Collectively common: the devastating impact of rare kidney diseases in the UK

A call for investment, innovation and quality care

Executive summary | September 2025

Kidney Research UK

ZS

Contents

Disclaimer

This report has been co-funded by Kidney Research UK and the following industry supporters: Alexion, AstraZeneca Rare Disease; CSL Vifor; Novartis U.K. and Vertex Pharmaceuticals. These companies had no control over or editorial input on the contents of this report.

Kidney Research UK

Charity registration no. 252892 (England and Wales) SC 039245 (Scotland)

www.kidneyresearchuk.org

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 £71 million into research.

We lobby governments and decision makers to change policy and practice to ensure that more than seven 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 voice is heard and is 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 are people – the patients and the carers who inspire our mission and push us forward to make a difference and change the future of kidney disease.

About this report

Kidney Research UK commissioned ZS Associates to prepare an independent report on the impact of rare kidney diseases in the UK. The report provides an overview of the evolving clinical, regulatory and policy landscape of rare kidney diseases in the UK; the impact on patients, families and the broader economy, illustrated by personal stories from people affected by rare kidney diseases; and strategic policy, research and clinical recommendations to ultimately improve rare kidney disease care and outcomes in the UK.

This report was prepared by ZS Associates in collaboration with Kidney Research UK and an expert advisory steering group in 2025.

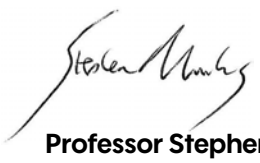
Endorsement

The UK Kidney Association (UKKA) is pleased to endorse this report, informed by extensive clinical expertise from our colleagues. We have confidence in the rigour of the process and high-quality clinical input, which ensures that these findings are robust and actionable. This report is an important, evidence-based contribution to our collective efforts in understanding and improving management of rare kidney diseases across all ages.

As the leading professional body for the UK kidney community, the UKKA is dedicated to improving lives by supporting professionals involved in the delivery of kidney care and research. We welcome initiatives that equip clinicians with the knowledge, tools and data they need to drive improvement in care for people with rare kidney diseases. We look forward to disseminating and implementing the report's recommendations across the professional kidney community.

Under the UKKA umbrella, the British Association of Paediatric Nephrology (BAPN) and Renal Pharmacy Group, also warmly welcome this report, which specifically highlights inequities in research and access to novel treatments for children with rare kidney diseases. We too look forward to sharing and implementing its findings around new medications and seeking opportunities to bridging the gap between paediatric and adult services.

Clare Morlidge
Joint President, UK Kidney Association



Professor Stephen Marks
President, British Association for Paediatric Nephrology

Paul Clarke
Chair, Renal Pharmacy Group, UK Kidney Association

UKKA
UK Kidney Association

BAPN
British Association for Paediatric Nephrology

UKRPG
UK Renal Pharmacy Group

Foreword

Dame June Raine DBE
Former Chief Executive,
Medicines and Healthcare Regulatory Authority (MHRA)

This timely report comes at a pivotal moment for people with kidney disease. We are entering an era where understanding the molecular basis of an individual patient's disease is increasingly possible, supporting earlier diagnosis. For people with rare kidney diseases, this offers immense opportunities for targeted therapies and personalised care.

This report sets out a powerful case for change by shining a light on the breadth and complexities of rare kidney diseases, mixing research and evidence alongside patient experiences and clinical insight. For those living with one of these diseases, the impact is profound. They may represent between just 5% and 10% of people living with the most advanced stages of kidney disease, but when it comes to kidney failure, they make up 25% of the adult patient population and 60% of the paediatric population, enduring treatments that seriously impact their life chances.

In 2023, Kidney Research UK published a major report which painted a stark picture of the current reality and future picture of kidney disease, which is forecast to be the fifth leading cause of premature death globally by 2040. The economic burden in the UK was projected to grow from £7 billion to £13.9 billion by 2033, whilst demand for dialysis could overwhelm the NHS.

I welcome this new report as a call to action for rare kidney disease. This patient group remains significantly underserved. Diagnosis is delayed. Research and innovation are increasing, and although there is a burgeoning pipeline of exciting new drugs, new treatments remain years away. In particular, the current approach to drug development means access to new medicines for children lags behind adults by up to 13 years. Most patients rely on decades-old treatments that manage symptoms but are not a cure, whilst unequal care pathways undermine outcomes.

If taken forward, the clear recommendations in this report could transform care for people with rare kidney diseases. But closing the gaps in treatment access, delays in paediatric access to therapies, poor transition from paediatric to adult services, and underinvestment in research will require sustained commitment, cross-sector collaboration and bold policy action. The time to make that commitment and take that action is now.

June M. Raine

Dame June Raine DBE

Context

Kidney disease is a public health emergency costing the UK economy £7 billion annually, with rare kidney diseases – a group of over 150 distinct conditions – contributing disproportionately. Although individually affecting fewer than 1 in 2,000 people, we estimate that these rare diseases affect over 160,000 people in the UK.

People with rare kidney diseases tend to reach kidney failure at a younger age and spend more of their lives needing treatment than those with more common causes of chronic kidney disease (CKD). Consequently, they require treatment such as dialysis for longer leading to markedly higher lifetime costs. Despite representing less than 10% of the CKD population, people with rare kidney diseases disproportionately account for more than 25% of dialysis and transplant patients. It is also important to note that dialysis and transplants are not curative: people endure disrupted education, employment, and family life, and the NHS bears significant long-term costs.

In May 2025, the World Health Assembly prioritised kidney and rare diseases, catalysing research momentum. Promising therapies are entering trials, but most remain years from approval. The effects on children with rare kidney diseases are compounded due to exclusion from research, with access to new medicines lagging behind adults for up to 13 years.

This report calls for urgent action to transform care. Key priorities include:

- raising awareness and policy focus
- improving diagnostics through biomarkers and genetic testing
- accelerating evidence generation and clinical trial access
- streamlining access to new medicines; and
- personalising care to reflect disease heterogeneity.

Despite some progress, the rare kidney disease community remains underserved. Bridging gaps in treatment, diagnosis, and care transitions demands sustained investment, cross-sector collaboration, and bold policy reform – ensuring that innovation and quality care reaches every patient, regardless of how rare their condition is or where they live.

Key findings

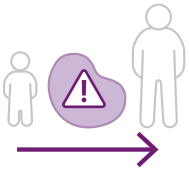
1 **Rare kidney diseases include over 150 distinct diseases** that, while individually uncommon, are estimated to collectively affect around **160,000** people in the UK

2 We estimate that rare kidney diseases cause between 5% and 10% of all cases of CKD at the most advanced stages but disproportionately account for **25% of all dialysis and transplant patients**

3 The cost to the NHS of dialysis for rare kidney diseases **is approximately £263 million per year**

4 Rare kidney diseases disproportionately affect children: **more than 60% of children with kidney failure have a rare kidney disease**

5 Children with rare kidney diseases are **likely to be on dialysis or living with a kidney transplant by the time they reach adulthood**



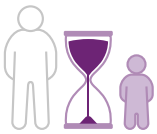
6 Children on dialysis will on average **miss more than 100 days of school per year**, while one person interviewed for this report **missed an entire year of school**

7 In addition to having worse health, **people with rare kidney diseases are economically disadvantaged**: the majority of people with a rare kidney disease have a **64% chance of being out of work by the time they reach kidney failure**

8 Despite the significant impact of rare kidney diseases on economic productivity, this is underresearched in the UK: a global systematic review identified 33 productivity studies on the impact of kidney disease on patients' ability to work, but **none covered the UK**

9 There are a limited number of new targeted therapies in development for several rare kidney diseases; however, of the 13 we reviewed, **about 40% of trials did not include a UK centre**, meaning UK patients do not get the opportunity to try new therapies soon enough, and the UK economy is missing out on R&D investment

10 The impact on children is compounded as they are almost universally excluded from trials: as a result, **treatment innovations for children lag by up to 13 years** behind those for adults



Introduction

Rare kidney diseases include over 150 distinct diseases that, while individually uncommon, collectively affect around 160,000 people in the UK. They account for 5%–10% of CKD cases at the most advanced stages. These lifelong diseases can lead to kidney failure requiring dialysis or a kidney transplant and have a heavy and often hidden impact on families and the NHS. Despite this, rare kidney diseases remain underrecognised in health policy, research funding and clinical services. Delays in diagnosis, limited effective treatments and fragmented care systems lead to suffering that could be avoided and to significant costs, both personal and economic.

Nearly 80% of these conditions are inherited, and many begin in childhood. Most children who develop kidney failure do so because of a rare kidney disease. Over 25% of adults and more than 60% of children receiving dialysis or a kidney transplant are affected by a rare kidney disease. Although many types begin in early life, the average age at diagnosis across the UK National Registry of Rare Kidney Diseases (RaDaR) is 41, highlighting how long some people wait for a correct diagnosis. These delays cause physical and emotional harm and prevent timely access to specialist care. The purpose of this report is to raise awareness of the impact of rare kidney diseases in the UK and to call for action to improve outcomes for every person affected.

Research methods utilised included:

- Targeted review of academic literature
- Further pragmatic search of academic and grey literature
- Expert input from leading UK clinical experts
- Case studies from nine patients or their carers across four rare kidney diseases

Rare kidney diseases

Rare kidney diseases are underdiagnosed and often misunderstood. This gap in recognition among clinicians, the public and policymakers delays diagnosis, hinders access to treatment (if available) and limits the adoption of new advances in care. Added to these challenges are the high costs of developing and bringing new treatments to market, as well as the difficulty of conducting scientifically rigorous clinical trials in small patient populations, which further complicate efforts to deliver timely therapies for rare conditions. In addition, smaller patient populations further disincentivise industry to invest in developing new treatments.

Overview of rare kidney diseases

Rare kidney disease is defined in the UK and the European Union as a kidney condition affecting fewer than 1 in 2,000 people. Current estimates indicate that over 35,000 people in the UK are affected by serious kidney impairment attributable to more than 150 distinct rare kidney diseases, many of which are genetic or autoimmune in nature and disproportionately affect children.

Rare kidney diseases are also over-represented among individuals requiring dialysis and kidney transplants. While rare kidney diseases affect 5%–10% of the general kidney disease population, they account for more than 25% of all patients receiving dialysis and kidney transplants and more than 50% of paediatric kidney transplant recipients. In people with kidney failure, over 25% of adults and 60% of children have an underlying rare kidney disease. This disproportionate representation reflects the early onset, progressive nature and often limited treatment options available for rare kidney diseases.

Beyond direct healthcare costs, the indirect economic and social impact of rare kidney diseases remain poorly understood. Families often face challenges such as lost income, educational disruption, long-term caregiving responsibilities and emotional strain – yet these effects have not been systematically studied in the UK. This represents a major gap in the evidence base and a barrier to fully understanding the impact of rare kidney diseases on patients, families and society.

> Kidney disease made me feel sad, as I was always poorly and spent a lot of time in hospital. My dialysis machine put warm water in my tummy to help stop me getting poorly. George, my new kidney, makes me happy and healthy and gives me energy to do stuff."
>
> **Poppy Lancaster, seven-year-old transplant recipient with polycystic kidney disease**

"[My husband] Ian and I don't get to see each other much because one of us always needs to stay in hospital with Asher, and we both need time at home with our other children. I own a hair salon but had to step away from my job because I'm never at home. We have been financially affected, but Ian continues to work full time to provide for us… we've been lucky that my mum has been able to move in with us to look after our other children while we are not home."

Eloise Pyper, mother of two-year-old Asher, who was born with posterior urethral valves, a congenital anomaly of the kidneys and urinary tract (CAKUT)

The rarity and heterogeneity of these diseases also pose challenges for timely diagnosis, coordinated care and equitable access to specialist services. In addition, for many rare kidney diseases, there are no specific approved treatments available, leaving people with kidney diseases reliant on symptom management or non-targeted therapies, further compounding the burden and limiting opportunities for improved outcomes. Even where treatments do exist, there remains a critical need for more effective, better-tolerated and disease-modifying medications.

Based on the significant impact demonstrated, rare kidney diseases warrant targeted policy attention, investment in research and tailored models of care to improve outcomes and optimise resource allocation across the healthcare system.

Challenges in the management of rare kidney diseases

Accurately diagnosing rare kidney diseases remains one of the most pressing and persistent challenges. Many of these diseases present with non-specific symptoms or resemble more common renal or systemic diseases, leading to frequent misdiagnoses, diagnostic delays or ineffective treatments. These challenges are especially acute in children, as medicine is mainly oriented around adults with common conditions. Care for children with rare kidney diseases suffers due to limited investment, a shortage of academic paediatric nephrologists and regulatory constraints that often require treatments to be tested in adults first, delaying access to new therapies for younger patients. This prolonged uncertainty can substantially postpone the initiation of appropriate treatment, if available, increasing the risk of irreversible kidney damage and accelerating progression to kidney failure.

> I try to live my life to the fullest despite the setbacks, particularly for my wife and two children who I am blessed with. It's frustrating to know that if my kidney disease had been detected sooner, I might not have gotten so ill, so it is my hope that new patients are diagnosed much sooner."
>
> **Adam Musa, born with congenital renal dysplasia which remained undetected until he was diagnosed at 21 years old**

People with rare kidney diseases typically have a limited range of therapeutic options. For many disorders, there are no disease-specific treatments available, and clinical management remains largely generic. Interventions are often based on generalisation from treatments used in more prevalent conditions, which do not adequately address the underlying disease mechanisms. This scarcity of targeted therapies reflects the broader challenges inherent in developing new treatments for rare diseases.

Several systemic and scientific barriers hinder the development of novel therapies. These include limited understanding of disease pathophysiology due to small patient numbers, a lack of agreed clinical endpoints for clinical trials, and insufficient natural history data. Fragmented care pathways and variability in diagnostic coding further obscure disease tracking and impede recruitment for research.

In children with rare kidney diseases, collecting and storing biological samples (biobanking) presents additional challenges. Parental permission and the child's agreement are usually needed, and stricter ethical rules apply. Only small biological samples can be taken – especially from younger or seriously ill children – and it is often difficult to track children over time as they move between services. Without dedicated investment in child-friendly research infrastructure, valuable opportunities to improve diagnosis and treatment for childhood-onset rare kidney diseases will be missed.

As a result, there have been relatively few clinical studies and randomised controlled trials focusing on rare kidney diseases for both paediatric and adult patients. The small and geographically dispersed patient population makes trial recruitment difficult, particularly in earlier stages of disease when individuals may remain undiagnosed. Trials in children face additional barriers and, in many cases, fail to recruit sufficiently or terminate early due to feasibility challenges, as recently highlighted. In addition, the complexity of trial design – including the need to define meaningful, disease-specific outcomes – and the demands of regulatory approval processes present additional hurdles. Together, these factors contribute to a persistent gap in the evidence base, slowing innovation and limiting the development of, and access to, new treatments for those affected.

> Although receiving an earlier diagnosis would not have changed the outcome, it would have allowed me earlier access to medical interventions that would have made life more enjoyable. I would like to see a world that offers children the same access to prevention, protection and treatment as adult kidney patients have. You have the power to hand us back our childhoods."
>
> **Charlie Frieland, 15-year-old with nephronophthisis**

These challenges create a situation in which people living with rare kidney diseases face considerable uncertainty, not only in receiving a timely diagnosis and appropriate treatment but also in accessing emerging therapies and participating in research. This uncertainty is further compounded by the wide variation in how these diseases present and progress; even individuals with the same diagnosis may experience vastly different outcomes, and many do not know whether or when they will require dialysis or a kidney transplant.

Addressing these issues requires coordinated investment in rare kidney disease infrastructure, enhanced data and biological sample collection, and targeted incentives to drive innovation in this underserved area of kidney health.

> My symptoms never felt serious or interconnected... I was diagnosed with IgA nephropathy [and] was told my kidney function had fallen to 25%. At every subsequent hospital visit, it dropped further, until my kidneys began to fail. It was a rapid decline, and the need for a kidney transplant became urgent to avoid dialysis."
>
> **Paul Vallois, 49-year-old with IgAN**

Financial, social and emotional impacts of rare kidney diseases

Despite the substantial impact of rare kidney diseases on those living with them, their carers and the NHS, robust economic data specific to each disease remain scarce. Most available information is derived from CKD data, which do not clearly outline the financial impact or resource use for each rare condition.

Because most rare kidney diseases lack targeted treatment, many people require dialysis or time-consuming medication regimens, which can be disruptive to daily life. For children and young adults, even minor absences from school can severely impact their educational attainment. Children on dialysis may miss more than 100 days of school a year. Lower attendance is strongly associated with poorer attainment at both key stage 2 (ages 7–11), where pupils with higher absence rates score lower in primary school assessments, and key stage 4 (ages 14–16). At key stage 4, persistently absent pupils (defined as missing 10% or more of school sessions) are significantly less likely to achieve good GCSE passes in English and Maths. Beyond the academic impact, each additional day of school missed between Years 7 and 11 is associated with an average lifetime earnings loss of approximately £750, with those missing a year potentially losing up to £100,000 in lifetime earnings. Persistently absent students are three times more likely to receive benefits Persistently absent students are three times more likely to receive benefits by age 28 and have about a 60% lower chance of sustained employment.

Dialysis schedules and the physical toll of treatment likely contribute to these lower educational and employment outcomes. A UK survey of adolescents with kidney failure found that 78% of transplant recipients were in full-time employment compared with just 20% of those on dialysis. Many of those diagnosed as children reported lasting impacts on education and job prospects. Broader national data confirm this pattern: average earnings for people with CKD fall sharply within months of diagnosis (about £293 per month) and remain lower for at least five years. Average earnings fell by approximately £14,700 over five years after diagnosis. People with CKD are also 16% more likely to require benefits and are less likely to be in sustained employment within four years of diagnosis.

Beyond the physical and financial impact, rare kidney diseases take a heavy emotional toll. Data from systematic reviews and international initiatives report concerning levels of anxiety, depression and suicidal thoughts among people living with these conditions and their caregivers. Caregivers, mothers especially, often reduce hours or stop working, adding financial pressure. Children with CKD struggle with body image, bullying, social isolation, restrictions on activities and psychological trauma from repeated medical interventions. Many parents worry their children will never form lasting relationships or live independently. Despite these profound needs, access to appropriate psychological support is often limited, especially in rural areas.

Rare kidney diseases create a huge and wide-ranging impact on individuals, their families and the NHS. All these problems together – such as frequent hospital visits, high treatment costs, interrupted schooling and fewer job opportunities – make it much harder for people to live full lives and exacerbate existing inequities.

> I'd got talking to a mum who has a little boy with a similar story to me, just 20 years apart. He's about ten now but also was diagnosed with IgA vasculitis and within five months his kidneys had failed – the same as me in 1999. It became clear that the treatments and outcomes hadn't really changed in 20 years, and I was shocked. Hopefully in the next 20 years or less, what I've experienced since childhood will be a thing of the past, because I don't want anyone to go through what I have."
>
> **Kathryn Croker, diagnosed with IgA vasculitis at 13 years old**

Summary and recommendations

Diagnostic challenges

Rare kidney diseases may mimic common conditions and are often asymptomatic at early stages, leading to delayed diagnoses or misdiagnoses. Delays in diagnosis can lead to further disease progression, and misdiagnoses can lead to inappropriate treatment, leaving **patients with worse outcomes and closer to kidney failure**.

Recommendation 1: Ensure sufficient and equitable access to diagnostics, including genetic testing

Recommendation 2: Develop targeted screening programmes for people at known risk of rare kidney diseases

Recommendation 3: Enhance education and support for kidney specialists and primary care providers to improve early recognition of potential rare kidney diseases and ensure timely, appropriate referrals for further evaluation and diagnosis

Fifteen-year-old Morven lives with cystinosis. Diagnosed in infancy, they now follow a strict, round-the-clock medication schedule to slow the progression of kidney disease. Their medication, mercaptamine, is taken orally every six hours, including during the night, and disrupts sleep and daily life. While the treatment helps protect their kidneys, it comes with side effects like nausea and a strong, egg-like smell that can cause bad breath and body odour. This can be embarrassing and may lead to teasing or social exclusion. At school, Morven must visit the first aid room during breaktimes to take their medication, missing time with friends and sometimes feeling isolated as a result.

Healthcare challenges

NHS care pathways are not well adapted to the needs of people with rare kidney diseases, particularly children. Renal clinical networks and paediatric renal services improve coordination but lack national consistency, and there is inadequate support for transition from paediatric to adult care. In addition, regional access to specialist care is inconsistent. **Rare kidney disease care should be prioritised as the UK Government develops new policy to replace the current UK Rare Diseases Framework and ensure it is implemented across the four nations, to manage the disproportionate impact of rare kidney disease.**

> As more children with rare kidney diseases are now surviving into adulthood, nephrologists treating adults are increasingly encountering conditions they may not have seen before. Historically, many of these were considered childhood diseases. To keep pace with this shift, adult nephrologists need additional training and support to recognise and manage rare kidney diseases that may be unfamiliar to them."
>
> **Dr Ben Reynolds, Consultant Paediatric Nephrologist**

Recommendation 4: Strengthen interconnection and collaboration between specialist centres and other health settings, e.g. via renal networks

Recommendation 5: Improve integration and continuity of care between paediatric and adult services, including increased support for transitional care and adolescent mental health services, and secure additional training for adult nephrologists on paediatric kidney diseases

Access to new medicines

The limited availability of disease-specific treatments means many people with rare kidney diseases rely on supportive or generalised treatments with considerable side effects. There is some hope, however, with a number of clinical trials ongoing for new targeted medicines. It is essential that regulatory and reimbursement pathways for medicines are optimised for rare diseases to **ensure patients receive access to new treatments as soon as possible**:

Recommendation 6: Ensure coordination between regulatory and reimbursement evidence needs so that rare disease studies are appropriately designed and inclusive across age groups

Recommendation 7: Include people with rare kidney diseases in research studies and clinical trials so that future treatments for mixed causes of CKD are also understood in rare diseases

"Gareth's kidneys were slowly deteriorating, but we embraced life together… We held on to the thought that advances in medicine could bring better therapies, or even a cure, in his lifetime." Due to a lack of treatment options for his ADPKD beyond hypertension control, he required heart and kidney transplants. He died aged 50.

Caroline Prodger, wife of Gareth

Clinical trials

Enrolment in a clinical trial offers participants early access to new medicines and can boost UK R&D investment. However, in a recent review of 13 clinical trials for rare kidney diseases, 40% did not have a UK site, **meaning UK patients and the UK economy are not benefiting as much as they could be**. Furthermore, the exclusion of children from rare kidney disease trials means they are unable to benefit from new therapies at the same time as adults.

Recommendation 8: Support UK participation in regional and international clinical trials to increase UK patient access and representation

Recommendation 9: Address inequities around the exclusion of children from clinical trials where this is safe and appropriate

Recommendation 10: Offer everyone with a rare kidney disease the opportunity to participate in a clinical trial or research for their disease

Enhance RaDaR

RaDaR is a world-leading patient registry and an invaluable resource for the study of rare kidney diseases in the UK. However, enrolment into the database is time-consuming, and there is no government funding to support doing so. This means **we lack an accurate picture of the true prevalences of rare kidney diseases in the UK, and the data we do have are geographically skewed. Furthermore, patients who might benefit from participating in research are missing out**.

Recommendation 11: Increase capacity to enrol patients earlier, growing the cohort over time, to facilitate and expedite recruitment for clinical trials

Recommendation 12: Increase communication and education within the rare kidney disease community in the UK to foster trust and information exchange between patients and clinicians, and within RaDaR and beyond

Kathryn Croker was 13 when she was diagnosed with IgA vasculitis. Within five months, Kathryn's kidneys failed. She missed an entire year of school and, now in her twenties, works reduced hours due to ongoing symptoms and extreme tiredness.

Lack of economic evidence

Primary research into the economic impact of rare kidney diseases is lacking. A systematic review of the economic literature focused on rare kidney diseases published over the last ten years found 33 studies globally, but **none covered the UK**.

Recommendation 13: Demonstrate the economic value of delaying the progression of rare kidney diseases – either by reporting these conditions separately in large studies or conducting specific ones, e.g. through expansion and provision of access to the underlying dataset to researchers of the 2025 Office for National Statistics report: impact of health conditions requiring hospitalisation on earnings

Recommendation 14: Ensure rare kidney diseases are accurately captured in administrative data, which inform cost analyses

Rare kidney diseases are a complex and underaddressed challenge within the UK healthcare system. While individually uncommon, their collective burden on patients, families and the NHS is substantial, ranging from delayed diagnosis and fragmented care to limited treatment options and minimal economic data. Patient experiences throughout this report highlight the personal and systemic toll of these conditions. To meaningfully improve outcomes, a coordinated response is needed that combines earlier detection, integrated and equitable care pathways, investment in targeted therapies and clinical research, and improved national data infrastructure. Implementing the recommendations outlined here is critical to ensuring that people with rare kidney diseases are no longer overlooked in policy, research and care delivery.

ZS is a management consulting and technology firm focused on transforming global healthcare by driving toward a connected ecosystem. For more information, please visit our website: https://www.zs.com/

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This report has been co-funded by Kidney Research UK and the following industry supporters: Alexion, AstraZeneca Rare Disease; CSL Vifor; Novartis U.K. and Vertex Pharmaceuticals.

These companies had no control or editorial input to the contents of this report.