Citizen Participation and Public Petitions Committee
Wednesday 10 December 2025
19th Meeting, 2025 (Session 6)

PE2081: Make chronic kidney disease a key clinical priority

Introduction

Petitioner	Professor Jeremy Hughes on behalf of Kidney Research UK in Scotland
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to make chronic kidney disease a key clinical priority.
Webpage	https://petitions.parliament.scot/petitions/PE2081

1. The Committee last considered this petition at its meeting on 7 May 2025. At that meeting, the Committee agreed to write to the Cabinet Secretary for Health and Social Care.

2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.

3. The Committee has received new written submissions from the Minister for Public Health and Women's Health and the Petitioner, which are set out in **Annexe C**.

4. Written submissions received prior to the Committee's last consideration can be found on the petition's webpage.

5. Further background information about this petition can be found in the SPICe briefing for this petition.

6. The Scottish Government gave its initial response to the petition on 13 February 2024.

7. Every petition collects signatures while it remains under consideration. At the time of writing, 1,300 signatures have been received on this petition.

Action

8. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee
December 2025

Annexe A: Summary of petition

PE2081: Make chronic kidney disease a key clinical priority

Petitioner

Professor Jeremy Hughes on behalf of Kidney Research UK in Scotland

Date Lodged

31 January 2024

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to make chronic kidney disease a key clinical priority.

Previous action

In January 2023, a Holyrood exhibition invited MSPs to support a national action plan for chronic kidney disease (CKD) in Scotland.

A motion **(S6M-07555)** to mark the launch of our report Changing the future for chronic kidney disease in Scotland received cross party support from 47 MSPs.

Clinicians, peer educators, and patients took part in a parliamentary roundtable held in March 2023, attended by the then-Minister for Public Health.

In May 2023, we met with the Cabinet Secretary for Health.

Background information

Chronic kidney disease is common, with an estimated 600,000 people affected in Scotland, and can progress to dialysis or transplantation. It is silent, often undetected, and simply not on the agenda to the extent that it should be for policymakers, NHS leaders, and the public.

Ministers say they do not intend to publish more action plans for individual conditions. However, we believe a national Chronic Kidney Disease (CKD) action plan, similar to those for diabetes and heart disease (designated ‘clinical priorities’, and risk factors for CKD) is the ONLY way to ensure Scotland implements change to identify those at-risk of CKD, diagnoses CKD earlier, and prevents progression.

We believe the designation of CKD as a clinical priority will lead to the higher level of ministerial oversight and government input needed to achieve better health outcomes for people with kidney disease in Scotland.

Annexe B: Extract from Official Report of last consideration of PE2081 on 7 May 2025

The Convener: The next petition is PE2081, which was lodged by Professor Jeremy Hughes on behalf of Kidney Research UK in Scotland, and it calls on us to do exactly what it says on the tin, which is to urge the Scottish Government to make chronic kidney disease a key clinical priority.

When we previously considered the petition, on 15 May 2024, we agreed to write to the Cabinet Secretary for Health and Social Care to seek further clarity on the Scottish Government's approach to the designation of clinical priorities. We have received a response from the cabinet secretary that states that the Scottish Government does not have a list of conditions that are clinical priorities and that there are, therefore, no criteria for the designation of clinical priorities.

The cabinet secretary goes on to say that,

"even ... where there is no specific policy or strategy"

for an individual condition,

"the Scottish Government is still undertaking work to support all people living with long-term conditions to access the best possible care and support".

That includes, for example, a

"national policy on the reimbursement of electricity costs for home dialysis".

It is the Scottish Government's view that publishing more strategies for individual health conditions would not be the most effective way to improve care.

We have also received two submissions from the petitioner. The first responds to the cabinet secretary's letter and draws our attention to the existence of a clinical priorities team in the civil service with staff aligned to particular clinical conditions.

The petitioner's second submission provides an update on the work that Kidney Research UK has been doing to improve awareness, prevention, early detection, treatment and monitoring of chronic kidney disease in Scotland. That includes the launch of an action plan for Scotland and efforts to work constructively with the national health service and Government bodies to improve the lives of people with chronic kidney disease.

The petitioner remains concerned that there is no named civil servant to help to oversee and support the changes that are proposed in Kidney Research UK's action plan, and he has invited the cabinet secretary to intervene directly in the matter by attending a summit on chronic kidney disease. This is the first time that such an event has been convened in Scotland.

Those are two significant contributions from the petitioner in response to the cabinet secretary. Do colleagues have any suggestions for action?

David Torrance: I wonder whether the committee would consider writing to the Cabinet Secretary for Health and Social Care again, to highlight the petitioner's submissions and ask whether the Scottish Government will provide a dedicated team leader to support the recommendations that are set out in Kidney Research UK's "Chronic Kidney Disease: An Action Plan for Scotland"; what assurances the Scottish Government can provide that specific actions to improve the prevention, early diagnosis and treatment of chronic kidney disease will be included in the long-term conditions strategy; and whether the cabinet secretary and the Minister for Public Health and Women's Health will commit to attending Kidney Research UK's summit on chronic kidney disease.

The Convener: Do we know whether a date has been set for that summit? The clerk tells me that it is open at the moment. Do those suggestions from Mr Torrance meet the committee's approval?

Members *indicated agreement.*

The Convener: Thank you. We will keep the petition open and pursue the issue further in the way that Mr Torrance has suggested.

Annexe C: Written submissions

Minister for Public Health and Women's Health written submission, 20 May 2025

PE2081/F: Make chronic kidney disease a key clinical priority

Thank you for your letter of 9 May to Neil Gray, Cabinet Secretary for Health and Social Care. I am responding as Long Term Conditions, including Chronic Kidney Disease, as part of my portfolio.

Firstly, I want to assure you that the Scottish Government is committed to ensuring that all people living in Scotland with long term conditions including Chronic Kidney Disease (CKD) are able to access the best possible care and support, and benefit from healthcare services that are safe, effective and put people at the centre of their care.

As you know, the Scottish Government is currently consulting on a new long term conditions framework to better recognise the fact that many people living with long term conditions, including CKD need the same types of support and care, regardless of their condition. The consultation will provide a valuable opportunity for us to hear from individuals, organisations and members of the public to contribute their views and I welcome Kidney Research UK's participation in the early engagement work that officials have already undertaken with clinicians, patients, carers and third sector organisations to find out what matters to them.

The themes of the subsequent framework will be informed by the consultation responses we receive, and I would therefore welcome responses from Kidney Research UK, other organisations and patients who have CKD.

In regard to the specific point you raise on Clinical Priorities and the team within the Health and Social Care Directorates. The Scottish Government does not designate certain conditions as 'key clinical priorities'. While there is a Long Term Conditions Policy (formally Clinical Priorities) Unit in DG Health, the unit does not cover all major conditions, instead working on the implementation of specific policies established prior to the development work on the Long Term Conditions Framework. There is a separate Long Term Conditions Strategy Unit which is leading on the consultation mentioned above.

I was pleased to confirm that I will attend the Kidney Research Summit on Chronic Kidney Disease, and I look forward to hearing when the event will take place.

I hope this update provides some assurance of our commitment to those living with long terms conditions including CKD.

Regards

Jenni Minto MSP

Petitioner written submission, 26 November 2025

PE2081/G: Make chronic kidney disease a key clinical priority

Thank you for the opportunity to provide a further submission to Petition PE2081, calling for chronic kidney disease (CKD) to be recognised as a key clinical priority. CKD is common and largely symptomless in its early stages but early detection and intervention can prevent progression to kidney failure and reduce the significant associated cardiovascular risk to affected individuals. I am grateful to the Committee for its continued consideration of this important health issue and for seeking additional comment ahead of your meeting on 10 December 2025.

The healthcare landscape in Scotland is evolving with the Scottish Government developing the long-term conditions framework to manage all long-term conditions including CKD. A Government consultation has been held and the kidney community provided comprehensive input to this in July 2025.

I was pleased to hear MSPs from all parties offer support for motion S6M-18369 on recognising the impact of CKD during the debate held on 3rd September 2025. The adverse personal and economic impact of CKD upon individual constituents and the wider NHS was thoughtfully discussed.

The motion noted the belief that the **Scottish Government should include CKD as a dedicated strand within the long-term conditions strategy**. In her response to the motion it was gratifying to hear the Minister for Public Health and Women's Health Jenni Minto indicate that the government '*will soon announce the governance arrangements, including the role of the third sector and those with lived experience in the development of the framework's action plans*' as they '***develop the framework and the on-going action plans to improve services for people with long-term conditions, including CKD, especially highlighting inequalities***'.

CKD is typically silent and affects more than 10% of Scotland's adult population (600,000 people). CKD is closely linked to hypertension, diabetes, cardiovascular disease, obesity, frailty, and health inequalities. Despite this, FOI requests indicated that no health board in Scotland has accurate population data for the incidence or prevalence of CKD. Although the Scottish Government and MSPs now have crystal clarity regarding the adverse impact of CKD upon constituents and their families and carers, I would urge the committee to **strongly support the need for CKD to have an action plan embedded within the long-term conditions framework** to ensure that progress on early detection, disease coding, monitoring and effective treatment of CKD is made soon and maintained in the future.

This key message was powerfully reinforced in the Scotland CKD Summit held on 17th September 2025 and attended by the Minister for Public Health and Women's Health Jenni Minto and the Cabinet Secretary for Health and Social Care Neil Gray who spoke at the meeting. Presentations by patients, the parent of a teenager affected by CKD, researchers and primary and secondary care clinicians outlined the scale of CKD in Scotland but also what is needed and can be done to make a real sustained difference in the future.

It is evident that the successful implementation of the long-term conditions framework will need leadership at many levels but especially from experts in those long-term health conditions. In addition, clear and effective communication is needed between clinical experts and the Scottish Government to ensure success and progress. Despite previous correspondence between the Committee, the Scottish Government and Kidney Research UK, a central concern remains unchanged as **there is still no named national clinical lead for CKD** and **no dedicated civil service team member responsible for driving forward improvements in CKD prevention, diagnosis and care**.

This leadership gap has been repeatedly acknowledged in earlier letters. However, as of this submission, the Government has not provided clarity on who holds responsibility for CKD at a national level. This is in stark contrast to England where there is a National Clinical Director for Renal Medicine. Without defined accountability, progress will be inconsistent, and the health system will not be able to deliver the scale of improvement required. In my view, the absence of an identified national lead stands in stark contrast to the scale and complexity of the challenge of CKD in Scotland.

I welcome the reference to kidney disease within the emerging long-term conditions framework and the Government's acknowledgement of CKD as a significant population health issue. However, the inclusion of CKD in a broad framework does not replace the need for a specific action plan to drive progress in CKD: a condition that has been significantly overlooked compared to other long-term conditions such as cardiovascular disease. In addition, leadership will be key to delivering success.

The long-term conditions framework is a positive and holistic development for patients, yet it lacks:

- defined CKD-specific actions,
- implementation timelines, and
- clear accountability for delivery.

If not addressed, this will risk repeating the mistake made in 2004 when CKD was recognised but not prioritised for action by the Scottish Government of the time.

I respectfully repeat the core request of the petition: **that chronic kidney disease be designated a key clinical priority within the long-term conditions framework, together with the appointment of:**

1. **A named national clinical lead for CKD**, and
2. **A dedicated civil service lead with responsibility for CKD policy and delivery.**

This is consistent with how other major long-term conditions are managed at national level.

I remain very grateful to the Committee for its attention to this matter over the past two years. The burden of CKD continues to rise, and without dedicated national

leadership, Scotland risks falling further behind in prevention and care. I urge the Committee to support the petition's request and to recommend the appointment of the designated leaders required to deliver meaningful and sustained progress.

I would be happy to provide further evidence or speak with the Committee if that would be helpful.