Appendix A

Definitions and methodologies used in the 21st Annual Report – data to the end of 2017

Contents

1 The UK Renal Registry (UKRR) Annual Report

The UKRR was established by The Renal Association in 1995 with the primary aim of collating data centrally from all adult UK renal centres to improve the care of patients with end-stage kidney disease (ESKD). Children on renal replacement therapy (RRT) were initially captured by a separate registry established by the British Association for Paediatric Nephrology, but this activity passed over to the UKRR from 2009. The Renal Association has an active and involved patient council (https://www.renalreg.org/study-groups/the-uk-renal-registry-patient-council-study-group/).

Although originally limited to patients on RRT – dialysis treatments and kidney transplant (Tx) recipients – the UKRR has started to collect all cases of acute kidney injury (AKI) in primary and secondary care (in England only) and all cases of chronic kidney disease (CKD) stages 2–5 in secondary care not on dialysis. Collecting and reporting AKI and CKD data will in time allow the UKRR to report the journeys of patients who go on to start RRT, as well as those who choose responsive management instead of RRT.

The UKRR collects data to benchmark each of the UK's 71 adult and 13 paediatric renal centres against The Renal Association audit standards (https://renal.org/guidelines/) and publishes an annual report comprising centre comparisons, attainment of audit standards, national averages and long term trends for measures of renal care and patient outcomes.

The UKRR Annual Report focuses predominantly on patients with ESKD who are on RRT. Each chapter of the report analyses a subset of these patients as detailed in the populations section.

1.1 Groups of patients with kidney disease

1.1.1 Patients with ESKD on RRT

Throughout this report the term ESKD is used to describe individuals with kidney disease who have progressed to such a point in their disease trajectory that they require either RRT or responsive management. The term ESKD is synonymous with established renal failure, end-stage renal failure and end-stage renal disease. The start date of ESKD is defined as the date of the first dialysis session or receipt of a pre-emptive kidney Tx.

1.1.2 Patients with ESKD on responsive management

Through the addition of CKD data, the UKRR will in future report on patients with ESKD who do not start RRT. However, identifying patients receiving responsive management will depend on patients being coded as such on the treatment timeline.

1.1.3 Patients with CKD

A preliminary analysis of the CKD dataset suggests only around 12 renal centres currently return any CKD data. Before CKD data are incorporated into analyses, further work is required to understand the nature of the data and how patients are defined as having CKD.

1.1.4 Patients with AKI

The term AKI applies to individuals who experience a sudden decline in kidney function, which can be graded from mild to severe. The UKRR reports on the subset of patients with severe AKI receiving acute dialysis whose data are submitted to the UKRR through quarterly renal centre data returns, but there may be gaps in the dataset because of coding issues, or because some patients start in an intensive therapy unit (renal filtration) rather than in a renal centre. Some of these people may recover their kidney function and therefore not require any further RRT, some may die during this period, while others may become established on RRT and be classified as ESKD patients. Patients with AKI are not included in the current UKRR Annual Report.

2 Data flows to the UKRR and data completeness

2.1 Data flows

Patient data flows to the UKRR from different sources, in different ways and with varying frequency, but primarily via quarterly electronic returns from renal centres. Data are collected without patient consent using section 251 permissions of the NHS Act (2006) as detailed in the UKRR privacy notice (https://www.renalreg.org/wp-content/uploads/2019/02/Privacy-statement-GDPR-UKRR.pdf). The current dataset (version 4.2) – the data variables which the UKRR has permission to collect – is available on the UKRR website (https://www.renalreg.org/datasets/the-uk-renal-registry-dataset/). In reality, many variables are currently not well reported to the UKRR and an exercise is being undertaken to improve transparency and completeness of data collection.

The UK Renal Data Collaboration (UKRDC) is an ongoing development which will allow data to flow daily from renal centres to the UKRR. The first renal centres have started sending data to the UKRDC and in future, quarterly returns will be replaced by near real time reporting across all centres. Currently, the UKRDC is being used for those patients signed up to PatientView, a mobile-friendly platform allowing patients near real time access to much of the information in their health record.

2.1.1 CKD and RRT data

The main source of data is the UK's 84 renal centres (adult and paediatric) which mostly send automatic downloads to the UKRR at the end of each quarter (figure A1), although not all centres routinely manage this. English, Welsh and Northern Irish renal centres send their data directly to the UKRR, where data are cleaned and validated prior to analysis. Scottish data are collected, validated and published by the Scottish Renal Registry before they are shared with the UKRR. The data items collected from renal centres are detailed below.

2.1.2 AKI data

Hospital laboratories in England send AKI data to the UKRR on a monthly basis forming the AKI master patient index – an NHS England safety initiative (figure A1). The aim is to collect all episodes of AKI in England. The blood results of a patient with AKI continue to be reported to the UKRR for a further 12 months after the AKI episode to monitor potential renal recovery. The data items in the AKI data flow are limited to demographic and location data rather than the extensive data collected as specified in the CKD and ESKD 4.2 dataset. AKI data are also collected under section 251 permissions. The AKI data are not currently used in the UKRR Annual Report and are instead subject to separate analysis, reporting and publication (https://www.thinkkidneys.nhs.uk/aki/aki-data/).

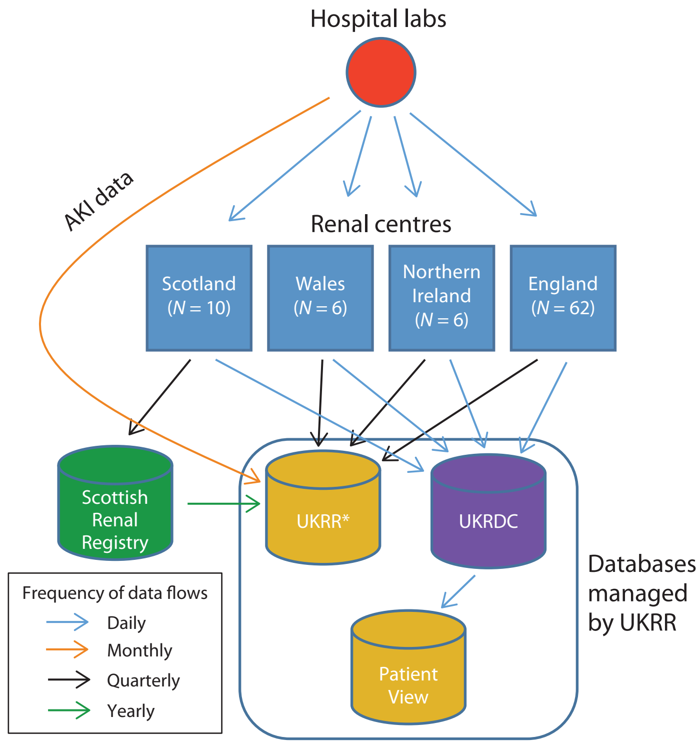

Figure A1 Frequencies and directions of patient data flows between hospital labs, renal centres and databases
*The UKRR database includes the British Association for Paediatric Nephrology database
UKRDC – UK Renal Data Collaboration (at present daily data flows to the UKRDC are for PatientView only)

2.1.3 Other regular sources of data for the UKRR Annual Report

NHS Blood and Transplant (NHSBT) – the UKRR and NHSBT share a dataset on patients who are wait-listed for or who have received a kidney Tx.

Public Health England (PHE) – PHE send the UKRR a dataset on patients on dialysis who have had specific types of blood stream or gut infection in a 12 month period.

NHS Digital Hospital Episode Statistics (HES) for England and the Patient Episode Database for Wales (PEDW) – these datasets include information on patient comorbidities, hospital admissions and lengths of stay, surgical procedures and causes of death. These linkages have the potential to enhance UKRR data in a number of ways, by:

- enabling adjustment for case-mix in centre survival comparisons
- providing information about differences in rates of hospital admission between renal centres
- making it possible to study equity of access to other non-renal services, such as cardiology, stroke and orthopaedics.

2.2 Data completeness

Unless otherwise stated, the data completeness threshold for a data item is ⩾70%, i.e. where a renal centre's data completeness for a data item falls below 70%, the individual centre will be excluded from an analysis, but the national total will include the centre's available data. While poor completeness may reflect a failure to accurately record patient data, other contributing factors include the incompatibility of local renal information technology (IT) systems and the loss of data during the transfer and validation processes on account of coding issues. Data completeness is likely to improve with the development of the UKRDC and increasing uptake of the UKRR dataset 4.2. The dataset has evolved and expanded over time in response to audit guidelines, with an understandable variable lag in the ability of local renal IT systems to respond to those changes.

2.2.1 RRT data
Completeness of data items for patients receiving RRT varies between renal centres as detailed within each chapter.

2.2.2 CKD data
So far only a small number of renal centres are returning CKD data as part of their quarterly extract.

2.2.3 AKI data
Currently 93% of hospital laboratories in England submit AKI data to the UKRR, although not all manage this every month. Until 100% of laboratories consistently report AKI data, some caution will be needed in their interpretation, because a blood test showing recovery may go to a laboratory not currently sharing data. The UKRR reports AKI data in quarterly Clinical Commissioning Group (CCG) reports (https://www.thinkkidneys.nhs.uk/aki/aki-data/).

2.2.4 Comorbidity data
Comorbidity data completeness at the start of RRT remains poor. The linkage of the main UKRR database to HES and PEDW datasets will help to address this issue.

3 How the UKRR looks after patient data

3.1 Information governance

The UKRR continues to receive support under section 251 of the NHS Act (2006) to collect data without individual patient consent. This ensures the robustness and validity of analyses. The fair processing of patient data remains a key principle of the General Data Protection Regulation (2016) and the Data Protection Act (2018). This requires organisations to be clear and open with individuals about how their information is used. The UKRR publishes this information on the UKRR website and in patient information leaflets and posters, which are distributed to all renal centres. Each year the UKRR completes NHS Digital's Data Security and Protection Toolkit. Further information on information governance is available on the UKRR website – see the UKRR privacy notice.

3.2 Small numbers

Data are withheld from some tables due to small numbers of patients in a category, which increases the possibility of identifying patients and sensitive information. Primary suppression is the withholding of information from risky cells for publication. To reach the desired protection for risky cells, it is necessary to suppress additional non-risky cells – this is called complementary (secondary) suppression. The pattern of complementary suppressed cells has to be carefully chosen to provide the desired level of ambiguity for the risky cells, with the least amount of suppressed information. Small numbers may also be suppressed, as stated in the report, where the number of patients is too small to allow meaningful statistical analysis.

4 How the UKRR codes and organises data prior to analysis or categorisation

The data collected by the UKRR are organised onto a chronological timeline of events and treatments for each patient. Some key dates are detailed below. For patients receiving haemodialysis (HD), the treatment element of the timeline can be validated against data supplied each time the patient has a dialysis treatment – this is termed 'session data'. UKRR data managers check timeline entries and liaise with renal centres to identify discrepancies within timelines, and between timeline and session data.

4.1 Key dates – the renal 'treatment timeline'

4.1.1 Date first seen by a nephrologist

This is the date the patient first attended clinic or was an inpatient under the care of a nephrologist (whichever is the earlier). If a patient transfers into a renal centre from another renal centre then this date should be left blank by the new renal centre. For the purposes of this report, referral date is defined as the same as date first seen by a nephrologist.

4.1.2 Late presentation

First seen date and date of RRT start (see below) are used to define late presentation with a 90 day cut-off differentiating early versus late presentation. Date first seen by a nephrologist is not collected from the Scottish Renal Registry and Scottish centres are excluded from time of presentation analyses. Two year cohorts may be used for analyses to make the late presentation percentages more reliably estimated and to allow these to be shown for subgroups of patients. Only data from those centres with ⩾70% completeness for the relevant year are used. This data item is investigated with centres, and possibly excluded, if an unexplained large proportion of patients are reported to have started RRT on the same date as the first presentation, because this is likely due to incorrect recording of data.

4.1.3 Date of first dialysis access

This is the date of insertion or construction of first ever dialysis access. If the access type is a Moncrief peritoneal dialysis (PD) catheter, then the date of externalisation is selected.

4.1.4 Date of RRT start

A patient with ESKD starting RRT on 'chronic' HD (or PD or pre-emptive Tx) should be entered as such on the UKRR timeline on the date of the first HD (or PD) episode.

If a patient starts RRT with an episode of acute (or acute-on-chronic) kidney injury in which it was felt that kidney function had potential to recover, then 'acute' HD (or acute HD or renal filtration) or acute PD (where appropriate) should be entered on the UKRR timeline. If subsequently it is felt that kidney function is no longer likely to recover, a timeline modality should be added of 'chronic dialysis' at the time when this becomes apparent (accepting that the timing of this change will vary by clinician practice and interpretation). The UKRR will interrogate the timeline of patients starting 'chronic' RRT and if there is evidence of recent 'acute' RRT, will backdate the date of start of RRT to the first episode of 'acute' RRT, provided there has been <90 days recovery of kidney function between acute and chronic episodes.

If a patient was started on dialysis and dialysis was temporarily stopped for <90 days for any reason (including access failure and awaiting the formation of further access), the date of start of RRT in UKRR analyses remains the date of first dialysis. If a patient recovers for ⩾90 days, subsequent RRT start dates are used.

The date of start of PD is defined as the date of first PD fluid exchange given with the intention of causing solute or fluid clearance. This is in contrast with a flush solely for confirming or maintaining PD catheter patency. In general, exchanges which are part of PD training should be considered as the start of PD (unless earlier exchanges have already been given). However, if it is not planned that the patient starts RRT until a later date, exchanges as part of PD training need not be considered the start of RRT.

4.1.5 Change of modality date

Renal centres are requested to log in their timeline changes from PD to HD if the modality switch is for >30 days.

4.1.6 Date of death

See section 8.1.

4.2 Allocation of patients to a renal centre

The default method for allocating a patient to a renal centre is based on the centre sending their quarterly data.

Where applicable, pre-emptive Tx patients are allocated to their work-up centre rather than their Tx centre. This is not possible for all patients because some centres do not supply the 'transfer out for pre-emptive Tx' timeline code. Consequently, some patients remain allocated to their transplanting centre.

More generally, there are centre-specific variations in the repatriation of Tx recipients. Some Tx centres continue to follow-up and report on all patients they transplant, whereas others refer patients back to non-transplanting centres at some point post-Tx. Some Tx centres only refer back patients when their graft is failing. The time post-transplantation that a patient is referred back to their local centre varies between Tx centres, but the UKRR can detect patients being reported from both Tx and referring centres and in such situations care is usually attributed to the referring centre (see section 7.2).

5 Variables used to categorise patients in the UKRR Annual Report

5.1 Demographics

5.1.1 Location

This includes renal centre, region, country and CCG.

5.1.2 Sex

Patients are defined as male or female.

5.1.3 Age

Age adjusted analyses allow comparisons between centres with differing age distributions by adjusting the analysis as if all the patients were the same chosen age.

5.1.4 Biometrics

Height, weight, body mass index (BMI) – these variables are only used for paediatric analyses. Data for height, weight, BMI and systolic blood pressure (SBP) vary with age, sex and size in children and are therefore presented as z-scores as described in the relevant chapter.

5.1.5 Ethnicity

Most centres electronically upload ethnicity coding to their renal IT system from the hospital patient administration system (PAS). Ethnicity coding in PAS is based on self-reported ethnicity. For the remaining centres, ethnicity coding is performed by clinical staff and recorded directly into the renal IT system (using a variety of coding systems). Data on ethnic origin are grouped into White, South Asian, Black, Chinese or Other. The details of regrouping the PAS codes into these ethnic categories are detailed below.

Tables A1 and A2 show the old and new groupings of ethnicity information used in this report as centres transition to the new codes. Ethnic categories are condensed into five groups (White, South Asian, Black, Chinese and Other). For all current analyses Chinese are grouped into Other.

Table A1 Old ethnicity groupings

Code	Ethnic category	Assigned group
9S1..	White	White
9SA9.	Irish (NMO)	White
9SAA.	Greek Cypriot (NMO)	White
9SAB.	Turkish Cypriot (NMO)	White
9SAC.	Other European (NMO)	White
9S6..	Indian	South Asian
9S7..	Pakistani	South Asian
9S8..	Bangladeshi	South Asian
9SA6.	East African Asian	South Asian
9SA7.	Indian Subcontinent	South Asian
9SA8.	Other Asian	South Asian
9S2..	Black Caribbean	Black
9S3..	Black African	Black
9S4..	Black/Other/NMO	Black
9S41.	Black British	Black
9S42.	Black Caribbean	Black
9S43.	Black North African	Black
9S44.	Black other African country	Black
9S45.	Black East African Asian	Black
9S46.	Black Indian subcontinent	Black
9S47.	Black Other Asian	Black
9S48.	Black Black Other	Black
9S5..	Black other/mixed	Black
9S51.	Other Black – Black/White origin	Black
9S52.	Other Black – Black/Asian origin	Black
9S9..	Chinese	Chinese
9T1C.	Chinese	Chinese
9SA..	Other ethnic non-mixed (NMO)	Other
9SA1.	British ethnic minority specified (NMO)	Other
9SA2.	British ethnic minority unspecified (NMO)	Other
9SA3.	Caribbean Island (NMO)	Other
9SA4.	North African Arab (NMO)	Other
9SA5.	Other African countries (NMO)	Other
9SAD.	Other ethnic NEC (NMO)	Other
9SB..	Other ethnic/mixed origin	Other
9SB1.	Other ethnic/Black/White origin	Other
9SB2.	Other ethnic/Asian/White origin	Other
9SB3.	Other ethnic/mixed White origin	Other
9SB4.	Other ethnic/Other mixed origin	Other

NMO – non-mixed origin
NEC – not elsewhere contained

Table A2 New ethnicity groupings

Code	Ethnic category	Assigned group
A	White – British	White
B	White – Irish	White
C	Other White background	White
D	Mixed – White and Black Caribbean	Other
E	Mixed – White and Black African	Other
F	Mixed – White and Asian	Other
G	Other Mixed background	Other
H	Asian or Asian British – Indian	South Asian
J	Asian or Asian British – Pakistani	South Asian
K	Asian or Asian British – Bangladeshi	South Asian
L	Other Asian background	South Asian
M	Black Caribbean	Black
N	Black African	Black
P	Other Black background	Black
R	Chinese	Chinese
S	Other ethnic background	Other

5.2 Health

5.2.1 Primary renal disease (PRD)

Patients should be allocated a code for the PRD based on the histological or clinical picture, with codes available for where the cause is unknown. New PRD codes were produced by the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) in 2012. The data used for this report include a mixture of old and new ERA-EDTA codes. Old codes cannot be mapped to new codes, but the reverse mapping is possible. Therefore, the old codes are used where available, and for those people without an old code, new codes (where available) are mapped back to old codes, using the mapping available on the ERA-EDTA website (https://era-edta-reg.org/prd.jsp). As recommended in the notes for users in the ERA-EDTA's PRD code list document, the mapping of new to old codes is provided for guidance only and has not been validated. Therefore, care must be taken not to over interpret data from this mapping.

The old codes (both those received from centres and those mapped back from new codes) are then grouped into the same eight categories as in previous reports as shown in table A3.

Table A3 Old primary renal disease (PRD) groupings

Code	Old PRD grouping	Assigned group
0	Chronic renal failure; aetiology uncertain unknown/unavailable	Uncertain aetiology
10	Glomerulonephritis; histologically NOT examined	Glomerulonephritis*
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 glomerulonephritis; type II (proven by immunofluorescence and/or electron microscopy)	Glomerulonephritis
14	Membranous nephropathy	Glomerulonephritis
15	Membrano-proliferative glomerulonephritis; 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

Table A3 Continued

Code	Old PRD grouping	Assigned group
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)	Other
31	Nephropathy (interstitial) due to analgesic drugs	Other
32	Nephropathy (interstitial) due to cis-platinum	Other
33	Nephropathy (interstitial) due to cyclosporin A	Other
34	Lead induced nephropathy (interstitial)	Other
39	Drug induced nephropathy (interstitial) not mentioned above	Other
40	Cystic kidney disease – type unspecified	Polycystic kidney
41	Polycystic kidneys; adult type (dominant)	Polycystic kidney
42	Polycystic kidneys; infantile (recessive)	Polycystic kidney
43	Medullary cystic disease; including nephronophthisis	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
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	Hypertension
72	Renal vascular disease due to hypertension	Hypertension
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 ureaemic 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

*Prior to the 15th UKRR Annual Report categorised as 'uncertain aetiology'
IgA – immunoglobulin A

5.2.2 *Cause of death*

ERA-EDTA codes for cause of death are grouped as shown.

Table A4 Cause of death groupings

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

*Prior to the 15th Annual Report categorised as 'uncertain aetiology'

5.2.3 Infections

Patients on dialysis are susceptible to infections because of an impaired immune system and the need to regularly access the vascular system in HD or use of a catheter in PD. PHE carries out mandatory enhanced surveillance of methicillin-resistant *Staphylococcus aureus* (MRSA) bacteraemia, methicillin-sensitive *Staphylococcus aureus* (MSSA) bacteraemia, *Escherichia coli* bacteraemia and *Clostridium difficile* reporting for NHS acute trusts. A data sharing agreement exists between the UKRR and PHE to identify infections in dialysis patients in England in a given year through data linkage. In the 21st UKRR Annual Report, Wales provided data for the first time, which were extracted locally from the renal and hospital IT systems.

In previous reports, infection data were validated by securely emailing individual renal centres to confirm that infections were related to dialysis patients. Historically, this has resulted in only a small number of alterations in cases and so was not undertaken for this report.

PHE reports individual blood culture results. However, the annual report details individual infection episodes – repeated positive blood cultures within a two week timeframe are treated as a single infection episode for MSSA/MRSA/*E. coli* bacteraemia; beyond two weeks they are treated as a new episode or re-infection. Four weeks, rather than two weeks, is used as the cut-off for repeated *C. difficile* infections. Centre-specific rates for each infection are presented per 100 dialysis patient years. The denominator for this rate is calculated for each centre by summing the number of days that each dialysis patient contributes between 1 January and 31 December of the year in question. When calculating the modality specific rates, the number of days that every dialysis patient spends on each modality during the collection period is totalled.

To illustrate the variation in precision of the estimated infection rate, the rate of bacteraemia (MRSA and MSSA) per 100 dialysis patient years is plotted against the centre size in a funnel plot. This is plotted for each infection type.

5.2.4 Comorbidity

The comorbidity data items collected in the UKRR dataset are listed below.

At the time of each patient starting RRT, clinical staff in each centre are responsible for recording, in yes/no format on their renal IT system, the presence or absence of the following comorbid conditions and information on current smoking status.

Patients are classified as having complete comorbidity data if there is at least one entry (yes/no) for any one or more of the comorbid conditions, excluding smoking.

'Ischaemic heart disease' is defined as the presence of one or more of the following conditions: angina, myocardial infarction (MI) in the three months prior to starting RRT, MI more than three months prior to starting RRT or coronary artery bypass graft (CABG)/angioplasty.

'Peripheral vascular disease' is defined as the presence of one or more of the following conditions: claudication, ischaemic or neuropathic ulcers, non-coronary angioplasty, vascular graft, aneurysm or amputation for peripheral vascular disease.

'Non-coronary vascular disease' is defined as the presence of cerebrovascular disease or any of the data items that comprise 'peripheral vascular disease'.

Specific consideration needs to be made regarding diabetes coding. The UKRR also collects data on PRD and uses these data alongside the comorbidity data to determine which patients have diabetes mellitus. The comorbidity screen is intended to capture those patients who have diabetes only when it is not the PRD, but some clinicians enter 'yes' in the comorbidity field in such cases. Prior to statistical analyses, these fields are examined together to identify these cases and to ensure diabetes is only counted as either the PRD or a comorbid condition for a certain individual.

Several renal centres submit an expanded list of comorbidities (non-ST segment elevation MI; atrial fibrillation; transient ischemic attack; cerebrovascular event/stroke; peripheral vascular disease; and dementia) with associated dates as specified in the current dataset (version 4.2). Comorbidities at start of RRT are subsequently derived from the date of the comorbidity and the date of starting RRT.

Angina – history of chest pain on exercise with or without electrocardiogram (ECG) changes, exercise tolerance test, radionucleotide imaging or angiography.

Previous MI within last three months – detection of rise and/or fall of a biomarker (creatinine kinase (CK), CK-MB or troponin) with at least one value above the 99th percentile, together with evidence of myocardial ischaemia with at least one of either:

- ischaemic symptoms
- ECG changes indicative of new ischaemia (new ST-T changes or new left bundle branch block)
- development of pathological Q waves
- imaging evidence of new loss of viable myocardium or new regional wall motion abnormality.

Previous MI more than three months ago – any previous MI at least three months prior to start of RRT.

Previous CABG or coronary angioplasty.

Previous episode of heart failure – whether or not due to fluid overload.

Cerebrovascular disease – any history of strokes (whatever cause) and including transient ischaemic attacks caused by carotid disease.

Diabetes (not causing ESKD, i.e. not as the PRD) – this includes diet controlled diabetics.

Chronic obstructive pulmonary disease (COPD) – this is characterised by airflow obstruction. The airflow obstruction is usually progressive, not fully reversible and does not change markedly over several months:

- airflow obstruction is defined as a reduced forced expiratory volume in one second (FEV1) and a reduced FEV1/FVC ratio (where FVC is forced vital capacity), such that FEV1 is $<80\%$ predicted and FEV1/FVC is <0.7
- the airflow obstruction is due to a combination of airway and parenchymal damage
- the damage is the result of chronic inflammation that differs from that seen in asthma and which is usually the result of tobacco smoke.

There is no single diagnostic test for COPD. Making a diagnosis relies on clinical judgement based on a combination of history (exertional breathlessness, chronic cough, regular sputum production, frequent winter 'bronchitis', wheeze), physical examination and confirmation of the presence of airflow obstruction using spirometry (source: British Thoracic Society guidelines).

Liver disease – persistent enzyme evidence of hepatic dysfunction or biospy evidence or hepatitis B antigen or hepatitis C antigen (polymerase chain reaction) positive serology.

Malignancy – defined as any history of malignancy (even if curative) e.g. removal of melanoma, excludes basal cell carcinoma.

Claudication – current claudication based on a history, with or without Doppler or angiographic evidence.

Ischaemic/neuropathic ulcers – current presence of these ulcers.

Angioplasty, stenting, vascular graft (all non-coronary) – this category now includes vascular grafts (e.g. aortic bifurcation graft) and renal artery stents.

Amputation for peripheral vascular disease.

Smoking – current smoker or history of smoking within the last year.

5.2.5 Hypo/hypertension

Hypertension is analysed for Tx and paediatric patients using the relevant targets described in the chapters. Hypotension during dialysis is not currently routinely analysed due to poor data completeness.

5.2.6 Diabetic/non-diabetic

In general, where the UKRR report refers to diabetics it refers to patients with diabetes as a PRD, but excludes patients with diabetes as a comorbidity. Non-diabetics, by contrast, includes patients with diabetes as a comorbidity.

5.3 Treatment

5.3.1 Referral time and surgical assessment

Time of presentation, the time a patient first sees a nephrology specialist and referral time are interchangeable for the purposes of this report and late presentation is defined above. Surgical assessment is the time at which a patient is seen by a surgeon for assessment for dialysis access – either an arteriovenous fistula (AVF), arteriovenous graft (AVG) or PD catheter. As with late presentation, three months prior to RRT start is used as a measure of care.

5.3.2 RRT modality

The RRT treatment modalities available are a Tx, home haemodialysis (HHD), in-centre haemodialysis (ICHD) and PD – these are defined in the relevant chapters of the report.

5.3.3 Dialysis access

AVF, AVG, central venous catheter (CVC) – non-tunnelled line (NTL) and tunnelled line (TL) – and catheter insertion technique for PD are defined in chapter 1.

5.3.4 HD session frequency and length

For patients on ICHD, the length and frequency of HD sessions are described in chapter 3. Patients on HHD will be reported in a separate chapter in next year's annual report.

5.3.5 Tx type

Donor after brain death (DBD), donor after circulatory death (DCD) and living kidney donor (LKD) Tx are defined in chapter 5.

5.3.6 Tx wait-listing

Tx wait-listing is discussed in detail in chapter 6 and the methodology used described in section 7.6.

5.3.7 Laboratory data items

The UKRR does not currently collect data regarding different assay methods, mainly because a single dialysis centre may process samples in several different laboratories.

The UKRR dataset contains a number of laboratory variables, many of which are not currently returned by renal centres. It is planned to expand this work as part of an ongoing data completeness exercise.

The collection methods and statistical analyses undertaken on the core laboratory data items of the annual report are as follows.

5.3.7.1 Incident biochemical and haematology variables

For the analyses of biochemical variables for incident patients (with the exception of start estimated glomerular filtration rate (eGFR) – see below), those patients commencing RRT (HD/PD/Tx) are included. Measurements for variables taken from after starting dialysis, but still within the same quarter of RRT start are used. Therefore, depending on when in the quarter a patient starts RRT, the data could be from zero to 90 days later. Due to possible deficiencies with extract routines it is possible that a small number of the values extracted electronically may actually be from before the person started dialysis. This problem will not occur for Scottish data. Results are also shown with the cohort subdivided into early and late presenters (date first seen by a nephrologist $\geqslant$90 days and $<$90 days before starting dialysis, respectively). For these analyses only centres with at least 70% completeness of presentation time data are included.

eGFR at RRT start – eGFR is calculated from serum creatinine. The start eGFR is studied amongst patients with eGFR data within 14 days before the start of RRT. In line with the National Institute for Clinical Excellence advice and for consistency across the UKRR Annual Report, the Chronic Kidney Disease Epidemiology Collaboration creatinine equation is used to calculate eGFR. In previous years the Modification of Diet in Renal Disease equation was used. In light of this change, the UKRR advises caution in comparing eGFR results with previous UKRR annual reports.

A wide variety of creatinine assays are in use in clinical biochemistry laboratories in the UK and it is not possible to ensure that all measurements of creatinine concentration collected by the UKRR are harmonised.

For the purpose of the eGFR calculation, patients who have missing ethnicity data but a valid serum creatinine measurement are classed as White. The eGFR values are log transformed due to their skewed distribution and geometric means are calculated.

In children, eGFR is calculated using the updated 'bedside' Schwartz formula, using centre-specific individual correction factors submitted to the UKRR.

Prevalent haemoglobin (Hb) and ferritin – for the analyses of prevalent dialysis patients, those patients receiving dialysis on 31 December at the end of the analysis year are included if they have been on the same dialysis modality in the same centre for at least three months. To improve completeness, the last available measurement for each patient from the last two quarters of the year are used for Hb and from the last three quarters for ferritin.

The completeness of data items are analysed at both centre and country level. All patients are included in analyses but centres with <70% completeness are excluded from the caterpillar and funnel plots showing centre level results. Centres providing relevant data from <10 patients are also excluded from the plots.

Erythropoiesis stimulating agents (ESA) – ESA data from the last quarter of the year of analysis are used to define which patients are receiving ESAs. Scotland is included in the ESA analysis for ICHD patients, but not PD patients, because Scotland does not submit ESA data for PD patients. Each individual is defined as being on an ESA if a drug type and/or a dose is present in the data. Centres reporting <70% of HD or PD patients being treated with ESAs, respectively, are considered to have incomplete data and are excluded from further analysis. It is recognised that these exclusion criteria are relatively arbitrary. The percentage of patients on ESAs is calculated from these data and incomplete data returns risk seriously impacting on any conclusions drawn.

For analyses of ESA dose, values are presented as weekly ESA dose. Doses of <150 IU/week (assumed to be darbepoietin or methoxy polyethylene glycol–epoetin beta) are harmonised with ESA data by calculating a weekly dose and multiplying by 200. No adjustments are made with respect to route of administration. Patients who are not receiving ESAs are not included in analyses of dose (rather than being included with dose = zero). Many centres provide data on ESA dose but not on ESA frequency. The ESA dose field is defined as the weekly dose and the dose is presumed to have been converted accordingly on submission to the UKRR. This may be an incorrect assumption for a number of patients and this needs to be considered when interpreting the ESA information.

The ESA data are collected electronically from renal IT systems, but in contrast to laboratory linked variables the ESA data require manual data entry. The reliability depends upon the data source – whether the entry is linked to the prescription or whether the prescriptions are provided by the primary care physician. In the latter case, doses may not be as reliably updated because the link between data entry and prescription is indirect. It is worth noting that ESA data are the only medication that is reported by the UKRR, because of data completeness (iron replacement is also not included).

5.3.7.2 Prevalent biochemical variables

Quarterly values are extracted from the database for the last two quarters for calcium, phosphate, bicarbonate and potassium and the last three quarters for parathyroid hormone (PTH). Patients who do not have these data are excluded from the analyses. Data completeness is analysed at centre and country level. All patients are included in analyses, but centres with <70% completeness are excluded from plots and tables showing centre level performance. Data are also excluded from plots and tables when there are <10 patients with data, both at centre or country level.

Calcium – the adjusted calcium is calculated by adjusting for the binding of albumin to a proportion of the calcium in the blood depending on albumin levels. Not all centres return adjusted calcium. For centres providing adjusted calcium values, these data are analysed directly because it is these values on which clinical decisions within centres are based. For centres providing unadjusted calcium values, the formula provided by each centre (or, if this is not available, the standard formula in widespread use) is used to calculate adjusted calcium.

PTH and phosphate – these variables no longer have target ranges in the most recent adult Renal Association audit guidelines and are therefore not currently reported in the UKRR Annual Report. The data variables are still collected and available for analysis in research work.

Bicarbonate – the audit measures used for serum bicarbonate in the HD cohort and PD cohort differ as per the most recent guidelines.

Potassium – centres are requested to send pre-dialysis potassium levels for HD patients, which like all biochemical samples should be collected from a short-gap session (i.e. a gap of one day between HD sessions rather than the longer two day gap). Outlying centres are contacted and if it is identified that post-dialysis potassium data have inadvertently been submitted, these centres are excluded from the analysis. However, post-dialysis samples may remain within the analysis for some centres. Future data extracts will aim to ensure that only pre-dialysis results are submitted.

Urea reduction ratio (URR), session duration and frequency – the prevalent adult HD patient population for a given year is analysed using URR data taken from the third quarter of the year, unless that data point is missing, in which case data from the second quarter are taken. The use of URR data from the third quarter is preferred over the fourth quarter due to better data completeness.

Since 2015, centres have been submitting quarterly HD sessional data as specified in version 4.2 of the UKRR dataset. These data are used to augment the quarterly data on the frequency and duration of dialysis sessions across all centres, for those centres with poor completeness on those two items.

Data from patients known to be receiving more than or less than thrice weekly HD are omitted from the analysis. Patients who have missing data for the number of dialysis sessions per week are assumed to be dialysing thrice weekly. However, because not all centres report frequency of HD, it is possible that data from a small number of patients receiving HD at a different frequency are included in the analyses. HHD patients are excluded from the analysis.

The URR is calculated as the percentage fall in urea during a dialysis session by taking a urea sample before and after the dialysis session. Post-dialysis blood samples should be collected either by the slow-flow method, the simplified stop-flow method, or the stop dialysate flow method. The method used should remain consistent within renal centres and should be reported to the UKRR.

6 Statistical methods and analyses used in the UKRR Annual Report

SAS software (https://www.sas.com/) is used for all analyses.

6.1 Estimation of renal centre dialysis catchment populations

Estimates of each renal centre's catchment area are needed to calculate estimates of the incidence and prevalence rates of RRT at renal centre level. The UKRR database of the incident dialysis population between 1 January 2008 and 31 December 2012 was used to estimate the size of each UK renal centre's catchment area. This used the postcode and renal centre for each patient at the time of starting RRT on dialysis.

Polygons were constructed to define an area around the geographical location of each dialysis patient. The lines of the polygons, representing the boundaries between areas, were drawn such that they were equidistant between adjacent patients, creating a map of non-overlapping polygons covering the entire area of England, Northern Ireland, Scotland and Wales (the process was done separately for each country). This method produces Thiessen polygons which have the property that all locations within each polygon share the same nearest dialysis patient (Boots BN: Voronoi (Thiessen) Polygons (Concepts and Techniques in Modern Geography); Norwich: Geo Books, 1986).

The polygons of all patients starting at the same renal centre were combined to create the catchment area for that centre. The catchment area for one centre might comprise multiple unconnected polygons as a result of adjacent patients attending different renal centres. The Office for National Statistics (ONS) map of 2011 census merged wards contains population estimates for England and Wales divided into 8,546 wards. The Northern Ireland Statistics and Research Agency (NISRA) published population estimates based on the 2011 census for 4,537 geographical regions referred to as small areas. The General Register Office for Scotland published 2011 population estimates at 6,505 data zone level areas. Wards, small areas and data zones will collectively be referred to as wards in the following paragraphs.

The wards were overlaid on the map of renal centre catchment areas, enabling the proportion of each ward's area covered by each of the renal centre catchment areas to be calculated. Each ward's population was then allocated to the renal centres in proportions equal to the proportions of the overlaid areas. Summing these proportions of populations across all of the wards for each renal centre produced the estimates of the total catchment population for each centre.

There are some limitations to these estimates. The main one is that the ward allocated to each renal centre was based upon dialysis patients only. Therefore it is possible that non-dialysis patients may come from a different catchment population. This is more likely where a renal centre provides specialist services and especially likely for patients undergoing kidney transplantation. The catchment population for kidney Tx patients will depend largely upon the distribution of workload between the referral centre and the transplanting centre for pre-Tx work-up, donor nephrectomy work-up and post-Tx care (including if and when care is returned to the referring centre).

Despite the limitations, this is the most valid methodology to date to estimate the size of the catchment populations for renal centres in the UK.

Thanks are expressed to Professor Andrew Judge for calculating these catchment populations for the UKRR.

There is a need for centre catchment populations to be re-estimated for future analyses as populations will have changed. For the 2017 analyses, the catchment population of each centre was updated by upscaling the previous estimate so that for each UK country, the sum of centres' populations covered was equal to the 2017 national population estimates from the ONS.

6.2 Adjusted analyses

Most analyses presented in this report are unadjusted. However, a few analyses are adjusted to take into account the difference in baseline characteristics between groups that may influence the outcome, thereby allowing better comparisons between renal centres. See each chapter for more details.

6.3 Graphs

Percentages achieving The Renal Association guidelines and other standards are displayed in several ways in the UKRR Annual Report.

6.3.1 Caterpillar plots

Caterpillar plots show the percentage meeting the targets along with 95% confidence intervals (CIs) for each centre, country and overall.

6.3.2 Funnel plots

Funnel plots show the percentage meeting the target plotted against the size of the centre (the number of people with a measurement). A 'funnel' is plotted either around the average percentage meeting the target or the target itself as specified in the plot title. There is evidence that any centres which fall outside the funnel are significantly different from the average or the target. The funnel shape of the limits reflects the fact that for smaller centres, for which the percentage meeting the target is less reliably estimated, a greater observed difference from the average/target is required for it to be statistically significantly different.

In each funnel plot, the lines (see legends) indicate the national mean and the 95% and 99.9% CIs as stated, corresponding to two and three standard deviations from the mean, respectively. Each point on the plot represents one renal centre. For each outcome measure, if no significant inter-centre variation was present, three of 71 adult renal centres would be expected to fall between the 95% and 99.9% CIs and no centre should fall outside the 99.9% CI. In survival analysis the funnel plot methodology is similar except that the funnel plots show the percentage survival plotted against the size of the centre (the number of patients in the cohort) and a 'funnel' is plotted around the average survival in the UK. Survival for any centres falling outside the 95% CIs is therefore significantly different from the average survival in the UK.

6.3.3 Box and whisker plots

These are only used to report MSSA and MRSA infection rates. The box shows the median in the middle and the upper and lower quartiles, i.e. 25th and 75th centiles. The whiskers show the full measured range of that variable.

6.3.4 Kaplan-Meier (KM) method/plots

In the KM method, the probability of surviving more than a given time period can be estimated for all members of a cohort of patients overall (or by subgroup such as age group). Its estimator is a series of declining horizontal steps that approaches the true survival function for the given population with a large enough sample size. The declining step function (i.e. the KM curve) takes the censoring of data into account (right-censoring in the UKRR analysis), which occurs if the patient is lost to follow-up or is alive without the event occurrence at last follow-up. The KM method can also estimate median time to event in conjunction with right-censoring information; median time is when 50% of patients within the population experienced the event (see section 8.1 for further discussion of the KM methods used in the survival analysis).

6.4 How to interpret centre-specific analyses and outlying centres

The UKRR continues to advise caution in the interpretation of the comparisons of centre-specific attainment of clinical audit measures provided in this report. As in previous reports, the UKRR does not test for 'significant difference' between centres and arbitrary 95% and 99.9% CIs are created from the data to show compliance with an audit standard. For many of these analyses no adjustment can be made for the range of factors known to influence the measured variable.

Despite these shortcomings, for a number of years de-anonymised centre-specific reports on survival of RRT patients have been published in the annual report. Centres are contacted if survival is lower than expected in patients starting dialysis and for prevalent RRT patients

The UKRR has no statutory powers. However, because the UKRR provides centre-specific de-anonymised analyses of important clinical outcomes, including survival, it is important to define how the UKRR responds to apparent under-performance. The UKRR senior management team communicates survival outlier status with the renal centres prior to publication. Centres are asked to report their outlying status internally at trust level and to follow-up with robust mortality and morbidity meetings. They are also asked to provide evidence that the clinical governance department and chief executive of the trust housing the service have been informed. In the event that no such evidence is provided, the chief executive officer or medical director of the UKRR inform the president of The Renal Association, who then takes action to ensure that the findings are properly investigated.

7 Populations of patients analysed by UKRR Annual Report chapter

Analyses in the report are presented on cohorts of patients who share either the time at which they initiated RRT e.g. incident population, or share a treatment modality e.g. PD patients.

7.1 Incident adult renal replacement therapy (RRT) population (chapter 1)

The incident adult RRT population is all patients aged 18 years and over with ESKD who started RRT (dialysis or pre-emptive Tx) at a UK renal centre for the first time in the calendar year applicable to the analyses. It excludes patients who recover their renal function for >90 days within 90 days of starting dialysis. Furthermore, patients restarting dialysis after a failed Tx are not counted as incident patients. A patient can therefore appear only once in the incident cohort.

The treatment timeline is used to define incident patients. If a patient has timeline entries from more than one centre these are combined and sorted by date. The first RRT treatment entry from any centre is used to determine the first date they commenced RRT. This is defined as a 'start date'. However, in the following situations there is evidence that the patient was already receiving RRT before this 'start date' and consequently these people are not classed as incident patients:

- those with an initial entry on the timeline of transferred in (modality codes 39 to 69)
- those with an initial entry of transferred out (modality code 38)
- those with an initial treatment of lost to follow-up (modality code 95)
- those who had graft acute rejection (modality code 31) and did not have a Tx on the same day
- those with an initial entry of transfer to adult nephrology (modality code 37)
- those with an initial entry of graft functioning (modality code 72)
- those with an initial entry of nephrectomy Tx (modality code 76).

Where none of the above apply, the patient is defined as an incident patient, providing there is no recovery of >90 days starting within 90 days of the start date. If there is a recovery lasting >90 days, modality codes after this date would indicate that the patient restarted RRT. If they did, this second (or third etc.) starting point is defined as their start date, providing that they did not have a recovery lasting >90 days starting within 90 days of start.

Provided the UKRR received a modality code 36 (pre-emptive Tx) from the work-up centre, pre-emptive Tx are allocated as incident patients of the work-up centre and not of the centre where the Tx took place.

NHS England mandates the collection of data regarding acute HD sessions and since the 19th UKRR Annual Report, data have been published for patients who received acute HD as coded by their reporting centre. However, sessional HD data carry no information about whether the HD was for AKI or ESKD. Distinguishing between these two indications depends entirely upon the accuracy of timeline data provided by centres.

Patients who receive acute HD are only reported if their dialysis is subsequently recoded as being for ESKD, when they fail to recover native renal function. Recoding to RRT is automatically applied at 90 days for individuals still on RRT, but can also be applied at any point between zero and 90 days by the reporting centre. Individuals who commence HD for AKI (i.e. acute HD by definition) and subsequently recover renal function or die within the first 90 days of treatment without receiving an ESKD code are the focus of a separate piece of work.

Initial work published in previous reports used sessional HD data alongside treatment timeline codes. HD sessional data were submitted to the UKRR by renal centres in England, as mandated by NHS England. Centres in Northern Ireland and Wales provided data voluntarily. Centres in Scotland did not provide HD sessional data. Centres were asked to report details related to each HD session, including vascular access used and blood pressure before and after the session (data not shown). The approach used to define HD as acute or for ESKD was based purely on timeline codes. Sessional HD data were used to check for individuals who received HD without a timeline entry and to check start dates. Where timeline and sessional dates were inconsistent, it was not possible to determine whether this was due to a missing acute HD code or an inaccurate first timeline entry. As such, neither the dates nor content of timelines were corrected using sessional HD data.

Differences in RRT incidence can be seen in the most recent years when compared with previous publications because of retrospective updating of data in collaboration with renal centres. In addition, patients with AKI requiring dialysis may be coded in the subsequent year as having developed ESKD, allowing the UKRR to backdate the start date of RRT.

7.2 Prevalent adult RRT population (chapter 2)

The prevalent adult RRT population is all patients on RRT for ESKD aged 18 years and over at a UK renal centre who were alive on 31 December of the year applicable to the analyses. It includes both incident patients for that year (who remained on RRT until the end of the year) and patients who had been on RRT for longer. Excluded are patients who had transferred out, recovered renal function, stopped treatment without recovery of function, died or been lost to follow-up before the end of the year. Also excluded are any patients aged 18 years and over still being treated at a paediatric renal centre.

When quarterly data are received from more than one centre (often when there is joint care of kidney Tx recipients between the referring centre and the Tx centre) the patient is only included under one of these. The allocated centre is defined by the steps below (as many steps as necessary are followed in this order until data are only left from one centre):

- the treatment timeline is used to eliminate any centre(s) which the patient was not still attending, at the end of the quarter
- a centre with biochemistry data (at least one of the six fields: creatinine, Hb, albumin, aluminium, serum potassium, urea) is favoured over one without
- a centre with quarterly modality of Tx is favoured over one without
- non-Tx centres are favoured over Tx centres
- the centre with the highest number of the six biochemistry fields (listed above) populated is favoured
- if the above steps do not decide between centres (unusual) then the choice is made based on the sort order of the centre codes.

In some situations (generally where timeline data are seen to be inaccurate/incomplete) the centre used is set manually on an ad hoc basis.

There are exclusions for analyses of quarterly biochemistry or blood pressure data:

- patients who had 'transferred in' to the centre in that particular quarter are excluded
- patients who had changed treatment modality in that particular quarter are excluded
- patients who had been on RRT for $<$90 days are excluded.

Note the length of time on RRT is calculated from the most recent start date (i.e. the point at which they are defined as an incident patient using the definition detailed above. So if a patient starts, then recovers and then starts again, this second start date is used. Also, for patients who are not defined as incident patients because their start date is unknown (for example, if their first timeline entry is a transfer in code) it is assumed that they have been on RRT for $>$90 days and they are included for every quarter.

7.3 Prevalent adult in-centre haemodialysis (ICHD) population (chapter 3)

This chapter describes the population of adult patients with ESKD who were receiving regular ICHD in the UK at the end of the year applicable to the analyses. Throughout this chapter, ICHD refers to all modes of ICHD treatment, including haemodiafiltration (HDF). Several centres reported significant numbers of patients on HDF, but other centres did not differentiate this treatment type in their UKRR returns. Analyses in this chapter exclude patients on HHD unless stated – HHD patients will be analysed in a separate chapter in the next annual report.

7.4 Prevalent adult peritoneal dialysis (PD) population (chapter 4)

The PD chapter includes analyses of prevalent patients on continuous ambulatory PD (CAPD) and automated PD (APD).

7.5 Prevalent adult transplant (Tx) population (chapter 5)

There are 23 UK adult renal Tx centres – 19 in England, two in Scotland and one each in Northern Ireland and Wales.

Annual organ-specific updates and five-year reports with comprehensive data concerning the number of patients on the Tx waiting-list, percentage of pre-emptive listing, the number of transplants performed, the number of deceased kidney donors (DBD and DCD), LKDs, patient survival and graft survival are available on the NHSBT website (https://www.organdonation.nhs.uk/statistics/).

Where joint care of kidney Tx recipients between the referring centre and the Tx centre occurs, the patient is usually allocated to the referring centre (see section 7.2). Thus, the number of patients allocated to a Tx centre is often lower than that recorded by the centre itself and conversely, pre-emptively transplanted patients are sometimes allocated to the transplanting centre rather than the referring centre if no transfer out code is submitted to the UKRR. Queries and updated information are welcomed by the UKRR at any point during the year if this has occurred.

In the eGFR slope analysis, a minimum duration of 18 months graft function is required and three or more creatinine measurements from the second year of graft function onwards are used to plot the eGFR slope. If a Tx failed but there are at least three creatinine measurements between one year post-Tx and graft failure, the patient is included, but no creatinine measurements after the quarter preceding the recorded date of Tx failure are analysed.

Slopes are calculated using linear regression, assuming linear change in eGFR over time and the effect of age, ethnicity, sex, diabetes, donor type, year of Tx and current Tx status are analysed.

7.6 Adult Tx wait-listed population (chapter 6)

For this chapter, UKRR data include start date of RRT and patient characteristics including age group, sex (male, female), ethnicity (White, non-White, missing), and PRD (diabetes, other, missing). Date of wait-listing and date of transplantation are provided by the UK Transplant Registry, held by the Organ Donation and Transplantation Directorate of Blood and Transplant.

To identify factors which influence the likelihood of wait-listing for transplantation, an incident RRT cohort was analysed. All adult patients starting RRT between 1 January 2012 and 31 December 2014 at renal centres returning data to the UKRR were considered for inclusion. Patients $\geqslant$65 years, patients listed for multi-organ transplants other than kidney and pancreas and patients who were suspended for $>$30 days within 90 days of wait-listing were excluded. The latter exclusion avoided any potential bias from centres that may activate patients on the Tx waiting list and then immediately suspend them before reactivation after medical assessment of a patient's fitness for transplantation. The remaining patients were followed up for two years after starting RRT, to assess the proportion of patients registered on the waiting list for a kidney Tx alone or kidney and pancreas Tx. To identify factors which influence the likelihood of transplantation after wait-listing, patients were followed-up for two years after wait-listing, to access the proportion of patients who received a kidney Tx alone or kidney and pancreas Tx.

Logistic regression models were fitted to examine the relationship between patient characteristics (age group, ethnicity, sex, PRD) and Tx wait-listing within two years of starting RRT, or receipt of a Tx within two years of wait-listing. The proportion of all incident RRT patients listed for transplantation within two years of starting RRT and the proportion of wait-listed patients who were transplanted within two years were calculated for each renal centre, with adjustment for the above patient characteristics.

The odds ratio from the logistic regression model was used to assess the impact of age, sex, ethnicity, and PRD on the probability of the patients being wait-listed within two years after RRT, and also the probability of the patients being transplanted within two years after wait-listing. The odds of patients who were treated at non-Tx centres getting a Tx was compared to those treated at Tx centres, adjusted by age, sex, ethnicity and PRD.

DBD Tx were considered separately from DCD Tx or LKDs, because of differences in the process of allocation. Kidneys from DBD are allocated according to national allocation policy, while kidneys from DCD are allocated regionally according to the 2006 DBD kidney allocation scheme, and one kidney from each donor is offered to the local Tx centre. The process of LKD transplantation is managed by the transplanting centre (and referring non-transplanting centre). The overall proportion transplanted from any donor type was also calculated.

Funnel plots were used to present results for each outcome, providing a visual comparison of the relative performance of renal centres, based on the results of the logistic regression models described above. Funnel plots showing the proportion of patients transplanted at two years after wait-listing excluded centres with <10 patients wait-listed at the start of the study period.

Median time from starting RRT to wait-listing at each renal centre was estimated by KM analysis, censored at death or on 31 December 2016, whichever was earlier. CIs of median time to wait-listing by centre in the funnel plot were derived using a statistical technique called bootstrapping. In centres where the KM curve did not reach 50% (and therefore median time could not be calculated), the final event time point was used instead.

Patients transplanted after starting dialysis were assigned to the renal centre recorded by the UKRR as the centre providing dialysis. For patients transplanted pre-emptively, there may be instances where the renal centre recorded was the transplanting centre, even when work-up took place in a non-transplanting centre.

For patients wait-listed after starting dialysis, time from starting dialysis to wait-listing was recorded. Patients receiving a pre-emptive Tx (living or deceased donor) were recorded as wait-listed on the day of transplantation (i.e. time from starting RRT to wait-listing: zero days). Patients who received a LKD Tx after starting dialysis who had not been formally wait-listed prior to transplantation were recorded as wait-listed six months before the date of their Tx (with a minimum time to wait-listing of zero days). This aimed to account for the time needed to prepare patients for a LKD Tx, assuming suitability for wait-listing six months before LKD transplantation.

7.7 Paediatric RRT population (chapter 7)

This chapter describes the population of children (aged <18 years) with ESKD who received RRT in the year applicable to the analyses. Definitions of ‘incident’ and ‘prevalent’ cohorts are equivalent to those used in the analysis of adult RRT patients. However, by contrast to adult chapters, paediatric patients coded as ESKD who died within the first 90 days of RRT are excluded from the paediatric analyses.

In the UK, RRT for children is managed by 13 paediatric renal centres, all of which are equipped to provide both HD and PD. Ten of these centres also perform kidney transplantation. Young people aged 16–18 years may be managed in either paediatric or adult renal centres. This is variable across the UK and dependent on local practices, social factors and patient/family wishes.

In this chapter, data are only reported for patients aged <18 years who are managed within UK paediatric renal centres; young people aged 16–18 years who have only ever received nephrology care from adult renal centres are excluded from the analyses.

The populations used to calculate incidence and prevalence are obtained from the ONS. The mid-current-year population estimate produced by the ONS, based on the 2011 census, is used to calculate the current year incidence and prevalence rates. For analyses performed using historic years, an incident 15 year cohort is divided into three five year periods – with the mid-year estimate for each five year period being used as the population estimate. Incidence and prevalence for 16–18 year olds are not reported because data would not be representative of the UK because these young people may also be managed in adult services.

PRD is coded according to 2012 diagnostic groupings used by the ERA-EDTA: these include tubulointerstitial disease, glomerular disease, familial and hereditary nephropathies, systemic disease affecting the kidney and miscellaneous. Further details on how PRDs are coded and grouped can be found on the ERA-EDTA website (https://era-edta-reg.org/prd.jsp).

Data for height, weight, BMI and blood pressure vary with age, sex and size and are therefore presented as z-scores as described in the chapter.

Table A5 Summary of age-specific biochemical clinical audit measures for children

	Age (years)			
Parameter	<1	1–5	6–12	>12
Hb (g/L)	Maintain 95–115 if aged <2 years	Maintain 100–120 if aged >2 years	100–120	100–120
Ferritin (μg/L)	200–500	200–500	200–500	200–500
Adjusted calcium (mmol/L)	2.24–2.74	2.19–2.69	2.19–2.69	2.15–2.55
Phosphate (mmol/L)	1.10–1.95	1.05–1.75	1.05–1.75	1.05–1.75
PTH (individual centre)	Within twice the normal range Levels may be maintained within normal range if growing appropriately			
Bicarbonate (mmol/L)	Reported as either within or outside centre reference range			

Hb – haemoglobin; PTH – parathyroid hormone

8 Specific analyses for adults

8.1 Survival and cause of death analyses

The unadjusted survival probabilities (with 95% CIs) are calculated using the KM method, in which the probability of surviving more than a given time can be estimated for all members of a cohort of patients overall or by subgroup such as age group, but without any adjustment for confounding factors such as age that affect the chances of survival. Where centres are small, or the survival probabilities are >90%, the CIs are only approximate.

To estimate the difference in survival of different subgroups of patients within the cohort, a stratified proportional hazards model (Cox) is used where appropriate. The results from the Cox model are interpreted using a hazard ratio. When comparing two groups, the hazard ratio is the ratio of the estimated hazard for group A relative to group B, where the hazard is the risk of dying at time *t* given that the individual has survived until this time. The underlying assumption of a proportional hazards model is that the hazard ratio remains constant throughout the period under consideration. Whenever used, the assumptions of the proportional hazards model are tested.

To allow for comparisons between centres with differing age distributions, survival analyses are adjusted for age and reported as survival adjusted to age 60 years. This gives an estimate of what the survival would have been if all patients in that centre had been aged 60 years at the start of RRT. This age was chosen because it was approximately the average age of patients starting RRT 17 years ago at the start of the UKRR's data collection. The average age of patients commencing RRT in the UK has recently stabilised around an age of 63 years, but the UKRR has maintained age adjustment to 60 years for comparability with all previous years' analyses.

Defining when a patient starts RRT (day zero) is reliant on centres following consistently the methodology described in section 4.1.1. Previous work suggests that is not always the case. As well as variability in defining start date within the UK, there is international variability when patient data are collected by national registries (often for financial reimbursement or administrative reasons). Some countries define the 90th day after starting RRT as day zero, whilst others collect data only on those who have survived 90 days and report as zero the number of patients dying within the first 90 days.

Therefore, as many other national registries do not include reports on patients who do not survive the first 90 days, survival from 90 days onwards is also reported to allow international comparisons. This distinction is important, as there is a much higher death rate in the first 90 days, which would distort comparisons.

8.1.1 Methodology for incident patient survival

Patients incident to RRT are analysed over a number of years as stated in each analysis to help more readily identify differences between the survival of the populations being compared. Two years' incidence data is used to identify differences between the four UK countries. One year after 90 day survival using a rolling four year combined incident RRT cohort is used to compare survival between centres. A 10 year rolling cohort is used when analysing trends over time and for long term survival.

The incident survival cohort is not censored at the time of transplantation and therefore includes the survival of the subset of patients who start RRT with a pre-emptive Tx. An additional reason for not censoring is to facilitate comparison between centres. Centres with a high proportion of patients of South

Asian and Black origin are likely to have a healthier dialysis population, because South Asian and Black patients are less likely to undergo early transplantation and centres with a high pre-emptive Tx rate are likely to have a less healthy dialysis population because transplantation selectively removes fitter patients. However, censoring at transplantation is performed in a 10 year cohort to establish the effect on long term survival by age group and also in a four year cohort to investigate the effect on the outlying status of centres.

The one year incident survival is for patients who started RRT from 1 October of two years earlier until the 30 September of the previous year and followed up for one full year (e.g. patients starting RRT on 1 December 2014 are followed through to 30 November 2015). Using the same example, for analysis of one year after 90 day survival, patients who started RRT from 1 October 2014 until 30 September 2015 are included in the cohort and are followed up for a full year after the first 90 days of RRT.

The death rate per 1,000 patient years is calculated by dividing the number of deaths by the person years exposed. Person years exposed are the total years at risk for each patient (until death, recovery or lost to follow-up). The death rate is presented by age group.

Adjustment of one year after 90 day survival for the effect of comorbidity is undertaken using a rolling four year combined incident RRT cohort. Only those centres returning ⩾85% of comorbidity data for patients in the combined cohort are included. Adjustment is first performed to a mean age of 60 years, then to the average distribution of PRDs for the centres with ⩾85% comorbidity completeness. The individual centre data are then further adjusted for average distribution of comorbidity present at these centres.

8.1.2 Methodology for prevalent dialysis patient survival

The prevalent dialysis patient group is defined as all adults, alive and receiving dialysis at the start of the given year who had been on dialysis for at least 90 days at one of the UK adult renal centres. It does not include patients coded as being on chronic dialysis but yet to reach 90 days, unlike other definitions of the prevalent population. Prevalent dialysis patients on 31 December of the previous year are followed-up in the current year and are censored at transplantation. When a patient is censored at transplantation, this means that the patient is considered as alive up to the point of transplantation, but the patient's status post-Tx is not considered.

As discussed in previous reports, comparison of survival of prevalent dialysis patients between centres is complex. Survival of prevalent dialysis patients can be studied with or without censoring at transplantation and it is common practice in some registries to censor at transplantation. Censoring could cause apparent differences in survival between those renal centres with a high Tx rate and those with a low Tx rate, especially in younger patients where the Tx rate is highest. Censoring at transplantation systematically removes younger fitter patients from the survival data. The differences are likely to be small due to the relatively small proportion of patients being transplanted in a given year compared to the whole dialysis population (about 14% of the dialysis population aged <65 years and about 2% of the population aged ⩾65 years). To allow comparisons with other registries the survival results for prevalent dialysis patients censored for transplantation are quoted. To understand survival of patients, including survival following transplantation, the incident patient analyses should be viewed.

8.1.3 *Methodology for comparing mortality in prevalent RRT patients with mortality in the general population*

Data on the UK population in mid-2016 and the number of deaths in each age group in 2017 were obtained from the ONS. The age specific UK death rate was calculated as the number of deaths in the UK per 1,000 people in the population. The age specific expected number of deaths in the RRT population was calculated by applying the UK age specific death rate to the total of years exposed for RRT patients in that age group. This is expressed as deaths per 1,000 patient years. The age specific number of RRT deaths is the actual number of deaths observed in 2017 in RRT patients. The RRT observed death rate was calculated as number of deaths observed in 2017 per 1,000 patient years exposed. Relative risk of death was calculated as the ratio of the observed and expected death rates for RRT patients. The death rate was calculated for the UK general population by age group and compared with the same age group for prevalent patients on RRT on 31 December 2016.

8.1.4 *Methodology of cause of death*

Completeness of cause of death data is calculated for all prevalent patients on RRT who died in a specific year with cause of death data completed for that year. Patients who were lost to follow-up or who recovered are not included in the cause of death completeness calculation.

Adult patients from England, Wales, Scotland and Northern Ireland are included in the analyses of cause of death. The incident patient analysis included all patients starting RRT in the years 2013–2016. Analysis of prevalent patients included all those aged ⩾18 years and receiving RRT on 31 December 2016 and followed-up for one year in 2017.

8.2 Dialysis access

Each year, all adult renal centres in England, Wales and Northern Ireland are asked to provide vascular and peritoneal access data for incident and prevalent dialysis patients. Access data for incident patients are collected at patient level, whereas centre level data are submitted for prevalent patients. Records are validated against the UKRR database to confirm that the population collected at each centre for the audit was representative of the incident/prevalent population at that centre collected via the routine quarterly return.

For the purposes of this audit, patients categorised as having AKI are excluded from the analyses as well as those with missing information for access at start, age and date of starting RRT. Patients with no matching record in the UKRR database (patients assumed to be AKI patients) and those aged <18 years are excluded. If a centre reports prevalent numbers that differed by more than 10% from those in the UKRR database, it is excluded. Cross-referencing with the UKRR database also enables ascertainment of mortality within three months of commencing dialysis.

Patients starting HD are grouped by type of first vascular access: AVF, AVG, TL and NTL. Patients starting PD are categorised by the insertion technique: open surgery, laparoscopic, peritoneoscopic or percutaneous. Access at three months is defined as the type of access in use at three months after starting dialysis. If a patient is no longer receiving dialysis at three months (but had not recovered renal function), the reason is recorded instead, for example, 'death' or 'transplantation'. Referral time is defined as the number of days between the date of first being seen by a renal physician (as an inpatient or outpatient) and the date of commencing dialysis. A patient is classified as presenting 'late' if they have a referral time of <90 days.

Access failure is defined as when it is no longer usable for dialysis, with the date and cause of access failure reported. For the purposes of analysis, HD access failure is grouped into five causes: maturation, mechanical, infection, other and unknown. PD technique failure is grouped into six causes: infection, catheter related, solute/water clearance, leaks/hernia, other and unknown. Access failure is censored for death, transplantation, withdrawal from RRT and elective switching of access type. It is the intention to only capture access failures relating to the first access that is performed. If the reason recorded for access failure is not related to the first type of access recorded, then the data are not included in this analysis.

Centres that report data on PD patients in the previous vascular and peritoneal access audit are asked to complete a one year follow-up of their PD patients. Additional information is requested on the date of PD catheter failure, the reason for catheter failure, the number of catheters used during the year and the modality in use at one year after starting PD. Analyses that use these data are titled 'PD follow-up audit'.

Dialysis access is best interpreted in the context of all patients starting RRT, thus data for pre-emptive Tx recipients are included and sourced from the UKRR database to augment the dialysis access audit data. This reflects the amended (2014) Renal Association guidelines for planned RRT initiation, which include Tx in the audit standard. Tx and non-Tx centres work together to prepare patients for Tx, but for the purpose of these analyses, patients are allocated to their most likely treatment centre (Tx or non-Tx).