Supplemental Information

**Supplemental Methods.** Details on the literature screening and Delphi survey procedures

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Supplemental Methods. Details on the literature screening and Delphi survey procedures

For the literature review of QoL instrument in MDS studies, we excluded systematic reviews, studies without adult patients with MDS, and studies not including QoL assessment or without an available English version. Two reviewers (IS, HB) were involved in the process of title/abstract screening and data extraction using a pre-specified extraction form. A third researcher (UR) was consulted in case of disagreement. Data regarding the type of the QoL instrument, studied population, examined intervention and study type were extracted and summarized in a standardized evidence table.

Following the recommendations of the COMET initiative, we used a Delphi survey as a method for deriving consensus among participants, based on anonymous ratings and the learning process from previous results. The Delphi survey questionnaire consisted of a project description, a consent form, a section with questions about the participants’ demographics, the list of potential PROs with a graphical nine point scale for rating each outcome, and a final section for suggestion of yet unlisted PROs or additional comments. The proposed rating was performed by using the Grading of Recommendations Assessment, Development and Evaluations scale (1-3 low importance for decision making; 4-6 important, but not critical for decision making; 7-9 critical for decision making). In addition to the rating, an explanation was given in the form of a general non-MDS specific definition and/or descriptive examples, ensuring clear and uniform understanding of the PROs among the two groups. The first round of the Delphi survey did not provide the final ratings but was intended to increase the consensus and agreement among the participants within the two groups. In the second survey round, the results from the previous round and the newly suggested outcomes were presented to each of the two groups.
For the survey among hematologists, reminders were sent online before each survey deadline and invitations were counted as received if at least one of the sequential emails within each round reached the potential participant. Collection of the patients’ responses was performed in the Saint Louis Hospital in Paris, France during routine patients’ visit including patients who were willing to participate in the survey. The survey participants were not offered any monetary benefits.

1. Williams PL, Webb C. The Delphi technique: a methodological discussion. *J Adv Nurs* 1994;19(1):180-186.

2. Guyatt GH, Oxman AD, Kunz R, et al. GRADE guidelines: 2. Framing the question and deciding on important outcomes. *J Clin Epidemiol*. 2011;64(4):395-400.
Supplemental Figure 1. Frequency of the identified QoL instruments in MDS studies

Frequency of QoL instruments in MDS studies stratified by intervention type, used to extract potential core PROs and to form the basis for the Delphi survey.

EORTC QLQ-C30 - European Organization for Research and Treatment of Cancer Quality of life Questionnaire; EQ-5D - EuroQol-5 dimension; FACT-An - Functional Assessment of Cancer Therapy-Anemia; FACT-BMT - Functional Assessment of Cancer Therapy-Bone Marrow Transplant; FACT-F - Functional Assessment of Cancer Therapy, Fatigue Scale; FACT-G - Functional Assessment of Cancer Therapy, General Measures; FLIC - Functional Living Index–Cancer; HUI – Health utilities index; HSCT - Hematopoietic stem cell transplantation; MHI - Mental Health Inventory; PROMIS - Patient reported outcomes measurement information system; QOL-E - Quality of life for hematologic diseases; QUALMS - Quality of Life in Myelodysplasia Scale; SF–36 – Short Form 36-item, Health Survey; SF–12 – 12-Item Short Form Survey; SF–6D – Short Form Survey-6D; SIP - Sickness impact profile; SLDS-C - Satisfaction with Life Domains Scale for Cancer; TTO - Time Trade-Off; VAS - Visual Analogue Scale; WHOQOL-BREF - WHO Quality of Life-BREF.
### Supplemental Table 1. First and second round Delphi survey results: ratings of the potential core PROs, based on COMET categorization

| Potential core PROs | First Round | Second Round |
|---------------------|-------------|--------------|
|                     | Patients N=40 | Hematologists N=38 | Patients N=38 | Hematologists N=32 |
| General QoL¹        | Rating 7-9, % 42.5 | Rating 1-3, % 22.5 | Rating 7-9, % 71.1 | Rating 1-3, % 13.2 |
|                     |               |               |               |               |
| Transfusion-        | Rating 7-9, % 81.6 | Rating 1-3, % 0.0 | Rating 7-9, % 35.0 | Rating 1-3, % 6.3 |
| dependency burden²  |               |               |               |               |
| Ability to work/ADL³| Rating 7-9, % 30.0 | Rating 1-3, % 42.5 | Rating 7-9, % 2.6 | Rating 1-3, % 42.1 |
|                     |               |               |               |               |
| General health      | Rating 7-9, % 37.5 | Rating 1-3, % 17.5 | Rating 7-9, % 35.0 | Rating 1-3, % 17.5 |
|                     |               |               |               |               |
| Fatigue             | Rating 7-9, % 37.5 | Rating 1-3, % 10.0 | Rating 7-9, % 20.0 | Rating 1-3, % 22.5 |
|                     |               |               |               |               |
| Confidence in HCS   | Rating 7-9, % 65.0 | Rating 1-3, % 17.5 | Rating 7-9, % 65.0 | Rating 1-3, % 7.9 |
|                     |               |               |               |               |
| Weakness            | Rating 7-9, % 42.5 | Rating 1-3, % 15.0 | Rating 7-9, % 12.5 | Rating 1-3, % 15.6 |
|                     |               |               |               |               |
| Disease knowledge   | Rating 7-9, % 57.5 | Rating 1-3, % 25.0 | Rating 7-9, % 52.6 | Rating 1-3, % 52.6 |
|                     |               |               |               |               |
| Shortness of breath | Rating 7-9, % 35.0 | Rating 1-3, % 35.0 | Rating 7-9, % 35.0 | Rating 1-3, % 35.0 |
|                     |               |               |               |               |
| Relationship with   | Rating 7-9, % 42.5 | Rating 1-3, % 32.5 | Rating 7-9, % 20.0 | Rating 1-3, % 22.5 |
| friends/relatives   |               |               |               |               |
| Need to rest        | Rating 7-9, % 35.0 | Rating 1-3, % 17.5 | Rating 7-9, % 52.6 | Rating 1-3, % 52.6 |
|                     |               |               |               |               |
| Basic mobility      | Rating 7-9, % 25.0 | Rating 1-3, % 52.5 | Rating 7-9, % 42.1 | Rating 1-3, % 42.1 |
|                     |               |               |               |               |
| Fear of MDS         | Rating 7-9, % 25.0 | Rating 1-3, % 60.0 | Rating 7-9, % 42.1 | Rating 1-3, % 68.8 |
| progression*        |               |               |               |               |
| Medication use      | Rating 7-9, % 40.0 | Rating 1-3, % 27.5 | Rating 7-9, % 34.4 | Rating 1-3, % 34.4 |
|                     |               |               |               |               |
| Eye problems        | Rating 7-9, % 22.5 | Rating 1-3, % 47.5 | Rating 7-9, % 50.0 | Rating 1-3, % 73.7 |
|                     |               |               |               |               |
| Hearing problems    | Rating 7-9, % 22.5 | Rating 1-3, % 67.5 | Rating 7-9, % 58.8 | Rating 1-3, % 58.8 |
|                     |               |               |               |               |
| Physical activity   | Rating 7-9, % 32.5 | Rating 1-3, % 45.0 | Rating 7-9, % 73.7 | Rating 1-3, % 73.7 |
|                     |               |               |               |               |
| Vomiting/Nausea     | Rating 7-9, % 20.0 | Rating 1-3, % 67.5 | Rating 7-9, % 57.9 | Rating 1-3, % 57.9 |
|                     |               |               |               |               |
| Fear of side effects| Rating 7-9, % 22.5 | Rating 1-3, % 57.5 | Rating 7-9, % 36.8 | Rating 1-3, % 36.8 |
| of treatment        |               |               |               |               |
| Defecation/Change in| Rating 7-9, % 22.5 | Rating 1-3, % 40.0 | Rating 7-9, % 9.4  | Rating 1-3, % 9.4  |
| digestion           |               |               |               |               |
| Loss of independence| Rating 7-9, % 15.0 | Rating 1-3, % 75.0 | Rating 7-9, % 15.6 | Rating 1-3, % 15.6 |
| Pain                | Rating 7-9, % 20.0 | Rating 1-3, % 47.5 | Rating 7-9, % 43.8 | Rating 1-3, % 43.8 |
| Memory difficulties/Cognition | Rating 7-9, % 20.0 | Rating 1-3, % 57.5 | Rating 7-9, % 34.4 | Rating 1-3, % 34.4 |
| Colds/Infections    | Rating 7-9, % 12.5 | Rating 1-3, % 65.0 | Rating 7-9, % 9.4  | Rating 1-3, % 9.4  |
| Urinary incontinence| Rating 7-9, % 15.0 | Rating 1-3, % 77.5 | Rating 7-9, % 9.4  | Rating 1-3, % 9.4  |
| Hospital dependence | Rating 7-9, % 30.0 | Rating 1-3, % 35.0 | Rating 7-9, % 15.6 | Rating 1-3, % 15.6 |
| Tremor              | Rating 7-9, % 7.5  | Rating 1-3, % 85.0 | Rating 7-9, % 63.2 | Rating 1-3, % 63.2 |
| Body image          | Rating 7-9, % 17.5 | Rating 1-3, % 45.0 | Rating 7-9, % 43.8 | Rating 1-3, % 43.8 |
| Depression          | Rating 7-9, % 17.5 | Rating 1-3, % 62.5 | Rating 7-9, % 44.7 | Rating 1-3, % 44.7 |
| Impatience          | Rating 7-9, % 17.5 | Rating 1-3, % 60.0 | Rating 7-9, % 25.0 | Rating 1-3, % 25.0 |
| Skin problems       | Rating 7-9, % 15.0 | Rating 1-3, % 65.0 | Rating 7-9, % 9.4  | Rating 1-3, % 9.4  |
| Loss of weight      | Rating 7-9, % 15.0 | Rating 1-3, % 62.5 | Rating 7-9, % 15.6 | Rating 1-3, % 15.6 |
| Headache            | Rating 7-9, % 10.0 | Rating 1-3, % 82.5 | Rating 7-9, % 9.4  | Rating 1-3, % 9.4  |
| Change in sense of  | Rating 7-9, % 20.0 | Rating 1-3, % 70.0 | Rating 7-9, % 9.4  | Rating 1-3, % 9.4  |
| taste               |               |               |               |               |
| Loss of appetite    | Rating 7-9, % 22.5 | Rating 1-3, % 60.0 | Rating 7-9, % 15.6 | Rating 1-3, % 15.6 |
| Emotional wellbeing | Rating 7-9, % 15.0 | Rating 1-3, % 32.5 | Rating 7-9, % 9.4  | Rating 1-3, % 9.4  |
|                         | 10.0 | 80.0 | 18.4 | 18.4 | 26.3 | 47.4 | 15.6 | 25.0 |
|-------------------------|------|------|------|------|------|------|------|------|
| Speaking difficulties/SLP |      |      |      |      |      |      |      |      |
| Sexuality/Sexual activity | 5.0  | 67.5 | 18.4 | 18.4 | 18.4 | 60.5 | 9.4  | 37.5 |
| Sleep disturbances      | 27.5 | 27.5 | 18.4 | 28.9 | 18.4 | 36.8 | 25.0 | 18.8 |
| Financial difficulties   | 15.0 | 82.5 | 10.5 | 36.8 | 13.2 | 65.8 | 21.9 | 43.8 |
| Difficulty concentrating†| -    | -    | -    | -    | 34.2 | 36.8 | -    | -    |
| Dental problems†         | -    | -    | -    | -    | 23.7 | 42.1 | -    | -    |
| Fear of falling†         | -    | -    | -    | -    | 26.3 | 31.6 | -    | -    |

ADL - Activities of daily living; HCS - Health care services; MDS - Myelodysplastic syndromes; N - Number of participants; PRO - Patient-reported outcomes; QoL - Quality of life; SLP - Speech language problems;
*Fear of MDS progression or transformation to acute myeloid leukemia;
† New outcome suggested after the first patients’ round;
‡ Outcomes fulfilling the inclusion criteria after the second round of the Delphi survey.

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| QoL instrument | Year of establishment | Brief description | Examined intervention | MDS study population | Study type |
|----------------|-----------------------|------------------|-----------------------|----------------------|-----------|
| EORTC QLQ-C30 | 1993 | Cancer specific instrument assessing functional scales, symptom scales, global QoL and financial impact. | 13-Medications<sup>8,11-15,18,20-22,24-26</sup> 6-Health/molecular prognostic values<sup>1,3,5-8</sup> 5-HSCT<sup>10,16,17,23</sup> 2-Transfusion<sup>2,19</sup> | 11-LRMDS<sup>1</sup> 12-IRMDS<sup>1</sup> 9-Non-spec<sup>4,9,10,12,13,16,17,21,23</sup> 8-HRMD<sup>1</sup> 7-HSCT T<sup>17</sup> 6-Health/molecular prognostic values<sup>35,39</sup> 3-Transfusion<sup>2,27,32</sup> 3-Medications<sup>31,52,54</sup> 3-Health/molecular prognostic values<sup>43,53,55</sup> 1-Transfusion<sup>2</sup> | 11-COH<sup>1</sup> 9-RCT<sup>16-22,24,26</sup> 5-CT<sup>11-15</sup> 1-CSS<sup>10</sup> |
| FACT-An<sup>2,17,27,41</sup> | 1997 | Cancer specific instrument assessing physical, social/family, emotional, and functional well-being, including 20 items related to fatigue and anemia. | 11-Medications<sup>28,31,33,34,36-38,40,41</sup> 3-Transfusion<sup>2,27,32</sup> 2-Health/molecular prognostic values<sup>35,39</sup> 1-HSCT<sup>17</sup> | 10-LRMDS<sup>2</sup> 7-Non-spec<sup>17,27,32,35,39,41</sup> | 7-RCT<sup>17,30-34,36</sup> 5-CT<sup>28,37,38,40,41</sup> 4-COH<sup>3,27,29,39</sup> 1-CSS<sup>35</sup> |
| 36-Item Short Form Survey<sup>2,31,42-54</sup> | 1992 | Generic instrument assessing physical functioning, role-physical, role-emotional, bodily pain, vitality, mental health, social functioning, and general health. | 9-HSCT<sup>42,44-51</sup> 3-Medications<sup>31,52,54</sup> 3-Health/molecular prognostic values<sup>43,53,55</sup> 1-Transfusion<sup>2</sup> | 10-Non-spec<sup>42-55</sup> 2-LRMDS<sup>31</sup> | 12-COH<sup>2,42-51,55</sup> 2-SS<sup>52,53</sup> 2-RCT<sup>31,54</sup> |
| QoL-E<sup>15,18,56-63</sup> | 2013 | MDS specific instrument assessing general perception of well-being and 26 items addressing physical, functional, social, sexual, fatigue, and disease-specific domains. | 6-Medications<sup>15,18,56-58,63</sup> 3-Health/molecular prognostic values<sup>59,61,62</sup> 1-Transfusion<sup>60</sup> | 7-LRMDS<sup>15,18,56,57,61-63</sup> 6-IRMDS<sup>15,36,57,61-63</sup> 2-Non-spec<sup>58-60</sup> | 3-COH<sup>15,61-63</sup> 3-CT<sup>15,57,58</sup> 2-CSS<sup>59,60</sup> 2-RCT<sup>15,63</sup> |
| FACT-BMT<sup>10,51,64-68</sup> | 1997 | Cancer (BMT) specific instrument assessing physical, social/family, emotional, and functional well-being including 23 items for disease/treatment related bone marrow transplantation. | 7-HSCT<sup>10,51,64-68</sup> | 7-Non-spec<sup>10,51,64-68</sup> | 5-COH<sup>1,64-67</sup> 2-SS<sup>10,68</sup> |
| Measure                        | Year | Description                                                                 | Health/molecular prognostic values | Non-specific   | COH   |
|-------------------------------|------|-----------------------------------------------------------------------------|------------------------------------|----------------|-------|
| VAS                           | 1983 | Generic instrument rating health status on a scale from 0 to 100.            | 4-LRMDS37,61,62,70,1-IRMDS37,61,62,70 | 1-CT37         | 1-CSS53,1-RCT22 |
| EQ-SD                         | 1990 | Generic instrument assessing mobility, self-care, usual activities, pain/discomfort and anxiety/depression. | 4-LRMDS37,61,62,70,4-IRMD33,61,62,70,2-Non-spec43,69 | 5-COH43,61,62,69,70 | 1-RCT21,24 |
| FACT-G                        | 1993 | Cancer specific instrument assessing physical, social/family, emotional, and functional well-being. | 3-Health/molecular prognostic values39,72,74,3-Medications71,73,75 | 4-Non-spec39,72,74,2-LRMDS71,75,2-IRMD371,75,1-HRM375 | 2-RCT21,24,2-CT12 |
| Mental Health Inventory       | 1983 | Generic instrument assessing psychological distress and well-being.          | 3-Medications12,21,24               | 1-IRMDS24,1-Non-spec24,2-Non-spec12,21 | 2-CT12 |
| Satisfaction with life domains scale for cancer | 1993 | Cancer specific instrument assessing social functioning, appearance, physical functioning, communication with medical providers, and spirituality. | 2-HSCT44,49,2-Non-spec44,49,2-COH44,49 | 1-LRMDS71,1-IRMDS71,1-Non-spec9,1-COH9,1-CT71 |
| FACIT-F                        | 1997 | Generic instrument assessing physical, social/family, emotional, and functional well-being including 13 items related to fatigue. | 2-Medications53,71                  | 1-LRMDS71,1-Non-spec9,1-HSCT76 | 1-COH55,1-HSCT76 |
| Functional living index-cancer | 1984 | Cancer specific instrument assessing physical well-being and ability, emotional state, sociability, family situation and nausea. | 1-Health/molecular prognostic values55,1-HSCT76 | 1-Non-spec55,76,1-HSCT76 | 1-CT71 |
| WHO Quality of Life-BREF      | 1991 | Generic instrument assessing physical health, psychological health, social relationships, and environment. | 1-HSCT77                           | 1-Non-spec77,1-HSCT77 | 1-COH77 |
| Instrument                                                                 | Year | Description                                                                                                                                                                                                 | Key1 | Key2 | Key3 |
|----------------------------------------------------------------------------|------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------|------|------|
| Patient reported outcomes measurement information system (78)            | 1997 | Generic instrument assessing physical, mental, and social health.                                                                                                                                             | 1-HSCT78 | 1-Non-spec78 | 1-COH78 |
| Quality of Life in Myelodysplasia Scale (79)                               | 2012 | MDS specific instrument assessing fatigue, emotional health, uncertainty/sense of control, disease information, disruption of life/logistics of care, family relationships, symptoms other than fatigue, financial concerns, awareness of positives/hope, social/role functioning, sexual health, and appearance/self-image. | 1-Health/molecular prognostic values79 | 1-Non-spec79 | 1-COH79 |
| Time trade-off (69)                                                        | 1976 | Generic instrument for assessing QoL using life-length trading technique.                                                                                                                                   | 1-Transfusion69 | 1-Non-spec69 | 1-COH69 |
| 6D-Short Form Survey (80)                                                  | 1998 | Generic instrument assessing physical functioning, role physical, role emotional, bodily pain, vitality, mental health, and social functioning.                                                               | 1-Medications80 | 1-Non-spec80 | 1-COH80 |
| Health utilities index (81)                                                | 1982 | Generic instrument assessing cognition, vision, hearing, speech, ambulation, dexterity, emotion, and pain.                                                                                                 | 1-HSCT81 | 1-Non-spec81 | 1-COH81 |
| 12-Item Short Form Survey (81)                                             | 1996 | Generic instrument assessing physical functioning, role-physical, role-emotional, bodily pain, vitality, mental health, social functioning, and general health.                                                   | 1-HSCT81 | 1-Non-spec81 | 1-COH81 |
| Sickness impact profile | 1981 | Generic instrument assessing sleep and rest, eating, work, home management, recreation and pastimes, ambulation, mobility, body care and movement, social interaction, alertness behavior, emotional behavior, communication. | 1-HSCT<sup>51</sup> | 1-Non-spec<sup>51</sup> | 1-COH<sup>51</sup> |

BMT – Bone marrow transplantation; COH – cohort study; CSS – Cross-sectional study; CT – Control-trial; EORTC QLQ-C30 – European Organization for Research and Treatment of Cancer Quality of life Questionnaire; EQ-5D – EuroQol-5 dimension; FACT-An – Functional Assessment of Cancer Therapy-Anemia; FACT-BMT – Functional Assessment of Cancer Therapy-Bone Marrow Transplant; FACT-F – Functional Assessment of Cancer Therapy, Fatigue Scale; FACT-G – Functional Assessment of Cancer Therapy, General Measures; FLIC – Functional Living Index–Cancer; HRMDS – High risk MDS patients; HSCT – Hematopoietic stem cell transplantation; HUI – Health utilities index; IRMDS – Intermediate risk MDS patients; LRMDS – Low risk MDS patients; MHI – Mental Health Inventory; MDS – Myelodysplastic syndromes; Non-spec – MDS patients not classified according the Revised/International Prognostic Scoring System; PRO – Patient-reported outcome; PROMIS – Patient reported outcomes measurement information system; QoL – Quality of life; QOL-E – Quality of life for hematologic diseases; QUALMS – Quality of Life in Myelodysplasia Scale; RCT – randomized control trial; SF-36 – Short Form 36-item, Health Survey; SF-12 – 12-Item Short Form Survey; SF-6D – Short Form Survey-6D; SIP – Sickness impact profile; SLDS-C – Satisfaction with Life Domains Scale for Cancer; TTO – Time Trade-Off; VAS – Visual Analogue Scale; WHOQOL-BREF – WHO Quality of Life-BREF.
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### Supplemental Table 3. Summary of the extracted and categorized items and domains from the identified QoL instruments in MDS studies

| Potential core PROs | Extracted items and domains |
|---------------------|-----------------------------|
| **Shortness of breath** | Were you short of breath?[^A]  
I have been short of breath [^B][^E]  
During the last week, did shortness of breath while climbing the stairs disturb you?[^B]  
During the past week, how often have you experienced shortness of breath?[^P] |
| **Weakness** | Have you felt weak?[^A]  
Were you tired?[^A]  
I have a lack of energy [^B][^E][^H]  
I feel weak all over [^B][^K]  
I feel listless (“washed out”) [^B][^K]  
I feel tired [^B][^K]  
I have trouble starting things because I am tired [^B][^K]  
I have trouble finishing things because I am tired [^B][^K]  
I have energy [^B][^K]  
I feel lightheaded (dizzy) [^B]  
I am too tired to eat [^B][^K]  
I am frustrated by being too tired to do the things I want to do [^B][^K]  
I have to limit my social activity because I am tired [^B][^K]  
Did you feel tired?[^C]  
Did you feel full of pep?[^C]  
Did you feel worn out?[^C]  
I get tired easily [^E]  
I have trouble starting things because I am tired [^O]  
How run down did you feel on average? [^O]  
During the past week, how often did low energy levels cause you to change your schedule?[^P]  
During the past week, how often have you felt weak?[^P]  
During the past week, how often did you feel too tired to drive?[^P]  
During the past week, how often have you been too tired to take care of a family member or loved one?[^P]  
I spend most of the time partly undressed or in pajamas[^U] |
| **Need to rest** | Did you need to rest?[^A]  
Do you need to stay in bed or a chair during the day?[^A]  
I need to sleep during the day [^B][^K]  
I spend much of the day lying down in order to rest [^U]  
I am forced to spend time in bed [^B][^E][^H]  
Being bedridden [^D]  
I stay in bed most of the time [^U]  
I spend more time in bed [^U]  
I remain lying most of the day [^U]  
I sit during much of the day [^U]  
I am sleeping or dozing most of the time - day and night [^U]  
I lie down more often during the day in order to rest [^U]  
I sit around half-asleep [^U]  
I sleep or nap more during the day [^U]  
I stay lying down most of the time [^U]  
I am staying in bed more [^U]  
I am staying in bed most of the time [^U]  
I stay home most of the time [^U] |
| **Fatigue** | Fatigue?[^A][^O]  
I feel fatigued. [^B][^K]  
In the last week, how much did fatigue get in the way with your daily chores?[^D]  
In the last week, how much fatigue did you have?[^D] |
I feel fatigued.  
How fatigued were you on average?  
During the past week, how often did you take into account that you might be fatigued when planning your activities?

### Sleep disturbances
- Have you had trouble sleeping?  
- I am sleeping well  
- During the last week, did you get enough sleep?  
- How satisfied are you with your sleep?  
- Sleep Disturbance  
- My sleep quality was  
- My sleep was refreshing  
- I had a problem with sleep  
- I had difficulty falling asleep  
- I sleep less at night, for example, wake up too early, do not fall asleep for a long time, and awaken frequently  
- I change position frequently

### Emotional wellbeing
- Emotional wellbeing?  
- Emotional role  
- Emotional health  
- Emotions and energy  
- Emotional health  
- Emotions and energy  
- Emotional problems interfered with your normal social activities with family, friends, neighbors, or groups  
- During the past week, how often did you feel a sense of gratitude for a part of life that you took for granted before?  
- Positive feelings  
- I am satisfied with how I am coping with my illness  
- I am enjoying the things I usually do for fun  
- I have accepted my illness  
- I am motivated to do my usual activities  
- Have you felt calm and peaceful?  
- Did you have a lot of energy?  
- Have you been a happy person?  
- How much time, during the past month, has your daily life been full of things that were interesting to you?  
- During the past month, how much of the time have you felt that the future looks hopeful and promising?  
- During the past month, how much of the time have you generally enjoyed the things you do?  
- Satisfied with work?  
- How much do you enjoy life?  
- Do you have enough energy for everyday life?  
- To what extent do you feel your life to be meaningful?  
- How satisfied are you with yourself?  
- Happy and interested in life  
- When have you got up in the morning, this past month, about how often did you expect to have an interesting day?  
- How much of the time, during the past month, have you felt calm and peaceful?  
- How much of the time, during the past month, have you felt emotionally stable?  
- During the past month, how much of the time have living been a wonderful adventure for you?  
- How much of the time, during the past month, have you felt cheerful, lighthearted?  
- During the past month, how much of the time were you a happy person?  
- How often, during the past month, have you been waking up feeling fresh and rested?  
- How much comfortable do you feel?

Your ability to control your personal circumstances?[^1]
During the past week, how often did you find yourself grateful for tomorrow?[^2]
Negative feelings
I am losing hope in the fight against my illness[^3][^4][^5]
How much of the time have you felt lonely during the past month?[^1]
During the past month, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory?[^1]
During the past month, how often did you feel that you had nothing to look forward to?[^1]
How much of the time, during the past month, have you felt downhearted and blue?[^1]
How often have you felt like crying, during the past month?[^1]
During the past month, how often have you felt that others would be better off if you were dead?[^1]
How often, during the past month, did you feel that nothing turned out for you the way you wanted it to?[^1]
How often, during the past month, have you felt so down in the dumps?[^1]
During the past month, did you think about taking your own life?[^1]
During the past month, how much of the time have you been moody or brooded about things?[^1]
During the past month, how much of the time have you been in low or very low spirits?[^1]
Discouraged about life?[^1]
Feel uncomfortable?[^1]
Hardship on yourself?[^1]
During the past week, how often have you felt there was limited emotional support available for patients with MDS beyond their families?[^2]
During the past week, how often did you feel angry about your diagnosis?[^2]
So unhappy that life is not worthwhile.[^5]
I say how bad or useless I am, for example that I am a burden on others[^7]
I laugh or cry suddenly[^9]
I stay alone much of the time[^9]
I feel sad[^9][^10][^13][^14]
Somewhat happy[^9]
Somewhat unhappy[^9]
Very unhappy[^9]
I feel oppressed by my disease[^10]
Think about illness?[^10]
During the past week, how often were you concerned about bruising?[^2]
I have attempted suicide[^9]

**Depression**
Did you feel depressed?[^1]
Have you felt so down in the dumps that nothing could cheer you up?[^3]
Have you felt downhearted and blue?[^4][^5][^6]
Anxiety/depression[^6]
Did you feel depressed during the past month?[^1]
Feel depressed?[^1]
How often do you have negative feelings such as blue mood, despair, anxiety, depression?[^8]
Depression[^9]
I felt worthless[^9]
I felt helpless[^9]
I felt depressed[^9]
I felt hopeless[^9]
During the past week, how often did you feel as though you couldn’t do anything about your disease?[^2]
During the past week, how often have you felt a sense of hopelessness?[^2]
I talk about the future in a hopeless way[^9]

**Fear of MDS progression or**
Did you worry?[^1]
I worry about dying[^2][^3][^4][^10]
| Transformation to leukemia | I worry that my condition will get worse [I] [K] [L]  
| | Stress and worry because of the disease [I]  
| | I am concerned about keeping my job [include work at home] [E]  
| | I worry that the transplant will not work [K]  
| | I have concerns about my ability to have children [E]  
| | I regret having the bone marrow transplant [E]  
| | Your future? [J]  
| | Your transplant? [J]  
| | During the past week, how often did you feel as though your life was organized around medical appointments? [P]  
| | During the past week, how often were you worried about bleeding? [P]  
| | Cope well with stress? [L]  
| | Frightened of future? [L]  
| | How safe do you feel in your daily life? [N]  
| | During the past week, how often did you feel the course of your disease was unpredictable? [P]  
| | During the past week, how often were you afraid of dying? [P]  
| | During the past week, how often did you worry about your MDS progressing or developing into leukemia? [P]  
| | During the past week, how often did you avoid crowds because of fear of getting an infection? [P]  
| | During the past week, how often were you afraid of losing your job? [P]  
| | During the past week, how often were you afraid that your MDS treatment would stop working? [P]  
| | I get sudden frights [U]  
| | I often express concern over what might be happening to my health [L] |
| Body image | I like the appearance of my body [E]  
| | Your body? [J]  
| | Your appearance? [J]  
| | Appear well? [L]  
| | Are you able to accept your bodily appearance? [N] |
| Loss of independence | I am able to get around by myself [E]  
| | I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid [U]  
| | I make difficult moves with help, for example, getting into or out of cars, bathtubs [U]  
| | Able to walk around the neighborhood without difficulty, and without walking equipment [S]  
| | Able to walk around the neighborhood with difficulty; but does not require walking equipment or the help of another person [S]  
| | Able to walk around the neighborhood with walking equipment, but without the help of another person [S]  
| | Able to walk only short distances with walking equipment, and requires a wheelchair to get around the neighborhood [S]  
| | Limitations in the use of hands or fingers, but does not require special tools or help of another person [S]  
| | Limitations in the use of hands or fingers, is independent with use of special tools (does not require the help of another person) [S]  
| | Limitations in the use of hands or fingers, requires the help of another person for some tasks (not independent even with use of special tools) [S]  
| | Limitations in use of hands or fingers, requires the help of another person for most tasks (not independent even with use of special tools) [S]  
| | Limitations in use of hands or fingers, requires the help of another person for all tasks (not independent even with use of special tools) [S]  
| | Unable to walk alone, even with walking equipment. Able to walk short distances with the help of another person, and requires a wheelchair to get around the neighborhood [S]  
| | I use stairs only with mechanical support, for example, handrail, cane, crutches [U]  
| | I walk up or down stairs only with assistance from someone else [U]  
| | I get around in a wheelchair [U] |
I walk by myself but with some difficulty, for example, limp, wobble, stumble, have stiff leg [U]
I walk only with help from someone [U]
I stand up only with someone’s help [U]
I kneel, stoop, or bend down only by holding on to something [U]
I get in and out of bed or chairs by grasping something for support or using a cane or walker [U]
I hold on to something to move myself around in bed [U]
I do not get around in the dark or in unlit places without someone’s help [U]
I do not bathe myself completely, for example, require assistance with bathing [U]
I do not bathe myself at all, but am bathed by someone else [U]
I use bedpan with assistance [U]
I have trouble getting shoes, socks, or stockings on [U]
I do not fasten my clothing, for example, require assistance with buttons, zippers, shoelaces [U]
I dress myself, but do so very slowly [U]
I get dressed only with someone’s help [U]
Do you need help with eating, dressing, washing yourself or using the toilet? [A]
I need help doing my usual activities [B] [K]
Bathing or dressing yourself [C] [R]
I am unable to wash or dress myself [G]
I have no/slight/moderate/severe problems in washing or dressing myself [G]
In the last week, some daily activities may have been limited by your health, such as: climbing stairs, lowering myself, taking care of myself (washing, dressing, feeding myself) [R]
Difficulty in taking care of yourself [B]
Self-Care [G]

Physical activity
Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? [A]
Do you have any trouble taking a long walk? [A]
Physical well-being [B] [E] [H]
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports [C] [R]
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf [C] [R] [T]
Walking several blocks [C]
Walking more than a mile [C]
Physical health problems [C]
In the last week, some daily activities may have been limited by your health, such as performing heavy activities? [O]
How much physical strength do you have? [I]
Physical Function [O]
Are you able to do chores such as vacuuming or yard work? [O]
Are you able to go up and down stairs at a normal pace? [O]
Are you able to run errands and shop? [O]
Ambulation [B]
I do not walk up or down hills [U]

Ability to work/Activities of daily living
Were you limited in doing either your work or other daily activities? [A]
I am able to work (include work at home) [B] [E] [H]
My work (include work at home) is fulfilling [B] [E] [H]
Cut down the amount of time you spent on work or other activities? [C]
Accomplished less than you would like? [C] [R] [T]
Were limited in the kind of work or other activities? [C] [R] [T]
Had difficulty performing the work or other activities (for example, it took extra effort)? [C]
I got very little done [O]
I had more fatigue doing my work [O]
Your health is an impediment for you to keep a paid job (whether you are of retirement age or not). [O]
Able to complete housework? [L]
How satisfied are you with your capacity for work? [N]
I am satisfied with how much work I can do [O]
I am satisfied with my ability to work [O]
Dexterity [S]
I am not working at all [U]
I am doing part of my job at home [U]
I am not accomplishing as much as usual at work [U]
I often act irritable toward my work associates, for example, snap at them, give sharp answers, criticize easily [U]
I am working shorter hours [O]
I am doing only light work [U]
I work only for short periods of time or take frequent rests [U]
I am working at my usual job but with some changes, for example, using different tools or special aids, trading some tasks with other workers [U]
I do not do my job as carefully and accurately as usual [U]
Were you limited in pursuing your hobbies or other leisure time activities? [A]
Functional well-being [B][E][H]
I am able to enjoy life [B][E][H]
I am able to do my usual activities [B][K]
Limitations in activities [C]
Lifting or carrying groceries [C]
Not being able to travel [D]
Not being able to do house chores [D]
Usual activities [G]
I have no/slight/moderate/severe problems doing my usual activities [G]
I am unable to do my usual activities [G]
Your ability to go about your daily activities? [J]
Your job/school/household work? [J]
The way you spend leisure time? [J]
Maintain leisure activities? [L]
Pain/discomfort interfering activities? [L]
To what extent do you have the opportunity for leisure activities? [M]
How satisfied are you with your ability to perform your daily living activities? [N]
I am satisfied with my ability to do regular personal and household responsibilities [O]
I am satisfied with my ability to perform my daily routines [O]
During the past week, how often have you considered changing long-term plans due to health concerns? [P]
During the past week, how often have you had sufficient energy for routine tasks? [P]
During the past week, how often have you been too tired to take on the responsibilities you used to have? [P]
During the past week, how often were you unable to participate in activities you are used to doing? [P]
Did work or activities less carefully than usual? [P]
I do work around the house only for short periods [U]
I am doing less of the regular daily work around the house that I would usually do [U]
I am not doing any of the regular daily work around the house that I would usually do [U]
I am not doing any of the maintenance or repair work that I would usually do in my home or yard [B]
I am not doing any of the shopping that I would usually do [U]
I am not doing any of the house cleaning that I would usually do [U]
I have difficulty doing handwork, for example, turning faucets, using kitchen gadgets, sewing, carpentry [U]
I am not doing any of the clothes washing that I would usually do [U]
I am not doing heavy work around the house [U]
I have given up taking care of personal or household business affairs, for example, paying bills, banking working on budget [U]
| I am not now using public transportation | I stay away from home only for brief periods of time | I do my hobbies and recreation for shorter periods of time | I am going out for entertainment less often |
|----------------------------------------|-----------------------------------------------|-----------------------------------------|-----------------------------------------|
| I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading | I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading | I am doing more inactive pastimes in place of my other usual activities | I am doing fewer community activities |
| I am cutting down on some of my usual physical recreation or activities | I am not doing any of my usual physical recreation or activities | | |

**Basic mobility**

- Do you have any trouble taking a short walk outside of the house? Yes
- I have trouble walking
- Climbing one flight of stairs
- Climbing several flights of stairs
- Bending, kneeling, or stooping
- Walking one block
- Mobility
  - I have no/slight/moderate/severe problems in walking about
  - I am unable to walk about
- Are you able to go for a walk of at least 15 minutes? Yes
- Cannot walk at all
- Full use of two hands and ten fingers
- I do not walk at all
- I go up and down stairs more slowly, for example, one step at a time, stop often
- I do not use stairs at all
- I get around only by using a walker, crutches, cane, walls, or furniture
- I walk more slowly
- I stand only for short periods of time
- I do not maintain balance
- I move my hands or fingers with some limitation or difficulty
- I am in a restricted position all the time
- I am very clumsy in body movements
- I am getting around only within one building
- I stay within one room
- I walk shorter distance or stop to rest often
- I am not going into town
- I have more minor accidents, for example, drop things, trip and fall, bump into things
- How well are you able to get around?

**Memory difficulties/Cognition**

- Have you had difficulty remembering things?
- Have you had difficulty in concentrating on things, like reading a newspaper or watching television?
- I am able to concentrate
- During the past month, have you been in firm control of your behavior, thoughts, emotions or feelings?
- How well are you able to concentrate?
- During the past week, how often did you have trouble concentrating?
- Able to remember most things, think clearly and solve day to day problems
- Able to remember most things, but have a little difficulty when trying to think and solve day to day problems
- Somewhat forgetful, but able to think clearly and solve day to day problems
- Somewhat forgetful, and have a little difficulty when trying to think or solve day to day problems
- Very forgetful, and have great difficulty when trying to think or solve day to day problems
- Unable to remember anything at all, and unable to think or solve day to day problems
I am confused and start several actions at a time
I react slowly to things that are said or done
I do not finish things that I start
I have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things
I sometimes behave as if I were confused or disoriented in place or time, for example, where I am, who is around, directions, what day it is
I forget a lot, for example, things that happened recently, where I put things, appointments
I do not keep my attention on any activity for long
I make more mistakes than usual
I have difficulty doing activities involving concentration and thinking
I can remember things
Speaking
difficulties/Speech-language problems
Able to be understood completely when speaking with strangers or friends
Able to be understood partially when speaking with strangers but able to be understood completely when speaking with people who know me well
Able to be understood partially when speaking with strangers or people who know me well
Unable to be understood when speaking with strangers but able to be understood partially by people who know me well
Unable to be understood when speaking to other people (or unable to speak at all)
I communicate mostly by gestures, for example, moving head, pointing, sign language
My speech is understood only by a few people who know me well
I often lose control of my voice when I talk, for example, my voice gets louder or softer, trembles, changes unexpectedly
I don't write except to sign my name
I carry on a conversation only when very close to the other person or looking at him
I have difficulty speaking, for example, get stuck, stutter, stammer, slur my words
I am understood with difficulty
I do not speak clearly when I am under stress
Transfusion
dependency burden
Being dependent on transfusions
Medication use
How much do you need any medical treatment to function in your daily life?
Fear of side effects
doI
The side effects of treatment are worse than I had imagined
Pain
Have you had pain?
Did pain interfere with your daily activities?
I have pain in my chest
How much bodily pain have you had during the past 4 weeks?
How much did pain interfere with your normal work (including both work outside the home and housework)?
Palpitations (i.e., heart pounding)
I have no/slight/moderate/severe/extreme pain/discomfort
Pain/discomfort related to cancer?
To what extent do you feel that physical pain prevents you from doing what you need to do?
Pain Interference
Pain Intensity
How much did pain interfere with your day-to-day activities?
How much did pain interfere with work around the house?
How much did pain interfere with your ability to participate in social activities?
How much did pain interfere with your household chores?
How would you rate your pain on average?
| **Free of pain and discomfort**[^5]  
| Mild to moderate pain that prevents no activities[^5]  
| Moderate pain that prevents a few activities[^5]  
| Moderate to severe pain that prevents some activities[^5]  
| Severe pain that prevents most activities[^5]  
| I often moan and groan in pain or discomfort[^U]  
| I keep rubbing or holding areas of my body that hurt or are uncomfortable[^U]  
| **Headache**  
| I get headaches[^B]  
| **Colds/Infections**  
| I have frequent colds/infections[^E]  
| During the past week, how often have you been worried about getting an infection?[^P]  
| **Urinary incontinence**  
| I am only going to places with restrooms nearby[^B]  
| I do not have control of my bladder[^U]  
| **Hearing problems**  
| Able to hear what is said in a group conversation with at least three other people, without a hearing aid[^S]  
| Able to hear what is said in a conversation with one other person in a quiet room without a hearing aid, but requires a hearing aid to hear what is said in a group conversation with at least three other people[^S]  
| Able to hear what is said in a conversation with one other person in a quiet room with a hearing aid, and able to hear what is said in a group conversation with at least three other people, with a hearing aid[^S]  
| Able to hear what is said in a conversation with one other person in a quiet room, without a hearing aid, but unable to hear what is said in a group conversation with at least three other people even with a hearing aid[^S]  
| Able to hear what is said in a conversation with one other person in a quiet room with a hearing aid, but unable to hear what is said in a group conversation with at least three other people even with a hearing aid[^S]  
| Unable to hear at all[^S]  
| **Eye problems**  
| My eyesight is blurry[^S]  
| Vision[^S]  
| Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, without glasses or contact lenses[^S]  
| Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, but with glasses[^S]  
| Able to read ordinary newsprint with or without glasses but unable to recognize a friend on the other side of the street, even with glasses[^S]  
| Able to recognize a friend on the other side of the street with or without glasses but unable to read ordinary newsprint, even with glasses[^S]  
| Unable to read ordinary newsprint and unable to recognize a friend on the other side of the street, even with glasses[^S]  
| Unable to see at all[^S]  
| **Impatience**  
| Did you feel tense?[^A]  
| Did you feel irritable?[^A]  
| I feel nervous[^B][E][H]  
| Have you been a very nervous person?[^C][R]  
| Anxiety/depression[^I]  
| I have no/slight/mild/moderate/severe/extreme anxiety or depression[^I]  
| How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month?[^I]  
| How much time, during the past month, did you feel relaxed and free from tension?[^I]  
| How much time, during the past month, have you been a very nervous person?[^I]  
| During the past month, how much of the time have you felt tense or “high strung”?[^I]  
| How much of the time, during the past month, were you able to relax without difficulty?[^I]  
| How much have you been bothered by nervousness, or your “nerves”, during the past month?[^I]  

[^5]: Required if relevant.  
[^B]: Required if relevant.  
[^C]: Required if relevant.  
[^E]: Required if relevant.  
[^H]: Required if relevant.
| Question                                                                 | Response                                                                 |
|-------------------------------------------------------------------------|--------------------------------------------------------------------------|
| During the past month, how much of the time have you felt restless, fidgety, or impatient? | [I]                                                                       |
| During the past month, how often did you get rattled, upset or flustered? | [I]                                                                       |
| During the past month, have you been anxious or worried?                | [I]                                                                       |
| How often, during the past month, did you find yourself trying to calm down? | [I]                                                                       |
| During the past month, have you been under or felt you were under any strain, stress or pressure? | [I]                                                                       |
| Anxiety [O]                                                             |                                                                           |
| I felt fearful [O]                                                       |                                                                           |
| I found it hard to focus on anything other than my anxiety [O]           |                                                                           |
| My worries overwhelmed me [O]                                            |                                                                           |
| I felt uneasy [O]                                                        |                                                                           |
| During the past week, how often have you felt anxious about test or lab results? | [P]                                                                       |
| I act nervous or restless [U]                                            |                                                                           |
| I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen [U] |                                                                           |
| I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily [U] |                                                                           |
| I show less affection [U]                                                |                                                                           |
| Tremor                                                                  |                                                                           |
| I have tremors [I]                                                       |                                                                           |
| During the past month, how often did your hands shake when you tried to do something? | [P]                                                                       |
| I am having trouble writing or typing [U]                                |                                                                           |
| Skin problems                                                           |                                                                           |
| I am bothered by skin problems (e.g., rash, itching) [E]                 |                                                                           |
| Loss of appetite                                                         |                                                                           |
| Have you lacked appetite? [A]                                            |                                                                           |
| I have a good appetite [I]                                               |                                                                           |
| Your ability to eat? [J]                                                 |                                                                           |
| Well enough for meals or repairs? [I]                                    |                                                                           |
| I am eating much less than usual [U]                                     |                                                                           |
| I feed myself but only by using specially prepared food or utensils [U]  |                                                                           |
| I am eating special or different food, for example, soft food, bland diet, low-salt, low-fat, low-sugar [U] |                                                                           |
| I eat no food at all but am taking fluids [U]                           |                                                                           |
| I just pick or nibble at my food [U]                                    |                                                                           |
| I am drinking less fluids [U]                                            |                                                                           |
| I feed myself with help from someone else [U]                           |                                                                           |
| I do not feed myself at all, but must be fed [U]                        |                                                                           |
| I am eating no food at all, nutrition is taken through tubes or intravenous fluids [U] |                                                                           |
| Loss of weight                                                           |                                                                           |
| Suggested by hematologists prior to the Delphi survey                   |                                                                           |
| Vomiting/Nausea                                                          |                                                                           |
| Have you vomited? [A]                                                    |                                                                           |
| Have you felt nauseated? [A]                                             |                                                                           |
| I have nausea [B][E][H]                                                  |                                                                           |
| Nausea affecting daily functioning? [N]                                  |                                                                           |
| How much nausea? [N]                                                    |                                                                           |
| During the past week, how often did you feel nauseated? [P]              |                                                                           |
| Change in sense of taste                                                |                                                                           |
| I am bothered by a change in the way food tastes [E]                    |                                                                           |
| Defecation/Change in digestion                                           |                                                                           |
| Have you been constipated? [A]                                           |                                                                           |
| Have you had diarrhea? [A]                                               |                                                                           |
| I have trouble with my bowels [E]                                       |                                                                           |
| During the past week, how often did you experience a change in bowel habits? [P] |                                                                           |
| I do not have control of my bowels [U]                                  |                                                                           |
| Financial difficulties                                                  |                                                                           |
| Has your physical condition or medical treatment caused you financial difficulties? [A] |                                                                           |
| The cost of my treatment is a burden on me or my family [E]             |                                                                           |
| Have you enough money to meet your needs? [N]                           |                                                                           |
| Question                                                                 | Answer |
|-------------------------------------------------------------------------|--------|
| How satisfied are you with the conditions of your living place?         |        |
| How satisfied are you with your transport?                              |        |
| During the past week, how often were you concerned that your MDS caused a financial burden for you or your family? |        |

**Relationship with friends/relatives/partner**

- Has your physical condition or medical treatment interfered with your social activities? [A]
  - I feel close to my friends [B] [E] [H]
  - I get support from my friends [B] [E] [H]
- Social activity [C]
  - My present condition interferes too much with my life [D]
  - I feel distant from other people [E]
- Your relations with other relatives? [J]
  - Your relations with friends? [J]
  - Hardship on the closest? [K]
  - Disruptive to the closest? [K]
- Willing to spend time with friends? [L]
  - How satisfied are you with your personal relationships? [N]
  - How satisfied are you with the support you get from your friends? [N]
- Satisfaction with social role [O]
  - During the past week, how often did you have difficulty explaining MDS to your friends or family? [P]
  - I am going out less to visit people [U]
  - I am not going out to visit people at all [U]
  - I show less interest in other people's problems, for example, don't listen when they tell me about their problems, don't offer to help [U]
  - I am doing fewer social activities with groups of people [U]
  - I am cutting down the length of visits with friends [U]
  - I am avoiding social visits from others [U]
  - I talk less with those around me [U]
- Has your physical condition or medical treatment interfered with your family life? [A]
  - Because of my physical condition, I have trouble meeting the needs of my family [B] [E] [H]
- Social wellbeing [B] [E] [H]
  - I get emotional support from my family [B] [E] [H]
  - My family has accepted my illness [B] [E] [H]
  - I am satisfied with family communication about my illness [B] [E] [H]
  - I feel close to my partner (or the person who is my main support) [B] [E] [H]
  - I feel that I am a burden for my family [D]
  - My illness is a personal hardship for my close family members [E]
  - Your relations with your wife or husband (boyfriend or girlfriend)? [J]
  - Willing to spend time with family? [L]
  - During the past week, how often did you feel your family relationships were strained by your disease? [P]
  - During the past week, how often did you worry about becoming a burden to your friends or family? [P]
  - I act disagreeable to family members, for example I act spiteful I am stubborn [U]
  - I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them [U]
  - I isolate myself as much as I can from the rest of the family [U]
  - I am paying less attention to the children [U]
  - I refuse contact with family members, for example, turn away from them [U]
  - I am not doing the things I usually do to take care of my children or family [U]
  - I am not joking with family members as I usually do [U]
  - I make many demands, for example, insist that people do things for me, tell them how to do things [U]
- Sexuality/Sexual activity [B] [E] [H]
  - I am satisfied with my sex life [B] [E] [H]
  - I am interested in sex [B] [E]
  - In the last week, was sexual arousal a problem for you? [D]
  - The effect on your sex life? [D]
During the past month, how much of the time have you felt loved and wanted? [I]
How much of the time, during the past month, did you feel that your love relationships, loving and being loved were full and complete? [I]
Your ability to attain sexual satisfaction? [I]
How satisfied are you with your sex life? [N]
During the past week, how often were you afraid to have sex due to your blood counts? [P]
My sexual activity is decreased [U]

| Hospital dependence | Being dependent on the hospital, doctors and/or nurses [O] |
|---------------------|----------------------------------------------------------|
| Confidence in health care services | I have confidence in my nurse(s) [I]
Confident of treatment? [I]
How satisfied are you with your access to health services? [N] |
| Disease knowledge | How available to you is the information that you need in your day-to-day life? [N]
I feel adequately informed about my loved one’s illness [P]
During the past week, how often did you feel as though there was a lack of clear information about your disease? [P]
During the past week, how often did you feel you were able to find quality information about MDS treatments? [P]
During the past week, how often did you feel as though there were a lack of concrete answers about what will happen with your MDS? [P] |
| General health | How would you rate your overall health during the past week? [A]
I feel ill [B] [E] [H]
General health [C] [T]
Compared to one year ago, how would you rate your health in general now? [C]
My health is excellent [C]
I expect my health to get worse [C]
I am as healthy as anybody I know [C]
I seem to get sick a little easier than other people [C]
In general, you would say that your health is? [D]
Compared to a month ago, your health is? [D]
We would like to know how good or bad your health is today [G]
Your health? [I]
Feel well? [L]
How satisfied are you with your health? [N]
How healthy is your physical environment? [N] |
| General quality of life | How would you rate your overall quality of life during the past week? [A]
I am content with the quality of my life right now [B] [K] [M]
How happy, satisfied, or pleased have you been with your personal life during the past month? [I]
Quality of life linear scale from 0 to 100 [P]
How satisfied you feel with your life as a whole? [I]
Patients were asked to make a set of paired comparisons between living in the MDS health state for five years, or in perfect health for a shorter period of time [Q]
The quality of your life? [U]
How would you rate your quality of life? [O] |

A – EORTC QLQC30; B – Fact-An; C – SF-36; D – Qol-E; E – Fact-BMT; F – VAS; G – EQ-5D; H – Fact-G; I – Mental health inventory; J – Satisfaction with Life Domains Scale for Cancer; K– FACIT Fatigue Scale; L – Functional Living Index-Cancer; M – Profile of Health-Related Quality of Life in Chronic Disorders; N – WHO Quality of Life-BREF; O – Patient reported outcomes measurement information system; P – QUALMS; Q – Time trade-off; R – 6D-Short Form Survey; S – Health Utilities Index; T – SF-12; U – Sickness impact profile;
Supplemental Survey 1. First round survey among hematologists

MDS-RIGHT SURVEY

Providing the right care to the right patient with MyeloDysplastic Syndrome at the right time
Establishment of a Core Set of Patient-Reported Outcomes (PROs) for MDS

Welcome to the MDS online survey. Please complete the following questionnaire and proceed to the next section, which provides a more detailed description of the project.

*Required
Mark only one square.

General information from the participant:

1. Choose your work/practice country
   - □ Austria
   - □ Croatia
   - □ Czech Republic
   - □ Denmark
   - □ United Kingdom
   - □ France
   - □ Germany
   - □ Greece
   - □ Israel
   - □ Switzerland
   - □ Italy
   - □ Netherlands
   - □ Poland
   - □ Portugal
   - □ Romania
   - □ Serbia
   - □ Spain
   - □ Sweden

2. Gender*
   - □ Male
   - □ Female

3. Age* ___________

4. Specialty*
   - □ Geriatric Medicine
   - □ Hematology & Oncology
   - □ Internal Medicine
   - □ Hematology
   - □ Oncology
   - □ Others __________

5. Work experience*
   - □ <5 years
   - □ 5-10 years
   - □ >10 years

6. Experience with MDS patients*
   - □ <5 years
   - □ 5-10 years
   - □ >10 years
MDS-RIGHT project: Providing the right care to the right patient with MyeloDysplastic Syndrome at the right time

The aim of our study is to identify and select the most relevant patient-reported outcomes (PROs), which will be included in the MDS-specific core outcomes set (COS).

The COMET (Core Outcome Measures in Effectiveness Trials) initiative defined a COS as follows: “A core outcome set (COS) is an agreed minimum set of outcomes that should be measured and reported in all clinical trials, audits of practice or other forms of research for a specific condition”.1

In addition, the patient-reported outcomes (PROs) are referred as: "Any report coming directly from patients about a health condition and its treatment".2

In the following section, we present 40 potential PROs based on our previously performed MDS systematic literature search. For each outcome, please provide the following grading:

Rate, on a scale from 1-9, the general importance of including the PRO in the COS for MDS patients:
1-3 Low importance for decision-making
4-6 Important, but not critical for decision-making
7-9 Critical for decision-making

The survey will be used to identify and select important and critical PROs among the MDS experts and a group of MDS patients.

Many thanks for your contribution,
Reinhard Stauder (Leader, WP3)
Theo de Witte (Coordinator, EUMDS and MDS-RIGHT & Leader, ELN WP8)

Additional information: Technical support:
https://mds-europe.eu/right mdsonlinesurvey@gmail.com
http://www.comet-initiative.org/

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Please fill out the ratings for all outcomes. A general/non-MDS specific outcome interpretation has been provided for several of the outcomes.

Scale 1-9:
1-3 Low importance for decision-making
4-6 Important, but not critical for decision-making
7-9 Critical for decision-making

**Shortness of breath**
Inclusion of the outcome into the core PROs: *

Mark only one number

|                  | 1         | 2         | 3         | 4         | 5         | 6         | 7         | 8         | 9         |
|------------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| Low importance   |           |           |           |           |           |           |           |           |           |
| for decision-    | 1         | 2         | 3         | 4         | 5         | 6         | 7         | 8         | 9         |
| making           | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  |

**Weakness**
General definition: Weakness refers to a decrease in muscle strength.³
Inclusion of the outcome into the core PROs: *

Mark only one number

|                  | 1         | 2         | 3         | 4         | 5         | 6         | 7         | 8         | 9         |
|------------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| Low importance   |           |           |           |           |           |           |           |           |           |
| for decision-    | 1         | 2         | 3         | 4         | 5         | 6         | 7         | 8         | 9         |
| making           | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  |

**Need to rest**
Inclusion of the outcome into the core PROs: *

Mark only one number

|                  | 1         | 2         | 3         | 4         | 5         | 6         | 7         | 8         | 9         |
|------------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| Low importance   |           |           |           |           |           |           |           |           |           |
| for decision-    | 1         | 2         | 3         | 4         | 5         | 6         | 7         | 8         | 9         |
| making           | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  |

**Fatigue**
General definition: Fatigue is tiredness that may be either independent of, or associated with exertion.³
Inclusion of the outcome into the core PROs: *

Mark only one number

|                  | 1         | 2         | 3         | 4         | 5         | 6         | 7         | 8         | 9         |
|------------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| Low importance   |           |           |           |           |           |           |           |           |           |
| for decision-    | 1         | 2         | 3         | 4         | 5         | 6         | 7         | 8         | 9         |
| making           | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  | Critical  |
**Sleep disturbance**

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Emotional wellbeing**

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Depression**

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Fear of MDS progression or transformation to leukemia**

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Body image**

General definition: Person's perceptions, thoughts, and feelings about his or her body.

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |
**Loss of Independence**

General definition: Decline in function or mobility, increased care-needs at home, or discharge to a non-home destination.⁵

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Critical for decision-making |

**Physical activity**

General definition: Physical activity is defined as any bodily movement produced by skeletal muscles that result in energy expenditure (e.g., household or occupational activities, doing sports, moderate walks etc.).⁶

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Critical for decision-making |

**Ability to work/Activities of daily living**

General definition: Having the health, the basic standard competence and the relevant occupational virtues required for managing the work tasks along with the activities of the daily living, which are routine activities that people tend do every day without needing assistance (e.g., dressing, bathing/showering, functional mobility, self-feeding or toilet hygiene).⁷,⁸

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Critical for decision-making |

**Basic mobility**

General definition: The ability of getting in and out of bed, sitting down and standing up from a chair or taking a short walk outside of the house.⁹

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Critical for decision-making |
Memory difficulties/Cognition

General definition: Cognition is a superior cortical function involving multiple brain processes that allows an individual to perceive information, learn and remember specific knowledge and use them for problem solving and plan actions in the challenges of daily life. Inclusion of the outcome into the core PROs: *

Mark only one number

Low importance for decision-making

1 2 3 4 5 6 7 8 9

Critical for decision-making

Speaking difficulties/Speech-language problems

General definition: Speech-language disorders refer to impairment in the articulation of speech sounds, fluency, and voice as well as language disorders which refer to impairments in the use of the spoken (or signed or written) system and may involve the form of language (grammar and phonology), the content of language, and the function of language. Inclusion of the outcome into the core PROs: *

Mark only one number

Low importance for decision-making

1 2 3 4 5 6 7 8 9

Critical for decision-making

Transfusion-dependency burden

Inclusion of the outcome into the core PROs: *

Mark only one number

Low importance for decision-making

1 2 3 4 5 6 7 8 9

Critical for decision-making

Medication use

Inclusion of the outcome into the core PROs: *

Mark only one number

Low importance for decision-making

1 2 3 4 5 6 7 8 9

Critical for decision-making

Fear of side effects of treatment

Inclusion of the outcome into the core PROs: *

Mark only one number

Low importance for decision-making

1 2 3 4 5 6 7 8 9

Critical for decision-making
Pain
Inclusion of the outcome into the core PROs: *  
Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

Headache
Inclusion of the outcome into the core PROs: *  
Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

Colds/Infection
Inclusion of the outcome into the core PROs: *  
Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

Urinary incontinence
Inclusion of the outcome into the core PROs: *  
Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

Hearing problems
Inclusion of the outcome into the core PROs: *  
Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

Eye problems
Inclusion of the outcome into the core PROs: *  
Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |
**Impatience**

Inclusion of the outcome into the core PROs: *

*Mark only one number*

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Tremor**

Inclusion of the outcome into the core PROs: *

*Mark only one number*

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Skin problems**

Inclusion of the outcome into the core PROs: *

*Mark only one number*

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Loss of appetite**

Inclusion of the outcome into the core PROs: *

*Mark only one number*

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Loss of weight**

Inclusion of the outcome into the core PROs: *

*Mark only one number*

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Vomiting/Nausea**

Inclusion of the outcome into the core PROs: *

*Mark only one number*

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |
**Change in sense of taste**

General definition: Oral dysgeusia is defined as a gustatory disturbance relating to a distorted taste perception, or to a persistent taste sensation in the absence of stimulation.\(^{12}\)

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Defecation/Change in digestion**

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Financial difficulties**

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Relationship with friends/relatives/partner**

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

**Sexuality/Sexual activity**

General definition: Sexuality exhibits different dimensions such as lust, reproduction, and relationship that are indeed closely interrelated.\(^{13}\)

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |
### Hospital dependence

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

### Confidence in health care services

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

### Disease knowledge

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

### General health

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |

### General quality of life

Inclusion of the outcome into the core PROs: *

Mark only one number

| Low importance for decision-making | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-----------------------------------|---|---|---|---|---|---|---|---|---|
| Critical for decision-making      |   |   |   |   |   |   |   |   |   |
Thank you for taking the time to fill out this survey! 😊

Filling out and handing in the survey indicates that:

• you have read and understood the above mentioned project description and instructions
• you voluntarily agree to participate
• you are at least 18 years of age
• you fill and submit the survey only once
• you agree that the information you provided is stored, analyzed and may be used for publication

If you do not wish to participate in the survey, feel free to decline your participation.
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MDS-RIGHT SURVEY

Providing the right care to the right patient with

MyeloDysplastic Syndrome at the right time
Dear Patient,

Thank you for agreeing to complete this survey as part of the MDS-RIGHT project – “Providing the right care to the right patient with MyeloDysplastic Syndrome (MDS) at the right time”. This multinational collaboration between clinical experts and patients from 17 different countries, intends to improve the health-care of MDS patients by emphasizing the importance of the quality of life and its improvement. Your opinions are therefore very valuable.

The aim of the survey is to gain the views of MDS patients regarding the most important outcomes that should be used in the future evaluation of MDS. Therefore, in the next section, according to your opinion, you will have the opportunity to rate the 40 pre-identified outcomes on a scale from 1 to 9:

1-3 Low importance
4-6 Important, but not critical
7-9 Highly important

The questionnaire is completely anonymous and it shouldn’t take you more than 15 minutes to complete it. For rating of each item a scale (1-9) is mentioned and for some outcomes we provide additional explanations. Although not obligatory, we would appreciate if you answer all the questions. The results from this first round will help us to prepare the second round of this selection process and afterwards to identify the most essential outcomes from the patients’ perspective.

We would be grateful if you complete this survey.
General information from the participant

1. Country

2. Gender
   □ Male  □ Female

3. Age

4. Education level
   □ Primary school or lower vocational education
   □ Lower secondary education or intermediate vocational education
   □ Higher secondary education, vocational education, or university
   □ Other

5. Marital status
   □ Single  □ Married  □ Divorced  □ Widowed

6. Living with partner/family
   □ Yes  □ No

7. Work status
   □ Employed  □ Unemployed  □ Retired  □ Other

8. Current therapy
   □ Supportive (blood transfusions, antibiotics, iron chelators, growth factors)
   □ Disease-modifying (lenalidomide - revlimid®, azacitidine - vidaza®,
     decitabine - dacogen®, anti-thymocyte globulin, cyclosporine)
   □ Hematopoietic stem cell transplantation
   □ No therapy

9. Months after diagnosis
How important do you think it is that these topics are included in the health evaluation of patients diagnosed with myelodysplastic syndromes?

Scale 1-9:
1-3 Low importance
4-6 Important, but not critical
7-9 Highly important

Shortness of breath
Decrease in your general strength.

Weakness

Need to rest

Fatigue
Feeling of tiredness.

Sleep disturbances
**Emotional wellbeing**

Low importance 1 2 3 4 5 6 7 8 9 Highly important

**Depression**

Low importance 1 2 3 4 5 6 7 8 9 Highly important

**Fear of MDS progression or transformation to leukemia**

Feeling stressed or worried because of your disease getting worse in the future.

Low importance 1 2 3 4 5 6 7 8 9 Highly important

**Body image**

The appearance of your body.

Low importance 1 2 3 4 5 6 7 8 9 Highly important

**Loss of independence**

The need for help with eating, dressing, transferring, washing yourself or using the toilet.

Low importance 1 2 3 4 5 6 7 8 9 Highly important

**Physical activity**

Being able to do moderate activities, such as moving a chair, pushing a vacuum cleaner, carrying a shopping bag.

Low importance 1 2 3 4 5 6 7 8 9 Highly important
**Ability to work/Activities of daily living**
Being able to pursue your work and/or your hobbies, regular daily work in and around the house or other leisure time activities.

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Basic mobility**
For example, having trouble taking a short walk outside of the house?

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Memory difficulties/Cognition**
The ability to remember, concentrate and actively participate in reasoning and solving problems.

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Speaking difficulties/Speech-language problems**
Interfering with the ability to be understood completely/partially when speaking with strangers or people who know you well.

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Transfusion-dependency burden**
Being dependent upon the need for blood transfusions.

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Medication use**
### Fear of side effects of treatment

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |

### Pain

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |

### Headache

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |

### Colds/Infection

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |

### Urinary incontinence

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |

### Hearing problems

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |

### Eye problems

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |

### Impatience

Feeling anxious, tense, restless, fidgety or nervous.

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
**Tremor**
Involuntary shaking of the muscles or small body movements.

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Skin problems**

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Loss of appetite**

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Loss of weight**

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Vomiting/Nausea**

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Change in sense of taste.**

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|

**Defecation/Change in digestion**
Experiencing changes in the bowel habits.

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|------------------|
### Financial difficulties

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|-----------------|

### Relationship with friends/relatives/partner

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|-----------------|

### Sexuality/Sexual activity

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|-----------------|

### Hospital dependence

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|-----------------|

### Confidence in health care services

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|-----------------|

### Disease knowledge

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|-----------------|

### General health

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|-----------------|

### General quality of life

| Low importance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Highly important |
|----------------|---|---|---|---|---|---|---|---|---|-----------------|
**Additional outcomes that matter to you and should be measured?**

**Comments/suggestions?**

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**Thank you for taking the time to fill out this survey! 😊**

For additional questions please contact igor.stojkov@umit.at

Filling out and handing in the survey indicates that:
- you have read and understood the above mentioned project description and instructions
- you voluntarily agree to participate
- you are at least 18 years of age
- you agree that the information you provided is stored, analyzed and may be used for publication

If you do not wish to participate in the survey, feel free to decline your participation.