Instruction

Thank you for completing this survey

This questionnaire asks about how you treat patients in your unit aged 75 years and over with advanced chronic kidney disease who do not have dialysis.

Many of the questions address practice patterns that may vary among staff members in your unit. Please try to give the answer that is most representative of the unit as a whole (i.e. the whole renal service including satellite units).

In order to complete this questionnaire, you may want to consult other members of the renal team or to delegate this task to a more appropriate person who has responsibility for such patients (e.g. you will be asked who has received CKM training; how many full time equivalent hours are allocated to CKM for your staff). For some questions, you will need to retrieve unit data (e.g. you will be asked the number of patients aged 75 years and over on CKM; the amount of funding your unit received for CKM in the last financial year). The questionnaire will take about 40 minutes to fill in. You may find the survey is rather lengthy; however, we tried to limit the number of questions as much as possible.

Instructions for completing the questionnaire
• Please answer each question by ticking the box.
• In most cases you will only have to tick one box
but please read the directions carefully, as occasionally you may need to tick more than one box.
• By clicking the 'next' or 'done' button your answers will be saved automatically. You can leave the survey and resume it later. You can also edit your survey at any time even after you click the 'done' button.
• The survey can be completed by multiple respondents. If you would like someone else to continue to fill in the survey, you can forward the web link to the next person. However, the survey should not be opened and filled in by more than one person simultaneously. Please also note that you will still have only a single response registered per unit even if it is completed by multiple respondents.

We would be very grateful if you could complete the survey by Friday 19th April.

Prof Paul Roderick (Chief investigator) Professor of Public Health, University of Southampton
Dr Hugh Rayner Consultant Nephrologist, Heart of England NHS Foundation Trust

If you have any queries regarding this questionnaire, please contact:
Sarah Tonkin-Crine on 023 8024 1080, S.K.Tonkin-Crine@soton.ac.uk
or
Dr Ikumi Okamoto on 023 8079 5734, io@soton.ac.uk

This survey has been developed with the support of CKMAPPS steering committee group members.

Professor Julia Addington-Hall
Dr Fergus Caskey
Dr Rob Elias
Professor Ken Farrington
Dr Richard Fluck
Dr Roger Greenwood
Dr Geraldine Leydon
Fiona Loud
Beverley Matthews
Dr Natasha McIntyre
Emma Murphy
Dr Fliss Murtagh
Dr Donal O'Donoghue
Dr Charlie Tomson
Dr Ian Wilkinson

Questions regarding CKD in your unit

Before asking questions regarding conservative care in your unit, we would like to know how your unit is organised with regard to patients with CKD in general.

In order to supplement the data publicly available from the UK Renal Registry, please answer the following questions.

***1. Please choose your centre from one of the renal centres listed below in alphabetical order**

Renal centre

2. How many FTE (full time equivalent) consultants (including CKD, dialysis and transplant) do you have working in nephrology in your unit?

_ _._ FTE

(e.g. 60% clinical work with no academic/research activity and no general medicine responsibility = 0.6 FTE)

***3. Do you have a Multi-Skilled Renal Team (MSRT) available to manage patients approaching RRT in your unit?**

- ◯ Yes
- ◯ No

Questions regarding CKD in your unit

4. Do you have regular MSRT meetings?

- ◯ Yes
- ◯ No

Questions regarding CKD in your unit

5. If yes, how often do you have the meetings?

- ◯ Once a week
- ◯ Once a fortnight
- ◯ Once a month
- ◯ Other (please specify)

Questions regarding CKD in your unit

*6. Which of the following staff members are involved in your MSRT and usually attend the MSRT meeting?

Please tick all that apply in each column below

	Staff involved in MSRT	Staff who usually attend MSRT meeting
Consultant nephrologists	☐	☐
Renal registrars	☐	☐
Renal nurses	☐	☐
Palliative care consultants	☐	☐
Palliative care registrars	☐	☐
Renal palliative care clinical nurse specialists	☐	☐
Surgeons	☐	☐
SAS grade doctors	☐	☐
Diabetes nurses	☐	☐
Social workers	☐	☐
Occupational therapists	☐	☐
Physiotherapists	☐	☐
Dieticians	☐	☐
Pharmacists	☐	☐
Psychologists	☐	☐
Pre-dialysis education providers	☐	☐
Anaemia nurses	☐	☐
Vascular access coordinators	☐	☐
Counsellors	☐	☐
Other	☐	☐

Please specify

*7. Do you run clinics for CKD patients in neighbouring hospitals?

◯ Yes

◯ No

Questions regarding CKD in your unit

8. How many neighbouring hospitals do you serve?

Please enter number

9. In how many of the neighbouring hospitals do you have renal clinics?

Please enter number

***10. Do you have a pre-dialysis clinic or equivalent for managing patients approaching RRT?**

- ◯ Yes
- ◯ No
- ◯ No, but we are planning to set up similar clinics

Questions regarding CKD in your unit

***11. Do all consultants who have CKD patients use the pre-dialysis clinic?**

- ◯ Yes
- ◯ No

Questions regarding CKD in your unit

12. Why don't all consultants who have CKD patients use the pre-dialysis clinic? Please tick one

- ◯ Because some consultants think that long-term continuity of care by the same consultant is more important.
- ◯ Because some consultants' clinics are at one of a neighbouring hospitals and the pre-dialysis clinic is in the main hospital. They don't want their patients to travel to the main hospital.
- ◯ Other (Please specify)

13. What percentage of the outpatients under follow up in your renal clinic, who are approaching dialysis, receive the following?

	≤25%	26-50%	51-75%	76-100%
Nurse-led education	◯	◯	◯	◯
Home visit	◯	◯	◯	◯
Trained counsellor/psychologist input	◯	◯	◯	◯
OT and/or social work input	◯	◯	◯	◯

Questions regarding CKD in your unit

14. How is pre-dialysis education delivered in your unit?

Please tick all that apply

- [ ] Consultant/registrar consultation
- [ ] DVD education materials to take home
- [ ] Written material to take home
- [ ] Translated (if appropriate) written material (except Welsh)
- [ ] Computer-based education programme
- [ ] Group session with other pre-dialysis patients
- [ ] Talk from a patient on conservative care
- [ ] Talk from a patient on centre HD
- [ ] Talk from a patient on home HD
- [ ] Talk from a patient on PD
- [ ] Talk from a patient with functioning transplant
- [ ] Cultural/language-matched nurse educators
- [ ] Flexibility to allow extra education time for those who need it
- [ ] Visit to an HD unit
- [ ] Formal case-by-case MSRT discussion
- [ ] Other (please specify)

15. Do you have a pre-dialysis education day?

- ◯ Yes
- ◯ No

*Group session with other pre-dialysis patients

Questions regarding CKD in your unit

16. Which of the following topics are usually covered during the pre-dialysis education day?

Please tick all that apply

- [ ] Types of dialysis
- [ ] Transplantation
- [ ] Conservative care
- [ ] Side effects
- [ ] Medicines
- [ ] Dietary restrictions
- [ ] Fluid balance
- [ ] CKD-related anaemia
- [ ] Renal bone disease
- [ ] Cardiovascular risk factors
- [ ] Sexual matters
- [ ] Psychological support
- [ ] Other (please specify)

***17. Do your consultants share responsibility for patients with each other?**

Please tick one

- ◯ Yes, they share responsibility for all patients
- ◯ No, they work on a named-patient basis
- ◯ They share responsibility for most patients but take a lead role for individual patients with particular needs
- ◯ Other (Please specify)

Availability of an alternative to dialysis

The following questions ask you about conservative care in your unit

***18. Does your unit ever have patients with CKD5* where an active decision is made not to dialyse even when they are symptomatic?**

- ◯ Yes
- ◯ No

*CKD5 is an eGFR less than 15 ml/min for at least 3 months (established kidney failure)

Availability of an alternative to dialysis

***19. How does your unit follow up patients with CKD5 where a decision is made not to dialyse?**

Please indicate the approximate percentages followed up as specified below. Totals do NOT need to add up to 100%.

	≤25%	26-50%	51-75%	76-100%	N/A
In a dedicated programme with its own clinic for those patients	◯	◯	◯	◯	◯
In a pre-dialysis clinic/low clearance clinic	◯	◯	◯	◯	◯
In a general nephrology clinic	◯	◯	◯	◯	◯
Patients are referred back to primary care and unit provides care in collaboration with GPs	◯	◯	◯	◯	◯
Other	◯	◯	◯	◯	◯

(Please specify and indicate percentage)

20. What words do you most commonly use in your unit when referring to the care of patients with CKD5 where a decision is made not to dialyse?

Please tick one.

- ◯ Conservative kidney management
- ◯ Conservative management
- ◯ Conservative care management
- ◯ Maximum conservative management
- ◯ Non-dialysis care
- ◯ Supportive care
- ◯ Palliative care
- ◯ Other (Please specify)

***21. Do all consultant nephrologists follow the same practice regarding patients with CKD5 where a decision is made not to dialyse?**

- ◯ Yes
- ◯ No

Availability of an alternative to dialysis

22. How much do they differ?

Please tick one

- ◯ Slightly
- ◯ Moderately
- ◯ Greatly
- ◯ Other (Please specify how)

***23. How do they differ?**

Availability of an alternative to dialysis

***24. Please explain why you always offer RRT to patients irrespective of their comorbidities.**

***25. Please add any additional thoughts on care for patients with CKD5 where a decision is made not to dialyse.**

The development and implementation of conservative care in your unit

In the following questions, the term ‘conservative care’ will be used to describe the situation where a decision is made not to dialyse. Although different terminology may be used in your unit, please answer the questions with this patient group in mind.

26. Is there a written guideline for how to manage patients on conservative care (other than a palliative care/symptom control guideline)?

- ◯ Yes
- ◯ No, but in preparation
- ◯ No

The development and implementation of conservative care in your unit

27. Which staff member(s) predominantly led the development of this policy?
Please tick all that apply

- ☐ Consultant nephrologist
- ☐ Consultant in palliative care
- ☐ Renal nurse
- ☐ Palliative care nurse within the renal unit
- ☐ Palliative care nurse from community team/other hospital department
- ☐ Other (Please specify)

28. Is there a single person or team primarily responsible for conservative care in your unit?

- ◯ Yes
- ◯ No

The development and implementation of conservative care in your unit

29. What is their position?
Please tick all that apply

- ☐ Consultant nephrologist(s)
- ☐ Palliative care consultant(s)
- ☐ Nurse(s)
- ☐ Other (Please specify)

***30. Does your unit provide renal staff with formal training or education regarding conservative care?**

- ◯ Yes
- ◯ No, in preparation
- ◯ No

The development and implementation of conservative care in your unit

31. Approximately what percentage of the following staff members have received the training?

	≤25%	26-50%	51-75%	76-100%	N/A
Consultant nephrologists	◯	◯	◯	◯	◯
Renal registrars	◯	◯	◯	◯	◯
Renal nurses	◯	◯	◯	◯	◯
Diabetes nurses	◯	◯	◯	◯	◯
Social workers	◯	◯	◯	◯	◯
Occupational therapists	◯	◯	◯	◯	◯
Physiotherapists	◯	◯	◯	◯	◯
Dieticians	◯	◯	◯	◯	◯
Pharmacists	◯	◯	◯	◯	◯
Psychologists	◯	◯	◯	◯	◯
Pre-dialysis education providers	◯	◯	◯	◯	◯
Anaemia nurses	◯	◯	◯	◯	◯
Vascular access coordinators	◯	◯	◯	◯	◯
Counsellors	◯	◯	◯	◯	◯
Management/administrative staff	◯	◯	◯	◯	◯
Other	◯	◯	◯	◯	◯

(Please specify and indicate percentage)

The development and implementation of conservative care in your unit

32. Why is formal training or education regarding conservative care not provided for your staff?

Please tick all that apply

- [ ] Lack of funding
- [ ] Lack of time
- [ ] Lack of appropriate person to organise the training
- [ ] Consultants' lack of interest in the training
- [ ] Clinical director's lack of interest in the training
- [ ] Other staff members' lack of interest in the training
- [ ] We do not need formal training as conservative care is an ingrained culture in the unit
- [ ] Other (Please specify)

The development and implementation of conservative care in your unit

***33. How did each of the factors listed below influence the development of the conservative care programme in your unit?**

Please indicate if each of the factors below positively or negatively influenced the development of the conservative care programme.

	Positively influenced	Negatively influenced	No effect
Frequency of late referrals	◯	◯	◯
Nephrologists' attitudes towards conservative care	◯	◯	◯
Nurses' attitudes towards conservative care	◯	◯	◯
Other unit staff's attitudes towards conservative care	◯	◯	◯
Patient/family/carers' attitudes towards conservative care	◯	◯	◯
Attitudes of people from different ethnicity/culture towards conservative care	◯	◯	◯
Availability of staff experienced in conservative care	◯	◯	◯
Availability of funding specifically for conservative care	◯	◯	◯
Payment-by-Results tariff for dialysis	◯	◯	◯
Other	◯	◯	◯

(Please specify)

***34. In calendar year 2012, approximately how many CKD5 patients aged 75 and over were cared for by your renal service?**

(Please exclude patients with a failing kidney transplant)

Please enter number

35. Of those, how many were on conservative care and followed up in your unit?

If you don't know the number, please answer the next question instead.

Please enter number

36. Of those, approximately what % were on conservative care and followed up in your unit?

- ◯ 0%
- ◯ 1-9%
- ◯ 10-19%
- ◯ 20-29%
- ◯ 30-39%
- ◯ 40-49%
- ◯ 50-59%
- ◯ 60-69%
- ◯ 70-79%
- ◯ 80-89%
- ◯ 90-99%
- ◯ 100%
- ◯ Don't know. (please tell us why not)

***37. In 2012, how many patients aged 75 and over in your unit chose to have conservative care, became symptomatic of advanced CKD and did not have dialysis?**

Please enter number

If you don't know, please tell us why not.

***38. Does your unit have staff whose time is specifically allocated for CKD 5 patients on conservative care?**

- ◯ Yes
- ◯ No

The development and implementation of conservative care in your unit

39. How much time do the following staff have specifically allocated for CKD 5 patients on conservative care?

Please enter number of full-time equivalent (FTE) hours for each discipline.

(e.g. If you have two nurses with 0.5 FTE, enter 1.0)

Consultant nephrologists	
Renal registrars	
Renal nurses	
Diabetes nurses	
Social workers	
Occupational therapists	
Dieticians	
Pharmacists	
Psychologists	
Pre-dialysis education providers	
Anaemia nurses	
Vascular access coordinators	
Counsellors	
Management/administratie staff	
Other (Please specify and enter number of FTE hours)	

***40. Do you have clinics exclusively for CKD 5 conservative care patients?**

- ◯ Yes
- ◯ No

The development and implementation of conservative care in your unit

41. How often do you run conservative care clinics in your renal unit and outside the main renal unit?

Please tick one for each row

	Once a week	Once a fortnight	Once a month	Other	N/A
In your renal unit	◯	◯	◯	◯	◯
Outside the main renal unit	◯	◯	◯	◯	◯

If other is chosen please give details

The development and implementation of conservative care in your unit

42. Where are CKD 5 patients receiving conservative care most commonly seen or followed-up by clinical staff?

Please tick one

- ◯ In a general nephrology clinic
- ◯ In a pre-dialysis clinic/low clearance clinic
- ◯ In own home by renal team
- ◯ In own home by GP/community team
- ◯ At GP surgery
- ◯ Telephone clinics run by renal unit
- ◯ Other (Please specify)

The development and implementation of conservative care in your unit

43. How often are your CKD 5 conservative care patients most commonly seen?

Please tick one for each row

	Weekly	Monthly	3 monthly	6 monthly	Other
Symptomatic patients	◯	◯	◯	◯	◯
Asymptomatic patients	◯	◯	◯	◯	◯

If other is chosen please give details

***44. What are the key components of conservative care provided to patients in your renal service?**

Please tick all that apply

- [ ] Clinic consultations
- [ ] Blood results review
- [ ] The provision of EPO (erythropoietin) and iron therapy
- [ ] Symptom assessment and management
- [ ] Prescription of medication for renal symptoms (fluid retention, itching, etc)
- [ ] Telephone support for patients
- [ ] Telephone support for carers
- [ ] Home visits by renal staff
- [ ] Dietary advice
- [ ] Social circumstances review by social workers attached to the renal unit or hospital
- [ ] Advice on home environment by occupational therapist attached to the renal unit or hospital
- [ ] Advanced care planning
- [ ] Communication with primary care team for Gold Standards Framework approach
- [ ] Psychological support
- [ ] Other (Please specify)

***45. Do you have any funding dedicated to providing conservative care in your renal service?**

- ◯ Yes
- ◯ No

The development and implementation of conservative care in your unit

46. Is the funding part of routine NHS income or from non-NHS sources?

Please tick one

- ◯ Routine NHS income
- ◯ Non-NHS sources
- ◯ Both

47. How much annual funding was dedicated to providing conservative care in the 2011/12 financial year (April 2011 – March 2012)?

Please enter number

Overall £

If you don't know, please tell us why not.

Discussing conservative care with patients

***48. In your unit, is the option of conservative care discussed with all CKD 5 patients aged 75 years and over? (excluding emergency patients)**

- ◯ Yes
- ◯ No
- ◯ I don't know (Please tell us why not)

Discussing conservative care with patients

***49. If the option of conservative care is not discussed with all CKD 5 patients aged 75 years and over, please tell us how the decision is made whether or not to discuss conservative care with a patient?**

Please tick all that apply

- ☐ Consultant nephrologist in charge of patient decides alone
- ☐ Consultant nephrologist in charge of patient decides with input from other consultants
- ☐ Consultant nephrologist in charge of patient decides with input from other professionals during an MSRT meeting
- ☐ Clinical nurse specialist/consultant nurse in charge of patient decides alone
- ☐ Clinical nurse specialist/consultant nurse in charge of patient decides with input from consultants
- ☐ Clinical nurse specialist/consultant nurse in charge of patient decides with input from other professionals during an MSRT meeting
- ☐ The decision-making is a reactive process during the consultation
- ☐ Only if patient/carer asks about alternatives to dialysis
- ☐ Other (Please specify)

***50. Which of the following factors are likely to influence staff when contemplating the suitability of conservative care for a patient?**

Please indicate how strongly each would influence a decision to discuss conservative care with a patient/carer. Please answer on behalf of all staff members.

	Not at all	Very little	Little	Somewhat	Strongly	Very strongly
Response to the 'surprise' question*	◯	◯	◯	◯	◯	◯
Frailty	◯	◯	◯	◯	◯	◯
Extent and severity of co-morbidities	◯	◯	◯	◯	◯	◯
Cognitive status	◯	◯	◯	◯	◯	◯
Functional status	◯	◯	◯	◯	◯	◯
Uraemic symptoms	◯	◯	◯	◯	◯	◯
Rate of decline of kidney function	◯	◯	◯	◯	◯	◯
Social support	◯	◯	◯	◯	◯	◯
Distance from dialysis unit to home	◯	◯	◯	◯	◯	◯
Patient's current quality of life	◯	◯	◯	◯	◯	◯
Patient preference for conservative care	◯	◯	◯	◯	◯	◯
Carer preference for conservative care	◯	◯	◯	◯	◯	◯
Consultant preference for conservative care	◯	◯	◯	◯	◯	◯
Other	◯	◯	◯	◯	◯	◯

(Please specify and rate)

* "Would I be surprised if this patient died in the next year?"

***51. When is the option of conservative care most commonly first raised with a patient?**

Please tick one

- ◯ When estimated GFR reaches a certain level
- ◯ When they are referred to the pre-dialysis/low clearance clinic
- ◯ When dialysis access needs to be performed
- ◯ When symptoms start
- ◯ At a specific time prior to the anticipated start of dialysis
- ◯ Other (Please specify)

Discussing conservative care with patients

52. Please specify estimated GFR

eGFR

Discussing conservative care with patients

53. Please specify when

Months

Discussing conservative care with patients

54. How are patients' family/carers involved in decision making about conservative care?

Please tick all that apply

- [ ] They are invited to patient education day
- [ ] They are encouraged to attend clinics with patient
- [ ] They are involved in home visits
- [ ] They are involved when patient is revisited regarding conservative care decision
- [ ] Other (please specify)

55. Do any renal staff members use practical tools (see below for examples) when discussing the option of conservative care with a patient?

- ◯ Yes
- ◯ No

Examples
Booklets / hand outs from national organisation(s)
Booklets / hand outs written by own renal unit staff
DVDs from national organisations(s)
NHS Right Care Patient Decision Aid

Discussing conservative care with patients

56. What do they use when discussing the option of conservative care with a patient? Please tick all that apply

- [ ] Booklets / hand outs from national organisation(s)
- [ ] Booklets / hand outs written by own renal unit staff
- [ ] DVDs from national organisations(s)
- [ ] NHS Right Care Patient Decision Aid
- [ ] Other (Please specify)

57. If a decision is made not to have dialysis, where is this information recorded? Please tick all that apply

- [ ] Medical notes
- [ ] Renal database
- [ ] GP database
- [ ] Out of hours (ambulance service) database
- [ ] Other (Please specify)

58. If a decision is made not to have dialysis, is this decision reviewed at any time?

- ◯ Yes
- ◯ No

Discussing conservative care with patients

59. When is the decision reviewed?

***60. Do patients who decide not to have dialysis ever change their mind and start dialysis?**

- ◯ Yes
- ◯ No

Discussing conservative care with patients

61. How frequently is the change of mind due to the following reasons?

Please indicate how frequently each of the reasons listed below cause the change of mind.

	Never	Very rarely	Rarely	Occasionally	Frequently	Very Frequently
Because patients change their mind after having had longer to think about their decision	◯	◯	◯	◯	◯	◯
Because a patient's family wants them to have dialysis and a patient agrees	◯	◯	◯	◯	◯	◯
Because patients are acutely admitted to hospital and dialysis is started without time for a full discussion between family and clinical team	◯	◯	◯	◯	◯	◯
Because patients present unconscious without having recorded their wishes in writing and the family insist on dialysis	◯	◯	◯	◯	◯	◯
Because patients have symptoms that cannot be controlled with conservative treatment	◯	◯	◯	◯	◯	◯
Other	◯	◯	◯	◯	◯	◯

(Please specify)

62. Is vascular access ever created for patients who have opted for conservative care?

◯ Yes

◯ No

Discussing conservative care with patients

63. Please tell us why vascular access is created.

Working with primary care and general practitioners

***64. Once a decision has been made that a patient aged 75 years and over with CKD5 will not have dialysis, how are GPs involved in their care?**

Please tick one

- ◯ Patients are primarily kept under the care of the renal unit with little GP involvement
- ◯ Patients are referred back to GPs but care of patients is shared between GPs and the renal unit (e.g. patients are seen by GPs who liaise with the renal unit regarding renal symptom control)
- ◯ Patients are referred back to GPs and cared for under primary care only
- ◯ Mix of all three as it varies between nephrologists
- ◯ Mix of all three as it varies by patient/patient preference
- ◯ Other (Please specify)

65. What is the role of GPs in the management of CKD 5 patients receiving conservative care?

Please tick all that apply

- ☐ GPs liaise with the renal unit for specialist support
- ☐ GPs arrange and interpret blood tests
- ☐ GPs arrange blood tests but liaise with renal unit for their interpretation
- ☐ GPs check patients' medication
- ☐ GPs regularly (not on demand) assess patients in the GP surgery
- ☐ GPs regularly (not on demand) assess patients via home visits
- ☐ GPs/primary care staff provide/organise palliative care support at the end of life
- ☐ GPs discuss advance care planning (ACP*) with patients
- ☐ Other (Please specify)

*ACP is a voluntary process of discussion about future care between an individual and their care providers, and their family and friends if the individual wishes. An ACP discussion might include: the individual's concerns and wishes, their important values or personal goals for care, their understanding about their illness and prognosis, and their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

***66. Do you provide GPs and/or their practice team with information or advice regarding the treatment of CKD5 patients receiving conservative care?**

- ◯ Yes
- ◯ No

Working with primary care and general practitioners

67. What do you provide to GPs regarding the treatment of CKD5 patients receiving conservative care?

Please tick all that apply

- [ ] Verbal advice
- [ ] Written advice / guidelines
- [ ] Educational meetings
- [ ] Other (Please specify)

Working with primary care and general practitioners

68. Please tell us why information/advice regarding conservative care is not provided to GPs and/or their practice team.

Please tick all that apply

- [ ] Lack of time
- [ ] Lack of funding
- [ ] Opinion of consultants
- [ ] Opinion of clinical directors
- [ ] Opinion of other staff members
- [ ] GPs do not wish to have any information/advice from the renal unit
- [ ] Other (Please specify)

Working with primary care and general practitioners

69. Please use the space below to tell us any other thoughts on the role of primary care in the provision of conservative care for renal patients.

End of life care

70. Does your unit have a written guideline for renal end of life care?

- ◯ Yes
- ◯ No, but in preparation
- ◯ No

***71. Do you identify conservative care patients approaching end of life through use of a register?**

- ◯ Yes
- ◯ No

End of life care

***72. How likely are the following factors to influence a decision to add a patient to the end of life register?**

Please indicate how strongly each of the factors listed below influence this decision

	Not at all	Very little	Little	Somewhat	Strongly	Very strongly
Surprise question	◯	◯	◯	◯	◯	◯
Estimated GFR level	◯	◯	◯	◯	◯	◯
Measured GFR level	◯	◯	◯	◯	◯	◯
Comorbidities	◯	◯	◯	◯	◯	◯
Frailty	◯	◯	◯	◯	◯	◯
Unexpected weight loss	◯	◯	◯	◯	◯	◯
Quality of Life	◯	◯	◯	◯	◯	◯
Symptoms	◯	◯	◯	◯	◯	◯
Frequent hospitalisation	◯	◯	◯	◯	◯	◯
Other	◯	◯	◯	◯	◯	◯

(Please specify and rate)

End of life care

***73. If you do not use a register, how do you identify conservative care patients approaching end of life?**

End of life care

74. Is advance care planning (ACP*) used in end of life care by renal staff?

- ◯ Yes
- ◯ No

*ACP is a voluntary process of discussion about future care between an individual and their care providers, and their family and friends if the individual wishes. An ACP discussion might include: the individual's concerns and wishes, their important values or personal goals for care, their understanding about their illness and prognosis, and their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

End of life care

75. Who is involved in advance care planning in your unit?
Please tick all that apply

- ☐ Consultant nephrologist(s)
- ☐ Nurse(s)
- ☐ Palliative care specialist(s)
- ☐ Social worker(s)
- ☐ Counsellor(s)/psychologist(s)
- ☐ Other (Please specify)

76. Have any of your staff had any training in palliative/end of life care specifically for renal patients?
Please tick one

- ◯ Yes, everyone has
- ◯ Yes, the majority of the staff have
- ◯ Yes, about half of the staff have
- ◯ Yes, but only the small number of the staff have
- ◯ No

***77. With which services does your unit liaise for patients receiving conservative care approaching end of life?**

Please tick all that apply

- [ ] Specialist palliative care services within the hospital
- [ ] Specialist palliative care services from local hospice
- [ ] Specialist palliative care services in the community (e.g. Macmillan nurses)
- [ ] Primary care team
- [ ] None
- [ ] Other (please specify)

End of life care

***78. You have chosen 'none' in the previous question. Please tell us why your unit does not liaise with any services for patients receiving conservative care approaching end of life.**

End of life care

79. Where do patients receive these services?

Please tick all that apply

- [ ] Within the hospital as in-patients
- [ ] Within the hospital as out-patients
- [ ] At home
- [ ] At hospice where patient is admitted at end of life
- [ ] At GP practice
- [ ] Other (Please specify)

80. What services do they provide for renal patients receiving conservative care in your unit?

Please tick all that apply

- [ ] They help to write guidelines on how to treat patients receiving conservative care
- [ ] They provide symptom management at the end of life
- [ ] They support patients at home out of hours
- [ ] They discuss ACP with patients
- [ ] Admission to the hospice as required
- [ ] Other (Please specify)

End of life care

***81. Do you provide palliative care specialists with training or advice regarding the management of renal patients?**

- ◯ Yes
- ◯ No

82. What do you provide?

Tick all that apply

- [ ] Verbal advice
- [ ] Written advice / guidelines
- [ ] Educational meetings
- [ ] Other (please specify)

Evaluation of the provision of conservative care in your unit

***83. Is the quality of conservative care provided in your unit regularly evaluated?**

- ◯ Yes
- ◯ No

Evaluation of the provision of conservative care in your unit

84. What measures or information do you use?

Please tick all that apply

- [ ] Symptoms
- [ ] Survival
- [ ] Hospitalisation
- [ ] Quality of life
- [ ] Carer burden
- [ ] Place of death
- [ ] Survey with patients/carers about their experience of conservative care
- [ ] Other (please specify)

***85. Which factors do you think could help improve the provision of conservative care in your unit?**

Please indicate how strongly you agree or disagree with each of the following

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Increasing the number of staff dedicated to conservative care	◯	◯	◯	◯	◯
Increasing the number of times conservative care patients are seen by staff	◯	◯	◯	◯	◯
Increasing clinic time	◯	◯	◯	◯	◯
Providing better end of life care by implementing ACP	◯	◯	◯	◯	◯
Improving computer systems by integrating primary care data with renal data	◯	◯	◯	◯	◯
Increasing involvement of allied healthcare professionals (e.g. social worker) in treatment decision-making	◯	◯	◯	◯	◯
Increasing communication/involvement with GPs	◯	◯	◯	◯	◯
Increasing communication/involvement with community teams	◯	◯	◯	◯	◯
Increasing communication/involvement with other hospitals	◯	◯	◯	◯	◯
Increasing communication/involvement with palliative care teams	◯	◯	◯	◯	◯
Providing renal staff members with more education/training regarding conservative care	◯	◯	◯	◯	◯
Providing GPs with more education/training regarding conservative care	◯	◯	◯	◯	◯
Providing palliative care teams with more education/training regarding renal conservative care	◯	◯	◯	◯	◯
Providing patients with better decision aids about conservative care	◯	◯	◯	◯	◯
More funding to develop conservative care within unit	◯	◯	◯	◯	◯
Having funding models specifically designed to reimburse the costs of delivering CKM	◯	◯	◯	◯	◯

Having a written conservative care policy	◯	◯	◯	◯	◯
Having dedicated conservative care clinics	◯	◯	◯	◯	◯
Establishing a system for evaluating the provision of conservative care	◯	◯	◯	◯	◯
Having better evidence of the comparative outcomes between patients who receive conservative care and those who receive dialysis	◯	◯	◯	◯	◯
Having better evidence of the comparative costs between patients who receive conservative care and those who receive dialysis	◯	◯	◯	◯	◯
Other	◯	◯	◯	◯	◯

(Please specify and rate)

***86. What, if any, of the following changes are planned in your unit regarding the provision of conservative care?**

Please tick all that apply

- [ ] Increasing the number of staff dedicated to conservative care
- [ ] Increasing the number of times conservative care patients are seen by staff
- [ ] Increasing clinic time
- [ ] Providing better end of life care by implementing ACP
- [ ] Improving computer systems by integrating primary care data with renal data
- [ ] Increasing involvement of allied healthcare professionals (i.e. social worker) in treatment decision-making
- [ ] Increasing communication/involvement with GPs
- [ ] Increasing communication/involvement with community teams
- [ ] Increasing communication/involvement with other hospitals
- [ ] Increasing communication/involvement with palliative care teams
- [ ] Providing renal staff members with more education/training regarding conservative care
- [ ] Providing GPs with more education/training regarding conservative care
- [ ] Providing palliative care teams with more education/training regarding renal conservative care
- [ ] Providing patients with better decision aids about conservative care
- [ ] Obtaining funding to develop conservative care
- [ ] Writing up a conservative care policy
- [ ] Having dedicated conservative care clinics
- [ ] Establishing a system for evaluating the provision of conservative care
- [ ] None planned
- [ ] Other (Please specify)

Evaluation of the provision of conservative care in your unit

***87. You have chosen 'none planned' in the previous question. Please indicate why no change is planned in your unit regarding the provision of conservative care.**

88. If you would like to make any further comments on conservative care, please use the space below.

Future research

There is a lack of high quality evidence on the outcomes of conservative care for patients and clinicians to consider when deciding whether to have dialysis or conservative care, and for commissioners and providers on the cost effectiveness of such care. We are keen to address this evidence gap by building on this current research.

***89. Would your unit consider it appropriate to enter a patient aged 75 and over with CKD5 into a randomised clinical trial comparing conservative care versus dialysis? (An abstract of the proposed design is provided below)**

- ◯ Yes, for some patients
- ◯ No, never

The following is an abstract of the proposed research described above. The study will be informed by the findings from this national survey and called CKMAPPS 2.

CKMAPPS (2): a multicentre study to compare the efficacy and effectiveness of conservative kidney management (CKM) and dialysis.

Rationale
The UK has been at the forefront of developing alternative pathways to dialysis as an option for older patients with end-stage renal failure. Limited research to date suggests that in elderly dependent patients with high co-morbidity, dialysis confers only a small survival advantage in terms of hospital-free days.

However all studies have been single centred, retrospective and observational, and have not fully addressed the problem of bias by indication. In addition there are little data comparing quality of life on conservative kidney management (CKM) and dialysis, or a health economic evaluation.

To facilitate patient choice and to inform commissioning decisions, information on quality of life, prognosis and health care resource use in comparable patients on CKM and dialysis is required. We are planning a multicentre study to compare the effects of CKM and dialysis on outcomes for patients and their carers, and associated resource use and costs for NHS and social care.

The study design could be a randomised controlled trial or a prospective observational study. Although an RCT would be scientifically more rigorous, it would raise ethical and practical issues. We compare these alternatives below:

RCT
- Patients aged 75+ with progressive ESRF in whom there is uncertainty of the benefits and risks of dialysis vs CKM.
- Patients would be approached and asked whether they would be willing to be randomised on an intention to treat basis to CKM or dialysis.
- Patients would be followed for up to 3 years to capture: Hospitalisation, Mortality, Cause and place of death, Quality of life (repeated assessments, 6 monthly) e.g. EQ5D, KDQoL, POS , NHS and social care resource use (GP and OP visits, medication, IP days), Carer burden and quality of life.

Advantages
- Most robust design to overcome selection effects

Disadvantages
- Units would require CKM pathway and capacity to provide both modes as required over course of the study
- Low patient recruitment given likely patient preferences and lack of clinician uncertainty

Prospective observational study
- Patients aged 75+ with progressive ESRF who reach eGFR of 15ml/min/1.73m2 would be recruited and followed up for 3 years with similar data collection as in the RCT.
- This is a complex design given the very strong selection effects for CKM.
- Potential methods for adjusting for this are to use:
i) the Instrumental variable (IV) approach at Renal Unit level as used in DOPPS [the current CKMAPPS survey would provide data for this]
ii) Marginal structural models allowing for time varying start of RRT (and CKM) and time varying covariates such as comorbidity
iii) Propensity scoring to adjust for confounding where socio-demographic and clinical factors associated with starting CKM are used to derive a score which is used to match patients who start dialysis

Advantages
- Higher patient recruitment
- Can include units with and without CKM pathway

Disadvantages
- Bias because of the selection effects.
- Number of units needed for IV approach (20+)

Future research

***90. Would your unit be willing to participate in such a trial?**

- ◯ Yes, definitely
- ◯ Maybe
- ◯ No
- ◯ Other (Please specify)

***91. Would your unit consider entering CKD5 patients aged 75 and over into a prospective multicentre observational study to compare conservative care and dialysis, which addresses the major selection bias?**
(The same abstract shown previsously is provided below again)

- ◯ Yes, for some patients
- ◯ No, never

The following is an abstract of the proposed research described above. The study will be informed by the findings from this national survey and called CKMAPPS 2.

CKMAPPS (2): a multicentre study to compare the efficacy and effectiveness of conservative kidney management (CKM) and dialysis.

Rationale
The UK has been at the forefront of developing alternative pathways to dialysis as an option for older patients with end-stage renal failure. Limited research to date suggests that in elderly dependent patients with high co-morbidity, dialysis confers only a small survival advantage in terms of hospital-free days.

However all studies have been single centred, retrospective and observational, and have not fully addressed the problem of bias by indication. In addition there are little data comparing quality of life on conservative kidney management (CKM) and dialysis, or a health economic evaluation.

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Advantages
- Most robust design to overcome selection effects

Disadvantages
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- Low patient recruitment given likely patient preferences and lack of clinician uncertainty

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ii) Marginal structural models allowing for time varying start of RRT (and CKM) and time varying covariates such as comorbidity
iii) Propensity scoring to adjust for confounding where socio-demographic and clinical factors associated with starting CKM are used to derive a score which is used to match patients who start dialysis

Advantages
- Higher patient recruitment
- Can include units with and without CKM pathway

Disadvantages
- Bias because of the selection effects.
- Number of units needed for IV approach (20+)

Future research

***92. Would your unit be willing to participate in such a study?**

- ◯ Yes, definitely
- ◯ Maybe
- ◯ No
- ◯ Other (Please specify)

Details of person completing the questionnaire

***93. Please give your role in renal unit.**

***94. If someone else helped you complete this questionnaire, please give their role in renal unit.**

***95. Please provide your contact details* in case we need to contact you.**

Name:	
Email Address:	
Phone Number:	

*This information will not be used in any research reports