

**Table S1** Comparisons<sup>†</sup> of FROM-16 and GQ scores for gender and for age groups (n=4,413)

Measure	Gender		p-value**	Age ( years)		p-value**
	Male (n=1533) Mean score	Female (n=2858) Mean score		Group1 (n=2190) Mean age	Group 2 (n=2223) Mean age	
Total FROM-16 score	12.92	16.13	0.001	15.53	14.53	0.001
GQ score	2.04	2.46	0.001	2.3	2.33	0.391

<sup>†</sup>Mann Whitney U test;

\*\*p values were calculated using mean rank scores but mean scores are presented here for ease of understanding.

While difference between males and females for FROM1-6 and GQ scores was significant ( $p > 0.001$ ), Cohens effect size was 0.4, overall difference in banding pattern did not vary much from proposed banding, therefore separate banding was not considered based on gender.

Difference between two age group1 and 2 was significant for FROM-16 total score ( $p > 0.001$ ), Cohens effect size was 0.1. Therefore separate banding was not considered.

### The Extreme Value Groups

Considering the data (Table 4) describing the proposed set of bands (0-1, 2-8, 9-16, 17-25, 26-32), altogether 87 family members (1.97%) in bands 0, 1 & 2 whose actual GQ score was two or more points higher than the band would have predicted. (the "high Extreme Value Group (EVG)"). There were 47 family members ( 1.06%) in bands 2, 3 & 4 whose GQ scores were 2 or more points lower than their banding allocation (the "low EVG").

All the patients whose GQ scores were 2 or more points away from the banding allocation (both low and high EVG) were compared to those patients whose GQ scores agreed with the FROM-16 banding (the "Normal Value Group", NVG), by doing a sub-score analysis of the FROM-16 individual questions on the DLQI. The sub-score comparison was done within each FROM-16 band (Table S1). For the EVG with high scores, there was no single FROM-16 question that was consistently related to high GQ scores.

Considering the EVG with high scores in bands 1 and 2, there was a higher proportion of 'maximum sub-scores' (sub-scores of 2; A lot ) in the high EVG compared to the NVG (8.8% vs. 2.7% for band 1; and 25.8% vs. 15.8% for band 2) (Table S3). The opposite was true for EVG with low scores compared to the NVG ( 13% Vs 15.8 for band 2; 36.5% vs 44.2% for band 3; and 73.5 vs 80.9% for band 4) indicating lower proportion of maximum sub-scores (A lot) in low EVG than NVG (Table S3).

**Table S2. The frequency distribution of the sub-scores of each individual FROM-16 question.** Data describes the subjects whose GQ score falls exactly in the proposed band allocation (Normal Value Group, NVG) and the subjects whose GQ score is at least 2 points away from the proposed band allocation (Extreme Value Group, EVG).

FROM-16 Question and Sub-score		FROM-16 bands										
		Band 0 (0-1)		Band 1 (2-8)		Band 2 (9-16)			Band 3 (17-25)		Band 4 (26-32)	
		NVG n=61	high EVG n=3	NVG n=591	high EVG n=35	NVG n=765	high EVG n=49	low EVG n=12	NVG n=693	low EVG n=18	NVG n=364	low EVG n=17
Q1	0	42	2	74	2	17	4	0	3	0	1	0
	1	19	1	464	19	412	19	9	151	3	21	3
	2	0	0	53	14	336	26	3	539	15	342	14
Q2	0	61	3	505	29	356	25	5	148	4	11	1
	1	0	0	81	5	348	16	5	378	13	144	11
	2	0	0	5	1	61	8	2	167	1	209	5
Q3	0	58	3	240	11	75	4	1	15		1	1
	1	3	0	306	13	426	20	8	259	10	29	5
	2	0	0	45	11	264	25	3	419	8	334	11
Q4	0	61	3	299	12	77	8	2	11	1	1	1
	1	0	0	252	17	449	23	5	233	9	40	0
	2	0	0	40	6	239	18	5	449	8	323	16
Q5	0	60	3	467	28	292	24	7	86	2	13	1
	1	1	0	108	5	330	18	2	305	7	85	5
	2	0	0	16	2	143	7	3	304	9	266	11
Q6	0	60	3	450	20	160	9	8	22	0	2	0
	1	1	0	134	14	504	28	3	284	12	27	5
	2	0	0	7	1	101	12	1	387	6	335	12
Q7	0	61	3	533	30	313	16	9	52	3	0	2
	1	0	0	57	3	420	20	3	367	11	37	5
	2	0	0	1	2	32	13	0	274	4	327	10
Q8	0	61	3	557	31	565	32	7	232	12	27	4
	1	0	0	34	4	175	11	5	293	3	74	7
	2	0	0	0	0	25	6	0	168	3	263	6
Q9	0	60	3	482	32	566	38	9	243	5	19	
	1	1	0	103	3	175	9	3	352	10	109	10
	2	0	0	6	0	24	2	0	98	3	236	7
Q10	0	61	3	322	14	106	8	6	12	2	0	0

	1	0	0	261	19	527	23	4	232	11	18	0
	2	0	0	8	2	132	18	2	449	5	346	17
Q11	0	61	3	437	24	239	10	5	47	2	2	0
	1	0	0	144	8	363	15	6	191	5	11	0
	2	0	0	10	3	163	24	1	455	11	251	17
Q12	0	59	3	402	29	385	24	3	194	6	43	0
	1	2	0	144	3	187	9	8	182	2	46	1
	2	0	0	45	3	193	16	1	317	10	275	16
Q13	0	61	3	567	33	511	37	8	243	6	45	0
	1	0	0	24	2	238	10	4	338	11	46	4
	2	0	0	0	0	16	2	0	112	1	273	13
Q14	0	61	3	521	33	369	32	10	128	4	7	0
	1	0	0	68	1	346	16	2	399	8	65	5
	2	0	0	2	1	50	1	1	166	6	292	12
Q15	0	61	3	468	25	345	22	8	121	3	15	0
	1	0	0	109	9	367	19	3	340	10	52	1
	2	0	0	14	1	53	8	2	232	5	297	16
Q16	0	61	3	412	21	204	13	4	37	0	0	0
	1	0	0	173	12	464	20	7	289	8	22	0
	2	0	0	6	2	97	16	1	367	10	342	17
<b>Mean total FROM-16</b>		<b>0.44</b>	<b>0.33</b>	<b>4.60</b>	<b>5.31</b>	<b>10.01</b>	<b>9.76</b>	<b>8.50</b>	<b>13.70</b>	<b>13.22</b>	<b>15.21</b>	<b>15.41</b>

Table S3. Proportion of 'sub-score 2' (A lot) in NVG and EVG

FROM-16 questions and sub-score 2		FROM-16 bands										
		Band 0 (0-1)		Band 1 (2-8)		Band 2 (9-16)			Band 3 (17-25)		Band 4 (26-32)	
		NVG n=61	high EVG n=3	NVG n=591	high EVG n=35	NVG n=765	high EVG n=49	low EVG n=12	NVG n=693	low EVG n=18	NVG n=364	low EVG n=17
Q1	2	0	0	53	14	336	26	3	539	15	342	14
Q2	2	0	0	5	1	61	8	2	167	1	209	5
Q3	2	0	0	45	11	264	25	3	419	8	334	11
Q4	2	0	0	40	6	239	18	5	449	8	323	16
Q5	2	0	0	16	2	143	7	3	304	9	266	11
Q6	2	0	0	7	1	101	12	1	387	6	335	12
Q7	2	0	0	1	2	32	13	0	274	4	327	10
Q8	2	0	0	0	0	25	6	0	168	3	263	6
Q9	2	0	0	6	0	24	2	0	98	3	236	7
Q10	2	0	0	8	2	132	18	2	449	5	346	17
Q11	2	0	0	10	3	163	24	1	455	11	251	17
Q12	2	0	0	45	3	193	16	1	317	10	275	16
Q13	2	0	0	0	0	16	2	0	112	1	273	13
Q14	2	0	0	2	1	50	1	1	166	6	292	12
Q15	2	0	0	14	1	53	8	2	232	5	297	16
Q16	2	0	0	6	2	97	16	1	367	10	342	17
<b>% of A lot</b>		<b>0</b>	<b>0</b>	<b>2.7</b>	<b>8.8</b>	<b>15.8</b>	<b>25.8</b>	<b>13.0</b>	<b>44.2</b>	<b>36.5</b>	<b>80.9</b>	<b>73.5</b>