

Changing the future for chronic kidney disease in Scotland.

Report and recommendations from a policy roundtable of patients and clinicians in Scotland



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About this report.



Chronic kidney disease (CKD) affects more people in Scotland than cancer and there is no cure.

This statistic alone should ensure CKD is a national priority but, instead, it is simply not on the agenda to the extent that it needs to be for government, the Scottish Parliament, NHS senior leaders and the wider public.

Only around two thirds of those affected by CKD have received a diagnosis – many of them diagnosed too late to prevent kidney failure – and others by accident as they are tested for other conditions.

Despite this, we lack a full picture of this condition for people in the early stages of CKD, as routine testing and collection of important data ended several years ago. Our research shows that the likelihood of a person being diagnosed and achieving better health outcomes depends on their relative affluence. This should not be acceptable in the modern era of healthcare in Scotland.

As the leading kidney research charity in the UK, Kidney Research UK's ambitions include both preventing people developing chronic kidney disease and ultimately – our urgent mission – ending kidney disease altogether.

Kidney Research UK brought together patients, clinicians and researchers for a virtual roundtable held on 20 September 2022 to identify the opportunities to transform the outcomes for people with CKD in Scotland.

We are grateful for the support of AstraZeneca, Bayer, CSL Vifor and Novartis who helped fund this project and to the team at Etrickburn who led the roundtable and helped us draft this report. However, the recommendations that Kidney Research UK has drawn together from the meeting are ours alone.

We are determined to continue our work with patients, clinicians, and policymakers to prevent the significant rise in the numbers of people developing CKD, to enable much earlier diagnosis and to ensure that everyone has both fair and equitable access to the best care and treatment available, that will ultimately reduce the burden of the disease and in many cases save lives.

Sandra Currie
Chief executive, Kidney Research UK

What is kidney disease

Living with kidney disease can make every day a challenge. It is a life-threatening condition that never goes away. Kidney disease affects, and sometimes governs, every aspect of people's lives. When kidneys fail, for whatever reason, people need either dialysis or a transplant to survive. Dialysis is burdensome, usually requiring four-hour hospital visits three times a week. A transplant is not a cure and will last on average 20 years.

There are 3.5m people living with CKD in the UK and the numbers are growing. A third remain undiagnosed. By 2040, kidney disease will be the fifth biggest killer worldwide.

Overview.

It is time for Scotland to deliver a step change for people with chronic kidney disease.

Kidney Research UK is asking Scotland's policymakers to work with us to bring together patients, their families, clinicians, and researchers and recognise chronic kidney disease as a clinical priority – allowing for an equitable *Once for Scotland* national approach or strategy, to drive effective early identification and intervention to prevent people progressing into more severe stages of the disease.

There is a need for a step change in policy that builds a systematic approach to identify everyone at risk of chronic kidney disease in Scotland. To achieve this, updated, clear guidelines and protocols are needed to detect CKD early, provide opportunities for timely intervention and to stop it progressing. There is an urgent need for a step change in how we use data and digital platforms to join up care and treatment – with every patient able to be an informed partner in realising the goal of living well and living longer.

This national approach is needed to improve information and education – for clinicians as well as patients and the wider public – with updated national guidelines and protocols, so healthcare professionals in all settings are fully equipped to identify and manage the condition. There needs to be far wider availability of peer support and digital aids for patients to cope when they are diagnosed and then live better with their condition.

As a starting point, we recommend that Scottish ministers commission a strategic audit of chronic kidney disease management across Scotland to identify any guidelines being used, asking clinicians in both primary and secondary care to share their protocols and pathways for the identification, diagnosis, and treatment of people with chronic kidney disease.



The best time is early

Chronic kidney disease is invisible, overlooked, and diagnosis often comes as a bolt from the blue.

With few, if any, early symptoms, many people are not aware they have the condition. Chronic kidney disease is diagnosed from blood and urine tests – tests that are often carried out as part of investigations for other conditions.

There is no cure for CKD, and when people reach kidney failure, the only treatment options are dialysis or a transplant. For some whose kidney function is in decline, the only treatment options are dialysis, transplant or end of life care.

This is a condition that disproportionately affects people from ethnic minority and lower social economic communities – with lower and often later diagnosis, higher incidence, poorer outcomes, and poorer access to organs for transplantation, and to choices around dialysis mode.

Clinicians at our roundtable expressed concern that many people are falling through the net. A particular risk is that those from deprived communities, and those who are less likely to engage with health services, are the least likely to be diagnosed early. They are more likely to be diagnosed in secondary care after the disease has progressed to a late stage.

It is estimated that for every two people diagnosed with CKD, there is a third person who is unaware they have it. There are some factors that put people at greater risk of chronic kidney disease such as: family history, poorly controlled diabetes, high blood pressure, heart disease, ethnicity, obesity, smoking and drug use. But many people are diagnosed with chronic kidney disease who had none of these risk factors.

A significant issue for Scotland is that, with the ending of the general practice Quality Outcomes Framework in 2015, routine testing in primary care of people at risk from chronic kidney disease came to an end. As a result, no robust data exist for the prevalence, and severity, of chronic kidney disease in the community. While we are not advocating for population screening, we are calling for systems to be put in place to identify – and record engagement with – all those at risk, allowing Scotland to *re-establish* an understanding of incidence, prevalence, and impact across its communities.

A national pathway

As a charity, our goal is to end kidney disease. In the meantime, we believe that Scotland must put as much emphasis on identifying people with chronic kidney disease early – and preventing their condition from progressing – as it does supporting those with renal failure.

Early diagnosis allows early intervention. Clinicians at the roundtable told us they worry about the people they don't see, who are invisible to primary care services and who don't access healthcare until their disease is at an advanced stage.

We agree with the clinicians who said Scotland cannot continue with 'accepted dogma' that every person's condition will progress. Indeed, if, as one clinician put it, we intervene "quickly, harder, faster and more aggressively", those whose illness is identified early can often be managed effectively in their own communities by GPs and pharmacists.

As the clinicians at the table reminded us, this is not about simply preventing kidney failure. *Preventing progression* allows people with chronic kidney disease to live longer, better lives, free from other consequences of the condition such as heart failure, cardiovascular disease, and stroke. It will allow people to work, contribute to their communities and the economy, and reduce pressure on the NHS.

We heard that, although the specialist understanding and the data for chronic kidney disease is currently located in secondary care, the focus should move to primary care – not just in making the diagnosis but also in supporting and empowering GPs and other community-based professionals to make the right decisions at the earlier stages of the treatment pathway.

We were told that primary care teams may be passing patients to secondary care colleagues to make decisions. However, in most cases, the GP is the best person to take lead responsibility for their patients in early stage CKD.

There are no up-to-date Scottish guidelines for CKD and no clear recommendation for GPs in Scotland as to what guidance they should follow. Guidelines from the National Institute for Health and Care Excellence (NICE) are based on the way laboratories in England report some kidney function results. We believe that, backed by updated national guidelines relevant to Scotland, GPs could be provided with decision trees and clinical dashboards to support clinical assessments, treatment, and monitoring.

Lifting the invisibility cloak – information for clinicians and patients

Patients highlighted that their diagnosis of chronic kidney disease had come as a complete shock – and that they were largely left to educate themselves via the internet.

The overall level of education for healthcare professionals, and availability of support information they can pass on to patients, needs to be improved. This, supported by growing existing community-centred projects, could help reduce the stark inequality of people from more deprived communities being less likely to engage with health services and having poorer outcomes.

Patients described diagnosis as a ‘lonely experience’: they felt they had nobody to talk to or to answer their questions once the initial shock of the diagnosis had sunk in. That is why we are calling for the setting up of peer support networks of people with lived experience of chronic kidney disease.

Patients told us of the fears and anxiety of living with chronic kidney disease and the impact of the condition on their mental health. We call on the Scottish Government to ensure that psychosocial support for people living with chronic conditions, including CKD, is a core aim of the forthcoming mental health and wellbeing strategy.

People with chronic kidney disease, as is the case with many other chronic conditions, can be highly effective partners in their own care when provided with the right information. This is why we are concerned to hear that ‘Patient View’, a platform that allows people to access their own health information from NHS records – such as blood test results, medications, clinic letters, and details of their diagnosis and treatment – may not be supported by NHS Scotland for much longer. We are calling for clarity on the funding and format of alternative platforms.

Recommendations.

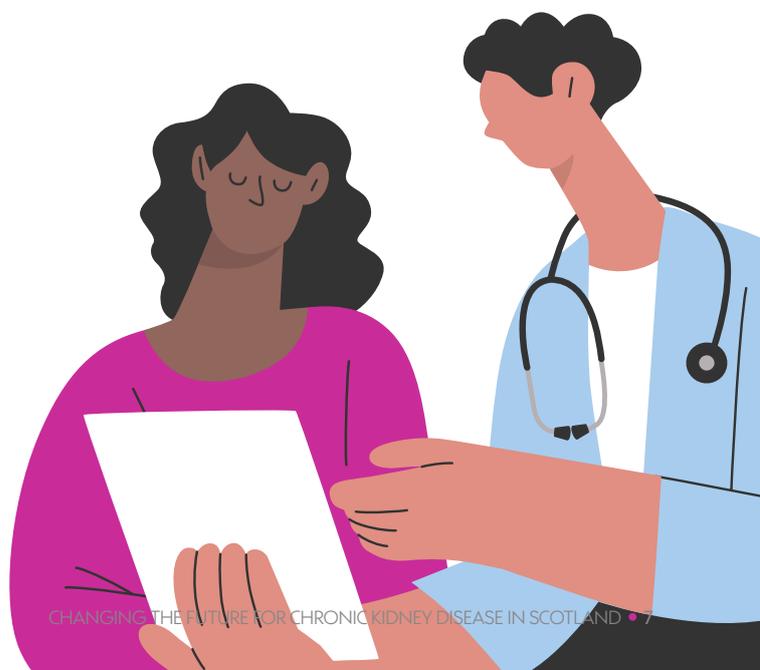
1. Groundwork

- 1.1. Scottish ministers should recognise chronic kidney disease as a clinical priority and ensure that the appropriate civil service team is instructed to oversee policy on best pathways for the earliest identification, diagnosis, treatment, and support of people with CKD
- 1.2. Scottish ministers should commission a strategic review of current CKD management to establish a baseline for all NHS boards on:
 - 1.2.1. access to current guidelines; and
 - 1.2.2. current services, pathways, and protocols.

2. A strategy or national commitment for chronic kidney disease

- 2.1. Scottish ministers should oversee the development of a new national priority approach to chronic kidney disease for Scotland, accompanied by the necessary resources for its delivery, to:
 - 2.1.1. raise awareness of chronic kidney disease, dialysis, organ donation and transplantation – with programmes designed to reach ethnic minority and deprived communities
 - 2.1.2. ensure consistent clinical knowledge across all healthcare professionals by providing adequate training
 - 2.1.3. ensure identification and consistent screening of at-risk groups, including the embedding of best practice in blood pressure measurement across all settings
 - 2.1.4. provide all practitioners in primary care with access to the same risk recognition and case management dashboard, and to community surveillance data systems

- 2.1.5. embed and support the lead role of healthcare professionals in primary care in advocacy and care management of people with a diagnosis of chronic kidney disease
 - 2.1.6. address the data gap created by the ending of the Quality and Outcomes Framework and invest in the expansion of the Scottish Renal Registry. This should include every patient with a diagnosis of chronic kidney disease in both primary and secondary care and be linked with diabetes and cardiovascular disease datasets. This would create a powerful tool (similar to those available in diabetes) to flag high risk patients and to track incidence trends and outcomes associated with different factors – both clinical and societal
 - 2.1.7. ensure dataflow and dialogue between primary and secondary care are simplified, consistent and uniform
 - 2.1.8. include a system to 'red flag' the use of potentially nephrotoxic pain management medicines.
- 2.2. Ensure consistent reporting against agreed metrics on delivery of these commitments.



3. Pathways and patient support

- 3.1. Scottish ministers should commission the NHS national Centre for Sustainable Delivery (or other expert clinical group) to develop a consistent pathway that integrates both primary and secondary care for the identification, diagnosis, treatment, and support for people with chronic kidney disease.
- 3.2. Scottish ministers should clarify as a matter of urgency the Scottish Government's policy and funding intentions around Patient View, or a similar tool that empowers patients in decisions made about their care.
- 3.3. The Scottish Government's forthcoming mental health and wellbeing strategy should recognise people living with long-term, chronic and potentially life-limiting conditions including CKD, as a group in their own right and ensure they have access to the support they need.
- 3.4. Scottish ministers should ensure the NHS works with third sector organisations to deliver peer support for people newly diagnosed with chronic kidney disease that also recognises associated mental health risks.
- 3.5. Scottish ministers should ensure the continued funding of existing projects involving Scotland's ethnic minority and deprived communities, that seek to reduce health inequalities and address poorer outcomes in kidney disease.



Contributors.

Kidney Research UK is grateful to those who took part in the roundtable

Roundtable participants

Dr Samira Bell, consultant nephrologist, University of Dundee; Chair Scottish Renal Registry and Co-lead of UK Renal Data Network

Jelina Berlow-Rahman, Kidney Research UK lay advisory group and patient representative

Liz Brown, patient representative

Sandra Currie, chief executive, Kidney Research UK

Aileen Dunleavy, renal pharmacist, NHS Ayrshire; Editor, Renal Drug Database

Dr Peter Gallacher, GP trainee, East Lothian

Professor Colin Geddes, consultant nephrologist at NHS Greater Glasgow & Clyde

Melany Gray, patient representative

Rona Grieve, renal senior nurse, Access and Care Assurance, Specialist Services, Ninewells Hospital, NHS Tayside

Professor Jeremy Hughes, professor of experimental nephrology, University of Edinburgh; honorary consultant nephrologist, Edinburgh Royal Infirmary; chair of trustees, Kidney Research UK

Professor Patrick Mark, professor of nephrology, University of Glasgow; honorary consultant nephrologist, NHS Greater Glasgow and Clyde and co-lead of the UK Clinical Trials Network

Jamie McGregor, patient representative

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Dr Shona Methven, deputy chair, Scottish Renal Registry; member, Scottish Donation and Transplant Group, Scottish government; consultant nephrologist and renal service clinical director, NHS Grampian

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Dr Stuart Ritchie, clinical director, Edinburgh Centre for Endocrinology and Diabetes NHS Lothian; honorary clinical senior lecturer, University of Edinburgh

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Observers and supporters

- AstraZeneca
- Bayer
- CSL Vifor
- Ettrickburn
- Kidney Research UK Policy Team
- Novartis

Summary of roundtable discussion.

We listened to the thoughts, experiences and suggestions of patients living with chronic kidney disease and healthcare professionals, including consultants, GPs and pharmacists.

We heard that the approach to CKD in Scotland is currently centred on secondary, specialist care of people whose condition has advanced, rather than primary care teams identifying patients early and delaying progression of this disease. A lack of understanding of CKD among the public and primary care staff, combined with disjointed data systems and interfaces, has resulted in people falling through the net, leading to the focus on late-stage care at the expense of early identification.

We heard that Scotland now has an important opportunity to recognise CKD as a clinical priority through an equitable 'Once for Scotland' national approach or strategy, which could drive these necessary changes.

Participants called for improved information and education and updated guidelines on management of the condition – accessible to all clinicians. We were told that, with the right early interventions and access to support and resources in their own communities, people with a diagnosis of CKD could live better and live longer without the condition progressing.

Identification of CKD patients

Early identification of people with CKD was highlighted by the roundtable participants as essential to improving outcomes for patients. One clinician said that 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.

You need to intervene much earlier [across] a bigger group. You need to find out who they are and bring them in proactively and treat them. We procrastinate too much.

A clinician

Data

A barrier to early identification of patients was felt to be the lack of data, particularly in primary care. While clinicians agreed that Scotland has relatively good data for those patients at a later stage in their illness, there is no clear national picture of prevalence.

There's good data for those at the end of the journey, which is dialysis and transplantation. But we don't know exactly what's happening before that.

A clinician

I think in terms of understanding the burden of CKD out there, it's not currently possible in Scotland.

A clinician

The Quality and Outcomes Framework supported GPs to undertake targeted testing for CKD but, since the Framework's withdrawal in 2015, there has been no routine testing and, as a result, we heard Scotland has “lost its handle” on community prevalence.

One clinician said the current approach to testing in primary care is “haphazard”, with huge variation in approach from practice to practice, meaning many patients must rely on an “opportunistic blood test” in order to be diagnosed. Another voiced fears that “people are falling through the net, all over Scotland”. The meeting heard that, as things stand, those already less likely to engage with health services and those from more deprived communities will be least likely to be identified until their disease has progressed:

We worry about the people we don't see in clinic – the people that are not engaged with primary care and the ones that when they are diagnosed, will be at an advanced stage.

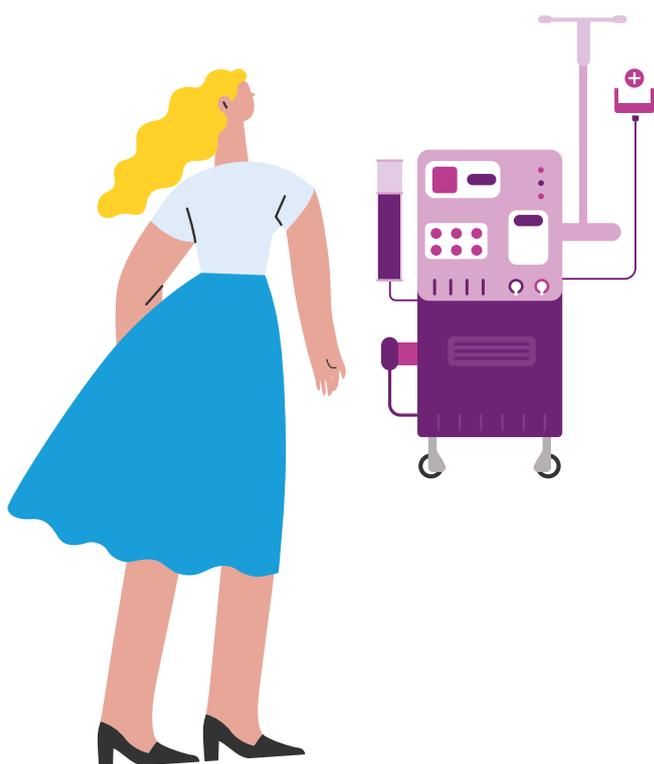
A clinician

Rather than endeavour toward a mass screening campaign, it was felt by clinicians that a systematic programme, targeted at those most at risk, would be most beneficial to ensuring those who will need earlier treatment will be found in time:

We need to deal with those data sensibly so that we're not just capturing everybody who has CKD, but we're capturing those people in whom intervention is going to make the difference.

A clinician

Scotland would be "at the pinnacle of CKD management", according to one clinician, if systematic screening of high-risk groups was in place. This could allow the creation of a surveillance dashboard at the community level, which would also be a powerful tool for monitoring the effects of interventions and initiatives. Though seen as a challenge, it was felt this would be possible within an organisation the size of NHS Scotland.



Clinical guidelines

It was felt that Scotland's GPs currently lack the necessary tools and guidance to identify those most at risk of progressive CKD – or to manage clinical decisions about their care. An absence of Scotland-specific clinical guidelines means primary care professionals follow guidance issued for England, which does not always fit the Scottish system. One clinician said, in their experience, many GPs are completely unaware of what standards they should be upholding in the screening and management of CKD, and that messaging from the Scottish government on this has been unclear:

There is nothing from SIGN on CKD since 2008 so, therefore, we're supposed to refer to the NICE guidelines, although it's not clear how that applies here in Scotland.

A clinician

There are standards in secondary care which at least we can stick to. It's slightly different though in primary care because it's really not clear who is responsible at Health Board level. We don't have the data on what guidelines GPs are operating to. So all that seems to just have been completely lost. I think once one is in secondary care, I'm not saying things are perfect, but at least there are fairly clearly defined standards from the UK Kidney Association. And there's a registry report which backs all those things up.

A clinician

Having a universal approach across Scotland, with the same quality of tools as those in use for other chronic conditions – notably for diabetes – was said to be key:

The same tools which support people with other conditions should be readily available in every GP surgery in Scotland, as opposed at the minute it seems randomly, they have to look up a guideline. And it's great that the patient gets empowered as well.

A clinician

Better interface between primary and secondary care

A “cross sector divide” between primary care and secondary care was highlighted by one clinician, which has been exacerbated by the lack of a data and digital interface between the two. There was a feeling among clinicians that the main focus of improvements must be in primary care, as the majority of people with CKD – both diagnosed and not – are within their care.

We heard that Scotland could be much better at joining up computer systems, data, and clinical practice between primary and secondary care – as well as making it much clearer where responsibility lies for patient care:

“There’s no way of being able to link all the data up across Scotland to see how many people have got CKD. So we can’t link the laboratories with all the prescribing and hospitalisations on a national level. And also, I don’t think there is availability across Scotland, yet, of looking at GP coded data and linking that all together. So I think we have got very good data available in Scotland, but there’s [still] a big deficiency.”
A clinician

“There’s an invisibility, that’s very specific to what’s available in the data. But there’s also an invisibility in terms of who has their eye on the results and is taking responsibility for them. So it’s at two levels.”

A clinician

Awareness and management of CKD

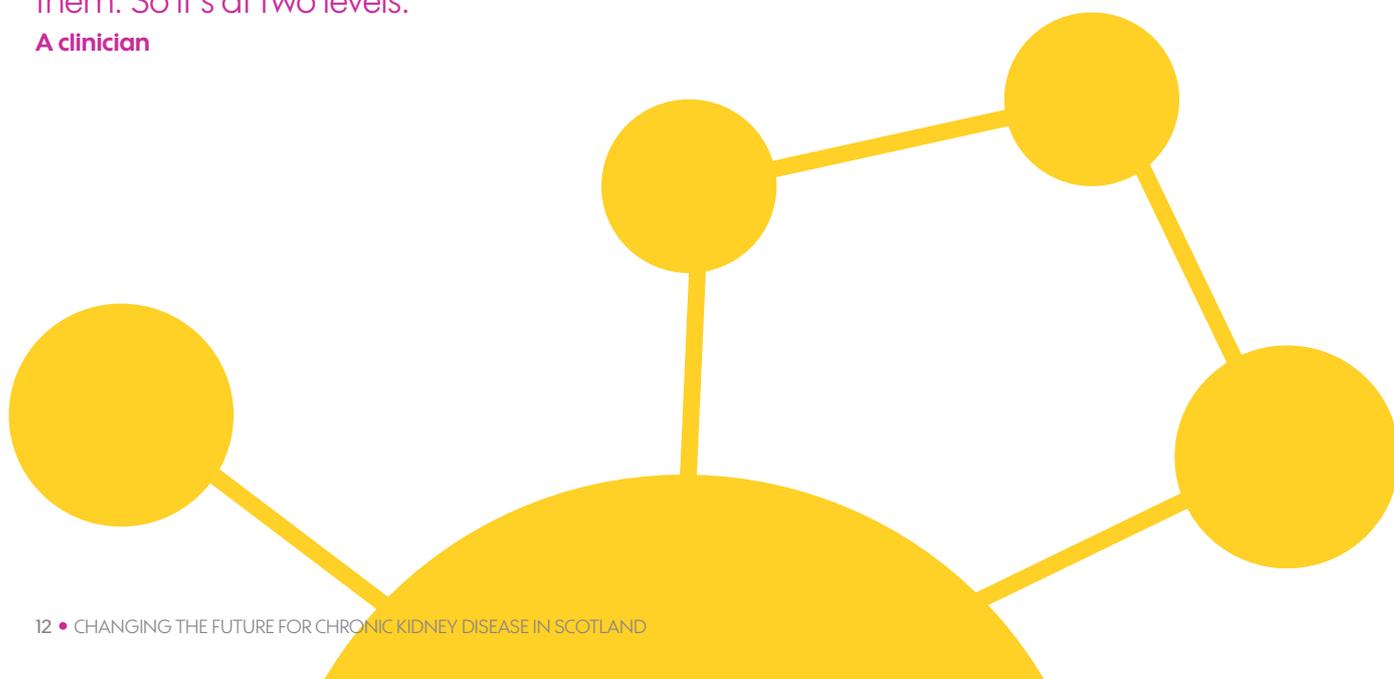
Amongst the public, patients and their families, there was felt to be a lack of understanding of all aspects of CKD, from the vital role played by the kidneys to symptoms of CKD and what factors make a person more at risk. One clinician said it was not uncommon for people to be referred to a nephrology clinic with no understanding of why they were there. Another compared the situation with cancer:

“Everyone knows that cancer is bad, but nobody really understands CKD. So I think that would be an important aspect to try and target general awareness.”

A clinician

The need for more public education on CKD was supported by both clinicians and patient advocates. One clinician suggested a simple primary care education campaign could help empower patients and potentially lead to earlier identification for some people.

Every patient at the roundtable said their diagnosis came as a shock, despite many being part of an at-risk group. Each one highlighted the value of online research and the help of charities after receiving their diagnoses. One patient described their experience as being like “a rabbit in headlights”; prior to their diagnosis, no clinician had mentioned the possibility of CKD or what having the condition would entail.



I don't mean to sound negative about the team that I have, because they have been brilliant, it's just a lot of the information, I haven't understood. I do feel that, leading up to that point, there needs to be better education for people in general. I'm still a bit in the dark

A patient

Another patient advocate, who has diabetes, echoed these sentiments:

Growing up, it was something that was maybe mentioned once or twice, as something that could happen, but there was never any further information. There was no information on how to prevent things maybe from happening, you were never sort of given any warnings that these could be symptoms, or these are things to look out for.

A patient

Patients described having CKD as "a lonely experience". There was a shared feeling among patients that health professionals in primary and secondary care do not have enough time to fully support patients after diagnosis, but that there is a role to be played by peers with lived experience. One patient said mental health support is currently lacking and suggested that others with lived experience could play a role:

Is there the possibility at some point of using lived experience to pass on to those who are just diagnosed. It maybe makes a bit more understandable, and less scary?

A patient

I've found that not knowing anybody who had kidney disease or anything about it is quite a lonely experience. And I think once you can get to speak to people, and get a bit more awareness and knowledge, that that helps a lot.

A patient

Patient View – a tool that allows people to access their patient information, like test results and clinic letters – was seen by both patients and clinicians as essential to empowering people to become fully engaged in making informed decisions about their own care. One clinician recommended further enhancing the functionality of Patient View, but raised concerns that, under current plans, the platform will be discontinued in January 2023 with no replacement yet in place.

We have to protect the things we already have as well as trying to build on them.

A clinician

Health professionals too, we heard, need to be better trained and supported with information about CKD, both so clinicians can recognise those groups at risk and the symptoms of progression, and help their patients understand their condition.

If health professionals are better educated as well, that then means that they're able to pass that information on to the patients that they see. And they see far more patients than we ever would in the hospital – when it's usually too late – so they can prevent patients becoming patients and being admitted.

A clinician

One clinician said the "accepted dogma" that CKD patients will progress to late stage must be challenged and that preventing progression of the disease, so that people can live longer, better lives in their communities, must be a higher priority. Getting a grip on the data will be key to this they said, and other clinicians highlighted the role of correctly measuring blood pressure and the consideration of iatrogenic harms (eg from prescribing certain drugs) to improve outcomes.

What needs to happen now?

The need for a strategic review was highlighted as an important first step for Scotland to achieve real improvement, to understand the current situation within services, pathways, and protocols within Scotland.

Once you have that national strategic review, out of that will follow everything: clinical guidelines, requirements for using data in an ongoing way, patient awareness and public awareness. I think I would start with that strategic document. Someone made a good point about it not being tokenistic, and I think it will require many conversations across Scotland, with GPs, patients in primary care, community pharmacy, because it's going to be delivered by a broad team. I think everything that's been discussed here would come out of that.

A clinician

A national strategy or approach by government and to hold the government to task was agreed to be a priority. Participants said this would enable benchmarking and oversight which is currently lacking. Meanwhile, having a designated team in government directly responsible for monitoring improvements was highlighted as "absolutely essential" by one clinician.

Another clinician said a national approach would address the current "mis-calibrated" situation in Scotland, where people receiving care in specialist clinics are not always those most in need:

Having a better national strategy and better implementation of the tools that we have to identify the people who are at greatest risk, get them in to meeting the right people to provide their care, and also allowing a safety net to allow people to be discharged from services back into the community so that you complete the loop, so that people are receiving the level of care that they require – that's a major aspiration, and it's one that requires data, education, joined up working, but I think it should be the ultimate aspiration.

A clinician



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About Kidney Research UK

As the leading kidney research charity in the UK, nothing is going to stop us in our urgent mission to end kidney disease. We're here to be heard, to make a difference, to change the future. Our ambition is to be bigger, faster, and bolder than ever before, and grounded in the hopes and needs of the kidney community.

Our purpose is to prevent kidney disease by finding ways to see it coming and stop it happening. We will protect people from reaching kidney failure by learning how to spot disease early, halting disease progression, and repairing kidney damage. We are determined to transform treatments by making dialysis easier and kinder, and making transplants last longer until better alternatives are available.

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kidney disease ends here.

