

Journal Club on August 18, 2021: time 1.30- 3.00 p.m. room 2222: Assoc. Prof. Dr. Kittikorn Nilmanat

**Topic: Advance care planning in chronic kidney disease: A survey of current Practice in Australia**

**Objectives:**

- 1 Gaining knowledge in advance care planning in CKD

**Questions for the discussion part**

1. What is Gap of knowledge of the research study? How is it important?

ประเด็นปัญหา (gap of knowledge) ของงานวิจัยนี้คืออะไร สำคัญอย่างไร

2. What is the main aim of this study?

วัตถุประสงค์ของการศึกษาคืออะไร

3. What variables, instruments, method were used in this study?

การศึกษาวินิจฉัยนี้ศึกษาตัวแปร/เครื่องมือวิจัย/วิธีการวิจัย อย่างไร

4. What was the study result and how the finding can be applied for the further research?

What was the strength and limitation of this study?

ผลของการศึกษา และการนำผลงานวิจัยไปใช้ประโยชน์เป็นอย่างไร มีจุดแข็ง และข้อจำกัดอย่างไร

**Main Article**

Luckett, T., Spencer, L., Morton, R. L., Pollock, C. A., Lam, L., Silvester, W., Sellars, M., Detering, K. M., Butow, P. N., Tong, A., & Clayton, J. M. (2017). Advance care planning in chronic kidney disease: A survey of current practice in Australia. *Nephrology (Carlton, Vic.)*, 22(2), 139–149. <https://doi.org/10.1111/nep.12743>

**Related articles and additional resources**

Davison S. N. (2012). Advance care planning in patients with chronic kidney disease. *Seminars in dialysis*. 25(6), 657-663. <https://doi.org/10.1111/sdi.12039>

## Original Article

## Advance care planning in chronic kidney disease: A survey of current practice in Australia

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**KEY WORDS:**

advance care planning, chronic kidney disease, conservative care, current practice, health professional view.

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**ABSTRACT:**

**Aim:** Advance care planning (ACP) in nephrology is widely advocated but not always implemented. The aims of this study were to describe current ACP practice and identify barriers/facilitators and perceived need for health professional education and chronic kidney disease (CKD)-specific approaches.

**Methods:** An anonymous cross-sectional survey was administered online. Nephrology health professionals in Australia and New Zealand were recruited via professional societies, email lists and nephrology conferences. Multiple regression explored the influence of respondents' attributes on extent of involvement in ACP and willingness to engage in future.

**Results:** A total of 375 respondents included nephrologists (23%), nurses (65%), social workers (4%) and others (8%) with 54% indicated that ACP at their workplace was performed *ad hoc* and 61% poorly. Perceived barriers included patient/family discomfort (84%), difficulty engaging families (83%), lack of clinician expertise (83%) and time (82%), health professional discomfort (72%), cultural/language barriers (65%), lack of private space (61%) and lack of formal policy/procedures (60%). Respondents overwhelmingly endorsed the need for more dialysis-specific ACP programs (96%) and education (95%). Whilst 85% thought ACP would be optimally performed by specially trained staff, comments emphasized that all clinicians should have a working proficiency. Respondents who were more willing to engage in future ACP tended to be non-physicians (odds ratio (OR) 4.96, 95% confidence intervals (CI) 1.74–14.07) and reported a greater need for CKD-specific ACP materials (OR 10.88, 95% CI 2.38–49.79).

**Conclusion:** Advance care planning in nephrology needs support through education and CKD-specific resources. Endorsement by nephrologists is important. A multidisciplinary approach with a gradient of ACP expertise is also recommended.

**SUMMARY AT A GLANCE**

This survey of nephrologists in Australia and New Zealand provides data on the current practice of advance care planning and highlights the need for CKD-specific educational tools and a multidisciplinary approach.

**INTRODUCTION**

Chronic kidney disease (CKD) is a progressive, life-limiting condition that is associated with cognitive impairment in its advanced stages. Advance care planning (ACP) refers to a process of reflection and discussion by which an individual's values and preferences for future care are clarified and communicated to clinicians and family members so they can make decisions on

their behalf should they become unable to make treatment decisions at the time.<sup>1</sup> ACP often results in the appointment of a substitute decision-maker and documentation of a person's wishes. In the context of CKD, ACP also addresses the questions of commencing, withholding, continuing or withdrawing dialysis. When properly implemented, ACP has been found to improve the concordance between patient wishes and end-of-life care received, congruence between patient and surrogate

decision-maker wishes, and surrogate decision-making confidence as well as improve satisfaction and psychological outcomes in bereaved families.<sup>2,3</sup>

Clinical practice guidelines recommend ACP for people with CKD.<sup>4</sup> However, a recent systematic review showed that there is limited research on ACP in CKD, especially studies developing and evaluating interventions.<sup>5</sup> One study conducted in Canada found that less than 10% of patients with stage 4 or 5 CKD had discussed end-of-life care in the previous year with healthcare providers.<sup>6</sup> Barriers to ACP include a difficulty in identifying the right timing to undertake ACP,<sup>7</sup> reluctance to raise ACP for fear of upsetting patients, and lack of support from senior staff.<sup>8</sup> In Australia and New Zealand, the Society of Nephrology's *Renal Supportive Care Guidelines* have highlighted that appropriate systems are needed to support ACP in CKD care.<sup>9</sup> Yet no research to date has evaluated national practice patterns or offered a systems perspective of barriers and facilitators to ACP in this setting.

A study was designed that aimed to: (i) describe current ACP practice in Australia and New Zealand nephrology from systems-level and clinician-level perspectives, (ii) identify barriers and facilitators to ACP and (iii) establish the perceived need for, and desirable content of, health professional education and CKD-specific approaches to ACP. The survey was focused on the perspectives of health professionals because of their influence and insight into likely levels of support for different interventions.<sup>10</sup> We were particularly interested to understand the ACP-related perceptions among motivated clinicians most likely to drive change at their workplace.<sup>11</sup>

## METHODS

This study used a cross-sectional survey design. The survey was administered online via a secure platform, SurveyMonkey® (<https://www.surveymonkey.com/>). Survey data were anonymous to minimize the risk of social desirability bias. The study was approved by the University of Technology Human Research Ethics Committee. The survey opened on 30 May 2014 and closed on 21 January 2015. Survey questions were developed by experts in ACP implementation/education, a nephrologist, nephrology nurse, palliative care physician, psychologist and health economist. The draft survey was piloted by 10 renal clinicians from varying disciplines and refined based on their feedback prior to wider circulation.

The survey included 43 questions, some of which were divided into sub-questions (Supporting Information Content 1). Respondent characteristics collected included age, gender, country of birth, religious views, clinical role, including discipline, experience in nephrology and setting and state/territory of primary workplace. Further questions related to experience, skills, comfort and knowledge regarding ACP, workplace policies and procedures concerning ACP, perceived barriers/facilitators to ACP and perceived need for and desirable content of new CKD-specific ACP programs and materials.

Item response options included yes/no, multiple choice, Likert scales and comment boxes allowing free text to be entered after most items.

## Participants and recruitment

Respondents were eligible if they self-identified as a health professional involved in caring for adults with CKD in Australia or New Zealand. Participants were recruited via email invitations and newsletters sent out by peak professional societies and the authors' networks. Invitations were also extended to delegates at the 2014 annual conferences of the Renal Society of Australasia and the Australian and New Zealand Society of Nephrology via satchel inserts, an oral presentation and display stands. Open online surveys are subject to selection bias because participants self-select, leading to a 'volunteer effect'. In the current study, an over-representation of respondents with experience of and interest in ACP was considered supportive of our aims in that a more representative sample would likely have included only a small proportion with insight into problems and solutions.

## ANALYSIS

Data were analysed using SPSS V23.0 statistical software (IBM Corporation, Armonk, NY). Descriptive statistics were calculated as frequencies with percentages and means with standard deviation. Inferential statistics used both bivariate and multivariate methods to examine relationships between variables of interest and the extent of involvement in ACP discussions with each of three patient groups (patients with CKD (estimated glomerular filtration rate < 30 ml/min per 1.73 m<sup>2</sup>) considering treatment options, patients on dialysis and patients with end-stage kidney disease being managed with a supportive care approach), as well as willingness to engage more often in ACP discussion in the future. Variables tested for association included respondent characteristics (age (</≥45 years), sex, discipline (physician *vs* non-physician), years in nephrology (</≥10 years) and status as a unit manager), as well as variables hypothesized to influence behaviour based on the theory of planned behaviour.<sup>12</sup> This theory posits that an individual's behavioural intentions and behaviour are shaped by his or her attitudes towards the behaviour (e.g. perception that ACP falls within one's role), normative beliefs (e.g. knowledge of ACP legislation) and perceived control over the behaviour (e.g. perceptions of barriers and facilitators). The theory of planned behaviour has been used to design and interpret surveys of health professionals in the past.<sup>13</sup> Bivariate analyses were used to identify unadjusted relationships, with a significance level of  $P < 0.10$  used to select variables for inclusion in multivariate analyses of adjusted relationships. Students *t*-tests and correlation analyses were applied for testing group differences or relationships between continuous variables. Multiple linear or logistic regression analyses were used, with the calculation of

95% confidence intervals (CI). These analyses controlled for ACP opportunity, as measured by the number of patients seen each month and proportion of these offered ACP within the unit as a whole. As this was an exploratory study, no attempts were made to examine the interaction terms between variables included in the multivariate analyses. A type I error of 5% was adopted for all analyses.

Free-text comments were summarized descriptively by a single researcher (TL) and reviewed by another (JC), with any disagreements resolved by discussion.

## RESULTS

In total, 417 health professionals responded to the survey, of whom 375 (90%) were deemed to provide sufficient data ( $\leq 5\%$  missing on any item) to be included in statistical analyses. Sample characteristics are summarized in Table 1. Data on respondents' occupational postcode suggest that the sample represented at least 157 different renal units – 61% of the 259 Australian total.<sup>14</sup> The Australian Health Practitioner Regulation Agency's annual report indicated that there were 388 nephrologists registered nationwide in 2010–2011,<sup>15</sup> suggesting that inclusion of 85 nephrologists registered a response rate of 22%. No data were available to estimate response rates for other disciplines.

The main survey results are reported in Tables 2 and 3. Results regarding current practice in ACP with people with CKD are reported in Table 2. Results concerned with ways to improve ACP for people with CKD are presented in Table 3. Other results are described subsequently, including comments made in free-text responses.

Of 88% ( $n = 329$ ) of respondents who were not already regularly discussing ACP with their CKD patients, 88% ( $n = 289$ ) said they would be willing to engage more often in ACP and 8% ( $n = 27$ ) were unsure, leaving only 4% ( $n = 13$ ) who were not willing to discuss ACP. Twenty percent ( $n = 69$ ) indicated there were patient groups with whom they perceived it would not be appropriate to discuss ACP, most commonly citing young patients with few co-morbidities and a good prognosis, or who might be transplant candidates. Seventy-nine percent ( $n = 296$ ) of respondents reported having had no experience of ACP with Aboriginal and/or Torres Strait Islanders, and 51% ( $n = 151$ ) reported no experience of ACP with people from culturally and linguistically diverse backgrounds.

Whilst discouragement from colleagues or managers was considered a barrier by only 19% ( $n = 69$ ) of respondents, the gate-keeping role played by nephrologists was frequently commented upon in free-text responses. Whilst 85% ( $n = 300$ ) thought it would be helpful to make ACP the role of a specially trained clinician, open-ended responses qualified this by recommending that all clinicians should be sufficiently skilled to discuss ACP should opportunities spontaneously arise. Respondents also highlighted that ACP might be best undertaken by someone with an established relationship to the

**Table 1** Characteristics of participants ( $n = 375$ )

Characteristics of respondents	$n$ (%)†
Clinical role	
Nephrologists	85 (23%)
Nephrology nurses	243 (65%)
Nephrology social worker	15 (4%)
Other‡	32 (8%)
Age (years)	
Mean (standard deviation)	48.7 (8.8)
$\leq 45$	116 (31%)
$> 45$	259 (69%)
Sex	
Male	76 (20%)
Female	299 (80%)
Place of birth	
Australia/New Zealand	263 (70%)
UK	46 (12%)
Asia	39 (10%)
Others	27 (8%)
State and territories (% Australian population)§	
ACT (1.6)	6 (2%)
NSW (32.3)	139 (37%)
NT (1.0)	3 (1%)
QLD (20.2)	64 (17%)
SA (7.3)	23 (6%)
TAS (2.3)	18 (5%)
VIC (24.9)	81 (22%)
WA (10.4)	26 (7%)
New Zealand	15 (4%)
Religious views self-reported to influence approach to ACP	
None	342 (91%)
Christianity	27 (7%)
Others	6 (2%)
Years of experience in nephrology	
$\leq 10$	113 (30%)
10+	262 (70%)
Work setting (multiple responses)	
Dialysis unit	289 (77%)
Outpatient renal clinic	156 (42%)
Inpatient ward	138 (37%)
Private practice	42 (11%)
Others	40 (10%)
In charge of a renal unit	
Yes	106 (28%)
No	269 (72%)
Training in ACP	
Online	89 (24%)
Attend lecture and workshop	250 (67%)
Small group experiential	58 (16%)
Simulated patient	34 (9%)
Role play in a small group	36 (10%)
Mentoring from colleagues	86 (23%)
Feedback from supervisor or mentor	29 (8%)
Others	105 (28%)
Knowledge of state and national legal framework of ACP	
Detailed knowledge of most aspects	23 (6%)
Working knowledge of important features	252 (68%)
No knowledge or almost no knowledge	96 (26%)

(Continues)

**Table 1** (Continued)

Characteristics of respondents	<i>n</i> (%)†
Agreement that 'the need to discuss ACP does not arise in my clinical practice'	
Strongly disagree	218 (58%)
Disagree	113 (30%)
Agree	27 (7%)
Strongly agree	15 (4%)
Agreement that 'ACP discussions are not part of my role'	
Strongly disagree	210 (56%)
Disagree	127 (34%)
Agree	27 (7%)
Strongly agree	9 (3%)

†Frequency may not add to 375 owing to missing data, and percentages may not add to 100% owing to rounding. ‡Based on demographic data from the Australian Bureau of Statistics.<sup>16</sup> §Clinical roles classified as 'other' included educators, nurses from specialties other than nephrology (e.g. palliative care), psychologists, dietitians and managers. ACP, advance care planning; ACT, Australian Capital Territory; NSW, New South Wales; NT, Northern Territory; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia.

patient, although it was acknowledged that this might increase emotional difficulty for the clinician involved. Suggestions in free-text responses regarding ways to improve ACP included the following: calls for public health campaigns aimed at helping people understand the limits of modern medicine and the need for ACP; better systems for storage, governance, updating and sharing of advance care directives; and the value of seeking expert advice from specialist palliative care services. There was a concern that ACP for people with CKD should not be considered the sole responsibility of nephrology, with primary and acute care episodes being cited as important opportunities for ACP with this patient group. Respondents commonly suggested for ACP to be integrated as a standard process into routine care to ensure necessary resources (e.g. staff time), enable the development of metrics to drive performance and elicit more positive perceptions and less stigma from patients and staff. However, a small number of respondents expressed concerns that overly formalizing ACP might make the process overly intimidating and lead to a 'tick-box' approach that would not allow for tailoring of timing/content according to the health profile and psychological readiness of individual patients. There were some common suggestions in the free-text responses that re-occurred across items. These are summarized in Table 4.

## Inferential analyses

Results of bivariate analyses for unadjusted associations between variables of interest and the involvement in ACP discussions with different patient groups are presented in Table 5, and those for multivariate analysis of adjusted associations in Table 6.

**Table 2** Results from survey questions asking about current practice in ACP for patients with CKD (*n* = 375)

Question/response options	<i>n</i> (%)
With what proportion of dialysis patients do you discuss ACP?	
All or almost all	62 (17%)
A majority	60 (16%)
A minority	145 (39%)
None or almost none	92 (24%)
N/A (I don't look after this group of patients)	14 (4%)
With what proportion of end-stage kidney disease patients who are being managed with a supportive care approach do you discuss ACP?	
All or almost all	87 (23%)
A majority	56 (15%)
A minority	54 (15%)
None or almost none	131 (35%)
N/A (I don't look after this group of patients)	45 (12%)
With what proportion of CKD patients (GFR < 30 ml/min per 1.73 m <sup>2</sup> ) who are considering their treatment options do you discuss ACP?	
All or almost all	41 (11%)
A majority	64 (18%)
A minority	102 (27%)
None or almost none	128 (34%)
N/A (I don't look after this group of patients)	38 (10%)
Across patient groups, in what proportion of ACP discussions do you involve the patient's family as well as the patient?	
All or almost all	94 (25%)
A majority	109 (29%)
A minority	88 (24%)
None or almost none	44 (12%)
N/A (I don't discuss ACP with patients)	38 (10%)
Agreement that 'I lack access to appropriate ACP materials for CKD patients'	
Strongly disagree	97 (26%)
Disagree	139 (37%)
Agree	99 (27%)
Strongly agree	38 (10%)
Who mostly initiates ACP with CKD patients in your experience?	
Myself	105 (28%)
The patient	15 (4%)
The family	1 (0.3%)
(Another) nephrologist	49 (13%)
(Another) nurse	45 (12%)
(Another) social worker	29 (8%)
Patient's GP	5 (1%)
Another health professional from other team	10 (3%)
It varies too much to say	88 (24%)
N/A – rarely initiated	26 (7%)
Proportion answering 'skilled' or 'very skilled' to the question 'Please indicate how skilled you feel, or would feel, in doing the following with your patients?'	
Discussing ACP	243 (66%)
Assisting patients to complete an advance care directive	170 (46%)
Discussing prognosis	250 (67%)
Discussing death and dying	287 (77%)
Discussing potential future withdrawal or withholding of dialysis	289 (78%)
Discussing whether or not to attempt CPR or intensive care	264 (71%)

(Continues)

**Table 2** (Continued)

Question/response options	n (%)
Proportion answering 'comfortable' or 'very comfortable' to the question 'Please indicate how comfortable you feel, or would feel, in discussing the following with your patients?'	
ACP	310 (84%)
Prognosis	292 (78%)
Death and dying	307 (83%)
Potential future withdrawal or withholding of dialysis	319 (86%)
Whether or not to attempt CPR or intensive care	292 (78%)
At your primary workplace, how routinely is ACP discussed with the patients on dialysis?	
Never and hardly ever	61 (17%)
Some of the time	161 (45%)
Most of the time	68 (19%)
Always or almost always	45 (13%)
Unsure	18 (5%)
N/A (my workplace does not look after this group of patients)	8 (2%)
At your primary workplace, how routinely is ACP discussed with patients with end-stage kidney disease who are being managed with a supportive care approach (i.e. dialysis will not be commenced even if the patients renal function further deteriorates)?	
Never and hardly ever	47 (13%)
Some of the time	82 (23%)
Most of the time	71 (20%)
Always or almost always	95 (26%)
Unsure	25 (7%)
N/A (my workplace does not look after this group of patients)	41 (11%)
At your primary workplace, how routinely is ACP discussed with CKD patients (with a GFR < 30 ml/min per 1.73 m <sup>2</sup> ) who are considering their treatment options (e.g. different types of dialysis, transplant or supportive care)?	
Never and hardly ever	57 (16%)
Some of the time	134 (37%)
Most of the time	64 (18%)
Always or almost always	46 (13%)
Unsure	25 (7%)
N/A (my workplace does not look after this group of patients)	35 (10%)
Across patient groups, what proportion of patients at your primary workplace have a completed advance care directive in their medical file (paper and/or electronic)?	
All or almost all	11 (3%)
A majority	35 (10%)
A minority	220 (61%)
None or almost none	62 (17%)
Unsure	33 (9%)
At your primary workplace, at what stage of a patient's kidney disease is a conversation about ACP usually first initiated?	
ESKD (dialysis, transplantation or conservative care pathway with eGFR < 15 ml/min per 1.73 m <sup>2</sup> )	63 (17%)
CKD stage 5 (pre-dialysis)	65 (18%)
CKD stage 4	46 (13%)
CKD stage 3 or earlier	10 (3%)
Not initiated	17 (5%)
Unsure	49 (14%)
It varies so much could not say	90 (25%)
Others	21 (6%)

(Continues)

**Table 2** (Continued)

Question/response options	n (%)
Who most often carries out Advance Care Planning (ACP) at your primary workplace?	
Nephrologists	102 (28%)
Nephrology registrars	12 (3%)
Nurses	54 (15%)
Social workers	39 (11%)
ACP facilitator	31 (9%)
Health professional from another team	5 (1%)
Unsure	22 (6%)
It varies so much could not say	44 (12%)
Not initiated	9 (3%)
Others	43 (12%)
Which of the following most accurately reflects current practice in ACP at your primary workplace?	
A formal program of ACP is implemented	81 (22%)
ACP is carried out on <i>ad hoc</i> basis at the discretion of individual clinicians	201 (54%)
ACP never or hardly occurs	50 (13%)
Unsure	29 (8%)
Which ACP program(s) and/or materials are used at your primary workplace? Tick as many as applicable.	
CKD-specific program/materials developed	59 (16%)
Kidney Health Australia information	91 (24%)
Generic program developed by health area	93 (25%)
Generic state and national program	97 (26%)
A range of program/materials at the discretion of the user	67 (18%)
Unsure	110 (29%)

ACP, advance care planning; CKD, chronic kidney disease; CPR, cardiopulmonary resuscitation; eGFR, estimated glomerular filtration rate; ESKD, end-stage kidney disease; GP, general practitioner.

Analysis of variables associated with the intention for future involvement in ACP discussions showed significant relationships with respondents: having a clinical role other than a nephrologist (odds ratio (OR) 4.96, 95% CI 1.74–14.07); being comfortable discussing ACP (OR 1.29, 95% CI 1.12–1.48); and agreeing that more CKD-specific ACP programs/patient education materials might facilitate ACP (OR 10.88, 95% CI 2.38–49.79). Respondents were significantly less likely to indicate willingness to be involved in future ACP discussions if they were aged  $\geq 45$  years (OR 0.25, 95% CI 0.08–0.75) or agreed with the statement that ACP did not fall within their role (OR 1.29, 95% CI 1.12–1.48) (Fig. 1).

## DISCUSSION

To our knowledge, this is the first nationwide survey of renal clinicians' views about current practice of ACP to be conducted anywhere in the world. Responses to our survey suggest that ACP needs targeted support to improve access and overcome barriers in nephrology. Nearly two-thirds of respondents reported ACP to be performed 'poorly' or 'very poorly' at their primary workplace, less than a third reported undertaking ACP

**Table 3** Results from survey questions asking about ways to improve ACP for patients with CKD (n = 375)

Question/response options	n (%)
How well do you think ACP is currently undertaken in your primary workplace?	
Very poorly	61 (17%)
Poorly	159 (44%)
Well	92 (26%)
Very well	23 (6%)
Unsure	26 (7%)
Answered 'somewhat of a barrier' or 'substantial barrier' to the question 'please rate the degree to which you perceive the following to be barriers to ACP at your work place'.	
Lack of clinician time	290 (82%)
Patient/family discomfort in discussing end-of-life care	298 (84%)
Health professional discomfort in discussing end-of-life care	257 (72%)
Health professional lack of experience in discussing ACP	294 (83%)
Difficulty involving family	293 (83%)
Discouragement from colleagues or manager	69 (19%)
Lack of policy or procedures for ACP	212 (59%)
Environmental problems (e.g. lack of space)	215 (61%)
Cultural or language barriers	232 (65%)
Answered 'somewhat helpful' or 'very helpful' to the question 'please rate the degree to which you think the following might facilitate ACP at your work place'.	
More education about ACP for health professionals in the renal team	335 (95%)
Make ACP the role of a specially trained health professional	300 (85%)
More CKD-specific ACP program/education materials	340 (97%)
What sort of health professional education or training about ACP do you think would be helpful? Tick all that applies.	
Online	231 (62%)
Attending a lecture or workshop	270 (72%)
Small group experiential learning	203 (54%)
Practice with a simulated patient or caregiver with feedback from a facilitator	145 (39%)
Practice in role play in a small group with colleagues playing the role of a patient or caregiver	110 (29%)
Mentoring from a colleague	196 (52%)
Feedback from a supervisor or mentor after observing me talking about ACP with a patient and/or family member	110 (29%)
Don't think training is useful	9 (2%)
Others	27 (7%)
Which health professionals should be targeted for ACP training within your renal unit, clinic or ward? Tick all that applies.	
Renal nurses	315 (84%)
Nephrologists	296 (79%)
Renal registrars	247 (66%)
Renal social workers	255 (68%)
No health professionals	9 (2%)
Others	37 (10%)
Answered 'essential' to the question 'To what extent do you think the following contents should be included in patient and family CKD-specific ACP education materials and/or discussions, over and above those in general resources (e.g. information about CPR/ventilation and surrogate decision-making)?'	
Information about disease trajectory in CKD	285 (81%)
Information about prognosis on dialysis	323 (92%)
Information on the option to withdraw from dialysis	333 (95%)

(Continues)

**Table 3** (Continued)

Question/response options	n (%)
Practicalities of dialysis withdrawal	303 (87%)
Information about conservative care including symptom management	332 (95%)
First-person accounts from other CKD patients/family	170 (49%)
When do you think is the best time to begin to discuss ACP with patients with CKD who are receiving or being considered for dialysis? Please tick only one option.	
With all patients when considering treatment options (e.g. different types of dialysis or supportive care)	208 (59%)
With all patients before starting dialysis as part of pre-dialysis education	68 (19%)
With all patients after starting dialysis	8 (2%)
Only when the patient has poor prognostic factors (e.g. elderly, significant co-morbidities, if you wouldn't be surprised if they were to die within 12 months) or patients choosing a supportive care pathway to care	20 (6%)
Optimal timing varies between patients	46 (13%)
How often should ACP ideally be discussed with patients who are receiving dialysis? Tick all that applies.	
Annually	174 (46%)
When there is a change of clinical status	260 (69%)
Whenever the patient requests it	196 (52%)
Other	39 (10%)

ACP, advance care planning; CKD, chronic kidney disease.

with a majority of patients, and a quarter reported having no or almost no knowledge of ACP legislative frameworks. Reports of low initiation by, and involvement of, families in ACP are of particular concern given that family members act as substitute decision-makers when patients lose capacity. Engagement of families in ACP has been shown to improve uptake by patients in other settings.<sup>17</sup> Whilst guidelines recommend routinely offering ACP to CKD patients and commencing ACP early in the disease trajectory<sup>4</sup> and 80% of respondents thought that ACP discussions should occur prior to starting dialysis, only a third of respondents stated that ACP was usually initiated prior to commencement of renal replacement therapies at their workplace. Even patients being managed with a supportive care (non-dialysis) approach were reported to receive ACP all or as a majority by only half of respondents. Given that our sample was likely biased towards clinicians with a greater interest in ACP, these results probably underestimate current gaps and challenges in ACP implementation in Australian CKD settings. However, our results are consistent with those of research that found nephrology and respiratory specialists to have significantly poorer ACP-related knowledge and comfort than physicians from other specialties.<sup>18</sup>

On a more positive note, a large majority of respondents reported willingness to engage more often in ACP in the future and supported approaches for improving ACP, especially education and dialysis-specific ACP program/education materials. Potential for the role of education is highlighted by the finding that respondents consistently rated their level of comfort with discussing ACP higher than their skill. The aspect of ACP that

**Table 4** Descriptive summary of free-text comments related to improving advance care planning for people with chronic kidney disease

Suggestions	Illustrative verbatim comments
Societal	
Address community myths	'Unrealistic expectations of the community in general' (barrier)
'Stigma that "palliative care" = death imminent still persists in some people's minds' (barrier)	
Health system	
Health professionals across settings share responsibility for ACP	'GP's and practice nurses play an important role with this group of patients'
'Often the life-limiting condition is non-renal. Therefore I wonder if we should be taking up the discussion for the cardiologists'	
Develop better systems for sharing ACD	'Once a ACP is in place it is not always adhered to because there seems to be a lack of being able to communicate this across other services' (barrier)
'Integrated eMR tools that allow documentation to a source of truth than can be shared across the health system, including to the PCEHR' (facilitator)	
Involve palliative care	'More involvement with palliative care' (suggestion for improving ACP)
'I use palliative care doctors to help me'	
Health service	
Acknowledge ACP importance through dedicated time, space and resources	'Due to the number of patients under the care of the renal unit it is hard to allocate sufficient time to dedicate an appropriate degree of time to discuss in depth ACP'
'Current clinic demands mean there is no space available to have dedicated ACP clinics'	
'Previously our renal unit had a staff member who was working for the ACP unit specifically to see the renal patients but funding was not continued and therefore the percentage of our patients completing the ACP has decreased'	
Integrate ACP into routine care	'Stop making it a special deal, make it routine, link to Medicare card'
'Should be a formal step in the CKD pathway'	
Clinician	
Provide more education and training	'More education will increase acceptance'
'Educate staff to become skilled in ACP discussions'	
Foster support among colleagues (especially nephrologists)	'Old school physicians who don't have inclination and/or the skills to undertake ACP but won't allow others to facilitate the process' (barrier)

(Continues)

**Table 4** (Continued)

Suggestions	Illustrative verbatim comments
'Often feel that we are restricted by what the nephrologist wants for the patient'	
Patient/family	
Overcome reluctance to discuss ACP	'People will often join in a discussion about ACP but are reluctant to go to the next step'
'Patients unwilling to discuss ACP'	
Ensure patients are informed	'Poor health literacy – patients not understanding the concepts well' (barrier)
'Patient and family unrealistic expectations despite being fully informed' (barrier)	
Engage families	'We do not see a lot of some families so this is a challenge'
'Families disagree with the patients' wishes and convince them to change their decisions' (barrier)	
Materials/resources	
Cater for variability	'The problem with general information and particularly content about trajectory is that patients differ'
'Culturally appropriate material, material available in several languages'	

ACD, advance care directive; ACP, advance care planning; eMR, electronic medical record; PCEHR, Personally Controlled Electronic Health Record (now rebadged as 'My Health Record').

respondents felt least skilled in was assisting patients to complete advance care directives, suggesting that this could be a specific focus for education and training. Preferred modes of learning included lectures/workshops and online courses rather than role play or observation/feedback, which respondents thought would be intimidating. On the other hand, published studies suggest that experiential learning, with opportunities for constructive feedback and reflection, are the most effective ways to improve clinician's communication skills about sensitive topics.<sup>19–21</sup> With regard to CKD-specific materials for ACP, Kidney Health Australia provides information sheets and a decision aid to help people choose among treatment options, including supportive care.<sup>22</sup> Similar resources are provided in the USA by the National Kidney Foundation,<sup>23</sup> and the American Association of Kidney Patients provides an information web page on advance care directives.<sup>24</sup> It may be that an ACP workbook tailored specifically to the needs of CKD patients and their families may be a useful addition to the available online resources.

One-fifth of respondents felt that there were some patients for whom ACP may not be appropriate, such as young patients being considered for transplantation. However, at least basic education about ACP and encouraging patients to consider appointing their preferred substitute decision-maker in case of an emergency is arguably relevant to all patients with CKD



**Table 5** Results of unadjusted bivariate associations between variables of interest and the extent of involvement in ACP discussions with dialysis, and end-stage and chronic kidney disease patients

Variables	Patients on dialysis (P)	Patients with end-stage kidney disease being managed with a supportive care approach (P)	Patients with CKD (with an eGFR < 30 ml/min per 1.73 m <sup>2</sup> ) who are considering treatment options (P)
<b>Characteristics</b>			
Clinical role non-physician	<0.001	<0.01	<0.001
Sex		<0.001	<0.001
Age group (above/below 45 years)		<0.01	<0.05
In charge of unit		<0.01	<0.01
<b>Attitudes</b>			
The need to discuss ACP does not arise in my clinical practice	<0.001	<0.001	<0.001
ACP discussions are not part of my role	<0.001	<0.001	<0.001
<b>Skills, confidence and knowledge</b>			
ACP training	<0.001	<0.01	<0.05
Skills discussing ACP	<0.001	<0.001	<0.001
Comfort discussing ACP	<0.001	<0.001	<0.001
Knowledge about ACP legislature	<0.001	<0.001	<0.001
<b>Perception of barriers and facilitators</b>			
Discouragement from colleagues or manager	<0.01		
Lack of policy or procedures for ACP	<0.001	<0.05	
Agrees they lack access to appropriate ACP materials for CKD patients	<0.001	<0.001	<0.001
Agrees more education about ACP would be helpful	<0.05	<0.001	<0.05
Agrees that making ACP the role of a specially trained health professional would be helpful	<0.01	<0.01	<0.001
<b>Other</b>			
Patients in this group seen each month		<0.001	<0.001
Unit's ACP practice with this group	<0.001	<0.001	<0.001

ACP, advance care planning; CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate.

even those with a relatively good prognosis.<sup>9</sup> On the other hand, in view of the significant time barriers noted by respondents, it may be pertinent for renal units who are not already regularly engaging in ACP to initially prioritize more in-depth discussions of ACP with pre-dialysis and dialysis patients who are at the greatest risk of dying, such as elderly patients and those with significant co-morbidities. Certainly, guidelines recommend that ACP is needed for all end-stage kidney disease patients who are being managed with a supportive care (non-dialysis) approach.<sup>4,9</sup>

Ideas for improving the quality of ACP volunteered by respondents commonly included the need for time and private space to undertake ACP, as well as systems and processes to ensure storage and access to advance care directives, and closer links with palliative care services. Respondents' call for better systems for accessing patient's advance directives is consistent with previous findings that highlight the need to instil CKD patients with confidence that their wishes can be acted upon.<sup>5</sup> The need for improved access to advance care directives across sectors has also been acknowledged in Australia by policy<sup>25</sup> and the Personally Controlled eHealth System initiative.<sup>26</sup> In addition, respondents' suggestions

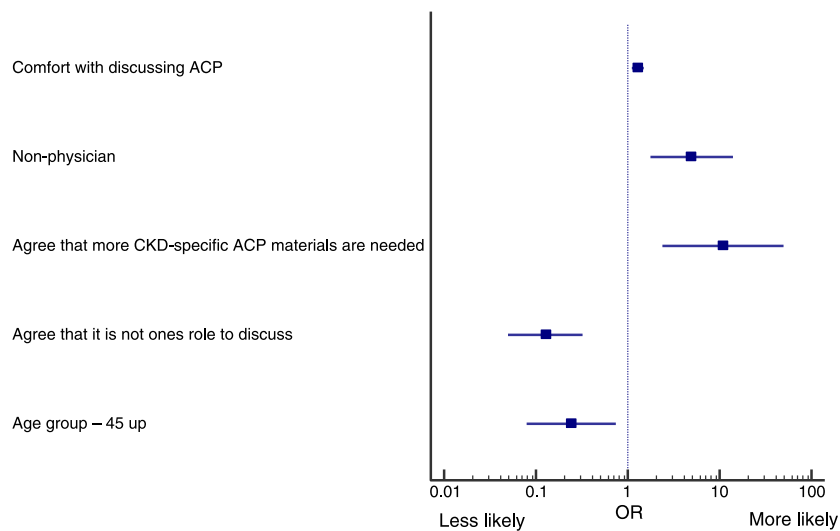
represent a call for greater institutional engagement with ACP through acknowledgement of it as core business, development of governance structures around the process and provision of material support.

Some respondents were ambivalent about allocating responsibility of ACP to expert staff rather than to all clinicians. Whilst a model of having trained and dedicated non-physician ACP facilitators has been shown to be effective in general medical settings,<sup>2</sup> others argue that all clinicians involved in caring for patients with CKD should be comfortable discussing ACP<sup>27</sup> and that nephrologists should take responsibility for initiating ACP with their patients.<sup>28</sup> The reality is that nephrologists often lack time to facilitate ACP conversations, as reflected by our survey results. Perhaps a combination of leadership and endorsement by nephrologists, general education about ACP for all renal clinicians and allocation of dedicated ACP nurse facilitators to help coordinate the more time-consuming parts of the process may prove most fruitful. An approach of this kind might also strike a balance between embedding ACP as a routine part of care and a 'one size fits all' process that some respondents were concerned would overlook variability between individual patient's needs with regard to timing and

**Table 6** Results from the multiple linear regression analysis for the extent of involvement in ACP discussions with three groups of patients: those on dialysis, those with end-stage kidney disease on supportive care and those with chronic kidney disease considering their treatment options

Variables†	Patients on dialysis		Patients with end-stage kidney disease being managed with a supportive care approach		Patients with CKD (with a GFR < 30 ml/min per 1.73 m <sup>2</sup> ) who are considering treatment options	
	$\beta$ (SE)	Significance (P)	$\beta$ (SE)	Significance (P)	$\beta$ (SE)	Significance (P)
<b>Characteristics</b>						
Clinical role non-physician			-0.81 (0.12)	<0.001		
In charge of unit			0.38 (0.11)	<0.001	0.40 (0.10)	<0.001
<b>Attitudes</b>						
The need to discuss ACP does not arise in my clinical practice	-0.31 (0.15)	<0.05	-0.59 (0.16)	<0.001		
ACP discussions are not part of my role	-0.45 (0.17)	<0.01			-0.72 (0.17)	<0.001
<b>Skills, confidence and knowledge</b>						
Skills discussing ACP	0.05 (0.01)	<0.001	0.07 (0.02)	<0.001	0.05 (0.02)	<0.01
Knowledge about ACP legislature	0.19 (0.08)	<0.05				
<b>Perception of barriers and facilitators</b>						
Agrees that making ACP the role of a specially trained health professional would be helpful					-0.16 (0.06)	<0.01
<b>Other</b>						
Patients in this group seen each month			0.22 (0.08)	<0.01	0.23 (0.05)	<0.001
Unit's ACP practice with this group	0.60 (0.05)	<0.001	0.47 (0.05)	<0.001	0.38 (0.05)	<0.001

†Only variables that maintained a significant relationship ( $P < 0.05$ ) after controlling for other variables are listed. ACP, advance care planning; CKD, chronic kidney disease; GFR, glomerular filtration rate; SE, standard error.

**Fig. 1** Forest plot of the odds ratios and 95% confidence intervals of variables associated with the intention to engage more often in ACP discussion in the future.

content. Further research is needed to evaluate such an approach.

Our study informs a better understanding of which clinicians typically carry out ACP in nephrology and who may need more support to do so. In multivariate analyses, only self-rated skills and opportunity according to local practice remained consistently predictive across dialysis, CKD and end-stage patients.

To a lesser extent, negative attitudes towards ACP were also associated with ACP practice, albeit inversely. Less expectedly, perceptions of workplace barriers and facilitators did not remain predictive after controlling for respondent characteristics, attitudes and normative beliefs, suggesting that these may not play as major a role in impeding or promoting ACP practice as respondents thought. Self-rated comfort was strongly

associated with conducting ACP with all three patient groups in bivariate analysis but lost significance when other factors were controlled for. This was in contrast to the significant role comfort played in predicting willingness to engage in future ACP discussion, suggesting that comfort may be necessary but not sufficient to carry willingness into practice. Respondents willing to engage in more ACP tended to be younger, from disciplines other than medicine, and report a need for more CKD-specific ACP materials, providing clear direction on ways to target interventions aimed at promoting greater ACP by clinicians most likely to respond.

Finally, it is worth noting that more than three-quarters of respondents had no experience with conducting ACP with patients from Aboriginal and/or Torres Strait Islander backgrounds; targeted strategies may be needed to promote culturally competent ACP in this population given higher incidence of CKD and different rates of dialysis withdrawal compared with those in other Australians.<sup>29</sup>

## LIMITATIONS

As already indicated, the greatest limitation of this study is that the sample is unlikely to be representative of the Australian nephrology workforce more generally. We accepted the likelihood of a volunteer effect on the grounds that we were primarily interested in the views of motivated clinicians likely to drive change. This likelihood is supported by the fact that our sample was relatively experienced, had mostly received previous training in ACP and had at least a working knowledge of legal frameworks, most frequently identified themselves as the person initiating ACP at their workplace. Whilst geographic spread was impressive within Australia, numbers from each discipline were small, particularly for nephrology registrars and social workers. This prevented meaningful comparison between responses from different disciplines beyond physician *versus* others combined. Whilst more nurses (65%) than physicians (23%) completed the survey, this proportion may somewhat approximate to the composition of the Australian nephrology workforce. The fact that only 4% of respondents worked in New Zealand also mean that our results are mainly focused on Australia. Data from a larger, representative sample would provide useful context within which to consider our findings. The fact that information about systems and processes for ACP collected in this study was clinician reported represents both a strength and limitation. Clinician perceptions provide important insights into likely levels of support for interventions. However, without data from other sources, it is impossible to ascertain the reliability of these perceptions. For example, the prevalent perception that patient/family discomfort posed a barrier to ACP may have been based on misguided assumptions or projected clinician discomfort. Qualitative research suggests that patients on haemodialysis may sometimes want to discuss ACP but feel that opportunities are lacking.<sup>30</sup>

## CONCLUSION

Advance care planning in patients with CKD needs promotion and support to improve access and quality. Health professionals responding to our survey were highly supportive of more education about ACP for all renal clinicians and development of CKD-specific ACP materials as ways of enhancing ACP. Further leadership and endorsement of ACP by nephrologists may also be needed. The training and appointment of dedicated ACP facilitators to help coordinate the more time-consuming aspects of ACP was endorsed by the majority of participants. The latter approach needs further evaluation to examine its effectiveness and cost-effectiveness in the CKD setting.

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## CONFLICT OF INTEREST

The authors have no conflicts of interest to declare. The results presented in this paper have not been published previously in whole or part, except in abstract format.

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