Citizen Participation and Public Petitions Committee
Wednesday 7 May 2025
8th Meeting, 2025 (Session 6)

PE2081: Make chronic kidney disease a key clinical priority

Introduction

Petitioner	Prof 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 15 May 2024. 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 Cabinet Secretary for Health and Social Care 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 position on this petition on 13 February 2024.

7. Every petition collects signatures while it remains under consideration. At the time of writing, 1,275 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
May 2025

Annexe A: Summary of petition

PE2081: Make chronic kidney disease a key clinical priority

Petitioner

Prof 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 15 May 2024

The Convener: PE2081, on making chronic kidney disease a key clinical priority, which was lodged by Professor Jeremy Hughes, on behalf of Kidney Research UK in Scotland, 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.

The SPICe briefing notes that chronic kidney disease is a term that can be used to cover a range of kidney impairments, from a small loss of kidney performance with no symptoms to a life-threatening condition that requires regular dialysis or a kidney transplant.

In responding to the petition, the Scottish Government states that the relevant cabinet secretary and minister have previously corresponded with the petitioner to advise that Scottish Government does not intend to increase the number of health strategies for individual conditions at this time. It is noted that the Government's approach to clinical conditions policy is kept under regular review. The Government response also notes work to support people with kidney disease, including the launch of a national policy on the reimbursement of electricity costs for home dialysis for patients.

We have also received a submission from the petitioner, who is concerned that the Scottish Government's criteria for choosing what will and will not be designated a clinical priority remains unclear. The petitioner poses two specific questions: why is chronic kidney disease not already a clinical priority, and why has the Scottish Government taken the decision not to increase the number of health strategies for individual conditions or to assign the status of clinical priority, and the civil service support that goes with it, to any additional conditions. The petitioner also highlights the potential benefits to patients and the clinical community where a condition affecting them has been designated a clinical priority: for example, bringing clarity on who within the Scottish Government has day-to-day responsibility for developing condition-specific strategies and action plans.

Do any members have any comments or suggestions for action?

Maurice Golden (North East Scotland) (Con): We should write to the Cabinet Secretary for Health and Social Care to highlight the petitioner's submission and seek information on the criteria for determining clinical priorities; an explanation as to why chronic kidney disease is not already designated a clinical priority; and further detail on the Scottish Government's decision not to increase the number of health strategies for individual conditions, including chronic kidney disease.

The Convener: Yes, that responds directly to what I thought are two perfectly legitimate questions that the petitioner has raised: why is there not one already and what exactly are the criteria to determine why there cannot be any more? Is the committee agreed?

Members *indicated agreement*.

Annexe C: Written submissions

Cabinet Secretary for Health and Social Care written submission, 12 June 2024

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

Thank you for your letter of 20 May regarding Petition PE2081 – 'Make chronic kidney disease a key clinical priority', created by Professor Jeremy Hughes on behalf of Kidney Research UK in Scotland. You have asked for more information about:

- the criteria for determining 'clinical priorities';
- why chronic kidney disease is not already designated a 'clinical priority'; and
- the Scottish Government's decision not to increase the number of health strategies for individual conditions, including chronic kidney disease.

I believe there may have been a misunderstanding about how the Scottish Government approaches policy-making on long-term conditions that I hope my response can clarify.

I would like to make clear that the Scottish Government does not have a designated list of conditions that are 'clinical priorities' and therefore there is no set of criteria. Our policy work is driven both by policy need and by parliamentary and stakeholder interest. In some cases this results in policy work that is specific to individual conditions or groups of conditions, but even in cases where there is no specific policy or strategy, the Scottish Government is still undertaking work to support all people living with long-term conditions to access the best possible care and support to enable them to live longer in better health. An example of this for chronic kidney disease is the national policy on the reimbursement of electricity costs for home dialysis which we launched earlier this year to protect kidney dialysis patients from the impact of the cost of living crisis.

On the question of health strategies for individual conditions, there are already a number of these and we do not believe that publishing more of them is currently the most effective way to improve care. We keep our approach to policy-making in this area under regular review and engage with the input of partners such as Kidney Research UK, along with the views of people living with the conditions, in doing so. The Minister for Public Health and Women's Health met with Kidney Research UK on 5 June to listen to their views.

I hope this response is helpful.

Yours sincerely

NEIL GRAY

Petitioner written submission, 16 July 2024

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

Thank you for forwarding the 12 June written submission by the Cabinet Secretary for Health and Social Care to the above petition, and for giving me the opportunity to respond.

A central basis of our petition is, or has been, the existence of a clinical priorities team within the Scottish Government civil service whose members are aligned to particular clinical conditions. Our contention is that the named conditions chosen for that team to focus on are thus 'clinical priorities', and my petition seeks to add chronic kidney disease (CKD) to that list.

A response to a Freedom of Information request by the Scottish Government, albeit back in 2018, sets out roles and conditions that fall within the remit of the Clinical Priorities team: https://www.gov.scot/publications/foi-18-01678/.

Earlier this year my colleagues and I had reason to work with a very helpful official whose email signature identified their role as:

> Team Leader, [named condition 1 and named condition 2]
> Clinical Priorities
> Planning and Quality Division
> Scottish Government

I accept that it is possible that this team has been disbanded since the Spring of this year.

Although beyond the scope of my petition, we note that the Scottish Government does not want to publish more health strategies for individual conditions. However, there a number of extant strategies and action plans for conditions such as diabetes and heart disease, that are important, "Once for Scotland" documents that unify government, patients, and clinicians around a programme to reduce the burden of these conditions on individuals and the NHS.

We believe that there is both a demonstrable need for strategic innovative policy on CKD and parliamentary and stakeholder interest in taking such work forward.

Petitioner written submission, 24 April 2025

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

Since our last correspondence in July 2024, Kidney Research UK in Scotland and I have been working alongside clinicians, external stakeholders and patients, trying to encourage improvements in chronic kidney disease (CKD) awareness, prevention, early detection, treatment and monitoring and establishing accurate data on CKD incidence and prevalence in Scotland.

These areas are the focus of our coproduced Chronic Kidney Disease: An Action Plan for Scotland which was launched last November alongside the Minister for Public Health and Women's Health. Despite assurances from the minister that government will support this work, our experiences following the launch event have

left us with concerns around the policy priority being given to CKD and the growing number of people affected by it.

This contrasts with positive engagement with Public Health Scotland, one of the government's Deputy Chief Medical Officers and members of its Realistic Medicine team, NHS Inform, MSPs from across the chamber and representative groups of nurses, pharmacists and kidney doctors: all of whom are supportive of our action plan and its recommendations for change.

Despite our attempts to work constructively with NHS and government bodies to improve the lives of people with CKD, we continue to come up against barriers. This is largely down to the fact that there is still no named civil service team member responsible for CKD who can oversee and support the changes we all agree are needed.

We have not had the assurances we have sought from the Scottish Government that specific actions to improve the prevention, early diagnosis and treatment of CKD will be included in the upcoming long term conditions strategy. Recent announcements as part of NHS renewal, most notably the launch of a new GP enhanced service in cardiovascular disease (CVD), also do not currently appreciate that CKD is a leading cause of CVD, and with growing numbers of CKD patients in Scotland, CVD cannot be addressed without acting on CKD. We believe this is because CKD is still not considered a clinical priority area in Scotland.

We noted with interest the recent letter sent by the Public Health Minister to the Health, Social Care and Sport Committee which says audiology is now being considered a clinical priority area, with improvement work being progressed under the National Planning and Delivery Board and the Strategic Planning Board which sit under the NHS Chief Operating Officer. We take this to confirm our assertion that there is a list of named priority conditions, from which CKD – a condition thought to affect more than 600,000 people in Scotland – is excluded.

My colleagues and I have invited the Health Secretary to intervene directly, by taking part in a Scotland-first summit on CKD we plan to convene, to bring everyone into the same room to discuss what concrete steps we can take forward. At the time of writing, we have not yet heard back from the Cabinet Secretary's office.

We believe now more than ever that there is both a demonstrable need for government to actively support strategic and innovative policy on CKD, and both parliamentary and patient interest in taking such work forward.