# Let's talk kidneys

## Opportunities for early intervention in chronic kidney disease

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Kidney Care UK

# Contents

# Executive Summary

Around 1 in 10 of the global population have chronic kidney disease (CKD)[1] and an estimated half of those people are undiagnosed.[2,3] All CKD stages are associated with increased risk of mortality, cardiovascular disease (CVD) and the need for kidney replacement therapy – dialysis or kidney transplantation.[1] Yet CKD's lack of prominence in health policy is costing lives and risks putting unsustainable pressure on the NHS. People affected by CKD have clearly articulated their desire to take control of their kidney health. It is time to change the dynamic on kidney health and take simple steps to save lives.

Our research and national data identify opportunities for change in early CKD care. Quotes from our patient survey, included throughout the report, illustrate challenges but also the excellent care from which everyone with CKD should benefit.

> Having stage 3a [of CKD] trivialised by saying 'We don't worry until you need dialysis' was really distressing."

> My GP gave me superb care and advice and my condition was well monitored."

## Challenge 1 – Raising patient awareness and understanding of kidney risk.

- Helping people understand their CKD risk encourages engagement with monitoring and care, yet in our survey over 6 in 10 people with diabetes or high blood pressure (and therefore at increased risk of developing CKD) said they were not told of their increased risk prior to CKD diagnosis.
- Many of our survey respondents wished they had known earlier about kidney problems and how their condition was likely to progress.
- Our GP survey found over 4 in 10 GPs would not routinely share CKD risk with highest-risk patients as well as varying levels of confidence in discussing likely progression of CKD with diagnosed patients.

## Recommendations for action:

**The devolved NHS leadership teams across the UK should enhance local primary care management of CKD and ensure healthcare professionals are supported to communicate the risks of CKD progression.** This means:

- People in the highest risk groups should be informed of their CKD risk, how to reduce it and be supported to access appropriate monitoring.
- Everyone with a diagnosis of CKD must have the opportunity to discuss with their doctor their CKD diagnosis, risk of progression and potential complications.
- The Kidney Failure Risk Equation (KFRE) should be embedded in primary care electronic patient record systems and patients informed of their five-year KFRE risk alongside the current CKD 1-5 staging system.
- Integrated Care Systems (ICSs) and health boards should support programmes of shared CKD care across primary and secondary care, learning from existing schemes.

## Challenge 2 – Underdiagnosis and late presentation indicate missed opportunities

- Nearly 4 in 10 people with diabetes do not have the National Institute for Health and Care Excellence (NICE) recommended annual urine test to detect early CKD. [4]
- Nearly 2 in 10 people starting kidney replacement therapy in 2021 had only been seen by a kidney specialist for the first time within the previous 90 days.[5] This suggests opportunities to intervene early may have been missed.

## Recommendations for action:

**Every Integrated Care System (ICS) and Health Board should have a CKD prevention and management strategy** developed in collaboration with people affected by CKD and the broad range of partners with a role to play in CKD and associated conditions.

**ICSs and health boards should use audit data (CVDPrevent, National Diabetes Audit) to identify gaps in monitoring and coding for CKD, and work with patient representatives on plans for improvement.** There must be consistency in:

- Annual testing for those most at risk of CKD.
- Appropriate monitoring for people diagnosed with CKD, with a focus on urine as well as blood testing.

**The Department of Health and Social Care's upcoming Major Conditions Strategy and equivalent strategies for devolved nations,** should include commitments to:

- Increase early detection of CKD in high-risk individuals in primary care through tools that promote screening, including Quality and Outcomes Framework indicators, implementation of patient-evaluated testing technology and incorporation of CKD into Health Checks.
- Incentivise the delivery of evidence-based interventions to delay progression in CKD including access to newer medications such as SGLT-2 inhibitors.

## Challenge 3 – Support people to take control of their own kidney health with tailored advice and support

- Our survey showed many people wanted more information following a diagnosis of CKD – particularly on diet and fluid intake, likely progression of disease, maintaining health and wellbeing.
- People wanted to be more physically active, but barriers included cost and uncertainty about exercising safely.
- Patient charities have a wealth of accredited information, yet only 3 in 10 survey respondents were told how to contact charities for further support.

## Recommendations for action:

**Clinicians diagnosing CKD should ensure individuals are provided with tailored information on living well with kidney disease.** This can be supported by:

- Signposting on diagnosis to patient charities such as Kidney Care UK.
- Development of tools such as the NHS App and linkages to kidney health information.

**ICSs and health boards in devolved nations should incorporate in their Social Prescribing schemes support for people with kidney disease to maintain health and wellbeing.**

Now is the time to shift the dial in CKD by seriously focusing on prevention. Kidney Care UK stands ready to work with national and local health bodies to bring about this change.

> "I think it is very important for GPs to foster a warm and trusting approach during consultations. I take real comfort in not only being able to divulge my mental worries with my GP but also appreciate being seen as an expert of my own health."
>
> **Ruban Nathan,** person living with chronic kidney disease

# Background

## Kidneys are vital to good health

Kidneys not only filter toxins from our bodies and manage body chemistry, but produce and regulate hormones for blood pressure control, red blood cell production, and keeping bones healthy. Well-functioning kidneys are essential for good health.

## What is chronic kidney disease (CKD)?

CKD means that your kidneys do not work as well as they should. They are not as effective in removing waste products from your body. Damage to the kidneys' filter system can also allow blood and protein to leak into the urine. This is not always visible but can be found with a urine test.

Most people are diagnosed by a blood and urine test. These tests may be done as part of a routine check-up or because people are at risk of developing CKD (for example, those with diabetes or high blood pressure). Blood tests measure the levels of a waste product called creatinine in your blood and are used to calculate e-GFR level. This is a measure of how quickly your kidneys are cleaning your blood and is measured in millilitres per minute. Urine tests check whether you have a protein called albumin in your urine. The results are used to calculate your albumin to creatinine ratio (ACR). When you have albumin (protein) in your urine, it is called albuminuria or proteinuria and can be a sign of kidney disease even if your e-GFR is 'normal' (above 60 ml/min).

A staging system is currently used to describe the severity of disease. The five stages of CKD range from being at risk through to kidney failure, when kidneys stop working (see Table 1). Most people with CKD stages 1 to 3 can manage their condition with their GP with treatment aimed at slowing down its progress. Only around one in 50 people with CKD ends up with kidney failure.[6]

| Stage of Chronic Kidney Disease | Description | e-GFR Level |
|---|---|---|
| One | Kidney functions remains normal but urine findings suggest kidney disease | 90ml/min or more |
| Two | Slightly reduced kidney function with urine findings suggesting kidney disease | 60 to 89ml/min |
| Three | Moderately reduced kidney function | 30 to 59ml/min |
| Four | Severely reduced kidney function | 15 to 29ml/min |
| Five | Very severe or end-stage kidney failure | Less than 15ml/min or on dialysis |

Table 1: Stages of Chronic Kidney Disease

## Prevalence of CKD and associated costs

Recent health economics analysis by Kidney Research UK estimated:[7]

- There are 7.2 million people living with kidney disease in the UK. This includes 3.25 million people living with CKD stages 3 to 5, and a further 3.9 million people with earlier stages of CKD.
- The current cost of CKD to the NHS is estimated to be £6.4 billion – 3.2% of total NHS spend. Dialysis alone costs the NHS £1.05 billion per year.
- The number of people with CKD in the UK is expected to grow significantly over the coming decade because of an ageing population, increasing prevalence of type 2 diabetes and hypertension.
- By 2033, there will be an estimated 7.6 million people with CKD in the UK, with the largest increases occurring in the later stages of the disease where the vast majority of NHS resources are spent and the impact on individuals is greatest.

People from socio-economically deprived communities and ethnic minority groups are disproportionately affected by CKD.

## Why does CKD matter?

People affected by kidney disease have told us that they want to do all they can to maintain their health and wellbeing, and slow the progression of damage to their kidneys, but were not always given the opportunity. Keeping the condition at bay means continuing to enjoy family time, hobbies and employment, to participate in education and have children, to avoid a life dictated by hospital visits, debilitating fatigue and pain, and reduce risk of premature death from cardiovascular disease. The psychosocial heath impact of this condition, which of course puts a further strain on the individual as well as the NHS system, should not be under-estimated. Reducing the human cost of CKD provides a huge incentive for improving secondary prevention – catching it early and stopping or delaying it from getting worse.

**Early intervention in CKD also addresses some of the most pressing issues in current UK health and wider public policy:**

**Reducing the burden of cardiovascular disease (CVD) –** the heart and kidneys are inextricably linked. In fact, people with CKD are 20 times more likely to die of CVD than end-stage kidney disease.[8] Early intervention in CKD can reduce risk of death from cardiovascular complications.

Cardiovascular risk is far higher in people with CKD than in people with normal kidney function:[9,10]

- 50% of everyone with CKD stage 4 to 5 have CVD
- Cardiovascular mortality accounts for around 40% to 50% of all deaths in CKD 4 and 5, compared with 26% in people with normal kidney function
- CVD risk doubles in CKD stage 3

The Major Conditions Strategy interim report showed kidney problems contribute to the burden of CVD in the UK, contributing 6% of the disability adjusted life years (DALY) burden of CVD.[11] CKD also contributes to high blood pressure, which accounts for 45% of the CVD DALY burden.

New treatments that reduce CVD risk in people with CKD provide more incentive for early identification and intervention in CKD. A pooled analysis of 13 trials of SGLT-2 inhibitors in people with CKD found the risk of cardiovascular death or hospitalisation for heart failure was reduced by 23% compared to placebo.[12]

**Reducing avoidable harm from acute kidney injury (AKI)** - people with CKD are at heightened risk from AKI, where kidneys suddenly stop working properly, usually as a complication of another serious illness. Identifying and carefully monitoring people at risk reduces harm and preventable deaths from AKI. Data shows:

- Up to 30% of AKI deaths could be prevented through early intervention.[13]
- There are around 615,000 episodes of AKI in the UK each year.[14]
- AKI is seen in 13% to 18% of all people admitted to hospital, with older people more likely to be affected.[14]
- The costs to the NHS of AKI (in hospitals alone) are estimated to be between £434- 620m per year (more than the costs of breast cancer, lung cancer and skin cancer combined).[14]

People with CKD stage 4 and 5 are at greatest risk of AKI, but people with earlier CKD are also more vulnerable to AKI. This is also the group least likely to have a CKD diagnosis on their records. Consistently identifying and recording diagnoses of CKD reduces the risk of AKI, because it guides monitoring and clinical decision making.

**Pressure on NHS resources -** better management of CKD has a key part to play in addressing the current huge pressure on the NHS and its workforce. Treating CKD and its complications is already extremely costly, with dialysis treatment being a key cost. We must act now to get ahead of the expected increase in prevalence and cost.

**Transplant waiting list –** Transplantation is the gold standard kidney replacement therapy for kidney failure and also represents significant cost savings for the NHS compared to dialysis. However, transplant waiting lists have not recovered from the Covid-19 pandemic and, following years of steady improvement, have returned to levels last seen in 2014.[15] Currently over 5,500 people in the UK are waiting for a kidney transplant. Reducing the numbers of people reaching end stage kidney disease by earlier identification and treatment will help manage demand and waiting times.

**Economic activity -** While many people with earlier CKD (stage 1-3) may have very few symptoms and still feel well, the symptoms of more advanced CKD can make it difficult to stay in work. Taking time off for hospital appointments and the burden of dialysis also makes employment a challenge – employment rates for people on dialysis are 26%.[16] Early identification and intervention mean people with CKD are better able to stay in work – the benefits to individuals and local economies are huge and it also addresses the key government priority of reducing economic inactivity.

**Psychological health impact -** The impact of kidney health on psychological health is profound and should not be ignored. Depression is experienced by many and adds to pressure on the mental health system.

## Can early intervention in CKD make a difference?

CKD is common and harmful if the condition progresses, but control and delay of deterioration is possible for some, if action is taken.

Once CKD is identified, personalised plans tailored to risk of progression and cause of CKD should be developed collaboratively between the individual and their doctor. These should have the joint aims of:

1. delaying further damage to kidneys where possible and reducing risk of needing kidney replacement therapy (dialysis and transplant)
2. reducing risk of CVD complications.

Many individuals with CKD will not progress to kidney failure, but complications of CKD are common – it is important to treat both.

The following can help delay progression of CKD in some people:[17]

- Carefully controlling blood pressure (recommended range informed by urine ACR test results)
- Improving management of diabetes
- Maintaining a healthy BMI
- Stopping smoking
- Avoiding binge drinking of alcohol

There are also medications recommended for use to delay progression and reduce CVD risk. These include:

- Angiotensin-converting enzymes (ACEIs) and angiotensin receptor blockers (ARBs) delay the progression of CKD and lower the risk of CVD complications.
- SGLT-2 inhibitors. The emergence of these drugs has been described as the most significant advance in the treatment of progressive CKD in the last 20 years.
- Pooled results of 13 trials of SGLT-2 inhibitors found the drugs reduced the risk of kidney disease progression by 37% overall, with similar effects in those with and without diabetes.[12]
- The benefits of these drugs potentially mean people living many more years free of the burden of kidney failure.

# Methodology

This report incorporates information from two surveys; one of people affected by kidney disease and one of a sample of general practitioners. It also uses data from published research, national registries and audits, including the UK Renal Registry, CVDPrevent, National Diabetes Audit and National CKD Audit.

## Survey of people affected by kidney disease

Kidney Care UK ran an online survey to inform our submission to the Major Conditions Strategy consultation. The survey was open for responses between 24 May 2023 and 17 June 2023 and was advertised widely on our website, via our digital newsletters and our social media channels. We received 569 responses from people at all stages of kidney disease – approximately 2 in 3 responses were from people with kidneys very close to failure or already failed and 1 in 3 from people in the earlier stages of CKD.

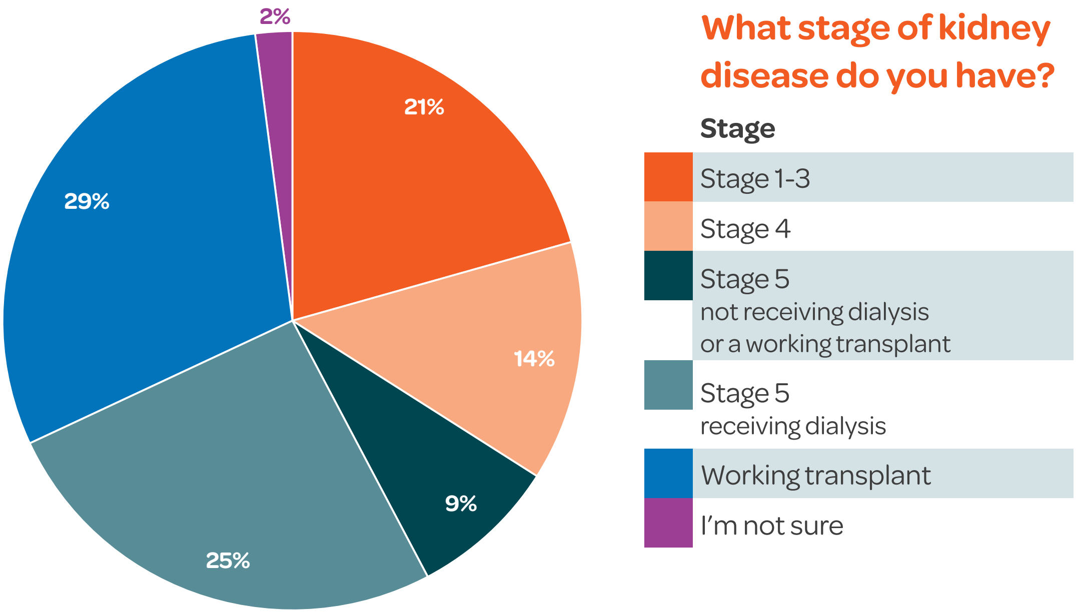


**Figure 1:** The proportion of respondents with different stages of kidney disease.

A full list of survey questions can be found in appendix 1.

## GP survey

Kidney Care UK commissioned medeConnect to interview 1,003 regionally representative GPs between 5 and 26 October 2023; all interviews were conducted online with members of the Doctors.net.uk community.

A full list of questions is available in appendix 1.

# Challenges and recommendations for change

> I have always received excellent and very well co-ordinated treatment from all of my medical support teams."

> The whole process is very vague and very little explanation is given or indeed what is going to happen or more importantly are you listened to as a patient ... Lots of keep going and carry on which is not helpful at all and potentially damaging to patients' health both physically and psychologically."

Our research and nationally collected data highlight major opportunities for improvements in identification and early intervention in CKD. Central to this is enabling people at risk from CKD, or living with CKD in its early stages, to take control of their own health. Knowledge is power and making people partners in their own care by sharing information and decision making has huge potential for making a difference in CKD care.

> My GP at the time did not act for a long time and dismissed my problems as something else (I was even told by one GP women of my age get these problems!) I went to another doctor and was treated properly, and the hospital were amazing."

Below we describe key challenges and recommendations for specific actions to address these challenges. For change to happen, national health leaders must give CKD the prominence in policy it requires. **We also encourage local health system leaders to assess their unique challenges throughout the CKD identification and early intervention pathway:**

**We recommend that every Integrated Care System (ICS) and Health Board should have a CKD prevention and management strategy.**

This should be developed in collaboration with people affected by CKD, informed by national and local audit data and involve the broad range of partners who have a role to play - primary care, including GPs and community pharmacists, specialist kidney, diabetes and CVD services, patient charities and community partners that deliver local health and wellbeing support.

# Challenge 1 - Raising patient awareness and understanding of kidney risk to increase engagement with care and monitoring

> " I was never told that my diabetes caused kidney failure."

Our surveys of patients and GPs both suggest people in the highest risk groups are not always told about their risk of kidney disease. People who are informed and engaged in their own care are more likely to access appropriate healthcare.[18] It's vital that tailored information about kidney risk is shared with people with diabetes and high blood pressure, to encourage monitoring and increase the potential for early intervention.

Among respondents who had diabetes or high blood pressure prior to their CKD diagnosis:

- 65% of people with diabetes said they were not told they were at increased risk of CKD
- 65% of people with high blood pressure were not told they were at increased risk of CKD

Our survey of 1,003 GPs similarly found inconsistency in whether people in the highest risk groups were made aware of their risk of CKD. Figures 2 and 3 show how frequently GPs advised their patients with diabetes and high blood pressure, respectively, of their risk of CKD:

■ Never ■ Rarely ■ Sometimes ■ Often ■ Always

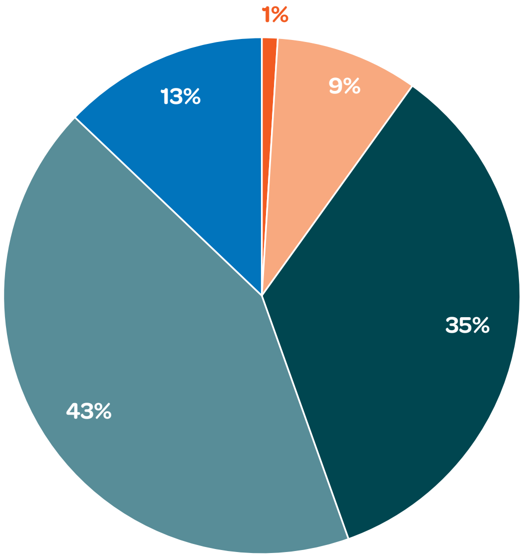


**Figure 2:** How frequently, if at all, are you to advise your patients with diabetes about their risk of CKD?

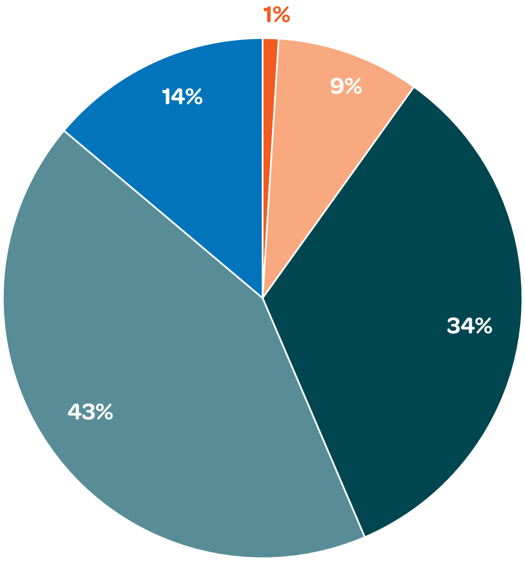


**Figure 3:** How frequently, if at all, are you to advise your patients with high blood pressure about their risk of CKD?

We want to see a significant shift in these figures, so that sharing risk of CKD with those living with the most common causes of the condition becomes the norm, alongside advice on reducing risk and the need for careful monitoring.

## Informing people of their CKD diagnosis and likelihood of progression

> I was never told I had stage 3. I believe it was on my blood test 12 years before. I could have taken steps to stop further deterioration."

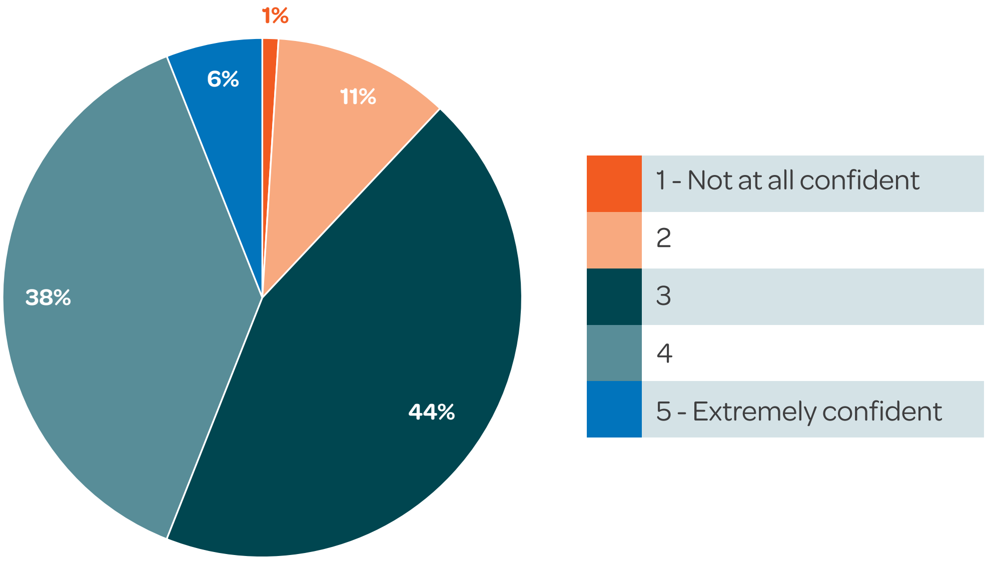
A strong theme in our survey of people diagnosed with CKD was a wish to have been told earlier about their kidney problems. People described the extra incentive it would have given to adopt healthy diet and lifestyle habits, as well as the desire to understand their own health status and to avoid finding out inadvertently.

> I was not informed that I had had CKD for 4 years by my surgery. I found out after I asked for a copy of my medical history."

Previous research has suggested a reluctance to share a diagnosis of CKD.[19] This research has reported that because kidney function naturally declines with age, and that in the majority of cases progression is unlikely, some felt sharing the diagnosis did not outweigh risk of creating anxiety.

Our survey of GPs found varying levels of confidence in talking to people about their risk of progression.

**Figure 4:** How confident are you in talking to people with CKD about the likely progression of their CKD?



**For Kidney Care UK, this highlights the need for support for primary care to offer tailored information about kidney function and likely progression in a way that does not create anxiety and provides reassurance for people less likely to progress.** We want to see individuals helped to understand their kidney health status and risk of worsening function or complications, followed by the collaborative development of a plan for appropriate monitoring and treatment to optimise kidney health and reduce risk of cardiovascular problems.

**Tools are now available which help to overcome the challenge of understanding and talking to people about likely progression of their kidney disease. NICE recommend the Kidney Failure Risk Equation (KFRE)** be used for personalising care and guiding referrals among people with CKD stage 3a to 5.[20] It uses age, sex, e-GFR (measure of kidney function) and urine ACR (measures of protein levels in urine) and is a well validated risk prediction for requiring kidney replacement therapy in the next 2 or 5 years.

We believe there is a strong argument for moving to reporting and sharing with patients their five-year KFRE risk alongside the current CKD stage 1-5 scale. As Major et al (2022) argue, this gives individuals more information on their individualised risk of progression, which patients have highlighted as a clear wish, and also helps clinicians with the management of people's care and timely referrals to secondary care.[21] Embedding the KFRE within electronic patient record systems would encourage its use.

**A number of programmes around the UK focused on joint working between primary care and hospital kidney teams** are helping to increase confidence and experience in primary care, optimise patient care in the community and identify appropriate patients for referral to secondary teams. In one such programme, LUCID (Leicester, Leicestershire, and Rutland Chronic Kidney Disease Integrated Care Delivery Project), specialist kidney doctors work with primary care networks, meeting regularly with time to review patients on the CKD register or newly diagnosed, streamline management, optimise medications and fast track referrals where necessary.

> Both my GP and renal team seem to know what's going on."

> Consultant nephrologist passed my card back to the GP due to me only being stage 3a. GP answered my long term health questions by saying "I'm no expert". I want to know how to achieve my best prognosis."

**Lack of public understanding of CKD**, the essential role that kidneys play in maintaining overall health and links with other conditions make it more difficult for healthcare professionals to talk to their patients about CKD. Kidney Care UK's public awareness work is addressing this, but we cannot do it alone.

## Our recommendations for change:

**The devolved NHS leadership teams across the UK should enhance local primary care management of CKD and ensure healthcare professionals are supported to understand and communicate the risks of CKD progression. This means:**

- ICSs and health boards should support the development of shared care programmes between primary care and secondary care kidney services. All areas of the UK should learn from existing programmes and adapt according to local populations and NHS structures, to enhance GP confidence and knowledge
- Everyone with a diagnosis of CKD should have the opportunity to discuss with their doctor their CKD diagnosis, risk of progression and potential complications. People in the highest risk groups should be informed of their risk, how to reduce it and be supported to access appropriate monitoring
- The KFRE should be embedded within primary care electronic patient record systems and patients informed of their five-year KFRE risk alongside the current CKD 1-5 staging system

# Challenge 2 - Underdiagnosis and late referrals indicate missed opportunities

> At the time of diagnosis I had no symptoms, I was told how disease was likely to progress and was monitored at least annually over a period of around 25 years with more frequent monitoring in the years leading up to end stage failure and transplant."

> For a very long time I was not told of my e-GFR [kidney function] until I was at 45%. There was little information on how to keep my kidneys as healthy as possible to slow down the deterioration."

It is estimated around half of the people living with CKD are undiagnosed.[2,3] UK Renal Registry data shows nearly 1 in 5 people (18.2%) starting kidney replacement therapy (dialysis or transplant) in 2021 had first been seen by a kidney specialist within the previous 90 days, with considerable variation between units.[5] This is considered late presentation. It means preparation and surgery for dialysis have to start urgently, rather than in a planned way, and suggests opportunities to treat early and delay progression were missed. An unplanned start to dialysis is associated with up to fivefold more healthcare expenditure than a planned transition.[22] It also increases morbidity and mortality.[23]

Not all cases could be avoided but there must be a focus on interventions that increase identification and reduce avoidable late referral. Monitoring and optimal treatment of people most at risk of progressive CKD is key.

## Monitoring the kidney health of those most at risk

Audit data[4,24] starkly highlights unacceptable variation in monitoring of high-risk groups. Given the potential to intervene with well-established treatments and new medicines such as SGLT-2 inhibitors that can delay progression and reduce CVD risk, it's vital that everyone can access monitoring.

In 2021, around one in five people who started kidney replacement therapy within 90 days of first seeing a kidney specialist had one of the most common causes of CKD as the primary cause of their kidney disease (diabetes or high blood pressure).[5]

Due to their increased risk of CKD, people with diabetes and high blood pressure are among the groups that should be offered testing to identify early signs of kidney damage.[20] However, national audits highlight inconsistencies in NICE recommended monitoring:

- The latest National Diabetes Audit found only 61% of people with diabetes had the NICE recommended urinary albumin test to detect the earliest stages of kidney disease.[44]
- The National CKD Audit found urine tests were done in less than 30% of people with hypertension.[24]

Blood tests were more frequently carried out in people with diabetes (91%) but both blood and urine tests must be done. Tests to check for albumin (protein) in the urine help identify very early kidney damage and individuals at greater risk of disease progression and death.[25]

The role of new technologies aimed at increasing testing rates, for example home testing kits, should be explored, particularly those that can address health inequalities. It is important to involve patients in the development of new technologies and their implementation, to make sure they are patient friendly and therefore likely to be used.

## Improving coding and monitoring of people with diagnosed CKD to support better treatment

> "Diagnosis wasn't followed by any information or advice and there was no follow up. Diagnosis experience itself was awful, but such a missed opportunity for a long-term condition. Neither hospital or GP ever followed up, so I had no support until I developed more severe symptoms many years later and pushed hard to eventually get some specialist care."

Monitoring of people with an existing diagnosis of CKD in primary care, as per NICE guidelines, helps clinicians offer appropriate treatment and lifestyle advice that can delay progression, identify people with rapidly declining function and make appropriate referrals. The CVDPrevent audit indicators highlight inconsistencies and shows a dramatic increase in urine testing is needed to support individualized risk prediction.[26]

- CVDPrevent data shows while 86.7% of adults with CKD had an e-GFR test in the preceding 12 months (a blood test), only 39% had a record of a urine ACR test (albumin:creatinine ratio) or protein:creatinine ratio) during that time.

**Consistent coding of CKD in primary care** can support regular monitoring and follow up. Olaitan et al. (2019) found an absence of a SNOMED code for CKD was the most important modifiable factor predictive of unplanned dialysis.[22]

The 2023 CVDPrevent audit found 300,000 people with CKD did not have a coded diagnosis of their condition, despite recorded readings which indicate that they have these conditions.[26] The authors add "moving these people onto the CKD register would support more systematic monitoring suggest an opportunity to identify, and therefore treat, CKD."

## Our recommendations for change:

**ICSs and health boards should use audit data (CVDPrevent, National Diabetes Audit) to identify gaps in coding, screening and monitoring and work with patient involvement representatives on localised plans for improvement**. Everyone at high risk of CKD and its complications must have access to screening and monitoring. There must be consistency in:

- Annual testing for those most at risk of CKD
- Appropriate monitoring for people with a CKD diagnosis, with a particular focus on urine ACR testing

**The Department of Health and Social Care's upcoming Major Conditions Strategy and equivalent strategies developed in devolved nations**, must include commitments to:

- Increase early detection of CKD in high-risk individuals in the primary care setting
- Incentivise the delivery of evidence-based interventions to delay progression in CKD

# Challenge 3 - Enable people to take control of their own health with tailored advice and support

> No specific advice on diet or healthcare or medication required or referrals given after diagnosis - told to have an annual blood test only.”

> I try to watch my diet by looking at the traffic light system on food packages! My GP sent me to a course on this in the community. “

Our research identified opportunities to improve outcomes by providing tailored CKD information and support. Survey respondents expressed a wish to do more to manage their health through diet and exercise but often could not access information or felt overwhelmed by the amount available which was often conflicting.

The top three areas people wished to receive information on were:

- More specific advice on diet and fluid intake
- Having the likely progression of my kidney disease explained to them
- More advice about how to maintain health and wellbeing

It’s vital to encourage patient activation, which means ‘having the knowledge, skill, and confidence to manage one’s health and health care’,[27] through accessible patient information. It leads to better health outcomes, better care experiences and reduced use of healthcare resources.[28] There is a huge amount of literature available on healthy diets and lifestyles, which can help people achieve the better management of BMI, blood pressure and/or diabetes that may delay CKD progression. However, comments in our survey highlighted that people want to know whether and how they need to adapt this advice because of their kidney condition.

**Ensuring everyone diagnosed with CKD is referred to kidney patient charities**, such as Kidney Care UK (who have a wealth of quality assured information on a wide range of issues including diet and lifestyle modifications), can help patients access reliable information and alleviate pressure on clinicians. Our survey highlights that increasing referrals to patient charities could address the information gap and support early engagement with self-management of kidney health.

Nearly 7 out of 10 of our survey respondents either disagreed or strongly disagreed that they were told how to contact charities for further information and support.

> I would have liked to been able to talk about why I have it and how to deal with it better, I found everything I know about CKD from the internet.”

## Promoting physical activity for health

A number of survey respondents highlighted that they wished to be more physically active, but there were barriers to doing so including cost and concerns about how to exercise safely. Practical support to access ways of being physically active was the most frequent selected response to the question 'What would help you now to manage and live well with CKD? (tick all that apply)'

- Practical support to access active leisure facilities (for example, free specialist fitness sessions/swimming walking) – 51% of respondents selected this answer
- More dietary advice – 44% of respondents selected this answer
- Being able to talk to other people with CKD, for information and support about how to live well – 41% of respondents selected this answer

The establishment of ICSs across England, involving a broad alliance of partners concerned with improving the health and wellbeing of the local population, is an opportunity to explore how different partners and existing community assets can come together to offer opportunities to exercise safely. Social prescribers across the country are already helping people overcome barriers to being physically active (see the Social Prescribing Academy physical activity hub). We want to see people with kidney disease involved in local collaborations and inputting into the design and delivery of local support for physical activity.

## Our recommendations for change:

**Clinicians diagnosing CKD should ensure individuals are provided with tailored information on living well with kidney disease.** This can be supported by:

- Signposting on diagnosis to patient charities such as Kidney Care UK, who provide quality assured information and access to support.
- Development of tools such as the NHS App which can link to information about kidney health and steps patients can take to maintain it.

**Integrated Care Systems and health boards in devolved nations should incorporate in their Social Prescribing schemes support for people living with kidney disease to maintain their health and wellbeing,** developed with the collaboration of people with CKD so that it is tailored to particular needs of people with the condition.

## Concluding remarks: the time for CKD is now...

The findings in this patient-powered report demonstrate the potential for improvements in early CKD care and the benefits these will bring to the health, life chances and economic wellbeing of a vulnerable group, as well as more efficient use of NHS resources. Given the wide-ranging benefits that could be achieved, CKD must play a prominent role in preventative health policy plans.

The views and experiences of people affected by kidney disease point to clear actions that can drive the change that it is needed in CKD. We urge government, NHS England and the devolved bodies, ICSs and health boards to work with us to bring this change.

# Kidney Care UK patient resources

Kidney Care UK is the UK's leading kidney patient support charity. We offer practical, emotional and financial help, and make sure no one faces kidney disease alone.

Being diagnosed with a kidney condition can be a worrying time. Kidney Care UK offers wide-ranging information and support for all stages of the disease.

## Patient information

Our patient information booklets are produced in partnership with the UK Kidney Association (UKKA), the leading professional body for the UK kidney community. As a 'trusted information provider', Kidney Care UK has been awarded the PIF TICK. This is the UK's only assessed quality mark for print and online health and care information.

All of our information booklets can be freely downloaded from the Kidney Care UK website. Printed copies can be ordered free of charge by kidney units, Kidney Patient Associations (KPAs) and patients (some titles are only available as downloads). Topics include:

- Information for people when they are first diagnosed
- Detailed information about specific conditions
- The different ways kidney-related illnesses are treated
- Why maintaining a healthy lifestyle is important for people with kidney problems

Visit www.kidneycareuk.org for more information.

## Kidney Kitchen

Kidney Care UK's Kidney Kitchen is a free resource which provides recipes and ideas for healthy and delicious food at every stage of kidney disease. The meal ideas have been modified by our team of chefs and kidney dietitians to fit more closely with the needs of people with CKD. Every Kidney Kitchen recipe is analysed and approved by the British Dietetic Association Renal Nutrition Specialist Group (RNG).

Kidney Kitchen also produces special sets of recipe ideas and advice focused on particular topics including low-salt food, safer weight loss, eating well on a tight budget and baking on a low phosphate diet.

As well as the online resource, via www.kidneykitchen.org, Kidney Kitchen also publish printed magazines.

## Patient support

Kidney Care UK's national Patient Support & Advocacy Service provides in-depth information, support and representation to patients, their families or carers, and local Kidney Patient Associations on a range of issues. This includes benefits and employment advice, treatment options and emotional health.

The Patient Support & Advocacy Service provides one-to-one help over the phone or, where appropriate and required, in person. It can also be a gateway to the other patient support services offered by Kidney Care UK, such as financial grants and counselling.

Contact us to find out more about this service.

# Appendix 1 – Survey Questions

## Kidney Care UK Patient Survey

1. Are you or a family member living with kidney disease?

   I have kidney disease

   Another adult in my household has kidney disease

   A child in my household has kidney disease

   No, neither me or anyone else in my family has kidney disease.

2. Which country do you live in?

   England

   Scotland

   Wales

   Northern Ireland

3. What is your gender?

   Female

   Male

   Other

4. What age group do you belong to?

   Under 18

   18-24

   25-34

   35-44

   45-54

   55-64

   65-74

   75+

5. What stage of kidney disease do you have?

   Stage 1 -3

   Stage 4

   Stage 5 - not receiving dialysis or a working transplant

   Stage 5 - receiving dialysis

   Working transplant

   I'm not sure

6. How was your CKD diagnosed?

   It was diagnosed in childhood

   Picked up through routine/regular blood tests at my GP

   I went to the GP because of the symptoms I was experiencing

   It was identified by my hospital care team that treat another condition I have

   Following diagnosis of Acute Kidney Injury (AKI)

   I'm not sure

   Other (please specify)

7. Thinking back to when you were diagnosed, do you know what stage your kidney disease was at that point?

   Stage 1-3a

   Stage 3b

   Stage 4

   Stage 5

   At the point of kidney failure

   Not sure

8. Did you experience any of these barriers to getting a diagnosis at the right time? (tick any that apply)

   I didn't know I was at risk of CKD

   I didn't know the symptoms of CKD, so didn't seek help

   My kidney function was not tested regularly

   I didn't feel medical staff were listening to me when I explained how I was feeling

   There was a long waiting list for the tests I needed

   The focus on my other health conditions put CKD in the background

   I didn't experience any barriers to getting a diagnosis at the right time

   I'm not sure

   Other (please specify)

9. Thinking back to when you were diagnosed with kidney disease, please say if you strongly agree, agree, neither agree nor disagree, disagree or strongly disagree with each of the following statements, or if they are not applicable.

I felt listened to and my questions about kidney disease were answered

I received written or verbal (talking) information which helped me understand kidney disease

I received written or verbal information which helped me understand how to stay as well as possible with kidney disease

I was told how to contact charities such as Kidney Care UK for further information and support

I was helped to understand how my disease was likely to progress in the future

Please add any additional comments:

**10. Would any of the following have improved your experience of being diagnosed with CKD? (please tick any that apply)**

Being able to talk to other people with CKD, for information and support

Having more time to discuss my condition with my doctor or nurse

More written information about CKD

More specific advice on diet and fluid intake

More advice about how to maintain my health and wellbeing

Being able to speak to a healthcare professional about my feelings or mental health

Having the likely progression of my kidney disease explained to me

Being more involved in the decisions about the treatment and care I received

More help to understand and manage medications

In the box below, please say what else might have improved your experience of being diagnosed with CKD?

None of the above

**11. What would help you now to manage and live well with CKD? (please tick all that apply)**

More dietary advice

Psychological support to help me cope (eg a counsellor)

Advice about how to be physically active safely

Practical support to access active leisure facilities (eg free specialist fitness sessions/swimming/walking)

Being able to talk to other people with CKD, for information and support about how to live well

More help to understand and manage the medications

Other (please specify)

**12. What do you do to maintain your health and wellbeing, while living with CKD?**

**13. Do you have a diagnosis of any long term conditions in addition to CKD? (please tick all that apply)**

I do not have a diagnosis of any other long term condition in addition to CKD

Diabetes T1 or T2

High blood pressure (hypertension)

Heart disease (cardiovascular diseases like heart failure or vascular disease)

Hyperlipidemia (high cholesterol)

Respiratory disease (lung diseases like COPD, pulmonary fibrosis, asthma and others)

Musculoskeletal disease (affecting your joints, bones and muscles like arthritis or back pain and others)

Dementia

Mental health condition

Other (please specify)

**14. How would you rate the coordination of the care for your different conditions? Is it joined-up?**

Poor Fair Good Very good
Excellent N/A

**Why did you give the coordination of your care that score? What is good or bad, or could be improved about the coordination of care for your different conditions?**

**16. If you had a diagnosis of diabetes before you were diagnosed with CKD, were you made aware people with diabetes are at higher risk of CKD?**

Yes No I'm not sure

I did not have a diagnosis of diabetes

**17. If you had a diagnosis of high blood pressure before you were diagnosed with CKD, were you made aware people with high blood pressure are at higher risk of CKD?**

Yes No I'm not sure

I did not have a diagnosis of high blood pressure

**18. Have you been given advice about how to reduce your risk of heart disease?**

Yes No I'm not sure

**19. Have you been given medications to manage your blood pressure?**

Yes No I'm not sure
Other (please specify)

## Medeconnect GP Survey

1 How frequently, if at all, do you share a diagnosis of CKD to patients at CKD stages 1-3?

Never Rarely Sometimes Often Always

2 How confident are you in talking to people with CKD about the likely progression of their CKD?

1 - Not at all confident 2 3 4 5 - Extremely confident

3 How frequently, if at all, do you advise your patients with diabetes about their risk of CKD?

Never Rarely Sometimes Often Always

4 How frequently, if at all, do you advise your patients with high blood pressure about their risk of CKD?

Never Rarely Sometimes Often Always

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Kidney Care UK is the UK's leading kidney patient support charity, providing practical, financial and emotional assistance for kidney patients and their families throughout the UK. We believe that no one should face kidney disease alone.

For further details of all the support we provide to people living with kidney disease, please visit our website www.kidneycareuk.org or call us on 01420 541 424.

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