MDS UK
Supporting Patients with Bone Marrow Failure

KING'S College LONDON
University of London

Dear participants,

Thank you so much for participating in this survey. This survey will help us to learn more about the impact that MDS has on your life.

This questionnaire is designed to be filled in anonymously. There is no need to add your name or contact details.

If you have completed this questionnaire before, thank you for participating and please disregard this questionnaire.

Why we are conducting this survey:

The information gathered from these questionnaires will be used to develop programmes to assist patients and their families, to educate physicians, nurses, and other allied healthcare professionals.

It will also help us to work with governmental and private agencies/companies to provide better care and service to you, the MDS patient.

The anonymised data may be used for future publications, and shared with other researchers interested in MDS Quality of Life data. You will not be identifiable in any publications as all data will be used anonymously.

How to fill out this questionnaire:

This questionnaire contains questions concerning your quality-of-life, the referral process you went through, the information you received, the knowledge that you have about MDS as a disease, and the impact that MDS treatment has on your life and the lives of those around you.

There are no right or wrong answers. **Please try to answer all of the questions if you can** – this will help greatly with the quality of the results of this important project. If you do not know the answer to a question please just write "I don't know", rather than leaving it blank.

This should take between 30 – 45 minutes of your time to fill out.

Please post it back to us using the reply paid envelope by this date:

Questionnaires posted or emailed to us will be fully anonymised when entered into our database.

Thank you again for your participation!

Thank you very much for completing the questionnaire.

Your input is very valuable in helping the MDS UK Patient Support Group to focus its efforts on providing the things patients, their families and carers want and need.

Please detach this page and keep it

If you have any additional comments, which you wish to remain anonymous, please add them at the end of the survey.

Alternatively – for comments outside this survey – please use the contact details below:

Email:	**mds-uk@MDS-Foundation.org**
Write to:	**Sophie Wintrich, Chief Executive** **MDS UK Patient Support Group** **Haematology – Bessemer Wing** **King's College Hospital** **Denmark Hill Campus** **London** **SE5 9RS**
Tel:	**020 7733 7558**
Web:	**www.mdspatientsupport.org.uk**

Survey Contents

This survey contains 5 parts. Please only answer the questions applicable to you and your circumstances. Please follow the instructions where given (for example: ⟶ Skip to **Q 1.1**).

Part 1	Demographic questions
Part 2	MDS diagnosis process and information
Part 3	Your MDS subtype and MDS treatment
Part 4	Practical impact of MDS
Part 5	General support for MDS patients and carers

Part 1 – Demographic questions

1.1 **Your age (in years):**

1.2 **Are you:** ☐ Male ☐ Female

1.3 **To which of these ethnic groups would you say you belong?**

- ☐ White – British or Irish
- ☐ White - Other
- ☐ Mixed – White & Black Caribbean
- ☐ Mixed – White & Black African
- ☐ Mixed – White & Asian
- ☐ Asian – Indian
- ☐ Asian - Bangladeshi
- ☐ Asian - Pakistani
- ☐ Asian - Chinese
- ☐ Black - Caribbean
- ☐ Black - African
- ☐ Other, **please specify:**

1.4 **Specify the total number of years spent in education/ training:**

1.5 **Please indicate the highest level of education you have completed:**

- ☐ Did not finish secondary school
- ☐ Secondary school graduate
- ☐ College/Technical qualification
- ☐ University – first degree
- ☐ University – higher degree
- ☐ Other, **please specify:**

1.6 **Please tick the box that best describes your current marital status:**

- ☐ Married/ civil partnership
- ☐ Not married but living together
- ☐ Never married
- ☐ Separated
- ☐ Divorced
- ☐ Widowed

1.7 **Please tick the box that best describes your living arrangements:**

- ☐ Live alone
- ☐ Live with spouse/significant other only
- ☐ Live with other family (may include spouse/significant other)
- ☐ Live with non-family members
- ☐ Assisted living accommodation
- ☐ Other, **please specify**:

1.8	**What is the first part of your postcode? (The first 2, 3 or 4 characters, such as E9, CR2 or PL12)** Please note this **cannot** be used to identify your exact address.
1.9	**Please tick the box that best describes which area of the UK you currently live in:** ☐ Greater London ☐ Yorkshire and the Humber ☐ East Midlands ☐ South West England ☐ Scotland ☐ West Midlands ☐ South East England ☐ North West England ☐ Wales ☐ East of England ☐ North East England ☐ Northern Ireland
1.10	**Please tick the box that best describes your current employment status:** ☐ Full-time employment ☐ Unemployed – and seeking work ☐ Part-time employment ☐ Unemployed – unable to work for health reasons ☐ Retired ☐ Student ☐ Disability ☐ Other, **please specify:**
1.11	**Please indicate the level of income for your immediate household per annum (yearly):** ☐ Below £15,000 ☐ £50,000 and above ☐ £125,000 and above ☐ £15,000 and above ☐ £75,000 and above ☐ Prefer not to say ☐ £25,000 and above ☐ £100,000 and above
1.12	**Has your MDS necessitated a change in your employment at any time? (For example, you now work part-time instead of full-time/ you retired sooner than you had planned)** ☐ No → Skip to **Q 1.13** ☐ Yes
1.12.1	**If yes, please describe the change:**
1.13	**Please tick the ONE box that best describes your abilities at the PRESENT time:** ☐ I feel as well as usual; I have no complaints or symptoms ☐ I am able to carry on my usual activities; I have minor signs or symptoms of my MDS ☐ It takes a bit of effort to engage in my usual activity ☐ I can care for myself, but am unable to carry on usual activity or do active work ☐ I require occasional assistance but am able to take care of most of my personal needs ☐ I require a considerable amount of assistance and frequent medical care ☐ I require special care and assistance ☐ I am or feel severely disabled and need to be hospitalised

Part 2 - MDS diagnosis process and information

2.1 **Before you were diagnosed, did you have any symptoms subsequently attributed to MDS (e.g. fatigue/ breathlessness/ repeated infection/ bruising and bleeding easily/ weight loss)?**

- ☐ No ⟶ Skip to **Q 2.1.2**
- ☐ Yes, **please list your symptoms:**

2.1.1 **How much time passed from symptoms to seeing a General Practitioner (GP)?**

- ☐ I didn't see a GP regarding my symptoms
- ☐ Less than 1 week
- ☐ 1 week – 2 months
- ☐ 2 months – 6 months
- ☐ 6 months – 1 year
- ☐ More than 1 year, **please specify**:

2.1.2 **What were the events that eventually led to your MDS diagnosis?**

- ☐ A blood test carried out to investigate my symptoms revealed abnormal results
- ☐ A routine blood test or a blood test carried out for any other reason revealed abnormal results.
- ☐ Emergency admission
- ☐ Other, please specify:

2.2 **Please specify the role of the health professional who ordered the first blood test, which revealed abnormal results (e.g. GP, rheumatologist, cardiologist etc.):**

Please specify the role of the health professional who referred you to a haematologist (e.g. GP, rheumatologist, cardiologist etc.):

2.2.1 **How much time passed from first seeing a GP (regarding the health issues caused by MDS) to eventually seeing a haematologist at a hospital?**

- ☐ I didn't see a GP ⟶ Skip to **Q 2.2.3**
- ☐ Less than 1 week
- ☐ 1 week – 3 weeks
- ☐ 3 weeks – 2 months
- ☐ 2 months – 6 months
- ☐ More than 6 months, **please specify:**

2.2.2 **<u>How many GP visits</u> did you have before seeing a haematologist at a hospital (regarding the health issues caused by MDS)?**

- ☐ 1 visit
- ☐ 2 – 3 visits
- ☐ 4 – 6 visits
- ☐ More than 6 visits, **please specify:**

2.2.3 **How many blood tests did you have before seeing the haematologist at a hospital?**

2.2.4	**When you saw your GP, do you think he/she was already familiar with MDS?** ☐ No ☐ Yes – definitely ☐ Yes – to some extent ☐ Don't know
2.2.5	**Have you ever heard of the MDS Centres of Excellence?** ☐ No – this is the first time I have heard of the MDS Centres of Excellence ☐ Yes
2.2.6	**Have you been referred to an MDS expert at a tertiary hospital/ MDS Centre of Excellence (specialist centre)?** ☐ Yes, my haematologist made the decision to refer me ☐ Yes, but I had to request my haematologist/GP to refer me ☐ No, I have not been referred to a tertiary hospital/ MDS Centre of Excellence (specialist centre) → Skip to **Q2.4** ☐ My local hospital is an MDS Centre of Excellence → Skip to **Q2.4** ☐ Don't know → Skip to **Q2.4**
2.3	**How much time passed from seeing a haematologist to a referral to a tertiary hospital/ MDS Centre of Excellence (specialist centre)?** ☐ Less than 1 week ☐ 6 months – 1 year ☐ 1 week – 2 months ☐ More than 1 year, **please specify:** ☐ 2 months – 6 months .....
INFO	**MDS Centres of Excellence (CoE) are treatment centres, that have been recognised for maintaining the highest standards of care in MDS. The MDS CoE status is awarded by MDS Foundation.** **In UK, there are 9 MDS CoE:** King's College Hospital, London MDS experts: Prof Mufti, Prof Marsh, Dr Kulasekararaj, Prof Pagliuca St. James's University Hospital, Leeds MDS expert: Prof David T. Bowen Addenbrookes NHS Trust, Cambridge MDS expert: Prof Alan J. Warren Queen Elizabeth Hospital, Birmingham MDS experts: Prof Craddock, Dr Raghavan, Radcliffe Hospitals and University of Oxford MDS expert: Dr Vyas, Prof Boultwood The Royal Bournemouth Hospital, MDS expert: Dr Killick Aberdeen Royal Infirmary, MDS expert: Dr Culligan University Hospital of Wales, Cardiff MDS Expert: Dr Kell Christie NHS Foundation Trust, Manchester MDS expert: Dr Dennis **Other UK tertiary hospitals with MDS experts:** Nottingham University Hospitals NHS Trust MDS expert: Dr Das-Gupta Brighton and Sussex University Hospital MDS expert: Dr Dalley Hull and East Yorkshire Hospitals MDS experts: Dr Carter Worcestershire Royal Hospital MDS expert: Dr Mills Beatson West of Scotland Cancer Centre, Glasgow MDS expert: Dr Drummond Royal Cornwall Hospital, Truro MDS expert: Dr Kruger Great Western Hospital, Reading MDS expert: Dr Sternberg Northampton General Hospital MDS expert: Dr Parker Newcastle Hospitals NHS Foundation Trust MDS expert: Dr Jones

2.4	**Which type of physician provided the <u>confirmed diagnosis of MDS</u>?** ☐ GP ☐ General haematologist ☐ Specialist MDS haematologist at tertiary hospital/MDS Centre of Excellence
2.5	**Overall, how long was it from the first indication that something was wrong with your health, until <u>confirmed diagnosis of MDS?</u>** ☐ 1 month or less ☐ 2 months – 3 months ☐ 3 months – 6 months ☐ 6 months – 1 year ☐ More than 1 year, **please specify**: .....
2.6	**AT TIME OF DIAGNOSIS, were you given sufficient <u>verbal information</u> for your needs about MDS by healthcare staff?** ☐ No – I only received minimal verbal information ☐ I received some verbal information ☐ Yes – I was sufficiently informed for my needs
2.7	**AT TIME OF DIAGNOSIS who provided the <u>verbal information</u>? (Such as GP, nurse, clinician, other)**
2.8	**AT TIME OF DIAGNOSIS how was MDS explained? What words were used? What key words do you remember?**
2.8.1	**AT TIME OF DIAGNOSIS was MDS referred as any of the following? (tick all that apply)** ☐ Refractory anaemia/cytopenia ☐ Blood disorder ☐ Blood cancer ☐ Bone marrow failure disorder ☐ Malignant condition ☐ Pre-leukaemia
2.9	**How do you feel about the way you were told you had MDS?**

2.10 **AT TIME OF DIAGNOSIS what indication was given to you about the possible outcome of your MDS (the prognosis)?**

2.11 **AT TIME OF DIAGNOSIS how useful was the verbal information you received?**
Please answer using the scale where 1 = Not at all useful and 5 = Extremely useful

	Not at all useful				**Extremely useful**
Verbal information	1	2	3	4	5

2.12 **AT TIME OF DIAGNOSIS, were you given written information about MDS?**

☐ No ⟶ Skip to **Q 2.13** ☐ Yes

2.12.1 **AT TIME OF DIAGNOSIS who provided the written information? (Such as GP, nurse, clinician, other)**

2.12.2 **AT TIME OF DIAGNOSIS what type of written information did you receive and how useful was it? Please tick and rate all that apply.**
Please answer using the scale where 1 = Not at all useful and 5 = Extremely useful

Tick if received:		**Not at all useful**				**Extremely useful**
☐	Leaflet	1	2	3	4	5
☐	Booklet	1	2	3	4	5
☐	Newsletter	1	2	3	4	5
☐	CD	1	2	3	4	5
☐	DVD	1	2	3	4	5
☐	Other, **please specify**:	1	2	3	4	5

2.13 **AT TIME OF DIAGNOSIS were options of treatment given?**

☐ No – I was told I was watch-and-wait status ⟶ Skip to **Q 2.16**

☐ Yes – Active treatment and/or supportive care/ transfusions

☐ Don't know/ can't remember ⟶ Skip to **Q 2.16**

☐ Other, **please specify:**

2.14 **AT TIME OF DIAGNOSIS were options of treatment mentioned in Q 2.13 explained clearly?**

☐ No ☐ Yes

☐ Other, **please specify:**

2.16	**AT TIME OF DIAGNOSIS was either IPSS (International Prognostic Scoring Scale) or IPSS-R mentioned?** ☐ No ☐ Yes ☐ Don't know/ can't remember
INFO	**IPSS stands for the International Prognostic Scoring System, used by haematologists to evaluate the prognosis in MDS patients. IPSS-R is the revised versions of the IPSS, which was published in 2012. Both IPSS and IPSS-R are currently in use by clinicians in UK.**
2.17	**When you think about <u>your feelings on your diagnosis</u>, what words come to mind?**
2.18	**FOLLOWING DIAGNOSIS did you seek further sources of information e.g. other charities, libraries, internet (other than that received at time of diagnosis) to learn about MDS?** ☐ No ☐ Yes, **please list these further sources of information below and rate their usefulness using a scale where 1 = Not at all useful and 5 = Extremely useful:**

Source of information	Not at all useful				Extremely useful
.....	1	2	3	4	5
.....	1	2	3	4	5
.....	1	2	3	4	5
.....	1	2	3	4	5
.....	1	2	3	4	5

Part 3 - Your MDS subtype and MDS treatment

3.1	**What date was your MDS diagnosed?** ..... / ..... **M M Y Y**
3.2	**AT TIME OF DIAGNOSIS were you told what subtype of MDS you had?** ☐ No ☐ Yes ⟶ Skip to **Q 3.3** ☐ Don't know/ can't remember
3.2.1	**Did you later find out what subtype of MDS you had?** ☐ No ☐ Yes – my physician told me ☐ Yes – but I had to request the information specifically ☐ Don't know/ can't remember

3.3 **Please specify what subtype of MDS you had AT TIME OF DIAGNOSIS and what subtype of MDS you have NOW. Please tick both boxes even if no change:**

MDS subtype AT DIAGNOSIS		MDS subtype NOW	
☐	Don't know/ can't remember	☐	Don't know/ can't remember
☐	RA (refractory anaemia)	☐	RA (refractory anaemia)
☐	RARS (refractory anaemia with ringed sideroblasts)	☐	RARS (refractory anaemia with ringed sideroblasts)
☐	RCMD (Refractory cytopenia with multilineage dysplasia)	☐	RCMD (Refractory cytopenia with multilineage dysplasia)
☐	RCMD –RS (Refractory cytopenia with multilineage dysplasia with ringed sideroblasts)	☐	RCMD –RS (Refractory cytopenia with multilineage dysplasia with ringed sideroblasts)
☐	RAEB (refractory anaemia with excess blasts)	☐	RAEB (refractory anaemia with excess blasts)
☐	RA with excess blasts-1 (RAEB 1)	☐	RA with excess blasts-1 (RAEB 1)
☐	RA with excess blasts-2 (RAEB 2)	☐	RA with excess blasts-2 (RAEB 2)
☐	RAEB-t (refractory anaemia with excess blasts in transformation)	☐	RAEB-t (refractory anaemia with excess blasts in transformation)
☐	CMML (chronic myelomonocytic leukaemia)	☐	CMML (chronic myelomonocytic leukaemia)
☐	Del (5q) or 5q- or 5q- syndrome	☐	Del (5q) or 5q- or 5q- syndrome
☐	Unclassified MDS	☐	Unclassified MDS
☐	Other, **please specify:**	☐	Other, **please specify:** ....

3.4 **What was your most recent IPSS or IPSS-R risk category? See INFO box on page 7 under question 2.16 for explanations of IPSS and IPSS-R.**

IPSS risk categories		IPSS-R risk categories
☐ I don't know my IPSS Score		☐ I don't know my IPSS-R Score
☐ Low risk MDS		☐ Very low risk MDS
☐ Intermediate 1	OR	☐ Low risk MDS
☐ Intermediate 2		☐ Intermediate
☐ High risk MDS		☐ High risk MDS
		☐ Very high risk MDS

3.5 **Did you have a bone marrow biopsy as part of the tests your physician used to diagnose your MDS?**

☐ No ☐ Yes

☐ Don't know

3.6 **Have you had a bone marrow biopsy (at any time) since diagnosis?**

☐ No ☐ Yes, **please specify how many:** .....

☐ Don't know

3.7	**Did your physician do <u>cytogenetic testing</u> (tests for chromosome abnormalities) as part of your diagnosis?** ☐ No → Skip to **Q 3.8** ☐ Yes ☐ Don't know - this was not explained to me → Skip to **Q 3.8** ☐ Can't remember → Skip to **Q 3.8**
3.7.1	**If yes, do you know what your cytogenetic (chromosome) classification is?**
3.8	**Have you ever needed <u>transfusions</u> as part of your MDS treatment?** ☐ No → Skip to **Q 3.9** ☐ Yes
3.8.1	**What type(s) of transfusion have you had as part of your MDS treatment?** ☐ Red blood cells ☐ Platelets
3.8.2	**Overall, <u>for how long</u> have you had transfusions?** ☐ 1 month or less ☐ 1 year – 2 years ☐ 1 month – 6 months ☐ More than 2 years, **please specify**: ☐ 6 months – 1 year .....
3.8.3	**At the present time, <u>how often</u> do you have transfusions?** ☐ At present I do not need transfusions ☐ More than once a week ☐ Once every 2 weeks – 1 month ☐ Once every 3 months ☐ Once a week ☐ Once every 1 month – 2 months ☐ Infrequently - when I become symptomatic ☐ Infrequently - when my haemoglobin drops below a specific level determined by my clinicians ☐ Other, **please specify**: .....
3.8.4	**How many units (pints) of blood (red blood cells and/or platelets) have you had in the <u>past 2 months</u>?** ..... Units of red blood cells ..... Units of platelets
3.8.5	**How much time – on average - do you spend in hospital each time you have a transfusion (including waiting time)?** ☐ 0-3 hours ☐ More than 8 hours ☐ 3-5 hours ☐ Overnight stay ☐ 5-8 hours

3.8.6	**Have you had any complications or side effects from transfusions?** ☐ No ⟶ Skip to **Q 3.9** ☐ Yes
3.8.7	**Did you need additional treatment as a result of these side effects? Please give details:**
3.8.8	**Were you hospitalised as a result of these side effects?** ☐ No ☐ Yes, **please specify number of days:** _____
3.8.9	**How long did these complications last overall?**
3.9	**Have you received information from your health care staff about transfusion related iron overload?** ☐ No ☐ Yes
3.10	**Have you ever had a <u>ferritin level check</u>?** ☐ No ⟶ Skip to **Q 3.11** ☐ Yes ☐ Don't know ⟶ Skip to **Q 3.11**
3.10.1	**What was your most recent ferritin level (in micrograms/ mcg)?** ☐ Below 500 ☐ 2,000 – 3,000 ☐ 500-1,000 ☐ More than 3,000 ☐ 1,000-2,000 ☐ Don't know
3.11	**Have you ever had <u>iron chelation therapy</u> (removal of excess iron from your blood)?** ☐ No ⟶ Skip to **Q 3.12** ☐ Yes
3.11.1	**Which type of iron chelation therapy have you received? Please tick all that apply:** ☐ Oral Exjade/ deferasirox ☐ Deferoxamine injections /pump ☐ Venesection
3.11.2	**Are you still receiving iron chelation therapy?** ☐ No ☐ Yes
3.11.3	**What did/ do you find to be the greatest challenge of your treatment for iron overload?**

3.12	**Have you ever had <u>growth factor</u> injections (shots) as treatment for your MDS? (Medications to increase your red blood cells, white blood cells, or platelets.)** ☐ No ⟶ Skip to **Q 3.13** ☐ Yes ☐ Don't know ⟶ **please check list in Q 3.12.1**
3.12.1	**Which growth factor(s) have you received? Please tick all that apply:** ☐ Erythropoietin/ 'EPO' (Aranesp, Eprex, Epogen, Epoetin, Procrit, Neorecormon) ☐ G-CSF (Neupogen, Neulasta, Filgrastim, Lenograstim) ☐ Other, **please specify**: _____ ☐ Don't know/ can't remember
3.12.2	**Please give the dose and frequency of the growth factor injections if you know them:**
3.12.3	**Are you still receiving growth factor treatment?** ☐ No ☐ Yes
3.13	**Have you ever had any <u>chemotherapy</u> (or any <u>MDS specific drugs</u> such as azacitidine/ Vidaza or lenalidomide/ Revlimid)?** ☐ No ⟶ Skip to **Q 3.14** ☐ Yes – I have had chemotherapy as a treatment option. **Please list drug names if you know them:** _____ _____ ☐ Yes – I have had chemotherapy as a conditioning regimen prior to a bone marrow transplant ☐ Yes – I have had azacitidine/ Vidaza ☐ Yes – I have had lenalidomide/ Revlimid
3.13.1	**Are you still taking chemotherapy (or any MDS specific drugs such as azacitidine/ Vidaza or lenalidomide/ Revlimid)?** ☐ No ☐ No – I have had a bone marrow transplant ☐ Yes – I still take chemotherapy as a treatment option ☐ Yes – as part of my conditioning regimen prior to a bone marrow transplant ☐ Yes – I still take azacitidine/ Vidaza **Please specify number of cycles:** _____ ☐ Yes – I still take lenalidomide/ Revlimid **Please specify for how long:** _____

3.14	**Since you have had MDS, have you needed antibiotic medication for any infection(s)?** ☐ No ⟶ Skip to **Q 3.15** ☐ Yes
3.14.1	**What kind of infection(s) (pneumonia, bladder, etc.)?**
3.14.2	**Did you need to be hospitalized for treatment of your infection(s)?** ☐ No ☐ Yes
3.15	**Have you had an infection that required medical treatment in the past month?** ☐ No ☐ Yes
3.16	**Have you received any other treatment or medications for your MDS?** ☐ No ⟶ Skip to **Q 3.17** ☐ Yes
3.16.1	**If yes, please list the names of the drugs or other treatment you received:**
3.17	**Do you have any other health issues? Please tick all that apply:** ☐ Deafness or severe hearing impairment ☐ Blindness or partially sighted ☐ A long standing physical condition ☐ A learning disability ☐ A mental health condition ☐ A long standing illness (such as diabetes, chronic heart disease, HIV, epilepsy) ☐ I do not have any other health problems ⟶ Skip to **Q 3.18** ☐ Other, **please specify**: ----------
3.17.1	**Has MDS had an impact on the care or treatment of any of these health issues?** ☐ No ☐ Yes – treatment or care **delayed** due to MDS ☐ Yes – treatment or care **cancelled** due to MDS ☐ Yes – treatment of care **altered** due to MDS

3.18 **Does anyone in your household have any of the health issues listed in Q 3.17?**

- ☐ No
- ☐ Yes, **please specify:**

3.19 **To what extent do you make decisions about your treatment?**

- ☐ My doctor always makes decisions about my treatment
- ☐ All decisions are shared between me and my doctor
- ☐ I always make my treatment decisions

3.20 **Please add any other comments about treatment/ treatment decisions:**

3.21 **In the last 4 weeks, how frequently have you experienced the following:**
Please answer using the scale where 1 = None of the time, 2 = A little of the time, 3 = Some of the time, 4 = Most of the time, 5 = All of the time

	None of the time	**A little of the time**	**Some of the times**	**Most of the time**	**All of the time**
I think about MDS	1	2	3	4	5
I worry about MDS	1	2	3	4	5
MDS is an emotional burden to me	1	2	3	4	5
Physical health issues caused by MDS/ MDS treatments affect me	1	2	3	4	5
My daily activities are affected by MDS	1	2	3	4	5

3.22 **What do you find to be the greatest challenge about <u>having MDS</u> <u>generally</u>?**

3.23 **What did/ do you find to be the greatest challenge in the <u>diagnosis process</u> of MDS?**

3.24	**What did/ do you find to be the greatest challenge in your <u>treatment</u> for MDS?**
3.25	**What do you now know about MDS and its treatment that you wish you had been aware of at the diagnosis stage and why?**

<u>Part 4 – Practical impact of MDS</u>	
INFO	**The following questions ask about the practical impact of MDS on you and those who support you.**
4.1	**IN THE LAST MONTH, How many hours did you spend travelling to and from the hospital for your MDS care?**
4.2	**Which method of transport do you generally use to travel to the hospital?** ☐ Public transport (such as bus, train, tube, tram) ☐ Drive (or driven by friends or family) in private car or vehicle ☐ Taxi arranged and paid for myself ☐ Hospital provided transport (such as hospital transport or ambulance service vehicle or a taxi or car arranged by the hospital) ☐ Combination of the methods above, **please specify:**
4.3	**How much of an impact do hospital travel costs have on your household budget?** ☐ Travel costs **do not** have an impact on my household budget ☐ Travel costs have **somewhat** of an impact on my household budget ☐ Travel costs have a **significant** impact on my household budget ☐ This does not apply to me
4.4	**How much of an impact do car parking costs (whilst you are at the hospital) have on your household budget?** ☐ Car park costs **do not** have an impact on my household budget ☐ Car park costs have **somewhat** of an impact on my household budget ☐ Car park costs have a **significant** impact on my household budget ☐ This does not apply to me

4.5 **IN THE LAST MONTH, what other help did you receive from any paid or unpaid helpers because of your MDS? Please list all your helpers (e.g. spouse, child, friend, neighbour, colleague, volunteer, cleaner, gardener) and estimate the number of hours each helper spent supporting you.**

Area of support:	Helpers:	Hours spent helping in the last month:
Transport to medical appointments	.....	☐ h/month
	.....	☐ h/month
Assistance in daily activities	.....	☐ h/month
	.....	☐ h/month
Assistance in administration of treatment for MDS	.....	☐ h/month
	.....	☐ h/month
Emotional support	.....	☐ h/month
	.....	☐ h/month
Other, **please specify:**	.....	☐ h/month
.....	.....	☐ h/month

Part 5 - General support for MDS patients and carers

5.3 **Have you sought a private (non-NHS) consultation at any point regarding your MDS care?**

☐ No ☐ Yes, **please give details:**

.....

.....

5.4 **Do you have access to a specific MDS nurse or Haematology CNS/Clinical Nurse Specialist or Nurse Consultant?**

☐ Yes – I **have access** but **have not contacted the specific MDS nurse or Haematology CNS/Clinical Nurse Specialist or Nurse Consultant**
→ Skip to **Q 5.5**

☐ Yes – I **have access** and **have contacted the specific MDS nurse or Haematology CNS/Clinical Nurse Specialist or Nurse Consultant**

☐ No – I do not have access to **a specific MDS nurse or Haematology CNS/Clinical Nurse Specialist or Nurse Consultant** - but I **would like** to see one
→ Skip to **Q 5.5**

☐ No – I do not have access to **a specific MDS nurse or Haematology CNS/Clinical Nurse Specialist or Nurse Consultant** – but I **have no need** to see one
→ Skip to **Q 5.5**

☐ Don't know – I have **never been offered** this service
→ Skip to **Q 5.5**

5.4.2 **Please rate how useful contact with your MDS nurse or Haematology CNS/ Clinical Nurse Specialist or Nurse Consultant is for helping you to deal with the following:**

Please answer using the scale where 1 = Not at all useful and 5 = Extremely useful

Please tick the '**Not relevant to me**' box if you feel the issue is not relevant to you.

	Not at all useful				**Extremely useful**	**Not relevant to me**
Reducing my level of worry about MDS	1	2	3	4	5	☐
Reducing the emotional burden caused by MDS	1	2	3	4	5	☐
Dealing with physical health issues caused by MDS/ MDS treatments	1	2	3	4	5	☐
Dealing with practical issues connected to MDS	1	2	3	4	5	☐

5.5 **Please add any relevant comments about access or lack of access to a specific MDS nurse or Haematology CNS/Clinical Nurse Specialist or Nurse Consultant:**

5.6 **Do you have access to a Haemato/Oncology counsellor ? (Healthcare staff specialising in emotional/psychological assistance for people diagnosed with blood related disorders/ cancers)**

- ☐ Yes – I **have access** but **have not contacted** the counsellor
  → Skip to **Q 5.7**
- ☐ Yes – I **have access** and **have contacted** the counsellor
- ☐ No – I do not have access to a counsellor - but I **would like** to see one
  → Skip to **Q 5.7**
- ☐ No – I do not have access to a counsellor – but I **have no need** to see one
  → Skip to **Q 5.7**
- ☐ Don't know – I have **never been offered** this service
  → Skip to **Q 5.7**

5.6.1 **Please rate how useful contact with the Haemato/Oncology counsellor for helping you deal with the following:**

Please answer using the scale where 1 = Not at all useful and 5 = Extremely useful

Please tick the '**Not relevant to me**' box if you feel the issue is not relevant to you.

	Not at all useful				**Extremely useful**	**Not relevant to me**
Reducing my level of worry about MDS	1	2	3	4	5	☐
Reducing the emotional burden caused by MDS	1	2	3	4	5	☐
Dealing with practical issues connected to MDS	1	2	3	4	5	☐
Helps me think less frequently about MDS	1	2	3	4	5	☐

5.7	**Please add any relevant comments about access or lack of access to Haemato/Oncology counsellors:**
5.7.1	**Have complementary therapies ever been offered to you?** ☐ No ☐ Yes
5.8	**Do you wish to have contact with other MDS patients?** ☐ No → Skip to **Q 5.8.1** ☐ Yes → Skip to **Q 5.8.2**
5.8.1	**Please say why you would not like contact with other MDS patients:**
5.8.2	**Please say why you would like contact with other MDS patients:**
INFO	**The next 5 questions relate to MDS UK patient information events.** **We provide the following 2 types of information events:** **Annual Patient Forum** – Yearly full day events in larger cities, free of charge and open to all MDS patients/ carers/ families. Include Quality of Life sessions for patients and carers to share their MDS experiences, as well as presentations by specialist MDS clinicians. **Local Patient Meeting** – 2-3 hour meetings every 2-4 months, free of charge and open to MDS patients/ carers /families in the local area. Open sessions for patients to meet and share their MDS experiences. Occasionally short informal presentations by specialist MDS clinicians. Opportunities for patients to get involved in the running of the meetings.
5.9	**Have you ever attended an MDS UK Annual Patient Forum or MDS UK Local Patient Meeting?** ☐ No → Skip to **Q 5.10** ☐ Yes
5.9.1	**How useful has attendance to an MDS UK Annual Patient Forum or MDS UK Local Patient Meeting been? Please rate one/both event types depending on what you have attended.** Please answer using the scale where 1 = Not at all useful and 5 = Extremely useful

	Not at all useful			**Extremely useful**		**N/A**
MDS UK Annual patient forum	1	2	3	4	5	☐
MDS UK Local patient meeting	1	2	3	4	5	☐

5.9.2	**Please add additional comments/ criticisms about MDS UK patient events you have attended:**

5.10	**Do you wish to attend any MDS UK patient events in the future? Please tick all that apply:** ☐ No → Skip to **Q 5.11** ☐ Yes – I wish to attend MDS UK Annual Patient Forum events ☐ Yes – I wish to attend MDS UK Local Patient Meetings
5.10.1	**What subjects /aspects of MDS would be particularly useful to discuss/to listen to/to learn about?**
5.11	**If you have had any contact with other MDS patients, how was this experience overall? What did you gain? Was it positive/negative?**
5.12	**Do you have easy access to a computer and the internet?** ☐ No ☐ Yes
5.12.1	**Has a friend or family member ever looked on your behalf/ have you ever looked yourself for information about MDS on the internet?** ☐ No → Skip to **Q 5.13** ☐ Yes – a friend or family member has looked for information on my behalf ☐ Yes – I have looked for information myself
5.12.2	**Have you been able to get sufficient, reliable and helpful information on MDS via the internet?**
5.14	**AT THE TIME OF DIAGNOSIS, Did you receive information on the MDS UK Patient Support Group at the hospital?** ☐ No ☐ Yes – via hospital staff → Skip to **Q 5.15** ☐ Yes – via leaflet in waiting room / saw poster → Skip to **Q 5.15**
5.14.1	**If not, how did you hear about the MDS UK Patient Support Group?** ☐ This is the first time I have heard of the MDS UK Patient Support Group ☐ At tertiary hospital/MDS Centre of Excellence (specialist centre) ☐ Family member/ carer ☐ Internet ☐ Another patient ☐ Other, **please specify**: ----------

5.15.1 **Please check this list of MDS UK Patient Support Group services and information resources. Rate the ones you have used according to their usefulness.**

Please answer using the scale where 1 = Not at all useful and 5 = Extremely useful

Tick if used:		Not at all useful				Extremely useful
☐	Practical advice/support via phone call/email to MDS UK	1	2	3	4	5
☐	Received an MDS UK Patient Information Pack	1	2	3	4	5
☐	Emotional support via phone call/email	1	2	3	4	5
☐	Attended MDS UK patient event	1	2	3	4	5
☐	Consulted MDS UK website	1	2	3	4	5
☐	Consulted MDS UK online Message Forum	1	2	3	4	5
☐	Read MDS UK Newsletter	1	2	3	4	5
☐	Consulted MDS UK Facebook pages	1	2	3	4	5
☐	I have never used any of the services/resources listed above					

5.15.2 **Please add additional comments/ criticisms about MDS UK support services:**

5.16 **Are there any reasons you <u>do not access</u> <u>some or all</u> of the support services offered by the MDS UK Patient Support Group? Please tick all that apply:**

- ☐ Fatigue – I am just too tired
- ☐ Anxiety
- ☐ I get sufficient support from family and friends
- ☐ I get sufficient support from the clinical staff
- ☐ I am so busy with medical appointments that I don't have the time for anything else
- ☐ I am worried about meeting with other people with MDS and hearing about their problems
- ☐ I am worried about contacting the support group and hearing or receiving worrying information about MDS
- ☐ I don't want to focus too much on MDS
- ☐ I am unaware of what support options there are
- ☐ I am a private person and would rather keep to myself
- ☐ Other, **please specify:**

5.17	**From your experience as a patient, what type of information (including which subjects) would be of benefit or helpful for you?**
5.18	**From your experience, what type of information do you think would be of benefit or helpful for carers/family members?**
5.19	**Have you heard of/ are you aware of NICE (National Institute for Health and Clinical Excellence)?** ☐ No ☐ Yes – but only since contacting the MDS UK Patient Support Group ☐ Yes – independently from the MDS UK Patient Support Group
5.20	**Where did you obtain this questionnaire?** ☐ Included in a newsletter ☐ Via a nurse/doctor in a hospital ☐ Posted or emailed to me personally by MDS UK Patient Support Group ☐ From another patient ☐ From the internet ☐ Other, **please specify**:
5.21	**Any final comments:**

This is the end of the main questionnaire.

In addition please also complete the following important and new health related Quality of Life questionnaire (QOL-E v.2) on pages 21 & 22. This is the only existing validated instrument designed specifically for MDS. Your answers will help to support its use in research and clinical settings.

When you finish - please DETACH THE FRONT PAGE containing our contact details and return the completed questionnaire back to us following the instructions on the cover letter.

QOL-E v. 2

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INTRODUCTION

1) In general, you would say that your health is:

Excellent	Good	Acceptable	Poor

2) Compared to a month ago, your health is:

Improved	The same	Worse	Much Worse

PHYSICAL WELL-BEING

3) In the last week, some daily activities may have been limited by your health, such as:

		I find it very difficult	I find it partially difficult	It is not difficult at all
A	Performing heavy activities (for example, running, jumping, etc.)			
B	Climbing stairs			
C	Lowering myself			
D	Taking care of myself (washing, dressing, feeding myself)			

FUNCTIONAL WELL-BEING

4) In the last week, what problems have you had in daily activities because of your health?

		Yes	No
A	I got very little done		
B	I had more fatigue doing my work		

5) During the last week was it difficult for you to stay awake during the daytime?

Always	For many hours	For a few hours	Never

SOCIAL OR FAMILY WELL-BEING

6) According to you, are the following statements true or false?

		True	I do not know	False
A	My present condition interferes too much with my life			
B	I feel oppressed by my disease			
C	I feel that I am a burden for my family			

7) Your health is an impediment for you to keep a paid job (whether you are of retirement age or not).

True	False

8) In the last week, was getting sexually excited a problem for you?

Never	Rarely	Sometimes	Often

DISTURBANCES, RELATED TO THE DISEASE

9) In the last week, how much did fatigue get in the way with your daily chores?

Not at all	A little	A lot	Extremely

10) In the last week, how much fatigue did you have?

Not at all	A little	A lot	Extreme

11) In the last week, how much did the following problems disturb you?

		Not at all	A little	A lot	Extremely
A	Headache				
B	Palpitations (i.e., heart pounding)				
C	Difficulty in taking care of yourself				
D	Being bedridden				

12) During the last week, did you get enough sleep?

Always	Often	Rarely	Never

13) During the last week, did shortness of breath while climbing the stairs disturb you?

Never	Sometimes	Often	Very often

14) What effects of the disease disturb your daily life?

		No, not at all	A little bit	Yes, extremely
A	Being dependent on transfusions			
B	Not being able to do house chores			
C	Not being able to travel			
D	Being dependent on the hospital, doctors and/or nurses			
E	Stress and worry because of the disease			
F	The effect on your sex life			
G	Side effects of treatment			