

# A national study of practice patterns in UK renal units in the use of dialysis and conservative kidney management to treat people aged 75 years and over with chronic kidney failure

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## Scientific summary

CKMAPPS – patterns of conservative care in UK renal units

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# Scientific summary

## Background

Conservative kidney management (CKM) is increasingly recognised as an alternative treatment option to dialysis for older adults with multimorbid stage 5 chronic kidney disease (CKD5). CKM is management of CKD5 without dialysis and it has two main phases:

- i. early conservative care – CKM is opted for and this is the time before clinical manifestations of the kidney disease occur that would have triggered dialysis if that had been the chosen mode of care
- ii. alternative to dialysis – care after this time point.

End-of-life and bereavement care are part of both CKM and dialysis pathways. There are no data across UK renal units on the way CKM has been developed or how it is delivered. A better understanding of patients' and clinicians' needs and values, and of the timing and organisation of CKM, would inform service development and health policy.

## Study aim

To determine the practice patterns for the CKM of older patients with CKD5, to inform service development and future research.

## Objectives

- i. To describe the different approaches and variation between renal units in the extent and nature of CKM (staff interview study, survey).
- ii. To explore how and when decisions are made in renal units about the main treatment options for older patients with CKD5, and what are the main clinical and patient factors that influence the decisions (staff interview study, survey, patient interview study).
- iii. To explore clinicians' willingness to randomise patients with CKD5 to CKM versus dialysis and to assess the feasibility of a subsequent prospective study (survey).
- iv. To describe the interface between renal units and primary care in managing CKD5 patients [staff interview study, survey, general practitioner (GP) interview study, data linkage].
- v. To identify the resources involved and potential costs of CKM (staff interview study, survey).

## Methods

This was a mixed-methods study divided into five parts:

1. patient interview study: a qualitative study in nine renal units with patients with CKD5 aged 75 years and over, exploring their experiences of choosing between CKM and dialysis
2. staff interview study: a qualitative study in the same nine renal units exploring the views and experiences of staff members who provide care for CKD5 patients
3. survey: a national survey of all UK renal units assessing the delivery of CKM

4. data linkage: linking data on new CKD5 patients aged 75 years and over from laboratory records with renal unit patient data, achieved in three of the nine renal units
5. GP interview study: a qualitative study of GPs exploring their views and experiences of managing CKD patients and referring patients to four of the renal units.

### **Interview studies**

These three studies were undertaken in a purposive sample of UK renal units that were selected based on a previous estimate of the scale of their CKM programme and geographical spread.

### **Patient**

Semistructured interviews were carried out in nine renal units with a purposive sample of patients with CKD5 aged 75 years and over, selected by unit staff in three groups: (1) those who had opted for a CKM pathway, (2) those who had opted to have dialysis in the future but had not yet started dialysis (pre-dialysis pathway) and (3) those who were established on dialysis (dialysis pathway). Patients were interviewed using a semistructured interview guide.

### **Staff**

In the same units, clinical directors identified staff members who were involved in the care of CKM patients. For units that had very few CKM patients, staff were recruited who cared for patients in low-clearance clinics or for those whose estimated glomerular filtration rate (eGFR) was less than 20 ml/minute/1.73 m<sup>2</sup>. Staff members included a minimum of one lead nephrologist and one nurse per unit. Participants were interviewed using a semistructured interview guide.

### **General practitioners**

General practitioners were identified from general practices in the catchment areas of four of the nine renal units. Interviews were carried out by telephone using a semistructured interview guide.

### **Qualitative analysis**

A similar approach was used in all three studies. Interviews were audio-recorded and transcribed verbatim by an independent transcriptionist, and checked by the interviewer to ensure accuracy. Thematic analysis was used to analyse the transcripts.

For the staff interviews, a content analysis of all 60 interviews was undertaken as well as a more detailed thematic analysis in 28 interviews sampled using maximum variation sampling to ensure variation of units and experience of being involved with renal patients.

### **Survey**

The content of the survey was developed using existing literature, findings from the staff qualitative study and feedback from the steering group. It focused on the management of patients aged 75 years and over with CKD5 with whom a decision had been made not to start dialysis. Data analysis was conducted using basic statistics and cross-tabulation to explore the relationship between practice patterns and selected key factors.

### **Data linkage**

The same nine renal units were contacted to identify an information technology (IT) professional who could obtain patient data. Data sets were requested from the renal unit and its associated biochemistry laboratory. Laboratory data identified patients aged 75 years and over with two eGFR results < 15 ml/minute/1.73 m<sup>2</sup> at least 3 months apart on record for the first time between January 2010 and June 2011. Laboratory data were matched with data from their respective renal units by an IT professional to identify patients with new CKD5 who were known to a renal unit. Cross-matched data were sent to the research team for them to identify patients with CKD5 not known to renal units. Approval was obtained from the National Information Governance Board and the linkage was undertaken in a secure setting at the UK Renal Registry.

## Results

### *Patient interview study*

Forty-two patients were interviewed, 14 in each category. Four themes emerged: (1) patients' understanding of the management of CKD; (2) patients' perceptions of their CKD; (3) patients' experiences of making a management decision for their CKD; (4) patients' experiences of revising management decisions.

While all categories of CKD patients considered the same factors when making a treatment decision, patients who chose different treatments held contrasting beliefs about what dialysis could offer. These beliefs appeared to be influenced by the information provided by renal staff, which differed between units, particularly in regard to CKM. Few patients were aware of CKM as an option if they had not chosen it, although patients from units with a more established CKM pathway were more aware. While most acknowledged the severity of their CKD, some CKM patients did not appear to think of their CKD as serious, despite information from staff.

There was a divide between CKM patients and dialysis/pre-dialysis patients in their belief about whether or not they would live longer on dialysis and whether their quality of life would be better or worse on dialysis. Information from units with less established CKM pathways focused on the number of additional years a patient could live on dialysis. Patients from units with more established CKM pathways were told that living longer on dialysis was not a guarantee and that choosing CKM was 'not unusual'.

Overall, few patients reported speaking to staff about the future, in terms of the consequences of either starting dialysis or receiving CKM. Patients from units with more established CKM pathways had discussed the future with renal staff and some indicated that they had begun conversations about advanced care planning. For others, being unaware of how their disease was likely to progress added to misperceptions about their CKD and the need for dialysis.

### *Staff interview study*

Twenty-eight detailed analyses were performed, based on interviews with 14 nephrologists, nine renal nurses and five allied health professionals. Three themes emerged: (1) providing CKD care; (2) discussing management options with patients (preparation for renal replacement therapy/CKM); (3) working with other health-care professionals to care for patients approaching the end of life.

Staff generally accepted CKM as a treatment option. Most staff found it difficult to assess if a patient was suitable for CKM, but all supported having open discussions informing patients of their treatment options, and ensuring family members were involved.

Decision-making about treatment options, including CKM, was acknowledged as challenging for both patients and staff. Some CKM patients subsequently changed their minds and had dialysis, and many staff emphasised the importance of revisiting patients' decision over time. Having a good relationship with the patient and interpersonal continuity were reported as facilitating good decision-making.

Towards the end of their life, many CKM patients were referred back to their GP. Staff felt it was vital for renal units to care for CKM patients in collaboration with the primary, community and palliative care teams, while providing teams with renal-specific education.

### *General practitioner interview study*

Of 353 GPs invited, 25 responded and 19 were interviewed, three to six in each of the four renal unit catchment areas. Five themes emerged: (1) managing CKD in primary care; (2) explaining CKD to patients; (3) getting advice on managing CKD; (4) referring patients with CKD to secondary care; (5) managing CKM patients and palliative care.

Previous experience of treating patients with CKD was a good indicator of how familiar GPs were with guidelines and when to refer. Some GPs had little experience of managing patients with stage 4 chronic kidney disease (CKD4) or CKD5. GPs with older patient populations felt more comfortable managing patients with CKD, who were usually older adults with comorbidities. All felt that patients with CKD4 and 5 would be aware of their CKD and were happy to be referred.

Most GPs reported that they had good communication with their local renal units. They sought advice about when to refer and how to manage patients who were not referred or had been discharged. Referral practice was influenced by the eGFR level and rate of decline, the well-being of the patient, age, comorbidities and occasionally the distance to the renal unit. Most GPs identified older adults with multiple comorbidities as patients for whom referral decisions were more difficult.

Most had little experience of palliative care for CKM patients. Those who had experience were comfortable with this as long as the patient had made an informed decision in secondary care that had been communicated to primary care.

### Survey

Of the 71 renal units in the UK, 67 (94%) responded. All but one had an 'alternative to dialysis' pathway. A range of terminology was used, 'conservative management' being most frequent. Only 52% of units reported numbers of CKM patients, and the very wide range (0–152) implied a lack of an agreed definition for CKM and differing interpretation of the designation 'CKM'. This hampered evaluation of these data. The number of patients reported who were at a stage equivalent to postdialysis was small (median 8).

Conservative kidney management practice patterns varied across units: some showed considerable investment of staff time with evidence of dedicated clinics, a written CKM guideline and staff training initiatives. Only one quarter of units had clinics exclusively for CKM patients.

Similar criteria were used across units to assess suitability patients for CKM, foremost being patients' preference. The CKM decision-making process was similar across units. Most undertook informed, shared decision-making, presenting treatment options including CKM to all patients with CKD5 aged 75 years and over. Decision aids were widely used, both locally and nationally produced. Family and carers were actively involved in decision-making. After the initial CKM decision, the decision was reviewed at clinic visits. All units had patients who had changed their mind after deciding not to have dialysis, although they could not quantify them.

Only a minority of units had funding dedicated to CKM. This was modest (median £40,000). Most CKM care is funded out of the overall renal budget. Having funding was associated with greater numbers of CKM patients; however, our survey could not identify cause or effect.

All responding units worked collaboratively with primary and palliative care teams; many provided GPs and their practice team with information or advice regarding CKM patients, and all liaised with palliative care services for patients approaching the end of life.

Many units felt that increasing communication and involvement with GPs, community teams and palliative care teams was very important to improve CKM. Information sharing was reported as vital for better collaborative work, with integration of primary care and renal unit data. All units had some staff trained in palliative or end-of-life care but the extent varied widely.

Lack of funding and time was an issue for many units. Although many units thought that more funding could help develop CKM services, only a minority were planning to apply for funding.

There was strong support for further research into the relative benefits and costs of CKM and dialysis. There was almost universal support for an observational study and 18 units reported being definitely willing to participate in a randomised clinical trial.

### **Data linkage**

Compatible data from both laboratory and renal units allowed linkage in only three units. One per cent, 9% and 18% of patients with incident CKD5 were not known to those three renal units. These limited data suggest that most patients with CKD5 are known to local renal units, and that GPs were referring most patients, though this requires further confirmation.

## **Conclusions**

The findings support the following conclusions:

- Conservative kidney management is widely recognised and delivered across the UK, but through differing models of care and sizes of CKM programmes.
- An agreed terminology and definition of CKM are needed to enable future evaluation.
- The designation of a patient as having CKM must recognise two key points on the CKM pathway: (1) stating an informed preference or intention to opt for conservative care rather than have dialysis in the future, made at an unspecified level of kidney function and time before dialysis is indicated, and (2) a decision to reaffirm or opt for CKM made at a level of kidney function or despite symptoms that would otherwise justify starting dialysis.
- Communication and information given to patients with CKD5 should (1) support patients and their carers/families to understand the underlying kidney disease, (2) routinely include details of the CKM pathway, (3) include realistic discussions of what is likely to happen in the future and (4) recognise that decision-making in this setting is a process rather than an event and that decisions need to be reviewed periodically.
- Renal staff need education and training in (1) advanced communication skills, adapted to include the specific issues around dialysis decision-making, and (2) how to discuss and address palliative and supportive care needs.
- Research is required to measure the benefits and costs of CKM and dialysis, and to inform decision-making by staff, patients and their families.

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