Social and economic disparities in patients with kidney failure in England and Wales

A UK Kidney Association Disparities Sub-report





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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 socioeconomic factors. The reports looking at age, sex, and ethnicity 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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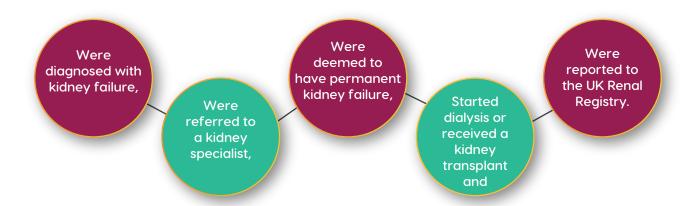
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Whose data are shown?

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 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?

This report includes data describing the level of socioeconomic deprivation experienced by people with kidney failure. Socioeconomic is a term used to describe social and economic factors that can affect someone's opportunities in life, their health, and their quality of life. Social factors include where someone lives, where they work, and what education and training opportunities someone has had. Economic or financial factors include whether someone can work full time, how much they get paid, and whether they own a house or a car. We use the words 'socioeconomic deprivation' to describe experiencing less good/less favourable social and economic circumstances than other people. People who are in full-time employment, have a large income, own a house and car would be described as having a 'low level of socioeconomic deprivation'. People who have no or temporary employment, who have no, low or unreliable income, and who live somewhere they don't own would be described as having a 'high level of socioeconomic deprivation'.

The Registry does not know patients' individual circumstances, so instead uses a measure called the Index of Multiple Deprivation (IMD) based upon where they live. IMD is the official measure of relative deprivation in England and Wales and is derived from patient's postcodes. The English IMD includes seven domains: income, employment, health deprivation/disability, education/skills, crime, barriers to housing/services and living environment. The Welsh IMD includes eight domains: income, employment, health, education, access to services, housing, community safety, and physical environment. IMD scores are categorised into five groups called 'quintiles' for our analysis: group 1 includes people living in the most deprived areas, and group 5 includes people living in the least deprived areas. In some instances, the data are presented for those living in the areas of above-average and below-average deprivation.

Socioeconomic deprivation is complex and influenced by many different factors. It is dynamic: a person's socioeconomic deprivation level will not necessarily stay the same throughout their life. Events such as illness, relationship breakdown, and loss of employment can change someone's socioeconomic factors.

We also present the following characteristics:

- Age in years,
- Binary male / female sex as assigned at birth

 Ethnicity categorised as per the <u>Office of National Statistics</u> Asian, Black, Mixed,

 Other, White or missing,



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

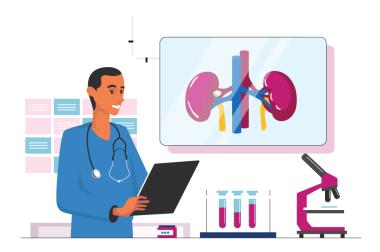
Survival one year after starting treatment for kidney failure

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 <u>openly available</u>. 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

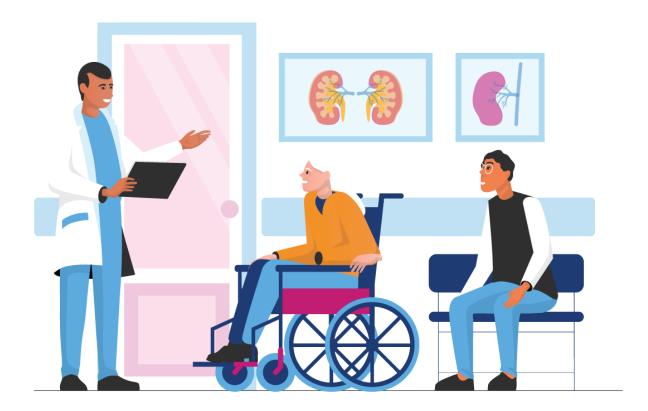


Associations between people's characteristics and healthcare must be made carefully, because one thing may not cause the other. This gets complicated because people's characteristics tend to group together, and it is not straightforward to tell which is 'most important'. For example, diabetes is one 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.



Deprivation at each kidney centre



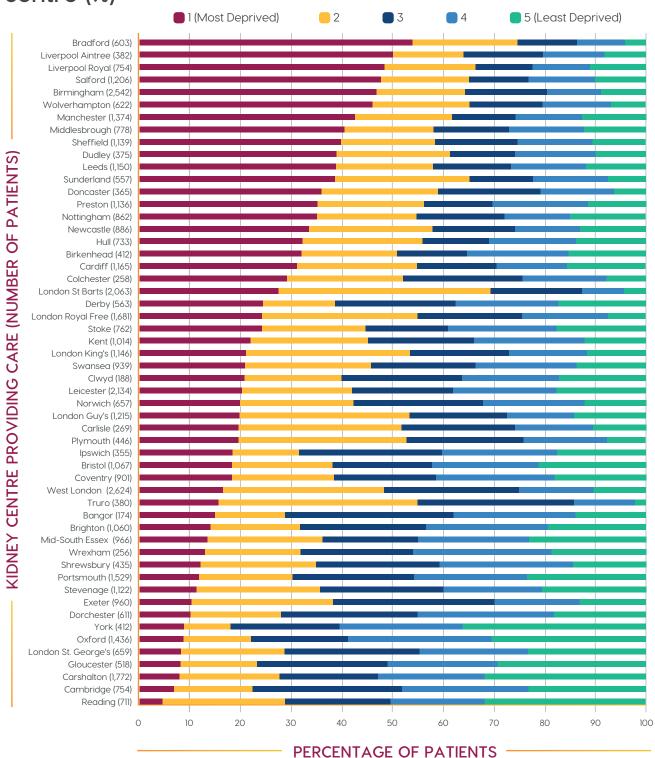
The following figures show levels of socioeconomic deprivation for the kidney failure population at each of the adult and children's kidney centres in England and Wales.

The populations cared for also differ in their size, age, and sex distribution, as well as ethnic diversity.

The total number of individuals cared for in each centre is listed next to the centre name. The coloured bars show the deprivation levels in each centre.



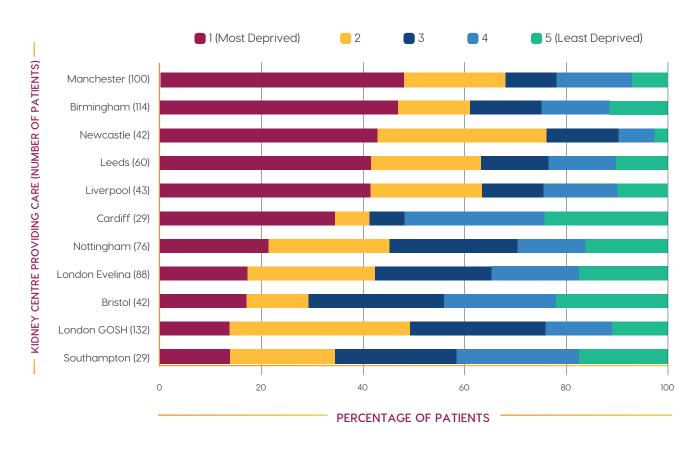
Figure 1a – Deprivation quintile of adults by treating centre (%)



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



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



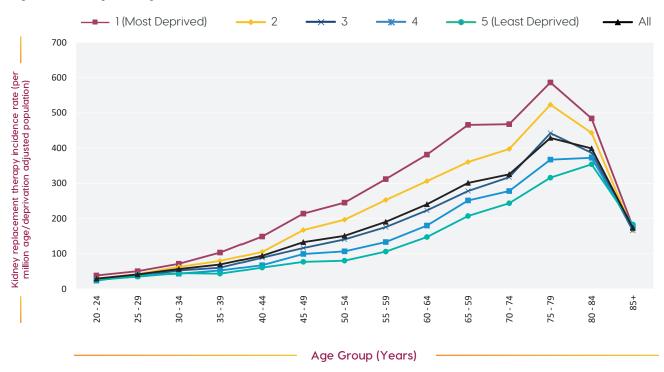
Number of children reported to the UK Renal Registry who started treatment for kidney failure in each centre between 2014 and 2020, by deprivation quintile. GOSH - Great Ormond Street Hospital.



2 Deprivation, age and sex

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 'age/deprivation adjusted population'. For each deprivation quintile, the rate is calculated using the number of people in that quintile who started treatment, per million people in the population with the same deprivation level. 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 deprivation quintile per year



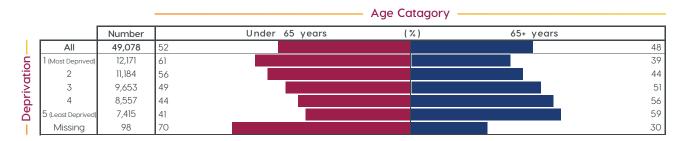
The rate of new adult patients starting kidney replacement therapy (incidence) between 2014 and 2020 by age group and deprivation quintile per year per million age/deprivation adjusted population (using data from the 2011 Census and the English indices of deprivation 2019). We have excluded patients who are aged 18-20 years as population data by deprivation quintile were not available for these patients.



- Adults living in more deprived areas have higher rates of kidney failure than those living in less deprived areas.
 - As the level of deprivation increases, the incidence of kidney failure increases. There is no evidence of a threshold effect: even amongst the least deprived quintiles, there is an increased rate of kidney failure for people in quintile 4 compared to quintile 5.
 - The association between deprivation and kidney failure is seen across all adult age groups except the oldest (those over 85 years of age).
 - The highest rate of kidney failure is seen for those living in the most deprived areas who are aged 75-79 years: approximately 600 in a million (roughly one in 1,600 people).
- The lowest rate of kidney failure for people aged 75-79 years is seen for those living in the least deprived areas: approximately half as common at 300 in a million (roughly one in 3,200 people).

The following tables show the percentage of people in each deprivation quintile who are under or over 65 years old, and the percentage who are male or female. 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 (all) 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, %)

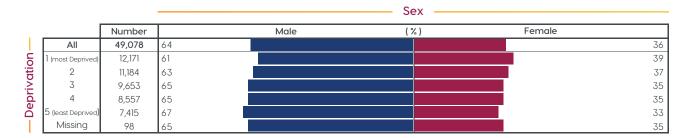


Age of adults in each deprivation quintile who started treatment for kidney failure between 2014 and 2020.



- People starting treatment for kidney failure who live in more deprived areas are more likely to be younger than those living in less deprived areas.
- People for whom postcodes are not available (and deprivation score is therefore missing) appear to be younger than people who have postcodes recorded.

Table 2b - Sex of adults (all people over 18 years of age, %)



Sex distribution of adults in each deprivation quintile who started treatment for kidney failure between 2014 and 2020.

Main Findings

 More males than females start treatment for kidney failure across all deprivation groups. However, as the level of deprivation increases, the proportion of females with kidney failure increases.

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

					s	ex —		
		Number		Male	(%)	Female	
	All	755	60					40
ivation	1 (most Deprived)	231	62					38
	2	171	60					40
	3	139	55					45
ebr	4	113	62					38
۵	5 (least Deprived)	93	58					42
	Missing	8	88					13

Sex distribution of children in each deprivation quintile who started treatment for kidney failure between 2014 and 2020.



- More boys than girls get kidney failure across deprivation groups, but there is no clear association between sex and deprivation.
- Only 8 children have a missing postcode (and therefore missing deprivation data). With such small numbers it is not appropriate to conclude that there is a pattern here.





The following tables show the percentage of patients in each deprivation quintile who belong to a specific ethnic group. Statistics for the whole kidney failure population (all) are also shown. The size of the bar represents the percentage in each cell – the bigger the number, the longer the bar.

Table 3a – Ethnicity amongst adults (%)

		Ethnicity —						
		Number	White	Asian	Black	Other	Mixed	Missing
	All	49,078	73	13	7	2	1	4
on	1 (most Deprived)	12,171	64	17	12	2	2	3
ij	2	11,184	67	15	11	2	2	4
. <u>≥</u>	3	9,653	74	12	6	2	1	5
ebr	4	8,557	81	9	3	1	1	4
Ď	5 (least Deprived)	7,415	83	8	2	1	1	5
	Missing	98	78	7	5	1	1	8

Split of deprivation quintile in each ethnic group reported to the UK Renal Registry, for adults starting treatment for kidney failure between 2014 and 2020.

- Whilst more people of White ethnicity start treatment for kidney failure across all deprivation groups, there is a tendency for those living in more deprived areas to include more people of Black and Asian ethnicity.
- Note that national statistics show people from Black and UK minority ethnicity are more likely to live in deprived areas, whether or not they have kidney disease.



Table 3b – Ethnicity amongst children (%) -

			Ethnicity —							
		Number	White	Asian	Black	Other	Mixed	Missing		
	All	755	61	20	6	5	1	6		
privation	1 (most Deprived)	231	45	30	10	6	1	7		
	2	171	64	26	9	5	2	5		
	3	139	66	16	3	9	1	4		
	4	113	81	8	5	0	1	5		
De	5 (least Deprived)	93	81	9	1	3	0	6		
1	Missing	8	75	0	0	13	0	13		

Split of deprivation quintile in each ethnic group reported to the UK Renal Registry, for children starting treatment for kidney failure between 2014 and 2020.

Main Findings

• Simlarly to adults, while more people of White ethnicity start treatment for kidney failure across all deprivation groups, there is a tendency for those living in more deprived areas to include more people of Black and Asian ethnicity.





4 Deprivation 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
- 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

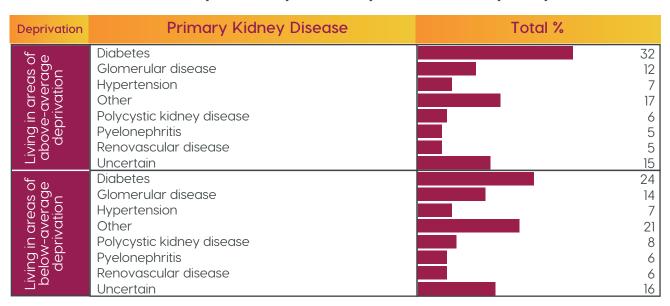
The list of causes in children is as follows:

- 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 adults living in regions of above or below-average deprivation. 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 deprivation quintile 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 deprivation (%)



Primary kidney disease for adults living in areas of above- and below-average deprivation (by <u>Index of Multiple Deprivation</u>) who started kidney replacement therapy between 2014 and 2020. Not including those with no recorded primary kidney disease.

Main Findings

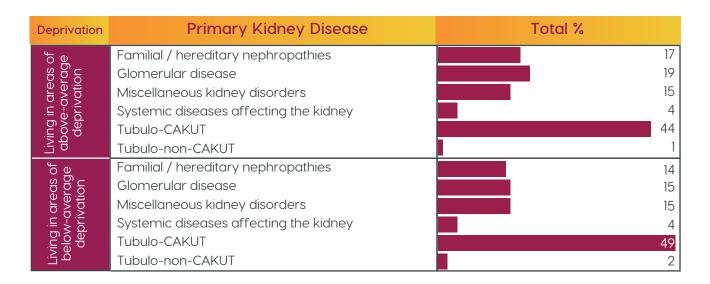
• Diabetes is the most commonly attributed cause of kidney failure in both groups, but is especially common for individuals who come from areas of above average deprivation.





In table 4b, the breakdown of primary kidney diseases is shown for children living in regions of above and below-average deprivation. 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 deprivation quintile 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 deprivation (%)



Primary kidney disease for children living in areas of above- and below-average deprivation (by <u>Index of Multiple Deprivation</u>) who started kidney replacement therapy 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 groups.



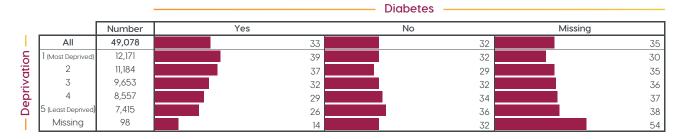


5 Deprivation and diabetes

People with kidney failure often have multiple other health conditions (comorbidities). Table 5 shows the percentage of adults in each deprivation quintile 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 in each deprivation quintile who started treatment for kidney failure between 2014 and 2020.

- Diabetes is more prevalent in people who live in areas of high deprivation, compared to people who live in areas of lower deprivation.
- As the level of deprivation increases, the likelihood that someone has diabetes as well as kidney failure increases.

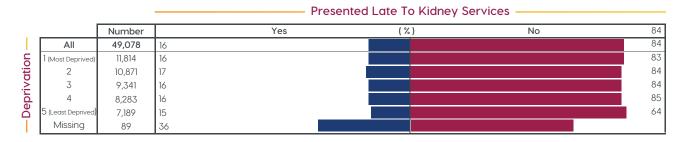


Operivation, presentation and first treatment

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 (%)

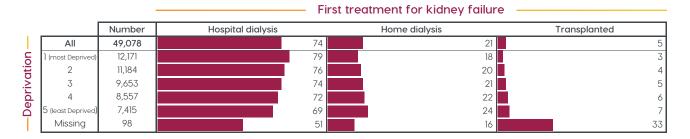


Percentage of adults starting treatment for kidney failure between 2014 and 2020 after a late presentation in each deprivation quintile.

- Levels of late presentation do not appear to differ between deprivation groups.
- Late presentation is more common amongst those whose postcode is unavailable (and deprivation score is therefore missing).



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



Percentage of adults starting treatment for kidney failure with hospital haemodialysis, home dialysis, or transplant between 2014 and 2020, in each deprivation quintile.

Main Findings

- Hospital dialysis is the most common treatment across adult deprivation groups. More people in the least deprived groups have a transplant or home dialysis compared to people in more deprived groups.
- Transplantation is most common amongst those whose postcode is unavailable (and deprivation score is therefore missing).

Table 6c – Late presentation amongst children (%)

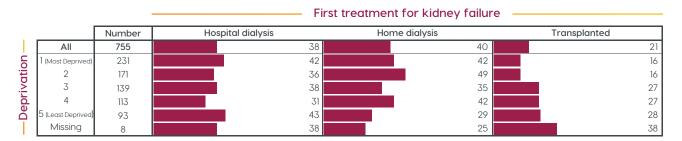
		Number	Yes	3	(%)	No			
	All	755	25				75		
n	1 (Most Deprived)	231	28				72		
atior	2	171	23				77		
.≥	3	139	23				77		
ğ	4	113	22				78		
De	5 (Least Deprived)	93	30				70		
	Missing	8	13				88		

Percentage of children starting treatment for kidney failure between 2014 and 2020 after a late presentation in each deprivation quintile.



- Levels of late presentation do not appear to differ between childhood deprivation groups.
- Only 8 children have a missing postcode and only one of these children presented late to kidney services. With such small numbers it is not appropriate to conclude that there is a pattern here.

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



Percentage of children starting treatment for kidney failure with hospital haemodialysis, home dialysis, or transplant between 2014 and 2020, in each deprivation quintile.

- Overall, home and hospital dialysis are started equally frequently.
- Transplantation is the first treatment for one in five children.
- Transplantation is less common as a first treatment for those who live in more deprived areas.





Deprivation 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, but does not provide breakdown by deprivation. This diagram shows what happens in the first year after starting kidney replacement therapy. Here, 42,443 adults of all deprivation groups are included. Most people continued the modality they started, but others changed modality, and some died.

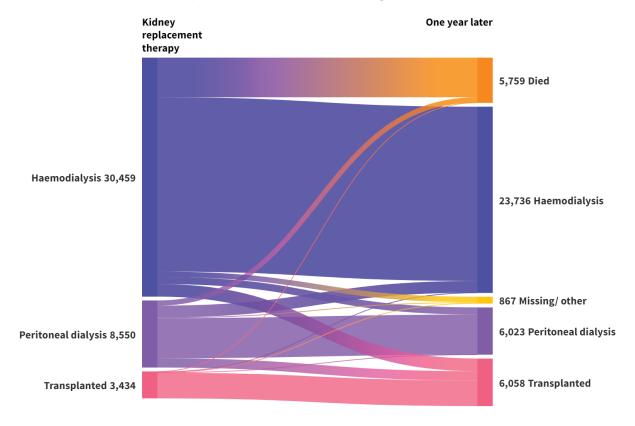


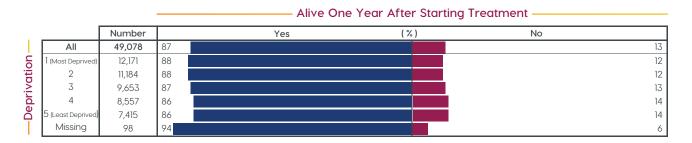
Figure 7 - outcomes one year after starting kidney replacement therapy

Click here to go to an interactive page where you can look at these data for those living in regions of above and below-average deprivation.

The following tables show the percentage of adults and children from each deprivation 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 (%)

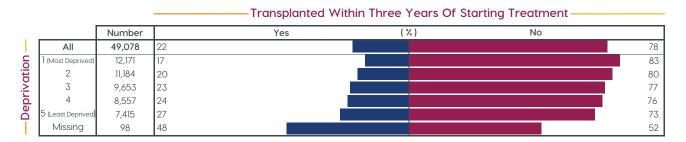


Percentage of adults who are alive one year after starting treatment for kidney failure between 2014 and 2020, by deprivation quintile.

Main Findings

- One year survival does not appear to differ between deprivation groups.
- The better survival and much higher transplantation rates for those with missing deprivation data suggest they represent a different group of people likely younger and in better general health than people in the other categories.

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

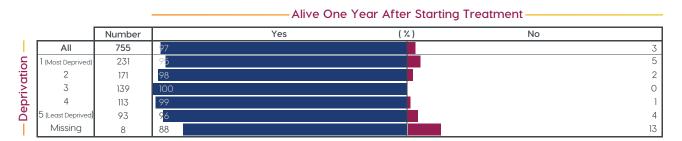


Percentage of adults who were transplanted within three years of after starting treatment for kidney failure between 2014 and 2020, by deprivation quintile.



- Individuals who live in more deprived areas are less likely to have a kidney transplant within three years of starting treatment..
- The much higher transplantation and survival levels for those with missing deprivation data suggest they represent a different group of people likely younger and in better general health than people in the other categories.

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

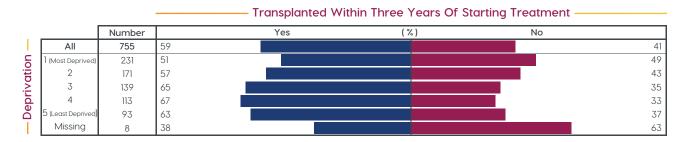


Percentage of children who were alive one year after starting treatment for kidney failure between 2014 and 2020, by deprivation quintile.

- More than 95% of children starting treatment for kidney failure were alive one year later across all deprivation groups.
- The lower survival for children with missing deprivation data suggests they might represent a different group of children, with more severe illness, but there are only eight individuals included.



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, by deprivation quintile.

Main Findings

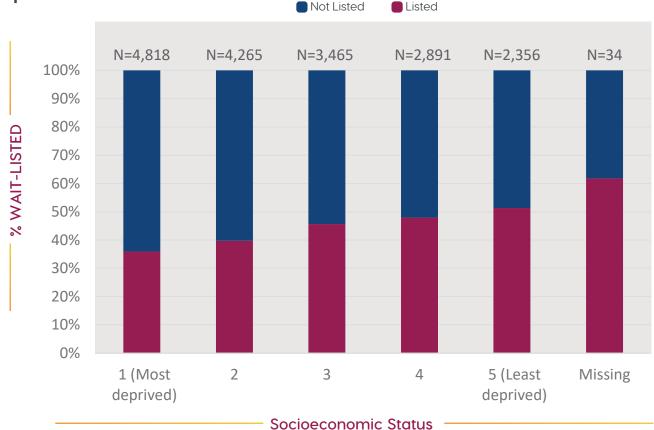
 Individuals who live in more deprived areas have lower rates of transplantation three years after starting treatment.



8 Deprivation 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 deprivation quintile



(Index of Multiple Deprivation quintile)

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



- The proportion of people listed for a kidney transplant ranges between 36% for people living in the most deprived regions, and 51% for people from the least deprived regions.
- The likelihood of being listed for a kidney transplant decreases as deprivation level increases. There is no evidence of a threshold effect: even amongst the least deprived quintiles, there is an increased proportion of people listed in quintile 5 compared to quintile 4.
- This suggests that lower use of kidney transplantation as a first treatment and within three years of starting is partly explained by lower likelihood of wait-listing for people living in more deprived areas.





9 Conclusion

This descriptive report using UK Renal Registry (UKRR) data presents well-recognised disparities: people who live in areas of greater deprivation have higher rates of kidney failure and diabetes, and reduced access to home therapies, transplant listing, and early transplantation. These differences do not appear to be explained by an increased likelihood of late presentation. People from more deprived areas who have kidney failure are different from people from less deprived areas: they are younger, and a greater proportion of them are female, and from UK minority ethnic groups.

There is evidence of a socioeconomic gradient: as the level of deprivation increases, the risk of kidney failure increases and timely access to the best treatments decreases. This socioeconomic gradient in health means that health disparities affect everyone, including those in the least deprived groups. More people with kidney failure are on the transplant waiting list in quintile 5 than in quintile 4. Rather than thinking about deprivation as having only two groups: 'deprived' and 'not deprived' it is crucial that we recognise the gradient. As the level of deprivation increases, even for those we might consider 'not disadvantaged', the chance of kidney failure increases and access to the best treatments decreases.

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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