Time To Act:
A New Review of Kidney Health Inequalities

This report provides an overview of the key findings from Time To Act: A New Review of Kidney Health Inequalities

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The full report can be downloaded from the Kidney Research UK website.
Disclaimer

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Note on terminology

Language is continually evolving. Since publication of Kidney Research UK’s 2018 report Kidney Health Inequalities in the United Kingdom: Reflecting on the Past, Reducing in the Future, there has been a move towards the use of ‘health inequity’ as a term to emphasise that some differences in health are unfair and reasonably avoidable. This recognises that not all health differences represent forms of injustice. For example, older adults might be expected to experience poorer general health compared to younger people, a health difference that is not inherently an inequity given the impact of aging. However, in the UK, it is widely acknowledged that many health differences are unfair, and so the report retains the use of health inequalities to describe patterns in kidney health while attributing a moral dimension.

The 2018 report, following convention at that time, also used the acronym of Black, Asian and Minority Ethnic (BAME) when describing broad trends affecting those who have an ethnicity other than white heritage. The current report refers to specific ethnic communities as far as possible. In some places, the term ‘minority ethnic’ is used to describe issues that more often impact people from a non-white ethnic background. In doing so, the intention is to highlight issues related to social justice stemming from being part of a minoritised community rather than emphasising attributes associated with cultural identity.
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About Kidney Research UK

Kidney Research UK is the leading charity in the UK focused on funding research into the prevention, treatment and management of kidney disease.

Our vision is the day when everyone lives free from kidney disease and for more than 60 years the research we fund has been making an impact.

But kidney disease is increasing as are the factors contributing to it, such as diabetes, cardiovascular disease and obesity, making our work more essential than ever.

At Kidney Research UK we work with clinicians and scientists across the UK, funding and facilitating research into all areas of kidney disease. We collaborate with partners across the public, private and third sectors to prevent kidney disease and drive innovation to transform treatments.

Over the last ten years we have invested more than £65 million in research.

We lobby governments and decision makers to change policy and practice to ensure that the estimated 7.2 million people living with kidney disease in the UK have access to the most effective care and treatment, and to make kidney disease a priority.

Most importantly, we also work closely with patients, ensuring their voices are heard and are at the centre of everything we do, from deciding which research to invest in to how we plan our priorities and our work across the charity.

Those patient contributions are vital, always helping us and our partners to understand what life is like with kidney disease, always ensuring we see the patient behind the treatment and always reminding us that behind every statistic and every number is a person – the patients and the carers who inspire our mission and push us forward to make a difference and change the future of kidney disease.
Foreword

Professor Bola Owolabi, Director of the National Healthcare Inequalities Improvement Programme, NHS England.

UK data reveals that people living in the most deprived regions are expected to live around one-third of their life in poor health and have around 20 fewer years of healthy life than those living in the least deprived regions\(^1\).

Like me, anyone who works in the field of health inequalities spends a lot of time discussing data like this. But we must never forget that underlying these numbers are individual human stories, and these are our motivation to make change.

It is therefore important to note that this report – which brings together the latest evidence surrounding kidney health inequalities – has been created with the involvement of people affected by those inequalities. People who have their own stories of how hard it can be to access services and information designed without them in mind and who see how this impacts their own health and the communities around them.

Thanks to these contributions, and involvement of a host of other experts, this report has given focus to efforts to narrow the gaps in kidney health. It spotlights specific priorities that offer a starting point for action, in the same way that Core20PLUS5 – NHS England’s framework for tackling health inequalities – is helping to support a system-wide approach to mitigating avoidable disadvantage.

In the words of one of the report’s patient advisors, health inequalities are inherently complex. Solutions don’t come in an easy, one-size-fits-all package. Our best chances of improving patient experiences and outcomes lies in drawing the right people together to design and implement solutions.

As Kidney Research UK acknowledges, no single organisation, profession or sector can reduce kidney health inequalities. Agents of change must work together in their respective spheres of influence. The NHS, local and central government, third sector, academia and business must work together, and with vulnerable communities, to build trust, find the answers and make changes.

All of us can contribute something to the solution, and we must all embrace our agency to act.

“In health inequalities are complex because people and their lives are so different. To be able to respond to this in a meaningful way will require the right people teaming up to work on solutions together. One size will never fit all.”

Kola Ponnle, expert by experience

Professor Bola Owolabi
Director of the National Healthcare Inequalities Improvement Programme, NHS England
About kidney disease

The kidneys are master regulators and essential for life, when they fail, the result is devastating. Responsible for a multitude of functions, kidneys are vital organs, yet Kidney Research UK’s own research has found that 80% of people don’t know where they are or what they do. The kidneys are located on either side of the spine, and they are responsible for hormone secretion into the bloodstream, removing waste, toxins and excess fluids from the blood.

The term ‘kidney disease’ encompasses a broad range of conditions that lead to poor kidney function. Since the kidneys are necessary for many bodily functions, kidney disease increases the risk of developing other diseases, and conversely other diseases are risk factors for kidney disease. There is no cure for kidney disease, and managing it is a complex task, as kidney abnormalities exist across every age group, gender and ethnicity and can appear without warning.

Kidney disease is often labelled as a silent killer due to its frequent lack of physical symptoms. Even when symptoms are present, they are often overlooked or attributed to a different diagnosis or other health issues. Since early diagnosis is key to managing and slowing progression to kidney failure, patients face devastating consequences if symptoms go undiagnosed. The majority of kidney diseases can be characterised as acute kidney injury, chronic kidney disease or end-stage kidney disease.

Acute kidney injury is a rapid deterioration in kidney function and typically occurs in people who are hospitalised, especially those who require treatment in intensive care units. Acute kidney injury causes a build-up of waste products in the blood, affecting other organs such as the brain, heart, and lungs. Acute kidney injury requires most patients to be hospitalised for kidney function to recover and in most cases is reversible. However, it is recognised as an important risk factor for progression of chronic kidney disease.

Chronic kidney disease is usually categorised into five stages (Table 1).

Chronic kidney disease affects more than 10% of the UK population and is rapidly becoming more common as the population ages. Despite its high prevalence, early detection and awareness are low, in part because of an absence of early symptoms.

Many health conditions can contribute to chronic kidney disease, but two primary risk factors are diabetes and high blood pressure. Diabetes and the accompanying high levels of blood sugar can damage various organs in the body, including the kidneys and heart. High blood pressure, or hypertension, damages blood vessels throughout the body, including those in the kidneys. When these blood vessels are damaged, the kidneys are less effective at removing waste and excess fluid from the body. In addition to clinical risk factors, there are environmental and social factors that contribute to an increased risk of developing chronic kidney disease. These factors include access to healthcare, societal inequalities, and biological, genetic and cultural factors. Rare and genetic forms of kidney disease collectively affect a large number of people, while health inequalities make it challenging for people to receive the medical attention, access to care and support they need.

Complications associated with kidney disease can accelerate progression and increase the risk of cardiovascular-related events as chronic kidney disease worsens and becomes kidney failure (end-stage kidney disease).

End-stage kidney disease is defined by permanent kidney damage, and kidney function is reduced to 15% or less. Patients may experience a variety of symptoms which include fatigue, drowsiness, reduction or absence of urine production, itchy skin, headache, weight loss, nausea, bone pain, skin and nail changes and easy bruising. This stage is ultimately fatal and requires either dialysis or a kidney transplant. The number of people with end-stage kidney disease requiring kidney replacement therapy is increasing worldwide and is predicted to double by 2030.

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To date in 2024, there are around 30,000 people in the UK relying on dialysis to stay alive\(^4\). There are two main types of dialysis to manage end-stage kidney disease – haemodialysis and peritoneal dialysis.

In the UK, the majority (73%) of the 7,500 adults a year starting kidney replacement therapy begin with haemodialysis\(^4\), where an artificial kidney machine is used to clean the blood. Most people receiving haemodialysis dialyse three times a week for four hours at a time. The other main form of dialysis, peritoneal dialysis, uses the lining of the abdomen (peritoneum) to filter the blood. In 2021, around 3,900 patients in the UK were on peritoneal dialysis\(^4\).

An alternative treatment for patients with kidney failure is a kidney transplant. In the UK, around 3,000 adult transplants and 120 paediatric transplants are performed annually\(^2\). For adult patients waiting for a kidney transplant, the average time frame is 2-3 years, with about 5,300 patients on the waiting list in 2023\(^5\). On average, a transplant from a deceased donor lasts 15-20 years and a transplant from a living donor around 20-25 years\(^6\), with the longevity affected by a variety of factors including age, health and other risk factors including diabetes and cardiovascular complications.

Table 1: Stages of chronic kidney disease (CKD)

<table>
<thead>
<tr>
<th>Stages of chronic kidney disease</th>
<th>% of kidney function</th>
<th>Symptom / implication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Kidney damage with normal kidney function</td>
<td>100-90%</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Kidney damage with mild loss of kidney function</td>
<td>89-60%</td>
</tr>
<tr>
<td>Stage 3a</td>
<td>Mild to moderate loss of kidney function</td>
<td>59-45%</td>
</tr>
<tr>
<td>Stage 3b</td>
<td>Moderate to severe loss of kidney function</td>
<td>44-30%</td>
</tr>
</tbody>
</table>
| Stage 4 | Severe loss of kidney function | 29-15% | - Patients with kidney failure require dialysis\(^1\) or a kidney transplant to stay alive.  
  - A proportion of people with kidney failure will not receive either dialysis or transplant, instead undergoing conservative care. |
| Stage 5 | Kidney failure (end-stage kidney disease) | Less than 15% |

\(^1\) Dialysis is a type of kidney replacement therapy that replaces the blood-filtering function of the kidneys.
Why this? Why now?

Gaps in kidney health have been discussed for a generation. Now it is time to act.

Health is a human right. And yet, in the UK – one of the richest nations in the world and with healthcare free at the point of delivery – access to good kidney health is not equally available to all.

**Kidney Research UK and health inequalities**

We have been working to understand and take action on this issue since 2001, when we commissioned a report into ethnicity and kidney disease. A follow-on project led to the launch of our ‘peer educator’ programme started by engaging with minority ethnic communities – recognising that trust, inclusion and cultural relevance are essential for effective health education, promotion and intervention.

Over the years that followed, more and more data came to light around wider kidney health inequalities, and we grew increasingly active in this area. This included securing funding to run a wide range of outreach projects across the UK, aimed at addressing inequalities across the kidney health spectrum. In 2018, we asked experts (clinicians, researchers and patients) to summarise the existing evidence, work out where the gaps lay and recommend ways in which the kidney research community could play a role in tackling unfair disadvantage in kidney health.

The report – Kidney Health Inequalities in the United Kingdom: Reflecting on the Past, Reducing in the Future – painted a stark picture. It highlighted multiple aspects of inequality, including that adults living in the poorest parts of the country are more likely to develop kidney disease, progress faster to end-stage kidney disease where dialysis or a transplant might be needed, and die younger. And those of South Asian, Black African and Black Caribbean descent are over-represented on dialysis programmes, then making up 22.7% of people in the UK receiving kidney replacement therapy.

The report was welcomed as an agenda for change. Then the world was changed by events that few had predicted.

**A challenging environment**

In the years immediately following the publication of that report, the world was rocked by the Covid-19 pandemic. Kidney patients were more severely impacted by the virus than others – many lost their lives and many more suffered major complications. In the UK, preventative medicine, waiting lists and care for long-term conditions all took a hit as the NHS responded to the health emergency.

The subsequent cost of living crisis has amplified existing gaps between those living in deprivation and those who are not, while health providers have needed to balance cost savings with increasing demand for kidney services. These factors impact adults and children alike, but a lack of evidence around health inequalities in children may hide the true extent.

Our 2023 report – Kidney Research UK 2023. Kidney Disease: A UK Public Health Emergency – showed the economic burden of kidney disease in the UK is £7 billion per year and growing, threatening to overwhelm the NHS without action. And the personal costs to patients – be they physical, financial or emotional – are enormous. Yet chronic kidney disease is still often overlooked in health policy.

In the meantime, the conversation around health inequalities has matured and gained traction. There are national efforts to address unfairness in the delivery of healthcare and there is recognition across sectors of the significance and complexity of the issues. The term ‘intersectionality’ has entered our vocabulary – referring to the reality that many people experience multiple overlapping disadvantages.
Renewed push for change

It is now time to take stock. How has the understanding around kidney health inequalities changed since 2018? What actions have made a difference? And where do we go from here?

Time To Act: A New Review of Kidney Health Inequalities brings together evidence from people affected by kidney disease, health professionals and researchers to build on our 2018 report for today’s post-pandemic UK. It sets out recommended actions for the research community, to move us towards equitable kidney health for all. Importantly, it also presents some specific priorities considered by patients and the wider kidney community to be the most urgent.

Takeaway

There is a huge body of evidence describing widespread unfairness in the opportunity for good kidney health in underserved populations, but not enough action. Kidney Research UK’s latest review into health inequalities describes the progress made over the past five years and sets out the current evidence about these inequalities in the UK’s challenging post-pandemic environment. It provides a set of recommendations for the research community, including urgent priorities.

“...there are so many dimensions of injustices. Inequality of risk of development of chronic kidney disease, access to care and treatment, how useful and relatable education and awareness campaigns are, equality of outcomes from treatments. It’s time to take a hard look at how well the initiatives to address these issues are working. And where they are not working, or not fast enough, what else will make a difference?”

Tejal Amin, contributing author, expert by experience.
Equity in kidney health is influenced by a wide range of factors in 2024, such as:

**Negative factors**
- Post-pandemic NHS capacity and workforce pressures (e.g., difficulty getting a GP appointment, long waiting lists, lack of prevention work)
- Systemic biases (conscious and unconscious differences in care, based on individual attributes such as sex and ethnicity)
- Wide variation in health literacy (ability to access and understand health information, e.g., around risk factors and symptoms)
- Cost of living crisis (e.g., affecting ability to travel to appointments)
- Regional issues (e.g., poorer access to health services in coastal regions)
- The digital divide (some people being less able to access online services or information)
- As yet unidentified barriers
- Mistrust in state agencies (public services or institutions)

**Positive factors**
- National prioritisation to tackle inequalities (e.g., Core20PLUS, Integrated Care Boards tasked with reducing health inequalities as a priority)
- Integrated Care Boards now have a legal mandate to reduce health inequalities
- Healthcare innovations (e.g., introduction of SGLT2-inhibitors to stem kidney disease progression)
- Greater quantity and quality of data available to guide evidence-based action
- Emphasis on patient partnerships and inclusion as a lever for more relevant solutions
Kidney health inequalities.
What do we know now?

More than 
7.2 million
— that’s more than 10% of the population — are living with kidney disease in the UK, many of whom will be undiagnosed and unaware, that they are in the early stages of disease.

Kidney disease impacts some communities much more than others:

South Asian adults develop kidney disease younger than white adults.

People from low socioeconomic groups are more likely to develop chronic kidney disease than those in higher socioeconomic groups.

Acute kidney injury is more common in men than women after accounting for socioeconomic status, ethnicity, alcohol intake and smoking history.

Disease progresses faster in some people:

People of Black, Asian or mixed heritage are more likely to experience kidney failure than people of white heritage.

Under-70s living in deprivation are more than twice as likely to progress to kidney failure than those in more affluent areas.

More men than women start treatment for kidney failure.

Mental health conditions are associated with faster disease progression and worse outcomes for people with kidney disease.

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Not everyone gets the same quality of care or focus in research:

- The largest gap in early diagnosis is among Black, Asian and other minority populations.
- There is evidence reporting delays of up to 13 years for children to receive new medications which slow the progression of kidney disease as these are only being trialled in adults.
- Women, people from Black heritage communities and people living in the most deprived areas are less likely to get tests and treatments for kidney disease.

- Children from deprived areas are less likely to avoid dialysis by having a pre-emptive transplant and people of any age from these areas are less likely to have a transplant within three years of starting treatment, compared to those from more affluent areas.

- Older people are less likely to go on the waiting list for a transplant.
- People from minority ethnic communities still experience longer waiting times for a transplant.
- People living in deprivation are less likely to receive timely aftercare after acute kidney injury.

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Covid-19 impacted all kidney patients – with some worse hit:

People with severe chronic kidney disease (stage 4 or 5) had a higher risk of dying from Covid-19 than other vulnerable groups.

Asian kidney patients receiving hospital dialysis who were infected with Covid-19 were 16% more likely to die than patients from a white heritage background.

Kidney patients from lower socioeconomic groups were more likely to get Covid-19 and have more severe infection.

Sources of inequality overlap, adding up to even greater risk of poor kidney health:

Poor mental health can lead to the faster progression of kidney disease.

Black patients are more likely to live in deprived areas than those from any other ethnic group.

Black men are more likely to experience severe mental illness than men from other ethnic groups.

Low health literacy affects 25% of people with chronic kidney disease, particularly minority ethnic communities and lower socioeconomic groups. People with lower health literacy tend to enter the health system when they are sicker.

Research has shown that cells in Black people living in deprivation age faster than in others.
Progress since 2018

In recent years the UK has experienced challenges that have increased kidney health inequalities. Several of the recommendations from our 2018 report are yet to be addressed. Despite this, there have been pockets of progress; discoveries that will fuel medical advances, and infrastructure and policy developments that will pave the way for greater fairness and equity.

Underpinning research

- There has been a major boost to research with the establishment of the NURTuRE kidney bio-resource (co-funded by Kidney Research UK) and the US-based Kidney Precision Medicine Project. These are large and growing libraries of samples and health information from people with kidney diseases that will make it quicker and easier to carry out research. Now, instead of having to gather new data or patients for every study, scientists can apply to use the stored data and samples. As these libraries are expanded to be more representative, so the discoveries that are made will help to deliver medical advances for everyone.

- Research has shown that cells in Black people living in deprivation age faster than in others. This points to a possible underlying link between ethnicity, poverty and chronic kidney disease.

Prevention of kidney disease

- The NHS Health Check scheme has enabled GPs and practice nurses to find and speak to more people with the major risk factors for chronic kidney disease: obesity, high blood pressure, diabetes and heart and circulatory disease. But data shows it isn’t reaching enough people facing social disadvantages.

- The urgency of addressing this gap is further confirmed by research showing that low socioeconomic status puts under-65s at increased risk of acute kidney injury.

- Kidney Research UK’s peer educator programme continues to trial innovative prevention and early detection initiatives in underserved and/or minority ethnic communities by building trust. For example, HIDDEN-CKD is working with Black communities in south London and a project in Wales is educating and empowering South Asian people and those of lower socioeconomic status living with diabetes to get their kidney function checked and monitored.

Treatment and care

- The Kidney Failure Risk Equation (KFRE) is now recommended to help GPs calculate if a person has a high five-year risk of kidney failure and needs a referral to specialist kidney services. However, there are fears that the KFRE may underestimate the risk in minority ethnic groups, so research is underway to make sure it works equally well for everyone.

- In 2023, regulators recommended medicines called SGLT2-inhibitors (which can slow down progression of chronic kidney disease) should be prescribed to many more patients. This is a potentially game-changing advance, but an early follow-up analysis of GP records showed huge inequalities in prescribing. Kidney Research UK has funded researchers to investigate this disparity.

- Guidelines were released in 2019 to improve the standard and consistency of care of women with chronic kidney disease who are pregnant, to reduce the risk of complications for mother and baby.

- A new drug treatment designed to combat the effects of a version of the APOL1 gene, which is linked to a range of kidney diseases especially in Black heritage communities is being trialled at the time of writing this report.

- Research has shown that kidney transplantation improves survival in people of all ethnicities compared to dialysis. However, people from minority ethnic communities still experience longer waiting times for a transplant.

- In 2021, NHS England began to provide free transport to all hospital dialysis patients, making it more accessible to people on low incomes.

- Kidney Research UK’s Acceptance, Choice and Empowerment (ACE) pilot project showed peer educators helped patients from deprived and South Asian communities in Birmingham make more informed treatment choices. It also increased their confidence to choose home-based therapies, which offer better outcomes and quality of life. The charity is now working with partners to develop a larger scale, multi-site project.
Covid-19

- The Covid-19 RECOVERY trial was pioneering in its inclusion of people with a range of long-term conditions including chronic kidney disease. This meant that doctors were confident the important findings – that dexamethasone significantly reduced deaths from Covid-19 – applied to kidney patients too, so they did not miss out on life-saving treatment.
- Bespoke Covid-19 vaccination programmes, tailored to minority ethnic communities and socially deprived areas via trusted local providers, have shown promising results in reducing health inequalities.

Takeaway

- Since 2018, the research community has made progress in understanding that different communities need bespoke approaches for equity in kidney health to be achieved, together with new ways to combat it. Wider health inequalities have been recognised in various policies and guidelines, and some innovations brought about by the Covid-19 pandemic provided a blueprint for equity-led approaches. However, due in part to the challenging economic and health service environment, this hasn’t yet translated into closing the unfair gaps in kidney health, access to care and progression of disease.
Urgent priorities

The genes people are born with, and the circumstances in which people live, work and age, as well as wider societal and political factors, can have an enormous impact on kidney health and the risk of dying from kidney disease.

There is no quick fix to overcome a lifetime of increased risk for kidney disease. It requires system-level change and collaboration across government, the healthcare system, the charity sector and industry – in partnership with patients and the public.

Reducing health inequalities must be hardwired into thought, planning and action. From making kidney health information appropriately tailored to each audience, to developing effective and accessible kidney tests and treatments for every ethnicity and social circumstance, and eradicating bias in kidney care. There are countless opportunities to make a difference.

An equity-led approach

We call on everyone involved in kidney education, research, policy and health service design and delivery to take on three ‘always actions’. Adopting these actions into everything we do will help to embed a mindset and approach that ensures that progress is inclusive, leaving no-one behind:

Always actions

- Always design and conduct research in ways that encourage and enable truly representative populations to participate
- Always involve people who experience health inequalities in co-designing research and services
- Always identify, consider and address barriers to accessing information, treatments or research for kidney disease

“Health inequalities are complex because people and their lives are so different. To be able to respond to this in a meaningful way will require the right people teaming up to work on solutions together. One size will never fit all.”

Kola Ponnle, contributing author, expert by experience.

Research priorities

Time To Act: A New Review of Kidney Health Inequalities makes 44 new and updated recommendations for research – from discovery science to clinical trials needed to tackle health inequalities in prevention, progression and treatment of kidney disease. An update on the full list of new recommendations, and an update on previous recommendations that are yet to be fully addressed, can be found in the report and at www.kidneyresearchuk.org/time-to-act

“Often the people who experience health inequalities are hidden themselves. This might be because their voice is not loud enough, or because they are excluded, or because they are not part of the ‘system’, due to factors such as homelessness. People might not realise they need to seek help and might not know how to access support for chronic kidney disease.”

Keith Bucknall, contributing author, expert by experience.

The main recommendations from each theme in the report have been prioritised by a panel of experts across the kidney community including patients, kidney doctors and researchers.

Recommendations that emerged as some of the most urgent are summarised as follows under Kidney Research UK’s three strategic aims: prevent, protect and treat.
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Prevent

Identify how the healthcare system can reduce the risk of people developing kidney disease and prevent kidney disease progressing in those that have it, by looking at how additional services and new approaches for high-risk and underserved groups can remove barriers and increase access.

Progression of chronic kidney disease could often be delayed or slowed down, but bespoke strategies are needed to reach communities that currently miss out on advice and support to look after their kidney health.

Protect

Research ways to improve outcomes for high risk and underserved groups.

People living in deprivation, older people and those from minority ethnic communities often miss out on quality care for acute kidney injury. We must find ways to change this.

Evaluate whether screening for chronic kidney disease could play a role in improving health outcomes in high risk and underserved groups.

There are vast numbers of people living with undiagnosed kidney disease in the UK. Screening may be a way to find this hidden population and intervene before the disease progresses irreversibly.

Develop blood and urine tests to identify which patients are most at risk of irreversible acute kidney injury, so they get proactive management and care.

Half a million people experience acute kidney injury each year in the UK. It is reversible in most people but can cause chronic kidney disease if left undetected or untreated for too long. If it is picked up early in patients who have pre-existing risk factors or damage to their kidneys from other causes, proactive acute kidney injury care can reduce the risk of it leading to chronic kidney disease.

Trial new ways to manage chronic kidney disease in high-risk groups, from earlier detection and accurate risk prediction to personalised management of disease.

Taking an integrated and personalised approach through the course of kidney disease may protect more people from progression of disease, and prevent the need for dialysis or transplant.
**Treat**

**Make home dialysis accessible for more patients.**

Despite its advantages and recommendations from the National Institute for Health and Care Excellence (NICE)\(^47\), the uptake of home dialysis is poor, especially among those living in deprivation\(^48\). We must understand the barriers to dialysis treatment at home and find ways to reduce them for those who wish to have home dialysis.

**Investigate how best to support informed treatment decisions for kidney failure in frail older people.**

Kidney replacement therapies are the default strategy for end-stage kidney disease, but dialysis can be life-limiting and difficult and transplantation is associated with increased risks. We must ensure that frail older patients are supported to understand their options and given the freedom to choose conservative care if they wish.

**Find ways to make sure kidney patients have equal opportunities to receive a kidney transplant.**

Children and adults from deprived areas and older people are much less likely to be given the chance of a pre-emptive transplant. We must develop strategies to eradicate bias in transplant listing and access to living donation – and implement them nationwide.

**Cross-cutting priorities**

**Develop and test new ways to improve awareness and understanding of chronic kidney disease and acute kidney injury among the population, kidney patients and health professionals.**

Health knowledge and understanding is vital for individuals to make informed choices about their lifestyle, identify risk factors and know when and how to seek help. Concerted efforts are needed to raise the profile and knowledge of kidney health and disease, particularly among those most at risk, using tailored and accessible communications.

**Include people with chronic kidney disease in clinical trials, as a default.**

The frequent exclusion of people with chronic kidney disease from clinical trials for other conditions means they do not routinely benefit from new treatments because they have not been evaluated in these patients. Clinical trials must reflect real life – where multiple long-term conditions often co-exist.

**Boost the inclusion of people of all ages in clinical trials for chronic kidney disease**

Excluding children from clinical trials has led to delays in children accessing new treatments. Age-inclusive clinical trials are urgently needed.
The role of policymakers

National policy has a major role to play in tackling kidney health inequalities, most fundamentally by addressing the social factors that play a role in determining kidney health and other long-term conditions – from education and employment to housing and access to resources to enable a healthy lifestyle.

In parallel to this essential cross-government work, policymakers must recognise and act according to the enormous cost of poor kidney health – to the nation and to individuals – and the unfairness of its impact on the poorest, most marginalised communities.

We are calling for increased resources for kidney research and prioritisation of kidney disease in national and regional policies:

1. Increase the funding available for research into the understanding, prevention and treatment of kidney diseases to at least £50 million per year.

   Chronic kidney disease affects 10% of the UK population⁴⁹, costs the NHS £6.4 billion a year and yet in 2021/22 received just 1.4% of relevant government research funding (£17.7 million).

2. Include kidney disease in government health strategies, programmes and action plans addressing health inequities, prevention, major conditions, multimorbidity and screening.

   Kidney health and disease has been absent from important health plans, including the NHS Long Term Plan, and was significantly reduced in the Quality and Outcomes Framework (QOF).

3. Include kidney disease in NHS initiatives on health disparities across the four nations.

   Initiatives focused on health inequalities such as Core2PLUS5 in England offer great potential, but kidney disease needs to be explicitly included in order to maximise outcomes for kidney patients and those at-risk of kidney disease from underserved communities.

4. Make funding available to enable rapid implementation and embedding of research findings within the patient care pathway for chronic kidney disease and related risk conditions.

   Resource is needed so learnings from short term pilots can benefit more people, faster.

For a breakdown of how kidney disease impacts people and services in your local area, see Kidney Research UK’s 2023 report: Kidney Disease: A UK Public Health Emergency. The Health Economics of Kidney Disease to 2033, which looks into the economic impact of kidney disease⁵⁰ at www.kidneyresearchuk.org
Our commitment

At Kidney Research UK we’re committed to playing a leading role in tackling kidney health inequalities through research and by amplifying the voices of patients and their families.

Real progress depends on organisations across the kidney community, and beyond, working together. We will expand our collaborations with other charities and patient groups, the NHS, funders and government to drive this work forward.

We also commit to using our resources and expertise to:

- Provide focused research investment to address the priorities highlighted in this five-year review
- Work with others to pilot and evaluate new models of care to help transform the patient pathway, and make it more equitable
- Work with grassroots organisations to increase engagement and trust with underserved communities to improve:
  - kidney health awareness
  - early detection and diagnosis
  - representation within research and data studies
- Work with others to improve representation in sample and data collection, data studies and clinical trials so that advances and discoveries are relevant to and benefit everyone
- Work tirelessly for systemic change to reduce health inequalities by working with and lobbying governments and decision-makers
- Ensure patients and their families are equal partners in addressing ongoing health inequalities priorities in order that our pursuit of equitable health care is itself, collaborative and inclusive.

“Living with kidney disease has shown me the critical need for equitable care. It is imperative that we address the health inequalities present in our system to ensure that every patient has access to the comprehensive and compassionate care they require. Additionally, we must provide targeted support to communities lacking digital resources, enabling them to leverage technology for improved health outcomes and equitable access to necessary care services.”

Sanjay Mistry, contributing author, expert by experience

To find out more about how you can support or get involved with our work, visit our website www.kidneyresearchuk.org or email healthequity@kidneyresearchuk.org
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Full report and graphics available for download at www.kidneyresearchuk.org/time-to-act

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