

Supplementary File 1

Mapping of Family Reported Outcome Measure (FROM-16) scores to EQ-5D: Algorithm to calculate Utility Values

Shah RM, Salek MS, Finlay AY, Kay R, Nixon SJ, Otwombe K, Ali MF, Ingram J

Corresponding author:

ShahR45@cardiff.ac.uk

INDEX: Tables/figures included in the online resource

Table S1 FROM-16 items compared to EQ-5D domains

Table S2a Descriptive statistics: Medical specialties included in the study

Table S2b EQ-5D-3L dimension scores (n=4228)

Table S2c FROM-16 Individual item scores

Table S2d Spearman's rho Correlations showing relationship between different items and testing multicollinearity#

Table S3 Correlation between FROM -16 and EQ-5D-3L

Table S4 Predicted EQ-5D responses across 10 cross validation Sets

Table S5 Mean utility value difference across all ten cross validation sets

Table S6 Actual utility values to predicted utility values across ten models (n=2114) using the Expected utility method

Figure S1 Comparison of predicted and observed EQ-5D-3L responses across ten validation sets

Figure S2 (a)-(j) The cumulative percentage of observed EQ-5D-3L data vs. simulated data across ten validation sets.

Figure S3 (a)-(j) Histograms demonstrating the mean difference between predicted and actual utility scores for each Monte Carlo simulation

Table S1 FROM-16 items compared to EQ-5D domains*

EQ-5D Domain	Covariates: age/sex			Covariates: FROM-16 items			Covariates: age/sex/FROM-16 items		
	-2 log likelihood	Chi-square comparing to full model	Degrees of freedom (df)	-2 log likelihood	Chi-square comparing to full model	Degrees of freedom (df)	-2 log likelihood	Chi-square comparing to full model	Degrees of freedom (df)
Mobility	781.6	151.9	4	4946.9	341.9	32	5173.7	466.1	36
Selfcare	744.8	12.6	4	3582.8	342.2	32	3772.6	352.6	36
Usual activities	1049.8	50.7	4	6258.6	712.0	32	6589.8	764.1	36
Pain and discomfort	1068.3	114.8	4	6885.2	448.4	32	7279.9	551.8	36
Anxiety and depression	1078.1	177.3	4	5975.6	1642.9	32	6298.1	1703.2	36

*The significance of the FROM-16 items and age and sex compared to the model containing age, sex, and the FROM-16 items for each EQ-5D domain

Table S2a Descriptive statistics: Medical specialties included in the study

Patients (n=4228)	Number (%)
Medical specialties	
Audiology	19 (0.4)
Cardiology	239 (5.7)
Chronic pain	7 (0.2)
Critical care	1 (0.02)
Dermatology	127 (3.0)
Endocrinology	266 (6.3)
Gastroenterology	151 (3.6)
Genetic/ Rare disease	44 (1.0)
Gynaecology	37 (0.9)
Haematology	179 (4.2)
Hepatology	10 (0.2)
Immunology	12 (0.3)
Infectious diseases	10 (0.2)
Movement disorder	10 (0.2)
Nephrology	55 (1.3)
Neurology	1522 (36.0)
Oncology	241 (5.7)
Ophthalmology	89 (2.1)
Orthopaedics	24 (0.6)
Otolaryngology	6 (0.1)
Rehabilitation medicine	30 (0.7)
Paediatrics	134 (3.2)
Psychiatry	311 (7.4)
Respiratory medicine	261 (6.2)
Rheumatology	302 (7.1)
Urology	21 (0.5)
Wound healing	1 (0.02)
Multiple health conditions	91 (2.2)
Not stated	28 (0.7)

Table S2b EQ-5D-3L dimension scores (n=4228)

EQ-5D dimensions	No problems N (%)	Some problems N (%)	Extreme problems N (%)
Mobility	2939 (69.5)	1231 (29.1)	58 (1.4)
Selfcare	3588 (84.9)	540 (12.8)	100 (2.4)
Usual activity	2468 (58.4)	1447 (34.2)	313 (7.4)
Pain and discomfort	2063 (48.8)	1780 (42.1)	385 (9.1)
Anxiety and depression	1618 (38.3)	2157 (51)	453 (10.7)

Table S2c FROM-16 Individual item scores

FROM-16 item	Not at All N (%)	A little N (%)	A lot N (%)
Worried	239 (5.7)	1805 (42.7)	2184 (51.7)
Angry	1878 (44.4)	1638 (38.7)	712 (16.8)
Sad	645 (15.3)	1769 (41.8)	1814 (42.9)
Frustrated	791 (18.7)	1710 (40.4)	1727 (40.8)
Talking about Thoughts	1599 (37.8)	1421 (33.6)	1208 (28.6)
Difficulty caring	1179 (27.9)	1748 (41.3)	1301 (30.8)
Time for self	1660 (39.3)	1543 (36.5)	1025 (24.2)
Travel	2553 (60.4)	991 (23.4)	684 (16.2)
Eating habits	2425 (57.4)	1242 (29.4)	561 (13.3)
Family activities	902 (21.3)	1821 (43.1)	1505 (35.6)
Holiday	1341 (31.7)	1294 (30.6)	1593 (37.7)
Sex life	1901 (45)	944 (22.3)	1383 (32.7)
Work/study	2496 (59)	1127 (26.7)	605 (14.3)
Family relationships	1929 (45.6)	1530 (36.2)	769 (18.2)
Family expenses	1769 (41.8)	1460 (34.5)	999 (23.6)
Sleep	1233 (29.2)	1644 (38.9)	1351 (32)

Table S2d Spearman's rho Correlations showing relationship between different items and testing multicollinearity[#]

FROM-16 Items	Worried	Angry	Sad	Frustrated	Talking about thoughts	Difficulty caring	Time for self	Travel	Eating habits	Family activities	Holiday	Sexlife	Work /study	Family relationships	Family expenses	Sleep
Worried	1	.	.													
Angry	.424**	1														
Sad	.534**	.482**	1													
Frustrated	.453**	.573**	.497**	1												
Talking about thoughts	.411**	.453**	.383**	.444**	1											
Difficulty caring	.465**	.454**	.471**	.501**	.444**	1										
Time for self	.398**	.373**	.394**	.406**	.440**	.619**	1									
Travel	.285**	.284**	.263**	.314**	.328**	.443**	.557**	1								
Eating habits	.283**	.305**	.260**	.313**	.342**	.388**	.455**	.437**	1							
Family activities	.364**	.355**	.389**	.421**	.385**	.511**	.567**	.501**	.455**	1						
Holiday	.352**	.332**	.342**	.383**	.370**	.497**	.584**	.532**	.418**	.633**	1					
Sex life	.209**	.228**	.186**	.239**	.290**	.237**	.332**	.320**	.322**	.356**	.415**	1				
Work/study	.335**	.339**	.341**	.339**	.361**	.446**	.505**	.418**	.414**	.461**	.411**	.290**	1			
Family relationships	.392**	.397**	.420**	.405**	.426**	.548**	.528**	.406**	.412**	.512**	.435**	.222**	.511**	1		
Family expenses	.341**	.334**	.334**	.358**	.348**	.462**	.501**	.437**	.403**	.479**	.480**	.273**	.426**	.450**	1	
Sleep	.462**	.418**	.436**	.424**	.459**	.510**	.566**	.442**	.481**	.507**	.513**	.384**	.451**	.486**	.492**	1

** Correlation is significant at the 0.01 level (2-tailed). [#]Multicollinearity is present when Correlation coefficient > .7

Table S3 Correlation[†] between FROM -16 and EQ-5D-3L

FROM-16	Correlation to EQ-5D	r
Emotional domain (item 1-6)	Anxiety/depression> Activity>Self care>Pain>mobility	0.523*>0.279*>0.176*>0.165*>0.132*
Personal and social (item 7-16)	Anxiety/depression>Activity> Pain>Self care> mobility	0.495*>0.367*>0.239*>0.220*>0.190*
FROM-16 total score	EQ-5D utility values	0.450*

† Spearman correlation; * p-value 0.05

Table S4 Predicted EQ-5D responses across 10 cross validation Sets

% of accuracy	Set 1	Set 2	Set 3	Set 4	Set 5	Set 6	Set 7	Set 8	Set 9	Set 10	Average
90-100%	80	86.66	86.66	86.66	86.66	73.33	73.33	73.33	73.33	73.33	79.33
70-100%	93.33	100	100	93.33	100	100	93.33	100	93.33	93.33	96.67
<70%	0.06	0.06	0	0.06	0	0	0.06	0	0.06	0.06	0.04

Table S5 Mean utility value difference across all ten cross validation sets

	Set 1	Set 2	Set 3	Set 4	Set 5	Set 6	Set 7	Set 8	Set 9	Set 10	Average
Mean Utility Value Difference	0.006	0.008	0.027	0.005	0.027	0.020	0.029	0.005	0.017	0.007	0.015
% Utility Values within 0.05 of Actual UV	53.6	54.6	51.8	58.6	53.3	53.8	51.6	56.6	54.3	54.5	54.27
% Utility Values within 0.1 of Actual UV	58.8	59.5	56.3	62.9	57.9	58.6	56.5	61.9	59	59.8	59.12
% Utility Values within 0.2 of Actual UV	73.4	73.9	70.2	74.6	73.3	72.8	71.3	75.4	71.8	73.6	73.03
% Utility Values within 0.3 of Actual UV	84.1	83	80.6	83.2	81.8	82.3	81.6	83.8	81.7	82.9	82.50

Table S6 Actual utility values to predicted utility values across ten models (n=2114)
using the Expected utility method

Expected Utility Method*									
Cross-validation Set	Actual Utility			Predicted Utility			Actual versus Predicted		
	Mean (SD)	Min	Max	Mean (SD)	Min	Max	Diff in means	MSE	MAE
Set 1	0.667(0.342)	-0.594	1	0.653(0.159)	0.187	0.905	0.014	0.090	0.229
Set 2	0.669(0.331)	-0.594	1	0.655(0.166)	0.040	0.912	0.014	0.088	0.226
Set 3	0.673(0.331)	-0.594	1	0.637(0.161)	0.197	0.906	0.037	0.087	0.229
Set 4	0.672(0.326)	-0.594	1	0.657(0.164)	0.161	0.921	0.015	0.085	0.222
Set 5	0.680(0.326)	-0.594	1	0.645(0.162)	0.142	0.896	0.035	0.085	0.226
Set 6	0.679(0.320)	-0.594	1	0.648(0.163)	0.158	0.914	0.030	0.083	0.223
Set 7	0.677(0.331)	-0.594	1	0.643(0.160)	0.208	0.910	0.033	0.089	0.230
Set 8	0.672(0.330)	-0.594	1	0.660(0.166)	0.140	0.909	0.012	0.087	0.224
Set 9	0.674(0.336)	-0.594	1	0.654(0.152)	0.185	0.897	0.020	0.087	0.227
Set 10	0.666(0.336)	-0.594	1	0.656 (0.162)	0.204	0.921	0.010	0.090	0.227
Average of 10 Sets	0.673(0.331)	-0.594	1	0.651(0.162)	0.162	0.909	0.022	0.087	0.226

*Level 1 (No effect) was a reference category; SD, Standard Deviation; Min, Minimum; Max, Maximum; Diff in means, Difference in means; MSE, Mean Square Error; MAE, Mean Absolute Error.

Fig S1 Comparison of predicted and observed EQ-5D-3L responses across ten validation sets

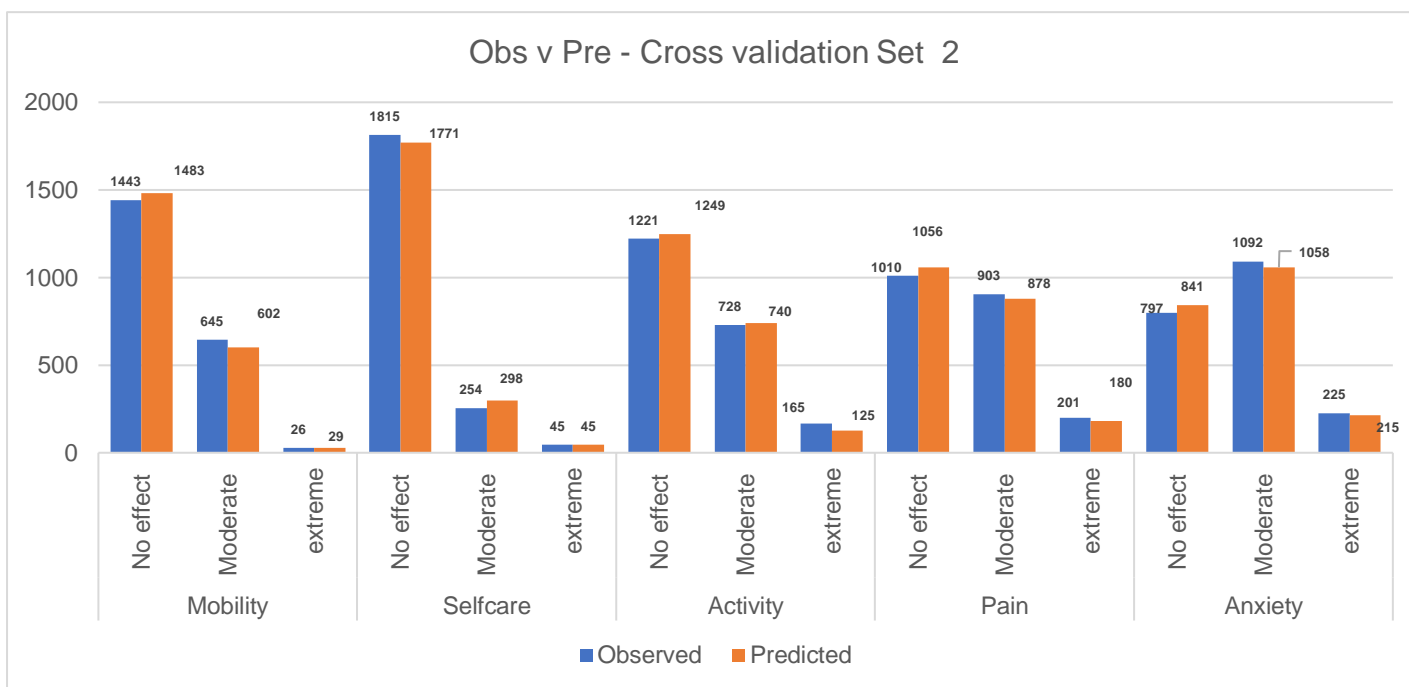
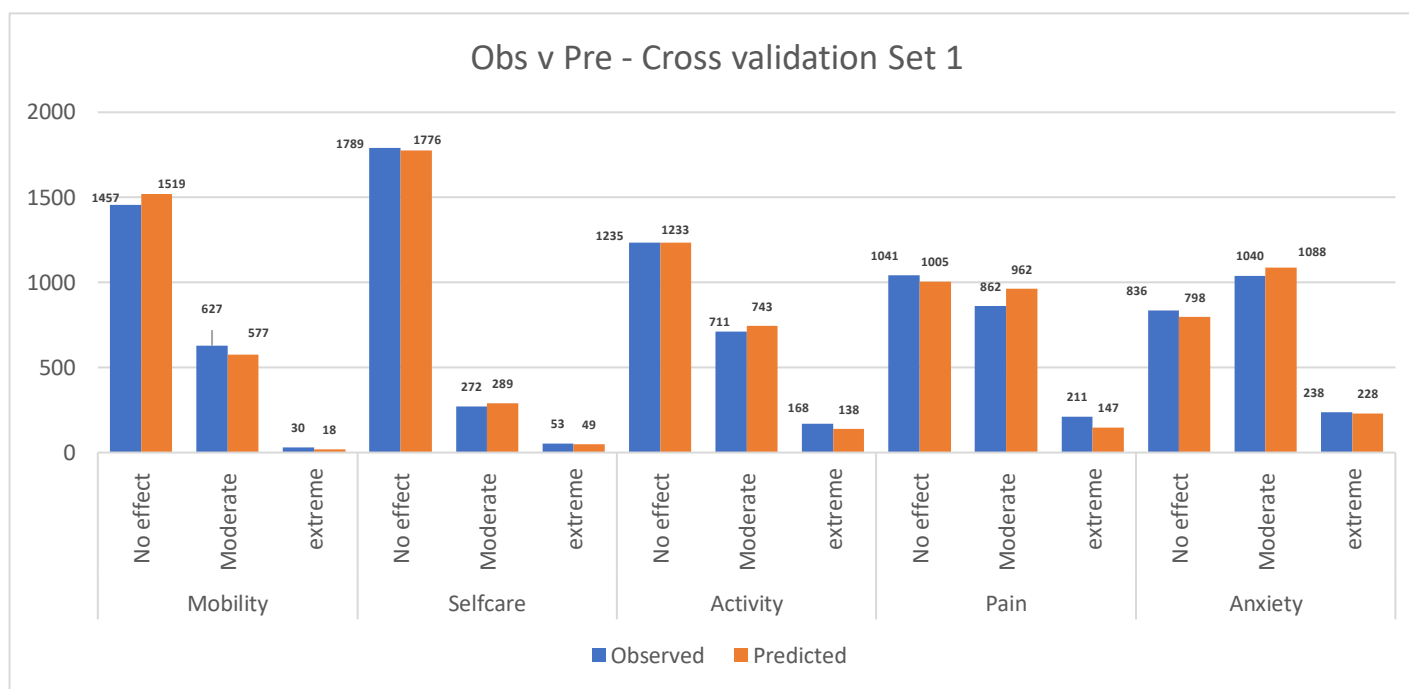


Fig S1 (Contd)

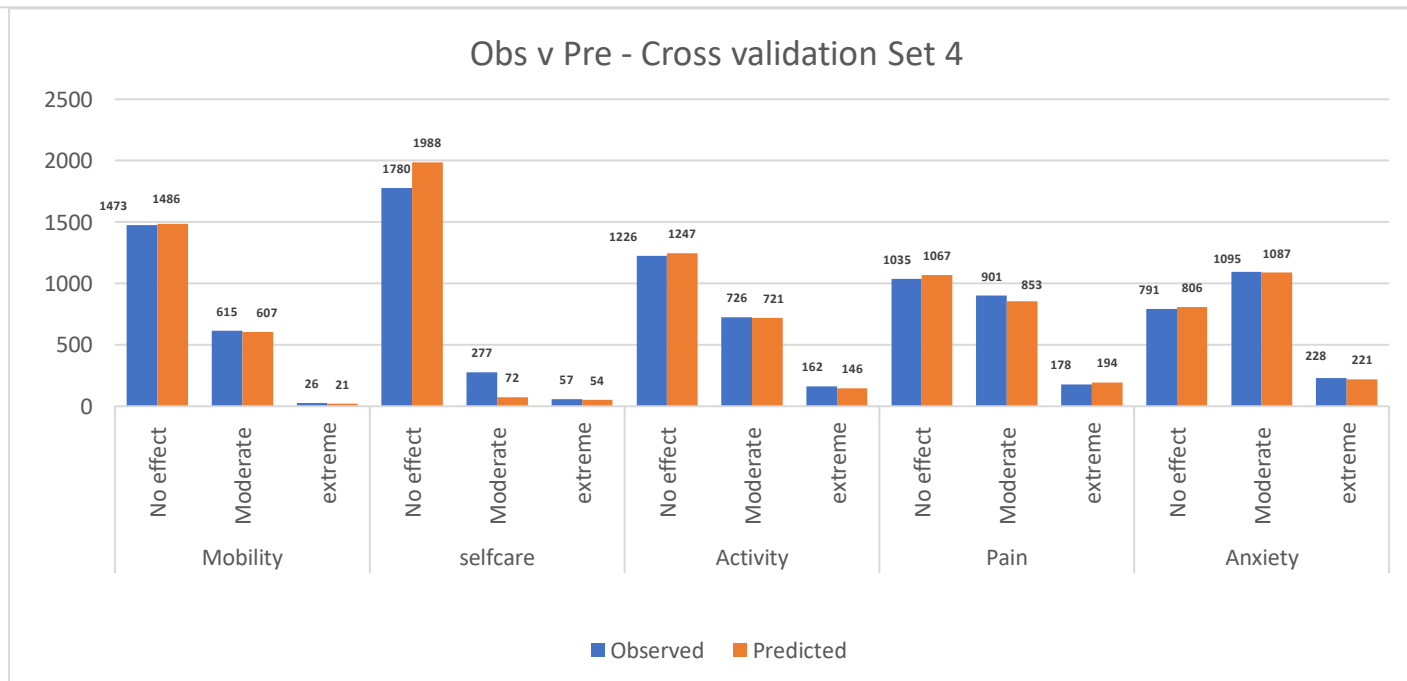
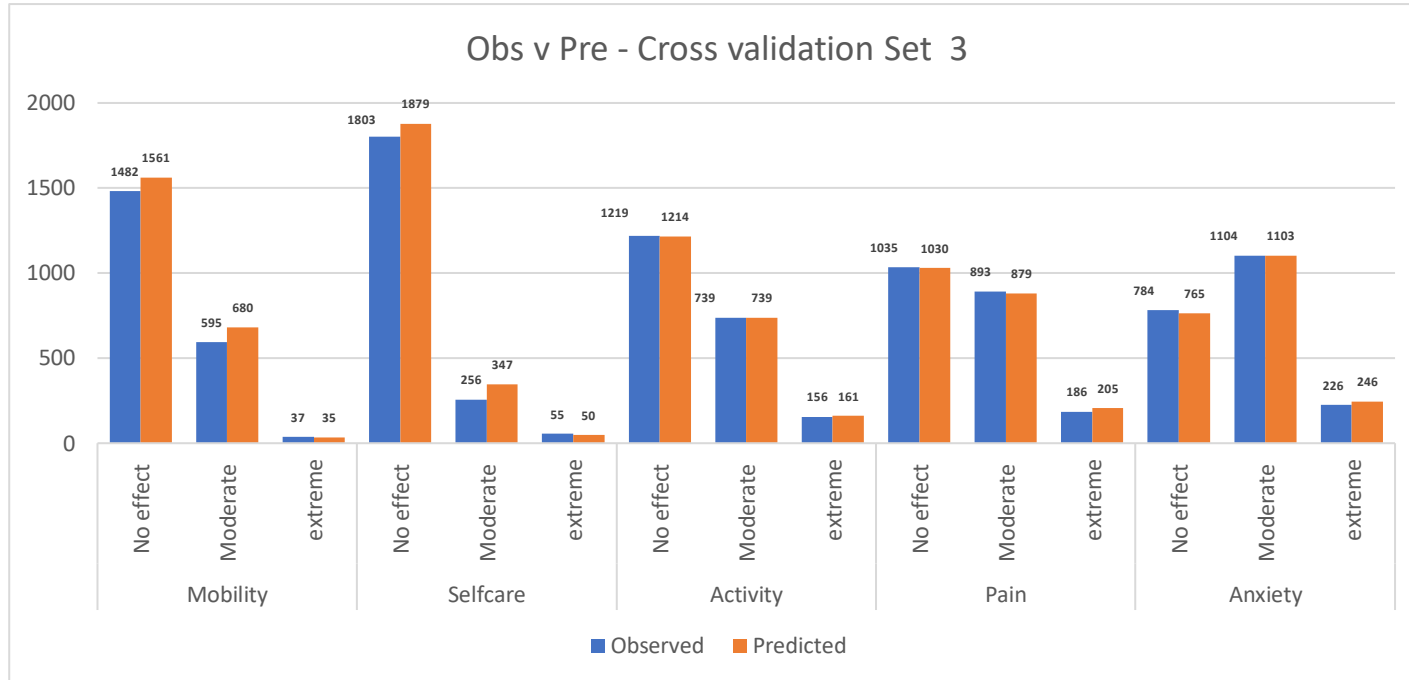
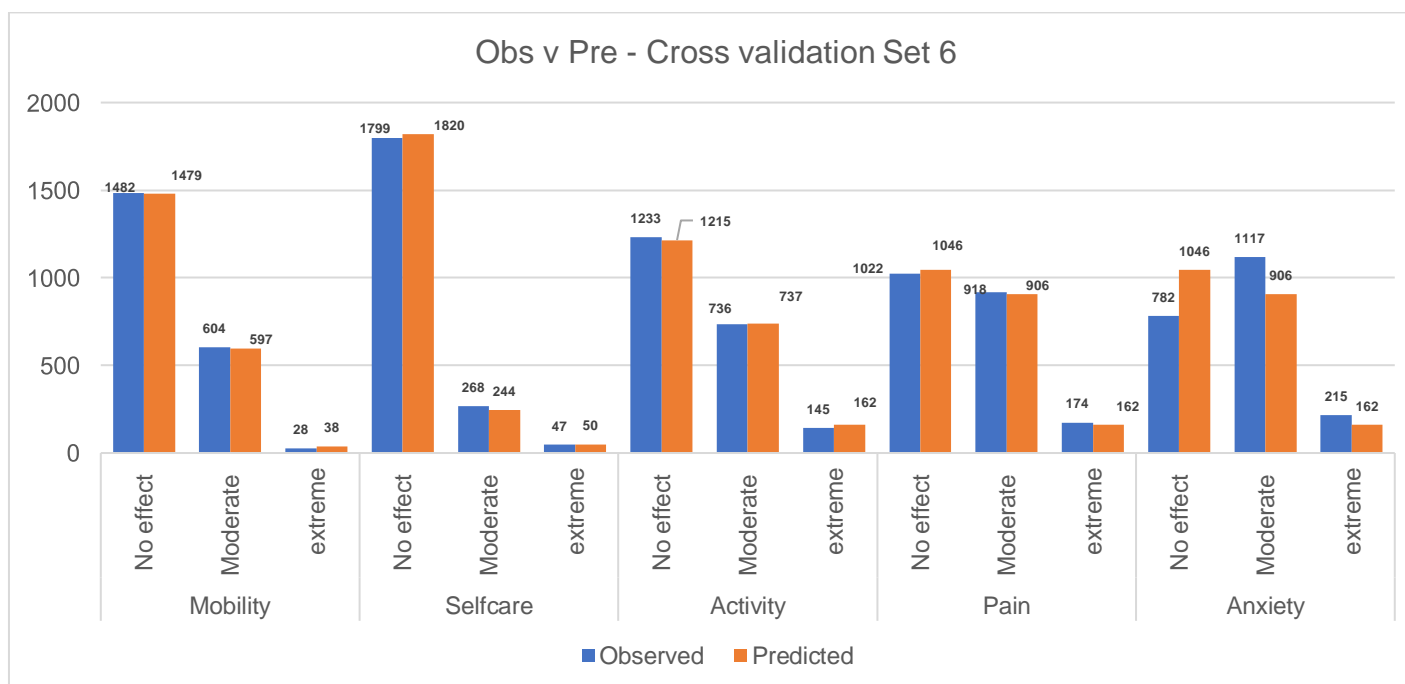
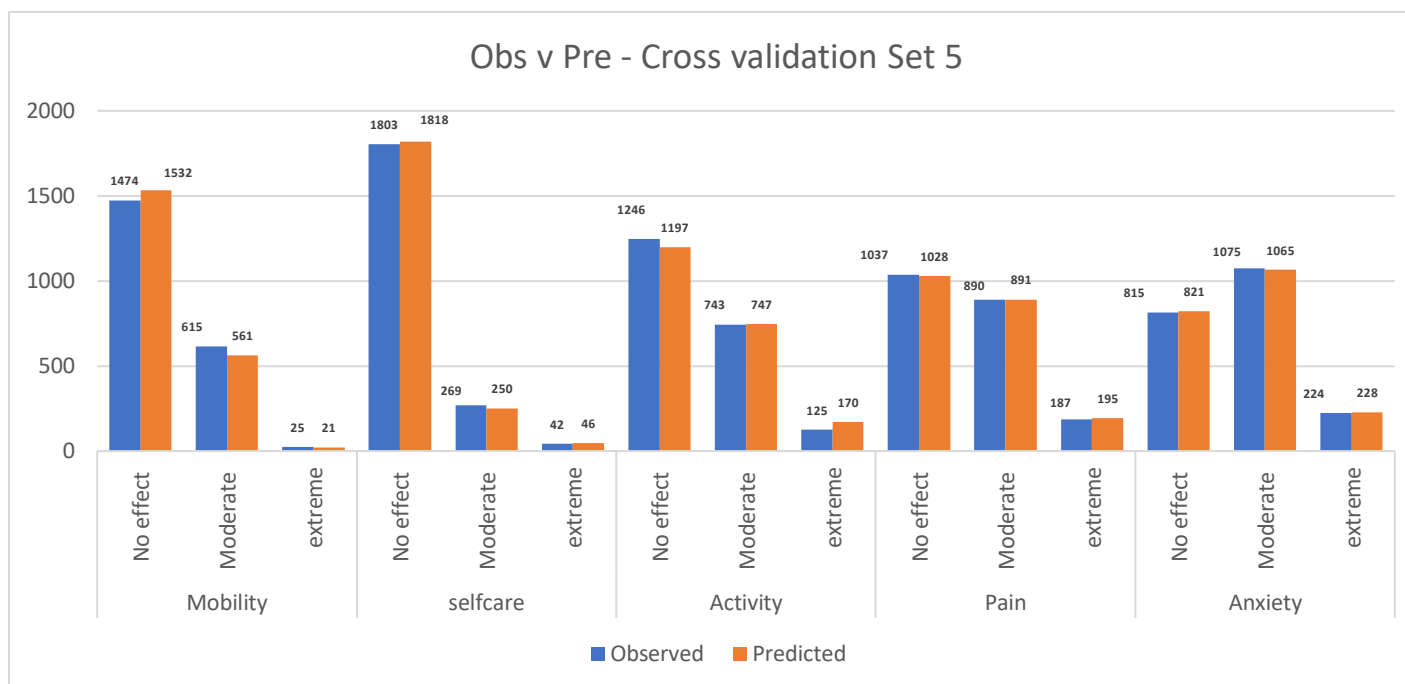
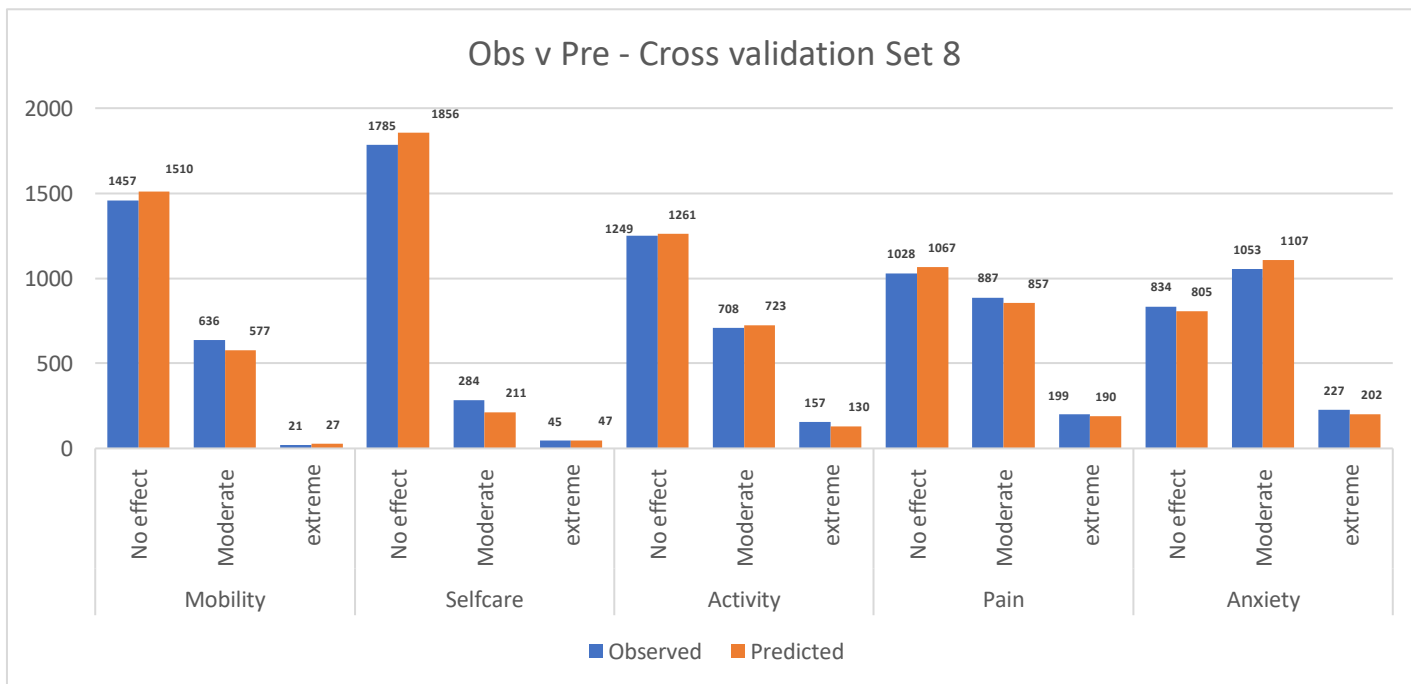
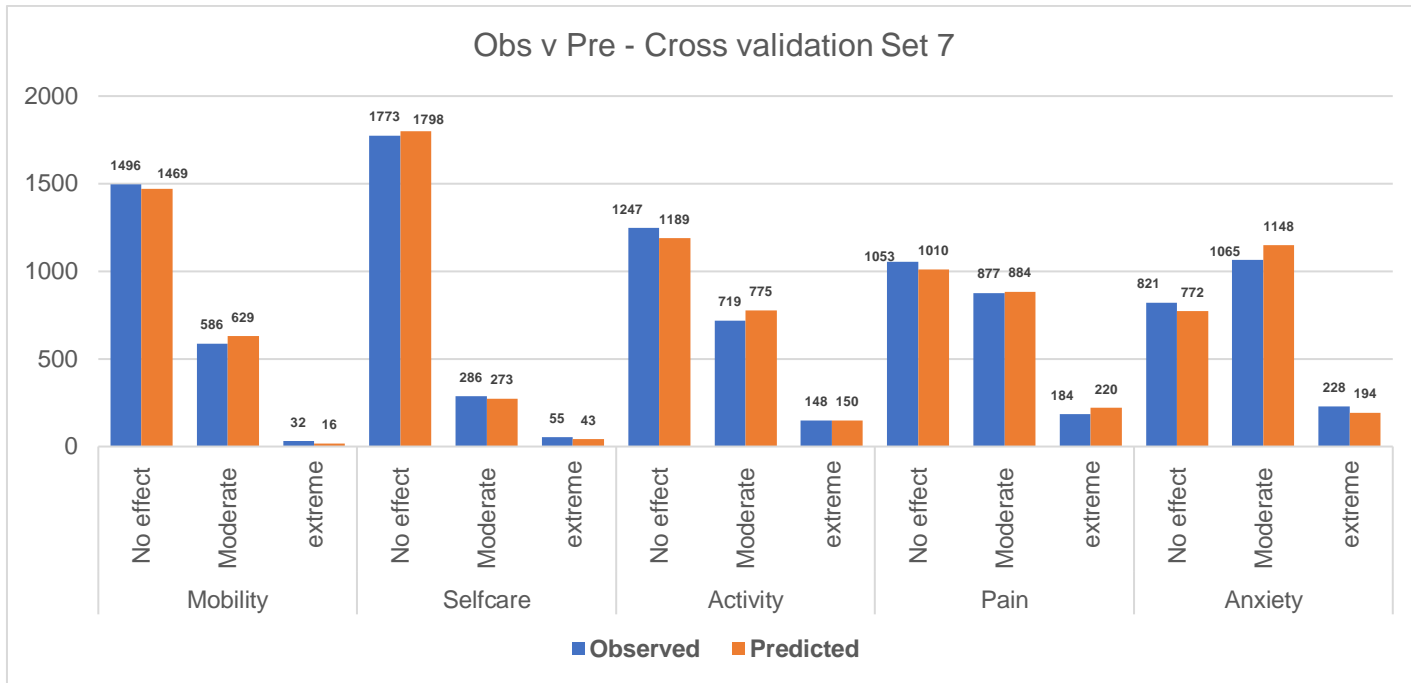


Fig S1 (Contd)





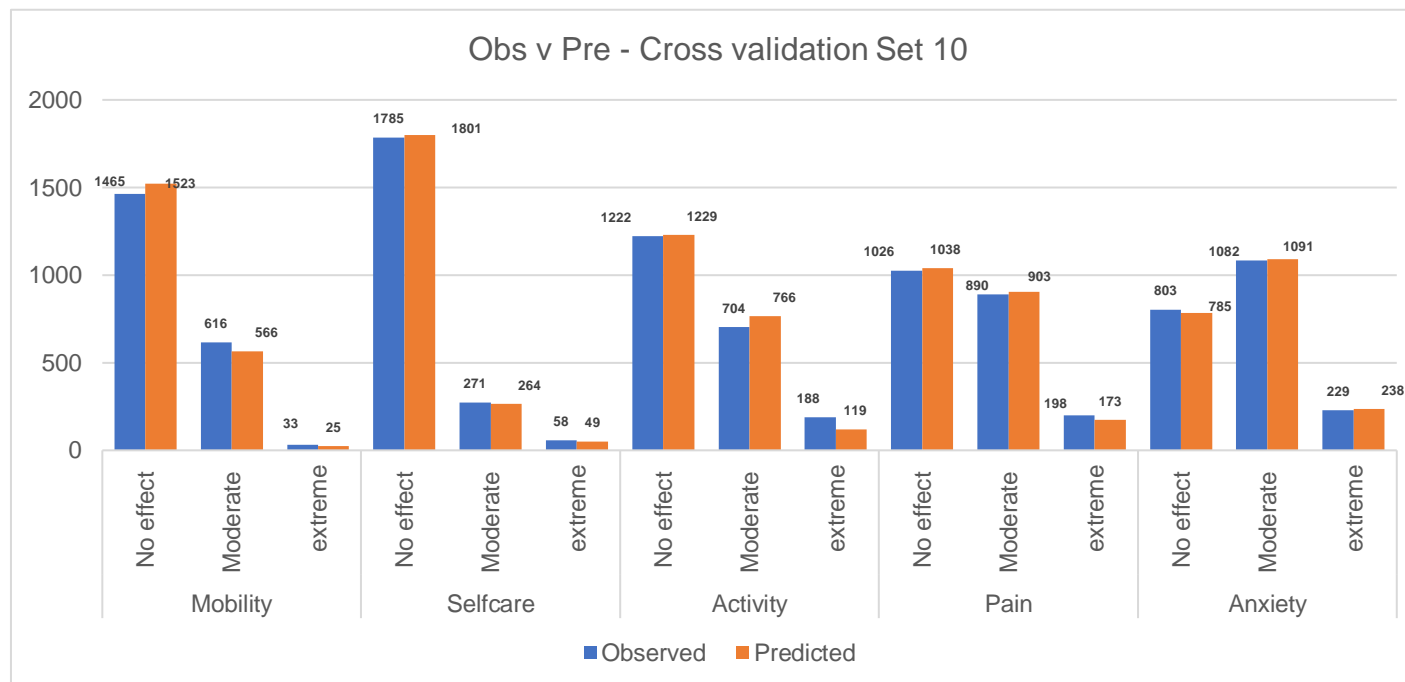
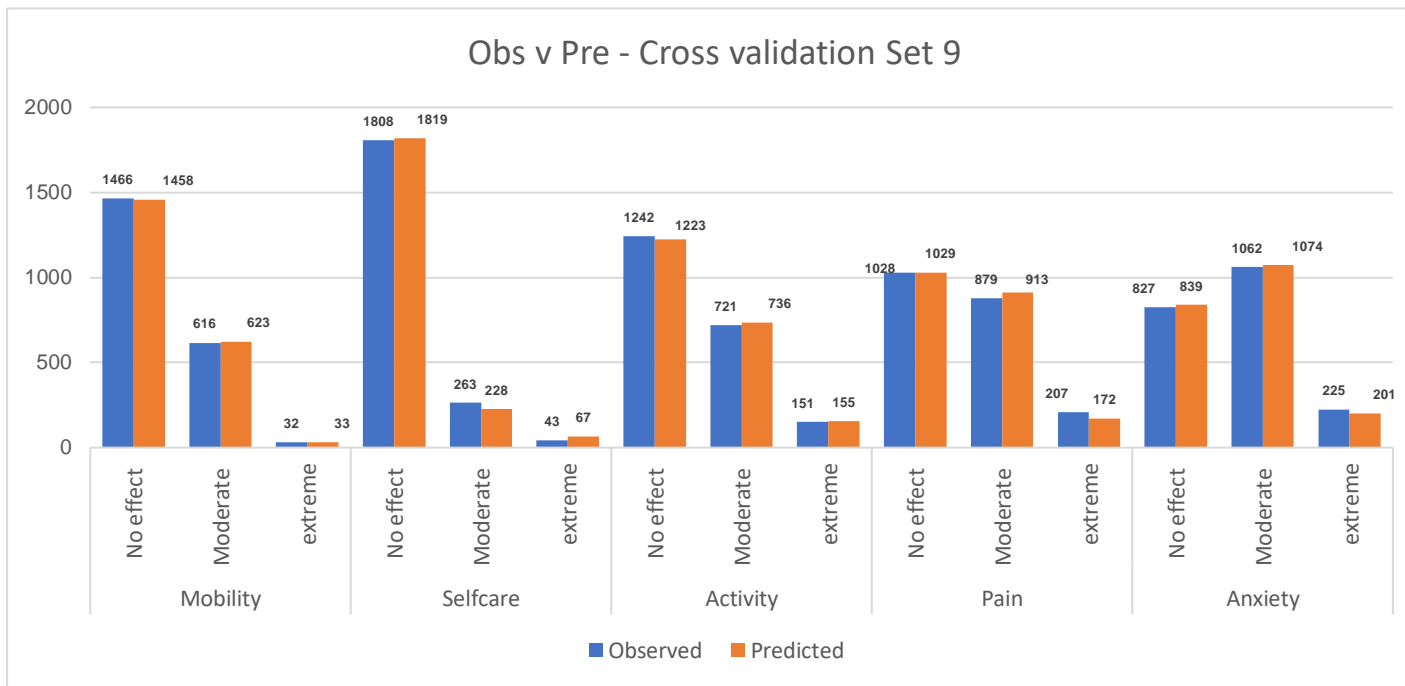
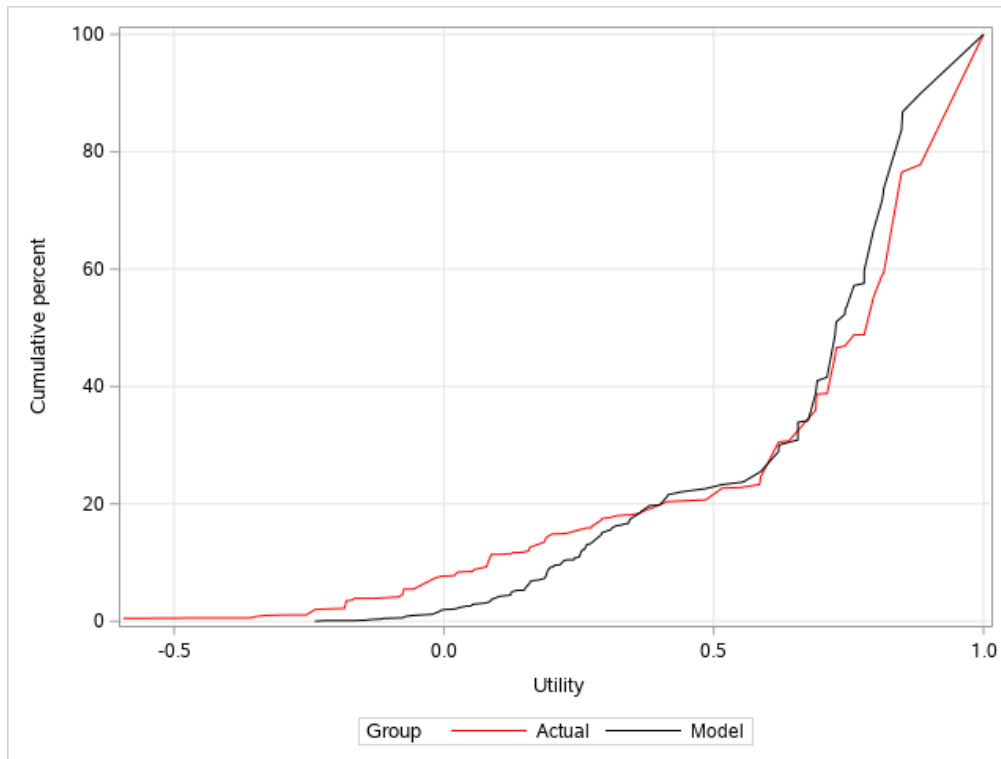
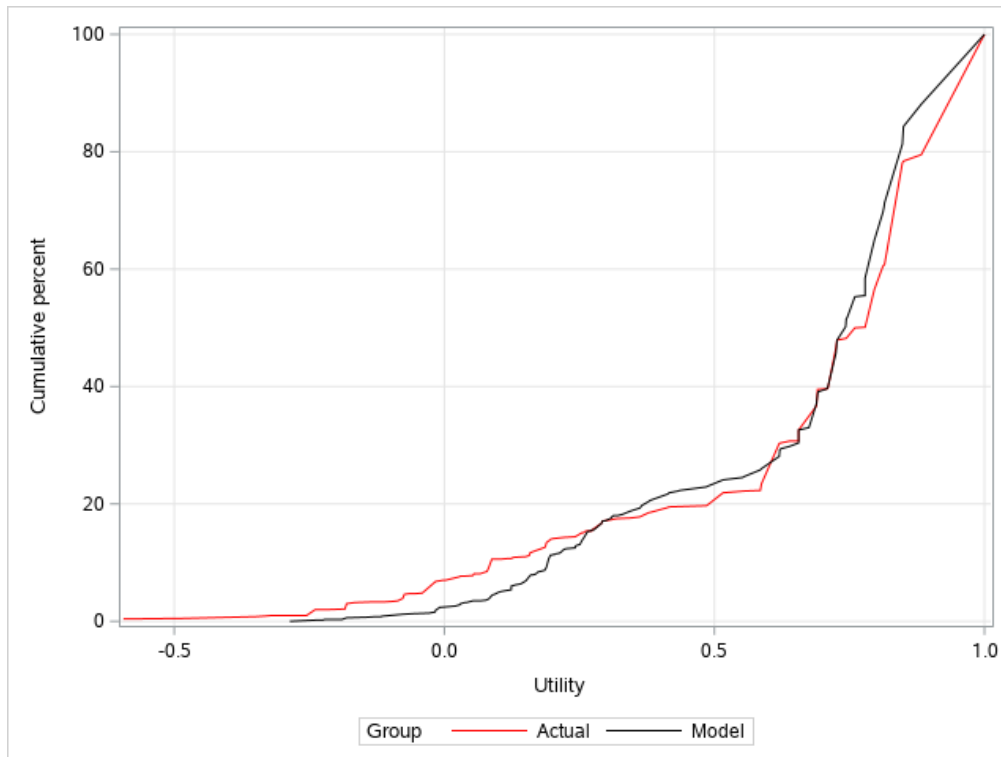


Fig S2 (a)-(j) The cumulative percentage of observed EQ-5D-3L data vs. simulated data across ten validation sets.

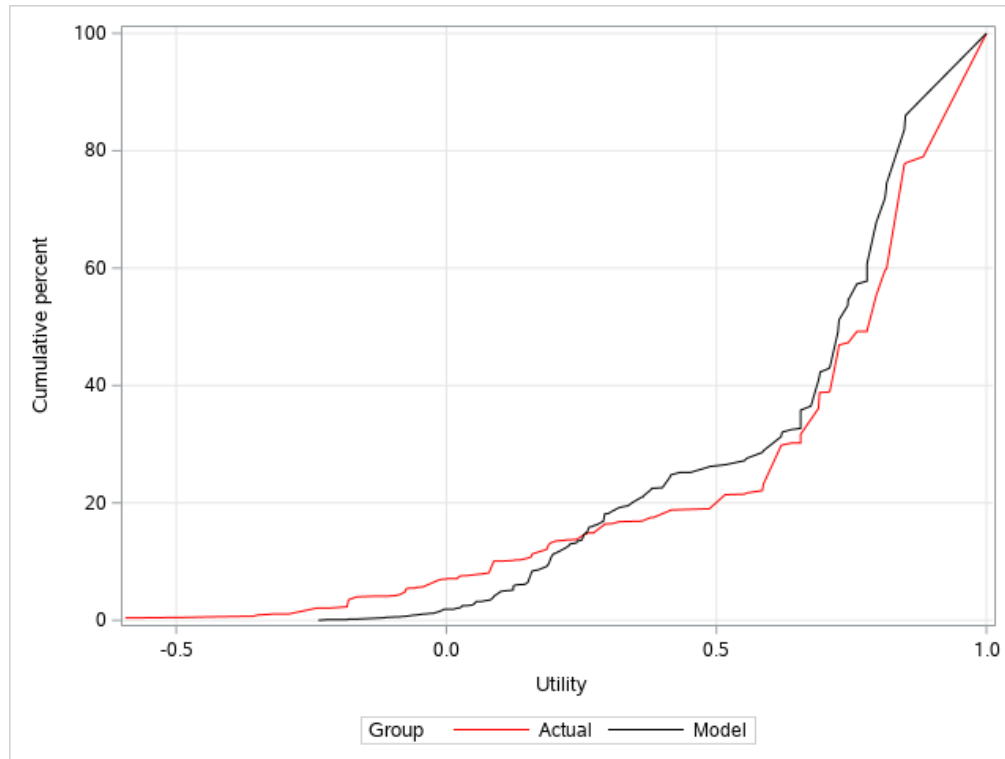
(a) Model one: Cross validation set 1



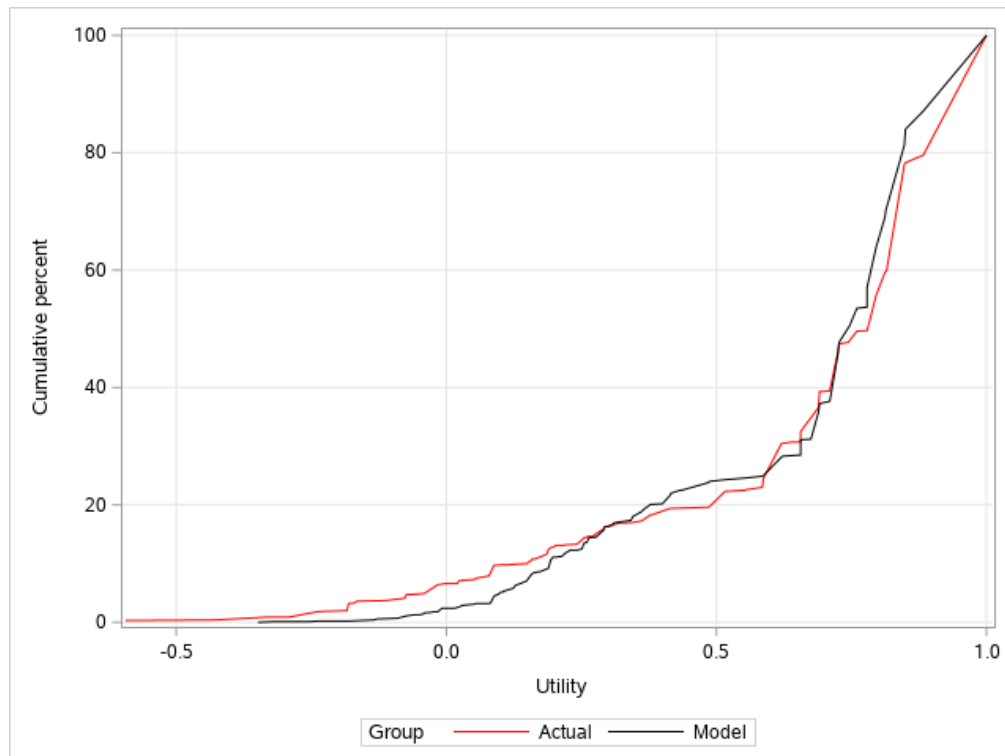
(b) Model one: Cross validation set 2



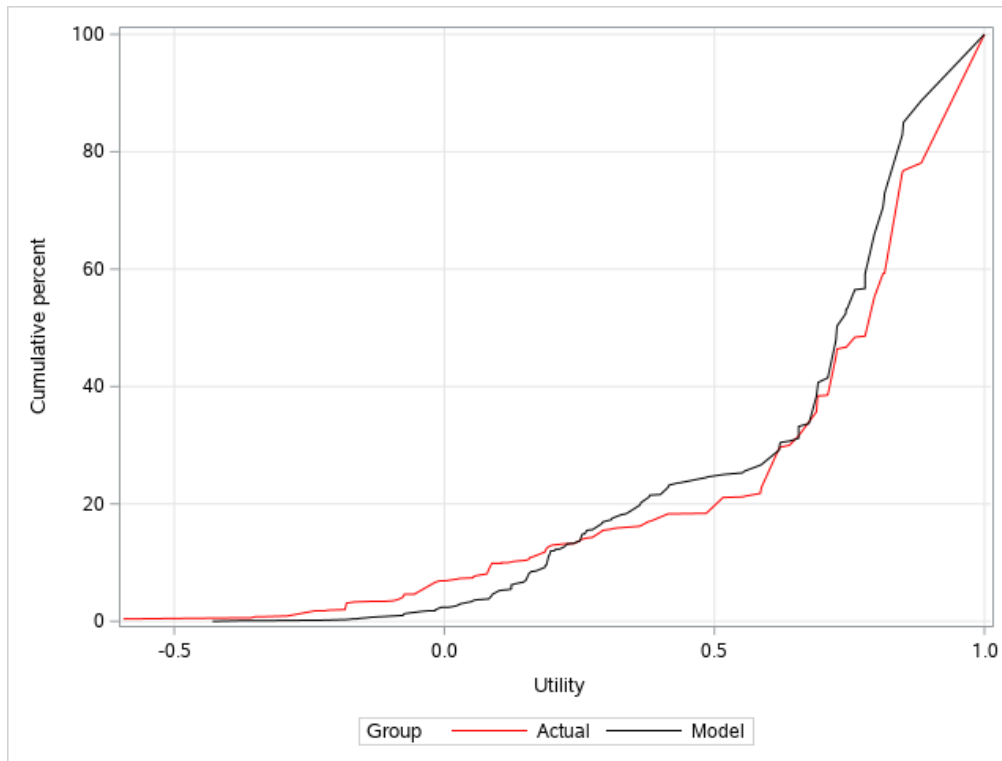
(c) Model three: Cross validation set 3



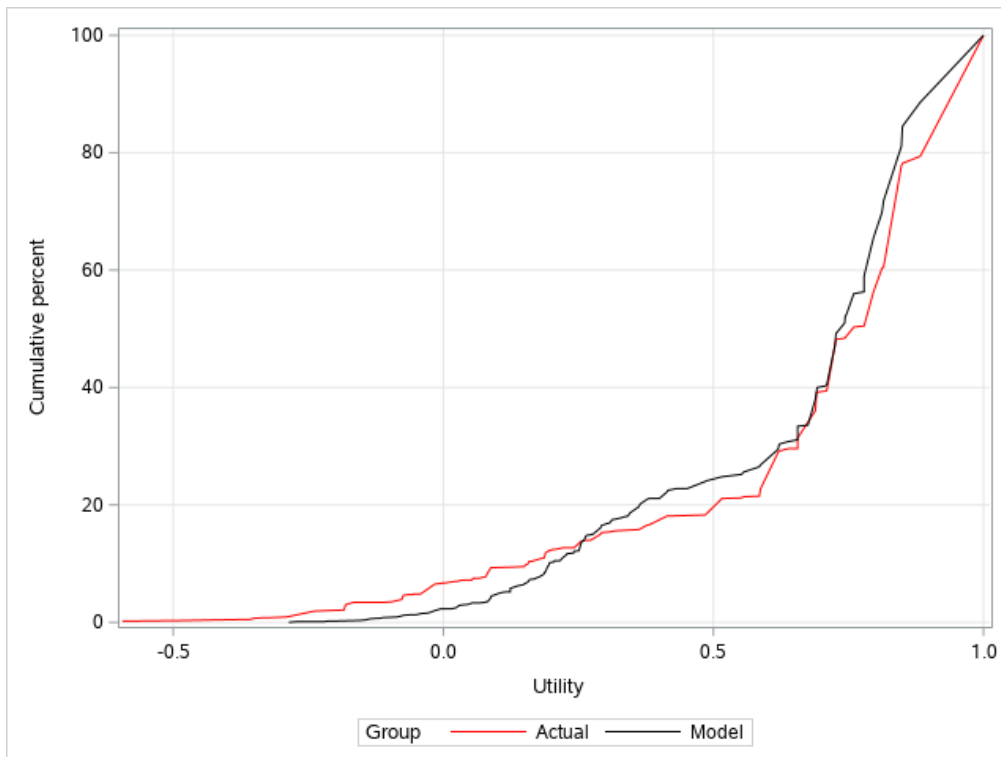
(d) Model four: Cross validation set 4



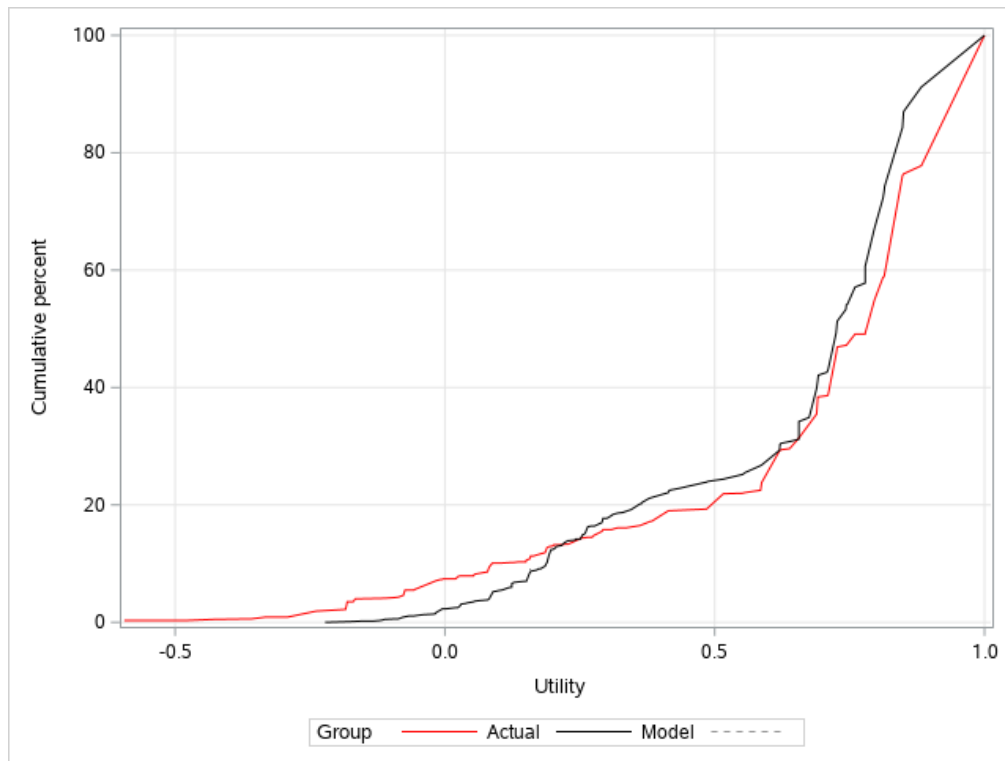
(e) Model five: Cross validation set 5



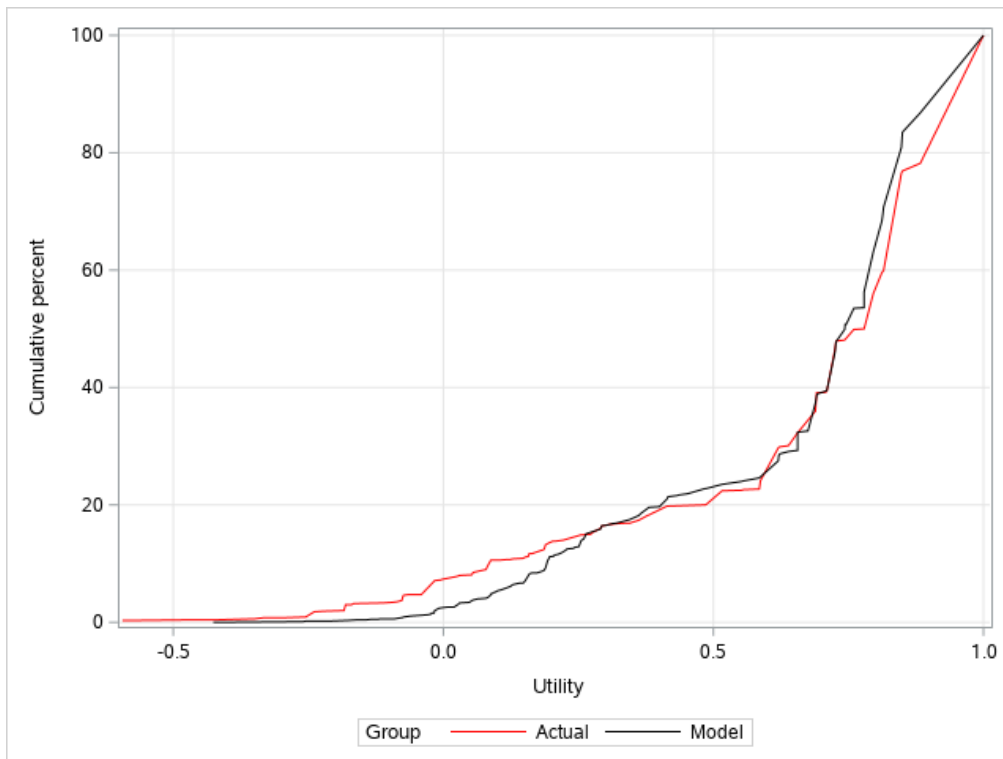
(f) Model six: Cross validation set 6



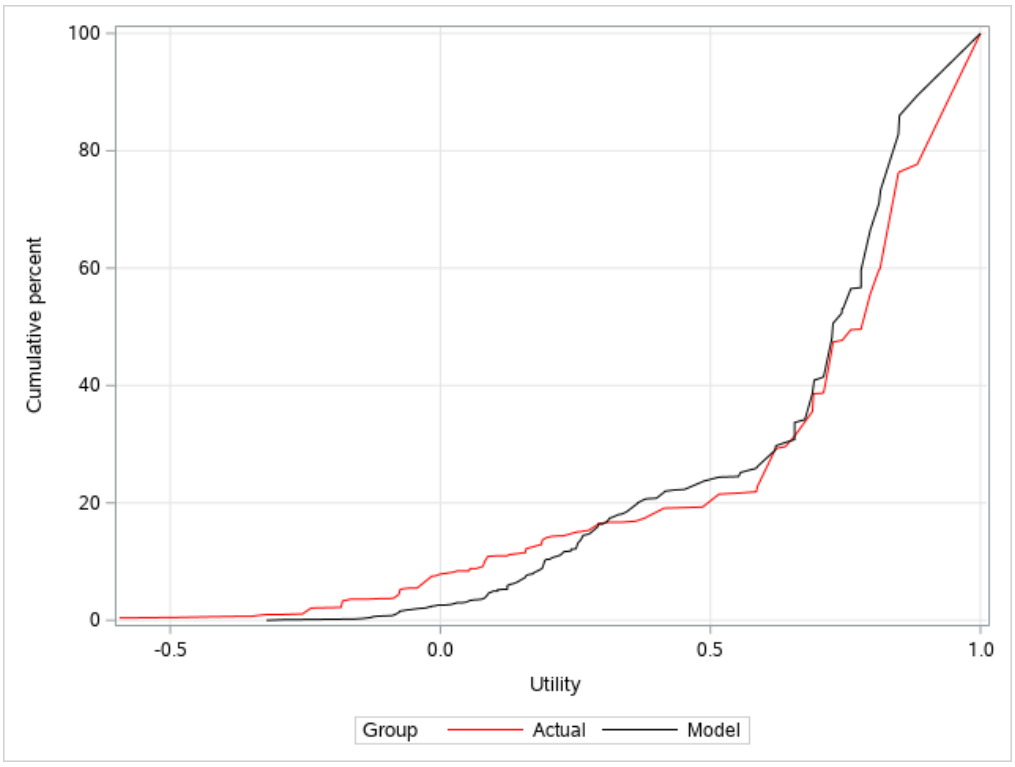
(g) Model seven: Cross validation set 7



(h) Model eight: Cross validation set 8



(i) Model Nine: Cross validation set 9



(j) Model ten: Cross validation set 10

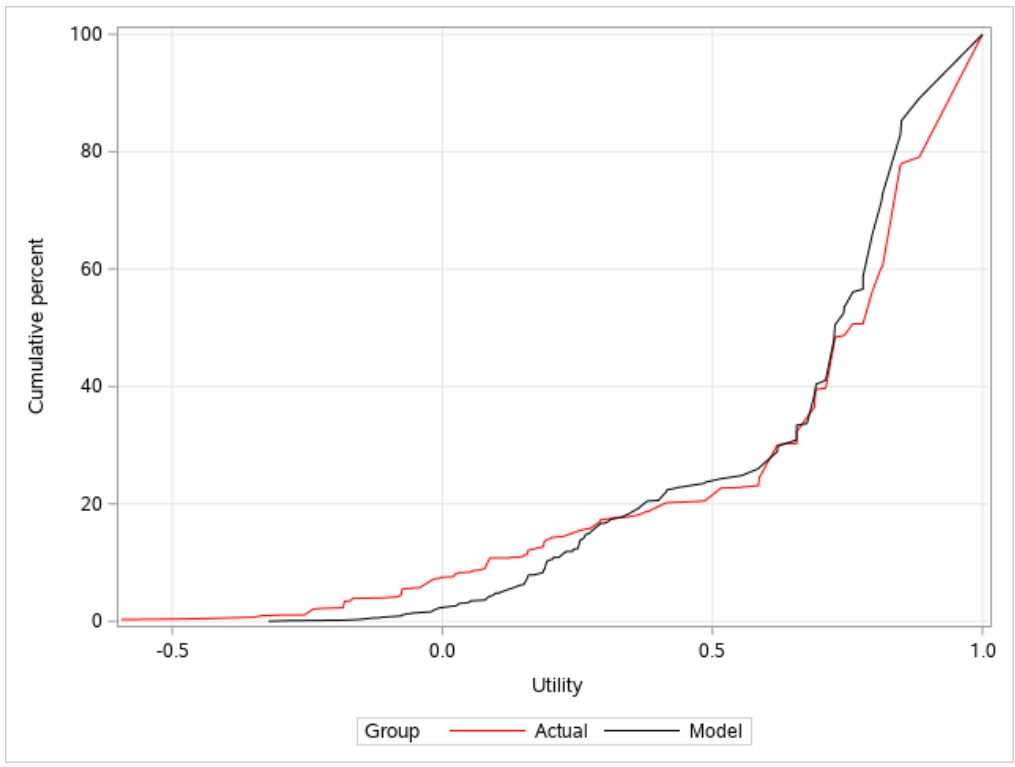
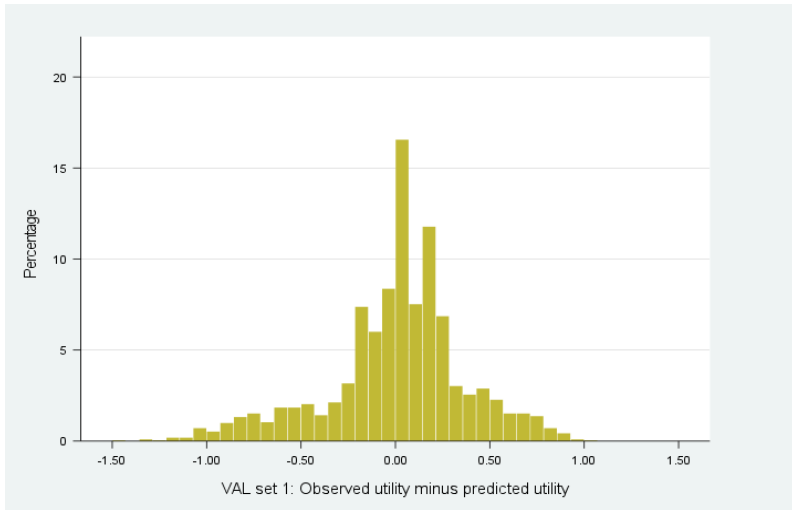
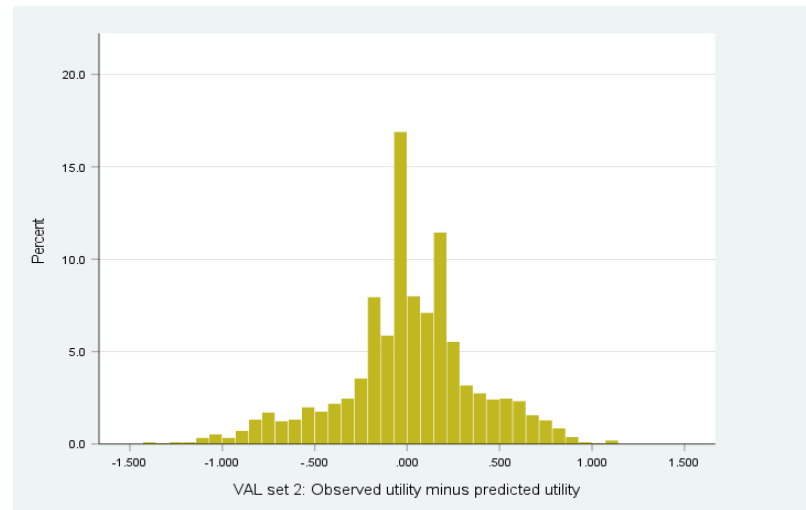


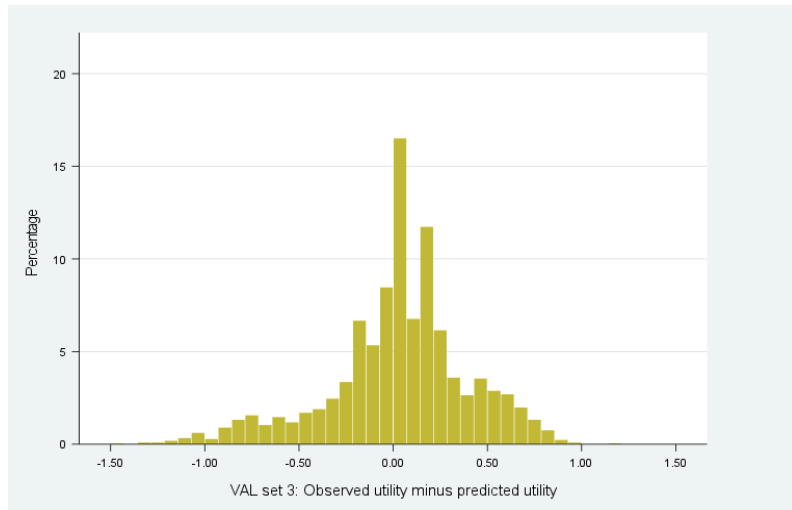
Fig S3 (a)-(j) Histograms demonstrating the mean difference between predicted and actual utility scores for each Monte Carlo simulation



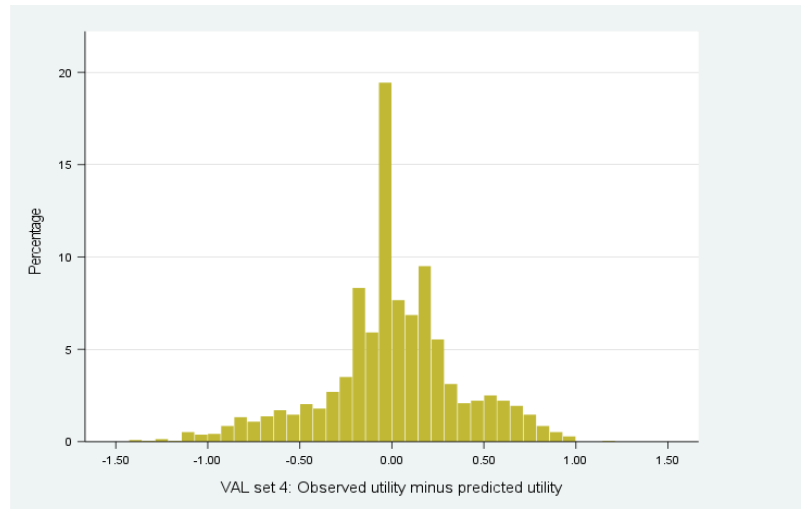
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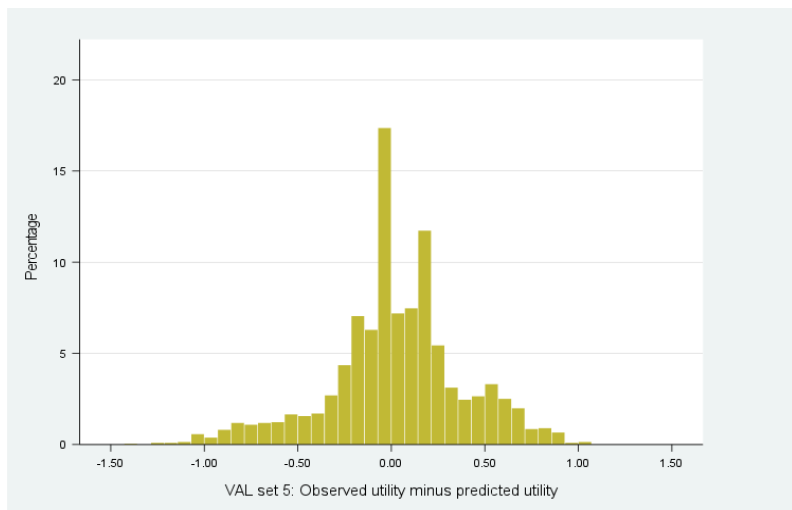
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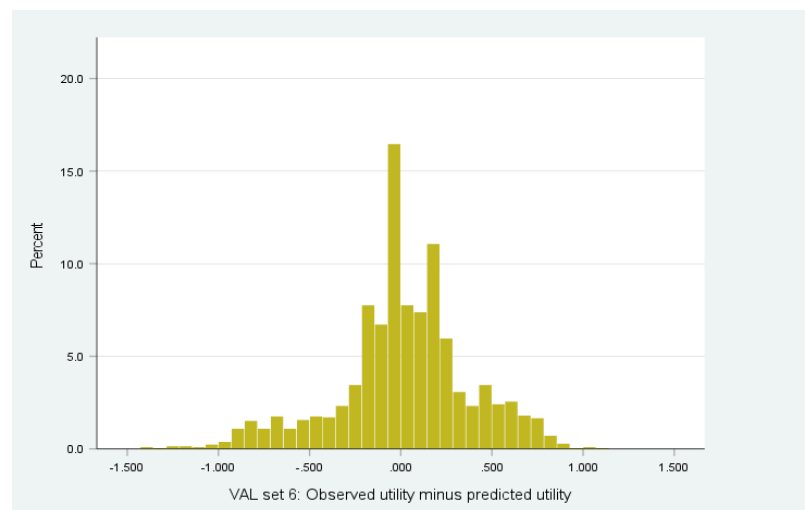
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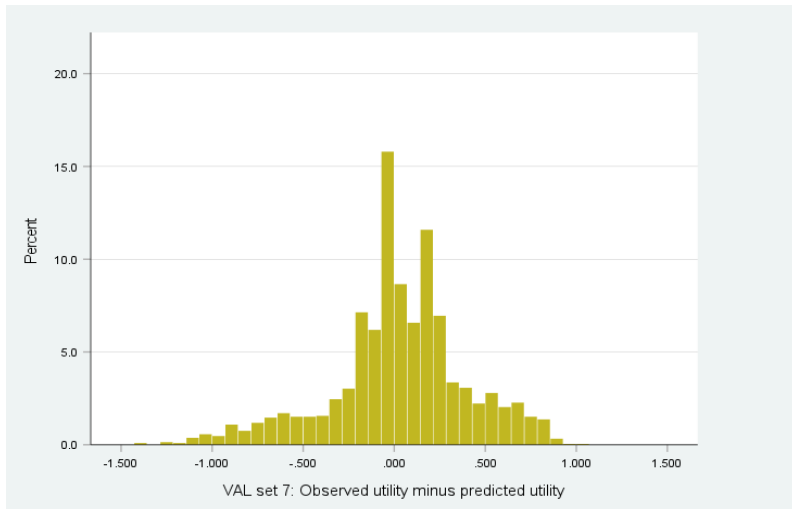
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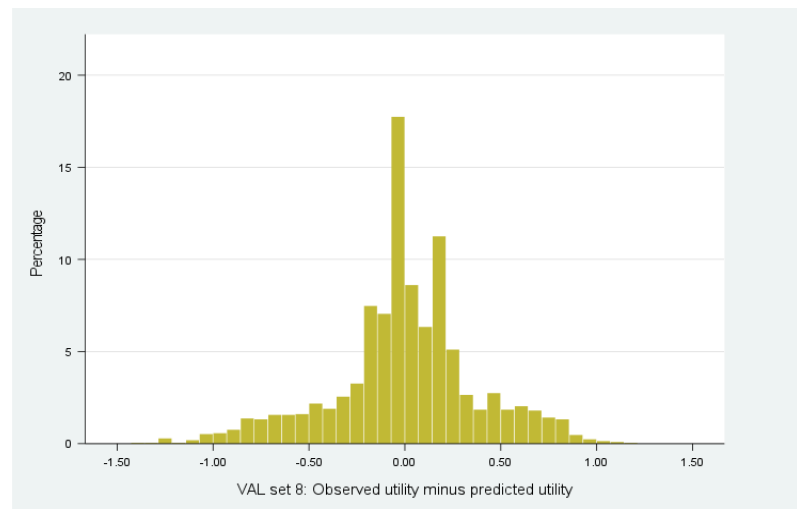
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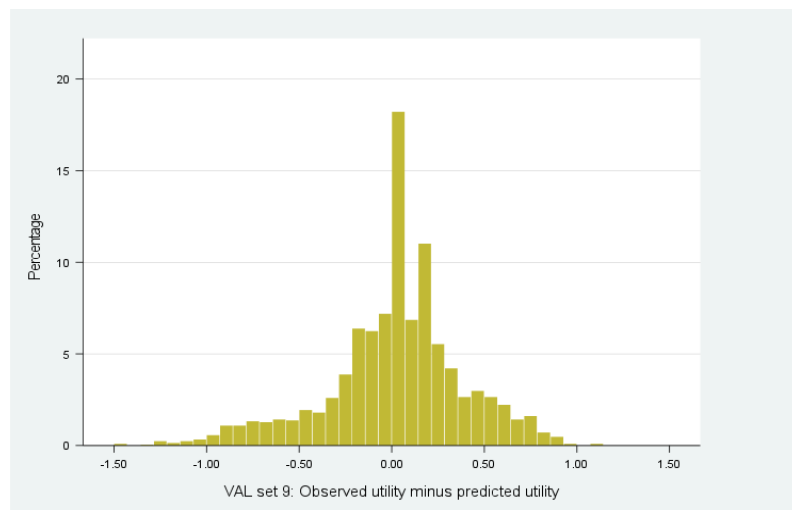
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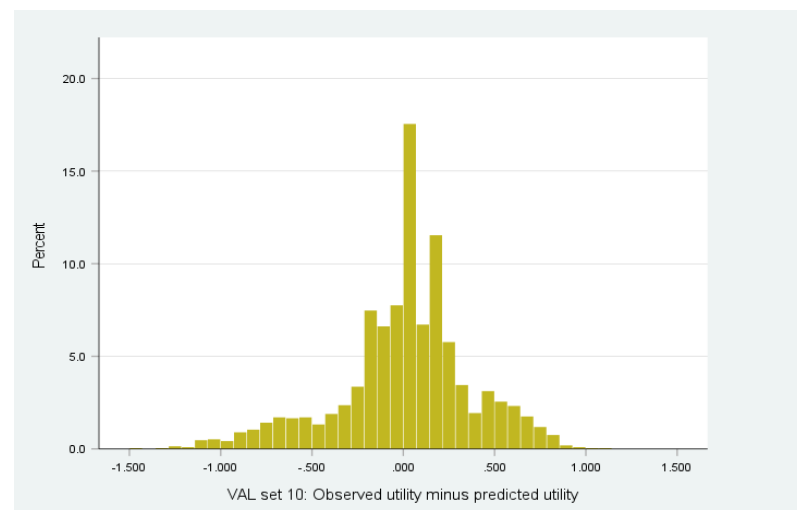
(g)



(h)



(i)



(j)