

Supplementary material

Responsiveness and Minimal Important Change of the Family Reported Outcome Measure (FROM-16)

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Table S1 Independent t-test for differences between male and female genders

	Mean		Mean difference	p-value *
	Male Mean(SD)	Female Mean(SD)		
Family members	(n=37)	(n=46)		
B_FROM	8.32 (6.88)	10.52 (6.71)	-2.20	0.146
F_FROM	7.24 (7.57)	8.80 (6.37)	-1.56	0.311
Patients	(n=40)	(n=43)		
B_EQ-5D	0.75 (0.22)	0.73 (0.23)	0.02	0.607
F_EQ-5D	0.82 (0.17)	0.78 (0.20)	0.04	0.376
B_EQ-5D-VAS	60.25 (23.72)	58.91 (22.19)	1.34	0.791
F_EQ-5D-VAS	69.83 (18.64)	67.74 (21.06)	2.09	0.636
B_GSQ	5.23 (2.81)	5.26 (2.17)	-0.03	0.956
F_GSQ	3.95 (2.33)	4.58 (2.54)	-0.63	0.242

*Significant at < 0.05 level.

Table S2. Classification Table MIC improvement

Classification Table MIC improvement					
Cut point	Sensitivity	Specificity	1-Sensitivity	1 - Specificity	(1-sensitivity) + [1-specificity]
-17	1	0	0	1	1
-15.5	1	0.011	0	0.989	0.989
-14.5	1	0.023	0	0.977	0.977
-12.5	1	0.034	0	0.966	0.966
-10.5	1	0.046	0	0.954	0.954
-8	1	0.069	0	0.931	0.931
-5.5	0.923	0.08	0.077	0.92	0.997
-4.5	0.923	0.092	0.077	0.908	0.985
-3.5	0.923	0.138	0.077	0.862	0.939
-2.5	0.923	0.161	0.077	0.839	0.916
-1.5	0.846	0.241	0.154	0.759	0.913
-0.5	0.846	0.322	0.154	0.678	0.832
0.5	0.692	0.414	0.308	0.586	0.894
1.5	0.692	0.563	0.308	0.437	0.745
2.5	0.615	0.713	0.385	0.287	0.672
3.5	0.462	0.782	0.538	0.218	0.756
4.5	0.462	0.851	0.538	0.149	0.687
5.5	0.462	0.931	0.538	0.069	0.607
6.5	0.462	0.977	0.538	0.023	0.561
7.5	0.308	0.977	0.692	0.023	0.715
9	0.231	0.989	0.769	0.011	0.78
10.5	0.154	1	0.846	0	0.846
18.5	0.077	1	0.923	0	0.923
27	0	1	1	0	1

Table S3 Classification Table MIC improvement

Classification Table MIC deterioration					
Cut point	Sensitivity	Specificity	1-Sensitivity	1 - Specificity	(1-sensitivity) + [1-specificity]
-27	1	0	0	1	1
-18.5	1	0.011	0	0.989	0.989
-10.5	1	0.022	0	0.978	0.978
-9	1	0.045	0	0.955	0.955
-7.5	1	0.067	0	0.933	0.933
-6.5	1	0.09	0	0.91	0.91
-5.5	1	0.135	0	0.865	0.865
-4.5	1	0.213	0	0.787	0.787
-3.5	1	0.281	0	0.719	0.719
-2.5	1	0.371	0	0.629	0.629
-1.5	0.909	0.517	0.091	0.483	0.574
-0.5	0.818	0.652	0.182	0.348	0.53
0.5	0.727	0.753	0.273	0.247	0.52
1.5	0.727	0.831	0.273	0.169	0.442
2.5	0.455	0.888	0.545	0.112	0.657
3.5	0.364	0.899	0.636	0.101	0.737
4.5	0.364	0.944	0.636	0.056	0.692
5.5	0.273	0.944	0.727	0.056	0.783
8	0.182	0.955	0.818	0.045	0.863
10.5	0.091	0.966	0.909	0.034	0.943
12.5	0.091	0.978	0.909	0.022	0.931
14.5	0	0.978	1	0.022	1.022
15.5	0	0.989	1	0.011	1.011
17	0	1	1	0	1

Table S4 Change in scores in patients and their family members across medical specialities

Medical specialty	Family Member/Partner					Patient				
	B_FROM	F_FROM	Mean diff FROM	ES	SRM	B_EQ-5D	F_EQ-5D	Mean diff EQ-5D	ES	SRM
Dermatology (n=33)	9.03	7.12	1.91	0.258	0.310	0.71	0.80	-0.09	-0.374	-0.552
Diabetes (n=29)	8.38	6.93	1.45	0.242	0.424	0.79	0.80	-0.01	-0.056	-0.125
Rheumatology (n=15)	11.40	11.27	0.13	0.022	0.024	0.68	0.76	-0.08	-0.489	-0.517
Haematology (n=5)	13.60	12.60	1.00	0.101	0.365	0.78	0.79	-0.01	-0.099	-0.447
IBD (n=1)	12.00	5.00	7.00			0.81	1.00	0.19		

IBD, Inflammatory Bowel Disease; ES, Effect Size; SRM, Standard Response Mean

Confidence Interval calculation of MIC_{pred} and Adj_MIC_{pred}

We entered the output of the regression analysis into the Excel worksheet given by Terulin and colleagues in 2015 (Available at:

<https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fars.els-cdn.com%2Fcontent%2Fimage%2F1-s2.0-S0895435615001602-mmc2.xlsx&wdOrigin=BROWSELINK>

to obtain confidence interval values for MIC pred and Adj MIC predict. Below are screenshots of Excel sheet for confidence interval calculation for MIC pred and Adj_MIC pred for Improvement and Deterioration.

Figure S1 Calculating 95% confidence intervals MICpred (Improvement)

1					
2	Prevalence (0-1)	0.130			
3	Change score (X) =	2.498			
4	Intercept (C) =	-2.423	se(C) =	0.418	
5	Regression coeff (B)=	0.209	se(B) =	0.082	
6			r(C-B) =	-0.648	
7	ln(odds-post) =	-1.901	se(ln(odds)	0.325	
8	odds(post)* =	0.149			
9	odds(pre) =	0.149			
10	ln(odds-pre)	-1.901			
11	ln(oddspost)lo =	-1.264	odds(post)l	0.283	
12	ln(oddspost)hi =	-2.538	odds(post)h	0.079	
13					
14	LR =	1.000			
15	LR(upper limit) =	1.891			
16	LR(lower limit) =	0.529			
17					
18	prob-post =	0.130			
19	prob-post(lo) =	0.220			
20	prob-post(hi) =	0.073			
21					
22	X for which LR=1	2.498			
23	X for which LR(upper limit)=1	-3.574			
24	X for which LR(lower limit)=1	6.241			
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Figure S2 Calculating 95% confidence intervals Adj_MICpred (Improvement)

1					
2					
3	Prevalence (0-1)	0.130			
4	Change score (X) =	3.867			
5	Intercept (C) =	-2.423	se(C) =	0.418	
6	Regression coeff (B)=	0.209	se(B) =	0.082	
7			r(C-B) =	-0.648	
8	ln(odds-post) =	-1.615	se(ln(odds)	0.322	
9	odds(post)* =	0.199			
10	odds(pre) =	0.199			
11	ln(odds-pre)	-1.615			
12	ln(oddspost)lo =	-0.984	odds(post)	0.374	
13	ln(oddspost)hi =	-2.245	odds(post)	0.106	
14					
15	LR =	1.000			
16	LR(upper limit) =	1.879			
17	LR(lower limit) =	0.532			
18					
19	prob-post =	0.166			
20	prob-post(lo) =	0.272			
21	prob-post(hi) =	0.096			
22					
23	X for which LR=1	3.867			
24	X for which LR(upper limit)=1	-0.105			
25	X for which LR(lower limit)=1	9.469			
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Figure S3 Calculating 95% confidence intervals MICpred (deterioration)

	A	B	C	D	E	F	G	H	I
1									
2		Prevalence (0-1)			0.110				
3		Change score (X) =			0.7811				
4		Intercept (C) =			-2.229		se(C) =	0.365	
5		Regression coeff (B)=			0.177		se(B) =	0.061	
6							r(C-B) =	-0.349	
7		ln(odds-post) =			-2.091		se(ln(oddspost)) =	0.351	
8		odds(post)* =			0.124				
9		odds(pre) =			0.124				
10		ln(odds-pre)			-2.091				
11		ln(oddspost)lo =			-1.402		odds(post)lo =	0.246	
12		ln(oddspost)hi =			-2.779		odds(post)hi =	0.062	
13									
14		LR =			1.000				
15		LR(upper limit) =			1.991				
16		LR(lower limit) =			0.502				
17									
18		prob-post =			0.110				
19		prob-post(lo) =			0.197				
20		prob-post(hi) =			0.058				
21									
22		X for which LR=1			0.781				
23		X for which LR(upper limit)=1			-5.700				
24		X for which LR(lower limit)=1			5.070				
25									
26									
27									
28									
29									

Figure S4 Calculating 95% confidence intervals Adj_MICpred (deterioration)

	A	B	C	D	E	F	G	H	I	J
1		Prevalence (0-1)			0.110					
2		Change score (X) =			2.287					
3		Intercept (C) =			-2.229		se(C) =	0.365		
4		Regression coeff (B)=			0.177		se(B) =	0.061		
5							r(C-B) =	-0.349		
6		ln(odds-post) =			-1.824		se(ln(oddspost)) =	0.342		
7		odds(post)* =			0.161					
8		odds(pre) =			0.161					
9		ln(odds-pre)			-1.824					
10		ln(oddspost)lo =			-1.153		odds(post)lo =	0.316		
11		ln(oddspost)hi =			-2.495		odds(post)hi =	0.082		
12										
13		LR =			1.000					
14		LR(upper limit) =			1.956					
15		LR(lower limit) =			0.511					
16										
17		prob-post =			0.139					
18		prob-post(lo) =			0.240					
19		prob-post(hi) =			0.076					
20										
21		X for which LR=1			2.287					
22		X for which LR(upper limit)=1			-2.687					
23		X for which LR(lower limit)=1			7.594					
24										
25										
26										
27										
28										
29										

Figure S5: Flow chart of recruitment: Baseline to follow-up (Responsiveness study)

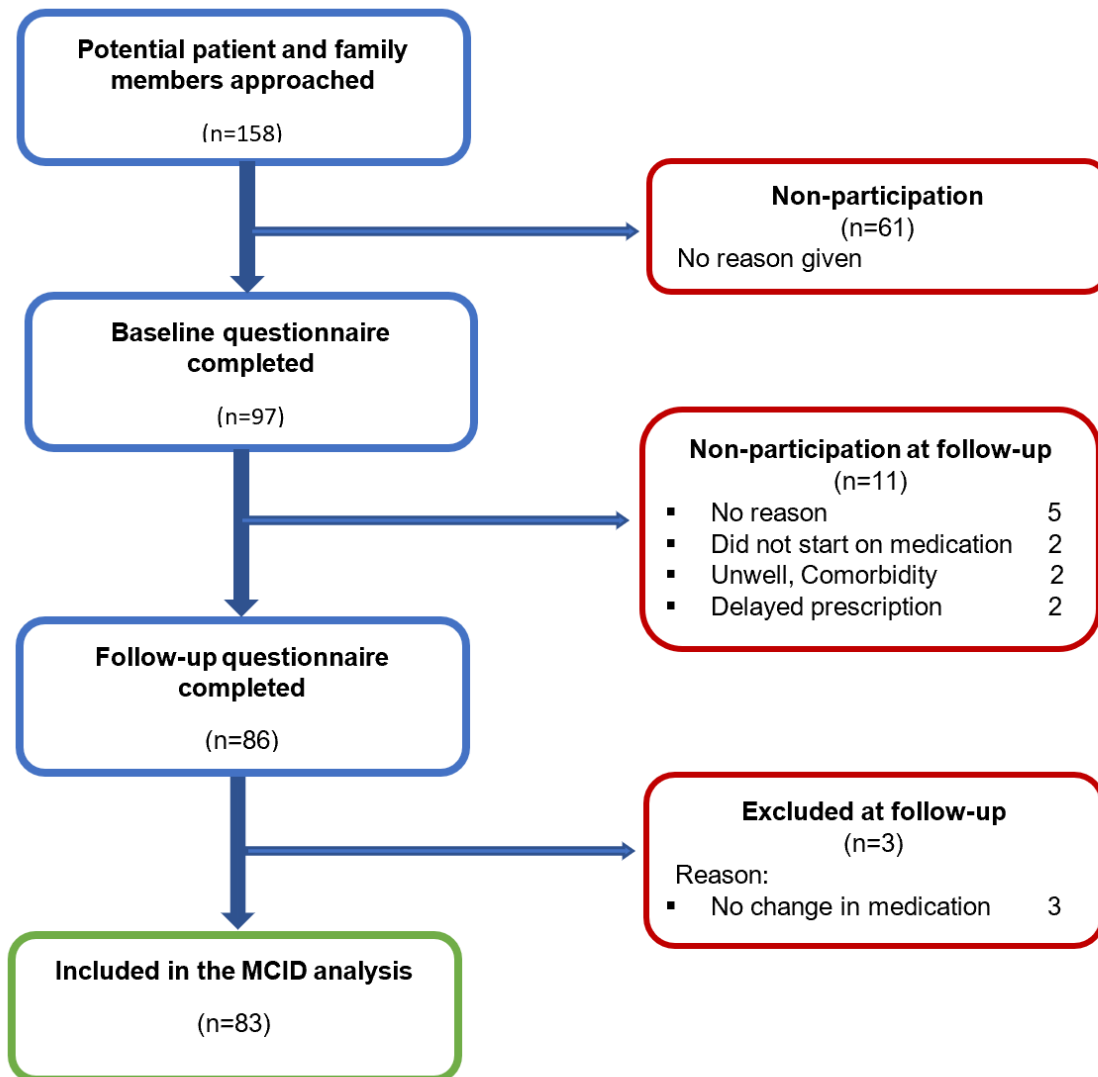


Figure S6: Flow chart of recruitment: Baseline to follow-up (MIC study)

