Briefing for the Citizen Participation and Public Petitions Committee on petition <u>PE2081</u>: Make chronic kidney disease a key clinical priority, lodged by Professor Jeremy Hughes on behalf of Kidney Research UK in Scotland

# 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 '<u>Changing the future for chronic kidney disease in Scotland</u>'. The report was published in December 2022 and contains recommendations from a policy roundtable of patients and clinicians in Scotland.

<u>The report</u> 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 <u>Scottish Public Health Observatory</u> (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 diagnosedHowever, <u>a health</u> <u>economics report</u> "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 (<u>Marks et al. 2013</u>).

### Renal replacement therapy (RRT)

Data on renal replacement therapy (RRT) are collected by the <u>Scottish Renal</u> <u>Registry</u> and published in their <u>annual reports</u>. 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 <u>Scottish Public Health Observatory</u> also collates information and data about many conditions, including chronic kidney disease (CKD). Their webpages also include the following on <u>UK and international data /</u> <u>comparisons:</u>

"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 <u>QOF reports for England</u> 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 <u>QOF calculator reports for 2018/19</u>. The UK Renal Registry report RRT data for the UK (England, Scotland, Northern Ireland). Their <u>25th annual report</u> (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 <u>information on incidence and prevalence</u> 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 (<u>Robertson et al. 2014</u>) and AKI (<u>Sawhney et al. 2015</u>, <u>Kerr et al. 2014</u>) 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**

<u>NICE guidelines CG182</u>. Chronic kidney disease in adults: assessment and management. 2015.

<u>NICE guidelines NG148</u> Acute kidney injury: prevention, detection and management. 2019.

The Renal Association. Clinical Practice Guidelines.

The Renal Association. Clinical Practice Guidelines. <u>Planning, Initiating and</u> <u>Withdrawal of Renal Replacement Therapy</u> (627Kb). 2014

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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

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