UK Kidney Association
UK Renal Registry

Appendix A

Definitions and methodologies used in the 27th Annual Report – data to the end of 2023

Contents

1. The UK Renal Registry (UKRR) Annual Report

The UKRR was established by the then Renal Association in 1995 with the primary aim of collating data centrally from all adult UK kidney centres to improve the care of patients with end-stage kidney disease (ESKD). Children on kidney replacement therapy (KRT) were initially captured by a separate registry established by the British Association for Paediatric Nephrology (BAPN), but this activity passed over to the UKRR from 2009. The Renal Association merged with the British Renal Society (BRS) in 2020 to become the UK Kidney Association (UKKA). The UKKA has an active and involved patient council (ukkidney.org/patients/patient-council).

Although originally limited to patients on KRT – dialysis treatments and kidney transplant (Tx) recipients – the UKRR now collects all episodes of acute kidney injury (AKI) in primary and secondary care (in England only) and some cases of chronic kidney disease (CKD) 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 KRT, as well as those who choose conservative care instead of KRT. The UKRR also conducts the annual Kidney PREM (patient reported experience measures) survey, more details of which can be found at https://ukkidney.org/kidney-patient-reported-experience-measure.

The UKRR Annual Report includes analyses of clinical data to benchmark each of the UK's 67 adult and 13 paediatric kidney centres against the UKKA audit standards (ukkidney.org/health-professionals/guidelines/guidelines-commentaries). The report comprises centre comparisons, attainment of audit standards, national averages and long term trends for measures of kidney care and patient outcomes. AKI episodes and patient measures data are published separately to this annual report.

The report focuses predominantly on patients with ESKD who are on KRT, but also includes a chapter in which patients who have CKD but are not receiving KRT (either because they do not yet require it, or because they are receiving conservative care), are reported. Each chapter of the report presents analyses about a subset of kidney patients, as detailed in section 7.

2. Data flows to the UKRR and data completeness

2.1 Data flows

Patient data for the annual report flows to the UKRR from different sources, in different ways and with varying frequency, but primarily via quarterly electronic returns from the UK's 80 kidney centres (adult and paediatric) (figure A1). English, Welsh and Northern Irish kidney centres send their data directly to the UKRR, where data are cleaned and validated prior to analysis. Data from centres in Scotland are collected, validated and published by the Scottish Renal Registry (SRR) before they are shared with the UKRR.

Most data are collected without patient consent under permissions granted under section 251 of the NHS Act (2006) by the Health Research Authority's Confidentiality Advisory Group (HRA CAG). These permissions allow the UKRR to collect data to support the registry's audit of KRT, AKI, and CKD. The current clinical dataset (version 5) for these audits, describing the data variables which the UKRR collects and are used in the annual report is available to download from ukkidney.org/audit-research/data-permissions/data. In reality, many variables are currently not well reported to the UKRR – see the data portal: ukkidney.org/audit-research/data-portals.

The UK Renal Data Collaboration (UKRDC) is an ongoing development which allows clinical data to flow daily from kidney centres to the UKRR. So far less than 10 kidney centres send their full data submissions via the UKRDC, but submission of data in version 5 of the dataset will only be permitted via this pathway, opening up the potential for near real time reporting.

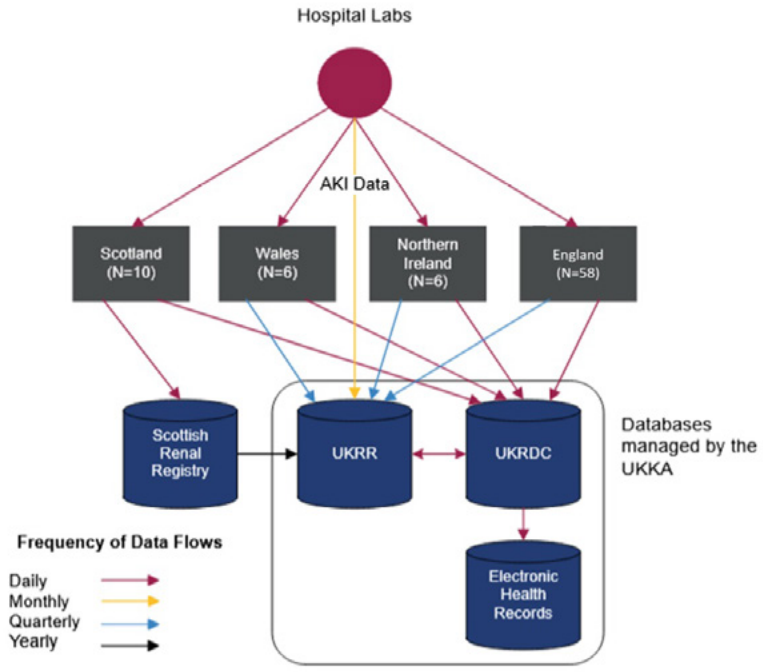

Figure A1 Frequencies and directions of patient data flows to the UKRR for the annual report

The UKRR database includes the British Association for Paediatric Nephrology database.
With the ongoing adoption of the UKRDC, data flows between kidney centres and the UKRR will move to a daily frequency.

Data from the following sources are also included in the 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 transplant.

NHS England Hospital Episode Statistics (HES) and Civil Registration Mortality Data for England and the NHS Wales Informatics Service 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 enhance the UKRR annual report data by enabling adjustment for case-mix in centre survival comparisons. Some of this data, admissions for example, is shown only in the data portal: https://ukkidney.org/audit-research/data-portals.

2.2 Data completeness

Unless otherwise stated, the data completeness threshold for a data item is ≥70%, i.e. where a kidney 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. Centres providing relevant data from <10 patients are also excluded from funnel and caterpillar plots for biochemistry and dialysis access analyses. While poor completeness may reflect a failure to accurately record patient data, other contributing factors include the incompatibility of local kidney 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 most current UKRR renal clinical dataset (version 5). The dataset has evolved and expanded over time in response to audit guidelines and quality improvement initiatives, with an understandable variable lag in the ability of local kidney IT systems to respond to those changes.

Completeness of data items for patients receiving KRT varies between kidney centres as detailed within each chapter. Twenty-four kidney centres submitted CKD data as part of their quarterly extract in 2023, with varying

completeness of data items. Reporting on CKD data only began in 2019 so we aim simply to describe the current data. All 24 centres were therefore included regardless of data completeness.

Comorbidity data derived from diagnostic and procedure codes in HES and PEDW are used to augment comorbidity data for adults submitted by kidney centres to the UKRR. A corresponding analysis of paediatric patients will soon be published. Where UKRR comorbidities are absent (meaning the patient does not have the comorbid condition), but the comorbidity in HES/PEDW is present (meaning the patient has the comorbid condition), the UKRR 'absent' comorbidity is overwritten with the HES/PEDW 'present' comorbidity. Enriching the latest dataset with comorbidities from HES/PEDW for patients in England and Wales increased comorbidity completeness from 64% to 99% and all kidney centres in England and Wales had ≥85% comorbidity completeness.

3. How the UKRR looks after patient data

3.1 Data governance

The UKRR continues to receive support for the secondary use of confidential patient data without patient consent. In England and Wales secondary use permissions are granted under section 251 of the NHS Act (2006) by the Health Research Authority's Confidentiality Advisory Group (HRA CAG); in Scotland, permission is granted by Public Health Scotland under Paragraph 4(2) of the Public Health Scotland Order 2019. In Northern Ireland the legal instruments to support the secondary use of patient data without patient consent are currently pending, awaiting the approval of the Northern Ireland Assembly.

Patients who have their confidential data collected and processed by the UKRR have the right to opt-out and only have their de-identified medical data included in the audit. Patients can opt-out by speaking to hospital staff in the kidney centre where they are being treated, or by contacting the UKRR directly. As of April 2023, patients are no longer able to opt-out of the UKRR's KRT and AKI audits via the National Data Opt-Out (NDOO) programme run by NHS England. These audits have been granted exemption by HRA CAG after the UKRR submitted analysis evidencing that the NDOO was introducing uncontrollable biases into its audit, reducing the validity of its outputs, including the Annual Report.

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 UKKA website (ukkidney.org/data-protection-privacy-notice) as well as in patient information leaflets and posters, which are distributed to all kidney centres. Each year the UKRR completes NHS England's Data Security and Protection toolkit.

3.2 Small numbers

From time to time, due to the rarity of a condition or other factors, data for only a small number of patients (<7) will be available for analysis and inclusion in the UKRR's annual report. With so few patients the risk of re-identification is increased. To assess this risk, the UKRR conducts an assessment on each chapter of the annual report, identifying the level of risk of re-identification for each cell containing a small number and balancing this with the benefits of publication. Where the risk of re-identification is deemed too high, or the benefits of publication fail to outweigh that risk then the cell is supressed. Where small numbers are included in this report, it was deemed that the risk of re-identification was low, because no one cell can provide insight into an individual patient, unless that patient is already known to the reader. The same process is applied to data presented on the UKKA data portal. Where published data includes or is derived from data provided by NHS England (HES and ONS data) cells reporting <7 patients are automatically suppressed or excluded.

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

The data collected by the UKRR are organised into 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 kidney centres to identify discrepancies within timelines, and between timeline and session data.

4.1 Key dates – the kidney 'treatment timeline'

4.1.1 Date first seen by a nephrologist

For England, Wales and Northern Ireland, 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 kidney centre from another kidney centre then this date should be left blank by the new kidney centre. For the purposes of this report, referral date and presentation date are both the same as the date first seen by a nephrologist. Date first seen is not currently collected in Scotland.

4.1.2 Late presentation

First seen date and date of KRT start (see below) are used to define late presentation, with a 90 day cut-off differentiating early versus late presentation. 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 KRT on the same date as the first presentation, because this is likely due to incorrect recording of data.

4.1.3 Date of KRT start

A patient with ESKD starting KRT 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 or pre-emptive Tx) episode.

If a patient starts KRT with an episode of AKI in which it was felt that kidney function had potential to recover, then 'acute' HD (or acute HD or kidney 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' KRT and if there is evidence of recent 'acute' KRT, will backdate the date of start of KRT to the start of the first episode of 'acute' KRT, 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 KRT in UKRR analyses remains the date of first dialysis. If a patient recovers for ≥90 days, subsequent KRT 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 KRT until a later date, exchanges as part of PD training need not be considered the start of KRT.

4.1.4 Change of modality date

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

4.1.5 Date of death

See section 8.1.

4.2 Allocation of patients to a kidney centre

The default method for allocating a patient to a kidney 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. Manchester is a transplanting centre that has been unable to submit patient level data since October 2022. For the dialysis centres that feed into Manchester for transplantation, we were able to recover information on pre-emptive transplantation using data from NHSBT.

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 sections 7.2 and 7.3).

5. Variables used to categorise patients

5.1 Demographics

5.1.1 Location

This includes kidney centre, country and Integrated Care Board (England), Health and Social Care Trust (Northern Ireland), Scottish Health Board (Scotland) or Local Health Board (Wales).

5.1.2 Sex

Patients are defined as male or female as reported by the kidney centre.

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 under 16 years and are therefore presented as z-scores as described in the relevant chapter. See section 7.8 for definitions.

5.1.5 Ethnicity

Most centres electronically upload ethnicity coding to their kidney 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 kidney IT system (using a variety of coding systems). 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, Asian, Black, Mixed and Other). Ethnic categories have been updated to be consistent with the categories used in the 2021 census.

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	Asian
9S7..	Pakistani	Asian
9S8..	Bangladeshi	Asian
9SA6.	East African Asian	Asian
9SA7.	Indian Subcontinent	Asian
9SA8.	Other Asian	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	Mixed
9S51.	Other Black – Black/White origin	Mixed
9S52.	Other Black – Black/Asian origin	Mixed
9S9..	Chinese	Asian
9T1C.	Chinese	Asian
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	Mixed
9SB1.	Other ethnic/Black/White origin	Mixed
9SB2.	Other ethnic/Asian/White origin	Mixed
9SB3.	Other ethnic/mixed White origin	White
9SB4.	Other ethnic/Other mixed origin	Mixed

NEC – not elsewhere contained; NMO – non-mixed origin

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	Mixed
E	Mixed – White and Black African	Mixed
F	Mixed – White and Asian	Mixed
G	Other Mixed background	Mixed
H	Asian or Asian British – Indian	Asian
J	Asian or Asian British – Pakistani	Asian
K	Asian or Asian British – Bangladeshi	Asian
L	Other Asian background	Asian
M	Black Caribbean	Black
N	Black African	Black
P	Other Black background	Black
R	Chinese	Asian
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, new codes are used were available and mapped back to old codes, using the mapping available on the ERA-EDTA website (http://era-edta-reg.org/prd.jsp). Where new codes are not available, old codes were used. 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
23	Pyelonephritis due to acquired obstructive uropathy	Pyelonephritis
24	Pyelonephritis due to vesico-ureteric reflux without obstruction	Pyelonephritis

Table A3 Continued

Code	Old PRD grouping	Assigned group
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. Patients with a cause of death code 107 (advanced CKD not on dialysis) with no other information to determine the group were assigned to missing cause of death.

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
19	Elevated PVR/pulmonary hypertension	Other
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	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
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

Table A4 Continued

Code	Cause of death grouping	Assigned group
73	Chronic obstructive pulmonary disease	Other
79	Multi-system failure	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
103	Peripheral vascular disease	Other
104	Calciphylaxis	Other
105	Ischaemic bowel	Other
106	Ruptured abdominal aortic aneurysm	Other
108	Acute kidney injury	Other
109	*Clostridium difficile* colitis	Infection
110	Line related sepsis	Infection

5.2.3 Comorbidity

Comorbidities are submitted either at time of starting KRT or as accrued comorbidities over time with a date of when a new comorbidity was diagnosed. When kidney centres in England and Wales implement version 5 of the dataset, they are no longer required to submit all comorbidities, but centres are asked to submit only comorbidities diabetes and malignancy, along with the date of diagnosis. Other comorbidities for patients treated in kidney centres in England and Wales are derived from a HES and PEDW data linkage (see 2.2 for more information). Kidney centres in Northern Ireland are asked to continue submitting all the comorbidities as specified in version 4.2 of the dataset as no hospital data linkage is currently possible for patients in Northern Ireland. No comorbidity data is submitted by renal centres in Scotland.

5.2.3.1 Comorbidities submitted at start of KRT

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

Comorbidities collected at start of KRT are:

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 KRT.

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. diabetic nephropathy not as the PRD) – type 1 and type 2 diabetes are coded separately and diet controlled diabetics are included in type 1.

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 biopsy 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 kidney artery stents.

Amputation for peripheral vascular disease (PVD)

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

Atrial fibrillation – whether the patient has atrial fibrillation; irregular, often abnormally fast heart rate.

PVD – usually lower limb; claudication, angioplasty (non-coronary) and amputation for PVD separately coded.

Dementia – any form of dementia: dementia, vascular dementia, Alzheimer's disease, memory loss (short or long term).

5.2.3.2 Submitting accrued comorbidities

Several kidney centres submit accrued comorbidities which include a date of diagnosis for each comorbidity and an expanded list of comorbidities in addition to the above listed comorbidities: ischaemic heart disease, non-ST segment elevation MI, atrial fibrillation, transient ischemic attack, cerebrovascular event/stroke, PVD and dementia. Comorbidities at start of KRT are subsequently derived from the date of the comorbidity diagnosis and the date of starting KRT.

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.

5.2.4 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.

5.2.5 Diabetes/non-diabetes

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

5.3 Treatment

5.3.1 Referral time

Time of presentation, the time a patient first sees a nephrology specialist and referral time are interchangeable for the purposes of this report.

5.3.2 KRT modality

The KRT treatment modalities available are transplantation (Tx), home haemodialysis (HHD), in-centre haemodialysis (ICHD) and PD – these are defined in the relevant chapters of the report. Paediatric patients on ICHD or HHD are reported in a combined HD group.

5.3.3 Dialysis access

AVF, AVG, PD catheter, central venous catheter (CVC) – non-tunnelled line (NTL) and tunnelled line (TL) – are defined in chapter 2.

5.3.4 HD session frequency and length

For patients on ICHD, the length and frequency of HD sessions are described in chapter 5. Patients on HHD are reported in chapter 7.

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 4.

5.3.6 Tx wait-listing

Pre-emptive Tx wait-listing is presented in chapter 2, while Tx wait-listing in the dialysis population is presented in chapter 3. Listing status before start of KRT for incident patients (analysis in chapter 2) or at end of year for the prevalent dialysis cohort (analysis in chapter 3) are obtained using NHSBT data regularly matched to the UKRR database.

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 kidney centres.

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

5.3.7.1 KRT incident biochemical and haematology variables

For the analyses of biochemical variables for incident patients, patients commencing any form of KRT (HD/PD/Tx) are included, unless otherwise specified. With the exception of starting estimated glomerularfiltration rate (eGFR, see below) measurements are taken after starting KRT, but still within the same quarter of KRT start. Therefore, depending on the quarter a patient starts KRT, 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 prior to the person starting KRT. Results are also shown with the cohort subdivided into early and late presenters (date first seen by a nephrologist ≥90 days and <90 days before starting KRT, respectively). For these analyses only centres with at least 70% completeness of presentation time data are included.

eGFR at KRT start – eGFR is calculated from serum creatinine. The start eGFR is studied amongst patients with eGFR data within 14 days before the start of KRT. In line with the National Institute of Health and Care Excellence (NICE) advice and for consistency across the UKRR Annual Report, the Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI 2009) creatinine equation, not adjusted for ethnicity, has been used to calculate eGFR from the 25th annual report. Previous reports used the CKD-EPI equation with ethnicity adjustment and eGFR across years may not therefore be strictly comparable.

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.

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. For young adults (16–18 years old), the Full Age Spectrum (FAS) creatinine equation is used because of low completeness of height in young adults managed in adult centres.

5.3.7.2 KRT prevalent biochemical and haematology variables

Haemoglobin (Hb) and ferritin – for the analyses of prevalent dialysis patients, those patients receiving KRT on 31 December at the end of the analysis year are included if they have been on the same 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.

Erythropoiesis stimulating agents (ESA) – The ESA data are collected electronically from kidney 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. ESA was not included in this year's report as we are implementing improvements in how medications data are processed. ESA data will be processed and analysed again once this work is completed.

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.

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 UKKA audit guidelines and are therefore not currently reported in the UKRR Annual Report for the adult dialysis population. However, they are reported in paediatric patients and at the national level for the adult transplant population.

Bicarbonate – the audit measures used for serum bicarbonate in the HD cohort and PD cohort differ as per the most recent guidelines. For children and young people aged <18 years, the paediatric reference range has been used (see section 7.8)

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.

Urea reduction ratio (URR), session duration and frequency – the prevalent adult ICHD 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.

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 of URR and session duration. 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 kidney centres.

5.3.7.3 CKD data

The data presented for CKD patients not on KRT in chapter 1 are given below; for further description of the measures see the previous sections for KRT patients.

eGFR – eGFR is calculated in the same way as for incident adult KRT patients, using the CKD-EPI creatinine equation. Patients are grouped into CKD stage G5 (eGFR <15 mL/min/1.73m^2) and stage G4 (eGFR 15–30 mL/min/1.73m^2) using their last recorded creatinine measurement. Patients whose last measurement was over two years old were excluded.

Hb and calcium – the last available measurement from the last two quarters of the year was used.

Blood pressure – the last available SBP and DBP measurements from the last three quarters of the year were used. Normal range is considered to be where SBP is <140 mmHg and DBP is <90 mmHg.

6. Statistical methods and analyses used

SAS version 9.4 software (https://www.sas.com/en_gb/home.html) is used for all analyses.

6.1 Estimation of kidney centre catchment populations

Estimates of each adult kidney centre's catchment population are needed to calculate incidence and prevalence rates of CKD and KRT at kidney centre level.

For England, Wales and Scotland, the UKRR database comprising the incident ICHD population between 1 January 2010 and 31 December 2019, supplemented with data from the prevalent ICHD population alive at the end of 2019, was used to estimate the size of each kidney centre's catchment population. Patients who started KRT with a pre-emptive Tx were excluded to avoid potential inflation of Tx centres' catchment populations, because this group of patients is only correctly assigned to the referring centre (rather than the Tx centre) when the coding of transfer out for pre-emptive Tx is used. Only the ICHD population was used, rather than the entire dialysis cohort, because ICHD patients are more likely to attend their closest centre than patients on home therapies (HHD or PD).

Following consultation with kidney experts in Northern Ireland, the entire KRT population was used for this region as its smaller size means that treatment patterns differ. While in England, Wales and Scotland the incident ICHD patients define the catchment, and pre-emptive Tx patients are predominantly from the same area, there is much more movement of people in NI, such that no population is ideal.

For England and Wales, data at the Middle Layer Super Output Area 2011 (MSOA11) level (of which there are 7,201) were used to assign populations to each kidney centre. The MSOA was determined for each incident ICHD patient using the postcode data held by the UKRR and the proportions of patients residing in that MSOA who were treated at each centre were calculated. These proportions were then applied to the overall adult mid-2019 population estimates for each MSOA published by the Office for National Statistics (ONS). In cases where there were zero incident ICHD patients in a given MSOA, the prevalent ICHD cohort was used instead. If there were also no prevalent ICHD patients, information from neighbouring MSOAs was used to allocate people to kidney centres.

For Scotland and Northern Ireland, intermediate zones (IZs) and electoral wards, respectively, were used to assign populations to each kidney centre. The General Register Office for Scotland has published 2011 population estimates for 1,279 IZs and the Northern Ireland Statistics and Research Agency (NISRA) has

published 2011 population estimates for 582 electoral wards. In instances where an area was not covered by the incident or prevalent ICHD cohorts, information from the neighbouring covered areas or from larger geographies was used.

The total catchment population for each centre was then determined by summing the populations assigned to each kidney centre as described above. Given that all geographies were assigned to a centre, the sum of all centres' catchment populations was equal to the total 2019 adult population estimate for the UK. While the sum of centres' catchment populations in Scotland and Northern Ireland was exactly the same as the total national populations, there was a small difference for England and Wales, because some patients residing in MSOAs in the border region were treated at kidney centres across the national border.

The above process was used to derive the proportion of the population of each MSOA (or IZ and electoral ward for Scotland and Northern Ireland respectively) that was assigned to each centre. Each year the latest populations for MSOA, IZ and electoral wards are obtained, and the same proportions applied to estimate the latest catchment population for each centre. This year, as the population data for all countries were not available for 2023, the catchment population was further upscaled so that the sum of centres' populations covered was equal to the 2023 national adult (≥18 years) population estimates for each country.

It is noted that this methodology has its limitations. The allocation of MSOAs in England and Wales and IZs in Scotland to each kidney centre was based upon ICHD patients only and so it is possible that non-ICHD patients may come from a different catchment population. This is more likely where a kidney centre provides specialist services and especially likely for patients undergoing kidney transplantation.

Catchment populations of paediatric kidney centres were estimated to calculate prevalence rates of KRT at kidney centre level, using a methodology similar to the one used for adult kidney centres. For England and Wales, the incident KRT population between 1 January 1997 and 31 December 2019 aged <16 years was used for the estimation. Given the small number of children on KRT, data at Clinical Commissioning Group (CCG) level, rather than MSOA, were used to assign populations to each paediatric kidney centre. Proportions of patients residing in each CCG who were treated at each English or Welsh centre were calculated. These proportions were then applied to the overall children (<16 years) mid-2023 population estimates for each CCG published by the ONS. Given that all geographies were assigned to a centre, the sum of all centres' catchment populations was equal to the total 2023 children population estimate for England and Wales. The sum of centres' catchment populations in England and Wales was slightly different to the total national populations, because some patients residing near the Welsh border were treated at kidney centres across the national border. Scotland and Northern Ireland are both covered by a single kidney centre, therefore their national population <16 years old was assigned to the respective centre, accepting some error in allocation for patients living around the Scottish border.

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 kidney centres. See each chapter for more details.

6.3 Graphs

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

6.3.1 Caterpillar plots

Caterpillar plots show the value of the audit measure for each centre along with 95% confidence intervals (CIs) for each centre, country and overall. The percentage of patients with missing data is usually shown in brackets next to each centre name.

6.3.2 Funnel plots

Funnel plots show the value of the audit measure for each centre plotted against the size of the centre (the number of people with a measurement, or the number of patient-years at risk). A 'funnel' is plotted around the average. 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 value of the audit measure for each centre is less reliably estimated, a greater observed difference from the average 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 99.7% confidence limits (CLs) as stated, corresponding to two and three standard deviations from the mean, respectively. Each point on the plot represents one kidney centre. For each outcome measure, if no significant inter-centre variation was present, three of 67 adult kidney centres would be expected to fall between the 95% and 99.7% CLs and no centre should fall outside the 99.7% CL. 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% CLs is therefore significantly different from the average survival in the UK.

6.3.3 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 95% and 99.7% CIs are created from the data to show compliance with an audit standard or variation from the national average. Centres are contacted if survival is lower than expected in patients starting KRT and for prevalent KRT 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 kidney 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 informs the president of the UK Kidney Association, who then takes action to ensure that the findings are properly investigated.

7. Populations and analyses by annual report chapter

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

7.1 Prevalent adult CKD population (chapter 1)

The prevalent adult CKD population is all patients aged 18 years and over with an eGFR <30mL/min/1.73m^2 at their last creatinine measurement, who are reported to the UKRR as receiving specialist treatment for CKD (excluding KRT or dialysis for AKI) in an adult kidney centre on 31 December 2023. It includes both patients who started treatment for CKD in 2023 and those who had been receiving treatment for longer. Any patients who were treated for CKD earlier in the year, but by the end of 2023 were on KRT for ESKD, would be part of the prevalent KRT population instead (there is no overlap between these two populations). Also excluded are patients who died before the end of 2023.

Patients who were recorded as receiving conservative care (and therefore might have clinical need for KRT, but not be in receipt of it) are included in this population, provided they meet the other criteria previously described. However, patients in receipt of conservative care are not analysed as a separate subgroup, because of the wide variation across centres in the proportions reported.

CKD data were submitted by 24 of the 67 adult kidney centres: Bangor, Birmingham, Cambridge, Cardiff, Carlisle, Clwyd, Derby, Gloucester, London Guys, London Kings, London Royal Free, Leicester, Middlesbrough, Nottingham, Oxford, Plymouth, Portsmouth, Preston, Reading, Salford, Sheffield, Swansea, Truro and Wrexham. Birmingham consists of two centres (QEH and Heartlands) but only QEH submitted CKD data (although the extracts include some Heartlands patients). Allocations to kidney centres follow the same pattern as described for the prevalent KRT population.

7.2 Incident adult kidney replacement therapy (KRT) population (chapter 2)

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

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 KRT treatment entry from any centre is used to determine the first date they commenced KRT. This is defined as a 'start date'. However, in the following situations there is evidence that the patient was already receiving KRT 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 an initial 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 KRT. 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. A patient can therefore appear only once in the incident cohort.

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. 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 kidney function. Recoding to KRT is automatically applied at 90 days for individuals still on KRT, unless the centre confirms a patient was on an unusually long period of dialysis for acute kidney failure, but can also be applied at any point between zero and 90 days by the reporting centre.

Differences in KRT incidence can be seen in the most recent years when compared with previous publications because of retrospective updating of data in collaboration with kidney 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 KRT.

7.3 Prevalent adult KRT population (chapter 3)

The prevalent adult KRT population is all patients on KRT for ESKD aged 18 years and over at a UK kidney 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 KRT until the end of the year) and patients who have been on KRT for longer. Excluded are patients who had transferred out, recovered kidney function, stopped treatment without recovery of function, died or were lost to follow-up before the end of the year. Patients who had transferred out, then transferred in to another centre before the end of the year would be included at the incoming centre. Also excluded are any patients aged 18 years and over still being treated at a paediatric kidney 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 (unlikely) then the choice is made based on the order in which the centres appear in the data.

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 KRT for <90 days are excluded.

Note the length of time on KRT 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 in section 7.2 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 KRT for ≥90 days and they are included for every quarter.

7.4 Prevalent adult transplant (Tx) population (chapter 4)

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

Annual organ-specific updates 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), living kidney donors (LKD), patient survival and graft survival are available on the NHSBT website (NHSBT website. https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports/).

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 7.3). 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.

Adjusted funnel plots visualise between-centre variation in the proportion of patients waitlisted or receiving an LKD transplant within two years of KRT initiation, accounting for case-mix differences and centre size. Proportions were adjusted using indirect standardisation via logistic regression for sex, age, and primary renal disease (PRD). The model calculates an expected probability for each patient based on their characteristics. For each centre, the observed proportion was divided by the sum of the expected probabilities. This ratio was multiplied by the overall mean to create an adjusted rate for the centre. Centres are benchmarked against the overall mean, with control limits identifying the range where we would expect 95% and 99.8% of centres to lie.

The median PTH by CKD stage is reported nationally, despite poor PTH completeness across all centres – therefore this has to be interpreted with caution. PTH is submitted to the UKRR in two different units from different centres (pmol/L or pg/mL). We assume each centre submits PTH using the same unit for all patients within their centre. During our data cleaning process, we convert the data to pmol/L if the overall median PTH of the centre suggested they had used pg/mL.

In the eGFR slope analysis, a minimum duration of 18 months graft function is required and three or more creatinine measurements taken at least 1 year after the date of transplant 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.

7.5 Prevalent adult in-centre haemodialysis (ICHD) population (chapter 5)

This chapter describes the population of adult patients with ESKD who were receiving 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 are analysed in a separate chapter.

7.6 Prevalent adult peritoneal dialysis (PD) population (chapter 6)

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

7.7 Prevalent adult home haemodialysis (HHD) population (chapter 7)

The HHD chapter includes analyses of prevalent patients on home haemodialysis. Due to small numbers, haematological and biochemical results are not shown for many of the UK kidney centres.

7.8 Paediatric KRT population (chapter 8)

This chapter describes the population of children (aged <18 years) with ESKD who received KRT or are receiving specialist treatment for CKD not on KRT in the year applicable to the analyses. Definitions of 'incident' and 'prevalent' cohorts are equivalent to those used in the analysis of adult KRT patients.

In the UK, KRT for children is managed by 13 paediatric kidney 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 kidney centres. This is variable across the UK and dependent on local practices, social factors and patient/family wishes.

In this chapter, data are reported separately for patients on KRT aged <16 years who are managed within UK paediatric kidney centres and for young people aged 16 to <18 years (including both young adults managed by paediatric kidney centres and those who received nephrology care from adult kidney centres).

Data are also presented for a prevalent CKD population aged <18 years for children with egfr <30mL/min/1.73m2 at their last creatinine measurement reported as receiving specialist treatment for CKD not on KRT in a paediatric kidney centre. Six of the 13 kidney centres were able to submit data on their CKD population, two of the centres were able to provide only a restricted dataset. Only basic demographics are presented for this group of children.

Mid-current-year population estimates obtained from ONS are used to calculate incidence and prevalence rates. For analyses performed using historic years, an incident 15 year cohort is divided into three five year periods – the middle year of each five year period being used as the population estimate. Incidence and prevalence for 16 to <18 year olds are also reported, however these are possibly under-estimated because adult centres are not currently required to send data on young people aged <18 years.

PRD is coded according to the 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 (http://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.

Analysis of cardiovascular risk factors is shown in children <16 years old. Risk factors considered are hypertension (SBP and/or DBP over the 90th percentile), BMI (overweight or obese, defined as a height-age z-score ≥1.3 in male and ≥1.19 in female) and hypercholesterolaemia (cholesterol ≥5.2 mmol/L, and/or high triglycerides, defined as triglycerides >1.13 mmol/L for those aged under 9 years and >1.46 mmol/L for those aged 9 years and over).

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
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			
Bicarbonate* (mmol/L)	Levels may be maintained within normal range if growing appropriately Reported as either within or outside centre reference range			

*In young adults, the range of 20–26 mmol/L was used.
Hb – haemoglobin; PTH – parathyroid hormone

8. Specific analyses for adults

8.1 Survival and cause of death analyses

The unadjusted survival probabilities (with 95% CLs) 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 CLs 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 KRT. This age was chosen because it was approximately the average age of patients starting KRT at the start of the UKRR's data collection. The median age of patients commencing KRT in the UK has recently stabilised around 63 years, but the UKRR has maintained age adjustment to 60 years for comparability with all previous years' analyses.

For some analyses, further adjustment was carried out for not only age, but also sex and comorbidities. Comorbidity data derived from diagnostic and procedure codes in HES and PEDW were used to augment

comorbidity data submitted by kidney centres to the UKRR. A comorbidity score was derived from a multivariable Cox proportional hazards model including all the comorbidities. Each comorbidity was allocated a weight determined by the size of the estimated hazard ratio. A comorbidity score was calculated by summing the weights of the individual comorbidities present for the patient.

Defining when a patient starts KRT (day zero) is reliant on centres consistently following the methodology described in section 4.1.3. 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 KRT 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 KRT 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 KRT 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 KRT 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.

The one year incident survival is for patients who started KRT from 1 October or two years earlier until the 30 September of the previous year and followed-up for one full year (e.g. patients starting KRT on 1 October 2021 are followed through to 30 September 2022). Using the same example, for analysis of one year after 90 day survival, patients who started KRT from 1 October 2021 until 30 September 2022 are included in the cohort and are followed-up for a full year after the first 90 days of KRT.

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.

Case-mix adjustment of one year after 90 day survival for the effect of age, sex and comorbidity is undertaken using a rolling four year combined incident KRT cohort. Data on age and sex are 100% complete. Only those centres returning ≥85% of comorbidity data (after augmentation from HES and PEDW) for patients are included. A Cox proportional hazards model with statistical frailty was fitted to account for heterogeneity and random effects between kidney 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 kidney 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 alive up to the point of transplantation, but the patient's status post-Tx is not considered.

Case-mix adjusted 1 year survival for prevalent dialysis patients at the end of 2022 is reported. The methodology followed is the same as described in section 8.1.1.

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 kidney 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 10% 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.

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

Data on the UK population in mid-2023 and the number of deaths in each age group in 2023 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 KRT population was calculated by applying the UK age-specific death rate to the total of years exposed for KRT patients in that age group. This is expressed as deaths per 1,000 patient-years. The age-specific number of KRT deaths is the actual number of deaths observed in 2023 in KRT patients. The KRT observed death rate is the number of deaths observed in 2023 per 1,000 patient-years exposed. Relative risk of death is the ratio of the observed and expected death rates for KRT patients. The death rate is presented for the UK general population by age group and compared with the same age group for prevalent patients on KRT on 31 December 2023.

8.1.4 Methodology of cause of death

Cause of death records from Civil Registration were used where the cause of death was missing in the UKRR data. This resulted in improved completeness and changes in proportions of the causes of death. Completeness of cause of death data is calculated for all prevalent patients on KRT 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 KRT in the years 2019-2022. Analysis of prevalent patients included all those aged ≥18 years and receiving KRT on 31 December 2022 and followed-up for one year in 2023.

8.2 Dialysis access

Each year, all adult kidney centres in England, Wales and Northern Ireland are asked to provide vascular access data for incident and prevalent dialysis patients. For Scottish centres, data on first access for incident dialysis patients are provided through the quarterly return. Since last year we have supplemented the audit returns with information from the HD sessional data, and from the access at start in the quarterly returns. The audit is still the primary source of data as the other sources are only complete for some centres. For 15 centres who

were known to have sufficient data quality (based on 2020-2022 data), the UKRR waived the audit submission to reduce the burden of data collection. This process will be expanded to other centres as data quality of the sessional and quarterly access data improves.

For the purposes of this audit, the following patients are excluded: those categorised as having AKI; those with missing information for access at start; those who did not start dialysis for the first time in 2023 based on UKRR quarterly data submissions. Centres are excluded if they return audit data for less than 70% of the incident or prevalent patient population.

Patients starting HD are grouped by type of first vascular access: arteriovenous fistula (AVF), arteriovenous graft (AVG), tunnelled line (TL) and non-tunelled line (NTL). Referral time is defined as the number of days between the date of first being seen by a kidney physician (as an inpatient or outpatient) and the date of commencing dialysis.

Dialysis access is best interpreted in the context of all patients starting KRT, thus for some analyses data for pre-emptive Tx recipients are included. This reflects the UK Kidney Association commentary on the NICE Guideline on Renal Replacement Therapy and Conservative Management, 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 work-up centre (Tx or non-Tx), see section 4.2 for more details.