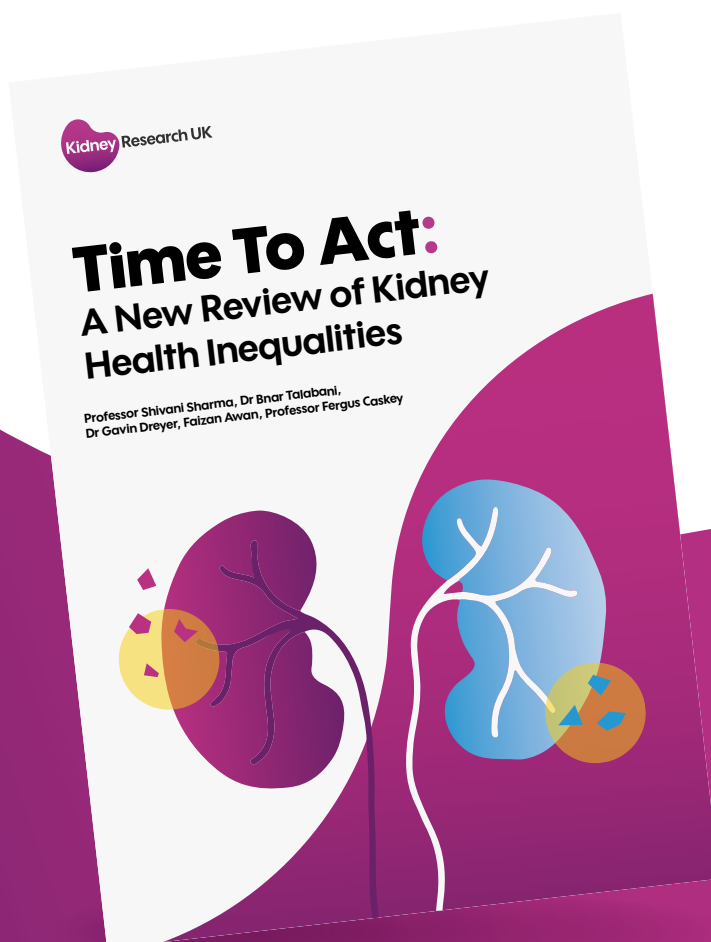


# Excerpt from **A Time To Act:** **A New Review of Health Inequalities Report**

The full report can be downloaded from the Kidney Research UK [website](#).

This chapter from the report is written by patients and highlights the everyday physical, psychological, social, and economic impact of CKD.



We have created this standalone pdf to ensure their lived experience and perspectives of kidney health inequalities can be heard, and acted upon, more widely.

# Looking back to look forward: Patient perspectives on kidney health inequalities then, now and in the future

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Living with kidney disease can be frustrating, exhausting and potentially all-consuming, impacting across every part of someone's life.

People living with and affected by kidney disease were an integral part of the creation of this review and both Kidney Research UK and the report authors are grateful for their insight, input and openness in their approach to writing this chapter.

Just a small window into their experiences is a vital reminder about why it is so important that patients and their voices remain at the heart of everything we do.

## Why focus on kidney health inequalities?

There are countless stories from patients and carers about their CKD journey. What is apparent from this is that not all patients have the same or similar experience of developing and managing CKD. In the UK, some people have a much harder time staying healthy when it comes to their kidneys. This unfairness is often referred to as health inequality. It means that where you live, how much money you have, and factors such as your age, sex and ethnicity can affect how likely you are to have kidney disease and how it progresses. For example, people who are from deprived areas often have a harder time getting check-ups or seeing specialists. They might also struggle to afford healthy foods, live in poorer quality homes, and struggle to protect their health due to lack of access to information or knowing how to use or implement it.

All of this adds up and makes kidney problems more likely. People from minority ethnic backgrounds are also affected by kidney disease more often than the rest of the population. Sometimes this is due to genetics, or other life factors including the likelihood of living in deprivation. Minority ethnic people often face unfair treatment when they try to get help from services, which negatively impacts care experiences and outcomes. It is also true that living with a co-occurring mental health condition, including severe mental illness, adds to the already wide-reaching consequences of kidney disease, making keeping well despite CKD more challenging. We must change these realities. Everyone deserves a fair chance at a healthy life.

From the patient's viewpoint, this is why the 2018 report on kidney health inequalities was an important step in acknowledging the deep-rooted disparities affecting our health outcomes, whether you are a child, young person, or adult with CKD. That report was not just about the statistics; it reflected the real struggles faced by many due to factors such as income, age, sex, ethnicity, and geographic location. The report challenged the kidney care and research community as well as patients to reflect on the question 'are personal and life attributes affecting CKD experience and outcomes fair?'. Since this is a rhetorical question, the report placed an emphasis on what action needed to be taken to reduce these injustices. The report highlighted the need for focused advocacy, interventions, and policy reforms at a time when global health challenges were escalating.

"We can't ignore that there are historic factors that mean that some people fall through the gaps. We need to plug those gaps before we just carry on trying to "fix" inequalities. A holistic view will help prevent them from happening in the first place."

Fez Awan



## Life is not static: Societal factors and their impact on kidney patients

Living with CKD can be full of uncertainty and anxiety at the best of times. Layered on this is the impact of life more generally, which plays out in different ways for different people because of education, income or deprivation, sex, ethnicity, disability, and age as well as issues such as historical mistrust, community exclusion, low health literacy, and their experience of systemic racism. This means that major issues in society in the past five years have had a differential impact on kidney patients because of the way in which aspects of life circumstances come together:

- **Covid-19:** Though a virus does not discriminate, there is evidence that its impact acted to widen health inequalities. Patients have experienced these inequalities first-hand, from increased difficulties in accessing care to navigating overstretched health services. The pandemic underscored the necessity of resilient health systems capable of providing equitable care during crises, bringing to light the urgency of addressing health disparities more effectively.

One example of inequality is that people who already waited longer to access a kidney transplant now had an even greater delay, with geography making a difference to when transplants resumed and who was most likely to be treated. This all contributes to growing concerns over fair management, especially for those who already have reasons for mistrust in health services.

What this emphasises is that in times of crisis, those who are already disadvantaged or experience health disparities will be most impacted. So, looking to the future, we are hopeful that learning from this time will mean that policies and initiatives truly try to safeguard all patients fairly. This means recognising that doing the same for everyone might not reduce inequalities. For example, as the pandemic has placed a sharper focus on the advantages of home therapies, it will be important for agendas on this to work for people regardless of geography or postcode lottery, ethnicity, income/deprivation or a combination of these factors. Data already suggest that some patients are more likely to take up home therapies than others and efforts to increase this modality overall should equally benefit all patient communities. Some patients may need more support in making decisions.

"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



- **Cost of living crisis:** It's not long since a UK patient charity described that for many with CKD, the current economic climate means that we are in a 'cost of staying alive crisis' (Kidney Care UK). The National Kidney Federation has also emphasised how the current economic climate is challenging patients. Transport costs for appointments and attending hospital-based dialysis, cost of managing a healthy, kidney-friendly diet, job security for those of working age, and heating costs are some of the everyday considerations that occupy the minds of patients and their families. The issue is that such worries do not sit in isolation, they complicate the whole experience of CKD and so where there are already difficulties in the care experience, co-occurring mental health or wider conditions, factors such as everyday costs and ability to sustain them adds further challenge to experience and outcomes. Scaling up support in such times is important, but making this a reality is a challenge when health systems, charities and other community organisations have the same challenge of meeting the demands on them under resource constraints. This will inevitably mean that some people continue to feel a greater toll of life with CKD unless there is more innovation in how support can reach those who need it most.

"Living with a mental health condition can change both your voice and its volume so that you blend into the background. The frustration may come across angry or stroppy and you may then be misjudged. The clock is always ticking in the kidney world on dialysis so there is no leeway. The health system flows and one's own soul sighs again."

Keith Bucknall

"It's daunting that there are so many dimensions of injustices. Inequality of risk of development of CKD, 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 working fast enough, what else will make a difference?"

Tejal Amin

- **Digital divide:** There is a pressing need to leverage digital technology to improve access to health data, empowering patients to take proactive roles in their care. Innovations such as telehealth services, mobile health apps and digital platforms can revolutionise patient engagement and health management, especially for marginalised groups. However, it is crucial to bridge digital divides and design inclusive technologies that cater to the diverse needs of the patient community, including children and young people not being excluded from such advances to care. Collaborative efforts between technology developers, healthcare providers, patients and families are essential in creating solutions that not only address health inequalities but also pave the way for a more equitable health future.

- **Equality, diversity and inclusion landscape:** There has never been so much discussion in society about issues related to equality, diversity and inclusion. This has been driven by a number of high-profile and significant events.

The murder of George Floyd by police officers in the USA caused an international ripple effect and reignited important conversations about racism in policing. In the UK, the Windrush Scandal revealed systemic prejudice against a generation of people who thought the UK was their safe home, and government figures show that people from minority ethnic groups in the UK are over-represented at almost every point in the criminal justice system, compared to population levels.

Meanwhile, multiple studies have researched racial bias in the investigation and treatment of pain and illness in healthcare systems, whilst Black women in the UK are four times more likely to die in pregnancy and childbirth than their white counterparts.

Structural issues were also brought into sharp focus in UK health services during the pandemic with stories about deaths amongst minority ethnic doctors and patients alike. In response, many organisations are looking more closely at what inclusion and equity means for them and how it is experienced. The same should be true for patient advocacy groups, care providers, and researchers. We see the past and current reality as a huge opportunity for the kidney community, patients included, to redesign a future that works better in all spheres for its patients, workforce, and society.

- **Health policy:** Not all patients are engaged with developments in health policy and prioritisation. For those of us who are, it is disappointing that Core20PLUS5 – an NHS England initiative to target the reduction of health inequalities in specific patient groups – did not include CKD. Still, the focus on diabetes in young people and hypertension in adults are important to reducing inequalities in CKD prevention, which we hope the kidney community will be able to draw on as key policy enablers for actions that matter to prevent or slow down the impact of CKD for patients and their families.

“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.”

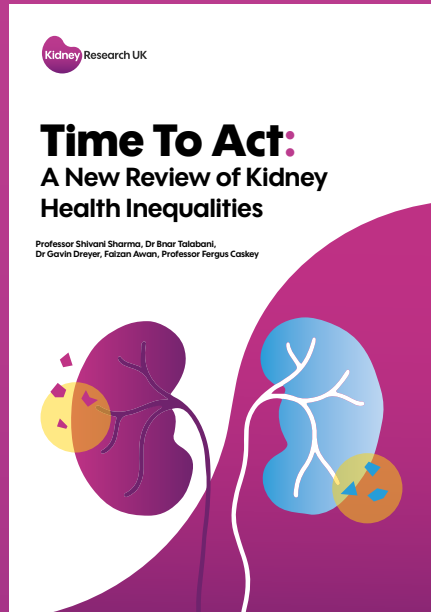
Kola Ponnle



## Looking forward

This five-year review is the first to include a chapter dedicated to the patient and family voice. Though those of us contributing are not representative of the entire kidney patient community, we have varied experiences (paediatrics and adult), varying ethnic heritage, different gender identities, faith backgrounds, geography, education and income. Some of us identify with disability, as well as multiple health conditions. Drawing on this collective experience, we have attempted to highlight why health inequalities matter, and some of the factors that are challenges of our time that will shape the future trajectory of health inequalities and their reduction.

The review encapsulates the ongoing journey towards addressing health inequalities and underscoring the progress made since the 2018 report whilst acknowledging the considerable work that remains. What we hope we have contributed is a lens that emphasises what difference the recommendations can make to people living with CKD at any age and stage of disease, calling for action that consistently centres health inequality reduction. We would finish by saying that prioritising patients and their families as equal partners in addressing what matters and how is essential. No one should be left behind in our pursuit of equitable health care, which itself is a collaborative task.



Full report, lay summary including statistics highlighting many of the kidney health inequalities and downloadable graphics are available at [www.kidneyresearchuk.org/time-to-act](http://www.kidneyresearchuk.org/time-to-act)



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