

Citizen Participation and Public Petitions Committee
Wednesday 15 May 2024
9th Meeting, 2024 (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. This is a new petition that was lodged on 31 January 2024.
2. A full summary of this petition and its aims can be found at **Annexe A**.
3. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe B**.
4. Every petition can collect signatures while it remains under consideration. At the time of writing, 1,229 signatures have been received on this petition.
5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered.
6. Written submissions have been received from the Scottish Government and the Petitioner, which are included at **Annexe C** of this paper.

Action

7. The Committee is invited to consider what action it wishes to take on this petition.

Clerks to the Committee
May 2024

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.

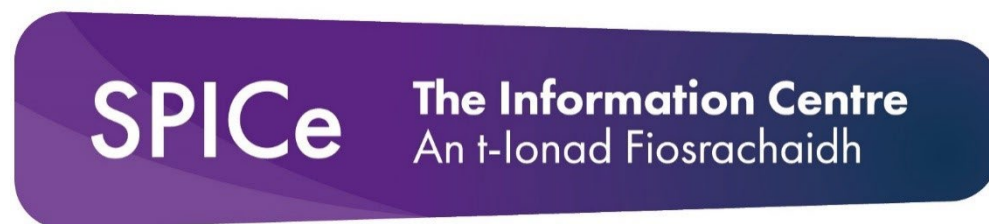
Background information

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: SPICe briefing on petition PE2081



Brief overview of issues raised by the petition

The petitioners are calling for the Scottish Government to produce an action plan for chronic kidney disease (CKD) to raise awareness and, in particular, clinical prioritisation of the condition.

A motion ([S6M-07555](#)) marked the launch of the Kidney Research UK in Scotland report '[Changing the future for chronic kidney disease in Scotland](#)'. The report was published in December 2022 and contains recommendations from a policy roundtable of patients and clinicians in Scotland.

[The report](#) makes recommendations under three headings: Groundwork – strategic overview of CKD management; a strategy for a national commitment for CKD; and pathways and patient support. (pp 7-8)

Chronic kidney disease (CKD)

CKD is a term 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.

[NHS Inform provides a range of information on symptoms, causes, diagnosis and treatment of CKD.](#)

According to the [Scottish Public Health Observatory](#) (ScotPHO) the main risk factors include diabetes, high blood pressure, acute kidney injury and heart disease.

Treatments include control of the condition through lifestyle changes, medications for high blood pressure and others to reduce cholesterol. In more severe CKD, phosphates can build up in the body and may require treatment. It is a disease which is 'staged' (as cancer is), and when someone is in a position where one or both of their kidneys has stopped working they can be treated with dialysis or transplant, or continue with medicines. Kidney failure rarely happens suddenly.

The table below shows what is meant by the 'staging' of kidney disease in descriptions, and refers to the level of kidney function. Stage 1 disease, which is 'good', does not mean that the kidneys will be working at 100% capacity, but any symptoms will be minimal. The link to the source provides further explanation.

Kidney function	CKD stage
Good	1
Mild loss of function	2
Mild or moderate disease	3a
Moderate to severe disease	3b
Severe disease	4
Kidney failure	5

[Source: PKD charity](#)

Data

There are no nationally reported data on CKD incidence in Scotland, and it is difficult to provide an accurate figure for incidence because some people will have kidney disease which has not been diagnosed. However, [a health economics report](#) “Chronic Kidney Disease in England: The Human and Financial Cost”, published by NHS England in 2017 states that:

“More than 1.8 million people in England have diagnosed chronic kidney disease (CKD). In addition, there are thought to be around a million people who have the condition but are undiagnosed. CKD can substantially reduce quality of life, and leads to premature death for thousands of people each year... . It is estimated that there are 40,000–45,000 premature deaths each year in people with CKD. A large proportion of deaths in people with CKD are due to cardiovascular events such as strokes and heart attacks.”

There is data on those receiving renal replacement therapy and on transplant operations (see below), but this does not capture all those with CKD. ScotPHO does provide some data, mainly on those receiving renal replacement therapy (RRT), that is, those with diagnosed renal failure that is severe enough to require RRT, as well as some covering comparison of international data.

Mortality

There are no national data on mortality caused by CKD. CKD mortality has been reported for a single health board region as part of the Grampian based GLOMMS-1 study ([Marks et al. 2013](#)).

Renal replacement therapy (RRT)

Data on renal replacement therapy (RRT) are collected by the [Scottish Renal Registry](#) and published in their [annual reports](#). The following information comes from the most recently available 2023 report (covering 2022 data).

Renal replacement therapy (RRT) includes kidney transplant, haemodialysis and peritoneal dialysis. In 2018, 112 patients per million population started RRT for established renal failure.

Incidence of RRT

In 2022, 543 people in Scotland (11 per 100,000 population) started renal replacement therapy (RRT) for established renal failure. The incidence of new patients starting RRT in 2022 was highest in those aged 65-74 years. The median age of patients starting RRT in 2022 across Scotland was 61 years. For the period 2014-22 the most common reason for starting RRT was diabetes.

Prevalence of RRT

On 31 December 2022 there were 5,601 patients receiving RRT in Scotland. The age group with the highest prevalence receiving RRT was those aged 65-74 years (215.6 per 100,000 population).

Kidney transplant

247 patients resident in Scotland received a kidney transplant in Scotland in 2022. Of these, 46 (19%) were pre-emptive, meaning they were performed before the patient had required any other form of RRT. In 2022, 37% of kidney transplants were from live kidney donors.

Mortality and survival

There has been a trend of improving survival for patients starting RRT. For example, 71.9% of patients starting RRT in 2009 survived 1 year, compared to 87.5% of patients starting RRT in 2021. However, the life expectancy of patients receiving RRT is shorter than that of the general population. The survival of patients is influenced by their age at the time of starting RRT, their primary renal diagnosis and by their level of social deprivation. ([ScotPHO](#))

The [Scottish Public Health Observatory](#) also collates information and data about many conditions, including chronic kidney disease (CKD). Their webpages also include the following on [UK and international data / comparisons](#):

“The two main sources of UK comparison data are historic QOF registers and the UK Renal Registry data. The prevalence of CKD (stage 3-5) in [QOF reports for England](#) in 2018/19 in England was 4.09 per 100 among those aged 18 years and above, compared to 3.08 per 100 in Scotland from [QOF calculator reports for 2018/19](#). The UK Renal Registry report RRT data for the UK (England, Scotland, Northern Ireland). Their [25th annual report](#) (for data up to the end of 2021) notes that the incidence rate of RRT among those aged 18 and over was 156 per million population in England and 131 per

million in Scotland. The prevalence of RRT among those aged 18 and over was 1314 per million population in England and 1207 per million in Scotland.”

ScotPHO also presents some [information on incidence and prevalence](#) in Scotland, but also highlights that:

“National reporting of CKD and Acute Kidney Injury (AKI) data is hampered by the fact that hospital discharge records are generally poor for identifying people with CKD ([Robertson et al. 2014](#)) and AKI ([Sawhney et al. 2015](#), [Kerr et al. 2014](#)) compared with laboratory data.

Policy context

The Scottish Government published the Scottish Primary Care Collaborative Summary - [Improving Care for People with Chronic Kidney Disease](#) in 2010. A [Donation and Transplantation Plan for Scotland 2021-2026](#) was published in 2021.

In [January 2024 the Scottish Government published information about a national policy to reimburse the electricity costs of home dialysis](#).

Clinical Guidelines

[NICE guidelines CG182](#). Chronic kidney disease in adults: assessment and management. 2015.

[NICE guidelines NG148](#) Acute kidney injury: prevention, detection and management. 2019.

The Renal Association. [Clinical Practice Guidelines](#).

The Renal Association. Clinical Practice Guidelines. [Planning, Initiating and Withdrawal of Renal Replacement Therapy](#) (627Kb). 2014

Anne Jepson

Senior Researcher Health and Social Care

23 February 2024

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at spice@parliament.scot

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

Annexe C: Written submissions

Scottish Government submission of 13 February 2024

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

Thank you for your email of 31 January regarding Petition PE2081 – ‘Make chronic kidney disease a key clinical priority’, created by Professor Jeremy Hughes on behalf of Kidney Research UK in Scotland.

I know that both the former Cabinet Secretary for NHS Recovery, Health and Social Care, Michael Matheson, and the Minister for Public Health and Women’s Health have previously written to Kidney Research UK explaining that the Scottish Government does not intend to increase the number of health strategies for individual conditions at this time. Rather, we are focussed on how best to support NHS boards to deliver high quality, value-based, person-centred care for everyone, irrespective of condition. Our approach to clinical conditions policy is something that we keep under regular review, and we are grateful to Kidney Research UK for sharing their views.

The Scottish Government continues to support people with kidney disease. We recently launched a national policy on the reimbursement of electricity costs for home dialysis for patients, to protect kidney dialysis patients from the impact of the cost of living crisis. The Minister for Public Health and Women’s Health appeared at a roundtable at the Scottish Parliament on 1 February to mark the launch of the policy and to hear from kidney patients directly about the impact of the cost of living crisis on them.

The policy was developed with input from Kidney Care UK, renal nurses and technicians who install dialysis equipment. It asks NHS boards to proactively identify patients receiving home haemodialysis, automated peritoneal dialysis and continuous automated peritoneal dialysis, and ensure they are reimbursed according to a set formula for the additional electricity costs of running their dialysis equipment. This policy will ensure that people who choose home dialysis will be reimbursed for their electricity costs, no matter where in Scotland they live. NHS boards will implement the policy and the Scottish Government will review it in 6-12 months to ensure it is providing the support intended.

We want all people living with long-term conditions to access the best possible care and support to enable them to live longer in better health. We will continue to work with stakeholders, people with lived experience, academic experts, and clinicians to achieve improvements.

I hope this information is helpful.

Healthcare Quality and Improvement Division: Clinical Priorities

Petitioner submission of 13 March 2024

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

Thank you for forwarding the response of 13 February to the petition from the Scottish Government's Healthcare Quality and Improvement Division: Clinical Priorities team, and for giving me the opportunity to comment.

The Scottish Government has chosen certain clinical conditions to be clinical priorities with dedicated civil service support for continuing policy development and delivery in these areas.

The criteria for choosing what will, and what will not, be designated a clinical priority is unclear to us and has evidently not been based on disease incidence or impact alone.

We believe there is an undoubted clear benefit to patients and the clinical community where the condition affecting them has been designated as a clinical priority as this brings real clarity on who has day to day responsibility within the Scottish Government. In recent years, important condition-specific strategies and action plans seem most likely to have been developed and delivered for conditions that have clinical priority status, such as cancer, diabetes and heart disease.

Chronic kidney disease affects, or is a risk factor for, comparable numbers of people in Scotland.

As stated in my petition, the kidney disease clinical, research and patient community believes that chronic kidney disease policy and services would benefit from being given the status of clinical priority.

The response from the Scottish Government, which we are interested to see comes from the government division and team whose support we would very much like to have, does not address our two core questions – the answers to which may help the Committee in their consideration of my petition:

Why is chronic kidney disease not already a clinical priority?

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?

Without knowing the criteria used, it seems arbitrary and inequitable to patients to close the door on adding any new conditions to those not already designated as clinical priorities.