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

## Petitioner written submission, 26 November 2025

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 <u>S6M-18369</u> on recognising the impact of CKD <u>during the debate held on 3<sup>rd</sup> September 2025</u>. 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 <u>dedicated strand</u> 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 17<sup>th</sup> 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.