Nephrol Dial Transplant (2019) 1–12
doi: 10.1093/ndt/gfz148

ndt
Nephrology Dialysis Transplantation

Identifying critically important vascular access outcomes for trials in haemodialysis: an international survey with patients, caregivers and health professionals

Andrea K. Viecelli[1,2], Martin Howell [3,4], Allison Tong[3,4], Armando Teixeira-Pinto[3], Emma O'Lone[3,4], Angela Ju[3,4], Jonathan C. Craig[5], Lai-Seong Hooi[6], Timmy Lee[7,8], Charmaine E. Lok[9,10], Kevan R. Polkinghorne[11,12,13], Robert R. Quinn[14], Tushar J. Vachharajani [15], Raymond Vanholder[16,17], Li Zuo[18], Jan Tordoir[19], Roberto Pecoits-Filho[20], Theodore Yuo[21], Pascal Kopperschmidt[22], Rob Smith[23], Ashley B. Irish[24,25], Trevor A. Mori[25], Elaine M. Pascoe[2], David W. Johnson[1,2,26] and Carmel M. Hawley[1,2,26]

[1]Department of Nephrology, Princess Alexandra Hospital, Brisbane, QLD, Australia, [2]Australasian Kidney Trials Network, Centre for Health Services Research, University of Queensland, Brisbane, QLD, Australia, [3]Sydney School of Public Health, University of Sydney, Sydney, NSW, Australia, [4]Centre for Kidney Research, Children's Hospital at Westmead, Sydney, NSW, Australia, [5]College of Medicine and Public Health, Flinders University, Adelaide, SA, Australia, [6]Department of Medicine and Haemodialysis Unit, Hospital Sultanah Aminah, Johor Bahru, Malaysia, [7]Department of Medicine and Division of Nephrology, University of Alabama at Birmingham, Birmingham, AL, USA, [8]Section of Nephrology, Veterans Affairs Medical Center, Birmingham, AL, USA, [9]Division of Nephrology, University Health Network, Toronto, ON, Canada, [10]Department of Medicine, University of Toronto, Toronto, ON, Canada, [11]Department of Nephrology, Monash Medical Centre, Melbourne, VC, Australia, [12]Department of Medicine, Monash University, Melbourne, VC, Australia, [13]School of Public Health and Preventive Medicine, Monash University, Melbourne, VC, Australia, [14]Departments of Medicine & Community Health Sciences, University of Calgary, Calgary, AB, Canada, [15]Department of Nephrology & Hypertension, Glickman Urological & Kidney Institute, Cleveland Clinic Foundation, Cleveland, OH, USA, [16]Faculty of Medicine and Health Sciences, Ghent University, Ghent, Belgium, [17]Department of Nephrology, Ghent University Hospital, Ghent, Belgium, [18]Department of Nephrology, Peking University People's Hospital, Beijing, China, [19]Department of Surgery, University Hospital Maastricht, Maastricht, The Netherlands, [20]School of Medicine, Pontificia Universidade Católica do Paraná, Curitiba, Brazil, [21]Department of Surgery, Division of Vascular Surgery, University of Pittsburgh School of Medicine, Pittsburgh, PA, USA, [22]Fresenius Medical Care, Global Research & Development, Schweinfurt, Germany, [23]Nightcliff Renal Unit, Darwin, NT, Australia, [24]Department of Nephrology, Fiona Stanley Hospital, Perth, WA, Australia, [25]Medical School, University of Western Australia, Perth, WA, Australia and [26]Translational Research Institute, Brisbane, QLD, Australia

Correspondence and offprint requests to: Andrea K. Viecelli; E-mail: andrea.viecelli@health.qld.gov.au

ABSTRACT

Background. Vascular access outcomes reported across haemodialysis (HD) trials are numerous, heterogeneous and not always relevant to patients and clinicians. This study aimed to identify critically important vascular access outcomes.

Method. Outcomes derived from a systematic review, multidisciplinary expert panel and patient input were included in a multilanguage online survey. Participants rated the absolute importance of outcomes using a 9-point Likert scale (7–9 being critically important). The relative importance was determined by a best–worst scale using multinomial logistic regression. Open text responses were analysed thematically.

Results. The survey was completed by 873 participants [224 (26%) patients/caregivers and 649 (74%) health professionals] from 58 countries. Vascular access function was considered the most important outcome (mean score 7.8 for patients and caregivers/8.5 for health professionals, with 85%/95% rating it critically important, and top ranked on best–worst scale), followed by infection (mean 7.4/8.2, 79%/92% rating it critically important, second rank on best–worst scale). Health professionals rated all outcomes of equal or higher importance than patients/caregivers, except for aneurysms. We identified six themes: necessity for HD, applicability across vascular access types, frequency and severity of debilitation, minimizing the risk of hospitalization and death, optimizing technical competence and adherence to best practice and direct impact on appearance and lifestyle.

Conclusions. Vascular access function was the most critically important outcome among patients/caregivers and health professionals. Consistent reporting of this outcome across trials in HD will strengthen their value in supporting vascular access practice and shared decision making in patients requiring HD.

Keywords: core outcome set, haemodialysis, outcome, survey, vascular access

INTRODUCTION

Vascular access complications such as infection, vascular access failure, cannulation problems and bleeding are associated with increased morbidity, mortality and health-related costs [1, 2] and are a major stressor for patients receiving haemodialysis (HD) [3–5]. Despite increasing numbers of trials in this area, their implementation into clinical practice is limited by highly variable, often selectively reported outcomes, which may be of little relevance to patients and health professionals [6]. In a recent analysis of 168 contemporary HD trials, 23 different vascular access outcomes were reported and assessed by >1400 different measures [7], thereby limiting comparisons of findings across trials [8, 9]. Furthermore, vascular access outcomes identified as highly relevant to patients, such as pain and bleeding [3, 5], were reported in <15% of HD trials [7], which can limit decision making.

Consensus-based core outcome sets can help to improve consistent reporting of outcomes that are critically important to patients and health professionals [10–12]. Core outcome sets are defined as 'an agreed standardised set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or healthcare' [13]. The Standardized Outcomes in Nephrology – Hemodialysis (SONG-HD) initiative aims to identify core outcomes that are critically important to patients and health professionals. Through an international, multiphase consensus process involving >1300 patients, caregivers and health professionals from >70 countries, vascular access complications, fatigue, cardiovascular disease and mortality were established as core outcome domains for HD [14–16]. This study aimed to identify the most critically important vascular access outcome based on the priorities of patients, caregivers and health professionals and the reasons for their priorities [16]. This will inform the development of a standardized core outcome measure for vascular access to be reported in all HD trials.

MATERIALS AND METHODS

Study design

This open international survey (Supplementary data, Item S1) assessed the absolute and relative importance of vascular access outcomes. It was administered online and available in English, Malay, Chinese and Spanish. The survey design and process are shown in Supplementary data, Figure S1. The Checklist for Reporting Results of Internet E-Surveys was used for study reporting [17].

Participant selection and recruitment

Participants ≥18 years of age, including patients, caregivers/family members, nephrologists, general physicians, radiologists, surgeons, nurses, physiotherapists, social workers, psychologists, dietitians, pharmacists, policymakers, researchers and industry representatives with an interest or experience in HD and vascular access, were invited to complete this survey. Multiple recruitment strategies were used to be broadly inclusive. Patients and caregivers were invited via the SONG database and patient organizations worldwide (Supplementary data, Item S2) using an opt-in snowball sampling, which included the use of social media. Health professionals were recruited via professional organizations (Supplementary data, Item S2) using standardized e-mail invitations to membership lists, investigator networks and via the SONG database. Participants registered their e-mail on the SONG website to receive an e-mail invitation with the survey link. All participants provided informed voluntary consent. The study was approved by the ethics board of the University of Sydney (2015-228).

Data collection

The 12 outcomes included in the survey were identified from a systematic review of vascular access outcomes reported in clinical trials [7] and qualitative research [18, 19] and discussed with the SONG Vascular Access Expert working group [20]. Outcomes were accompanied by a plain-language definition (Box 1). The English survey was translated into Malay, Chinese and Spanish by a bilingual health professional and cross-checked by a second bilingual health professional to ensure accuracy. The survey was custom programmed and tested for usability and technical functionality prior to being piloted among 10 participants for every language included (5 patients and 5 health professionals).

Participants rated the 'absolute' importance of each of the 12 outcomes based on a 9-point Likert scale. A score of 7–9 indicated that the outcome was of 'critical importance', 4–6 indicated 'important but not critical' and 1–3 indicated 'limited importance'. An 'unsure' option was available. For each outcome, participants had the option to enter comments about their choices. Participants could also suggest new outcomes that were not included in the survey. The 'relative' importance of the 12 outcomes was assessed on a best–worst scale, whereby participants were presented with five blocks consisting of 6 of the 12 possible outcomes, randomly selected and ordered. For each block, participants were required to choose the most and the least important outcome. Like discrete choice experiments, the best–worst scale is a preference elicitation method that involves less cognitive burden and provides better discrimination and greater information retrieval [21–23]. The survey was completed using LimeSurvey from October 2016 to July 2017.

Data analysis

The absolute importance of each outcome was assessed by the mean, median and proportion of participants who rated the outcome as critically important (scores of 7–9) on the Likert scale. The relative importance was estimated using a multinomial logistic regression model. Utility functions containing all

outcomes and interaction terms for participant characteristics were constructed for the best–worst choice task. Following this approach, the mean regression coefficients are the relative importance scores for each outcome [23]. As the regression coefficients have the same underlying scale, preference scores can be adjusted to any convenient scale to aid interpretation. Absolute importance scores were calculated separately for patients/caregivers and health professionals, whereas relative importance scores were calculated using interaction terms in the regression model. Mean differences and 95% confidence intervals (CIs) were calculated for absolute (Likert) and relative (Best–Worst scale). Analyses were stratified by participant group (patients/caregivers and health professionals) to ensure equal weighting. Complete survey responses for the Likert scale and best–worst scale, respectively, were analysed. Stata/SE version 14.0 (StataCorp, College Station, TX, USA) and NLOGIT 6 (Econometric Software, Plainview, NY, USA) were used to analyse the data. Excel (version 16.0; Microsoft, Redmond, WA, USA) and HyperRESEARCH (version 3.7; ResearchWare, Randolph, MA, USA) were used to code the text and inductively identify themes focusing on reasons for outcome ratings.

Definition of consensus for the core outcome. The core outcome was defined as the outcome with the highest absolute and relative importance scores on the Likert and best–worst scales in both stakeholder groups. A priori cut-off points were not possible because of the unknown distribution of scores.

RESULTS

Participant characteristics

Overall, 984 participants commenced the survey, 956 provided demographic details, 873 completed rating each outcome on a Likert scale and 828 also completed the best–worst scale ratings (87% completion rate). Characteristics of included participants are shown in Table 1 for patients [$n = 196$ (22%)] and caregivers [$n = 28$ (4%)] and Table 2 for health professionals [$n = 649$; (74%)].

Patients/caregivers were from 16 countries. Most patients had an arteriovenous fistula (AVF) or central venous catheter (CVC) as their current (62% AVF and 8% CVC) and/or previous vascular access (54% AVF and 32% CVC) and the most commonly experienced vascular access complications were cannulation problems (40%) and pain (40%). Most patients had been on HD for <12 months (47%). Health professionals included 341 (53%) nephrologists, 184 (28%) nurses, 25 (4%) general physicians, 17 (3%) surgeons and 82 (12%) stakeholders in other roles from 56 countries.

Absolute importance of outcomes

Table 3 shows the absolute importance scores. Both patients/caregivers and health professionals considered function as the most critically important outcome for vascular access (Figure 1). Based on mean scores, the three outcomes rated the highest by patients/caregivers were function (mean 7.8), infection (7.4) and aneurysms (7.2). The top three outcomes for health professionals were function (8.5), infection (8.2) and maturation (7.4). Patients/caregivers and health professionals considered vascular access appearance as the least important outcome (mean score 5.2 and 5.4, respectively). Additional outcomes suggested by survey participants are provided in Supplementary data, Table S1. None of these new outcomes were suggested by >1% of all participants.

Relative importance of outcomes

Patients/caregivers and health professionals ranked function highest among the 12 outcomes (mean best–worst scale scores 6.3 and 9, respectively), followed by infection (mean 5.6 and 7.7, respectively; Table 3 and Figure 2). Patients and caregivers ranked aneurysms third followed by cannulation problems, steal syndrome and hospitalization. Health professionals ranked hospitalization third followed by steal syndrome, cannulation problems and maturation.

Differences between stakeholder groups

Differences in mean rating scores between stakeholder groups are shown in Figure 3. Compared with patients and caregivers, health professionals rated the following eight outcomes higher on the Likert scale: maturation [mean difference 1.23 (95% CI 0.95–1.51)], steal syndrome [0.89 (95% CI 0.62–1.16)], hospitalization [0.83 (95% CI 0.54–1.12)], infection [0.79 (95% CI 0.55–1.03)], function [0.67 (95% CI 0.45–0.89)], bleeding [0.63 (95% CI 0.34–0.92)], pain [0.57 (95% CI 0.26–0.87)] and cannulation problems [0.31 (95% CI 0.03–0.59)]. Mean differences between relative importance scores from the best–worst scale outlined clearer differences between the two stakeholder groups (Figure 3), particularly for function [mean difference 2.67 (95% CI 2.40–2.93)], hospitalization [2.37 (95% CI 2.09–2.65)], maturation [2.37 (95% CI 2.09–2.64)] and infection [2.11, (95% CI 1.85–2.38)]. The only outcome that patients/caregivers rated higher on the best–worst scale compared with health professionals was aneurysm/pseudoaneurysm [mean difference 0.59 (95% CI 0.36–0.81)].

Differences by language groups

Surveys were completed in English ($n = 518$), Chinese ($n = 191$), Malay ($n = 131$) and Spanish ($n = 33$). Overall, importance ratings were similar across all four languages and function and infection were consistently considered the two most important outcomes (Supplementary data, Figures S2 and S3).

Themes. Based on comments from both stakeholder groups, we identified six themes that reflected reasons for the rating of vascular access outcomes: necessity for HD, applicability across vascular access types, frequency and severity of debilitation, minimizing the risk of hospitalization and death, optimizing technical competence and adherence to best practice and direct impact on appearance and lifestyle. Supporting quotations are provided in Table 4.

Necessity for HD. Vascular access function was rated critically important because 'No access, no dialysis. Poor access, poor dialysis'. A functioning vascular access was described as

Table 1. Characteristics of patients and caregivers [$N = 224$ (26%)]

Characteristics	*n* (%)	Characteristics	*n* (%)
Participant type		Education[a]	
Patient	196 (88)	Did not complete high school	52 (25)
Caregiver/family member	28 (12)	High school graduate	29 (14)
		Professional certificate/diploma	43 (21)
Gender		Undergraduate degree	57 (27)
Male	109 (49)	Postgraduate degree	27 (13)
Female	115 (51)		
		Current type of treatment[a]	
Age group (years)		In-centre HD	74 (36)
18–40	53 (24)	Satellite HD	18 (9)
41–50	46 (21)	Home HD	37 (18)
51–60	52 (23)	Peritoneal dialysis	4 (2)
61–70	60 (27)	Transplant	67 (32)
71–80	12 (5)	Not applicable	8 (4)
≥81	1 (<1)		
		Years on HD[a]	
Marital status[a]		<1	85 (47)
Single	43 (21)	1–5	38 (21)
Partner/de facto	7 (3)	6–10	12 (7)
Married	125 (60)	11–15	11 (6)
Divorced/separated/widowed	33 (16)	>15	14 (8)
		Not applicable	19 (11)
Number of children[a]			
0	85 (41)	Current vascular access[a]	
1–2	89 (43)	AVF	129 (62)
3–4	31 (15)	AVG	6 (3)
≥5	2 (1)	CVC	16 (8)
		Not applicable	57 (27)
Employment status[a]			
Employed (full time/part time)	80 (39)	Previous vascular access	
Unemployed	35 (17)	AVF	111 (54)
Retired	71 (34)	AVG	13 (6)
Student	2 (1)	CVC	67 (32)
Other	19 (9)	Not applicable	16 (8)
Country		Experienced vascular access complications[a]	
Australia	49 (22)	Bleeding	77 (37)
USA	36 (16)	Hospitalization	42 (20)
China	35 (16)	Infection	29 (14)
Malaysia	32 (14)	Needling problems	83 (40)
UK	23 (10)	Pain	83 (40)
Canada	14 (6)	Dysfunction	72 (35)
New Zealand	12 (5)		
Other[b]	23 (10)	Current type of treatment[a]	
		In-centre HD	74 (36)
		Satellite HD	18 (9)
		Home HD	37 (18)

[a]Total numbers do not add up to the total number of participants due to undisclosed responses (excluded).
[b]Other includes nine countries (in descending order of frequency): Brazil, Denmark, South Africa, India, Ireland, Spain, Cuba, Greece and The Netherlands.
AVG, arteriovenous graft; AVF, arteriovenous fistula; CVC, central venous catheter; HD, haemodialysis.

indispensable for survival and therefore was regarded as a key issue to address in research and clinical practice.

Applicability across vascular access types. Function was known to apply to all access types. However, outcomes such as infection and interference with activities were predominantly viewed as being more specifically related and relevant to CVC and were thus regarded to be of lesser importance.

Frequency and severity of debilitation. Certain outcomes, such as steal syndrome, bleeding and pain, were prioritized based on the severity and overall frequency of the outcome: 'Steal [syndrome] is an important complication but it occurs in <5% of AVF patients. Thus, in relative terms, it is not as important as the other complications (e.g. primary failure)'. However, a rare event like steal syndrome was recognized as a severe complication. Similarly, bleeding was considered 'important because a bleeding fistula can lead to potential mortality and morbidity', yet was downgraded on the importance scale in view of the low frequency of occurrence.

Table 2. Characteristics of health professionals [$N = 649$ (74%)]

Characteristics	*n* (%)	Characteristics	*n* (%)
Participant type		Number of trials as investigator[a]	
Nephrologists	341 (53)	0	147 (33)
Nurses	184 (28)	1–5	169 (38)
General physicians	25 (4)	6–10	45 (10)
Surgeons	17 (3)	11–15	9 (2)
Trainees	16 (2)	≥16	27 (6)
Social worker	4 (1)	Not applicable	49 (11)
Radiologist	2 (<1)		
Psychologists	2 (<1)	Other roles[a]	
Dietitian	3 (<1)	Government, policy	58 (13)
Researcher	15 (2)	CPG	140 (31)
Pharmacist	1 (<1)	Funding	32 (7)
Policy maker	2 (<1)		
Industry/private sector	7 (1)	Country	
Other	47 (7)	China	159 (25)
		Malaysia	109 (17)
Gender		Australia	88 (14)
Male	293 (45)	Spain	27 (4)
Female	356 (55)	Canada	27 (4)
		UK	26 (4)
Age group (years)		USA	24 (4)
18–40	268 (41)	Portugal	18 (3)
41–50	198 (31)	India	15 (2)
51–60	138 (21)	Brazil	14 (2)
61–70	38 (6)	New Zealand	10 (2)
71–80	6 (1)	The Netherlands	9 (1)
≥81	1 (<1)	Italy	9 (1)
		Belgium	8 (1)
Experience with HD (years)[a]		Other[b]	106 (16)
<11	166 (37)		
11–20	146 (33)		
21–30	76 (17)		
>30	40 (9)		
Not applicable	18 (4)		

[a]Total numbers do not add up to the total number of participants due to undisclosed responses (excluded).
[b]Other includes 42 countries (in descending order of frequency): Uruguay, Saudi Arabia, Greece, France, Romania, Poland, Peru, Germany, Egypt, Colombia, Argentina, Sweden, Chile, Bolivia, Turkey, Slovenia, Singapore, Serbia, Russian Federation, Montenegro, Mexico, Lithuania, Israel, Ireland, Croatia, Austria, Vietnam, Syria, Switzerland, Sri Lanka, South Africa, Rwanda, Philippines, Paraguay, Nigeria, Morocco, Kosovo, Hungary, Finland, El Salvador, Bulgaria and Belarus.
CPG, Clinical Practice Guidelines.

Minimizing the risk of hospitalization and death. Outcomes, including vascular access dysfunction, infection, aneurysm, bleeding and steal syndrome, were prioritized highly if they were expected to increase the risks of death, need for interventions and hospitalization.

Optimizing technical competence and adherence to best practice. Participants believed that consistent demonstration of technical competence, adherence to best practice and ability to optimize technique skills could help mitigate avoidable complications related to maturation, cannulation or aneurysm formation. Cannulation problems were closely related to the 'competency/skill level of the cannulation technician's. Infections were considered avoidable with adherence to good clinical practice. Achieving consensus on the optimal timing of first cannulation of a mature/maturing vascular access to improve maturation and ensuring implementation of protocols for sterile handling of vascular accesses to minimize infection risks were highlighted as two important research priorities.

Direct impact on appearance and lifestyle. Some participants gave higher priority to outcomes that had a palpable and severe impact on their personal identity, self-esteem, independence and daily life. For example, appearance was considered least important overall, however, this outcome was ranked highly by patients who viewed the vascular access as 'ugly' and 'unpleasant' and by patients who had been asked if they were victims of domestic abuse due to bruising and scarring. Cannulation problems were viewed as critically important for home dialysis training units, because the inability to cannulate the arteriovenous access by patients or their family members was identified as a limiting step to dialysing independently at home.

DISCUSSION

The most critically important vascular access outcome identified by patients/caregivers and health professionals was vascular access 'function'. This finding was consistent across the two groups, whether measured as absolute or relative importance. Participants identified the necessity of a functioning vascular

Table 3. Summary of importance scores for patients/caregivers and health professionals

Outcomes	Likert score, median (IQR)		Likert score, mean (95% CI)		Proportion critically important (7–9) (%)		BWS score, mean (95% CI)	
	Patients/caregivers	HP	Patients/caregivers	HP	Patients/caregivers	HP	Patients/caregivers	HP
Vascular access function[a]	9 (7–9)	9 (7–9)	7.8 (7.6–8.0)	8.5 (8.5–8.6)	85	95	6.3 (5.9–6.8)	9.0 (8.6–9.4)
Infection	8 (7–9)	8 (7–9)	7.4 (7.2–7.6)	8.2 (8.1–8.3)	79	92	5.6 (5.2–6.0)	7.7 (7.3–8.0)
(Pseudo-)aneurysm	8 (7–9)	7 (6–8)	7.2 (7.1–7.3)	7.4 (7.2–7.6)	78	70	5.3 (4.9–5.7)	4.7 (4.4–4.9)
Cannulation problems	7 (6–8)	7 (6–8)	6.8 (6.6–7.1)	7.1 (7.0–7.3)	67	69	4.6 (4.2–5.0)	5.9 (5.6–6.2)
Steal syndrome	7 (5–9)	8 (7–9)	6.7 (6.4–6.9)	7.6 (7.4–7.7)	61	80	4.6 (4.2–5.0)	6.0 (5.7–6.2)
Hospitalization	7 (5–9)	8 (7–9)	6.6 (6.4–6.9)	7.4 (7.3–7.6)	63	76	4.1 (3.2–4.5)	6.5 (6.2–6.8)
Oedema	7 (5–8)	7 (6–8)	6.5 (6.2–6.7)	6.7 (6.6–6.9)	57	55	3.2 (2.9–3.5)	4.0 (3.8–4.3)
Maturation	7 (5–9)	8 (7–9)	6.4 (6.2–6.7)	7.7 (7.5–7.8)	56	79	2.7 (2.8–3.5)	5.1 (3.5–4.0)
Bleeding	7 (5–8)	5 (7–8)	6.3 (6.1–6.6)	7.0 (6.8–7.1)	52	65	3.1 (2.4–3.7)	3.8 (2.9–3.6)
Interference with activities	6 (4–8)	6 (5–7)	5.9 (5.7–6.2)	6.2 (6.0–6.3)	40	45	1.9 (2.3–3.2)	2.5 (4.8–5.4)
Pain	6 (4–8)	7 (5–8)	5.9 (5.6–6.1)	6.4 (6.3–6.6)	42	51	3.1 (1.4–2.3)	3.2 (2.2–2.7)
Appearance	5 (4–8)	5 (4–6)	5.2 (5.1–5.4)	5.4 (5.1–5.6)	33	24	1 (ref)	1 (ref)

[a]Core outcome (i.e. most critically important outcome) based on highest absolute and relative importance scores in both stakeholder groups (i.e. patient/caregiver and health professionals).
BWS, best–worst scale; HP, health professionals; IQR, interquartile range.

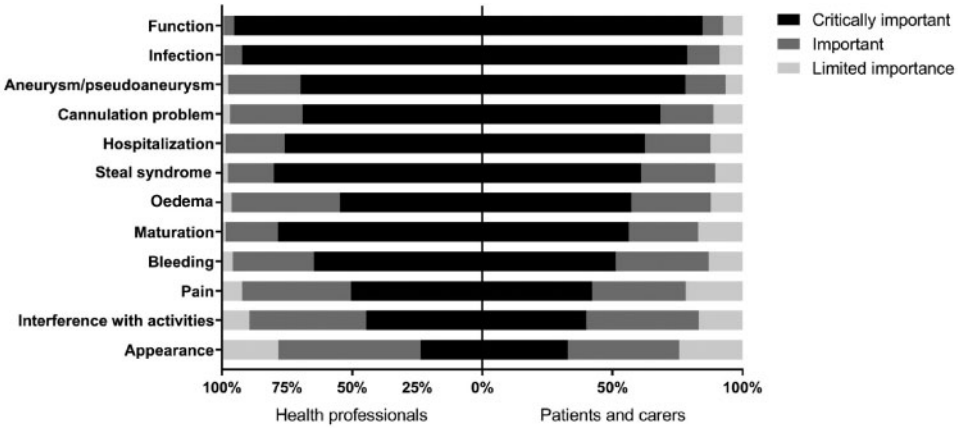

FIGURE 1: Proportion of patients/caregivers (right) and health professionals (left) considering outcomes as critically important, important or of limited importance. Critically important (black): 7–9 points on Likert scale; important (dark grey): 4–6 points on Likert scale; limited importance (light grey): 1–3 points on Likert scale.

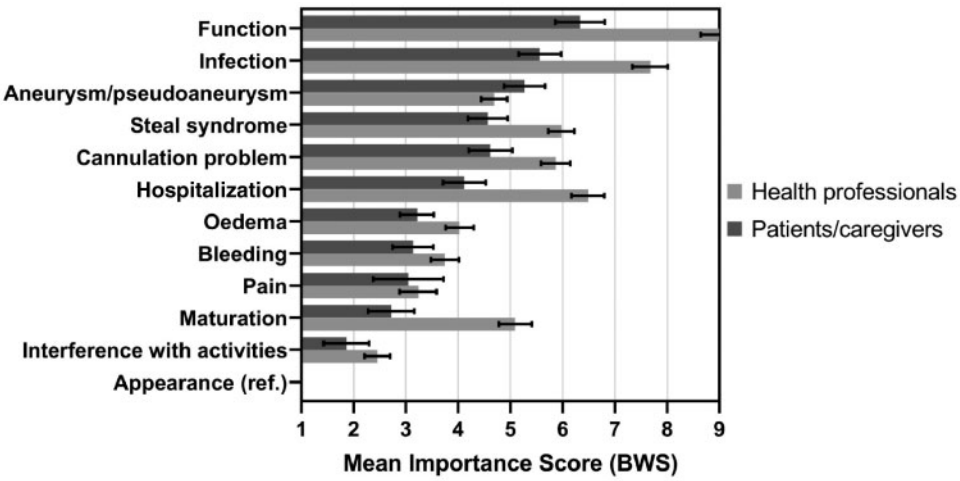

FIGURE 2: Mean relative importance scores of patients (light grey) and health professionals (dark grey) based on the BWS. Ordered by the mean importance scores of patients/caregivers (bars with 95% CIs). BWS, best–worst scale.

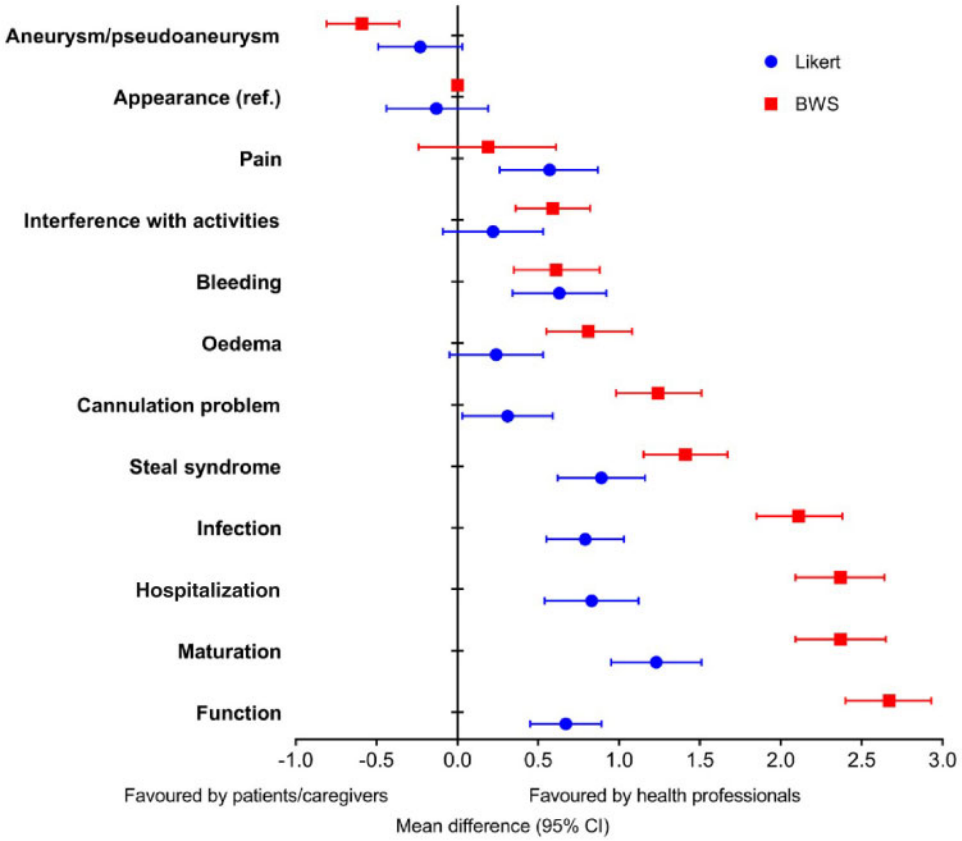

FIGURE 3: Difference in absolute (Likert) and relative (BWS) mean scores between patients/caregivers and health professionals. Error bars refer to 95% CI. BWS, best–worst scale (assessment of the relative importance of outcomes); Likert, Likert scale (assessment of the absolute importance of outcomes).

access to provide adequate dialysis and the devastating and costly consequences of a failing vascular access, including invasive procedures, hospitalizations and death, as important reasons for prioritizing this outcome. The second highest-ranking outcome, vascular access-related infection was deemed critically important because of the detrimental consequences of prolonged hospitalization and associated increased morbidity and mortality. Infection was considered as largely preventable through best clinical practice and to be mostly a consequence of CVC use. It was deemed not as relevant to all forms of vascular access, whereas function was equally applicable to all vascular access types. While there was consensus on function and infection as the most critically important outcomes across both stakeholder groups, patients and caregivers considered aneurysms to be more important and health professionals particularly viewed maturation, steal syndrome and hospitalizations to be of greater importance.

Concordant with our findings, problems with vascular access function have been voiced as the most prominent concern by HD patients. In a survey of 128 patients from a single US dialysis programme, 59% reported vascular access thrombosis as their major concern [5]. A survey administered to 132 HD patients in Canada identified that within the dialysis complications domain, concerns regarding vascular access longevity caused the highest level of dissatisfaction [24]. An international study with patients and different health professional groups on priorities for guidelines regarding vascular access found that decisions related to vascular access type and site selection and prevention of infections were the highest priorities to be addressed. However, while patients' highest priority was how to manage catheter thrombosis, nephrologists, nurses and surgeons/radiologists considered the management of arteriovenous access stenosis and central vein obstruction within their top 10 priorities to be covered by international guidelines [25].

Aligned with patients' concerns, vascular access function has been a major focus of HD trials. In a systematic review of 168 contemporary randomized trials in HD, function was the most frequently reported vascular access outcome (81% of trials) followed by infection (38%), yet function was the most heterogeneous outcome and measured in nearly 500 different ways [7]. Based on this review, the uptake of standardized outcome definitions has been minimal. Less than 13% of trials published or registered between 2011 and 2016 used standardized definitions to measure vascular access patency and only 22% of trials used standardized definitions to assess vascular access–related infections [7]. These findings underpin the need for broader implementation of internationally agreed and standardized patient-important outcome measures to enhance the consistency and relevance of outcome reporting in clinical trials and beyond. Recently the Kidney Health Initiative (KHI) published a series of papers on recommended trial endpoint definitions tailored to the different types of vascular access and time points of their life cycle to facilitate the development of effective interventions and products to improve vascular access

Table 4. Themes with selected illustrative quotations

Themes with illustrative quotations	Outcome	Likert score
Necessity for HD		
'No access, no dialysis. Poor access, poor dialysis'. (Health professional)	Function	9
'Without vascular access that works effectively, patients could either get a less than adequate dialysis dose or have to spend more time on dialysis'. (Health professional)	Function	9
'Without vascular access there is no hemo!' (Health professional)	Function	9
'Vascular function = patient's life. There is no doubt that any problems related to blood vessels should be regarded as a key issue'. (Patient)	Function	9
Applicability across vascular access types		
'Depends on kind of vascular access. . .per example catheter versus native AVF'. (Health professional)	Infection	7
Not applicable as neckline used. (Caregiver)	Pain	NA
'This would relate more to tunnelled CVC than AVF I would think. (Health professional)	Interference with activities	7
Weak evidence that arteriovenous accesses are superior to CVC; therefore, maturation of an arteriovenous access should not be the first question to ask'. (Health professional)	Maturation	1
Frequency and severity of debilitation		
'Although rare, this might be a cause for giving up to that access'. (Health professional)	Steal syndrome	7
'Experienced a number periods of hospitalisation due to failed fistulas and emergency measures taken (e.g. a temporary line in the groin) to ensure haemodialysis could continue to be performed at scheduled times'. (Patient)	Hospitalization	7
'Frequent in the beginning but usually no patient complains after some weeks or months'. (Health professional)	Pain	3
'I applied a cream to my site before needling so did not feel any pain'. (Patient)	Pain	7
'Importance would depend on the frequency and severity of the bleeding'. (Health professional)	Bleeding	6
'No significant problems with bleeding, just odd occasions of incidents when either I or my carer were a little too impatient when removing the needle at the end of the session'. (Patient)	Bleeding	6
'Infective complications in my country is very high'. (Health professional)	Infection	8
'Most of my haemodialysis related complications are related to vascular access'. (Health professional)	Hospitalization	9
'Occurs 1–3×/year/patient and lasts 1–2 weeks; cumbersome in practice!' (Health professional)	Bleeding	8
'The needling process was my regular nightmare, even after the addition of using an anesthetic injection it was still a treatment that had me in tears. When I had a catheter pre a fistula I had painful episodes of machine alarming, blockage, nausea'. (Patient)	Pain	9
'Steal can be really distressing and it seems very unfair to add this to all the other complications of a dialysis patient's life'. (Health professional)	Steal syndrome	9
'Steal is an important complication but it occurs in less than 5% of AVF patients. Thus, in relative terms, it is not as important as the other complications (e.g. primary failure)'. (Health professional)	Steal syndrome	4
'This is the most common reason why our patients are admitted to my hospital . . . vascular access patency is a thorny issue'. (Health professional)	Function	9
'Very important if you get it, but fortunately true steal syndrome is uncommon'. (Health professional)	Steal syndrome	5
'When/if this happens it is very, very painful'. (Patient)	Aneurysm	7
Minimizing the risk of hospitalisation and death		
'A serious problem in patients with long standing in dialysis that needs a rapid solution	Function	9
Frequently, the patient will need some intervention over the fistula, or even closing it. It's very important'. (Health professional)	Steal syndrome	8
'It is a cause of death and has to be prevented by careful disinfection and handling'. (Health professional)	Infection	6
'In the meanwhile, the patient will need a catheter, and this fact increases the risk of infection, hospitalisation, etc. Good vascular access function is critical'. (Health professional)	Function	9
'Infection can be life-threatening'. (Health professional)	Infection	9
'Important because a bleeding fistula can lead to potential mortality and morbidity e.g. insertion of line with associated sepsis risks'. (Health professional)	Bleeding	6
'This is very important not just because of the morbidity and mortality to the patients, but also because of the burden that infection, particularly of temporary [vascular] access, puts on us for hospital beds and other resources'. (Health professional)	Infection	9
'We had 2 patients who died because of this'. (Health professional)	Aneurysm	8
'The weakening of the blood vessel wall is definitely a dangerous situation for the patient, and there may be many reasons for this situation and the consequences are severe'. (Patient)	Aneurysm	8
'This problem should be prioritised, it affects patients' life'. (Patient)	Infection	9
Optimizing technical competence and adherence to best practice		
'Ensuring that the effort that goes into creating an AVF results in a working access is really important. I expect some units have better records than ours and I would love to know why'. (Health professional)	Maturation	6
'This can be a problem sometimes due to the competency/skill level of cannulation technicians'. (Patient)	Cannulation problems	9
'We need a consensus in time to maturation, needles to use, etc. tackle the maturation time with the same approach in every dialysis units'. (Patient)	Maturation	9
	Infection	9

Continued

Table 4. Continued

Themes with illustrative quotations	Outcome	Likert score
'We need to apply sterile protocols during manipulation of vascular access, in every dialysis units worldwide, in for profit and no-profit centres'. (Patient)		
'Perhaps the only way to solve this problem is to find a professional key opinion leader surgeon'. (Patient)	Maturation	3
'Need staff who are expert at cannulating with needles in the area of the vascular access'. (Patient)	Maturation	8
'It may be a serious problem that may imply the need to close the access but it is avoidable. I do not understand why the vascular surgeons treat the varicose veins with contention but not the fistulae. All my patients use an elastic brace on their fistulae'. (Health professional)	Aneurysm	3
'Suggestion that training for nurses for standardised needling was ignored'. (Patient)	Pain	4
'Important but should be avoidable with good clinical practice. Anything that makes it easier for patients and staff to minimise the risk of infection would be good'. (Health professional)	Infection	8
'This should not happen at all, if it does then bad practices are being adopted'. (Patient)	Infection	6
Direct impact on appearance and lifestyle		
'Can't wear my wedding ring do to the change in my hands due to my fistula'. (Patient)	Oedema	8
'Due to the bruising and scarring I've been asked many times if my husband has been abusing me'. (Patient)	Appearance	9
'I found I was not as active as I was and could not do things I used to do, This I found very frustrating'. (Patient)	Interference with activities	9
'This is a very ugly side effect of the fistula and the buzzing is also unpleasant'. (Patient)	Appearance	9
'Mine looks like a Kiwi fruit. Living on a rural property, mowing, chain sawing, gardening etc. Needs a tie off, but I'm a high chance of rejection'. (Patient)	Appearance	9
'Women seemed more concerned about this but my experience majority of patients understand that access is their lifeline'. (Health professional)	Appearance	7
'This can be an issue for us as we are primarily a home training unit, with the expectation that patients or family members will be cannulating the access. Unfortunately, they are training on AVF that are still maturing'. (Health professional)	Cannulation problem	9

AVF, arteriovenous fistula; CVC, central venous catheter; HD, haemodialysis; NA, not applicable.

outcomes [26–29]. Complementing this work by the KHI, the inclusion of vascular access function as part of the core outcome set for HD established through the international SONG initiative will help to ensure more consistent reporting of outcomes in HD research that are considered important by all relevant stakeholders [16, 30]. A core outcome measure for vascular access function applicable to all three access types is currently being established, piloted and validated by the SONG initiative to facilitate global implementation in research and clinical practice.

Increasingly, clinical performance measures have been used for quality improvement for enhanced transparency through public reporting and calculating service payments. The clinical performance measures for end-stage kidney disease used by the Centers for Medicare and Medicaid Services include mortality, hospital readmissions, patient experience of care, dialysis adequacy, vascular access type in use, blood transfusions, bloodstream infections and hypercalcaemia [31]. Clinical performance measures are a powerful tool for quality improvement and have become a driving force to determine care delivery. However, current clinical performance measures are largely chosen by health professionals and may not reflect what patients care most about. Adding core outcomes that are considered critically important by patients, caregivers and health professionals, like vascular access function, may help improve the relevance of performance-based measures to patients. For example, monitoring the rate of vascular access interventions needed to maintain its use for HD as a measure of function rather than targeting a percentage of AVF and CVC use may be recommended. This is a more patient-centred goal of finding the optimal vascular access requiring the fewest number of procedures to provide adequate dialysis [32, 33]. Incentivizing a reduction in interventions is anticipated to reduce health care costs and hospitalizations while simultaneously reducing the burden of invasive, often painful and anxiety-provoking procedures that are disruptive to patients' lives [3, 34].

Vascular access infection was the second most important outcome identified by patients/caregivers and health professionals. Infections are an important cause of morbidity and death in HD patients [2, 35, 36]. Approximately 30% of patients using a CVC experience a bloodstream infection per year and each episode costs the health care system US$17 000–32 000 [37]. However, infection is less relevant to vascular access problems as a whole, because it primarily relates to CVC use with a minimum 9-fold higher rate of access-related bloodstream infections compared with AVF use [8, 38]. Survey participants emphasized that infection is preventable if there is strict adherence to best practice guidelines. A Centers for Disease Control and Prevention evidence-based quality improvement project across 17 HD facilities confirmed that staff training and competence assessment, aseptic technique, chlorhexidine use for CVC exit site care and staff performance feedback can reduce access-related bloodstream infections by 54% [39]. For these and other reasons, infection was deemed less suitable as a core outcome compared with function [34].

Patients/caregivers rated the importance of aneurysms/pseudoaneurysms third and significantly higher compared

Box 1. Outcomes and definitions

Outcome	Definition
Function	The ability to use the vascular access for HD. Problems with function are difficulties or the inability to use the vascular access for HD because the access is not working well. This includes poor blood flow because of blood clots or narrowing of vessels, blocked lines (catheters), needing extra procedures (such as surgery for declotting) to try and get the access to work properly and loss of the vascular access with the need for a new vascular access.
Maturation	Maturation is the time needed for a new fistula or graft to work and be used for HD. Problems with maturation include the need for a line (catheter) because the fistula or graft is not ready for use or the need to have further tests (such as ultrasound) and procedures (such as surgery) until the graft or fistula can be used for HD.
Bleeding	Bleeding or bruising where the vascular access is located, immediately before, during or after dialysis or a procedure (examples include bleeding during needling/cannulation or ongoing bleeding after dialysis for fistulas/grafts or bleeding after a line insertion).
Pain	Pain (including fear of pain) at or around where the vascular access is located (e.g. during needling/cannulation or during or after vascular access procedures).
Infection	Disease/harm caused by organisms such as bacteria that enter the body via the vascular access. This includes blood infection and infection in and around the vascular access.
Reduced blood supply (steal syndrome)	Pain, tingling, paleness or coolness of the hand or forearm on the side of the vascular access caused by problems with blood supply. This can also lead to numbness, weakness in finger/hand/forearm, ulcers (dying tissue) or dead (black) tissue.
Interference with activities	Problems with or inability to perform activities you wish to do because of your vascular access, such as bathing, sports, wheeling a wheelchair, being in an uncomfortable position during dialysis or unable to do something because of an appointment/procedure for your vascular access.
Weakening of the vessel wall (aneurysm/pseudo-aneurysm)	A balloon-like swelling in the wall of the vessels of the fistula or graft. This swelling weakens the vessel wall and can burst/rupture.
Cannulation (needling) problem	Problems with placing the dialysis needles into the fistula or graft or the need for repeated punctures.
Oedema	Swelling of the body part where the vascular access is located (leg, arm, can also extend to neck or face).
Hospitalization	The need to be in hospital because of vascular access problems such as infection, procedures or bleeding.
Appearance	Changes in appearance because of the vascular access (e.g. bulging veins and scars).

with health professionals. The responses from patients in our survey and the SONG-HD vascular access consensus workshop [34] suggest that fear of a catastrophic haemorrhage was a key reason for the high importance of this outcome. Other reasons may include associated pain, displeasing appearance and physical activity restriction to mitigate risks like rupture [3, 18].

Cannulation problems were considered an important outcome that could be overcome by optimizing cannulation skills and technique. Cannulation technique has a significant impact on vascular access outcomes. In 2009, a survey conducted across 171 European HD units revealed that area cannulation technique, although used in 66% of patients, was associated with inferior access survival compared with the rope ladder or buttonhole technique [40]. Compared with rope ladder, the buttonhole technique is associated with a higher risk of infection without proven advantages regarding cannulation-associated pain, vascular access interventions, survival or haematoma and aneurysm formation [41–43]. Quality improvement programmes to guide optimal cannulation practices and future research evaluating the effectiveness of structured cannulation skill training, remuneration of expert cannulators and promotion of self-cannulation may help reduce cannulation-associated problems and resulting concerns for patients [4, 44].

This international survey included a broad group of stakeholders across 58 countries and a large proportion of patients/caregivers. Administering the survey in multiple languages allowed for recruitment from countries, such as China and Malaysia, that have not been included in previous vascular access surveys [4, 18, 25]. The large sample size, coupled with a quantitative assessment of absolute and relative importance ratings enabled detailed and robust assessment of vascular access outcomes prioritization. Qualitative data analysis provided further insights into the meaning and reasons for outcome prioritization by survey participants. However, there are some potential limitations. We used broad recruitment strategies, but the number of individuals who accessed the survey but did not continue is unknown, and thus we could not calculate an accurate response rate. We acknowledge that the characteristics of those who received an invitation to complete the survey but did not respond to the survey cannot be determined. The survey was administered online to ensure efficient dissemination and minimize data transfer errors, which restricted the sampling frame to computer literate participants with Internet access. This, together with the administration of the survey in only four languages, may have led to ascertainment bias (e.g. overrepresentation of nephrologists compared with other health professional groups). Differences in patient/caregiver experiences with respect to specific access types and their complications may have impacted on outcome prioritization. However, these data were generally not disclosed by survey respondents, thereby preventing reliable exploratory analysis of this issue. The survey was restricted to the 12 most commonly reported outcomes; however, the option to suggest new outcomes ensured that additional important outcomes were not missed. A further limitation inherent to all surveys is the potential for

response bias, including demand bias and neutral or extreme responses.

In conclusion, 'function' was the most critically important vascular access outcome for patients/caregivers and health professionals. The broad applicability of this outcome to all access types, the absolute necessity of a functioning vascular access to provide adequate dialysis and the detrimental consequences of a failing access make this outcome a meaningful and suitable core outcome. A definition and metric for vascular access function are currently in development and will be piloted and validated in an international, multicentre study to ensure it is a reliable and feasible outcome measure to be used in research and clinical practice without adding undue burden to researchers and health professionals to ensure global implementation [16, 20, 34]. Consistent reporting of a validated, feasible, robust and meaningful outcome measure for vascular access function in research and ultimately in quality improvement projects will help to inform clinical practice and decision making in a meaningful way.

SUPPLEMENTARY DATA

Supplementary data are available at ndt online.

ACKNOWLEDGEMENTS

The authors thank the SONG Steering Committee and SONG Coordinating Committee for advice and comments. The authors thank the following organizations for their support: International: Cochrane Kidney and Transplant, Dialysis Outcomes and Practice Patterns Study (DOPPS), International Society of Nephrology (ISN), Kidney Disease: Improving Global Outcomes (KDIGO), PKD International, The Transplantation Society (TTS), World Transplant Games Federation; Australia/New Zealand: Australian and New Zealand Society of Nephrology (ANZSN), Australasian Kidney Trials Network (AKTN), Christchurch Kidney Society, Kidney Health Australia (KHA), Caring for Australasians with Renal Impairment (CARI), Kidney Health New Zealand (KHNZ), PKD Foundation of Australia, Renal Society of Australasia (RSA), Transplant Australia; Canada: Kidney Foundation of Canada (KFOC), Canadian Society of Nephrology (CSN), Canadian Society of Transplantation (CST); Europe: British Kidney Patient Association, British Renal Society (BRS), European Kidney Patients Federation (EKPF), European Kidney Transplant Association (EKITA), European Society of Transplantation (ESOT), European Renal Best Practice (ERBP), UK National Kidney Federation (NKF), PKD Charity, Société Francophone de Transplantation, The Renal Association; USA: American Association of Kidney Patients, Home Dialysis Central, National Kidney Foundation Southern California, Sociedad Latinoamericana de Nefrología e Hipertensión.

FUNDING

This project is supported by a National Health and Medical Research Council (NHMRC) programme grant (1092597) and project grant (1098815). A.K.V. receives grant support from the NHMRC Medical Postgraduate Scholarship (1114539) and the Royal Australasian College of Physicians (Jacquot NHMRC Award for Excellence). E.O. receives support from the NHMRC Medical Postgraduate Scholarship (1114189), A.T. and T.A.M. are supported by NHMRC Research Fellowships (1106716 and 1136046) and D.W.J. is supported by an NHMRC Practitioner Fellowship (1117534). The funding organization had no role in the design and conduct of the study; collection, management, analysis and interpretation of the data or preparation, review or approval of the manuscript.

AUTHORS' CONTRIBUTIONS

A.K.V., A.T., E.O., J.C.C., L.-S.H., T.L., C.E.L., K.R.P., R.R.Q., T.J.V., R.V., L.Z., R.P.-F., D.W.J. and C.M.H. were responsible for the concept and design of the study. A.K.V., M.H. and A.T. were responsible for drafting of the manuscript. All authors contributed to the data collection, analysis and interpretation and review and approval of the final version of the manuscript.

CONFLICT OF INTEREST STATEMENT

D.W.J. reports grants and personal fees from Baxter Healthcare and Fresenius Medical Care, other from Amgen, personal fees from AstraZeneca and grants from the National Health and Medical Research Council of Australia during the conduct of the study. R.R.Q. has a patent DMAR Software Platform for Quality Improvement issued. C.M.H. reports grants from Baxter Australia, Fresenius Medical Care, Shire and the Medical Research Council of Australia during the conduct of the study; other from Johnson and Johnson and GlaxoSmithKline, personal fees and other from Otsuka and grants from PKD Foundation of Australia outside the submitted work. A.B.I. reports personal fees from Amgen Australia and Astellas Pharmaceuticals outside the submitted work. R.P.-F. reports grants from Fresenius Medical Care and personal fees from AstraZeneca, Akebia, Fresenius Medical Care and Novo Nordisk outside the submitted work. All other authors have no conflicts of interest to disclose.

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Received: 1.2.2019; Editorial decision: 18.6.2019