Title: *Conservative Management and End-of-life Care in an Australian Cohort With End-stage Kidney Disease*

Supplemental Material

Supplemental Table 1. Survival status of PINOT cohort at 3 years by baseline treatment modality

Initial treatment modality	Patients	Deceased	Alive	Unknown	KM estimate of proportion surviving (95% CI)	
Pre-emptive transplant	25	1	24	0	96%	(75%-99%)
Peritoneal dialysis	134	36	89	9	68%	(57%-77%)
Home hemodialysis	12	2	9	1	61%	(8%-91%)
Facility[a] hemodialysis	443	131	274	38	66%	(60%-71%)
Conservative management	102	72	20	10	23%	(15%-31%)
Died before starting planned dialysis	5	5	0	0	0	0
Total	721	247	416	58		

[a] Facility hemodialysis = satellite or in-center hemodialysis

Supplemental Table 2. Factors associated with 3-year mortality

Characteristic	Number of patients	Number of deaths	Unadjusted hazard ratio	Unadjusted 95%CI	Adjusted[a] hazard ratio	Adjusted[a] 95%CI
Age (years)						
Age group < 75 years	495	117	1.00 (referent)		1.00 (referent)	
Age group ≥ 75 years	226	130	3.45	2.68-4.44	**2.42**	**1.69-3.47**
Sex						
Males	423	155	1.00 (referent)		1.00 (referent)	
Females	298	92	0.81	0.62-1.05	0.86	0.63-1.21
Language spoken at home						
English	573	204	1.00 (referent)		1.00 (referent)	
Other[b]	148	43	0.75	0.54-1.04	**0.62**	**0.38-0.99**
Treatment modality						
Renal replacement therapy	619	175	1.00 (referent)		1.00 (referent)	
Conservative care	102	72	4.07	3.08-5.37	**2.47**	**1.53-4.00**
Marital status						
Married / de facto	367	144	1.00 (referent)		1.00 (referent)	
Single	89	11	0.28	0.15-0.51	**0.37**	**0.17-0.80**
Separated / divorced / widowed	142	71	1.44	1.08-1.91	0.96	0.67-1.38
Area deprivation index						
High SES[c] (deciles 8-10)	178	56	1.00 (referent)		1.00 (referent)	
Mid SES (deciles 4-7)	305	110	1.05	0.76-1.45	0.88	0.56-1.38
Low SES (deciles 1-3)	202	75	1.12	0.79-1.58	1.03	0.61-1.75
ARIA[d] – remoteness index						
Major city	403	145	1.00 (referent)		1.00 (referent)	
Inner regional	169	58	0.90	0.66-1.22	**0.57**	**0.37-0.89**
Outer regional	74	27	0.92	0.61-1.41	0.63	0.31-1.27
Remote or very remote	39	11	0.63	0.34-1.18	0.76	0.23-2.48
Type of health insurance						
Public only	475	153	1.00 (referent)		1.00 (referent)	
Private	149	43	0.88	0.63-1.23	0.98	0.61-1.56
Department of Veterans' Affairs	24	16	3.23	1.93-5.42	**2.41**	**1.20-4.84**
Time known to a nephrologist						
> 2 years	306	102	1.00 (referent)		1.00 (referent)	
1-2 years	132	39	0.90	0.62-1.31	1.12	0.69-1.82
3-12 months	126	49	1.21	0.86-1.71	1.34	0.83-2.15
< 3 months	157	57	1.18	0.85-1.63	1.19	0.77-1.84
Baseline serum albumin						
High 3.7-5.4 g/dL	164	34	1.00 (referent)		1.00 (referent)	
Mid 3.1-3.6 g/dL	228	66	1.46	0.96-2.21	**1.64**	**1.01-2.67**
Low ≤ 3.0 g/dL	203	117	3.69	2.51-5.41	**4.78**	**2.89-7.89**
Baseline hemoglobin						
High 11.5-15.5 g/dL	181	61	1.00 (referent)		1.00 (referent)	
Mid 10.1-11.4 g/dL	205	68	1.03	0.73-1.45	1.29	0.86-1.95
Low ≤ 10.0 g/L	209	89	1.46	1.05-2.02	1.26	0.83-1.91

[a]Stratified by center and adjusted for age, sex, home language, marital status, socio-economic status, remoteness, health insurance, late referral to a nephrologist, serum albumin and hemoglobin
[b]Other language includes predominantly Greek, Italian, Arabic, Chinese, Vietnamese and Indigenous languages
[c]SES = socio-economic status
[d]ARIA = Accessibility / Remoteness Index of Australia

Supplemental Table 3. Major themes regarding the presence or absence of an Advance Care Directive, and advance care planning

Factors related to having an Advance Care Directive	**Illustrative survey comments**
• Seen by a social worker who was instrumental in discussions about advance care planning and documentation of Advance Care Directives	*"Patient had seen social worker and renal outreach nurse - documented care plan."*
• Residents of a nursing home where Advance Care Directives were a requirement	*"Patient transitioned to residential care. ACD[a] standard requirement."*
• Prolonged hospitalizations that prompted the documentation of Advance Care Directives	*"After prolonged hospital admission, family and patient decision for palliative care."*
• Electing for conservative non-dialytic care, that prompted advance care planning and Advance Care Directives	*"Patients initial choice was conservative management."*
Factors related to <u>not</u> having an Advance Care Directive	**Illustrative survey comments**
• Initial discussions with the patient and / or family had been undertaken, but no plan or directive had been decided upon, or documented in the patient's medical record at the time of the study	*"Discussed with daughters - during care planning but no formal document as yet."*
• Patients declined offers to discuss advance care planning or end-of-life wishes	*"Patient refused discussions about treatment and planning for end of life care."*
• Renal staff were unable to initiate discussions about advance care planning due to language barriers or mental ill-health	*"Patient's English too poor...We have no official interpreters for indigenous languages at our hospital."*
• Advance Care Directives were not encouraged among some renal units	*"ACDs not formalized at this unit."* *"Very few patients at [this hospital] had ACDs during the study period. It is more commonly discussed now."*
• A 'Not For Resuscitation' order was in place and considered sufficient	*"NFR[b] orders [only] family not comfortable with full ACD"*
• Patients were too young	*"Pediatric patient."*
• Expectation that patient's renal failure would not be permanent	*"Expected to recover renal function."*

[a]ACD = Advance Care Directive, [b]NFR = Not For Resuscitation

Summary: The main reasons for having an advance directive were the involvement of a social worker in the patients' care; prolonged hospitalizations; being a resident of a nursing home where advance directives are required; or planning for comprehensive conservative care rather than dialysis. The main reasons for not having an advance directive included: not being 'unit policy' nor encouraged at the particular renal unit; the patient was too young; the patient declined; there were language barriers or patient's mental ill-health; a 'not for resuscitation' order was in place and this was deemed sufficient; or advanced care planning discussions had commenced but had not progressed to the point where an advance directive was documented.

Supplemental Table 4. Major themes regarding place of death.

Reasons for death in hospital	**Illustrative survey comments**
• Acute admission to Intensive Care Unit or Emergency Department	*"Patient became septic and transferred to High Dependency Unit - died ICU."*
• Transfer from Nursing home to hospital for acute pain or fluid overload	*"Following admission for fluid overload and pain."*
• Admitted from home to a geriatric ward	*"Admitted to geriatric ward."*
• Died while an in-patient on the renal ward or whilst on dialysis	*"Patient died on renal ward after failed resuscitation attempt."*
Reasons for death in hospice	**Illustrative survey comments**
• Able to access hospice care through the war veterans association	*"As a veteran patient was able to get a place in local hospice."*
• Able to access hospice care through a religious charity organization	*"Hospice near Catholic hospital. Patient had supportive wife and children - and community support. Patient had refused to go to a nursing home or hostel prior to ESKD."*
• Transferred from acute hospital to hospice following planned withdrawal from dialysis	*"Admitted to hospital following collapse/loss of consciousness at home, next day transferred to hospice. A week before these events patient had conversation with nephrologist about planned withdrawal from dialysis."*
Reasons for death at home	**Illustrative survey comments**
• Planned death at home with family support	*"Family ensured patient did not get admitted to hospital."*
• Unexpected death at home	*"Wife notified renal unit - patient died at home."*
• Transferred from regional hospital to remote community to be nearer family	*"Was an inpatient in the hospice. Transferred home to remote community, [died] in community with family."*

ICU = Intensive Care Unit, ESKD = end-stage kidney disease

Summary: The primary reason for dying in hospital was due to an event following an acute admission from home or a nursing home for symptom management. The main reasons for dying in hospice was through prior planning or when patients could access a hospice via community membership of a war veterans or religious charity organization. The main reasons for dying at home included prior planning involving transfer of the patient from an acute or sub-acute care facility; or an unexpected death at home.

Supplemental Figure 1. Multivariable analysis of factors associated with 3-year mortality among 590 participants

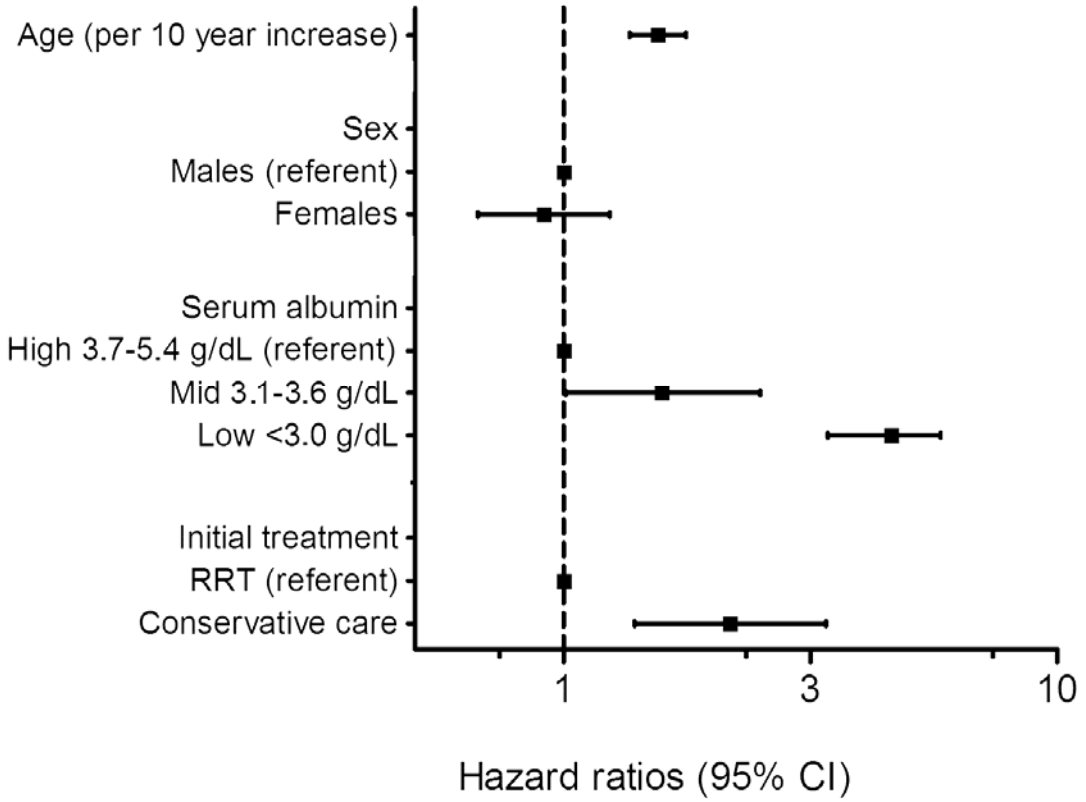

Figure legend: Cox proportional hazards model stratified by renal centre and adjusted for age, sex, baseline serum albumin and initial treatment modality. Serum albumin was available for 590 participants.

Technical Supplemental Appendix

PINOT study methods:

All nephrology Heads of Department were invited to participate in PINOT. The person or people with the most knowledge about each study participant (i.e. their treating nephrologist, or senior renal nurse) completed the survey forms, using available databases and the patients' medical records. Respondents completed a survey for each cohort member at baseline and at 3 years. Data collected included patient demographics, biochemistry results, treatment modalities, survival and end-of-life care outcomes.

Eligibility criteria

The PINOT study did not include patients with acute kidney injury, or those with a failed transplant who returned to dialysis. All 66 renal units were invited to participate in the follow-up study. All participants in the baseline study were eligible for follow-up.

Qualitative data

The main reasons for the presence or absence of a documented advance directive were tabulated from the free text responses in the follow-up questionnaire. Similarly, free text responses regarding the location of death for deceased participants were summarized and tabulated.

SHORT PINOT Follow-up survey

Please enter data collector's initials _____ **Date of data entry** ____/___/_____ (dd/mm/yyyy)

Section 1: Additional Patient Information

1.1 PINOT Patient Identification Number
As provided in the "Patient Excel Spreadsheet" _____

1.2 Patient Date of Birth
Please record the patient's date of birth ____/___/_____ (dd/mm/yyyy)

1.3 Postcode
Please record the patient's main residential postcode in 2009 _____

1.4 Marital Status
Please select the patient's marital status in 2009
Why? A person's marital status has been associated with treatment choices for end stage renal disease.

- ○ Single
- ○ Married/Defacto
- ○ Divorced
- ○ Widowed
- ○ Not known

1.5 Baseline serum albumin level (g/L): *(please report level closest to 30 September 2009)*
Sept 2009: _____

1.6 Baseline haemoglobin level (g/L): *(please report level closest to 30 September 2009)*
Sept 2009:_____

1.7 Has the patient had an Advanced Care Directive between 30 July 2009 and 30 September 2012?

- ○ Yes
- ○ No
- ○ Not documented / Unknown

Please make a comment on your choice here:

1.8 Confirmation of initial treatment modality
Please confirm which initial treatment modality this patient commenced between 1 July 2009 and 30 Sept 2012.
*Please choose **only one** of the following:*

- ○ Haemodialysis or Peritoneal dialysis
- ○ Conservative care
- ○ Pre-emptive transplant
- ○ The patient died before starting any planned treatment

For patients who initially commenced **Haemodialysis or Peritoneal dialysis**: *Go to Section 2, page 2*
For patients who initially commenced **Conservative care**: *Go to Section 3, page 4*
For patients who initially commenced **Pre-emptive transplant**: *Go to Section 4, page 5*
For patients who died before starting any planned treatment: *Go to Section 4, page 5*

Section 2. Dialysis Patient Activity 1 July 2009 and 30 September 2012

2.1 Home dialysis therapy

Has the patient ever received a home dialysis therapy (Home HD, CAPD or APD treatment) between 1 July 2009 and 30 September 2012 (including the therapy stated in Question 1.8)

- Yes
- No

2.2 Main reason for home dialysis

If the patient received a home dialysis therapy (ie. Home HD, CAPD or APD treatment) between 1 July 2009 and 30 September 2012, please select the main reason that home dialysis therapy was initiated: *(please select **only one** reason)*

- Patient wish to dialyse at home
- Caregiver(s) wish for patient to dialyse at home
- Encouragement from renal unit medical staff for patient to dialyse at home
- Travel time from home to haemodialysis unit
- Vascular access
- Capacity issues eg. no space in satellite haemodialysis centre
- Funding issues (please provide detailed explanation in the box below)
- Transport problems (please provide detailed explanation in the box below)
- Not known
- Other (please provide detailed explanation in the box below)

2.3 If there were also additional reasons that the patient received a home dialysis therapy (i.e. Home HD, CAPD or APD treatment) between 1 July and 30 September 2012 please select all relevant reasons from the list below: *(you may select more than one reason)*

- Patient wish to dialyse at home
- Caregiver(s) wish for patient to dialyse at home
- Encouragement from renal unit medical staff for patient to dialyse at home
- Travel time from home to haemodialysis unit
- Vascular access
- Capacity issues eg. no space in satellite haemodialysis centre
- Funding issues
- Not known
- Other (please provide detailed explanation in the box below)

2.4 Was the patient ever planned for a home dialysis therapy in 2009 (please refer to columns Q and R in the Patient Excel Spreadsheet)?

- Yes
- No

If Yes, but they did NOT transfer to a home therapy within the three year time frame please select the reasons why they have NOT transferred to a home therapy *(you may select more than one reason)*

- Not applicable – home therapy never planned
- Patient refused
- Carers/ family refused
- Vascular access
- Peritoneal access
- No home training capacity in renal unit
- Increased severity of physical comorbidities eg. stroke, cancer
- Mental health comorbidities eg. depression, psychosis, dementia
- Patient's residential home not appropriate (eg. Insufficient water or power supply, extremely remote location, poor hygiene, renting accommodation, no fixed address, residential aged care facility)
- No partner / inadequate carer support
- Other (please provide detailed explanation in the box below)

Section 3. Conservative Care Patient Activity 1 July 2009 and 30 September 2012

3.1 Did the patient receive any form of renal replacement therapy between 1 July 2009 and 30 September 2012?

- Yes
- No

3.2 If the patient received dialysis between 1 July 2009 and 30 September 2012, please select <u>all applicable reasons</u> why dialysis was initiated *(you may select more than one reason):*

- Symptom management (ie. Uremic symptoms and/or fluid overload)
- Patient wish
- Caregiver(s) wish for dialysis
- Physician wish
- Emergency/ICU admission
- Short term trial dialysis
- Other (please provide explanation in the box below)

Section 4. Patient Survival as at 30 September 2012

4.1 Mortality status

As at 30 September 2012, what is the patient's mortality status:

- ○ Alive
- ○ Deceased

If alive, please go to question 4.6; If deceased, please go to question 4.2

4.2 Date of death: ____/___/_____ (dd/mm/yyyy)

4.3 Please select the recorded cause of death:

- ○ Cardiac
- ○ Vascular disease
- ○ Infectious
- ○ Cancer
- ○ Dialysis access related
- ○ Withdrawal of renal replacement therapy
- ○ Other (*Please provide detailed explanation)*

4.4 Please select the patient's place of death:

- ○ Hospital
- ○ Main residence
- ○ Nursing home
- ○ Hospice
- ○ Unknown
- ○ Other *(Please provide detailed explanation)*

4.5 The surprise question is: "Would I be surprised if this patient died in the next year?"
Was the "surprise question" used as a prognostic tool with this patient?

- ○ Yes
- ○ No
- ○ Unknown or not documented

4.6 Between 1 July 2009 to 30 September 2012, did the patient receive treatment from a palliative care health professional?

- ○ Yes (go to 4.7)
- ○ No (survey end – THANK YOU)
- ○ Unknown (survey end – THANK YOU)

4.7 What was the context of the initial palliative care consultation?

- In-patient acute care episode
- Pre-planned palliative care referral
- Unknown

4.8 Palliative care medical team

Please select the palliative care professionals that the patient saw:

Did the patient see:

- A joint nephrology / palliative care service
- An existing regular palliative care service
- Other *(Please provide detailed explanation)*

4.9 Palliative care professionals

Please select the following palliative care health professionals involved in the patient's care *(you may select more than one):*

- Palliative care physician
- Palliative care nurse (hospital)
- Palliative care nurse (community)
- GP
- None
- Unknown
- Other *(Please provide detailed explanation)*

4.10 Duration of palliative care

What was the approximate duration (from first consult to the patient's date of death) of the patient's palliative care?

- < 1 week
- 1 week up to 1 month
- 1 month up to 3 months
- 3 months up to 6 months
- > 6 months

THANK YOU