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Identification and Prioritization of Canadian Society of Nephrology Clinical Practice Guideline Topics

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Introduction: Nephrology clinical practice guideline topics are routinely determined by clinicians and researchers, without extensive engagement of people with lived experience (PWLE) of kidney disease and their caregivers. The Canadian Society of Nephrology (CSN) Clinical Practice Guidelines Committee (CPGC) completed this modified Delphi study to incorporate diverse stakeholder perspectives in identifying and prioritizing future guideline topics.

Methods: We recruited nephrology clinicians, researchers, PWLE of kidney disease or their caregivers for this study. We collated literature-derived guideline topics from international and national guideline organizations that had relevance to nephrology, in addition to suggestions from participants. Consenting participants were taken through a 3 round Delphi survey process, where items were ranked on a 9-point Likert scale in terms of their importance. Based on predetermined consensus criteria, items were accepted as a priority or excluded from further consideration. We ranked the prioritized topics and compared the median ranking between clinicians or researchers and PWLE in the round where consensus was reached.

Results: Of the 85 consenting participants, 76 to 78 completed each Delphi round. From the initial list of 100 topics for consideration, 12 were priorities. All stakeholder groups felt it was important for PWLE to be included in topic prioritization and guideline development. The 3 most highly prioritized topics were *de novo* guidelines on novel therapeutics to prevent or slow progression of chronic kidney disease (CKD), recommendations for primary care, and patient-oriented guidelines on diet and exercise in kidney disease. There were no statistical differences in the median ranking between stakeholder groups ($P > 0.05$).

Conclusion: This study will inform the future nephrology guidelines and commentaries developed by the CSN.

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KEYWORDS: clinical practice guideline; kidney disease; patient engagement; priority setting; topic prioritization

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Breakthroughs in science related to kidney disease and the subsequent growth of the medical literature, has by necessity led to multidisciplinary health care providers relying on clinical practice guidelines to inform them of evidence-based diagnostic and management strategies. Although there are many guidelines and best practices documents produced by international and national kidney organizations, many areas of clinical nephrology care have not yet benefited from the development of a methodologically rigorous clinical practice guideline. For example, guidelines on anticoagulation management in people with advanced kidney disease or in CKD care for gender-diverse or other marginalized populations, among many other topics, represent important gaps in the clinical practice guidelines. With this consideration, balanced by scarcity of time and other resources necessary for guideline development, guideline organizations are often faced with having to determine the focus of upcoming initiatives from many alternatives.

Although many guideline organizations and standards recognize that diverse stakeholder engagements involving patients is necessary to ensure relevance and acceptability in recommendations,[1,2] how this is operationalized at the priority setting and topic determination phase is less clear in the literature, with only a minority including patients.[3] In contrast, literature has shown that stakeholder perspectives in the medicine environment differ such that clinicians' and researchers' priorities are not consistently aligned with priorities of PWLE.[4] Within the nephrology domain, stakeholder differences have been demonstrated in identifying priorities for research and clinical outcomes.[5-12] Taken together, many guideline organizations are not aware of the priorities of the groups that they are developing guidelines for.

The CSN CPGC mandates that patients are included in guideline development panels. However, the committee itself, which is composed entirely of nephrologists, often helps determine the scope and focus of committee activities, including novel guidelines and commentaries of other society guidelines. Because this process has historically been exclusive of input from PWLE, we have made it a priority to ensure that PWLE are involved in future committee activities. Thus, in an effort to determine the focus of future clinical practice guidelines and consensus statements development by the CSN, and with a person-centered lens with multidisciplinary stakeholder involvement, we conducted a modified Delphi study. This method to generate consensus was chosen over others to foster diverse electronic collaboration across a large geographic region. The overall objective of this study was to identify and compare priorities for future clinical practice guideline topics and sources for potential consensus statements between multidisciplinary clinicians, researchers, and PWLE.

METHODS

We conducted this modified Delphi study using a prespecified protocol,[13] guided by published recommendations on using Delphi surveys in health-related research.[14-16] We followed the reporting guidance in the Accurate Consensus Reporting Document recommendations[17] (Supplementary Table S1). Ethics approval was obtained through the Hamilton Integrated Research Ethics Board via McMaster University (Ethics ID 14626). Our overall study process is outlined in Figure 1 and organized into major steps of participant recruitment, literature review, Delphi survey rounds, and analysis of results. We conducted all surveys online with 1 initial demographics survey, followed by 3 rounds of surveys where participants ranked the items. For both the second and third rounds, the participants were shown the median scores of remaining items for both major categories of stakeholders (i.e., patients and caregivers, compared with clinicians and researchers).

Selection of Participants and Recruitment

Eligible participants for our panel were adults from Canada with self-identified proficiency reading and writing in either English or French; they were either PWLE of kidney disease or their caregivers; or were part of multidisciplinary groups of health care professionals and researchers, with expertise in caring for or conducting research focused on people with kidney disease. For our PWLE and caregiver group, we recruited broadly by engaging with national, provincial, and jurisdictional patient stakeholder groups with and without affiliation with national nephrology or research organizations. We used social media channels as well to disseminate our recruitment materials and snowball sampling methods to allow recruited participants to engage additional eligible participants. PWLE were compensated for their time with a gift card per the recommendations from the Canadian Institutes of Health Research and Canadian Strategy for patient-oriented research.[18] For our clinician and researcher group, we recruited via emails sent through national kidney organizations in Canada, including groups from pediatric nephrology, transplantation, and allied health nephrology groups. We encouraged recruited participants to suggest additional participants, to enrich our recruitment outside of national nephrology organizations. As mentioned in our protocol, there is no standard sample size for Delphi methods, though in a systematic review of the literature, the median number of participants was 17 (interquartile range [IQR]: 20).[13,14] With this in mind, we aimed to recruit at least 20 people from each stakeholder group for our study, as outlined in our protocol. After agreeing to participate, and providing informed consent, participants were asked to answer demographics questions via a survey

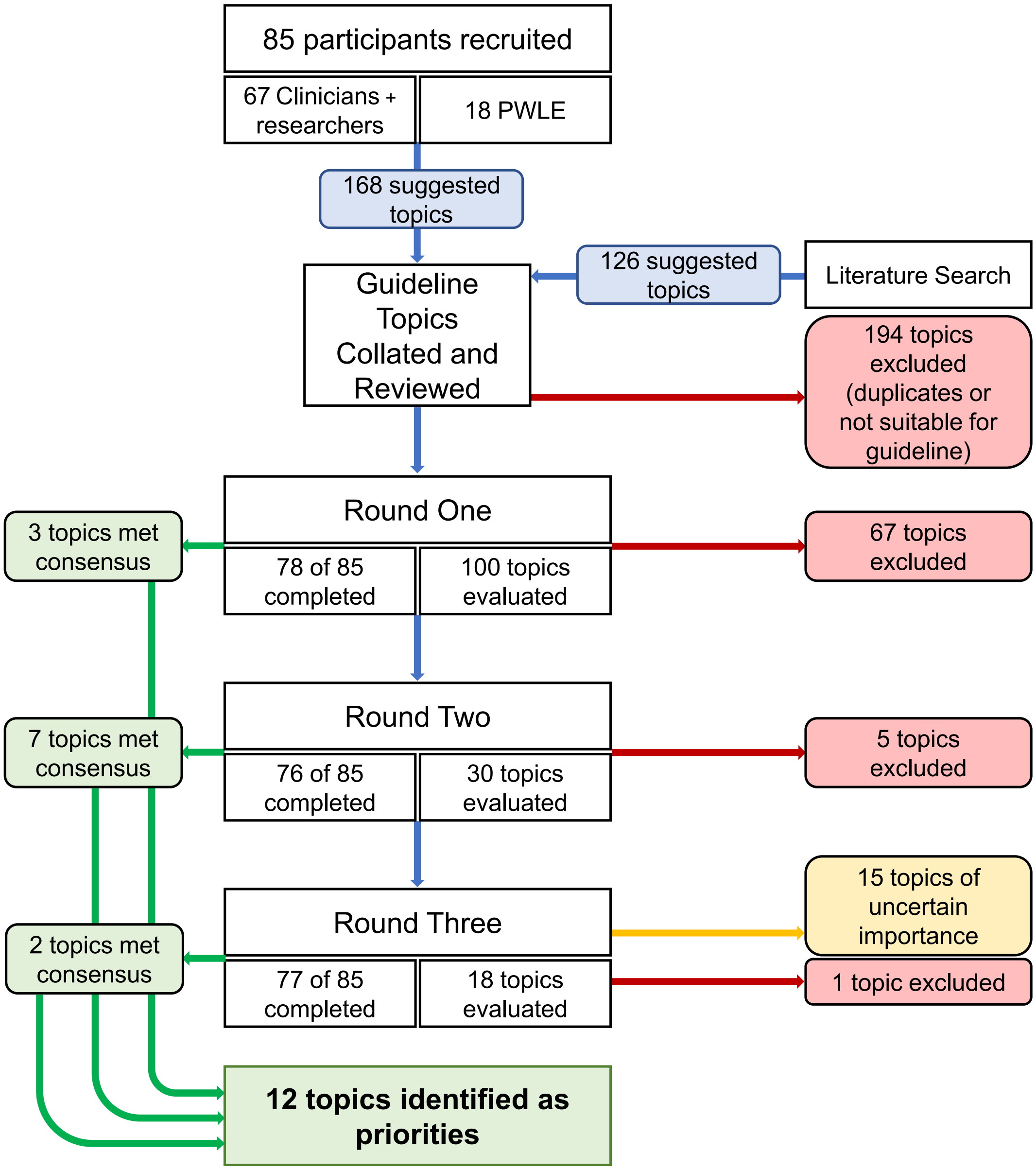

Figure 1. Delphi survey process and consensus generation diagram. In this figure, the overall movement of both participants and potential guideline topics between rounds of the Delphi survey process are summarized.

developed and administered using SurveyMonkey in English or French. For PWLE and caregivers, they were asked about their biological sex assigned at birth, gender identity, age, ethnicity background, province of residence, awareness of clinical practice guidelines, and their importance. Clinicians and researchers were also asked similar questions along with those related to their professional experience (title and years of experience), expertise in kidney disease clinical care or research focus, and experience with clinical practice guidelines.

Preparatory Research

Members of the CSN CPGC were asked to suggest an initial list of guidelines in the following 3 categories: (i) novel guideline topics, (ii) international kidney guidelines that warrant a Canadian contextualization via a CSN commentary, and (iii) Canadian guidelines from nonnephrology guideline organizations that are of relevance to people living with kidney disease (e.g., hypertension guidelines, stroke care guidelines, etc.). This was supplemented by a Medline search completed in January 2023 (Supplementary Item S1), focused on search terms related to clinical practice guidelines in the last 3 years and adapted to international kidney and Canadian nonnephrology guideline concept areas. After consenting to participate, recruited participants were asked to suggest guideline topics. All were reviewed by the CSN guidelines committee for feasibility considerations (and to eliminate duplicate topics), with additional clarifications made before incorporation into subsequent surveys.

Assessing Consensus

There were 3 planned rounds to this Delphi ranking survey process. Once a final list of candidate guidelines or commentaries was compiled, they were transferred into the first ranking survey. For the first and subsequent rounds, the clinician and researcher survey was developed in English and translated to French, with pilot testing for face and content validity of each version completed by members of the CSN guidelines committee. A version of the survey was drafted for PWLE and caregivers using person-centered and accessible language, with help with drafting and pilot testing provided by our patient research partners (NV and TW). Each survey included items organized into 3 categories as indicated above, and each item included a 9-point Likert scale with 1 representing that the participant strongly disagreed with it being important and 9 representing a topic they strongly agreed as important. For each item, consensus was reached if the median score was 7 or higher for all participants, and the percentage agreement was 75% or higher; these criteria were based on the available literature that summarized the most accepted and common methods of Delphi survey consensus determination.[14] The percentage agreement was determined by calculating the proportion of survey participants with a median ranking of greater than and equal to 7. Items in a survey round that had a median ranking < 7 were categorized as not important and removed from subsequent rounds. If an item had a median ranking of 7 or higher, and did not meet percentage agreement criteria, it was propagated into the next round. At the end of 3 ranking rounds, if items did not meet consensus criteria, they were identified as being of "uncertain importance." The research team had no decision-making authority in the consensus generation.

Analysis

We summarized participant demographics and reported the participation throughout the rounds of the Delphi survey process. The topic flow through the surveys, including the round where consensus was reached, the median score in this round or the final ranking round, and percentage agreement were provided. We calculated a priority score for each item that met consensus, which involved addition of the Likert score for each topic across participants in the survey round where consensus was reached and standardized for the number of respondents in that round. Median scores for each participant group were compared with a nonparametric test on the equality of medians, with a continuity correction; $P < 0.05$ represents a statistically significant difference in median scores of stakeholder groups.

RESULTS

The participants were recruited between October 2022 and January 2023. The ranking surveys were conducted between May 2023 and September 2023. Of the initial 86 respondents, 85 (99%) consented to participate, 78 (91%) completed round 1, 76 (88%) completed round 2, and 77 (90%) completed the round 3 survey. PWLE had excellent retention with 15 of 18 participating after the original demographics survey. These 15 individuals completed each of the 3 ranking rounds with no dropout after the initial ranking survey. Round 1 involved 100 candidate guideline topics, and took place in May 2023 with several email reminders sent to nonresponders at 2-week intervals. The survey was closed in June 2023 and each item was evaluated using the consensus criteria listed above. The round 2 survey included the 31 items from round 1 that had a median ranking of 7 or higher and a percentage agreement less than the consensus metric of 75%. In this round, the median overall score and percentage agreement from the previous round were provided to the participants. Round 2 took place between July and August 2023. The same criteria were applied to these rankings, and the final round of the Delphi surveys (round 3) with 18 items was conducted between August and September 2023.

Participant Characteristics

There were 85 participants recruited to the study (Table 1). Of these, 67 (79%) were either clinician or researchers, and 18 (21%) were either PWLE or caregivers of those with kidney disease. Most preferred to read and/or write in English (85%), whereas the rest preferred to read and/or write in French (15%). Most were female (66%) and cisgender, with a median age of respondents 48 years (IQR: 15). Ontario, Quebec, and Alberta were the most frequent provinces or territories of residence, and 75% of participants were of European cultural background. Of the PWLE and caregiver group, 89% were PWLE themselves (Table 2), and most (61%) were living with a functional kidney transplant. Most had heard of clinical practice guidelines (72%) and felt that it was very important for health care providers to follow-up with them (mean score: 8.5/9; IQR: 1.75). Overall, it was felt to be very important for PWLE to participate on guideline committees as they are developed (score: 9; IQR: 1) and to determine guideline topic priorities (score 8; IQR: 2.75). Of the clinician and researcher group, most were physicians (49%) and nurses (22%), with a diverse group of respondents otherwise (Table 3); most practiced with adult kidney disease populations (85%). Clinical research was most common as a research focus (75%).

Table 1. Characteristics of survey participants

Characteristics	Number (%), *n* = 85
Participant group	
Health care provider or researcher	67 (79)
Patient or caregiver	18 (21)
Preferred language to read or write	
English	72 (85)
French	13 (15)
Other	0 (0)
Median age, yr (IQR)	48 (15)
Sex assigned at birth	
Female	56 (66)
Male	28 (33)
Prefer not to answer	1 (1)
Other	0 (0)
Gender identity[a]	
Woman	56 (66)
Man	28 (33)
Prefer not to answer	1 (1)
Other	0 (0)
Province or territory of residence	
British Columbia	8 (9)
Alberta	15 (18)
Saskatchewan	2 (2)
Manitoba	4 (5)
Ontario	32 (38)
Quebec	17 (20)
Nova Scotia	3 (4)
New Brunswick	2 (2)
Newfoundland and Labrador	1 (1)
Northwest Territories	1 (1)
Cultural background[b]	
African	1 (1)
European	64 (75)
East Asian (China, Mongolia, North Korea, South Korea, Japan, Hong Kong, Taiwan, Macau)	3 (4)
South Asian (Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, Sri Lanka)	8 (9)
South East Asian (Brunei, Burma (Myanmar), Cambodia, Timor-Leste, Indonesia, Laos,	2 (2)
Malaysia, the Philippines, Singapore, Thailand, Vietnam)	
First Nations	0 (0)
Metis	1 (1)
Inuit	0 (0)
Hispanic or Latinx	0 (0)
Metis	1 (1)
Middle Eastern	2 (2)
Prefer not to answer	1 (1)
Other (open text responses included Canadian [*n* = 3], Eurasian [*n* = 1], North American [*n* = 1])	5 (6)

IQR, interquartile range.
[a] Additional gender identities included transgender woman, transgender man, gender nonconforming, and other.
[b] indicates that more than 1 category could be selected by participants.

Table 2. Patient and caregiver characteristics and perceptions

Characteristics	Number (%), n=18
Relationship with kidney disease	
Person with kidney disease (current or historical)	16 (89)
Caregiver or family member of person with kidney disease	2 (11)
Degree or category of kidney dysfunction of participant (or the person that the participant knew)	
Functioning kidney transplant	11 (61)
Treated with in-center hemodialysis	1 (6)
Treated with home hemodialysis	2 (11)
Chronic kidney disease	4 (22)
Identified etiology of kidney disease	
Diabetes	2 (11)
Polycystic kidney disease	4 (22)
Autoimmune kidney disease, glomerulonephritis, vasculitis	7 (39)
Genetic	1 (6)
Acute kidney injury	1 (6)
Unknown	3 (17)
Proportion that have heard about clinical practice guidelines	13 (72)
Perceptions on clinical practice guidelines[a]	Median Score (IQR)
"How important do you think it is for health care providers (doctors and nurses etc.) to follow clinical practice guidelines?"	8.5 (1.75)
"How important do you think it is for patients with kidney disease and caregivers/family members to participate on guideline committees as they are developed?"	9 (1)
"How important do you think it is for patients with kidney disease and caregivers/family members to determine the guideline topic priorities?"	8 (2.75)

IQR, interquartile range.
[a] Responses were scored for their importance on Likert Scale 1 to 9, with 9 being extremely important.

They worked in their primary clinical or research role for a median of 12 years (IQR: 14). The vast majority had read a clinical practice guideline in the last 5 years (96%), with a median of 4 (IQR: 3) reads each year. Almost half (40%) had participated in a CPGC or in guideline development. This group also felt it very important for PWLE to participate in guideline development (score: 8; median: 2.5) and priority setting (score 8; IQR: 2).

Guideline Topic Prioritization Throughout Delphi Process

From the initial 100 topics from the literature and suggestions from participants, 12 were prioritized as important, 14 were of uncertain importance, and 74 were not important as priorities for the CSN CPGC (Table 4, Supplementary Table S2). Of those that were prioritized, 8 were novel guidelines suggested by the participants, 4 were commentaries on Kidney Disease: Improving Global Outcomes clinical practice guidelines, and none were commentaries on Canadian guidelines from other societies. The 5 highest priority items were all novel guidelines, focused on the topics of kidney protection and slowing progression of kidney disease with novel therapeutics, guidelines for primary care setting, patient-oriented guidelines on diet and exercise in CKD and kidney failure, management of symptoms of early and late CKD, and provision of mental health care for patients and caregivers with CKD (Table 4). Four of the priorities were commentaries of the Kidney Disease: Improving Global Outcomes guidelines on management

Table 3. Clinician and researcher characteristics and perspectives

Characteristics	Number (%), n=67
Primary clinical role	
Administration or clinical operations	1 (1)
Dietitian	5 (7)
Nurse	15 (22)
Nurse practitioner	3 (4)
Pharmacist	8 (12)
Physician	33 (49)
No clinical role	2 (3)
Age group of clinical focus	
Adult	57 (85)
Pediatric	4 (6)
Both adult and pediatric	1 (1)
No current clinical role	5 (7)
Type of research they participate in[a]	
Clinical research	50 (75)
Fundamental/basic science	1 (1)
Medical education	1 (1)
Research trainee	4 (6)
Do not participate in research	17 (25)
Median number of years worked in primary clinical or research role (IQR)	12 (14)
Clinical practice guideline experiences	
Number that have read clinical practice guideline in last 5 years	64 (96)
Number of clinical practice guidelines read each year (median; IQR)	4 (3)
Number that have participated in clinical practice guidelines committee or in guideline development	27 (40)
Perceptions on clinical practice guidelines[b]	Median score (IQR)
"How important do you think it is for patients with kidney disease and caregivers/family members to participate on guideline committees as they are developed?"	8 (2.5)
"How important do you think it is for patients with kidney disease and caregivers/family members to determine the guideline topic priorities?"	8 (2)

IQR, interquartile range.
[a] Indicates that more than one category could be selected by participants.
[b] Indicates that responses were scored for their importance on Likert Scale 1 to 9 with 9 being extremely important.

of glomerular disease, evaluation and management of candidates for kidney transplantation, diabetes management in CKD, and blood pressure management in CKD. The remaining prioritized topics focused on self-management in dialysis, anticoagulation in advanced CKD, and Indigenous health and kidney disease. There were no statistically significant differences between stakeholder participant groups for any of the 12 prioritized topics ($P > 0.05$; Table 5).

DISCUSSION

In this study, we used a modified Delphi survey process to identify and prioritize clinical practice guideline topics in nephrology, with the inclusion of perspectives of PWLE and their caregivers, researchers, and multidisciplinary clinicians from across Canada. Through the 3 rounds of surveys, 12 topics met our consensus criteria after 3 rounds, and included 8 novel topics and 4 commentaries on international Kidney Disease: Improving Global Outcomes guidelines; priorities were similar between the PWLE or caregiver group and that of clinicians and researchers. All groups felt that it was important to include PWLE in guideline topic prioritization and development.

Participants prioritized diverse topics for guideline development across the spectrum, from slowing progression of kidney disease to management (and self-management) of symptoms of kidney disease and failure. The most highly prioritized topic was for protecting kidney function and slowing progression of kidney disease with novel therapeutics. With the growth in evidence supporting the use of sodium glucose cotransporter 2 inhibitors, glucagon-like peptide 1 receptor agonist, mineralocorticoid antagonists, and others, guidance on their use is of great importance for the Canadian kidney disease community. Although the novel therapeutics have evolved with time, this perspective was shared by multidisciplinary Canadian stakeholders that identified research priorities for people with CKD.[5] It is important to note that research priorities are related to but are also distinct from guideline topic priorities, because the latter are dependent on the availability of sufficient literature to inform guidance. The top research question in this study was "what are the most effective new interventions and treatments to prevent the development and progression of kidney disease?" Many other guideline topic priorities had significant overlap with research priorities, including those related to diet and exercise, symptom management, optimal CKD strategies comanaged with primary care, and kidney disease self-management. Together, these shared priorities reflect the consistent interest from Canadians in these clinical domains over the past decade.

Our study participants felt strongly that people with kidney disease and their caregivers or family members should be involved in both identifying guideline topic priorities and in guideline development. This perspective aligns with guideline patient engagement frameworks, including that from Armstrong *et al.*,[1] where meaningful engagement by patients is proposed at 10 separate steps in guideline development. Of note, our study achieved 2 of these 10 steps, because we both nominated and prioritized topics. The impact of this patient and public involvement (PPI) was assessed qualitatively during the development process of a guideline focused on dementia, where one guideline development group had PPI and the other did not.[19] In this study, PPI allowed for identification of issues that may have been overlooked by medical professionals on the guideline panel, and helped select topics and outcomes for the guideline to focus on what

Table 4. Prioritized topics for novel guideline or commentary

Guideline topic	Final median score (IQR)	Final mean score (SD)	Percentage agreement (%)	Round where consensus reached	Standardized priority (% of max. score)	Priority Score Ranking
Novel guideline: Kidney protection and slowing progression with novel therapeutics (Including SGLT2 inhibitors, GLP-1RA, and other medication use in CKD)	8 (1)	7.71 (1.32)	85.9	1	85.61	1
Novel guideline: Guidelines for primary care setting	8 (1)	7.47 (1.31)	77.6	2	85.09	2
Novel guideline: Patient-oriented/education guidelines on diet and exercise in CKD/kidney failure	7.5 (1)	7.3 (1.42)	78.9	2	83.19	3
Novel guideline: Management of symptoms of early and late CKD	7 (1)	7.21 (1.33)	77.63	2	82.16	4
Novel guideline: Provision of mental health care for patient and caregivers with CKD and kidney failure	7 (1)	7.21 (1.54)	81.58	2	82.16	4
Novel guideline: Self-management for dialysis recipients	7 (1)	7.2 (1.48)	78.95	2	82.02	6
Commentary on International guideline: 2021/2023 KDIGO Clinical Practice Guideline for the Management of Glomerular Disease	7 (1.25)	7.14 (1.47)	75	2	81.43	7
Commentary on International guideline: 2020 KDIGO Clinical Practice Guideline on the Evaluation and Management of Candidates for Kidney Transplantation	7 (1)	7.22 (1.19)	75.32	3	81.24	8
Commentary on International guideline: KDIGO 2020 Clinical Practice Guideline for Diabetes Management in Chronic Kidney Disease	8 (1)	7.28 (1.47)	75.64	1	80.91	9
Novel guideline: Anticoagulation in advanced CKD and kidney failure	7 (1)	7.18 (1.22)	76.62	3	80.81	10
Commentary on International guideline: KDIGO 2021 Clinical Practice Guideline for the Management of Blood Pressure in Chronic Kidney Disease	7.5 (1)	7.23 (1.64)	75.64	1	80.34	11
Novel guideline: Indigenous health and kidney disease	7 (1.25)	6.95 (1.38)	75	2	79.23	12

CKD, chronic kidney disease; GLP-1RA, glucagon-like peptide 1 receptor agonist; KDIGO, Kidney Disease: Improving Global Outcomes; IQR, interquartile range; SGLT2, sodium glucose cotransporter 2.

were patient-relevant; there were many other noted benefits to PPI inclusion. In a related exercise involving CKD guideline development in Australia, there were similar benefits noted with patients and caregivers involved.[20] They noted that PPI involvement allowed for additional guideline topics to be included, prioritization of topics with patient perspective, recommendations were reframed to include patient-focused issues, and their involvement led to the creation of a plain language version of the guidelines for public accessibility. A recent descriptive summary of the PPI in Australian and New Zealand kidney guidelines highlighted that PWLE were involved throughout the guideline lifecycle, from informing the scope of guidelines to being part of the working groups.[21] They concluded that although PWLE can and should be involved in the guideline development process, the impact of this requires

Table 5. Comparison of prioritized topics between stakeholder groups

Guideline topic	Overall Median Score (IQR)	Health Care Provider and Researcher Median Score (IQR)	Patient and Caregiver Median Score (IQR)	P-value for differences
Novel guideline: Kidney protection and slowing progression with novel therapeutics (Including SGLT2 inhibitor, GLP-1RA, and other medication use in CKD)	8 (1)	8 (2)	8 (1)	0.361
Novel guideline: Guidelines for primary care setting	8 (1)	8 (2)	8 (0.5)	0.920
Novel guideline: Patient oriented/education guidelines on diet and exercise in CKD/kidney failure	7.5 (1)	7 (1)	8 (1.5)	0.564
Novel guideline: Management of symptoms of early and late CKD	7 (1)	8 (1)	7 (1)	0.421
Novel guideline: Provision of mental health care for patient and caregivers with CKD and kidney failure	7 (1)	7 (1)	8 (1)	0.354
Novel guideline: Self-management for dialysis recipients	7 (1)	7 (1)	8 (1)	0.489
Commentary on International guideline: 2021/2023 KDIGO Clinical Practice Guideline for the Management of Glomerular Disease	7 (1.25)	7 (2)	7 (1)	0.909
Commentary on International guideline: 2020 KDIGO Clinical Practice Guideline on the Evaluation and Management of Candidates for Kidney Transplantation	7 (1)	7 (2)	8 (1)	0.277
Commentary on International guideline: KDIGO 2020 Clinical Practice Guideline for Diabetes Management in Chronic Kidney Disease	8 (1)	8 (1)	8 (1.5)	0.681
Novel guideline: Anticoagulation in advanced CKD and kidney failure	7 (1)	7 (1)	7 (0)	0.242
Commentary on International guideline: KDIGO 2021 Clinical Practice Guideline for the Management of Blood Pressure in Chronic Kidney Disease	7.5 (1)	8 (1)	7 (2.5)	0.774
Novel guideline: Indigenous health and kidney disease	7 (1.25)	7 (2)	7 (1)	0.823

Median scores for the health care provider and researcher group were compared to that of the patient and caregiver group using a nonparametric k-sample test of medians, with a continuity correction; $P < 0.05$ represented a significant result.
CKD, chronic kidney disease; GLP-1RA, glucagon-like peptide 1 receptor agonist; KDIGO, Kidney Disease: Improving Global Outcomes; IQR, interquartile range; SGLT-2, sodium glucose cotransporter 2.

further investigation. In a specific Australian initiative that involved consumer (i.e., patient and caregiver) perspectives in the Kidney Health Australia guidelines for autosomal dominant polycystic kidney disease, the importance of involving patients was noted because important differences were identified, compared with clinician stakeholders.[22] In their study, many priorities were similar between clinicians and patients, though there were many important differences in priorities related to guideline topics of lifestyle, psychosocial support, pain, quality of life, and kidney-related outcomes. Although our study did not reveal significant discordance in priorities between stakeholder groups, PWLE involvement ensured that their important suggestions were incorporated from the outset of the prioritization exercise. Considering that our CPGC makes decisions on which topics to pursue and support, we are now able to reference this prioritized list of topics. This will ensure that future activities are not solely driven by the goals of clinicians and scientists, but rather the people for whom our guidelines are developed to improve care for.

Further, the importance of patient involvement in guideline development has led to major international guideline standards being set so that patient engagement is encouraged or mandated.[1] This includes the Appraisal Guidelines for Research and Evaluation,[2] the World Health Organization, the Guideline International Network,[23] the Institute of Medicine,[24] and the National Institute for Clinical Excellence.[25] Interestingly, though most major guideline standards recommend patient engagement, this is not routinely operationalized. In the United States, less than 1 in 10 guideline developing groups require patient involvement[26]; internationally, this proportion is higher with 39% of guideline developers reporting the inclusion of patients on their guideline development committees.[27] El-Harakeh *et al*.[3] completed a scoping review to evaluate the characteristics of clinical, public health, or health systems guideline topic prioritization research. They identified 12 studies overall that reported prioritization efforts for *de novo* guideline development, and although all included clinicians in their guideline topic prioritization, only 1 included patients in any capacity. Thus, our study aligns with international guidance on involving PWLE in clinical practice guideline processes and importantly contributes to the literature where priorities are not informed by clinicians alone. As these findings are mobilized with Canadian nephrology guideline development, the impact will be fully realized.

Though our study captured the important perspectives of Canadian kidney disease stakeholders, there are several limitations to the Delphi survey method and our study to acknowledge. First, there are several considerations for the modified Delphi compared to other consensus-generation methods. The James Lind Alliance Priority Setting Partnership method involves structured in-person meetings, which is enriched by interparticipant dialogue that can additionally be used to inform priorities.[28] However, because we aimed to reach the broadest group of stakeholders across a geographically expansive country, our study design with electronic survey dissemination was more feasible and appropriate. Further, given that any consensus-generation exercise is based on collective democratic principles with regression to the group's average score, the lack of statistical differences between participant groups are likely impacted by this; and important marginalized or minoritized perspectives will potentially be missed. In addition, the use of a Likert scale might have made it more difficult to delineate differences between topics and group ratings. Alternatives such as a Best-Worst scale may have accounted for this,[29] though this would have significantly extended the survey time if applied to the 100 candidate topics. Although this was one of the fundamental drivers for including people of diverse clinical and research backgrounds and PWLE, there are certainly gaps in recruitment that may have led to this limitation. For example, though we included 18 PWLE or caregivers, the majority of participants were those with functioning kidney transplants and only 11% identified diabetes as the etiology of their kidney disease; thus, our participants did not reflect the overall kidney disease burden in the Canadian kidney disease population. Our recruitment strategy involved broad consultation with Canadian kidney disease groups and social media; thus our PWLE demographics reflect the participants in these formats. Of note, though only 1 participant reported Indigenous background, a novel guideline focused on Indigenous health and kidney disease was prioritized. Our initial search of the published guidelines was limited to 1 database, and thus there may have been some relevant but unidentified guidelines topics. Finally, people who volunteered to participate are likely more interested and motivated to participate in guideline development, suggesting that our findings of patient engagement being very important may be impacted by selection bias and overestimate the importance if compared with the general population of PWLE and other kidney stakeholders.

In conclusion, with a group of Canadian multidisciplinary kidney clinicians, researchers, PWLE, and their caregivers, we were able to identify and prioritize important topics for future guideline development by the CSN CPGC. Many of the 12 prioritized topics have relevance in other countries, and our approach could be adapted to identify consensus priorities for other national guideline organizations as well. From this work, each topic will be evaluated for feasibility by the committee, which will be dependent on the availability of published knowledge syntheses, and emergence of practice-changing evidence. Further, topics suggested for *de novo* guideline development may end up being adapted to commentaries of international guidelines as they are released. For example, the recently published 2024 Kidney Disease: Improving Global Outcomes CKD Evaluation and Management guideline covers much of the content that the top prioritized "novel therapeutics" guideline from our study. Given that this guideline was published after our Delphi exercise, our findings must be tailored to accommodate; this prioritized list we hypothesize will continue to evolve and be adapted with time and require frequent updating. Overall, participants in this study have made it clear that the Canadian nephrology community is invested in the development of person-centered guidelines, with the involvement of PWLE throughout the guideline development process.

APPENDIX

List of the Canadian Society of Nephrology Clinical Practice Guidelines Committee

The committee at the time of this topic prioritization work consisted of Drs. Ahsan Alam, Rahul Chanchlani, David Clark, Tyrone Harrison, Gregory Hundemer, Phil McFarlane, Anna Mathew, Lisa Miller, Reem Mustafa, Annie-Claire Nadeau-Fredette, Gihad Nesrallah, Krista Ryz, Melissa Schorr, Manish Sood, Michelle Wong, and Somaya Zahran.

DISCLOSURE

All the authors declared no competing interests.

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DATA AVAILABILITY STATEMENT

Our aggregate dataset is available upon reasonable request by contacting the corresponding author. We are not able to provide participant level data at the request of our ethics approval via McMaster University (HiREB 14626), particularly because the perspectives of patient participants as linked to their demographics may identify them.

AUTHOR CONTRIBUTIONS

Research idea, study design, data analysis and interpretation, and drafting of the manuscript was done by all the authors. Statistical analysis was done by TGH. Each author contributed important intellectual content during manuscript drafting or revision and agrees to be personally accountable for the individual's own contributions and to ensure that questions pertaining to the accuracy or integrity of any portion of the work, even one in which the author was not directly involved, are appropriately investigated, and resolved, including documentation in the literature if appropriate.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Table S1. Reporting guidance per the Accurate Consensus Reporting Document.

Table S2. Topics throughout phases of modified Delphi study. The topics that were prioritized for importance by Delphi participants are included. They are color-coded, where green represents items that were priorities, yellow represents items that are of uncertain importance, and red represents items that did not meet consensus criteria. In the topic ID column, those that start with a C represent Canadian guidelines with nephrology relevance, I represents International nephrology guidelines, and N represents novel or *de novo* topics for guideline development. For the previously produced national or international guidelines, the URL for the relevant guideline is included. IQR, interquartile range. Full measures of variance and standardized priority scores are provided for the items that met consensus criteria.

Item S1. Medline search strategy.

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