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CKJ REVIEW

Partnering with patients and caregivers to enrich research and care in kidney disease: values and strategies

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ABSTRACT

Patient and caregiver involvement broadens the scope of new knowledge generated from research and can enhance the relevance, quality and impact of research on clinical practice and health outcomes. Incorporating the perspectives of people with lived experience of chronic kidney disease (CKD) affords new insights into the design of interventions, study methodology, data analysis and implementation and has value for patients, healthcare professionals and researchers alike. However, patient involvement in CKD research has been limited and data on which to inform best practice is scarce. A number of frameworks have been developed for involving patients and caregivers in research in CKD and in health research more broadly. These frameworks provide an overall conceptual structure to guide the planning and implementation of research partnerships and describe values that are essential and strategies considered best practice when working with diverse stakeholder groups. This article aims to provide a summary of the strategies most widely used to support multistakeholder partnerships, the different ways patients and caregivers can be involved in research and the methods used to amalgamate diverse and at times conflicting points of view.

Keywords: chronic kidney disease, consensus techniques, consumer involvement, involvement frameworks, multistakeholder research, patient and caregiver involvement

INTRODUCTION

Research partnerships involving patients, caregivers, researchers and health professionals are now widely recognised as necessary to ensure that research is meaningful to all end users to maximise uptake and impact [1–3]. This has also been reinforced by policy and funding agencies worldwide. Ideally, partnerships with patients, caregivers and health professionals should occur across the research cycle from priority setting through to dissemination and implementation [1, 4–7]. Despite this, patients and caregivers have had limited involvement in research in nephrology and across other medical specialties.

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Consequently, most clinical research fails to address the shared priorities of patients, caregivers and clinicians [8].

The lack of patient and caregiver involvement in clinical research may be due to various challenges and barriers. The ongoing burden of treatment, prognostic uncertainty and pervasive and debilitating symptoms in patients with chronic kidney disease (CKD) can undermine their ability to contribute to research [9]. Patients are often unaware of opportunities to become involved with research, and some have expressed that uncertainty and a lack of confidence limit their willingness to take part [9, 10]. For researchers, constraints relating to funding, time and personnel to support logistics have consistently been reported as barriers to supporting meaningful involvement of patients in research [9–11]. Uncertainty about best practice for how to initiate, organise and sustain working relationships and fear of managing multiple and diverse stakeholder views have also impeded efforts to involve patients in research [12–14].

Stakeholders include any ‘individual or group who is responsible or affected by health- and healthcare-related decisions that can be informed by research evidence’ [5], namely researchers, patients, caregivers, clinicians and policymakers. In this article we focus on patients and caregivers. We outline the benefits and summarise current initiatives for involving patients and caregivers in CKD research, describe strategies and values to support their involvement and discuss formal methods to bring together diverse and at times conflicting views of all stakeholder groups in the research setting.

BENEFITS OF STAKEHOLDER INVOLVEMENT

Patient and caregiver involvement in research priority setting, study design and dissemination of findings can enhance the relevance, quality and impact of clinical research through alignment of research priorities, improved patient participation in clinical trials and broader translation of research into policy and practice [15–18]. Incorporating the perspectives of people with lived experience of CKD allows the generation of new insights informing the design of interventions, study methodology and data analysis, broadening the scope of knowledge on which evidence is based and thereby maximising its utility [16, 17, 19–21]. Engaging with underrepresented groups can help identify contributors to health inequities and inform the design of interventions to address them. For example, workshops involving patients from rural and remote regions across Australia, which focused on developing strategies to improve access to kidney replacement therapy, identified the need for patient navigators with lived experience and cultural expertise to improve patients’ access to healthcare [22]. This was led by a local researcher with lived experience of CKD, and the researchers conducted the workshop within their local setting. Participants were also reimbursed for out-of-pocket costs (e.g. transportation) to attend the workshops [22].

Personal benefits for patients, clinicians and researchers gained from multistakeholder collaboration have also been reported. For patients, these include learning new skills, having greater access to information about their disease, expanding social and support networks and the satisfaction of contributing to new knowledge for the benefit of the medical community and other patients [10, 23–25]. Researchers gain skills and knowledge related to managing research partnerships, a deeper understanding of the area under study, enhanced motivation and access to more opportunities for funding and career advancement [2, 25]. Successful partnerships afford the chance to view research through a new lens, illuminating new perspectives on the importance of the work, and a new respect for what the outcomes of that work mean for different stakeholder groups [18, 19, 26].

Despite these reported benefits, patient and caregiver involvement in nephrology research is often absent. Recent surveys found that only about 7% of patients and caregivers had been involved with kidney disease research, and less than a third of researchers had involved patients and caregivers in research projects [27]. A review of 45 self-management interventions for people with CKD found that <1% involved patients in designing the intervention [28]. Failing to incorporate the views of patients and caregivers results in research outcomes with limited potential to make real-world impacts on clinical decision making [3, 8, 29]. A 2015 review found that 80% of clinical research in CKD does not address the top 10 research priorities identified by patients [29]. Trials in CKD commonly report surrogate biochemical or physiological endpoints, yet they neglect outcomes of higher priority to patients, such as life participation and fatigue [21, 30]. For example, only 2% of trials in kidney transplantation report quality of life [31]. Involving end users in the planning and execution of clinical research in kidney disease is postulated to address this gap and enhance the responsiveness of research to patient and caregiver needs.

CURRENT INITIATIVES

Globally, funding agencies and professional and patient organisations have been increasingly advocating for and supporting patient involvement. In some countries, including the UK, USA and Australia, national funding agencies encourage applications to describe how patients and caregivers have been involved in research [32, 33]. The National Institute for Health and Care Research (NIHR) in the UK, the Patient-Centered Outcomes Research Institute (PCORI) in the USA and the Canadian Institutes of Health Research (CIHR) recommend public involvement across all stages of research [34–36]. Major initiatives, including INVOLVE in the UK [34], James Lind Alliance [37], Core Outcome Measures in Effectiveness Research (COMET) [38] and Strategy for Patient-Oriented Research (SPOR) [36] in Canada, have been established to support patients’ and other stakeholders’ involvement in research.

In the field of nephrology, there are an increasing number of initiatives to involve patients in research. Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE) currently involves 75 patient partners in 18 research projects across Canada [39] and in 2022 the International Society of Nephrology launched its’ Patient Liaison Advisory Group, tasked with the responsibility of embedding patient perspectives in health initiatives and research programmes to address the global burden of kidney disease [40]. Priority setting for research in CKD has been conducted in collaboration with patients and caregivers in Canada and Australia [41, 42]. The Standardised Outcomes in Nephrology (SONG) Initiative has involved >10 000 patients, caregivers, health professionals and policymakers in consensus processes to establish core outcome sets for clinical trials across the spectrum of CKD [21, 43, 44].

FRAMEWORKS FOR PATIENT AND CAREGIVER INVOLVEMENT

In 2016, the Better Evidence and Translation in Chronic Kidney Disease (BEAT-CKD) initiative in Australia consulted with patients, caregivers and health professionals about how to achieve

Table 1: Activities that reflect core values for patient and caregiver involvement in clinical research.

Value	Goal	Activity [2, 23, 24, 57, 71, 93]
Respect	Setting the foundation for partnership by creating a culture of mutual respect	• Co-produce codes of conduct and terms of reference • Give sufficient notice for meetings • Follow through on commitments, e.g. meetings or requests for information • Document all suggestions and ideas, along with the reasons for accepting or rejecting them
Transparency	Information sharing	• Share study resources such as funding applications and study protocols • Clearly document stakeholder roles • Create a project 'road map' with clear and realistic timelines • Openly share project successes and failures • Conduct ongoing monitoring and evaluation
Reciprocity	Bi-directional knowledge exchange and learning	• Distribute meeting materials prior to meetings • Schedule meetings with enough time for questions • Allocate dedicated time during meetings for stakeholder input • Provide lay summaries where necessary • Have briefing/debriefing sessions after major involvement activities, e.g. a consensus workshop
Inclusion	Equal opportunity for stakeholders to be involved in research	• Create an engagement plan • Include multiple patient partners in steering committees • Work with physicians, nurses and community liaisons to engage patients and caregivers • Alternate location and timing of meetings to suit stakeholder needs • Offer flexible meeting arrangements, e.g. in person and online
Diversity	A broad range of perspectives are included	• Promote partnership opportunities through patient networks and community organisations • Purposively sample partners based on relevant knowledge and experience • Purposively sample partners to reflect a broad range of demographics • Undertake cultural training

partnerships in research. The findings were consolidated into a framework for engagement with practical guidance on how to involve patients and caregivers across the spectrum of research into CKD [24]. The elements of this framework mirror those described by other major initiatives such as the PCORI Engagement Rubric [35] and the UK Standards for Public Involvement [45]. Three recent reviews of patient partnerships in health or health services research have reported 14–65 different frameworks, mostly developed in collaboration with patients and other stakeholders, containing up to 75 distinct elements [46–48]. These models and frameworks provide an organised conceptual structure to guide planning and implementation of multistakeholder research partnerships [48]. Despite being developed by different groups and in different contexts, most partnership frameworks are made up of similar and consistent elements [47], including overarching values/principles for multistakeholder research, followed by specific strategies for involvement. While the ideal framework for effectively bringing together patients, caregivers and other stakeholders in CKD research may need to be developed independently to the fit the needs of individual groups and projects, some of the most consistently reported values and strategies are summarised below and in Tables 1 and 2.

VALUES

Hierarchies and perceived or real power imbalances present significant barriers to engagement of patients in research [25, 49]. Limited power in healthcare decision making or opportunities to build trusting relationships with healthcare providers in healthcare settings may limit the willingness of patients to engage in the research setting [9]. And, while research culture is changing, some researchers still do not recognise patient involvement as being useful or necessary [13, 50], resulting in tokenistic patient and caregiver involvement strategies that are perceived by patients as 'paternalistic' [9]. The values and strategies often cited in partnership frameworks strive to undermine these perceptions by describing attitudes and actions necessary to challenge barriers in research and patient communities alike.

Respect

Partnerships demonstrate respect when they value patients' experience-based knowledge on an equal footing with scientific expertise [25, 51, 52]. Patients and caregivers need to believe that their contributions are taken seriously and have the potential to influence outcomes [50, 53]. Actively listening to diverse perspectives and demonstrating a willingness to adapt the research accordingly conveys an authentic respect for patient and caregiver insights, which in turn encourages sustained involvement and continued sharing of their experiences and knowledge [25]. As relationship-building processes, research partnerships will inevitably face conflicts of opinion. Valuing respect in partnerships is demonstrated when such conflicts are dealt with openly and honestly and where justification is provided when ideas and suggestions, regardless of who makes them, are deemed inappropriate and not acted upon [54]. Equitable and shared decision making in a non-hierarchal power structure is consistently reported as being the cornerstone of meaningful partnerships [14, 55].

Table 2: Activities that support key strategies for patient and caregiver involvement in clinical research.

Strategy	Goal	Activity [2, 23, 24, 57, 71, 93]
Relationship building	Creating a supportive and productive intellectual environment; establishing trust	• Develop relationships with advocacy groups and community organisations • Allow time for casual interactions during face-to-face meetings e.g. morning tea and afternoon tea • Plan team-building activities • Be conscious of power imbalances and avoid the use of titles
Recognition	Acknowledge contributions	• Acknowledge stakeholder input in publications • Co-present at project meetings and conferences • Provide financial reimbursement for incurred expenses • Follow up involvement activities with expressions of gratitude and be explicit about how stakeholder input has made an impact
Communication	Information is shared in a timely and accessible manner	• Avoid jargon and acronyms • Organize written information in manageable chunks using clearly defined headers • Use innovative methods such as infographics or YouTube videos • Provide regular updates about study progress • Create a glossary of common terms • Ask about preferred mode of communication
Capacity building	Stakeholders have the knowledge and skills to partner effectively in research	• Ask stakeholders what they would like to know • Ask stakeholders what they would like other team members to know • Design flexible training programs tailored to stakeholder needs
Support	Sufficient time and resources are available to initiate and maintain partnerships	• Designate a point of contact for patient partners, i.e. someone to approach for one-on-one support • Employ experienced personnel dedicated to organising engagement activities • Provide orientation

Transparency

Transparency refers to the sharing and accessibility of information so that stakeholders can contribute in a meaningful way. To be transparent, this information needs to be shared in a format that is appropriate and accessible [11]. Patients and caregivers have a right to understand the purpose, scope and limitations of the research being undertaken; they also have a right to be made aware of why their input is needed, how it will be sought and the degree to which it is able to make an impact [34, 35].

Reciprocity

Opportunities for bidirectional communication and knowledge sharing [56] facilitate the give-and-take nature of involving stakeholders in health research. Patients and caregivers can both learn about new research, interventions and methodologies while also providing insights from their unique perspectives of CKD. Researchers learn to ask different questions and incorporate new perspectives while also sharing knowledge and expertise. Reciprocal knowledge exchange is an iterative process through which ideas can be refined, questions refocused and solutions redesigned. It creates a learning environment where stakeholders feel valued, and valuable, and is key for maintaining stakeholder engagement [57].

Inclusion

Although there is no magic number on how many patients and caregivers to engage, consideration needs to be given to power dynamics and conflicting interests [55]. Some patients and caregivers may be interested and able to commit to long-term partnerships, while others may prefer short-term involvement. Allowances must be made for periods of illness and conflicting schedules to ensure that all voices are represented and that no stakeholder group dominates [12, 24]. On a broader scale, inclusivity is reflected in the attitudes, language and interactions of those undertaking research with diverse stakeholders by demonstrating cultural and political awareness [58], flexibility and a willingness to adapt to the needs of people living with CKD or with varying levels of health and research literacy.

Diversity

Partnerships strive to ensure the needs and preferences of underserved and underrepresented populations are given equal opportunity to influence health research and its' outcomes. In the field of kidney research, the increased risk of poor health outcomes and unique challenges faced by people from minority ethnic and cultural backgrounds, low socio-economic groups and remote geographical areas [59–61] makes their inclusion in shaping research outcomes critical if widespread benefits are to be achieved. Yet, there is little opportunity for diverse populations to engage with research [62], with the vast majority of patient partners being female, White and highly educated [57]. Tailored strategies to involve patients and caregivers from diverse backgrounds in research are needed [27, 63]. For example, this could include engaging with underrepresented groups in the context of their own environment, building relationships with community leaders and gaining a greater understanding of historical tensions and cultural beliefs and practices [50, 64]. Also, efforts may be needed to develop and implement specific educational and communication strategies to support health literacy and confidence in being involved in research.

STRATEGIES

Planning

Mapping out goals for expected outcomes from partnerships helps to identify where stakeholder contributions will have the most impact and make it easier to identify when, how and with whom to engage [1, 12, 65]. Various frameworks describe the core stages of the research cycle in variable ways, but all agree that patients and caregiver engagement should be commenced from the outset and be across all stages [12]. For high-level strategic decisions in the field of kidney research, involving patients and caregivers in setting priorities, identifying gaps and formulating research questions is essential [41, 42]. For individual research projects, it means involving patients and caregivers at a time when their perspectives can shape intervention design and study protocol rather than seeking feedback after all the major decisions have already been made [34]. Various tools for planning involvement strategies have been developed, such as the Multi Stakeholder Engagement Consortia (MuSE) planning matrix [12] and the Can-SOLVE Patient Engagement Roadmap [66].

Documentation and reporting

Roles, responsibilities and expectations of stakeholders should be agreed upon and clearly stated [57, 65]. Memorandums of understanding, terms of reference, position descriptions or similar items can help to achieve cohesion, manage expectations about project progress and avoid conflicts [23, 57]. Co-developed codes of conduct can assist by explicitly describing expectations of mutual respect, professionalism, confidentiality and behaviours required to support open and honest communication [23, 57]. There is a well-recognised need for more thorough and consistent reporting and publishing of patient and caregiver involvement in research [67]. Many international academic journals require researchers to report if and how patients were involved, and several tools have been developed to assist authors in meeting this requirement; the GRIPP2 reporting tool was devised specifically to standardise the reporting of patient and public involvement in research [68]. Uptake and use of these tools will help strengthen the evidence base for partnerships and facilitate comparisons across studies.

Relationship building

Creating a cohesive partnership is more likely when stakeholders connect as people [57] and partnerships that make time for stakeholders to develop social as well as working relationships are more likely to be effective [1, 69]. Opportunities for face-to-face interactions conducted at locations convenient to participants are particularly useful, especially when engaging hard-to-reach populations and individuals limited by the high symptom burden of CKD [70]. Interactions need to allow sufficient time for patients and caregivers to absorb new information and express their views [34]. Consideration should also be given to alternating meeting locations, as requiring patients and caregivers to attend academic institutions or healthcare settings can reinforce power dynamics [56].

Communication

Efforts to maintain frequent, consistent and reliable communication with stakeholders serves to sustain long-term relationships and foster meaningful involvement in research [57]. Patients and caregivers often cite a lack of updates from the research team and not being informed of study results as reasons for feeling that their research participation is not meaningful [27]. Given the varied modes of communication available, strategies can be tailored to the needs and interests of various stakeholder groups: social media can be beneficial to engage younger populations and interviews can be useful to engage those with lower literacy [56]. Complex information should be communicated in ways that are digestible and relatable [25, 57]; the importance of avoiding jargon and acronyms and using accessible language cannot be stressed highly enough [23, 57].

Capacity building

Preparing patients, caregivers, health professionals and researchers to collaborate in research through flexible training programs has been consistently identified as one of the core strategies underlying successful partnerships [50]. Training is crucial for patients and caregivers who are unfamiliar with research and for researchers who are new to working with multi-stakeholder teams [14, 69]. Preparing patient and caregivers for the realities of carrying out research within the confines of funding and organisational limitations and mobilising researchers with an understanding of the principles and strategies of co-production [14, 56, 71] can help manage expectations and reduce potential conflicts. Several resources have been developed to support capacity building for patient partnerships in the field of kidney research. Can-SOLVE has created a new online learning tool with plain-language learning content designed by and for patients, called KidneyPRO [72]. The National Kidney Foundation is developing Kidney Research Connect to train patients, caregivers, researchers and other stakeholders in patient-centred outcomes research via online webinars and training workshops [73].

Support

The availability and allocation of resources to support partnerships can be one of the biggest barriers to success [62]. Time-intensive activities such as scheduling meetings (logistics), providing information and feedback to patient partners (communications) and maintaining interest and participation (stakeholder support) have been identified as significant barriers to stakeholder involvement [56]. One strategy to mitigate these barriers is the employment of dedicated staff with appropriate expertise in involvement methods to provide the support for organising and carrying out partnership activities [2, 56, 57]. Importantly, involvement frameworks consistently identify one-on-one mentorship and support for patients and caregivers as being a crucial factor in determining partnership longevity [57, 74].

Recognition

Feeling that their input is valued and acknowledged is a key motivator for sustained patient and caregiver involvement [25]. At the most basic level, personal recognition is a simple way of reinforcing the value of others contributions, yet one that is often overlooked by researchers [75]. Financial support demonstrates that patient and caregiver contributions are recognized as equal to the other, salaried, members of the research team and facilitates ongoing involvement [23, 25, 75]. Also, for some patients, the costs of involvement can become prohibitive [9, 14]. At a minimum it is recommended that patients and caregivers be reimbursed for expenses incurred, such as time off work, transportation and accommodations [14, 75]. Academic recognition (e.g. shared authorship) is considered fair for patients and caregivers who contribute as co-investigators in the co-production of research [75].

Evaluation

Ongoing monitoring and evaluation of stakeholder involvement in health research can support continuous improvement and leveraging of lessons learned, positive and negative, for greater future impact [14, 26, 76]. However, studies specifically focusing on the evaluation of frameworks and strategies for patient and caregiver engagement in research and their impact on health outcomes are few, limited in scope and largely qualitative in nature [65, 77–79]. Contributing to this is the lack of tools available for evaluation of partnership research [4, 77, 78]. Esmail *et al.* [78] recommend four essential elements for evaluating research partnerships: including a clearly planned and documented evaluative framework, scheduling regular check-in points along the engagement process and the use of validated tools incorporating both subjective (e.g. stakeholder satisfaction) and objective (e.g. patient recruitment) measures.

STAKEHOLDER ROLES AND RESPONSIBILITIES

In this section we outline the roles that patients, caregivers and other stakeholders can play and the methods by which diverse perspectives can be brought together.

Levels of stakeholder involvement

The term role has been used to describe the capacity in which stakeholders are involved and how intensive the engagement is [12]. Various frameworks consider stakeholder roles on a spectrum [53, 80, 81]. At one end, stakeholders are merely receivers of information, gaining awareness about their condition and building health literacy via one-way communication, e.g. through information flyers and seminars. At the next level, stakeholder views and preferences may be sought via surveys and feedback opportunities or via attendance at priority-setting workshops. At the highest level, stakeholders can contribute to research as co-investigators, sharing full control over the design and management of a study [12]. For most studies, it is likely that a mix of these approaches will be necessary for different stages of the research [12, 23]. Examples of how patients and caregivers have been involved at various levels in the field of kidney research are given in Table 3.

Approaches to achieving consensus

The values described can help to minimise conflicts in research partnerships and the strategies can be used to deal with conflicts fairly and respectfully. In some contexts, however, there may be a need for formal methods to establish consensus among patients, caregivers, researchers and health professionals. For example, these may include setting priorities for research topics or to identify outcome sets for clinical trials. In the field of kidney health, and in health research more broadly, techniques commonly used to establish consensus include the Nominal Group Technique (NGT), the Delphi process and consensus workshops. These consensus techniques are a means of consolidating ideas and opinions [82] and aim to achieve a general agreement or confluence of opinion on a particular topic [83].

The NGT typically involves four stages [82, 84, 85]: idea generation, where participants are asked to independently record initial thoughts in response to a posed problem or question; round robin, where participants take turns contributing their thoughts, one at a time, to a list recorded on a flipchart or whiteboard by the facilitator; clarification stage, where similar ideas can be grouped together and participants get a chance to ask questions and discuss the ideas to ensure understanding of each idea; and anonymous ranking of ideas, which are collated, discussed and then reranked. Variations exist relating to how ideas are generated and the methods of voting and ranking, and the conditions for consensus are usually predetermined by the researchers running the nominal group [85].

The Delphi process uses self-completed questionnaires over multiple rounds [82, 83, 85]. The first round presents a set of statements related to the topic in question that the respondent is asked to rate [83]. The content of the statements may come from a preliminary open-ended opinion survey, the literature, clinical practice or from previous research findings, e.g. focus groups or NGTs [83]. Responses are collated, analysed by researchers and used to create the second-round questionnaire, which presents the same statements together with the respondents' original rating and the group scores [83]. Respondents reflect on the data presented, rerate the statements and the results are again analysed for degree of consensus. The process continues until a predetermined level of consensus is reached.

Consensus workshops are arguably the most versatile and flexible of the consensus techniques under consideration and are often used in combination with other methods, e.g. NGTs and Delphi. The general objectives of the consensus workshop are to create meaningful and productive dialogue among stakeholders [86]. Contributors are invited according to experience and expertise relevant to the topic of discussion. Workshops often begin with a synopsis of the topic, issues to be addressed and any preliminary findings, e.g. results of an NGT or Delphi process. Attendees are then broken up into smaller discussion groups, facilitated by a member of the research team who is guided by a set of scripted discussion questions. Discussions are recorded and analysed for common themes. The preliminary analysis is drafted into a workshop report that is shared with the workshop attendees and any additional feedback is integrated into the final report [87].

The benefits and limitations of these three techniques are summarised in Table 4. The objective of consensus techniques is not to force agreement, but to reach an agreement that all participants can accept and support [12, 86]. Understanding where and why participants disagree is also important [12, 88], as this information can be used to tailor communication strategies when disseminating and implementing the final outcomes. Although not devoid of risk [89], the highly structured and transparent procedures employed in consensus techniques lend credibility to the outcomes and impart a sense of collective ownership of the resulting decisions [88]. Consensus techniques have been used in the field of kidney research to set priorities for research, select core outcomes for trials and establish guidelines [43, 44, 90–92].

CONCLUSION

For clinical research to translate into clinical practice with a direct impact on health outcomes it needs to be relevant to people who make healthcare-related decisions, including patients and caregivers. In order to achieve this, there is a recognised need to incorporate the perspectives of patients and caregivers in all aspects of clinical research in CKD. The values consistently described in frameworks for patient and caregiver involvement in research include respect, transparency, reciprocity and inclusion, which describe an attitudinal foundation on which solid relationships can be built. The strategies suggested by these

Table 3: Levels of patient and caregiver engagement in kidney research.

Approach[a]	Input	Level of Engagement	Examples
Inform	Receive information with limited opportunity to contribute and no decision-making power	Seminars/conferences Newsletters	• The ISPD Scientific Committee opened registration to the 17th Congress to all patients and their families [24] • The 2022 Annual Scientific Meeting of the Australian and New Zealand Society of Nephrology included a Consumer Session on Telehealth • Nutritional education sessions and written materials delivered to patients in haemodialysis clinics [94]
Consult	Provide personal perspectives, limited influence on decision making	Interviews Surveys Focus groups	• Patient surveys identified factors considered when making decisions about dialysis modality, and conditions likely to support increased rates of home dialysis [95] • Focus groups with patients and caregivers identified facilitators and barriers to self-management in peritoneal dialysis [90] • Focus groups identified patient and caregiver needs to support informed decision making in testing for ADPKD [96]
Involve	Provide personal perspectives as equal contributors	NGT	• Patients, caregivers, clinicians and policymakers involved in consensus workshop involving NGT to establish research priorities for patients with CKD not on dialysis [41] • Public involvement (characteristics not provided) in NGT to reach consensus for management of nocturia in primary care and in specialist clinics [97]
		Delphi process	• Patients, caregivers, researchers and health professionals were involved in developing consensus-based core outcome domains for trials in ADPKD [43] • Patients, caregivers, researchers and health professionals were involved in developing core outcome domains for trials in peritoneal dialysis [98]
		Consensus workshops	• Patients, researchers and health professionals met to establish a core outcome set for trials in peritoneal dialysis [44] • Patient partners, clinicians, researchers, regulators and funder representatives involved in developing definitions for clinical trial kidney failure outcomes and surrogates that predict progression to kidney failure [99]
Partner	Provide advice based on experiential knowledge	Steering Committee Advisory Group	• The development of an online patient decision aid for kidney failure treatment modality decisions was guided by a steering committee which included a patient advocate [100] • A trial investigating the use of an electronic patient-reported outcome measure in the management of patients with advanced CKD was guided by a patient advisory group and included patient partners in the trial management committee [101]
	Participate as full members of the research team, equal decision-making power	Co-investigator(s)	• Patients and caregivers were included as co-investigators on a project testing a health system intervention for patients with advanced CKD [63]
Empower	Lead, propose and drive research projects/agendas	Patient-led research network Lead investigator(s)	• A consumer-led consensus workshop to improve rural and remote patient experiences in accessing healthcare [22]

[a] Based on Australian Department of Health Stakeholder Engagement Framework 2005 [80].

ADPKD: autosomal dominant polycystic kidney disease; ISPD: International Society for Peritoneal Dialysis.

Table 4: Attributes of formal consensus techniques.

Technique	Conditions	Benefits	Limitations
NGT	• Face to face • Independent and unlimited idea generation phase • No anonymity for participants during discussion • Individual scoring is confidential	• Adaptable • Results can be obtained quickly • Participants given time to clarify thought processes and suggestions • Opportunity to change opinion • Qualitative and quantitative	• Limited in scope • Dependent on facilitator skill • Geographic limitations • Power dynamics may limit contribution of some stakeholders • Expensive and complicated to organize • Relatively small number of participants • Potential for group think
Delphi process	• Anonymous • Questionnaires can be hard copy or electronic	• No geographic limitations • Can involve a greater number of participants • Cost efficient • Does not require specified meeting times • Opportunity for participants to adjust ranking • Power differentials may be less relevant • Qualitative and quantitative	• Can take weeks or months to complete • May be complex for patients and caregivers to complete • Participant burnout after multiple rounds • Judgments after the first round may be influenced by feedback given by others • Questionnaire design and content may affect quality and introduce bias • Selection of participants may introduce bias
Consensus workshop	• Face to face or online • No anonymity • Preliminary information session followed by small group discussion	• Adaptable • Rapid • Collaborative • Opportunity for discussion and reflection	• Power dynamics—dominant voices may limit contributions of some participants • Dependent on facilitator skill • Geographic limitations depending on format • Potential of bias in participant selection • Workshop reports subject to bias • Preliminary workshop materials and discussion topic may be complex for patients and caregivers

frameworks describe behaviours and activities to foster these relationships, encourage meaningful involvement and support partnership longevity. Ultimately, however, involving patients and caregivers in research is not a 'one-size-fits-all' process, and best practice methods will be the ones that work within the context of each project and that are agreed upon by all stakeholders, remain flexible and are open to adapting to new challenges as they arise.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

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