

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: <input type="checkbox"/> Male <input type="checkbox"/> Female
1.3	To which of these ethnic groups would you say you belong? <input type="checkbox"/> White – British or Irish <input type="checkbox"/> Mixed – White & Asian <input type="checkbox"/> Asian - Chinese <input type="checkbox"/> White - Other <input type="checkbox"/> Asian – Indian <input type="checkbox"/> Black - Caribbean <input type="checkbox"/> Mixed – White & Black Caribbean <input type="checkbox"/> Asian - Bangladeshi <input type="checkbox"/> Black - African <input type="checkbox"/> Mixed – White & Black African <input type="checkbox"/> Asian - Pakistani <input type="checkbox"/> 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: <input type="checkbox"/> Did not finish secondary school <input type="checkbox"/> University – first degree <input type="checkbox"/> Secondary school graduate <input type="checkbox"/> University – higher degree <input type="checkbox"/> College/Technical qualification <input type="checkbox"/> Other, please specify: -----
1.6	Please tick the box that best describes your current marital status: <input type="checkbox"/> Married/ civil partnership <input type="checkbox"/> Separated <input type="checkbox"/> Not married but living together <input type="checkbox"/> Divorced <input type="checkbox"/> Never married <input type="checkbox"/> Widowed
1.7	Please tick the box that best describes your living arrangements: <input type="checkbox"/> Live alone <input type="checkbox"/> Live with spouse/significant other only <input type="checkbox"/> Live with other family (may include spouse/significant other) <input type="checkbox"/> Live with non-family members <input type="checkbox"/> Assisted living accommodation <input type="checkbox"/> Other, please specify: -----

1.8	<p>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.</p>
1.9	<p>Please tick the box that best describes which area of the UK you currently live in:</p> <p> <input type="checkbox"/> Greater London <input type="checkbox"/> Yorkshire and the Humber <input type="checkbox"/> East Midlands <input type="checkbox"/> South West England <input type="checkbox"/> Scotland <input type="checkbox"/> West Midlands <input type="checkbox"/> South East England <input type="checkbox"/> North West England <input type="checkbox"/> Wales <input type="checkbox"/> East of England <input type="checkbox"/> North East England <input type="checkbox"/> Northern Ireland </p>
1.10	<p>Please tick the box that best describes your current employment status:</p> <p> <input type="checkbox"/> Full-time employment <input type="checkbox"/> Unemployed – and seeking work <input type="checkbox"/> Part-time employment <input type="checkbox"/> Unemployed – unable to work for health reasons <input type="checkbox"/> Retired <input type="checkbox"/> Student <input type="checkbox"/> Disability <input type="checkbox"/> Other, please specify: </p>
1.11	<p>Please indicate the level of income for your immediate household per annum (yearly):</p> <p> <input type="checkbox"/> Below £15,000 <input type="checkbox"/> £50,000 and above <input type="checkbox"/> £125,000 and above <input type="checkbox"/> £15,000 and above <input type="checkbox"/> £75,000 and above <input type="checkbox"/> Prefer not to say <input type="checkbox"/> £25,000 and above <input type="checkbox"/> £100,000 and above </p>
1.12	<p>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)</p> <p> <input type="checkbox"/> No → Skip to Q 1.13 <input type="checkbox"/> Yes </p>
1.12.1	<p>If yes, please describe the change:</p>
1.13	<p>Please tick the ONE box that best describes your abilities at the PRESENT time:</p> <p> <input type="checkbox"/> I feel as well as usual; I have no complaints or symptoms <input type="checkbox"/> I am able to carry on my usual activities; I have minor signs or symptoms of my MDS <input type="checkbox"/> It takes a bit of effort to engage in my usual activity <input type="checkbox"/> I can care for myself, but am unable to carry on usual activity or do active work <input type="checkbox"/> I require occasional assistance but am able to take care of most of my personal needs <input type="checkbox"/> I require a considerable amount of assistance and frequent medical care <input type="checkbox"/> I require special care and assistance <input type="checkbox"/> I am or feel severely disabled and need to be hospitalised </p>

Part 2 - MDS diagnosis process and information

2.1	<p>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)?</p> <p><input type="checkbox"/> No —→ Skip to Q 2.1.2</p> <p><input type="checkbox"/> Yes, please list your symptoms:</p> <p>.....</p> <p>.....</p> <p>.....</p>
2.1.1	<p>How much time passed from symptoms to seeing a General Practitioner (GP)?</p> <p><input type="checkbox"/> I didn't see a GP regarding my symptoms <input type="checkbox"/> 2 months – 6 months</p> <p><input type="checkbox"/> Less than 1 week <input type="checkbox"/> 6 months – 1 year</p> <p><input type="checkbox"/> 1 week – 2 months <input type="checkbox"/> More than 1 year, please specify:</p> <p>.....</p>
2.1.2	<p>What were the events that eventually led to your MDS diagnosis?</p> <p><input type="checkbox"/> A blood test carried out to investigate my symptoms revealed abnormal results</p> <p><input type="checkbox"/> A routine blood test or a blood test carried out for any other reason revealed abnormal results.</p> <p><input type="checkbox"/> Emergency admission</p> <p><input type="checkbox"/> Other, please specify:</p>
2.2	<p>Please specify the role of the health professional who ordered the first blood test, which revealed abnormal results (e.g. GP, rheumatologist, cardiologist etc.):</p> <p>.....</p> <p>Please specify the role of the health professional who referred you to a haematologist (e.g. GP, rheumatologist, cardiologist etc.):</p> <p>.....</p>
2.2.1	<p>How much time passed from first seeing a GP (regarding the health issues caused by MDS) to eventually seeing a haematologist at a hospital?</p> <p><input type="checkbox"/> I didn't see a GP —→ Skip to Q 2.2.3</p> <p><input type="checkbox"/> Less than 1 week <input type="checkbox"/> 2 months – 6 months</p> <p><input type="checkbox"/> 1 week – 3 weeks <input type="checkbox"/> More than 6 months, please specify:</p> <p><input type="checkbox"/> 3 weeks – 2 months</p>
2.2.2	<p><u>How many GP visits</u> did you have before seeing a haematologist at a hospital (regarding the health issues caused by MDS)?</p> <p><input type="checkbox"/> 1 visit <input type="checkbox"/> 4 – 6 visits</p> <p><input type="checkbox"/> 2 – 3 visits <input type="checkbox"/> More than 6 visits, please specify:</p>
2.2.3	<p>How many blood tests did you have before seeing the haematologist at a hospital?</p>

2.2.4	<p>When you saw your GP, do you think he/she was already familiar with MDS?</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes – definitely</p> <p><input type="checkbox"/> Yes – to some extent <input type="checkbox"/> Don't know</p>		
2.2.5	<p>Have you ever heard of the MDS Centres of Excellence?</p> <p><input type="checkbox"/> No – this is the first time I have heard of the MDS Centres of Excellence</p> <p><input type="checkbox"/> Yes</p>		
2.2.6	<p>Have you been referred to an MDS expert at a tertiary hospital/ MDS Centre of Excellence (specialist centre)?</p> <p><input type="checkbox"/> Yes, my haematologist made the decision to refer me</p> <p><input type="checkbox"/> Yes, but I had to request my haematologist/GP to refer me</p> <p><input type="checkbox"/> No, I have not been referred to a tertiary hospital/ MDS Centre of Excellence (specialist centre) —————> Skip to Q2.4</p> <p><input type="checkbox"/> My local hospital is an MDS Centre of Excellence —————> Skip to Q2.4</p> <p><input type="checkbox"/> Don't know —————> Skip to Q2.4</p>		
2.3	<p>How much time passed from seeing a haematologist to a referral to a tertiary hospital/ MDS Centre of Excellence (specialist centre)?</p> <p><input type="checkbox"/> Less than 1 week <input type="checkbox"/> 6 months – 1 year</p> <p><input type="checkbox"/> 1 week – 2 months <input type="checkbox"/> More than 1 year, please specify:</p> <p><input type="checkbox"/> 2 months – 6 months</p>		
INFO	<p>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.</p> <table border="0" style="width: 100%;"> <tr> <td style="vertical-align: top; width: 50%;"> <p>In UK, there are 9 MDS CoE:</p> <p><u>King's College Hospital, London</u> MDS experts: Prof Mufti, Prof Marsh, Dr Kulasekararaj, Prof Pagliuca</p> <p><u>St. James's University Hospital, Leeds</u> MDS expert: Prof David T. Bowen</p> <p><u>Addenbrookes NHS Trust, Cambridge</u> MDS expert: Prof Alan J. Warren</p> <p><u>Queen Elizabeth Hospital, Birmingham</u> MDS experts: Prof Craddock, Dr Raghavan,</p> <p><u>Radcliffe Hospitals and University of Oxford</u> MDS expert: Dr Vyas, Prof Boulwood</p> <p><u>The Royal Bournemouth Hospital,</u> MDS expert: Dr Killick</p> <p><u>Aberdeen Royal Infirmary,</u> MDS expert: Dr Culligan</p> <p><u>University Hospital of Wales, Cardiff</u> MDS Expert: Dr Kell</p> <p><u>Christie NHS Foundation Trust, Manchester</u> MDS expert: Dr Dennis</p> </td> <td style="vertical-align: top; width: 50%;"> <p>Other UK tertiary hospitals with MDS experts:</p> <p><u>Nottingham University Hospitals NHS Trust</u> MDS expert: Dr Das-Gupta</p> <p><u>Brighton and Sussex University Hospital</u> MDS expert: Dr Dalley</p> <p><u>Hull and East Yorkshire Hospitals</u> MDS experts: Dr Carter</p> <p><u>Worcestershire Royal Hospital</u> MDS expert: Dr Mills</p> <p><u>Beatson West of Scotland Cancer Centre, Glasgow</u> MDS expert: Dr Drummond</p> <p><u>Royal Cornwall Hospital, Truro</u> MDS expert: Dr Kruger</p> <p><u>Great Western Hospital, Reading</u> MDS expert: Dr Sternberg</p> <p><u>Northampton General Hospital</u> MDS expert: Dr Parker</p> <p><u>Newcastle Hospitals NHS Foundation Trust</u> MDS expert: Dr Jones</p> </td> </tr> </table>	<p>In UK, there are 9 MDS CoE:</p> <p><u>King's College Hospital, London</u> MDS experts: Prof Mufti, Prof Marsh, Dr Kulasekararaj, Prof Pagliuca</p> <p><u>St. James's University Hospital, Leeds</u> MDS expert: Prof David T. Bowen</p> <p><u>Addenbrookes NHS Trust, Cambridge</u> MDS expert: Prof Alan J. Warren</p> <p><u>Queen Elizabeth Hospital, Birmingham</u> MDS experts: Prof Craddock, Dr Raghavan,</p> <p><u>Radcliffe Hospitals and University of Oxford</u> MDS expert: Dr Vyas, Prof Boulwood</p> <p><u>The Royal Bournemouth Hospital,</u> MDS expert: Dr Killick</p> <p><u>Aberdeen Royal Infirmary,</u> MDS expert: Dr Culligan</p> <p><u>University Hospital of Wales, Cardiff</u> MDS Expert: Dr Kell</p> <p><u>Christie NHS Foundation Trust, Manchester</u> MDS expert: Dr Dennis</p>	<p>Other UK tertiary hospitals with MDS experts:</p> <p><u>Nottingham University Hospitals NHS Trust</u> MDS expert: Dr Das-Gupta</p> <p><u>Brighton and Sussex University Hospital</u> MDS expert: Dr Dalley</p> <p><u>Hull and East Yorkshire Hospitals</u> MDS experts: Dr Carter</p> <p><u>Worcestershire Royal Hospital</u> MDS expert: Dr Mills</p> <p><u>Beatson West of Scotland Cancer Centre, Glasgow</u> MDS expert: Dr Drummond</p> <p><u>Royal Cornwall Hospital, Truro</u> MDS expert: Dr Kruger</p> <p><u>Great Western Hospital, Reading</u> MDS expert: Dr Sternberg</p> <p><u>Northampton General Hospital</u> MDS expert: Dr Parker</p> <p><u>Newcastle Hospitals NHS Foundation Trust</u> MDS expert: Dr Jones</p>
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2.4	<p>Which type of physician provided the <u>confirmed diagnosis of MDS</u>?</p> <p><input type="checkbox"/> GP</p> <p><input type="checkbox"/> General haematologist</p> <p><input type="checkbox"/> Specialist MDS haematologist at tertiary hospital/MDS Centre of Excellence</p>
2.5	<p>Overall, how long was it from the first indication that something was wrong with your health, until <u>confirmed diagnosis of MDS</u>?</p> <p><input type="checkbox"/> 1 month or less <input type="checkbox"/> 6 months – 1 year</p> <p><input type="checkbox"/> 2 months – 3 months <input type="checkbox"/> More than 1 year, please specify:</p> <p><input type="checkbox"/> 3 months – 6 months</p>
2.6	<p>AT TIME OF DIAGNOSIS, were you given sufficient <u>verbal information</u> for your needs about MDS by healthcare staff?</p> <p><input type="checkbox"/> No – I only received minimal verbal information</p> <p><input type="checkbox"/> I received some verbal information</p> <p><input type="checkbox"/> Yes – I was sufficiently informed for my needs</p>
2.7	<p>AT TIME OF DIAGNOSIS who provided the <u>verbal information</u>? (Such as GP, nurse, clinician, other)</p>
2.8	<p>AT TIME OF DIAGNOSIS how was MDS explained? What words were used? What key words do you remember?</p>
2.8.1	<p>AT TIME OF DIAGNOSIS was MDS referred as any of the following? (tick all that apply)</p> <p><input type="checkbox"/> Refractory anaemia/cytopenia <input type="checkbox"/> Bone marrow failure disorder</p> <p><input type="checkbox"/> Blood disorder <input type="checkbox"/> Malignant condition</p> <p><input type="checkbox"/> Blood cancer <input type="checkbox"/> Pre-leukaemia</p>
2.9	<p>How do you feel about the way you were told you had MDS?</p>

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 <u>AT DIAGNOSIS</u>		MDS subtype <u>NOW</u>	
<input type="checkbox"/>	Don't know/ can't remember	<input type="checkbox"/>	Don't know/ can't remember
<input type="checkbox"/>	RA (refractory anaemia)	<input type="checkbox"/>	RA (refractory anaemia)
<input type="checkbox"/>	RARS (refractory anaemia with ringed sideroblasts)	<input type="checkbox"/>	RARS (refractory anaemia with ringed sideroblasts)
<input type="checkbox"/>	RCMD (Refractory cytopenia with multilineage dysplasia)	<input type="checkbox"/>	RCMD (Refractory cytopenia with multilineage dysplasia)
<input type="checkbox"/>	RCMD –RS (Refractory cytopenia with multilineage dysplasia with ringed sideroblasts)	<input type="checkbox"/>	RCMD –RS (Refractory cytopenia with multilineage dysplasia with ringed sideroblasts)
<input type="checkbox"/>	RAEB (refractory anaemia with excess blasts)	<input type="checkbox"/>	RAEB (refractory anaemia with excess blasts)
<input type="checkbox"/>	RA with excess blasts-1 (RAEB 1)	<input type="checkbox"/>	RA with excess blasts-1 (RAEB 1)
<input type="checkbox"/>	RA with excess blasts-2 (RAEB 2)	<input type="checkbox"/>	RA with excess blasts-2 (RAEB 2)
<input type="checkbox"/>	RAEB-t (refractory anaemia with excess blasts in transformation)	<input type="checkbox"/>	RAEB-t (refractory anaemia with excess blasts in transformation)
<input type="checkbox"/>	CMML (chronic myelomonocytic leukaemia)	<input type="checkbox"/>	CMML (chronic myelomonocytic leukaemia)
<input type="checkbox"/>	Del (5q) or 5q- or 5q- syndrome	<input type="checkbox"/>	Del (5q) or 5q- or 5q- syndrome
<input type="checkbox"/>	Unclassified MDS	<input type="checkbox"/>	Unclassified MDS
<input type="checkbox"/>	Other, please specify: ----- -----	<input type="checkbox"/>	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	
<input type="checkbox"/>	I don't know my IPSS Score	<input type="checkbox"/>	I don't know my IPSS-R Score
<input type="checkbox"/>	Low risk MDS	<input type="checkbox"/>	Very low risk MDS
<input type="checkbox"/>	Intermediate 1	<input type="checkbox"/>	Low risk MDS
<input type="checkbox"/>	Intermediate 2	<input type="checkbox"/>	Intermediate
<input type="checkbox"/>	High risk MDS	<input type="checkbox"/>	High risk MDS
	OR	<input type="checkbox"/>	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	<p>Did your physician do <u>cytogenetic testing</u> (tests for chromosome abnormalities) as part of your diagnosis?</p> <p><input type="checkbox"/> No —————> Skip to Q 3.8</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Don't know - this was not explained to me —————> Skip to Q 3.8</p> <p><input type="checkbox"/> Can't remember —————> Skip to Q 3.8</p>
3.7.1	<p>If yes, do you know what your cytogenetic (chromosome) classification is?</p>
3.8	<p>Have you ever needed <u>transfusions</u> as part of your MDS treatment?</p> <p><input type="checkbox"/> No —————> Skip to Q 3.9 <input type="checkbox"/> Yes</p>
3.8.1	<p>What type(s) of transfusion have you had as part of your MDS treatment?</p> <p><input type="checkbox"/> Red blood cells <input type="checkbox"/> Platelets</p>
3.8.2	<p>Overall, <u>for how long</u> have you had transfusions?</p> <p><input type="checkbox"/> 1 month or less <input type="checkbox"/> 1 year – 2 years</p> <p><input type="checkbox"/> 1 month – 6 months <input type="checkbox"/> More than 2 years, please specify:</p> <p><input type="checkbox"/> 6 months – 1 year </p>
3.8.3	<p>At the present time, <u>how often</u> do you have transfusions?</p> <p><input type="checkbox"/> At present I do not need transfusions</p> <p><input type="checkbox"/> More than once a week <input type="checkbox"/> Once every 2 weeks – 1 month <input type="checkbox"/> Once every 3 months</p> <p><input type="checkbox"/> Once a week <input type="checkbox"/> Once every 1 month – 2 months</p> <p><input type="checkbox"/> Infrequently - when I become symptomatic</p> <p><input type="checkbox"/> Infrequently - when my haemoglobin drops below a specific level determined by my clinicians</p> <p><input type="checkbox"/> Other, please specify:</p>
3.8.4	<p>How many units (pints) of blood (red blood cells and/or platelets) have you had in the <u>past 2 months</u>?</p> <p>..... Units of red blood cells</p> <p>..... Units of platelets</p>
3.8.5	<p>How much time – on average - do you spend in hospital each time you have a transfusion (including waiting time)?</p> <p><input type="checkbox"/> 0-3 hours <input type="checkbox"/> More than 8 hours</p> <p><input type="checkbox"/> 3-5 hours <input type="checkbox"/> Overnight stay</p> <p><input type="checkbox"/> 5-8 hours</p>

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

3.14	<p>Since you have had MDS, have you needed antibiotic medication for any infection(s)?</p> <p><input type="checkbox"/> No ————> Skip to Q 3.15 <input type="checkbox"/> Yes</p>
3.14.1	<p>What kind of infection(s) (pneumonia, bladder, etc.)?</p>
3.14.2	<p>Did you need to be hospitalized for treatment of your infection(s)?</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p>
3.15	<p>Have you had an infection that required medical treatment in the past month?</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p>
3.16	<p>Have you received any other treatment or medications for your MDS?</p> <p><input type="checkbox"/> No ————> Skip to Q 3.17 <input type="checkbox"/> Yes</p>
3.16.1	<p>If yes, please list the names of the drugs or other treatment you received:</p>
3.17	<p>Do you have any other health issues? Please tick all that apply:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Deafness or severe hearing impairment <input type="checkbox"/> Blindness or partially sighted <input type="checkbox"/> A long standing physical condition <input type="checkbox"/> A learning disability <input type="checkbox"/> A mental health condition <input type="checkbox"/> A long standing illness (such as diabetes, chronic heart disease, HIV, epilepsy) <input type="checkbox"/> I do not have any other health problems ————> Skip to Q 3.18 <input type="checkbox"/> Other, please specify: <p>-----</p>
3.17.1	<p>Has MDS had an impact on the care or treatment of any of these health issues?</p> <ul style="list-style-type: none"> <input type="checkbox"/> No <input type="checkbox"/> Yes – treatment or care delayed due to MDS <input type="checkbox"/> Yes – treatment or care cancelled due to MDS <input type="checkbox"/> Yes – treatment of care altered due to MDS

3.18	<p>Does anyone in your household have any of the health issues listed in Q 3.17?</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes, please specify:</p> <p>.....</p> <p>.....</p>																																				
3.19	<p>To what extent do you make decisions about your treatment?</p> <p><input type="checkbox"/> My doctor always makes decisions about my treatment</p> <p><input type="checkbox"/> All decisions are shared between me and my doctor</p> <p><input type="checkbox"/> I always make my treatment decisions</p>																																				
3.20	<p>Please add any other comments about treatment/ treatment decisions:</p>																																				
3.21	<p>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</p> <table border="1" data-bbox="229 1003 1520 1391"> <thead> <tr> <th></th> <th>None of the time</th> <th>A little of the time</th> <th>Some of the times</th> <th>Most of the time</th> <th>All of the time</th> </tr> </thead> <tbody> <tr> <td>I think about MDS</td> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td>I worry about MDS</td> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td>MDS is an emotional burden to me</td> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td>Physical health issues caused by MDS/ MDS treatments affect me</td> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td>My daily activities are affected by MDS</td> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> </tbody> </table>		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
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3.22	<p>What do you find to be the greatest challenge about <u>having MDS generally</u>?</p>																																				
3.23	<p>What did/ do you find to be the greatest challenge in the <u>diagnosis process</u> of MDS?</p>																																				

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?

Part 4 – Practical impact of MDS

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	<p>Which method of transport do you generally use to travel to the hospital?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Public transport (such as bus, train, tube, tram) <input type="checkbox"/> Drive (or driven by friends or family) in private car or vehicle <input type="checkbox"/> Taxi arranged and paid for myself <input type="checkbox"/> Hospital provided transport (such as hospital transport or ambulance service vehicle or a taxi or car arranged by the hospital) <input type="checkbox"/> Combination of the methods above, please specify:
4.3	<p>How much of an impact do hospital travel costs have on your household budget?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Travel costs do not have an impact on my household budget <input type="checkbox"/> Travel costs have somewhat of an impact on my household budget <input type="checkbox"/> Travel costs have a significant impact on my household budget <input type="checkbox"/> This does not apply to me
4.4	<p>How much of an impact do car parking costs (whilst you are at the hospital) have on your household budget?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Car park costs do not have an impact on my household budget <input type="checkbox"/> Car park costs have somewhat of an impact on my household budget <input type="checkbox"/> Car park costs have a significant impact on my household budget <input type="checkbox"/> 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	-----	<input type="text"/> h/month
Assistance in daily activities	-----	<input type="text"/> h/month
Assistance in administration of treatment for MDS	-----	<input type="text"/> h/month
Emotional support	-----	<input type="text"/> h/month
Other, please specify:	-----	<input type="text"/> h/month
-----	-----	<input type="text"/> 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	<p>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.</p> <table border="1" data-bbox="220 286 1520 696"> <thead> <tr> <th data-bbox="220 286 770 405"></th> <th colspan="3" data-bbox="770 286 1035 405">Not at all useful</th> <th colspan="2" data-bbox="1035 286 1378 405">Extremely useful</th> <th data-bbox="1378 286 1520 405">Not relevant to me</th> </tr> </thead> <tbody> <tr> <td data-bbox="220 405 770 461">Reducing my level of worry about MDS</td> <td data-bbox="770 405 818 461">1</td> <td data-bbox="818 405 903 461">2</td> <td data-bbox="903 405 987 461">3</td> <td data-bbox="987 405 1072 461">4</td> <td data-bbox="1072 405 1157 461">5</td> <td data-bbox="1157 405 1520 461"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 461 770 539">Reducing the emotional burden caused by MDS</td> <td data-bbox="770 461 818 539">1</td> <td data-bbox="818 461 903 539">2</td> <td data-bbox="903 461 987 539">3</td> <td data-bbox="987 461 1072 539">4</td> <td data-bbox="1072 461 1157 539">5</td> <td data-bbox="1157 461 1520 539"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 539 770 618">Dealing with physical health issues caused by MDS/ MDS treatments</td> <td data-bbox="770 539 818 618">1</td> <td data-bbox="818 539 903 618">2</td> <td data-bbox="903 539 987 618">3</td> <td data-bbox="987 539 1072 618">4</td> <td data-bbox="1072 539 1157 618">5</td> <td data-bbox="1157 539 1520 618"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 618 770 696">Dealing with practical issues connected to MDS</td> <td data-bbox="770 618 818 696">1</td> <td data-bbox="818 618 903 696">2</td> <td data-bbox="903 618 987 696">3</td> <td data-bbox="987 618 1072 696">4</td> <td data-bbox="1072 618 1157 696">5</td> <td data-bbox="1157 618 1520 696"><input type="checkbox"/></td> </tr> </tbody> </table>		Not at all useful			Extremely useful		Not relevant to me	Reducing my level of worry about MDS	1	2	3	4	5	<input type="checkbox"/>	Reducing the emotional burden caused by MDS	1	2	3	4	5	<input type="checkbox"/>	Dealing with physical health issues caused by MDS/ MDS treatments	1	2	3	4	5	<input type="checkbox"/>	Dealing with practical issues connected to MDS	1	2	3	4	5	<input type="checkbox"/>
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5.5	<p>Please add any relevant comments about <u>access</u> or <u>lack of access</u> to a specific MDS nurse or Haematology CNS/Clinical Nurse Specialist or Nurse Consultant:</p>																																			
5.6	<p>Do you have access to a Haemato/Oncology counsellor ? (Healthcare staff specialising in emotional/psychological assistance for people diagnosed with blood related disorders/ cancers)</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes – I have access but have not contacted the counsellor ————> Skip to Q 5.7 <input type="checkbox"/> Yes – I have access and have contacted the counsellor <input type="checkbox"/> No – I do not have access to a counsellor - but I would like to see one ————> Skip to Q 5.7 <input type="checkbox"/> No – I do not have access to a counsellor – but I have no need to see one ————> Skip to Q 5.7 <input type="checkbox"/> Don't know – I have never been offered this service ————> Skip to Q 5.7 																																			
5.6.1	<p>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.</p> <table border="1" data-bbox="220 1686 1520 2116"> <thead> <tr> <th data-bbox="220 1686 687 1805"></th> <th colspan="3" data-bbox="687 1686 1082 1805">Not at all useful</th> <th colspan="2" data-bbox="1082 1686 1347 1805">Extremely useful</th> <th data-bbox="1347 1686 1520 1805">Not relevant to me</th> </tr> </thead> <tbody> <tr> <td data-bbox="220 1805 687 1883">Reducing my level of worry about MDS</td> <td data-bbox="687 1805 735 1883">1</td> <td data-bbox="735 1805 820 1883">2</td> <td data-bbox="820 1805 904 1883">3</td> <td data-bbox="904 1805 989 1883">4</td> <td data-bbox="989 1805 1074 1883">5</td> <td data-bbox="1074 1805 1520 1883"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 1883 687 1962">Reducing the emotional burden caused by MDS</td> <td data-bbox="687 1883 735 1962">1</td> <td data-bbox="735 1883 820 1962">2</td> <td data-bbox="820 1883 904 1962">3</td> <td data-bbox="904 1883 989 1962">4</td> <td data-bbox="989 1883 1074 1962">5</td> <td data-bbox="1074 1883 1520 1962"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 1962 687 2040">Dealing with practical issues connected to MDS</td> <td data-bbox="687 1962 735 2040">1</td> <td data-bbox="735 1962 820 2040">2</td> <td data-bbox="820 1962 904 2040">3</td> <td data-bbox="904 1962 989 2040">4</td> <td data-bbox="989 1962 1074 2040">5</td> <td data-bbox="1074 1962 1520 2040"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 2040 687 2116">Helps me think less frequently about MDS</td> <td data-bbox="687 2040 735 2116">1</td> <td data-bbox="735 2040 820 2116">2</td> <td data-bbox="820 2040 904 2116">3</td> <td data-bbox="904 2040 989 2116">4</td> <td data-bbox="989 2040 1074 2116">5</td> <td data-bbox="1074 2040 1520 2116"><input type="checkbox"/></td> </tr> </tbody> </table>		Not at all useful			Extremely useful		Not relevant to me	Reducing my level of worry about MDS	1	2	3	4	5	<input type="checkbox"/>	Reducing the emotional burden caused by MDS	1	2	3	4	5	<input type="checkbox"/>	Dealing with practical issues connected to MDS	1	2	3	4	5	<input type="checkbox"/>	Helps me think less frequently about MDS	1	2	3	4	5	<input type="checkbox"/>
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5.7	Please add any relevant comments about <u>access</u> or <u>lack of access</u> to Haemato/Oncology counsellors:																					
5.7.1	<p>Have complementary therapies ever been offered to you?</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p>																					
5.8	<p>Do you wish to have contact with other MDS patients?</p> <p><input type="checkbox"/> No \longrightarrow Skip to Q 5.8.1 <input type="checkbox"/> Yes \longrightarrow Skip to Q 5.8.2</p>																					
5.8.1	Please say why you <u>would not like</u> contact with other MDS patients:																					
5.8.2	Please say why you <u>would like</u> contact with other MDS patients:																					
INFO	<p>The next 5 questions relate to MDS UK patient information events. We provide the following 2 types of information events:</p> <p>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.</p> <p>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.</p>																					
5.9	<p><u>Have you ever attended an MDS UK Annual Patient Forum or MDS UK Local Patient Meeting?</u></p> <p><input type="checkbox"/> No \longrightarrow Skip to Q 5.10 <input type="checkbox"/> Yes</p>																					
5.9.1	<p>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</p> <table border="1" data-bbox="245 1756 1501 1912"> <thead> <tr> <th></th> <th colspan="3">Not at all useful</th> <th colspan="2">Extremely useful</th> <th>N/A</th> </tr> </thead> <tbody> <tr> <td>MDS UK Annual patient forum</td> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> <td><input type="checkbox"/></td> </tr> <tr> <td>MDS UK Local patient meeting</td> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> <td><input type="checkbox"/></td> </tr> </tbody> </table>		Not at all useful			Extremely useful		N/A	MDS UK Annual patient forum	1	2	3	4	5	<input type="checkbox"/>	MDS UK Local patient meeting	1	2	3	4	5	<input type="checkbox"/>
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MDS UK Local patient meeting	1	2	3	4	5	<input type="checkbox"/>																
5.9.2	Please add additional comments/ criticisms about MDS UK patient events you have attended:																					

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

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	
<input type="checkbox"/>	Practical advice/support via phone call/email to MDS UK	1	2	3	4	5
<input type="checkbox"/>	Received an MDS UK Patient Information Pack	1	2	3	4	5
<input type="checkbox"/>	Emotional support via phone call/email	1	2	3	4	5
<input type="checkbox"/>	Attended MDS UK patient event	1	2	3	4	5
<input type="checkbox"/>	Consulted MDS UK website	1	2	3	4	5
<input type="checkbox"/>	Consulted MDS UK online Message Forum	1	2	3	4	5
<input type="checkbox"/>	Read MDS UK Newsletter	1	2	3	4	5
<input type="checkbox"/>	Consulted MDS UK Facebook pages	1	2	3	4	5
<input type="checkbox"/>	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 do not access some or all 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 <u>for you</u> ?
5.18	From your experience, what type of information do you think would be of benefit or helpful <u>for carers/family members</u> ?
5.19	<p>Have you heard of/ are you aware of NICE (National Institute for Health and Clinical Excellence)?</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes – but only since contacting the MDS UK Patient Support Group</p> <p><input type="checkbox"/> Yes – independently from the MDS UK Patient Support Group</p>
5.20	<p>Where did you obtain this questionnaire?</p> <p><input type="checkbox"/> Included in a newsletter</p> <p><input type="checkbox"/> Via a nurse/doctor in a hospital</p> <p><input type="checkbox"/> Posted or emailed to me personally by MDS UK Patient Support Group</p> <p><input type="checkbox"/> From another patient</p> <p><input type="checkbox"/> From the internet</p> <p><input type="checkbox"/> Other, please specify: _____</p>
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

2002 © Esther N Oliva, Borislav D Dimitrov, Francesco Nobile

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			