Sex disparities in patients with kidney failure in England and Wales

A UK Kidney Association Disparities Sub-report

UKKA
UK Kidney Association

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What is this document?

This document is part of the UK Kidney Association's Disparities Report, which looks at age, sex, ethnicity, and social and economic factors amongst people with kidney failure. The analyses presented here are for sex. The reports looking at age, ethnicity and social and economic factors are available here.

The decision to share these routinely collected data reflects increasing awareness that kidney health is strongly influenced by people's backgrounds. A document published by Kidney Research UK in 2018 highlighted how kidney disease is more likely, progresses faster, and is associated with earlier death amongst people from more deprived backgrounds. It also progresses faster in people from Black, Asian and UK minority ethnic populations, who are also less likely to receive a transplant. Women are more likely to get kidney disease, but men are more likely to start dialysis. Older people are less likely to receive a transplant. Organisations like the UK Kidney Association were advised in Kidney Research UK's report to make reporting and analysis of inequalities in kidney care part of their role.

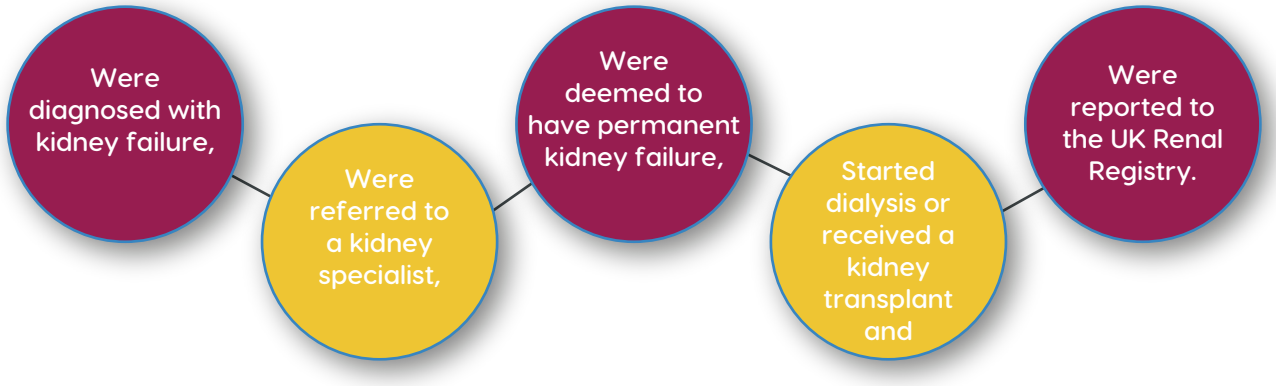
Reporting of these disparities is the purpose of this document. We use the term 'disparities' as opposed to 'inequalities' for this report because it only looks at differences in the care and outcomes of patient groups. We are not able to provide insight on whether care and outcomes would be equal or fair, if all differences between the groups were considered. This is discussed further under *A note on statistics*, below.

Contents

Whose data are shown?

This report includes all adults and children in England and Wales reported to the UK Renal Registry as having started long-term treatment for kidney failure between 1st January 2014 and 31st December 2020. UK Kidney centres provide care for either adults or children. Adult centres reported 49,078 people. Children's centres reported 755 people under the age of 16. These are the same people who were in the UK Renal Registry's annual reports, where you can find more information about how these data reach us.

All people included in this report:



The UK Renal Registry does not reliably capture information on individuals who reach kidney failure, but do not start dialysis or receive a transplant – so these people cannot be included. Individuals who needed temporary dialysis are also not included.

What data are shown?

Whilst we hold detailed information about individuals' kidney care, we hold only limited information about who they are, taken from the health record provided by the kidney unit providing the person's care.

We present the following characteristics:

- Age in years
- Binary male / female sex as assigned at birth
- Ethnicity categorised as per the Office of National Statistics – Asian, Black, Mixed, Other, White, or missing
- Socioeconomic deprivation - This is based on a measure of deprivation called the "Index of Multiple Deprivation" based on where the individual lives.

We do not hold any data relating to the following protected characteristics: disability, gender and gender reassignment, marital and partnership status, pregnancy and maternity, religion and beliefs, or sexual orientation. The absence of these characteristics – or others such as mental illness – from this report does not mean that they are not associated with disparities in kidney care.

We present the following medical and health factors:

Diagnosis of diabetes, since this is a common cause of kidney failure

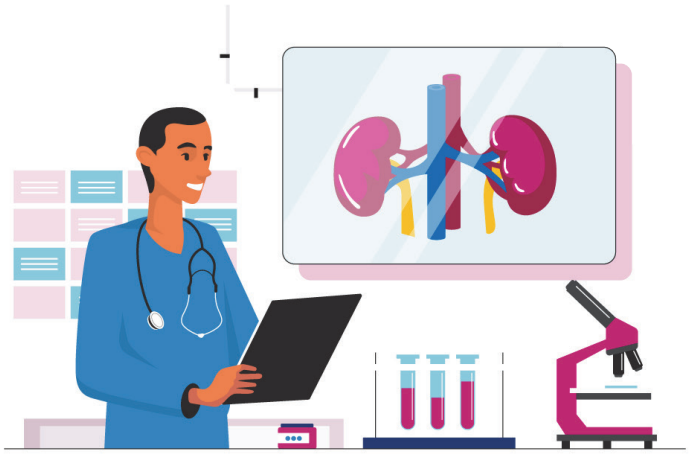
Survival one year after starting treatment for kidney failure

Whether or not the person has been transplanted within three years of reaching kidney failure

Whether the individual first met a kidney specialist more than three months (early presentation), or less than three months (late presentation) before starting treatment

Starting treatment type: hospital haemodialysis, home treatment (peritoneal dialysis or home haemodialysis), or a pre-emptive kidney transplant (transplantation without first doing dialysis)

How were these factors chosen?



The presented factors were chosen by people living with kidney disease, supported by clinicians and researchers. Our aim was to provide accessible data describing the care and outcomes of people living with kidney disease, without overwhelming detail. If you think something is missing, or you would like access to the UK Renal Registry data, please contact us [ukka@ukkidney.org].

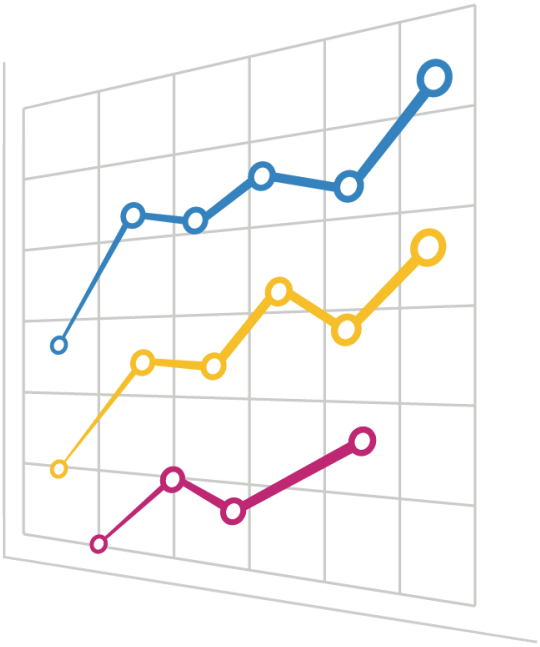
We chose to present data from 2014 onwards as the UK Kidney Association last formally reported on inequalities in kidney health in 2013.

Some analyses use general population data, drawn from the Office of National Statistics, whose data are openly available. At the time of preparing this document, the published 2021 census data were incomplete, so data were drawn from the 2011 census, or ONS annual reports, where available.

While the data held by the UK Renal Registry provide the most reliable indicators of national kidney care, some of the data are incomplete. Complete data means that we have information for every person about a factor in a given centre or country – for example we have the age of every person in the database.

Completeness varies by centre. This means that we can be less certain about the importance and effects of some factors, especially when making comparisons between centres. Completeness is not the same as accuracy – we may hold a diabetic status for every record, but some of those listed as not having diabetes may have it, and some listed as having it may not.

A note on statistics



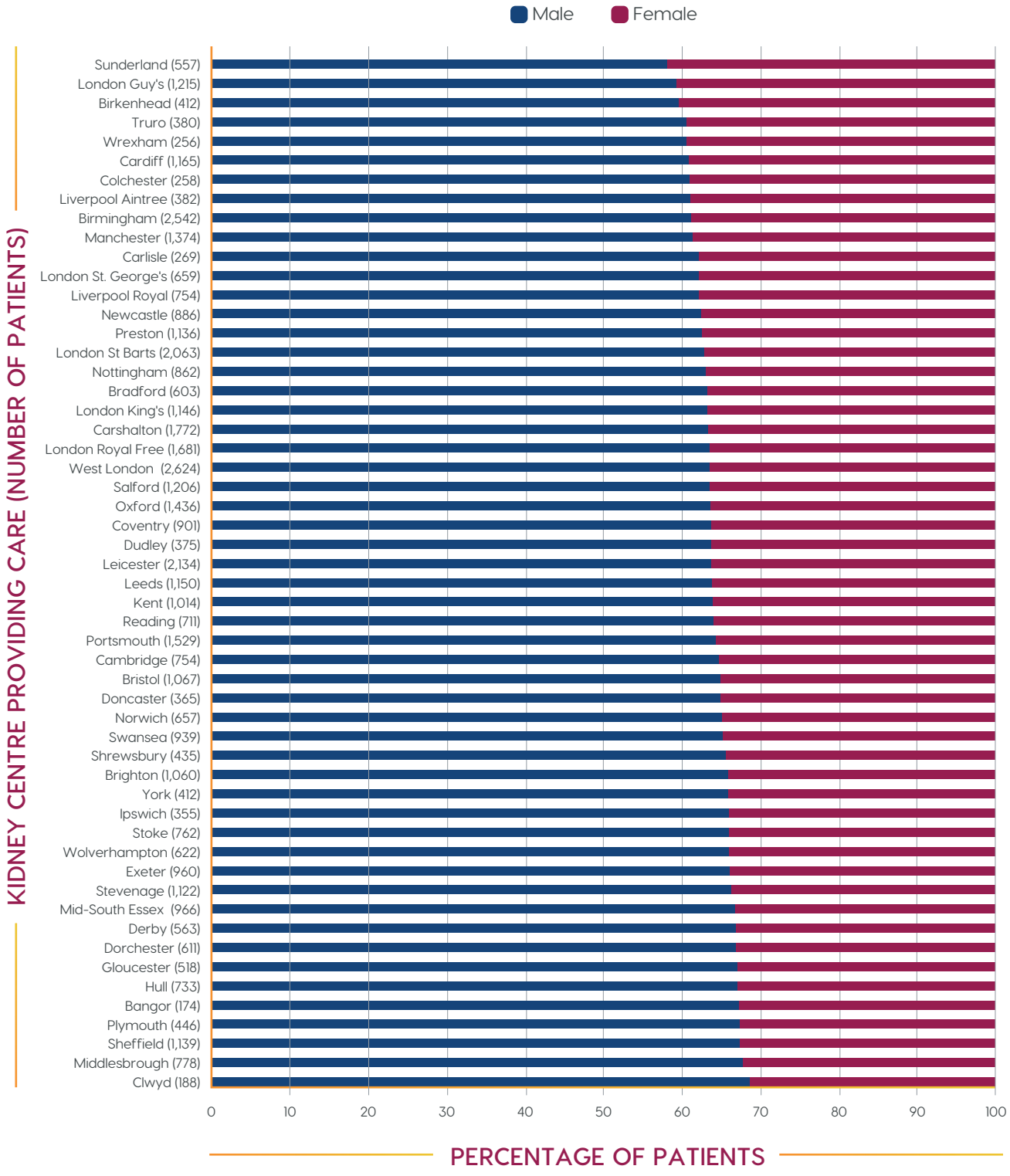
Associations between people's characteristics and healthcare must be made carefully, because one thing may not cause the other. This gets complicated because people's characteristics tend to group together, and it is not straightforward to tell which is 'most important'. For example, diabetes is one of the main causes of kidney failure, and a risk factor for other health problems such as heart disease. Rates of diabetes differ markedly between ethnicities. So, when comparing ethnicities, comparisons are also unintentionally made between those with higher and lower rates of diabetes. On the other hand, comparing those with and without diabetes leads to unintentional comparisons between people from different ethnicities. Ethnicity is itself a risk factor for kidney failure and is associated with other social and economic factors.

Researchers often use statistics to 'adjust' for such effects. This means using maths to unpick how much of one thing would be explained by another if all other things were equal. For example, examining how the age of onset of kidney failure would differ between ethnic groups if diabetes were equally common in each. These approaches can improve understanding of data, often revealing 'invisible' patterns. However, the output is less intuitive, and 'real-life' meaning can be lost. For example, such analysis would 'adjust away' the association between ethnicity and diabetes. This may not be meaningful if higher rates of diabetic kidney disease are genetic – a risk factor that cannot be eliminated. No statistical adjustment is provided in this report. Instead, the tables and figures have been designed to help people see patterns in the data.

1 Sex distribution at each kidney centre

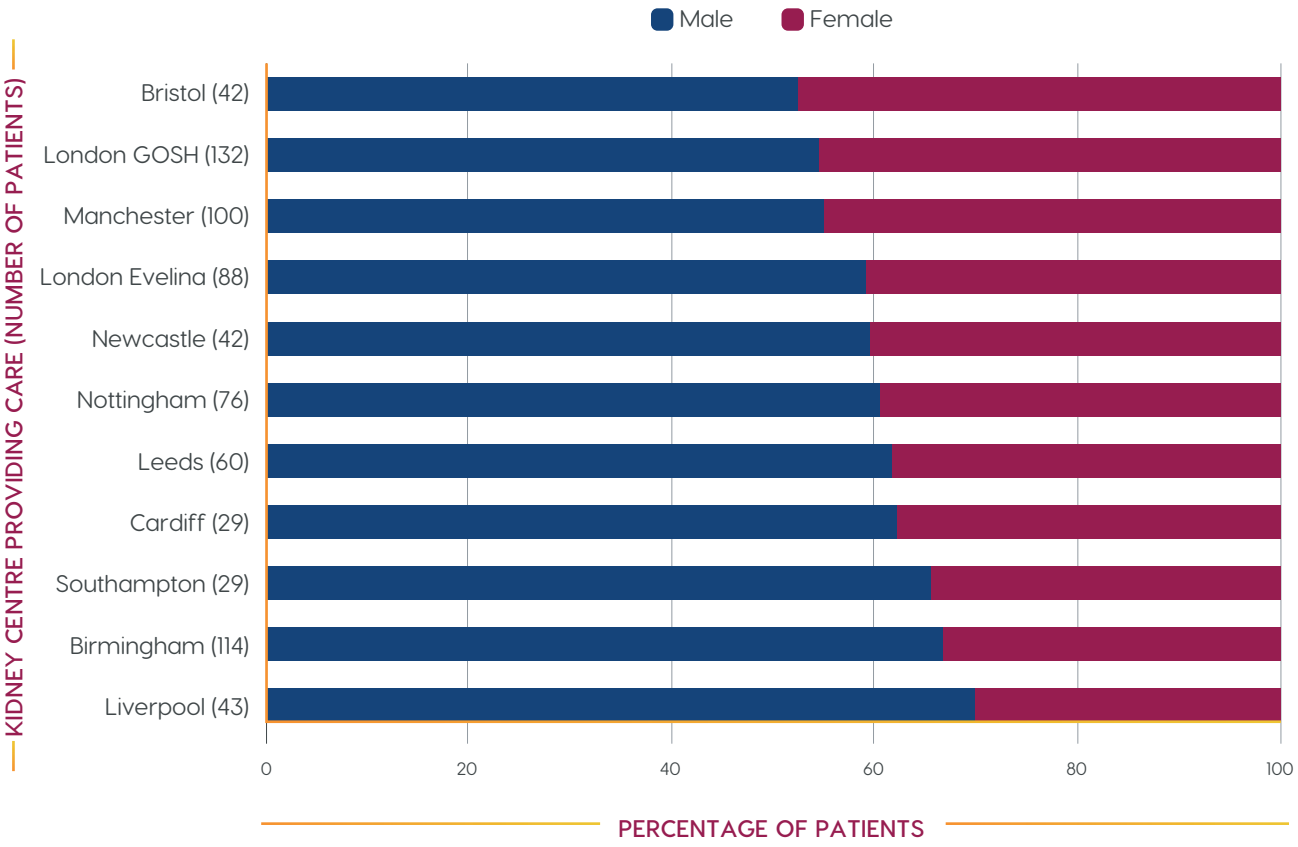
The following figures show the proportion of males and females in the kidney failure population at each of the adult and children's kidney centres in England and Wales. The total number of individuals cared for in each centre is listed next to the centre name. The coloured bars show the breakdown by sex in the population with kidney failure treated at each centre.

Figure 1a – Sex of adults by treating centre (%)



Sex distribution of adults who started treatment for kidney failure between 2014 and 2020.

Figure 1b – Sex of children by treating centre (%)

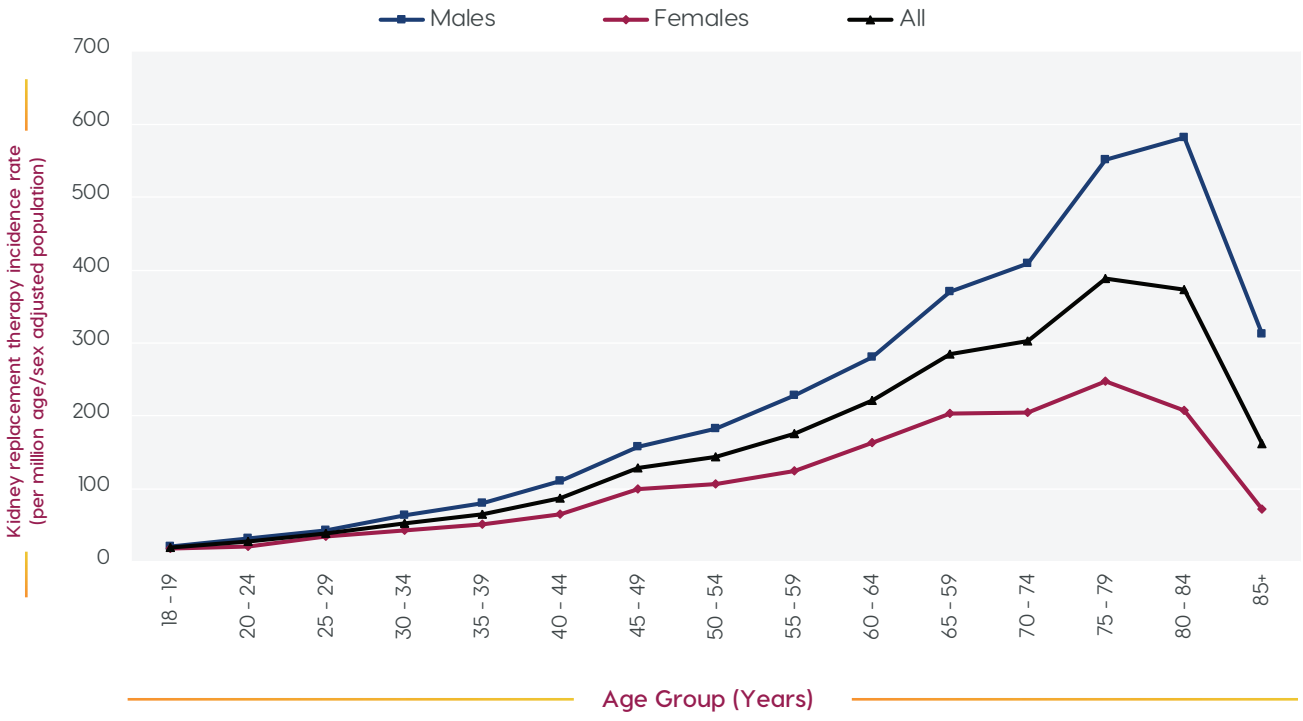


Sex distribution of children who started treatment for kidney failure between 2014 and 2020. GOSH - Great Ormond Street Hospital.

2 Sex, age and ethnicity

Figure 2 shows rates of adults starting treatment for kidney failure – so called incidence. Along the horizontal axis is age, so that incidence rates can be compared between age groups. The vertical axis shows the number of people who started treatment per million people in the population, labelled as 'age/sex adjusted population'. For each sex, the incidence rate is calculated using the number of males/females who started treatment per million people in the population with the same sex. For each age, the incidence rate is calculated using the number in that age group who started treatment, per million people in the population in the same age group. The rate for the total population is shown as a solid black line.

Figure 2 – Incidence rates for adults by sex per year



The rate of new adult patients starting kidney replacement therapy (incidence) between 2014 and 2020 by age group and sex, per year per million age/sex adjusted population (using age and sex data from the 2011 Census).

Main Findings

- More males than females start treatment for kidney failure at all ages. This is well known and is seen in other countries too but is incompletely understood.

The following tables show the percentage of male and female patients who are under or over 65 years old, and the percentage of males and females in each ethnic group. An age of 65 was chosen because approximately half the total kidney failure population is older than 65. The percentages for the whole kidney failure population are also shown. The size of each coloured bar matches the percentage in its cell – the bigger the number, the longer the bar.

Table 2a – Age of adults (all people over 18 years of age, %)

Age Category

Sex	Number	Under 65 years (%)	65+ years
All	49,078	52	48
Male	31,280	50	50
Female	17,798	54	46

Age of adults by sex who started treatment for kidney failure between 2014 and 2020.

Main Findings

- Males receiving treatment for kidney failure are slightly older, on average, than females. In the general population, females tend to live longer, so have a higher average age than males.

Table 2b – Ethnicity amongst adults (all people over 18 years of age) (%)

Ethnicity

Sex	Number	White	Asian	Black	Other	Mixed	Missing
All	49,078	73	13	7	2	1	4
Male	31,280	73	12	7	2	1	4
Female	17,798	71	14	8	2	1	4

Ethnicity breakdown by sex of adults who started treatment for kidney failure between 2014 and 2020.

Main Findings

- There do not appear to be marked differences in ethnicity between adult males and females receiving treatment for kidney failure.

Table 2c – Ethnicity amongst children (under 16 year-olds treated in children's centres, %)

Sex	Number	Ethnicity: White	Asian	Black	Other	Mixed	Missing
All	755	61	20	6	5	1	6
Male	452	61	20	7	6	1	5
Female	303	61	20	6	5	2	7

Ethnic breakdown by sex of children who started treatment for kidney failure between 2014 and 2020.

Main Findings

- There do not appear to be marked differences in ethnicity between male and female children receiving treatment for kidney failure.

3 Sex and socioeconomic factors

The following tables show the percentage of patients of each sex who live in regions of above-average deprivation (left) or below-average deprivation (right). The percentage for the whole kidney failure population is also shown. The size of the bar represents the percentage in each cell – the bigger the number, the longer the bar.

Table 3a – Deprivation amongst adults (%)

Deprivation

Sex	Number	Living in the regions of above-average deprivation (%)	Living in the regions of below-average deprivation
All	49,078	58	42
Male	31,280	56	44
Female	17,798	60	40

Male and female adults living in the most and least deprived 50% of regions (by Index of Multiple Deprivation) who started treatment for kidney failure between 2014 and 2020.

Main Findings

- On average, adult females receiving treatment for kidney failure come from slightly more deprived regions than males.

Table 3b – Deprivation amongst children (%)

Deprivation

Sex	Number	Living in the regions of above-average deprivation (%)	Living in the regions of below-average deprivation
All	755	65	35
Male	452	64	36
Female	303	65	35

Male and female children living in the most and least deprived 50% of regions (by Index of Multiple Deprivation) who started treatment for kidney failure between 2014 and 2020.

Main Findings

- There does not appear to be a difference between male and female children's levels of deprivation, but deprivation is high for both.

4 Sex and cause of kidney failure

Whenever possible, doctors try to identify the cause of a person's kidney failure, their "primary kidney disease". Kidney failure tends to have different causes in children than in adults, as they experience different health conditions from one another.

The list of causes in adults is as follows:

- **Diabetes –** diabetes mellitus type 1 or 2
- **Glomerular disease –** conditions that damage the microscopic filters of the kidney, such as IgA disease or vasculitis
- **Hypertension –** kidney damage associated with high blood pressure
- **Polycystic kidney disease –** a genetic disorder that causes fluid-filled cysts to grow in the kidneys
- **Pyelonephritis –** damage to the kidney from infection and/or reflux (backwashing) of urine
- **Renovascular disease –** damage to the blood vessels of the kidneys
- **Uncertain –** used when no cause of kidney failure can be diagnosed
- **Other –** any other cause of kidney failure listed

The list of causes in children is as follows:

- **Familial / hereditary nephropathies –** conditions that affect the kidneys which may run in families, or may be due to a new genetic mutation. Includes conditions such as nephronophthisis and cystinuria
- **Glomerular disease –** conditions that damage the microscopic filters of the kidney, such as nephrotic syndrome and IgA nephropathy
- **Miscellaneous kidney disorders –** where no primary kidney problem was identified
- **Systemic diseases affecting the kidney –** conditions that affect the body and can also damage the kidney. Includes Systemic Lupus Erythematosus (SLE)
- **Tubulo-CAKUT –** conditions that people are born with which affect the kidney and/or urinary tract.
- **Tubulo-non-CAKUT –** conditions that are acquired after birth which affect the kidney and/or urinary tract

In table 4a, the breakdown of primary kidney diseases is shown for each sex. Data are shown for patients with a recorded primary kidney disease, even when recorded as 'uncertain'. Six percent of adults had no recorded primary kidney disease. The cells for each sex add up to 100%. The size of the bar represents the percentage in each cell – the bigger the number, the longer the bar.

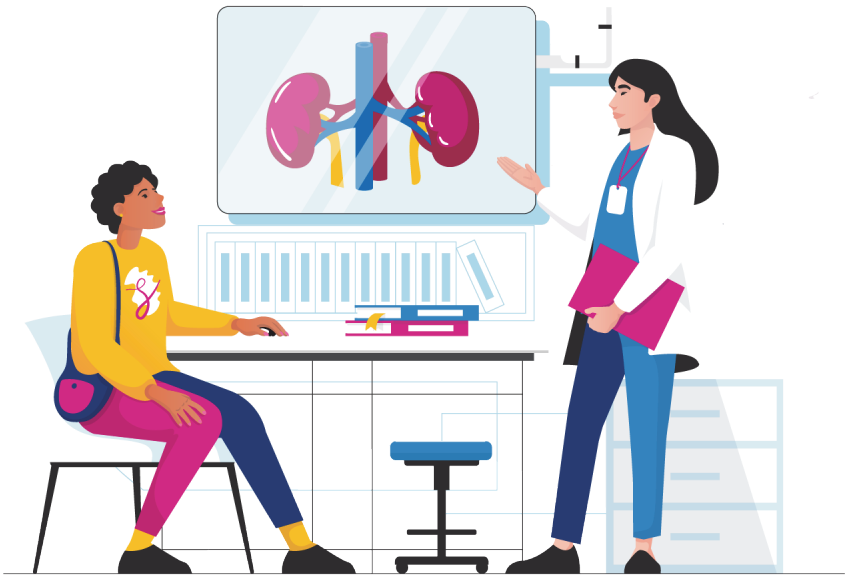
Table 4a – Adult primary kidney disease by sex (%)

Sex	Primary Kidney Disease	Total %
Male	Diabetes	29
	Glomerular disease	14
	Hypertension	8
	Polycystic renal disease	6
	Pyelonephritis	6
	Renovascular disease	6
	Uncertain	15
	Other	17
Female	Diabetes	28
	Glomerular disease	11
	Hypertension	6
	Polycystic renal disease	8
	Pyelonephritis	6
	Renovascular disease	5
	Uncertain	16
	Other	21

Primary kidney disease by sex for adults who started treatment for kidney failure between 2014 and 2020. Not including those with no recorded primary kidney disease.

Main Findings

- Diabetes is the most commonly attributed cause of kidney failure amongst both adult males and females.
- There does not appear to be a marked relationship between primary kidney disease and sex for adults receiving treatment for kidney failure.



In table 4b, the breakdown of primary kidney diseases is shown for male and female children. Data are shown for patients with a recorded primary kidney disease. Two percent of children had no recorded primary kidney disease. The cells for each sex add up to 100%. The size of the bar represents the percentage in each cell – the bigger the number, the longer the bar.

Table 4b – Children's primary kidney disease by sex (%)

Sex	Primary Kidney Disease	Total %
Male	Familial / hereditary nephropathies	14
	Glomerular disease	17
	Miscellaneous renal disorders	12
	Systemic diseases affecting the kidney	4
	Tubulo-CAKUT	52
	Tubulo-non-CAKUT	2
Female	Familial / hereditary nephropathies	19
	Glomerular disease	19
	Miscellaneous kidney disorders	19
	Systemic diseases affecting the kidney	5
	Tubulo-CAKUT	37
	Tubulo-non-CAKUT	1

Primary kidney disease by sex for children who started treatment for kidney failure between 2014 and 2020. Not including those with no recorded primary kidney disease.

Main Findings

- Tubulo-CAKUT disorders – conditions that people are born with which affect the kidney and/or urinary tract – are the most common causes of kidney failure in both males and females but are especially common amongst male children.

5 Sex and diabetes

People with kidney failure often have multiple other health conditions (comorbidities). Table 5 shows the percentage of adults who have diabetes by sex, as diabetes is especially common amongst adults with kidney failure. Sometimes diabetes is also their primary kidney disease (the cause of their kidney failure). The size of the coloured bars represents the percentage in each cell – the bigger the number, the longer the bar.

Approximately two in three adults (66%) and less than half of children (<50%) in our system have comorbidity data. Whether comorbidity data are reported may depend upon a person's characteristics, or where they receive their care. Given these high levels of missing data, no figures are provided for conditions other than diabetes. Given its importance in kidney disease, we expect coding for diabetes to be better than that for many other conditions. However, it is likely that some adults with missing data have diabetes too.

Table 5 – Diabetes amongst adults (%)

Sex	Number	Diabetes: Yes	Diabetes: No	Diabetes: Missing
All	49,078	33	32	35
Male	31,280	34	32	34
Female	17,798	32	33	35

Percentage of male and female adults with diabetes who started treatment for kidney failure between 2014 and 2020.

Main Findings

- Diabetes levels appear to be similar between adult males and females receiving treatment for kidney failure.

6 Sex, presentation and first treatment

Individuals in this report all received dialysis or a kidney transplant for kidney failure. They may have started treatment with a transplant, or they may have first had haemodialysis or peritoneal dialysis. These treatments all require a person to have met a kidney specialist. The time between first meeting a specialist and starting treatment influences the kind of treatment someone will begin. If there is a short time (fewer than 90 days) between someone first seeing a specialist and starting dialysis or having a transplant, the person is said to have presented late. An individual might present late because their kidney disease was new and rapidly progressing, because their disease was advanced when first detected, or if their kidney condition was diagnosed, but their referral or appointment was delayed.

The following tables show the **percentage of people presenting late** to a kidney specialist, and the **breakdown of first treatment type.** The size of the coloured bars represents the percentage in each cell – the bigger the number, the longer the bar.

Table 6a – Late presentation amongst adults (%)

Presented Late To Kidney Services

Sex	Number	Yes (%)	No
All	49,078	16	84
Male	31,280	17	83
Female	17,798	15	85

Percentage of male and female adults who started treatment for kidney failure after a late presentation between 2014 and 2020.

Main Findings

- Late presentation to kidney services appears similarly common amongst adult males and females receiving treatment for kidney failure.

Table 6b – First treatment type amongst adults (%)

First treatment for kidney failure

Sex	Number	Hospital dialysis	Home dialysis	Transplanted
All	49,078	74	21	5
Male	31,280	75	21	4
Female	17,798	74	21	6

Percentage of male and female adults who started treatment for kidney failure between 2014 and 2020 with hospital haemodialysis, home dialysis, or a transplant.

Main Findings

- There is no appreciable difference between males and females in terms of first treatment for kidney failure.

Table 6c – Late presentation amongst children (%)

Presented Late To Kidney Services

Sex	Number	Yes	(%)	No
All	755	23		77
Male	452	18		82
Female	303	27		73

Percentage of male and female children who started treatment for kidney failure after a late presentation between 2014 and 2020.

Main Findings

- Late presentation to kidney services is more common for female children.

Table 6d – First treatment type amongst children (%)

Sex	Number	First treatment for kidney failure: Hospital dialysis	Home dialysis	Transplanted
All	755	38	40	21
Male	452	36	38	26
Female	303	41	44	15

Percentage of male and female children who started treatment for kidney failure between 2014 and 2020 with hospital haemodialysis, home dialysis, or a transplant.

Main Findings

- A higher proportion of female children start kidney replacement therapy on dialysis; a higher proportion of male children receive a transplant as first treatment compared to females.
- Transplantation is the first treatment for one in five children.

7 Sex and treatment outcomes

The UK Renal Registry reports annually on survival and transplant listing, and its reports are available here. NHS Blood and Transplant also provide data and summaries of transplantation rates, available here. This diagram shows what happens in the first year after starting kidney replacement therapy. Here, 42,443 adults of both sexes are included. Most people continued the modality they started, but others changed modality, and some died.

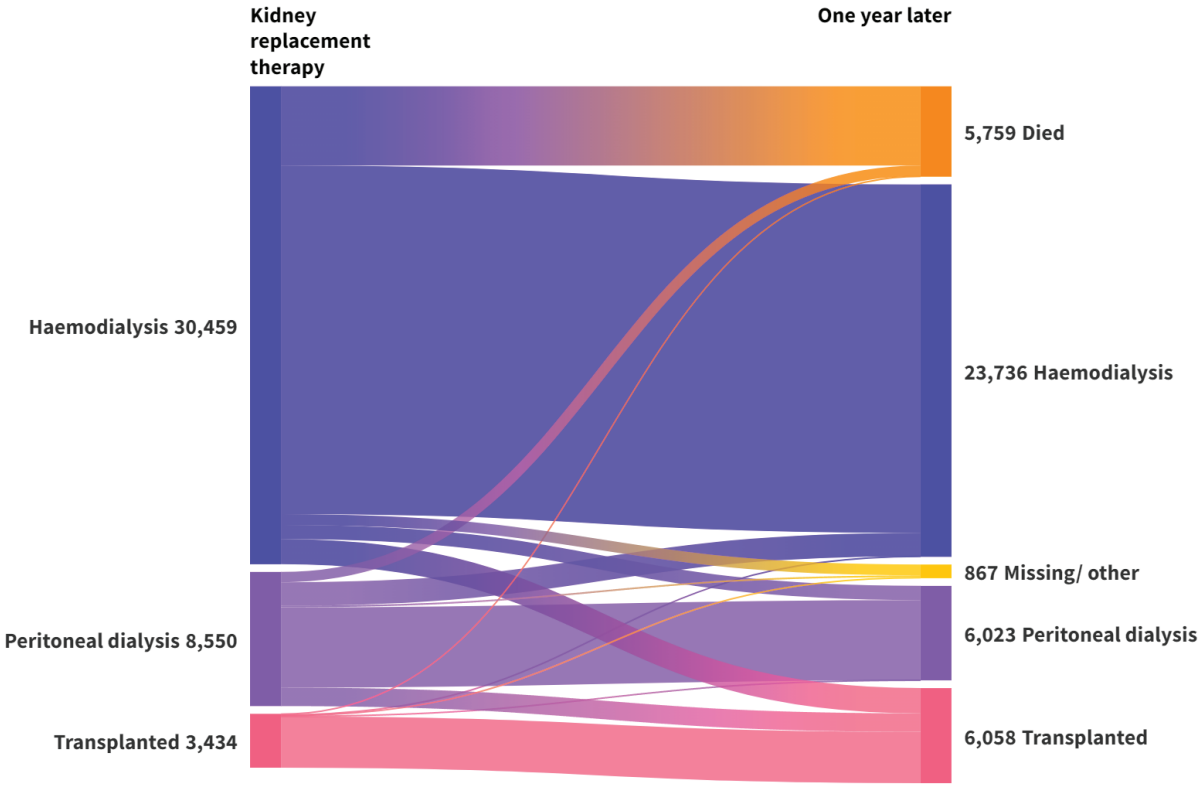


Figure 7 - outcomes one year after starting kidney replacement therapy

Click here to go to an interactive page where you can look at these data by sex.

The following tables show the percentage of patients in each sex, who were alive one year after starting treatment for kidney failure and the percentage who were transplanted within three years of starting treatment. The statistics for the whole kidney failure population are also shown. The size of the coloured bars represents the percentage in each cell – the bigger the number, the longer the bar.

Table 7a – Adult survival after starting treatment for kidney failure (%)

Alive One Year After Starting Treatment

Sex	Number	Yes (%)	No
All	49,078	87	13
Male	31,280	87	13
Female	17,798	88	12

Percentage of male and female adults who were alive one year after starting treatment for kidney failure between 2014 and 2020.

Main Findings

- Survival appears similar amongst adult males and females.

Table 7b – Adult transplantation after starting treatment for kidney failure (%)

Transplanted Within Three Years Of Starting Treatment

Sex	Number	Yes (%)	No
All	49,078	22	78
Male	31,280	21	79
Female	17,798	22	78

Percentage of male and female adults who were transplanted within three years of starting treatment for kidney failure between 2014 and 2020.

Main Findings

- Transplantation rates appear similar amongst adult males and females.

Table 7c – Child survival after starting treatment for kidney failure (%)

Alive One Year After Starting Treatment

Sex	Number	Yes (%)	No
All	755	97	3
Male	452	98	2
Female	303	96	4

Percentage of male and female children who were alive one year after starting treatment for kidney failure between 2014 and 2020.

Main Findings

- Survival one year after starting treatment is slightly higher for male children than for females.

Table 7d – Child transplantation after starting treatment for kidney failure (%)

Transplanted Within Three Years Of Starting Treatment

Sex	Number	Yes (%)	No
All	755	59	41
Male	452	63	37
Female	303	52	48

Percentage of male and female children who were transplanted within three of starting treatment for kidney failure between 2014 and 2020.

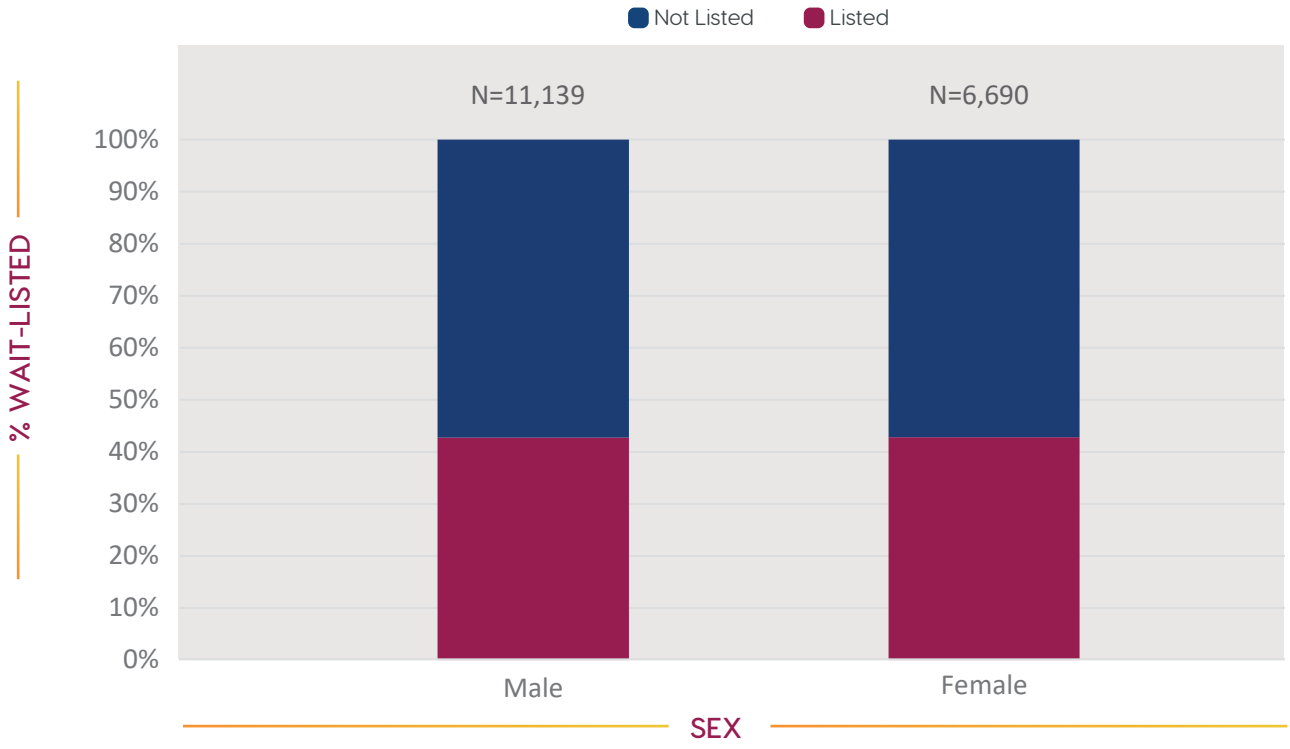
Main Findings

- Transplant rates are higher for male children compared to female children.

8 Sex and transplant wait-listing

Transplant 'wait-listing' refers to the point at which an individual is placed on the waiting list to receive a donated kidney. A report of a separate piece of work looking at wait-listing will be available on the UKKA website soon. Early findings are provided below. These data come from 17,829 adults aged between 18 and 75 who started treatment for kidney failure between March 2017 and February 2020. This report does not include children.

Figure 8 – Adult transplant wait-listing by sex



Number of 18–75-year-olds who started kidney replacement therapy between March 2017 and February 2020 by sex. Red and blue shading indicates the proportion listed, and not listed for transplantation within two years of starting.

Main Findings

- Transplant wait-listing proportions are similar for adult males and females.

In the past, there were concerns that adult females were less likely to be wait-listed than adult males. However, this updated analysis suggests that the chance of being wait-listed is the same for males and females, even once other factors are considered.

9 Conclusion

This descriptive report using UK Renal Registry (UKRR) data presents well-recognised and poorly explained disparities: males outnumber females starting treatment for kidney failure. Amongst children, late presentation is rarer, and transplantation as first treatment is more common for boys. Meanwhile, most other areas discussed in this report show males and females to be broadly similar. This is reassuring, given past evidence suggesting adult females, too, had poorer access to transplant listing.

Since this report describes rather than analyses UKRR data, a robust scientific approach will be needed if we are to understand the precise factors that lead to suboptimal outcomes and, critically, the factors that we can modify. In the meantime, further descriptive work will help reveal how demographic factors such as age, sex, ethnicity, and socioeconomic deprivation intersect to influence outcomes. And in the future, regular reporting will help us to identify rising or declining standards of care, and guide where we should invest to address inequalities.

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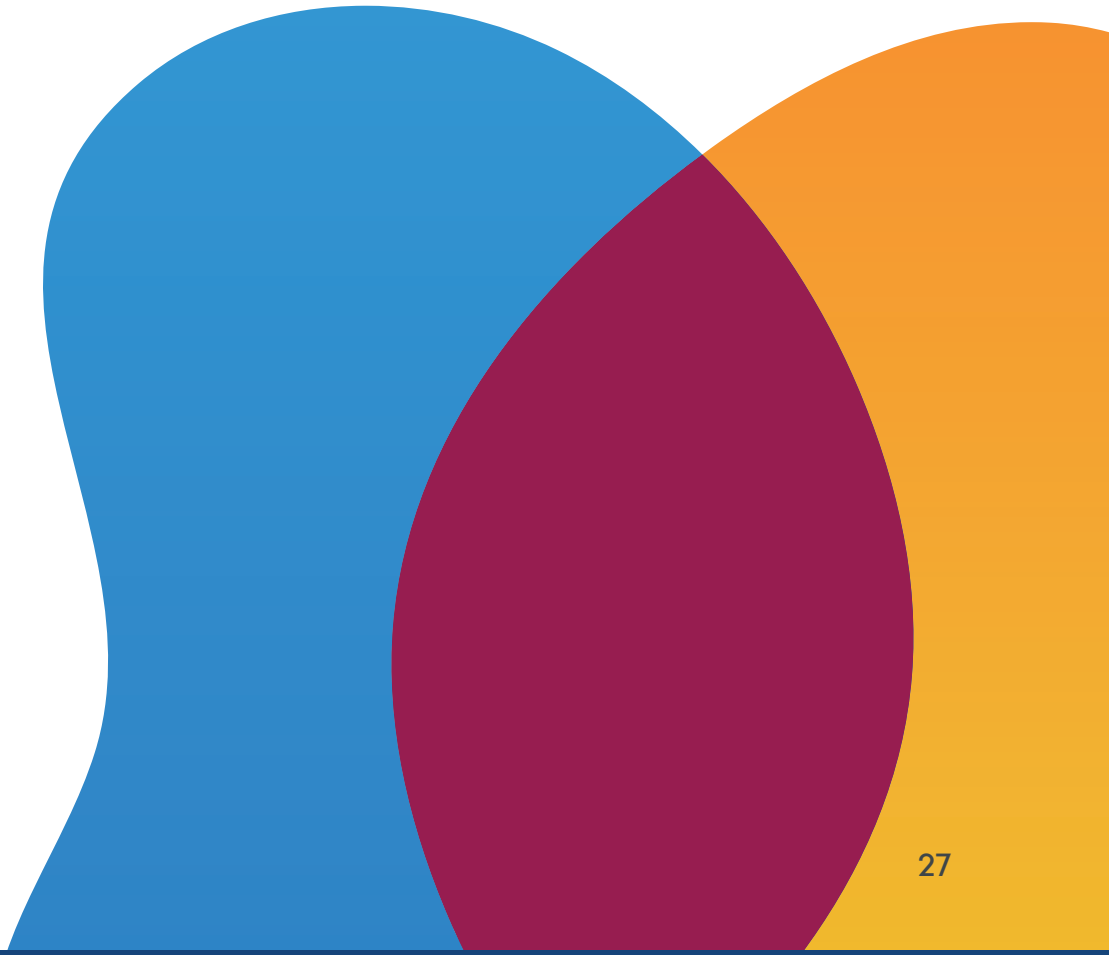

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