

Appendix G

Coding: Ethnicity, EDTA Primary Renal Diagnoses, EDTA Causes of Death and Treatment Timeline Modality Codes

G1: Ethnicity coding

Ethnicity data is recorded in the clinical information systems in the individual renal centres in the format of 9S... read codes.

Ethnic category	Read code	Old PAS	Renal Assoc	New PAS
White	9S1..	0	W	A1
Black Caribbean	9S2..	1		M1
Black African	9S3..	2		N1
Black other/non-mixed origin	9S4..	3		P1
Indian	9S6..	4		H1
Pakistani	9S7..	5		J1
Bangladeshi	9S8..	6		K1
Chinese	9S9..	7	C	R1
Black British	9S41.			PD
Black Caribbean	9S42.			
Black North African	9S43.			
Black other African country	9S44.			
Black East African Asian	9S45.			
Black Indian sub-continent	9S46.			
Black other Asian	9S47.			
Black Black other	9S48.		B	PE
Black other/mixed	9S5..			
Other Black Black/White origin	9S51.			GC
Other Black Black/Asian origin	9S52.			GA
Other ethnic non-mixed (NMO)	9SA..			
Brit. ethnic minor. spec. (NMO)	9SA1.			
Brit. ethnic minor. unsp. (NMO)	9SA2.			
Caribbean Island (NMO)	9SA3.			
North African Arab (NMO)	9SA4.			
Other African countries (NMO)	9SA5.			
East African Asian (NMO)	9SA6.			
Indian sub-continent (NMO)	9SA7.			
Other Asian (NMO)	9SA8.		A	L1

Ethnic category	Read code	Old PAS	Renal Assoc	New PAS
Irish (NMO)	9SA9.			B1
Greek Cypriot (NMO)	9SAA.			CG
Turkish Cypriot (NMO)	9SAB.			CJ
Other European (NMO)	9SAC.			C1
Other ethnic NEC (NMO)	9SAD.			S1
Other ethnic mixed origin	9SB..	8		
Other ethnic Black/White origin	9SB1.			E1
Other ethnic Asian/White origin	9SB2.			F1
Other ethnic mixed white origin	9SB3.			
Other ethnic other mixed origin	9SB4.			G1

G2: EDTA primary renal diagnoses

Code	Title	Group
0	Chronic renal failure; aetiology uncertain unknown/unavailable	Uncertain
10	Glomerulonephritis; histologically NOT examined	Uncertain
11	Focal segmental glomerulosclerosis with nephrotic syndrome in children	Glomerulonephritis
12	IgA nephropathy (proven by immunofluorescence, not code 76 and not 85)	Glomerulonephritis
13	Dense deposit disease; membrano-proliferative GN; type II (proven by immunofluorescence and/or electron microscopy)	Glomerulonephritis
14	Membranous nephropathy	Glomerulonephritis
15	Membrano-proliferative GN; type I (proven by immunofluorescence and/or electron microscopy – not code 84 or 89)	Glomerulonephritis
16	Crescentic (extracapillary) glomerulonephritis (type I, II, III)	Glomerulonephritis
17	Focal segmental glomerulosclerosis with nephrotic syndrome in adults	Glomerulonephritis
19	Glomerulonephritis; histologically examined, not given above	Glomerulonephritis
20	Pyelonephritis – cause not specified	Pyelonephritis
21	Pyelonephritis associated with neurogenic bladder	Pyelonephritis
22	Pyelonephritis due to congenital obstructive uropathy with/without vesico-ureteric reflux	Pyelonephritis
23	Pyelonephritis due to acquired obstructive uropathy	Pyelonephritis
24	Pyelonephritis due to vesico-ureteric reflux without obstruction	Pyelonephritis
25	Pyelonephritis due to urolithiasis	Pyelonephritis
29	Pyelonephritis due to other cause	Pyelonephritis
30	Interstitial nephritis (not pyelonephritis) due to other cause, or unspecified (not mentioned above)	Interstitial
31	Nephropathy (interstitial) due to analgesic drugs	Interstitial
32	Nephropathy (interstitial) due to cis-platinum	Interstitial
33	Nephropathy (interstitial) due to cyclosporin A	Interstitial
34	Lead induced nephropathy (interstitial)	Interstitial
39	Drug induced nephropathy (interstitial) not mentioned above	Interstitial
40	Cystic kidney disease – type unspecified	Cystic/poly
41	Polycystic kidneys; adult type (dominant)	Cystic/poly
42	Polycystic kidneys; infantile (recessive)	Cystic/poly
43	Medullary cystic disease; including nephronoptosis	Other
49	Cystic kidney disease – other specified type	Other
50	Hereditary/Familial nephropathy – type unspecified	Other
51	Hereditary nephritis with nerve deafness (Alport's Syndrome)	Other
52	Cystinosis	Other
53	Primary oxalosis	Other
54	Fabry's disease	Other
59	Hereditary nephropathy – other specified type	Other
60	Renal hypoplasia (congenital) – type unspecified	Other
61	Oligomeganephronic hypoplasia	Other

Code	Title	Group
63	Congenital renal dysplasia with or without urinary tract malformation	Other
66	Syndrome of agenesis of abdominal muscles (Prune Belly)	Other
70	Renal vascular disease – type unspecified	Renal vascular disease
71	Renal vascular disease due to malignant hypertension	Renal vascular disease
72	Renal vascular disease due to hypertension	Renal vascular disease
73	Renal vascular disease due to polyarteritis	Renal vascular disease
74	Wegener's granulomatosis	Other
75	Ischaemic renal disease/cholesterol embolism	Renal vascular disease
76	Glomerulonephritis related to liver cirrhosis	Other
78	Cryoglobulinemic glomerulonephritis	Other
79	Renal vascular disease – due to other cause (not given above and not code 84–88)	Renal vascular disease
80	Type 1 diabetes with diabetic nephropathy	Diabetes
81	Type 2 diabetes with diabetic nephropathy	Diabetes
82	Myelomatosis/light chain deposit disease	Other
83	Amyloid	Other
84	Lupus erythematosus	Other
85	Henoch-Schoenlein purpura	Other
86	Goodpasture's Syndrome	Other
87	Systemic sclerosis (scleroderma)	Other
88	Haemolytic Uraemic Syndrome (including Moschcowitz Syndrome)	Other
89	Multi-system disease – other (not mentioned above)	Other
90	Tubular necrosis (irreversible) or cortical necrosis (different from 88)	Other
91	Tuberculosis	Other
92	Gout nephropathy (urate)	Other
93	Nephrocalcinosis and hypercalcaemic nephropathy	Other
94	Balkan nephropathy	Other
95	Kidney tumour	Other
96	Traumatic or surgical loss of kidney	Other
98	Not known	Missing
99	Other identified renal disorders	Other
199	Code not sent	Missing

G3: EDTA cause of death

EDTA code	Cause
0	Cause of death uncertain/not determined
11	Myocardial ischaemia and infarction
12	Hyperkalaemia
13	Haemorrhagic pericarditis
14	Other causes of cardiac failure
15	Cardiac arrest/sudden death; other cause or unknown
16	Hypertensive cardiac failure
17	Hypokalaemia
18	Fluid overload/pulmonary oedema
21	Pulmonary embolus
22	Cerebro-vascular accident, other cause or unspecified
23	Gastro-intestinal haemorrhage (digestive)
24	Haemorrhage from graft site
25	Haemorrhage from vascular access or dialysis circuit
26	Haemorrhage from ruptured vascular aneurysm (not code 22 or 23)
27	Haemorrhage from surgery (not codes 23, 24, 26)
28	Other haemorrhage (not codes 23–27)
29	Mesenteric infarction
31	Pulmonary infection bacterial (not code 73)
32	Pulmonary infection (viral)
33	Pulmonary infection (fungal or protozoal; parasitic)
34	Infections elsewhere except viral hepatitis
35	Septicaemia
36	Tuberculosis (lung)
37	Tuberculosis (elsewhere)
38	Generalized viral infection
39	Peritonitis (all causes except for peritoneal dialysis)
41	Liver disease due to hepatitis B virus
42	Liver disease due to other viral hepatitis
43	Liver disease due to drug toxicity
44	Cirrhosis – not viral (alcoholic or other cause)
45	Cystic liver disease
46	Liver failure – cause unknown
51	Patient refused further treatment for end stage renal failure (ESRF)
52	Suicide
53	ESRF treatment ceased for any other reason
54	ESRF treatment withdrawn for medical reasons
61	Uraemia caused by graft failure
62	Pancreatitis
63	Bone marrow depression (Aplasia)
64	Cachexia
66	Malignant disease in patient treated by immunosuppressive therapy
67	Malignant disease: solid tumours except those of 66
68	Malignant disease: lymphoproliferative disorders (except 66)
69	Dementia
70	Peritonitis (sclerosing, with peritoneal dialysis)
71	Perforation of peptic ulcer
72	Perforation of colon
73	Chronic obstructive pulmonary disease
81	Accident related to ESRF treatment (not 25)
82	Accident unrelated to ESRF treatment
99	Other identified cause of death
100	Peritonitis (bacterial, with peritoneal dialysis)
101	Peritonitis (fungal, with peritoneal dialysis)
102	Peritonitis (due to other cause, with peritoneal dialysis)

G4: Treatment timeline – modality codes RR7 (version 3.14)

EDTA code	RR code TXT timeline*	RR code QUA/QBL treatment**	Description
1	1	1	Haemodialysis
2	2	2	Haemofiltration
3	3	3	Haemodiafiltration
1	4	4	Haemodialysis >4 days per week/daily
4	5	5	Ultrafiltration
4	9	9	Haemodialysis – type unknown
5	10	10	CAPD connect
5	11	11	CAPD disconnect
6	12	12	Cycling PD ≥6 nights/wk dry
6	13	13	Cycling PD <6 nights/wk dry
6	14	14	Cycling PD ≥6 nights/wk wet (day dwell)
6	15	15	Cycling PD <6 nights/wk wet (day dwell)
	16	16	Assisted Cycling PD ≥6 nights/wk dry
	17	17	Assisted Cycling PD ≥6 nights/wk wet (day dwell)
7	19	19	Peritoneal dialysis – type unknown
8	20	20	Transplant; Cadaver donor
9	21	21	Transplant; Live related – sibling
10	22	22	Transplant; Live related – parent or child
	23	23	Transplant; Live related – other
11	24	24	Transplant; Live genetically unrelated
12	25	25	Transplant; Cadaver donor + transp other organ
13	26	26	Transplant; Live donor + transplant other organ
	27	27	Transplant; Cadaver donor non-UK transplant
	87	87	Transplant; Live donor non-UK transplant
8	28	28	Transplant; non-heart-beating donor
14	29	29	Transplant; type unknown
	30		Graft failure
	31		Graft acute rejection episode – biopsy proven
	32	29	Graft acute rejection episode – no biopsy
	35	29	Transfer in pre-emptive transplant
	36		Transfer out pre-emptive transplant
	37		Transfer to adult nephrology
15	38		Patient transferred out
16	39		Transfer in from another centre treatment unknown
16	41	1	Transfer in on: Haemodialysis
16	42	2	Transfer in on: Haemofiltration
16	43	3	Transfer in on: Haemodiafiltration
16	44	4	Transfer in on: Haemodialysis >4 days per week
16	45	5	Transfer in on: Ultrafiltration
16	49	9	Transfer in on: Haemodialysis – type unknown
16	50	10	Transfer in on: CAPD connect
16	51	11	Transfer in on: CAPD disconnect
16	52	12	Transfer in on: Cycling PD ≥6 nights/wk with without bag
16	53	13	Transfer in on: Cycling PD <6 nights/wk dry
16	54	14	Transfer in on: Cycling PD ≥6 nights/wk wet (day dwell)
16	55	15	Transfer in on: Cycling PD <6 nights/wk wet (day dwell)
16	56	16	Transfer in on: Assisted Cycling PD ≥6 nights/wk dry
16	57	17	Transfer in on: Assisted Cycling PD ≥6 nights/wk wet (day dwell)
16	59	19	Transfer in on: Peritoneal dialysis – type unknown
16	60	20	Transfer in on: Transplant; Cadaver donor
16	61	21	Transfer in on: Transplant; Live related – sibling
16	62	22	Transfer in on: Transplant; Live related – parent or child
16	63	23	Transfer in on: Transplant; Live related – other
16	64	24	Transfer in on: Transplant; Live genetically unrelated

EDTA code	RR code TXT timeline*	RR code QUA/QBL treatment**	Description
16	65	25	Transfer in on: Transplant; Cadaver + transp other organ
16	66	26	Transfer in on: Transplant; Live donor + transp other organ
	68	28	Transfer in on: Transplant; non-heart-beating donor
16	69	29	Transfer in on: Transplant; type unknown
	72		Graft functioning
	76		Nephrectomy – transplant
	79		Transplant pancreas (only)
	80		Acute renal failure not dialysed
	81		Acute haemodialysis – ARF
	82		Acute haemofiltration – ARF
	83		Acute peritoneal dialysis – ARF
	84		ARF recovered
	85		ARF – stopped dialysis (without recovery of function)
	86		ARF – transferred out
18	90		Patient – renal function recovered
	91		Patient – treatment stopped (without recovery of function)
	92		Treatment stopped without recovery – conservative management
	93		Conservative Management – mutual decision not to offer RRT
	94		Clinical Decision not to offer RRT – conservative management
17	95		Patient lost to follow up
			Died

*TXT timeline – Registry timeline

**QUA/QBL treatment – quarterly and monthly treatment blocks