

Real-world study of the burden of myelodysplastic syndromes in patients and their caregivers in Europe and the United States

Katie Lewis¹, Mellissa Williamson², Elliott Brown¹, Emily Trenholm¹, Cosmina Hoge²

¹Adelphi Real World, Adelphi Group, Bollington, UK; ²Gilead Sciences, Inc., Foster City, California, USA

Corresponding author: Katie Lewis

Adelphi Real World, Bollington, UK

katie.lewis@adelphigroup.com

SUPPLEMENTARY MATERIAL

Table S1. Demographic characteristics of physicians treating patients with MDS and source of referrals (>10%)

	Overall n=264	France n=48	Germany n=49	Italy n=50	Spain n=52	UK n=33	US n=32
Specialty							
Hematologist-Oncologist	139 (53%)	16 (33%)	47 (96%)	17 (34%)	7 (13%)	22 (67%)	30 (94%)
Hematologist	123 (47%)	32 (67%)	2 (4%)	33 (66%)	45 (87%)	11 (33%)	0 (0%)
Oncologist	2 (1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (6%)
Referral patterns*							
Low-risk patients							
	Overall n=100	France n=20	Germany n=15	Italy n=20	Spain n=21	UK n=11	US n=13
Cardiologist	26 (26%)	5 (25%)	3 (20%)	7 (35%)	8 (38%)	1 (9%)	2 (15%)
Hematologist	25 (25%)	7 (35%)	1 (7%)	5 (25%)	7 (33%)	3 (27%)	2 (15%)
Hematologist -Oncologist	23 (23%)	5 (25%)	5 (33%)	4 (20%)	1 (5%)	4 (36%)	4 (31%)
GP/PCP	22 (22%)	7 (35%)	2 (13%)	7 (35%)	2 (10%)	2 (18%)	2 (15%)
Stem cell transplant specialist	21 (21%)	7 (35%)	5 (33%)	2 (10%)	2 (10%)	2 (18%)	3 (23%)
Nephrologist	14 (14%)	0 (0%)	3 (20%)	3 (15%)	7 (33%)	0 (0%)	1 (8%)
Gastroenterologist	9 (9%)	0 (0%)	4 (27%)	2 (10%)	2 (10%)	1 (9%)	0 (0%)
Geneticist	8 (8%)	2 (10%)	0 (0%)	0 (0%)	2 (10%)	1 (9%)	3 (23%)
Oncologist	8 (8%)	3 (15%)	2 (13%)	0 (0%)	0 (0%)	0 (0%)	3 (23%)
Pulmonologist	7 (7%)	1 (5%)	4 (27%)	1 (5%)	1 (5%)	0 (0%)	0 (0%)
ER physician	6 (6%)	2 (10%)	0 (0%)	0 (0%)	0 (0%)	1 (9%)	3 (23%)
Urgent care physician	6 (6%)	1 (5%)	0 (0%)	0 (0%)	1 (5%)	1 (9%)	3 (23%)
High-risk patients							
	Overall n=177	France n=36	Germany n=36	Italy n=26	Spain n=37	UK n=24	US n=18
Stem cell transplant specialist	114 (64%)	25 (69%)	20 (56%)	19 (73%)	24 (65%)	15 (63%)	11 (61%)
Cardiologist	41 (23%)	9 (25%)	7 (19%)	11 (42%)	9 (24%)	3 (13%)	2 (11%)
Hematologist	40 (23%)	11 (31%)	4 (11%)	6 (23%)	13 (35%)	4 (17%)	2 (11%)
Hematologist -Oncologist	40 (23%)	5 (14%)	15 (42%)	5 (19%)	4 (11%)	5 (21%)	6 (33%)
Nephrologist	17 (10%)	0 (0%)	3 (8%)	3 (12%)	8 (22%)	2 (8%)	1 (6%)
Geneticist	15 (8%)	3 (8%)	2 (6%)	0 (0%)	4 (11%)	2 (8%)	4 (22%)
Pulmonologist	12 (7%)	2 (6%)	5 (14%)	1 (4%)	3 (8%)	0 (0%)	1 (6%)
Oncologist	11 (6%)	3 (8%)	3 (8%)	0 (0%)	1 (3%)	0 (0%)	4 (22%)
Gastroenterologist	11 (6%)	0 (0%)	6 (17%)	2 (8%)	2 (5%)	1 (4%)	0 (0%)
GP/PCP	11 (6%)	6 (17%)	0 (0%)	1 (4%)	0 (0%)	2 (8%)	2 (11%)
ER physician	8 (5%)	1 (3%)	0 (0%)	3 (12%)	1 (3%)	1 (4%)	2 (11%)
Urgent care physician	5 (3%)	1 (3%)	0 (0%)	0 (0%)	1 (3%)	1 (4%)	2 (11%)

*Physicians were asked which healthcare professionals they most frequently referred their lower-risk and higher-risk MDS patients to (Physician survey data), responses are only included if the physician referred some of their MDS patients.

Table S2. Demographic characteristics of patients with MDS (physician-reported data)

	Overall			France			Germany			Italy			Spain			UK			US		
	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS
Age (years)																					
Base	n=1444	n=731	n=713	n=228	n=118	n=110	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
Mean (SD)	72.8 (9.1)	73.2 (9.6)	72.4 (8.5)	76.6 (7.7)	77.9 (7.5)	75.2 (7.7)	70.1 (9.7)	68.9 (11.6)	71.3 (7.0)	72.1 (8.2)	72.4 (8.2)	71.8 (8.2)	74.8 (9.1)	73.4 (8.8)	73.8 (9.3)	74.8 (7.4)	73.8 (6.8)	72 (7.7)	69.1 (10.4)	69.1 (10.1)	69.2 (10.8)
Median	74.0	74.0	74.0	77.0	78.0	76.0	71.0	71.0	71.0	74.0	74.0	74.0	76.0	77.0	75.0	75.0	76.0	74.0	71.0	71.0	71.5
Sex																					
Base	n=1444	n=731	n=713	n=228	n=118	n=110	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
Male	849 (59%)	422 (58%)	427 (60%)	143 (63%)	72 (61%)	71 (65%)	190 (66%)	93 (64%)	97 (67%)	165 (55%)	79 (53%)	86 (57%)	167 (56%)	78 (52%)	89 (61%)	95 (52%)	53 (58%)	42 (47%)	89 (60%)	47 (62%)	42 (58%)
Female	594 (41%)	308 (42%)	286 (40%)	85 (37%)	46 (39%)	39 (35%)	100 (34%)	53 (36%)	47 (33%)	135 (45%)	71 (47%)	64 (43%)	130 (44%)	72 (48%)	58 (39%)	86 (48%)	38 (42%)	48 (53%)	58 (39%)	28 (37%)	30 (42%)
Intersex	1 (<1%)	1 (<1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1%)	1 (1%)	0 (0%)
Ethnicity - (unable to collect ethnicity data in France)																					
Base	n=1216	n=613	n=603	n=0	n=0	n=0	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
White	1131 (93%)	570 (93%)	561 (93%)	0 (0%)	0 (0%)	0 (0%)	285 (98%)	144 (99%)	141 (98%)	300 (100%)	150 (100%)	150 (100%)	289 (97%)	148 (99%)	141 (96%)	162 (90%)	84 (92%)	78 (87%)	95 (64%)	44 (58%)	51 (71%)
Black	62 (5%)	35 (6%)	27 (4%)	0 (0%)	0 (0%)	0 (0%)	1 (<1%)	1 (1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	5 (2%)	2 (1%)	3 (2%)	14 (8%)	5 (5%)	9 (10%)	42 (28%)	27 (36%)	15 (21%)
Other*	24 (2%)	9 (1%)	15 (2%)	0 (0%)	0 (0%)	0 (0%)	4 (1%)	1 (1%)	3 (2%)	0 (0%)	0 (0%)	0 (0%)	4 (1%)	1 (1%)	3 (2%)	5 (3%)	2 (2%)	3 (3%)	11 (7%)	5 (7%)	6 (8%)
BMI																					
Base	n=1445	n=731	n=714	n=229	n=118	n=111	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
Mean (SD)	25.8 (13.0)	25.6 (8.0)	25.9 (16.7)	25.1 (12.3)	24.8 (3.4)	25.5 (17.4)	27.2 (26.2)	26.1 (16.4)	28.4 (33.4)	25.0 (3.0)	25.0 (2.9)	25.1 (3.0)	25.4 (3.4)	25.4 (3.2)	25.4 (3.6)	25.4 (3.5)	25.9 (4.1)	25.0 (2.8)	26.4 (4.3)	27.2 (4.9)	25.5 (3.2)
Median	24.8	24.8	24.6	23.9	24.4	23.5	24.2	24.2	24.5	25.0	25.2	25.0	24.8	24.8	24.9	24.7	24.8	24.4	25.7	26.0	25.3
Employment																					
Base	n=1444	n=731	n=713	n=228	n=118	n=110	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
Not working due to retirement	1097 (76%)	558 (76%)	539 (76%)	209 (92%)	110 (93%)	99 (90%)	248 (86%)	125 (86%)	123 (85%)	219 (73%)	108 (72%)	111 (74%)	217 (73%)	108 (72%)	109 (74%)	139 (77%)	73 (80%)	66 (73%)	65 (44%)	34 (45%)	31 (43%)
Working full time	88 (6%)	46 (6%)	42 (6%)	4 (2%)	1 (1%)	3 (3%)	8 (3%)	3 (2%)	5 (3%)	30 (10%)	15 (10%)	15 (10%)	14 (5%)	9 (6%)	5 (3%)	10 (6%)	5 (5%)	5 (6%)	22 (15%)	13 (17%)	9 (12%)
Working part time	49 (3%)	23 (3%)	26 (4%)	2 (1%)	2 (2%)	0 (0%)	4 (1%)	2 (1%)	2 (1%)	9 (3%)	6 (4%)	3 (2%)	8 (3%)	2 (1%)	6 (4%)	14 (8%)	7 (8%)	7 (8%)	12 (8%)	4 (5%)	8 (11%)
Unemployed	46 (3%)	25 (3%)	21 (3%)	4 (2%)	2 (2%)	2 (2%)	3 (1%)	2 (1%)	1 (1%)	6 (2%)	3 (2%)	3 (2%)	14 (5%)	7 (5%)	7 (5%)	2 (1%)	0 (0%)	2 (2%)	17 (11%)	11 (14%)	6 (8%)
On long term sick leave	32 (2%)	6 (1%)	26 (4%)	3 (1%)	0 (0%)	3 (3%)	7 (2%)	3 (2%)	4 (3%)	4 (1%)	1 (1%)	3 (2%)	12 (4%)	1 (1%)	11 (7%)	3 (2%)	0 (0%)	3 (3%)	3 (2%)	1 (1%)	2 (3%)
Homemaker	96 (7%)	54 (7%)	42 (6%)	1 (<1%)	1 (1%)	0 (0%)	16 (6%)	7 (5%)	9 (6%)	31 (10%)	16 (11%)	15 (10%)	31 (10%)	22 (15%)	9 (6%)	10 (6%)	4 (4%)	6 (7%)	7 (5%)	4 (5%)	3 (4%)
Student	6 (<1%)	5 (1%)	1 (<1%)	0 (0%)	0 (0%)	0 (0%)	4 (1%)	4 (3%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (1%)	1 (1%)	1 (1%)
Not known	30 (2%)	14 (2%)	16 (2%)	5 (2%)	2 (2%)	3 (3%)	0 (0%)	0 (0%)	0 (0%)	1 (<1%)	1 (1%)	0 (0%)	1 (<1%)	1 (1%)	0 (0%)	3 (2%)	2 (2%)	1 (1%)	20 (14%)	8 (11%)	12 (17%)
Physician reported caregiver relationship																					
	n=846	n=416	n=430	n=124	n=60	n=64	n=189	n=91	n=98	n=192	n=92	n=100	n=189	n=95	n=94	n=85	n=40	n=45	n=67	n=38	n=29
Partner/spouse	638 (75%)	304 (73%)	334 (78%)	92 (74%)	41 (68%)	51 (80%)	179 (95%)	83 (91%)	96 (98%)	116 (60%)	53 (58%)	63 (63%)	121 (64%)	62 (65%)	59 (63%)	76 (89%)	34 (85%)	42 (93%)	54 (81%)	31 (82%)	23 (79%)
Child over 18 years	246 (29%)	116 (28%)	130 (30%)	32 (26%)	18 (30%)	14 (22%)	25 (13%)	13 (14%)	12 (12%)	101 (53%)	48 (52%)	53 (53%)	68 (36%)	30 (32%)	38 (40%)	11 (13%)	4 (10%)	7 (16%)	9 (13%)	3 (8%)	6 (21%)
Professional caregiver(s)	61 (7%)	28 (7%)	33 (8%)	31 (25%)	12 (20%)	19 (30%)	1 (1%)	1 (1%)	0 (0%)	3 (2%)	1 (1%)	2 (2%)	16 (8%)	7 (7%)	9 (10%)	6 (7%)	5 (12%)	1 (2%)	4 (6%)	2 (5%)	2 (7%)
Other relative(s)	39 (5%)	18 (4%)	21 (5%)	7 (6%)	3 (5%)	4 (6%)	1 (1%)	1 (1%)	0 (0%)	14 (7%)	4 (4%)	10 (10%)	11 (6%)	5 (5%)	6 (6%)	3 (4%)	3 (8%)	0 (0%)	3 (4%)	2 (5%)	1 (3%)
Child under 18 years	25 (3%)	17 (4%)	8 (2%)	0 (0%)	0 (0%)	0 (0%)	2 (1%)	0 (0%)	2 (2%)	10 (5%)	6 (7%)	4 (4%)	13 (7%)	11 (12%)	2 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Other non-professional caregiver(s)	24 (3%)	15 (4%)	9 (2%)	8 (6%)	3 (5%)	5 (8%)	1 (1%)	0 (0%)	1 (1%)	5 (3%)	4 (4%)	1 (1%)	10 (5%)	8 (8%)	2 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Friend(s)/neighbor(s)	15 (2%)	8 (2%)	7 (2%)	4 (3%)	1 (2%)	3 (5%)	0 (0%)	0 (0%)	0 (0%)	5 (3%)	3 (3%)	2 (2%)	3 (2%)	2 (2%)	1 (1%)	0 (0%)	0 (0%)	0 (0%)	3 (4%)	2 (5%)	1 (3%)
Parent/guardian	12 (1%)	9 (2%)	3 (1%)	0 (0%)	0 (0%)	0 (0%)	2 (1%)	2 (2%)	0 (0%)	4 (2%)	2 (2%)	2 (2%)	2 (1%)	1 (1%)	1 (1%)	1 (1%)	1 (2%)	0 (0%)	3 (4%)	3 (8%)	0 (0%)

*Other ethnicity included: East or Southeast Asian, South Asian (Indian subcontinent), Middle Eastern or North African, South or Central American Native, American Indian, Indigenous American, or Alaska Native and other.

Table S3. Demographic characteristics of caregivers matched with patients with MDS (physician-reported data)

	Overall			France			Germany			Italy			Spain			UK			US		
	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS
Age (years)																					
Base	n=106	n=57	n=49	n=6	n=3	n=3	n=61	n=31	n=30	n=8	n=6	n=2	n=21	n=12	n=9	n=10	n=5	n=5	n=0	n=0	n=0
Mean (SD)	65.1 (9.7)	64.2 (10.8)	66.2 (8.2)	61.5 (15.0)	57.3 (21.4)	65.7 (7.5)	66.5 (6.2)	66.8 (5.5)	66.2 (7.0)	60.9 (10.4)	56.5 (7.3)	74 (5.7)	62.7 (13.6)	62.8 (15.3)	62.7 (11.9)	67.3 (12.4)	64.6 (16.9)	70 (6.6)	0 (0)	0 (0)	0 (0)
Median	67.5	67.0	68.0	66.0	66.0	66.0	68.0	68.0	67.5	56.5	55.5	74.0	63.0	65.5	63.0	69.0	70.0	68.0	0	0	0
Employment status																					
Base	n=107	n=57	n=50	n=6	n=3	n=3	n=62	n=31	n=31	n=8	n=6	n=2	n=21	n=12	n=9	n=10	n=5	n=5	n=0	n=0	n=0
Working full time	15 (14%)	10 (18%)	5 (10%)	1 (17%)	1 (33%)	0 (0%)	4 (6%)	2 (6%)	2 (6%)	4 (50%)	4 (67%)	0 (0%)	5 (24%)	2 (17%)	3 (33%)	1 (10%)	1 (20%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Working part time	6 (6%)	4 (7%)	2 (4%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)	0 (0%)	1 (3%)	1 (12%)	1 (17%)	0 (0%)	4 (19%)	3 (25%)	1 (11%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Homemaker	6 (6%)	2 (4%)	4 (8%)	1 (17%)	0 (0%)	1 (33%)	1 (2%)	1 (3%)	0 (0%)	2 (25%)	1 (17%)	1 (50%)	2 (10%)	0 (0%)	2 (22%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Retired	80 (75%)	41 (72%)	39 (78%)	4 (67%)	2 (67%)	2 (67%)	56 (90%)	28 (90%)	28 (90%)	1 (12%)	0 (0%)	1 (50%)	10 (48%)	7 (58%)	3 (33%)	9 (90%)	4 (80%)	5 (100%)	0 (0%)	0 (0%)	0 (0%)
Habitation																					
Base	n=107	n=57	n=50	n=6	n=3	n=3	n=62	n=31	n=31	n=8	n=6	n=2	n=21	n=12	n=9	n=10	n=5	n=5	n=0	n=0	n=0
Living with patients	91 (85%)	45 (79%)	46 (92%)	5 (83%)	2 (67%)	3 (100%)	58 (94%)	29 (94%)	29 (94%)	5 (62%)	3 (50%)	2 (100%)	15 (71%)	8 (67%)	7 (78%)	8 (80%)	3 (60%)	5 (100%)	0 (0%)	0 (0%)	0 (0%)
Relationship																					
Base	n=107	n=57	n=50	n=6	n=3	n=3	n=62	n=31	n=31	n=8	n=6	n=2	n=21	n=12	n=9	n=10	n=5	n=5	n=0	n=0	n=0
Partner / spouse	89 (83%)	45 (79%)	44 (88%)	5 (83%)	2 (67%)	3 (100%)	59 (95%)	30 (97%)	29 (94%)	5 (62%)	3 (50%)	2 (100%)	11 (52%)	6 (50%)	5 (56%)	9 (90%)	4 (80%)	5 (100%)	0 (0%)	0 (0%)	0 (0%)
Mother / father	3 (3%)	3 (5%)	0 (0%)	1 (17%)	1 (33%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (5%)	1 (8%)	0 (0%)	1 (10%)	1 (20%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Friend / neighbour	1 (1%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (5%)	1 (8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Daughter / son	13 (12%)	7 (12%)	6 (12%)	0 (0%)	0 (0%)	0 (0%)	3 (5%)	1 (3%)	2 (6%)	3 (38%)	3 (50%)	0 (0%)	7 (33%)	3 (25%)	4 (44%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Other	1 (1%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (5%)	1 (8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
ZBI 22																					
Base	n=107	n=57	n=50	n=6	n=3	n=3	n=62	n=31	n=31	n=8	n=6	n=2	n=21	n=12	n=9	n=10	n=5	n=5	n=0	n=0	n=0
Mean (SD)	25.4 (11.1)	24.5 (11.4)	26.4 (10.8)	42.8 (6.7)	46.3 (2.1)	39.3 (8.5)	20.7 (3.9)	20.2 (3.4)	21.3 (4.4)	23.2 (12.1)	17.7 (3.8)	40 (14.1)	30.2 (15.8)	27.6 (16.4)	33.8 (15.2)	35.6 (11.3)	39.2 (10.28)	32 (12.3)	0 (0)	0 (0)	0 (0)
Median	22.0	21.0	23.5	45.5	47.0	39.0	20.0	19.0	20.0	20.0	19.0	40.0	29.0	27.0	34.0	34.0	36.0	32.0	0	0	0

Table S4. Clinical characteristics of patients with MDS (physician-reported data)

	Overall			France			Germany			Italy			Spain			UK			US		
	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS
Diagnosis																					
Base	n=1445	n=731	n=714	n=229	n=118	n=111	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
Primary/de novo MDS	1331 (92%)	708 (97%)	623 (87%)	216 (94%)	118 (100%)	98 (88%)	264 (91%)	141 (97%)	123 (85%)	274 (91%)	145 (97%)	129 (86%)	265 (89%)	143 (95%)	122 (83%)	176 (97%)	90 (99%)	86 (96%)	136 (92%)	71 (93%)	65 (90%)
Secondary MDS	114 (8%)	23 (3%)	91 (13%)	13 (6%)	0 (0%)	13 (12%)	26 (9%)	5 (3%)	21 (15%)	26 (9%)	5 (3%)	21 (14%)	32 (11%)	7 (5%)	25 (17%)	5 (3%)	1 (1%)	4 (4%)	12 (8%)	5 (7%)	7 (10%)
IPSS-R score at time of data collection																					
Base	n=1445	n=731	n=714	n=229	n=118	n=111	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
Very low	109 (8%)	109 (15%)	0 (0%)	15 (7%)	15 (13%)	0 (0%)	27 (9%)	27 (18%)	0 (0%)	25 (8%)	25 (17%)	0 (0%)	16 (5%)	16 (11%)	0 (0%)	11 (6%)	11 (12%)	0 (0%)	15 (10%)	15 (20%)	0 (0%)
Low	622 (43%)	622 (85%)	0 (0%)	103 (45%)	103 (87%)	0 (0%)	119 (41%)	119 (82%)	0 (0%)	125 (42%)	125 (83%)	0 (0%)	134 (45%)	134 (89%)	0 (0%)	80 (44%)	80 (88%)	0 (0%)	61 (41%)	61 (80%)	0 (0%)
Intermediate	116 (8%)	0 (0%)	116 (16%)	11 (5%)	0 (0%)	11 (10%)	50 (17%)	0 (0%)	50 (35%)	29 (10%)	0 (0%)	29 (19%)	17 (6%)	0 (0%)	17 (12%)	3 (2%)	0 (0%)	3 (3%)	6 (4%)	0 (0%)	6 (8%)
HR-MDS	492 (34%)	0 (0%)	492 (69%)	86 (38%)	0 (0%)	86 (77%)	82 (28%)	0 (0%)	82 (57%)	98 (33%)	0 (0%)	98 (65%)	107 (36%)	0 (0%)	107 (73%)	66 (36%)	0 (0%)	66 (73%)	53 (36%)	0 (0%)	53 (74%)
Very high	106 (7%)	0 (0%)	106 (15%)	14 (6%)	0 (0%)	14 (13%)	12 (4%)	0 (0%)	12 (8%)	23 (8%)	0 (0%)	23 (15%)	23 (8%)	0 (0%)	23 (16%)	21 (12%)	0 (0%)	21 (23%)	13 (9%)	0 (0%)	13 (18%)
WHO classification of MDS																					
Base	n=1445	n=731	n=714	n=229	n=118	n=111	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
Single lineage dysplasia	293 (20%)	273 (37%)	20 (3%)	40 (17%)	36 (31%)	4 (4%)	72 (25%)	64 (44%)	8 (6%)	64 (21%)	61 (41%)	3 (2%)	51 (17%)	48 (32%)	3 (2%)	33 (18%)	33 (36%)	0 (0%)	33 (22%)	31 (41%)	2 (3%)
Multilineage dysplasia	288 (20%)	154 (21%)	134 (19%)	56 (24%)	30 (25%)	26 (23%)	52 (18%)	17 (12%)	35 (24%)	47 (16%)	31 (21%)	16 (11%)	57 (19%)	37 (25%)	20 (14%)	50 (28%)	27 (30%)	23 (26%)	26 (18%)	12 (16%)	14 (19%)
Excess blasts-2	232 (16%)	3 (<1%)	229 (32%)	43 (19%)	0 (0%)	43 (39%)	21 (7%)	1 (1%)	20 (14%)	70 (23%)	0 (0%)	70 (47%)	42 (14%)	0 (0%)	42 (29%)	45 (25%)	2 (2%)	43 (48%)	11 (7%)	0 (0%)	11 (15%)
Excess blasts-1	222 (15%)	23 (3%)	199 (28%)	36 (16%)	7 (6%)	29 (26%)	31 (11%)	2 (1%)	29 (20%)	57 (19%)	8 (5%)	49 (33%)	63 (21%)	1 (1%)	62 (42%)	18 (10%)	2 (2%)	16 (18%)	17 (11%)	3 (4%)	14 (19%)
Ring sideroblasts single lineage dysplasia	156 (11%)	127 (17%)	29 (4%)	22 (10%)	19 (16%)	3 (3%)	45 (16%)	35 (24%)	10 (7%)	27 (9%)	24 (16%)	3 (2%)	20 (7%)	16 (11%)	4 (3%)	17 (9%)	15 (16%)	2 (2%)	25 (17%)	18 (24%)	7 (10%)
Ring sideroblasts multilineage dysplasia	115 (8%)	57 (8%)	58 (8%)	13 (6%)	12 (10%)	1 (1%)	33 (11%)	6 (4%)	27 (19%)	10 (3%)	7 (5%)	3 (2%)	28 (9%)	22 (15%)	6 (4%)	11 (6%)	7 (8%)	4 (4%)	20 (14%)	3 (4%)	17 (24%)
Isolated del(5q)	67 (5%)	55 (8%)	12 (2%)	7 (3%)	7 (6%)	0 (0%)	14 (5%)	9 (6%)	5 (3%)	14 (5%)	14 (9%)	0 (0%)	25 (8%)	21 (14%)	4 (3%)	3 (2%)	2 (2%)	1 (1%)	4 (3%)	2 (3%)	2 (3%)
Unclassifiable	46 (3%)	25 (3%)	21 (3%)	5 (2%)	3 (3%)	2 (2%)	8 (3%)	5 (3%)	3 (2%)	9 (3%)	4 (3%)	5 (3%)	8 (3%)	3 (2%)	5 (3%)	4 (2%)	3 (3%)	1 (1%)	12 (8%)	7 (9%)	5 (7%)
Unknown	26 (2%)	14 (2%)	12 (2%)	7 (3%)	4 (3%)	3 (3%)	14 (5%)	7 (5%)	7 (5%)	2 (1%)	1 (1%)	1 (1%)	3 (1%)	2 (1%)	1 (1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Diagnosis of LR-MDS (days)																					
Base	n=690	n=690	n=0	n=111	n=111	n=0	n=143	n=143	n=0	n=144	n=144	n=0	n=144	n=144	n=0	n=82	n=82	n=0	n=66	n=66	n=0
Mean (SD)	694 (803)	670 (765)	0 (0)	957 (1101)	891 (1000)	0 (0)	432 (334)	432 (336)	0 (0)	769 (706)	770 (714)	0 (0)	929 (1012)	897 (1008)	0 (0)	496 (536)	463 (425)	0 (0)	358 (447)	358 (451)	0 (0)
Median	426.5	407.0	0	574.0	567.0	0	320.5	319.0	0	575.0	571.5	0	620.0	607.0	0	366.0	366.0	0	163.0	158.5	0
Diagnosis of HR-MDS (days)																					
Base	n=662	n=0	n=662	n=106	n=0	n=106	n=141	n=0	n=141	n=137	n=0	n=137	n=138	n=0	n=138	n=81	n=0	n=81	n=59	n=0	n=59
Mean (SD)	325 (413)	0 (0)	325 (413)	375 (410)	0 (0)	375 (410)	391 (442)	0 (0)	391 (442)	252 (236)	0 (0)	252 (236)	214 (305)	0 (0)	214 (305)	325 (413)	0 (0)	325 (413)	375 (410)	0 (0)	375 (410)
Median	225.5	0	225.5	220.5	0	220.5	252.0	0	252.0	272.0	0	272.0	220.5	0	220.5	183.0	0	183.0	103.0	0	103.0
ECOG score* at time of data collection																					
Base	n=1445	n=731	n=714	n=229	n=118	n=111	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
0	252 (17%)	156 (21%)	96 (13%)	25 (11%)	14 (12%)	11 (10%)	22 (8%)	13 (9%)	9 (6%)	92 (31%)	57 (38%)	35 (23%)	50 (17%)	35 (23%)	15 (10%)	33 (18%)	18 (20%)	15 (17%)	30 (20%)	19 (25%)	11 (15%)
1	721 (50%)	374 (51%)	347 (49%)	110 (48%)	61 (52%)	49 (44%)	149 (51%)	86 (59%)	63 (44%)	118 (39%)	57 (38%)	61 (41%)	170 (57%)	81 (54%)	89 (61%)	94 (52%)	46 (51%)	48 (53%)	80 (54%)	43 (57%)	37 (51%)
2	402 (28%)	179 (24%)	223 (31%)	81 (35%)	38 (32%)	43 (39%)	103 (36%)	44 (30%)	59 (41%)	79 (26%)	31 (21%)	48 (32%)	55 (19%)	26 (17%)	29 (20%)	51 (28%)	27 (30%)	24 (27%)	33 (22%)	13 (17%)	20 (28%)
3	68 (5%)	22 (3%)	46 (6%)	13 (6%)	5 (4%)	8 (7%)	16 (6%)	3 (2%)	13 (9%)	11 (4%)	5 (3%)	6 (4%)	21 (7%)	8 (5%)	13 (9%)	2 (1%)	0 (0%)	2 (2%)	5 (3%)	1 (1%)	4 (6%)
4	2 (<1%)	0 (0%)	2 (<1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (<1%)	0 (0%)	1 (1%)	1 (1%)	0 (0%)	1 (1%)	0 (0%)	0 (0%)	0 (0%)

*ECOG score, 0, Fully active, able to carry on all pre-disease performance without restriction; 1 Restricted in physically strenuous activity but ambulatory and able to carry out light work; 2 Ambulatory and capable of all self-care but unable to carry out work activities. Up and about more than 50% of waking fours; 3 Capable of only limited self-care, confined to bed or chair more than 50% of waking hours; 4 Completely disabled. Cannot carry out any self-care. Confined to bed or chair.

Table S5. Treatment for patients with MDS (physician-reported data)

	Overall			France			Germany			Italy			Spain			UK			US		
	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS
Supportive treatments receiving at time of data collection																					
Base*	n=1445	n=731	n=714	n=229	n=118	n=111	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
Erythropoietins ^a	756 (52%)	440 (60%)	316 (44%)	133 (58%)	81 (69%)	52 (47%)	121 (42%)	65 (45%)	56 (39%)	181 (60%)	101 (67%)	80 (53%)	171 (58%)	101 (67%)	70 (48%)	88 (49%)	54 (59%)	34 (38%)	62 (42%)	38 (50%)	24 (33%)
Iron chelation agents ^b	271 (19%)	135 (18%)	136 (19%)	32 (14%)	20 (17%)	12 (11%)	93 (32%)	40 (27%)	53 (37%)	53 (18%)	28 (19%)	25 (17%)	61 (21%)	31 (21%)	30 (20%)	17 (9%)	9 (10%)	8 (9%)	15 (10%)	7 (9%)	8 (11%)
White blood cell growth factors ^c	123 (9%)	41 (6%)	82 (11%)	15 (7%)	8 (7%)	7 (6%)	7 (2%)	2 (1%)	5 (3%)	19 (6%)	3 (2%)	16 (11%)	50 (17%)	18 (12%)	32 (22%)	19 (10%)	5 (5%)	14 (16%)	13 (9%)	5 (7%)	8 (11%)
Antibiotic treatments	121 (8%)	30 (4%)	91 (13%)	16 (7%)	3 (3%)	13 (12%)	29 (10%)	9 (6%)	20 (14%)	26 (9%)	5 (3%)	21 (14%)	19 (6%)	6 (4%)	13 (9%)	27 (15%)	6 (7%)	21 (23%)	4 (3%)	1 (1%)	3 (4%)
Luspatercept	104 (7%)	70 (10%)	34 (5%)	11 (5%)	7 (6%)	4 (4%)	23 (8%)	14 (10%)	9 (6%)	23 (8%)	21 (14%)	2 (1%)	21 (7%)	14 (9%)	7 (5%)	1 (1%)	1 (1%)	0 (0%)	25 (17%)	13 (17%)	12 (17%)
Platelet growth factors ^d	51 (4%)	14 (2%)	37 (5%)	8 (3%)	1 (1%)	7 (6%)	22 (8%)	8 (5%)	14 (10%)	3 (1%)	1 (1%)	2 (1%)	8 (3%)	1 (1%)	7 (5%)	3 (2%)	1 (1%)	2 (2%)	7 (5%)	2 (3%)	5 (7%)
Vitamins	40 (3%)	28 (4%)	12 (2%)	5 (2%)	3 (3%)	2 (2%)	1 (<1%)	1 (1%)	0 (0%)	16 (5%)	11 (7%)	5 (3%)	16 (5%)	11 (7%)	5 (3%)	0 (0%)	0 (0%)	0 (0%)	2 (1%)	2 (3%)	0 (0%)
Antithymocyte globulin (ATG) +/- cyclosporine	15 (1%)	5 (1%)	10 (1%)	3 (1%)	1 (1%)	2 (2%)	3 (1%)	1 (1%)	2 (1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	9 (6%)	3 (4%)	6 (8%)
Other	32 (2%)	6 (1%)	26 (4%)	12 (5%)	3 (3%)	9 (8%)	7 (2%)	1 (1%)	6 (4%)	2 (1%)	1 (1%)	1 (1%)	6 (2%)	1 (1%)	5 (3%)	3 (2%)	0 (0%)	3 (3%)	2 (1%)	0 (0%)	2 (3%)
None	369 (26%)	154 (21%)	215 (30%)	58 (25%)	19 (16%)	39 (35%)	76 (26%)	41 (28%)	35 (24%)	59 (20%)	18 (12%)	41 (27%)	75 (25%)	31 (21%)	44 (30%)	59 (33%)	28 (31%)	31 (34%)	42 (28%)	17 (22%)	25 (35%)
Anti-AML treatment*																					
Base	n=1445	n=731	n=714	n=229	n=118	n=111	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
Ever received	641 (44%)	143 (20%)	498 (70%)	91 (40%)	16 (14%)	75 (68%)	108 (37%)	33 (23%)	75 (52%)	148 (49%)	23 (15%)	125 (83%)	160 (54%)	37 (25%)	123 (84%)	77 (43%)	17 (19%)	60 (67%)	57 (39%)	17 (22%)	40 (56%)
Lines of anti-AML treatment received																					
Base	n=641	n=143	n=498	n=91	n=16	n=75	n=108	n=33	n=75	n=148	n=23	n=125	n=160	n=37	n=123	n=77	n=17	n=60	n=57	n=17	n=40
Mean (SD)	1.1 (0.3)	1.1 (0.4)	1.1 (0.3)	1.1 (0.3)	1.1 (0.3)	1.1 (0.3)	1.1 (0.4)	1.0 (0.2)	1.1 (0.4)	1.0 (0.2)	1.1 (0.3)	1.0 (0.1)	1.0 (0.2)	1.1 (0.4)	1.0 (0.2)	1.1 (0.3)	1.1 (0.2)	1.1 (0.3)	1.2 (0.6)	1.3 (1.0)	1.2 (0.4)
Median	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Min	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Max	5	5	4	3	2	3	4	2	4	2	2	2	3	3	2	3	2	3	5	5	2

^aerythropoietin, epoetin alfa, epoetin beta, epoetin zeta, darbepoetin alfa

^bdeferoxamine, deferasirox, deferiprone

^cfilgrastim, sargramostim, pegfilgrastim

^dromiplostim, eltrombopag, avatrombopag, lusutrombopag

^echemotherapy, hypomethylating agent, immunotherapy, or targeted therapy

Table S6. Transfusion history with involvement of patients and caregivers (physician-reported data)

	Overall			France			Germany			Italy			Spain			UK			US		
	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS
Number received																					
Base	n=1445	n=731	n=714	n=229	n=118	n=111	n=290	n=146	n=144	n=300	n=150	n=150	n=297	n=150	n=147	n=181	n=91	n=90	n=148	n=76	n=72
0	246 (17%)	160 (22%)	86 (12%)	38 (17%)	28 (24%)	10 (9%)	40 (14%)	28 (19%)	12 (8%)	64 (21%)	35 (23%)	29 (19%)	60 (20%)	42 (28%)	18 (12%)	14 (8%)	10 (11%)	4 (4%)	30 (20%)	17 (22%)	13 (18%)
1	274 (19%)	146 (20%)	128 (18%)	34 (15%)	15 (13%)	19 (17%)	63 (22%)	35 (24%)	28 (19%)	71 (24%)	36 (24%)	35 (23%)	39 (13%)	17 (11%)	22 (15%)	19 (10%)	14 (15%)	5 (6%)	48 (32%)	29 (38%)	19 (26%)
2	318 (22%)	164 (22%)	154 (22%)	49 (21%)	23 (19%)	26 (23%)	52 (18%)	28 (19%)	24 (17%)	66 (22%)	36 (24%)	30 (20%)	54 (18%)	29 (19%)	25 (17%)	55 (30%)	27 (30%)	28 (31%)	42 (28%)	21 (28%)	21 (29%)
3+	607 (42%)	261 (36%)	346 (48%)	108 (47%)	52 (44%)	56 (50%)	135 (47%)	55 (38%)	80 (56%)	99 (33%)	43 (29%)	56 (37%)	144 (48%)	62 (41%)	82 (56%)	93 (51%)	40 (44%)	53 (59%)	28 (19%)	9 (12%)	19 (26%)
Transfusions received in the past 12 months*																					
Base	n=1075	n=532	n=543	n=178	n=86	n=92	n=236	n=111	n=125	n=193	n=103	n=90	n=226	n=105	n=121	n=143	n=76	n=67	n=99	n=51	n=48
Mean (SD)	4.1 (5.8)	3.7 (5.3)	4.5 (6.3)	4.7 (5.8)	5 (6.2)	4.5 (5.5)	4.7 (7.2)	4.3 (6.2)	5.0 (8.0)	4 (5.9)	3.3 (5.4)	4.7 (6.3)	4.9 (6.3)	4.4 (5.4)	5.3 (7.0)	3.2 (3.0)	2.7 (2.7)	3.6 (3.2)	1.9 (1.8)	1.6 (1.7)	2.3 (1.8)
Median	2.0	2.0	2.0	2.0	2.0	2.0	2.0	2.0	3.0	2.0	1.0	2.0	3.0	2.0	3.0	2.0	2.0	3.0	2.0	1.0	2.0
Patient involvement in their transfusion schedule from the physician's perspective																					
Base	n=233	n=107	n=126	n=29	n=16	n=13	n=76	n=34	n=42	n=33	n=13	n=20	n=46	n=26	n=20	n=30	n=14	n=16	n=19	n=4	n=15
Not at all	55 (24%)	20 (19%)	35 (28%)	13 (45%)	5 (31%)	8 (62%)	29 (38%)	8 (24%)	21 (50%)	0 (0%)	0 (0%)	0 (0%)	10 (22%)	6 (23%)	4 (20%)	1 (3%)	1 (7%)	0 (0%)	2 (11%)	0 (0%)	2 (13%)
A little	25 (11%)	10 (9%)	15 (12%)	0 (0%)	0 (0%)	0 (0%)	7 (9%)	2 (6%)	5 (12%)	6 (18%)	3 (23%)	3 (15%)	5 (11%)	3 (12%)	2 (10%)	3 (10%)	2 (14%)	1 (6%)	4 (21%)	0 (0%)	4 (27%)
Somewhat	36 (15%)	17 (16%)	19 (15%)	8 (28%)	6 (38%)	2 (15%)	8 (11%)	3 (9%)	5 (12%)	8 (24%)	3 (23%)	5 (25%)	7 (15%)	2 (8%)	5 (25%)	2 (7%)	2 (14%)	0 (0%)	3 (16%)	1 (25%)	2 (13%)
Moderate	49 (21%)	27 (25%)	22 (17%)	2 (7%)	2 (12%)	0 (0%)	7 (9%)	6 (18%)	1 (2%)	14 (42%)	5 (38%)	9 (45%)	18 (39%)	11 (42%)	7 (35%)	4 (13%)	2 (14%)	2 (12%)	4 (21%)	1 (25%)	3 (20%)
Very	64 (27%)	31 (29%)	33 (26%)	5 (17%)	3 (19%)	2 (15%)	24 (32%)	15 (44%)	9 (21%)	5 (15%)	2 (15%)	3 (15%)	6 (13%)	4 (15%)	2 (10%)	18 (60%)	5 (36%)	13 (81%)	6 (32%)	2 (50%)	4 (27%)
Not known	4 (2%)	2 (2%)	2 (2%)	1 (3%)	0 (0%)	1 (8%)	1 (1%)	0 (0%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (7%)	2 (14%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Caregiver involvement in the transfusion schedule from the physician's perspective																					
Base	n=233	n=107	n=126	n=29	n=16	n=13	n=76	n=34	n=42	n=33	n=13	n=20	n=46	n=26	n=20	n=30	n=14	n=16	n=19	n=4	n=15
Not at all	88 (38%)	37 (35%)	51 (40%)	16 (55%)	8 (50%)	8 (62%)	47 (62%)	18 (53%)	29 (69%)	4 (12%)	1 (8%)	3 (15%)	18 (39%)	9 (35%)	9 (45%)	2 (7%)	1 (7%)	1 (6%)	1 (5%)	0 (0%)	1 (7%)
A little	20 (9%)	10 (9%)	10 (8%)	2 (7%)	1 (6%)	1 (8%)	7 (9%)	4 (12%)	3 (7%)	2 (6%)	0 (0%)	2 (10%)	4 (9%)	3 (12%)	1 (5%)	3 (10%)	2 (14%)	1 (6%)	2 (11%)	0 (0%)	2 (13%)
Somewhat	33 (14%)	14 (13%)	19 (15%)	4 (14%)	3 (19%)	1 (8%)	6 (8%)	2 (6%)	4 (10%)	9 (27%)	4 (31%)	5 (25%)	7 (15%)	2 (8%)	5 (25%)	3 (10%)	3 (21%)	0 (0%)	4 (21%)	0 (0%)	4 (27%)
Moderate	34 (15%)	19 (18%)	15 (12%)	2 (7%)	2 (12%)	0 (0%)	7 (9%)	5 (15%)	2 (5%)	10 (30%)	4 (31%)	6 (30%)	10 (22%)	7 (27%)	3 (15%)	2 (7%)	0 (0%)	2 (12%)	3 (16%)	1 (25%)	2 (13%)
Very	47 (20%)	19 (18%)	28 (22%)	3 (10%)	1 (6%)	2 (15%)	7 (9%)	4 (12%)	3 (7%)	6 (18%)	2 (15%)	4 (20%)	6 (13%)	4 (15%)	2 (10%)	17 (57%)	5 (36%)	12 (75%)	8 (42%)	3 (75%)	5 (33%)
Not known	11 (5%)	8 (7%)	3 (2%)	2 (7%)	1 (6%)	1 (8%)	2 (3%)	1 (3%)	1 (2%)	2 (6%)	2 (15%)	0 (0%)	1 (2%)	1 (4%)	0 (0%)	3 (10%)	3 (21%)	0 (0%)	1 (5%)	0 (0%)	1 (7%)

*This includes patients diagnosed within 12 months.

Table S7. Concordance of symptoms of MDS between patient and physician, and their impact

	Base			France			Germany			Italy			Spain			UK		
	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS
Patient-reported symptoms at time of data collection (reported by >10% of patients)																		
Base	n=324	n=170	n=154	n=26	n=13	n=13	n=178	n=87	n=91	n=32	n=23	n=9	n=76	n=41	n=35	n=12	n=6	n=6
Anemia	257 (79%)	126 (74%)	131 (85%)	15 (58%)	7 (54%)	8 (62%)	157 (88%)	72 (83%)	85 (93%)	19 (59%)	15 (65%)	4 (44%)	54 (71%)	26 (63%)	28 (80%)	12 (100%)	6 (100%)	6 (100%)
Feeling tired or fatigued	219 (68%)	106 (62%)	113 (73%)	14 (54%)	7 (54%)	7 (54%)	130 (73%)	58 (67%)	72 (79%)	17 (53%)	13 (57%)	4 (44%)	53 (70%)	26 (63%)	27 (77%)	5 (42%)	2 (33%)	3 (50%)
Excessive bruising	98 (30%)	42 (25%)	56 (36%)	3 (12%)	0 (0%)	3 (23%)	83 (47%)	37 (43%)	46 (51%)	2 (6%)	1 (4%)	1 (11%)	9 (12%)	3 (7%)	6 (17%)	1 (8%)	1 (17%)	0 (0%)
Bone pain	89 (27%)	44 (26%)	45 (29%)	2 (8%)	0 (0%)	2 (15%)	59 (33%)	28 (32%)	31 (34%)	6 (19%)	4 (17%)	2 (22%)	22 (29%)	12 (29%)	10 (29%)	0 (0%)	0 (0%)	0 (0%)
Breathing difficulties	88 (27%)	40 (24%)	48 (31%)	8 (31%)	5 (38%)	3 (23%)	60 (34%)	25 (29%)	35 (38%)	6 (19%)	4 (17%)	2 (22%)	14 (18%)	6 (15%)	8 (23%)	0 (0%)	0 (0%)	0 (0%)
Unusually pale skin	81 (25%)	31 (18%)	50 (32%)	7 (27%)	3 (23%)	4 (31%)	59 (33%)	17 (20%)	42 (46%)	5 (16%)	5 (22%)	0 (0%)	10 (13%)	6 (15%)	4 (11%)	0 (0%)	0 (0%)	0 (0%)
Frequent infections	64 (20%)	28 (16%)	36 (23%)	4 (15%)	1 (8%)	3 (23%)	49 (28%)	23 (26%)	26 (29%)	0 (0%)	0 (0%)	0 (0%)	8 (11%)	3 (7%)	5 (14%)	3 (25%)	1 (17%)	2 (33%)
GI side effects)	62 (19%)	25 (15%)	37 (24%)	8 (31%)	3 (23%)	5 (38%)	40 (22%)	13 (15%)	27 (30%)	2 (6%)	1 (4%)	1 (11%)	12 (16%)	8 (20%)	4 (11%)	0 (0%)	0 (0%)	0 (0%)
Bleeding (i.e. nosebleeds or bleeding gums)	55 (17%)	18 (11%)	37 (24%)	3 (12%)	0 (0%)	3 (23%)	47 (26%)	17 (20%)	30 (33%)	0 (0%)	0 (0%)	0 (0%)	5 (7%)	1 (2%)	4 (11%)	0 (0%)	0 (0%)	0 (0%)
Chest pain	51 (16%)	19 (11%)	32 (21%)	3 (12%)	2 (15%)	1 (8%)	39 (22%)	12 (14%)	27 (30%)	2 (6%)	1 (4%)	1 (11%)	5 (7%)	2 (5%)	3 (9%)	2 (17%)	2 (33%)	0 (0%)
Low white blood cell count	50 (15%)	19 (11%)	31 (20%)	3 (12%)	2 (15%)	1 (8%)	28 (16%)	8 (9%)	20 (22%)	4 (12%)	2 (9%)	2 (22%)	14 (18%)	6 (15%)	8 (23%)	1 (8%)	1 (17%)	0 (0%)
Low platelet count	49 (15%)	10 (6%)	39 (25%)	8 (31%)	2 (15%)	6 (46%)	29 (16%)	7 (8%)	22 (24%)	1 (3%)	0 (0%)	1 (11%)	9 (12%)	1 (2%)	8 (23%)	2 (17%)	0 (0%)	2 (33%)
Heart palpitations	48 (15%)	24 (14%)	24 (16%)	4 (15%)	3 (23%)	1 (8%)	28 (16%)	12 (14%)	16 (18%)	6 (19%)	4 (17%)	2 (22%)	8 (11%)	3 (7%)	5 (14%)	2 (17%)	2 (33%)	0 (0%)
Leukopenia	46 (14%)	13 (8%)	33 (21%)	5 (19%)	2 (15%)	3 (23%)	27 (15%)	7 (8%)	20 (22%)	1 (3%)	0 (0%)	1 (11%)	13 (17%)	4 (10%)	9 (26%)	0 (0%)	0 (0%)	0 (0%)
Small red spots on the skin	43 (13%)	15 (9%)	28 (18%)	1 (4%)	0 (0%)	1 (8%)	35 (20%)	12 (14%)	23 (25%)	1 (3%)	0 (0%)	1 (11%)	5 (7%)	3 (7%)	2 (6%)	1 (8%)	0 (0%)	1 (17%)
Swelling of lymph nodes	36 (11%)	15 (9%)	21 (14%)	0 (0%)	0 (0%)	0 (0%)	35 (20%)	15 (17%)	20 (22%)	0 (0%)	0 (0%)	0 (0%)	1 (1%)	0 (0%)	1 (3%)	0 (0%)	0 (0%)	0 (0%)
Top 5 most burdensome symptoms according to patients																		
Base	n=324	n=170	n=154	n=26	n=13	n=13	n=178	n=87	n=91	n=32	n=23	n=9	n=76	n=41	n=35	n=12	n=6	n=6
Feeling tired or fatigued	143 (44%)	69 (41%)	74 (48%)	11 (42%)	5 (38%)	6 (46%)	69 (39%)	31 (36%)	38 (42%)	12 (38%)	9 (39%)	3 (33%)	46 (61%)	22 (54%)	24 (69%)	5 (42%)	2 (33%)	3 (50%)
Anemia	97 (30%)	50 (29%)	47 (31%)	5 (19%)	2 (15%)	3 (23%)	48 (27%)	21 (24%)	27 (30%)	5 (16%)	4 (17%)	1 (11%)	30 (39%)	17 (41%)	13 (37%)	9 (75%)	6 (100%)	3 (50%)
Breathing difficulties	28 (9%)	17 (10%)	11 (7%)	2 (8%)	2 (15%)	0 (0%)	15 (8%)	8 (9%)	7 (8%)	2 (6%)	2 (9%)	0 (0%)	9 (12%)	5 (12%)	4 (11%)	0 (0%)	0 (0%)	0 (0%)
Bone pain	25 (8%)	13 (8%)	12 (8%)	0 (0%)	0 (0%)	0 (0%)	13 (7%)	5 (6%)	8 (9%)	1 (3%)	1 (4%)	0 (0%)	11 (14%)	7 (17%)	4 (11%)	0 (0%)	0 (0%)	0 (0%)
Excessive bruising	18 (6%)	10 (6%)	8 (5%)	0 (0%)	0 (0%)	0 (0%)	13 (7%)	7 (8%)	6 (7%)	0 (0%)	0 (0%)	0 (0%)	4 (5%)	2 (5%)	2 (6%)	1 (8%)	1 (17%)	0 (0%)
Physician reported symptoms at time of data collection (reported for ≥10% of patients)																		
Base	n=324	n=170	n=154	n=26	n=13	n=13	n=178	n=87	n=91	n=32	n=23	n=9	n=76	n=41	n=35	n=12	n=6	n=6
Anemia	231 (71%)	118 (69%)	113 (73%)	18 (69%)	10 (77%)	8 (62%)	132 (74%)	62 (71%)	70 (77%)	22 (69%)	15 (65%)	7 (78%)	48 (63%)	25 (61%)	23 (66%)	11 (92%)	6 (100%)	5 (83%)
Feeling tired or fatigued	181 (56%)	97 (57%)	84 (55%)	12 (46%)	6 (46%)	6 (46%)	107 (60%)	55 (63%)	52 (57%)	11 (34%)	7 (30%)	4 (44%)	45 (59%)	26 (63%)	19 (54%)	6 (50%)	3 (50%)	3 (50%)
Breathing difficulties	55 (17%)	24 (14%)	31 (20%)	2 (8%)	1 (8%)	1 (8%)	44 (25%)	19 (22%)	25 (27%)	0 (0%)	0 (0%)	0 (0%)	7 (9%)	4 (10%)	3 (9%)	2 (17%)	0 (0%)	2 (33%)
Bone pain	48 (15%)	18 (11%)	30 (19%)	0 (0%)	0 (0%)	0 (0%)	33 (19%)	10 (11%)	23 (25%)	1 (3%)	0 (0%)	1 (11%)	14 (18%)	8 (20%)	6 (17%)	0 (0%)	0 (0%)	0 (0%)
Excessive bruising	45 (14%)	21 (12%)	24 (16%)	2 (8%)	0 (0%)	2 (15%)	39 (22%)	21 (24%)	18 (20%)	0 (0%)	0 (0%)	0 (0%)	3 (4%)	0 (0%)	3 (9%)	1 (8%)	0 (0%)	1 (17%)
Unusually pale skin	44 (14%)	22 (13%)	22 (14%)	6 (23%)	3 (23%)	3 (23%)	30 (17%)	13 (15%)	17 (19%)	2 (6%)	2 (9%)	0 (0%)	6 (8%)	4 (10%)	2 (6%)	0 (0%)	0 (0%)	0 (0%)
Thrombocytopenia	42 (13%)	15 (9%)	27 (18%)	7 (27%)	1 (8%)	6 (46%)	19 (11%)	8 (9%)	11 (12%)	7 (22%)	3 (13%)	4 (44%)	8 (11%)	3 (7%)	5 (14%)	1 (8%)	0 (0%)	1 (17%)
Frequent infections	37 (11%)	17 (10%)	20 (13%)	1 (4%)	0 (0%)	1 (8%)	34 (19%)	15 (17%)	19 (21%)	1 (3%)	1 (4%)	0 (0%)	1 (1%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Leukopenia	37 (11%)	16 (9%)	21 (14%)	5 (19%)	1 (8%)	4 (31%)	8 (4%)	4 (5%)	4 (4%)	6 (19%)	3 (13%)	3 (33%)	16 (21%)	8 (20%)	8 (23%)	2 (17%)	0 (0%)	2 (33%)
Neutropenia	32 (10%)	11 (6%)	21 (14%)	8 (31%)	3 (23%)	5 (38%)	6 (3%)	1 (1%)	5 (5%)	3 (9%)	2 (9%)	1 (11%)	13 (17%)	5 (12%)	8 (23%)	2 (17%)	0 (0%)	2 (33%)

Table S8. Caregiver needs by patients with MDS and associated burden

	Overall			France			Germany			Italy			Spain			UK			US		
	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS
Patient reported activities requiring assistance																					
Base	n=737	n=366	n=371	n=116	n=59	n=57	n=143	n=68	n=75	n=185	n=89	n=96	n=172	n=87	n=85	n=69	n=33	n=36	n=52	n=30	n=22
Transportation	441 (60%)	210 (57%)	231 (62%)	63 (54%)	28 (47%)	35 (61%)	96 (67%)	43 (63%)	53 (71%)	143 (77%)	67 (75%)	76 (79%)	84 (49%)	44 (51%)	40 (47%)	29 (42%)	15 (45%)	14 (39%)	26 (50%)	13 (43%)	13 (59%)
Housekeeping	394 (53%)	188 (51%)	206 (56%)	62 (53%)	31 (53%)	31 (54%)	110 (77%)	51 (75%)	59 (79%)	67 (36%)	29 (33%)	38 (40%)	108 (63%)	51 (59%)	57 (67%)	30 (43%)	16 (48%)	14 (39%)	17 (33%)	10 (33%)	7 (32%)
Shopping/ meal preparation:	376 (51%)	182 (50%)	194 (52%)	61 (53%)	30 (51%)	31 (54%)	106 (74%)	50 (74%)	56 (75%)	71 (38%)	33 (37%)	38 (40%)	96 (56%)	44 (51%)	52 (61%)	29 (42%)	14 (42%)	15 (42%)	13 (25%)	11 (37%)	2 (9%)
Managing medications	247 (34%)	128 (35%)	119 (32%)	32 (28%)	19 (32%)	13 (23%)	50 (35%)	25 (37%)	25 (33%)	68 (37%)	32 (36%)	36 (38%)	70 (41%)	35 (40%)	35 (41%)	9 (13%)	6 (18%)	3 (8%)	18 (35%)	11 (37%)	7 (32%)
Managing finances	220 (30%)	113 (31%)	107 (29%)	34 (29%)	24 (41%)	10 (18%)	52 (36%)	25 (37%)	27 (36%)	37 (20%)	21 (24%)	16 (17%)	69 (40%)	30 (34%)	39 (46%)	17 (25%)	8 (24%)	9 (25%)	11 (21%)	5 (17%)	6 (27%)
Personal hygiene	127 (17%)	64 (17%)	63 (17%)	22 (19%)	10 (17%)	12 (21%)	27 (19%)	10 (15%)	17 (23%)	14 (8%)	9 (10%)	5 (5%)	42 (24%)	22 (25%)	20 (24%)	7 (10%)	4 (12%)	3 (8%)	15 (29%)	9 (30%)	6 (27%)
Managing communication	124 (17%)	62 (17%)	62 (17%)	15 (13%)	9 (15%)	6 (11%)	24 (17%)	8 (12%)	16 (21%)	25 (14%)	11 (12%)	14 (15%)	47 (27%)	25 (29%)	22 (26%)	5 (7%)	3 (9%)	2 (6%)	8 (15%)	6 (20%)	2 (9%)
Dressing	105 (14%)	58 (16%)	47 (13%)	11 (9%)	7 (12%)	4 (7%)	19 (13%)	9 (13%)	10 (13%)	11 (6%)	5 (6%)	6 (6%)	38 (22%)	21 (24%)	17 (20%)	12 (17%)	6 (18%)	6 (17%)	14 (27%)	10 (33%)	4 (18%)
Ambulation	100 (14%)	61 (17%)	39 (11%)	18 (16%)	9 (15%)	9 (16%)	2 (1%)	0 (0%)	2 (3%)	18 (10%)	11 (12%)	7 (7%)	34 (20%)	24 (28%)	10 (12%)	11 (16%)	5 (15%)	6 (17%)	17 (33%)	12 (40%)	5 (23%)
Feeding	70 (9%)	39 (11%)	31 (8%)	19 (16%)	10 (17%)	9 (16%)	4 (3%)	1 (1%)	3 (4%)	7 (4%)	3 (3%)	4 (4%)	22 (13%)	16 (18%)	6 (7%)	5 (7%)	1 (3%)	4 (11%)	13 (25%)	8 (27%)	5 (23%)
Toileting	62 (8%)	32 (9%)	30 (8%)	8 (7%)	4 (7%)	4 (7%)	6 (4%)	0 (0%)	6 (8%)	8 (4%)	4 (4%)	4 (4%)	28 (16%)	15 (17%)	13 (15%)	3 (4%)	3 (9%)	0 (0%)	9 (17%)	6 (20%)	3 (14%)
Continence	39 (5%)	26 (7%)	13 (4%)	4 (3%)	3 (5%)	1 (2%)	3 (2%)	0 (0%)	3 (4%)	1 (1%)	0 (0%)	1 (1%)	21 (12%)	13 (15%)	8 (9%)	3 (4%)	3 (9%)	0 (0%)	7 (13%)	7 (23%)	0 (0%)
Other	16 (2%)	11 (3%)	5 (1%)	6 (5%)	4 (7%)	2 (4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	8 (5%)	5 (6%)	3 (4%)	2 (3%)	2 (6%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Caregiver-reported most troublesome activity to caregiver (top 10)																					
Base	n=107	n=57	n=50	n=6	n=3	n=3	n=62	n=31	n=31	n=8	n=6	n=2	n=21	n=12	n=9	n=10	n=5	n=5	n=0	n=0	n=0
Transport to work / hospital/ appointment	27 (25%)	13 (23%)	14 (28%)	5 (83%)	2 (67%)	3 (100%)	11 (18%)	5 (16%)	6 (19%)	2 (25%)	1 (17%)	1 (50%)	8 (38%)	5 (42%)	3 (33%)	1 (10%)	0 (0%)	1 (20%)	0 (0%)	0 (0%)	0 (0%)
Help with preparing meals / cooking food	24 (22%)	16 (28%)	8 (16%)	1 (17%)	1 (33%)	0 (0%)	22 (35%)	14 (45%)	8 (26%)	0 (0%)	0 (0%)	0 (0%)	1 (5%)	1 (8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Remembering / making appointments	20 (19%)	13 (23%)	7 (14%)	1 (17%)	1 (33%)	0 (0%)	15 (24%)	9 (29%)	6 (19%)	1 (12%)	1 (17%)	0 (0%)	2 (10%)	1 (8%)	1 (11%)	1 (10%)	1 (20%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Emotional support / encouragement	17 (16%)	10 (18%)	7 (14%)	2 (33%)	1 (33%)	1 (33%)	8 (13%)	4 (13%)	4 (13%)	2 (25%)	2 (33%)	0 (0%)	4 (19%)	2 (17%)	2 (22%)	1 (10%)	1 (20%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Help getting in and out of bed	13 (12%)	5 (9%)	8 (16%)	0 (0%)	0 (0%)	0 (0%)	11 (18%)	4 (13%)	7 (23%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (20%)	1 (20%)	1 (20%)	0 (0%)	0 (0%)	0 (0%)
Helping with finances/money	13 (12%)	4 (7%)	9 (18%)	2 (33%)	1 (33%)	1 (33%)	7 (11%)	2 (6%)	5 (16%)	2 (25%)	1 (17%)	1 (50%)	1 (5%)	0 (0%)	1 (11%)	1 (10%)	0 (0%)	1 (20%)	0 (0%)	0 (0%)	0 (0%)
Communication with others	11 (10%)	8 (14%)	3 (6%)	0 (0%)	0 (0%)	0 (0%)	9 (15%)	6 (19%)	3 (10%)	1 (12%)	1 (17%)	0 (0%)	1 (5%)	1 (8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Help with shopping	11 (10%)	5 (9%)	6 (12%)	3 (50%)	1 (33%)	2 (67%)	6 (10%)	4 (13%)	2 (6%)	0 (0%)	0 (0%)	0 (0%)	2 (10%)	0 (0%)	2 (22%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Using household appliances	9 (8%)	5 (9%)	4 (8%)	0 (0%)	0 (0%)	0 (0%)	8 (13%)	4 (13%)	4 (13%)	0 (0%)	0 (0%)	0 (0%)	1 (5%)	1 (8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Help in giving treatment	8 (7%)	3 (5%)	5 (10%)	0 (0%)	0 (0%)	0 (0%)	7 (11%)	2 (6%)	5 (16%)	0 (0%)	0 (0%)	0 (0%)	1 (5%)	1 (8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Physician-reported burden of caregiving (hours per week)																					
Partner/spouse	n=283	n=136	n=147	n=34	n=16	n=18	n=108	n=48	n=60	n=42	n=20	n=22	n=53	n=30	n=23	n=29	n=12	n=17	n=17	n=10	n=7
Mean (SD)	28.2 (32.7)	30.6 (35.2)	26.0 (30.1)	15.7 (14.5)	20.5 (16.3)	11.5 (11.5)	21.1 (15.2)	22.0 (14.9)	20.4 (15.5)	40.3 (39.1)	48.6 (49.9)	32.8 (24.5)	50.6 (53.2)	48.0 (51.0)	54.1 (57.0)	11.4 (8.6)	9.3 (5.8)	12.9 (10.0)	26.3 (18.8)	26.3 (20.1)	27.9 (18.3)
Median	20.0	20.0	15.0	7.5	22.0	6.5	15.5	20.0	15.0	27.0	32.5	22.5	30.0	27.5	30.0	10.0	10.0	10.0	24.0	24.0	24.0
Child over 18	n=104	n=55	n=49	n=11	n=8	n=3	n=18	n=9	n=9	n=45	n=24	n=21	n=27	n=13	n=14	n=2	n=1	n=1	n=1	n=0	n=1
Mean (SD)	17.5 (20.7)	14.7 (15.5)	20.7 (25.0)	7.8 (7.5)	7.4 (7.3)	9.0 (9.6)	7.7 (6.4)	8.3 (7.8)	7.1 (4.9)	21.4 (24.5)	16.0 (11.7)	27.6 (32.9)	22.9 (21.2)	22.0 (24.6)	23.8 (18.3)	5.0 (4.2)	2.0 (0.0)	8.0 (0.0)	5.0 (0.0)	0.0 (0.0)	5.0 (0.0)

Median	10.0	10.0	12.0	4.0	3.5	5.0	6.0	6.0	10.0	14.0	10.0	14.0	14.0	10.0	17.0	5.0	2.0	8.0	5.0	0	5.0
All caregivers	n=383	n=192	n=191	n=55	n=27	n=28	n=116	n=54	n=62	n=73	n=37	n=36	n=86	n=46	n=40	n=32	n=15	n=17	n=21	n=13	n=8
Mean (SD)	29.2 (35.1)	29.4 (36.9)	29 (33.2)	14.7 (15.1)	16.9 (18.5)	12.7 (10.8)	21.0 (14.9)	21.0 (14.6)	21.0 (15.4)	40.0 (45.8)	39.5 (49.6)	40.4 (42.3)	47.3 (49.2)	47.0 (50.5)	47.6 (48.3)	11.3 (8.6)	8.9 (5.6)	13.4 (10.3)	28.2 (17.6)	23.6 (18.2)	35.6 (14.6)
Median	20.0	20.0	20.0	8.0	8.0	8.0	15.5	20.0	15.0	20.0	20.0	20.0	25.5	25.0	29.0	10.0	10.0	10.0	24.0	20.0	40.0
Patient-reported burden of caregiving (hours per week)																					
Partner/spouse	n=150	n=74	n=76	n=8	n=4	n=4	n=100	n=45	n=55	n=9	n=7	n=2	n=22	n=13	n=9	n=11	n=5	n=6	n=0	n=0	n=0
Mean (SD)	25.6 (25.1)	25.4 (24.5)	25.8 (25.8)	4.1 (2.2)	3.8 (2.8)	4.5 (1.7)	23.5 (14.8)	23.1 (12.6)	23.9 (16.4)	28.4 (27.0)	24.3 (24.5)	43.0 (41.0)	51.0 (45.8)	47.9 (43.5)	55.3 (51.3)	7.5 (3.0)	7.4 (3.7)	7.6 (2.7)	0 (0)	0 (0)	0 (0)
Median	20.0	20.0	20.0	4.0	3.5	4.0	20.0	20.0	20.0	15.0	15.0	43.0	30.0	30.0	30.0	10.0	10.0	8.0	0	0	0
Child over 18	n=79	n=33	n=46	n=6	n=4	n=2	n=42	n=12	n=30	n=10	n=8	n=2	n=20	n=8	n=12	n=1	n=1	n=0	n=0	n=0	n=0
Mean (SD)	13.8 (15.5)	15.9 (18.5)	12.4 (12.8)	1.5 (1.1)	2.0 (0.8)	0.5 (0.7)	10.3 (4.9)	10.8 (5.8)	10.2 (4.5)	21.3 (21.0)	23.1 (23.4)	14.0 (0.0)	21.8 (23.3)	25.0 (25.1)	19.7 (22.9)	2.0 (0.0)	2.0 (0.0)	0 (0)	0 (0)	0 (0)	0 (0)
Median	10.0	10.0	10.0	1.5	2.0	0.5	10.0	10.0	10.0	14.0	13.5	14.0	14.5	20.0	11.0	2.0	2.0	0	0	0	0
All caregivers	n=186	n=92	n=94	n=12	n=7	n=5	n=106	n=47	n=59	n=13	n=11	n=2	n=43	n=21	n=22	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	28.2 (27.62)	27.7 (28.13)	28.6 (27.25)	4.6 (3.12)	3.6 (2.76)	6 (3.32)	26.7 (17.77)	25 (14.34)	28 (20.11)	37.2 (35.29)	33.2 (35.15)	59 (38.18)	41.6 (41.32)	45.1 (42.57)	38.2 (40.8)	7 (3.31)	6.5 (3.99)	7.6 (2.73)	0 (0)	0 (0)	0 (0)
Median	20.0	20.0	20.0	3.0	2.0	7.0	30.0	30.0	30.0	20.0	20.0	59.0	25.0	30.0	20.0	8.0	7.5	8.0	0	0	0
Caregiver-reported burden of caregiving (hours per week)																					
All caregivers*	n=107	n=57	n=50	n=6	n=3	n=3	n=62	n=31	n=31	n=8	n=6	n=2	n=21	n=12	n=9	n=10	n=5	n=5	n=0	n=0	n=0
Mean (SD)	45.4 (42.9)	42 (47.4)	49.3 (37.2)	18.2 (13.2)	12.0 (7.8)	24.5 (16.0)	35.6 (19.2)	27.0 (14.6)	44.2 (19.6)	74.6 (78.2)	43.5 (62.5)	168.0 (0.0)	85.5 (57.5)	102.3 (60.2)	63.1 (47.9)	14.8 (16.5)	6.2 (4.5)	23.4 (20.1)	0 (0)	0 (0)	0 (0)
Median	35.0	24.0	47.0	16.5	16.0	21.0	32.5	23.0	49.0	32.0	22.0	168.0	68.0	89.0	49.0	10.0	4.0	14.0	0	0	0

*All caregivers includes the participants own time as well as time they perceive other carers assist them.

Table S9. Patient-reported outcomes

	Overall			France			Germany			Italy			Spain			UK			US		
	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS
EQ-5D Current health state overall																					
Base	n=329	n=174	n=155	n=30	n=17	n=13	n=179	n=87	n=92	n=32	n=23	n=9	n=76	n=41	n=35	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	64.8 (15.9)	66.4 (15.9)	63.0 (15.6)	70.9 (14.0)	73.5 (14.2)	67.5 (13.6)	62.3 (15.9)	64.1 (16.1)	60.5 (15.5)	63.1 (15.0)	63.8 (15.2)	61.1 (15.2)	67.5 (16.0)	68.3 (16.3)	66.7 (15.8)	74.9 (13.0)	76.7 (9.8)	73.2 (16.4)	0 (0)	0 (0)	0 (0)
Median	65.0	65.5	65.0	70.0	72.0	70.0	65.0	65.0	60.0	64.0	65.0	60.0	70.0	70.0	70.0	75.5	75.5	74.5	0	0	0
EQ-5D 5L Utility score – German Tariff																					
Base	n=326	n=173	n=153	n=30	n=17	n=13	n=177	n=86	n=91	n=31	n=23	n=8	n=76	n=41	n=35	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	0.84 (0.12)	0.86 (0.12)	0.83 (0.12)	0.91 (0.09)	0.91 (0.1)	0.9 (0.08)	0.83 (0.12)	0.84 (0.12)	0.83 (0.12)	0.85 (0.14)	0.86 (0.16)	0.85 (0.08)	0.85 (0.14)	0.88 (0.1)	0.82 (0.16)	0.8 (0.11)	0.81 (0.11)	0.79 (0.11)	0 (0)	0 (0)	0 (0)
Median	0.86	0.88	0.84	0.92	0.96	0.91	0.84	0.84	0.84	0.89	0.91	0.85	0.88	0.91	0.84	0.82	0.80	0.82	0	0	0
EORTC QLQ-C30																					
Global health status	n=328	n=174	n=154	n=30	n=17	n=13	n=178	n=87	n=91	n=32	n=23	n=9	n=76	n=41	n=35	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	56.3 (16.7)	59.2 (16.8)	52.9 (15.8)	66.4 (17.8)	71.6 (20.2)	59.6 (11.7)	53.5 (13.9)	57.1 (12.9)	50.0 (14.1)	57.3 (17.4)	57.2 (17.1)	57.4 (19.3)	60.9 (19)	63 (19.4)	58.3 (18.5)	41.0 (12.0)	37.5 (11.5)	44.4 (12.6)	0 (0)	0 (0)	0 (0)
Median	50.0	58.3	50.0	66.7	66.7	58.3	50.0	58.3	50.0	58.3	58.3	50.0	66.7	66.7	66.7	41.7	41.7	41.7	0	0	0
Physical functioning	n=325	n=170	n=155	n=29	n=16	n=13	n=178	n=86	n=92	n=32	n=23	n=9	n=74	n=39	n=35	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	70.0 (17.5)	72.1 (16.0)	67.7 (18.8)	80.3 (16.3)	79.8 (16.7)	81.0 (16.5)	67.5 (17.2)	71.2 (14.7)	64.0 (18.7)	72.9 (16.0)	74.5 (15.7)	68.9 (17.0)	72.2 (18.3)	71.8 (18.4)	72.6 (18.5)	62.2 (12.8)	57.8 (8.1)	66.7 (15.78)	0 (0)	0 (0)	0 (0)
Median	73.3	73.3	66.7	86.7	86.7	86.7	66.7	73.3	60.0	80.0	80.0	73.3	73.3	73.3	73.3	60.0	56.7	66.7	0	0	0
Role functioning	n=324	n=172	n=152	n=29	n=16	n=13	n=177	n=87	n=90	n=32	n=23	n=9	n=74	n=40	n=34	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	63.8 (26.98)	67 (25.58)	60.2 (28.13)	77 (23.74)	78.1 (24.88)	75.6 (23.19)	57 (29.28)	60.5 (27.62)	53.5 (30.55)	72.4 (24.54)	75.4 (22.4)	64.8 (29.4)	72.1 (19.53)	73.8 (19.93)	70.1 (19.15)	58.3 (8.7)	52.8 (6.8)	63.9 (6.8)	0 (0)	0 (0)	0 (0)
Median	66.7	66.7	66.7	83.3	83.3	66.7	66.7	66.7	50.0	66.7	66.7	66.7	66.7	66.7	66.7	58.3	50.0	66.7	0	0	0
Emotional functioning	n=325	n=172	n=153	n=30	n=17	n=13	n=175	n=85	n=90	n=32	n=23	n=9	n=76	n=41	n=35	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	72.6 (21.0)	73.8 (20.4)	71.4 (21.6)	80.7 (23.6)	85.1 (20.3)	75.0 (27.0)	71.6 (20.3)	73.4 (19.3)	69.9 (21.2)	69.5 (20.9)	69.2 (20.5)	70.4 (23.2)	74.9 (21.5)	74.7 (21.8)	75.0 (21.6)	61.8 (13.0)	56.9 (9.7)	66.7 (14.9)	0 (0)	0 (0)	0 (0)
Median	75.0	75.0	75.0	90.3	100.0	75.0	75.0	75.0	75.0	70.8	66.7	75.0	75.0	75.0	75.0	58.3	54.2	62.5	0	0	0
Cognitive functioning	n=325	n=172	n=153	n=30	n=17	n=13	n=175	n=85	n=90	n=32	n=23	n=9	n=76	n=41	n=35	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	77.1 (20.2)	78.1 (19.3)	75.9 (21.1)	82.8 (20.3)	81.4 (22.0)	84.6 (18.6)	76.6 (20.9)	77.6 (19.5)	75.6 (22.2)	79.7 (17.8)	80.4 (16.4)	77.8 (22.1)	76.3 (19.7)	78.5 (19.8)	73.8 (19.5)	68.1 (15.1)	63.9 (12.6)	72.2 (17.2)	0 (0)	0 (0)	0 (0)
Median	83.3	83.3	83.3	100.0	100.0	100.0	83.3	83.3	83.3	83.3	83.3	83.3	83.3	83.3	83.3	66.7	66.7	66.7	0	0	0
Social functioning	n=327	n=174	n=153	n=30	n=17	n=13	n=177	n=87	n=90	n=32	n=23	n=9	n=76	n=41	n=35	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	72.5 (22.5)	75.3 (22.6)	69.3 (22.1)	79.4 (20.9)	84.3 (22.4)	73.1 (17.4)	69.5 (22.6)	72.4 (21.7)	66.7 (23.2)	79.2 (20.7)	82.6 (19.1)	70.4 (23.2)	76.3 (23.0)	76.4 (25.0)	76.2 (20.7)	56.9 (11.1)	55.6 (13.6)	58.3 (9.1)	0 (0)	0 (0)	0 (0)
Median	66.7	83.3	66.7	83.3	100.0	66.7	66.7	66.7	66.7	83.3	83.3	66.7	66.7	83.3	66.7	58.3	58.3	58.3	0	0	0
Fatigue	n=324	n=171	n=153	n=29	n=16	n=13	n=176	n=86	n=90	n=32	n=23	n=9	n=75	n=40	n=35	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	39.7 (20.7)	36.5 (20.3)	43.2 (20.7)	37.9 (29.6)	33.3 (29.8)	43.6 (29.6)	40.0 (20.3)	36.5 (19.3)	43.3 (20.9)	39.9 (17.8)	36.2 (17.8)	49.4 (14.8)	37.9 (19.8)	35.3 (20.0)	40.8 (19.6)	50.0 (11.1)	53.7 (13.0)	46.3 (8.4)	0 (0)	0 (0)	0 (0)
Median	22.2	22.2	33.3	11.1	11.1	16.7	22.2	22.2	33.3	25.0	22.2	38.9	22.2	22.2	22.2	44.4	41.7	41.7	0	0	0
WPAI																					
Overall activity impairment	n=320	n=170	n=150	n=28	n=16	n=12	n=178	n=87	n=91	n=32	n=23	n=9	n=70	n=38	n=32	n=12	n=6	n=6	n=0	n=0	n=0
Mean (SD)	43.5 (21.4)	40.3 (22.6)	47.1 (19.4)	36.1 (25.6)	31.2 (27.5)	42.5 (22.2)	45.3 (18.7)	42.0 (19.7)	48.6 (17.2)	37.8 (20.8)	37.0 (21.0)	40.0 (21.2)	45.7 (25.7)	43.9 (27.4)	47.8 (23.8)	35.0 (17.8)	30.0 (16.7)	40.0 (19.0)	0 (0)	0 (0)	0 (0)
Median	40.0	40.0	50.0	35.0	30.0	50.0	40.0	40.0	50.0	40.0	40.0	50.0	50.0	50.0	50.0	30.0	30.0	40.0	0	0	0
HADS																					
Base	n=302	n=166	n=136	n=28	n=16	n=12	n=155	n=81	n=74	n=32	n=23	n=9	n=75	n=40	n=35	n=12	n=6	n=6	n=0	n=0	n=0
Anxiety score, mean (SD)	7.2 (3.6)	7 (3.6)	7.5 (3.6)	4.4 (2.9)	4 (3.2)	4.9 (2.6)	7.2 (3.5)	7 (3.3)	7.3 (3.8)	7.9 (3.2)	7.7 (3.3)	8.6 (2.8)	7.4 (3.8)	7.1 (4.2)	7.8 (3.2)	10.8 (1.5)	10.7 (1.2)	10.8 (1.9)	0 (0)	0 (0)	0 (0)
Median	7.0	6.0	7.0	7.0	9.0	7.0	7.0	8.0	11.0	10.5	11.5	0	0	0	7.0	6.0	7.0	7.0	9.0	7.0	7.0
Depression score, mean (SD)	8.4 (4.1)	7.8 (3.9)	9.1 (4.1)	5.1 (3.6)	4.8 (4.0)	5.6 (3.1)	9.2 (4.1)	8.4 (3.7)	10 (4.5)	7.6 (4.2)	7.5 (4.5)	7.8 (3.6)	7.9 (3.5)	7.4 (3.6)	8.5 (3.4)	10.2 (1.7)	10.7 (1.2)	9.8 (2.0)	0 (0)	0 (0)	0 (0)
Median	9.0	9.0	9.0	4.5	3.5	5.5	9.0	9.0	10.0	8.0	7.0	8.0	9.0	7.5	9.0	10.0	10.5	10.0	0	0	0

EQ-5D VAS, EuroQol 5 dimension visual analog HRQoL questionnaire; SD, standard deviation; EORTC QLQ-C30, European Organization for the Research and Treatment of Cancer, Quality of Life Questionnaire, 30 items; WPAI, Work Productivity and Activity Index; HADS, Hospital Anxiety and Depression Scale

Table S10. Caregiver-reported outcomes

	Overall			France			Germany			Italy			Spain			UK			US		
	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS	Base	LR-MDS	HR-MDS
Health status at time of data collection (EQ-5D-5L VAS)																					
Base	n=100	n=54	n=46	n=6	n=3	n=3	n=62	n=31	n=31	n=7	n=6	n=1	n=21	n=12	n=9	n=4	n=2	n=2	n=0	n=0	n=0
Mean (SD)	61.62 (18.82)	62.93 (19.1)	60.09 (18.58)	81 (8.15)	81 (8.54)	81 (9.64)	49.68 (12.04)	49.52 (12.2)	49.84 (12.08)	81.43 (7.48)	83.33 (6.06)	70 (0)	82.29 (10.11)	80.83 (11.04)	84.22 (8.97)	74.5 (3.32)	75 (0)	74 (5.66)	0 (0)	0 (0)	0 (0)
Median	60.0	65.0	60.0	82.5	80.0	85.0	45.0	50.0	45.0	80.0	82.5	70.0	80.0	80.0	80.0	75.0	75.0	74.0	0.0	0.0	0.0
EQ-5D 5L – German Tariff																					
Base	n=106	n=56	n=50	n=6	n=3	n=3	n=62	n=31	n=31	n=8	n=6	n=2	n=20	n=11	n=9	n=10	n=5	n=5	n=0	n=0	n=0
Mean (SD)	0.86 (0.08)	0.86 (0.09)	0.86 (0.07)	0.84 (0.09)	0.8 (0.1)	0.88 (0.07)	0.82 (0.06)	0.82 (0.08)	0.82 (0.04)	0.94 (0.07)	0.94 (0.06)	0.92 (0.12)	0.96 (0.06)	0.95 (0.07)	0.97 (0.04)	0.87 (0.07)	0.88 (0.1)	0.87 (0.05)	0 (0)	0 (0)	0 (0)
Median	0.84	0.86	0.83	0.86	0.76	0.91	0.83	0.83	0.82	0.95	0.95	0.92	0.97	0.97	0.97	0.87	0.89	0.86	0	0	0

EQ-5D VAS, EuroQol 5 dimension visual analog HRQoL questionnaire; SD, standard deviation