Kidney Research UK

Chronic Kidney Disease: An Action Plan for Scotland

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 £8.6m into research in Scotland. We lobby governments and decision makers to change policy and practice to ensure that more than 3 million people living with the most severe stages of 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.

Disclaimer

This project has been co-funded by Kidney Research UK and the following industry supporters: AstraZeneca, Bayer, Boehringer Ingelheim, CSL Vifor and Novartis. These companies had no control over the contents of this plan. This report and the analysis contained herein have been produced on a ‘best efforts’ basis. Kidney Research UK does not accept any liability arising out of or in connection with third party use of the plan and its contents.

Kidney Research UK charity registration no. 252892 (England and Wales), SC039245 (Scotland)

www.kidneyresearchuk.org

Contents

Forewords

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Professor of Experimental Nephrology, University of Edinburgh;
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Chronic kidney disease (CKD) is Scotland's single biggest public health challenge that nobody is talking about despite affecting over 10% of the population.

CKD is where a person's kidneys silently deteriorate over time ultimately, in some cases, leading to kidney failure and the need for regular dialysis or a kidney transplant. Many of the risk factors for CKD are common and well recognised whilst every GP can arrange the simple blood tests that allow a diagnosis of CKD to be made. Despite this, one third of individuals with CKD remain undiagnosed and thus untreated.

There is no screening programme in place and CKD is rarely diagnosed as soon as it could be. Some communities do less well than others, and patients sometimes feel they are not given the information and opportunities they would want to be able to manage their illness. Indeed, while we know the number of people with CKD in Scotland continues to increase, we simply do not have accurate data for the incidence, prevalence, treatment or progression of CKD in Scotland despite the vital need for such data to ensure Scotland is doing everything it can for every patient with CKD regardless of where they live.

This Action Plan is the first attempt in two decades to try to turn the tide.

I have been pleased to act as chair for the Kidney Research UK in Scotland working group that brought together patients, clinicians, researchers and industry observers to develop this plan.

We have together imagined a better future for people with CKD and now recommend 19 actions to deliver it. Some will cost money, and we know money is tight. Most, though, can be achieved by doing what we are already doing, but doing it more widely and comprehensively and in a more joined-up way – and by talking about CKD in policy, in the media, across the health service and in our homes. This plan has patients with CKD and their families and carers at its core and embraces innovation, enterprise, digital health, team working and data to drive and sustain real change across Scotland.

In the early years of the new Scottish parliament, a group of patients and eminent colleagues asked for CKD to be made a priority by the then government. Tens of thousands of people have been affected by the decision to ignore that advice. Now is the time for a new focus on CKD with concerted and coordinated action.

Professor Andy Rees

Chair of the advisory group to the former Cross-Party Group on Kidney Disease (2002–2004); former president of the Renal Association of Great Britain and Ireland (2001–2004); former Regius Professor of Medicine, University of Aberdeen (1994–2007)

It was more than two decades ago that a group of clinicians, patients and MSPs first came together in the Scottish Parliament to lay out a vision for improved services for patients with kidney disease.

We believed back in 2004 that the only way to ensure people with chronic kidney disease (CKD) had quick and equitable access to the right treatment was through a national plan.

The Health Minister at that time told us that a national plan was not the best way forward and that the Scottish Government would instead seek alternative ways to drive improvements for people with CKD.

Twenty years later and that positive change is yet to happen.

Back then we estimated that, without a national plan to set renal standards and improve services, the number of people requiring dialysis or transplantation by the year 2014 would rise by 50%. Our prediction was right.

We thought then that around 40,000 people in Scotland were living with undiagnosed chronic kidney disease. Two decades later, the true number is closer to 240,000 people.

Our group in 2004 recognised the importance of early identification and management of CKD in slowing its progression. We asked back then that all patients with CKD be entered into disease care plans with their GPs and for all patients with worsening kidney function to be regularly monitored and referred quickly to secondary care. We also highlighted the inadequacy of the support available for patients being treated with dialysis or transplantation, and how many were insufficiently prepared for the toll it takes. We knew then of the importance of the multi-disciplinary team, including renal social workers, in the care of people with CKD and the importance of data and integrated IT systems.

The present action plan prepared by a new generation of clinicians and patients asks for many of the same things: for earlier detection of people with CKD, improved management of people with CKD and joined-up data and IT to improve services.

Scotland simply cannot wait another 20 years for change.

Executive summary

Despite being among the fastest rising causes of death in the world, chronic kidney disease (CKD) has received limited attention by governments and health systems around the world, when compared to other major non-communicable diseases like diabetes, cancer, heart disease, obesity and stroke.

Without action now, modelling commissioned by Kidney Research UK suggests that by 2033 as many as 10,000 people in Scotland could see their illness progress to the point of needing dialysis. The total cost to the Scottish economy is rising as a result, and is likely to reach more than £1bn by 2033.[1] Treatments and symptoms for the condition are absent or mild at the outset and devastating later on. Early treatment is cheap and effective at preventing or delaying progression to kidney failure. Treatments for the later stages of the disease (especially life-sustaining dialysis) are costly and are unfortunately associated with substantial greenhouse emissions, natural resources depletion and waste generation.[2]

A Scottish working group, convened by Kidney Research UK and made up of patients, clinicians, GPs, and industry observers, has concluded that there are 19 actions the Scottish Government, NHS Scotland and partners must now implement to have any hope of turning the tide and addressing this major contributor to premature and preventable mortality, and to mitigate the spiralling economic and environmental burden of CKD.

The recommendations are focused around four key themes, aligned with Scottish Government priorities in eradicating health inequities, delivering data-backed health and care services, and supporting the delivery of Value-Based Health and Care:

- **Prevention:** If detected early enough and managed appropriately, the worst impacts of CKD can be avoided or significantly delayed. Achieving this should start with a community-based awareness and prevention programme, tailored to local contexts with a particular focus on underserved communities most at risk, and ensuring those with some of the underlying conditions that can lead to CKD – like diabetes and high blood pressure – are properly managed.
- **Timely and equitable access to diagnosis and treatment:** Giving primary care professionals the skills, training and tools they need to lead on diagnosis, care and monitoring is the only way to ensure people with CKD are detected quickly and given the care they need to stay as healthy as possible for as long as possible. Assistive tools should provide feedback on groups of people who are missing out on evidence-based care to ensure that all people with CKD receive care that is both timely and equitable.
- **Empowered patients throughout the kidney pathway:** The roll-out of digital tools and access to the biopsychosocial model of healthcare for patients when they need it most. This model views a patient as a complete person with a complex range of behaviours, thoughts and feelings which may influence physical functioning and play a role in health and illness. Understanding this will enable individuals to take greater control over decisions affecting their health, reducing harms and, ultimately, improving outcomes.
- **Informed decision making:** Underpinning everything in the Action Plan is the need for robust, accurate data infrastructure, to make sure the right information is being gathered at the right time to inform quality improvements, identify risks, monitor capacity and support services.

The Action Plan

Vision statement

Preventable chronic kidney disease is minimised and everyone living with chronic kidney disease in Scotland has timely and equitable access to the diagnosis, treatment and care they need to live well.

The context

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 leads 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. A key consequence of CKD is that it increases the risk of early death from associated cardiovascular disease (i.e. heart attacks and strokes), regardless of whether a person ever reaches kidney failure. 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. Left untreated, CKD can progress from stage 1 through to stage 5, with those in the most advanced stages of kidney disease requiring kidney replacement therapy (dialysis or transplantation) to survive.

Kidney disease is usually diagnosed by blood and urine tests. A blood test will show low eGFR (estimated glomerular filtration rate) levels or high levels of creatinine; or a uACR (urine albumin creatinine ratio) test will show the presence of a protein called albumin.

CKD has also been linked to significant physical limitations, reduced quality of life, financial hardship, emotional and cognitive disorders and social isolation.

Scale of CKD in Scotland

More than one in ten people in Scotland are estimated to have CKD. Of those, 45% (around 273,000) are already in the more severe, later stages of the condition.

However, only around two thirds of those affected by CKD are thought to have received a diagnosis – many of them diagnosed too late to prevent kidney failure – and others identified incidentally as they are tested for other conditions. Kidney Research UK's recent health inequalities review cites that recent studies have found poorer diagnosis and management of CKD for older people and people of Black African ethnicity and an association between socio-economic deprivation/low health literacy and mortality.[3]

As of December 2023, 5,732 people in Scotland were living with kidney failure, requiring kidney replacement therapy (KRT) – 60.9% had a functioning transplant with the rest being treated with haemodialysis, peritoneal dialysis or conservative care.[4] This means more than 2,000 people in Scotland are reliant on dialysis to stay alive, which could rise to as many as 10,000 people by 2033, if more is not done now to prevent CKD arising.[5]

In 2023, 265 patients received a kidney transplant.[6] For context, 485 adults were on the transplant waiting list in Scotland as of March 2024. CKD in Scotland is currently costing the economy more than £0.5bn a year. Without significant government intervention, this could rise to more than £1bn by 2033.[7]

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CKD is a leading cause of health expenditure worldwide and treatments leave a considerable carbon footprint, with dialysis one of the most carbon-intensive fields in medicine. The treatment is associated with substantial greenhouse emissions (including patient travel to dialysis centres), natural resources depletion, and waste generation.[8]

An overlooked chronic condition

Despite the toll that CKD takes on the people who live with it, as well as the burden on the NHS, the condition has received only limited attention by governments and public health officials across Europe.[9] A coalition of leading global experts came together earlier this year to call for urgent action to address CKD, in response to the 'deplorable' underrepresentation of the disease in media and public discourse.[10]

Scotland is no different: people with kidney disease here report that they feel "misunderstood and overlooked", and that their condition simply is not on the agenda to the extent that it needs to be for government, MSPs, the public or the NHS in Scotland.[11]

CKD often co-exists with other conditions such as heart disease, diabetes and high blood pressure and together they can accelerate health decline. Heart disease and diabetes share many of the same addressable risk factors as CKD but, while heart disease and diabetes have been designated national clinical priority status with their own government-aligned teams, clinical leads and standalone plans, little attention has been paid to CKD.

The Diabetes Improvement Plan recognises kidney disease as a key risk factor for poor outcomes among those with diabetes, though little consideration is given to its prevention, management or treatment in this context.[12] Despite being so closely related to heart disease, both as a cause and consequence, CKD is not mentioned within The Heart Disease Action Plan.[13]

The decision of the Scottish Government to take forward condition-specific action plans has allowed excellent progress to be made across prevention and timely and equitable access to diagnosis, treatment and care for these conditions. However, by omitting CKD – a condition that is so closely linked with both diabetes and heart disease, in a time where people are increasingly presenting with complex comorbidities – a key piece of the jigsaw has been left out. The full ambitions of these plans simply cannot be met without a similar commitment to drive forward improvements for people living with CKD.

With recent advances in care and treatments, there is now an opportunity for Scotland to take forward a dedicated action plan for CKD, complementary to and aligned with the outcomes and actions laid out for chronic conditions previously. With CKD expected to become the world's fifth leading cause of premature death by 2040, it is time to end the 'poor relation' status of CKD and allow Scotland to achieve its ambitions to improve the care for the hundreds of thousands of people living with chronic conditions.[14]

The development of this action plan

This action plan is the culmination of the efforts of a committed expert working group made up of clinicians from primary and secondary care, patients, industry observers and patient advocacy organisations. The work of the group has been underpinned by Value-Based Health and Care, with a subgroup set up to consider how to meet ambitious targets in sustainable health and care, optimised use of resources and focusing on personalised outcomes that matter most to people.

Health inequities remain a significant challenge in kidney care, and a subgroup was set up to explore specific actions to reach groups often underrepresented and least well served by current services.

Understanding our patients is at the core of achieving significant change, and this can be greatly facilitated by relevant, accurate, and timely data. Taking learnings from Scotland's well-established renal registry, experts came together in a third subgroup to consider how Scotland can move closer to establishing the data infrastructure that will provide a comprehensive understanding of CKD in the population and improved surveillance and monitoring capacity.

Members of the working group

Professor Jeremy Hughes, (Chair) consultant nephrologist, NHS Lothian; Professor of Experimental Nephrology, University of Edinburgh; former chair of trustees, Kidney Research UK

Dr Kashif Ali, GP NHS Greater Glasgow and Clyde; Primary Care Lead, Diabetes Managed Clinical Network

Dr Samira Bell, consultant nephrologist, NHS Tayside; NHS Research Scotland Renal Research Network Lead; Associate Director of the Kidney Data Science Catalyst and co-lead of the UK Renal Health Data Research Network; former chair of the Scottish Renal Registry

Jelina Berlow-Rahman, patient advocate

Professor Colin Geddes, consultant nephrologist, NHS Greater Glasgow and Clyde

Dr Wendy Metcalfe, consultant nephrologist, NHS Lothian

Dr Eleanor Murray, consultant nephrologist, NHS Greater Glasgow and Clyde

Dr Ben Reynolds, consultant paediatric nephrologist, NHS Greater Glasgow and Clyde

Angela Riley, patient advocate

Dr Simon Sawhney, senior clinical lecturer in nephrology, University of Aberdeen

With support from:

Liz Brown, patient advocate

Melany Gray, patient advocate

Dr Clare MacRae, GP, NHS Lothian

Dr Michael Sullivan, renal trainee, NHS Greater Glasgow and Clyde

Organisation representation:

AstraZeneca

Bayer

CSL Vifor

Ettrickburn Limited (secretariat)

Kidney Research UK

Novartis

Theme:
Prevention

For many people, the worst health impacts of CKD, like cardiovascular complications and the need for treatment such as dialysis or kidney transplant, could be prevented or delayed, if the condition is detected early and managed appropriately. The delivery of care for later-stage CKD patients, particularly haemodialysis treatment, is expensive (costing around £34,000 per patient, per year) and is associated with high and recurrent consumption of water and energy, waste generation and a significant carbon footprint. Early diagnosis and prevention will thus be key to minimising its impact on patients, whilst tackling the societal, financial and environmental burden of the disease. Effective interventional treatments to prevent or limit disease severity in CKD contribute to both the health of the patient and the mitigation of environmental impact.

Socioeconomic factors continue to drive health inequities within long-term conditions and CKD is no exception as the incidence and outcomes of the condition are not equal across Scotland. This means it is particularly important that education, awareness and early intervention are targeted at those from currently underserved communities.

The Scottish Government's Care and Wellbeing Portfolio looks to bring a systematic approach to improving population health and addressing health inequalities while improving the sustainability of the health and care system. However, CKD is not a current government clinical priority.

Outcome 1: People understand the role of their kidneys and the actions they can take to reduce their risk of developing later-stage CKD.

Education and awareness must be the first step. Kidneys are highly complex organs and many people do not understand the vital role they play in health. Those at highest risk of developing CKD – including people living with high blood pressure, diabetes, obesity or a severe or frequent previous kidney infection – are often unaware of their risk of developing the disease or what this could entail for them until it is simply too late.

CKD is a condition that disproportionately affects people from minority ethnic and lower socioeconomic communities, accompanied with a risk of lower and often later diagnosis and poorer long-term outcomes. It is therefore crucial that kidney-specific education, targeted at these traditionally underserved groups, is rolled out across Scotland. This ties into action 8 of the Value Based Health and Care Action Plan, to address racialised inequities in health and care.[15] While cardiovascular disease and type 2 diabetes prevention and detection are highlighted, CKD must also form part of this focus.

Lifestyle changes are also important to CKD management and prevention. Dietary recommendations are an important part of CKD self-management, but guidance can be unclear and difficult to adhere to. Commitments made by the Scottish Government in its collection of recent plans for improving public health will play an important role in CKD prevention. This includes actions within:

- Tobacco and vaping framework: roadmap to 2034[16]
- A Healthier Future: Scotland's Diet & Healthy Weight Delivery Plan 2018[17]
- A More Active Scotland: Scotland's Physical Activity Delivery Plan 2018[18]
- Alcohol Framework 2018: Preventing Harm[19]
- Cleaner Air for Scotland: The Road to a Healthier Future[20]

> **Action 1:** A community-based awareness and prevention programme for CKD is rolled out in Scotland, co-designed and person-centered, with a particular focus on underserved communities most at risk.

Kidney Research UK's evidence-based volunteer peer educator programme continues to trial innovative prevention, early detection and organ donation initiatives in underserved and/or minority ethnic communities by building trust.[21] For example, the charity has over 10 years of experience running the Scottish Government funded peer educator programme to raise awareness of organ and tissue donation amongst South Asian communities; HIDDEN-CKD is screening 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 have uACR tests.

Outcome 2: There is clear, comprehensive, accurate and accessible information readily available online, and in printed form, at all points of contact within the NHS and care providers for people at risk of developing, or with a diagnosis of, CKD – co-produced by patients and clinicians.

Digital access to information and support services for all is an essential element of shifting the focus of health and care systems from crisis intervention towards prevention, early intervention, enablement and supported self-management.

NHS Inform is currently going through a period of expansion of its resources, advice and guidance, to ensure it can act in the future as a triage service for those accessing health services in Scotland and promote greater self-management. NHS Inform pages on CKD must be refreshed in line with these aims and with the most recent developments to ensure they are fit for purpose for, and designed inclusively with, those worried about their kidney function, all the way through to individuals receiving kidney replacement therapy, including transplantation. The best way to achieve this is by working with patients and clinicians to co-produce the content, format and signposting links, in a way that is accessible for adults and children.

There is precedent for this: NHS Inform has worked successfully with groups of patients and clinicians to develop and publish pages on autism spectrum disorder, heart disease, palliative care and women's health.

> **Action 2:** Kidney Research UK provides support to the NHS 24 team to refresh and keep up to date the NHS Inform renal pages with the most recent developments in diagnostics, treatments and management, and signposting to relevant charities as appropriate.

Outcome 3: Underlying conditions that can lead to CKD are properly managed.

The most recently available data shows that in 2016–2019 combined, just 24% of adults with high blood pressure in Scotland had their high blood pressure treated and controlled to below the Scottish Intercollegiate Guideline Network (SIGN) recommended threshold of 140/90mmHg.[22] Approximately 1 in 7 people with type 1 diabetes and 1 in 10 people with type 2 diabetes did not have the levels of creatinine in their blood recorded in 2022. Almost half of people with either type 1 or type 2 diabetes did not have their urinary albumin level recorded.[23]

A key commitment within the Value Based Health and Care Action Plan is to focus on better identification and management of the clinical risk factors for cardiovascular disease to reduce excess deaths. A focus on CKD prevention must be an integral part of this.

> **Action 3:** All clinical guidelines for the treatment of diabetes, cardiovascular disease and high blood pressure include a requirement for routine and regular kidney function testing.

Theme:

Timely and equitable access to diagnosis and treatment

Outcome 4: Every person with CKD is diagnosed as early as possible in the development of their condition, reducing unwarranted variation among those at highest risk.

There is a need to 'be much harder, much faster and much more aggressive' in identifying people with CKD to slow progression of the disease and enable people to manage their condition in the community.[24] Currently, those least likely to engage with health services and those from more deprived communities are the people least likely to be diagnosed with CKD in the early stages until it has progressed. Access to and experience of health care depends on multiple, overlapping sociodemographic factors, including but not limited to age, sex, gender, ethnicity, health literacy, education, digital literacy, geography, culture and beliefs. The way these intersect can promote or undermine experiences of healthcare. We welcome news that the Scottish Government's Chief Scientist Office is funding a research project looking at how to address inequities in kidney healthcare in Scotland (June 2024). Kidney Research UK is an advisor on the project. Evidence supports a systematic approach to screen for, determine the risk of the condition significantly worsening, and treat people with CKD, though implementation should be accompanied by an evaluation of its effects.[25]

> **Action 4:** Introduce and evaluate implementation of a systematic CKD screening programme, targeting those at highest risk, to identify those in need of treatment who have gone unidentified.

Outcome 5: Primary and community care is empowered to lead on CKD diagnosis, care and monitoring.

Primary care is currently firefighting and the people providing primary and community services do not have the support they need to proactively manage patients presenting with reduced kidney function.

The current approach to testing in primary care has been described by clinicians as "haphazard", with huge variation in approach from practice to practice, meaning many patients must rely on an 'opportunistic' blood or urine test to be diagnosed.[26]

Dedicated CKD training of healthcare professionals working in the community, structured and streamlined CKD pathways (including screening and access to treatments), multidisciplinary team-based care, and the use of risk-based assessments to support timely shared decisions and prioritisation of referrals to secondary care will all be key to enabling people with early-stage CKD to be managed effectively in the community. This should lead to lower spending on late-stage disease interventions and better outcomes for many.

Guidelines and pathways

The National Institute for Health and Care Excellence (NICE) publishes guidelines on clinical practice for England and Wales which, for certain conditions, are followed in Scotland. These guidelines currently inform who is tested for CKD in Scotland, after routine testing in primary care for people at risk of CKD came to an end in 2015 with the withdrawal of the Quality and Outcomes Framework (QOF). Though GPs' practice is often still driven by its legacy, alongside national and international guidance, a full return to this system is not expected due to time, resource constraints and the system's emphasis on a single-disease approach. However, it is still important that patients with CKD receive the tests they need to monitor their condition. CKD is common among people over 60 years old visiting their GP and is one of several comorbidities that can complicate effective and safe prescribing decisions. There is a need to identify consistently which patients require input, escalation or ongoing monitoring in the community using tools such as the Kidney Failure Risk Equation (KFRE). This should reduce the number of people needing dialysis without warning. There is also a need to continuously identify and feedback when groups of patients are consistently presenting late or receiving insufficient monitoring.

Management guidelines for CKD in primary care must be streamlined and access to guidelines made straightforward on IT systems.

The Right Decision Service moving into ownership of Healthcare Improvement Scotland offers an opportunity for greater systematisation of guidance available to healthcare professionals. The multiple and duplicative current guidelines on the Right Decision Service should be audited to ensure that a Once for Scotland approach to guidelines and data sharing is taken forward into the new single system with regular expert review and updating.

Monitoring in the community

The establishment of community treatment and care (CTAC) services, where the provision of basic disease data collection and biometrics, chronic disease monitoring and blood tests (phlebotomy) would move to board-led provision, was a core part of the 2018 GMS contract.[27] This was reinforced in a second Memorandum of Understanding between Scottish Government, the British Medical Association, integration authorities and NHS boards which looked to deliver a safe and sustainable service delivery model, based on appropriate local level design, from April 2022.[28] However, as of March 2023, while 86% of GP practices in Scotland reported having access to board-provided phlebotomy services, only 61% said they had access to chronic disease monitoring within CTAC services.[29] CKD is not a priority, even within chronic disease monitoring, so these locally designed services must allow for local population health needs and provide care and monitoring that takes into account patients' increasingly complex comorbidities to ensure disease management is not siloed. Chronic disease clinics can be led by trained nurses, and these posts must be funded, staffed and supported with protected learning and development time. Pharmacists can also be given a role to carry out medication reviews and provide additional support within the community, which could be enhanced by them having full access to patient records.

Patients with CKD require regular blood tests, and there is variation across Scotland in whether primary or secondary care teams are responsible for their provision and oversight. A lack of a seamless 'Once for Scotland' pathway or process for prescribing ongoing monitoring for adults has resulted in blind spots across the country. Furthermore, there is a need for greater clarity on which professionals are responsible for asking for laboratory tests, recording the results and sharing these with patients. This will need careful consideration and discussion with local GP committees.

Managed Clinical Networks, GP clusters and continuing professional development

A lack of managed clinical network (MCN) support for CKD is causing challenges at a local level for GPs with CKD patients. MCNs bring together patients, carers and health professionals from all disciplines to identify local needs and drive forward local priorities, adopting a patient-centered approach to service development. The restructuring of MCNs within some health boards is an opportunity to increase the visibility of CKD within local decision making around chronic disease services.

GP clusters have great potential to improve the quality of healthcare in primary care, but implementation has not been fully supported or prioritised. Without the incentives provided by the QOF, variation exists depending on individual GPs' enthusiasm and experience.[30] Oversight of CKD quality improvement sits within these practice quality lead/cluster quality lead (PQL/CQL) cluster structures and would benefit from the support of an appointed clinical champion for CKD to ensure prioritisation at board level. Having a renal or CKD clinical champion within primary care, who is able to help clusters and health and social care partnerships implement early CKD diagnosis, assessment and management via quality improvement activities could also be beneficial. Part of this role could be encouraging and supporting colleagues to undertake continuing professional development (CPD) within CKD, including with greater take-up of Practice Based Small Group Learning (PBSGL). This is a rapidly growing, innovative approach to CPD which is predominantly accessed by GPs, pharmacists, pharmacy technicians and nurses working in primary care. A module on CKD is currently available.

IT solutions

We acknowledge that the first full rollout of Cegedim Vision as the new cloud hosted National GP IT System will complete by 2026. This is an opportunity to ensure IT used by GPs links in with secondary care and community pharmacy, is fit-for-purpose and modern and assumes permission for data sharing for research and clinical purposes.

It is unclear what the IT system's functionality will be in terms of embedded prescribing and clinical decision support, but this could be an opportunity to fully integrate clinical decision support for kidney disease, such as the Kidney Failure Risk Equation (KFRE), across primary care.

The KFRE is an innovative tool that uses adult patients' urine test results, sex, age and eGFR to provide the two- and five-year probability of kidney failure for adult patients with CKD stage 3a to 5 and has the potential to transform the way patients and their clinical team manage CKD. The KFRE is already integrated into Serva software in secondary care in NHS Greater Glasgow and Clyde, but its roll out in primary care has been slowed due to its classification as a medical device rather than as a calculator, thus requiring individual GP practices to give consent to its usage.

Action 5: Ensure relevant health and care professionals, especially those in primary and community care, are supported to access training and information as early as possible in their careers so they are equipped to support and to refer patients with CKD in their care, as appropriate.

Action 6: Designate kidney disease leads at board or health and social care partnership level, or renal/CKD clinical champions in primary care, to support local governance, upskilling and accountability for progress.

Action 7: Implement kidney failure risk tools (such as the Kidney Failure Risk Equation (KFRE)) across relevant systems with the resource to support its roll out.

Action 8: Undertake a review of CKD management guidelines across Scotland, to support the establishment of 'Once for Scotland' CKD management guidelines as a baseline for all NHS boards, which can be easily accessed in primary care.

Action 9: Fully fund the roll out of community-based chronic disease monitoring centres, and ensure equitable focus on the needs of people living with CKD.

Action 10: Mobilise other roles across primary care, such as nurses and pharmacists, to lead on CKD management and outreach.

Theme:

Empowered patients throughout the kidney pathway

Knowledgeable patients are empowered patients, enabling them to confidently have greater control over decisions and actions affecting their health. The earlier chapter on prevention explores how to put in place the necessary foundations to ensure everyone in Scotland can access the information they need, when they need it. This chapter looks to embed this greater understanding into practice, to support shared decision making, reduce harm and ultimately lead to better outcomes for people living with CKD.

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 dialysis, which offer better outcomes and quality of life.

Outcome 6: Patients have access to digital tools to assess and track their own key metrics, such as their kidney function, in an easy-to-understand way that can be shared with their clinicians.

However, in Kidney Research UK's recent health inequalities report, patients noted: "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."

Appropriate use of digital tools can delay and even reduce demand, by slowing the progress of disease in people already affected by CKD and by releasing more time for professionals to work with people to manage their conditions more effectively. There is clear opportunity to act and rapidly bring forward digital innovations.

The scale up and adoption of Connect Me, enabling people to access remote health monitoring and self-management without the need for a face-to-face appointment, by March 2025, is a key commitment within the Digital Delivery Plan.[31] Telemonitoring for high blood pressure is now being adopted at scale across Scotland within an evaluative framework.

A pilot is underway in NHS Ayrshire and Arran which allows people with CKD and/or other long-term conditions to remotely complete their long-term conditions review questionnaire, ahead of their annual chronic disease management appointment review meeting, to give as much time as possible during face-to-face appointments to discuss what matters most to patients. However, there is an opportunity to go further and completely re-orient care for CKD patients through putting digital technology in the hands of patients. This should be co-designed with patients, with proactive and intentional monitoring to ensure that those at risk of digital exclusion are equitably supported.

Digital healthcare solutions are under development that could revolutionise CKD management with a focus on education, engagement and empowerment for kidney patients accessing secondary care.

Digital platforms can:

- engage patients to self-monitor including blood pressure and kidney function measured locally
- educate patients about how they can achieve their best possible health outcome in easy-to-digest videos
- empower patients to determine when they need help and give them direct access to their clinical team as part of patient-initiated follow up
- enable clinical teams to remotely make informed decisions using patients' continuous data, rather than infrequent data points at clinic visits
- reduce face-to-face outpatient appointments and improve system efficiency, reducing emissions from travelling and increasing patient autonomy
- increase clinic capacity significantly, allowing people who need or want face-to-face appointments to be seen promptly.

It is important to remember that children with CKD will not benefit in the same way from these digital initiatives. Supporting parents and carers of young people and children living with CKD and other complex long-term conditions to engage with digital tools should be a key part of efforts to increase digital inclusion – priority one of the Digital Health and Care Delivery Plan.

> **Action 11:** The Scottish Government should work with innovation partners to trial digital platforms and apps in Scotland with the view to scaling them up nationally within the Connect Me service.

Outcome 7: Everyone with kidney disease who needs it can access emotional, psychological and practical kidney-specific support.

Health and wellbeing for people living with CKD extends beyond physical health. Patients describe having CKD as a very lonely journey. They have highlighted the lack of mental health support at all stages of the pathway.[32] Kidney Research UK's 2022 survey found that 67% of kidney patients experience depression, 27% had considered self-harm or suicide, yet 68% were offered no mental health support. One of the recommendations in the charity's subsequent policy report was the implementation of a more tailored approach to mental health care through a stepped model that becomes more specialised depending on the individual's need.[33]

Scotland's Mental Health and Wellbeing Strategy recognises the need for people living with long-term physical health conditions to be able to access evidence-based approaches for support, and the need to work more closely with the third sector to support communities most in need.[34] Third sector organisations in Scotland, backed by volunteers with lived experience, could help to fill these gaps in community outreach and peer support for people living with CKD with the right resources and infrastructure. Patient networks provide a beneficial source of education, reassurance and guidance to those at all stages of their kidney journey.

There must be a Once for Scotland framework to support the expansion of these programmes across Scotland, with a robust evaluation process to determine their effectiveness in supporting patients at different stages of the CKD pathway and those engaging in research. It will also be crucial to understand how peer support groups can meet the needs of patients from different backgrounds, especially those from deprived areas and ethnic minority groups. Children and their carers or parents must also be supported to access support and guidance through these networks.

Renal social workers and young people workers can play an important role in signposting CKD patients and their families and carers to bespoke support, but not everyone who needs this has access to their services. This is also true of renal psychologists. People with CKD report a strong preference for kidney-specific psychological support at all stages of their journey, from professionals trained in both psychology and kidney disease.[35] Periods of significant change, such as when children transition to adult services or as a person's disease progresses, should be key focuses in enhancing cradle-to-grave support.

Action 12: Map out the availability of renal social workers, young people support workers and mental health and peer support services across Scotland to understand gaps with the aim of ensuring equitable access to these for people across boards who would benefit from their services.

Action 13: Ensure CKD is included in the long-term physical health conditions listed within the Mental Health and Wellbeing Strategy's ambition to ensure people with CKD have access to evidence-based mental health interventions.

Action 14: Peer support programmes led by trained volunteers are supported with funding to grow throughout Scotland, with modes of evaluation incorporated, to become a key part of the CKD pathway.

Action 15: Sustainably fund existing peer education projects involving Scotland's ethnic minority and deprived communities that seek to reduce health inequities, engage patients in research and address poorer outcomes.

Theme:

Informed decision-making

The previous chapters have laid out a vision for Scotland's health system to more effectively meet the health and care needs of patients with CKD. However, these ambitions depend on having in place the necessary foundation of data systems and intelligence to inform quality improvements and support services.

We welcome the close working of academics, industry and the NHS within CKD, embodied in 2024 launch of a 'triple helix partnership' between NHS Scotland, the universities of Dundee and Glasgow and AstraZeneca which will look to develop new medicines to slow progression of the disease, while building infrastructure and enhancing expertise in renal clinical trial delivery.

Given one in ten of Scotland's population is estimated to be living with CKD, commitments made in the Digital Delivery Plan for health and care will be crucial to our ambitions for kidney disease in Scotland.[36] These include:

- improved collection and quality of ethnicity data by April 2025
- the delivery of SNOMED CT coding for all digital systems by March 2026
- a national approach to information governance
- the delivery of a Primary Care Data and Intelligence Platform which makes available data from all GP IT systems daily for statistical analysis and reporting through the SEER platform, by March 2026.

Outcome 8: Scotland has accurate data on CKD derived from a funded national linked incidence and tracking dataset for CKD, using consistent coding across primary and secondary care.

There is an abundance of routinely collected data relevant to CKD in Scotland, however, it is not always recorded, coded or used consistently. Underreporting of the true burden of CKD has significantly limited the ability to identify unwarranted variation and support learning and has even contributed to the de-prioritisation of the condition among clinicians and policymakers.

Other downstream work and priorities can only be delivered once Scotland has an accurate picture of CKD prevalence. There is good data in Scotland for patients who are on dialysis or have received a transplant but, with no routine testing in primary care, Scotland has simply 'lost its handle' on the community incidence and prevalence of CKD and therefore cannot accurately plan for future demand for dialysis and transplantation.

The Scottish Atlas of Healthcare Variation is a key Public Health Scotland programme, recognised by the Value Based Health and Care Action Plan as contributing to eliminating unwarranted variation, harm and waste within the health service and realising Realistic Medicine. There are currently no measures of kidney function within this Atlas. Their inclusion would provide vital data to enable a greater understanding of inequity in CKD diagnosis and care and enable carbon footprinting approaches to tackle the high environmental costs of CKD progression.

> **Action 16:** Scottish Government to commission PHS to undertake a mapping exercise to understand what CKD data is available and linked in Scotland to allow for better utilisation and expansion.

> **Action 17:** Include CKD measures within the Atlas of Healthcare Deprivation.

Outcome 9: The Scottish Renal Registry is extended, supported by appropriate funding, to allow for data collection on CKD including proteinuria testing; the extent of prescribing of medicines known to reduce CKD progression including ACE inhibitors, angiotensin receptor blockers and SGLT2 inhibitors; and ethnicity of patients.

The Scottish Renal Registry is currently felt to be a poor relative to other Scottish audits, with relatively lower funding allowing only the employment of a part-time analyst. A full-time analyst and full-time clinical coordinator in post would allow the Renal Registry to realise its potential in the way similar registries have in informing national understanding of prevalence and outcomes – and informed best clinical management.

> **Action 18:** Increase core funding of the Scottish Renal Registry to a level to support the employment of a full-time analyst and full-time clinical coordinator.

Outcome 10: Scotland has an integrated real-time CKD dashboard, accessible to both primary and secondary care.

Case study: SCI-Diabetes

SCI-Diabetes is an example of a fully integrated shared electronic patient record, which provides functionality for both primary and secondary care clinicians. SCI-Diabetes has been successfully supporting the needs of the Scottish diabetes community in every health board in Scotland for a number of years, by providing clinical information, support for diabetic screening services and the provision of data for national and local audit programmes. The system used by SCI-Diabetes was designed to provide IT support for the management of long-term conditions. Lessons learned through the SCI-Diabetes experience can and should inform the use of such technology to manage care for other chronic conditions, including CKD.

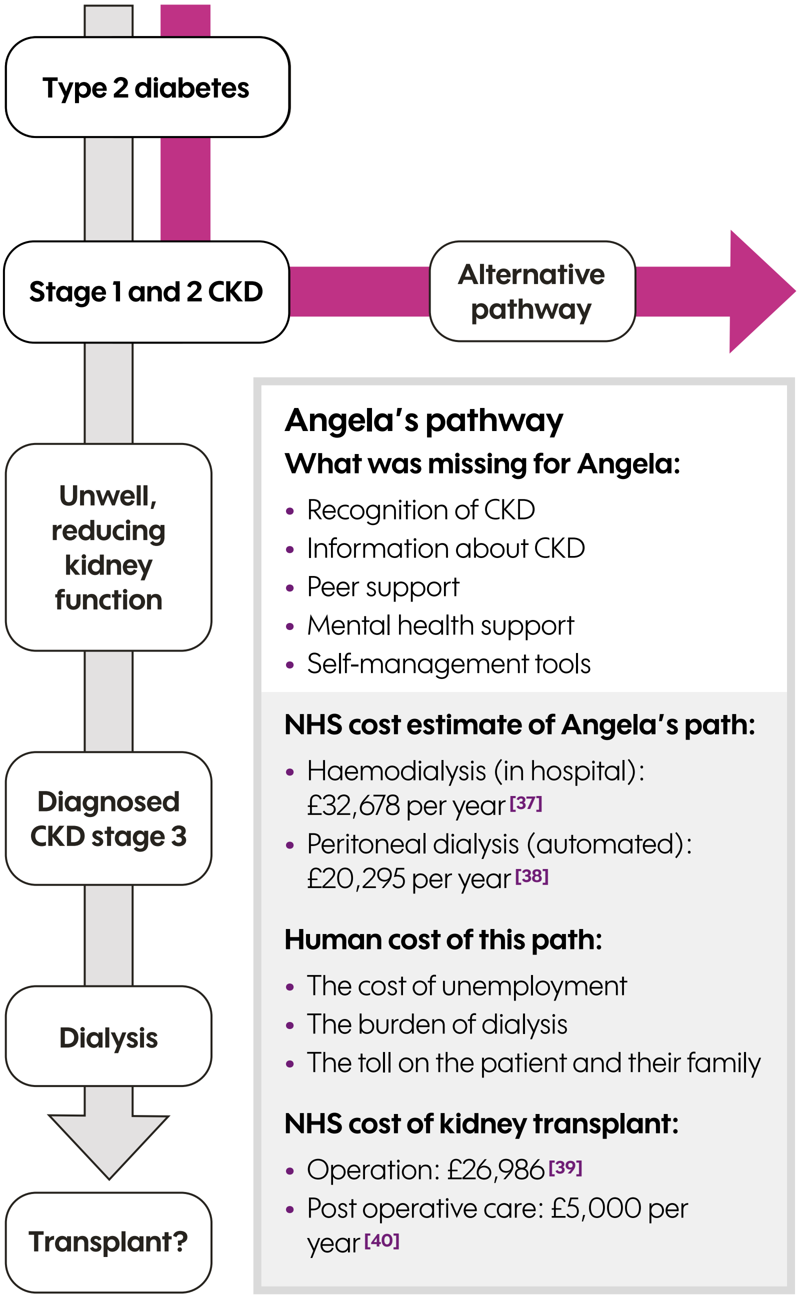
Broader efforts across Scotland to strengthen data-sharing and a move to cloud-hosted primary care systems also provide a timely opportunity to innovate in CKD.

> **Action 19:** Explore the addition of CKD to the SCI-Diabetes system to allow for the integration of key clinical information and data which could be fed into the Scottish Renal Registry.

Appendix A

Patient pathway: Angela's journey

Angela was diagnosed with CKD in 2020. She knew she was unwell but had little idea that her T2 diabetes might affect her kidney function, which was eventually tested after heart problems were ruled out. She says she was completely unprepared – or supported – for her diagnosis of CKD at stage 3, her kidney function having halved.



Angela's pathway

What was missing for Angela:

- Recognition of CKD
- Information about CKD
- Peer support
- Mental health support
- Self-management tools

NHS cost estimate of Angela's path:

- Haemodialysis (in hospital): £32,678 per year [37]
- Peritoneal dialysis (automated): £20,295 per year [38]

Human cost of this path:

- The cost of unemployment
- The burden of dialysis
- The toll on the patient and their family

NHS cost of kidney transplant:

- Operation: £26,986 [39]
- Post operative care: £5,000 per year [40]

Realistic Medicine and Value Based Health and Care

Scotland is committed to person-centred care that reduces environmental harm and waste. Haemodialysis has an environmental cost: 18,720 litres of water are required per patient annually for thrice weekly haemodialysis [44], while haemodialysis is estimated to result in 3.8 tCO$_2$-eq emissions per patient annually. [45]

Alternative pathway

If Scotland focuses on better early detection, diagnosis and prevention, we could take patients down a different primary care-led path.

Angela would:

- receive clear advice and information
- have her kidney function screened because of her T2 diabetes
- use a smartphone app to help her manage her own condition
- be prescribed the best medicine.

Angela's kidney function is maintained to prevent progression from early stages with the help of her local primary care team.

Annual NHS cost of this path:

- Four albumin and creatine tests: £36.40 [41]
- ACEi or ARB: £170.87 [42]
- One GP and six nurse consultations: £115.36 [43]
- Total £322.63 per year

Having cut short a career in social care, Angela now works to raise awareness of CKD, campaigning for change and volunteering as a community ambassador for Kidney Research UK. Read her full story at www.kidneyresearchuk.org/angela

Appendix B

Our recommendations

Immediate, begin in 2024

Theme	Outcome	Action	Lead	Helping to deliver	Resource implication
Prevention	There is clear, comprehensive, accurate and accessible information readily available online, and in printed form at all points of contact within the NHS and care providers, for people at risk of developing, or with a diagnosis of, CKD – co-produced by patients and clinicians.	**Action 2:** Work with the NHS 24 team to refresh and keep up to date the NHS Inform renal pages with the most recent developments in diagnostics, treatments and management, and signposting to relevant charities as appropriate.	Public Health Scotland (PHS); with patient advocacy organisations and the clinical kidney community	Promote the practice of Realistic Medicine Eliminate unwarranted variation Public engagement	Included in current work programme and funded from existing budgets
Timely and equitable access to diagnosis and treatment	Primary and community care is empowered to lead on CKD diagnosis, care and monitoring.	**Action 6:** Designate renal or CKD leads at board or health and social care partnership level, or renal/CKD clinical champions in primary care, to support local governance, upskilling and accountability for progress.	Scottish Government Chief Medical Officer (CMO)	Eliminate unwarranted variation Culture of stewardship	None
Timely and equitable access to diagnosis and treatment	Primary and community care is empowered to lead on CKD diagnosis, care and monitoring.	**Action 8:** Undertake a review of CKD management guidelines across Scotland, to support the establishment of 'Once for Scotland' CKD management guidelines as a baseline for all NHS boards, which can be easily accessed in primary care.	PHS; with patient advocacy organisations and the clinical kidney community	Promote the practice of Realistic Medicine Eliminate unwarranted variation	Included in current work programme and funded from existing budgets

Theme	Outcome	Action	Lead	Helping to deliver	Resource implication
Empowered patients throughout the kidney pathway	Everyone with kidney disease who needs it can access emotional, psychological and practical kidney-specific support.	**Action 12:** Map out the availability of renal social workers, young people support workers and mental health and peer support services across Scotland to understand gaps with the aim of ensuring equitable access to these for people across Scotland who would benefit from their services.	Care Inspectorate, Scottish Social Services Council and Healthcare Improvement Scotland; with patient advocacy organisations	Outcomes that matter Eliminate unwarranted variation Culture of stewardship Public engagement	Included in current work programme and funded from existing budgets
Informed decision-making	Scotland has accurate data on CKD derived from a funded national linked incidence and tracking dataset for CKD, using consistent coding across primary and secondary care.	**Action 16:** Scottish Government to commission PHS to undertake a mapping exercise to understand what CKD data is available and linked in Scotland to allow for better utilisation and expansion.	PHS	Eliminate unwarranted variation Culture of stewardship	Included in current work programme and funded from existing budgets

Short term by end of 2025

Theme	Outcome	Action	Lead	Helping to deliver	Resource implication
Prevention	The public understands the role of their kidneys and the actions they can take to reduce their risk of developing later-stage CKD.	**Action 1:** A community-based awareness and prevention programme for CKD is rolled out in Scotland, co-designed and person-centred, with a particular focus on underserved communities most at risk.	PHS; with patient advocacy organisations	Culture of stewardship Public engagement	Included in current work programme and funded from existing budgets
Prevention	Underlying conditions that can lead to CKD are properly managed.	**Action 3:** All clinical guidelines for the treatment of diabetes, cardiovascular disease and high blood pressure include a requirement for routine and regular kidney function testing.	Scottish Intercollegiate Guidelines Network (SIGN) or Healthcare Improvement Scotland with clinical leaders	Eliminate unwarranted variation	Add to SIGN work programme and funded from existing budgets
Timely and equitable access to diagnosis and treatment	Every person with CKD is diagnosed early in the development of their condition, reducing unwarranted variation.	**Action 4:** Introduce and evaluate implementation of a systematic screening programme, targeting those at highest risk, to identify those in need of treatment who have gone unidentified.	Scottish Government via Scottish Screening Committee / NHS Boards	Outcomes that matter Eliminate unwarranted variation	The effectiveness of this programme will depend on the level of investment
Timely and equitable access to diagnosis and treatment	Primary and community care is empowered to lead on CKD diagnosis, care and monitoring.	**Action 5:** Ensure relevant health and care professionals, especially those in primary care, are supported to access training and information as early as possible in their careers to equip them to know what to do in terms of referral, support and wellbeing, of someone in their care who has a diagnosis of CKD.	NHS National Education Scotland; with clinical leaders	Promote the practice of Realistic Medicine Culture of stewardship Sustainable care	Included in current work programme and funded from existing budgets

Theme	Outcome	Action	Lead	Helping to deliver	Resource implication
Timely and equitable access to diagnosis and treatment	Primary and community care is empowered to lead on CKD diagnosis, care and monitoring.	**Action 7:** Fully implement the Kidney Failure Risk Equation (KFRE) across all relevant systems with the resource to support its roll out.	Scottish Government CMO with clinical leaders	Promote the practice of Realistic Medicine Eliminate unwarranted variation Culture of stewardship Public engagement	None, if built into new National GP IT system offer
Empowered patients throughout the kidney pathway	Patients have access to digital tools to assess and track their own key metrics, such as their kidney function, in an easy-to-understand way that can be shared with their clinicians.	**Action 11:** Work with innovation partners to trial digital platforms in Scotland with the view to scaling this up nationally within the Connect Me service.	National or regional innovation partners initially, with patient advocacy organisations and clinical community	Promote the practice of Realistic Medicine Outcomes that matter Culture of stewardship Sustainable care Public engagement	Included in current work programme and funded from existing budgets (note this will generate cost savings)
Empowered patients throughout the kidney pathway	Everyone with kidney disease who needs it can access emotional, psychological and practical kidney-specific support.	**Action 13:** Ensure CKD is included in the long-term physical health conditions within the Mental Health and Wellbeing Strategy's ambition to ensure people with CKD have access to evidence-based mental health interventions.	Scottish Government	Promote the practice of Realistic Medicine Eliminate unwarranted variation	Added to work programme, and funded from existing budgets
Empowered patients throughout the kidney pathway	Everyone with kidney disease who needs it can access emotional, psychological and practical kidney-specific support.	**Action 15:** Sustainably fund existing peer education projects involving Scotland's ethnic minority and deprived communities that seek to reduce health inequities, engage patients with research and address poorer outcomes.	Patient advocacy organisations	Eliminate unwarranted variation Public engagement	Applications for funding made in the usual way

Theme	Outcome	Action	Lead	Helping to deliver	Resource implication
Informed decision-making	Scotland has accurate data on CKD derived from a funded national linked incidence and tracking dataset for CKD, using consistent coding across primary and secondary care.	**Action 17:** Include CKD measures within the Atlas of Healthcare Deprivation.	Public Health Scotland	Eliminate unwarranted variation Culture of stewardship Sustainable care	Included in current work programme and funded from existing budgets
Informed decision-making	The Scottish Renal Registry is extended, supported by appropriate funding, to allow for data collection on CKD including proteinuria testing; the extent of prescribing of medicines known to reduce CKD progression including ACE inhibitors, angiotensin receptor blockers and SGLT2 inhibitors; and ethnicity of patients.	**Action 18:** Increase core funding of the Scottish Renal Registry to a level to enable them to support the employment of a full-time analyst and full-time clinical coordinator.	Public Health Scotland (as successor body to ISD)	Promote the practice of Realistic Medicine Eliminate unwarranted variation Culture of stewardship	Additional funding will be required with a commitment to sustain this for at least five years

Longer term by end of 2026

Theme	Outcome	Action	Lead	Helping to deliver	Resource implication
Timely and equitable access to diagnosis and treatment	Primary and community care is empowered to lead on CKD diagnosis, care and monitoring.	**Action 9:** Fully fund the roll out of community-based chronic disease monitoring centres and ensure equitable focus on the needs of people living with CKD.	Scottish Government and PHS; with NHS Boards	Eliminate unwarranted variation Culture of stewardship Sustainable care Public engagement	Cost of implementing existing chronic disease commitments in primary care
Timely and equitable access to diagnosis and treatment	Primary and community care is empowered to lead on CKD diagnosis, care and monitoring.	**Action 10:** Mobilise other roles across primary care, such as nurses and pharmacists, to lead on CKD management and outreach.	NHS National Education for Scotland; with multidisciplinary clinical leaders	Eliminate unwarranted variation Culture of stewardship	Cost of implementing existing chronic disease commitments in primary care
Empowered patients throughout the kidney pathway	Everyone with kidney disease who needs it can access emotional, psychological and practical kidney-specific support.	**Action 14:** Peer support programmes led by trained volunteers are supported with funding to grow throughout Scotland, with modes of evaluation baked in, to become a key part of the CKD pathway.	Patient advocacy organisations	Eliminate unwarranted variation Public engagement	Applications for funding made in the usual way
Informed decision-making	Scotland has an integrated real-time CKD dashboard, accessible to both primary and secondary care.	**Action 19:** Explore the use of the SCI-DC system for CKD, to allow for the integration of key clinical information and data which could be fed into the Scottish Renal Registry.	Public Health Scotland (as successor body to ISD)	Promote the practice of Realistic Medicine Culture of stewardship	Additional funding may be required over at least five years

Thank you to the Scottish government's Realistic Medicine Team for allowing use of these icons from the Value Based Health and Care Action Plan.

Appendix C

Stakeholder engagement

A late draft of 'Chronic Kidney Disease: An Action Plan for Scotland' was sent to a wide range of key stakeholders and delivery partners to seek feedback and support.

We received responses from:

- Burden of Disease Team, Public Health Scotland
- Fresenius Medical Care
- GPs, Lothian
- Obesity Action Scotland
- Public Health Scotland
- Renal dietician lead, Royal Infirmary of Edinburgh
- Renal pharmacists, NHS Greater Glasgow and Clyde
- Renal psychologists, NHS Greater Glasgow and Clyde
- Royal College of Nursing
- Royal College of Physicians of Edinburgh
- Royal Pharmaceutical Society
- Voluntary Health Scotland
- A number of renal clinicians and researchers not involved in the working group

Summary of feedback

There was strong support for the key themes, aims and actions of the Action Plan from all the stakeholders and delivery partners. All respondents recognised that the professional group they represent has an important role in achieving positive change for CKD patients in Scotland and most expressed directly a willingness to collaborate and be involved in taking the Action Plan forward.

The importance of achieving support from Scottish Government was highlighted by a number of respondents. We were told that central, national support, matched by funding, will be critical in order to make positive progress in achieving the momentum needed for the plan to succeed. Respondents said this will be particularly important in strengthening the role of GPs and members of the multidisciplinary team in CKD care, and to mitigate workforce pressures – including addressing nursing vacancies – which was felt to be a key barrier to future implementation of the actions in the plan.

The role of pharmacists, nurses and other members of the multidisciplinary team in managing CKD was highlighted. A lack of renal expertise among primary care pharmacists was raised, with scope to improve this by supporting colleagues already working in clinics for related conditions, like cardiac and diabetes. We were told that community pharmacists' contribution to the actions in the plan would be strengthened through them having full access to patient records. It was also noted that CKD specialist nurses could act as an important interface between primary and secondary care as these are brought closer together.

Respondents spoke about positive work going on around CKD awareness in other parts of the UK – such as the 'Think Kidneys' campaign for AKI in England – and the need to build upon similar, often more localised, work being done in Scotland. We were told that CKD awareness could be a topic for future public health messaging in community pharmacies through Public Health Scotland.

Respondents agreed with the focus of the Scotland CKD Action Plan on workforce pressures, funding, and early detection and prevention of CKD, with the latter being considered key to minimising avoidable CKD. There was an agreement that this can be driven through greater awareness and education.

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This project has been co-funded by Kidney Research UK and the following industry supporters:
AstraZeneca, Bayer, Boehringer Ingelheim, CSL Vifor and Novartis.

These companies had no control over the contents of this plan.

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November 2024

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