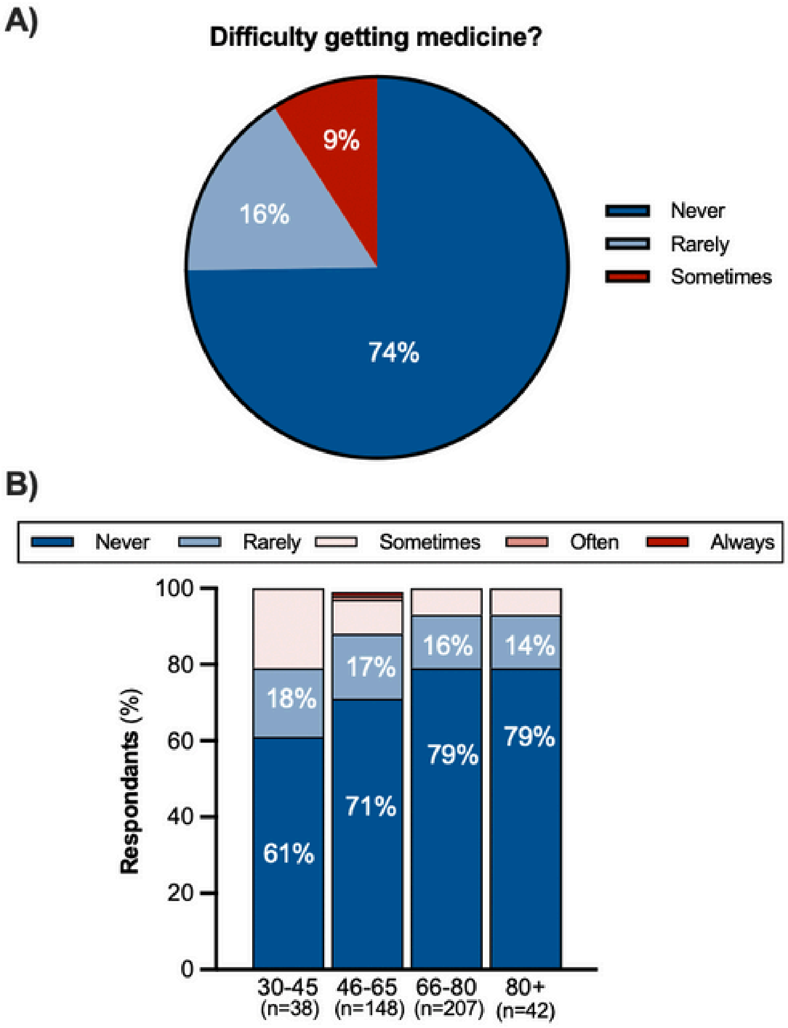


***Figure 51:* Overall effect (A) and effect of age (B) on Q40: Do you ever have difficulty getting the medicine you need for your MDS treatment?** *Data are shown as a % from n=442 respondents.*

BLOOD TRANSFUSIONS

Next, patients were questioned about blood transfusions including their frequency and site of receiving transfusions. A quarter (25%) of patients who have received red blood cell transfusions and /or platelet transfusions as treatment for their MDS have been receiving blood transfusions for less than 6 months, while one-fifth (20%) have been receiving blood transfusions for between 6 months to 1 year (Figure 52). Nearly a quarter (24%) have been receiving transfusions for 5 or more years.

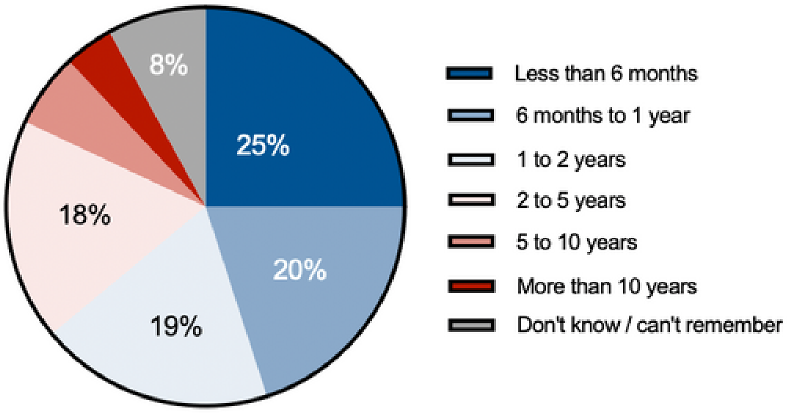


Figure 52: ***Q41: How long have you been receiving blood transfusions as treatment for your MDS?*** *Data are shown as a % from n=230 respondents.*

Of those that are receiving transfusion 14% sated they get the treatments fortnightly while more than half (52%) stated ‘other’ (Figure 53). Further analysis of these ‘Other’ responses showed a number of patients no longer required blood transfusions, while some patients indicated that they receive blood transfusions as and when needed.

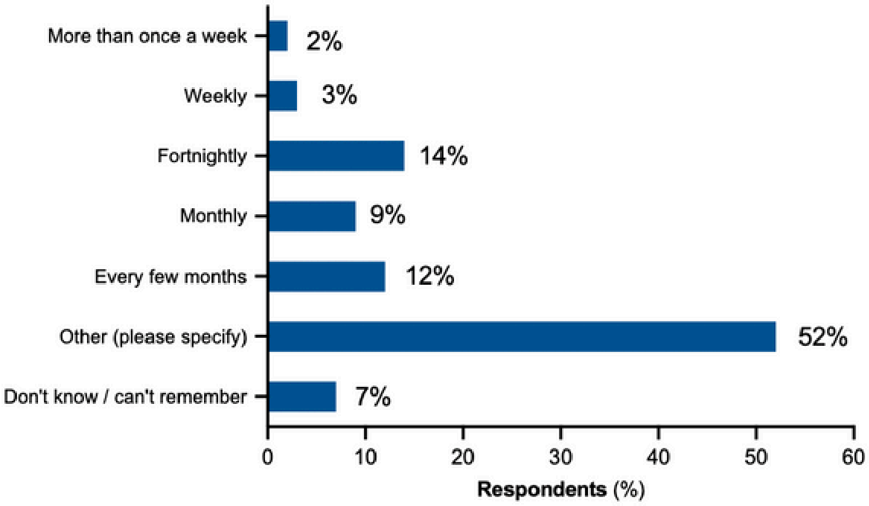


Figure 53: ***Q42: How often do you currently have blood transfusions for your MDS?*** *Data are shown as a % from n=230 respondents.*

Next, participants were asked about the wait times from having their blood tests to receiving their blood transfusions. A total of 83% said they received a transfusion within the first day of having their blood tests (Figure 54).

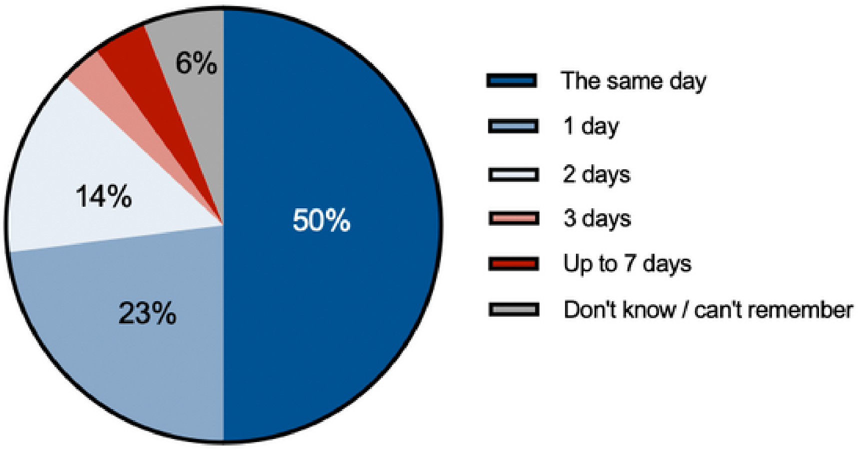


***Figure 54:* Q43: On average, how long do you have to wait from having your blood test to receiving your blood transfusion?** *Data are shown as a % from n=226 respondents.*

A total of 89% of patients living in Asia-Pacific received a blood transfusion within a day of having taken a blood test. This compared to 71% for North America and 64% for Europe (Figure 55).

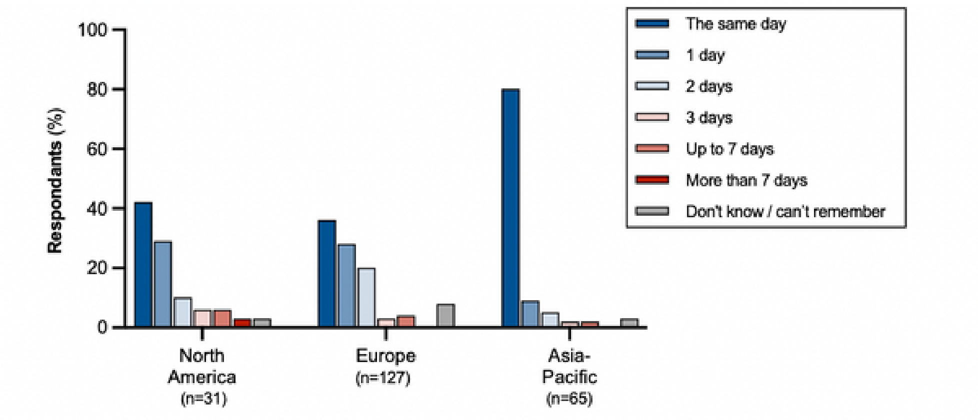


***Figure 55:* Effect of geographical location on Q43: On average, how long do you have to wait from having your blood test to receiving your blood transfusion?** *Data are shown as a % from n=226 respondents.*

Nearly seven out of ten patients (71%) received their transfusion in the outpatients or infusion clinic. Just over a quarter (26%) were admitted to hospital as an inpatient (Figure 56). Only 56% of patients in Europe received their blood treatments in an outpatient/ infusion clinic whereas 91% of patients in North America and Asia-Pacific received their treatment in an outpatient clinic. No patients received their treatments at home (Figure 56).

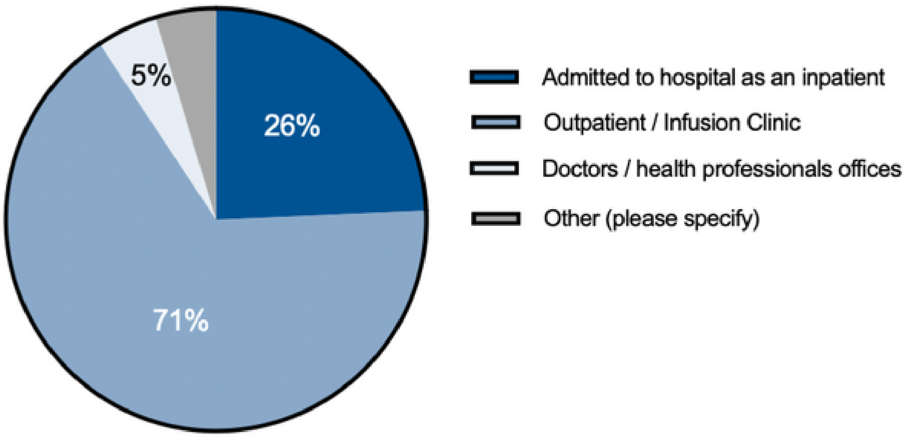


Figure 56: Q44: Where do you usually receive your blood transfusions? Please select all that apply. *Data are shown as a % from n=231 respondents.*

A total of 80% of respondents confirmed that they never experienced a blood shortage for their transfusion (Figure 57). The proportion of patients who have never experienced a blood shortage for their transfusions was highest in France (96%, n=47).

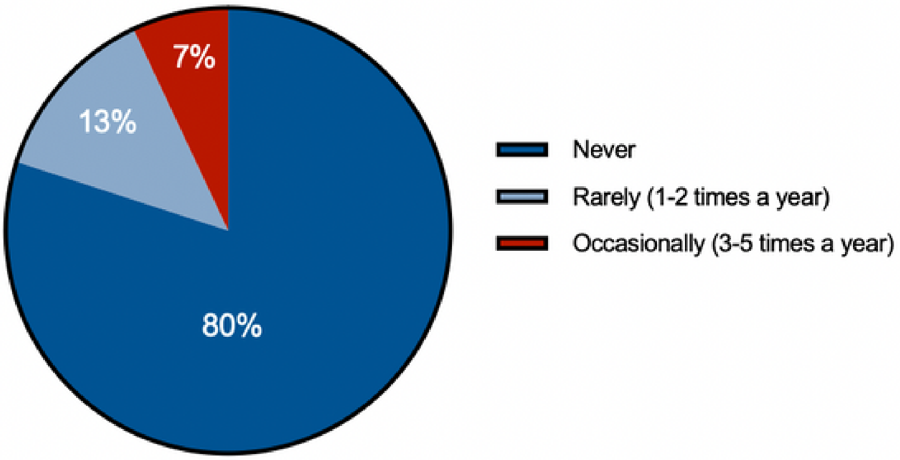


Figure 57: Q45: On average, do you experience blood shortages for your transfusions? If so, how often? *Data are shown as a % from n=230 respondents.*

MDS patients in Asia-Pacific a more likely to experience some level of blood shortage. Just over half of 56% (n=33) of respondents from the Republic of Korea / South Korea confirm that they have never experienced a blood shortage for transfusion (Figure 58).

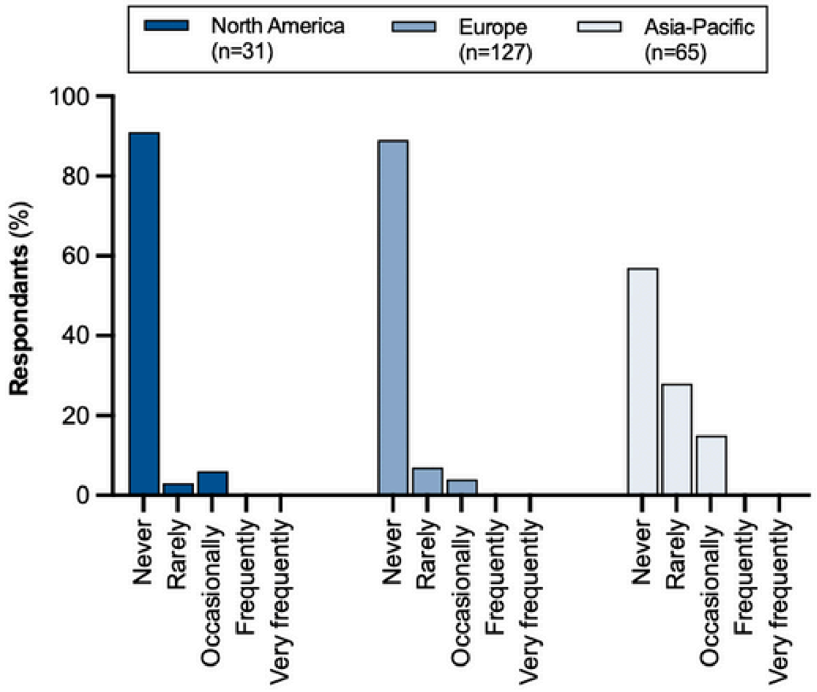


Figure 58: ***Q45: On average, do you experience blood shortages for your transfusions? If so, how often?*** *Please note; rarely (1-2 times a year), occasionally (3-5 times a year), frequently (6-10 times a year) and very frequently (more than 10 times a year). Data are shown as a % from n=230 respondents.*

BONE MARROW TRANSPLANTATIONS

Next, patients were asked a serious of questions about bone marrow transplants. 95% of respondents confirmed bone marrow transplants were available in their country (Figure 59). All patients in France (n=110), Germany (n=50), the UK (n=66) and the USA (n=58) reported bone marrow transplants were available in their country compared to 78% (n=71) in the Republic of Korea / South Korea.

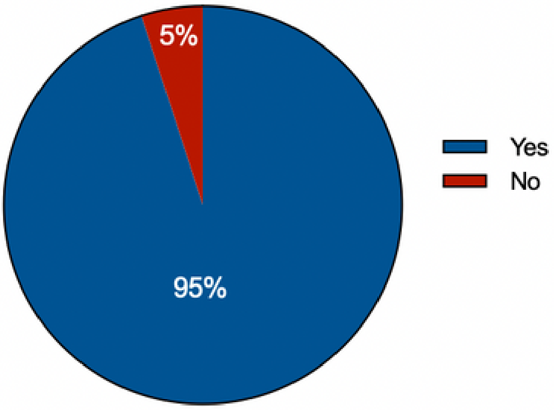


Figure 59: ***Q46: Are bone marrow transplants available in your country?*** *Data are shown as a % from n=230 respondents.*

Only 33% of patients surveyed have been offered a bone marrow transplant. This number was not altered by household income or gender (Figure 60). There were some trends with ageing observed. 68% of patients aged 30-45 years will be offered a bone

marrow transplant. This compares to 27% of those aged 80 and years (Figure 61).

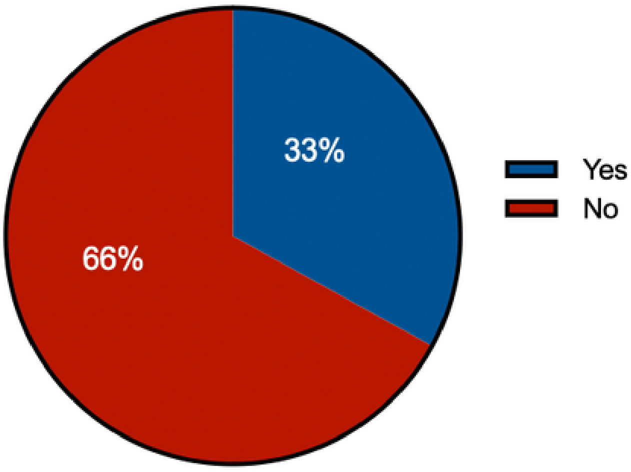


Figure 60: ***Q47: Were you offered a bone marrow transplant?*** *Data are shown as a % from n=450 respondents.*

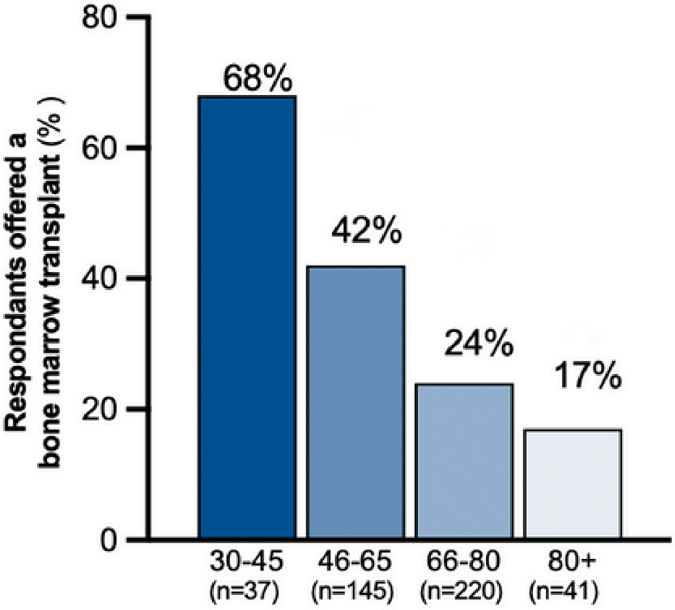


Figure 61: ***Effect of age on Q47: Were you offered a bone marrow transplant?*** *Data are shown as a % from n=450 respondents.*

VISITS TO HAEMATOLOGISTS

Half of the respondents (50%) only visit their haematologist up to twice a year. 17% of respondents visit their haematologist more than 12 times a year (Figure 62). Younger patients (30-45 years) are the group that visit the haematologist most often (37%) compared to 11% and 15% for 66-80 years and 80+ years respectively (Figure 63). more than double (29%) the number of patients living in Asia-Pacific are likely to see their haematologist most than 12 times compared to 14% and 13% for North America and Europe (Figure 64).

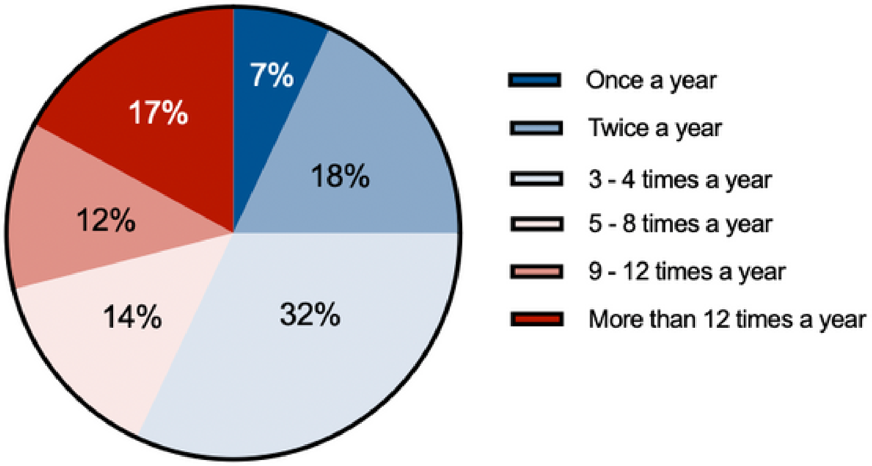


Figure 62: ***Q50: How many times per year do you see your haematologist?*** *Data are shown as a % from n=456 respondents.*

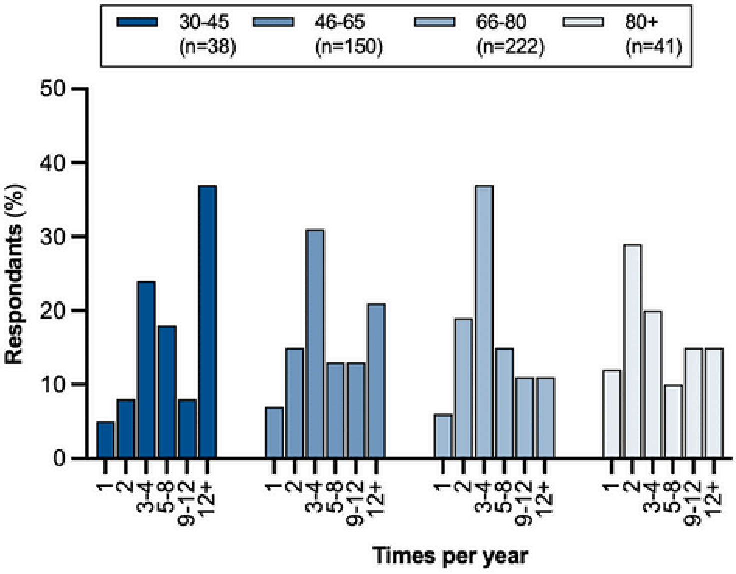


Figure 63: ***Effect of age on Q50: How many times per year do you see your haematologist?*** *Data are shown as a % from n=456 respondents.*

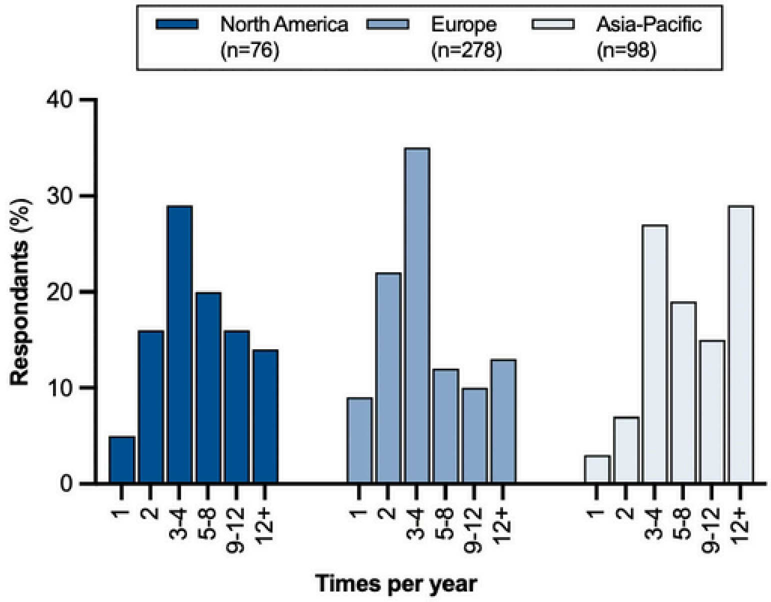


Figure 64: ***Effect of geographical location on Q50: How many times per year do you see your haematologist?*** *Data are shown as a % from n=456 respondents.*

ACCESS TO TREATMENT

Overall, 55% of patients reported that they definitely felt they had access to the best treatment for their condition (Figure 65). The proportion of patients who definitely felt they had access to the best treatment for their condition was highest in France (72%, n=76) and the USA (71%, n=41). 80% of those aged 80+ years compared to 32% of those aged 30-45 years felt they definitely had access to better treatments (Figure 66).

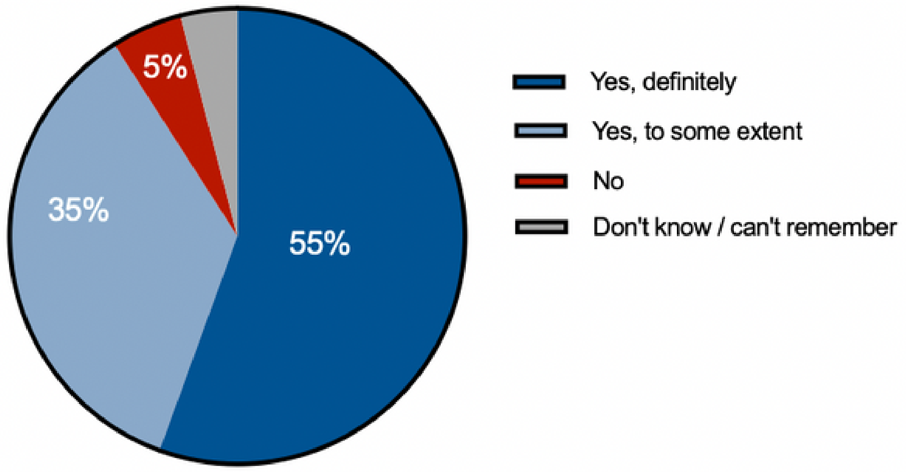


Figure 65: ***Q51: Do you feel you have access to the best treatment for your condition?*** *Data are shown as a % from n=456 respondents.*

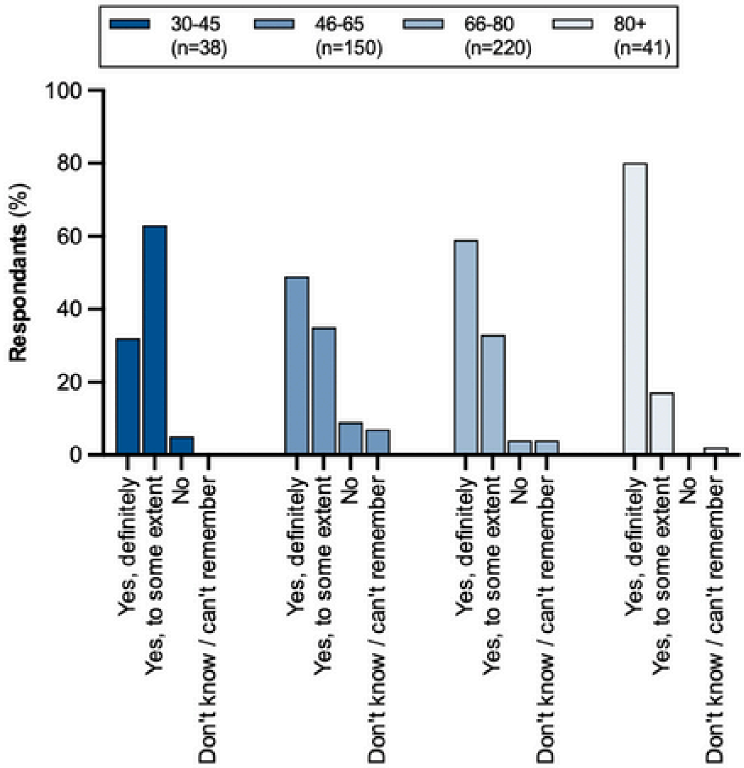


***Figure 66:* Q51: Effect of age on Q51 Do you feel you have access to the best treatment for your condition?** *Data are shown as a % from n=456 respondents.*

EXPERIENCES IN BARRIERS TO TREATMENT

Over half of patients (58%) confirmed that they do not experience any barriers related to treatment. Of the challenges that were faced, difficulty in managing caring duties (11%) and cost of treatment (10%) ranked highest. (Figure 67)

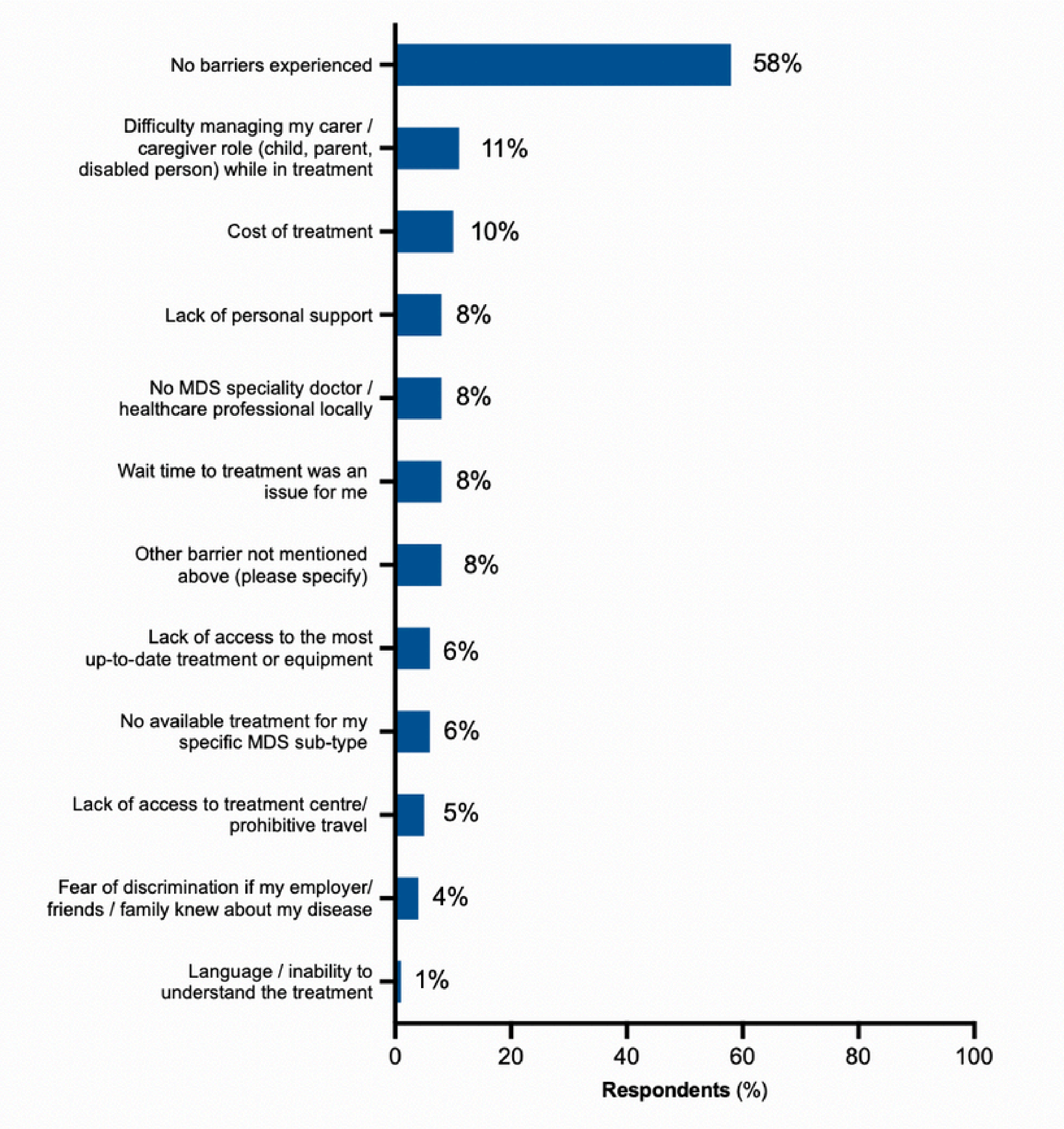


***Figure 67:* Q52: Which barriers, if any, have you experienced that affected your treatment? Please select all that apply.** *Data are shown as a % from n=436 respondents.*

FEELINGS OF INVOLVEMENT IN KEY DECISIONS ABOUT TREATMENTS

59% of patients felt they were definitely involved in decisions about their treatment while nearly one in ten (9%) felt they were not (Figure 68). Nearly three quarters felt that they could get answers they understood when they asked questions during their current or most recent treatments (Figure 69).

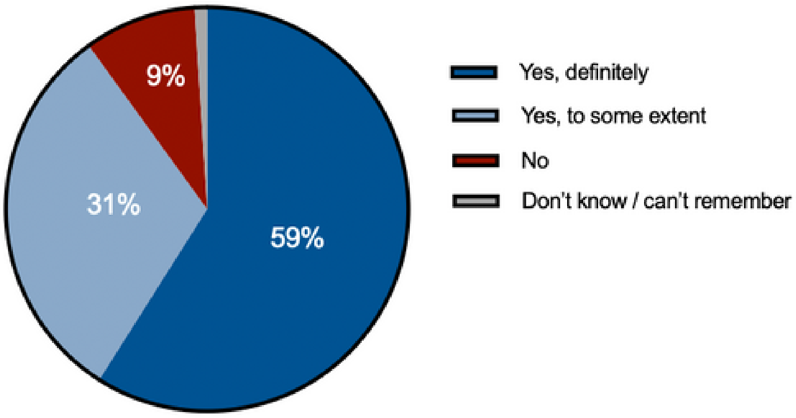


Figure 68. ***Q53: were you involved as much as you wanted to be in decisions about your treatment?*** *Data are shown as a % from n=446 respondents.*

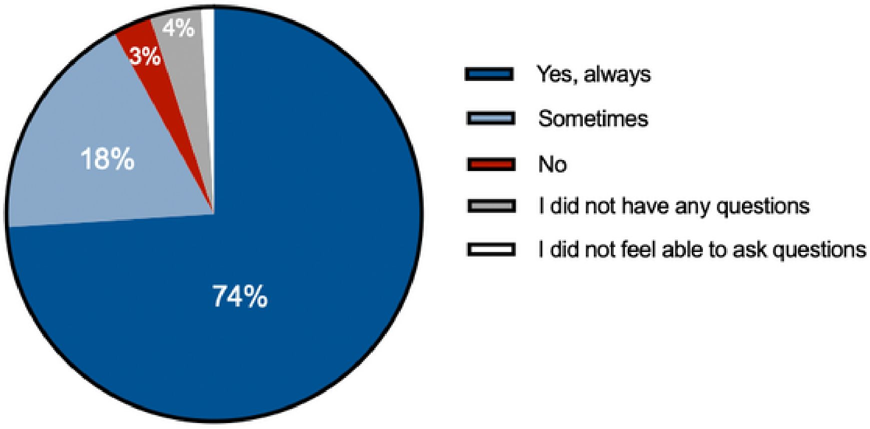


Figure 69: ***Q54: During your current or most recent treatment, when you asked questions, did you get answers you could understand?*** *Data are shown as a % from n=447 respondents.*

Although the numbers are relatively small, 7% of patients who were on a household income below €44,999 felt they did not get answers they could understand when they are questions about their treatment compared to 0% for those on an income of €45,000-69,999 and 2% for those over €70,000 (Figure 70).

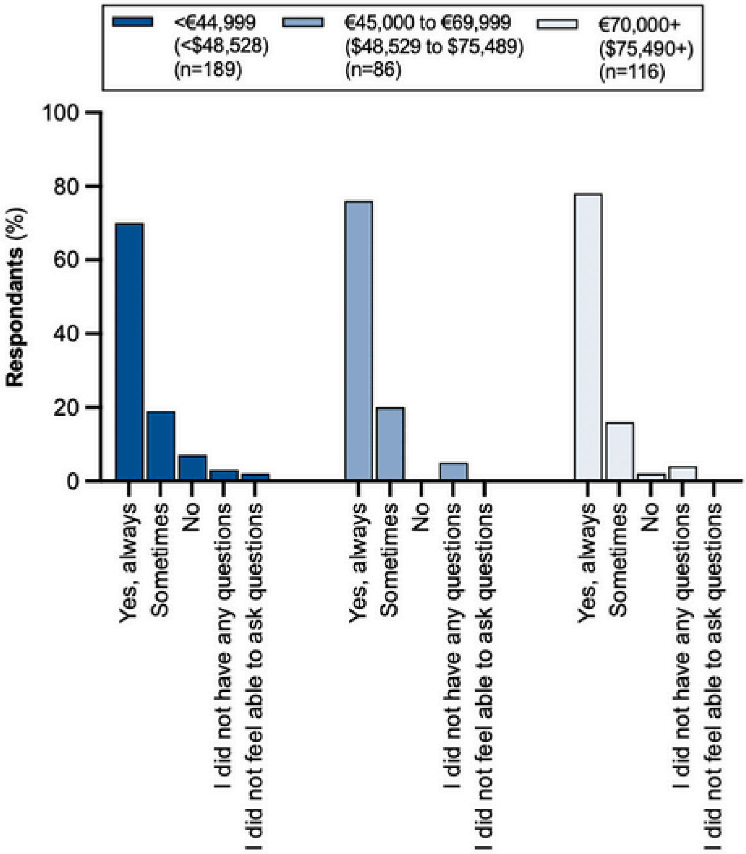


***Figure 70:* Effect of household income on Q54: During your current or most recent treatment, when you asked questions, did you get answers you could understand?** *Data are shown as a % from n=447 respondents.*

DECISIONS RELATED TO TREATMENTS

There are notable variations across countries regarding factors that impacted patients' decisions about their current or most recent treatment for MDS (Figure 71). Improved quality of life was the most selected aspect for each country, except for the USA, where 73% (n=40) of patients chose improved / longer survival.

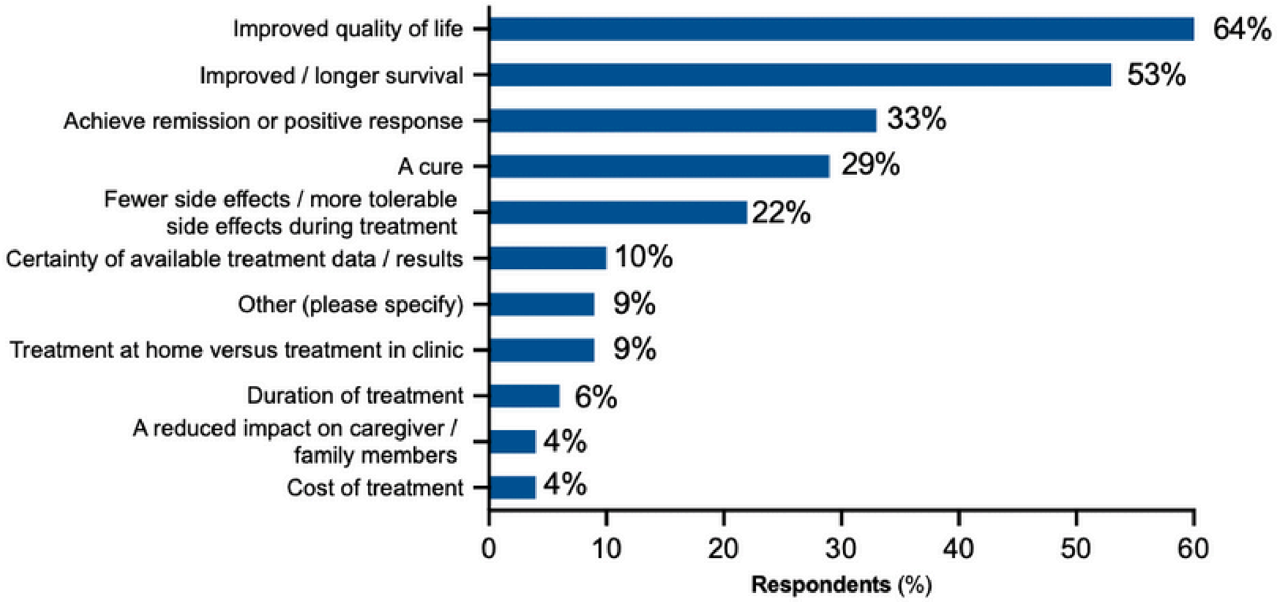


Figure 71: ***Q55: When deciding on your current or most recent treatment for your MDS, which of the following impacted your decision? Please select all that apply.*** *Data are shown as a % from n=447 respondents.*

Analysis be age shows various trends including the following (Figure 72):

- 70% of patients aged 30-45 selected improve quality of life, compared to 54% of patients aged 80+ (Figure 72A).
- 38% of patients aged 30-45 selected improved/ longer survival, compared to 66% of patients aged 80+ (Figure 72B).
- 49% of patients aged 30-45 selected achieve remission, compared to 32% of patients aged 80+ (Figure 72C).
- 51% of patients aged 30-45 selected improved joint or bone paint, compared to 22% of patients aged 80+ (Figure 72D).
- 27% of patients aged 30-45 selected improved side effects, compared to 24% of patients aged 80+ (Figure 72B).

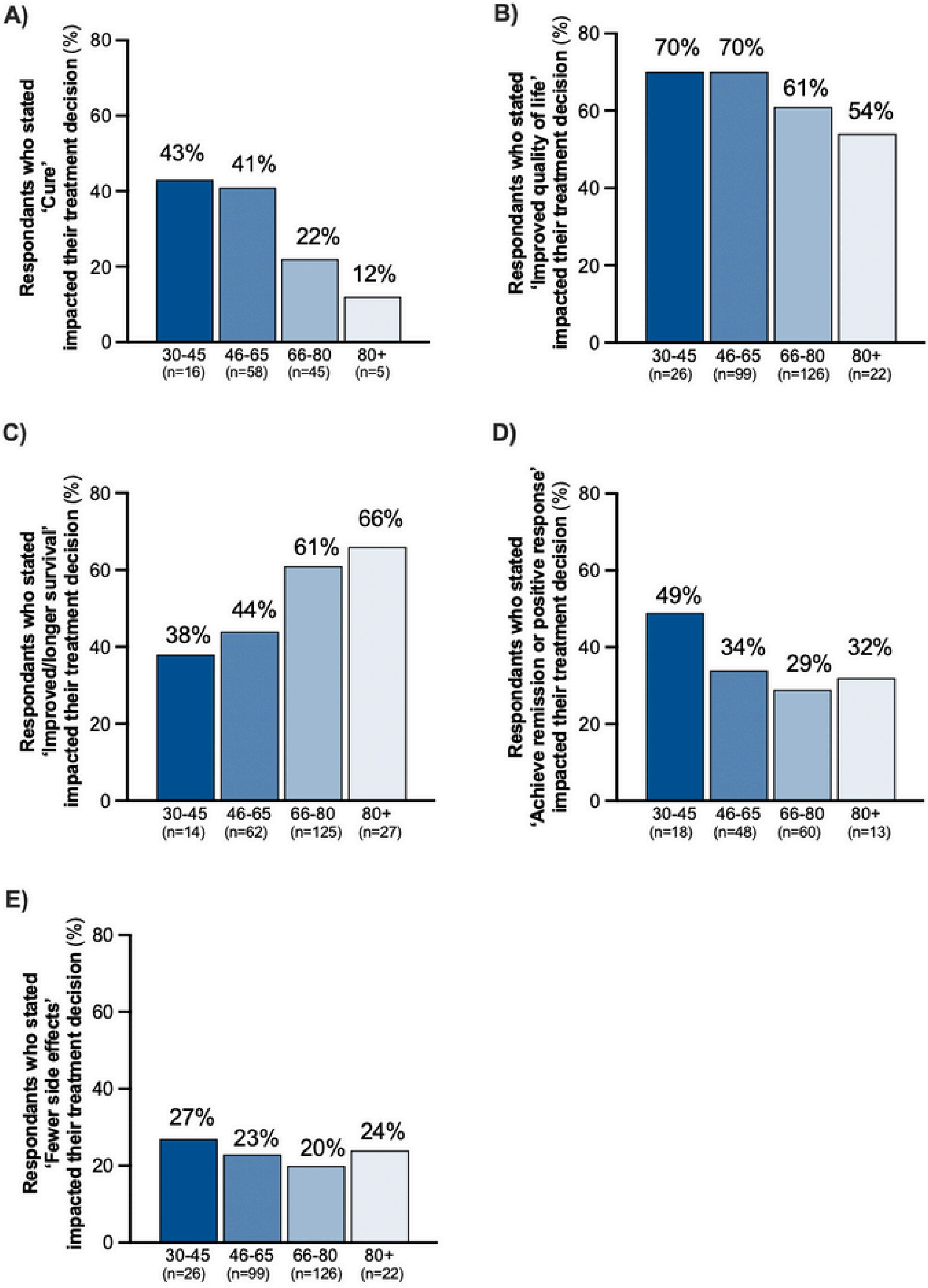


Figure 72: ***Q55: When deciding on your current or most recent treatment for your MDS, which of the following impacted your decision? Please select all that apply.*** *Data are shown as a % from n=14-126 respondents.*

Patients who said more than one aspect impacted their current or most recent treatment decision-making, were asked which one factor they considered to be most important. One-third (33%) of patients selected improved / longer survival, while 29% selected a cure, and 24% selected improved quality of life (Figure 73).

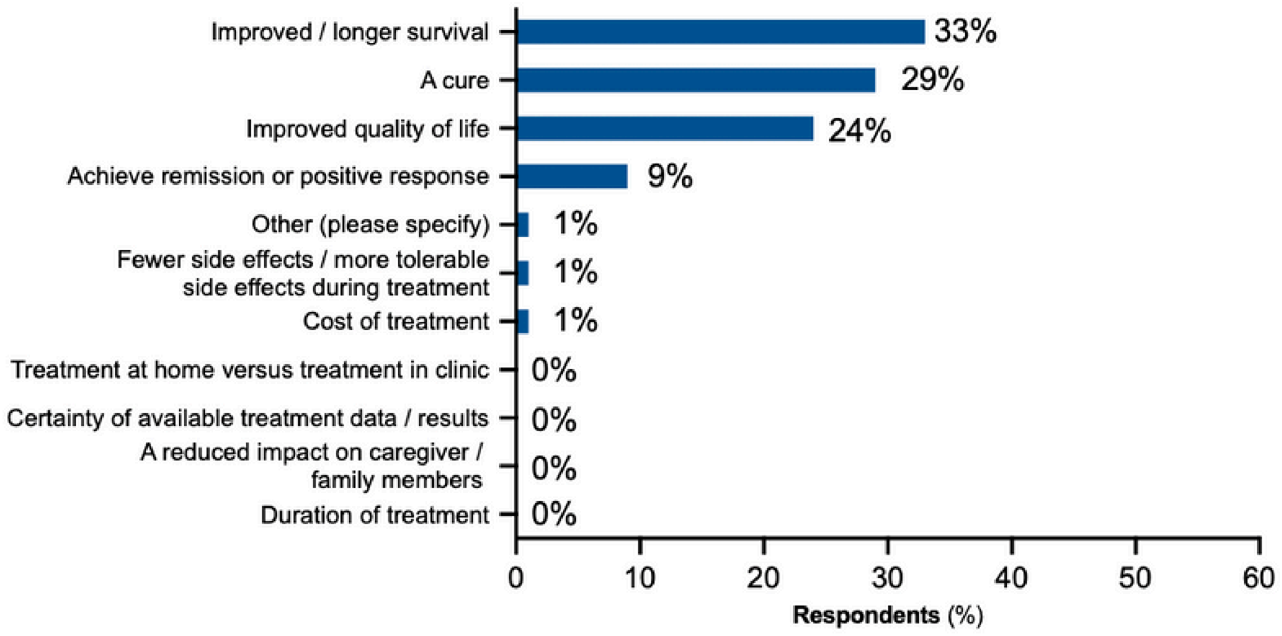


Figure 73: ***Q56: Which of the following do you consider to be most important?*** *Data are shown as a % from n=278 respondents.*

COMMON SIDE EFFECTS

A quarter (25%) of patients reported experiencing no side effects from their current or most recent treatment. The most commonly experienced side effects from current or most recent treatment were (Table 11).

- Fatigue / lack of energy / tiredness (46%)
- Joint or bone pain (34%)
- Anemia (33%)
- Low blood counts (32%)
- Shortness of breath / trouble breathing (31%)

Side effect	Overall	30-45	45-65	66-80	80+
Anaemia	33%	41%	30%	33%	39%
Ascites (Abdominal swelling)	4%	11%	5%	1%	5%
Body aches	26%	38%	32%	23%	7%
Constipation	25%	35%	26%	24%	24%
Diarrhoea	24%	35%	21%	22%	34%
Dizziness / lightheaded	28%	32%	36%	23%	20%
Easy or unusual bruising / bleeding	22%	38%	19%	20%	27%
Enlarged spleen	7%	22%	7%	4%	2%
Fatigue / lack of energy / tiredness	46%	32%	45%	46%	63%
Fever	11%	27%	11%	7%	10%
Frequent infections	13%	19%	18%	9%	5%
Hair loss	16%	35%	21%	10%	17%
Headache	19%	35%	27%	12%	12%
Joint or bone pain	34%	51%	36%	33%	22%
Loss of appetite	19%	32%	22%	16%	10%
Low blood counts	32%	30%	27%	34%	41%
Mouth ulcer/s	17%	27%	21%	13%	15%
Muscle weakness	28%	46%	29%	25%	29%

Nausea / vomiting	16%	38%	22%	8%	12%
Shortness of breath / trouble breathing	31%	35%	30%	30%	37%
Unusual paleness	13%	19%	18%	9%	12%
Weight loss	20%	30%	21%	18%	17%
Other (please specify)	7%	0%	4%	9%	15%
None of the above	25%	27%	31%	22%	7%
Don't know / can't remember	2%	5%	2%	0%	2%
Total Responses	100%	100%	100%	100%	100%
Number	437	37	147	205	41

Table 11. ***Effect of age on Q57: Have you experienced any of the following side effects as a result of your current or most recent treatment? Please select all that apply.***

Older patients tend to experience higher levels of tiredness and/or low blood counts with their treatments (Figure 74A and Figure 74D). Younger patients (aged 30-45 years) are more concerned about joint pain (51%) compared to older patients aged 80+ (22%) (Figure 74B).

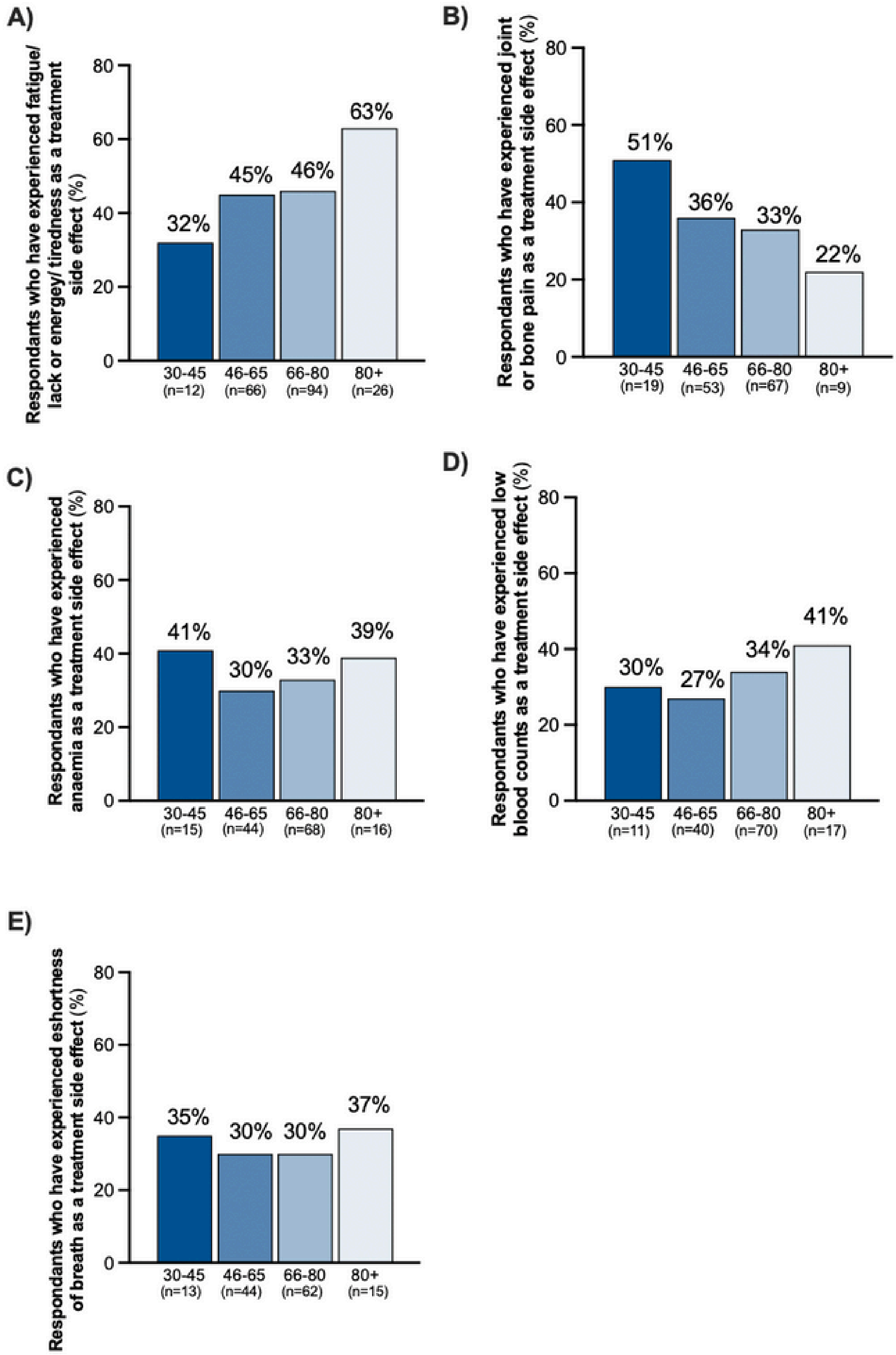


Figure 74: ***Effect of age on Q57: Have you experienced any of the following side effects as a result of your current or most recent treatment? Please select all that apply.*** *Data are shown as a % from n=13-94 respondents.*

There is little difference between males and females in terms of side effects for treatments (Figure 75). One interesting observation is that women (42%) are more likely to experience joint or bone pain (42%) compared to 26% of males (Figure 75B).

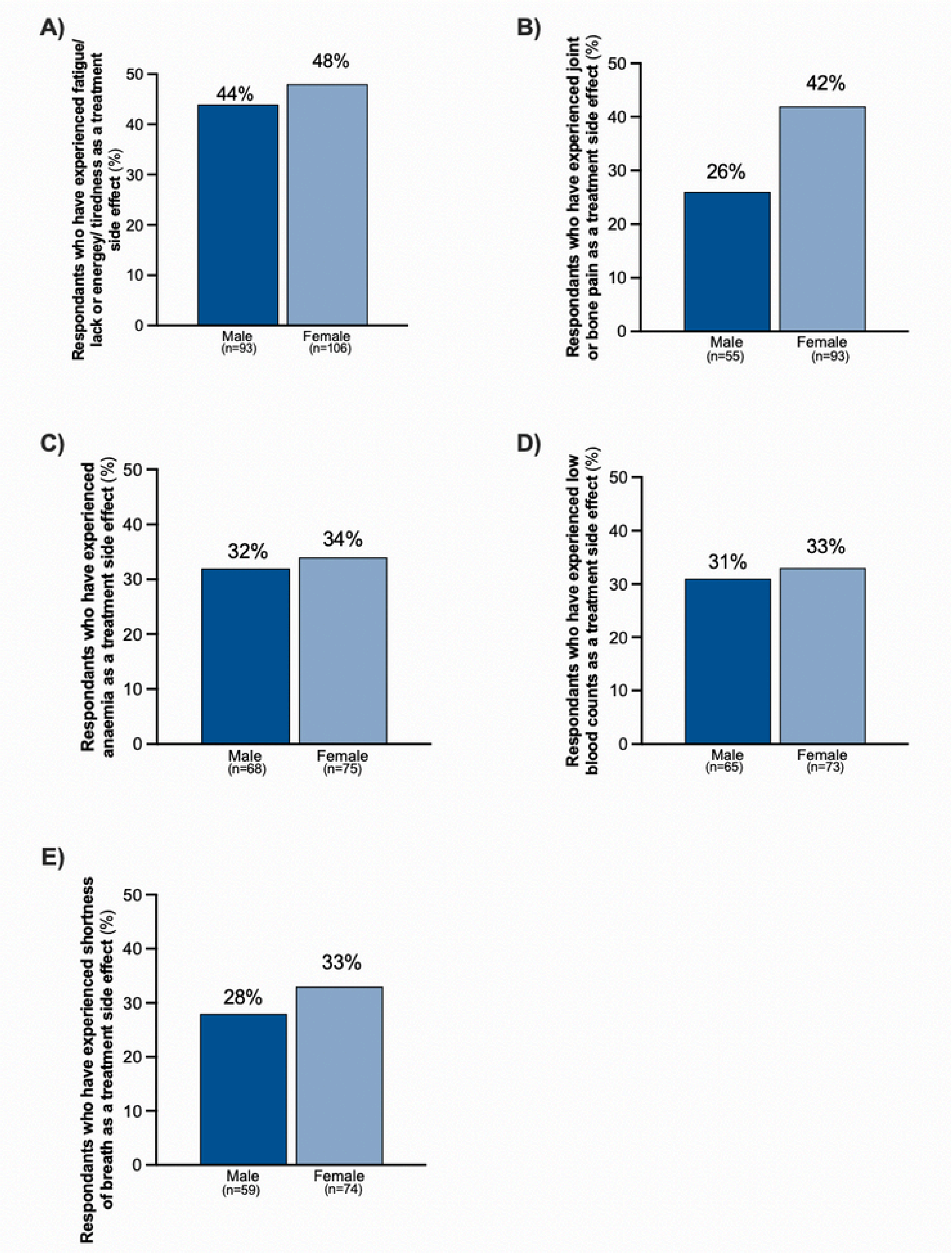


***Figure 75.* Effect of gender on Q57: Have you experienced any of the following side effects as a result of your current or most recent treatment? Please select all that apply.** *Data are shown as a % from n=55-106 respondents.*

People living in Asia-Pacific seem to have less side-effects to their treatments that include fatigue and lack of energy (10%), anaemia (27%) and low blood counts (21%) than those living in North America and Europe (Figure 76).

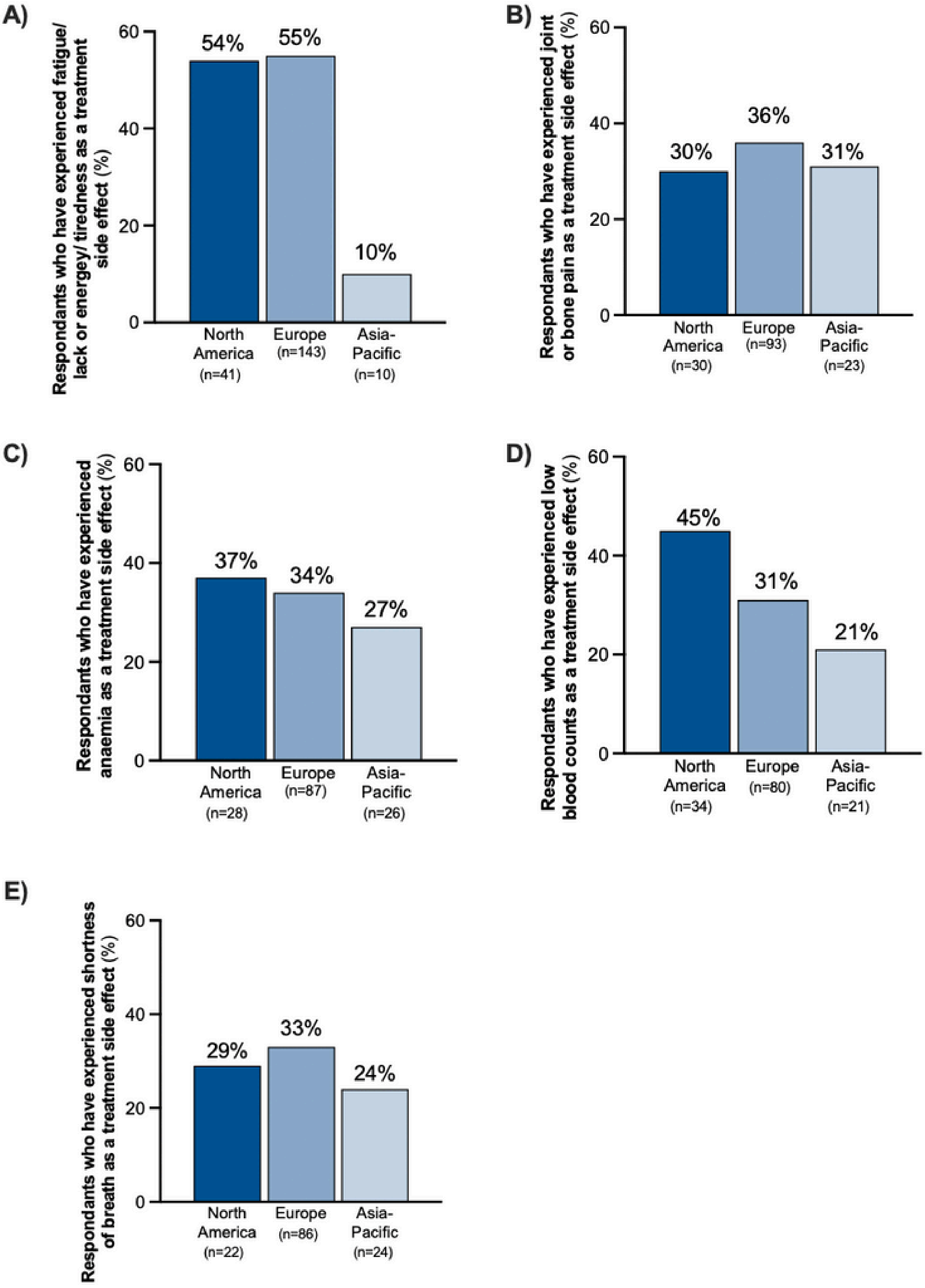


Figure 76. Effect of geographical location on Q57: Have you experienced any of the following side effects as a result of your current or most recent treatment? Please select all that apply. *Data are shown as a % from n=21-143 respondents.*

CLARITY OF INFORMATION ABOUT SYMPTOMS

Less than half of patients (45%) reported they were given completely clear information about any side effects from their current or most recent treatment (Figure 77).

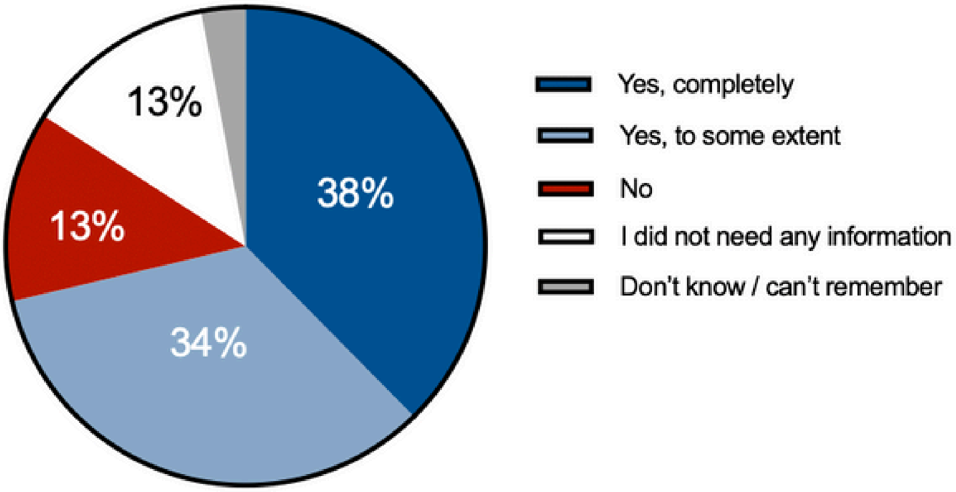


***Figure 77:* Q59: Were you given clear information about any side effects from your current or most recent treatment?** *Data are shown as a % from n=432 respondents.*

When asked about the impact their current or most recent treatment had on their symptoms, 46% of patients said their symptoms have improved, 45% said their symptoms have remained the same, and 9% said their symptoms have gotten worse (Figure 78).

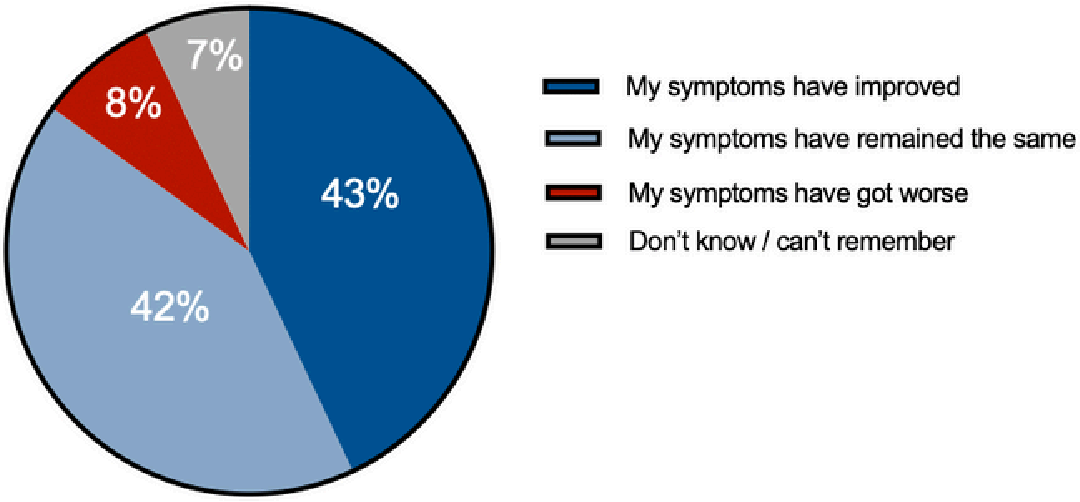


***Figure 78:* Q60: What impact has your current or most recent treatment had on the symptoms that you were experiencing?** *Data are shown as a % from n=404 respondents.*

Patients aged 30-45 (60%) were most likely to say their symptoms have improved as a result of their current or most recent treatment, compared to other age groups (Figure 79).

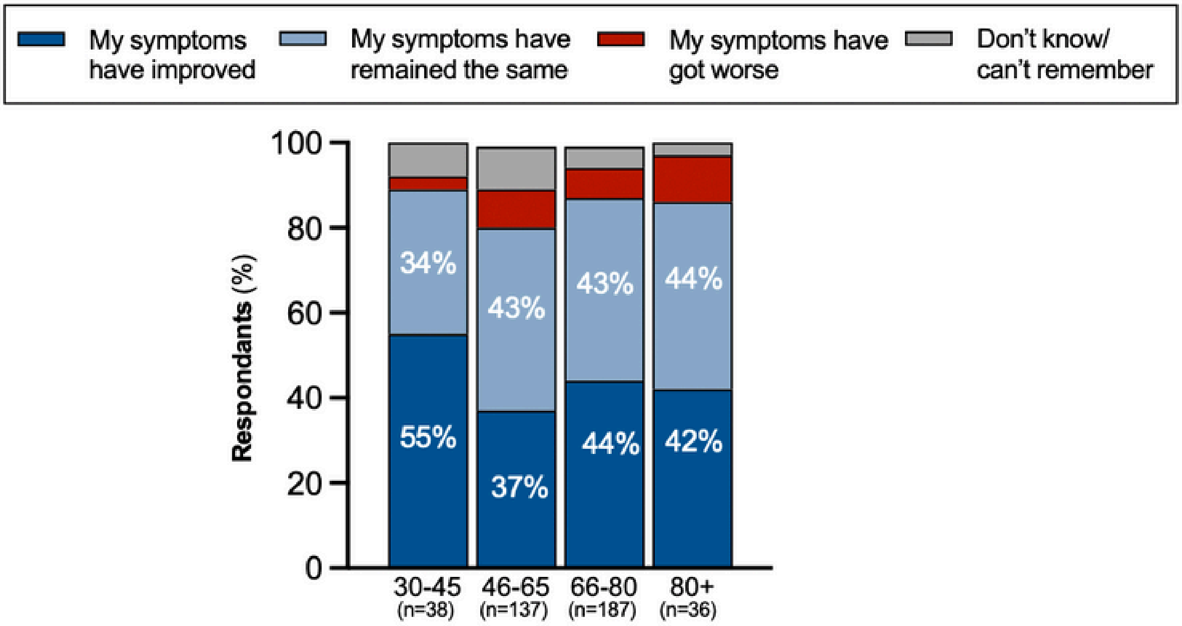


***Figure 79:* Effect of age on Q60: What impact has your current or most recent treatment had on the symptoms that you were experiencing?** *Data are shown as a % from n=404 respondents.*

INFORMATION RECEIVED REGARDING TREATMENT

More than half (54%) of patients reported that they were definitely given the information or explanations they needed during their current or most recent treatment. The proportion of patients who said they were definitely given the information or explanations they needed during their current or most recent treatment was highest in the USA (68%) and lowest in France (52%) and the Republic of Korea / South Korea (52%) (Figure 80).

Patients aged 30-45 (61%) were most likely to report they were definitely given the information or explanations they needed during their current or most recent treatment, compared to other age groups (Figure 81).

Patients living in a household with a total income of €70,000 or above (65%) were most likely to report they were definitely given the information or explanations they needed during their current or most recent treatment, while patients living in a household with a total income below €44,999 (49%) were least likely (Figure 82).

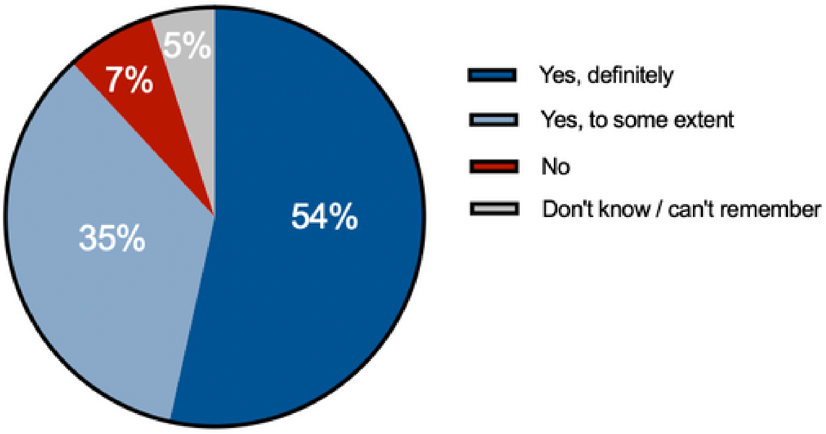


Figure 80: ***Q61: Thinking about the care you received during your current or most recent treatment, were you given the information or explanations you needed?*** *Data are shown as a % from n=414 respondents.*

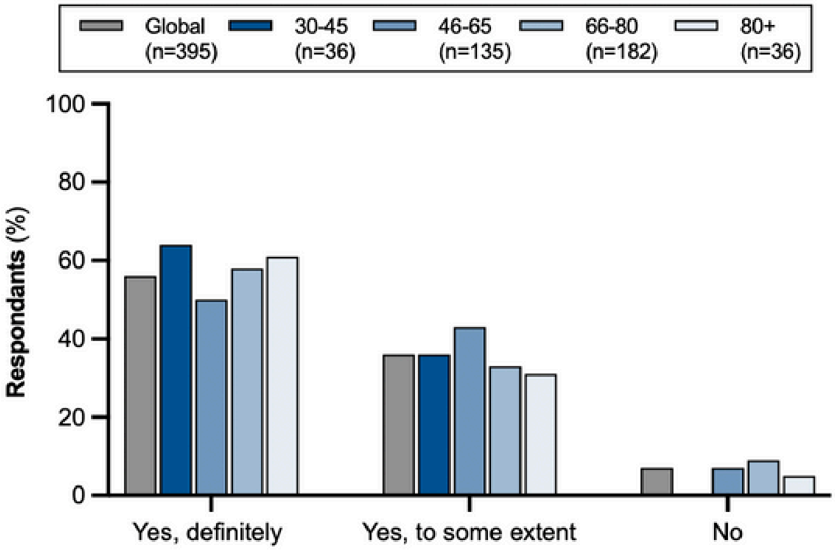


Figure 81: ***Effect of age on Q61: Thinking about the care you received during your current or most recent treatment, were you given the information or explanations you needed?*** *Data are shown as a % from n=395 respondents.*

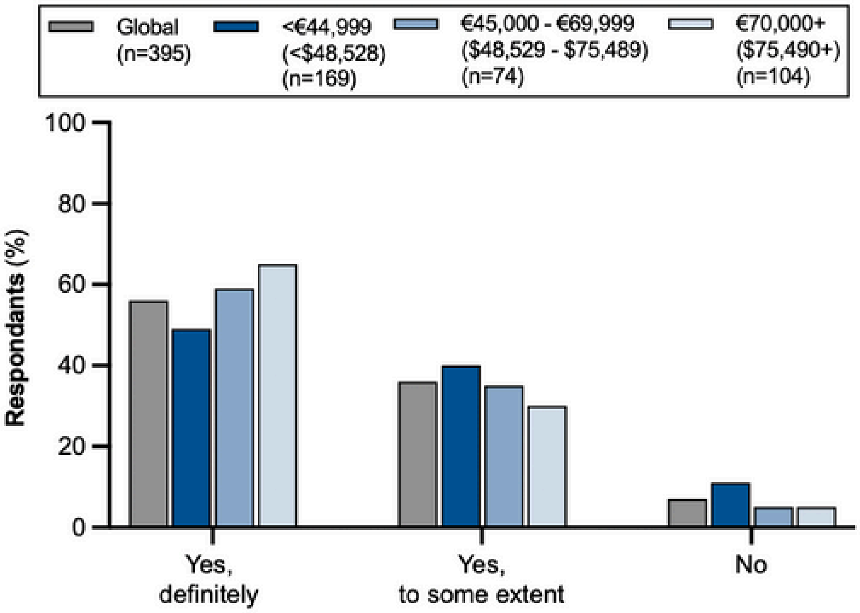


Figure 82:* *Effect of household income on Q61: Thinking about the care you received during your current or most recent treatment, were you given the information or explanations you needed? *Data are shown as a % from n=395 respondents.*

ACCESS TO MDS MULTIDISCIPLINARY TEAM

Globally, 52% of patients reported their MDS medical care was provided by a multidisciplinary team (Figure 83). The UK (61%) had the highest proportion of patients whose MDS medical care was provided by a multidisciplinary team.

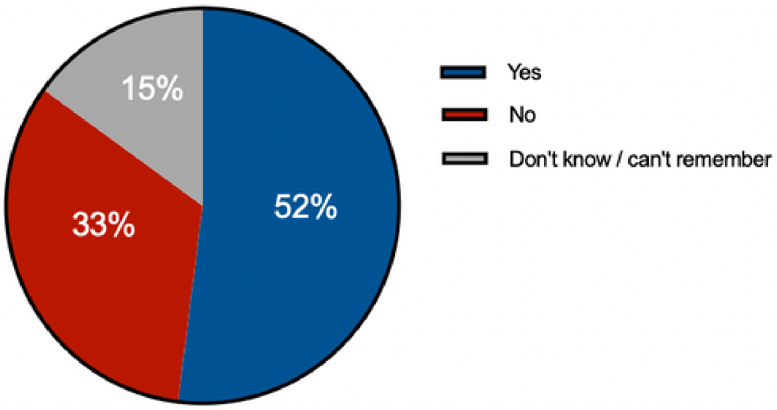


Figure 83:* *Q62: Is your MDS medical care provided by a multidisciplinary team? A multidisciplinary team (MDT) is a group of health and care staff from different professions (e.g. GPs, social workers, nurses), that work together to make treatment decisions. *Data are shown as a % from n=437 respondents.*

Of patients who had a multidisciplinary team, 60% reported they were definitely kept informed about the teams' decisions. 73% of patients in the USA felt they were kept informed Figure 84).

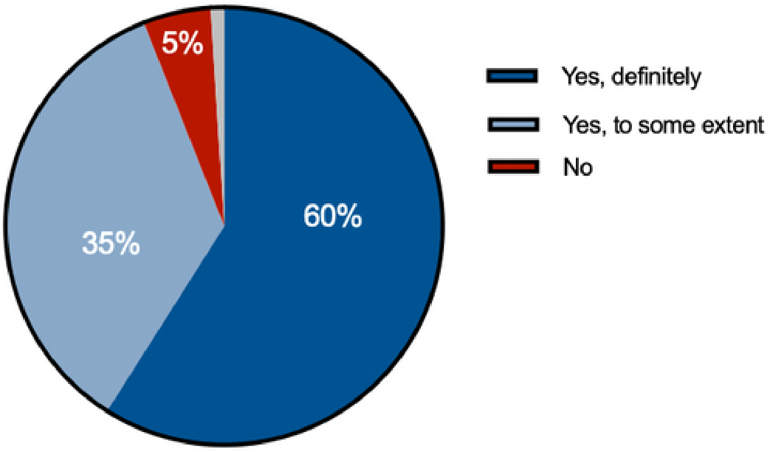


Figure 84:* *Q63: Does your multidisciplinary team keep you informed about their decisions? *Data are shown as a % from n=225 respondents.*

EXPERIENCES IN ACCESSING HEALTHCARE SERVICES

Globally, 37% of patients reported that they experienced a delay in accessing healthcare services in the last 12 months. Access was most likely to be delayed for (Figure 85):

- Appointment/s with a primary care doctor (e.g., a general practitioner) (14%)
- Appointment/s with a specialist (oncologist, hematologist, or MDS expert) (13%)

Patients in the Republic of Korea / South Korea (46%, n=42) and the UK (46%, n=32) were most likely to report they experienced a delay in accessing healthcare services in the last 12 months.

Of patients that experienced a delay in accessing healthcare services, 42% experienced delays due to a lack of available appointments, 28% reported there was not enough staff, and 18% said the delay was due to a high patient volume or demand (Figure 86).

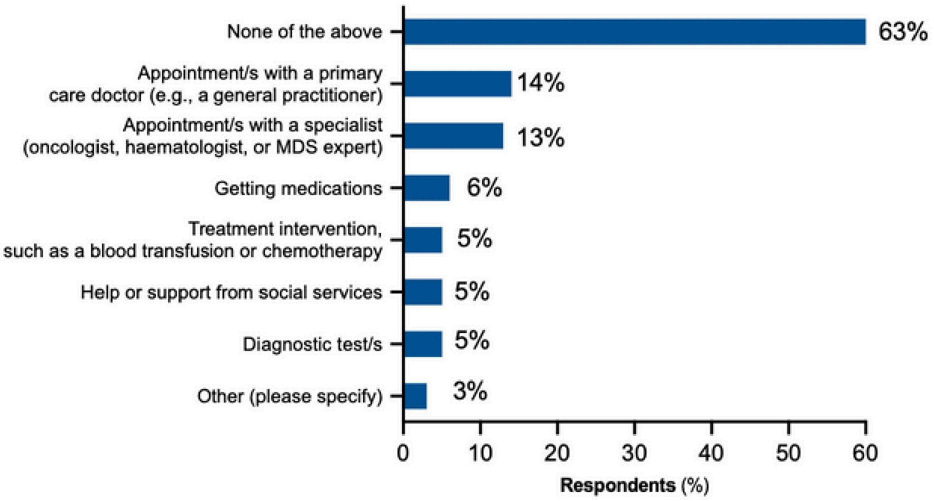


***Figure 85:* Q64: In last 12 months, have you experienced a delay in accessing any of the following? Please select all that apply.** *Data are shown as a % from n=431 respondents.*

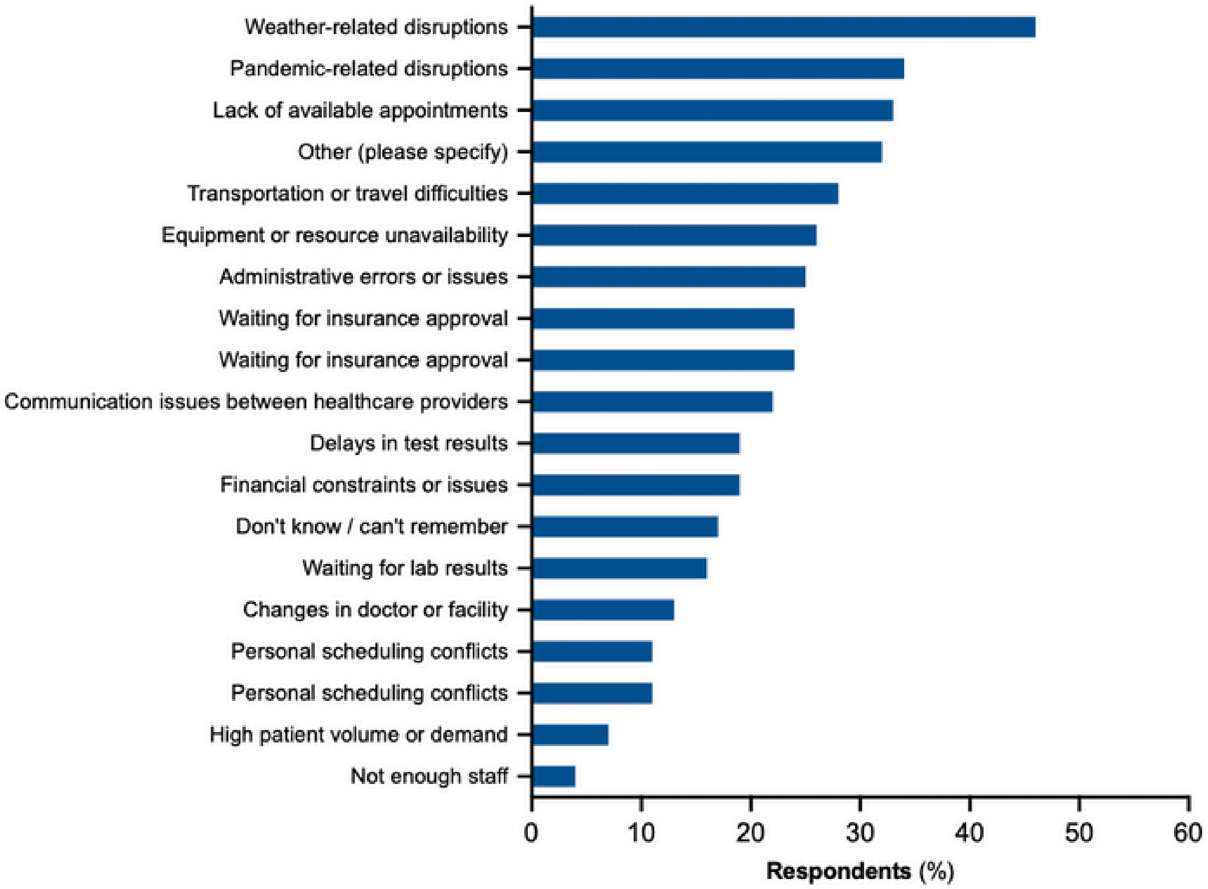


***Figure 86:* Q65: What was the reason for the delay? Please select all that apply.** *Data are shown as a % from n=151 respondents.*

SECTION 4: MDS TESTING AND MONITORING

- Younger patients take more bone marrow tests
- 9/10 go to the same place for testing
- Younger people felt they were less treated with kindness and compassion during their MDS treatment than older patients

Next respondents were asked a series of questions regarding the way the MDS was tested and/or monitored. These include ease of doing testing, participation in clinical trials and feelings related to patients' treatments.

BONE MARROW TESTING

Globally, just over half (51%) of patients had one-two bone marrow tests/ screenings to monitor their MDS since diagnosis (Figure 87). Patients in Germany (40%, n=20) were most likely to report they have had five or more bone marrow tests / screenings.

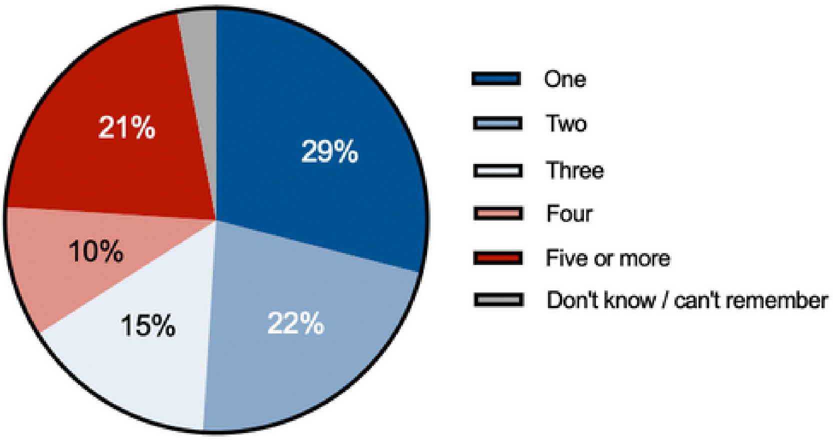


***Figure 87:* Q66: How many bone marrow tests / screenings have you had to monitor your MDS since your diagnosis?** *Data are shown as a % from n=40-215 respondents.*

Age is a determining factor on the number of bone marrow tests taken. 37% of patients aged 30-45 years to 5 or more bone marrow tests since their diagnosis compared to 13% of patients aged 80+ years (Figure 88A).

Geographical location may also contribute to the number of times patients have had bone marrow tests. 24% of patients in Europe have had 5 or more bone marrow tests compared to 19% and 14% in North America and Asia-Pacific respectively (Figure 88B). Nearly nine out of ten patients (91%) go to the same place for their MDS tests (Figure 89).

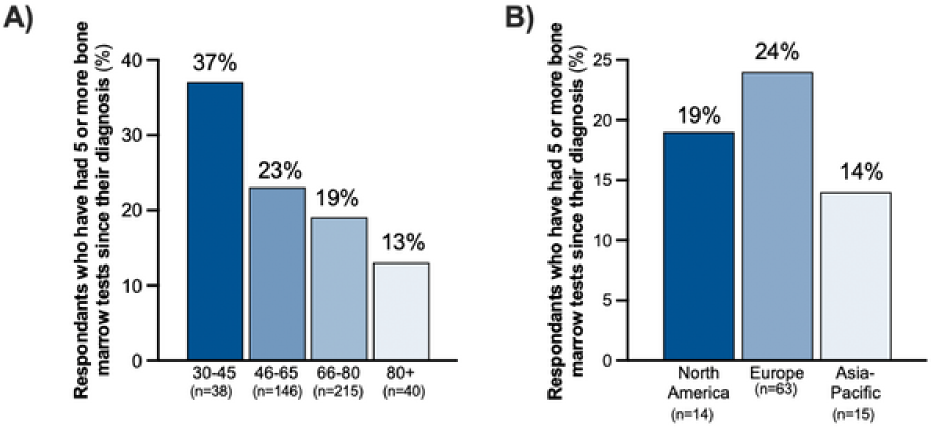


Figure 88: ***Effect of age (A) and geographical location (B) on Q66: How many bone marrow tests / screenings have you had to monitor your MDS since your diagnosis?*** *Data are shown as a % from n=446 respondents.*

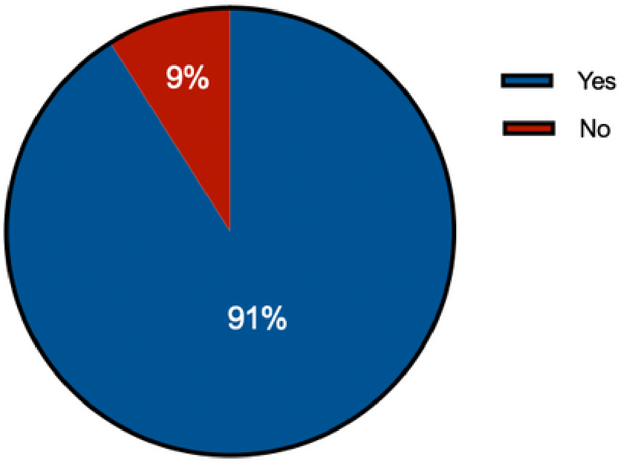


Figure 89: ***Q67: Do you go to the same place for your MDS tests?*** *Data are shown as a % from n=443 respondents.*

VISITS TO HEALTHCARE PROFESSIONALS

Globally, patients were most likely to visit a healthcare professional 3-5 times (34%) per year for their MDS appointments (Figure 90A). Of all the countries surveyed, patients in the Republic of Korea / South Korea were most likely to visit a healthcare professional for their MDS appointments more frequently, with 46% (n=42) of patients visiting more than 10 times per year.

Analysis by age reveals variance in the number of visits to a healthcare professional for MDS appointments each year. 42% of patients aged 30-45 visit a healthcare professional for their MDS appointments more than 10 times per year, compared to 13% of patients aged 66-80 (Figure 90B).

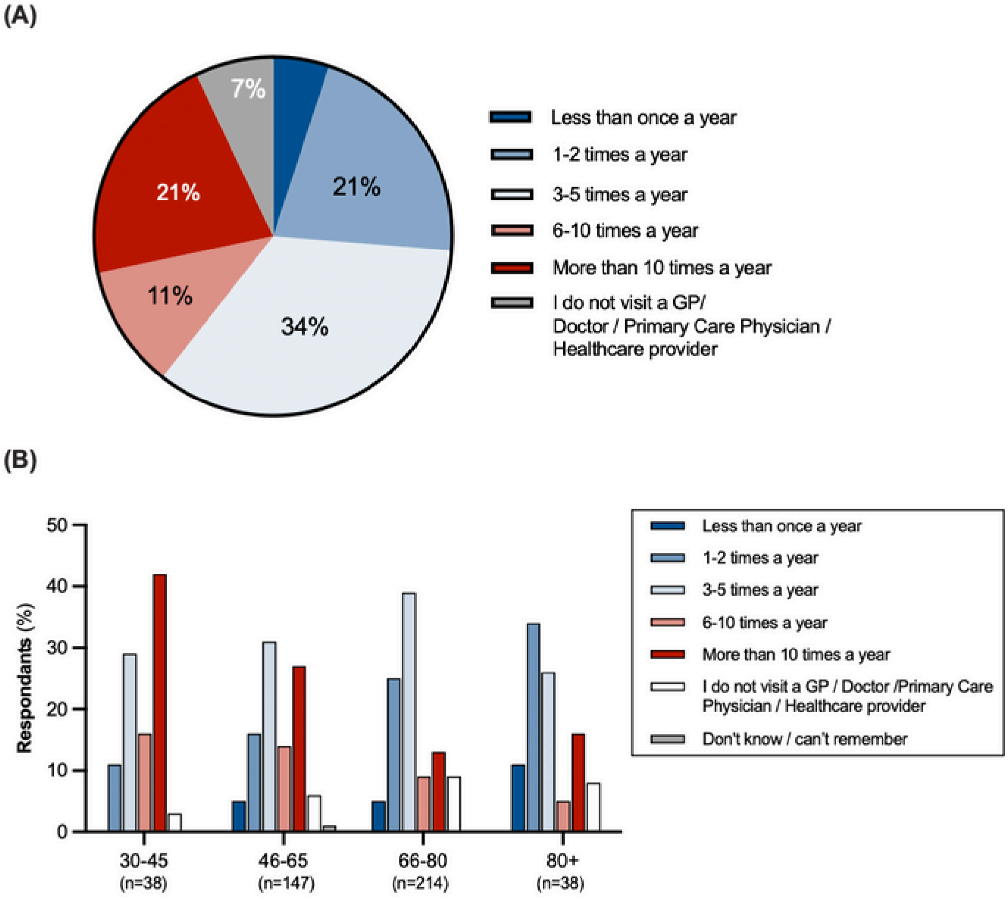


***Figure 90:* Q69: How often do you visit your healthcare professional each year for MDS appointments? By healthcare professional, we mean GP / Primary Care Physician / Doctor.** *Data are shown as a % from n=443 respondents.*

BARRIERS TO REGULAR HEALTHCARE VISITS

Patients who visit a healthcare professional at least one per year, were asked if anything prevented them from visiting their healthcare professional regularly about their MDS. Three-quarters (76%) of patients, globally, reported that nothing prevents them from visiting regularly; the lowest continent that agreed was Asia-Pacific (56%) (Figure 91). These findings were driven primarily by the Republic of Korea / South Korea who were most likely to report their schedule makes it difficult to access clinic appointments (22%) and a lack of health insurance or cost to attend appointments including travel etc. (20%) prevents them from visiting their healthcare professional regularly about their MDS.

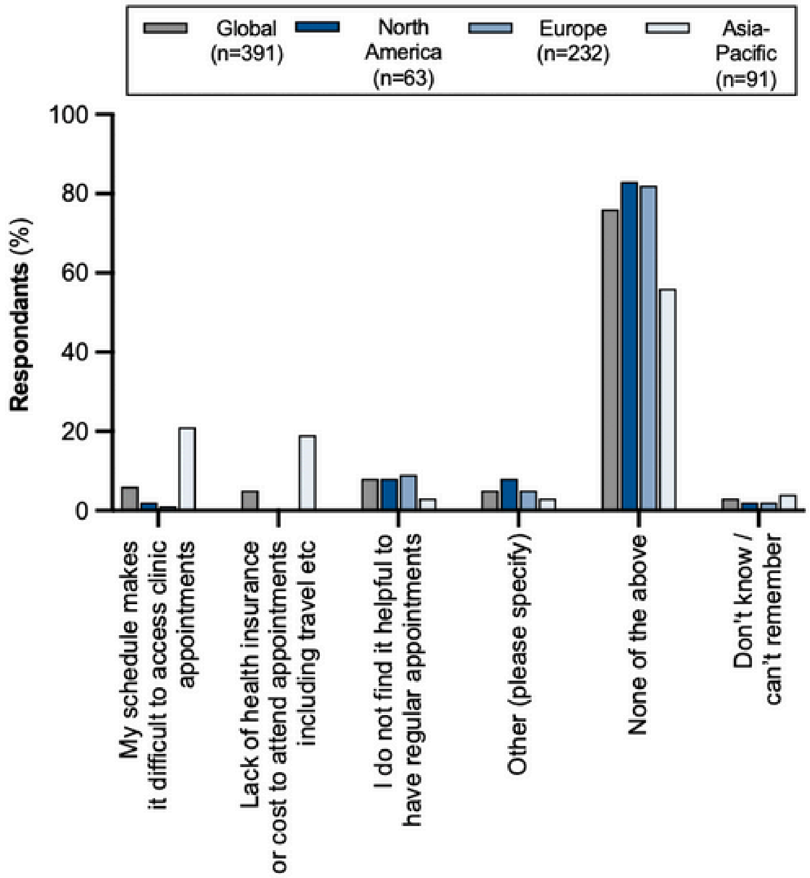


Figure 91: ***Q70: Do any of the following prevent you from visiting your healthcare professional regularly about your MDS? Please select all that apply. By healthcare professional, we mean GP / Primary Care Physician / Doctor.*** *Data are shown as a % from n=391 respondents.*

Analysis by age finds patients aged 30-45 were most likely to report their schedule makes it difficult to access clinic appointments (14%) and a lack of health insurance or cost to attend appointments including travel etc. (24%) prevents them from visiting their healthcare professional regularly about their MDS (Figure 92).

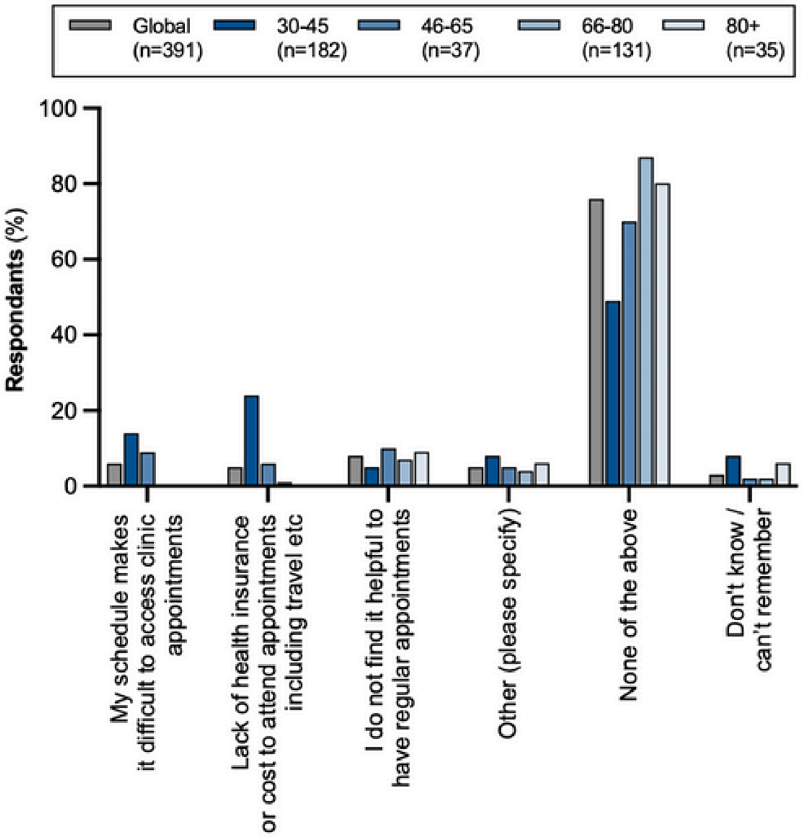


Figure 92: ***Q70: Do any of the following prevent you from visiting your healthcare professional regularly about your MDS? Please select all that apply. By healthcare professional, we mean GP/ Primary Care Physician / Doctor.*** *Data are shown as a % from n=391 respondents.*

INVITED TO PARTICIPATE IN CLINICAL TRIAL

More than 7 in 10 (71%) patients, globally, have never been invited to participate in a clinical trial. Patients in Germany (31%) were most likely to have participated in a clinical trial (Figure 93A). Analysis by age finds as age increases, the proportion of patients who participated in a clinical trial decrease. 27% of patients aged 30-45 had participated in clinical trial, compared to 13% of patients aged 80+ (Figure 93B).

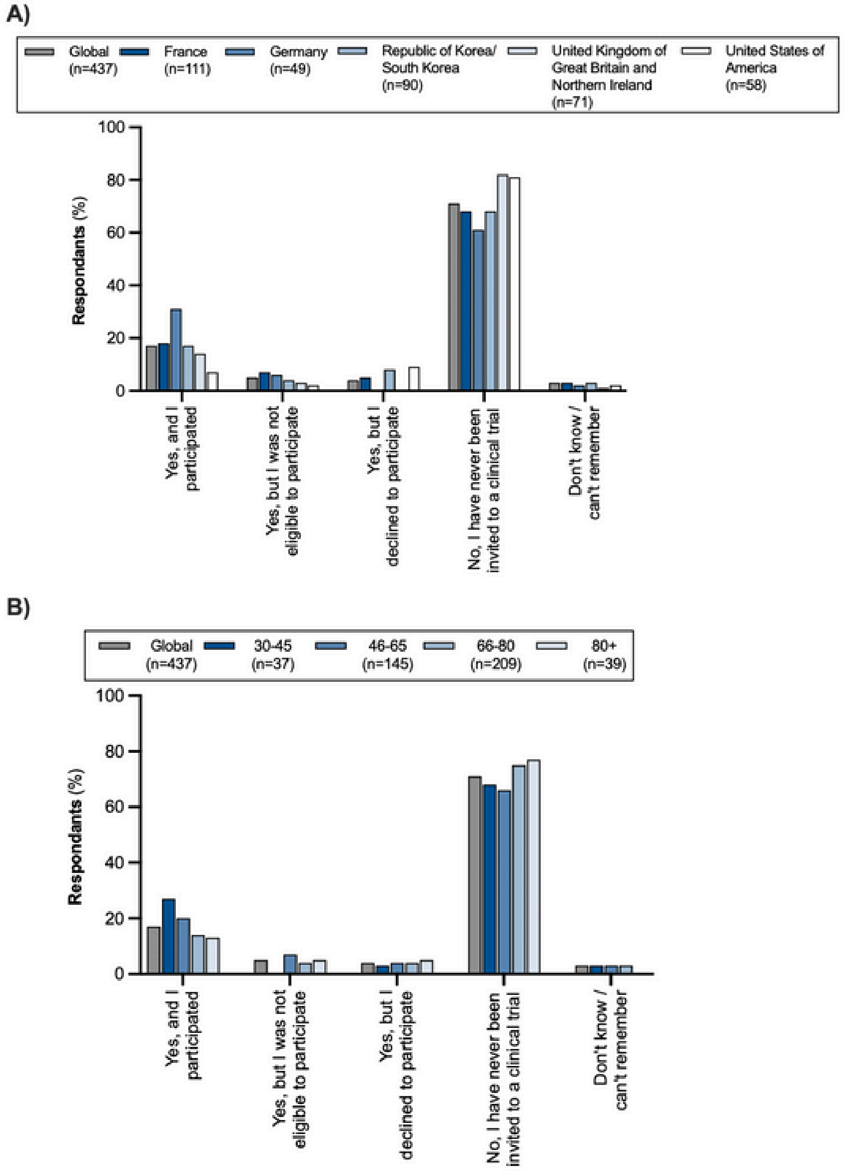


Figure 93: ***Effect of geographical location (A) and age (B) on Q71: Have you ever been invited to participate in a clinical trial?*** *Data are shown as a % from n=437 respondents.*

MAIN REASONS FOR PARTICIPATING IN A CLINICAL TRIAL

Patients who participated in a clinical trial were asked what their main reasons for participating were. The most commonly cited reasons were (Figure 94):

- To help others by participating in research (68%)
- A chance of a cure or slowing of disease (50%)
- Better treatment outcome (43%)

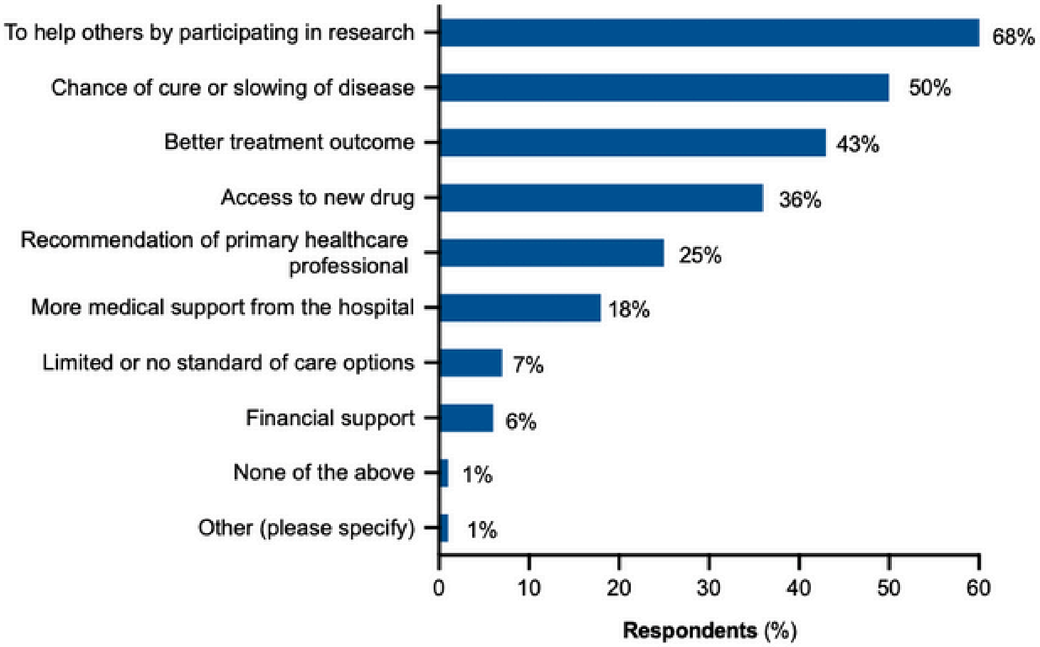


***Figure 94:* Q72: What are your main reasons for participating in a clinical trial? Please select all that apply.** *Data are shown as a % from n=72 respondents.*

TREATED WITH KINDNESS AND COMPASSION

Overall, 79% (n=345) of patients reported they always felt treated with kindness and compassion during their MDS treatment and care. The proportion of patients who always felt treated with kindness and compassion during their MDS treatment and care ranged from 67% in the Republic of Korea / South Korea, to 86% in the USA and France (Figure 95A).

Male patients (84%) were more likely to report they always felt treated with kindness and compassion during their MDS treatment and care, than female patients (75%) (Figure 95B).

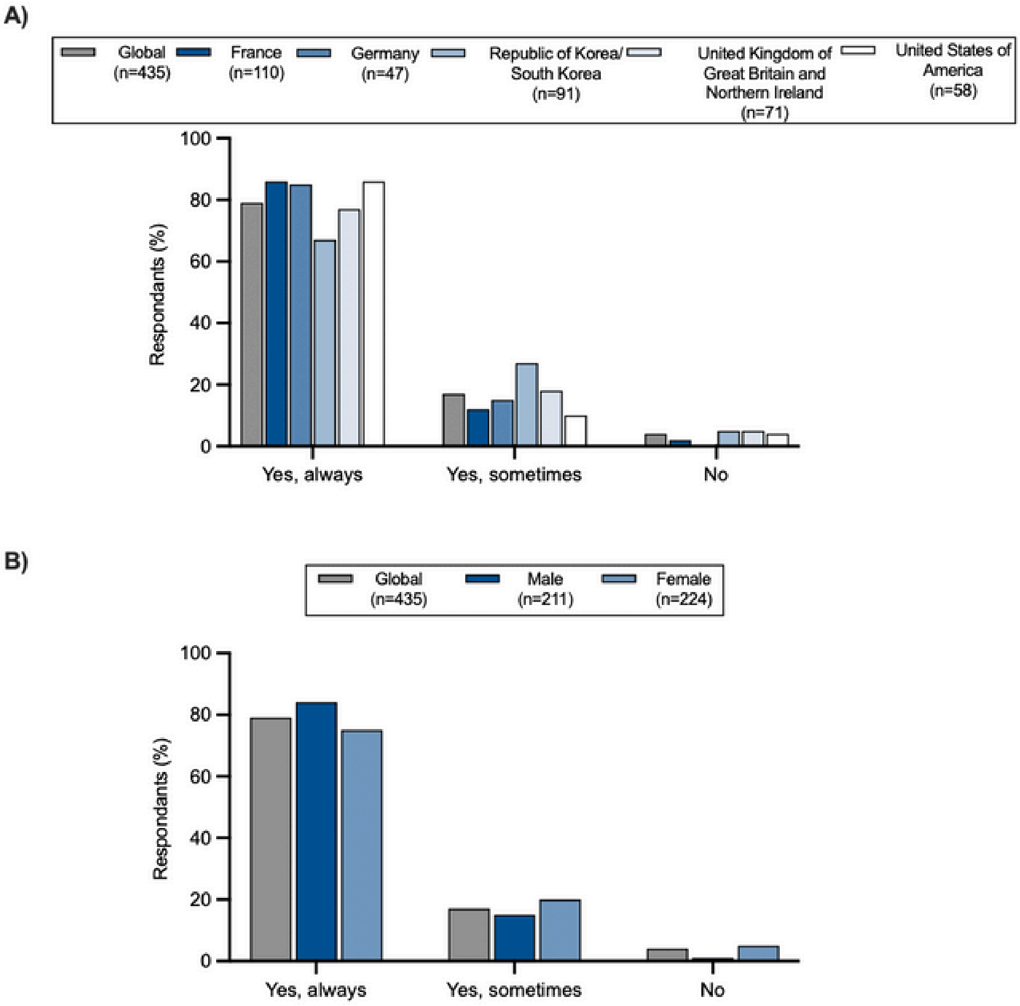


***Figure 95:* Effect of geographical location (A) and gender (B) Q73: Do you feel treated with kindness and compassion during your MDS treatment and care?** *Data are shown as a % from n=435 respondents.*

Just over two-thirds (68%) of patients aged 30-45 reported that they always felt treated with kindness and compassion during their MDS treatment, compared to 90% of patients aged 80+ (Figure 96).

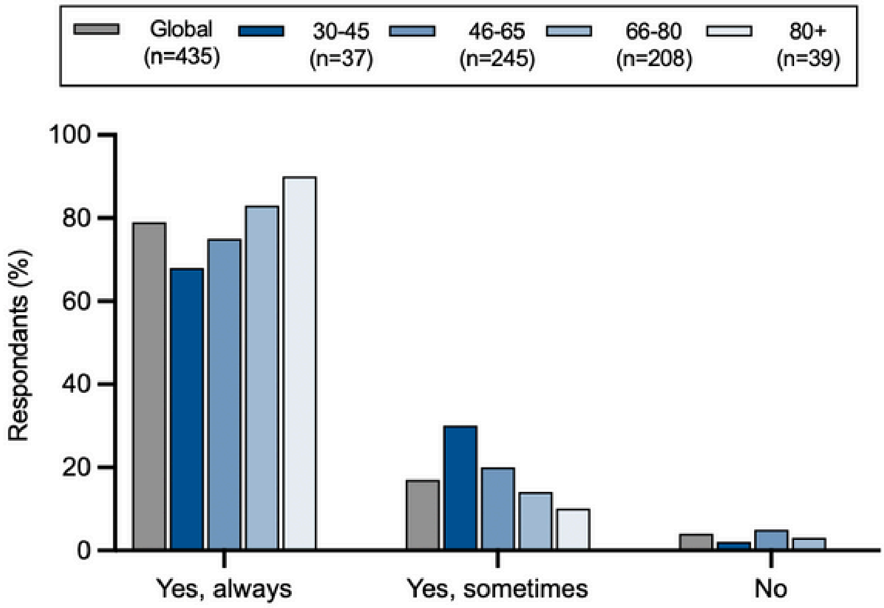


Figure 96: ***Effect of age on Q73: Do you feel treated with kindness and compassion during your MDS treatment and care?*** *Data are shown as a % from n=435 respondents.*

ACCESS TO SERVICES AND SUPPORT

Patients were asked how easy or difficult they found accessing health services and support. The following proportion of patients reported that they found it very easy or easy to access these services (Figure 97):

- Health services for blood transfusion (86%, n=239)
- Health services for infusions (84%, n=188)
- Prescription drugs related to your MDS treatment (79%, n=267)
- Individual counselling or support (61%, n=173)
- Group therapy / counselling or support (47%, n=75)

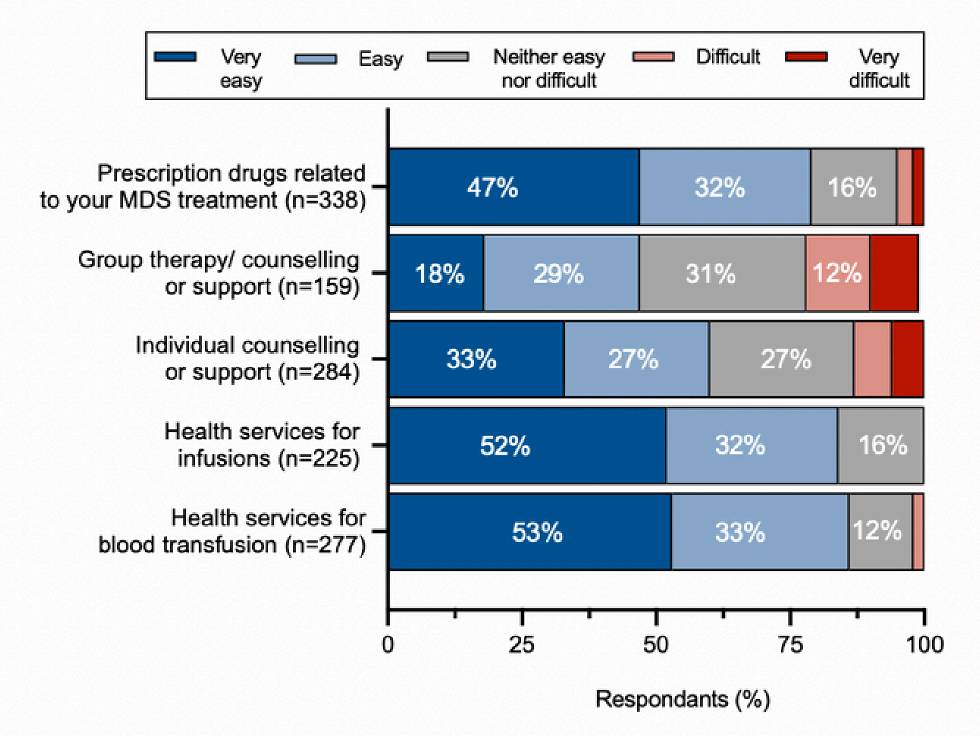


***Figure 97:* Q74: How easy was it for you to access the following?** *Data are shown as a % from n=159-338 respondents.*

EXPERIENCE OF STIGMA OR AGE-RELATED DISCRIMINATION IN CARE

More than 8 in 10 (84%, n=365) patients reported that they have not experienced stigma or felt they were given less attention because of their age.

There were no obvious differences in the responses between males and females or people living in different continents.

Analysis by age finds patients aged 80+ (79%) were most likely to report that they have not experienced stigma or felt they were given less attention because of their age, compared to other age groups (Figure 98).

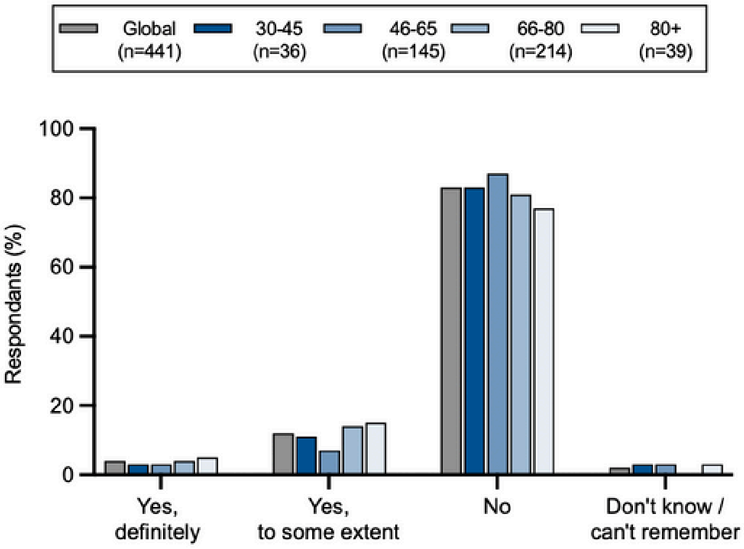


***Figure 98:* Q75: Have you experienced stigma or felt you were given less attention because of your age?** *Data are shown as a % from n=441 respondents.*

SURVEY ANALYSIS: CAREGIVER RESPONSES

SECTION 1: MDS DIAGNOSIS

- Caregivers reported that 61% of patients first spoke to a healthcare professional within three months of first experiencing symptoms.
- Nearly a half (44%) of caregivers reported knowing the patient's MDS subtype.
- Nearly a half (47%) of caregivers reported not knowing the patient's IPSS-R or IPSS-M risk level / category.

Respondents who identified as caregivers completed the survey based on their perspective of the patient's experience.

YEARS OF DIAGNOSIS

Caregivers were most likely to report the patients was diagnosed since 2020, with 43% diagnosed from 2023-until the time of responding to the survey and 23% diagnosed between 2020-22 (Figure 99).

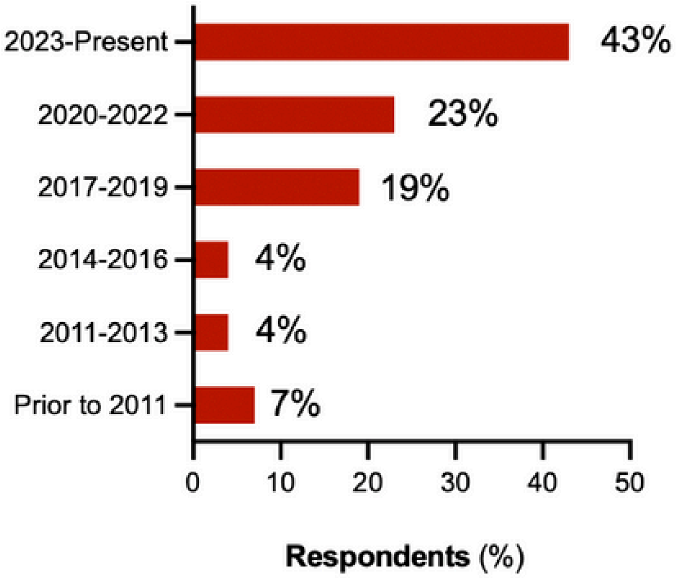


Figure 99: What year was the patient diagnosed with MDS? Please enter YYYY e.g., 2004. *Data are shown as a % from n=441 respondents.*

TIME FROM FIRST EXPERIENCING SYMPTOMS TO VISITING HEALTH PROFESSIONAL

Caregivers reported that 61% of patients first spoke to a healthcare professional within three months of first experiencing symptoms (Figure 100).

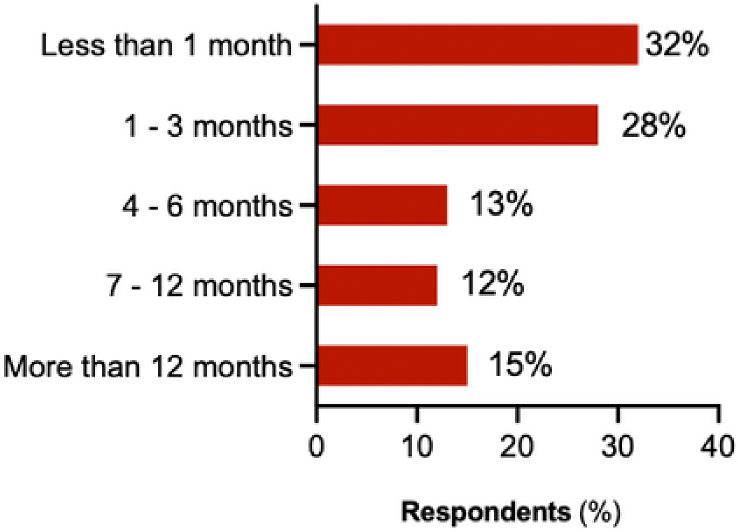


Figure 100: ***C_Q8+. How long was it from the time the patient first experienced symptoms until they first spoke to a healthcare professional about them? By this we mean any healthcare professional they saw, this could be a GP / family doctor, hospital doctor, etc.*** *Data are shown as a % from n=102 respondents.*

NUMBER OF HEALTHCARE VISITS BEFORE BLOOD TESTS

A third (34%, n=31) reported that patients saw a healthcare professional once about their symptoms before they had blood tests (Figure 101).

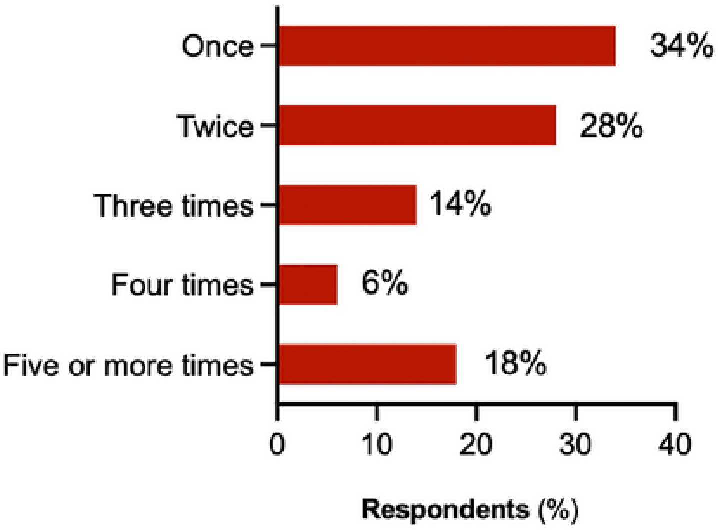


Figure 101: ***Q9+. How many times did the patient see a healthcare professional about their symptoms before they had blood tests? By this we mean any healthcare professional they saw, this could be a GP / family doctor, hospital doctor, etc.*** *Data are shown as a % from n=90 respondents.*

DETECTION OF MDS

Caregivers reported that 58% of the MDS patients were initially detected with a blood test, with 38%, from another test (Figure 102). 'Other' tests responses revealed several patients had a bone marrow biopsy, while some patients indicated that they had tests for other health conditions which detected their MDS.

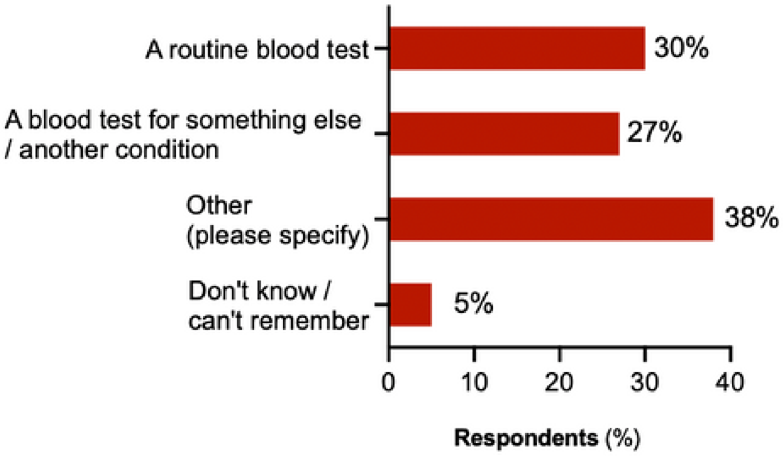


Figure 102: ***C_Q10. Was the patient's MDS initially detected from one of the following?*** *Data are shown as a % from n=106 respondents.*

BONE MARROW BIOPSY

When asked about the time between when the patient had their initial blood test and their bone marrow biopsy, 65% (n=67) of caregivers reported patients waiting less than three months (Figure 103).

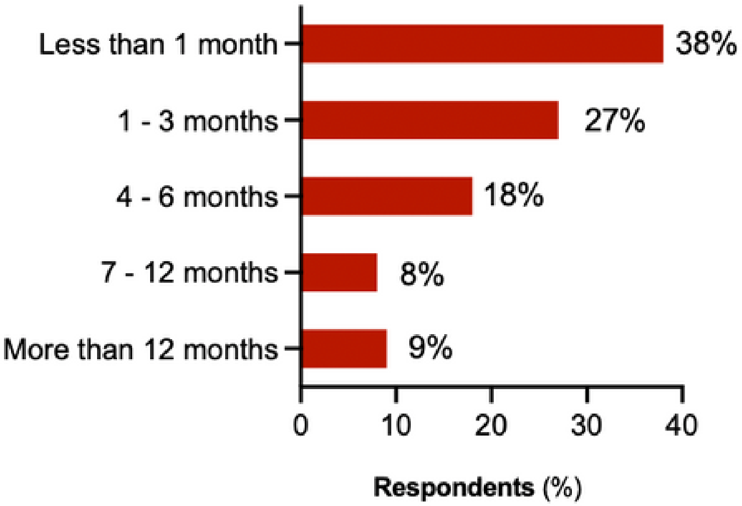


Figure 103: ***C_Q11+. How long was it from the time the patient had their initial blood test to having their bone marrow biopsy?*** *Data are shown as a % from n=103 respondents.*

LENGTH OF TIME BETWEEN FIRST ABNORMAL BLOOD TESTS AND MDS DIAGNOSIS

Caregivers were most likely to report that it took less than six months for patients to receive an MDS diagnosis following the first abnormal blood tests (70%) (Figure 104).

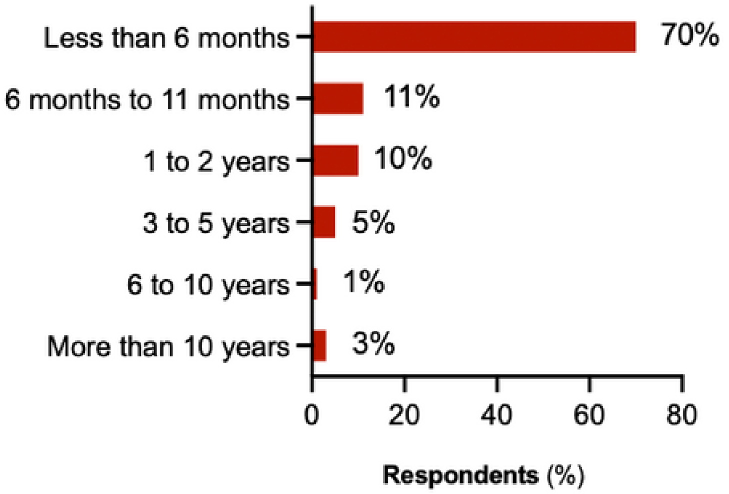


Figure 104: ***C_Q12+. How long was it from the time of the patient's first abnormal blood test to receiving their MDS diagnosis?*** *Data are shown as a % from n=100 respondents.*

Among caregivers who reported a delay of more than six months between the patient's first abnormal blood test and receiving an MDS diagnosis, 70% reported contributing factors to the delays. The most common reasons were (Figure 105):

- Inconclusive results or no diagnosis given (30%)
- Misdiagnosis or incorrect initial diagnosis (30%)
- None of the above (30%)

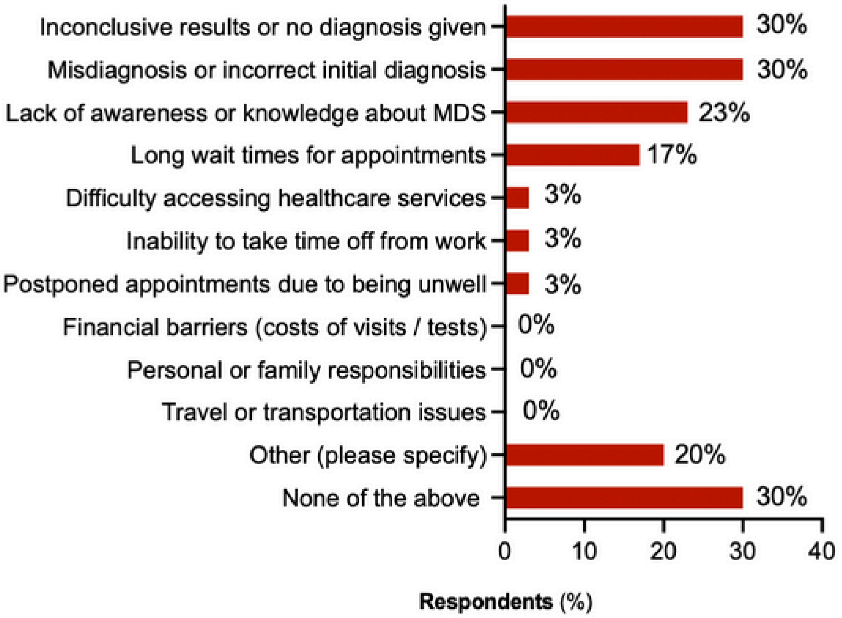


Figure 105: ***C_Q14. Did any of the following delay their MDS diagnosis? Please select all that apply.*** *Data are shown as a % from n=30 respondents.*

TESTS

Caregivers were asked about any tests the patient had. The most common were (Figure 106):

- Complete blood count testing (84%),
- Chromosome tests (genetic testing) (54%)
- Gene mutation testing (50%)

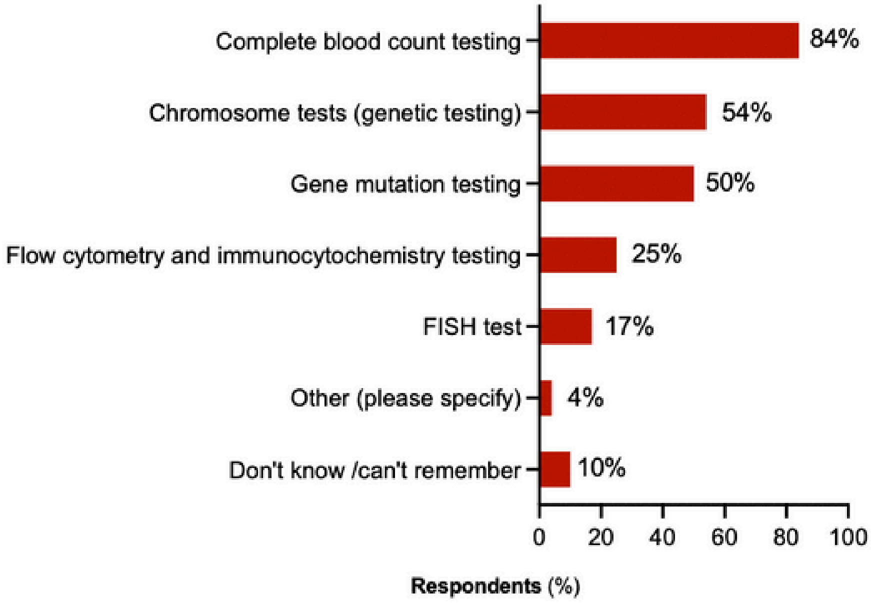


***Figure 106:* C_Q13. Has the patient had any of the following test(s)? Please select all that apply.** *Data are shown as a % from n=102 respondents.*

SUBTYPE KNOWN

Fewer than half of caregivers (44%) reported knowing the patient’s MDS subtype (Figure 107).

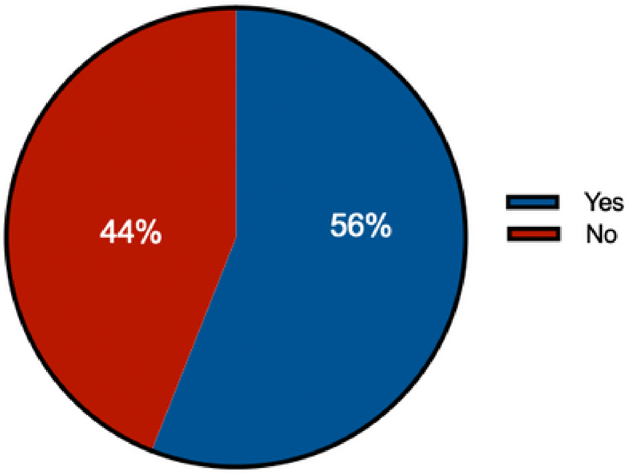


Figure 107: ***C_Q15+. Do you know the patient's MDS subtype? For example, MDS-LB, MDS-IB1, MDS-5q etc.*** *Data are shown as a % from n=103 respondents.*

Amongst caregivers who knew the patient’s MDS subtype, the subtypes reported are shown in Figure 108. The most common were:

- Other (please specify) (27%). For example, MDS-EB1 and MDS-EB2.
- MDS with increased blasts 2 (MDS-IB2) (11%)

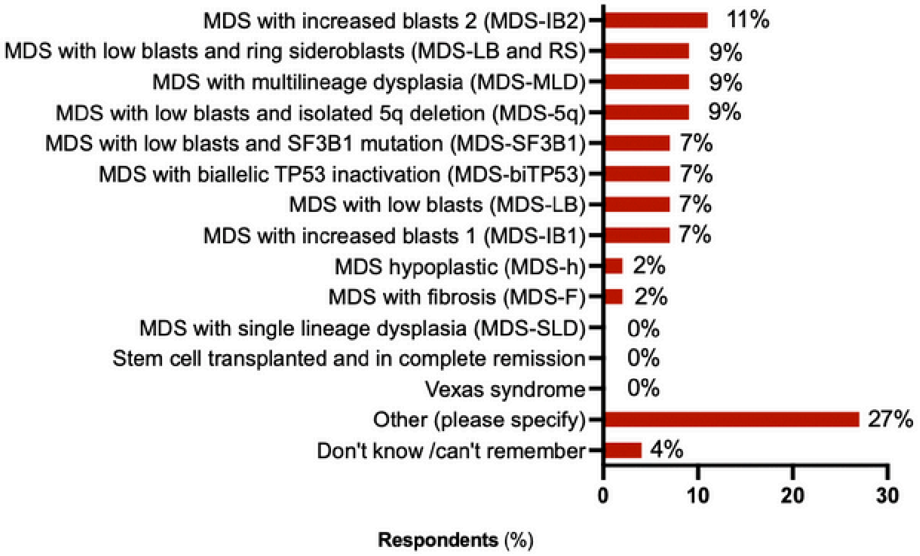


Figure 108: ***C_Q16. What MDS subtype were they diagnosed with?*** *Data are shown as a % from n=45 respondents.*

IPSS-R OR IPSS-M RISK LEVEL / CATEGORY KNOWN

When asked about the patient’s IPSS-R or IPSS-M risk level / category, 53% (n=53) of caregivers reported that they knew their risk level (Figure 109).

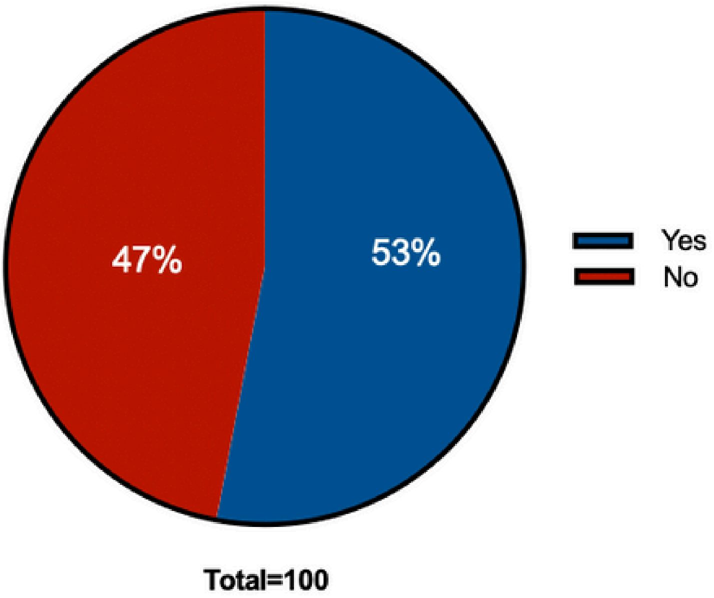


Figure 109: ***C_Q17+. Do you know the patient's IPSS-R or IPSS-M risk level / category?*** *Data are shown as a % from n=100 respondents.*

Caregivers who knew the patient’s IPSS-R or IPSS-M risk level / category when diagnosed were most likely to report the patient being assessed as IPSS-R risk score: High risk MDS at diagnosis (28%) (Table 12).

Caregivers who knew the patient’s current IPSS-R or IPSS-M risk level / category were most likely to report the patient being currently assessed as IPSS-M risk score: High risk MDS (15%, n=8) at the time of competing the survey (Table 12).

C_Q18_a: Patient IPPS-R risk level *at diagnosis*				
Very low 9%	Low 15%	Intermediate 9%	High 28%	Very high 4%
C_Q18_b: Patient IPPS-R risk level *at time of completing survey*				
Very low 4%	Low 6%	Intermediate 8%	High 10%	Very high 0%

C_Q18_a: Patient IPPS-M risk level *at diagnosis*					
Very low 2%	Low 4%	Moderate low 6%	Moderate high 4%	High 13%	Very high 6%
C_Q18_b: Patient IPPS-M risk level *at time of completing survey*					
Very low 2%	Low 8%	Moderate low 0%	Moderate high 12%	High 15%	Very high 12%

Table 12.* *C_Q18a and b. What was their IPSS-R or IPSS-M risk level / category at diagnosis and at time of completing the survey? If you know both their IPSS-R or IPSS-M risk level / category, please provide your IPSS-M risk level / category. *Data are shown as a % from n=43 and n=52 respondents for at diagnosis and at time of completing the survey respectively.*

SECTION 2: CARE AND SUPPORT

- 95% of caregivers are immediate family members with half being spouse/ partner.
- Most common support provided by caregivers included companionship/ emotional support (84%) and help with household tasks (70%).

RELATIONSHIP TO THE PATIENT

Half (50%) of caregivers, care for their spouse / partner and 45% care for a family member (parent, child, sibling, cousin, etc.). Only a small proportion care for a friend (5%) (Figure 110).

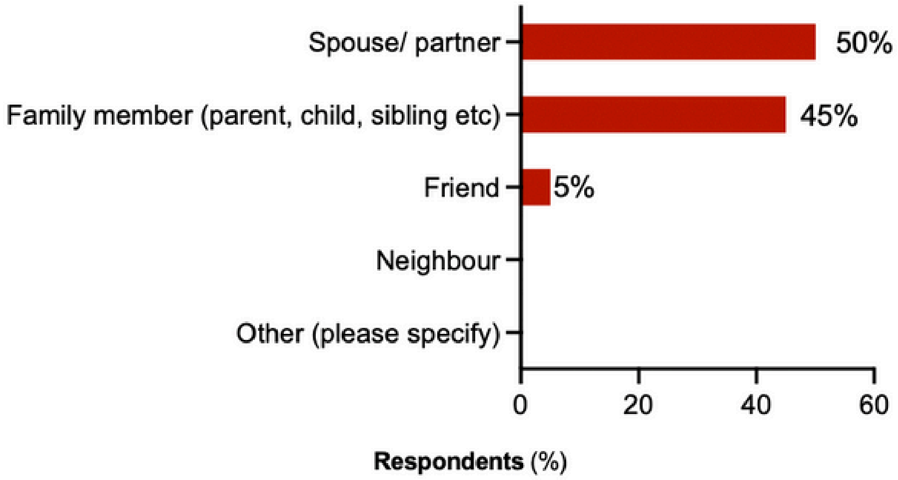


Figure 110: ***C_Q19. Which of the following best describes the person you care for?*** *Data are shown as a % from n=98 respondents.*

TYPES OF SUPPOR

The most common types of support provided by caregivers (Figure 111):

- Companionship and emotional support (84%, n=82)
- Household tasks e.g. cooking, cleaning, other household chores (70%, n=69)
- Communication e.g. Interaction with health & social care professionals/ helping with phone calls / write letters/ emails (59%, n=58)
- Providing companionship during trips or appointments (55%, n=54)
- Providing transport / travel (52%, n=51)

Figure 111: ***C_Q20. What type(s) of support do you provide? Please select all that apply.*** *Data are shown as a % from n=98 respondents.*

SECTION 3: TREATMENT

- Nearly one fifth (22%) reported it was difficult for the patient to access care from their MDS specialist.
- Nearly one in ten (9%) felt some level of difficulty getting the medicine needed for the patients MDS treatment.
- Fatigue and wight loss are symptoms that impacts patients most severely.
- Nearly a quarter (23%) reported that patients' symptoms have gotten worse after treatment.
- Over half (57%) reported delays in accessing services with the biggest challenge being accessing appointments with specialists.

TIME TO TRAVEL TO MDS SPECIALIST

Caregivers reported more than 7 in 10 (72%) of patients travel 60 minutes or less to see their MDS specialist. With patients most likely to travel either 16-30 minutes (22%) or 31-45 minutes (22%) to see them (Figure 112).

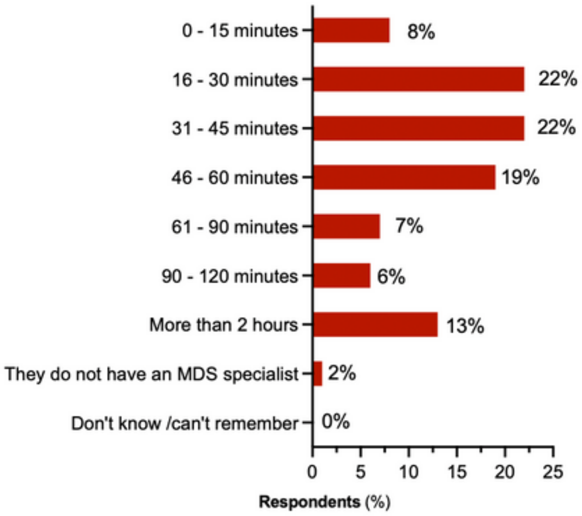


Figure 112: ***C_Q21. On average, how long does it take the patient to travel to their MDS specialist?*** *Data are shown as a % from n=98 respondents.*

EASE OF ACCESSING CARE FROM MDS SPECIALIST

When asked how easy it was for the patient to access care from their MDS specialist, 15% reported it was very easy and 30% reported it was easy (Figure 113).

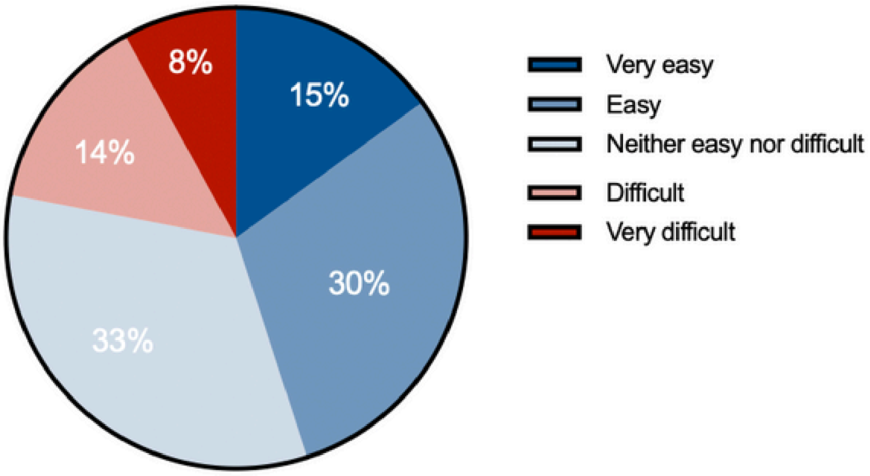


Figure 113: ***C_Q22+. How easy is it for the patient to access care from their MDS specialist?*** *Data are shown as a % from n=96 respondents.*

ACCESS TO AN MDS CENTRE OF EXCELLENCE

Seven in 10 (70%) caregivers reported that patients have access to an MDS Centre of Excellence (Figure 114).

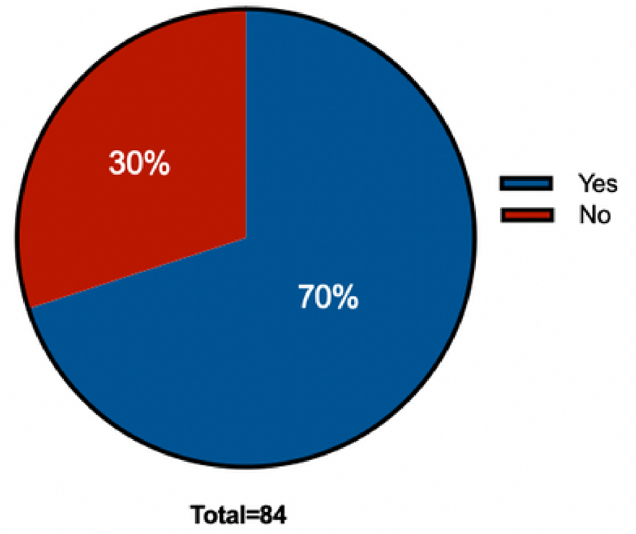


***Figure 114:* C_Q23+. Does the patient have access to an MDS Centre of Excellence?** *Data are shown as a % from n=84 respondents.*

DIFFICULTY ARRANGING APPOINTMENTS WITH HEALTHCARE PROVIDER / SPECIALIST

Six in 10 (60%) caregivers reported that patients never or rarely experience difficulty arranging appointments with healthcare provider or MDS specialist (Figure 115).

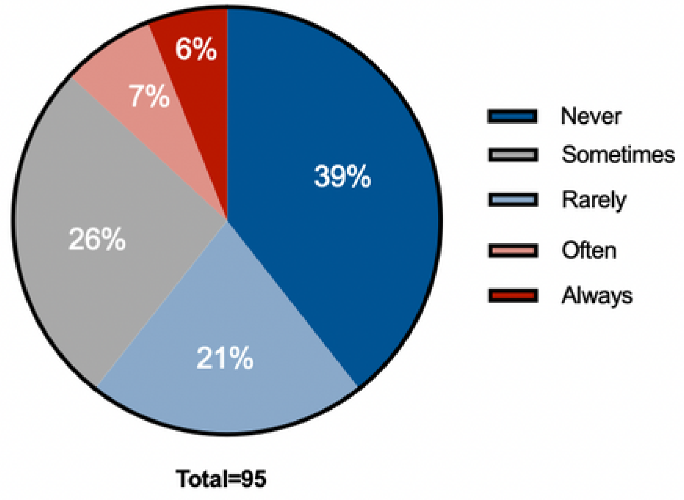


***Figure 115:* C_Q24+. Does the patient have difficulty arranging appointments with their healthcare provider / MDS specialist?** *Data are shown as a % from n=95 respondents.*

TREATMENTS RECEIVED

Caregivers reported 92% of patients have received treatment for their MDS. The most common treatments that patients received since being diagnosed with MDS were (Figure 116):

- Red blood cell transfusions (57%, n=55)
- Platelet transfusions (45%, n=43)
- Erythropoiesis-stimulating agents (Procrit, darbepoetin, Eprex/EPO) (38%, n=36)

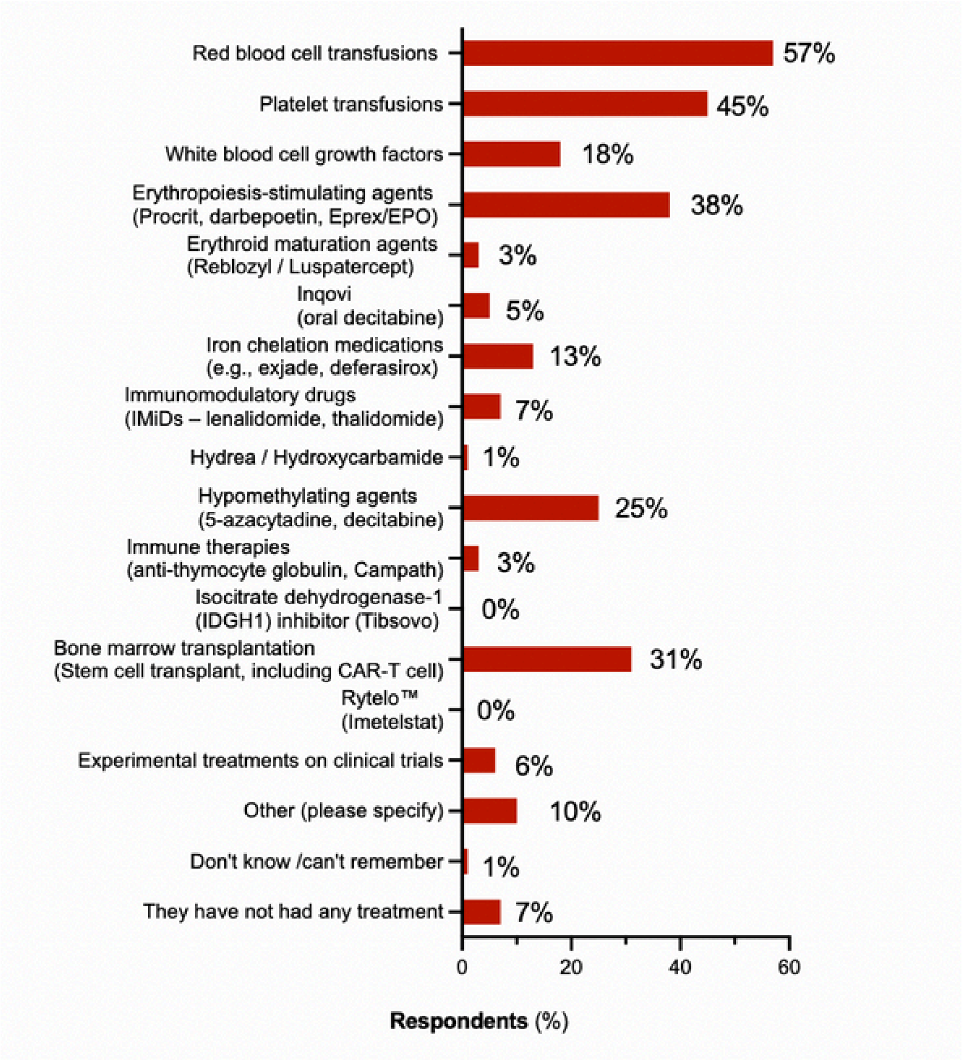


***Figure 116:* C_Q25. Which treatments have the patient received since being diagnosed with MDS? Please select all that apply.** *Data are shown as a % from n=96 respondents.*

MOST RECENT OR CURRENT TREATMENT

Caregivers who reported that the patient had received treatment, were asked about the type of current or most recent treatment. Figure 117 displays the most recent or recurrent treatment types. Patients were most likely to have received:

- Bone marrow transplantation (Stem cell transplant, including CAR-T cell) (24%, n=15)
- Red blood cell transfusions (21%, n=13)
- Hypomethylating agents (5-azacytadine, decitabine (14%, n=9)
- Erythropoiesis-stimulating agents (Procrit, darbepoetin, Eprex/EPO) (11%, n=7)

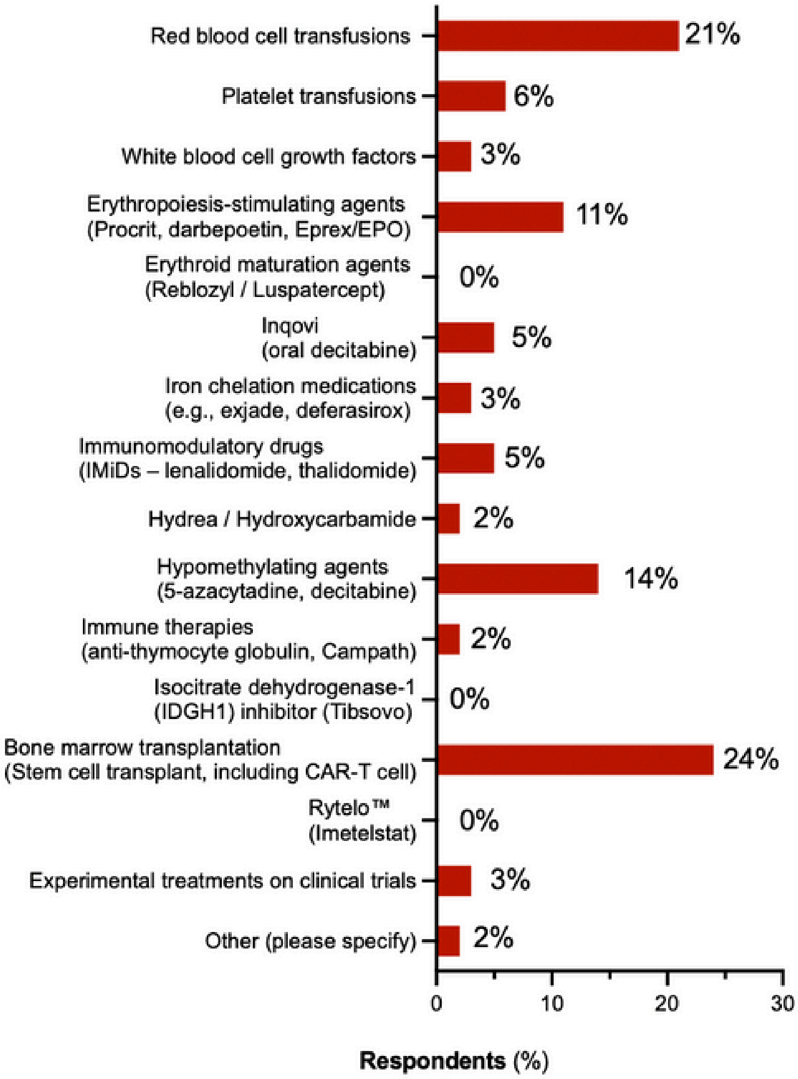


Figure 117: ***C_Q26. Of the following treatments the patient has received, which is the current or most recent treatment?*** *Data are shown as a % from n=63 respondents.*

GETTING MEDICINE NEEDED FOR MDS TREATMENT

Caregivers reported that 80% of patients never or rarely had difficulty getting the medicine needed for their MDS treatment (Figure 118).

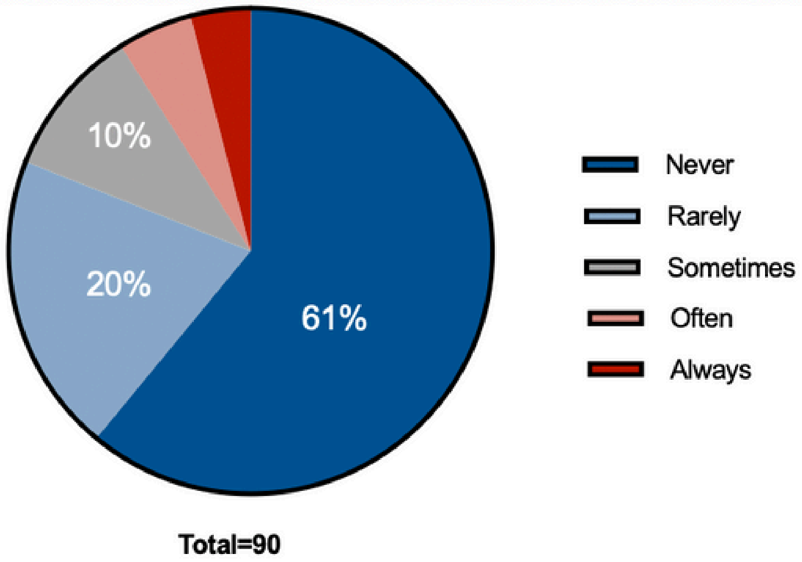


***Figure 118:* C_Q27+. Has the patient ever had difficulty getting the medicine they need for their MDS treatment?** *Data are shown as a % from n=90 respondents.*

FREQUENCY OF BLOOD TRANSFUSIONS

Caregivers who reported that the patient had received blood transfusions, were asked how often the patient currently receives them (Figure 119). Caregivers were most likely to report that patients received blood transfusions either non, only once or daily (33%), fortnightly (16%) or monthly (14%).

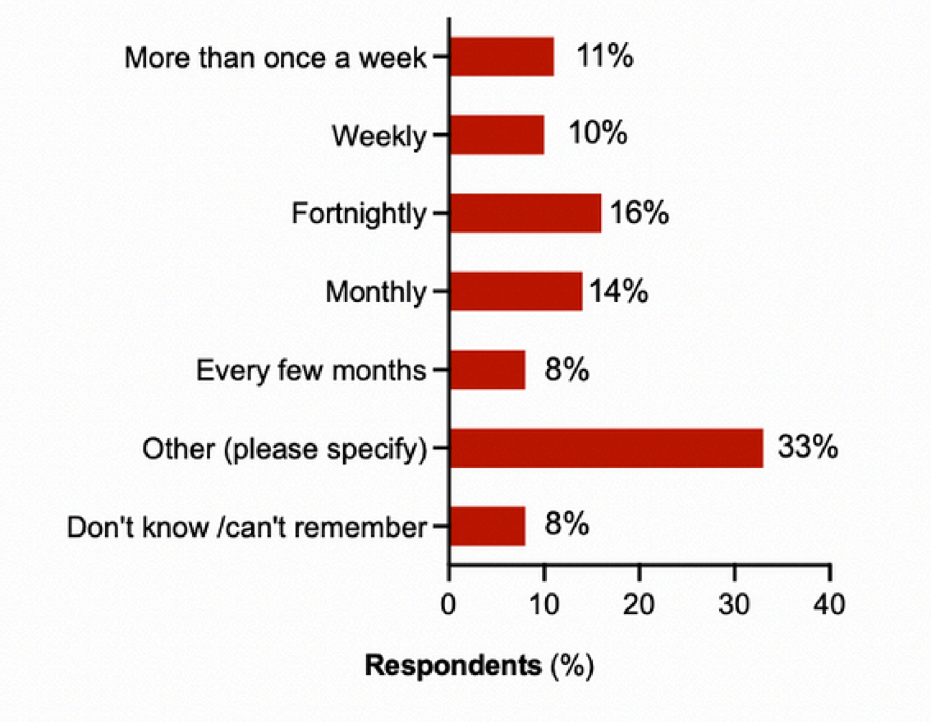


Figure 119: ***C_Q28. How often does the patient currently have blood transfusions for their MDS?*** *Data are shown as a % from n=63 respondents.*

LOCATION OF BLOOD TRANSFUSIONS

Caregivers who reported that the patient had received blood transfusions, were asked where the transfusion usually takes place (Figure 120). Caregivers were most likely to report that patients received blood transfusions at an outpatient / infusion clinic (70%) with 41% being admitted to hospital as an inpatient.

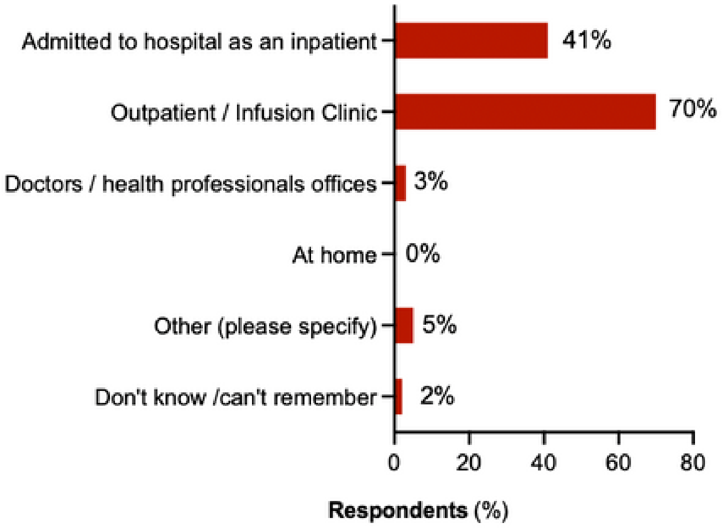


Figure 120: ***C_Q29. Where does the patient usually receive their blood transfusions? Please select all that apply.*** *Data are shown as a % from n=61 respondents.*

BARRIERS EXPERIENCED THAT AFFECTED TREATMENT

Caregivers reported 68% of patients have experienced barriers that have affected their treatment. The most common barriers were (Figure 121):

- Wait time to treatment (27%, n=24)
- Cost to treatment (26%, n=23)
- Difficulty managing their carer / caregiver role (child, parent, disabled person) while in treatment (21%, n=19)

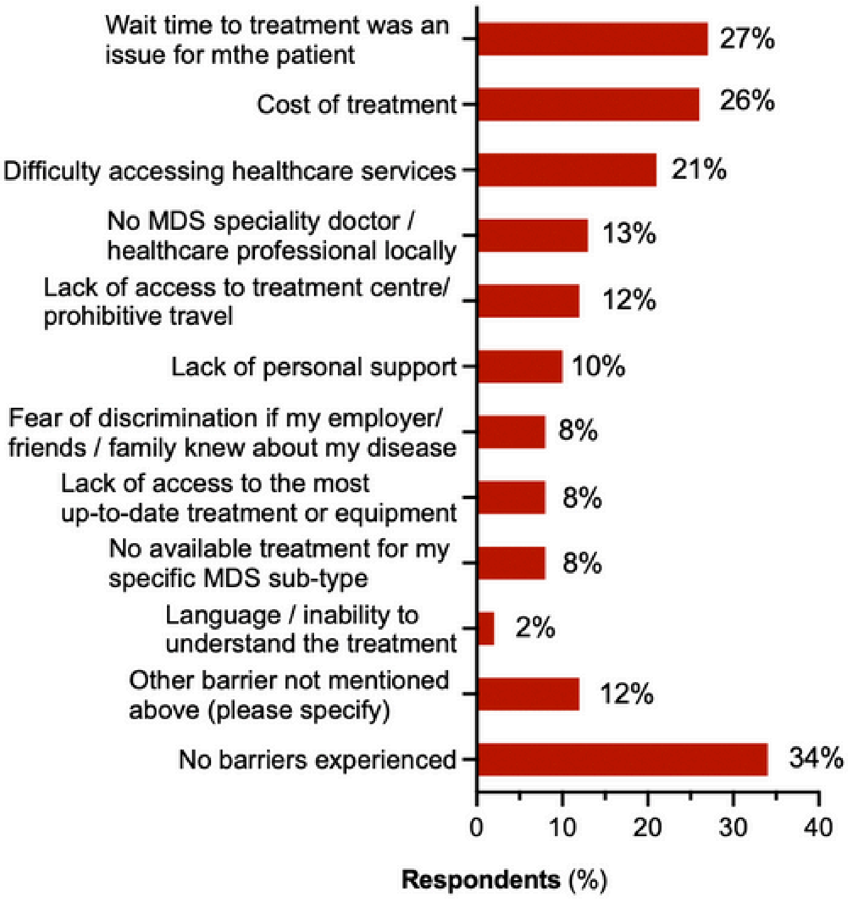


***Figure 121:* C_Q30. Which barriers, if any, has the patient experienced that affected their treatment? Please select all that apply.** *Data are shown as a % from n=89 respondents.*

INVOLVED AS MUCH AS WANTED TO BE IN DECISIONS ABOUT TREATMENT

Six in 10 (60%) caregivers reported that patients were definitely involved as much as they wanted to be in decisions about treatment (Figure 122).

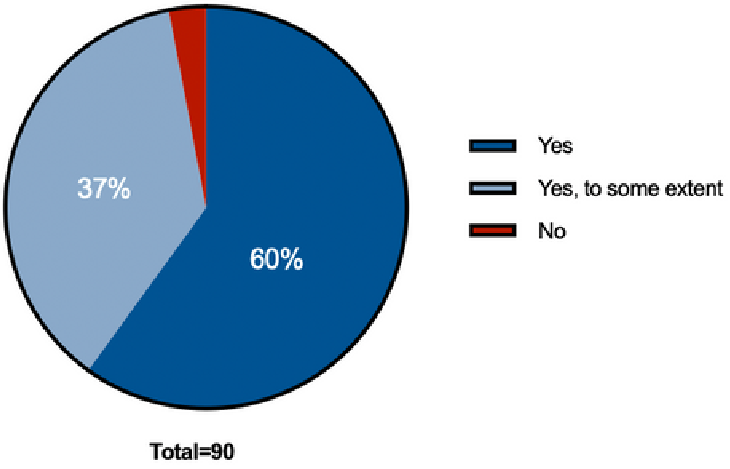


***Figure 122:* C_Q31+. Was the patient involved as much as they wanted to be in decisions about their treatment?** *Data are shown as a % from n=90 respondents.*

ANSWERS THAT COULD BE UNDERSTOOD WHEN ASKING QUESTIONS

When asked about the patient's current or most recent treatment, 62% of caregivers reported that when they asked questions, they always received answers that could be understood (Figure 123).

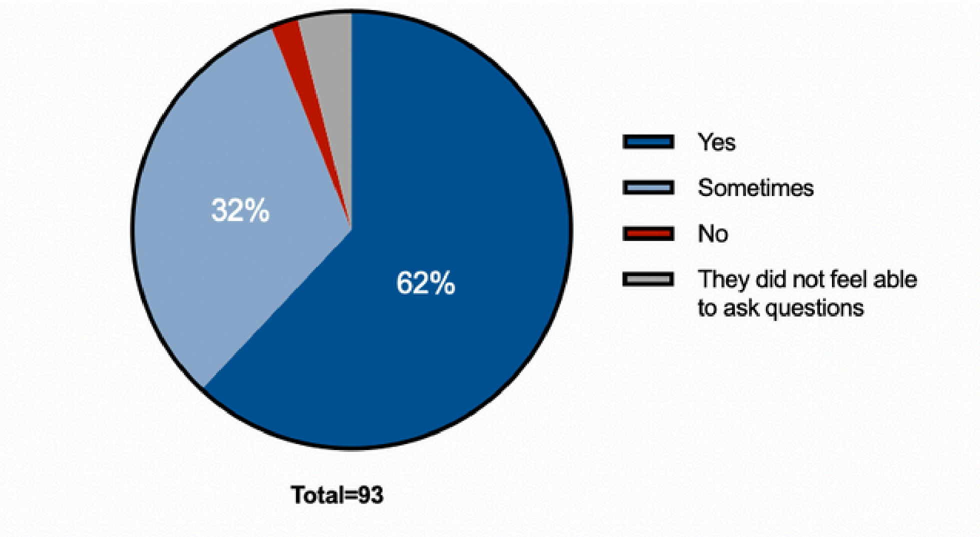


***Figure 123:* C_Q32+. During the patient's current or most recent treatment, when they asked questions, did they get answers they could understand?** *Data are shown as a % from n=93 respondents.*

SIDE EFFECTS OF CURRENT OR RECENT TREATMENT

Caregivers were asked if the patient had experienced any side effects as a result of their current or most recent treatment (Figure 124). Caregivers reported that 9% of patients experienced no side effects from their current or most recent treatment The most common side effects were:

- Fatigue / lack of energy / tiredness (52%, n=48).
- Weight loss (39%, n=36)
- Joint or bone pain (37%, n=34)
- Anemia (37%, n=34)

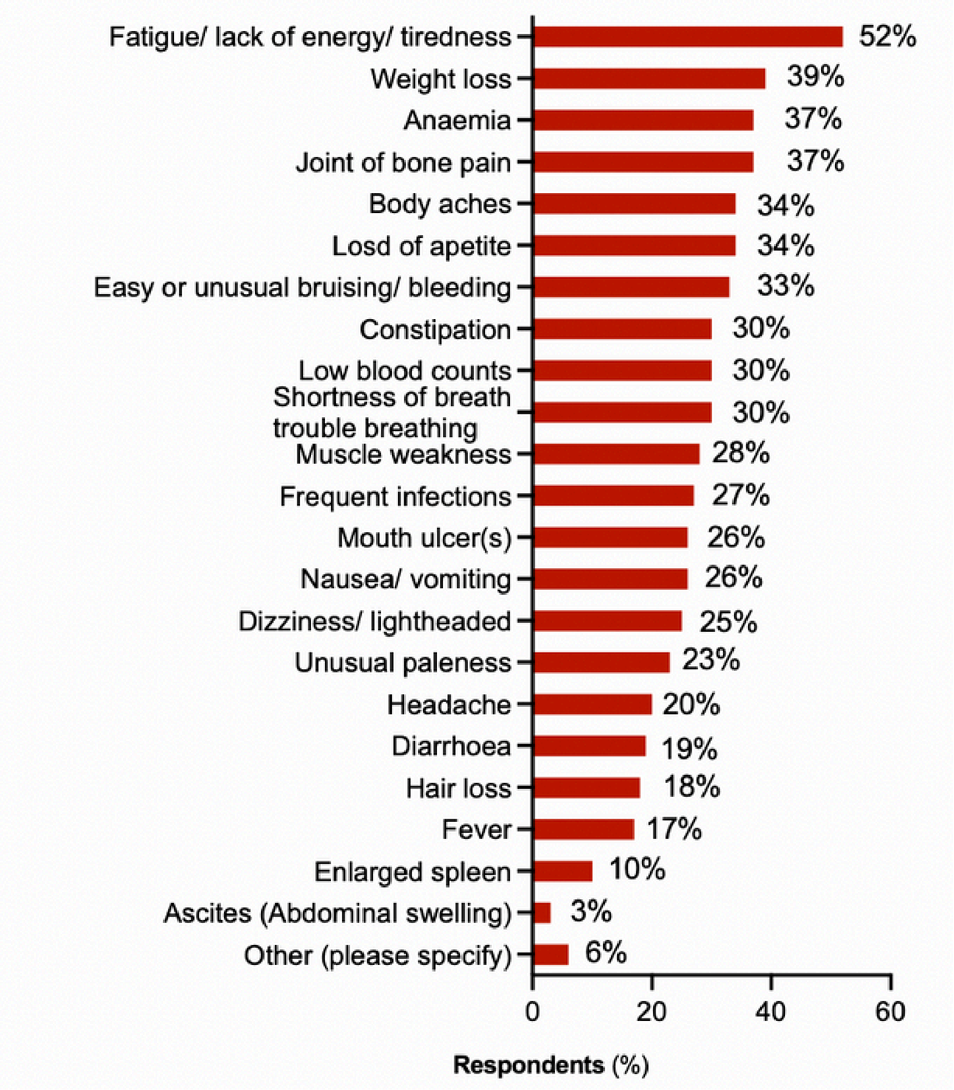


***Figure 124:* C_Q33. Has the patient experienced any of the following side effects as a result of their current or most recent treatment? Please select all that apply.** *Data are shown as a % from n=93 respondents.*

IMPACT OF SIDE EFFECTS

Caregivers were asked about the impact of any side effects amongst patients who experienced side effects as a result of their current or most recent treatment. Caregivers were most likely to report the following side effect as having a very severe or severe impact (Figure 125):

- Fatigue / lack of energy / tiredness (53%, n=24)
- Weight loss (45%, n=15)
- Loss of appetite (44%, n=13)
- Anemia (42%, n=13)
- Joint or bone pain (39%, n=13)
- Body aches (26%, n=8)

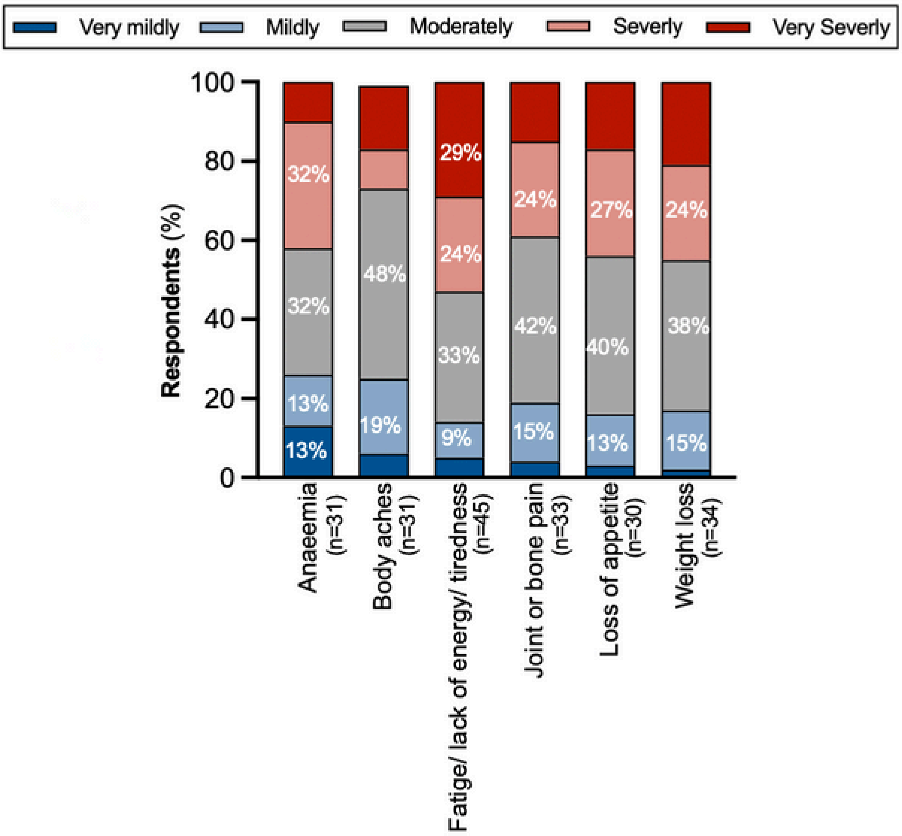


Figure 125: ***C_Q34 To what extent have the following side effect(s) impacted them?*** *Data are shown as a % from n=30-45 respondents.*

INFORMATION ABOUT ANY SIDE EFFECTS

Half of caregivers (48%) reported that the patient was given completely clear information about side effects from current or most recent treatment (Figure 126).

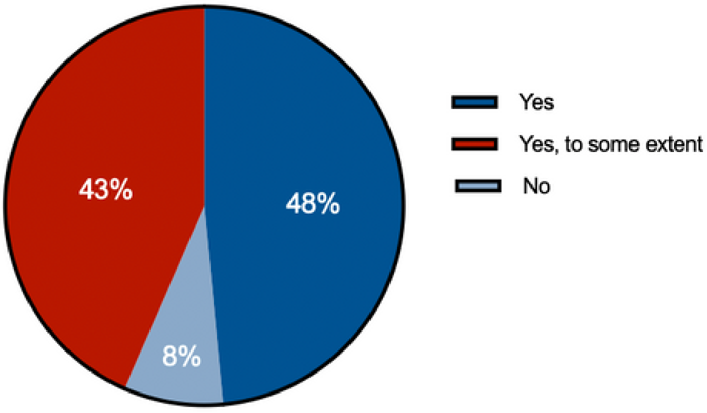


Figure 126: ***C_Q35+. Was the patient given clear information about any side effects from their current or most recent treatment?*** *Data are shown as a % from n=83 respondents.*

IMPACT OF TREATMENT

Half of caregivers (49%) reported that the patient's symptoms improved following their current or most recent treatment (Figure 127).

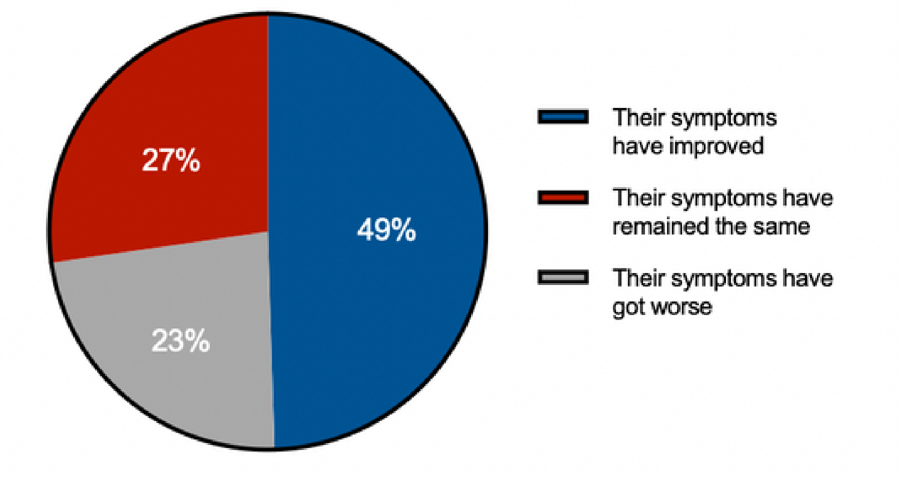


***Figure 127:* C_Q36+. What impact has the patient's current or most recent treatment had on the symptoms that they were experiencing?**

INFORMATION ABOUT TREATMENT

Half of caregivers (51%) reported that the patient definitely received the information or explanations they needed whilst receiving their current or most recent treatment (Figure 128).

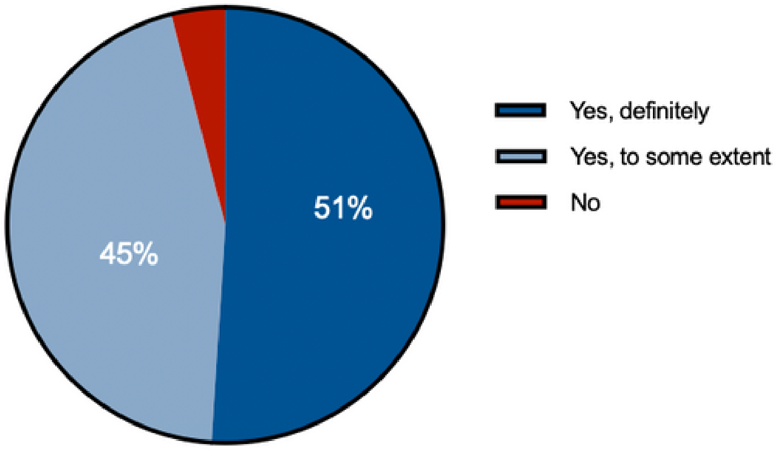


***Figure 128:* C_Q37+. Thinking about the care the patient received during their current or most recent treatment, were they given the information or explanations they needed?** *Data are shown as a % from n=89 respondents.*

DELAY IN ACCESSING SERVICES

Caregivers were asked whether the patients had experienced a delay in accessing services and 43% reported they had not. The most reported delay was in accessing appointment/s with a specialist (27%) (Figure 129).

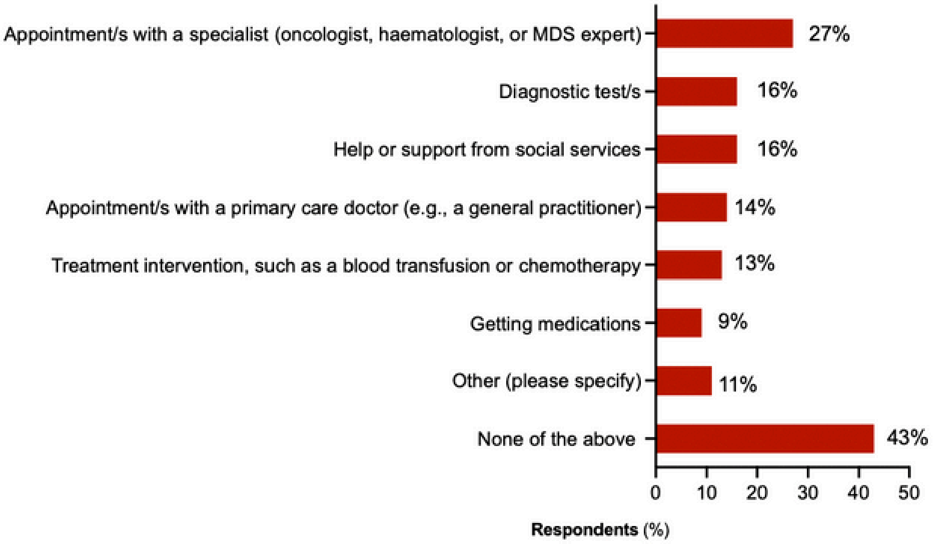


***Figure 129:* C_Q38. In last 12 months, has the patient experienced a delay in accessing any of the following? Please select all that apply.** *Data are shown as a % from n=88 respondents.*

REASON FOR DELAY

Those who reported experiencing delays were asked about the reason for delay. The most commonly experience delays were (Figure 130):

- Other (please specify) (38%, n=18) (This included answers such as ‘no other treatments were considered or offered’, ‘waiting on the days of the day hospital for the VIDAZA treatment’, ‘should have referred earlier’ and ‘Was going to go to trials, and was waiting on a spot to open’.
- Lack of available appointments (26%, n=12)
- Communication issues between healthcare providers (23%, n=11)
- Delays in test results (17%, n=8)
- Waiting for lab results (15%, n=7)

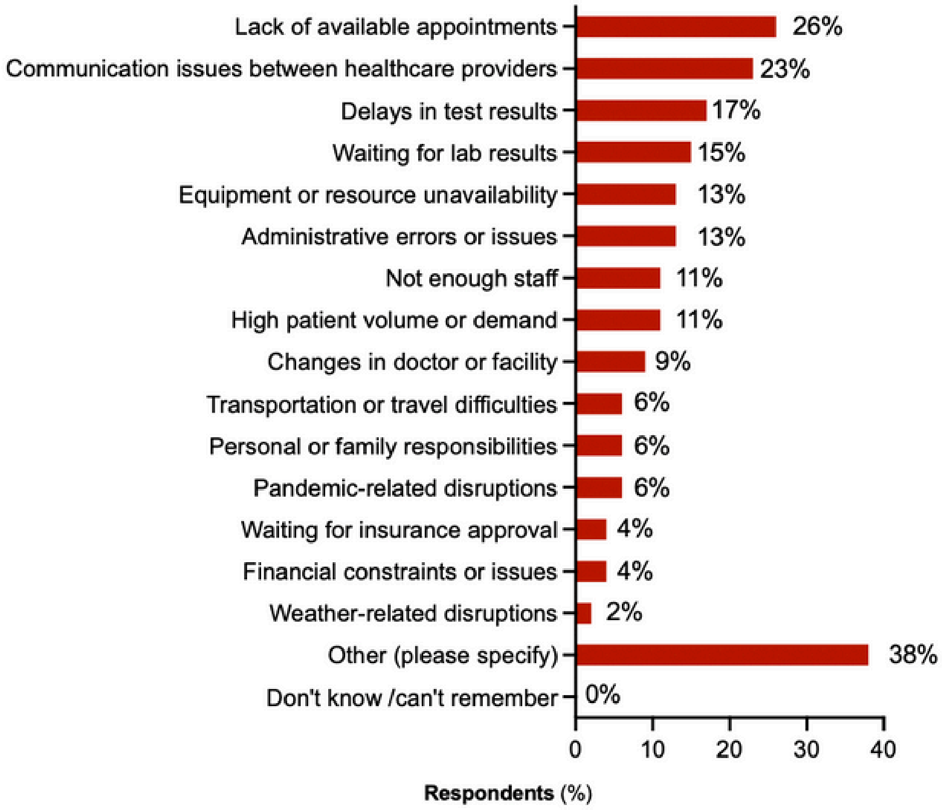


Figure 130: ***C_Q39. What was the reason for the delay? Please select all that apply.*** *Data are shown as a % from n=47 respondents.*

SECTION 4: TESTING AND MONITORING

- Nearly one in ten caregivers reported that patients felt they were not treated with kindness and compassion during their MDS treatment and care.

TREATED WITH KINDNESS AND COMPASSION

When asked if the patient felt treated with kindness and compassion during their MDS treatment and care, 63% of caregivers reported this was always the case whereas 8% felt this was not the case (Figure 131).

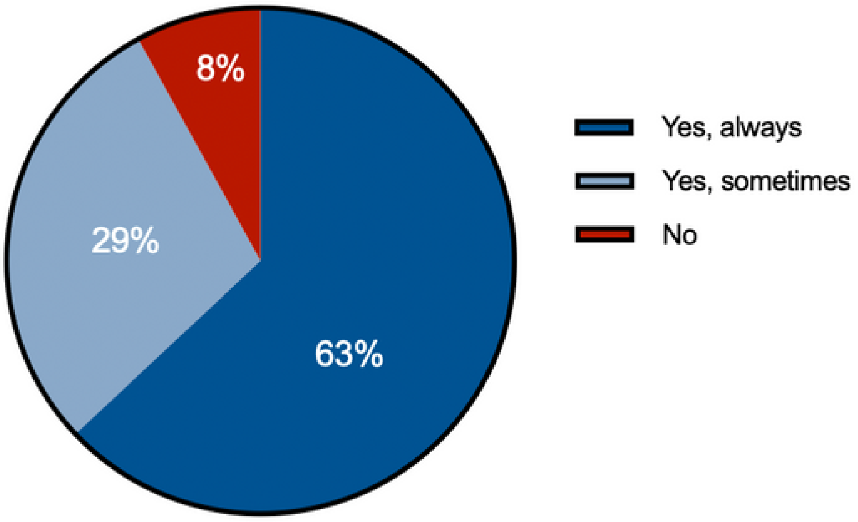


Figure 129: ***C_Q40+. Does the patient feel treated with kindness and compassion during their MDS treatment and care?*** *Data are shown as a % from n=89 respondents.*

CONCLUSION

This report presents findings from the MDS Alliance Global Patient Survey 2024, capturing the experiences of 520 patients and 108 caregivers across 31 countries. The insights gathered offer valuable perspectives on access to services, medications, and treatments for individuals living with MDS. Based on the survey data, key recommendations have been developed to guide the MDS Alliance, its member organisations, and partner networks in identifying and prioritising areas for action to improve care and support for patients and caregivers globally.

DIAGNOSIS

While many patients were diagnosed since 2020, awareness of MDS subtypes and individual risk levels remains limited. Just over half of patients and caregivers reported knowing specific subtypes, suggesting a significant educational gap. Many patients accessed healthcare within three months of symptom onset, and routine blood tests played a critical role in detection. However, delays in diagnosis, particularly those extending beyond six months were frequently linked to inconclusive test results, limited awareness among healthcare professionals, and misdiagnosis.

Recommendation:

1. Improved patient and caregiver education about MDS subtypes and risk levels
2. Faster and more accurate diagnosis.

CARE AND SUPPORT

Caregivers, particularly spouses and close family members, provide essential emotional and practical support for patients. Their involvement spans companionship, assistance with daily tasks, and support during medical appointments. Highlighting how important the role of spouses and family members are in providing support, particularly in emotional well-being, daily household tasks, and attending medical visits.

Recommendation:

1. Provide more support material for caregivers regarding the challenges faced by patients in particular fatigue.

TREATMENT

Most patients reported strong access to MDS care, often living within 60 minutes of a specialist and rarely encountering difficulties accessing medications. Treatments such as transfusions and erythropoiesis-stimulating agent are commonly used, but bone marrow transplants remain less frequent. Patients generally feel involved in treatment decisions, with improved quality of life and extended survival ranking as the most important treatment goals. Appointment cancellations were much higher in younger patients. The most common symptom to severely effect patients is fatigue and weight loss. Challenges remain in ensuring timely appointments and responsive care.

Recommendation:

1. Strengthening efforts to deliver patient-centred care that prioritises individual preferences and timely access to specialists.
2. Increasing awareness of main challenges through improved education to the general public and healthcare professionals including information about fatigue and wight loss.
3. Follow up with younger patients to ensure they attend appointments.

TESTING AND MONITORING

Most patients undergo regular monitoring, with consistent access to testing and follow-up care. However, participation in clinical trials remains low, largely due to lack of awareness or invitations to participate. While most patients report positive interactions with healthcare professionals and little evidence of age-related stigma, access to mental health services and emotional support remains limited.

Recommendation:

1. More consistent testing and monitoring
2. Stronger access to healthcare services, and positive patient experiences
3. Increased clinical trial participation and support services like counselling.

LIMITATIONS OF CURRENT SURVEY

Whilst all attempts were made to make the survey as accessible as possible, there were still regions around the world which did not participate. For this reason, whilst we have found differences between different geographical locations, it is important to remember that the data may be skewed in its current analysis and any differences observed may in fact be greater if data from additional countries in lower income groups are included. As such, having specific surveys that target specific regions may encourage participation. Also, the number of caregivers that completed the survey was relatively low compared to patients so drawing any obvious conclusions was made more difficult.

In summary this survey has found that patient age, gender, geographical location and household income may influence MDS patients’ diagnosis, level of care and support, access to treatments and testing and monitoring.