Chronic Kidney Disease Action Plan

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 in the next 10 years as many as 10,000 people in Scotland could see their illness progress to the point of needing dialysis, while the number of kidney transplants needed may increase more than four-fold to over 860. The total cost to the Scottish economy is rising as a result, and is likely to reach more than £1bn by 2033 (Kidney Research UK, 2023). Treatment of the condition, especially in the later stages of the disease, are also associated with substantial greenhouse emissions, natural resources depletion and waste generation.

A Scottish Working Group, convened by Kidney Research UK and made up of patients, clinicians, GPs, and industry representatives, has concluded that there are 19 actions the Scottish Government, NHS Scotland and partners must now take forward and action 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 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.
* **Empowered patients throughout the kidney pathway**: The roll-out of digital tools and a robust system of psychosocial support for patients when they need it most 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.

## **Our recommendations**

Culture of stewardship.

Sustainable care.

Public engagement.

****Theme: Prevention

Promote the practice of Realistic Medicine.

Outcomes that matter.

Eliminate unwarranted variation.

Theme: Timely and equitable access to diagnosis

and treatment

Theme: Empowered patients throughout

the kidney pathway

Theme: Informed decision-making

**Immediate in 2024**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Outcome | Action | Lead | Helping to deliver… | Resource Implication |
| 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 – coproduced 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 treatments, diagnostics and management. | Public Health Scotland; with patient advocacy organisations and the clinical kidney community | A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets |
| 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, progress and accountability. | Scottish Government CMO | **A logo of people connected to each other  Description automatically generated**A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | None |
| **Action 8**: Commission a strategic review of current CKD management to establish a baseline for all NHS boards on access to guidelines in primary care. | Public Health Scotland; with patient advocacy organisations and the clinical kidney community | A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets |
| Everyone with kidney disease can access assessments and support for their psychosocial health.  | **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. | Public Health Scotland; with patient advocacy organisations | A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidence**A logo of people connected to each other  Description automatically generated**A blue circle with a hand holding a clipboard and a gear  Description automatically generated | Added to work programme, from existing revenue budgets |
| 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**: 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.  | Public Health Scotland; with patient advocacy organisations | **A logo of people connected to each other  Description automatically generated**A blue and white logo  Description automatically generated with medium confidence | Added to work programme, from existing revenue budgets |

**Short Term by end of 2025**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Outcome | Action | Lead | Helping to deliver… | Resource Implication |
| 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. | Public Health Scotland; with patient advocacy organisations | **A logo of people connected to each other  Description automatically generated**A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidence | Added to work programme, from existing revenue budgets |
| 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. | SIGN or HIS with clinical leaders | A blue and white logo  Description automatically generated with medium confidence | Add to SIGN work programme, from existing revenue budgets |
| 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 | A blue and white logo  Description automatically generated with medium confidenceA blue circle with a hand holding a clipboard and a gear  Description automatically generated | The effectiveness of this programme will depend on the level of investment |
| Primary and community care is empowered to lead on CKD diagnosis, care and monitoring.  | **Action 5:** Ensure relevant health and care professionals have access to training and information 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 NES with clinical leaders | A green circle with a leaf and a globe  Description automatically generated**A logo of people connected to each other  Description automatically generated**A blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets |
| **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 | **A logo of people connected to each other  Description automatically generated**A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | None, if built into new National GP IT system offer |
| 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 the MyRenalCare app 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 | **A logo of people connected to each other  Description automatically generated**A green circle with a leaf and a globe  Description automatically generatedA blue circle with a hand holding a clipboard and a gear  Description automatically generatedA group of people in a circle  Description automatically generatedA blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets (Note this will generate cost savings) |
| Everyone with kidney disease can access assessments and support for their psychosocial health.  | **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 | A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets |
| **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 | A blue and white logo  Description automatically generated with medium confidenceA group of people in a circle  Description automatically generated | Applications for funding made in the usual way |
| 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 | A green circle with a leaf and a globe  Description automatically generated**A logo of people connected to each other  Description automatically generated**A blue and white logo  Description automatically generated with medium confidence | Added to work programme, from existing revenue budgets |
| The Scottish Renal Registry is extended, supported by appropriate funding, to allow for data collection on CKD including prescribing of SGLT2 inhibitors and proteinuria testing. | **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)  | A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated**A logo of people connected to each other  Description automatically generated** | Additional funding will be required with a commitment to sustain this for at least five years  |

**Longer Term by end of 2026**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Outcome | Action | Lead | Helping to deliver… | Resource Implication |
| Primary and community care is empowered to lead on CKD diagnosis, care and monitoring. | **Action 9:** Establish accessible community-based chronic disease monitoring centres for people living with CKD with consistent access to relevant support and education across Scotland.  | PHS or NHS Boards | A group of people in a circle  Description automatically generatedA green circle with a leaf and a globe  Description automatically generated**A logo of people connected to each other  Description automatically generated**A blue and white logo  Description automatically generated with medium confidence | Cost of implementing existing chronic disease commitments in primary care |
| **Action 10:** Mobilise other roles across primary care to lead on CKD management and outreach.  | NHS NES with multidisciplinary clinical leaders  | A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated**A logo of people connected to each other  Description automatically generated** |
| Everyone with kidney disease can access assessments and support for their psychosocial health. | **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 | A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidence | Applications for funding made in the usual way |
| 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)  | **A logo of people connected to each other  Description automatically generated**A blue and white light bulb with a cross in a circle  Description automatically generated | Additional funding may be required over at least five years  |

**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

Our kidneys are made up of millions of filters that sieve the blood to remove waste products while returning clean blood to the body. The kidneys also play an important role in bone health and in the production of red blood cells. Chronic kidney disease (CKD) is a serious long-term condition where the kidneys do not work effectively due to reduced filtering capacity as a result of kidney damage. A blood test will show low eGFR levels or high levels of creatinine; or a urine test will show the presence of a protein called albumin.

Known as a ‘silent killer’, for many people kidney disease worsens progressively over time before the effects become evident. CKD is usually detected through a blood or urine test, but for many people it is detected too late to reverse its effects. Left untreated, CKD can progress from Stage 1 through to Stage 5, with those in the most advanced stages of kidney failure requiring kidney replacement therapy (dialysis or transplantation) to survive. Kidney diseases are now recognised as among the fastest rising causes of death in the world (WHO Global Health Estimates, 2019) and people with kidney disease are five to ten times more likely to die prematurely (Webster AC, 2017).

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. A 21 year old on dialysis has the same risk of dying from a heart attack as an otherwise healthy 80 year old (Foley RN, 1998).

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 picked up incidentally as they are tested for other conditions.

In 2022, 5,601 people in Scotland were living with kidney failure, requiring kidney replacement therapy – 60.5% of whom had a functioning kidney transplant, with the rest being treated with either haemodialysis or peritoneal dialysis. 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 we don’t do more now to prevent CKD arising (Kidney Research UK, 2023).

In 2022, 247 adults and children received a kidney transplant (Public Health Scotland, 2023). For context, 422 adults were on the transplant waiting list as of March 2023.

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 (Kidney Research UK, 2023).

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 centers), natural resources depletion, and waste generation.

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 (Vanholder, et al., 2021).

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 (Kidney Research UK, 2022).

CKD often co-exists with other conditions such as heart disease, diabetes and high blood pressure and their presence together 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](https://www.gov.scot/publications/diabetes-improvement-plan-diabetes-care-scotland-commitments-2021-2026/) 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. Despite being so closely related to heart disease, both as a cause and consequence, CKD is not mentioned within [The Heart Disease Action Plan](https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2021/03/heart-disease-action-plan/documents/heart-disease-action-plan-2021/heart-disease-action-plan-2021/govscot%3Adocument/heart-disease-action-plan-2021.pdf).

The decision of the Scottish Government to take forward actions within chronic conditions aligned to 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 mortality by 2040, It is time to end the ‘poor relation’ status of CKD and complete the puzzle to allow Scotland to achieve its ambitions to improve the care for the hundreds of thousands of people living with chronic conditions.

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 representatives 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 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.

**Data** is at the core of achieving significant change. Though Scotland already has a 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, *Professor of Experimental Nephrology, University of Edinburgh; Chair of Trustees, Kidney Research UK (Chair)*

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

Dr Samira Bell, nephrologist, NHS Tayside; Chair of the Scottish Renal Registry

Jelina Berlow-Rahman, *patient advocate*

Dr Colin Geddes, *nephrologist, NHS Greater Glasgow & Clyde*

Dr Wendy Metcalfe, *nephrologist, NHS Lothian*

Dr Eleanor Murray, *renal consultant, NHS Greater Glasgow & Clyde*

Dr Ben Reynolds, *paediatric nephrologist, NHS Greater Glasgow & 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 & Clyde*

Organisation representation:

AstraZeneca

Bayer

CSL Vifor

Ettrickburn Limited (secretariat)

Kidney Research UK

Novartis

Theme: Prevention

For many people, the worst impacts of CKD, like cardiovascular complications and renal replacement therapy, 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 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 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 where 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 we seek: The public understands 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 are not well versed in the vital role they play. Those at highest risk of developing CKD – including people living with high blood pressure, diabetes, obesity or a severe or frequent previous kidney infection – often are unaware of their risk of developing the disease or what this could entail until it is too late.

CKD is a condition that disproportionately affects people from minority ethnic and lower social economic 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. While CVD and type 2 diabetes prevention and detection are highlighted, CKD must too form part of this focus.

Lifestyle changes are also important to CKD management and prevention. Dietary recommendations in particular 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:

* [Raising Scotland's Tobacco-Free Generation: Tobacco Control Action Plan 2018](https://www.gov.scot/publications/raising-scotlands-tobacco-free-generation-tobacco-control-action-plan-2018/);
* [A Healthier Future: Scotland’s Diet & Healthy Weight Delivery Plan 2018](https://www.gov.scot/publications/healthier-future-scotlands-diet-healthy-weight-delivery-plan/);
* [A More Active Scotland: Scotland’s Physical Activity Delivery Plan 2018](https://www.gov.scot/publications/active-scotland-delivery-plan/);
* [Alcohol Framework 2018: Preventing Harm](https://www.gov.scot/publications/alcohol-framework-2018-preventing-harm-next-steps-changing-relationship-alcohol/);
* [Cleaner Air for Scotland: The Road to a Healthier Future](https://www.gov.scot/publications/cleaner-air-scotland-road-healthier-future/).

**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.**

**Outcome: 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 – coproduced 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 of the way through to individuals receiving kidney replacement therapy, including transplant. The best way to achieve this is by working with patients and clinicians to coproduce 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: 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.**

**Outcome: 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 SIGN recommended threshold of 140/90mmHg (Scottish Government, 2019). 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 (Scottish Diabetes Group, 2022).

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: 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 in order to slow progression of the disease and enable people to manage their condition in the community (Kidney Research UK, 2022). Currently, those least likely to engage with health services and those from more deprived communities are the people least likely to be identified as having CKD 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 how care occurs. 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. Evidence supports a systematic approach to screen for, risk stratify and treat people with CKD, though implementation should be accompanied by an evaluation of its effects. (Shlipak MG & Participants., 2021)

**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.**

**Outcome: 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 (Kidney Research UK, 2022).

Dedicated CKD training of healthcare professionals working in the community, structured and streamlined CKD pathways, 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 enablers to effective CKD management in primary care.

Guidelines & 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 north of the border. The 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 prescribing decisions. There is a need to identify consistently which patients require input, escalation or ongoing monitoring in the community.

Management guidelines for CKD in primary care must be streamlined and access to guidelines 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 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](https://www.gov.scot/publications/gms-contract-scotland/). This was reinforced in [a second Memorandum of Understanding](https://www.sehd.scot.nhs.uk/publications/Memorandum_of_Understanding%202-GMS_Contract_Implementation_for_PC_Improvement%2030_July_2021.pdf) 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.

However, as of March 2023, while 87% of GP practices in Scotland reported having access to board-provided phlebotomy services, 56% said they had access to chronic disease monitoring within CTAC services (Scottish Government, 2023). CKD is not a priority, even within chronic disease monitoring, so these locally designed services must take into account local population health needs and provide care and monitoring that takes into account patients’ increasingly complex comorbidities. Chronic disease clinics can be led by trained nurses, and these posts must be funded and supported with protected learning and development time. There is also an important role for pharmacists within community care and support.

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.

Managed Clinical Networks and GP clusters

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 care in primary care, but implementation has not been fully supported or prioritised. Variation exists depending on individual GPs’ enthusiasm and experience (Healthcare Improvement Scotland, 2022). 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 CKD diagnosis, assessment and management via Quality Improvement activities could also be beneficial.

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 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.

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 make a step difference to the way patients and their clinical team are able to manage CKD. KFRE is already integrated into Serva software in secondary care, 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 have access to training and information 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.**

**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, progress and accountability.**

**Action 7: Assess and fully implement the Kidney Failure Risk Equation (KFRE) across relevant systems with the resource to support its roll out.**

**Action 8: Commission an optimal CKD Once for Scotland pathway and strategic review of current CKD management to establish a baseline for all NHS boards on access to guidelines in primary care.**

**Action 9: Establish accessible community-based chronic disease monitoring centres for people living with CKD with consistent access to relevant support and education across Scotland.**

**Action 10: Mobilise other roles across primary care 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.

**Outcome: 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.**

Appropriate use of digital tools can delay and even reduce demand, by slowing the progress of disease in people already affected by CKD and to release 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. 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.

**Case study:** *My Renal Care is a digital healthcare solution that uniquely revolutionises all aspects of CKD management with its focus on education, engagement and empowerment for people at all stages of kidney disease including early stage, kidney replacement therapy and transplant.*

*My Renal Care:*

* *engages patients to self-monitor including blood pressure and kidney function measured locally;*
* *educates patients about how they can achieve their best possible health outcome in easy-to-digest videos;*
* *empowers patients to determine when they need help and gives them direct access to their clinical team as part of patient-initiated follow up;*
* *enables clinical teams to remotely make informed decisions using patients’ continuous data, rather than infrequent data points at clinic visits;*
* *reduces face-to-face outpatient appointments and improves system efficiency, reducing emissions from travelling and increasing patient autonomy;*
* *increases clinic capacity by 30% so people who need or want face-to-face appointments can be seen promptly.*

*A recent review of more than 1,200 patients with CKD using My Renal Care, under the Wessex Kidney Centre at Portsmouth Hospitals University NHS Trust, saw miles travelling to appointments cut by 5,500 and referrals for new patients being cut from three months to just three weeks. Importantly, 93% of patients recommended use of My Renal Care and the cost of outpatient renal care was reduced by 25%.*

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](https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2023/08/care-digital-age-delivery-plan-2023-24/documents/care-digital-age-delivery-plan-2023-24/care-digital-age-delivery-plan-2023-24/govscot%3Adocument/care-di).

**Action 11: Work with innovation partners to trial the MyRenalCare app in Scotland with the view of scaling this up nationally within the Connect Me service.**

**Outcome: Everyone with kidney disease can access assessments and support for their psychosocial health.**

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 (Centre for Mental Health, 2023). Scotland’s [Mental Health and Wellbeing Strategy](https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2023/06/mental-health-wellbeing-strategy/documents/mental-health-wellbeing-strategy/mental-health-wellbeing-strategy/govscot%3Adocument/mental-health-wellbeing-s) recognises the need for people living with long-term physical health conditions to be able to access evidence-based approaches to support, and the need to work more closely with the third sector to support communities most in need.

Third sector organisations in Scotland, backed by a small army of enthusiastic volunteers with lived experience, are ready and willing to fill these gaps in community outreach and peer support for people living with CKD. Patient networks provide a hugely beneficial source of education, reassurance and guidance, especially to those at earlier stages of the journey.

There must be a ‘Once for Scotland’ framework to support these programmes to expand across Scotland, with a robust evaluation process to understand 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, who are especially beneficial to patients at a later stage of CKD.

**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 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 baked in, 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.

Given the high proportion of Scotland’s population affected by CKD, commitments made in the Digital Delivery Plan for health and care will be crucial to our ambitions for kidney disease in Scotland. These include:

* Improved collection and quality of ethnicity data by April 2024;
* The delivery of SNOMED CT coding for all digital systems by March 2026;
* A national approach to information governance by April 2024;
* 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: 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.

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 important and vital data to enable a greater understanding of inequity in CKD diagnosis and care, and enable carbon foot printing approaches to tackle the high environmental costs of CKD progression.

**Action 16: 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: 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: 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 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.**

Collected recommendations

Theme: Prevention

**Outcome that we seek: 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-centered, with a particular focus on underserved communities most at risk.

**Outcome: 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 – coproduced 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 treatments, diagnostics and management.

**Outcome: 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.

Theme: Timely and equitable access to diagnosis and treatment

**Outcome: People with CKD are diagnosed as early in the development of their condition as possible, reducing unwarranted variation.**

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

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

Action 5: Ensure relevant health and care professionals have access to training and information 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.

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, progress and accountability.

Action 7: Fully implement the Kidney Failure Risk Equation (KFRE) across relevant systems with the resource to support its roll out.

Action 8: Commission a strategic review of current CKD management to establish a baseline for all NHS boards on access to guidelines in primary care.

Action 9: Establish accessible community-based chronic disease monitoring centres for adults living with CKD with consistent access to relevant support and education across Scotland.

Action 10: Mobilise other roles across primary care to lead on CKD management and outreach.

Theme: Empowered patients throughout the kidney pathway

**Outcome: 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 the MyRenalCare app in Scotland with the view to scaling this up nationally within the Connect Me service.

**Outcome: Everyone with kidney disease can access assessments and support for their psychosocial health.**

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 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 baked in, 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

**Outcome: 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: 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: 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.

**Outcome: 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 pulling together of key clinical information and data which could be fed into the Scottish Renal Registry.

# References

Centre for Mental Health. (2023). *Addressing the mental health challenges of life with kidney disaease: The case for change.* Kidney Research UK.

Foley RN, P. P. (1998). Clinical Epidemiology of cardiovascular disease in chronic renal failure. *American Journal of Kidney Diseases*, 112-9.

Healthcare Improvement Scotland. (2022). *GP Cluster Working Learning Cycle.*

 Retrieved from <https://ihub.scot/media/9095/20220330-gp-cluster-report-v10.pdf>

Kidney Research UK. (2022). *Changing the future for chronic kidney disease in Scotland.* Edinburgh: Kidney Research UK. Retrieved from https://www.kidneyresearchuk.org/wp-content/uploads/2022/12/Scotland-CKD-report-final.pdf?\_gl=1\*9rlspd\*\_up\*MQ..\*\_ga\*MTEwMzY3NDkzNC4xNzExMDMwMDQ2\*\_ga\_737HY1XF35\*MTcxMTAzMDA0NC4xLjAuMTcxMTAzMDA0NC4wLjAuMA..

Kidney Research UK. (2023). *Kidney disease: A UK public health emergency.*

Retrieved from<https://www.kidneyresearchuk.org/wp-content/uploads/2023/06/Economics-of-Kidney-Disease-full-report_accessible.pdf>

Public Health Scotland. (2023). *Scottish Renal Registry Annual Report.*

Retrieved from <https://publichealthscotland.scot/media/22521/scottish-renal-registry-report-english-september2023.pdf>

Scottish Diabetes Group. (2022). *Scottish Diabetes Survey 2022.*

Retrieved from <https://www.diabetesinscotland.org.uk/wp-content/uploads/2023/10/Scottish-Diabetes-Survey-2022.pdf>

Scottish Government. (2019). *The Scottish Health Survey: Volume 1.*

Retrieved from <https://www.gov.scot/binaries/content/documents/govscot/publications/statistics/2020/09/scottish-health-survey-2019-volume-1-main-report/documents/scottish-health-survey-2019-edition-volume-1-main-report/scottish-health-survey-2019-edition-volume-1-main-report/govscot%3Adocument/scottish-health-survey-2019-edition-volume-1-main-report.pdf>

Scottish Government. (2023). *Primary Care Improvement Plans: Summary of Implementation Progress at March 2023.*

Retrieved from <https://www.gov.scot/binaries/content/documents/govscot/publications/statistics/2023/06/primary-care-improvement-plans-summary-implementation-progress-march-2023/documents/primary-care-improvement-plans-summary-implementation-progress-march-2023/primary-care-improvement-plans-summary-implementation-progress-march-2023/govscot%3Adocument/primary-care-improvement-plans-summary-implementation-progress-march-2023.pdf>

Shlipak MG, T. S., & Participants., C. (2021). The case for early identification and intervention of chronic kidney disease: conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. *Kidney International, 99*(1), 34-47. Retrieved from https://www.kidney-international.org/article/S0085-2538(20)31210-2/fulltext

Vanholder, R., Annemans, L., Bello, A. K., Bikbov, B., Gallego, D., Gansevoort, R. T., Wieringa, F. (2021, July). Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney. *Clinical Kidney Journal, 14*(7), 1719-1730.

Webster AC, N. E. (2017). Chronic Kidney Disease. *Lancet*, 1238-1252.

Retrieved from <https://www.kidneyresearchuk.org/wp-content/uploads/2023/05/CentreforMHKRUK_TheCaseForChange.pdf>

WHO Global Health Estimates. (2019). *Leading causes of death globally.*

Retrieved from <https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death>

# A diagram of a medical procedure  Description automatically generatedAppendix A – Patient Pathway

**Angela’s Story**

Angela Riley shared her story with Kidney Research UK in January. Having cut short a career in social care, she now works to raise awareness of CKD, campaigning for change and volunteering as a community ambassador for the charity. Read her full story at <https://www.kidneyresearchuk.org/2023/01/24/supporting-the-kidney-community-to-campaign-for-change-in-scotland/>

**References**

1 National Institute for Health and Care Excellence (NICE). Economic considerations for Delphi, in Preoperative Tests (Update): Routine Preoperative Tests for Elective Surgery. 2016

2 Kerr, M., et al., Estimating the financial cost of chronic kidney disease to the NHS in England. Nephrology Dialysis Transplantation. 2012. 27 (Suppl 3): p. 73-80

3 Kerr, M., et al., Estimating the financial cost of chronic kidney disease to the NHS in England. Nephrology Dialysis Transplantation. 2012.

4 Roberts G, Holmes J, Williams G, Chess G, Hartfiel N, Charles JM, McLauglin L, Noyes J, Tudor Edwards R. Current costs of dialysis modalities: A comprehensive analysis within the UK*.* *Peritoneal Dialysis International*. 2022; 42(6):578-584

5 Roberts G, et al. Current costs of dialysis modalities: A comprehensive analysis within the UK*.* *Peritoneal Dialysis International*. 2022.

6 NHS Improvement. National Schedule of NHS Costs 2018/19. 2021. Available from: <https://www.england.nhs.uk/publication/2018-19-national-cost-collection-data-publication>[/](https://www.england.nhs.uk/publication/2018-19-national-cost-collection-data-publication/)

7 NHS England. Service specifications: National/local context. 2017

8 Yeo SC, Ooi XY, Tan TSM. Sustainable kidney care delivery and climate change - a call to action. *Global Health*. 2022 Aug 3;18(1):75.

9 Connor A, Lilywhite R, Cooke MW. The carbon footprints of home and in-center maintenance hemodialysis in the United Kingdom. *Hemodial Int.*2011;15(1):39–51

# **Appendix B – Recommendations in a Grid**

**Value Based Health and Care commitments:**

****Theme: Prevention

Culture of stewardship.

Sustainable care.

Public engagement.

Promote the practice of Realistic Medicine.

Outcomes that matter.

Eliminate unwarranted variation.

Theme: Timely and equitable access to diagnosis

and treatment

Theme: Empowered patients throughout

the kidney pathway

Theme: Informed decision-making

**Immediate in 2024**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Outcome | Action | Lead | Helping to deliver… | Resource Implication |
| 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 – coproduced 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 treatments, diagnostics and management. | Public Health Scotland; with patient advocacy organisations and the clinical kidney community | A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets |
| 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, progress and accountability. | Scottish Government CMO | **A logo of people connected to each other  Description automatically generated**A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | None |
| **Action 8**: Commission a strategic review of current CKD management to establish a baseline for all NHS boards on access to guidelines in primary care. | Public Health Scotland; with patient advocacy organisations and the clinical kidney community | A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets |
| Everyone with kidney disease can access assessments and support for their psychosocial health.  | **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. | Public Health Scotland; with patient advocacy organisations | A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidence**A logo of people connected to each other  Description automatically generated**A blue circle with a hand holding a clipboard and a gear  Description automatically generated | Added to work programme, from existing revenue budgets |
| 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**: 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.  | Public Health Scotland; with patient advocacy organisations | **A logo of people connected to each other  Description automatically generated**A blue and white logo  Description automatically generated with medium confidence | Added to work programme, from existing revenue budgets |

**Short Term by end of 2025**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Outcome | Action | Lead | Helping to deliver… | Resource Implication |
| 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. | Public Health Scotland; with patient advocacy organisations | **A logo of people connected to each other  Description automatically generated**A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidence | Added to work programme, from existing revenue budgets |
| 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. | SIGN or HIS with clinical leaders | A blue and white logo  Description automatically generated with medium confidence | Add to SIGN work programme, from existing revenue budgets |
| 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 | A blue and white logo  Description automatically generated with medium confidenceA blue circle with a hand holding a clipboard and a gear  Description automatically generated | The effectiveness of this programme will depend on the level of investment |
| Primary and community care is empowered to lead on CKD diagnosis, care and monitoring.  | **Action 5:** Ensure relevant health and care professionals have access to training and information 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 NES with clinical leaders | A green circle with a leaf and a globe  Description automatically generated**A logo of people connected to each other  Description automatically generated**A blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets |
| **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 | **A logo of people connected to each other  Description automatically generated**A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | None, if built into new National GP IT system offer |
| 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 the MyRenalCare app 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 | **A logo of people connected to each other  Description automatically generated**A green circle with a leaf and a globe  Description automatically generatedA blue circle with a hand holding a clipboard and a gear  Description automatically generatedA group of people in a circle  Description automatically generatedA blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets (Note this will generate cost savings) |
| Everyone with kidney disease can access assessments and support for their psychosocial health.  | **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 | A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated | Added to work programme, from existing revenue budgets |
| **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 | A blue and white logo  Description automatically generated with medium confidenceA group of people in a circle  Description automatically generated | Applications for funding made in the usual way |
| 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 | A green circle with a leaf and a globe  Description automatically generated**A logo of people connected to each other  Description automatically generated**A blue and white logo  Description automatically generated with medium confidence | Added to work programme, from existing revenue budgets |
| 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)  | A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated**A logo of people connected to each other  Description automatically generated** | Additional funding will be required with a commitment to sustain this for at least five years  |

**Longer Term by end of 2026**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Outcome | Action | Lead | Helping to deliver… | Resource Implication |
| Primary and community care is empowered to lead on CKD diagnosis, care and monitoring. | **Action 9:** Establish accessible community-based chronic disease monitoring centres for people living with CKD with consistent access to relevant support and education across Scotland.  | PHS or NHS Boards | A group of people in a circle  Description automatically generatedA green circle with a leaf and a globe  Description automatically generated**A logo of people connected to each other  Description automatically generated**A blue and white logo  Description automatically generated with medium confidence | Cost of implementing existing chronic disease commitments in primary care |
| **Action 10:** Mobilise other roles across primary care to lead on CKD management and outreach.  | NHS NES with multidisciplinary clinical leaders  | A blue and white logo  Description automatically generated with medium confidenceA blue and white light bulb with a cross in a circle  Description automatically generated**A logo of people connected to each other  Description automatically generated** |
| Everyone with kidney disease can access assessments and support for their psychosocial health. | **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 | A group of people in a circle  Description automatically generatedA blue and white logo  Description automatically generated with medium confidence | Applications for funding made in the usual way |
| 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)  | **A logo of people connected to each other  Description automatically generated**A blue and white light bulb with a cross in a circle  Description automatically generated | Additional funding may be required over at least five years  |