KIDNEY HEALTH INEQUALITIES IN THE UK
An agenda for change

Containing a summary of the findings from

Kidney health inequalities in the United Kingdom: Reflecting on the past, reducing in the future
Dr Fergus Caskey & Dr Gavin Dreyer, 2018
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Contents

3 Kidney health inequalities
The facts

4 Preface
The case for reducing health inequalities in kidney disease

5 Background
on the report

6 Kidney disease
and treatment

7 Kidney health inequalities
The evidence

8 Evidence about Social deprivation

9 Evidence about Ethnicity

11 Evidence about Gender

11 Evidence about Mental health

12 Evidence about Age

13 Evidence about Geography

Research recommendations

Kidney Research UK’s commitment

A call to action
for everyone

References

20 Thanks to contributors

Thanks to contributors
Kidney health inequalities

The Facts

**PEOPLE FROM LOWER SOCIO-ECONOMIC GROUPS ARE MORE LIKELY TO:**

- Develop chronic kidney disease
- Progress faster towards kidney failure
- Die earlier with chronic kidney disease

Kidney disease may also contribute to social deprivation

**PEOPLE FROM BLACK, ASIAN AND MINORITY ETHNIC POPULATIONS**

- Are less likely to receive a kidney transplant
- Are more likely to progress faster towards kidney failure

**WOMEN**

- Are more likely to be diagnosed with chronic kidney disease

**MEN**

- Are more likely to start dialysis than women

**OLDER PEOPLE**

- Are less likely to receive a kidney transplant

**THERE ARE MORE PEOPLE WITH KIDNEY DISEASE IN AREAS OF HIGHER SOCIAL DEPRIVATION**

**ACCESS TO DIALYSIS SERVICES CAN BE VERY CHALLENGING IN SOME RURAL AREAS**

**THERE ARE HIGH RATES OF SEVERE MENTAL ILLNESSES AMONGST:**

- People with chronic kidney disease
- People on dialysis
Today in the UK, it is estimated that three million lives are at risk as a result of moderate to severe chronic kidney disease. Kidney disease severely impacts people’s lives and is associated with high levels of morbidity and mortality. End stage kidney failure requires treatment with dialysis, associated with a reduced quality of life and cardiovascular complications, or organ transplant, for which the supply of donor kidneys is insufficient to meet demand, or conservative care (treatment that focuses on quality of life, where patients opt not to have dialysis). Improving prevention and early detection, and ensuring that everyone in the UK has access to the right treatment for them, is key to improving kidney health for the whole UK population.

Yet, not everyone is equal when it comes to kidney disease in the UK. Some groups are particularly disadvantaged. For instance, people from South Asian and Black backgrounds are three to five times more likely to require dialysis treatment and typically wait between 168 and 262 days longer than people from Caucasian backgrounds to receive a kidney transplant.

Reducing inequalities in kidney health will bring benefits to individuals and their families, the healthcare system and wider society.

Chronic kidney disease and acute kidney injury also represent a significant burden to the healthcare system. They account for 2% of NHS spending, with hospital dialysis alone estimated to cost over £30,000 per year per patient. Reducing health inequalities, particularly preventing the development and progression of kidney disease in all UK populations may help alleviate the burden of kidney care to the NHS.

In addition, kidney diseases are also associated with other conditions, such as diabetes and cardiovascular diseases, which drive up the total costs associated with poor kidney health. Reducing inequalities in kidney health may also have a critical impact on individuals and wider society, beyond nephrology care.

It is the burden of end-stage kidney disease and its treatment that makes these inequalities such a policy and research priority.
Kidney Research UK has for some years been working to understand and address health inequalities. In 2001, we commissioned a report led by Professor Liz Lightstone, *Preventing kidney disease: the ethnic challenge*. The report highlighted the greater burden of risk factors for kidney disease, namely diabetes and hypertension (high blood pressure), in Black, Asian and minority ethnic (BAME) populations. It also flagged the possible role of genetic, environmental and socioeconomic factors.

Following Professor Lightstone’s report, the charity embarked upon a programme of engaging ‘at risk’ groups by recruiting ‘peer educators’, volunteers drawn from the target communities to engage people about kidney health, the risk of kidney disease and the shortage of organ donors within the community. This continues to form an important part of our health inequalities programme.

The charity wants to find answers to fundamental questions about why certain groups face higher risks of kidney disease, and why they can have worse outcomes. What are the drivers of these inequalities and how can research be used to reduce them? We commissioned an expert review of the existing evidence of health inequalities in kidney disease, to better understand this, and to develop an agenda to address the underlying causes.

*Kidney health inequalities in the United Kingdom: Reflecting on the past, reducing in the future*, led by Dr Fergus Caskey and Dr Gavin Dreyer, was published in 2018 [www.kidneyresearchuk.org/research/renal-reports](http://www.kidneyresearchuk.org/research/renal-reports)

It sets out an overview of what we know so far and crucially, provides recommendations for key research areas to improve our understanding of these inequalities and how to tackle them. This report will support the kidney health community in the design of evidenced-based programmes to effectively reduce health inequalities in kidney disease.

Drs. Caskey and Dreyer were assisted by nearly 60 members of the kidney community, including expert authors in this field. Around half were people affected by kidney disease, and they contributed to a consensus exercise to decide the priority areas for analysis. As a result, the report focuses on three key areas, outlined in the side panel.

Kidney Research UK also requested a review of the evidence for biological factors (basic science) that may drive inequalities.

This summary report sets out the key findings and the research recommendations that arose. We hope it will be of help to researchers, health policy-makers, healthcare professionals, people affected by kidney disease and those keen to support this area of our work.

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**THE FULL KIDNEY INEQUALITIES REPORT FOCUSES ON THREE KEY AREAS**

1. The risk of developing chronic kidney disease (CKD) for people living in socially deprived areas

2. The risk of poor outcomes and progression of CKD for people from BAME populations

3. The risk of poor outcomes for people from BAME populations whilst receiving dialysis
Kidney disease and treatment

What is chronic kidney disease?

The term chronic kidney disease (CKD) describes a wide variety of kidney problems that cause damage to the kidneys over a period of months or years. People are often unaware of their kidney problems until the damage has been done. It is estimated that one million people in the UK have chronic kidney disease, but are undiagnosed.7

Left unchecked, chronic kidney disease can result in life threatening end-stage kidney failure and an increased risk of cardiovascular disease. People with end-stage kidney failure are reliant on dialysis or a transplant to stay alive.

Dialysis either requires dialysis fluid being passed into the space inside the abdomen to wash out the waste (peritoneal dialysis), or the blood being filtered through a machine for several hours, three or more days a week (haemodialysis). The blood is cleaned of toxins, but patients are at a far greater risk of heart attack or stroke, regardless of the type of dialysis they receive.

A successful kidney transplant is reliant on accessing a suitable organ at the right time and living with immunosuppression (drugs to reduce the effect of the body’s immune system), to prevent the kidney being rejected. On average, a donor kidney lasts 10-15 years before it, too, starts to fail.

Dialysis and kidney transplantation are often referred to as ‘renal replacement therapy’.

Acute kidney injury

Acute kidney injury (AKI) describes a sudden, rapid loss of function due to kidney damage. This can be a reversible process. Some patients with AKI require dialysis for a few days or weeks until their kidney function improves. The small proportion who never recover kidney function will be reliant on long-term dialysis or transplant.

There are multiple causes of AKI, including dehydration, heart failure and infections. In England, over half a million people sustain AKI every year;9 AKI affects one in five of all emergency hospital admissions.9

AKI is harmful and often preventable, and is a major patient safety challenge for health care.
Kidney disease does not affect everyone equally in the UK. There is a complex and unequal distribution of risk factors across people’s life course and across stages of kidney disease.

Social deprivation, ethnic background, gender, mental health, age and geography are all factors that affect the risk of developing kidney disease, how the disease progresses, treatments and outcomes. These factors often interact with each other and it can be difficult to untangle the association between them.

The following sections summarise key findings from the report about affected groups and the recommendations for research.
Shaun’s long career battle

Shaun was working in the fire service at Heathrow Airport at the age of 29. Promoted to leading fireman, he was a real grafter, with two small businesses on the side. One day he went into work and developed a bad headache. He never returned to the career he loved so much. Finding his blood pressure was sky high, his GP rushed him into hospital. His potassium levels were so high he was about to have a heart attack; he started dialysis immediately.

His kidneys had failed completely, Shaun miraculously survived on dialysis for 25 years – but was unable to work. He moved in with his mum, was reliant on benefits, and was severely depressed for 18 months. He had lost his career, his house, his partner – and estimates he lost over £1.2m in potential income over that time.

In 2014, a new drug was developed which meant Shaun was able to have a successful transplant. He began a new career as a counsellor.

Unfortunately he now lives with the cardiac and vascular complications of being on haemodialysis for so long.

Recently, Shaun had an operation on his groin to clear a blocked artery, then developed life threatening sepsis. With no pulse in his right leg, the decision was made to amputate Shaun’s right leg above the knee.

Four days after being discharged from hospital he was back at work, determined to keep going, with the help of his disability car and wheelchair.

Evidence about Social deprivation

Social deprivation has been found to have an impact on developing a kidney condition. People from lower socioeconomic groups are more likely to have CKD and have an increased likelihood of progressing faster to more severe stages of the condition. They are also more likely to die earlier with CKD than people from other socioeconomic groups.

They tend to be diagnosed at a later stage of the disease, which may delay the start of adequate treatment and lead to poorer outcomes. When people from these groups experience kidney failure, they have poorer survival rates on dialysis and fewer of them are treated with peritoneal dialysis. Deprivation is further associated with lower rates of kidney transplants and increased rates of kidney transplants being affected by episodes of rejection.

These inequalities may be due to the fact that people from socially deprived groups are more likely to experience risk factors associated with CKD, such as obesity, hypertension and diabetes. Poor outcomes may also be due to higher death rates in lower socioeconomic groups more generally, as well as lower levels of health literacy and education. We need further research to understand these associations.

Housing can have a significant impact on the choice of treatment available to patients, limiting options for using home therapies. For peritoneal dialysis, patients need to be able to store large quantities of dialysis fluid. For home haemodialysis, sufficient space for the equipment and easy access to a water supply is necessary.

There may also be a converse relationship between kidney disease and social deprivation: kidney disease patients may fall down the socioeconomic scale because of their ill health.
Evidence about Ethnicity

Ethnicity is an important factor when it comes to developing CKD. There is a complex interaction between ethnicity and socioeconomic status.

Some BAME groups have been found to be at risk of developing CKD and progress faster to renal replacement therapy. In the UK, people from Black and South Asian backgrounds are more likely to suffer from obesity, type-2 diabetes, hypertension, and cardiovascular conditions which are risk factors for developing CKD, but the prevalence for these differ between ethnic groups. There is evidence of a higher prevalence of common underlying causes of CKD e.g. diabetes mellitus and hypertension as well as more severe CKD in South Asian populations.

Regarding genetic causes, there is evidence for the role of a particular gene across a number of kidney diseases in Black people, but this needs further research to understand its mechanism. We also need to undertake primary research to search for genetic causes in South Asian people.

The number of nephrons in the kidney (part of the filtering mechanism) can be reduced when birth weight is low. This is an early life risk factor for CKD and reduced birth weight is more common in South Asian and Black people in the UK, with socioeconomic and other factors involved.

Patricia’s journey with diabetes

Patricia suspects she was exhibiting symptoms of having diabetes from as young as 13 years old, but, growing up in the Caribbean, it remained undetected. It was diagnosed only once she had moved to the UK and was pregnant with her second child.

Patricia managed her diabetes with insulin, but fifteen years later, her health took a sudden turn for the worse. She did not realise that she had developed chronic kidney disease (CKD): “I remember sitting in hospital for 10 days, just vomiting over a bucket, with no treatment.”

Despite having type 2 diabetes (a known risk factor for CKD), it took three years for her kidney disease to be diagnosed. She describes it as “three years of suffering”, with prolonged vomiting, numerous tests, the removal of her gall bladder, a lack of communication between GPs and hospitals and, worst of all, medical staff not taking her seriously. It impacted not just her, but her family who had to take her to hospital every week for months.

Today, Patricia uses her experience of struggling to get a diagnosis, of managing dialysis and looking after her transplanted kidney to inform the voluntary work she carries out to support other kidney patients. “I don’t want anyone to have the horrible experience I had.”
Surma’s family

When Surma gave birth to her first child, it should have been a happy, joyous time but her daughter Fatima was born with nephrotic syndrome, which meant that there were tiny holes in her daughter’s kidneys, leaking protein and making her ill. A young mum herself, Surma faced weeks of worry as doctors struggled to diagnose the problem and Fatima spent nine months in hospital.

Two years later Surma gave birth to her second daughter Aisha who, sadly was also born with the same condition – it turned out that Surma and her husband were unwitting carriers of a gene which causes nephrotic syndrome.

Fatima received a transplant before she was ten and Aisha in her teens. However, Aisha’s transplant failed after four years and she is currently waiting for a transplant.

Aisha’s wait is made all the more complicated by the shortage of donors from Black, Asian and minority ethnic communities.

As kidney disease progresses, people from South Asian and Black backgrounds are three to five times more likely to start dialysis than people from Caucasian backgrounds. Those of South Asian, Black African and Black Caribbean descent are therefore over-represented on dialysis programmes, making up 22.7% of people in the UK receiving renal replacement therapy.

In some London boroughs, this rises to over 60% of people.

There is great variation in the uptake of home haemodialysis and peritoneal dialysis. Differences in the uptake of home therapies by ethnicity are identified by the UK Renal Registry, with overall only 13% of patients on home haemodialysis and 22% of those on peritoneal dialysis having non-White background, compared to 28% of those in hospital renal units.

We need to understand why patients in these groups are not accessing these forms of treatment as readily.

People from BAME populations are less likely to receive kidney transplants, particularly living donor transplants, waiting between 168 and 262 days longer than Caucasian kidney patients. In the UK over a third of people waiting for a kidney transplant are from BAME communities, while donors from these groups only make up 7.2% of the NHS Organ Donor Register.

Finally, waiting times and continuity of care have been evaluated more negatively by BAME groups which may affect their timely access to treatment. Language barriers and limited health literacy may lead to increased kidney health risk in both primary care and hospital settings. Further research is required to understand this interaction and its effect on kidney health inequalities.
Evidence about Gender

Women are more likely to be diagnosed with CKD, which may be linked to their higher attendance rate in healthcare services. When at the same level of kidney function as men, women are also at higher risk of progressing to end-stage kidney disease when taking their cardiovascular risk into account.\(^{31}\)

Counterintuitively, men currently represent up to 70% of the dialysis population in the UK and are more likely to start dialysis.\(^{32,33}\)

Further research is required to understand this reversal in imbalance between the comparatively high proportion of women diagnosed with CKD and the over-representation of men receiving dialysis treatment.

Evidence about Mental health

People with severe mental illnesses, such as schizophrenia and bipolar disorder, tend to have higher cardiovascular risks, due to lifestyle conditions (e.g. smoking and obesity) and poorer access to screening and treatment. Evidence is emerging that people with severe mental illnesses in the UK are more likely to have CKD and to be on renal therapy.\(^{34}\)

At the same time, cognitive impairment has also been shown to develop among kidney disease patients on dialysis, with older age a strong risk factor for faster decline in cognition.\(^{35}\)

More research is needed to investigate CKD amongst those with mental health problems and the effects of kidney disease on mental health.
Evidence about Age

Increasing age is a factor influencing kidney health. Cardiovascular conditions and the use of medicines that are toxic to the kidney both increase with age and contribute to the development of kidney disease. When the condition progresses to end-stage kidney disease, people at older ages are less likely to receive a kidney transplant. For patients on renal replacement therapy, advancing age is also associated with increased mortality.

Although they have the lowest relative risk of developing CKD compared to older people (aged 75 or more), younger people (18-54 years) have the highest relative risk of having poor clinical outcomes from CKD. Younger groups have been found to be tested less often for kidney disease than older age groups, and often start renal replacement therapy at a later stage of the disease.

Further research is required to understand how to mitigate the effect of older and younger age on kidney disease.

Sarah’s late stage diagnosis

Sarah was 18 when she was diagnosed with Goodpastures Syndrome, an aggressive immune disease causing the body to produce antibodies attacking kidneys, and her life was turned upside down.

Sarah, like many younger people with kidney disease, was diagnosed at a late stage of the disease. In her own words: “If my disease had been picked up earlier I wouldn’t have had to have the dialysis or even the transplant.”

She had been ill and constantly tired with sickness and nausea throughout most of her time doing A-levels. She assumed it was stress at first. Her doctor told her she had anaemia and prescribed medication.

After battling through A-levels her health got worse. She ended up sleeping up to 18 hours a day and still waking up exhausted. Her parents took her back to see her doctor, insisting that she be properly tested. It was finally discovered she was in end-stage kidney failure and she was rushed to a renal ward to start life-saving dialysis. Being treated with plasma exchange showed there was no way back, her kidneys would not recover.

Haemodialysis was almost unbearable. Life just stopped; her friends were off to start their adventures but she didn’t know if she would ever have those opportunities. Fortunately she received a successful kidney transplant in 2007.
Geographical location plays an important role in kidney disease and its treatment. In England, greater prevalence rates of stage 3-5 CKD exist in the north and along the southern and eastern coastal regions, suggesting a close link with the age distribution of the population. However, age-standardised rates show a greater association with the distribution of poverty.\textsuperscript{39} AKI incidence has been found to be remarkably consistent across the UK, with increased incidence among older people.\textsuperscript{40}

Geographical location is a critical factor when it comes to accessing dialysis. For rural populations, access to hospital-based haemodialysis may not be feasible due to a lack of local kidney health services known as satellite units. Transport to hospital can also be a challenge, particularly if the patient is dependent on the ambulance service for this. Both these factors can limit the treatment options or require patients to move.

Further research is required to shed light on the extent of the impact of geography on kidney disease, as well as ways to mitigate it.
Recommendations to reduce kidney health inequalities

These research recommendations mainly focus on inequalities experienced by BAME groups and socially deprived people, as prioritised in the full report. However, other disadvantaged groups must not be forgotten and we will need to progress research as the extent of these inequalities is defined.

Predicting or preventing kidney disease

GATHER ALL THE EVIDENCE on how beneficial biomarkers (new blood or urine tests) are in explaining differences in risk of AKI and outcomes between different ethnic groups

DEVELOP TECHNIQUES to identify people at high life-time risk of CKD early in life

INCREASE OUR UNDERSTANDING of how variants of genes increase the chance of developing CKD

IDENTIFY if there is sufficient evidence to test ways to target early life risk factors for CKD
### Protecting patients from progression of kidney disease and further harm

**INCREASE** our understanding of the range of age-related changes in cells of people from different ethnic backgrounds, in relation to CKD.

**INCREASE** our understanding of how the risk factors for CKD (e.g. high blood pressure, smoking, diabetes) impact the incidence of AKI amongst at risk groups.

**INCREASE** our understanding of the connections between environmental, socioeconomic and patient-specific factors which cause cardiovascular disease in people on dialysis.

**GATHER** all the evidence in respect of age, socioeconomic deprivation and ethnicity, about access to care and poor outcomes following cases of AKI.

**GATHER** all the evidence on the most promising interventions to address later life risk factors for CKD.

**INVESTIGATE** inequalities in rates of CKD, referrals to kidney specialists, rates of renal replacement therapy and competing mortality across all disadvantaged populations.

### Delivering treatment

**INCREASE** our understanding of the barriers for people in different ethnic groups to accessing diagnosis and good quality care for CKD and its risk factors.

**DEVELOP** an intervention to increase the use of home therapies (e.g. home dialysis) in groups that are traditionally low users of the service.

**ESTABLISH** if there are inequalities in the outcomes of kidney transplants specifically in the UK (these have been shown in other countries, but often reflect the health system or indigenous populations).

**ESTABLISH** if there is variation by transplant centre when adding patients to the waiting list for a transplant, amongst groups affected by health inequalities.

**INCREASE** our understanding of how disadvantaged groups are affected by the variation in provision of conservative care (treatment that focuses on quality of life, where patients opt not to have dialysis).

**IDENTIFY** if there is sufficient evidence to develop an intervention to improve outcomes for people from disadvantaged groups of working age living with CKD.

**GATHER** all the evidence on traditional outcomes e.g. cardiovascular events and non-traditional outcomes, e.g. employment status and mental health, in different ethnic groups.
Kidney Research UK’s commitment

As the leading UK charity dedicated to kidney health research, Kidney Research UK is committed to improving kidney health for all in the UK. We support research to drive reductions in kidney health inequalities highlighted in this document.

We want to increase our understanding of and find ways to address the underlying causes of health inequalities, through research and other initiatives. We will increase our impact in this area by:

- **Making health equalities a specific programme within our work**, integrated with our research, communications and patient engagement activities, with dedicated resources to lead this
- **Working with experts in the field** to prioritise and advance the research areas recommended in the full report
- **Communicating the research requirements** to the research community and encouraging high quality proposals into our core grants rounds
- **Embedding the theme of health inequalities** in the grants application process, where studies are relevant
- **Engaging with supporters, funders and policy-makers** to make the case for health equalities and increase investment in this research
- **Reaching out to disadvantaged communities** to increase engagement with research, through further developing and expanding our peer educator model
- **Continuing our work with at-risk communities** in raising awareness of kidney disease, organ donation and helping people access choice in healthcare
While some kidney health inequalities may reflect wider social and cultural trends in society, there is much that the renal community can do to improve experiences and outcomes for people living in the UK with all stages of kidney disease.

This will require coordinated and concerted action by policy-makers and all key stakeholders, alongside further investment in health inequalities research and care improvement measures.

The approach should be evidence-based, strategic and sustainable. This is crucial to fund research that will reduce kidney health inequalities across life stages, particularly where these inequalities represent inequities.

Based on the report *Kidney health inequalities in the United Kingdom: Reflecting on the past, reducing in the future*, this approach will be helped by some broad principles.

- **Align** kidney health inequality research with the wider renal community
- **Identify** and capitalise on existing research infrastructure, such as biorepositories and registries
- **Evaluate** new exposures and outcomes in kidney health inequalities, such as the role of religion, poverty and employment loss
- **Recognise** the changing UK population and its impact on kidney health inequalities
- **Translate** promising research findings into clinical practice and improvements in population health

It is also vital that people from disadvantaged populations are helped and encouraged to engage with and participate in research; this is a strategic aim within the 2016 UK Renal Research Strategy. It will require a change in approach to recruitment practice, communications and supporting materials.

Reducing unwarranted kidney health inequalities must become everyone’s responsibility. To achieve this, clinicians, renal services, the wider renal community in the UK and policy-makers need to think disruptively and create their own opportunities to change the system.
References


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The full kidney inequalities report, with those appendices not pending publication, can be accessed here:  
[www.kidneyresearchuk.org/research/renal-reports](http://www.kidneyresearchuk.org/research/renal-reports)