## Age

 disparities in patients with kidney failure in England and WalesA UK Kidney Association<br>Disparities Sub-report

OUUKA
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 age. The reports looking at sex, ethnicity and socioeconomic 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.

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## 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 lst 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 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) Age distribution at each kidney centre



The following figures show the age distribution of patients in the kidney failure population at each of the adult and children's kidney centres in England and Wales. The populations cared for also differ in their size, sex distribution, and ethnic diversity. The total number of individuals cared for in each centre is listed next to the centre name. The coloured bars reflect the different age categories.

Figure la - Age distribution of adults by treating centre (\%)
C 18-44

- 45-54
-55-64
-65-74
- $75+$


Number of adults reported to the UK Renal Registry who started treatment for kidney failure in each centre between 2014 and 2020, split by

Figure 1 lb - Age distribution of children by treating centre (\%)


PERCENTAGE OF PATIENTS

Number of children reported to the UK Renal Registry who started treatment for kidney failure in each centre between 2014 and 2020, split by age group. GOSH - Great Ormond Street Hospital.

## (2) Age, sex and ethnicity

Figure 2 shows rates of adults starting kidney replacement therapy (KRT) - 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. Thus, for each age group, the rate is calculated using the number of people who started treatment, per million people in the population in the same age group.

Figure 2 - Incidence rates for adults by age group per year
$\star$ KRT Population


Age Group (Years)

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

## Main Findings

- The rate of starting dialysis or receiving a transplant for kidney failure increases with age, consistent with the increased likelihood of kidney disease.

The fall in treatment rates above the age of 80 likely reflects the fact that an increasing proportion of older people are advised or decide not to start dialysis. People who choose not to have dialysis instead get treatment focused on the quality of their life rather than the length of it. This is called 'conservative kidney management'.

The highest rate is for those aged 75-79 years - at approximately 400 in a million (roughly one in 2,500 people).

- The lowest is for those aged 18-19 years - at approximately 20 in a million (roughly one in 50,000 people).

The following tables show the percentage of patients in each age group who are male or female. The percentages for the whole kidney failure population (all groups) are also shown. The size of each coloured bar matches the percentage in its cell - the bigger the number, the longer the bar.

## Table $2 a$ - Sex of adults (all people over 18 years of age, \%)



Sex of adults in each age category who started treatment
for kidney failure between 2014 and 2020..

## Main Findings

- More adult males than females start treatment for kidney failure in all age groups. As age increases, the proportion of males increases further, even though females live longer, on average.


## Table $2 b$ - Sex of children (under 16 years of age treated in children's centres, \%)



Sex of children in each age category who started treatment
for kidney failure between 2014 and 2020.

## Main Findings

- More boys than girls get kidney failure across all age groups.

Table 2c - Ethnicity amongst adults (\%)


Breakdown of ethnicity in each age category, for adults starting treatment for kidney failure between 2014 and 2020.

## Main Findings

- Whilst more people of White ethnicity start treatment for kidney failure across all age groups, younger age bands have an increased proportion of people of Black and Asian ethnicity.


## Table 2d - Ethnicity amongst children (\%)



Breakdown of ethnicity in each age category, for children starting treatment for kidney failure between 2014 and 2020.

## Main Findings

- More children of White ethnicity start treatment for kidney failure across all age groups.


## (3) Age and socioeconomic factors

The following tables show the percentage of patients in each age group who live in regions of above-average deprivation (left) or below-average deprivation (right). Statistics for the whole kidney failure population (all groups) are 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 (\%)



## Main Findings

- In more deprived areas, there are a greater proportion of younger adults with kidney failure. In less deprived areas, there are a greater proportion of older adults with kidney failure.


## Table 3b - Deprivation amongst children (\%)

Depriviation


Children living in the most and least deprived 50\% of regions (by Index of Multiple Deprivation) in each age group, who started treatment for kidney failure between 2014 and 2020.

## Main Findings

- There is no clear association between the age of children with kidney failure and deprivation level.


## (4) Age 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 $\lg A$ 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 $\lg A$ 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 in each age category is shown for adults. 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 age group 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 age category (\%)


Primary kidney disease for adults starting kidney replacement therapy between 2014 and 2020, split by age group. Not including those with no recorded primary kidney disease.

## Main Findings

- Diabetes is commonly attributed as the cause of kidney failure in all age groups, especially for those in middle age.

Glomerular disease is more common in younger age groups.

- Renovascular disease and uncertainty about the cause of kidney failure are both more common in older age groups.

In table 4b, the breakdown of primary kidney diseases is shown for children in each age group. 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 age group 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 age group (\%)


Primary kidney disease for children starting kidney replacement therapy between 2014 and 2020, split by age group. 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 commonest causes of kidney failure in all age groups. They become slightly less common as children reach their teens.


## (5) Age and diabetes

People with kidney failure often have multiple other health conditions (comorbidities). Table 5 shows the percentage of adults in each age category who have diabetes, 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 (\%)



Percentage of individuals with diabetes recorded for adults who started treatment for kidney failure between 2014 and 2020, split by age group.

## Main Findings

- Diabetes affects a third of people with kidney failure, but is most common in those aged 55-64.


## (6) Age, 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 (\%)



Percentage of adults starting treatment for kidney failure between 2014 and 2020 after a late presentation in each age group.

## Main Findings

- Late presentation is most common amongst those aged 18-44, but appears similar between age groups older than this.


## Table 6b - First treatment type amongst adults (\%)



Percentage of adults starting treatment for kidney failure with hospital haemodialysis, home dialysis, or transplanted between 2014 and 2020, in each age group.

## Main Findings

- Hospital dialysis is the most common first treatment across adult age groups.
- As people get older, they are less likely to have a transplant or home dialysis as their first treatment.


## Table 6c - Late presentation amongst children (\%)



## Main Findings

- Late presentation is most common amongst those aged 0-<2 years.


## Table 6d - First treatment type amongst children (\%)



Percentage of children starting treatment for kidney failure with hospital haemodialysis, home dialysis, or transplanted between 2014 and 2020, in each age group.

## Main Findings

- Overall, home and hospital dialysis are started equally frequently.

Transplantation is rarely performed as first treatment for children younger than two years, for whom home dialysis is more common.

Over the age of two, the treatments appear to be used similarly in all age groups.
Transplantation is the first treatment for one in five children.

## (7) Age 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 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 for each age group.

The following tables show the percentage of adults and children from each age group 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 (\%)



Percentage of adults who are alive one year after starting treatment for kidney failure between 2014 and 2020, split by age group.

## Main Findings

- One year survival falls with increasing age.

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


Percentage of adults who were transplanted within three years of starting treatment for kidney failure between 2014 and 2020, split by age group.

## Main Findings

- The likelihood of receiving a kidney transplant within three years of starting treatment falls with increasing age.
- Only $1 \%$ of over 75 year-olds receive a kidney transplant within three years of starting treatment.


## Table 7c - Child survival after starting treatment for kidney failure (\%)



Percentage of children who are alive one year after starting treatment for kidney failure between 2014 and 2020, split by age group.

## Main Findings

- More than $93 \%$ of children in each age band were alive one year after starting treatment for kidney failure, but survival was lowest amongst those who started treatment under the age of 2 years.


## Table 7d - Child transplantation after starting treatment for kidney failure (\%)



Percentage of children who were transplanted within three years of starting treatment for kidney failure between 2014 and 2020, split by age group.

## Main Findings

- Children under two years of age have lower rates of transplantation three years after starting treatment than other age groups.


## 8 Age 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 age group


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

## Main Findings

- The proportion of people listed for a kidney transplant ranges between $80 \%$ for those aged under 30, and 17\% for those aged 70-75.

The likelihood of being listed for a kidney transplant decreases as age increases. There is no evidence of a threshold effect: every group is less likely to be listed for transplant than those younger.

## 9 Conclusion

This descriptive report using UK Renal Registry (UKRR) data presents well-documented age-related disparities. As people get older, they are more likely to start treatment for kidney failure, experience worse survival rates, and have lower access to home therapies and transplantation. Not captured by this report are a group of people largely the oldest - who reach kidney failure, but do not start dialysis. Whether the stark disparities between age groups reflect natural variation in health as people age, or whether they also reflect differences in how people are able to access health services cannot be answered by this report. The other three reports in this series show interactions between age, ethnicity, sex, and socioeconomic deprivation - suggesting many factors are at play.

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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