SUPPLEMENTARY MATERIAL

Supplementary table 1. Summary of questionnaire scales.

Supplementary table 2. Psychological health in UK young adults receiving kidney replacement therapy, and regression analyses by gender, current treatment and starting unit.

Supplementary figure 1. Theoretical model of factors associated with quality of life in young adults receiving kidney replacement therapy.

Directly measured variables are shaded blue and domains are unshaded. There may be bidirectionality between variables.

Supplementary figure 2. Theoretical model of factors associated with medication adherence in young adults receiving kidney replacement therapy.

Directly measured variables are shaded green and domains are unshaded. There may be bidirectionality between variables.

Supplementary table 3. Coefficients and 95% confidence intervals for each variable in the wellbeing model in univariable analyses, for comparison to the mutually adjusted model shown in figure 2.

Supplementary table 4. Coefficients and 95% confidence intervals for each variable in the medication adherence model in univariable analyses, for comparison to the mutually adjusted model shown in figure 3.

Supplementary table 1. Summary of questionnaire scales.

Scale	Acronym	Purpose	Items	Format	Response	Scoring method used	Source	Permission	Adaptations	References
EuroQol 5- Dimensions	EQ-5D-3L	Brief self-report health status measure.	5	Five areas of mobility, self-care, usual activities, pain/discomfort and anxiety/depression.	3 level	Combinations converted into valuations using the time trade off method, providing a tariff with negative scores for states worse than death, a score of 0 for death and 1 for full health.	EuroQol Group	Used under licence from the EuroQol Research Foundation.	None	(1-4)
General health questionnaire	GHQ-12	Short term screening tool for minor psychiatric disorders/mental distress with a focus on depressive symptoms.	12	Questions concerning mental states prefaced by the lead in 'Have you recently', e.g. 'lost much sleep over worry?'.	4-item Likert scale	Binary scoring for each item, giving a total score of 12. Higher scores indicate worse psychological health. Scores can be grouped: 0 'No evidence of probable mental ill health'; 1 to 3 'Less than optimal mental health' and ≥4 'Probable psychological disturbance or mental ill health'	Goldberg	Used under licence from GL Assessment Ltd.	None	(5, 6)
Independence with Activities of Daily Living	IADL	Assess independent living skills.	9	Questions regarding everyday activities.	3 level	Each item scored (1 to 3), giving a total score of 27. Higher scores describe greater functional ability.	Lawton and Brody	Scale in the public domain.	None	(7, 8)
Morisky Medication Adherence Scale ¹	MMAS-8	Assess medication adherence.	8	Questions about circumstances when medication may be omitted.	Questions 1 to 7 are binary; question 8 has a five- item Likert scale.	Binary scoring, with frequency question scored (0 to 4) and divided by 4. Higher scores indicate better medication adherence. Scores can be grouped: <6 'low'; 6 to 7 'medium' and 8 'high' adherence.	Morisky	Used under licence from Professor Morisky.	None	(9-12)
Body Image Scale	BIS	Assess negative body image.	10	Questions about negative body image scenarios.	4-item Likert scale with 'Not applicable' option	Each item scored (0 to 3), giving a total score of 30. Higher scores indicate more negative body image change or dissatisfaction.	Hopwood	Scale in the public domain.	None	(13)

Those in full-time

Social Impact Scale	SIS	Assess the level of stigma over domains of social rejection, financial insecurity, internalised shame and social isolation.	24	Statements about experiences of stigma.	4-item Likert scale	Each item is scored (1 to 4), and summed to produce subscale and overall totals. Higher scores indicate greater stigma.	Fife and Wright	Scale in the public domain.	education were not asked the financial insecurity questions. For the item 'My employer/co-workers have discriminated against me', 'classmates' was added.	(14, 15)
Multidimensional Scale of Perceived Social Support	MSPSS	Assess perceptions of social support.	12	Items covering domains of family, friends and significant others.	7-item Likert scale	Each item is scored (1 to 7) and summed to produce subscale and overall totals. Higher scores indicate greater social support.	Zimet	Scale in the public domain.	None 'I think my	(16)
Patient Satisfaction Questionnaire	PSQ-18	Assess aspects of satisfaction with healthcare experiences.	18	Statements over areas of General Satisfaction, Technical Quality, Interpersonal Manner, Communication, Financial aspects, Time Spent with Doctor and Accessibility and Convenience.	5-item Likert scale	Each item is scored (1 to 5). Items 1 - 3, 5 - 6, 8, 11, 15 and 18 are reversed scored. Subscale scores are created from the mean score of the component items, with higher scores indicating greater satisfaction.	RAND corporation	Scale in the public domain.	doctor's office has everything needed to provide complete medical care' was changed to 'I think my kidney unit has everything needed to provide complete medical care'	(17, 18)
Warwick- Edinburgh Mental Wellbeing Scale	WEMWBS	Measure of mental wellbeing over last two weeks.	14	Positively-worded questions about feelings and psychological functioning.	5-item Likert scale	Each item is scored (1 to 5) and summed to produce an overall score, with higher scores indicating greater mental wellbeing.	NHS Health Scotland, University of Warwick and University of Edinburgh	Use registered with the University of Warwick.	None	(19)
Acceptance of Illness Scale	AIS	Assess acceptance of illness.	8	Statements regarding different opinions about having chronic disease.	5-item Likert scale	Each item is scored (1 to 5) and summed. Score thresholds have been defined; <18 being no acceptance, 19 to 29 moderate acceptance and >29 good acceptance.	Felton	Scale in the public domain.	'My health condition makes me feel a man of good value' was changed to 'My health condition makes me feel a person of good value'.	(20, 21)

Quality of Life Scale	QOLS	Assess quality of life.	16	domains of material and physical wellbeing; relationships with other people; social, community and civic activities; personal development and fulfilment; recreation; and independence, the ability to do for yourself.	7-item Likert scale	Each item is scored (1 to 7), and summed to produce an overall quality of life score, with higher scores indicating greater quality of life.	Flanagan, Burckhardt	Scale in the public domain.	British English used.	(29)
Patient Activation Measure	PAM-13	Assess a person's self-belief, ability and awareness in managing their own healthcare.	13	Statements about healthcare confidence, skills and knowledge. Statements covering	4-item Likert scale with ' <i>Not</i> applicable' option	Each item is scored (1 to 4), and summed. Raw scores are mapped onto a 0-100 scale, with higher scores indicating greater activation, and cut-offs for four levels of activation: <47.1 level 1, ≥47.1 - <55.2 level 2, ≥55.2 - <72.4 level 3 and ≥72.4 level 4.	Hibbard	Used under licence from Insignia Health via NHS England and the United Kingdom Renal Registry.	None	(25-28)
Big Five Inventory	BFI	Assess personality traits.	44	Statements about personality traits. The statements cover the domains of Extraversion, Agreeableness, Conscientiousness, Neuroticism, and Openness.	5-item Likert scale	Each item is scored (1 to 5; 16 items are reverse scored), and averaged to give domain scores. Higher scores indicate a higher degree of the domain characteristic.	John	Free for non- commercial research use.	British English used.	(24)
Multidimensional Health Locus of Control	МНСС	Assess beliefs of control over one's health outcomes. We used Form B, for those with chronic disease states.	18	Statements about control over health, covering domains of internality, powerful others externality and chance externality.	6-item Likert scale	Each item is scored (1 to 6), and summed to produce subscale scores (no total). Higher scores indicate a higher degree of the subscale characteristic.	Wallston	Scale in the public domain.	None	(22, 23)

References contain information on scale psychometric properties.

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Supplementary table 2. Psychological health in UK renal young adults receiving renal replacement therapy, and regression analyses by gender, current treatment and starting unit.

Scale	Possible range	N	Weighted average score	Weighted measure of variability					By modality (dialysis v. transplant), adjusted for age and sex				By start (adult v. paediatric), adjusted for age and sex				By duration (≥5 years v. <5 years), adjusted for age and sex			
	range		average score	variability	OR/β	959 Lower	% CI Upper	p value	OR/β		% CI Upper	p value	OR/β		% CI Upper	p value	OR/β		% CI Upper	p value
			Median	IQR	<u>OR</u>				OR				<u>OR</u>				<u>OR</u>			
EQ-5D-3L tariff ¹	-0.59, 1.00	538	0.80	0.62, 1.00	1.67	1.16	2.39	0.007	0.31	0.19	0.51	<0.001	0.78	0.47	1.28	0.3	1.07	0.66	1.77	0.8
General health questionnaire (GHQ-12) ²	0, 12	527	1	0,5	0.58	0.41	0.83	0.003	1.90	1.22	2.94	0.005	1.15	0.80	1.65	0.4	1.04	0.71	1.51	0.9
Morisky medication adherence scale (MMAS-8) ³	0, 8	543	6.5	4.75, 7	1.67	1.21	2.27	0.002	0.40	0.25	0.64	<0.001	0.78	0.52	1.16	0.2	1.16	0.82	1.65	0.4
Independence with activities of daily living scale	9, 27	545	26	21, 27	2.01	1.30	3.10	0.002	0.28	0.16	0.46	<0.001	1.35	0.90	2.03	0.1	0.99	0.67	1.46	0.96
Body image scale	0, 30	520	9	3, 18	0.38	0.24	0.59	<0.001	1.73	1.09	2.75	0.02	1.19	0.86	1.63	0.3	1.07	0.71	1.60	0.7
Social impact scale	21, 96	467	40	28, 53	0.45	0.29	0.70	0.001	2.46	1.57	3.86	<0.001	1.08	0.72	1.62	0.7	1.02	0.72	1.45	0.9
Multidimensional scale of perceived social support	12, 84	499	65	54, 75	0.87	0.58	1.31	0.5	0.90	0.61	1.35	0.6	0.77	0.52	1.14	0.2	1.14	0.78	1.67	0.5
Patient satisfaction questionnaire (PSQ-18)																				
General Satisfaction	1, 5	500	4	3, 4.5	1.34	0.85	2.08	0.2	0.55	0.38	0.80	0.002	0.99	0.66	1.48	0.9	0.76	0.52	1.12	0.2
Technical Quality	1, 5	499	4	3.5, 4.5	1.15	0.76	1.77	0.5	0.53	0.33	0.85	0.01	0.99	0.66	1.48	0.9	0.70	0.49	1.01	0.06
Interpersonal Manner	1, 5	502	4	3.5, 5	1.30	0.92	1.84	0.1	0.71	0.51	1.01	0.06	0.84	0.57	1.27	0.4	0.74	0.55	0.98	0.04
Communication	1,5	503	4	3.5, 4.5	1.42	0.90	2.23	0.1	0.58	0.40	0.84	0.004	0.68	0.44	1.06	0.09	1.03	0.70	1.51	0.9
Financial aspects	1,5	499	4.5	3.5, 5	1.14	0.80	1.63	0.4	0.88	0.54	1.42	0.6	0.87	0.57	1.35	0.5	0.85	0.55	1.31	0.5
Time Spent with Doctor	1, 5	501	4	3, 4	1.42	0.90	2.23	0.1	0.39	0.23	0.68	0.001	0.73	0.45	1.20	0.2	0.98	0.68	1.42	0.9
Accessibility and Convenience	1, 5	500	3.75	3.25, 4.25	1.30	0.82	2.05	0.3	0.52	0.36	0.75	0.001	0.61	0.42	0.89	0.01	0.94	0.67	1.32	0.72
			Mean	SD	<u>B</u>				β				<u>β</u>				<u>β</u>			
Warwick-Edinburgh mental wellbeing scale (WEMWBS)	14, 70	535	47.4	11.5	4.36	2.50	6.22	<0.001	-5.61	-7.92	-3.29	<0.001	-0.72	-3.12	1.68	0.6	-0.63	-2.72	1.46	0.6
Acceptance of illness scale	8, 40	485	26.1	7.4	2.95	1.38	4.53	<0.001	-5.35	-6.78	-3.91	<0.001	-1.61	-2.96	-0.26	0.02	0.81	-0.47	2.10	0.2
Multidimensional health locus of control scale																				
Internal	6, 36	486	22.2	5.3	2.02	1.13	2.90	<0.001	-1.16	-2.24	-0.08	0.04	-0.42	-1.28	0.44	0.3	0.87	-0.17	1.90	0.1
Chance	6, 36	483	20.3	5.1	-0.33	-1.23	0.57	0.5	0.05	-1.04	1.13	0.9	-0.02	-1.08	1.03	0.97	0.39	-0.77	1.55	0.5
Powerful others	6, 36	484	21.7	5.0	0.90	-0.01	1.81	0.05	-0.65	-1.81	0.51	0.3	-0.40	-1.66	0.86	0.5	-0.54	-1.61	0.52	0.3
Big five inventory (BFI-44)																				
Extraversion	1, 5	482	3.02	0.77	0.10	-0.07	0.27	0.2	-0.09	-0.27	0.08	0.3	-0.11	-0.28	0.06	0.2	0.12	-0.04	0.28	0.1
Agreeableness	1,5	482	3.76	0.58	-0.03	-0.14	0.08	0.6	-0.11	-0.21	-0.001	0.048	-0.09	-0.20	0.03	0.1	0.04	-0.11	0.18	0.6
Conscientiousness	1,5	479	3.43	0.66	0.03	-0.08	0.15	0.5	-0.20	-0.34	-0.05	0.01	-0.13	-0.27	0.02	0.1	0.11	-0.03	0.25	0.1
Neuroticism	1,5	481	3.12	0.85	-0.47	-0.62	-0.32	<0.001	0.21	0.05	0.37	0.01	0.02	-0.14	0.19	0.8	-0.005	-0.20	0.19	0.96
Openness	1, 5	480	3.40	0.56	0.13	0.04	0.22	0.005	-0.01	-0.11	0.10	0.9	0.05	-0.07	0.17	0.4	-0.04	-0.15	0.07	0.4
Patient activation measure (PAM-13)	0, 100	461	59.3	15.1	2.96	-0.33	6.25	0.08	-4.52	-6.94	-2.10	<0.001	-3.09	-5.89	-0.30	0.03	2.35	-0.85	5.56	0.1
Quality of life scale	16, 112	465	79.8	17.8	3.79	0.94	6.64	0.01	-6.79	-10.7	-2.85	0.001	-0.20	-3.98	3.58	0.9	-0.16	-4.14	3.81	0.9

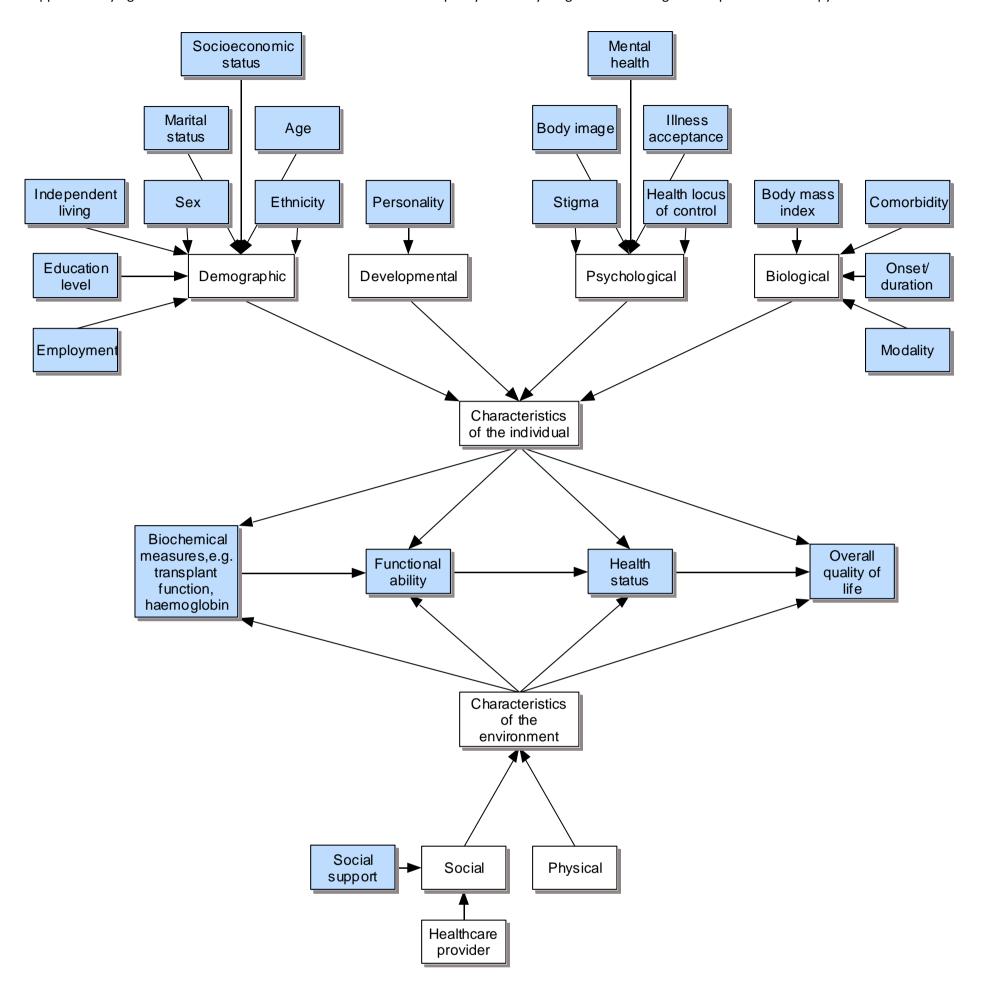
OR – Odds ratio; CI - confidence interval; IQR - interquartile range; SD - standard deviation

Data weighted by gender, ethnicity and index of multiple deprivation to be representative of prevalent UK young adults receiving RRT.

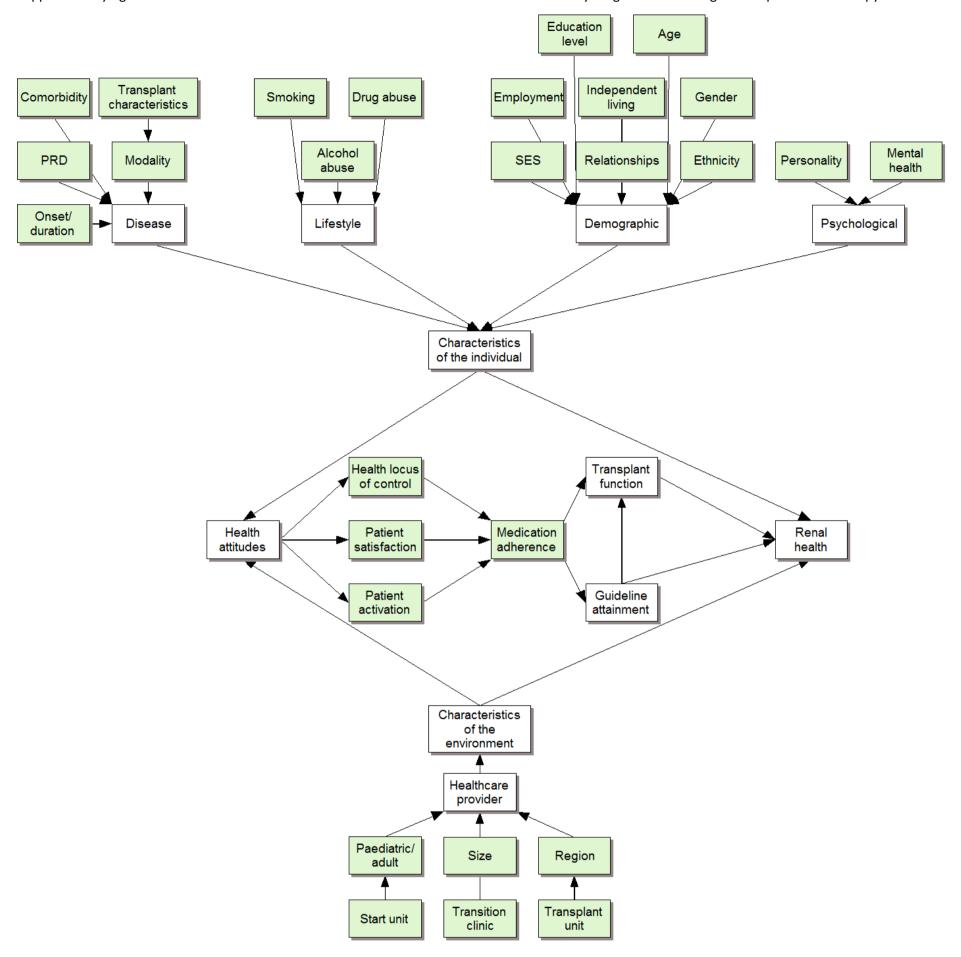
Where non-parametric, scale scores are grouped into whether >50th centile or not for logistic regression analyses unless otherwise stated. For parametric data, beta coefficients represent the change in scale units (described in table 2).

- 1. Grouped in logistic regression analyses as 'No problems/'Some problems' corresponding to a tariff of 1 or <1.
- 2. Grouped in ordered regression analyses as 'No evidence of probable mental ill health'/'Less than optimal mental health'/'Probable psychological disturbance or mental ill health' corresponding to a scale score of 0, 1 to 3, or 4+.
- 3. Use of the ©MMAS is protected by US copyright laws. Permission for use is required. A license agreement is available from Morisky Research LLC. The MMAS-8 was grouped in ordered regression analyses as low/medium/high adherence corresponding to a scale score of <6, 6 to 7, or 8.

Supplementary figure 1. Theoretical model of factors associated with quality of life in young adults receiving renal replacement therapy.



Supplementary figure 2. Theoretical model of factors associated with medication adherence in young adults receiving renal replacement therapy.



Supplementary table 3. Coefficients and 95% confidence intervals for each variable in the wellbeing model in univariable analyses, for comparison to the mutually adjusted model shown in figure 2.

Variable (adjusted for age and sex)	R	95%	p value	
variable (adjusted for age and sex)	β	Lower	Upper	p value
Personality				
Extraversion	7.57	6.42	8.71	<0.001
Openness	4.86	3.10	6.63	< 0.001
Neuroticism	-8.49	-9.47	-7.50	< 0.001
Psychosocial health				
Independent with activities of daily living	9.19	7.32	11.1	<0.001
Above average social support	10.2	8.44	12.0	<0.001
Negative body image	-7.33	-8.28	-6.39	<0.001
Greater social impact	-8.83	-9.92	-7.74	<0.001
Psychological disturbance	-15.4	-17.1	-13.8	<0.001
Treatment (cf. Transplant)				
Dialysis	-6.30	-8.44	-4.15	<0.001
Gender (unadjusted)				
Male	3.84	1.92	5.76	< 0.001
Age group (cf. 21 to <26 years) (unadjusted)				
16 to <21	2.53	-0.24	5.30	0.07
26 to 30	-0.29	-2.52	1.94	0.8

Supplementary table 4. Coefficients and 95% confidence intervals for each variable in the medication adherence model in univariable analyses, for comparison to the mutually adjusted model shown in figure 3.

Variable (adjusted for one and equi)	0	95%		
Variable (adjusted for age and sex)	β	Lower	Upper	p value
Clinical				
Any additional condition	-0.79	-1.12	-0.47	< 0.001
Dialysis	-1.12	-1.48	-0.76	<0.001
Age left education (cf. 19 and over)				
Not yet finished	-0.61	-1.17	-0.06	0.03
16 or under	-0.68	-1.16	-0.20	0.005
17 to 18	-0.44	-0.85	-0.04	0.03
Social				
Lives with parents	0.50	0.13	0.86	0.008
Ethnicity (cf. White)				
Asian	-0.44	-1.03	0.14	0.1
Black	-1.02	-1.90	-0.14	0.02
Mixed/Other	-1.01	-2.00	-0.02	0.05
Personality				
Conscientiousness	1.08	0.84	1.32	< 0.001
Psychosocial health				
Psychological disturbance	-1.33	-1.66	-0.99	< 0.001
Satisfaction with access to doctor	0.68	0.47	0.89	< 0.001
Patient activation (cf. Level 1)				
Level 2	0.84	0.34	1.33	0.001
Level 3	1.42	1.00	1.84	< 0.001
Level 4	1.59	1.11	2.08	< 0.001
Gender (unadjusted)				
Male	0.60	0.27	0.92	< 0.001
Age group (cf. 21 to <26 years) (unadjusted)				
16 to <21	0.44	-0.03	0.91	0.07
26 to 30	0.33	-0.04	0.71	0.08